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CHILD HEALTH ASSESSMENT ACT

HEARINGS

BEFORE THE

SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT

OF THE

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

HOUSE OF REPRESENTATIVES

NINETY-FIFTH CONGRESS

FIRST SESSION

ON

H.R. 6706 and H.R. 8974

BILLS TO STRENGTHEN AND IMPROVE THE EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT PROGRAM, AND FOR OTHER PURPOSES

AND

H.R. 7474 and H.R. 8401

BILLS TO AMEND TITLE XIX OF THE SOCIAL SECURITY ACT TO IMPROVE THE EARLY AND PERIODIC SCREENING, DIAGNOSIS, AND TREATMENT PROGRAM

AUGUST 8 AND 9, 1977

Serial No. 95–43

Printed for the use of the
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U.S. GOVERNMENT PRINTING OFFICE

97-633 O WASHINGTON : 1977

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CHILD HEALTH ASSESSMENT ACT

THURSDAY, SEPTEMBER 8, 1977

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 2 p.m., in Room 2322, Rayburn House Office Building, Hon. Paul G. Rogers (chairman of the subcommittee) presiding.

Mr. ROGERS. The subcommittee will come to order, please.

Today we are beginning hearings on proposals to reform and improve the early and periodic screening, diagnosis, and treatment program, [EPSDT], which has been part of the Medicaid program since 1967. Although our attention is primarily directed to H.R. 6706, which is the administration's proposal, we also expect to examine closely the alternative proposals suggested by other members of the subcommittee and the full committee.

I would particularly note the contributions of Congressman Ottinger, who will testify today, Congressman Maguire, and Congressman Moss of the full committee, and I commend them for their interests.

This subcommittee welcomes the administration's commitment to improving Medicaid and making it a more effective vehicle for bringing necessary help to the needy children of this Nation. EPSDT has been a program of great promise but severely limited effectiveness. Much of the blame for that must go to the lack of commitment in the early years of the program to its effective implementation.

We recognize and acknowledge that there have been improvements in implementation over the last several years, but we have a long way to go. Clearly our experience with EPSDT has indicated that legislative changes are necessary, but these changes must be coupled with a strong commitment by the Federal Government, by the States and by our medical care providers, to make a comprehensive health care program for poor children a reality.

This subcommittee has long recognized the importance of preventive health care services, good prenatal and postnatal care and the value of assuring good health services for children. We can make no better investment in the health care system.

Early detection of health problems in children and early intervention to treat them can result in a payoff of a healthier population which will justify manyfold the expenditures we make now.

It is widely recognized that the health status of poor children is less than that of children from families with adequate income. Their access to health services is often poor. Medicaid was designed to address these issues. I am convinced that it can become a much more effective program in serving the needs of children.

We will welcome the counsel of witnesses on how to do this.

Without objection the text of H.R. 6706, H.R. 7474, H.R. 8401, H.R. 8974, and agency reports on H.R. 6706 will be printed at this point in the record:

[Testimony resumes on p. 35.]

[The text of the bills referred to and agency reports thereon follow:]

95TH CONGRESS
1ST SESSION

H. R. 6706

IN THE HOUSE OF REPRESENTATIVES

APRIL 27, 1977

Mr. ROGERS introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

A BILL

To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be known as the "Child Health Assessment Act".

DECLARATION OF PURPOSE

SEC. 2. The purpose of this Act is to modify the early and periodic screening, diagnosis, and treatment program and broaden medicaid eligibility—

(1) to continue and expand the availability of health care to children whose families do not have adequate resources to cover the cost of such care and to

strengthen efforts to assure adequate child health assessments, diagnosis, treatment, and periodic reassessment of all eligible children;

(2) to increase the number of children eligible for such care;

(3) to assure the continuity of care for a period after a child would on account of income become ineligible for medical care under title XIX of the Social Security Act;

(4) to increase immunization levels of children; and

(5) to provide further incentives to States to arrange for and encourage quality health care for children.

REQUIREMENT FOR ASSESSMENT AND TREATMENT OF ALL INCOME ELIGIBLE CHILDREN

SEC. 3. Section 1902(a)(13) of the Social Security Act is amended by inserting "and" at the end of subparagraph (E), and by inserting after subparagraph (E) the following new subparagraph—

"(F) effective October 1, 1977, in the case of any individual under the age of six who is a member of a family who would, on the basis of income and resources, be eligible for aid under the State plan approved under part A of title IV of this Act, but who is not a dependent child as that term is

defined in section 406(a) of this Act, for the inclusion of the care and services specified in section 1905(a)(4)(B); and

"(G) effective October 1, 1977, in the case of any individual under the age of twenty-one who has received his periodic assessment pursuant to section 1912(b)(1), for the inclusion of all care and services appropriate for individuals under age twenty-one (but not necessarily including (i) those for the treatment of mental illness, mental retardation, or developmental disabilities, and (ii) dental care when not for the treatment of conditions discovered during an assessment) for which payment is available under this title, whether or not under the State plan for the State such care and services are provided to individuals who have not been periodically assessed pursuant to section 1912(b)(1);"

MEDICAID ELIGIBILITY OF CERTAIN CHILDREN UNDER SIX

SEC. 4. (a) Section 1902(a)(10) of the Act is amended by striking out "and" at the end of subparagraph (B), by redesignating subparagraph (C) as subparagraph (D), and by adding after subparagraph (B) the following new subparagraph:

"(C) for making medical assistance available to any individual under the age of six who is a member of a family who would, on the basis of income and resources, be eligible for aid under the State plan approved under part A of title IV of this Act, but who is not a dependent child as that term is defined in section 406 (a) of this Act; and.".

(b) (1) Section 1902 (a) (10) of the Act is amended by inserting "or clause (C)" after "clause (A)" each place it appears in that section.

(2) Section 1902 (a) (10) (I) of the Act is amended by inserting "or pursuant to clause (C) of this paragraph, clause (F) or (G) of paragraph (13), or section 1912" after "section 1905 (a)".

"CHILD HEALTH ASSESSMENT PROGRAM

SEC. 5. Title XIX of the Act is amended by inserting at the end thereof the following new section—

"CHILD HEALTH ASSESSMENT PROGRAM

"SEC. 1912. (a) Effective October 1, 1977, each State with a plan approved by the Secretary under section 1902 (b) must include the provision of child health assessments and primary care pursuant to this section to any individual under the age of twenty-one and eligible for such services pursuant to section 1902 (a) (13) (B), any individual under the age of six and eligible for such services pursuant to sec-

tion 1902(a)(13)(F), and any other individual under the age of twenty-one who is eligible for such services under the State plan approved under this title.

"(b) Child health assessments under this title may be provided only by a health care provider who enters into an agreement with the State agency responsible for administering or supervising the administration of the State plan under this title to—

"(1) provide to individuals specified in subsection (a) periodic health assessments, as required by regulations of the Secretary;

"(2) provide to individuals assessed a minimum range of diagnostic and treatment services (including immunization against childhood diseases) as required by regulations of the Secretary, except that in lieu thereof (A) during the period beginning October 1, 1977, and ending September 30, 1978, a State may enter into an agreement with any health care provider who agrees to refer such individuals for such diagnostic and treatment services; (B) during the period beginning October 1, 1978, and ending September 30, 1980, a State may enter into an agreement with any health care provider who has written arrangements for the referral of such individuals to appropriate providers for such diagnostic and treatment services; and (C) after September 30,

1980, the Secretary may, with respect to any geographic area in a State, continue to allow agreements pursuant to clause (B) if he determines that a State has made reasonable efforts to assure provider participation, but the number of providers who have agreed with the State to provide directly diagnostic and treatment services is insufficient to serve the number of children who are eligible pursuant to this paragraph for such services;

"(3) refer such individuals to appropriate providers for any corrective treatment the need for which is disclosed by an assessment but which is not available directly from the provider who has the agreement with the State, and followup to assure the provision of such treatment;

"(4) take responsibility for the management of the medical case of each individual assessed to assure that all medical services which are offered under the State plan (pursuant to section 1902(a)(13)(G) and which are found to be necessary pursuant to an assessment are made available in a timely manner and that reassessments are performed as required in regulations of the Secretary;

"(5) be reasonably accessible on an ongoing basis to individuals who have been assessed to assure the continuing availability of medical care; and

"(6) make reports which the State or the Secretary may require to assure compliance with the requirements of this section.

"(c) Any individual under the age of twenty-one who has received an assessment pursuant to this section shall, notwithstanding any other provision of this section or the State plan approved under this title, remain eligible for all care and services provided under the State plan to individuals who have been assessed for a period of six months following the date on which the income and resources of his family first exceeded the eligibility limits specified in the State plan for such care and services, or, if the individual was eligible for aid to families with dependent children under part A of title IV of this Act, for a period of six months following the date on which he became ineligible for such aid, except that in no case shall an individual be eligible for such care and services by reason of the application of this subsection (1) who has attained the age of twenty-one or (2) who has not been reassessed in a timely manner."

ADDITIONAL STATE PLAN REQUIREMENTS

SEC. 6. Section 1902(a) of the Act is amended by striking out "and" after paragraph (35), by striking out the period after paragraph (36) and inserting instead "; and" and by adding after paragraph (36) the following new paragraph—

"(37) provide that the State will encourage participation by physicians and health care centers in the program described in section 1912 of this Act; will assure coordination between State and local agencies participating in that program and community health centers funded under section 330 of the Public Health Service Act; and will assure the availability of appropriate support services (including case tracking and outreach), in accordance with regulations of the Secretary, to individuals and health care providers participating in the program described in section 1912."

FEDERAL REIMBURSEMENT

SEC. 7. (a) Section 1903(a) of the Act is amended by redesignating paragraph (6) as paragraph (7) and by adding after paragraph (5) the following new paragraph—

"(6) an amount equal to a per centum of so much of the sums expended during such quarter as are attributable to child health assessments performed pursuant to section 1912(b)(1) and to diagnosis, treatment (other than dental and inpatient care), referral, follow-up, and medical case management of individuals who have been assessed pursuant to that section and regulations of the Secretary promulgated thereunder; which per centum shall be equal to one-half of the sum of the Federal medical assistance percentage (as calculated for

purposes of paragraph (1) of this subsection) and 90 per centum or 75 per centum, whichever is greater; plus"

(b) Section 1903 of the Act is amended by adding at the end thereof the following new subsections—

"(l) Notwithstanding any other provision of this title, beginning October 1, 1977, whenever the Secretary determines that a State does not have a program, which meets such standards as he shall specify in regulations, for the purposes of—

"(1) informing families of children eligible, pursuant to subparagraphs (B) or (F) of section 1902 (a) (13), for services under the State plan pursuant to section 1912 of the availability of such services;

"(2) assuring the provision of child health assessments in a timely manner in cases where it is requested and required under the State plan;

"(3) assuring the provision, in a timely manner, of any medical care or service the need for which is disclosed by an assessment; or

"(4) assuring compliance with the terms of the agreements it has with providers of services under section 1912;

the Secretary shall notify the State of such failure and that the amount otherwise required to be paid to such State

with respect to each succeeding fiscal quarter following such notification pursuant to paragraphs (2), (3), (4), and (7) of this section for the administrating of the State plan shall be reduced by 20 per centum of that amount until the State shows to the satisfaction of the Secretary that the failure with respect to which the reduction applies has been corrected. Until the Secretary is so satisfied, he shall make any reduction referred to in the preceding sentence, except that if the Secretary is satisfied that the State intends to correct such failure, the Secretary may withhold the imposition of the reduction referred to in the preceding sentence for a period of time, not exceeding six months, to allow the State to fully comply with the requirements of this subsection, and where, at the end of any such period he determines that the failure with respect to which the reduction would apply has been corrected, he may waive the imposition of the reduction entirely. Nothing in this or any other section of this title shall be construed to require the Secretary to review a State's activities to assure compliance with this subsection more frequently than he determines is necessary based upon the State's previous performance in meeting the requirements of this subsection. Each State shall cooperate with the Secretary by providing appropriate documentation of its performance pursuant to this subsection.

"(m) Notwithstanding any other provisions of this title, with respect to any quarter beginning after September 30, 1977, for which the Secretary determines that a State has met the criteria for good performance applicable to the program required by section 1912 which he shall specify in regulations pursuant to this subsection, he shall pay, in addition to any other payments he is required to make to the State pursuant to this section, an amount equal to 25 per centum of the remainder specified in section 1903 (a) (7). The standards the Secretary shall specify for determining good performance under this subsection may include criteria such as the percent of children eligible for assessment under the State plan who are assessed; the percent of conditions identified during an assessment which are treated; and the percent of children eligible for assessment who are fully immunized following assessment.".

CONFORMING AMENDMENTS

SEC. 8. (a) (1) Section 403 (g) of the Act is repealed.

(2) The amendment made by paragraph (1) of this subsection shall be effective with respect to quarters beginning after September 30, 1977.

(b) (1) Section 1905 (a) (4) (B) of the Social Security Act is amended to read as follows: "(B) child health assessments, diagnosis, treatment, referral, and medical case management of individuals under the age of 21 who are eli-

gible for such services under the State plan in accordance with the requirements in section 1912;".

(2) The amendment made by paragraph (1) of this subsection shall be effective beginning October 1, 1977.

(c) Any individual who has been screened pursuant to section 1905(a)(4)(B), as in effect prior to October 1, 1977, and who meets the criteria pertaining to age and date of previous screening which the Secretary shall specify in regulations, shall, for purposes of the amendments made by this Act, be deemed to have been assessed according to section 1905(a)(4)(B), as amended by subsection (b) of this section, on the date when he was screened.

[H.R. 7474, introduced by Mr. Moss on May 26, 1977, and H.R. 8401, introduced by Mr. Moss (for himself, Mr. Maguire, Mr. Krebs, Mr. Perkins, Ms. Holtzman, Mr. Bedell, Mr. Corrada, Mr. Moffett, Mr. Murphy of Pennsylvania, Mr. Hawkins, Mr. Roe, Mr. Lent, Mr. Carney, Ms. Mikulski, Mr. Lundine, Mr. Nolan, Mr. Murphy of New York, Mr. Gephardt, Mr. Patterson of California, Mr. Walgren, Mr. Cornwell, and Mr. Gibbons), are identical as follows:]

A BILL

To amend title XIX of the Social Security Act to improve the early and periodic screening, diagnosis, and treatment program.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

INCREASE IN FEDERAL MATCHING FOR EPSDT PROGRAM

SECTION 1. (a) Section 1903 (a) of the Social Security Act (42 U.S.C. 1396b (a)) is amended—

(1) by inserting " (other than for services described in section 1905 (a) (4) (B)) " in paragraph (1) after "as medical assistance"; and

(2) by redesignating paragraph (6) as paragraph

(7) and by inserting after paragraph (5) the following new paragraph:

"(6) An amount equal to the sum of (A) 90 percent of the total amount expended during such quarter as medical assistance under the State plan for early and periodic screening and diagnosis (described in section 1905(a)(4)(B)(i)), and (B) 100 percent of the total amount expended during such quarter as medical assistance under the State plan for health care, treatment, and other measures (described in section 1905(a)(4)(B)(ii)) for defects and conditions discovered through such screening and diagnosis; plus".

(b) Section 1905(a)(4)(B) of such Act (42 U.S.C. 1396d(a)(4)(B)) is amended (1) by striking out "effective July 1, 1969," and inserting in lieu thereof "(i)", and (2) by inserting "(ii)" before "such health care, treatment, and other measures".

IMPLEMENTATION OF COUPON SYSTEM TO INDICATE SERVICES AVAILABLE UNDER EPSDT PROGRAM

SEC. 2. Section 1902(a) of the Social Security Act (42 U.S.C. 1396a(a)) is amended (1) by striking out "and" at the end of paragraph (35); (2) by striking out the period at the end of paragraph (36) and inserting in lieu thereof "; and"; and (3) by inserting after paragraph (36) the following new paragraph:

"(37) Provide (in accordance with regulations of the Secretary), in its furnishing of medical assistance under the early and periodic screening, diagnosis, and treatment program (described in section 1905(a)(4)(B)), for the distribution to those entitled to assistance under the program of coupons which (A) identify the services for which medical assistance is available under the program, and (B) can be used to indicate a child's entitlement to receive particular medical services covered under the program.".

AVAILABILITY OF PROVIDERS FOR EPSDT PROGRAM

SEC. 3. Section 1902(a)(37) of the Social Security Act (added by section 2 of this Act) is amended (1) by striking out "(A)" and "(B)" and by inserting in lieu thereof "(i)" and "(ii)", respectively; (2) by inserting "(A)" after "(37)"; (3) by striking out the period at the end thereof and inserting in lieu thereof "; and"; and (4) by adding at the end thereof the following new subparagraphs:

"(B) not less often than annually compile and publish a list of providers and institutions that are willing to provide medical services under the early and periodic screening, diagnosis, and treatment program (described in section 1905(a)(4)(B)); and

"(C) require that any hospital which offers services of the type described in section 1905(a)(4)(B), and which receives payment for providing any medical services under the plan, agree to provide to the maximum extent feasible the services described in such section to individuals entitled to receive such services under the plan.".

EFFECTIVE DATES

SEC. 4. (a) The amendments made by section 1 shall apply with respect to medical assistance furnished, under a State plan approved under title XIX of the Social Security Act, on and after October 1, 1977.

(b)(1) Except as provided in paragraph (2), the amendments made by sections 2 and 3 shall apply with respect to medical assistance furnished, under a State plan approved under title XIX of the Social Security Act, on and after the first day of the first calendar quarter beginning after the date of enactment of this Act.

(2) The amendment made by section 3, to the extent that it adds subparagraph (C) to section 1902(a)(37) of the Social Security Act, shall apply with respect to services furnished by a hospital, under a State plan approved under title XIX of such Act, on and after October 1, 1977.

95TH CONGRESS
1ST SESSION

H. R. 8974

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 8, 1977

Mr. MAGUIRE introduced the following bill; which was referred to the Committee on Interstate and Foreign Commerce

A BILL

To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be known as the "Child Health Assurance Act".

DECLARATION OF PURPOSE

SEC. 2. The purpose of this Act is to modify the early and periodic screening, diagnosis, and treatment program and broaden medicaid eligibility—

(1) to introduce children, whose families do not have adequate financial resources, into a health care system within their community that will provide the

children with comprehensive, continuing, primary, and preventive health care;

(2) to increase the number of children eligible for such care;

(3) to assure the continuity of care for a period after a child would on account of income became ineligible for medical care under title XIX of the Social Security Act;

(4) to increase immunization levels of children;

(5) to meet special health needs of adolescents; and

(6) to provide further incentives to States to arrange for and encourage quality health care for children.

REQUIREMENT FOR ASSESSMENT AND TREATMENT OF ALL INCOME ELIGIBLE CHILDREN

SEC. 3. Section 1902(a)(13) of the Social Security Act (hereinafter in this Act referred to as the "Act") is amended by inserting "and" at the end of subparagraph (E), and by inserting after subparagraph (E) the following new subparagraphs:

"(F) in the case of any individual under the age of 21 who is a member of a family which would, on the basis of income and resources, be eligible for aid under the State plan approved under part A of

title IV of this Act, but who is not a dependent child as that term is defined in section 406(a) of this Act, for the inclusion of the care and services specified in section 1905(a)(4)(B); and

"(G) in the case of any individual under the age of 21 who has received his periodic assessment pursuant to section 1912(b)(1), for the inclusion of all health care and services appropriate for individuals under age 21 for which payment is available under this title, whether or not under the State's plan such care and services are otherwise provided to individuals who have not been periodically assessed pursuant to such section;".

MEDICAID ELIGIBILITY OF CERTAIN CHILDREN UNDER TWENTY-ONE

SEC. 4. (a) Section 1902(a)(10) of the Act is amended by striking out "and" at the end of subparagraph (B), by redesignating subparagraph (C) as subparagraph (D), and by adding after subparagraph (B) the following new subparagraph:

"(C) for making medical assistance available to any individual under the age of 21 who is a member of a family which would, on the basis of income and resources, be eligible for aid under the State plan

approved under part A of title IV of this Act, but who is not a dependent child as that term is defined in section 406(a) of this Act; and".

(b) (1) Section 1902(a)(10) of the Act is amended by inserting "or clause (C)" after "clause (A)" each place it appears in that section.

(2) Section 1902(a)(10)(I) of the Act is amended by inserting "or pursuant to clause (C) of this paragraph, subparagraph (F) or (G) of paragraph (13), or section 1912" after "section 1905(a)".

(3) Section 1902(f) of the Act is amended by striking out "(10)(C)" each place it appears and by inserting in lieu thereof "(10)(D)".

CHILD HEALTH ASSURANCE PROGRAM

SEC. 5. Title XIX of the Act is amended by inserting at the end thereof the following new section:

"CHILD HEALTH ASSURANCE PROGRAM

"SEC. 1912. (a)(1) Each State with a plan approved by the Secretary under section 1902(b) must include the provision of child health assessments and primary care pursuant to this section to any individual who is under the age of 21 and who is eligible for such services under the State plan approved under this title.

"(2)(A) The Secretary may not require a State plan to provide dental screening of individuals under the age of

21 as a precondition to the provision of dental treatment to such individuals under the plan.

"(B) If a State plan includes provision for dental screening of individuals under the age of 21, such screening to such an individual shall be considered to be medical assistance for which payment may be made under section 1903 (a) only if it has been provided by a registered dental hygienist or by a dentist.

"(b) Child health assessments under this title may be provided only by a health care provider (which term includes a community health center, headstart program, visiting nurse association, and a rural health clinic) who enters into an agreement with the single State agency responsible for administering or supervising the administration of the State plan under this title under which agreement the provider agrees—

"(1) to arrange or provide to individuals specified in subsection (a) periodic health assessments, as required by regulations of the Secretary;

"(2) to arrange or provide to individuals who have been assessed at least such minimum range of diagnostic services and treatment (including immunization against childhood diseases), the need for which services and treatment is disclosed by the assessment, as shall be specified by the Secretary in regulations, except that in

lieu thereof (A) during the one-year period beginning on the effective date of this section, a State may enter into an agreement with any health care provider who agrees to refer such individuals for such diagnostic and treatment services; (B) during the two-year period beginning on the day after the end of such one-year period, a State may enter into an agreement with any health care provider who has written arrangements for the referral of such individuals to appropriate providers for such diagnostic and treatment services; and (C) after the last day of such two-year period, the Secretary may, with respect to any geographic area in a State, continue to allow agreements pursuant to clause (B) if he determines that a State has made reasonable efforts to assure provider participation, but the number of providers who agreed with the State to provide directly diagnostic and treatment services is insufficient to serve the number of children who are eligible pursuant to this paragraph for such services;

"(3) to arrange for the referral of or refer such individuals who have been assessed to appropriate providers for diagnostic services and treatment (beyond the minimum range of diagnostic services and treatment described in paragraph (2)) the need for which is dis-

closed by an assessment but which is not directly available from the provider;

"(4) be accessible on an ongoing basis to individuals who have been assessed to assure the continuing availability of health care;

"(5) to coordinate the medical case management of the individuals assessed;

"(6) to provide either—

"(A) for timely followup services to assure the provision of diagnostic services and treatment the need for which are disclosed by an assessment, or

"(B) for a written arrangement with an appropriate State or local public agency or a nonprofit community-based organization, which arrangement and agency or organization meet such standards as the Secretary may prescribe, whereby the agency or organization provides for timely followup services described in subparagraph (A); and

"(7) make such reports as the State or the Secretary may require to assure compliance with the requirements of this section.

"(c) Any individual under the age of 21 who has received an assessment pursuant to this section shall, notwithstanding any other provision of this section or the State

plan approved under this title, remain eligible for all care and services provided under the State plan to individuals who have been assessed for a period of six months following the date on which the income and resources of his family first exceeded the eligibility limits specified in the State plan for such care and services, or, if the individual is a member of a family which was eligible for aid to families with dependent children under part A of title IV of this Act, for a period of six months following the date on which he became ineligible for such aid, except that in no case shall an individual be eligible for such care and services by reason of the application of this subsection after he has attained the age of 21.

"(d) (1) The Secretary shall report to Congress, not later than February 1 of each year, on the administration of the child health assurance program.

"(2) The Secretary shall submit to Congress, with each other annual report submitted under paragraph (1), an evaluation of the Secretary's administration of the child health assurance program, which evaluation shall be prepared by a panel of experts who are independent of the Department of Health, Education, and Welfare and the administration of the program and who represent the interests of the recipients of services under the program.".

ADDITIONAL STATE PLAN REQUIREMENTS

SEC. 6. Section 1902(a) of the Act is amended by striking out "and" after paragraph (35), by striking out the period at the end of paragraph (36) and inserting in lieu thereof "; and", and by adding after paragraph (36) the following new paragraph:

"(37) provide that the State will (A) identify and offer contracts to all qualified health care providers on such terms as will reasonably be expected to elicit their involvement in the child health assurance program under section 1912; (B) develop, based on substantial public input, a State plan which demonstrates how the requirements for such a program will be met; (C) coordinate the services provided under such program with any other federally funded programs in the State providing health care services to children; (D) assure the provision of outreach and followup services, using nonprofit community-based organizations whenever possible, in accordance with regulations of the Secretary, to individuals and health care providers participating in such program; (E) taking into account inflation, not reduce the per capita level of outpatient medical services provided to children under the plan

below the per capita level provided to children under the plan before the date of enactment of this paragraph; and (F) in conjunction with the health planning activities in the State, identify areas where eligible children are unable to receive assessments and treatment promptly under the plan and devise methods of addressing these shortages.".

FEDERAL REIMBURSEMENT

SEC. 7. (a) Section 1903 (a) of the Act is amended by redesignating paragraph (6) as paragraph (8) and by adding after paragraph (5) the following new paragraphs:

"(6) an amount equal to the sum of (A) 75 per centum of sums expended during such quarter which are attributable to followup services provided by a State or local public agency under the child health assurance program under section 1912, and (B) 90 per centum of sums expended during such quarter which are attributable to other medical assistance (including outreach and followup services performed by approved nonprofit community-based organizations and followup services provided by health care providers) provided for the child health assessment program under section 1912; plus

"(7) an amount equal to 25 per centum of the amount specified in paragraph (8), if the State meets

the performance criteria relating to its child health assessment program specified in subsection (o); plus".

(b) Section 1903 of the Act is amended by adding after subsection (m) the following new subsections:

"(n) (1) Whenever the Secretary determines that a State does not have a program, which meets all such standards as he shall specify in regulations, including standards for—

"(A) informing families of children eligible, pursuant to subparagraph (B) or (F) of section 1902 (a) (13), for services under the child health assessment program of the State plan of the availability of such services under such program;

"(B) assuring the provision of child health assessments under such program in a timely manner in cases where it is requested and required under the State plan;

"(C) assuring the provision, in a timely manner, of any health care or service the need for which is disclosed by an assessment; and

"(D) assuring compliance with the terms of the agreements the State has with providers of any services in the program,

the Secretary shall notify the State of such failure and, except as provided in paragraph (2), the sum of the amounts other-

wise required to be paid to such State, under paragraphs (2), (3), (4), and (8) of subsection (a) shall be reduced by 20 per centum of that sum for each quarter beginning after the date of such notification until the State shows to the satisfaction of the Secretary that the failure with respect to which the reduction applies has been corrected. In lieu of imposing the reduction required under the previous sentence, the Secretary may bring an action in a court of competent jurisdiction to require the State to correct any such failure which the Secretary has determined, under the previous sentence, exists.

"(2) If the Secretary is satisfied that the State intends to correct such a failure, the Secretary may withhold the imposition of the reduction under paragraph (2) for a period of time, not exceeding two quarters, to allow the State to fully comply with the requirements of this subsection. If, at the end of any such period, he determines that the failure with respect to which the reduction would apply has been corrected, he may waive the imposition of the reduction entirely.

"(3) The Secretary shall review annually a State's activities to assure compliance with this subsection.

"(4) Each State shall cooperate with the Secretary by providing appropriate documentation of its performance pursuant to this subsection.

"(o) For purposes of subsection (a) (7), the Secretary

shall specify criteria for determining good performance of a State's child health assessment program under section 1912, which may include criteria such as the percent of children eligible for assessment under the State plan who are assessed; the percent of conditions identified during an assessment which are treated; and the percent of children eligible for assessment who are fully immunized following assessment.".

CONFORMING AMENDMENTS

SEC. 8. (a) Section 403(g) of the Act is repealed.

(b)(1) Section 1905(a)(4)(B) of the Act is amended to read as follows: "(B) child health assessments, diagnosis, treatment, outreach, followup, referral, and medical case management of individuals under the age of 21 who are eligible for such services under the State plan in accordance with the requirements of section 1912;".

(2) Any individual who has been screened pursuant to section 1905(a)(4)(B) of the Act, as in effect prior to the effective date of the amendments made by this Act, and who meets the criteria pertaining to age and date of previous screening which the Secretary shall specify in regulations, shall, for purposes of the amendments made by this Act, be deemed to have been assessed according to section 1905(a)(4)(B) of the Act, as amended by paragraph (1) of this section, on the date when he was screened.

EFFECTIVE DATE AND ESTABLISHMENT OF REGULATIONS

SEC. 9. (a) The amendments made by this Act shall apply to medical assistance provided, under a State plan approved under title XIX of the Social Security Act, and to calendar quarters beginning on and after the first day of the second calendar quarter that begins after the date of enactment of this Act.

(b) The Secretary of Health, Education, and Welfare shall first prescribe final regulations to carry out the amendments made by this Act not later than the end of the one-hundred-and-eighty-day period beginning on the date of enactment of this Act.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

JUL 5 1977

The Honorable Harley O. Staggers
Chairman, Committee on Interstate
and Foreign Commerce
House of Representatives
Washington, D. C. 20515

Dear Mr. Chairman:

This is in response to your request for a report on H.R. 6706, a bill "To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes."

H.R. 6706 is identical to draft legislation submitted by the President to the Congress on April 25, 1977. The bill is designed to improve health services for children of low-income families by strengthening Medicaid's Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) for children (which would be redesignated as the Child Health Assessment Program (CHAP)).

In his April 25, 1977 message to Congress on health initiatives, the President urged enactment of the proposed Child Health Assessment Program as a crucial first step toward the improvement of children's health programs. For the reasons stated by the President, we recommend that the Committee give favorable consideration to the bill.

We are advised by the Office of Management and Budget that enactment of H.R. 6706 would be in accord with the program of the President.

Sincerely,

/s/ Joseph A. Califano, Jr.

Secretary

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET
WASHINGTON, D.C. 20503

JUN 10 1977

Honorable Harley O. Staggers
Chairman, Committee on Interstate
and Foreign Commerce
House of Representatives
Washington, D. C. 20515

Dear Mr. Chairman:

This is in response to your request of May 6, 1977 for the views of this Office on H.R. 6706, a bill "To strengthen and improve the early and periodic screening, diagnosis, and treatment program, and for other purposes."

H.R. 6706 is identical to draft legislation submitted by the President to the Congress on April 25, 1977. The bill is designed to improve health services for children of low-income families and would replace Medicaid's Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) for children.

In his April 25, 1977 message to Congress on health initiatives, the President urged enactment of the proposed Child Health Assessment Program as a crucial first step toward the improvement of children's health programs. For the reasons stated by the President, we recommend that the Committee give favorable consideration to the bill. Enactment of H.R. 6706 would be in accord with the program of the President.

Sincerely,

[Signed] James M. Frey

James M. Frey
Assistant Director for
Legislative Reference

Mr. ROGERS. Our first witness today will be our own distinguished colleague on this subcommittee, the Honorable Richard L. Ottinger of New York, who has been most interested in this program.

Mr. MAGUIRE. Mr. Chairman, may I be recognized for just one moment before Mr. Ottinger begins his statement?

Mr. ROGERS. Certainly, Mr. Maguire.

Mr. MAGUIRE. I simply wanted to thank you for referring to legislation that I have introduced. I think it is clear that there is a great deal of interest on the part of the subcommittee and the Congress as well as the administration in improving the program that we have had to date, and I know that we all recognize the great need to provide quality health care to poor children.

We also have, as the witness list will testify, both today and tomorrow, a very distinguished set of panelists who are experts in this field, and who will be making recommendations to us.

I am also cognizant of the constant requirement to be aware of fiscal concerns. I know that these concerns are taken very seriously both by the administration and the subcommittee, but I also hope and expect that we will focus very squarely in on the long-term issues of human health and creativity and productivity, which of course bring us benefits far in excess of money well spent, that we should appropriate to improve this program.

I thank you very much, Mr. Chairman. I look forward to joining with you in addressing ourselves to this matter.

Mr. ROGERS. I thank the gentleman.

Mr. Ottinger, we are pleased to have you. Please proceed.

STATEMENT OF HON. RICHARD L. OTTINGER, A REPRESENTATIVE IN CONGRESS FROM THE STATE OF NEW YORK, ACCOMPANIED BY ELLIOT SEGAL, TASK FORCE DIRECTOR—HEALTH, OVERSIGHT AND INVESTIGATIONS SUBCOMMITTEE, COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

Mr. OTTINGER. Thank you very much.

I have with me, Mr. Elliot Segal who is the counsel for health of the Oversight and Investigations Subcommittee.

Mr. ROGERS. We welcome you, Mr. Segal.

Mr. OTTINGER. I am appearing on behalf of both myself and Congressman John Moss of California, who is the author of H.R. 7474 to reform the EPSDT program.

I am pleased that you have convened hearings beginning today on the very important topic of children's health under Title XIX of the Social Security Act—the Medicaid program. As a member of this subcommittee, I am very concerned that the program to provide comprehensive preventive health care for children—specifically the early periodic screening, diagnosis, and treatment [EPSDT] program—has not met the goals expected by Congress and that reform of the legislation is necessary. Hence, I am happy to join with Congressman John Moss in sponsoring a new thrust to this program.

On October 7 and 8, 1975, the Subcommittee on Oversight and Investigations held hearings, which I chaired, on the EPSDT program entitled "Getting Ready for National Health Insurance: Short-

changing Children." Those hearings presented tragic illustrations of the results of children not screened and treated for preventable diseases. I personally find it inexcusable that though 88 percent of American preschoolers were immunized against polio in 1964, that number had dropped to 63 percent in 1973 and is even lower for nonwhite children in the central cities of major metropolitan areas.

During those hearings, the subcommittee received testimony of genetic and familial diseases which could be cured or ameliorated by early treatment. For example, we received evidence from a family where phenylketonuria [PKU] was undiagnosed or misdiagnosed for three children. One member of that family is severely retarded and institutionalized in the State of Pennsylvania at a cost of more than $20,000 a year. PKU could have been detected in that child for less than $10. The potential benefits obviously far outweigh any treatment costs that would have been incurred—both in human and monetary terms.

An important issue raised at the hearings and discussed in the subsequent subcommittee report of September 1976 entitled "Department of Health, Education, and Welfare's Administration of Health Programs: Shortchanging Children" was the Department's failure to administer the penalty provisions of the EPSDT program. In that report the subcommittee determined there was a need to change the emphasis of the program from a punitive system to one of incentives to screen and treat more children, in effect providing a positive reason for States to provide health care to children.

The proposal of Chairman Moss and myself—as well as other members of the subcommittee—provides incentives in the form of increased Federal participation for the focus of the program to be on treatment of children. Under H.R. 7474, the Federal share would become 90 percent for screening and diagnosis and 100 percent for treatment.

Streamlining the current bureaucratic morass determining eligibility is another innovation. H.R. 7474 proposes a coupon system which would identify available services and be indicative of a child's eligibility for EPSDT services.

One explanation propounded for the small number of children screened and treated under the EPSDT program is the limited number of participating providers in some areas. H.R. 7474 calls for an annual compilation and publication of institutions and providers willing to provide these services and requires that all hospitals which receive payments under Title XIX of the Social Security Act will agree to provide services under EPSDT to the maximum extent feasible.

I strongly urge my colleagues on this subcommittee to support this important proposal. I can imagine few areas of our Nation's health care system more important than providing the care to our children necessary for healthy and productive lives.

There are basically just three or four differences between our legislation and the administration bill, but I think they are very important. The coverage is more extensive. The administration bill stops at age 6. Our legislation covers children up to age 21. The reimbursement is more generous in giving a particular incentive for treatment, by having 100 percent reimbursement, with 90 percent

for diagnosis. I believe the figure is 75 percent in the administration bill.

H.R. 7474 has this rather innovative coupon system, which I think will help to assure participation in the program. One of the things we found in the earlier hearings is that a good many of the children were just not getting the services that they were supposed to get. Because these programs were costing the States a good deal of money, the States felt they didn't have adequate incentive to reach out to include more children. This proposal envisages that there be a coupon, such as their is with a warranty on a car. The various services, immunizations, periodic examinations, and so forth that are considered important to a child's health would be on a coupon and the child would go to any qualified provider and present that coupon as means of payment for those services.

The legislation drops penalty provisions, as they apparently do not work.

I believe those are the major differences. The bill would cost substantially more. I believe the estimate is in the neighborhood of $200 million for the administration bill and $500 million for our legislation. I would like to make the point very strongly that here is a case where clearly an ounce of prevention is worth a pound of care, both in the health and the monetary sense, to the extent that we can diagnose early problems that children experience.

I am sure that Dr. Carter, who has a good deal of experience directly in this field, would agree that avoiding treatment later in life, will save a tremendous amount of money. I think the extra investment that is called for by the Moss legislation is going to be money very well spent, and in the long run, will save not only the Federal Government, but the State government a great deal of money.

I would hope that you would consider the more extensive coverages provided.

Mr. Segal, is there anything that I have left out with respect to the differences?

Mr. SEGAL. I don't think so, Mr. Congressman.

Mr. ROGERS. Thank you very much for a very helpful statement.

Dr. Carter.

Mr. CARTER. Thank you, Mr. Chairman.

I want to compliment the distinguished gentleman on his presentation here today. I think it is very apparent that phenylketonuria, which you mentioned, actually can be diagnosed by a simple urine test at the time that the child is born, and it should be routine throughout our country. I thought that it was. In most areas it is at the present time, and it is very necessary.

Also I feel that periodic screening is very, very necessary.

Sometimes we find hernias and heart conditions in children which can be corrected early. Moreover there are so many children, particularly poor children, who suffer from dental caries which in later life can lead to significant dental problems. Acute bacteriocarditis is often caused by teeth. I think this early detection of these problems should be a part of any child health program.

The third thing which you emphasized is the lack of mental assessment and care provided in the bill. I believe that each person,

whether child or adult should have these assessments regularly. These periodic assessments should begin with prenatal care, and continue with the birth of the child, postnatal care, and so on with examinations at periodic intervals. If we spend the money that is needed in these areas, it will be a saving in the long run to the taxpayer of the country; and what is more meaningful, it will bring an improvement of health to the indivdiual.

Mr. ROGERS. Thank you.

Mr. Maguire.

Mr. MAGUIRE. Thank you, Mr. Chairman.

While we don't have much time, I do want to ask about outreach. I think it is clear that when food stamps are available, the cause and effect of using them or not using them is very clear, and I wonder if the coupon necessarily is going to work as well in this kind of situation, and if there is some reason to believe that it might not, then other impetus for outreach becomes terribly important. I would hope the gentleman would join with me and members of the committee in trying to assure that we have an outreach program, which is really going to be effective and is really going to bring people in. This is what has been wrong with the existing program. I have provided in my piece of legislation some higher reimbursement rates, et cetera. How is the reimbursement expenditures for outreach handled under the Moss bill?

Mr. OTTINGER. Under the Moss bill, 100 percent of the treatment is covered.

Mr. MAGUIRE. Does this include outreach and follow-up, apart from treatment?

Mr. OTTINGER. Ninety percent would be for screening and outreach. The actual treatment would be covered by the coupon.

Mr. MAGUIRE. I really don't want to get into all the details but simply to signal that for me one of the key issues is outreach as I am sure it is for the gentleman.

Mr. OTTINGER. It absolutely is.

Mr. MAGUIRE. In other words, you can't screen somebody until they are there.

Mr. OTTINGER. That is right.

Mr. MAGUIRE. Or treat them until they are there. That is a key issue.

Mr. OTTINGER. We also had hearings in California on an HMO, prepaid insurance. We found there was an absolute incentive there for the health maintenance organization not to see children. They did nothing to try and get more patients in. They had been paid for their services and it was their incentive to see as few people as possible. So we found a high percentage of the children who were supposed to be receiving preventive care weren't getting it at all. This bill is an effort to try and create an incentive for outreach and for actually seeing these children.

In response to Dr. Carter, I would just like to say I am told that there are nine States at the present time that do not do PKU screening.

Mr. CARTER. Did you say there are nine that do not do PKU studies?

Mr. OTTINGER. Yes.

Mr. CARTER. Of course this procedure should be done at the birth of the child. The unusual thing about this condition is that it usually occurs in blue-eyed, blond children, but it can be diagnosed at birth and it should be.

Mr. ROGERS. May I ask this? States still set the income limitation so that a State like New York, you said $4,500, will cover many more people than coverage, say, in West Virginia, where they only have $1,900. Yet that determination is made by the State.

Should we have a set level, nationwide, set here?

Mr. OTTINGER. My own feeling is that we ought to have a minimum, but the States ought to be permitted to supplement that. You have always this tremendous problem where you set a national level. It generally is too low to cover the actual cost in your high cost of living States like New York.

Mr. ROGERS. In other words, if we did this New York might want to go up to $5,000 or $6,000, and all the money would go into New York, and wouldn't go anywhere else, not that you would object.

Mr. OTTINGER. You have given a very propitious example.

Mr. MAGUIRE. Not that that has been a problem in the past, Mr. Chairman.

Mr. OTTINGER. I think that children's needs ought to be attended wherever they are in the country.

Mr. ROGERS. Yes.

Mr. OTTINGER. But there ought to be a recognition.

Mr. ROGERS. But if you are giving 100 percent funding, then maybe we ought to set the entrance into that program here.

Mr. OTTINGER. I think if you are giving 100 percent funding, that you ought to have national standards, but I think the States ought to be allowed to exceed those standards out of their own funds to the extent that they wish to do so.

Mr. ROGERS. Thank you very much. Your testimony has been most helpful.

The committee stands in recess for 10 minutes to allow members to respond to the quorum.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order, please. We now have a panel, Dr. Judson Force, Director, Crippled Children's Program, Department of Health and Mental Hygiene, Baltimore, Maryland, on behalf of the Association of State and Territorial Health Officials; and Dr. J. Brett Lazar, who is the health officer of Montgomery County, Maryland, on behalf of the National Association of Counties.

We welcome you gentlemen to the committee with your associates, and we will be pleased to receive your statements. Your full statements will be made a part of the record at this point.

STATEMENTS OF JUDSON FORCE, M.D., ON BEHALF OF THE ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS, AND THE ASSOCIATION OF MATERNAL AND CHILD HEALTH AND CRIPPLED CHILDREN'S DIRECTORS, ACCOMPANIED BY ERIC FINE, M.D., DIRECTOR, MARYLAND MATERNAL AND CHILD HEALTH SERVICES; AND J. BRETT LAZAR, M.D., ON BEHALF OF

THE NATIONAL ASSOCIATION OF COUNTY HEALTH OFFICIALS, ACCOMPANIED BY MIKE GEMMELL, LEGISLATIVE REPRESENTATIVE

Dr. FORCE. Mr. Chairman, I am Judson Force, Director of Crippled Children's Service in Maryland, and today I speak on behalf of the State and Territorial Health Officials and an affiliate association, Maternal and Child Health. Also today with me is Dr. Eric Fine, Director of Maternal and Child Health Services in Maryland.

This statement has been prepared by a task force of the Association which represents some 97 physician directors and an estimated 1,600 other professionals working in State and territorial maternal and child health and crippled children's services programs. Professional staff located in local and regional areas of States who are involved with child health services represent an additional and substantial corps of trained and experienced personnel.

State and local staff include public health nurses, nurse practitioners, physicians, dentists, medical social workers, nutritionists, health educators, audiologists, speech pathologists, physical therapists, and occupational therapists. Responsibilities are such that most staff members provide both administrative and direct patient care services.

Therefore, it is appropriate to acknowledge that much of what is presented in this statement reflects the concern of persons who are very close to those for whom this Act is intended.

The Association of Maternal and Child Health, and Crippled Children's Directors of title V programs support the purpose of H.R. 6706 to strengthen and modify EPSDT and broaden program elibility. Congress in the past has recognized that a special public responsibility exists for the most dependent and vulnerable citizens who require more care and financial support than can be reasonably expected of most low-income families. This bill can provide a needed opportunity to reinforce previous congressional intent and commitments under Public Law 90-248 and the 1967 EPSDT amendments to Title V and Title XIX of the Social Security Act. Both title V and title XIX child health mandates need careful consideration as the language of H.R. 6706 undergoes further development.

The Child Health Assessment Act is an initiative that should promote healthy children and prevent unnecessary disease, disability, and hospitalization by improving the opportunities for more needy children to be identified and provided with a continuing source of quality medical care. A major goal of this act must be to emphasize the need and ensure the availability of necessary primary, secondary and tertiary preventive care services through a comprehensive and coordinated network of providers. The Association vigorously supports the intent to have every needy child introduced and assured a medical program where health needs would be periodically assessed, a prevention oriented care plan developed and necessary diagnostic, treatment and aftercare services provided in accordance with that plan.

The following statements and recommendations are made, then, in keeping with what we believe to be the basic health care

provisions that Congress intends for all children served through EPSDT services under title V and title XIX and to be further amended through H.R. 6706.

A. TREATMENT COVERAGE

In this country the prevalence of severe handicapping conditions is greatest among those children served by title V and title XIX programs. Section 1905 now requires title XIX payment coverage for EPSDT services of all eligible persons under 21 years of age regardless of diagnostic category. It is of great concern, therefore, that CHAP would amend this section whereby State title XIX programs would no longer be required to provide appropriate care and services to handicapped children with mental illness, mental retardation, or developmental disabilities.

This exclusion is contrary to the very intent of section 1901 which states that title XIX appropriations are for the purpose of enabling States to furnish (1) medical assistance on behalf of families with dependent children and disabled individuals and (2) rehabilitation and other services to help such families and individuals attain or retain capability for independence of self-care.

Some of the most urgent medical diagnostic and treatment needs and opportunities for secondary and tertiary prevention are in those conditions or categories which are not to be mandated for all appropriate care and services. To exclude these conditions or to limit treatment where there is a reasonable expectation of eventually attaining or retaining capability for at least independence of self-care may not be in a State's best fiscal interest. Many states are presently investing substantial amounts of limited program funds in developing health care resources and services to reduce the need for costly institutional care.

Also to be excluded under CHAP is dental treatment unless the need is discovered during an assessment. Since a large percentage of dental defects can only be detected after a thorough diagnostic examination, it is imperative that children receive diagnostic dental care on an ongoing regular preventive and curative basis. Furthermore, the vast majority of needy children are already known to have dental conditions requiring diagnosis and treatment. Assessment for disease in this circumstance is believed to be cost ineffective.

We also recommend that dental treatment services not be excluded from the increased Federal medical assistance reimbursement as described in section 7. Ambulatory dental care for poor and handicapped children is limited, and inadequate financial incentives will only make it more difficult for States to make these needed services available.

B. PROVIDER PARTICIPATION

It is believed that satisfaction with program direction and equitable reimbursement provisions have the greatest influence on EPSDT provider participation and practice patterns. Also of importance to the patient and provider is the organizational structure,

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setting and atmosphere in which health care services are to be delivered. Therefore diversity of choices in delivery systems and funding arrangements should be mandated by statute to allow for differences in personal preferences which exist among patients and providers.

We fully support the CHAP intent as expressed in section 1912 to require the responsible State administrative unit to provide greater access to programs and providers which can assure not only periodic assessments but also the necessary treatment and continuing follow-up care needs. However, the Association is greatly concerned that the requirements under section 1912 could interfere with a State's ability to deliver EPSDT services through title V programs. Under title V local community providers, including health departments, provide services to several million children annually. In particular, children and families served by health department programs could be adversely affected by this section.

Local health departments continue to be a major resource of a broad spectrum of health care specialties and disciplines in underserved areas throughout the country. Their outreach capability in the community is considerable. Depending on local needs, care available through these community programs can vary from assessment clinics to comprehensive services offered in primary care, community hospital, and university medical center settings. Most local programs have, however, traditionally focused on well child and primary preventive care; diagnostic consultation treatment and ongoing management services have been provided to a lesser extent and mainly developed for handicapped children followed through State title V crippled children's services. Arrangements have been worked out over the years to coordinate assessment services with necessary diagnostic, treatment and follow-up care to assure comprehensiveness and continuity.

It is imperative that local programs which have been developed and are continuing to meet community expectations and needs not be disrupted but hopefully reaffirmed and strengthened under this section. If this section is not changed, health departments could only continue assessment services in those geographic areas where it has been determined that the State has made reasonable efforts to assure provider participation but the number of enlisted providers is insufficient to serve the number of eligible children. There is great reservation about the efficacy of this provision as presently developed.

There is the potential for incalculable disruptive and damaging effects on local health departments; i.e., possible elimination of many local health programs and a decrease in available assessment health services particularly at a time when there is expected to be an increased demand for such services as a result of Public Law 94-142, the Education for the Handicapped Act, which is to be implemented soon by local education agencies.

At best it is felt that the provider requirement under section 1912 would have very little beneficial effect on the further development and strengthening of present delivery systems for the health needs of poor children. Most States would need total Federal funding to enable existing health department assessment programs to add the

required level of diagnostic and treatment services. It is conceivable that some health departments might be inappropriately forced to expand into primary care delivery programs; there is not any provision that would prohibit a local program from taking this course of action even if located in an area where there were already a sufficient number of diagnostic and treatment providers.

Lastly, the selection of appropriate criteria to be used for such a determination would appear formidable when considering the many geographic, provider and consumer variations that exist on a nationwide basis.

Accordingly, the Association recommends that section 1912(b)(2)(A), (B) and (C) be deleted except for the statement that in lieu thereof "a State may enter into an agreement with any health care provider who has written arrangements for the referral of such individuals to appropriate providers for such diagnostic and treatment services." This change should not have any significant adverse effect on the overall intent of the section to reach increasingly more title XIX children with a full range of appropriate and ongoing preventive health services. The change would eliminate, much earlier than otherwise, those assessment providers who cannot assure a minimum coverage of diagnostic and treatment services, or who have not been successful in affiliating with an appropriate health care provider. In addition, it is believed that the logistics involved in administering the compliance aspects of section 1912 over a 3-year phase-in period would be monumental.

C. PROGRAM AUTHORITY

Enabling legislation for title V programs is for the express purpose of extending and improving health care services to children throughout States, especially in under-served and economically depressed areas. Title V agencies have been directed by Federal and State statutes to administer or supervise the administration of the State plan for identifying health needs of children and developing strategies for meeting those needs including the provision of direct services by the agency when necessary. Under Public Law 90-248 Congress further specified and attempted to strengthen title V authority to provide for ongoing continuous programs of preventive care, by amending title V State plan requirements to provide specifically for EPSDT services: Section 505(a)(7) was added which provides for the early identification of children in need of health care and services, and for health care and treatment needed to correct or ameliorate defects or chronic conditions discovered thereby, through provision of such periodic screening and diagnostic services, and such treatment, care and other measures to correct or ameliorate defects or chronic conditions.

Also, under Public Law 90-248, confirming amendments were added to title XIX. These additions were seemingly intended to provide the necessary funding mechanisms for EPSDT services which were to be developed and made available under section 505(a)(7) of title V. Section 1905(a)(4)(B) defines EPSDT for the purposes of payment and section 1902(a)(11)(B) requires the title XIX agency to enter into reimbursement agreements with providers

receiving payments for part or all of the cost of plans or projects under title V.

The Association submits that most of the shortcomings of EPSDT can be attributed to the very low priority this program has received at the State level subsequent to these 1967 EPSDT amendments. Part of the failure of title V and title XIX agencies to establish EPSDT as a priority program is believed related to the difficulties and delays which surrounded the development of regulations and guidelines. In addition, when regulations and guidance material finally became available in 1972, many States were beginning major efforts to contain title XIX costs and were not particularly interested in providing funds for EPSDT program development. In fact, as of December 1973, 6 months after the date for full implementation, only about half of the States had some services available on a statewide basis.

Much of the initiative and most of the technical expertise for developing EPSDT standards and assessment schedules has been provided by title V agencies. However, the administrative responsibility for overall EPSDT program direction continues to reside with title XIX agencies. Since title XIX is a Federal-State grant-in-aid program, a serious constraint to fulfilling the EPSDT mandate has existed whereby States have opted to limit eligibility, the scope of services, and in some instances have even declined the opportunity to participate.

Interagency agreements between title V and title XIX agencies have been tried as a means to improve EPSDT performance but have generally proven inadequate for the need. It is believed that this administrative mechanism will fall short of well-intentioned hopes and promises because of inherent differences in agency mandates and goals. Title XIX, being administered by Welfare, is primarily aimed at income maintenance for families, the aged and disabled. Children's health needs are of only secondary importance as a factor in supporting the overall stability and functioning of the family unit. Title V orientation, as previously cited, is for the express purpose of improving health services for children and in particular those children from low-incomne families. Cost containment under title XIX is viewed primarily as providing less income maintenance for needy families, not as possibly denying a child the opportunity for a fair start in life.

The Association respectfully concludes that if the desire and intent of Congress is to meet the critical health needs of Medicaid children, then the responsibility for CHAP program authority must reside in Federal and State agencies that have as their primary objective the protection and promotion of children's health. These agencies must have the necessary professional capabilities and incentives to develop and ensure the availability of a comprehensive, integrated and continuing system of child health services. It is with regard to the issue of program authority that provisions of the existing title V child health and EPSDT statutes must be specifically addressed and references made in H.R. 6706. It is essential that CHAP intent and language reflect an understanding of both title V and title XIX child health mandates and activities.

Mr. MAGUIRE. Thank you very much, Dr. Force.

Dr. Lazar, would you proceed with your statement.

STATEMENT OF J. BRETT LAZAR, M.D.

Dr. LAZAR. I am Dr. Brett Lazar, Health Officer from Montgomery County, Maryland, and Immediate Past President of the National Association of County Health Officials (NACHO) on whose behalf I am appearing today. NACHO is the public health affiliate of the National Association of Counties (NACo)[1]. With me today is Mike Gemmell, Legislative Representative for both NACHO and NACo.

The purpose of my statement is to point out some of the opportunities and problems local government health agencies would face if H.R. 6706, the Child Health Assessment Act of 1977, were to be passed as presently written.

The National Association of Counties represents over 1,500 county governments which together make up over 90 percent of the U.S. population. The vast majority of these counties provide public health and medical care to their citizens[2]. It is also important to point out for the record that the National Association of County Health Officials and the National Association of Counties have been supportive of the goals of H.R. 6706. We have gone on record before the Congress and our constituents on the need to improve health services to all children. Our national organization passed unanimously a resolution supporting the objectives of H.R. 6706. That resolution is attached to this statement [see p. 50].

As you know, the major purpose of H.R. 6706 is to strenghthen Medicaid's early and period screening, diagnostic and treatment (EPSDT) services by: (1) requiring States and counties to provide EPSDT to those children not currently being reached; (2) providing incentives to States and counties by increasing the Federal Medicaid matching rate; and (3) requiring that all children reached under the program be immunized against childhood diseases. The attached resolution endorses these goals but does express concern over how these goals are to be achieved.

As proposed in section 5 of H.R. 6706, the bill requires that all federally aided child assessments be performed through comprehensive health care centers. This requirement, Mr. Chairman, will force many county health agencies currently providing screening and referring children to qualified providers, to either expand their public health and disease prevention services to include medical care or be disqualified from the EPSDT program. The requirement will not affect county health agencies that are currently providing

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[1] NACo is the only national organization representing county government in America. Its membership includes urban, suburban, and rural counties joined together for the common purpose of strengthening county government to meet the needs of all Americans. By viture of a county's membership, all its elected and appointed officials become participants in an organization dedicated to the following goals: improving county government; serving as the national spokesman for county government; acting as a liaison between the Nation's counties and other levels of government; and, achieving public understanding of the role of counties in the Federal system.

[2] Over 75% of the 3000 counties are administratively responsible for providing community health services. Over 68% provide medical assistance, 60% provide mental health services, 30% operate hospitals (nearly half of public hospitals are county operated), 38% provide emergency medical services, and 26% operate long term care facilities. Counties also provide traditional public health services: immunization programs, sanitation, home health, school health, V.D. clinics, well-baby clinics, alcoholism and drug abuse prevention and treatment, family planning, etc. To a large extent, these services are financed by local funds. Census data shows that counties spent $3 billion for hospitals and $1 billion for community health services in 1975. In 1976, counties spent $1.3 billion and $311 million, respectively.

comprehensive services under EPSDT; it will, however, encourage many prevention oriented agencies to go into the medical care business or be disqualified from the program. This would, in many cases, result in driving up the costs of county medical care. Counties presently finance over 10 percent of the annual $17 billion Medicaid bill. Coupled with inflation of health care costs, this will compound the financial burden on local government budgets.

Mr. Chairman, before we discuss our major concerns regarding the bill under consideration today, I would like to add our support to the following provisions:

We endorse the bill's emphasis on prevention. Prevention has long been the neglected part of Federal health care poli[illegible]

We support the increased technical assistance to States a[illegible] their political subdivisions to assist in carrying out the child assessment program (CHAPS);

We support the increases in HEW staff assigned to the program;

NACHO and NACo have long endorsed the concept of capacity building at the local level. Afterall, successful implementation of Federal initiatives depends on the level of expertise and training at the local level;

We endorse the promulgation of unified standards;

We support the immunization requirement, the expansion of services covered, the increased periodicity of health assessments and the inclusion of counseling, health education and advocacy;

We support strongly the increased financial assistance to States and counties to improve program performance and administration, especially the financial bonus provision for outstanding performance. Providing an increased Federal Medicaid match is a most needed incentive to States and counties that pay approximately 40 percent of the national Medicaid bill;

The extension of Medicaid eligibility to children under six, of families whose incomes meets State financial requirements for Medicaid but whose family structure makes them ineligible for Medicaid, is an excellent provision. H.R. 6706 will help counties meet their medical care obligations to children who cannot, for financial reasons, obtain their health care elsewhere. The bill does close one gap in Medicaid, that is, financial assistance in providing care to the so-called "Ribicoff kids." We will continue to seek Medicaid coverage for other gap groups presently financed by county governments—disabled but working persons, the working poor, nonresident aliens, alcoholics and drug abusers, among others; and

Finally, we support the provision providing resource development funds to start up comprehensive health care centers in areas where there are no other existing health care facilities, services and providers.

H.R. 6706 does lend itself extremely well to large urban counties operating HEW and/or OEO-sponsored comprehensive health care centers. Many of these centers are often run by county or city health departments which already provide primary care for patients screened in their EPSDT clinics. H.R. 6706 is also ideal for health maintenance organizations (HMO's) which provide primary care but have lacked resources to involve themselves in the prevention or public health aspects of health care.

Mr. Chairman, one section of H.R. 6706 that will create problems for county and city EPSDT clinics is the one that requires screening agencies to provide comprehensive care within 3 years of enactment. As such, H.R. 6706 does not lend itself well to the vast majority of county health departments in rural and suburban areas. In these areas screening and immunization functions have been carried out by most health departments but the medical care and consultation have been provided principally by private practitioners. If the bill were enacted as written, it would turn the screening, diagnosis and treatment over to primary care providers who have traditionally neglected prevention. Such a shift in existing practices would be a serious mistake since health departments went into immunization, well baby clinics and most recently EPSDT screening because the resources were not available, for whatever reasons, to provide such services to certain segments of the population.

We predict that if all screening and immunizations are left up to primary care providers, who are in most rural areas overburdened, immunization rates will drop, screening will be cut back and the cost of care will be increased.

Most county health agencies provide preventive care and limited treatment to low income and unsponsored patients—that is, those without Federal or private insurance or support for their medical care. Private practitioners, most often, treat the more affluent segments of the community. We strongly question HEW's assumption that private practitioners will assess, treat and take case management responsibility for CHAPS eligible children. The relatively low reimbursement rate will hardly overcome the existing patterns of dual-class care in many communities. Presently, counties supplement or pay totally for the needed services which the Federal and State Governments and third-party payors choose not to pay for. We do not believe that under H.R. 6706 the private sector will be willing to assume these increased costs. More likely, children will go unscreened, undiagnosed and not treated.

Mr. Chairman, the CHAPS proposal seems to us as another attempt by the Federal Government to preclude local governments from participating in federally supported health programs. We can document several examples of this trend. It started with the drafting and enactment of the Health Planning and Resources Development Act a few years ago. As originally proposed, the bill mandated that only private, nonprofit organizations could qualify as health planning agencies. The trend was repeated the following year with the enactment of an omnibus health bill that extended the authorities for community mental health centers, neighborhood health centers and migrant health programs. Recently, HEW has compounded the problem by administratively implementing the urban health initiative. This program has the same overall effect—to discourage local governments from participating.

These programs that I mentioned all have the same requirement that precludes local health agency sponsorship. It deals simply with the composition of the governing boards. In each instance, all require a majority of consumer representation on the governing board which automatically prevents local governments from becoming direct grantees for federally funded operational grants.

We have been told that the reason for precluding local governments from sponsoring health programs supported by Federal monies is that the programs need to be isolated from political pressures. However, we maintain that, in the long run, federally mandated programs initiated without the support of locally elected officials and their appointees and representatives are destined to fail. We have seen numerous examples of this end result.

Systematic changes can occur outside their local government structure. However, reform and improvement of programs generally occur within a locally accountable setting.

What assurances do we have that H.R. 6706 goals and objectives will be achieved by the private sector? We are not condemning nonprofit, private agencies, Mr. Chairman. Used in a proper way, they can serve as a sound vehicle to achieve needed Federal, State and local policy objectives. In most cases, they can accomplish a great deal. But we recognize that there are few private clinics and they do not cover or reach all low-income family children. Moreoever, we have serious reservations that private practitioners will improve the quality of care for children as proposed under CHAPS.

Another flaw in the approach advocated by CHAPS is that most private clinics are only concerned with one aspect of a child's well-being—that is, health status. Local health departments are in a position to deal with health problems on an interrelated basis. Public health agencies can ensure that all child health problems will be folded into a comprehensive community plan that addresses all their needs and problems. Child health needs and those of the community should be treated as a component of a total system aimed at solving problems affecting their health. This includes nutrition, inadequate housing, education, lack of social services, counseling and a host of other problems.

If all local health departments are expected to gear up to provide primary medical care, the $25 million that are proposed for bringing present EPSDT screening clinics up to primary care standards is grossly inadequate. Furthermore, there are not enough doctors being trained in primary care pediatrics to staff all of the assessment clinics proposed under CHAPS. The CHAPS proposal appears to be based on the assumption that EPSDT is not working because it does not offer "one-stop" care. This assumption does not take into consideration other findings which identify such things as the lack of outreach and case management services as the major barriers to its sucessful operation. As I mentioned earlier, the creation of "one-stop" care centers to serve one population group may result in increased costs due to duplication of services. We advocate that CHAPS should provide increased funds for outreach and should stress coordination of service and clear delineation of provider responsibilities.

Mr. Chairman, although we support the overall goals of H.R. 6706, we maintain that the following suggested amendments would strengthen the proposed CHAPS program.

First, the bill should allow county health departments to continue child health screening while at the same time referring patients to comprehensive health care facilities. This would prevent duplica-

tion and would maximize effective utilization of existing community resources.

Second, we favor the development of a comprehensive reporting system that would ensure proper screening, diagnosis and treatment by responsible public or private providers previously selected. Under this system, agencies would be assigned specific responsibilities. For example, county health departments would educate, advocate, broker, identify, locate, screen and, where appropriate, diagnose and treat children. Private practitioners would counsel and treat the same clients. Mr. Chairman, we should not debate who should provide services. Instead, we should advocate a system in which all components have a responsibility for either screening, diagnosis and/or treatment. Each agency, in turn, would be held accountable and responsible for carrying out its assigned functions.

Third, we suggest that the subcommittee and HEW look into the comparative performance of the National Health Service Corps and the health underserved rural areas (HURA) programs, both of which have more flexible board composition requirements. We have numerous case studies of the ways in which county governments have cooperated with HEW in ensuring adequate health care in rural areas.

Mr. CARTER. Mr. Chairman, I hate to interrupt, but certainly I have not seen much evidence of this. Although I have supported this particular National Health Service Corps very generously over the past few years, I have seen many deprived areas. I do not see Health Corps officials back there.

Dr. LAZAR. We would be happy to provide written case studies in support of that statement.

Mr. CARTER. You would not find very many of them in Kentucky.

Mr. ROGERS. You may proceed.

Dr. LAZAR. Finally we recommend that instead of attempting to phase out local health departments from the EPSDT program, it would make more sense to invest Federal funds in improving the capacity in local health departments to carry out their primary mission. That mission, Mr. Chairman, as you are well aware, is to protect the public's health through prevention activities, through early diagnosis of diseases and through efforts assuring access to health care for individuals without financial resources to acquire appropriate medical care.

H.R. 6706 should recognize that even with enactment of a comprehensive national health insurance program, which we support, a system will be needed to address major barriers to access of health care including lack of information, inappropriate or even justified fears, need for supporting or ancillary services, and inability to understand and/or accept those services.

If county health agencies are to assure access to mainstream health services for children, they must have the flexibility to be eligible for Federal health care reimbursement or support, not simply to susidize the status quo but to assist present child physical and mental health programs to more comprehensively address the needs of all children.

We thank the members for giving us the opportunity to comment on this child health assessment proposal. We are most willing to

work with your staff in seeking enactment of a bill that conforms with the points raised by our testimony.

[The resolution referred to follows:]

1735 new york avenue, n.w., washington, d.c. 20006 (202) 785-9577

Resolution Concerning NACo Policy
on Child Health Care (H.R. 6706; S.1392)

WHEREAS, counties are responsible for the bulk of public health protection and disease prevention among economically disadvantaged children; and,

WHEREAS, the existing effort to improve health services to poor children (early and periodic screening, diagnostic and treatment) reaches only 30 percent of the 12 million children currently eligible for medicaid; and,

WHEREAS, the EPSDT program does not reach an estimated 700,000 children under six who are in families whose income meets state financial requirements for medicaid but whose family structure (e.g., father living in house) makes them ineligible for medicaid and EPSDT; and,

WHEREAS, HEW has proposed a program (Child Health Assessment Program) to strengthen EPSDT by: requiring states and counties to provide EPSDT to those children not currently bring reached; providing incentives to states and counties by increasing the federal medicaid matching rate to 74 percent; and, requiring that all children reached under the program be immunized against childhood diseases; and;

WHEREAS, the proposal requires that assessments be performed through comprehensive health care centers; and,

WHEREAS, this proposal would drive up the costs of county medical care by requiring several county health departments to provide "hands-on" care; and,

WHEREAS, this provision would not complement the Administration's cost containment proposal because it would encourage additional health care spending; and,

WHEREAS, this requirement will force county health departments currently providing assessments (screening) and referring children to qualified providers to either expand their public health and disease prevention services to include medical care or be disqualified from the EPSDT program.

NACo URGES THAT Congress pass the proposed Child Health Assessment Program Act with the following amendment:

-Allow counties to continue screening and treating children or referring patients to comprehensive medical care facilities (this amendment would prevent duplication and would maximize effective utilization of existing community resources).

Adopted by General Convention
July 25, 1977

Mr. ROGERS. Thank you very much, Dr. Lazar.

Dr. Carter.

Mr. CARTER. Thank you, Mr. Chairman. Does this conclude the testimony?

Mr. ROGERS. Are there any other statements?

Yes, Dr. Carter.

Mr. CARTER. Dr. Lazar, I take it that you are a county health official?

Dr. LAZAR. Yes, county health officer, Montgomery County, Maryland.

Mr. CARTER. What are your duties there?

Dr. LAZAR. That is difficult to answer in a short time. I think generally if we categorize health services provided by local health agencies into community health, mental health, and environmental health, the county health office includes community health and mental health. Environmental health is in a separate agency in Montgomery County. However, we include other more traditional public health programs. We also have some treatment for children as would be included under CHAPS.

Mr. CARTER. Does your county have periodic screening programs for children?

Dr. LAZAR. Yes, sir, throughout the county.

Mr. CARTER. At what ages?

Dr. LAZAR. Through age 21.

Mr. CARTER. Through age 21. Is this program just for a certain group as determined by their financial condition?

Dr. LAZAR. No, sir, it is not. We attempt to provide the services to all those seeking the tax-supported services in Maryland. Generally it is true a certain segment of the population takes advantage of those services, but it is not limited by income except in the Silver Spring area.

Mr. CARTER. In other words, you take care of all of those under age 21?

Dr. LAZAR. Yes, sir. We do have a sliding scale fee.

Mr. CARTER. What happens to the fees which you get?

Dr. LAZAR. We are supported by all three—State, county and Federal funds—and the funds go back in the proportion they are collected on the basis of the payment. So that if 50 percent of the cost is borne by the State, the State takes 50 percent of the fees collected.

Mr. CARTER. What happens to the other 50 percent?

Dr. LAZAR. The county, if it is county funds.

Mr. CARTER. Are you on a salary?

Dr. LAZAR. Yes, sir.

Mr. CARTER. At what age do you begin screening the children?

Dr. LAZAR. We begin with the first visit following birth, generally in the sixth week or so.

Mr. CARTER. Is there a postnatal visit?

Dr. LAZAR. Yes, sir.

Mr. CARTER. At that time what do you do besides examine the child?

Dr. LAZAR. If I may defer that—and I do not like to do this to Dr. Hackman, who is going to speak later—I believe her testimony

more directly addresses what goes on. I was attempting to give a statement that was more general.

Mr. CARTER. I think we should get to the center of what you are doing and what you mean to do and how this legislation will change that. Traditionally health officials such as yourself have been people who have practiced preventive medicine, who have examined people periodically, who have given immunizations over time, and when they have found defects, have referred them to trained people in different fields. Crippled children, for instance, are referred to special types of hospitals for treatment, isn't that correct?

Dr. LAZAR. That is true, yes, sir.

Mr. CARTER. At the present time in addition to your preventive medicine are you advocating follow-up treatment?

Dr. LAZAR. No, sir, we do not, sir. As was mentioned in the testimony, in many areas local health agencies of necessity in most cases have become involved in treatment as well as in the screening and diagnoses because of lack of resources in the private sector. In Montgomery County, for instance, we have developed what we call a comprehensive care clinic for children in one area of the county because the private resources there and the need in the population was different than for the other five-sixths of the population elsewhere. We do not provide the diagnosis and treatment services outside the Silver Spring area.

Mr. CARTER. But you do provide treatment?

Dr. LAZAR. We do in that one area of the county. We do through crippled children's programs for specific segments of the population.

Mr. CARTER. You refer them, do you not?

Dr. LAZAR. Yes, sir.

Mr. CARTER. I would not think you would have the trained personnel for that within your department.

Dr. LAZAR. Yes, we do have trained personnel.

Mr. CARTER. I mean orthopedic surgeons and so on.

Dr. LAZAR. We have crippled children's clinics, consultative clinics that provide diagnosis and follow up. The specific treatment is often provided elsewhere.

Mr. CARTER. But you, within your department, do not treat crippled children, do you?

Dr. LAZAR. As I said, generally the diagnosis and the follow up is performed within these clinics in the treatment. The treatment is often done outside the department.

Mr. CARTER. Then do you treat orthopedic cases within the health department?

Dr. LAZAR. We do not provide surgical services.

Mr. CARTER. All right. That answers the question very well.

Thank you, Mr. Chairman.

Mr. ROGERS. All right, sir.

Mr. Maguire.

Mr. MAGUIRE. Thank you, Mr. Chairman.

There has been some justifiable concern with the record of local health agencies, in the aggregate, in the past, with respect to effectiveness of outreach for example, and I wonder if you could describe the outreach program your local department provides, by way of example; how effective has it been in reaching eligible children under the EPSDT program?

We have had problems in various parts of the country, including my own State. I am just wondering if you might have some positive examples on the basis of which we could hope to proceed.

Dr. LAZAR. I am not sure we are doing anything in Maryland that is greatly different from anything available elsewhere in the country. Generally we participate in the program, the prime sponsor of which has been the State.

Maryland's has been designed to refer all EPSDT children, eligible children, to local health agencies and sent out on a statewide basis. Each local agency has supplemented what is available by working closely with the Department of Social Services in the community, by making sure local media are available of the services that are available. I think probably our Public Health nurses are our primary agents of outreach in knowing the communities in which they work and their families. They work in the schools and are able to identify the school-age children who might be eligible for the services and not receiving them. They have a close link with the practicing physicians in the community and frequently physicians will refer children who might not otherwise get into the system. So there are a number of different ways of reaching out to the people who are qualified for the services.

Mr. MAGUIRE. What are the outcomes? What is your percentage of effectiveness as you look back on the EPSDT program?

Dr. LAZAR. I think you are going to find a great deal of variability across the country. I think probably that is good. As I mentioned, in Montgomery County we have a very different availability of resources in different parts of the county, and you are going to find that in different States and across the country, so that in some cases the private sector is meeting most of the needs and in just looking at the percentage of children participating in a local health agency EPSDT program, it might give you a very poor look at their outreach efforts.

On the other hand, in other agencies where the private resources are not available, the people are going to turn to the local health agency for the service, and the percentage of those participating is going to be much higher with or without the outreach.

Mr. MAGUIRE. I take it the answer to the question with respect to outcomes is that Montgomery County does not have anything in particular to tell us or to brag about; is that a fair conclusion?

Dr. LAZAR. Not at the tip of my tongue, I do not have. I really cannot tell you on a comparative basis. Dr. Fine may be able to, since he is working with the program at the State level in Maryland. I do not know what our record is compared to others in that respect.

Dr. FINE. I could not give you specifics for Montgomery County at this point. In fiscal 1976 we screened over 85,000 children throughout the State of Maryland exclusively through local health departments. Of those, approximately 25 percent were medical assistance eligible children. We have a policy in the State of Maryland that any child who comes to a local health department would be eligible for the comprehensive screening package.

Now, it just may be that children with medical assistance cards go to private practitioners or to emergrency rooms and do not

choose to come to local health departments. That may be one of the problems inherent in the carrying out of this program. I do not know if that has really been looked at.

The percentages are somewhat higher in Baltimore City, where there are larger numbers of Medicaid eligible children.

Mr. MAGUIRE. Dr. Lazar, or perhaps Dr. Force, you may want to comment also. As I understand it, head start now serves some 175,000 Medicaid eligible children. Do you think that other groups like head start, public schools, or community-based, nonprofit organizations, might be better able to provide the outreach to bring people in?

Dr. FORCE. I don't know that they would be better able but I think they are certainly a resource that should be looked at very carefully. I think that we can utilize many resources that up to now have not been fully utilized, and I would think that would fit into that category.

Mr. MAGUIRE. With head start you have the children there.

Dr. FORCE. That is right.

Mr. MAGUIRE. And you have follow-up and treatment directly under your wing, so to speak.

Dr. FORCE. Outreach is a very expensive proposition in terms of the personnel required to follow some of the typical families who move around very frequently. They are not families that will make and keep appointments regularly. Many of them do not have telephones. They have no source of transportation. They are just very difficult families to reach, and the number of personnel and time commitment that is required to provide this kind of outreach is substantial. We would like to do it. We would like to do more of it. It is going to take more funding.

Mr. MAGUIRE. Dr. Lazar, would you comment on the head start example?

Dr. LAZAR. I am generally in agreement. Frequently the head start programs are contracting with local health agencies to provide the services provided to the children. So we already work very closely with them. The population served in head start are receiving other services through local health agencies, and we would, as Dr. Force referred to, expect to continue to provide services to this captive population.

Mr. MAGUIRE. Dr. Force, what type of provisions do you think should be included in legislation, especially for adolescents, or other special services?

Dr. FORCE. I would like to defer that question to Dr. Fine, if I could, who actually directs the program in Maryland for the adolescent.

Dr. FINE. I would have to say that at the present time we are reaching adolescents primarily through local family planning clinics, through venereal disease services, through drug abuse clinics, and so on. Health care is not a priority with the adolescent population. We are seeing a good many of them because of teenage pregnancy and they are coming in increasing numbers to our prenatal clinics.

Insofar as specifically gearing health services toward adolescents, I think we have to recognize again that health is not a priority of

the adolescent population. Adolescents are more in need of activities and recreation where health would be provided as a secondary incentive.

I think there is an outstanding federally-funded program in Greenwich Village in New York City which has made extensive use of this model. They are funded through title X for family planning, and also with drug abuse legislation, and they have provided in essence a department store setting which is primarily recreational, music, crafts, and so on. Nutrition is brought in as a major effort, and these children in essence are referred to the health system secondarily. In this way they get excellent health services, but the outreach to adolescents is a tremendous problem.

Mr. MAGUIRE. Thank you, Mr. Chairman.

I could pursue a number of other avenues of inquiry here, but I see we do have a long witness list. I don't know how on earth we are going to get through everybody today.

Mr. ROGERS. I am going to make a suggestion on that in a minute.

Mr. MAGUIRE. I will try to help.

Mr. ROGERS. I thank the gentelman.

Thank you for your appearance here. It has been most helpful. We may be in touch with you as we proceed.

My suggestion is, since we do have quite a number of witnesses that we want to try to hear today, and many of them have to make airplane connections by about 6 o'clock, I would suggest that the statements be filed, and then that oral statements be confined to 5 minutes, highlighting the point each witness may desire to make. I think this would give sufficient time to get across the points, and your full statement will be made a part of the record and gone over by members and staff.

The next panel will be a panel of State welfare administrators on behalf of the American Public Welfare Association: Nancy Feldman, EPSDT supervisor, Minnesota Department of Public Welfare; Anne L. Shenberger, coordinator of Interagency Task Force on Early Health Screening, Governor's Office of Pennsylvania, and Department of Public Welfare; Dr. Helen Hackman, director, Arlington County, Virginia, Department of Human Resources; and Gerald Reilly, who is deputy commissioner, New Jersey Department of Human Services; and I understand the panel will be accompanied by Margo Vignola of the American Public Welfare Association.

We welcome each of you to the committee.

It would be helpful if statements could be filed and will be made a part of the record at this point, and if you could highlight for us in 5 minutes the testimony you think most important for the committee to concentrate upon.

STATEMENTS OF ANNE L. SHENBERGER, COORDINATOR, INTERAGENCY TASK FORCE ON EARLY HEALTH SCREENING, GOVERNOR'S OFFICE FOR HUMAN RESOURCES, COMMONWEALTH OF PENNSYLVANIA, ACCOMPANIED BY JAMES McKITTRICK, EPSDT PROJECT DIRECTOR, PENNSYLVANIA DEPARTMENT OF PUBLIC WELFARE; NANCY J. FELDMAN, SUPERVISOR, EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT PROGRAM, MINNESOTA DEPARTMENT OF PUBLIC

WELFARE; HELEN HACKMAN, M.D., DIRECTOR, ARLINGTON COUNTY, VIRGINIA, DEPARTMENT OF HUMAN RESOURCES; AND GERALD REILLY, DEPUTY COMMISSIONER, NEW JERSEY DEPARTMENT OF HUMAN SERVICES; PANEL ACCOMPANIED BY MARGO VIGNOLA, AMERICAN PUBLIC WELFARE ASSOCIATION

Ms. SHENBERGER. Mr. Chairman, I will be starting.

I am Anne Shenberger from Pennsylvania. I have brought with me the EPSDT program director from the Department of Welfare who is sitting at the middle of the table, Jim McKittrick, who can respond to questions related to operation.

I chair a task force run out of the Governor's Office in the State of Pennsylvania which is related to coordinating EPSDT with other programs for children. We have a couple of goals. Our long-term goal is to look at child health services in the State of Pennsylvania and make some recommendations about where we should be going.

Our short-term goal is to identify specific program areas, and make recommendations of two types: One is to develop a technical assistance tool which can be used by people who are delivering services in the field to children that would facilitate coordination with their program and EPSDT. The other is to look at State and Federal regulations relating to these program areas, and make recommendations for changes in the regulations which would facilitate coordination.

So far, since March of 1976, we have looked at five program areas: day care, head start, child health conferences, which are the title V child health programs in Pennsylvania and school health services, and the EPSDT program itself.

In each area we have found regulatory requirements which work against coordination. For example, in title XX day care programs, our State day care requirements call for a physical examination, tuberculosis testing and immunizations annually.

Our EPSDT program is based on standards of the American Pediatrics Association which requires that the screening be done once every 2 years. The testing and the physical examination on the off-years cost the Medicaid program anywhere between $60,000 and $100,000 because we have about 20,000 kids, half of whom are eligible for EPSDT.

In head start, we have had a similar situation where head start performance standards require annual testing of children for all the same tests plus a few additional ones that our EPSDT program provides, and it has only been recently, in 1976, that OCD has changed their period for head start to conform to the American Academy of Pediatric standards. So that head start programs were being faced with having their monitoring staff from OCD come out and tell them they were not in compliance even if they were using the screening program because they still needed to get the off-year examinations performed.

In the child health conferences again, as the gentlemen before me stated, many of the same services are provided in the child health conferences. And in our State, the children, a third of them, were eligible for EPSDT, we were estimating, and yet these children still were outreached by our local county assistance offices, although

they were connected with an ongoing source of health care, and they were receiving services. So that these very limited outreach resources on the part of our county assistance offices were being devoted to people who were already receiving services.

Finally, in school health, we have been looking at ways to involve the provision of school health services and EPSDT, and toward that end we have been looking at developing a demonstration project which would look at ways of utilizing nurse practitioners as well as bringing providers into school districts, into schools, to provide EPSDT, and agree to provide diagnosis and treatment in their own practices in the community so that we could facilitate ongoing care within a school setting.

Those are the areas that we have looked at in the past. We have some recommendations for changes in H.R. 6706, because one of the reasons that we are here today is that we feel that the issues of coordination have really been neglected in this legislation.

[Testimony resumes on p. 73.]

[Ms. Shenberger's prepared statement and attachment follow:]

97-633 O - 77 - 5

STATEMENT OF MEMBERS OF INTERAGENCY
TASK FORCE ON EARLY HEALTH SCREENING
OF THE GOVERNOR'S OFFICE OF THE
COMMONWEALTH OF PENNSYLVANIA ON THE
CHILD HEALTH ASSESSMENT PROGRAM (HR 6706)

Statement Presented by Anne L. Shenberger, Task Force Coordinator

My name is Anne Shenberger. I represent the Governor's Office for Human Resources of the Commonwealth of Pennsylvania. The Governor's Office has been interested in the implementation of the EPSDT Program and its coordination with other publically funded programs for children since April, 1975, when it organized the Interagency Task Force on Early Health Screening. I am the Coordinator of this Task Force.

The Task Force has two basic goals. Our long term goal is to study existing programs to determine alternative ways to provide efficient, comprehensive, high quality health services to the greatest number of children, and to work for the implementation of these alternative programs at the state and local levels. Our short term goal is to recommend administrative policies and procedures which will facilitate and institutionalize coordination between EPSDT and other publically funded health, education and social service programs for children. To meet this short term goal, we have involved a number of individuals with varied backgrounds in the work of the Task Force. These people include those with authority over program administration, those who operate programs and would be affected by policy and procedure changes and those with expertise in the field of child health. A membership roster and annual report is attached to copies of my written testimony.

Five program areas have been studied by the Task Force since March 1976: day care, Head Start, Title V maternal and child health services, the school

health program, and the EPSDT program itself. In each program area studied we have tried to develop a technical assistance document which will aid people actually delivering health, education or social services to eligible children in coordinating and integrating the EPSDT program into their operations. We feel strongly that people at the service delivery level should be provided with the tools necessary to achieve effective service coordination. Second, we have developed and worked for changes in state regulations and policies that require agencies to become concerned and active in coordinating their services with other health programs. We have been successful in both of these areas. These program areas are by no means exhaustive. In the coming year, the Task Force will address the areas of mental health and mental retardation, family planning, child welfare, youth services, dental health and the WIC program to identify possible areas of coordination with EPSDT (CHAP).

I am here today because I believe that the experience that we have had in pursuing our goals is fairly unique and will be of some value to the subcommittee in its consideration of HR 6706, the Child Health Assessment Act, and because we believe that the area of service coordination has been neglected in the proposed legislation.

In each program area studied, the Task Force has found policies or conditions which prevent program coordination and integration. For example, Pennsylvania regulations governing Title XX day care require that children receive an annual physical examination, TB test and complete immunizations. Pennsylvania's EPSDT program provides a full range of preventive services including those required by day care regulations, but the EPSDT periodicity schedule calls for screening

once every 24 months for children over age 18 months. The EPSDT periodicity schedule is based on the American Academy of Pediatrics Standards of Child Health Care. Proposed revisions in these day care regulations will remove this barrier to coordination by tying day care health requirements to the American Academy of Pediatrics Standards on which the EPSDT program is also based. Our Task Force has been an active participant in the regulations drafting process.

There are approximately 20,000 children in Title XX day care in Pennsylvania, 50% of whom are eligible for EPSDT. Therefore, this change could save the Medicaid program $60,000-$100,000 in payments to physicians and outpatient clinics for physical examinations.

HEW's Office of Child Development has been actively supporting collaboration between the Head Start and EPSDT programs since 1971. At the same time, OCD has been enforcing Head Start Performance Standards which contain requirements which present effective coordination between the two programs. Head Start Performance Standards require that a comprehensive range of preventive health services, basically identical to those provided by EPSDT, be provided annually. In Pennsylvania, the Head Start program serves approximately 10,000 children, 75% of whom are eligible for EPSDT. The cost of providing EPSDT level services to these children annually, as is required by Head Start Performance Standards, would be approximately $180,000.

In November of 1975, the Pennsylvania Head Start Administrators had requested policy clarification regarding the discrepancy in Head Start Performance Standards and EPSDT program requirements. In July of 1976, OCD issued a tentative policy interpretation regarding the periodicity of screening which changes Performance Standards requirements to more nearly reflect those of Pennsylvania's EPSDT program.

The preventive child health services funded by Titla V, called child health conferences, provide all services required by Pennsylvania's EPSDT program except urinalysis, and routine testing for sickle cell anemia and lead poisoning. Approximately 90,000 visits are made to the 181 bhild health conference sites in 60 counties annually. These visits are made by 37,333 children. We estimate that at least 1/3 or 12,577 of these children are eligible for EPSDT. By attending the child health conference, these children are receiving essentially the same services as those provided by EPSDT. However, in order to maintain compliance with Federal EPSDT regulations, each of these children must be offered participation in EPSDT by the local County Assistance Office. If EPSDT paid for these eligible children, the $249,212 generated could be used to increase the number of children in a community who can be served by the child health conference. Additionally, by eliminating children who are enrolled in the conferences, valuable outreach time can be concentrated on those families who have not utilized health services.

Our Task Force has actively supported coordination of these two programs and was involved in the development and implementation of a coordinated program based on an Interagency Agreement between The Department of Health and Public Welfare for the period June 1976-July 1977. The Agreement allows State Health Department participation in the EPSDT program as a provider in areas designated as provider shortage areas by The Department of Public Welfare. Currently, there are thirteen such areas. The Agreement provides that The Department of Public Welfare will reimburse The Department of Health directly for EPSDT services rendered by physicians who are under contract to The Department of Health and public health nurses who are employed by The Department of Health.

The Pennsylvania Public School Code requires that the school health program

provide a range of preventive health services, similar to EPSDT, at specified intervals. The school health program in the City of Philadelphia provided the mandated services to 350,000 children during the 1975-76 academic year at a cost of $922,365. 152,000 of the children (43%) were eligible for EPSDT. In Philadelphia, the EPSDT program expends $3 million to provide outreach and screening services, which are largely separate from the school system.

Our Task Force is currently drafting a proposal for a demonstration project in school health/EPSDT coordination which would encourage qualified practitioners from the community to provide EPSDT screening in schools as well as agree to provide necessary diagnosis and treatment in their regular offices. The project will also encourage the use of nurse practitioners in school health programs as providers and coordinators of care.

The examples cited from Pennsylvania's experience are probably not unique. They show that large amounts of public funds are being expended for outreach and screening generally without regard for the key role that community institutions such as schools and programs such as day care and Head Start play in the lives of the families who receive services from them.

Our Task Force works for coordination of services not only to reduce costly duplication of service; but also because we believe that coordination of EPSDT and the proposed CHAP with other service programs more appropriately meets the goal of assuring adequate utilization of health services. It is a fact that the current EPSDT program and the proposed Child Health Assessment Program are a part of Medicaid. Medicaid is a financing program. It provides payment for specific services rendered to specific individuals by specific practitioners at a specific point in time. The Medicaid financing system

does not approach the health needs of a child from a wholistic point of view. We believe that through coordination with service programs, whether they are health, education or social services, the services paid for by CHAP can be used as a part of a comprehensive service package. Further, we believe that those institutions and agencies which already interact in a generally positive way with families and children should be a focal point for informing families about this health service and assuring that services are obtained. Aggressive outreach will still be needed because there are many eligible families who do not routinely interact with community agencies.

We recommend the following changes in the proposed legislation HR 6706:

1. Section 2, Declaration of Purpose, should be amended to add an item (6) which should state: to assure optimum utilization of existing resources in both arranging for and providing adequate child health assessments, diagnosis treatment and reassments of all eligible children.

   This item would incorporate the utilization of existing agencies as outreach mechanisms as well as the utilization of existing health service programs as providers.

2. Section 1912 (b)(1). We advocate the adoption of flexible wording in the regulations adopted by the Secretary as well as the use of standards developed by a national standard setting body such as the American Academy of Pediatrics. Regulatory wording which uses references to "age appropriate preventive health services as recommended by the American Academy of Pediatrics" allows for changes in medical knowledge to occur without a need for changes in regulations.

3. Section 6. Section 1902 (a)(37) should be amended to state: provide that the state will encourage participation by physicians and health care centers in the program described in Section 1912 of this Act; will assure coordination between state and local agencies administering that program and other publically funded health service programs including those funded under Section 330 of the Public Health Service Act and Title V of the Social Security Act by providing reimbursement under Title XIX to these programs for services provided; will assure the availability of outreach services which include utilization of publically funded health, education and social service programs for families and children as well as other support services such as case tracking in accordance with regulations of the Secretary, to individuals and health care providers participating in the program described in Section 1912.

These words must be followed up by action on the part of the Department of Health, Education and Welfare. HEW action with regard to coordination of CHAP with existing programs should include several aspects. First, the Secretary should instruct the various branches of HEW involved with children and child health, including the Health Care Financing Administration, to develop procedures for coordination and communication among themselves. This may include the assignment of specific staff to coordination tasks. Second, regulatory and other policy changes should be coordinated with the activities of related agencies. Third, guidelines should be produced to provide technical assistance to states in the area of service coordination. Those at the service delivery level cannot and should not be expected to deliver services efficiently while wading through the maze of conflicting and fragmented regulations to determine the most effective coordination procedure. With adequate assistance from HEW through coordinated policy and technical assistance, states can develop the most appropriate mechanisms for coordinating services locally.

ANNUAL REPORT

INTERAGENCY TASK FORCE ON EARLY HEALTH SCREENING

MARCH 1976 -- FEBRUARY 1977

ANNE L. SHENBERGER
COORDINATOR

COMMONWEALTH CHILD DEVELOPMENT COMMITTEE
GOVERNOR'S OFFICE FOR HUMAN RESOURCES

February 10, 1977

The Interagency Task Force on Early Health Screening was formed in April of 1975 for two purposes. Its short term purpose is to recommend administrative procedures which will facilitate and institutionalize coordination between EPSDT and other publically funded social service and health services for children. Its long term purpose is to study the existing service delivery systems to determine alternative ways to provide flexible high quality, non-duplication child health screening, diagnostic and treatment services to the greatest number of children; to recommend such alternative systems; and to advocate their adoption by the relevant statewide authorities. In order to meet its short term goal, the Task Force has attempted to extend membership to those with authority over the program operations at the different areas studied, those who administer the programs who would be affected by program changes, and those with expertise in the field of child health. A membership roster is attached.

Five program areas have been analyzed by the Task Force to date. They are day care, Head Start, state Health Department funded child health conferences, school health and EPSDT. In each program area, the Task Force has attempted to do two things. First, we have tried to develop a document which will be useful to people actually delivering services to children who wish to coordinate their program with EPSDT. We feel strongly that because the EPSDT program is a complex one, people at the service delivery level should be provided with the technical assistance needed to implement effective coordination procedures. Second, we have analyzed existing EPSDT and related program regulations and recommended policy or regulations which would facilitate coordination. We have generally been successful in both of these areas. Task Force action with regard to each of the program areas and the results of this action are outlined below.

Day Care

A set of step by step coordinating procedures have been developed by the Task Force to aid local day care program staff in securing the preventive services that EPSDT has to offer for those children in their programs who are eligible. Coordination with EPSDT may not appear to benefit those children who are not eligible for EPSDT directly, we have found that day care programs can negotiate lower physician fees for similar services for these children. While these procedures speak specifically to day care programs, they have been found to be just as useful for Head Start programs. An added advantage in the Head Start program is the availability of funding to pay for provision of EPSDT level services to children who are not eligible for EPSDT. Such funds are usually not available to day care programs.

The procedures contain instructions for all aspects of the EPSDT program: determining eligibility for the service and obtaining information about whether or not the child has already been screened, obtaining screening appointments, obtaining screening when a parent cannot accompany the child, obtaining screening results for the day care health

record, and obtaining diagnosis and/or treatment if referral is indicated. After an initial draft of the procedures was completed, it was circulated for comment to a wide range of groups and individuals involved with both the day care and EPSDT programs. These groups and individuals included: The Pennsylvania Association of Child Care Administrators, Child Care Administrators Association of Southeastern Pennsylvania, Pennsylvania Head Start Administrators Association, Director, Bureau of Child Development, DPW, DPW Regional Office Day Care Monitoring and Licensing Staff, EPSDT Project Officer, DPW, DPW Regional Office EPSDT Coordinators, several County Board of Assistanct EPSDT Coordinators, and EPSDT Administrative contractors. These groups and individuals provided a wealth of comments and suggestions on which final revisions of the procedures were based. The process of developing these procedures was begun in March of 1976. The final revision of the procedures was prepared September 29, 1976.

The procedures are being adopted as DPW policy by the Bureau of Child Development Programs and the Bureau of Medical Care Systems through the issuance of joint social service and medical assistance memoranda. These memoranda will state the purpose for which the procedures are to be used, as guidelines for implementation of local program coordination with EPSDT, and will require the two program staffs to develop these plans together.

The Task Force has also been active in the process of drafting new child day care regulations which would facilitate day care coordination with EPSDT by eliminating several barriers contained in the current regulations. Proposed child care regulations were published October 16, 1976. A series of public hearings were scheduled across the state in addition to a 45/day public comment period. The Task Force organized the presentation of testimony at all four Regional hearings as well as the statewide hearing. This testimony was generally supportive of the proposed regulations since we had been involved in the drafting process. Some changes were recommended, however. Final regulations are expected by late summer, 1977.

Head Start

As has been noted above, the coordinating procedures developed by the Task Force have been useful to Head Start as well as day care programs. They have been endorsed by the Pennsylvania Head Start Administrators Association.

Pennsylvania is one of five states participating in a federal demonstration project in Head Start/EPSDT coordination. The Office of Child Development (HEW) has provided funding for the employment of a statewide Head Start/EPSDT coordination facilitator. This funding is the second phase of continuing efforts to identify effective ways in which local Head Start programs can coordinate with EPSDT. Phase I provided small grants to Head Start programs to employ health coordinators who would be responsible for coordination at the program level. There was one such grant awarded in Pennsylvania -- Chester County Head Start. Phase II provides a small grant to employ an individual who functions on a statewide basis. A Head Start program (Lancaster County Head Start) acts as administrator of the grant. This Phase II effort is intended to address the problems which arise from differing types of

administration of the Head Start and EPSDT programs. Head Start is a federally and locally funded program in which grants are awarded to local programs directly from HEW's Regional Office of Child Development. There is no statewide administrative body. Pennsylvania is unique in having an identifiable body, the Commonwealth Child Development Committee, which is charged with the Governor's Approval function. EPSDT, as a part of the Medical Assistance program, is a state-administered program.

The Phase II Statewide Health Coordinator in Pennsylvania is Paul Phelan. He is a staff member of the Task Force for Head Start. His activities have been oriented toward helping local Head Start programs coordinate with EPSDT through the use of the procedures developed by the Task Force. Other activities have included the planning of two conferences for Head Start Coordinators, EPSDT administrative contractor field representatives and County Board of Assistance EPSDT Coordinators.

Paul Phelan's presence as the Statewide Health Coordinator has provided a vital communications link with local Head Start programs for the provision of technical assistance and the channeling of problem areas to the Task Force for action.

Department of Health: Child Health Conferences

In Pennsylvania, the State Department of Health is responsible for the provision of public health services to children in most counties of the state. There are six county health departments (Allegheny, Allentown-Bethlehem, Bucks, Chester, Erie and Philadelphia) which provides their own infant and preschool health services and do not receive funding from the State Health Department for health services. Most of the counties with county health departments (Allegheny, Bucks, Chester and Philadelphia) participate in EPSDT as provider sites. However, the remaining counties served by the state Health Department infant and preschool health program (known as child health conferences) have not been involved in EPSDT. One of the reasons involved the difficulty in reimbursing the Health Department for providing services under the Medical Assistance program. On June 8, 1976, a meeting was held at which the Secretary of Health and the Deputy Secretary of Public Welfare for Family Assistance agreed that the state child health conferences should be involved in the EPSDT program and approved the preparation of an interagency agreement to outline the extent of coordination and the method of reimbursement to the Department of Health. This interagency agreement was drafted with Task Force input and signed in September of 1976 for the year July, 1976 - June, 1977. It allows state Health Department participation in the EPSDT program as provider sites in areas designated as provider shortage areas as by the Department of Public Welfare. Currently, there are thirteen counties designated as provider shortage areas (Beaver, Bradford, Crawford, Delaware, Fayette, Indiana, Lackawanna, Monroe, Montgomery, Northampton, Pike, Washington, Wayne, Westmoreland.) The agreement provides that the Department of Public Welfare will reimburse the Department of Health directly for the EPSDT services rendered by physicians who are under contract to the Department of Health and public health nurses who are employed by the Department of Health.

The planning process for implementation of the agreement began with a training meeting held July 22, 1976, for Health District directors and public health nurses from the thirteen counties. The Task Force prepared

a set of step by step coordinating procedures for use at this meeting and in the actual implementation of the coordinated service. The Task Force was also involved in planning for district by district implementation and receives periodic reports of the progress made toward actual implementation.

Department of Health: School Health

After studying the existing school health program and its possible points of interface with EPSDT, the Task Force felt that there is currently no clear indication of the most effective manner in which to coordinate these two programs on a statewide basis for a variety of reasons. The School Health Program is part of the total educational program administered by local school districts. There are 505 school districts in the state of Pennsylvania. Contact would need to be made with all 505 school superintendents and school boards in order to implement coordination with EPSDT on a statewide basis. The Department of Health is responsible for school health program content within the mandates of the Public School Code and provides the state reimbursement to school distracts for a portion of their school health program. Because the Department of Education, the Department of Health and the local school district are all involved with the school health program, program administration is complex.

There is one school district which currently operates a coordinated school health/EPSDT program. CHAP (Collaborative Health Assessment Program), operated by the School District of Philadelphia in collaboration with community based health providers and the EPSDT administrative contractor, provides EPSDT services in selected schools to those eligible children in grades in which a physical examination is mandated by the Public School Code (Kurl 5, 11). Health providers from the community in which the schools are located provide EPSDT level services to all children, billing EPSDT where the children are eligible and billing the regular school district hourly rates where they are not. The community based health providers also agree to provide further diagnosis and treatment at their facility if so desired by the child and/or parents. Parental consent and the child's health history are obtained through the child. Materials are sent home with and returned by the child. While this type of program may be feasible in other urban areas, the Task Force felt that other methods for coordination of the two programs might also be effective, particularly in rural areas of the state where there are few health providers who accept Medical Assistance patients.

The Task Force decided that the generation of reliable data regarding effective methods for coordination through the development of a demonstration project grant proposal would be the most important contribution to be made in this area. A demonstration project will allow experimentation with different methods of service delivery in the school setting. Evaluation of the efficiency and effectiveness of the methods will provide useful guidelines for the development of statewide policies regarding the coordination of these two programs. A subcommittee of the Task Force has been developing a project outline. The project will focus on a target population of children ages 12-21 who are in school. Two service delivery models will be tested. A control group will also be designated. One service delivery model will utilize health providers from the community and designate the County Board of Assistance as responsible for case management. The other service model will utilize trained school

nurse practitioners ad the providers of service and case managers. The Commonwealth Child Development Committee will serve as the grantee. Within the Committee, a policy council will be established including representatives from the Interagency Task Force, Department of Education, Department of Health and the Department of Public Welfare.

Prospects for funding seem reasonably good. The Task Force was advised to prepare a project outline or concept paper by Beatrice Moore, EPSDT Director, Medical Services Administration, HEW, Washington. Impact on the adolescent age group and coordination with school health programs are two of the priorities for research and demonstration project funding requested by the EPSDT program office in HEW. Pennsylvania is in a good position to receive funding because our EPSDT program is considered one fo the best in the country by HEW.

EPSDT

The Department of Public Welfare has accepted coordination with other programs for children as a legitimate function of the EPSDT program. As a result, significant regulatory and administrative changes have been made. Revised state EPSDT regulations were published August 14, 1976, and adopted finally October 9, 1976. The final regulations include coordination with other programs providing services to children as the responsibility of both the County Assistance Office and the administrative contractor. The County Assistance Office, EPSDT Operations Manual drafted by the DPW Supportive Services Unit to accompany the regulations, includes guidelines for actual implementation of coordination activities. Medical Assistance and Public Assistance Memoranda will be issued jointly with the Social Service Memorandum adopting the coordiaating procedures as DPW guidelines. Issuance through all three channels will assure that all those involved in the coordination process are aware of their responsibilities in this process. All these activities have been conducted by the Task Force.

Future Agenda

The Task Force has accomplished a great deal in the two years it has existed. However, there are still many unfinished tasks. With regard to the technical assistance documents developed by the Task Force for day care, a great need exists for training of DPW staff, particularly the Regional day care monitoring staff. Technical assistance provided day care program staff in coordinating with EPSDT is of little value if DPW program monitors interpret regulationsin a manner adverse to coordination. Additionally, written instructions for the use of the coordinating procedures do not take the place of training.

The school health demonstration project is still in its embryonic stages. Development of the project outline and funding proposal remain to be completed.

The coordinated child health conference/EPSDT program is still in the planning stages.

Head Start/EPSDT coordination is supported by the Office of Child Development in Washington through the Phase II demonstration project. Task force relationships with OCD need to be strengthened.

Finally, not all possible program areas have been studied. The next program area to be discussed by the Task Force will be child welfare.

INTERAGENCY TASK FORCE ON
EARLY HEALTH SCREENING

Membership Roster

February 17, 1977

Jerold M. Aronson, MD
Director, School Health Services
School District of Philadelphia
21st and Race Streets
Philadelphia, PA 19103
215/299-7481

Susan S. Aronson, MD
Project Director
Health Advocacy Training Project
Medical College of PA
3300 Henry Avenue
Philadelphia, PA 19129
215/842-6543

Glenn S. Bartlett, MD
Associate Professor of Pediatrics
Department of Pediatrics
Hershey Medical Center
500 University Drive
Hershey, PA 17033
717/534-8161

Bernice Baxter, RN
Director, Division of School Health
Bureau of Children's Svcs.
Department of Health
P.O. Box 90
Harrisburg, PA 17120
717/789-6471

Eva Byers, RN
Nursing Consultant
Bureau of Children's Svcs.
P.O. Box 90
Harrisburg, PA 17120
717/787-6471

Robert Diethorn
Staff Planner
Commonwealth Child Dev. Committee
Governor's Office for
Human Resources
700 State Street Bldg.
Harrisburg, PA 17101
717/787-8057

Arthur Egmore
Director
Chester County Head Start
300 High Street
West Chester, PA 19320
215/692-7189

Marian Lohr
Coordinator, School Health Svcs.
Department of Education
557 Education Bldg.
Harrisburg, PA 17120
717/787-8013

Annette Lynch, MD
Director
Bureau of Children's Services
Department of Health
P.O. Box 90
Harrisburg, PA 17120
717/787-6471

James J. McKittrick
EPSDT Project Director
Department of Public Welfare
533 Health and Welfare Bldg.
Harrisburg, PA 17120

Paul Phelan
Statewide Health Coordinator
c/o Head Start
630 Rockland Street
Lancaster, PA 17602
717/299-7301

Jean Quinn
EPSDT Monitor
Southeast Region
Department of Public Welfare
Room 304
1400 Spring Garden Street
Philadelphia, PA 19130
215/238-3416

Gary Rightmire
EPSDT Coordinator
Berks County Board of
Assistance
901 E. Wyomissing Blvd.
Reading, PA 19603
215/378-4304

Anne L. Shenberger
Coordinator
Interagency Task Force
on Early Health Screening
Commonwealth Child Development
Committee
Governor's Office for
Human Resources
700 State Street Bldg.
Harrisburg, PA 17101
717/787-3489

Margaret Stableford, RN
Health Services Coordinator
Chester County Head Start
300 South High Street
West Chester, PA 19320
215/692-7189

Rhea Weiss
Director of Education
Eastern State School and
Hospital
3740 Lincoln Highway
Trevose, PA 19049
215/671-3382

Sara Ann Williamson, RN
Montgomery County Supervising Nurse
Norristown District
Department of Health
750 E. Johnson Highway
Norristown, PA 19401
215/631-2280

Mr. ROGERS. I notice you make three specific recommendations in your statement and we will consider those recommendations that you have made.

Thank you for a most helpful statement.

STATEMENT OF NANCY J. FELDMAN

Ms. FELDMAN. Mr. Chairman, members of the subcommitte: my name is Nancy Feldman. I supervise the early and periodic screen diagnosis and treatment program.

I want to thank you for this opportunity to present our views on the proposed Child Health Assessment Act. We have already submitted a written paper [see p. 75]. Briefly I will highlight our main concerns with the bill.

Primarily we are concerned with the section on provider participation. We understand that a major problem with an EPSDT program is the undue emphasis which has been placed on screening, and without subsequent emphasis placed on diagnosis and treatment. However, we feel the way to solve this problem—I would echo what others have said here today—is not through the comprehensive provider concept, at least not in a State like Minnesota which is largely rural.

In my statement I have outlined a few reasons for feeling that.

First, comprehensive care providers, as the bill appears to define them—and we are not exactly sure what that definition would be in practice—do not exist in most of Minnesota.

I attached a couple of maps to my statement. I would ask you to refer to them briefly.

The first map shows areas in Minnesota which have been defined as health shortage areas by the Federal Government. 54 of our 87 counties or approximately 62 percent are defined as health shortage areas. These counties lack basic medical resources much less the type of comprehensive care provider which is envisaged in the bill.

The next map shows the location in Minnesota and surrounding areas in clinics which have 20 or more physicians. We sort of made that as a stab-in-the-dark guess at the size of clinic that would be needed to support the specialties and ancilliary personnel needed to provide complete screening diagnoses, treatment and medical case management. Only 15 clinics in Minnesota and 2 in the surrounding areas would qualify under this definition. In addition 11 of these clinics are located in the large metropolitan areas of Minneapolis/St. Paul, Duluth, and Rochester.

Based on those resources, we really don't see how we could build a statewide program.

Secondly, 20 percent of the children screened in Minnesota are currently receiving this service from small screening clinics which are operated by local nursing services. These are not health departments. They don't have physicians on staff. They are run by nurses with usually 1 or 2 days a month devoted to the screening clinic. These clinics we feel provide excellent screening services and they have thorough mechanisms in place for referring children and for following up on children who are referred. We see no reason for closing these clinics in over a 3-year period simply because they do

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not provide diagnosis and treatment. The children we feel can be referred for that diagnosis and treatment.

My final point on providers is that even if small group practices and solo physicians were defined as comprehensive care providers, we feel very strongly most of these clinics would be able or unwilling to provide the medical case management specified in the bill. We feel this way because we have begun in Minnesota assigning especially EPSDT providers with physicians.

We have received some opposition to our setting of State standards but a majority of physicians are signing those agreements. However, we have questioned them as we have gone around the State about their ability or desire to provide the medical case management and follow-up. We have overwhelmingly heard, especially from the smaller group practices or the solo physicians, that they simply would be unwilling or unable to provide that aspect.

I think we feel that that part of the program will need to continue to be a responsibility of State and local welfare departments.

Very briefly I will touch on the other points.

We feel that there should be some more specific mention of outreach in the bill, that outreach is really the crucial part of the screening program, and we would like to see, if possible, some sort of higher Federal financial participation for outreach, at least a specific encouragement to the States that outreach efforts be strengthened.

With the penalty provision, we very much agree with the changes that are in the legislation. What we would hope for is clear enforcement of the penalty by Federal authorities. We think that has been extremely ambiguous in the past and we would hope that implementing regulations would tell the States more clearly what they were required to do.

The incentive provision is excellent. We feel though that a State's total effort to implement EPSDT should be included as part of the measurement for receiving the incentive payment.

Finally, screening standards. We feel that some specific mention of screening standards should be made in the legislation, maybe not the specific standards spelled out, but rather some sort of statement that States must develop such standards with consumer and provider input and have those standards approved by HEW.

Thank you very much.

[Ms. Feldman's prepared statement and attachments follow:]

STATEMENT TO THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT OF THE INTERSTATE AND FOREIGN COMMERCE COMMITTEE ON THE CHILD HEALTH ASSESSMENT ACT
BY NANCY J. FELDMAN, EPSDT SUPERVISOR, MINNESOTA DEPARTMENT OF PUBLIC WELFARE
SEPTEMBER 8, 1977

My name is Nancy Feldman and I supervise the Early and Periodic Screening, Diagnosis and Treatment Program for the Minnesota Department of Public Welfare. I want to thank you for this opportunity to present our views on the proposed Child Health Assessment Act. I would like to begin by saying that we are pleased at the continuing emphasis being placed on health care for low income children and that we fully support all efforts to strengthen and improve the EPSDT Program. We have seen in Minnesota many of the benefits which the EPSDT Program can bring to eligible children. We wish to see these benefits broadened and expanded to more children, with administrative requirements kept to a minimum. We are pleased that many provisions of the Child Health Assessment Act would improve the current EPSDT Program. However, we are also concerned that some provisions of the bill would greatly reduce our ability to provide health services to low income children in Minnesota. Since we have already submitted a written position paper on the bill to the Subcommittee, I would like today to merely highlight some features of that paper.

1. Provider Participation: Our greatest concern with the bill centers on the provider participation section. We understand that a major problem with the EPSDT Program is the undue emphasis which has been placed on the numbers of screenings performed, with little subsequent emphasis placed on whether or not those children received needed diagnosis and treatment. However, the restriction of program participation to comprehensive care providers, as defined in the bill, is definitely not the way to solve this problem, especially in a largely rural state like Minnesota. Following are reasons why we feel the comprehensive care concept will not work in Minnesota.

   A. First, comprehensive care providers, as the bill appears to define them, do not exist in most of Minnesota. The first map attached to this statement shows areas in Minnesota which have been defined as health shortage areas by the federal government through various health programs. As you can see, 54 of Minnesota's 87 counties, or 62%, are defined as health shortage areas. These counties lack basic medical resources, much less the type of comprehensive care provider which this bill envisions. The next map shows the location in Minnesota and surrounding areas of clinics having twenty or more physicians. We feel a clinic of this size would be able to support the specialities and ancillary personnel required to provide complete diagnosis, treatment and case management to children screened. As you can see, only fifteen clinics in Minnesota and two in surrounding areas would qualify under this definition. In addition, eleven of these clinics are located in the metropolitan areas of Minneapolis-St. Paul, Duluth or Rochester. We would have little hope of developing a state-wide program based on these resources.

   B. Secondly, 20% of the children screened in Minnesota are currently receiving this service from small screening clinics which are operated by local nursing services, usually one or two days a month. These clinics often are developed in areas where there are insufficient physicians to provide

screening services or where local physicians are not interested in providing this service. The nursing service screening clinics do an excellent job of providing a comprehensive health screening and have thorough mechanisms in place for referring children and for following up on children who are referred. We can see no reason for closing these clinics simply because they do not provide a range of diagnostic and treatment services. In addition, these nurse-run clinics provide screening services on a sliding fee basis to children who are not eligible for Medical Assistance. If the clinics were forced to close, this subsidized service to low income families would also not be available. Of the other providers currently performing screenings in Minnesota, the large majority are solo physicians or small group practices. Because of the vast array of problems found in children who are screened, these screeners would still have to refer many children for problems uncovered in the screening, even if they were defined as comprehensive care providers. Therefore, referral and case management requirements would still be necessary.

C. Third, even if the small group practices and solo physicians were defined as comprehensive care providers, we feel strongly that most of these clinics would be unable or unwilling to provide the medical case management required in the bill. This opinion is based on actual experience we have had in Minnesota in attempting to define what components must be included in a screening and to have screening providers sign EPSDT Provider Agreements in which they agree to provide all of those components to children they screen. We have had strong opposition from some physicians to the setting of any screening standards. We can only assume that this opposition would be far more intense if these providers were also required to provide case management and to report this activity to the state agency. Even physicians who have signed EPSDT Provider Agreements have indicated to us that they would not participate in the program if case management responsibilities were added. Since the program is voluntary on the part of providers, I am most fearful of a situation developing in which we are required to implement a child health assessment program on a state-wide basis, but with only a handful of potential providers being willing or able to participate because of limits that have been set on provider participation. It seems far preferable to allow as many screening providers as possible to participate in the program and to simultaneously strengthen the mechanisms for referral and case management so that children have access to screening services on a state-wide basis and are also assisted in resolving their health problems.

2. Outreach: We are puzzled by the brief mention of outreach in the bill. We feel that good outreach is crucial to the success of a program like CHAP or EPSDT which depends on voluntary participation and which involves a concept not understood by many people. Our experience and that of most other states has shown that person-to-person outreach is the best way to assure participation in the program. A provision should be added which requires such outreach efforts and provides higher federal financial participation in order to encourage the employment of staff to perform these outreach activities.

3. Penalty Provision: The provisions for invoking a fiscal penalty against states which do not implement an adequate child health assessment program are a great improvement over current EPSDT penalty provisions. Giving states a chance to correct their programs before the penalty is imposed is also a marked improvement over the current ambiguous requirements. However, it is very important that the penalty requirements be clear and that the review standards be specified

and enforced uniformly across the country. It has been our experience that such is not the case with the current EPSDT penalty provisions.

4. Incentive Provision: The provision to increase the federal share of Medicaid administrative reimbursement if a state meets criteria for good performance is excellent. This provision will provide state administrators with a real incentive to develop a comprehensive program rather than one that simply meets federal requirements. However, the entire usefulness of this provision will depend on the performance criteria which are developed by HEW. We agree that such criteria should include measurements of the percentage of children screened and treated, but they should also include other state efforts at program implementation, such as coordination with other children's health programs, innovative outreach methods, and consumer and provider input into the program.

5. Screening Standards: The omission of a clear requirement for screening standards in the bill appears to us to be a serious oversight. In Minnesota, the development of screening standards has been very difficult and has required much input from all individuals with an interest in the program. Yet we feel the development of standards is essential. If uniform standards do not exist, then children screened at one site may receive a far less comprehensive assessment than children screened elsewhere, and yet both children are "counted" as having been screened. We would suggest that the development of standards be left to the individual states with approval from HEW required, and with provisions for provider and consumer input specified.

Again, thank you for this opportunity to explain our interpretations of the effects of the Child Health Assessment Act on state level program administration in Minnesota. At the state and local levels, we will continue to work to bring comprehensive health care to eligible children. We strongly support all aspects of this bill which will make it easier for us to do.

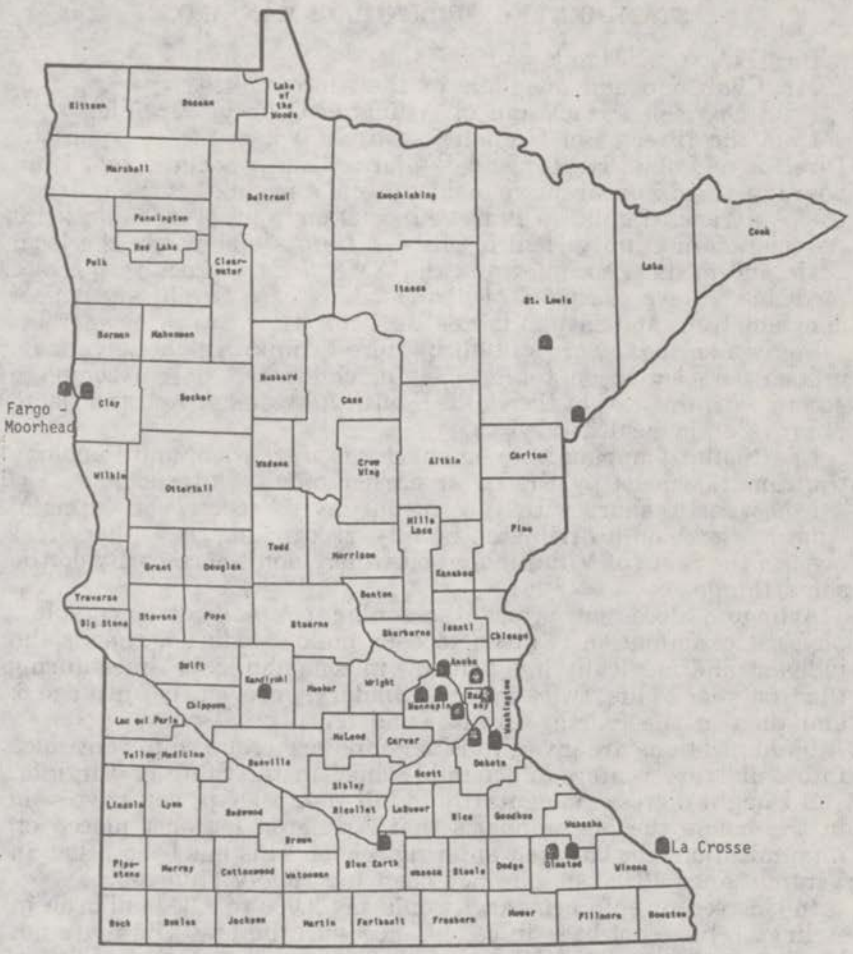
HEALTH PROFESSIONAL
SHORTAGE AREA

DPT-648
(9-71)

*Health Shortage areas as defined by Health Professional Student Loan Program, HMO legislation and/or Critical Health Manpower Shortage Areas, NHSC

GROUP PRACTICES OF 20 OR MORE PHYSICIANS

DPH-418
(9-71)



Mr. ROGERS. Thank you for an excellent statement.
Dr. Hackman.

STATEMENT OF HELEN HACKMAN, M.D.

Dr. HACKMAN. Thank you.
Mr. Chairman and members of the subcommittee:
I am Dr. Helen Hackman of Arlington County, Virginia.
I am the Director of Human Resources, which means I am the Director of Public Health and Welfare. I am a pediatrician. I am board certified in preventive medicine and a member of the board of the American Public Welfare Association and of the National Association of County Health Officers. I am a member of the local State and medical societies and the AMA. I have practiced private medicine. I have practiced medicine taking care of military dependent children, and in public health. I am also a working mother.
I only mention my credentials because I think this does give me a unique perspective on taking care of children. I am in complete accord with the goal of the Child Health Assessment Act, that is, to improve child health services.
I particularly applaud the emphasis on prevention, and I endorse the remarks made by Dr. Lazar earlier on this afternoon.
I do want to share with you though my perspective in terms of what has gone on in Arlington County, recognizing that other areas even in the State of Virginia and elsewhere don't necessarily do the same thing.
Arlington does not provide screening per se, but a complete physical examination is given to each child, Medicaid, that is the indigent and medically indigent low income child, six times during the first year of life, twice in the secondary, once yearly until age 6, and then in the fourth, seventh, and tenth grades.
Immunizations are given routinely and are required for entrance into child care centers and public school in the State of Virginia.
If I might digress momentarily to tell you, perhaps you have seen in the media the big emphasis that Arlington has just placed on immunizations for children entering school. This has been a law in Virgina since 1972 but has not been too rigidly enforced.
In this recent enforcement, I would say 2,000 to 3,000 children in Arlington have not been in compliance with the law. These are not low income or medically indigent children because they have been under the care of the local health department and have been immunized. These are children from middle and upper income families who, for some reason, have not received these services.
The only difference rendered in Medicaid children and non-Medicaid children is that for Medicaid we receive a $10 fee. Obviously it costs a great deal more than $10 to do this type of examination, somewhere between $40 to $50, but Arlington County and the State of Virginia bear the additional costs.
We do the same examination whether or not we get the reimbursement. The only difference is that for the Medicaid children we do fill out the form.
Children are referred for treatment when it is indicated. The department does not have the sophisticated diagnostic equipment,

nor do we take care of sick children. We do have an excellent crippled children's program partially funded under title V, and many children with chronic disabling conditions are taken care of in this particular program.

In no way could we be considered a comprehensive child care center and the provisions of CHAP essentially would disqualify us. Our services, particularly school health services, would be duplicated if indeed these services existed, but they do not exist.

I would just like to focus on the cost of some private and noncare centers in this area. It will give you an idea of the potential cost and I think cost is a tremendous factor of this whole program.

Under our State local hospitalization program here, locally, this is something that is additional. This is provided for medically indigent families. A clinic visit in Children's Hospital at the present costs $52, in Georgetown University Hospital we are paying $62.40, in Arlington Hospital, $44.58.

For inpatient care currently it costs us from $236 to $336 a day, the higher one being in Children's Hospital. Unless substantially more money is appropriated by the State legislature, even if matched by 75 percent or 90 percent Federal funds, medical bills of this order of magnitude cannot be absorbed by Medicaid in Virginia.

We are already cutting corners to contain the costs to keep within the State appropriation.

I would like to focus on another issue, because I don't think that has been emphasized to this point today, and that is of outreach and follow-up.

When patients do not keep appointments in out-clinics, a home visit is made by a public health nurse. Even when there is no valid reason, two more broken appointments are allowed. Transportation to clinics can be arranged if this is a problem. If the family still fails to attend the clinic then the record is temporarily closed. We must face the fact that some mothers simply will not bring their children to the doctor unless they think they are ill. Even in school where we have a captive audience or a captive group as it were, mothers or parents will not sign the permission slips to enable us to do the examinations there. So those are some of our failures.

Private providers certainly will not make the effort that local health departments do to get the children into private care. If we go the private route, I think more children will be lost in the shuffle, not less. Children in poor families do have more sickness and more missed school days. They are hungry. They are ill-clothed. They are ill-housed. The mothers of these children—worrying about where the next meal is coming from, that they don't have shoes, the rats, that the gas is going to be turned off—cannot be expected to be concerned about taking care of their well children. They certainly take care of them when they are sick.

Our new recent immigrant population, which of itself is expanding the Medicaid rolls, presents a new and different problem. These people have different cultural values and do not understand what we are trying to do or why, particularly when we talk about screening. They simply don't know what screening means. It is hard for a working mother to take time off to keep medical appointments for children. I know that from my own experience.

Our welfare programs are already paternalistic. I do not recommend that we try to take away further parental responsibility, nor in fact that we should be penalized because the parents fail to take advantage of these services that are offered to them.

I recommend that States and localities be allowed to continue to provide preventive care of children, and to refer them and to work in coordination with other providers of medical care for the treatment services. I ask you not to penalize providers of current screening services for circumstances over which they have no control.

I recommend that you consider the appropriations of additional funds to provide the range of medical care which is needed to improve the health status of poor children which, after all, is the goal of CHAP.

If I might add another recommendation, that there is a great deal more that goes into providing healthy children than any range of medical care and I think it is a fallacy to pretend that medical care in itself, even if you had a comprehensive health center or a doctor on every street corner, would do anything to provide for these children when everything else in their environment is contributing to ill health.

Thank you.

[Dr. Hackman's prepared statement follows:]

AMERICAN PUBLIC WELFARE ASSOCIATION

Statement of Helen Hackman, M.D.
Director
Arlington County Department of Human Resources

and

Member
Board of Directors
American Public Welfare Association

before
Subcommittee on Health and the Environment
Committee on Interstate and Foreign Commerce

U.S. House of Representatives

on

H.R. 6706 - The Child Health Assessment Act

September 8, 1977

MR CHAIRMAN, MEMBERS OF THE SUBCOMMITTEE, I am Dr. Helen Hackman, Director of the Arlington County Department of Human Resources, Arlington County, Virginia, Director of Public Health and Welfare. I am a Pediatrician, Board Certified in Preventive Medicine, a member of the Board of the American Public Welfare Association, and a working mother. My career has been devoted to helping to meet the needs of deprived families with particular emphasis on indigent and medically indigent children. I am in complete accord with the goal of the Child Health Assessment Act, that is to improve child health services. I particularly endorse your renewed emphasis on prevention. My commentary to you has two main themes, one is to point out what may be hazards or pitfalls in the Bill as presented and the other to make some suggestions as to how to improve the wording. To do this, I should like to share my experience with EPSDT. I recognize that other areas within the State of Virginia and elsewhere, cannot and may not provide the same quantity and/or quality of preventive care for children as does Arlington.

Arlington does not provide "screening" per se. A complete physical examination or well-child checkup is given six times during the first year of life, twice in the second year, once yearly until age six, and then in the fourth, seventh, and tenth grades, to every indigent or Medicaid child and every child from a medically indigent family. Immunizations are given routinely and are required for entry into child care centers or public school. The only difference in service rendered to Medicaid and non-Medicaid children is that for Medicaid, we complete a screening form and receive a ten dollar fee. It takes ten dollars worth of extra time and paperwork, and on occasion, we do not even bother to complete the form. The cost of the physical examination and laboratory tests is far more than ten dollars, with Arlington County and the State of Virginia making up the difference. Many families go on and off the Medicaid rolls, so we are not sure of the status of each child at any point in time, nor do we care about

this. We are already serving a wider range of low-income children than is proposed in the Bill. We serve all children in low-income families not limiting preventive care to those under six years of age or those previously Medicaid eligible. However, the Health Division of our Department does routinely receive a copy of every new or renewed Medicaid card and every eligible child is offered the series of examinations outlined above.

Children are referred for treatment when it is indicated. The Department does not have sophisticated diagnostic equipment, nor do we take care of sick children. We do have an excellent Crippled Children's Program partially funded under Title V and many children with chronically disabling and debilitating conditions are diagnosed and treated in this particular program.

In no way could we be considered a comprehensive child care center. The provisions of CHAP would, therefore, disqualify our participation in the new program. If feasible, we would continue to provide these services albeit with our meager reimbursement disallowed. Our services, particularly School Health Services, would be duplicative if the comprehensive care centers existed. The fact is that they do not. I must also mention that with the exception of dental problems for which we do provide treatment, we find very few defects which need correction.

Let us look at some of the private providers, those private physicians who take care of the non-indigent children, yours and mine. Firstly, they choose not to participate in a program with minimal reimbursement and massive paper requirements. It is actually easier and more cost effective for private providers to identify a minor illness and bill for a sick child visit. There is little in the CHAP proposal to indicate that sufficient sums of money will become available to the states to pay enough to purchase private care. For treatment in the non-profit sector, a clinic visit in the Washington area currently costs as follows under our State-Local Hospitalization Program:

- Children's Hospital $52.00
- Georgetown University Hospital - $62.40
- Arlington Hospital - $44.58

In-patient care currently costs us from $236 to $336 a day, the maximum being at Children's Hospital.

Unless substantially more money is appropriated by the State Legislature, even if matched by 75 percent Federal funds, medical bills of this order of magnitude cannot be absorbed by Medicaid.

I should like to focus on another issue, that of outreach and followup. When patients do not keep appointments at our clinics, a home visit is made by a public health nurse. Even when there is no valid reason, two more broken appointments are allowed. Transportation to clinic can be arranged if this is a problem. If the family still fails to attend clinic, then the record is temporarily closed. We must face the fact that some mothers simply will not bring their children to the doctor unless they think they are ill. Some parents will not even sign the permission slip for their children to be examined in school. We can educate, cajole, persuade, but we cannot force them to come to clinic, nor would we wish to do so. Under the provisions of the Act, the state would be penalized for the failure of the parents. Private providers certainly will not make the effort that the local health departments do to get the children into care. Even more children will be lost in the shuffle, not less.

Children from poor families do have more sickness and more missed school days. They are also hungry, ill-fed, ill-housed, and ill-clothed. They live in an environment which precipitates ill health. Yet, the mothers of these children, worrying about where the next meal is coming from, that the gas is about to be turned off, the rats, the lack of warm clothing, cannot be blamed for missing appointments for screening examinations or well-baby checks.

Our new recent immigrant population, which of itself is expanding the Medicaid rolls, presents a new and different problem. These people have different cultural values and do not understand what we are trying to do or why, particularly if we talk about screening.

It is hard for a working mother to take the time off to keep medical appointments for her children. I know that from experience too.

Our welfare programs are already paternalistic. I do not recommend that we try to take away parental responsibility.

I recommend that states and localities be allowed to continue to provide preventive care to children and to refer to and work in coordination with other providers of medical care. I ask you not to penalize providers of current screening services for circumstances over which they have no control. I recommend that you consider the appropriation of additional funds to provide the range of medical care which is needed to improve the health status of poor children, which is after all the goal of CHAP.

Mr. ROGERS. Thank you so much, Dr. Hackman. We will look at your suggestions.

There is a live quorum.

Is there any member who does not plan to make it so that hearings could continue?

Mr. MAGUIRE. I will be glad to run over and back, Mr. Chairman.

Mr. ROGERS. Why don't we go now then. This is the second call.

The committee will recess for 10 mintues to allow members to answer the quorum call.

[Brief recess.]

Mr. MAGUIRE [presiding]. The subcommittee will come to order.

Mr. Reilly, would you proceed with your statement.

STATEMENT OF GERALD REILLY

Mr. REILLY. I am Gerry Reilly, Deputy Commissioner of the Department of Human Services in New Jersey. We are the department with oversight responsibilities for the medical assistance program, which in turn has responsibility for administering the EPSDT program.

In addition, for two and a half years I was director of the medical assistance program and had direct responsibility for New Jersey's implementation of EPSDT.

I will confine my remarks here to four points that I would like to call your particular attention to after making the general statement that we are very much in favor of a comprehensive look at legislative reform with regard to the EPSDT program.

We welcome the CHAP initiative. We are concerned, however, that CHAP not scrap the positive lessons that have been learned in EPSDT and rather builds upon the successes of EPSDT while learning from its failures.

I think that the fact that the program has not been an unmitigated success ought not lead us to an overreaction of losing sight of the many accomplishments and sound principles that have been developed through this program.

We are very much in support of the expansion of eligibility to cover all children under six regardless of the status of the family who are in poverty. However, we would recommend that this coverage be extended to all children at least up to age 18. We don't see the basis for the distinction between a child of six and a child of seven.

We also strongly agree with the notion that we will extend coverage to a child who is in a course of treatment following a screening by six months after eligibility would have otherwise ended.

However, we would recommend that a similar provision of extending coverage be provided to all children who are in a course of treatment and who would have that course of treatment jeopardized by loss of eligibility, at least until the completion of their course of treatment.

I think this might be a difficult process administratively to deal with, but I think it is within the realm of our capacity. I think it is of fundamental importance.

Our prime criticism of the present proposal involves the notion of the comprehensive care provider. It seems to me that we are in danger of putting all of our eggs into a nonexistent basket.

We simply do not have the array of comprehensive care providers that the bill would seem to assume or assume that we have the capacity of developing over the next 3 years.

I think that we have to recognize that the medical delivery system is a pluralistic system, and I think we would be better advised to find out how we can adequately tie into the various aspects of that system.

We heard very excellent testimony today with regard to the role of county health agencies. In our State we use physicians, we use well baby clinics, we use hospitals, we use freestanding clinics, we use a variety of providers available to us.

To be faced with the concept of restricting ourselves to essentially one kind of provider, a comprehensive care center or a physician who was able to assume some of the responsibilities of such a comprehensive care center I think is unrealistic and would not be attainable, and probably would result in the diminution of health services available to poor children and not their expansion, which I am sure is the goal of the legislation.

We are also concerned that the bill is silent with regard to the notion of adequate and equivalent care. As we all know, particularly in States that have been faced with severe Medicaid cutbacks, resources are scarce, dollars are not available.

A premise in the New Jersey EPSDT program has to be to identify those children who have not received adequate equivalent care, make a special outreach effort with regard to those children, and get them into a course of treatment to attempt to avoid rescreening a child who is already under an appropriate regimen of care.

The statistics in New Jersey with regard to screening for the lastest month available show that we are reaching about 11.7 percent of the target population. Unless one understands that when coupled with those children who have been determined to be under adequate equivalent care comes up to 68 percent of the population, it seems to be a low figure.

We don't think it is a low figure. We don't believe that we are going to go much higher than that over the course of the next several years because of our ability through our claims processing system to identify those children who are under care and avoid the necessity of making special outreach efforts to those children, so that we make the most of the very scarce dollars that we have available.

I think this is a concept that perhaps ought to be explored as we reform the EPSDT program, to see whether with the onset of MMIS systems throughout the country, that more States will begin to have the capacity of developing that kind of tracking system.

The fourth and final point I want to make is that we have not addressed in this bill a critical problem of reimbursement for ambulatory care providers. We all talk about preventive services and their importance, and our excessive reliance upon institutional services.

Yet, the medical assistance program requires that we pay hospitals their actual costs, will require that we pay nursing homes their actual costs, but is silent with regard to the costs we pay to individual practitioners. We can pay them what the market will bear.

Given the difficult fiscal situations in many States, what the market will bear has drifted down to a few cents on the dollar. In our State we are paying about 50 cents on the dollar of what the usual and customary fees are. This is one of the primary problems in recruiting physicians.

Physicians are the current keystone of our health care delivery system. They are likely to continue to be the keystone of our health care delivery system.

It seems to me if we want to do something about providing services to children, we have to do something about providing adequate reimbursement to all practitioners who are on the front line of ambulatory care, physicians, dentists, so forth.

So in summary it is our hope that this legislation becomes the vehicle for genuine improvement in the current program and not take the tact of being an overreaction to some of the more obvious shortcomings of the present EPSDT program.

Thank you.

[Testimony resumes on p. 109.]

[Mr. Reilly's prepared statement and attachments follow:]

STATEMENT OF GERALD REILLY, DEPUTY COMMISSIONER

STATE OF NEW JERSEY

DEPARTMENT OF HUMAN SERVICES

I am Gerald Reilly, Deputy Commissioner of the New Jersey Department of Human Services. I am here on behalf of the Commissioner of our Department, Ann Klein and the Commissioner of the Department of Health, Joanne Finley. The Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program is administered by the Medicaid Agency, Division of Medical Assistance and Health Services in the Department of Human Services. The Department of Health has jurisdiction over many of the medical facilities and programs which are utilized in the EPSDT program as well as other components of the health delivery system in our State.

I am very pleased to be here to testify on the proposed Child Health Assessment Program (CHAP). As past Director of the Medicaid program, I supervised the implementation of the EPSDT program in our State. I consider the EPSDT program to be one of the most progressive and beneficial reforms of the Medicaid program in that it not only pays for health services but attempts to insure that these children receive the needed medical services as well.

We believe that the EPSDT program across the country should be expanded and upgraded, but we also believe we have made considerable progress in the program in our State in terms of improving the delivery of health services to eligible children. While we agree with the goals of CHAP and many of its provisions, there are also some provisions in the bill which would undermind much of the progress we have made in New Jersey and, we believe, interfere with attaining the goals of CHAP. In order to understand our position on this issue it is important to understand the EPSDT program in New Jersey.

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THE EPSDT PROGRAM IN NEW JERSEY

Because of the long delay in promulgating final federal regulations for the EPSDT program and the subsequent need for State planning, the current automated EPSDT program was not implemented in New Jersey until February 1975. Our interest in implementing the program was not to fragment the health services in New Jersey by randomly establishing screening centers, but rather to act as a catalyst in educating providers about the EPSDT program and connecting these providers with recipients. Since private physicians are our single largest provider resource, most of the services under EPSDT are provided by this group, followed by Independent Clinics and Hospital OPD's. (See Table I)

The Division of Medical Assistance and Health Services maintains and routinely updates a computerized provider file. Local Medical Assistance Units, in addition, seek out providers for participation on a regular basis and maintain current health resource files of all health related providers in their locality.

Children under the AFDC and SSI programs as well as children in foster care under the State supervision of the Division of Youth and Family Services are eligible for Medicaid to age 21. Children under the AFDC category also include those children who have a father present in the home. These families were previously under Aid to Families of the Working Poor, but have recently been reclassified under AFDC in order to receive comparable benefits. It is our understanding that these are the same children who would be eligible for services under CHAP to age 6.

The Division of Medical Assistance and Health Services maintains a complete eligibility file including client's ages which is kept current by regular additions and deletions submitted by County Welfare Agencies for the AFDC category, by the Division of Youth and Family Services for foster care children, and by the Social Security Administration for the Supplemental Security Income (SSI) program. Persons eligible for EPSDT are readily identified by numbers assigned to individual members of eligible families as well as by age.

All children under Medicaid are eligible for all health services for which Federal Financial Participation is available. These services, including mental health and dental care services, are available on a continuous basis whether or not they are found to be needed as a result of a screening. It has been New Jersey's position that every child does not need to be screened if they obtain regular preventive and palliative health services. Thus we have concentrated our EPSDT program on children not receiving adequate services and have attempted to link them up with a provider who will service them on a regular ongoing basis so they don't need to be screened again and again.

Direct determination of individual applicants' eligibility for medical assistance and the provision of social services are the responsibilities of the 21 County Welfare Agencies (CWA's), the District Offices of the Division of Youth and Family Services, for those children under the supervision of the State, and the Social Security Administration (eligibility only). The Division of Youth and Family Services also monitors the County social service delivery systems and offers technical assistance to assure that eligible individuals and families are provided with effective social services in accordance with Federal mandates and the State Plan for Social Services.

The Division of Medical Assistance and Health Services arranges for outreach to Medicaid eligible children in a variety of ways. All eligible AFDC recipients are informed of the EPSDT program in the initial interviews at the CWA's and are issued an EPSDT pamphlet. About 75% of our screenings are a result of referrals or examinations by the providers themselves. The Medicaid Division has worked closely with neighborhood health centers, day care centers, community action programs, and schools to outreach these children. EPSDT program information is included in monthly County Welfare newsletters to recipients. A bilingual brochure explaining EPSDT is mailed to all AFDC families and children in foster care annually. We have been provided T.V. spot announcements regarding the EPSDT program in addition to having appeared on TV and radio talk shows. The Division of Youth and Family Services Monthly Foster Parents Newsletter also includes a "Medicaid Memo" which frequently includes information on EPSDT.

One of the most effective methods we have used for outreaching those most in need and for follow-up is utilization of the EPSDT computer sub-system which generates notices for those children in need of these medical services. Monthly review of paid claims for Medicaid services rendered to the EPSDT target population provides a computer generated notification known as the EPSDT Referral Report Form MC-19, (Attachment A) for each individual who is an underutilizer according to the predetermined parameters for care adequate to or equivalent to EPSDT. These parameters were established by the Medicaid Agency with Federal approval.

The screening provider (physician, clinic or hospital) indicates the results of the screening examination, including referrals for diagnosis and treatment, on the EPSDT Referral Report form. The screening provider sends in the Referral form along with his claim for payment (Attachment B) to the Medicaid Fiscal Intermediary.

The Intermediary's computerized EPSDT sub-system notes any needed referrals in the recipient's file and subsequently sends a copy of the Referral Report form (indicating date of screening and referrals which need to be followed-up) back to the CWA's or the Division of Youth and Family Services' District Offices for timely follow-up by social service staff. These MC-19's for underutilizers are sent to the CWA or Division of Youth and Family Services District Office for the social service workers to contact the family and explain the value of EPSDT and to assist in setting up an appointment with an EPSDT provider. The MC-19 form is sent with the patient to the servicing provider. Through required documentation in the CWA client case record and log (Attachment C) we are able to determine if follow-up was carried through. This system has been very effective; a sample study disclosed that services were initiated for about 95% of children requiring follow-up.

Currently the school age population (age 6-16) is not included in the MC-19 computer generated notification to eligibles; school age eligibles are, however, offered EPSDT services through provider initiative, social service contact with newly eligible families and through annual mailings. We have surveyed the quality of school health services and are attempting to identify and utilize, through demonstration projects, those school districts which are able to provide EPSDT equivalent care without additional cost to the taxpayers. It is planned that ultimately all school age children for whom the schools do not provide equivalent care will be included in the computer generated notification process.

In June 1977, there were 4,349 EPSDT screening examinations, of which 57.6% were given to children between the ages of 6 and 20 (Table 2). More than 42.0% were found to have referrable conditions, with 39.1% of them under age 6. Almost

61% of the children with referrable conditions were between the ages of 6 and 20.

About 11.7% of the total eligible children were screened under EPSDT (Table 3). Though this figure appears low, if we add the number of children who were currently receiving adequate care to the number screened this figure increases to 68.7% of the total eligibles. This leaves 31.3% who were in need of screening, some of whom had refused screening or were currently receiving some degree of medical care possibly through other than the Medicaid program.

In conclusion, our EPSDT program benefits the eligible children in our State in that emphasis is placed on those children under six who are most in need of this service and by making available all services for which FFP is available. We also feel it is important that we include those children who are included under our AFDC program and have a father present in the household. We feel that a remarkably high number of children who are screened are receiving services as our sample study indicated.

Nevertheless, we feel that our program can be improved. We would like to increase our screening rate and include those children between the ages of 6 and 16 within our computer notification system. We would also like to recruit more providers, especially those providing comprehensive care. These objectives could be met with added Federal support and remedial legislation. CHAP, with appropriate amendments, is a start in that direction.

CHAP LEGISLATION

As mentioned earlier, we agree with the goals of CHAP which are to expand the availability of health care, to increase the number of children eligible for such care, to assure continuity of care, to increase immunization levels, and to provide incentive to states to arrange for quality health care for children. Though we do not believe that CHAP as it is now written can meet most of these goals, we do support some provisions in the bill which would have a salutary effect in improving the EPSDT program.

1. We support the inclusion of children which CHAP describes as income but not categorically eligible under Title IV-A. We agree that CHAP should not conflict with one of the administration's goals of welfare reform, which is to end discrimination against welfare families where the father is living in the household.

2. We agree that children under CHAP should be eligible for all medical services for which FFP is available. This is our policy in New Jersey. We should not treat part of the child but the whole child. Children are the most valuable resource in our society; we should accept nothing less than the highest quality medical care for those children who are most in need of this care.

3. We support the six months extension of Medicaid participation for those certain children who would otherwise become ineligible for these services and have recently been assessed while under the program and are involved in an incomplete course of treatment.

Our turnover rate in New Jersey for Medicaid recipients is about 25% per year and it is often important to continue treatment for those children who have been diagnosed as in need of care. This provision would be extremely difficult to administer, however, since each child within the same family would have to be monitored separately. We feel, however, that the benefits to these children outweigh the costs to the states and Federal government.

4. We agree that the states rather than the providers should be responsible for outreach. The states are in the best position to provide the social services and coordination which are necessary for this function.

5. We support the 75% FFP for services under this program. Given the difficult fiscal situation faced by our State, such an increase would be essential to enable us to afford the costs of providing services to additional eligible children and currently eligible children for a longer period of time.

6. We support the financial incentive to states for good performance. The Federal Government has too often relied on negative sanctions to enforce its programs. This will not be a viable incentive, however, if the standards for good performance are set unrealistically high by the Secretary. We recommend that the standards be set at a level where at least 25% of the states would be eligible for the incentive.

Though we approve of the above provisions, there are other provisions in this bill which would not only make the goals of CHAP unattainable, but would undermine what progress we have made under the EPSDT program as well. Some of the more salutary provisions of the bill also need to be expanded in order to have a significant impact.

1. We are completely opposed to CHAP's requirements for all providers which must be met within a three year period. These requirements could not possibly be met by most of the private physicians on whom we heavily rely to provide services under the EPSDT program. Even many of the clinics which we utilize would have difficulty meeting all of the requirements. It is unrealistic to expect that physicians would be willing, even if they were able, to meet these requirements since the bill provides no incentive to do so. These children make up only a very small percentage of the patients seen by our providers and it is very unlikely that they will restructure their entire delivery of service in order to serve children for whom they already are being reimbursed at a very low rate.

Recruiting adequate numbers of providers is already a problem in our State under the current program. If we insist that all providers provide, within three years, follow-up, comprehensive care, and reports to the State and Federal Government documenting these efforts subject to onsite federal CHAP audits, as well as sign a contract to insure that these services will be provided, we would have a dramatic decrease in the number of providers willing to participate in the program. In other words, this provision would result in a decrease in the availability of health care and not an increase. We could not possibly meet

the requirement until enough comprehensive care providers are established in our State and the bill provides no incentive for providers to develop this type of service. A possible remedy is suggested further on in the testimony.

2. We recommend that the State and not the providers be responsible for follow-up as well as outreach. Both of these functions often require social services in the field which clinics and physicians are usually unable to provide. It is also not productive to separate the outreach and follow-up functions since it often results in discontinuity of service. Our high follow-up rate, as previously explained, supports the inclusion of this function within the state's responsibilities.

3. The upper age limit under the CHAP program should be reduced to 18. The lowering of the age to 18 would be in conformity with other local, state, and federal laws which use this age for the separation of adults and children.

4. Likewise, those children who are income but not categorically eligible under Title IV-A should also be covered to the same age as the other children in the program. A child clearly should not be discriminated against on the basis of age simply because his or her father lives in the home. These children have the same medical needs as the other children.

5. CHAP provides that treatment of mental illness, mental retardation, or developmental disabilities, and dental care may not be provided by the states if these conditions are not discovered during an assessment. We feel treatment for these conditions should be made available on a continuous basis as a preventative measure. This is currently our policy in New Jersey.

6. The effective date of the legislation should be extended until at least one year after the Secretary has promulgated the rules and regulations for CHAP. Under EPSDT, the delay in promulgation of rules and regulations resulted in great uncertainty in how the program was to be structured and administered. One year after development of final regulations should be sufficient time for us to plan the initial phases of the program.

7. Uniform national standards regarding periodicity should be promulgated by the Secretary in accordance with the latest standards for health care established by the American Academy of Pediatrics.

A PROPOSAL TO PROVIDE INCENTIVES TO PROVIDERS IN CHAP

The greatest deficiency of the CHAP legislation is that it makes great demands on providers to provide comprehensive care but provides no incentives to do so. This problem is exacerbated by the fact that about 87% of our EPSDT exams are performed by private physicians in our State, few of whom could meet CHAP requirements for providers. Even under EPSDT, we have been unable to recruit a sufficient number of providers who can provide high quality medical care partly because of our low reimbursement rate to providers for services rendered to these children. Our current rate is 52% of parity based on UCR rates as established by the Medicare update of July 1, 1977 and we have been unable to increase this rate because of budget limitation.

Low rates of reimbursements to providers is a problem in other states as well and is one of the greatest barriers to an effective delivery of service in the EPSDT program nationally. These problems are ignored in the CHAP legislation as are the additional paperwork problems for providers. Though CHAP provides incentive to states for good performance, it does not provide incentive to providers, which may be even more important.

We are, therefore, proposing a more incremental approach to this problem with appropriate incentives to providers. States should be reimbursed by the Federal government at a maximum rate of 90% for those providers who meet all of the CHAP requirements. This higher rate of reimbursement to states would provide funds for states to increase their reimbursement to these providers. The legislation could require that rates of reimbursement to these providers be increased, or set at an adequate level. The states would be reimbursed at a maximum of 75% for those providers who are unable to meet all of the CHAP requirements. These providers would be reimbursed at the lower, prevailing rates by the states.

This provider incentive in our state is necessary in order to develop, upgrade, and recruit comprehensive care providers which are necessary before the goals of CHAP can be realized. No state can completely meet the goal of comprehensive care for every eligible child until those providers have been established and are willing to participate in the program.

Because of our heavy reliance on private physicians, it is unrealistic to expect that these providers can be replaced with comprehensive care centers in the near future. It would also be undesirable in that many private physicians can provide medical services to these eligible children at a lower rate than comprehensive care centers. We also believe that there should be a variety of providers available from which the parents or guardians of these children can choose as most appropriate to meet the special needs of their children. States should also be allowed to use added federal funds to encourage the development of innovative approaches to the delivery of health services to these children.

90% FFP for these providers who meet CHAP requirements would demonstrate a greater committment by the Federal government to improve the health delivery system in our country. These added funds would not only aid children under CHAP, but all children who utilized these comprehensive care providers which were developed as a result of this increased FFP.

CONCLUSION

We feel that we have made considerable progress under the EPSDT program and that this program needs to be strengthened and not scrapped in favor of a totally new program. This program has only been operational in our State in its current automated method for about two and a half years and it would be premature to abandon many of the components of this program in such a short period of time.

CHAP greatly underestimates the problems of achieving its stated goals. The EPSDT program is a part of the much larger health delivery system in our country and complete reform of the program cannot take place until the larger system is reformed as well.

Nevertheless, we do feel the program can be improved and support provisions in the bill which would upgrade the program. We have suggested a more incremental approach which we feel takes into consideration the complexities and problems which face reform of this program. We are confident that if Congress and the Administration support the goals of CHAP, practical and effective reform legislation can be enacted that will build on the experiences gained through the EPSDT program, and not merely overreact to its more obvious shortcomings.

STATE OF NEW JERSEY
DEPARTMENT OF HUMAN SERVICES
DIVISION OF MEDICAL ASSISTANCE AND HEALTH SERVICES

(A)

EPSDT REFERRAL REPORT

FOR OFFICIAL USE ONLY
CWB _____
FIELD OFFICE # _____
SOCIAL WORKER # _____

1. PATIENT'S NAME AND ADDRESS (if known) SEX AGE MEDICAID NUMBER AND PERSON NUMBER

FULL CASE NAME: Last First MI

2. TO BE COMPLETED BY SOCIAL WORKER

If, following contact, the client does not wish to be screened, or is ineligible, please check the appropriate block and return immediately to THE PRUDENTIAL INSURANCE COMPANY, P.O. BOX 1900, MILLVILLE, NEW JERSEY 08332.

_____ Not Medicaid Eligible (A)
_____ Not Able to be Contacted (B)
_____ SCREENING Refused (C)

CURRENTLY RECEIVING CARE FROM:
_____ Well Child Conference (G)
_____ Neighborhood Health Center (H)
_____ Head Start (I)
_____ School (J)
_____ Other _____ (L)
_____ Physician _____ (M)
If physician, Print Name and Address

_____
(If available) Parent/Parent-Person Signature

_____ _____
Social Worker Signature Date

3. TO BE COMPLETED BY SOCIAL WORKER ONLY IF NUMBER 2 DOES NOT APPLY

The above-named parent (parent-person) has been interviewed and has agreed to obtain services for the listed patient. Medical screening of this recipient is approved provided that this form is presented to a Medicaid participating New Jersey Physician, Approved Independent Clinic, Approved Well Child Center, or participating Hospital Outpatient Department, along with a Medicaid identification card valid at time the service is to be rendered.

_____ _____ _____
County Welfare Board Agency Social Worker Signature and Title Date Issued

_____
Parent/Parent-Person Signature

4. TO BE COMPLETED BY SCREENING PROVIDER AND FORWARDED WITH CLAIM FOR PAYMENT TO YOUR MEDICAID CONTRACTOR. Send two Contractor's Copies with your claim. You may not screen this patient more than once a year; follow-up services to this patient are billed according to established billing procedures. If the patient is referred to another provider, please print (or type) the provider's name and community, if known, in the last column below; otherwise indicate the referral with an "X."

Any New Problems Detected or Suspected? (0) [ ] YES NO [ ] *If "NO," leave columns below blank. If "YES," place an "X" in appropriate column(s) below.*

PROBLEM AREA	NEWLY DETECTED OR SUSPECTED DEFECT	TREATED BY ME (THIS FACILITY)	NO REFERRAL OR TREATMENT NEEDED	REFERRED FOR TREATMENT AND/OR DIAGNOSIS – REFERRAL SOURCE, IF KNOWN
Visual (1)				
Hearing (2)				
Dental (3)				
Lead Poisoning (4)				
Other Problem – Indicate Appropriate Body System: (5)				

I CERTIFY THAT THE ABOVE-NAMED PATIENT HAS BEEN EXAMINED IN ACCORDANCE WITH NEW JERSEY MEDICAID PROGRAM PROCEDURES AND STANDARDS FOR EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT, AND WHEN MEDICALLY INDICATED WAS TREATED BY ME (THIS FACILITY) OR REFERRED TO AN APPROPRIATE PRACTITIONER OR FACILITY FOR FURTHER DIAGNOSIS AND/OR TREATMENT, AS INDICATED ABOVE.

BEFORE SIGNING, SEE THE BACK OF THIS FORM FOR THE COLLECTIVE PROCEDURES THAT CONSTITUTE AN EPSDT SCREENING EXAMINATION.

PRINT OR TYPE: Provider Name and Address

_____ _____
Provider Signature Date of Service

_____
Social Security Number or Employer ID Number

MC—19 (Rev. 2-77) CONTRACTOR'S COPY Medicaid 80365 Ed. 2-77

DEFINITION OF EPSDT

Complete initial or interval history
Measurements (properly recorded), height and weight, head circumference to age 25 months
Physical and mental development assessment
Complete physical examination including dental, vision and hearing screening and blood pressure determination from age 5 up by physician or nurse practitioner under direct supervision of a physician.
Assessment of immunization status and initiation of steps to update immunizations.
Referral of all correctable abnormalities uncovered or suspected for further diagnosis and treatment.

The following laboratory procedures may be performed if medically indicated:

Hemaglobin or Hematocrit
Urinalysis (no less than four test dipstick)
Tuberculin
Sickle-cell Test
OVA and parasites
Lead Screening for specimen to be sent to State Department of Health Laboratory for lead screening
Other Laboratory tests as medically indicated.

Laboratory procedures performed by a physician for his patients in his office are reimbursable to the physician; if performed by outside independent laboratories, the laboratory must bill. The Medicaid Program does not reimburse for dipstick test; however, microscopic tests are reimbursable.

Department of Institutions and Agencies
Division of Medical Assistance and Health Services

PHYSICIANS AND PRACTITIONERS CLAIM

(B) **03**

1. Patient's Last Name | First Name | | | 2. Patient's Street Address | Telephone Number

3. Health Services Program Case No. | 4. Patient Person # | 5. Age | 6. Sex M/F | City | State | ZIP Code

7. Other Health Insurance or Liability Coverage? Yes No
If Yes, attach copy of Explanation of Payment from carrier. (If Medicare—See Section 304 of Manual)

8. Was Patient's Illness or Injury connected with his employment?
If Yes, give Name and Address of Employer here: Yes [X] No [X]

9. PROVIDER OF SERVICE INFORMATION

Social Security or Employer I.D. Number (Enter only when not printed below)

10. Did injury result from automobile accident? Yes [X] No [X]

Name and Address

Telephone Number

11. Give Name of Institution if Place of Service is other than Doctor's Office or Patient's Home.

FOR CONTRACTOR'S USE ONLY

TOTAL AMOUNT A	TOTAL AMOUNT B	C O D E	J A M	HOSPITAL PROVIDER NUMBER

12. REPORT OF SERVICES
1—Doctor's Office 2—Patient's Home 5—Skilled Nursing Home 6—Independent Laboratory 9—Other Locations 0—Emergency Room
3—Inpatient Hospital 4— 7—Outpatient Hospital 8—Clinic (Other than Hospital based) (Specify in 12C)

A. DATE OF EACH VISIT	B. PLACE OF SERV.	C. NATURE OF ILLNESS OR INJURY REQUIRING SERVICES	D. FULLY DESCRIBE SURGICAL OR MEDICAL PROCEDURES AND OTHER SERVICES OR SUPPLIES FURNISHED FOR EACH DATE OF SERVICE	E. CHECK (√) IF FAMILY PLANNING	P. CHARGE
					$

13. IF CONSULTATION - Give Name of Referring Physician | TOTAL CHARGES | $

14. PATIENT'S CERTIFICATION. Authorization to Release Information, and Payment Request. I certify that the service(s) covered by this claim has been received, and I request that payment for those services be made on my behalf. I authorize any holder of medical or other information about me to release to the Division of Medical Assistance and Health Services or its authorized Agents any information needed for this or a related claim.
Signature (Patient or authorized representative) Date Signed

15. PROVIDER CERTIFICATION. I certify that the services covered by this claim were personally rendered by me or under my direct personal supervision (as defined by Program regulations); that the foregoing information is true, accurate and complete; and I agree to keep such records as are necessary to disclose fully the extent of services provided, and to furnish information for such services as the State agency may request; and that the services covered by this claim and the amount charged therefore are in accordance with the regulations of the New Jersey Health Services Program; and that no part of the net amount payable under this claim has been paid, and that payment of such amount will be accepted as payments in full without additional charge to the patient or to others on his behalf. I also certify that the services have been furnished in full compliance with the non-discrimination requirements of Title VI of the Federal Civil Rights Act. I understand that fraud or concealment will be punishable under applicable Federal or State law, or both.
Provider Signature ☐MD ☐DO Date Signed
Other Degree

FOR PAYMENT MAIL TO: The Prudential Insurance Co. of America - P.O. Box 1900 - Millville, N.J. 08332

FOR CONTRACTOR'S USE ONLY

LINE NO.	DATES OF SERVICE FROM YR	FROM MO	FROM DAY	TO MO	TO DAY	PLACE OF SERV.	TYPE OF SERV.	# OF VISITS	DIAGNOSIS CODE	AMOUNT A	AMOUNT B	C O D E	J A M	DATE RECEIVED YR	DATE RECEIVED JULIAN DATE	CODER I.D.

LINE NO.	PROCEDURE CODE (1)	PROCEDURE CODE (2)	PROCEDURE CODE (3)	PRIMARY DX.	SECOND DX.	
						PATIENT
						PROVIDER

MC-8-B-C2 (224161) **PROVIDER'S COPY** Medicaid 32917 Part 2 ED. 1-75 (N.J.)

CASE NAME _____ CASE NO. _____ (C)

CASE WORKER _____

PHONE NO. _____ DATE SERVICE SCREENING _____

DATE: _____ EPSDT REQ. Yes _____ NO _____

MED. ELIG _____ REQ. _____ DEL. _____ REC'D MC 19 FROM PRUD. INS. CO. _____

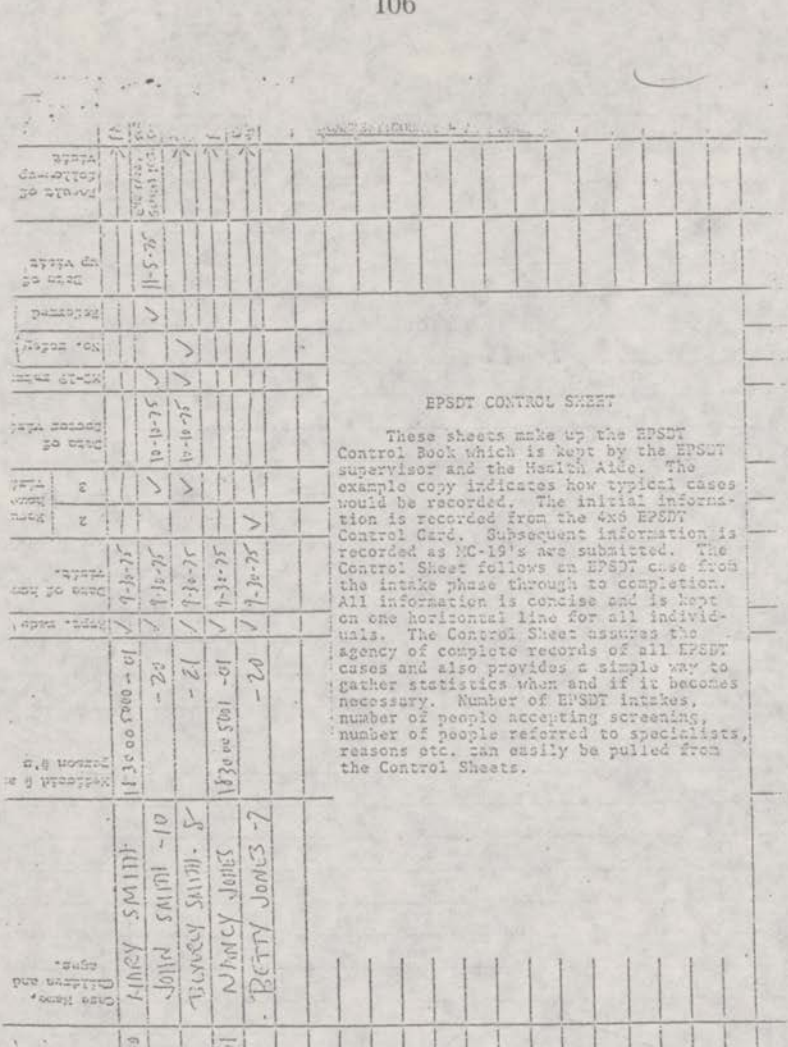
TRANS. Yes _____ NO _____ EPSDT PROVIDER: _____

PATIENT'S NAME	BIRTH DATE	PERSON NO.	DISPOSITION

LOG:

DATE	ACTION TAKEN	REMARKS

SOCIAL WORKER _____ DATE _____



EPSDT CONTROL SHEET

These sheets make up the EPSDT Control Book which is kept by the EPSDT supervisor and the Health Aide. The example copy indicates how typical cases would be recorded. The initial information is recorded from the 4x6 EPSDT Control Card. Subsequent information is recorded as MC-19's are submitted. The Control Sheet follows an EPSDT case from the intake phase through to completion. All information is concise and is kept on one horizontal line for all individuals. The Control Sheet assures the agency of complete records of all EPSDT cases and also provides a simple way to gather statistics when and if it becomes necessary. Number of EPSDT intakes, number of people accepting screening, number of people referred to specialists, reasons etc. can easily be pulled from the Control Sheets.

Department of Human Services
Division of Medical Assistance and Health Services
New Jersey Health Services Program

Table 1 Number of Exams and Payments for Exams by Type of Provider, June 1977

Type of Provider Performing Screening	Number of Exams Performed	Total Payments
Total	4,349	$96,182.49
Outpatient Hospital	50	2,627.23
Independent Clinic	495	7,920.50
Physicin	3,804	85,634.76

Table 2 EPSDT Statistical Report for June 1977

	Total	0-5	6-20
Payments	$96,182	$42,497	$53,685
Number Screened	4,349	1,842	2,507
Number with Referrable Conditions	1,859	727	1,132
Percent with Referrable Conditions	42.7%	39.5%	45.2%
Number of Individuals Screened with:			
Visual problems	125	38	87
Hearing problems	42	15	27
Dental problems	202	41	161
Lead poisoning	33	24	9
Other	1,629	647	982

Department of Human Services
Division of Medical Assistance and Health Services
New Jersey Health Services Program

Table 3 Number of Persons Screened and Number with Referrable Conditions

County	Number Screened			Number with Referrable Conditions		Percent with Referrable Conditions	
	June	FYTD	FYTD Per 1,000 Eligibles	June	FYTD	June	FYTD
Total	4,349	44,868	117	1,859	19,764	42.7	44.0
Atlantic	233	2,721	148	97	901	41.6	33.1
Bergen	101	1,195	147	21	284	20.8	23.8
Burlington	246	2,740	244	111	1,144	45.1	41.8
Camden	421	4,800	120	287	3,396	68.2	70.8
Cape May	47	396	125	14	117	29.8	29.5
Cumberland	229	2,382	225	93	879	40.6	36.9
Essex	831	8,619	88	387	4,316	46.6	50.1
Gloucester	120	818	114	39	310	32.5	37.9
Hudson	393	1,939	44	74	811	18.8	41.8
Hunterdon	27	184	161	10	59	37.0	32.1
Mercer	406	3,974	196	279	2,366	68.7	59.5
Middlesex	234	2,700	132	85	855	36.3	31.7
Monmouth	272	3,298	154	63	538	23.2	16.3
Morris	86	1,024	198	27	377	31.4	36.8
Ocean	97	1,031	77	19	260	19.6	25.2
Passaic	265	3,779	123	126	1,987	47.5	52.6
Salem	64	381	120	31	153	48.4	40.2
Somerset	53	758	198	9	175	17.0	23.1
Sussex	41	455	196	16	162	39.0	35.6
Union	166	1,510	91	61	611	36.7	40.5
Warren	17	164	78	10	63	58.8	38.4

Mr. MAGUIRE. Thank you. We only have about 5 minutes before I have to go back for a vote.

Mr. Reilly, New Jersey, as you well know, showed up very badly on the Children's Defense Fund study, EPSDT performance across the country. You have put a different interpretation on the computer tracking system here, which attempts to make the case that under Medicaid you can make assumptions about how people are being covered with respect to receiving health care.

I am wondering how you distinguish on a computer between somebody who has a broken arm and comes in to have it fixed and somebody who is getting a thorough screening in the sense that EPSDT was intended to provide, and that certainly CHAP would be intended to provide.

Are we kidding ourselves?

Mr. REILLY. No. First of all, with regard to the Children's Defense Fund, that was an extremely excellent, fine report. The difficulty with New Jersey is that it was dealing with data from 1975 and perhaps some 1976 data—I think we were running less—several hundred screens per month. We are now 4,000 per month.

That aside, I think it is possible in selecting appropriate parameters in your screening system, your computer system, that you are sure that the children that you select ought not to have been outreached, have in fact come under adequate equivalent care.

It is not one visit to the doctor per year. It is a series of visits, it is certain kinds of procedure codes.

Mr. MAGUIRE. And all of that can be programmed in?

Mr. REILLY. Oh, yes. The other thing about the screen—it has always been our assumption that the screens could be raised over time, that we had a constantly more ambitious definition of what is an adequate equivalent set—course of treatment or regimen of care, and that over time you can raise those screens and then you generate more children to be outreached.

I would point out, Mr. Chairman, that this outreach effort in New Jersey is over and beyond all of the requirements of EPSDT. This computer generated outreach through the county welfare agencies for the preschool children is not a requirement. It is an embellishment, it is something that we do that we don't have to do.

We do intend to extend that concept to the school age population as well. But, it is not a requirement of the program. It is an extra outreach effort.

Mr. MAGUIRE. I think this will require some further discussion, which we don't have time for right now.

Ms. Shenberger, does the State of Pennsylvania Medicaid office reimburse pediatric nurse practitioners for EPSDT services?

Ms. SHENBERGER. Not directly.

Mr. MAGUIRE. Do they do it indirectly? What does not directly mean?

Mr. MCKITTRICK. We allow pediatric nurse practitioners to participate in the screening room, but their work has to be under the supervision of a licensed medical physician. That physician would sign the invoice, the bill would go to him. We do not allow nurse practitioners to invoice on their own.

Mr. MAGUIRE. Is that a policy which you think might usefully be reviewed?

Mr. MCKITTRICK. It is under review right now. We feel by this October we will be allowing pediatric nurse practitioners to bill directly for Medicaid services.

Ms. SHENBERGER. One of the problems with this legislation, though, is that in relation to our school health initiative we are beginning to question whether that kind of service provided by a nurse practitioner would be reimbursible under this program at the increased reimbursement rate. If not, there would be very little incentive for the State agency to participate in a program where nurse practitioners were the main providers.

Mr. MAGUIRE. Clearly it is a resource which is being inadequately used at this time.

Ms. Feldman, on medical case management. If we are talking about continuity, and we want people to get comprehensive preventive care, and so on and so forth, who is going to be willing to do case management? How are we going to get them to do it?

Ms. FELDMAN. In Minnesota, local welfare agencies currently do it. I think they could do a better job of it. But I think having it centralized at least at the county level, that kind of case management would be far preferable to having that responsibility on every individual provider of service in the State.

In other words, right now local welfare——

Mr. MAGUIRE. In other words, they would not do the case management even if somebody else was doing the treatment?

Ms. FELDMAN. That is what the bill appears to say to me, that if they refer a child this provider would need to provide the medical case management to that child that they referred out. Our feeling very strongly is that most of those providers would not be able or willing, it depends on your definition, to do that.

Mr. MAGUIRE. Okay. I very much regret the problem of time here. We are having a lot of quorum calls and votes this afternoon. We will be in touch with you for further questions, if we have anything futher to discuss. If you have any additional points you would like to make, please be in touch with the committee.

We stand in recess for 10 minutes.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order, please.

The next panel will be made up of Marian Wright Edelman, Director and Wendy Lazarus, Health Specialist of the Children's Defense Fund; Helen K. Blank, Executive Director, American Parents Committee on behalf of members of the Health Cluster of the Coalition of Children and Youth; and William Scheutz, who is the staff attorney of the National Health Law Program.

Your statements will be made a part of the record in full and it would be helpful to the committee if you could make your remarks in the 5-minute period of time.

STATEMENTS OF WILLIAM SCHEUTZ, STAFF ATTORNEY, NATIONAL HEALTH LAW PROGRAM; MARIAN WRIGHT EDELMAN, DIRECTOR, CHILDREN'S DEFENSE FUND, ACCOMPANIED BY WENDY LAZARUS, HEALTH SPECIALIST; AND HELEN K. BLANK,

EXECUTIVE DIRECTOR, AMERICAN PARENTS COMMITTEE, ON BEHALF OF THE MEMBERS OF THE HEALTH CLUSTER OF THE COALITION OF CHILDREN AND YOUTH, ACCOMPANIED BY DONNA BROWN, DIRECTOR

Mr. SCHEUTZ. Mr. Chairman, I am William Scheutz. I bring a rather unique perspective to this hearing in the sense that I work for the National Health Law Program, which is a program whose purpose is to assist legal services programs in bringing the litigation on behalf of low income persons.

For the past 3 years the National Health Law Program has helped legal services attorneys in bringing litigation which has been aimed at implementing EPSDT programs in those States which have been reluctant to do so on their own.

For the last year, I have done work of this sort myself, and over 3 years ago I participated in litigation of this sort.

There have been many problems over the course of the last 10 years which have prevented EPSDT from being properly implemented. It is the position of our Program that the new CHAP bill must rectify these problems, or we cannot support the bill.

However, we do feel also that the problems with the bill are those that can be easily rectified through the use of clear and well thought out language.

Overall, there are two problems with EPSDT. One is that there are too few requirements, and the second is that many of the requirements which exist are in a form which are very clouded and unclear and uneasy to understand and to implement.

Specifically, in EPSDT there are these five problems. There is no screening package; that is to say, States are not required to provide certain types of screening. It is simply that screening must be early and periodic, it must be for mental and physical ailments.

By implication HEW has said it must be for hearing, vision and dental, since there must be treatment for those items.

Treatment is also very limited. It is limited to the State plan and to hearing, vision and dental problems.

Perhaps most importantly, there are very ineffective requirements regarding the involvement of eligibles in the program; that is to say, those things that we normally refer to as follow up or outreach are not set forth in the kind of language that makes it clear to States what they are to do.

There are no achievement criteria. Instead, States are told that they should make this attempt or that attempt, certain efforts to achieve certain things. But they are not told they must screen a certain percentage of children, they are not told they must diagnose a certain percentage of children or must treat a certain percentage of children. I feel that achievement criteria of this sort is definitely needed.

There is very limited and ineffective enforcement. Basically, there is a reduction in the grant for the failure of States to follow certain limited penalty provisions. There is not another type of enforcement as through injunctive relief. The type of enforcement which exists is subject to the reconsiderations process, and it is limited strictly for violations of the penalty provisions.

The question then becomes whether or not CHAP rectifies any of these problems.

I would like to start out by saying that though we understand that CHAP is not a comprehensive health care program for children, the CHAP preamble itself states that it is simply to strengthen and improve the EPSDT program.

We have nothing against limited goals in this respect. However, we feel that any bill which undertakes to improve another piece of legislation should at least accomplish those ends.

Especially in this case where there is increased eligibility and perhaps increased services, States are already somewhat reluctant to provide EPSDT as it currently stands. They need to be clearly told what is expected of them with regard to an increased program.

Quite the contrary, however, CHAP does not clearly set forth what is required.

The two problems with CHAP overall is that there is a lack of definition of terms. Perhaps this can be solved with regulations.

Secondly, there is a lack of conformity between terms. The most obvious example of this is that the legislation requires primary care and assessment, but does not define either term.

Mr. ROGERS. Would you like to have a concluding sentence?

Mr. SCHEUTZ. Yes. Simply this—that these terms need to be conformed, terms such as appropriate care and services, minimum diagnosis and treatment, outreach, follow-up, case management, case tracking. Those kinds of terms need to be clearly defined.

There needs to be conformity among the different provisions within the act to make sure when we talk about case tracking in one place we are talking about case management in another.

When we are talking about primary care, we are talking about diagnosis and treatment, or we are not talking about it.

Mr. ROGERS. May I suggest to you too that the committee would be pleased to receive suggested language.

Mr. SCHEUTZ. Yes, we would be willing to provide that.

Thank you.

[Mr. Scheutz prepared statement follows:]

STATEMENT
OF
THE NATIONAL HEALTH LAW PROGRAM
TO
THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE
ON
THE CHILD HEALTH ASSESSMENT ACT OF 1977, S. 1392
SEPTEMBER 8, 1977

Mr. Chairman and Members of the Subcommittee:

My name is William Schuetz. I work as a staff attorney for the National Health Law Program in Santa Monica, California.

The National Health Law Program, or NHeLP, is a California non-profit corporation funded by the Legal Services Corporation to provide technical and legal assistance to legal services attorneys nation-wide whose low-income clients have encountered difficulty in obtaining needed health care. During the last five years NHeLP has helped many of these attorneys with much of the litigation which they have brought to compel States to implement their Early and Periodic Screening, Diagnosis and Treatment (or EPSDT) programs for children on Medicaid.

We on the staff have observed first hand the many problems encountered in implementing or enforcing the law as it is currently written, and we have formed some opinions regarding the resolution of these problems. Similarly, we have followed with interest and concern the President's proposal to strengthen and improve the EPSDT program through the Child Health Assessment Act, or CHAP, and we have formed some opinions regarding the effectiveness of this effort. We appreciate this opportunity to share these observations and opinions with you.

The Problems with EPSDT:

Ten years ago, when it was first enacted as part of Medicaid, the EPSDT program was regarded as a great advance in providing health care to low-income children, for it included two elements missing in the provision of Medicaid generally: first, it stressed preventive care; and second, it obligated States to take an active role in helping children to obtain needed care. Five years later, in 1972, Congress became disturbed with the failure of States to establish active EPSDT programs and enacted the so-called penalty provisions. These provisions empowered HEW to reduce reimbursement for AFDC expenses to States which failed to take certain measures to assist children in obtaining EPSDT. Now another five years has passed, again without much change. Necessarily, this legislative body must ask the question, "Why?"

Generally speaking, there are two problems with EPSDT: first, it does not clearly establish what is required of States; and second, it does not require enough. Statutory provisions are couched in broad language that necessitates extensive administrative interpretation. Administrative interpretation, while more specific, is often unclear or only suggestive, and sometimes contradicts itself. Specifically, this lack of clear and sufficient requirements is manifested in five ways:

First, The Lack of a Screening "Package": States are not required to administer certain screening examinations, nor are they required to administer them at certain intervals. The original statute simply requires that screening be early and periodic, and that it detect both mental and physical defects. Administrative guidelines recommend, but expressly do not require, certain minimum examinations. Instead, they leave it to States to establish the exact content and frequency of examinations through consultation with experts.

Second, Limited Treatment: Although States are required to conduct whatever diagnosis is needed to definitively evaluate possible conditions discovered during screening, they are generally permitted to limit treatment to that normally covered by their State Medicaid plans, although they must offer visual, hearing and certain dental care in any case. Administrative discretion has caused treatment to be limited to the State plan in this way.

Third, Ineffective Outreach and Follow-up Requirements: Although both legislative history and administrative pronouncements make it clear that States are to actively assist children in obtaining needed services, States actually are mandated to do very little in this regard. Specifically, the penalty provisions require them to take certain steps to inform AFDC eligibles about the availability of services and to arrange for screening whenever it is requested and treatment whenever screening indicates that it is needed. These provisions are limited in scope, and the administrative provisions which interpret them are, for the most part, difficult to understand and implement.

Fourth, A Failure to Measure Performance by Results: States are not required to achieve results; they need only make an effort. To put it another way, all program requirements are geared to input (or effort), rather than to output (or achievement).

Fifth, Ineffective Enforcement: HEW is restricted to a limited and cumbersome means of compelling States to comply with their obligations. In essence, if a State fails to comply with the penalty provisions, HEW may reduce its reimbursement for AFDC expenses by 1%. HEW may not impose this penalty where a State fails to comply with non-penalty provisions, nor may it resort to other remedies, such as injunctive relief. Furthermore, this remedy is subject to the State's right to invoke a lengthy reconsideration process, which in practice has delayed the imposition and effect of the penalty.

How to Resolve the Problems with EPSDT:

To resolve these five problems, any new law must:

One: establish the required content and frequency of screening examinations;

Two: require treatment for all conditions definitively identified during either diagnosis and screening;

Three: describe in detail the measures which States must take to help children to obtain screening, diagnosis and treatment;

Four: require States to achieve results from their efforts, such as generating a minimum percentage of requests or providing a minimum percentage of services; and

Five: provide for remedies other than a cutoff of funds, which HEW can employ whenever States fail to comply with any program requirements.

How CHAP Addresses These Problems:

In analyzing the CHAP proposal, the members of this Subcommittee must determine whether or not it corrects these problems encountered in EPSDT. NHeLP has concluded that the proposal does address these problems in part, and commends the Administration for its efforts in this regard. However, several problems still deserve attention in order to make CHAP effective.

First: Although the CHAP proposal does not establish the required content and frequency of screening examinations, it instructs HEW to do so. However, it fails to offer HEW

any guidelines in this respect. This is particularly disturbing since treatment under the CHAP proposal is to some extent more limited, and consequently HEW can be expected to limit screening in a similar manner. (Specifically, the CHAP proposal requires States to provide "child health assessments," a term which it never defines, except indirectly by establishing that such assessments may be provided only by providers who provide "periodic health assessments," as required by the Secretary.)

Second: The CHAP proposal does require that States provide, to all children who have received a "periodic assessment," all the "care and services" appropriate under Medicaid, without regard to State plan limits. However, it then makes two exceptions for 1) mental and developmental treatment, which apparently States must provide only if their Medicaid plans include it or they opt to include it under CHAP, and 2) dental care, which States must provide only for dental conditions discovered during an assessment. It is not clear whether or not the phrase "appropriate care and services" encompasses diagnosis, as well as treatment. It is clear that the extent of required diagnosis is not established elsewhere. Thus it would appear that CHAP has narrowed the scope of required diagnosis. In any case, these two exceptions clearly could cause States to exclude much of the treatment which they now provide under EPSDT, especially since HEW could conceivably define "assessments" not to include examinations, or to include only cursory examinations, for mental, developmental or dental conditions.

(Specifically, the CHAP proposal requires that States provide "primary care," in addition to "assessments," but it never defines that term, except indirectly by requiring "appropriate care and services" for individuals who have received a "periodic assessment." Similarly, the CHAP proposal requires HEW to establish a "minimum range of diagnostic and treatment services" which providers of assessments must provide to children whom they have assessed, but it never establishes (or requires HEW to establish) the extent of diagnosis that States must provide generally.)

Third: The CHAP proposal does address more comprehensively the State's obligation to assist children in obtaining needed services. It imposes requirements upon assessment providers concerning "referrals," "follow-up," "medical case management," "reassessments," "continuing accessibility" and "compliance reporting." It also requires States, under the threat of a penalty, to "inform" children of the program, to "assure" the "timely" provision of services and to "assure" that providers comply with their obligations. In addition, it requires States to "assure" the availability of "support services," including "case tracking" and "outreach." However,

these provisions may cause more problems than they cure.

For one thing, the division or overlap of responsibility between the State and assessment providers is very unclear. For another, the proposal never defines such terms as "follow-up," "medical case management," "case tracking," "outreach," and others that are open to numerous interpretations. Instead, it leaves it to HEW in many, but not all, instances to establish, without any guidance, the parameters of these obligations. Lastly, the proposal specifically does not require States to "inform" the medically needy.

Fourth: The CHAP proposal does not require States to achieve any results in order to comply with their normal obligations or avoid the penalty. It does permit HEW to establish achievement criteria as one basis for awarding a financial bonus, but it provides no guidance in this regard, and HEW could base the bonus strictly upon input criteria.

Fifth: The CHAP proposal offers no new means for compelling States to comply with program requirements. It simply substitutes a new financial penalty and a new set of penalty provisions. The new penalty still is subject to a lengthy reconsideration process and can not be imposed for failure to comply with non-penalty provisions. Furthermore, the CHAP proposal expressly permits HEW to withhold or waive the penalty under certain circumstances and to even avoid a compliance review altogether.

What CHAP Needs to Do:

The CHAP proposal clearly must do more to resolve these problems. To make CHAP effective the proposal must:

One: Either establish the content and frequency of child health assessments, or provide guidance to HEW to ensure that such assessments detect mental, developmental and dental, as well as physical, conditions;

Two: Require States to provide a) all diagnosis needed to definitely evaluate all possible conditions discovered during an assessment, and b) all treatment considered appropriate under Medicaid, without regard to State plan limits;

Three: Describe in detail exactly how States must assist children in obtaining needed services through outreach, follow-up and case management, and delineate the division or overlap of responsibility between the State and assessment providers concerning these functions;

Four: Either establish that States must achieve certain results as a part of program requirements, or provide guidance to HEW and require it to establish such achievement criteria; and

Five: Authorize HEW to take remedial measures other than the imposition of a penalty, such as obtaining injunctive relief, and to invoke any remedial measure for any failure to comply with any program requirement.

Conclusion

On behalf of NHeLP, I thank you for the opportunity to share our observations and opinions. If the Chairman or any members of this Subcommittee wish me to elaborate upon any of my comments, please do no hesitate to contact me at your convenience.

STATEMENT OF MARIAN WRIGHT EDELMAN

Ms. EDELMAN. Mr. Chairman, I am Marian Edelman. Wendy Lazarus is here to answer difficult questions you may have.

We very much appreciate the opportunity to testify.

The Children's Defense Fund is a national child advocacy organization which is dedicated to uncovering problems faced by large numbers of American children and seeing they are corrected. One of our priorities is children's health.

We have spent the last 2 years studying the EPSDT program, through a five-State study. We want to share some of these findings with you.

We are very grateful that you have taken the time to hold these hearings, knowing how pressing your legislative agenda is. We are also very pleased with the congressional interest expressed in improving this program, particularly your bill, Congressman Maguire, which we think will add strength to many of the CHAP provisions.

We welcome your initiative, and are pleased to see that Congressman Moss has also taken a keen interest in this program.

I want to do several brief things in oral testimony.

We think CHAP is a very good step forward, and we are pleased at the administration's initiative in this.

There are many of its provisions that we support strongly. We think there are some serious omissions—many of which are addressed by Congressman Maguire's efforts—which we think need to be included if the bill is going to be effective in serving the children that so much need the service.

Some of the detailed amendments which we propose in our testimony will require no new money. Some of it will require some new money, but we don't think it is going to be inordinately expensive.

If this committee sees fit to include a maintenance State effort provision, proposed amendments we set forth in our testimony will

cost an additional $75 million. If this committee does not see fit to do that, we estimate the cost for the amendments that we think would strengthen CHAP to be around $13 million.

Even with this, the amount of money we are talking about would constitute less than 1 percent of the Medicaid expenditures, and we certainly think our children's health is worth this.

I want to impart two things today. One is the sense of urgency which we feel about enactment of this program right away. We are committed firmly to action this year, and we hope this comittment will be reflected in this committee's action and by the administration's when they come to testify tomorrow in getting this bill through.

Childhood is a very fleeting, irreplaceable time which often dictates adult outcome. I don't think that poor children who don't have health care now should be asked to endure anymore suffering, or to go through handicapping conditions which are undetected and correctible either medically or dentally when we have the means and ability to correct it.

Second, we think that nothing is more emotional, nothing is more basic than health care to any parent, and to their children.

Third, we think that the unmet health care needs of this program attempts to address are very well known but remain a very urgent problem. Nationally in fiscal year 1976 for every three children screened, two conditions were found needing follow-up care.

Between 60 and 80 percent of these problems were previously unidentified or cared for. Fewer than 1 percent of the children screened in EPSDT had received a complete physical exam.

The Congressional Budget Office suggests or estimates that there are 3,200,000 children on Medicaid who need immunizations in this country. I think that is a shame on Americans. There are 2,184,000 Medicaid children who need treatment for anemia. There are another 2,210,000 children who need vision and hearing impairment help. We think that these children's health needs should not wait for another session of Congress.

We think that this program should be enacted because it is going to save money in the long run. Prevention is always less expensive than cure.

We also think an added argument for its immediate enactment is the fact it is doable. It is a 10-year old program. There is a high degree of consensus about what is wrong with it, and also a high degree of consensus about what will make it work. We think this committee has it in its power to improve this program and provide needed services without delay.

In addition, we think that enacting CHAP now will help lay valuable groundwork for national health insurance by helping to create a delivery system.

In the remainder of this I want to address several things—what is in CHAP now we think should be changed and, second, what is not in it that ought to be added.

Before I do this, I would simply state two things. We think that CHAP is not the answer to children's health needs. Nothing short of a national health insurance program is going to adequately meet the needs of children and mothers.

Second, the resource development problem—there is a great need for resource development because there are many communities which do not have services but where children have great health needs.

An estimated 16 percent of AFDC children now live in counties designated as medical shortage areas. There is a great need for more attention to the resource development issue.

A brief word about the substance of our recommendations.

First, the issues in the bill that we think ought to be changed or strengthened—we think there is inadequate provision for public education about services and assistance in using them—outreach.

Many of the witnesses today have attested to that. We think outreach is one of the most important things that must be strengthened. CHAP must include provisions for involving organizations located in the target communities, known and trusted by target communities if this program is going to be effective.

Third, we think there has to be more attention to the lack of providers who are allowed or willing to provide care to children under this program. CHAP must require States to take affirmative steps to identify qualified providers and to encourage their participation by assuring reasonable rates of reimbursement, prompt payment of claims and the like.

CHAP should also include provisions which see that the assessments and needed treatments get to children. It is time to establish outcome standards which States and HEW should be expected to meet, standards which measure performance in enrolling a reasonable proportion of eligible children in the program and providing them with needed assessments and treatment.

The subcommittee must set a benchmark against which program progress can be monitored. Otherwise, there are no guarantees that this program's dismal performance to date will not be repeated or will not persist.

Finally, we feel very strongly that it is time, as you work to build in appropriate incentives and bonuses for good performance, to consider imaginatively how to get children the services they need and are entitled to in instances where States do not meet congressional mandates.

In our written testimony we recommend a measure which we think is an important supplement to the financial penalty for noncompliance already in the CHAP bill. It would allow the Secretary to require States to meet the congressional mandates, and allow him to seek that enforcement when it is failed by States in court.

Much has been learned during early screenings' 10-year history about the program's deficiencies and how to correct them. I have been struck even today, Mr. Chairman, and Dr. Carter, by the amount of testimony which seems to say let the States do it.

I think the chief focus of this subcommittee has to be services to children. The States have had 10 years to do it. I think our prime obligation and our prime objective has to be getting needed health care to children who don't have it.

This is the only program that can reach them immediately. Their needs cannot wait. We hope that strengthened amendments which

are needed to improve this program in the ways it should be improved will be given serious and prompt consideration by this subcommittee.

[Testimony resumes on p. 182.]

[Ms. Edelman's prepared statement and attachments follow:]

TESTIMONY OF THE CHILDREN'S DEFENSE FUND
ON THE CHILD HEALTH ASSESSMENT ACT
OF 1977: H.R. 6706
BEFORE THE SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
OF THE COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE
UNITED STATES HOUSE OF REPRESENTATIVES

September 8, 1977

Chairman Rogers and Members of the Subcommittee: the Children's Defense Fund appreciates the opportunity to appear before this Subcommittee to express our views on H.R. 6706, the Child Health Assessment Program (CHAP): "a bill to strengthen and improve the Early and Periodic Screening, Diagnosis and Treatment program and for other purposes." There is no proposal currently before the Congress which has greater significance for the health of children in this country. This important bill deserves prompt and careful consideration by the Subcommittee.

The Children's Defense Fund (CDF) is a national, nonprofit, child advocacy organization created in 1973 to gather evidence about the conditions of and to address systematically the needs of American children. We have issued reports on specific problems faced by large numbers of children in this country, in the areas of health care, education, juvenile justice, and foster care. We seek to correct problems uncovered by our research through federal and state policy changes, monitoring, litigation, public information and support to parents and local community groups representing children's interests.

CDF has recently published an in-depth report of the progress and problems of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program. EPSDT: Does It Spell Health Care For Poor Children?, issued in June, 1977, describes the way the program is operating, documents the extent to which it is failing to meet the basic health needs of poor children, and sets out the concrete steps needed to make EPSDT work better. Attached to this testimony is a copy of Chapter 1 from the report. It summarizes what we found and what we conclude should be done. (See Appendix I.)

Because many of the necessary reforms require legislative changes, CDF is delighted that the Administration has proposed a plan for modifying EPSDT. We believe it represents a very constructive beginning. We are pleased, too, that members of the House have taken an increasingly active interest in the important question of how to improve the EPSDT program. We appreciate the willingness of the Subcommittee to schedule these hearings at a time when the Congress is confronted with a full agenda of pressing issues, and we are standing by to help in any way we can to expedite consideration of this legislation. This increased interest in EPSDT is reflected not only in the scheduling of the hearings, but in the work of Representatives Moss and Maguire who have actually developed and introduced legislative

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proposals. We would be pleased to work with the Subcommittee and any other interested members of the House to shape all of these proposals into a bill which can be enacted this year.

During the course of this testimony we will recommend changes in H.R. 6706 which are crucial to make the plan effective. We urge this Subcommittee to act expeditiously to amend the bill accordingly.

Poor Children's Immediate Need for Better Health Care

As EPSDT has documented, children in low income families have a host of unmet health needs. Nationally in fiscal year 1976, for every three children screened, two conditions were found needing follow-up care. Between 60 and 80 percent of these problems were previously unidentified or uncared for. Fewer than 1 percent of children screened in EPSDT had ever received a complete physical examination. Screenings uncovered such conditions as incomplete immunizations, dental problems, low hemoglobins, vision and hearing disorders, high levels of lead in the blood, genitourinary and respiratory infections, parasites and skin diseases.

Most of the problems uncovered by EPSDT can be corrected or at least eased by providing children with basic health services. The consequences of not doing so are monumental. Children suffer needless pain; they encounter difficulty in school and in jobs; and society expends billions of dollars treating problems which could have been prevented.

"Archie Douglas" is a child now living in the District of Columbia. His story shows the frequent results of inadequate health care.

> Archie Douglas is now eight years old and has already failed the first grade twice. He has always avoided going to school whenever possible. Last year his teacher reported that when in class, he had a short attention span, misbehaved frequently and was generally disruptive. After two years of first grade instruction, his language skills are those of a five year old. This is true despite the fact that he excels in the nonverbal portion of standardized intelligence tests. Archie comes from a stable, intact, lower-income family.
>
> Archie was a full-term, normal healthy baby. He received his health care during infancy from a city clinic. When he was 18 months old, he had a fever and an earache. His mother, relying on her mother's advice, rocked him to soothe his crying and ease Archie's pain, gave him half

an aspirin every few hours and used a commercial ear-drop preparation. While rocking him, his mother noticed that some fluid began draining from his ear. Archie seemed less distressed after the fluid drained, and he recovered completely within a few days.

Three months later the fever and the earache recurred. This time both ears were affected. Home remedies brought no relief and Archie was taken to the clinic. The doctor diagnosed bilateral otitis media. This is a common childhood illness, easily diagnosed, and easily and effectively treated by antibiotics. Mrs. Douglas was able to pay $15 for antibiotics only by deferring her rent payment. Because Archie seemed to recover in a few days, his mother discontinued the medication prescribed by the doctor before the full antibiotic regimen was completed. Within a month, the condition returned, and this time rocking, ear drops and a few left over antibiotic pills were administered and Archie seemed to recover.

With the exception of these illnesses, Archie was a healthy, active child. Other than visits to the clinic for immunizations, his mother was grateful that he never needed to see a doctor.

This year Archie has a new first grade teacher. On his recommendation, Archie's mother took him to a speech and hearing center for an evaluation. They found that Archie has a bilateral hearing loss that probably resulted from his early bouts with otitis media. He has slightly more hearing in his left ear (30 dB) than in his right (45 dB).

Archie's hearing loss is considered significant. He has frequent difficulty with normal speech sounds, and his difficulty has probably been the cause of his school problems. Archie's hearing problem can be alleviated by a hearing aid, but at this point, he also needs remedial education and his mother needs counseling and support. Even with help, it will be difficult for Archie to overcome his initial impressions that school is incomprehensible, that he cannot keep up and that he is a failure.

Archie could have been spared much of his suffering through a program of early screening and follow-up care. While it is unlikely that screening could have identified his ear infection when it first developed (unless his screening appointment happened to be scheduled when he was sick), screening within the next year or so would have identified the hearing loss much earlier, when he was two or so years old, long before it seriously affected his language skills. Once his problem was identified, Archie could have gotten a hearing aid and services in school suited to his special needs.

Millions of children like Archie need the basic health care which they currently do not get. According to projections by the Congressional Budget Office, among Medicaid-eligible children in one year alone, 3,200,000 need immunizations, 2,184,000 need treatment for anemia, and 2,210,000 need care for vision or hearing impairments. If the health problems of children who are poor but not eligible for Medicaid were considered, the numbers would, of course, become much larger.

Why Improve EPSDT?

Numerous reports, experts, and other organizations have pointed up the shortcomings in the performance of EPSDT. In nearly every respect, this program has failed to realize the promise which many believed it held for poor children when it was enacted back in 1967. Our own findings have convinced us that the only way poor children will receive truly effective health care is through a national health insurance program designed to assure comprehensive care to all Americans. The enactment of such a program is our principal goal. However, poor children cannot go without basic health care until national health insurance is enacted. Experts agree that even if national health insurance legislation were introduced immediately, it would be at least four years until services become available. This delay is due to the time required to legislate, plan and implement a major new program.

The first reason to improve EPSDT now is that, over the next four years, there are no other sources of health care to which many poor children can turn for primary care services. Other federally-financed health programs for children -- including Community Health Centers, comprehensive programs under Title V, and Migrant and Indian Health programs -- reach only a fraction of the children on Medicaid. In 1975, these programs were estimated by HEW to have reached 1.7 million children. This compares to an estimated 13 million children certified for Medicaid.

These programs have been effective and their expansion is necessary to fill the gaps in the delivery system through which EPSDT

and national health insurance operate. Therefore, we urge that they be expanded immediately. However, it is unrealistic to expect them to gear up to meet the needs during the next year or two of the millions of children who do not presently have access to their services. As new resources are being developed, reforms in EPSDT can bring improved services to poor children now. Thus, we do not hesitate to recommend an increased investment in EPSDT, despite our clear awareness of its limitations.

The second reason to improve EPSDT is that, in the process of making EPSDT function more effectively, we will confront and help to resolve some of the key problems that any program of national health insurance will have to address in order to be effective. If we are not to duplicate the mistakes of wasteful, piecemeal and inadequate health care programs of the past, we must (a) develop effective ways to reach out to families currently outside the health care system; (b) establish standards for complete, quality care and methods to monitor and enforce these standards; (c) involve more doctors and clinics as providers in publicly-financed programs; and (d) provide incentives to develop health resources where they currently do not exist--in urban centers and remote rural areas. Reforms in the EPSDT program will strengthen the foundations on which a new universal program can be built.

The urgency of children's health needs and the business of laying groundwork for a system of national health insurance cannot wait. And because, we believe that much of this Subcommittee's attention next year should be devoted to the issue of national health insurance, it is essential that needed reforms in EPSDT be made before the Congress recesses this year.

The Adequacy of H.R. 6706 For Improving EPSDT

H.R. 6706 includes certain significant improvements in EPSDT and forms a basis on which additional legislative changes can be made. More specifically, we support the following features of CHAP:

- Inclusion in Medicaid of the estimated 760,000 additional children who would qualify as "income eligible" children under age 6.
- Provision of a clearly defined, comprehensive health assessment, rather than a screening.
- Provision of complete health services to children who have been assessed (except to children with specified conditions--a provision which we believe is very damaging and which we will take up later in our testimony).

- Extension of a child's eligibility for Medicaid to help assure that needed followup care is received.
- Defining providers' responsibilities under the program.
- Encouragement for providers to offer routine forms of treatment as well as assessment, within a reasonable period of time.
- Increased federal share of CHAP costs.
- Financial bonus to states which provide assessments, treatment, and immunizations to an especially high proportion of eligible children.
- Withholding 20% of states' administrative costs under Medicaid for failure to meet program requirements.

While we endorse the many good provisions listed above, nonetheless we believe that the CHAP bill lacks other crucial elements without which the package will not be nearly as effective as it could and should be. During EPSDT's ten-year history, a great deal has been learned about how best to meet the needs of children and in what respects the current EPSDT program is deficient. These lessons should certainly be applied to the design of CHAP.

Summary of Recommended Amendments to H.R. 6706

Some of the needed amendments require only nominal increased costs. The costs of others are slightly greater but extremely modest in the context of Medicaid as a whole. In fact, according to our projections (see Tab A for projected costs), the changes we believe are necessary would cost only an additional $135 million (or, if states kept their current level of financial commitment in the program, only $75 million) -- less than 1% of last year's Medicaid expenditures. Our children are worth that.

Below is a summary of CDF's recommended amendments to CHAP, followed by a discussion of each recommendation.

I. Amendments Which Involve No Cost or Minimal Costs

A. Encouraging All Qualified Providers to Participate in CHAP

- CHAP should require states to identify qualified providers (including dental providers) and to encourage their participation in CHAP by offering administrative arrangements (including reimbursement rates and prompt payment of claims) which can be expected to elicit their involvement. HEW should be charged with reviewing state performance on an annual basis.
- The criteria in the bill defining a CHAP provider should be modified to make clear that providers (such as physicians in group practice and Head Start programs) which can take responsibility for assuring that children receive CHAP services, even though they do not provide every service, should qualify.

B. Assuring that CHAP Services Get to Needy Children.

- As a program requirement, CHAP should establish outcome standards which states are expected to meet. The standard should measure performance in enrolling a reasonable proportion of eligible children in the program and providing them with needed assessments and treatment.
- CHAP should require that the Secretary gather data to assess states' performance in enrolling eligible children in CHAP and in providing a reasonable proportion of eligible children with health assessments and needed treatment.
- CHAP should be modified to require that states meet all program requirements and that the sanctions available to the Secretary be used for an infraction of any program responsibility.
- CHAP should require that the Secretary review every state's program at least once annually. The Department should complete its review by the end of the quarter following the quarter under review. If the Secretary determines that a state is not meeting CHAP's program requirements, he must levy the financial penalty or require the state to take necessary steps to meet the Congressional mandate. Before any order of the Secretary becomes effective, the state can seek judicial review on the appropriateness of the Secretary's finding. The process for reviewing a state's appeal should be carried out expeditiously.

C. Developing States' Capacity To Deliver CHAP Services.

- Under CHAP, states should submit plans to HEW which show how the requirements of CHAP are met and which demonstrate the capacity to carry them out as described. There should be substantial public input in the development of the plan.

- CHAP should require that Medicaid agencies in conjunction with Health Planning and Title V Maternal and Child Health programs identify shortage areas for children and develop a strategy for building the necessary resources.

D. Building Accountability in HEW's Administration of CHAP.

- H.R. 6706 should specify that Congress expects 80 percent of eligible children to be enrolled in the program, five years following CHAP's enactment. On an annual basis, the Secretary should report to the Congress on the Department's progress in reaching this goal.
- H.R. 6706 should require that within six months of CHAP's enactment, the Secretary issue final implementing regulations.
- H.R. 6706 should establish that, on a biennial basis, an independent evaluation of HEW's administration of the program be conducted and submitted to the Congress by an outside panel of experts representing the interests of recipients.

II. Amendments Which Involve Additional Costs

A. Assuring Effective Outreach

- CHAP should require states to allocate a certain minimum portion of funds for public education and for efforts to enroll children in the program. The exact amount should be in proportion to the percent of eligible children not currently enrolled in CHAP. Nonprofit organizations located in the target community as well as public agencies should qualify for reimbursement to perform outreach.
- For outreach performed by nonprofit organizations located in the target community, states should receive 90 percent federal reimbursement for the expenses of enrolling new children, up to a reasonable level for the cost of each child enrolled.
- States which fail to attract to the program a reasonable proportion of eligible children should be required to develop a new outreach program emphasizing the use of organizations located in the target community.

B. Covering Health Services Following An Assessment

- The language in H.R. 6706 should be clarified to make explicit CHAP's intent: that children in the program (i.e., who have been assessed) receive health care needed for problems found during the assessment as well as for problems which arise in between the times they are assessed.

- *The provision exempting states from treating children with "mental illness, mental retardation, or developmental disabilities" should be eliminated. CHAP should provide health services, including mental health services, for all conditions found during an assessment and should refer children, as appropriate, for needed educational and social services.*

C. *Providing Dental Care.*

- *The dental provision in CHAP should be replaced by a requirement that states provide such dental care as is necessary for relief of pain and infection and for restoration of teeth and maintenance of dental health. States should be discouraged from predicating dental care on the receipt of dental screening.*
- *States should be expected to provide needed dental care to an increasing proportion of eligible children each year so that 80 percent of eligible children receive such dental services five years after the enactment of CHAP.*
- *The level of federal reimbursement for dental care under CHAP should be modified to make it the same as for other health services.*

D. *Maintaining State Effort in the Program.*

- *The $80 million in the federal budget for CHAP which replace state dollars should be used for new benefits for children. Either states should be expected to maintain their current level of financial commitment for Medicaid outpatient services for children or the Congress should appropriate additional federal funds which will result in program expansion.*

E. *Extending Medicaid to "Income Eligible" Youth, Aged 6-21*

- *Medicaid eligibility should be extended to the estimated 1,140,000 million children and youth between the ages of 6 and 21 who meet states' income qualifications for welfare but do not presently qualify for Medicaid because they fail to meet other welfare requirements (e.g., they are poor but live in intact families).*

Rationale for CDF's Recommended Amendments

Our EPSDT report includes extensive justification for the changes we recommend in the program. Here we will describe briefly why they are necessary.

1. Encouraging All Qualified Providers to Participate in CHAP

CHAP's clear intent is to make sure that poor children have ready access to CHAP services by involving the range of providers who are acceptable to poor families and qualified to give needed care. These include Community Health Centers, Children and Youth programs, Head Start programs, solo and group practice physicians, outpatient departments of hospitals and the like. While we strongly support this goal, we believe that CHAP, as it now stands, lacks adequate provisions to attract all qualified providers' participation.

Medicaid law presently calls for EPSDT programs to make the maximum use of existing resources. However, the intent has not been carried out because the language is too general and the federal monitoring has been too lax. As a consequence, for instance, last year, 19 states relied primarily on county health departments, at the exclusion of other qualified providers, to screen eligible children. CDF found that in other states, qualified providers are effectively excluded from participating in EPSDT due to low reimbursement levels or inappropriate standards for certifying providers. Thus, children are denied access to comprehensive health centers and other providers which are often best suited to attend to their needs. During these hearings, the Subcommittee will hear the testimony of providers who have encountered first hand the barriers or disincentives to providing EPSDT services.

Although H.R. 6706 currently requires states to "encourage participation by physicians and health care centers," this provision can be expected to be no more effectual than the similarly vague requirement under EPSDT. Based on what is now known about the reasons qualified providers do not participate in EPSDT, a more explicit provision can and should be written. Therefore, we have recommended that H.R. 6706 give states specific responsibilities that will encourage participation by qualified providers and that HEW be required to monitor state performance in this regard. We recommend, too, that the definition of a CHAP provider be written to include the range of providers who can perform or arrange for CHAP services.

2. Assuring Effective Outreach

When the Congress enacted EPSDT in 1967, it recognized that "organized and intensified casefinding procedures" were among the essential first steps in getting basic health care to needy children. Since then, nearly every study of EPSDT has concluded that outreach (as public education about services and assistance in using services are called) is most effectively carried out by community residents who are known and trusted by the target population.1/ Although H.R. 6706 charges states with "assuring the availability" of outreach, it fails to include a means for states to support the most effective form of outreach--that which is community-based.

The outreach provisions under EPSDT currently, including the financial support available, have not been sufficient to properly inform the majority of eligible children and assist them to get health care. CDF found that EPSDT outreach usually consists of sending welfare recipients a written notice (which families often cannot understand or read) and sometimes having a welfare caseworker explain the program to the family during certification or recertification for welfare benefits. We found no organization other than the welfare department reimbursed by Medicaid for EPSDT outreach.

The results have been poor. In fiscal year 1976, for the 13 million children who were eligible, EPSDT provided only about one-quarter of the screenings children needed, according to minimum standards set by the American Academy of Pediatrics. Unless provisions for community-based outreach are included in the CHAP program, the same inadequate situation can be expected to prevail: although CHAP will pay for essential services, few children in need will receive them.

Therefore, we recommend that states be expected to earmark at least a certain portion of the program budget for outreach, totaling approximately $5 million nationwide; that non-profit organizations located in the target community (e.g., community clinics, Head Start programs and churches) qualify for reimbursement; and that states receive a financial incentive for community-based outreach, with federal reimbursement at 90%, up to an amount of approximately $6 per child enrolled. If, however, with this incentive, states do not attract a reasonable proportion of eligible children into CHAP, they should be required to establish a new outreach program emphasizing the use of community-based organizations.

1/ See EPSDT: Does It Spell Health Care for Poor Children?, p. 90 and following.

3. Covering Health Services Following An Assessment

According to HEW staff who developed the proposal, CHAP seeks to provide comprehensive health services to children who are in a program of ongoing health supervision. Thus, H.R. 6706 calls for providing to "any individual under the age of 21 who has received his periodic assessment...all care and services appropriate for individuals under age 21..." We strongly support the principle underlying this provision--that states should make available to children basic health services as needed. The fact that some states currently opt not to cover needed treatment services and primary care services (as is the case under EPSDT) is unconscionable. After all, the purpose of preventive and ongoing health care for children is to provide them with the services needed for the problem found.

While we strongly support CHAP's thrust regarding coverage of health services following an assessment, we find H.R. 6706 deficient in two major respects. First, the bill must make explicit that CHAP entitles children in the program (i.e., who have been assessed) to receive health services needed for problems found during the assessment as well as for problems which arise in between the times they are assessed, regardless of what services are covered under the state plan. Eligible children can, of course, receive other Medicaid services as well. In sum, CHAP provides children with a range of essential health services for needs which occur while they are in the program. This concept is clearly a step forward from EPSDT's narrow concept of a program which screens and assures treatment only for problems found during screening. Therefore, we recommend that the change be clearly reflected in the language in H.R. 6706.

Second, we oppose the provision in CHAP which allows states to avoid providing treatment for children with "mental illness, mental retardation, or developmental disabilities." Such an exemption runs counter to the coverage for children with all other conditions and is unacceptable for several reasons.

A significant proportion of children in CHAP will be denied important health services. As data on health conditions found through EPSDT screening show, roughly 20 percent are related broadly to growth or development. In our view, this exclusion may signal to states that one acceptable way of dealing with new financial demands of an expanded EPSDT program is to limit treatment coverage in these areas. As a result, states which opt to cut back on Medicaid coverage are likely to cut out the services needed by millions of children.

Writing an exclusion based on a particular health condition is extremely damaging to recipients. That approach requires that one determine the reason a child needs a particular service. Does, for example, a mentally retarded child need a medical and dental service as a result of the mental retardation or for some other reason? Because it is usually impossible to determine the cause, we fear that states will simply decide not to provide most health care for children who have the specified conditions. In addition to discriminating against children with certain kinds of special needs, an exemption tied to etiology encourages labelling and overclassification of children (with the excluded condition) in order to avoid payment for services.

We can find no acceptable rationale for denying needed health care to children with developmental conditions. While it is true that several other federal programs provide services to handicapped children (e.g., Developmental Disabilities, Crippled Children), they reach only a small portion of the children in CHAP who need such services. For instance, the largest program of health care for handicapped children, the Crippled Children's Program, serves roughly one-half million children each year. Yet of the 13 million children on Medicaid, a projected 2.6 million require health services for developmental needs.

The cost considerations, which in large part dictated establishing this exclusion, can be accommodated in other ways. First, if CHAP is amended to clarify that it provides for needed health care (as we recommended above), CHAP will not be required to pay for related services, such as educational and social services, which children with handicaps may need. (However, because children need comprehensive services, CHAP should retain the responsibility to refer children to other existing programs which can assist with related services, e.g., the Education for All Handicapped Children program and Title XX Social Services). In addition, there is considerable evidence that cost considerations can be accommodated by instituting careful quality control standards and peer review. Such measures must be established and enforced vigourously before we would find it acceptable to consider limiting coverage for essential children's services.

We therefore urge that the service exemption now in H.R. 6706 be dropped. Needed health services, including mental health services, must be provided. EPSDT, as well as other sources of data about children, show that mental health services constitute a vital part of health care for some children. They can be helped immensely by relatively inexpensive and short-term mental health interventions, mental health services which must be covered at the very least.

4. Providing Dental Care

Dental care represents one of the few respects in which CHAP is potentially a step backward from present practice in the states under EPSDT. EPSDT requires states to provide the dental services available under the state's Medicaid plan and "at least such dental care as is necessary for relief of pain and infection and for restoration of teeth and maintenance of dental health."1/ States have interpreted this regulation flexibly with the result that some pay for needed dental care for children who have not had a dental screening while other states predicate coverage of dental care on being referred during an EPSDT screen. Under EPSDT, the federal government reimburses states for EPSDT dental care at the same level as for other medical services.

CHAP's provisions for dental care are inappropriately restrictive on two counts: (1) CHAP would reimburse states for dental care at a lower rate than for other CHAP services, thereby demoting the importance of the services; and (2) states would be required to pay only for treatment of conditions discovered during an assessment. This is a narrower requirement than under present law. Coupled with the lower federal match and the fact that dental services are viewed as relatively expensive, we fear there will be minimal provision of dental care in the states. This is unacceptable.

There is wide consensus that children need routine dental care to avoid pain and subsequent problems, including the development of speech impairments and malnutrition. Because of the almost universal need for dental care, experts agree that it is unnecessary to screen children for dental problems but imperative that routine dental care be provided. Routine dental care for children should include an emphasis on the preventive measures which are known to be effective.

Based on the needs of children, the most sound dental policy under Medicaid would be to require states to cover routine and emergency dental care. While certainly it would be more costly than the dental portion of EPSDT currently, we believe the cost would not be as high as HEW has projected, largely because if all eligible children were entitled to such care, the experience under EPSDT suggests that a smaller portion than

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1/ C.F.R. 249.10 (a)(3)(iv).

all those eligible would actually use the services (particularly during the first few years of the program). In addition, the cost per child would decline as more children receive dental benefits and their dental health improves.

Given the shortage of dental resources for children and cost considerations, it may take several years until CHAP is able to provide comprehensive dental care to all eligible children. However, as a program to strengthen and improve EPSDT, CHAP must provide dental care to a greater proportion of needy children than does EPSDT. Thus, we recommend modifying the dental services covered under H.R. 6706, setting a standard for program expansion (a 15% annual increase in the number of children receiving dental care) that will lead incrementally to a comprehensive program for all children, and matching dental expenditures at the same level as other health services under CHAP.

5. Assuring That CHAP Services Get To Needy Children

The Congress expressed its desire to make sure that children get EPSDT services by enacting the EPSDT penalty provision in 1972. The experience with the EPSDT penalty points up the inadequacies of current enforcement activities, certain of which are not corrected by H.R. 6706.

Existing provisions have not guaranteed that children receive assessments and treatment. CDF found, for example, that during the first quarter the penalty was in effect, 20 states or territories which met the requirements under the penalty provisions performed fewer than one-third of the screenings required according to the AAP's standards. The nature and administration of the penalty requirements have led to this failure to achieve Congressional intent.

One element which must be built into CHAP is a requirement that states meet minimum outcome standards: enroll a reasonable proportion of eligible children in the program and provide them with needed assessments and treatment. H.R. 6706 includes such standards as the basis for giving states a bonus for good performance; however, using performance standards for this limited purpose will not assure that all states perform at a satisfactory level. Because of the built in financial disincentive to perform assessments (under CHAP, once children are assessed, states have an obligation to treat their problems and give them primary care services--all services for which the state bears a portion of the cost), there must be minimum expectations related to outcomes for children. The exact standard may vary for each state but it should represent a reasonable increase over performance each year. The Secretary should be specifically

authorized to gather data to assess states' progress. Unless there are such standards which are monitored and apply as minimum expectations of all states, it is predictable that many will continue to function at their current unacceptable level.

We are pleased that H.R. 6706 includes incentives for states to meet standards. In addition, there must be measures capable of eliciting compliance when states fail to do so. The financial penalty established in H.R. 6706 is an important tool. However, based on an examination of EPSDT's enforcement history,1/ we have concluded that the financial penalty is not always the most appropriate remedy and, in some cases, is not an effective one.

Thus, we recommend that the Secretary be given an additional enforcement tool: to require that, so long as states receive federal funds for CHAP, they take steps to meet Congressional mandates.2/

We recommend, too, that the sanctions available to the Secretary be used when any requirement of CHAP is not met. Each of the responsibilities given to states under CHAP is essential to carrying out an effective program. Thus, while we support the four requirements which are the only basis for assessing the penalty under H.R. 6706, they should be written as program responsibilities and any program infraction should be a penalty issue in CHAP.

Finally, for the sanctions to promote compliance with CHAP requirements, application of them must work more expeditiously than is the case under EPSDT. Because of the cumbersome process which now exists for appealing a finding of non-compliance, no funds have yet been withheld from any state even though the penalty provision has been in effect for more than three years. States should have the right to appeal HEW's finding of non-compliance, but the Congress should set timetables to assure prompt application of the sanctions.

1/ For discussion, see Chapter 2 of EPSDT: Does It Spell Health Care For Poor Children?

2/ For a discussion of how this measure would work, see recommendation 9, on p. 75 of EPSDT: Does It Spell Health Care For Poor Children?

6. Maintenance Of State Effort

The primary purpose of H.R. 6706 is to encourage states to strengthen and expand their EPSDT programs. Yet fully one-third of CHAP's $180 million federal budget will go to replace state dollars already in or expected to be in the program. This results from the fact that CHAP will increase the federal share of program costs without requiring that states maintain their current level of financial commitment to the program. Although we do not oppose fiscal relief to states, we cannot accept it at the expense of an improved, expanded program which children vitally need.

Therefore, we recommend that the $60 million in CHAP which are currently replacement dollars be used for new benefits for children. This can be accomplished either by requiring states to maintain their current level of financial commitment for Medicaid outpatient services for children or by appropriating additional federal funds which will result in program expansion.

7. Extending Medicaid To "Income Eligible" Youth Aged 6-21

While CHAP takes a much needed step by making children under age 6 who live in extreme poverty eligible for Medicaid, it fails to include children in the same family who are older. HEW estimates that there are about 1,140,000 youth between the ages of 6 and 21 who meet states' income qualifications for welfare but do not currently qualify for Medicaid because they fail to meet other welfare requirements (e.g., they are poor but live in intact families). They are in desperate need of health care. As EPSDT data show, children and adolescents aged 6-21 have as high or higher rates of problems found in screening, and are as much in need of basic health care as younger children. In order to reach the most needy poor children and to avoid discrimination among children of different ages in the same family, we recommend that Medicaid eligibility be extended to all children in families which meet the state's income but not welfare requirements.

8. Developing States' Capacity To Deliver CHAP Services

Unlike other Medicaid Services, CHAP charges states with putting in place a host of services and seeing that children receive them. This calls for a different kind of planning and administrative capability from other Medicaid provisions. H.R. 6706 does not adequately address these affirmative aspects of the program; nor does EPSDT as it is now administered.

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To carry out an effective CHAP program, states must set out a strategy capable of meeting program goals, build a statewide system for delivering the services, and gain broad based cooperation from a range of personnel who work with children and from Medicaid families. Under EPSDT, there has been little and, in some places, no attention to these activities. We therefore recommend that states develop an annual state plan demonstrating the capacity to meet program requirements. We urge, too, that there be public hearings as well as other mechanisms needed to assure substantial public input in the development of CHAP plans.

CHAP must also begin addressing problems of the inadequate number or the inappropriate kinds of health providers for children. While Medicaid, with its reimbursement approach, cannot single-handedly address resource problems, it can do a lot to help identify shortage areas and work with other health delivery and health planning programs to begin filling gaps. CHAP should require that Medicaid agencies in conjunction with Health Planning and Title V Maternal and Child Health programs identify shortage areas for children and develop a strategy for building the necessary resources.

9. Building Accountability in HEW's Administration of CHAP

As this Subcommittee is well aware, the history of EPSDT has been characterized by foot dragging at the federal and state levels and a pronounced failure by HEW to provide the necessary support and leadership. We have appended to this testimony a chronology of HEW's dismal 10-year record in implementing EPSDT. (Appendix II). We are extremely hopeful that this Administration is committed to vigorous action to see that children receive the benefits to which CHAP entitles them. At the same time, we believe it important for the Congress to institute certain minimal forms of accountability. CHAP, as presently written, does not include such measures.

Had EPSDT included benchmarks against which the Congress could monitor the progress in providing children with needed care, EPSDT's poor performance would not have persisted these ten years. We believe it essential that they be established under CHAP. Therefore, we recommend as a target that 80% of eligible children be enrolled in the program within five years of enactment. We urge, too, two measures for keeping the Congress apprised of the Department's progress in meeting these goals. In addition, we recommend that CHAP include a deadline for the Secretary to issue final program regulations.

Beyond EPSDT Reform

Our work has convinced us that changes in EPSDT can bring rapid and widespread payoff for poor children. But because of built-in limitations in what Medicaid can accomplish, measures beyond reforming EPSDT are called for. One crucial measure is the development of new health care providers in the many areas where children do not have sources of care close by. Based on preliminary analysis by HEW, an estimated 16% of children on AFDC live in counties designated as shortage areas; the percent is slightly higher when all children are taken into account.

We are extremely pleased that $25 million in the CHAP budget has been allocated for the purpose of developing resources in underserved areas. But while it signals attention to a very important problem, $25 million cannot begin to provide assistance in many of the communities across the country in need of it. We hope this Subcommittee will see fit to undertake a significantly expanded program of resource development to make available start up funds, technical assistance, and continuing subsidies as needed in shortage areas.

Finally, certain of the inherent flaws in Medicaid for children can be remedied only through a program of comprehensive national health insurance. But not any program of national health insurance will assure that children receive the type and quality of health care they need. Because sound policy formulation is dependent on the nature of the background work, we believe it is crucial that the options considered by the Administration and the Congress include those which go beyond presently prevalent practices and conventions about how care is best organized and paid for. We have shared with the Chairman of the Advisory Committee on National Health Insurance Issues our suggestions for analysis which should be part of the background work currently being undertaken. Attached, as Appendix III, is a copy of our letter which we hope will be useful as you consider the steps beyond EPSDT reform.

Thank you.

APPENDIX I

Chapter 1

What Have We Learned and Where Do We Go From Here?

Archie Douglas is now eight years old and has already failed the first grade twice. He has always avoided going to school whenever possible. Last year his teacher reported that when in class, he had a short attention span, misbehaved frequently and was generally disruptive. After two years of first grade instruction, his language skills are those of a five year old. This is true despite the fact that he excels in the nonverbal portions of standardized intelligence tests. Archie comes from a stable, intact, lower-income family.

Archie was a full-term, normal healthy baby. He received his health care during infancy from a city clinic. When he was 18 months old, he had a fever and an earache. His mother, relying on her mother's advice, rocked him to soothe his crying and ease Archie's pain, gave him half an aspirin every few hours and used a commercial ear-drop preparation. While rocking him, his mother noticed that some fluid began draining from his ear. Archie seemed less distressed after the fluid drained, and he recovered completely within a few days.

Three months later the fever and the earache recurred. This time both ears were affected. Home remedies brought no relief and Archie was taken to the clinic. The doctor diagnosed bilateral otitis media. This is a common childhood illness, easily diagnosed, and easily and effectively treated by antibiotics. Mrs. Douglas was able to pay $15 for antibiotics only by deferring her rent payment. Because Archie seemed to recover in a few days, his mother discontinued the medication prescribed by the doctor before the full antibiotic regimen was completed. Within a month, the condition returned, and this time rocking, ear drops and a few left over antibiotic pills were administered and Archie seemed to recover.

With the exception of these illnesses, Archie was a healthy, active child. Other than visits to the clinic for immunizations, his mother was grateful that he never needed to see a doctor.

This year Archie has a new first grade teacher. On his recommendation, Archie's mother took him to a speech and hearing center for an evaluation. They found that Archie has a bilateral hearing loss that probably resulted from his early bouts with otitis media. He has slightly more hearing in his left ear (30 dB) than in his right (45 dB). Archie's

hearing loss is considered significant. He has frequent difficulty with normal speech sounds, and his difficulty has probably been the cause of his school problems. Archie's hearing problem can be alleviated by a hearing aid, but at this point, he also needs remedial education and his mother needs counseling and support. Even with help, it will be difficult for Archie to overcome his initial impressions that school is incomprehensible, that he cannot keep up and that he is a failure.

Archie could have been spared much of his suffering through a program of early screening and follow-up care. While it is unlikely that screening could have identified his ear infection when it first developed (unless his screening appointment happened to be scheduled when he was sick), screening within the next year or so would have identified the hearing loss much earlier, when he was two or so years old, long before it seriously affected his language skills. Once his problem was identified, Archie could have gotten a hearing aid and services in school suited to his special needs.

EPSDT's Origins and Promise

Late in 1967, Congress amanded Medicaid to require states to provide "early and periodic screening, diagnosis and treatment" (EPSDT) to all children under the age of 21 who were eligible for the Medicaid program.[1] Although the language of the EPSDT amendment was extremely general and the legislative history sparse, the outlines of the program Congress intended were quite clear. Children eligible for Medicaid--estimated then to be approximately 6.5 million and now about 13 million--were to receive complete physical examinations and other screening procedures such as tests for vision and hearing deficiencies, for high levels of lead in the blood, for nutritional deficiencies, for dental problems and for other problems that could impede their normal growth and development. These screening procedures were to start early, preferably soon after birth, and were to be repeated periodically until the child reached age 21. Following screening, children were to receive the diagnostic and treatment services indicated necessary during their health assessments. It was hoped that this system of early detection and follow-up would control most chronic disorders suffered by poor children before they did permanent and costly damage.

[1] 42 U.S.C. §1396d(a)(4)(B). Congress enacted at the same time an amendment to the federal Maternal and Child Health Program (Title V of the Social Security Act), calling for early identification of children in need of health care and treatment to correct their health problems. (42 U.S.C. §705(a)(7).) These were part of the Child Health Act of 1967.

The backdrop for EPSDT's enactment included three critical developments during the 1960s. First, a growing public concern for the poor led to the creation of Great Society anti-poverty programs, which tried to break the cycle of poverty by improving the lives of poor children. Second, a number of categorical health programs as well as Medicaid and Medicare became law, creating a precedent for federally-subsidized health services.

Finally, the striking prevalence of chronic, handicapping conditions in children was being brought to the attention of the public. A Selective Service study found that more than 15 percent of 18 year olds examined for military duty were rejected because of conditions including dental, eye and ear problems; orthopedic problems; internal conditions such as heart disease; and a large percentage of emotional and developmental disorders.[2] Based on a review of medical literature, a group established by HEW estimated that 62 percent of the serious conditions found by the Selective Service were preventable or correctable through comprehensive and continuous health care. Thirty-three percent were estimated to be preventable or correctable through periodic screening and treatment.[3] The group also found that disabling conditions and inadequate care were far more common among poor children:

> Two-thirds had never been to a dentist; 60 percent of those with chronic conditions were not being treated. Physician visits were less frequent, although there was nearly twice as much hospitalization as among higher-income children.
>
> Compared to more affluent children, the prevalence of heart disease was three times as great. Seven times as many low-income children had visual impairments, six times as many had hearing problems, and five times as many had mental illness.[4]

It was to deal with these problems early--and cost effectively--that EPSDT was established.[5]

[2] These preliminary data were based on rejection rates in Selective Service examinations of 18-year-old, non-college bound youth from July 1964 to December 1965 under the "Conservation of Manpower" program. See Bernard Karpinos, Office of the Surgeon General, Department of the Army, cited in "Maternal and Child Health Care Programs," (Washington, D.C.: Office of the Assistant Secretary for Program Coordination, HEW, October 1966), Table 2.7.

[3] "Maternal and Child Health Care Programs," p. II.8.

[4] Task Force on Human Resources, Congressional Budget Office, "Prospects for Meeting Health Care Needs of Children Eligible for Medicaid Under EPSDT," *Working Papers on Major Budget and Program Issues in Selected Health Programs* (Washington, D.C.: Committee on the Budget, U.S. House of Representatives, 10 December 1976), p. 119.

[5] For more detailed analysis of the history and development of EPSDT during this period see, for example, Task Force on Human Resources, Congressional Budget Office, "Prospects for Meeting Health Care Needs of Children Eligible for Medicaid Under EPSDT," pp. 117-136; Anne-Marie Foltz, "The Development of Ambiguous Federal Policy: Early and Periodic Screening

EPSDT held a great deal of promise. First, it could begin to fill in the major gaps in the health care poor children received. And the need was great. Poor children suffered disproportionately from nutritional deficiencies, hearing and vision impairments, dental problems, parasites and skin diseases such as impetigo.[6] They suffered not only from poverty, substandard housing and nutritional deficiencies that caused or aggravated their health problems, but from the lack of health care to attend to them. The national immunization rates for polio and for other childhood diseases--good indices of whether children were receiving the most basic preventive care--were especially low for children living in poverty areas. In 1975, 47 percent of children under one year of age living in large metropolitan areas designated as poor had not received *any* polio vaccine; 58 percent of poor infants below age one in large central cities had not received shots for diphtheria, tetanus or whooping cough.[7] One study noted that poor children were more in need of medical care when they finally saw a doctor, even though they saw physicians less often than more affluent children.[8] Another showed that poor families in a central city area received medical services only 15 percent of the time their symptoms indicated they needed care.[9] Not surprisingly, poor children suffered the consequences of inadequate health care. They had twice as many hospital stays, spent more sick days in bed and lost more days of school than non-poor children.[10]

Diagnosis and Treatment (EPSDT)," *Milbank Memorial Fund Quarterly* (Winter 1975); and Joseph A. Wholey, *The Absence of Program Evaluation As An Obstacle to Effective Program Expenditure Policy: A Case Study of Child Health Care Programs* (Washington, D.C.: Urban Institute, 1970).

[6]For summaries of evidence on the health problems of poor children see, for example, Office of Child Health Affairs, "A Proposal for New Federal Leadership in Maternal and Child Health Care in the United States," (Washington, D.C.: HEW, November 1976), pp. 9-10, 15 (draft); and *Doctors and Dollars Are Not Enough* (Washington, D.C.: The Children's Defense Fund, 1976), pp. 10-11.

[7]Center for Disease Control, *United States Immunization Survey: 1975*, (Washington, D.C.: HEW, Publication No. (CDC) 76-8221, June 1976), Tables 4, 4c, 5, 5c, pp. 25, 28-29, 33, and 36-37.

[8]Data from the *Health Interview Survey*, cited in John A. Butler, "Improving the Delivery of Primary Medical Care Services for American Children" (Cambridge, Mass: Harvard Child Health Project, September 1975, unpublished and unpaged draft report).

[9]Alpert, et al., cited in Butler, "Improving the Delivery of Primary Medical Care Services for American Children."

[10]Medical Services Administration, "EPSDT: The Possible Dream" (Washington, D.C.: Social and Rehabilitation Service, HEW (SRS-FY 77-24-973), February 1977), p. 1. (Mimeo.)

Second, EPSDT represented the first major commitment in this country to reach large numbers of children in desperate need of basic health care. Prior to EPSDT, only a few federally-financed health programs provided health services to poor families and children, but these programs reached only a very small percentage of the poor children who needed them. Medicaid, which reached a greater number of poor families, paid for treatment for acute medical problems or emergencies. Rarely were its resources used to prevent or treat children's health problems early in their course.

And finally, not only did EPSDT focus on preventive services for an extremely large number of children, but it placed an affirmative obligation on the state agencies administering Medicaid to take steps to ensure that eligible children actually received the services they needed. States were to inform eligible families about the availability of EPSDT and about the value of preventive health care so that families could take advantage of the program. In addition, states had the responsibility to see that there were enough providers in the program so that all eligible children who wanted to use EPSDT services were able to receive them promptly. These affirmative obligations drastically altered the passive role which states had assumed previously in the Medicaid program--a role which had resulted in children's minimal receipt of preventive health care and in the absence of services in many parts of the country where providers had chosen not to participate in the program.

In short, to carry out EPSDT, state Medicaid programs had to move beyond their limited role of paying bills for health care to the more important and difficult role of seeing to it that health services were actually provided.

CDF Study

We had been concerned for a number of years with health services for children in general and with the development and improvement of EPSDT in particular. In 1975, after pressing HEW for several years to implement the EPSDT program more fully, we decided to look at how well EPSDT was fulfilling its promises. We wanted to know to what extent it was providing poor children with the health care we believed they needed;[11] what im-

[11] The principles we believed necessary for effective health care for children are articulated in our first report on child health, *Doctors and Dollars Are Not Enough* (Washington, D.C.: Children's Defense Fund, 1976).

provements were necessary for EPSDT to serve them properly; and what lessons could be learned from EPSDT for designing a program of national health insurance that would meet the needs of children and families. Specifically, we wanted to know how EPSDT measured up against six criteria that are basic to providing quality health care to children, whether through EPSDT or through other programs:

1. Was the program administered and enforced in such a way to assure children the benefits to which EPSDT entitled them?

2. To what extent was EPSDT reaching children who needed its services?

3. Were children's health problems being identified by screening?

4. Were the necessary diagnoses and treatments being provided?

5. How was the developmental assessment part of the program working and was it finding and helping children with developmental needs?

6. Was EPSDT linking children to sources of continuing health care?

To answer these questions, we studied five states' programs in various parts of the country and focused on one county in each state: Essex County (Newark), New Jersey; Florence County, South Carolina; Genesee County (Flint), Michigan; Oktibbeha County, Mississippi; and Suffolk County (eastern Long Island), New York. These programs presented a variety of administrative approaches and designs for implementing EPSDT,[12] and the areas represented a wide spectrum of ethnic, demographic, and geographic differences.[13] Also, all of these programs had been implemented relatively early in the history of EPSDT and, we hoped, were far enough advanced to have information on the questions we asked and to shed light on the problems other EPSDT programs would face after they moved beyond the initial start-up stage.

We collected whatever data existed from our study sites as well as for the program nationwide.[14] We reviewed laws, regulations, guidelines, and federal and state policies governing how EPSDT was

[12] See Appendix G for summary information on how EPSDT requirements were carried out in each of our study sites. Note that in New York State the EPSDT program is called CHAP, but for the sake of consistency in our report, we refer to it as New York's EPSDT program.

[13] For more discussion of how we chose our study sites and a description of them, see Appendix A.

[14] Information from our study sites was current as of the time of our visits, which were made between September 1975 and February 1976. Where more recent national data were available, we have collected it. It should be noted, however, that there were few reliable quantitative data about EPSDT, which was one of the most serious shortcomings of the program and which made it necessary to collect and use other kinds of information in assessing the program.

supposed to work, and we looked closely at the local policies and practices in our study sites. We visited each county and talked with parents, program administrators, physicians, dentists, state and county Medicaid agency personnel,[15] staff at neighborhood health centers, hospital outpatient clinics, welfare agencies, schools, Head Start and other child care centers and various community organizations.[16]

While the examples, stories and judgments come from five counties, we believe the lessons we have learned from them illustrate the progress and problems of EPSDT across the country.

Summary of CDF Findings

Have EPSDT's promises for health care for poor children been fulfilled? We found that they had been, but for very few children. We found that EPSDT had certain built-in limitations preventing it from being the best answer to children's health needs. Many of these deficiencies, however, can be corrected. We found too, that many of the changes needed to make EPSDT serve children better can be accomplished within existing law. As we have found, the health needs of children make it imperative that these improvements be made.

Our findings are summarized below. In Chapter 2 we look more closely at administration and enforcement questions, and in Chapters 3 through 7 we set forth detailed findings from our study as well as recommendations for each of the issues we looked at in the performance of EPSDT.

1. Many needy children were not reached by EPSDT screening.[17]

First, because it is tied to Medicaid eligibility criteria, EPSDT reached only a portion of children living in families too poor to pay for health care. Of the 23 million children living in families earning 150 percent of the poverty level (an income of about $7,500 for a family of four, covering only the necessities, with none left to pay for major medical expenses), only 13 million, or 56.4 percent of them, were eligible for Medicaid and EPSDT. The rest of the needy children remained out of EPSDT's reach.

But even among the 13 million children who were eligible, too few received EPSDT's services. While the screening rates increased

[15] New York was the only state in which we did not visit the state offices. We did, however, conduct several telephone interviews with state agency personnel.

[16] For a complete list of people interviewed in our study sites, see Appendix B.

[17] The bases for and further discussion of these findings are in Chapter 3.

steadily between fiscal 1973 (when 500,000 screenings were done) and 1976 (when 1.7 million screenings were done), these numbers still mean that only a fraction of eligible children who should have been screened were reached. Using the American Academy of Pediatrics' (AAP) screening schedule as a base for calculating expected screening rates, to date EPSDT has performed 5.4 percent of the screenings needed by eligible children. In 1976, it provided only 25.8 percent of assessments children needed that year. Actual performance varied greatly from state to state. In our study states, rates ranged from a low in New Jersey, which failed to carry out almost 19 out of every 20 screenings required to meet the AAP's standard, to a high in South Carolina, where 2 out of every 5 needed screenings were done.

According to our survey, there were a number of important reasons why so few poor children were actually being screened through EPSDT:

--Large numbers of eligible families were not adequately informed about EPSDT because the outreach methods adopted by the states were ineffective. States relied on written notices and conversations at welfare offices to inform families about the program, even though the evidence is clear that these forms of outreach alone are not successful. Methods proven to be effective, namely, personal outreach by people or organizations serving the community, seldom were used.

--Children who are in need of screening remain unreached because, in an effort to target outreach efforts on those most in need, states erroneously assumed some children were receiving "equivalent care," and therefore did not need EPSDT services. As one person put it, "They are spending more money trying to prove that particular children don't need care than to serve them."

--Even when outreach was effective, some children did not get EPSDT services because sufficient screening providers often were not available to serve all families. In many places, because of the state's reluctance to use all available providers, particularly neighborhood clinics and other trusted, community-based organizations, providers that were used were inconveniently located or unacceptable to families.

--Even though assuring needed transportation to and from EPSDT services is required by law, many families were unable to obtain the necessary transportation to bring their children to the screening site.

--Not only have many needy children never been screened for the first time, CDF's survey shows that almost no children were rescreened periodically, as Congress intended. Frequent changes in eligibility for

Medicaid have resulted in a turnover rate of approximately 30 percent of children each year. This means that about 34.7 percent of children eligible during the year drop out of the program before they can be screened or rescreened. For those who regain eligibility or stay in the program, few states have developed systems allowing staff to keep track of and rescreen children at the proper times.

2. While screening uncovered a host of unmet health needs, screens were often incomplete and inadequate.[18]

EPSDT screenings have found many unmet health problems in poor children. Nationally in fiscal year 1976, for every three screens, two conditions were found needing follow-up care. Between 60 and 80 percent of these problems were previously unidentified or uncared for.[19] Fewer than 1 percent of children screened in EPSDT had ever received a comparable physical examination.[20] Screenings uncovered such problems as incomplete immunizations, dental problems, low hemoglobins (indicating iron deficiency anemia), vision and hearing problems, high levels of lead in the blood, genitourinary and respiratory infections, parasites and skin diseases.

But although EPSDT was finding these problems, CDF found that screening in EPSDT programs was frequently not carried out thoroughly. We found great variations in the incidence of conditions found from program to program and state to state. These differences were too large to be explained solely by differences in the health of children in various places. For example, in Oktibbeha County, Mississippi, for every 2 screenings, 3 conditions were found, while in Florence County, South Carolina, for every 5 screenings, 1 condition was found. Rather, we found a variety of inadequacies in the way screening was performed:

--Health histories, which provide the information for identifying the majority of children's health problems, were inadequate or were sometimes not taken at all. Because parents were not encouraged or were unable to accompany their children during the hours screening was performed, they often could not give or supplement health history information.

--Certain essential procedures were omitted from the set of services states decided to offer. In practice, even procedures that were included in states' screening packages were omitted, particularly

[18] The bases for and further discussions of these findings are in Chapter 4.

[19] Harry W. Martin, et al., *EPSDT Demonstration Projects: An Interim Evaluation, April 1974-March 1975* (San Antonio, Texas: Health Services Research Institute, University of Texas Health Science Center, January 1976), p. iv.

[20] Martin, et al., *EPSDT Demonstration Projects: An Interim Evaluation, April 1974 - March 1975*, p. v.

vision and hearing testing and dental referrals.

--The special needs of adolescents were not taken into account when designing or implementing states' screening services, most of whose procedures are relevant to young children.

--Qualified personnel (including health aides and physician extenders) were frequently not used to perform screening and, conversely, some of the persons who were screening children were not sufficiently trained or supervised.

3. Many children did not receive the diagnoses and treatment they were found to need.[21]

Despite a statutory requirement that indicated diagnosis and treatment must be available within 60 days after screening, only about 60 percent of referred conditions ever received follow-up care. Thus, of the approximately 1.1 million conditions referred for follow-up care in fiscal year 1976, about half a million conditions were not treated. CDF found a variety of reasons for this failure:

--The 30 percent turnover rate among eligible children meant that many children dropped out along the path between screening and diagnosis, diagnosis and the start of treatment, or start to finish of treatment.

--In spite of the clear Congressional intent for EPSDT to treat all problems found in screening, federal regulations allowed states to limit the services they covered in their Medicaid plan and, as a result, certain treatment services indicated by screening were not paid for. For example, in some places, speech therapy, orthopedic shoes, mental health counseling, eyeglasses for certain needy children, dermatological services and certain kinds of dental care were not covered.

--We found, too, that many problems uncovered in screening called for the combined skills of social workers, health educators, counselors or others whose services were not covered under Medicaid.

--EPSDT's separate screening and treatment components, often provided at separate locations and at different times, meant many children were lost in the treatment maze. Even basic services such as immunizations or topical medication for a rash often were not provided at the time or in the same place as screening.

--We found, too, that there were too few or the wrong kinds of providers for diagnosis and treatment, and states had not taken adequate steps to encourage providers to participate in EPSDT or to arrange

[21] The bases for and further discussion of these findings are in Chapter 5.

for needed care. In some of our study sites, we found shortages of general pediatric care; in others, there were too few resources for dealing with children's special needs (cardiac, dental, dermatological, developmental). When we randomly called half of all the dentists in Florence County, only *one* took Medicaid patients without restrictions.

--With few exceptions, states had not set up adequate case management systems capable of following children to assure that needed treatment was received.

4. The capacity of EPSDT to find and help children with developmental problems was limited.[22]

Congress originally mandated that screening be done for "mental" (later defined as "developmental") as well as "physical" defects. The need for such services clearly exists. Large numbers of children suffer from perceptual, motor and cognitive difficulties that impair their growth and development. But disagreement among professionals regarding the suitability of a medical screening program and the appropriateness of available instruments for finding children with such problems has hindered the development of this part of the EPSDT program. In addition, we found that the ways the program was operating further limited its effectiveness in finding and assisting children with developmental problems:

--Parental involvement was minimal. Scant information was given to parents about the developmental assessment component of the program. In most places we visited, parents were not asked about their child's development. And in the rush to get basic procedures done, informing and counseling families about screening results and the next steps to take to follow up suspected problems often were omitted.

--Twenty-seven states report using the Denver Developmental Screening Test (DDST) even though its norms were not based on a population of children like those eligible for EPSDT and it is useful only for a narrow age range.[23]

--Many of the people doing screening and counseling did not have adequate training to find children's developmental problems and to counsel families.

[22] The bases for and further discussion of these findings are in Chapter 6.

[23] Preliminary analysis of an HEW survey shows that, of 38 states reporting, 27 use the DDST alone or with other tests to identify children with developmental problems. (Medical Services Administration, "Developmental Assessment in the EPSDT Program: Position Paper" (Washington,D.C.: Social Rehabilitation Service, HEW, 1976), p. 4).) For an evaluation of the DDST, see Oscar Krisen Buros, (ed.), *The Seventh Mental Measurements Yearbook*, (Highland Park, N.J.: Gryphon Press, 1972), pp. 733-735.

--Few places had treatment resources available in the numbers or kinds needed to help children identified as needing them. Furthermore, coordination with other federally-funded programs designed to serve children's developmental needs was minimal.

--In some places, the kinds of services and personnel covered under Medicaid impeded providing needed services to children with developmental problems.

--In some states, Medicaid policies encouraged screeners to label children by making a diagnosis on the basis of a screen.

5. EPSDT rarely linked children to an ongoing source of primary health care.[24]

Even if EPSDT were fully implemented it would not constitute comprehensive care for poor children. Targeted on screening and following up on conditions found during screening, EPSDT does not provide routine care for sore throats, earaches and other common childhood illnesses. However, EPSDT services *could* link poor children to a system of ongoing, comprehensive care by putting them in touch with or providing EPSDT services through comprehensive providers. Unfortunately, EPSDT's potential remains much greater than its performance. The reasons were several:

--Many states failed to use providers in their EPSDT programs that could offer ongoing, comprehensive care to children. Half of the states in the country elected to provide screening primarily through local health departments, which almost never had either the staff or the mandate to provide routine health care on a continuing basis. In fiscal 1975, these health departments accounted for over 58.8 percent of all screenings performed through EPSDT.

--In the remaining half of the states that allowed a variety of providers to do EPSDT screening--theoretically with greater potential to link children to continuing care--fewer children and a smaller proportion of eligible children were screened than in states using health departments. Programs using a variety of providers were more complex to administer and took longer to implement. Furthermore, various Medicaid policies such as low rates of reimbursement and failure to use certain qualified providers have discouraged or excluded many potential comprehensive care providers from participating in EPSDT and serving these children.

--Families were rarely told the range of options they could choose from in selecting a Medicaid provider for EPSDT screening or treatment, and they were rarely encouraged to use sources of ongoing health care. Nor were they referred

[24] The bases for and further discussion of these findings are in Chapter 7.

at the time of screening or treatment to a source of regular health care if they did not already have one.

6. Federal support and leadership in implementing EPSDT have been minimal. Federal enforcement has not been effective in assuring eligible children get the benefits to which they are entitled.[25]

Particularly given the ambitious nature of EPSDT, the states' lack of experience in mounting a program of its kind and the reluctance of some states to implement EPSDT fully, explicit program standards were vitally needed. Needed, too, were technical assistance, incentives and remedies capable of assuring that states complied with the law. HEW failed to provide adequate leadership, guidance or assistance. It did not set appropriate standards, review carefully states' performance or use effective sanctions to make sure EPSDT was implemented properly.

--Federal regulations were not issued until two-and-a-half years after EPSDT became effective. Even then, they defined the adequacy of states' programs by what steps states took toward compliance rather than by the extent to which children actually received services. As a result of the lack of specific outcome or performance-oriented criteria, during the first penalty review period, 20 states and territories were found to be in compliance even though they performed fewer than one-third of the screenings they should have according to the AAP's standards.

--Because of the slowness of implementation, in 1972 Congress enacted a penalty for noncompliance: 1 percent of the federal share of a state's AFDC funds. Although the EPSDT penalty requirements were clearly meant to supplement and not to replace broader requirements of the program, the existence of two sets of program requirements led to confusion. States have interpreted their obligation as having to comply with the far narrower penalty requirements; HEW has not taken steps to enforce the broader regulations. The result is that certain requirements essential to EPSDT's implementation (such as informing *all* eligible children about EPSDT and using all existing qualified providers) frequently are not met.

--Federal enforcement has not been vigorous. HEW has completed penalty reviews only through September 1975. And although HEW has found 9 states out of compliance with EPSDT requirements, to date no funds have been withheld.

[25] Further discussion of these findings is in Chapter 2.

Why Should We Care About Improving EPSDT?

Given this less than impressive record of achievement, why do we care about EPSDT? Why not eliminate it? Chalk it up as a bad experiment and reallocate the money spent on it? We know that the Medicaid system with its inherent imperfections will never reach all needy children, ensure quality care, contain costs or eliminate a two-track system that results in second-class care for the poor. Why tinker with this small piece of it, then?

There are two important reasons. The first is that the millions of poor children who need better and more accessible health services now can be helped by relatively simple improvements in the EPSDT program. According to projections by the Congressional Budget Office, among Medicaid-eligible children, 3,200,000 need immunizations, 2,184,000 need treatment for anemia, and 2,210,000 need care for vision or hearing impairments.[26] An improved EPSDT program can realistically be expected to do much toward meeting these and other pressing health needs.

And *while we are convinced that the only way poor children will receive truly effective health care is through a national health insurance program designed to assure comprehensive care to all Americans, it is clear that poor children's health needs cannot go unmet until such a program is enacted.* Experts agree that even if national health insurance legislation were introduced immediately, it would be at least four years until services became available because of the time required to legislate, plan and implement a major new program.

In the meantime, there is no other federal health program which can be built on with an equally rapid and widespread payoff for poor children. The other major federally-financed health programs for children--including Community Health Centers, comprehensive programs under Title V, and Migrant and Indian Health programs--have been effective and we support their expansion. However, it is unrealistic to expect them to gear up during the next year or two to meet the needs of the millions of children who do not now have access to their services. In 1975, these programs were estimated by HEW to have reached 1.7 million children.[27] This

[26] Task Force on Human Resources, Congressional Budget Office, "Prospects for Meeting Health Care Needs of Children Eligible for Medicaid Under EPSDT," p. 128.

[27] Office of Child Health Affairs, "A Proposal for New Federal Leadership in Maternal and Child Health Care in the United States" (Washington, D.C.: Office of the Assistant Secretary for Health, HEW, November 1, 1976), p. 31.

compares to an estimated 13 million children certified for Medicaid. While new resources are being developed through expansions of these programs, the more rapid reforms that can be made in EPSDT will result in improved services for poor children. Thus, we do not hesitate to recommend an increased investment in EPSDT, despite our clear awareness of its limitations.

The second reason to improve EPSDT now is that, in the process of making EPSDT function more effectively, we will confront and help to resolve some of the key problems that any program of national health insurance will have to address in order to be effective. If we are not to duplicate the mistakes of wasteful, piecemeal and inadequate health care programs of the past, we must (a) develop effective ways to reach out to families currently outside the health care system; (b) establish standards for complete, quality care and methods to monitor and enforce these standards; (c) involve more doctors and clinics as providers in publicly-financed programs; and (d) provide incentives to develop health resources where they currently do not exist--in urban centers and remote rural areas.

EPSDT has already taught us valuable lessons for the design of an effective national health insurance program. (The Postscript at the end of this chapter describes the most important of these.) The reforms we recommend for the EPSDT program will strengthen the foundations on which a new universal program can be built.

Despite its slow and difficult beginning, EPSDT has benefited many children who otherwise would not have received basic health services. Much has been learned about how to improve it. *Therefore, we recommend that EPSDT reform be undertaken at once, at the same time as planning for national health insurance goes forward.* Because the overriding purpose of EPSDT reform is to bring more needed health care to poor children now, we do not recommend a total overhaul of EPSDT. Rather we recommend changes that can be implemented quickly and will bring immediate benefits to children. Below are our broad recommendations for EPSDT reform. Following each chapter are our more detailed recommendations, setting out the specific steps which must be taken by the Congress, HEW, state and local administering agencies, providers, health advocates and parents.

We recognize that many of our recommendations will not be easy to implement, and will require considerable will, creativity, cooperation and effort on the part of administrators, physicians and a range of others who work on behalf of children. Nevertheless, we

believe these recommendations will move EPSDT in the direction of providing better health services to more children.

Major Recommendations

1. The focus of EPSDT should be shifted away from "screening" to a program providing regular, comprehensive health assessments to children eligible for Medicaid. The language in Title XIX to screen for "physical and mental defects" should be replaced by language requiring states to assure comprehensive, regular health assessments according to a child's needs. On the basis of consultation with health professionals and consumer groups, federal regulations should be issued defining what constitutes an assessment, the frequency with which children of various ages should be assessed and the procedures necessary at each visit.

2. Complete health services following an assessment should be provided. At a minimum, federal regulations should be amended to expand states' obligation to provide all health care indicated by an assessment and needed outpatient health services following an assessment. In addition, regulations should make explicit that where special educational and child development services are indicated by an assessment, states must at least arrange for them (as opposed to provide them directly).

3. Routine as well as emergency dental care should be provided as needed to children eligible for Medicaid. The existing regulation should be clarified to assure that any eligible child can receive needed dental care regardless of whether the child has received a dental screening or has been referred by a provider of an assessment.

4. There must be one clear set of regulations governing EPSDT. The original EPSDT regulations and the subsequent penalty regulations should be consolidated. The combined regulations should include explicit federal standards dealing with program performance, administration, and quality of care against which states' progress in implementing EPSDT can be measured.

Performance should be measured by criteria based on the extent to which services are provided to children. For example, outreach and the provision of assessments should be measured by comparing the number of children who receive assessments to the number who should have received them; treatment by the number of children who receive follow-up care compared to the number who need care, provider participation by the proportion of qualified providers who deliver EPSDT services.

In addition, specific procedures

should be mandated for informing, assessing and providing follow-up care, for assuring that the use of services is voluntary and for using qualified providers. (These are detailed in recommendations in Chapters 3-6.)

5. Maximum use must be made in EPSDT of all qualified providers. Title XIX should be amended to make the coverage of services provided in primary care clinics, which meet states' certification criteria, mandatory rather than optional. In addition, primary care services, when provided by physician extenders, nurses and paraprofessionals licensed in accordance with state law and working in organized clinic settings, should be reimbursed as clinic services.

Federal regulations should be revised to make explicit that states must use all qualified providers who want to participate in EPSDT for assessment and follow-up care (including community-based organizations such as neighborhood clinics and multi-service clinics) and must offer reasonable reimbursement rates for their services. In addition, HEW should enforce vigorously the existing Medicaid requirement that states establish reimbursement rates sufficient to assure that recipients have access to services to the same extent as do others in the community.

6. Congress should establish immediately a major program to develop needed resources for providing health assessments and needed primary care. Federal funds and technical assistance must be available to assist organized providers of limited services (e.g., screening programs) to expand their services so that children can receive assessments, routine treatment and other primary health services from the same provider. In addition, federal funds and assistance must be available to help communities develop *new* resources for providing general medical and specialty care where, due to scarcity, children currently are unable to receive services promptly.

7. Eligibility for Medicaid should be extended to individuals under age 21 who qualify on the basis of family income, and every child should remain eligible for Medicaid for at least one year following an assessment. Title XIX should be amended to require states to make eligible for Medicaid individuals under age 21 who meet the state's *financial* eligibility standard but not necessarily its other welfare requirements. In addition, Title XIX should be modified to allow any child who would otherwise lose eligibility to remain eligible for all Medicaid services for at least one year following an assessment.

8. EPSDT outreach must be strengthened considerably. In addition to maintaining the federal reimbursement arrangements for outreach services performed by public

agencies, there should be financial incentives for outreach to be done by private, nonprofit, community-based organizations (e.g., Head Start programs, community clinics). Title XIX should be amended to provide a national average of 90 percent federal reimbursement (the exact federal shares among the states would vary as they do now for medical services under Medicaid) for outreach services performed under contract by these organizations.

9. Developmental assessment should be performed within the context of the comprehensive health assessment. Federal regulations defining the assessment should not single out the developmental component. Rather, HEW should define, in consultation with professionals, administrators and consumer groups, how the comprehensive assessment should review selected aspects of children's development.

10. Every state's Medicaid plan should include a complete explanation of how EPSDT requirements will be carried out. There should be wide public participation in development of the EPSDT part of the plan. Title XIX should be amended to require that Medicaid state plans address how EPSDT provisions will be carried out (see, for example, recommendation 3 in Chapter 2 of this report) and that the planning process include meaningful public involvement. In addition, HEW should issue guidelines immediately, indicating those aspects of EPSDT programs for which states are encouraged to establish program development plans. The guidelines should identify important program features which have been most difficult to implement properly and should encourage states to set out steps to be taken during the year to address these problems.

11. Federal EPSDT reporting requirements should be revised to include: (a) services provided to children by the age groupings 0-3, 4-6, 7-12 and 13-21; (b) assessments according to whether they are initial, second, third or more; (c) more detailed breakdowns of the type of conditions found; and (d) information on whether and what treatment was provided to children for problems found in an assessment. Reports and state record keeping systems should collect and provide information on the basis of children (e.g., they should report the number of children screened and not number of screenings performed).

12. States and localities should receive financial assistance to improve the administration and program performance of EPSDT. Title XIX should be amended to increase the federal match to states for EPSDT administrative services, community-based outreach services, assessments and outpatient care following assessments to a national average of 90 percent (the exact federal shares among the states would vary as they do now for medi-

cal services under Medicaid). To assure that increased federal assistance leads to a strengthened EPSDT program, states must be required to maintain their current level of financial commitment.

13. At the state and county level, one person should be designated responsible for EPSDT. In addition, each state and county administrator should appoint a pediatric and a dental advisor whose job is to encourage cooperation and support of providers and to lend technical expertise to the program administrator.

14. Considerable technical assistance should be made available to states to improve EPSDT programs. HEW must increase immediately its capacity to provide technical assistance.

15. HEW must use a range of enforcement tools capable of assuring that EPSDT reaches its intended beneficiaries. HEW should conduct regular reviews of state compliance with EPSDT requirements by evaluating the adequacy of state plan material related to EPSDT and by making site visits to randomly selected counties in each state. As a supplement to the Secretary's authority to cut off a state's Medicaid funds, Title XIX should be amended to require the Secretary to use one of two remedies when, following the opportunity for an administrative hearing, violations in a state's EPSDT program are found. The Secretary should (1) have the authority to withhold 20 percent of the federal share of the state's administrative costs for the Medicaid program; and (2) have the authority to issue an order for the state to provide the requisite services. In the latter instance, the state should have a 30-day period during which to appeal the finding of noncompliance to a United States Court of Appeals. If the state does not appeal within 30 days or if the Court does not disagree with the Secretary's decision, then the order is enforceable through the courts. Strict timetables which guarantee that compliance reviews, citations for noncompliance, administrative hearings and consideration of appeals are carried out expeditiously must be established. These provisions should in no way interfere with the right of recipients to initiate private litigation to enforce their rights under the EPSDT program.

16. Parents and advocates must take an active role at the local, state and federal levels to plan EPSDT services and to monitor their implementation. EPSDT advocacy groups should be formed to carry out these functions as well as to help inform parents of their rights under the program and to help them use the EPSDT services to which their children are entitled.

Postscript: Lessons For the Design of National Health Insurance

The EPSDT experience is a rich one. It has provided new information about what health problems families bring to providers, how families use or do not use health services, what features of health care are crucial to its effectiveness and what policies and practices have failed dismally. It would be foolhardy to design a new program of national health insurance without drawing on the lessons EPSDT has taught us. Based on our review of the EPSDT experience, we are convinced that any program of national health insurance must have the following characteristics:

Eligibility for National Health Insurance Must Be Universal

EPSDT's--and Medicaid's--eligibility policies have taught us three things:

(1) Eligibility requirements based on criteria like income, employment or welfare status result in large numbers of people losing and regaining eligibility during the course of a year. On-again, off-again eligibility can never result in health services of high quality. Under these conditions, health providers are limited to providing episodic interventions; they are unable to establish continuing relationships with families; they cannot draw on accrued knowledge about their patients, their conditions, and the social and environmental circumstances of their lives; and they are hampered in educating families about the most effective use of services. Both providers and patients find health care delivered in this way inefficient and unacceptable. Many in both groups choose not to participate.

(2) Determining eligibility--especially when it is based on criteria that are complex or difficult to verify--is time-consuming and expensive. In EPSDT, welfare caseworkers spent so much time doing eligibility certification that there was almost no time or personnel left for adequate outreach, explanation about the program or provision of support services. This time-consuming task of determining eligibility eats up dollars better spent on services.

(3) Eligibility policies that restrict a program to poor people narrow the program's constituency and political base to such an extent that its ability to deliver effective health services is ultimately undermined. Witness EPSDT's record: no regulations issued for five years; crippling limits on staff in the federal office to administer the program; and continuing cutbacks in benefits. While vigorous national leadership supporting programs serving the poor may have had some short-run successes (as did the OEO programs of the mid-sixties), and while targeting re-

sources on the most needy may be a necessary interim step, programs for the poor alone will not work in the long run. Unless the participants in the program come from many strata in society, there is little assurance that the program will continue or that a double standard of services will not prevail, discriminating against the poor.

For all these reasons, eligibility for national health insurance should be universal. Nothing short of that will alleviate the two-track system Medicaid has engendered. If national health insurance is implemented in stages, the only acceptable way to phase in groups is to cover groups that are easily identifiable *and* whose status does not change frequently, such as all children under a given age. Neither income nor welfare nor employment status should be criteria for eligibility.

A National Health Insurance Program Must Cover Comprehensive Health Services, Including a Range of Health-Related Support Services

Children need comprehensive health services. EPSDT has shown conclusively that in order to deal effectively with children's health problems, a variety of services not typically included in conventional definitions of medical care must be provided. Iron deficiency anemia, parasites, learning difficulties--all commonly found in children through the EPSDT program--call, for example, for counseling; collaborative work among health providers, parents and other institutions caring for children; and putting families in touch with a variety of resources in the community to help solve problems related to their children's health. These health-related support services must be provided in close conjunction with needed medication or other medical procedures. For example, a physician can give iron supplements for anemia, but nutrition counseling may be necessary to prevent a recurrence of anemia. Similarly, while lead paint poisoning can be treated with medication, children will have high lead levels in their blood again unless the family's apartment can be rid of lead paint. A health program must have staff to help families find this needed help.

Attempts to short-cut the provision of comprehensive care have not worked in the past; nor is there reason to believe they will work in the future. EPSDT was based on the assumption that the nation could save money and that children could be well-served by providing targeted, limited services which had high payoffs for finding costly, crippling illnesses. This assumption has proven to be false. While screening and selected treatment services were, in theory, highly cost-effective, the

difficulty of actually finding, identifying and ameliorating serious conditions within the constraints of a program that does not deal with all the health needs of a child has produced ineffectiveness and waste. Health professionals are ill-equipped at a one-time screening to discover any one of myriad conditions that reveal themselves over time. And families do not always want the services such as screening which professionals have labeled as important or cost-effective. They use providers who can respond to the health needs that the family considers important. The EPSDT experience has confirmed findings from other sources that providing a full range of health services is more effective than complicated computerized case management systems (coordinating a host of disparate services) to make sure children get the health care they need when they need it.[28]

A National Health Insurance Program Must Make Maximum Use of Providers of Comprehensive Care; Where Such Providers Do Not Exist, the Program Should Provide Incentives for Their Development

While EPSDT has demonstrated beyond doubt that children need comprehensive care, it has also shown that the professionals and arrangements to provide it are lacking in many communities. EPSDT has shown, too, that simply making money available to reimburse providers, as does Medicaid, does not encourage providers to expand the services they offer; nor does it create comprehensive services where they are needed. National health insurance must be designed to remedy these problems.

First, policies governing reimbursement levels and methods, certification of providers and reporting must be carefully designed to encourage all qualified providers to participate in the program. Policies must be not only reasonable, but consistent with one another. Currently, they often undermine each other. For instance, the National Health Service Corps attempts to attract qualified young physicians into rural areas, but Medicaid compensates them at a lower rate than young physicians starting in practice in the city; the federal government sponsors physician-extender clinics in isolated rural communities, but in most states, Medicaid will not reimburse for services provided by physician extenders; HEW and private foundations encourage the establishment of primary care clinics in health-deprived areas, but many of these clinics do not qualify for Medicaid reimbursement.

[29] See, for example, evidence cited in *Doctors and Dollars Are Not Enough*, pp. 12-13 and 65.

Beyond underscoring the need to correct these sorts of problems, EPSDT has shown that in order for a sufficient number of providers to participate in the program, reimbursement rates must be competitive with going rates in the community. Otherwise, many providers simply will choose not to be involved, and beneficiaries will be left with too few providers or with an array of providers that does not match their needs.

Universal coverage would avoid these problems. But short of that, a federally-supported health insurance program must take steps to protect its beneficiaries from discrimination and scarcity. It should, for instance, require that physicians who participate in any federally-financed health program participate in all such programs (e.g., a physician could not participate in the federal employees health benefits program but not in Medicaid; or in Medicare but not in a health insurance program for all mothers and children). The federal government might also require that in return for the federal subsidy that is involved in educating medical students, when the students graduate, they have an obligation to take care of patients whose bills are paid from a federally-supported health insurance program.

But even if all or most existing qualified providers participated in the program, there would still be a need to develop new and better sources of health care. The EPSDT experience has demonstrated that organized settings where health and related support services can be provided together are lacking in most places. It is difficult for physicians practicing alone to provide all the health services children need. Comprehensive care requires a variety of personnel working together--a mode of care that is not amply available. The EPSDT experience has also shown that not any source of care will do. Services often go unused unless providers are trusted and accepted by the families who rely on them. Organized programs must be located in the community to be served and have strong ties to the people they aim to reach.

The need for modifications in the health delivery system is clear. National health insurance must be designed to bring these changes about, and to support the operation of a system that has the capacity to deliver appropriate services. Therefore, national health insurance must develop resources in shortage areas, and it must develop the kinds of providers that EPSDT and other experience have shown to be effective. For example, there is much evidence that organized providers such as Neighborhood Health Centers, Children and Youth centers and some Health Maintenance Organizations have performed these functions well and should be replicated. In addition,

smaller, low-technology primary care centers--attached to community programs such as child care centers which emphasize easy physical and psychological access--must be developed. Solo practitioners and other providers offering a narrow range of services should be able to obtain help in expanding the services they can deliver.

A major federal commitment is needed to assist professionals and consumer groups in local communities to establish and operate these organized programs. Specifically, this means:

- technical assistance and start-up funds for provider groups serving underserved areas;
- subsidies for health-related support services and for services designed to make health care accessible to people in underserved areas and to groups with special needs;
- the adoption of payment methods (including provisions to facilitate annual per capita payments and other alternatives to fee-for-service) which are simple to administer and which provide incentives for using the most appropriate services and personnel;
- suitable standards and methods of certifying providers and provider organizations, administered in ways that do not discriminate against any class of qualified providers or provider groups (be they physician assistants, nurse-midwives or neighborhood health centers).

National Health Insurance Should Include Periodic Screening as a Supplement to Comprehensive Care

As the EPSDT experience has shown, it has proven exceedingly cumbersome to build a program to meet major unmet health needs on the narrow foundation of screening. When children do not have access to ongoing, comprehensive health care, a program of screening and follow-up is a poor substitute. But given a comprehensive national health insurance program where children are assured access to continuing care, would there be a need or a useful role for screening? We believe there would.

Screening under such circumstances would be very different from that mandated by EPSDT. Selected tests such as those for anemia, vision or hearing problems would be performed at a few specified intervals: for example, once during infancy, once before entering elementary school and once before entering junior high school. Such screening would provide a check on the adequacy of the care being provided to children and would assure that at least those conditions which one-shot screening can reliably detect would not go unnoticed. In addition, screening for certain conditions such as

anemia could identify children who still are outside the system of health care and could enable efforts to be made to link them to sources of continuing care.

There have been promising experiences abroad using screening as a *supplement* to comprehensive care (e.g., in Sweden). Health professionals and HEW, in consultation with consumer groups, should identify what screening tests can usefully be provided as a supplement to comprehensive care; at what stages of life they should be given; under what auspices; and how their findings could most effectively be used to assure the provision of necessary follow-up diagnostic and treatment services to link children to ongoing health care.

A National Health Insurance Program Must Assure That Outreach, Transportation, and Other Access Services Which Help People Make Effective and Timely Use of Primary Health Services Are Provided

The EPSDT experience documents again that removing financial barriers is not enough to make health care accessible. Even though Medicaid paid medical bills, too many eligible children did not get needed care because EPSDT failed to provide information, transportation and other kinds of needed assistance in ways families used. EPSDT has also shown that not every measure labeled "outreach" will do. Personal outreach, done by community members known and trusted by parents, clearly is the method that best achieves its goals.

In the past, many have thought that such services are frills. But the evidence continues to mount that, in fact, these services are indispensible to making health care accessible to those who most need it. National health insurance must include provisions for outreach and other access services such as transportation. At a minimum, national health insurance should make subsidies for these services available to qualified, organized providers (including primary care centers, community clinics, group practices, Health Maintenance Organizations and hosptial outpatient clinics) serving areas with large numbers of persons who need them. Legislative authority and a funding mechanism for such services must be explicit.

A National Health Insurance Program Must Take Measures to Assure That Reasonable Standards of Quality of Care Are Met

One of EPSDT's most vivid lessons is that minimum standards of quality are not met unless they are clearly stated, monitored and enforced. Children who were screened through EPSDT often received incomplete health assessments. Even states with good administrators, relatively prosperous economies and reasonable amounts of resources did

not necessarily assure high quality services.

A national health insurance program must establish, monitor and enforce standards of care, especially in those areas of practice where optimal procedures are widely agreed upon within the medical profession. Without attention to these mechanisms, quality will be left unguarded, fraud or abuse will continue undisturbed and the inflationary trends in health care will soar well above our ability to pay.

Certain fundamental structural changes inherent in a national health insurance program would provide a considerably more propitious climate for upgrading quality of care. First, by including the entire spectrum of income groups in the society and giving the middle-class and the affluent a stake in how well the program is run, a national health insurance program will have taken the most important step toward safeguarding quality.[29]

Second, when such a program is enacted following widespread public interest and participation (which was not the case with EPSDT), citizen and professional pressures to improve and maintain quality tend to operate more effectively, leaving a smaller number of issues of quality to be dealt with through government enforcement mechanisms.

Third, to the extent that it encourages group practices and reimburses by methods other than fee-for-service, national health insurance will provide settings more conducive to the provision of quality care.[30]

And finally, ways must be developed through which the health system takes responsibility not only for those who come through the door seeking care, but also for those who fail to enter the system. Some existing programs, including HMO's

[29] Anne R. Somers and Herman M. Somers, "A New Framework for Health and Health Care Policies," *Inquiry* (June 1977) 14:2.

[30] Evidence of the advantageous effects on the quality of health care of group practice combined with capitation reimbursement can be found in the following studies: Sam Shapiro, Louis Weiner and Paul Densa, "Comparison of Prematurity and Perinatal Mortality in a General Population and in the Population of a Prepaid Group Practice, Medical Care Plan," *American Journal of Public Health*, Vol. 48 (February 1958), pp. 170-85; Mildred Morehead, Rose Donaldson and Mary Seravalli, "Comparisons between OEO Neighborhood Health Centers and Other Health Care Providers of Ratings of the Quality of Health Care," *American Journal of Public Health*, Vol. 61 (July 1971), pp. 1294-1306; Avedis Donabedian, "An Evaluation of Prepaid Group Practice," *Inquiry*, Vol. 6 (September 1969) pp. 3-27; Joy G. Cauffman and Milton I. Roemer, "The Impact of Health Insurance Coverage on Health Care of School Children," *Public Health Reports*, Vol. 82 (April 1967) pp. 323-328; Institute of Medicine, "HMO's: Toward a Fair Market Test," (Washington, D.C.: National Academy of Sciences, 1974), p. 52; Milton I. Roemer and William Shonick, "HMO Performance: The Recent Evidence," *Milbank Memorial Fund Quarterly* (Summer 1973), pp. 271-316. The last two of these studies also point out the hazards of underservicing in prepaid group practice, and emphasize the necessity of appropriate public monitoring to guard against new and different causes of diminished quality.

and Neighborhood Health Centers, have demonstrated the feasibility of assuming responsibility for a defined population (defined either through enrollment or place of residence). Such a defined population makes possible monitoring and assessments of performance which can have an enormous positive impact on quality of care. This concept must, however, be expanded beyond isolated groups of persons who are linked to a certain provider or group of providers. It is only when mechanisms are developed through which everyone becomes part of a defined population for purposes of planning and accountability (if not for purposes of delivering services) that we will be able to assure that required health services are available and accessible for the entire population.[31]

A National Health Insurance Program Must Provide More Than Financial Protection. It Must Include Strong Federal Leadership and Authority To Create and Maintain a Health System That Will Meet the Health Needs Of All American Families

Planners and administrators of a national health insurance program must demonstrate their commitment to a quality health care system. They must recognize that every decision about whether, how much, and under what circumstances to pay for a health service has a direct impact on whether and under what circumstances that service will be available. An exclusive preoccupation with narrow financial and cost considerations, without taking into account how people actually use health care, ultimately will lead to a program that will not be effective in helping children or saving money.

The goals of EPSDT were clearly compromised by an overemphasis on financing considerations which resulted in placing EPSDT in the context of welfare with all its eligibility requirements, its stigma of second-class services and its highly vulnerable constituency. Similarly, the health purposes of national health insurance can be subverted by an exclusive preoccupation with paying medical bills. A national health insurance program must do more than provide financial protection against the high costs of illness and remove financial barriers to needed care. For it to be effective, it must encourage and support the creation of a system of health services that will meet the needs of families who use the services. Since family members know best what kinds of services they will use, they should be included in the planning process.

The need is not to keep people

[31] Rashi Fein, *A Right to Health* (New York: John Wiley and Sons, 1976).

away from the health system, and not a matter of narrowing the services offered or erecting barriers to their use. Rather, parents must be given the opportunity, the information and the support to function as collaborators with health professionals in maintaining and restoring health. The fundamental question that the EPSDT experience raises for planners of national health insurance is whether we can harness an increasingly complex health system to serve simple human needs, or whether we are going to let it get away from us to the point we are fast approaching--where we pay increasingly enormous sums of money for services that are less likely to meet the most fundamental needs of children and families.

APPENDIX II

A Chronology

Date	Congressional or Federal Action	Progress in Implementing EPSDT in the States
December 15, 1967	Congress passes the law establishing EPSDT.	
January 2, 1968	President Johnson signs EPSDT into law, to be effective July 1, 1969.	
July 1, 1969	HEW publishes "basic regulations." These simply repeat the vague language of the statute, giving HEW no concrete requirements to enforce and giving states no real guidance. Until final regulations are published, states are considered complying with EPSDT requirements if state Medicaid officials indicate in the state plan that they will carry out program requirements once further regulations are established.	
End of 1969		Two years after the law's enactment and 6 months after its effective date, no more than five states are reported to be screening children.
December 11, 1970	HEW publishes proposed regulations which elaborate on the "basic regulations." The public is given a 30-day comment period, after which HEW is to issue final regulations.	
October 1971	After almost a year's delay in publishing proposed regulations and after many meetings to try to prod HEW to issue them, the National Welfare Rights Organization, represented by the Washington Research Project (the parent organization of the	

Date	Congressional or Federal Action	Progress in Implementing EPSDT in the States
October 1971 (Cont'd)	Children's Defense Fund) and the National Health Law Program, files a lawsuit calling for publication of final EPSDT regulations.	
November 9, 1971	HEW issues final regulations, to become effective February 7, 1972, two-and-a-half years after the effective date of the law. Under severe pressure from the states, these regulations limit required treatment services to only those otherwise covered by the state's Medicaid program, plus treatment for vision, hearing and dental problems.	
December 22, 1971	Under continuing pressure to explain the regulations further, HEW publishes "Interim" Guidelines for EPSDT, to be effective February 7, 1972. These give states an additional year and a half--until July 1, 1973--to provide EPSDT services to *all* age groups of eligible children (as of February 7, 1972, states need screen *only* children up to age 6 years).	
January 1972	HEW begins monitoring EPSDT compliance. Essentially, EPSDT enforcement becomes part of the regular compliance program conducted by SRS.[2] States' failure to implement EPSDT is to lead to a cutoff of all Medicaid funds.	

[2] The SRS compliance program assures that state plans and practices for welfare programs comply with federal requirements. Its main purpose is to detect technical violations easily discovered--on the basis of state plan material or reports about state practices which lend themselves to a simple determination of whether or not they are in compliance. Under the system, each quarter, staff in HEW's ten regional offices prepare a short report identifying regulatory requirements for which there may be a violation--for example: Do state requirements for eligibility meet federal requirements? Is there a State Medical Advisory Committee?

To determine compliance, SRS uses a "preprint": a form which lists Medicaid provisions with which states are expected to comply. A staff person from the regional office checks off whether or not the state meets the requirement. If there are questions of compliance, regional office staff must "clarify the situation and get the facts promptly..." and notify the state about the questions. (See, *SRS Compliance Manual* (Washington, D.C.: HEW, August 1971), Chapter II, p. 6.)

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Date	Congressional or Federal Action	Progress in Implementing EPSDT in the States
February 7, 1972		Nine states are known to have an operating EPSDT program. Fifteen states have submitted Medicaid plan amendments, stating they are in compliance with EPSDT requirements. SRS reviews indicate that 34 of the 45 states on which compliance reviews were conducted were out of compliance. For the first four calendar quarters after EPSDT regulations became effective, 41 states were cited for noncompliance. In only one was a hearing recommended, and no further action was taken.[3]
March 23, 1972	HEW Secretary Richardson writes a letter to Senator Mondale saying that HEW lacks information to determine whether eligible children are receiving EPSDT services.	
April 1972	The Senate Finance Committee, concerned about the cost of implementing EPSDT, proposes provisions which would give states additional time to implement EPSDT fully.	
June 1972	The Congressional Black Caucus holds hearings on "Government Lawlessness," including failure to implement EPSDT.	
June 28, 1972	HEW issues "Final" EPSDT Guidelines which have far more detail than the "Interim" Guidelines.	
July 1972 - June 1973		500,000 screenings have been performed nationwide.

2 (Cont'd)
After a maximum of six months of negotiations, the Commissioner in the HEW regional office is required to recommend to the Administrator of SRS that a formal compliance hearing be initiated, or, alternatively, to file a memorandum justifying why the Administrator should not initiate formal proceedings. If HEW finds a state out of compliance after a hearing, it has the authority to cut off all Medicaid funds.

[3]Memorandum from the Legal Committee of the National Welfare Rights Organization to Honorable Caspar Weinberger, Secretary of the Department of Health, Education and Welfare, "EPSDT of Medicaid Eligible Children," 30 March 1973.

Date	Congressional or Federal Action	Progress in Implementing EPSDT in the States
August 9, 1972	HEW initiates use of status reports (first serious attempt to collect information on the operation of states' EPSDT programs).	
October 1972	HEW begins collecting monthly statistics from states on the number of children screened and referred for various health problems.	
October 1, 1972		HEW compliance reviews find 43 states out of compliance with at least one EPSDT requirement. No funds are withheld.
October 30, 1972	In response to continued failure to implement EPSDT, Congress enacts the EPSDT penalty provision. Effective June 30, 1974, states are to be taxed 1 percent of the federal share of AFDC payments for failure to: inform AFDC eligible children at least once annually and in writing about EPSDT; assure that screening is available within 60 days of a request; and arrange for necessary treatment normally within 60 days of the time of screening. These "penalty requirements" supplement the obligations states have under the regulations issued in November 1971.	
November 10, 1972	HEW requires that each state not in compliance with EPSDT requirements submit a plan, by December 15, explaining how services will be made available by no later than February 1, 1973.	
July 1973 - June 1974		1.3 million screenings performed nationwide out of 6.5 million screenings that should have been done among the 9.75 million eligible children this year.[4]
December 19, 1973	HEW publishes proposed regulations for EPSDT penalty provisions.	

[4]For an explanation of how these numbers were derived, see Appendix H.

Date	Congressional or Federal Action	Progress in Implementing EPSDT in the States
June 30, 1974	HEW begins quarterly reviews of states' programs to determine compliance with EPSDT requirements established by the penalty provision. For each subsequent quarter, regional office staff are to conduct reviews of the adequacy of states' programs.[5]	
July 1974 - June 1975		1.5 million screenings performed nationwide out of 6.65 million screenings that should have been done among the 9.98 million eligible children this year.
January 9, 1975		The General Accounting Office (Comptroller General of the United States) issues report citing delays in implementing EPSDT.
June 2, 1975	HEW cites seven states (Indiana, Montana, North Dakota, Hawaii, Minnesota, New Mexico, Pennsylvania) for noncompliance with EPSDT penalty requirements for the quarter ending September 30, 1974. In July, California is added to the list, and in October, New York is cited for noncompliance. (States have appealed these decisions and, to date, no funds have been withheld.)	
June 1975 - July 1976		1.7 million screenings performed nationwide, out of 6.85 million screenings that should have been done among 10.3 million eligible children this year.

[5] "Penalty reviews" of each state's program are conducted by regional office staff each quarter. A review consists of a description of how the state fulfills the penalty requirements for informing, screening and treating eligible children and a small sampling of case records in six randomly selected sites in the state to determine whether the requirements for the prompt provision of screening and treatment services have been met for eligible children. Based on penalty reviews, the Secretary of HEW cites states found to be out of compliance. Before the 1 percent tax can be withheld, states may request reconsideration: a formal, legal process spelled out in regulation (45 C.F.R. §201.14).

Date	Congressional or Federal Action	Progress in Implementing EPSDT in the States
August 20, 1975	HEW proposes a second set of regulations to clarify states' obligations in complying with requirements of EPSDT's penalty provisions. To date, final regulations have not been issued.	
October 7-8, 1975	The House Subcommittee on Oversight and Investigation holds hearings on child health, with specific sessions on EPSDT, calling attention to failure by the states and HEW to implement EPSDT.	
January 12, 1976	Pennsylvania is cited as out of compliance with EPSDT penalty requirements for quarter ending December 31, 1974. On July 7, 1976, Hawaii is cited as out of compliance; and on December 14, 1976, HEW cites four more states (California, New Mexico, Indiana, New York) for noncompliance with EPSDT penalty requirements for the same quarter. No funds have been withheld yet.	
February 20, 1976	HEW revises procedures for penalty reviews to require that they be done every two quarters for states which are found in compliance during the past quarter. For states found out of compliance, penalty reviews are to be conducted each subsequent quarter.	

This chronology shows that more than four years after the program's enactment, and more than two years after its effective date of implementation, HEW had not promulgated regulations so critical in guiding states to begin EPSDT programs. Final regulations and guidelines eventually were published, but they deferred requiring full implementation for yet another year and a half. HEW did not conduct reviews of state programs until two-and-one-half years after EPSDT's effective date. Once having conducted such reviews, HEW failed to act on its findings. And to date, HEW has not issued final regulations to clarify states' obligations in complying with the requirements of EPSDT's penalty provisions.

What does this history teach us, both about improving the EPSDT program and about designing and implementing other child health programs?

APPENDIX III

CHILDREN'S DEFENSE FUND
of The WASHINGTON RESEARCH PROJECT, Inc.
1520 NEW HAMPSHIRE AVE., N.W.
WASHINGTON, D.C. 20036

(202) 483-1470

August 23, 1977

Honorable Hale Champion, Undersecretary
Department of Health, Education and Welfare
Chairman, Advisory Committee on National Health Insurance Issues
Washington, D.C., 20201

Dear Hale:

This is in response to your invitation to members of the Advisory Committee to comment on the "analytic work plan" which outlines the topics that are to be analyzed by the national health insurance staff of the Office of Planning and Evaluation.

I found it difficult to visualize how the detailed outline would be translated into material that could form the basis for judgments and decisions about critical issues. Much of the work that I believe is important in this connection may be contemplated by the outline, and may in fact be under way. Since I believe, however, that sound policy formulation in this area is so significantly dependent on the nature of the background work, I will take the risk of being redundant and suggest certain areas where I believe--from my particular perspective--careful staff work is especially important.

I am most concerned that the staff work done during the next several months include the accumulation and presentation of data, facts, and experience based on a wide range of assumptions, going beyond presently prevalent practices and conventions, about how care is best organized and paid for, its availability and accessibility most effectively assured, and its quality and responsiveness maximized. More specifically, this means inclusion of the following in the work to be undertaken by the staff:

A. Estimates of costs and utilization that are based on a variety of assumptions, specifically including major systems reforms, such as substantial departures from fee-for service practice and from solo practice, and improved access to organized primary care.

B. Estimates of administrative costs and total costs based on a variety of administrative arrangements, including mandated coverage, insurance carrier participation as in Medicare, and methods of reimbursement of providers based on other than usual and customary charges and negotiated fees for service.

C. Analysis of various options for administering national health insurance (i.e. role of insurance companies, states, federal government, etc.) in relation to:

1. Potential for assuring availability and receipt of needed and appropriate services.

2. Potential for assuring high quality services.

3. Potential for acceptability to professionals and to consumers.

4. Potential for controlling costs.

D. Analysis of a variety of methods to monitor and assure quality of care, including the effect of structural factors such as group practice and various methods of reimbursement, on quality of care.

E. Development of a clear definition of effective health-related support services, and an analysis of options for delivering and paying for these services.

F. Analysis of various staging alternatives in the implementation of national health insurance, in relation to projected effects on costs, and on the organization and functioning of the system.

G. Analysis of methods of assuring appropriate utilization, including:

1. Financial incentives aimed at consumers and at providers.

2. Professional peer review.

3. Other methods of review aimed at controlling utilization once a person is within the system (e.g. a team assessment of the need and best methods of providing long-term care of an aged or mentally handicapped person; use of non-physician personnel in various capacities to help people make optimal use of the health system).

4. Impact of structural factors (including ease of access, form of organization) on utilization.

H. Projections of alternative methods of financing and organizing health services in relation to their comparative effectiveness in meeting the health needs of special groups, including:

1. Poor children.
2. The chronically ill.
3. Pregnant women at high social risk.
4. Adolescents.
5. The mentally ill.
6. The aged.
7. Persons living in rural areas.
8. Persons in big city ghettos.

I. Analysis of data regarding the current use of non-physician professional health personnel, including current patterns of reimbursement, assessments of their effectiveness in delivering services, and a description and analysis of barriers (legal, administrative, consumer acceptability, professional acceptability, financial, etc.) to their optimal utilization.

J. Analysis of the kinds of federal action (in the form of technical assistance, start-up funds, subsidies, reimbursement and certification policies, expansion of National Health Service Corps, etc.) that would be required to assure universal availability of high quality primary care services.

There is a second category of issues, on which I believe extensive background information is also needed, but where there is considerably less experience to draw on. It may be difficult for presently available staff to provide comprehensive background papers on these issues under existing time constraints. Nevertheless, it seem to me important to make plans to address these issues:

A. Analysis of options through which providers or administrative entities (public health departments, health planning districts, etc.) would take responsibility for monitoring care to defined population groups.

B. Analysis of the limitations of existing outcome measures, and of available experience with the application of measures of outcome which are more discriminating and more sensitive than morbidity and mortality data; an analysis of the prospects of developing and applying more sensitive outcome measures.

C. Analysis of available experience, and the prospects for improving on available experience, with the development and application of effective methods to:

1. Enable consumers to monitor their own care and that of family members, including making more widely available better information about desirable standards of care, where these are clearly agreed upon by a preponderance of professionals.

2. Help consumers make more effective use of health services.

3. Make the health system more effective in helping individuals and families to improve personal health behavior.

4. Involve consumers as effective participants in planning health services and in influencing decisions about the commitment of health resources at all levels.

One final point. I am under the impression--on the basis of statements by the President and HEW officials--that a decision has already been made that any national health insurance program proposed by this Administration would be based on universal coverage, with a uniform set of benefits, and with no qualification for eligibility based on income, assets, or employment status. I trust that my impression is correct and that therefore, background work on this issue is not required to assist in the decision-making process for designing an Administration program. Nevertheless, such background work may be useful in providing documentation to support the program the Administration proposes, and I therefore believe it would be appropriate to assemble available data regarding administrative costs and barriers to ready access and effective use of services that are associated with programs whose coverage is contingent on proof of inadequate financial means or lack of employment.

I hope that you and your associates will find these recommendations useful.

Yours sincerely,

Lisbeth Bamberger Schorr

LBS/mg
cc: Dr. Julius Richmond
Dr. Karen Davis

bcc Wendy Lazarus

TAB A: Impact of CDF's Recommended Amendments to CHAP: Additional Children Receiving Services and Additional Costs

Additional Children Served by CDF Proposals Above Those Served Under the Administration's CHAP.

Under CDF's Proposal: During the First Full-Year of Program Operation

The Number of Children Eligible for Medicaid Not Previously Eligible	1,140,000 children
The Number of Children Entering Medicaid Who Would Not Have Entered	410,000 children
The Number of Children Receiving Health Assessment Who Would Not Have Been Assessed	1,260,000 children
The Number of Children Receiving More Complete Treatment Following Assessment	340,000 children
The Number of Children Receiving Dental Care Who Would Not Have Received It	480,000 children

Total Additional First Year Costs (Fiscal Year 1978) of CDF's Proposal Over the Administration's CHAP

	Additional Federal Cost (in millions)	Additional State Cost (in millions)	Additional Total Cost (in millions)
Additional Costs in Fiscal 1978, After Adjusting For Startup Time	$135.0	$ 62.2	$197.2
After Adjusting For Startup Time, Additional Costs in Fiscal 1978 If Maintenance of Effort Were Expected of the States	$ 75.0	$122.2	$197.2
Additional Costs For a Full Year of Program, Not Adjusted for Startup Time	$216.5	$ 90.2	$306.7

Assumptions Behind Projections of
Additional Children Served and Costs

1. We assume an assessment rate of 28 assessments per 100 eligible children in fiscal 1978. This rate approximately equals the rate assumed by HEW under the CHAP proposal. We assume that, in the absence of CDF's proposed outreach component, the rate of 28 assessments per 100 eligibles would also apply to newly eligible children included in CHAP ("income eligible children" under age six) and to newly eligible youth aged 6-21 included by CDF's eligibility extension. (The actual screening rate in fiscal 1976 was under 18 screenings per 100 eligible children.) The new "income eligible" children are likely to be harder to reach than the currently eligible group, largely because almost none of them have any existing relationship with AFDC caseworkers. We assumed that screening costs are $21 per child screened.

2. Except where noted below, we assume that all costs are subject to 75 percent federal reimbursement.

3. We assumed that outreach would contact 20 percent of the eligible children not previously assessed during each full year of program operations. Outreach would take 2 hours per family contacted, at an average cost of $4.00 per hour, with an average of 2.5 eligible children per family. Of the children contacted, we assume that 55 percent would enter the system for assessment (and for other Medicaid services, if not currently on Medicaid). Thus, the assumed outreach costs are $3.20 per child contacted and $5.82 per child entering the system as a result of outreach. The number of children entering the system in the first full year of program operations would be 850,000. Thus, the total costs of performing outreach would be $4,947,000. We assume that this direct cost of performing outreach would be subject to 90 percent reimbursement by the federal government.

4. There are about 10 million presently eligible children at any one point in time. The CHAP proposal would add 760,000 children as potentially eligible. Our eligibility extension would add another 1,140,000 children.

Neither the 760,000 new children under 6 nor the 1,140,000 new children over 6 are currently on Medicaid. We assume that the 28 percent of these newly eligible children who are brought into the system without outreach would entail total costs of $400 per child per year of Medicaid charges, which would be reimbursed at a 65 percent rate by the federal government. (Services provided subsequent to an assessment would be reimbursed under CHAP at 75% by the federal government. Other Medicaid services would be reimbursed at 55% by the federal government. These are charges exclusive of outreach, assessment, and assessment-related treatment costs.) This is approximately the same per child cost as assumed by HEW for the CHAP proposal. We also assume that the newly eligible children brought in by special outreach efforts would have lower annual Medicaid charges -- $260 per child per year, again reimbursed at a 65 percent rate by the federal government -- because they are less likely to be afflicted with known and costly conditions than are those who enter without outreach.

There are no additional Medicaid charges incurred for those children already on Medicaid who are brought in for assessment by the outreach efforts.

5. We assume that the treatment costs are presently (and would remain under the CHAP proposal):

   a. Medical: 50 percent of all assessments would lead to a medical referral. Of those referred, 80 percent would receive treatment at a cost of $35 per case.

      Improvement: CDF proposes more complete treatment services with the result that the average cost per treated case would be raised to $50. This is roughly the effect of assuming that 20 percent of the children treated would require an average of $110 per child, while the remaining 80 percent of children treated would continue at $35 per child.

   b. Dental: 25 percent of all assessments of children over the age of 3 would lead to referral. Of those referred, 75 percent would incur treatment charges of $90 per case.

Improvement: CDF proposes that dental programs be expanded so that dental care is extended to the number of children equal to 40 percent of those assessed over the age of 3 (an additional 15 percent of the assessed population). The children treated would not necessarily be drawn from the group who are assessed.

In all cases, we assume that dental as well as medical treatment costs would be reimbursed at a rate of 75 percent by the federal government.

6. We assume that in the first fiscal year of operation under CDF's proposal, only part of the full annual costs would be incurred. In particular:

   a. We assume that the full cost of adding the 6 to 21 year old age group would be incurred in the first full year of operation.

   b. We assume that the cost of more complete treatment (both medical and dental) would be incurred only in the last half of the first fiscal year (that is, only half the full annual costs would be incurred). This assumption primarily reflects the time needed to develop and promulgate policies for more complete treatment services and the time needed to identify new providers and expand the services of existing providers.

   c. We assume that new outreach will be performed only in the fourth quarter of the first fiscal year (that is, only one fourth of total costs will be incurred in the first fiscal year). This assumption reflects the fact that the kind of outreach in our proposal is a new function requiring both new standards and new providers. Further the chief cost of outreach is not the direct cost of performing outreach but the indirect cost of assessing, treating, and providing Medicaid services to children previously not participating. Those costs occur a number of months after the child is first contacted by outreach.

Mr. MAGUIRE. Thank you.
Ms. Blank?

STATEMENT OF HELEN K. BLANK

Ms. BLANK. I am Helen Blank, Director of the American Parents Committee. I am accompanied by Donna Brown, Director of the Health Cluster of the Coalition for Children and Youth.

The Coalition for Children and Youth, formerly the National Council of Organizations for Children and Youth, is an umbrella for over 1,300 national, State and local organizations and individuals who are concerned with Federal policies affecting the quality of life of our Nation's children. The Health Cluster is a subgroup of the coalition which devotes itself to advocacy for maternal and child health problems, and which represents a broad range of interests and expertise. The following views on H.R. 6706, the Child Health Assessment Act, have been endorsed by the following Health Cluster members:

American Foundation for the Blind, American Parents Committee, Association of Medical School Pediatric Department Chairmen, Association of State and Territorial Maternal and Child Health and Crippled Childrens Directors, Board of Church and Society, United Methodist Church, and Citizens Committee for Children of New York, Inc.

Commonwealth Child Development Committee, Pennsylvania Governor's Office of Human Resources, Cystic Fibrosis Foundation, Family Health Service Division, Colorado Department of Health, National Association of Children and Youth Programs, and National Easter Seal Society for Crippled Children and Adults.

The Health Cluster has monitored the early and periodic screening diagnosis and treatment (EPSDT) program since 1974, and in 1975 conducted a demonstration project in Baltimore to explore the potential of the participation in EPSDT of voluntary groups. We are glad to see an effort to improve the early and periodic screening, diagnosis and treatment program, which has long been riddled with problems.

However, we believe that no revisions will be sufficient to enable it to achieve our goal—assurance that all children receive comprehensive, continuing health care and supervision. We hope that the proposed child health assessment program will be just one admittedly small step toward that goal. With that in mind, we offer the following comments on H.R. 6706, which we believe can help it become a more productive first step.

QUALITY OF CARE

The quality of care under EPSDT would certainly be enhanced by CHAP's uniform Federal requirements for the content of health assessments and the frequency with which children should receive them. We believe that the recommendations of the American Academy of Pediatrics with respect to these issues should be implemented. This is particularly important to ensure that children receive immunizations at the appropriate intervals. Currently, out

of 52 million American children under the age of 15, some 20 million—almost 40 percent—are not immunized against one or more of the childhood diseases for which safe and effective vaccines are available.

Additionally, the program should be designed to ensure that newborns receive complete assessments, and that pregnant teenagers are able to receive adequate prenatal care to help minimize the increased risks of maternal and infant death, low birth weight, and toxemia and anemia that are associated with adolescent pregnancies. The need for prenatal coverage is large among the EPSDT eligible population—72 percent of the mothers who first gave birth at ages 15 to 17 are receiving welfare benefits.

TREATMENT COVERAGE

The proposed requirement that States provide all age-appropriate care and services to children assessed under CHAP recognizes that assessing a child without treating the problems thereby uncovered is purposeless. The extension of eligibility for tratment for a minimum of 6 months following an assessment is equally sensible.

However, we believe that the exclusion from mandatory coverage of treatment for mental illness, mental retardation, and developmental disabilities is both unwise and inequitable. These exclusions deny coverage to over 17 percent of the child population, which includes those children who are mentally retarded and those with seizure disorders, neuromotor disabilities, school learning problems and emotional disturbances. [1]

Exclusions defined in terms of diagnostic category may encourage the interpretation that children with those conditions need not be covered for any treatment related to such conditins. Current regulations require states at least to provide for corrective treatment by referral; the CHAP proposal does not assure even referral for children classified under these categories. Futhermore, such children can benefit from some services which some State Medicaid plans do cover presently, such as speech therapy, physical therapy and psychiatric services.

These proposed exclusions depart not only from the previous practice of limiting types of services that can be covered, but also from the intent of the Medicaid program, as stated in Section 1901 of the Social Security Act. Here it is stated that a purpose of medical assistance is to enable each State to furnish "rehabilitation and other services to help such (eligible) families and individuals attain or retain capability for independence or self-care."

We believe, therefore, that the phrase "but not necessarily including those for the treatment of mental illness, mental retardation or developmental disabilities" should be deleted, to foster nondiscrimination against handicapped children and to conform with existing practice evidenced by current regulations cited above.

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[1] William K. Frankenburg and A. Frederick North, "A Guide to Screening for EPSDT Program Under Medicaid," Social and Rehabilitation Service, USDHEW, June, 1974, p. 141).

DENTAL CARE

The provision excluding from mandatory coverage "dental care when not for the treatment of conditions discovered during an assessment" should also be deleted. Tying dental care to a referral from an assessment would preclude receipt of routine preventive services and of treatment for acute conditions arising at another time. We know that nearly all poor children need routine dental care. Dental screening as a prerequisite to such care is thus both inappropriate and uneconomical.

EXPANSION OF ELIGIBILITY

Expanding Medicaid eligibility to include children under age 6 who qualify on the basis of financial eligibility recognizes that these children have the same health needs as those who are categorically eligible. However, denying coverage to equally needy children, ages 6 to 21, makes an arbitrary and unjustifiable division. Sixteen States already cover all children under 21, on the basis of financial eligibility alone. The inappropriateness of an age restriction bcomes even more apparent when one ponders a situation in which a five-year-old has access to Medicaid benefits and the eight-year-old sibling does not. Such a divisive family policy is surely not the intent of CHAP. Eligibility for Medicaid should, we therefore believe, be extended to financially eligible children of all ages.

OUTREACH

The provisions of Section 6 of the Child Health Assessment Act would require States to encourage physicians and health care centers to participate in CHAP, to assure coordination between State and local agencies participating in CHAP and community health centers, and to assure the availability of appropriate support services, including case tracking and outreach.

These rather brief provisions strike at some important problems of the current EPSDT program: reluctance of providers to participate; poor coordination among available child health resources; inadequate outreach to ensure that children receive health assessment; and poor monitoring to determine whether children receive needed treatment or subsequent reassessments.

The magnitude of these problems warrants statutory attention more specific than is provided by this bill, especially because we know that the problems are not insoluble.

The importance of outreach to bring children into a system of regular health care is well accepted and examples of successful outreach have been documented by community health centers and children and youth projects, as well as by EPSDT demonstration projects.

Crucial steps in negotiating the health care system include establishing Medicaid elgibility; understanding the nature and purpose of the screening program, transportation to screening, diagnostic and treatment centers; and, effective referral for discovered conditions. Recent data indicate the potential impact of a successful outreach program. In fiscal year 1976, of those children eligible for EPSDT

services, 75 percent received no screening services and of those with discovered conditions 40 percent received no treatment or corrective care.[2]

It is clear that successful outreach must go beyond informing families in writing about a program, as is required by the current program, to personalized, supportive contact with the family. Low income families have many problems claiming their immediate attention; the tasks of meeting a child's daily needs can become all-consuming. Parents are much more likely to seek preventive health care for their children if the reasons have been carefully explained in understandable terms and if assistance in negotiating the health care system to obtain it is provided.

Effective outreach is so crucial to the success of CHAP that we believe its importance should be explicitly emphasized and that children will benefit from Federal requirements that States use all agencies and organizations with existing outreach capability in their CHAP programs.

COORDINATION AND PROVIDER PARTICIPATION

Section 6 also requires that States assure coordination between public agencies participating in CHAP and community health centers funded under Section 330 of the Public Health Service Act. The intent of this provision should be to ensure that not only community health centers are included in CHAP, but all federally funded health care programs, and particularly those child health programs funded by title V of the Social Security Act.

In fiscal year 1975, provider participation in screening under EPSDT was defined by State policies to be accomplished through health departments primarily in 25 States, by private physicians primarily in 8 States, and by a range of providers in 20 other States. The full range of qualified providers should be involved in CHAP in all States. Additionally, it should be noted that such coordination cannot be fully accomplished by States without back-up from the Department of Health, Education, and Welfare consistent with that objective. Federal policies for administration of health service programs should enable and encourage cooperative relationships among them at the State and local levels.

The success of the CHAP program clearly is dependent on the willingness of providers to participate by agreeing to the responsibilities that would be required of them. The language of section 6 requiring States to "encourage" physicians and health care centers to participate does not address specifically possible barriers to their participation, such as reimbursement rates insufficent to cover the cost of providing both the required medical and case management services, and the additional required reporting.

Because CHAP increases the responsibilities of providers in these areas substantially beyond those that they are currently required to fulfill under EPSDT, States should be required to offer providers reimbursement that can reasonably be expected to elicit their participation. For some types of providers, capitation and/or pro-

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[2] Children's Defense Fund, EPSDT: Does It Spell Health Care For Poor Children? Washington, D.C., 1977.

spective reimbursement may well be the most satisfactory method of reimbursing for the package of services required by CHAP.

STATE CHAP PLANS

Implementing CHAP effectively will clearly require a creative effort from the States, and it can be expected that the methods by which States carry out its various aspects will differ. However, we feel it is important that in order to maintain accountability along with flexibility, States can be required to file with the Secretary a State CHAP plan detailing how each of CHAP's requirements will be implemented. This is important both to ensure that the responsibilities of the numerous entities in a State working togther in CHAP are clarified and mutually understood, and to ensure public accountability. The Secretary's evaluation of a State's fulfillment of its CHAP plan might then be the basis for the application of financial penalties and bonuses.

FEDERAL FINANCIAL PARTICIPATION FOR CHAP

The increased rate of Federal financial participation for CHAP is the principal incentive to States to emphasize good child health care in their Medicaid programs. However, the method proposed in this bill will have different impacts on different States. States which currently receive the minimum match of 50 percent have the most to gain—an additional 25 percent. These tend to be the more rich and populous States, and include many which have the most generous possible Medicaid benefits, and which already extend those benefits to financially needy children.

However, 17 States receive a Federal percentage of 66 percent or greater, and could gain only a 12 percent or less increase. These are the more poor, rural States, which tend to offer minimal Medicaid benefits, and to restrict eligibility to the categorically needy. These States, which under CHAP would generally have to expand their programs more drastically than richer States, would also receive a much smaller proportionate increase in Federal funds.

A Federal reimbursement rate of 90 percent for all State CHAP expenditures would alleviate this inequity by giving all States a uniformly high rate. Medicaid currently reimburses 90 percent of State expenditures for the installation of mechanized Medicaid management information systems, and for family planning services and supplies.

This precedent of setting higher rates of Federal reimbursement for activities of high priority could appropriately be applied to CHAP, if indeed preventive child health care constitutes such a priority. We believe that it should.

Furthermore, increased Federal funding of CHAP should be accompanied by a requirement that States maintain their current financial effort, adjusted for inflation. Otherwise, the possibility remains that Federal funds will simply replace State funds, rather than result in program improvement and expansion.

We commend the Subcommittee on Health and the Environment for its attention of the CHAP proposal and are glad to cooperate further in any way we can.

We urge you to act very quickly. We agree with witnesses that we have learned much from the EPSDT program in the past 10 years. We are not asking for a major overhaul of the system, and we hope that you can mark up a bill as soon as possible.

Mr. MAGUIRE. Thank you very much, Ms. Blank. I must say I take some satisfaction in your points that mental disabilities, dental care, should be included, and the age restrictions ought to be eliminated.

I also very much appreciated Ms. Edelman's comments on my bill, and similar points she made. I wondered, however, in view of your strong point about the necessity of addressing children and not the prerogatives of States, given this is a Federal-State program, by definition, and given that we are going to have some sort of penalties, hopefully augmented by your proposal, how does one in the meantime, as the program proceeds, insure accountability from States? I see that as a very difficult problem.

Ms. EDELMAN. I am going to defer to Wendy Lazarus, who ha thought a lot about how we get this program operational.

Ms. LAZARUS. First of all, there are existing EPSDT requirements on the books right now, which if enforced vigorously by HEW would go a long way toward reaching many of the goals people have set out today.

For instance, using the range of qualified providers is something on which we could make progress right now, and for which we could hold States accountable. But additionally we believe very strongly that service outcome is what we ought to be talking about, and that that is the best single way to make sure that benefits get to the children. That is why we urge strongly that outcome standards be included in new legislation.

Mr. MAGUIRE. Okay. Again, I wish we had more time. I have 4 minutes to make it to the floor.

We stand in recess for 10 minutes.

[Brief recess.]

Mr. ROGERS. The last panel for the evening will be Dr. Walter Campbell, Executive Vice President and founder of the Community Health Foundation; Ruby Duncan, Chairwoman, Operation Life, Las Vegas, Nevada; and Nancy Spears, Association Director, Alabama Council on Human Relations, and Director, Lee County Head Start Program.

Dr. Campbell will be accompanied by Paul Allen.

We welcome you to the committee. We apologize for the lateness. We appreciate your patience. Each of your statements will be made a part of the record, and you may proceed as you desire. It will be helpful if you confine your remarks to 5 minutes. You might identify yourselves for the reporter.

STATEMENTS OF WALTER D. CAMPBELL, M.D., EXECUTIVE VICE PRESIDENT AND FOUNDER, COMMUNITY HEALTH FOUNDATION, ACCOMPANIED BY PAUL ALLEN, M.P.H.; NANCY S. SPEARS, DIRECTOR, LEE COUNTY HEAD START PROGRAM, AND ASSOCIATION DIRECTOR, ALABAMA COUNCIL ON HUMAN RELATIONS; AND RUBY DUNCAN, CHAIRPERSON, CLARK COUNTY (NEVADA) ECONOMIC AND WELFARE RIGHTS ORGANIZATION

Dr. CAMPBELL. Mr. Chairman and members of the subcommittee, I am Dr. Walter Campbell, a pediatrician, a faculty member at Northwestern University Medical School and Executive Vice President of Community Health Foundation. Appearing with me, as you indicated, is Mr. Paul Allen, who is an experienced public health planner and manager.

Our reason for being here, sir, is that we have for the past 27 months been working intensely with 12 States in their efforts to implement EPSDT programs. We wish to express our appreciation for an opportunity to provide you with some observations and recommendations.

We would like to congratulate the authors of the legislation for recognizing the need to expand title 19. Indeed, much has been written about this and the rising cost of health services and the need for assistance in financing the cost of such services, especially as they relate to children. We feel children have very special needs and deserve special consideration.

We do not wish to prolong your afternoon, so we will abbreviate our comments. We have four major areas of concern, and these are predicated on the assumption that the CHAPS program is indeed intended to strenghten EPSDT and would not delete some desirable aspects of it. Therefore we do not wish to reemphasize positive contributions that EPSDT has already made.

We would stress first the need to broaden and standardize the eligibility criteria for the citizens who might participate in this program.

Mr. ROGERS. I hope you will give us some specific suggestions in your testimony. If not, we will appreciate receiving a supplemental statement with suggestions.

Dr. CAMPBELL. We have. Second, we feel a profound need for EPSDT to be coordinated with other federally supported child health programs that have been in effect for some time. This point has been made repeatedly but it certainly is to be stressed.

Third, we feel there are problems with provider participation in EPSDT, CHAP and child health services in general. That problem area needs to be addressed in the legislation.

Fourth, we feel there is a very significant problem with program management in the current EPSDT program. We do not wish to focus exclusively on any one level but feel this is a program that is poorly managed from Federal through State and particularly at the local level.

If I might, I will make some brief comments about each of these areas.

We pointed to the fact that children have special health needs which, if overlooked, can result in lifetime handicaps. Unfortunately, many low-income children do not now qualify for health care services under EPSDT, and as a result the health needs of these children go unattended. Therefore, a critical need exists to broaden and standardize the eligibility criteria for child health services under the proposed legislation so that additional children would be covered and their care would not be interrupted, regardless of changes in family composition or income. The health of children is a valuable national resource in need of additional protection and improvement.

Currently, EPSDT has the distinction of being the largest Federal child health program. The proposed CHAP program would be even larger. Yet, one of the greatest potential stimulants to the expansion and improvement of EPSDT has not been addressed in the proposed CHAP legislation. That is the need of one child health care program to take the lead in this area of service.

There are currently several child health care programs which overlap with EPSDT and result in duplication of services and unnecessary administrative expense.

Examples of this might well be in some respects title V, head start programs, certain day care programs, and the like.

We therefore believe that the time has come when Federal child health care programs must be consolidated at all levels. The child health assessment program has the potential for being the lead child health program in this country. Eligible children and providers of health care services should be encouraged to view CHAP as the resource for the first dollar of support when personal resources are inadequate.

I will further abbreviate my comments.

On the matter of provider participation, there are problems. The legislation suggests that there is a need for comprehensive care providers. Currently there are several levels of capability among providers. We envision there will be an expanded need for comprehensive health care providers.

In the case of protecting physicians, if you anticipate increasing their participation in the program, there are certainly going to have to be some arrangements made for providing them with a competitive level of reimbursement for the services that you are requesting they provide.

On the matter of those who cannot currently provide comprehensive care services, there is indeed a need, not to discourage those people from continuing to participate, but to provide some arrangements and some appropriation for their combining their activities with other organizations who together could then become comprehensive care providers, particularly in inner city and rural underserved areas.

The last problem that I mention, Mr. Chairman, has to do with program management, and indeed this problem exists, as I indicated, at all levels.

At the Federal level program leadership has been slow in developing, and I think the record will bear that out. At the State level, there has been inadequate capability and relegation of program administration to a level of obscurity and low levels of authority. At the local level adequate administration within a framework of direction from State and Federal levels has been missing.

We are firmly convinced that these deficiencies must be corrected if CHAP is to be even partially successful.

Thank you.

[Testimony resumes on p. 200.]

[Dr. Campbell's prepared statement follows:]

TESTIMONY ON CHILD HEALTH ASSESSMENT ACT OF 1977

Presented by
Walter D. Campbell, M.D. and Paul Allen, M.P.H.
Community Health Foundation
Evanston, Illinois 60201

To the Interstate and Foreign Commerce Committee, Subcommittee on Public Health and Environment

Honorable Paul L. Rogers, Chairman

September 8, 1977

Mr. Chairman, Distinguished Members of the Subcommittee:

I am Dr. Walter D. Campbell, a pediatrician, a faculty member at Northwestern University Medical School and Executive Vice President of Community Health Foundation. Appearing with me is Mr. Paul Allen, an experienced public health planner and manager. For the past 27 months, the Community Health Foundation, a non-profit organization dedicated to improving the delivery of child health services, has been working intensely on assisting twelve states with implementing their Title XIX Early and Periodic Screening Diagnosis and Treatment efforts. We wish to express our appreciation to the Subcommittee for this opportunity to present our concerns and recommendations related to the proposed Child Health Assessment Act of 1977.

We congratulate the authors of this proposed legislation and the Subcommittee for recognizing the need to improve and expand the Title XIX Early and Periodic Screening, Diagnosis and Treatment program. Much has been written and said about

the rising cost of health services. We recognize the general need for assistance in financing the cost of such services, and we feel that the special needs of children demand special consideration.

Children have special health needs which, if overlooked, can result in lifetime handicaps and reduced productivity. However, children are usually born of young adults who may not have reached their full earning power and thus cannot always adequately provide for their families' needs. Unfortunately, many children of such low income families do not now qualify for health care services under EPSDT and, as a result, the health needs of these children go unattended. There is a critical need to broaden and standardize the eligibility criteria for Child Health Services under the proposed legislation so that additional children would be covered and their care would not be interrupted, regardless of changes in family composition and/or income. The health of children is a valuable national resource in need of additional protection and improvement.

EPSDT has the distinction among federally supported child health care programs of having the largest target population and receiving the largest amount of dollar support. The scope of the proposed Child Health Assessment program is to be even greater in terms of the number of people served, volume of services rendered and amount of dollars spent.

Yet, one of the greatest potential stimulants to the expansion and improvement of EPSDT has not been addressed in

the proposed CHAP legislation. That is, the need for one Child Health Care program to take the lead in this area of services. There are currently several Child Health Care programs which overlap with EPSDT and result in duplication of services and unnecessary administrative expense. Mr. Chairman, we know that federal and state resources for child health care services are limited. We know that many more children need services than are now receiving them. And, we know that services from a regularly available comprehensive care provider are most desirable. We, therefore, believe that the time has come when federally supported child health care efforts must be consolidated at all levels. The Child Health Assessment Program has the potential for being the lead child health care program in this country. Eligible children and providers of child health care services should be encouraged to view CHAP as the first dollar of support when personal resources are inadequate. The proposed legislation should mandate and provide for this coordination and consolidation of health care programs because of the need for increased efficiency, effectiveness, economy and quality of health care services.

Providers of EPSDT services are extremely variable in terms of their capabilities and the spectrum of services they have been providing. Some do screening; others do screening, diagnosis and treatment; still others do EPSDT plus episodic acute and chronic care. Unfortunately, large numbers of physicians who are capable of providing the full range of services are not willing to participate in the EPSDT program. The

proposed CHAP legislation requires the increasing use of providers who provide on-going comprehensive services.

There are two major problems associated with implementing this intent. First, where physicians in private practice are the source of CHAP services, it will not be possible to obtain their participation as providers unless full and competitive reimbursement is offered for services rendered. Secondly, in areas where there are inadequate numbers of practicing physicians, it will be important that providers who are not prepared to provide comprehensive care not be eliminated. In this regard it is important that the CHAP legislation provide incentives to health care institutions in underserved areas, which cannot provide comprehensive care independently, to enter into working relationships with other providers in order to qualify as providers of comprehensive pediatric care.

The proposed legislation should explicitly address these problems in conjunction with the intent of the legislation to utilize comprehensive care providers. We believe it would be inappropriate to pass this responsibility on to the program administrators for development and implementation. The legislation should clearly provide for the possibility that the elements of comprehensive care may be provided by a network of two or more agencies, if such an arrangement provides for more effective delivery of service.

Program management has been a major problem in the EPSDT program. Inadequate resources have been devoted to

program management on all levels.

On the federal level, program leadership has been slow to develop. On the state level, there has been inadequate management capability and relegation of the EPSDT program to a low level of authority and responsibility. In EPSDT, and we anticipate the same might easily be true for CHAP, adequate local administration within a framework of direction from state and federal levels has been missing. We are firmly convinced that this EPSDT deficiency must be corrected if CHAP is to be even partially successful.

If CHAP is to be successful, this program must be responsive to local administrative needs and constraints. At the state level, there must be a stable level of effort and program management which is capable of providing knowledgeable direction to the local programs. At the federal level there must be adequate advance planning and development before program implementation is undertaken at the state level. We strongly recommend that the proposed CHAP legislation take these administrative needs into account.

SUMMARY OF RECOMMENDATIONS

1. The current proposal should be revised to provide strong supports for coordination between CHAP and other child health programs.
2. The legislation should explicitly provide for strong enforcement of the requirement that the Medicaid dollar be the first dollar for reimbursement of federally financed health care.
3. The legislation should include a maintenance of effort clause.
4. The legislation should provide for reimbursement for diagnosis and management of developmental problems discovered during child health assessments.
5. The legislation should provide strong sanctions requiring that states provide transportation assistance to EPSDT clients.
6. The legislation should assure adequate resources are provided for program management.
7. Eligibility criteria should be broadened and standardized to maximize continuity of coverage.

In closing, Mr. Chairman, we support the intent of the proposed legislation and offer you these suggestions and recommendations for improving the Child Health Assessment Act of 1977.

Thank you.

RECOMMENDATIONS

1. Integration of Child Health Programs

Although the proposed legislation has the potential to substantially strengthen the EPSDT program, fundamental problems remain in the delivery of health services to children. In the long run, some of these problems will require broader legislative action than is within the scope of the current proposal.

There are 58 pieces of federal legislation covering 106 programs which are related to maternal and child health.* Ultimately, the goal of federal child health policy should be to develop a unified child health program funded by one appropriation and administered by a single agency. Until such a unified child health program is developed, new legislation should encourage the coordination of existing programs.

Existing programs should be mandated to develop:

1. Compatible child health standards including standards for frequency of visits and procedures to be administered.
2. Procedures for inter-agency exchange of information including appropriate safeguards for confidentiality.

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*Draft report, "A Proposal for New Federal Leadership in Child and Maternal Health Care in the United States," Office of Child Health Affairs, Office of the Assistant Secretary for Health, February 23, 1977.

3. Uniform reporting requirements.

4. Outcome-oriented reporting requirements which facilitate accountability and program management.

There is substantial duplication between the proposed CHAP program and the 105 other federal child health programs. Eligibility requirements and benefits overlap; and program requirements are broadly divergent. For example, one child might conceivably receive similar services through the Maternal and Child Health program, Head Start, Child Find, and CHAP. Yet the procedures required, the frequency of visits, the referral criteria, and the reporting requirements might differ for each program.

The proposed legislation calls for coordination between agencies participating in the CHAP program and community health centers funded under section 330 of the Public Health Service Act. However, no mandate is created for coordination with other child health programs such as Maternal and Child Health, Crippled Children's Services, Child Find, Head Start, etc.

Given the current proliferation of programs, structures for coordination should be required on all levels of program management: federal, state, county and municipal.

There should be a federal inter-agency group including representatives from the major programs providing health services to children. This group should be charged with developing federal regulations which facilitate and mandate coordination at the state and local levels.

The federal government should provide financial incentives

for the states to coordinate child health programs. Such incentives might include funding for staffing a state Office of Child Health which would be responsible for coordinating state child health programs. Coordination of existing programs might also be established as one of the criteria for good performance referred to in the amendment to section 1903.

The state Office of Child Health should be closely integrated with the state Health Planning and Development Agency and should provide leadership and staff for an Inter-Agency Council of State Child Health Programs. The Office of Child Health and the Inter-Agency Council should be responsible for assuring that the policies and procedures of the various state programs are compatible and facilitate coordination of the delivery of service at the local level.

2. Maintenance of Effort

We recommend that a maintenance of effort clause be added to the proposed legislation to discourage states from decreasing the absolute size of state funding in response to the increase in federal funding.

3. Developmental Screening

Given the lack of professional consensus on the appropriate role of developmental screening in national child health programs, we recommend that developmental screening not be required as a part of the CHAP program. However, the legislation should provide for reimbursement for the diagnosis and management of developmental problems identified during the

course of child health assessments.

4. Transportation

The current EPSDT regulations require that the state provide transportation assistance to EPSDT clients. However, some states have made no provision for transportation services to EPSDT clients in their state Medicaid plan.

We recommend that stronger sanctions be imposed in support of this requirement.

Mr. ROGERS. Can you give us any specifics to improve the management?

Dr. CAMPBELL. I certainly will.

[Testimony resumes on p. 218.]

[The following letter and attachment were received for the record:]

COMMUNITY HEALTH FOUNDATION
2650 Ridge Avenue Evanston, Illinois 60201 (312) 492-4661

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September 21, 1977

Congressman Paul G. Rogers
Chairman
Subcommittee on Health and
the Environment of the
Committee on Interstate
and Foreign Commerce
Room 2415
Rayburn House Office Bldg.
Washington, D.C. 20515

Dear Mr. Rogers:

Enclosed is an expanded version of the testimony related to the Child Health Assessment Act which we presented to your subcommittee on September 8, 1977. Please note that the recommendations on pp. 11-12 are relevant to the questions which you raised related to program management and eligibility criteria.

Also enclosed are our comments on the Child Health Assurance Act of 1977 introduced by Representative Andrew Maguire.

Thank you for the opportunity to present our concerns and recommendations. If we may be of further assistance, please feel free to contact us.

Sincerely,

Paul Allen

Paul Allen

PA:kd
cc: Karen Nelson
Dr. Walter D. Campbell
Representative Andrew Maguire
Jeff Sachs

Enc. (2)

TESTIMONY ON CHILD HEALTH ASSESSMENT ACT OF 1977

Presented by
Walter D. Campbell, M.D. and Paul Allen, M.P.H.
Community Health Foundation
Evanston, Illinois 60201

To the Interstate and Foreign Commerce Committee, Subcommittee on Health and the Environment

Honorable Paul G. Rogers, Chairman

September 8, 1977

Mr. Chairman, Distinguished Members of the Subcommittee:

I am Dr. Walter D. Campbell, a pediatrician, a faculty member at Northwestern University Medical School and Executive Vice President of Community Health Foundation. Appearing with me is Mr. Paul Allen, an experienced public health planner and manager. For the past 27 months, the Community Health Foundation, a non-profit organization dedicated to improving the delivery of child health services, has been working intensely on assisting twelve states with implementing their Title XIX Early and Periodic Screening, Diagnosis and Treatment programs. We wish to express our appreciation to the Subcommittee for this opportunity to present our concerns and recommendations related to the proposed Child Health Assessment Act of 1977.

We congratulate the authors of this proposed legislation and the Subcommittee for recognizing the need to improve and expand the Title XIX Early and Periodic Screening, Diagnosis and Treatment program. Much has been written and said about

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the rising cost of health services. We recognize the general need for assistance in financing the cost of such services, and we feel that the health needs of children demand special consideration.

Children have special health needs which, if overlooked, can result in lifetime handicaps and reduced productivity. Most children are born of young adults who, in many instances, may not have reached their full earning power and thus cannot always adequately provide for their families' needs. Unfortunately, many children of low income families do not now qualify for health care services under EPSDT and, as a result, the health needs of these children go largely unattended. Therefore, a critical need exists to broaden and standardize the eligibility criteria for Child Health Services under the proposed legislation so that additional children would be covered and their care would not be interrupted, regardless of changes in family composition and/or income. Mr. Chairman, the health of children is a valuable national resource in need of additional protection and improvement.

EPSDT has the distinction among federally supported child health care programs of having the largest target population and receiving the largest amount of dollar support. The scope of the proposed Child Health Assessment program is to be even greater in terms of the number of people served, volume of services rendered and amount of dollars spent. Yet, one of the greatest potential stimulants to the expansion and improvement of EPSDT has not been addressed in the proposed CHAP legislation.

This is the need for one Child Health Care program to take the lead in this area of service.

There are currently several Child Health Care programs which overlap with EPSDT and result in duplication of services and unnecessary administrative expense. We know that federal and state resources for child health care services are limited. We know that many more children need services than are now receiving them. And, we know that services from a regularly available comprehensive care provider are most desirable. We, therefore, believe that the time has come when federally supported child health care efforts must be consolidated at all levels.

The Child Health Assessment Program has the potential for being the lead child health care program in this country. Eligible children and providers of child health care services should be encouraged to view CHAP as the resource for the first dollar of support when personal resources are inadequate. The proposed legislation should mandate and provide for this coordination and consolidation of health care programs because of the need for increased efficiency, effectiveness, economy and quality of health care services.

Another problem associated with the EPSDT program involves the providers of EPSDT services who are extremely variable in terms of their capabilities and the spectrum of services which they have been providing. Some provide only screening; others provide screening, diagnosis and treatment; still others provide EPSDT plus acute and chronic episodic

care. Unfortunately, large numbers of physicians who are capable of providing the full range of services have not been willing to participate in the EPSDT program. The proposed CHAP legislation requires the increasing use of providers who provide on-going comprehensive services. There are two major problems associated with implementing this intent.

First, where physicians in private practice are to be the source of CHAP services, it will not be possible to obtain their participation as providers unless full and competitive reimbursement is offered for services rendered.

Second, in areas where there are inadequate numbers of practicing physicians, it will be important that providers who are not prepared to provide comprehensive care not be eliminated. In this regard it is important that the CHAP legislation provide incentives to health care institutions in underserved areas, which cannot provide comprehensive care independently, to enter into working relationships with other providers of selected services in order to qualify as providers of comprehensive pediatric care.

The proposed legislation should explicitly address these two provider problems in conjunction with the intent to increase utilization of comprehensive care providers. We believe it would be inappropriate to pass this responsibility on to the program administrators for development and implementation. The legislation should clearly provide for the possibility that the elements of comprehensive care may be provided by two or more sources who coordinate their activities if such an

arrangement provides for effective delivery of comprehensive service.

Program management has also been a major problem in the EPSDT program. Inadequate resources have been devoted to program management on all levels.

On the federal level, program leadership has been slow to develop. On the state level, there has been inadequate management capability and relegation of the EPSDT program to a low level of authority and responsibility. And, on the local level, adequate administration within a framework of direction from state and federal levels has been missing. We are firmly convinced that these EPSDT deficiencies must be corrected if CHAP is to be even partially successful.

CHAP must be responsive to local administrative needs and constraints. At the state level, there must be a stable level of effort and program management which is capable of providing knowledgeable direction to the local programs. At the federal level there must be adequate advance planning and development before program implementation is undertaken. We strongly recommend that the proposed CHAP legislation take these administrative needs into account.

RECOMMENDATIONS

These are our specific recommendations, based on our extensive experience working with EPSDT at the state and local levels.

1. The current legislative proposal should be revised to provide strong supports for coordination between CHAP and other child health programs.

   Although the proposed legislation has the potential to substantially strengthen the EPSDT program, fundamental problems remain in the delivery of health services to children. In the long run, some of these problems will require broader legislative action than is within the scope of the current proposal.

   There are 58 pieces of federal legislation covering 106 programs which are related to maternal and child health. Ultimately, the goal of federal child health policy should be to develop a unified child health program funded by one appropriation and administered by a single agency. Until such a unified child health program is developed, new legislation should encourage the coordination of existing programs.

   Existing programs should be mandated to develop:

   a. Compatible child health standards including standards for frequency of visits and procedures

to be administered.

b. Procedures for inter-agency exchange of information including appropriate safeguards for confidentiality.

c. Uniform reporting requirements.

d. Outcome-oriented reporting requirements which facilitate accountability and program management.

There is substantial duplication between the proposed CHAP program and the 105 other federal child health programs. Eligibility requirements and benefits overlap; and program requirements are broadly divergent. For example, one child might conceivably receive similar services through the Maternal and Child Health Program, Head Start, Child Find, and CHAP. Yet the procedures required, the frequency of visits, the referral criteria, and the reporting requirements might differ for each program.

The proposed legislation calls for coordination between agencies participating in the CHAP program and community health centers funded under section 330 of the Public Health Service Act. However, no mandate is created for coordination with other child health programs such as Maternal and Child Health, Crippled Children's Services, Child Find, Head Start, etc.

Given the current proliferation of programs, structures for coordination should be required on all levels of program management: federal, state,

county and municipal.

There should be a federal inter-agency group including representatives from the major programs providing health services to children. This group should be charged with developing federal regulations which facilitate and mandate coordination at the state and local levels.

The federal government should provide financial incentives for the states to coordinate child health programs. Such incentives might include funding for staffing a state Office of Child Health which would be responsible for coordinating state child health programs. Coordination of existing programs might also be established as one of the criteria for good performance referred to in the amendment to section 1903.

The state Office of Child Health should be closely integrated with the state Health Planning and Development Agency and should provide leadership and staff for an Inter-Agency Council of State Child Health Programs. The Office of Child Health and the Inter-Agency Council should be responsible for assuring that the policies and procedures of the various state programs are compatible and facilitate coordination of the delivery of service at the local level.

2. <u>The legislation should explicitly provide for strong enforcement of the requirement that the Medicaid</u>

dollar be the first dollar for reimbursement of federally financed health care.

Current regulations require that Medicaid funds be used first when clients are eligible for both Medicaid benefits and other federally funded health benefits. However, several states still will not provide Medicaid reimbursement for EPSDT services delivered by projects which are federally funded by other programs such as Title V. (The requirements for state matching funds are higher for Medicaid/EPSDT than for other federally funded child health programs. Consequently, an incentive exists for states to minimize the expenditure of Medicaid/EPSDT funds.)

A substantial portion (one third or more) of the children served by other federally funded programs are also eligible for Medicaid benefits. If Medicaid reimbursement is not provided for services delivered to children eligible for Medicaid, the amount of services available to other low-income children is reduced.

The revised legislation should require that states develop appropriate policies and regulations to assure that Medicaid benefits are exhausted before federal funds from other programs are used to provide child health services.

3. The legislation should include a maintenance of effort clause to discourage the withdrawal of state funds when additional federal funds become available.

4. The legislation should provide for reimbursement for diagnosis and management of developmental problems discovered during child health assessments.

Given the lack of professional consensus on the appropriate role of developmental screening in national child health programs, we recommend that developmental screening not be required as a part of the CHAP program. However, the legislation should provide for reimbursement for the diagnosis and management of developmental problems identified during the course of child health assessments.

5. The legislation should provide strong sanctions requiring that states provide transportation assistance to CHAP clients.

The current EPSDT regulations require that the state provide transportation assistance to EPSDT clients. However, some states have made no provision for transportation services to EPSDT clients in their state Medicaid plan.

We recommend that the CHAP legislation require states to include in the state Medicaid plan provisions for the transportation of clients in relationship to CHAP services. The state Medicaid plan should be required to provide for the reimbursement of non-profit community-based groups for transportation services provided to CHAP clients. States should also be required to make transportation services readily

available to clients by:

a. Notifying all clients eligible for CHAP services of the availability of transportation.

b. Making convenient administrative arrangements for clients to request and receive transportation services.

These requirements should be supported by strong sanctions for non-compliance.

6. The legislation should assure that adequate resources are provided for program management.

On the federal level, expertise should be available in each of the major functional program components:

Identification and notification of eligibles.

Outreach

Child health assessment and supervision.

Case management.

Program management.

Data systems.

Program evaluation and planning.

Resource development and interagency coordination.

On the state level, there should be a minimum of one full-time person in each state responsible only for the administration of CHAP. Incentives for increased support for program management might be created by providing for 90 to 100 percent federal match for state administrative personnel.

The state should be required to develop a plan

specifying criteria for the geographic allocation of resources within the state. Possible dimensions for the development of criteria might include number of eligibles, geographic dispersion, penetration rates, service backlogs, etc. The plan should also specify indices for evaluation of program performance at both the state and local levels.

7. Eligibility criteria should be broadened and simplified to maximize continuity of coverage.

As a minimum approach to broadening and simplifying eligibility criteria, all children enrolled in programs designed specifically to serve low-income children (e.g., Head Start, Community Coordinated Child Care) should be defined as eligible for CHAP services. Evidence of enrollment in such a program should be considered evidence of eligibility without further eligibility determination.

Alternative approaches which would even further minimize loss of coverage due to eligibility turnover are:

a. Provide CHAP eligibility to all children who meet the income and resource requirements for the current federal medically needy category.
b. Provide CHAP eligibility to all children who meet the current Community Services Administration poverty guidelines.

SUMMARY OF RECOMMENDATIONS

1. The current legislative proposal should be revised to provide strong supports for coordination between CHAP and other child health programs.

2. The legislation should explicitly provide for strong enforcement of the requirement that the Medicaid dollar be the first dollar for reimbursement of federally financed health care.

3. The legislation should include a maintenance of effort clause to discourage the withdrawal of state funds when additional federal funds become available.

4. The legislation should provide for reimbursement for diagnosis and management of developmental problems discovered during child health assessments.

5. The legislation should provide strong sanctions requiring that states provide transportation assistance to CHAP clients.

6. The legislation should assure that adequate resources are provided for program management.

7. Eligibility criteria should be broadened and simplified to maximize continuity of coverage.

COMMENTS ON THE CHILD HEALTH
ASSURANCE ACT OF 1977

Introduced by
Hon. Andrew Maguire
in the
House of Representatives
September 7, 1977

Comments Prepared by
Community Health Foundation
2650 Ridge Avenue
Evanston, Illinois 60601

The Child Health Assurance Act of 1977 includes several excellent provisions which are not present in the Child Health Assessment Act of 1977. We feel the provisions listed below should be included in the final form of the legislation.

1. Ninety percent federal reimbursement for outreach and follow-up services delivered by non-profit community-based organizations is included as an incentive to increase the utilization of community-based resources. (Community-based organizations are frequently the most effective providers for outreach and support services. However, most states have made little use of these resources in their EPSDT programs.)

2. The bill encourages private providers to provide follow-up services by establishing a 90 percent federal reimbursement rate for such services.

3. Diagnosis and treatment is provided for all conditions discovered during assessment with 90 percent federal reimbursement.

4. States are required to coordinate services with other federally funded child health programs.

5. States are required to identify all qualified health care providers and to offer contracts on terms which can reasonbly be expected to elicit provider participation.

6. The Secretary is required to provide an annual report on the administration of the program.

7. An annual evaluation of the program by independent experts who represent the interests of recipients is required.

8. The bill requires states to develop a state plan based on substantial public input which demonstrates how program requirements will be met.

9. The bill specifies a schedule for development of final regulations.

10. The Secretary is given authority to bring court action to require states to correct any failure to comply with regulations which the Secretary has identified.

The following points require clarification, elaboration or change prior to inclusion in the final form of the legislation.

1. Dental Screening. The Child Health Assurance Act refers to dental screening (Page 5, Section 1912(a) 2). Screening is usually viewed as a procedure which precedes diagnostic tests and procedures. Screening is a low cost method of separating apparently healthy individuals from individuals who require more expensive diagnostic procedures. Screening is a useful procedure only if a substantial portion of the population

does not require diagnostic examinations.

Since approximately 90 percent of the EPSDT population are found to require some dental treatment, dental screening is not a cost-effective approach, unless the benefit coverage for dental treatment is severely restricted (e.g., restricted to treatment of infections and conditions causing pain).

Unless benefit coverage for dental treatment is severely restricted, children should be referred directly for routine dental examination and care. The legislation should guard against the possibility that dental providers may bill for both dental screening and routine dental examination for the same visit.

2. Definition of health care providers (Section 1912(b). Perhaps school health programs should be mentioned as possible providers. It should be clear that child health assessment may be provided in the school, even though on-going care is provided in another setting. This approach can substantially decrease outreach costs per child assessed.

In general, the language used in definition might be revised to "includes but is not limited to."

3. Date of implementation. It may be desirable to postpone implementation at the state level until the final federal regulations are published. This would provide the opportunity for the states to plan for program implementation with full knowledge of the program requirements and constraints.

4. Comprehensive care requirements. The provisions of Section 1912(b) (2) (A, B, C) are in conflict with the provisions of Section 1912(b) (1) and the remainder of Section 1912 (b) (2). Clauses A, B, and C of Section 1912 (B) (2) should be eliminated.

STATEMENT OF NANCY S. SPEARS

Ms. SPEARS. Mr. Chairman, I am Nancy Spears and I am going to make this very short and to the point due to the essence of time.

You will find in my written testimony that I strongy support the previous panel.

As the head start director for the past 12 years, I wish to direct at least three comments. Those are provider participation, outreach, and follow-up. However, before I address these matters directly, I should review three key factors about head start.

First, head start is a comprehensive child development program that provides high quality health, nutrition, education, and social services to children and families in their own community.

Second, the majority of children served by head start are eligible for EPSDT.

Third, head start, a program with strong parent participation in all activities, is absolutely essential.

Through our involvement with parents, we became aware of a burden on poor families. They had to bring their head start child to us for medical screening and services, and take their other children elsewhere for the same service. Consequently it became obvious that head start should become an EPSDT provider offering coordinated services for all the children in each family.

Our experience as a provider has told us that provider participation on all private, nonprofit, community-based health centers is essential for quality medical care. Therefore, I urge to you to see that CHAP insures that States identify all qualified providers, that CHAP builds an incentive for nonprofit providers, and that CHAP requires States to solicit their participation.

Nonprofit providers are particularly effective because they understand the necessity of community outreach and because their strong community ties enables them to perform outreach work. We know the people. They respond to them and get the job done.

Therefore, I urge you to see that CHAP provides Federal reimbursement to States for outreach work performed by the nonprofit organizations. This reimbursement should cover outreach, expenditures for both initial and for follow-up.

Let me just say with that, and eligibility, I think we could serve the poor children of this country.

[Ms. Spear's prepared statement follows:]

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TESTIMONY
OF
NANCY S. SPEARS
DIRECTOR OF LEE COUNTY HEAD START
&
ASSOCIATE DIRECTOR
OF THE
ALABAMA COUNCIL ON HUMAN RELATIONS
BEFORE THE
SUBCOMMITTEE ON HEALTH AND ENVIRONMENT
OF THE HOUSE COMMITTEE
ON INTERSTATE AND FOREIGN COMMERCE

SEPTEMBER 8, 1977

Chairman Rogers and members of the Subcommittee, I am Nancy S. Spears, Director of Lee County Head Start in Auburn, Alabama, and Associate Director of the Alabama Council on Human Relations. On behalf of Head Start and the Alabama Council, which serve as non-profit providers of Early Periodic Screening, Diagnosic and Treatment, I appreciate the privilege of testifying here on the administration - proposed Child Health Assessment Act of 1977 (H.R. 6706 & S. 1392).

First, I wish to commend the administration on its effort to improve health care services for needy children and to commend this committee for its serious attention to legislation to that end. Administrative recommendations before you make important modifications of the present EPSDT program, but you can address additional important problems and thereby make the program more effective in meeting the needs of children who live in families too poor to pay for preventive, much less corrective, health care. To speak to the point on these problems, I will divide the remainder of my remarks into five subsections in the following order:

(1) eligibility, (2) health benefits, (3) federal standards and enforcement, (4) state standards and responsibilities, and (5) matters for special emphasis.

1. ELIGIBILITY -- The bill should expand eligibility to cover all individuals under age twenty-one who meet states' financial criteria for welfare but not other welfare requirements. These children, adolescents, and very young adults should remain eligible for at least one year following a health assessment -- regardless of changes in family status or income. A shorter period of eligibility risks the health of our young people and invites administrative log jams and inefficient operation.

2. HEALTH BENEFITS -- The bill should provide not only for regular health assessment but also for total health care following that assessment. Total health care includes dental needs and treatment of such developmental disorders as mental illness, mental retardation and learning disabilities. CHAP should require provision of all medical care indicated by assessment directly through the program or by arrangement with other community services at no cost to the families involved.

3. FEDERAL STANDARDS AND ENFORCEMENT -- The bill should establish one clear set of minimum federal program performance standrads for EPSDT with enforcement power residing with the Secretary of Health, Education, and Welfare. The bill should establish these standards on the basis of the percentage of eligible children assessed and treated fully and adequately within any given state. It should provide the Secretary of HEW not only with the power to impose financial penalties against states failing to attain minimum standards but also with the authority to direct a state to attain minimum standards through whatever remedial measures are necessary. HEW should monitor state programs on an annual basis.

4. STATE STANDARDS AND RESPONSIBILITIES -- The bill should require states to develop state plans demonstrating their ability to carry out an effective program of assessment and follow-up care. Provisions for public input into the formulation of state plans is essential. States should be required to maintain their current level of financial commitment to allow the increased federal share to expand and improve the quality of services.

5. MATTERS FOR SPECIAL EMPHASIS -- As a Head Start program director for the past twelve years, I wish to direct my concluding remarks to three matters of special interest and concern. These three are (a) provider participation, (b) outreach and (c) follow-up. However, before I address these matters directly, I should review three key facts about Head Start: First, Head Start is a comprehensive child development program that provides high quality health, nutrition, education, and social services to children and families in their community. Second, the majority of children served by Head Start are eligible for EPSDT. Third, Head Start is a program in which strong parent participation in all activities is essential. Through our involvement with parents, we became aware of a burden on poor families: They had to bring their Head Start children to us for medical screening and services and to take their other children elsewhere for the same services.

   Consequently, it became obvious that Head Start should become an EPSDT provider offering coordinated services for all children in each family. Our experience as a provider has taught us that provider participation by all private non-profit community-based health centers is essential for quality medical care to needy children. Therefore, I urge you to see that CHAP insures that states identify all qualified providers, that CHAP builds in incentives for non-profit provider participation, and that CHAP requires states to solicit contracts with non-profit providers.

Non-profit providers are particularly effective because they understand the necessity of community outreach and because their strong community ties enable them to perform outstanding outreach work: Staff members from such groups enter the homes not as strangers but as old friends and thus operate efficiently the most proven outreach technique -- person to person contact. Therefore, I urge you to see that CHAP provides federal reimbursement to states for outreach work performed by non-profit organizations. This reimbursement should cover outreach expenditures for both initial screening and for follow-up health care services. At this point, I should note that

the Congressional Budget office has reported that last year's cost of follow-up referral was only $10.40 per child.

Chairman Rogers and members of the Subcommittee, I cannot over-emphesize the importance of provider participation, of outreach, and of follow-up. With these ingredients and with adequately expanded eligibility standards, CHAT can notably improve the health of our children and enable them to become more productive, more effective, and happier citizens of our country. In other words, investment in a comprehensive CHAT is a humane investment in sound democracy for the future. Once again, I appreciate the opportunity of testifying before you and will be happy to entertain any questions you may ask. Thank you.

Mr. ROGERS. Thank you so much for a very concise and helpful statement.

STATEMENT OF RUBY DUNCAN

Ms. DUNCAN. Mr. Chairman, my name is Ruby Duncan and I am from Las Vegas, Nevada and I appreciate having a chance to come to talk with you today.

I must say that I am not a doctor. I am not a nurse. I am not a health professional, and I am not a welfare bureaucrat or a health department employee. I am Ruby Duncan, and I am the mother of seven children and the chairwoman of Clark County Economic and Welfare Rights Organization in Las Vegas, Nevada.

My message is simple in that the administration, mostly the health profession, has overlooked it. The message is "Don't make another program for us without us." With us, with poor women, with welfare mothers actively involved in operating the child health assessment program, you will have a success. Without us, you fail, but unfortunately the only ones that would lose would be our children.

I furthermore want to say that we have heard that 13 million children were eligible in this country for early periodic screening. Only 1 million have been screened. They said many screens were incomplete or poorly done. They also said many children who were screened and found to have medical problems were never treated. But instead of working on ways to improve the program, they spend most of their time trying to blame some others.

It became clear to me and the women in Welfare Rights that our children would never be screened if it was left up to those people. We, of course, did not have the college training or all the others. We

didn't have medical degrees and God knows we didn't have any money. But we did have some things, common sense, love for our children and a desire to see this program work. We said our children would not be shortchanged, so we learned about the program. We talked with others about it, how to make it work.

Basically we saw that to have a successful program, you need four things. Those are:

Every eligible child participating; quality screening; diagnosis and treatment; and follow-up.

Now each of you on the committee must understand that welfare departments don't have a good reputation in our community. Welfare recipients have had too many bad experiences with welfare workers. Therefore it had to be identified as our program—a community-based welfare rights program. Once people want to participate, you have to provide them the support to participate. This means transportation, babysitting, and whatever help the family needs, to be able to participate. This led us to the conclusion that we, welfare mothers, had to see that screening was done in the community, a friendly environment. We had to do the outreach. We had to provide transportation, and we had to provide babysitting and other support.

Then we had to deal with quality screening. We met with doctors, dentists, nurses, and other health workers. We explained EPSDT and the desperate health needs of our children. Most of these people, after hearing of the problem, were eager to help. The health people offered and did train welfare mothers to perform much of the screening. We now had built-in quality and sensitivity control.

Diagnosis and treatment was the next issue. No doctors practiced in our community and many Las Vegas doctors did not treat welfare recipients. We went out and talked to physicians, dentists, eye doctors, and clinics. We didn't yell, scream or call names. We just talked about the great health care needs of our children. Most all of the health professionals agreed to take referrals from us. They said our request was more human than the welfare division.

We then developed a record keeping system to insure follow-up for treatment and rescreening.

What I have just described in 5 minutes took 9 months to put together. It wasn't easy. The Nevada State Welfare Division offered resistance instead of assistance. What we did was in spite of, and not because of, the State Welfare Division. Money for outreach was denied. The State was content to do a mailing once or twice a year.

I guess what I am saying is that the State would only mail out little cards twice a year, and if they call that outreach, I think it is ridiculous.

They created red tape to effectively deny transportation and babysitting support. They refused to provide technical assistance to our staff.

We operated in spite of this. Programs were coordinated.

We got volunteers in, CETA workers, Vista workers. We provided transportation in making sure that babysitting was affordable. We made doctor and dental appointments. We reminded people of their appointments and gave them transportation to get there. Whenever necessary, we changed the program to meet people's needs rather than trying to change people to meet the program's needs.

Did it work? Were we able to do it? Within 18 months we screened 80 percent of the eligible children in our community. Nationwide less than 4 percent were being screened. Eighty percent of the children screened resulted in dental referrals. For over 50 percent this was the first time they had ever seen a dentist. Detection of visual problems was very high. Almost none of the children screened had ever had eye care. Hundreds of other very serious health problems were detected and treated. We think we made the program work.

I guess we have to say we do support the previous panels on children's health. We know it is very important.

I want to suggest a few things to you.

Encourage community-based programs. We hope that Congress does this.

Require the States to contract with community organizations to do screening.

Provide adequate money for community groups to do outreach and provide transportation, babysitting, and support services.

Provide developmental assistance so we can continually improve our program.

I would like to say to you that government has to work on. The ball is now in your lap. You have to give the directions. When I started out I said that we, the poor, can't do it alone. I also said you can't do it alone. Most importantly, I said that together we cannot fail. We will do our part. The question is: Will you do yours?

[Mrs. Duncan's prepared statement follows:]

TESTIMONY OF RUBY DUNCAN

CHAIRPERSON

CLARK COUNTY ECONOMIC AND WELFARE RIGHTS ORGANIZATION

MR. CHAIRMAN. HONORABLE MEMBERS OF THE COMMITTEE.

I APPRECIATE HAVING THIS OPPORTUNITY TO TALK WITH YOU ABOUT A CRITICAL ISSUE -- THE HEALTH OF POOR CHILDREN. I AM NOT A DOCTOR, A NURSE, A HEALTH PROFESSIONAL, A WELFARE BUREAUCRAT OR A HEALTH DEPARTMENT EMPLOYEE. I AM RUBY DUNCAN, THE MOTHER OF SEVEN CHILDREN AND CHAIRPERSON OF THE CLARK COUNTY Economic and WELFARE RIGHTS ORGANIZATION IN LAS VEGAS, NEVADA.

MY MESSAGE IS VERY SIMPLE, SO SIMPLE IN FACT THAT WELFARE DEPARTMENTS, H.E.W., THE ADMINISTRATION AND MOST HEALTH PROFESSIONALS HAVE OVERLOOKED IT. THE MESSAGE IS THIS: DON'T MAKE ANOTHER PROGRAM FOR US <u>WITHOUT</u> US. WITH US, WITH POOR WOMEN, WITH WELFARE MOTHERS ACTIVELY INVOLVED IN OPERATING THE CHILD HEALTH ASSESSMENT PROGRAM, YOU WILL HAVE A SUCCESS. WITHOUT US, <u>YOU</u> FAIL, BUT UNFORTUNATELY YOU ONLY LOSE INDIRECTLY WHILE OUR BABIES AND CHILDREN LOSE DIRECTLY. THAT IS WHY I AM HERE TODAY, BECAUSE THOSE CHILDREN ARE TOO PRECIOUS TO ME TO LOSE TO DISEASE. I BELIEVE THEY ARE ALSO THAT PRECIOUS TO YOU. THE POOR CANNOT DO IT ALONE; NO ONE CAN DO IT ALONE, BUT <u>TOGETHER</u> WE CAN DO IT.

MY EXPERIENCE WITH EPSDT GOES BACK SIX YEARS. I HAVE BEEN TO LEGAL SERVICES SEMINARS, H.E.W. CONFERENCES, WELFARE

DEPARTMENT MEETINGS, AND HEALTH DEPARTMENT SESSIONS--ALL ON EPSDT. THE MEETINGS ARE SO DEPRESSING. I HEARD THAT THIRTEEN MILLION CHILDREN WERE ELIGIBLE BUT ONLY A LITTLE OVER ONE MILLION WERE SCREENED. THEY SAID MANY SCREENINGS WERE INCOMPLETE OR POORLY DONE. THEY ALSO SAID MANY CHILDREN WHO WERE SCREENED AND FOUND TO HAVE MEDICAL PROBLEMS WERE NEVER TREATED. THE SAD PART OF ALL THIS WAS LISTENING TO ALL THOSE SMART PEOPLE SOUND SO HELPLESS. THEY ALL AGREED THE PROGRAM WAS FAILING. BUT INSTEAD OF WORKING ON WAYS TO IMPROVE THE PROGRAM, THEY SPENT MOST OF THEIR TIME TRYING TO BLAME SOMEONE. AT ONE MEETING IT WOULD BE H.E.W. THAT WAS TO BLAME, OR THE WELFARE DEPARTMENTS OR THE HEALTH DEPARTMENT; SOME WOULD SAY IT WAS THE DOCTORS AND OTHERS WOULD POINT TO THE LEGISLATION. EVERYONE WAS VERY DEFENSIVE. ALL OF THEM SEEMED TO BE TRYING TO PROTECT THEIR OWN LITTLE JOB OR AGENCY OR PROFESSION.

IT BECAME CLEAR TO ME, AND THE WOMEN AT WELFARE RIGHTS, THAT OUR CHILDREN WOULD NEVER BE SCREENED IF IT WAS LEFT UP TO THOSE PEOPLE. WE OF COURSE DID NOT HAVE THE COLLEGE TRAINING OF ALL THE OTHERS. WE DIDN'T HAVE MEDICAL DEGREES AND GOD KNOWS WE DIDN'T HAVE ANY MONEY. BUT WE DID HAVE SOME THINGS: COMMON SENSE; LOVE FOR OUR CHILDREN; AND A DESIRE TO SEE THIS PROGRAM WORK.

WE SAID "OUR CHILDREN WILL NOT BE SHORTCHANGED." SO WE LEARNED ABOUT THE PROGRAM AND TALKED WITH ONE ANOTHER ABOUT HOW TO MAKE IT WORK. BASICALLY WE SAW THAT TO HAVE A SUCCESSFUL PROGRAM, YOU NEED FOUR THINGS. THEY ARE:

(1) EVERY ELIGIBLE CHILD PARTICIPATING

(2) QUALITY SCREENING

(3) DIAGNOSIS AND TREATMENT, AND

(4) FOLLOW-UP

WE THEN SET OUT TO MAKE THOSE FOUR THINGS WORK. FIRST, WE KNEW THAT CHILDREN WOULD NOT PARTICIPATE UNLESS THEIR PARENTS REALIZED THE PROGRAM WAS A GOOD PROGRAM. NOW EACH OF YOU ON THIS COMMITTEE MUST UNDERSTAND THAT WELFARE DEPARTMENTS DON'T HAVE A GOOD REPUTATION IN OUR COMMUNITY. WELFARE RECIPIENTS HAVE HAD TOO MANY BAD EXPERIENCES WITH WELFARE WORKERS. THEREFORE, IT HAD TO BE IDENTIFIED AS OUR PROGRAM--A COMMUNITY-BASED WELFARE RIGHTS PROGRAM. ONCE PEOPLE WANT TO PARTICIPATE, YOU HAVE TO PROVIDE THEM THE SUPPORT TO PARTICIPATE. THIS MEANS TRANSPORTATION, BABYSITTING AND WHATEVER HELP THE FAMILY NEEDS TO BE ABLE TO PARTICIPATE. THIS LED US TO THE CONCLUSION THAT WE--WELFARE MOTHERS--HAD TO SEE THAT SCREENING WAS DONE IN THE COMMUNITY (A FRIENDLY ENVIRONMENT); WE HAD TO DO THE OUTREACH: WE HAD TO PROVIDE TRANSPORTATION AND WE HAD TO PROVIDE BABYSITTING AND OTHER SUPPORT.

THEN WE HAD TO DEAL WITH QUALITY SCREENING. WE MET WITH DOCTORS, DENTISTS, NURSES AND OTHER HEALTH WORKERS. WE EXPLAINED EPSDT AND THE DESPERATE HEALTH NEEDS OF OUR CHILDREN. MOST OF THESE PEOPLE, AFTER HEARING OF THE PROBLEM, WERE EAGER TO HELP. TOGETHER WE DEVELOPED A QUALITY SCREENING PACKAGE. AS IMPORTANTLY, THE HEALTH PEOPLE OFFERED AND DID

TRAIN WELFARE MOTHERS TO PERFORM MUCH OF THE SCREENING. WE NOW HAD BUILT-IN QUALITY AND SENSITIVITY CONTROL.

DIAGNOSIS AND TREATMENT WAS THE NEXT ISSUE. NO DOCTORS PRACTICED IN OUR COMMUNITY AND MANY Las Vegas Doctors DID NOT TREAT WELFARE RECIPIENTS. WE WENT OUT AND TALKED TO PHYSICIANS, DENTISTS, EYE DOCTORS, AND CLINICS. WE DIDN'T YELL, SCREAM OR CALL NAMES. WE JUST TALKED ABOUT THE GREAT HEALTH CARE NEEDS OF OUR CHILDREN. MOST ALL OF THE HEALTH PROFESSIONALS AGREED TO TAKE REFERRALS FROM US. THEY SAID OUR REQUEST WAS MORE HUMAN THAN THE WELFARE DIVISION.

WE THEN DEVELOPED A RECORD-KEEPING SYSTEM TO ENSURE FOLLOW-UP FOR TREATMENT AND RESCREENING.

WHAT I HAVE JUST DESCRIBED IN FIVE MINUTES TOOK NINE MONTHS TO PUT TOGETHER. IT WASN'T EASY. THE NEVADA STATE WELFARE DIVISION OFFERED RESISTANCE INSTEAD OF ASSISTANCE. WHAT WE DID WAS IN SPITE OF, AND NOT BECAUSE OF, THE WELFARE DIVISION. MONEY FOR OUTREACH WAS DENIED. THE STATE WAS CONTENT TO DO A MAILING ONCE OR TWICE A YEAR. TO THEM, THAT WAS OUTREACH. THEY CREATED RED TAPE TO EFFECTIVELY DENY TRANSPORTATION AND BABYSITTING SUPPORT. THEY REFUSED TO PROVIDE TECHNICAL ASSISTANCE TO OUR STAFF.

WE OPERATED IN SPITE OF THIS. PROGRAMS WERE COORDINATED. CETA SLOTS AND VISTA POSITIONS WERE CREATED. WE TRAINED WELFARE MOTHERS AS OUTREACH WORKERS. WE PROVIDED TRANSPORTATION AND BABYSITTING. WE RECRUITED HEALTH PROFESSIONALS, ~~THEY~~ who TRAINED WELFARE MOTHERS TO WORK WITH THEM IN THE SCREENING

CENTER. WE MADE DOCTOR AND DENTAL APPOINTMENTS. WE REMINDED PEOPLE OF THEIR APPOINTMENTS AND GAVE THEM TRANSPORTATION TO GET THERE. WHENEVER NECESSARY WE CHANGED THE PROGRAM TO MEET PEOPLE'S NEEDS RATHER THAN TRYING TO CHANGE PEOPLE TO MEET THE PROGRAM'S NEEDS.

DID IT WORK? WERE WE ABLE TO DO IT? WITHIN 18 MONTHS WE SCREENED 80% OF THE ELIGIBLE CHILDREN IN OUR COMMUNITY. NATIONWIDE LESS THAN 4% WERE BEING SCREENED. EIGHTY PERCENT OF THE CHILDREN SCREENED RESULTED IN DENTAL REFERRALS. FOR OVER 50% THIS WAS THE FIRST TIME THEY HAD EVER SEEN A DENTIST. DETECTION OF VISUAL PROBLEMS WAS VERY HIGH. ALMOST NONE OF THE CHILDREN SCREENED HAD EVER HAD EYE CARE. HUNDREDS OF ~~THESE~~ OTHER VERY SERIOUS HEALTH PROBLEMS WERE DETECTED AND TREATED. WE THINK WE MADE THE PROGRAM WORK.

A 1975 H.E.W. REPORT SHOWED THAT NEVADA LED THE NATION IN SCREENING. NEVADA SAID OUR CENTER ACCOUNTED FOR 80% OF THE SCREENING IN THE STATE. THE POINT IS THAT WITH US CHAP CAN BE A SUCCESS. BUT DON'T LET US STRUGGLE ALONE. WHILE WE WORKED TO MAKE THE PROGRAM GO, THE WELFARE DIVISION DID EVERYTHING IN THEIR POWER TO PREVENT IT FROM WORKING. IN 1976 THE NEVADA STATE WELFARE DIVISION TOLD H.E.W. THEY WERE GOING TO TERMINATE NEVADA'S PARTICIPATION IN EPSDT. I WILL NOT GO INTO THE DETAILS OF THEIR EFFORTS TO KILL THIS PROGRAM, BUT I POINT IT OUT TO SHOW YOU THE HOSTILE SETTING WE OPERATED IN. CAN YOU IMAGINE THE SUCCESS WE WOULD HAVE HAD WITH SUPPORT?

MEMBERS OF THIS COMMITTEE SHOULD SUPPORT CHAP. BUT IT NEEDS SOME CHANGES. THE BILL IN ITS PRESENT FORM DOES NOTHING TO STRENGTHEN OUTREACH AND COMMUNITY-BASED INVOLVEMENT. IT IS ANOTHER ATTEMPT TO DO SOMETHING FOR US WITHOUT US. I SUGGEST THAT THE BILL SHOULD:

(1) ENCOURAGE COMMUNITY-BASED PROGRAMS

(2) REQUIRE THE STATES TO CONTRACT WITH COMMUNITY ORGANIZATIONS TO DO SCREENING

(3) PROVIDE ADEQUATE MONEY FOR COMMUNITY GROUPS TO DO OUTREACH AND PROVIDE TRANSPORTATION, BABYSITTING AND SUPPORT SERVICES, and

(4) PROVIDE DEVELOPMENTAL ASSISTANCE SO WE CAN CONTINUALLY IMPROVE OUR PROGRAM.

WE CAN PULL OURSELVES UP BY OUR OWN BOOTSTRAPS, BUT WE NEED THE BOOTS!

IT WOULD BE A CRIME FOR CONGRESS TO ALLOW THIS PROGRAM TO FAIL. YOU MUST DEMAND INNOVATION FROM H.E.W. DON'T GO ALONG WITH A PROVEN FAILURE. REQUIRE A PLAN FOR SUCCESS WHICH MUST INCLUDE US.

THE BENEFITS ARE GREAT. GOOD HEALTH FOR LITTLE CHILDREN IS THE PRIMARY BENEFIT. BUT WE HAVE SEEN OTHER BENEFITS. TRAINED COMMUNITY RESIDENTS WORKING AT THE SCREENING CENTER PROVIDE NEW ROLE MODELS FOR CHILDREN. CHILDREN HAVE NEW DREAMS OF WHAT THEY WANT TO BE. THE WORKERS THEMSELVES DEVELOP NEW SKILLS AND A POSITIVE SELF-IMAGE. FOR MANY COMMUNITIES SUCH AS OURS IT IS THE FIRST TIME THAT ANY

HEALTH CARE HAS EVER COME TO THE COMMUNITY. IT IS EXCITING--
PEOPLE REALIZING THEIR OWN POTENTIAL AND ABILITY TO TURN OUR
COMMUNITIES AROUND. IT IS NOT ONLY THE HEALTH OF CHILDREN
BUT THE HEALTH OF A COMMUNITY.

THAT IS WHAT GOVERNMENT HAS TO WORK ON. THE BALL IS
NOW IN YOUR LAP. YOU HAVE TO GIVE THE DIRECTIONS. WHEN I
STARTED OUT I SAID THAT WE, THE POOR, CAN'T DO IT ALONE. I
ALSO SAID YOU CAN'T DO IT ALONE. MOST IMPORTANTLY, I SAID
THAT TOGETHER WE CANNOT FAIL. WE WILL DO OUR PART. THE
QUESTION IS: WILL YOU DO YOURS?

THANK YOU.

Mr. ROGERS. Thank you so much, Mrs. Duncan, for a very helpful statement. I think it is important for everyone to cooperate. I think your point is well made.

Mr. Maguire.

Mr. MAGUIRE. Thank you, Mr. Chairman.

I just wanted to say to Mrs. Duncan that I am very glad I was here to hear her statement.

Ms. DUNCAN. Thank you.

Mr. MAGUIRE. I would commend your attention to the legislation which I have introduced which does assist community-based organizations to participate in the program, and increases the level of reimbursement. These are proposals that I hope we can work into a final bill before this committee.

I think it is inspiring what you have managed to do in your community, and it just demonstrates the truth, that people who have a stake in the results are the ones who, if given the proper opportunity, should be able to put the program together. Without that kind of inspiration, I am afraid we are going to be shuffling papers and bureaucracies.

I appreciated your statement very much.

Thank you, Mr. Chairman.

Mr. ROGERS. Thank you so much.

If there is any additional information we need to get, we will be glad to receive it.

Thank you for your presence here today.

Tomorrow we will move to a different room 2167, and the hearings will begin at 9 o'clock with Secretary Califano as the first witness.

The committee stands adjourned until 9 o'clock tomorrow morning.

[Whereupon, at 6:10 p.m., the subcommittee was adjourned, to reconvene at 9 a.m., Friday, September 9, 1977.]

CHILD HEALTH ASSESSMENT ACT

FRIDAY, SEPTEMBER 9, 1977

HOUSE OF REPRESENTATIVES,
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT,
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 9 a.m., in Room 2167, Rayburn House Office Building, Hon. Paul G. Rogers (chairman of the subcommittee) presiding.

Mr. ROGERS. The subcommittee will come to order, please.

We are continuing hearings on the administration's proposal for a child health assessment program, and I am pleased that the administration has brought forth a proposal to give attention to the problem of health among youth and infants. Mr. Secretary, I commend you for your leadership and efforts. Too many young people do not receive public health care and still others receive no care at all. I think we are all very much concerned about this, and I question whether we really have a sufficient national goal in this area, and I do think we need a realistic one.

I am also concerned that one of the main problems has been, I think, the lack of centralization of leadership and responsibility. I am not sure that this is really recommended in the legislation. It is my understanding that there are some 56 programs in 5 departments, 15 agencies and 45 bureaus dealing with children. Of course, not all of these deal solely with health, but all touch on health in some degree.

There is a question, I presume, whether there should be a single office for mothers and children just below the secretarial level. Most countries, I understand, have such a priority on maternal and child care. I believe the Office of Maternal and Child Health is about four layers removed from the Secretary. On the welfare side, the Children's Bureau is about three layers from the top In the CHAP proposal I am not sure we are adequately dealing with the problems of first-time mothers; we need prenatal care. So I hope that we can look at this and make sure that as we design a program we include proper prenatal care too.

We are anxious to hear from you, Mr. Secretary, to have your testimony and your thinking, and we are very anxious to try to be cooperative and helpful in this area.

Dr. Carter.

Mr. CARTER. Thank you, Mr. Chairman. It has often been said that the children of our Nation are its greatest potential resources, and I strongly concur with this statement.

However, I regret that the performance of our health programs for children has not adequately reflected that conviction. Even though we enacted a program specifically designed to be a preventive effort for children's health—the EPSDT program—we find its record to be very disappointing. Of the 13 million children eligible for EPSDT, only about one-quarter actually received screening services, and only about 60 percent of those identified as needing treatment actually received any. Thus about half a million conditions went untreated.

Mr. Chairman, I share your commitment and that of the administration to improving the health of our Nation's children, and I strongly support the goals of the CHAP legislation. I have long advocated the importance of the preventive approach to medicine, and have introduced a preventive health services package as part of a comprehensive national health insurance program. I am looking forward to hearing our witnesses this morning and I especially would like to welcome Secretary Califano.

Mr. ROGERS. Mr. Secretary, we are honored to have you.

STATEMENT OF HON. JOSEPH A. CALIFANO, JR., SECRETARY, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY KAREN DAVIS, PH.D., DEPUTY ASSISTANT SECRETARY FOR HEALTH PLANNING AND EVALUATION

Secretary CALIFANO. Thank you very much. Dr. Carter, thank you. I realize that you and this subcommittee have for years been leaders in the child health area and in protecting America's children, and I believe that the program the administration has recommended will take some additional steps in that direction.

I appreciate the opportunity to testify before you today on H.R. 6706, the administration's proposed Child Health Assessment Act.

We consider CHAP a vital piece of legislation for three reasons:

Nothing is more precious than our children, and nothing is more precious to our children than their health;

CHAP will correct several serious weaknesses in the way we discover and care for the health problems of poor children under Medicaid today. And no segment of our population is in greater need of preventive health care, and less able to afford it, than the children of the poor.

The enactment of CHAP will also serve as a loud and clear signal that health care for our children, born and yet-to-be born, will be one of our top priorities under National Health Insurance.

This program is poised against a stark backdrop: our Nation is currently divided into two populations—those who receive adequate health care, and those poor who do not.

Among those in America who do not receive adequate health care, millions of poor children should cause us the greatest concern. That so many impoverished children receive inadequate health care in the richest Nation on God's earth shames our Nation's conscience. It scandalizes our social policy.

We must seek to guarantee that all children in America are given the opportunity to grow up healthy: immunized, as many in our generation were not, against childhood diseases; educated, as many in our generation were not, about the serious implications of cigarette smoking, excessive drinking, and other controlable lifestyle hazards which can kill or severely damage their health; protected by a rational, comprehensive, equitable system of national health insurance, pvoviding services accessible to all, in settings that are both effective and efficient.

To be sure, a number of significant gains in the health status of children have occurred in recent years, Mr. Chairman, under your leadership and, I might add, that of this subcommittee. For example, the rate of deaths caused by certain communicable diseases in early childhood has dropped dramatically. The death rate for children from influenza and pneumonia declined from 150 per 100,000 in 1925 to 6 per 100,000 in 1973.

Mortality rates for the early childhood years have shown a greater decline since the turn of the century than for any other age group.

But despite those gains, there can be no cause for joy in the current health status of children in America today.

Despite its decline, the infant mortality rate in the United States is higher than in 11 other industrialized nations.

More than one-third of children between ages one and four are not protected againt polio. One-third of the children in that group have not had measles immunization, and we have seen a large increase in outbreaks of measles. Some of those outbreaks might even be characterized as epidemics, as in Los Angeles, for example, last summer.

When children enter school, 17 percent have defective vision, often not corrected. By age 11, 27 percent have defective vision.

In 1974, the last year for which we have good numbers, there were 11,500 cases of gonorrhea reported in children under 15 years old.

Moreover, as you might expect, the burden of these problems in our health care system falls disproportionately on the children of the poor.

I will give you some numbers we are developing in connection with this work in the work of gathering data for national health insurance alternatives.

Twice as many children in families earning under $5,000 have a history of chronic kidney disease as in families earning $10,000 or more.

A recently released study indicates that the infant mortality rate for urban poor children is more than 50 percent higher than for nonpoor children.

Children in families earning less than $3,000 are four times more likely to be reported in poor or fair health than children in families with incomes of $15,000 or more.

Poor children are bedridden 25 percent more than nonpoor children—an average of 5.4 days per year, while the nonpoor spend 4.2 days in bed.

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The Department of Health, Education, and Welfare currently undertakes a variety of efforts to improve health care for children. Through research, education and prevention—and through the provision or support of health care services in programs such as community health centers, maternal and child health, and Medicaid, more than $2 billion a year is spent directly on the health problems of America's children.

Moreover, we are committed to upgrading the quality and availability of health care each and every one of those programs provide.

In April of this year, for example, the President launched an unprecedented initiative to immunize an additional 20 million children under the age of 15 in this country against childhood diseases such as polio, measles, rubella, diphtheria, tetanus and whooping cough.

In this immunization program, we seek to accomplish two principal goals: by December, 1979, to increase from 60 to 90 the percentage of children under 15 who are properly immunized; and to develop by that time a permanent system, so that every child will have access to comprehensive immunization services early in life.

Because of the urgency of that program, I have brought that office directly under me, at least in the early stages.

But despite these child health programs and services, we are both here today because we perceive serious shortcomings in our health care system for children. In particular, we are concerned with shortcomings in the way poor children receive—or do not receive—adequate health care services under Medicaid.

The Medicaid program in general is primarily a payment program—it assures eligible persons that when they need health care, the bill will be paid. A different focus, however, underlies a part of the Medicaid program which is designed to meet the health needs of children. Known as the EPSDT program—for early and periodic screening, diagnosis and treatment—this program operates as a health outreach and health status monitoring system.

Under EPSDT, the states are required: to make a positive effort to inform parents that their children are eligible for this service; to offer the service to them at appropriate intervals; to regularly assess the health status of eligible children, and diagnose their particular health problems; and to assure that needed and requested followup treatment is provided.

The underlying principle is not simply to pay the bill, but to arrange every stage of the care, but it does not work.

Despite our hopes for this program and our conviction that it is vitally necessary, there have been a number of serious problems with EPSDT: not all poor children have in fact been eligible for EPSDT; even among children reached by the program, large numbers never show up for appointments, and State systems to improve this aspect of the program have never been adequately developed; even among children who keep their appointments, well over half are seeing a physician or health care practitioner for the first time in their lives, making effective assessment a far more difficult and time-consuming task; even of the problems detected by screening, more than 25 percent are not being treated; penalties against States failing to reach eligible children have been too rigid and

unenforceable; and of 12 million children eligible for Medicaid, EPSDT is reaching only 2 million each year.

I would also note that as far as our own house is concerned, my own judgment is we have not done our job well at HEW. We are conducting a top-to-bottom examination of the whole EPSDT operation, the way it is organized, how it sits, how it is run. I hope to have that examination completed and to act within 30 days to do what we can administratively, because we have not done a good job over the last few years at HEW. So the problem lies not simply with the States in this area.

The CHAP proposal seeks to assist States to rectify these deficiencies in a number of ways:

CHAP will require States to cover all children under the age of 6 whose family income meets AFDC eligibility standards, for both screening and treatment, regardless of whether they are categorically eligible under AFDC for Medicaid. In other words, CHAP would also serve children in 2-parent families among those who are poor.

CHAP will provide added assistance and incentives for States to assure comprehensive assessment and treatment. We will pay States a higher Federal match—a minimum of 75 percent instead of the current average of 55 percent—for all screening under EPSDT. We will also pay the higher match for all ambulatory followup medical care, including care in physicians' offices, clinics, and outpatient care in hospitals. And we will also pay a State a higher Federal match for general administrative costs—75 percent rather than 50 percent—if the State meets certain standards of good performance.

CHAP will require States to be responsible for managing the medical care of each child assessed to assure continuity of treatment and to assure availability of support and follow-up services. The program will guarantee 6 months of continued eligibility for followup care for children who have been assessed, even if their eligibility for assistance otherwise terminates.

CHAP will also institute more rational and enforceable performance criteria for the States. Currently, the penalties that must be assessed under EPSDT are both too rigid and overly harsh. Any failure whatsoever by a State, no matter how minor or temporary, results in assessment of a penalty of 1 percent of all Federal AFDC funds. For example, current regulations could be read to require assessment of penalties against States failing to notify every single eligible or potentially eligible child of the availability of the program—a fine goal, but rather unrealistic if missing just one child requires a Federal penalty. Under CHAP, there will be considerably more flexibility in establishing and enforcing peformance criteria. States will be given ample opportunity and encouragement to correct their deficiencies before a prospective penalty is assessed.

Moreover, the penalty itself will be levied against Medicaid administrative funds, rather than all AFDC funds, or against the funds for children in CHAPS. In addition to seeking these changes in the penalty provision, I have also asked Congress to repeal the current penalty clause retroactively when the changes proposed in CHAP are enacted, so that no penalties need be taken under the current regulations.

Mr. Chairman, I strongly urge the Congress to act quickly on the administration's CHAP proposal. The current EPSDT program is badly in need of this overhaul, and we are shortchanging one of the weakest, most vulnerable groups in our society until we make these improvements.

In addition to CHAP, Mr. Chairman, this subcommittee has already demonstrated a wide range of interests and leadership this session. You have clearly demonstrated that you possess the skill, the insight, and the dedication to become one of the great health Congresses. From your work early this year on the 1-year extension bill we requested, down through your tireless efforts to mold legislation on fraud and abuse, clean air, DNA, clinical labs, and rural physician extender clinics, you have already built an impressive record.

Yet, despite your signal accomplishments to date, I think you will agree with me that equally significant work still lies ahead.

The President asked me to spend two minutes, if I may, on a subject of great importance to him, the hospital cost containment legislation he discussed with the House leadership yesterday. In that regard, we are pleased that your subcommittee will take up the cost containment legislation next week.

I cannot overemphasize the vital importance of your work in this area. Since the administration's bill was introduced, the cost of a hospital stay has already increased $100, from an average of $1300 to $1400. Hospital costs continue to rise at an annual rate of 15 percent a year. The longer we wait to enact a simple, temporary cap on these runaway costs, the more it costs the American taxpayer to feed the excessive appetite of obese American hospitals.

The administration's cost containment bill will, over a period of 5 years, result in a savings to the Government and to the taxpayer of $45.5 billion. That represents $18.1 billion in Medicare and Medicaid savings to the Federal Government, $1.8 billion in savings to the States, $2.5 billion in other governmental programs, and $23.1 billion savings to the private sector. Think what could be done for the health of children of America with just a small portion of those funds.

Those figures are staggering, Mr. Chairman—staggering for what they tell us about the tremendous waste in our present health care system—and staggering in their implications for the many vital goals we might realize if we stopped feeding the insatiable American hospitals.

Every single day of the year hospital costs inflate by over $24 million, Mr. Chairman. If Americans receive exactly the same amount of care today that they received yesterday, they will pay $24 million more for it today. In the hour since I left my office to come over to this hearing room, the country has paid nearly $1 million more for hospital care than they would have paid for the very same care the hour before.

Once our cost containment program is in place, we expect to save at least $10 million of that daily $24 million inflation.

I commend you for your plan to move ahead swiftly on cost containment, Mr. Chairman. It shows that you share with me—and with the President—the conviction that something must be done to deal with cost containment this year.

The other major administration initiative is CHAP. And again, I strongly urge you to take up the CHAP legislation as quickly as possible—both because CHAP is a vital program itself, and because a tremendous volume of other new and expiring health legislation will soon follow.

I look forward to working with you on this vast array of current and future health legislation, Mr. Chairman, members of the subcommittee. Because of the great health care leadership and commitment you have demonstrated—in cost containment—in child health—and in all other aspects of our Nation's health care policy—I truly believe we can succeed in our effort to realize a common goal: to produce a rational, efficient health care system for America, responsive to the needs of all Americans, not just those who can afford to purchase their health care from the health care industry.

Mr. ROGERS. Thank you very much, Mr. Secretary, for a very clear and helpful statement.

Mr. Maguire.

Mr. MAGUIRE. Thank you, Mr. Chairman.

Mr. Secretary, I want to express my enthusiastic support for the proposal in its basic outlines that you and the administration are making and to thank you for the leadership you have given us not only on this issue but on a series of major health issues in the very short period of time since you assumed the Secretaryship. I think this committee feels that the rigorous kind of leadership you are giving us is not only overdue but essential if we are going to address the complicated problems of health, and I do not think there is any area in which the problems are more complicated.

Many aspects of the program before us have been in effect under the EPSDT program for about 10 years and there are some who believe that while levels of funding have been inadequate that funding is only part of the problem; many of the problems really are of another sort, and they are going to continue to bedevil us even if we immediately adopt improvements.

I want to address a couple of questions in a little more depth. You have commented on the problem of accountability of States and you have devised a more flexible approach to penalties. I think that is helpful. But outreach seems to me to be still a critical problem. If we do not find people and get them in, they can neither be assessed nor treated.

What do you think about community-based nonprofit organizations as eligible providers? We had some testimony yesterday from Ruby Duncan, who has headed such a group in Las Vegas, which has been a most effective group. In my own State, in Newark, New Jersey, a tri-citizens union, which has had an excellent innovative program, but they also have not been reimbursed and would not be reimbursed under the proposal, as I understand it.

Would you comment on that particular difficulty.

Secretary CALIFANO. Mr. Maguire, let me thank you very much for your introductory comments and let me just note that you hav been one of many members of the subcommittee who have also provided a tremendous amount of leadership in this area.

With respect to your specific question, I believe that our legislation—and if it is not clear, it should be drafted more clearly—

reaches out for community-based nonprofit support as an avenue of outreach in provision of these services. It seems to me you have put your finger on one of many very difficult problems in this area. We must reach these children. The most successful immunization program in the country is in Arkansas. Betty Bumpers, Senator Bumpers' wife, literally went out and organized everything in the State. She used the National Guard to reach children, she used all kinds of private organizations to reach children, she got doctors to volunteer, and unquestionably, in the past few years, as a result of that activity, they have the best immunization program in this country.

As we go on with our immunization program, if the experience of just a few months is any indication, we have to have enough flexibility in this legislation to provide reimbursement and assistance and work with all kinds of organizations to reach these children, because there are different ways of reaching children in the urban ghetto than in the rural area. There are special problems of reaching children that are in farm families, and migrant families in Florida, for example, as the chairman well knows.

We would want the flexibility, and I would agree with what is the thrust of your question, Mr. Maguire.

Mr. MAGUIRE. It would be your hope and intention, then, such groups should be involved in this program?

Secretary CALIFANO. That is correct.

Mr. MAGUIRE. As we all know, a person-to-person mere kind of outreach is most effective.

Mr. ROGERS. Dr. Carter.

Mr. CARTER. I certainly support the intent of your proposal. In fact, we have a different one, which we hope will be helpful.

It has been brought to my attention that if we could just cut the average length of stay in the hospital by one day throughout our country, our hospital costs would be contained.

Now with regard to the bill we have before us, I believe the chairman mentioned the prenatal and postnatal care. Should these services be included?

Secretary CALIFANO. The CHAP program we have proposed does not deal with prenatal care. We have developed within HEW a proposal to cover low-income mothers regardless of whether they are categorically eligible under Medicaid for prenatal care. Personally I believe strongly that coverage should be provided in that area.

Mr. CARTER. Wouldn't this be an ideal way to get these children on the rolls and to record their names?

Secretary CALIFANO. As far as I am concerned, it would be an ideal way.

Mr. CARTER. Within the first few weeks of the youngsters' lives they are given their first immunizations. Starting immunization at that time is very important.

Secretary CALIFANO. Dr. Carter, I might note in line with what you are saying, I spent a half day in the South Bronx several weeks ago in a school in which every child was on welfare—1,600 children. I asked the guidance counselor and the principal at the end of the day, if we just had a few thousand dollars more, what would you do with $30,000 more? They said the first thing they would want would be a nurse about half time, so that as soon as a woman became

pregnant they could put that woman into some kind of adequate prenatal care, because so many of the children in that school were suffering from problems that were precipitated by inadequate care. So I feel strongly that you are right about this.

Mr. CARTER. We could extend our screening and examination through head start and preschool and school. That would be an ideal place to get the children, and see that they do appear at the examination and have their immunizations at that time. Is that not correct?

Secretary CALIFANO. It is, Dr. Carter. One of the things we are discovering, there are many States in this country in which the head start program is much more effective in getting children immunized than the schools are, because often school laws are not that strictly enforced, although they are being stepped up quite a bit this September.

Mr. CARTER. Many States require immunization before entry into school. Certainly I think periodic examinations are very necessary, followed by referral to the health officials or those who can correct such defects as they find.

Thank you, Mr. Chairman.

Mr. ROGERS. Mr. Preyer.

Mr. PREYER. Thank you. I want to commend you also, Mr. Secretary, for your leadership in this area. I thank you for the work you have provided.

In some of the bills we have been taking up recently like the rural health clinic bill, it has been brought very forcefully to our attention, as you mention in your testimony, how many millions of poor people are denied Medicaid eligibility for categorical reasons. I would hope that this CHAP bill will take the lead in trying to equalize the situation for all the poor people.

Do you have any figures on how many poor people are categorically ineligible for Medicaid?

Secretary CALIFANO. We estimate about one-third, overall, of the people who are poor in this country, in the sense of being below the poverty line, are presently ineligible for Medicaid. It probably would be about comparable with children.

We think in the age group of zero to six the additional children we would bring in if we cover all low-income people—and that still might not get everyone up to the poverty line—would be 700,000 that are presently not eligible for this program.

Mr. PREYER. Do you think the CHAP bill can extend assessment for all poor people, Medicaid eligible or not, up through the age of 21?

Secretary CALIFANO. Mr. Chairman, obviously the legislation could do that. Our legislation does not do that. In all candor, that was a budgetary decision. With limited resources, we put our focus on children 0 to 6.

In terms of the children to whom we extend coverage, I think that is a judgment for you to make.

Mr. PREYER. Do you have any thoughts on when budgetarily it might be possible to extend it to all children up to 21?

Secretary CALIFANO. The cost of covering all children from 7 to 21, as best as we can estimate it, is about $75 million. I do not have

the final say on how budgets are made. I think I would answer it that way. I would think certainly this would be a very high priority in the current budget process which we are just beginning for fiscal 1979.

Mr. PREYER. If we pass the Hospital Cost Containment Act, we can probably pick it up in a few hours.

Secreary CALIFANO. That is correct.

Mr. PREYER. In the testimony yesterday there were some suggestions made of changes that could be made that would not cost very much. One of the suggestions was that HEW would be mandated to set out company standards as final goals or realistic goals for States to shoot at. There was a suggestion that States be required to identify qualified providers. Do you have any comments on that?

Secretary CALIFANO. With respect to the setting of goals, one of the problems that pervades HEW is that we do not have a systematic apparatus which sets goals, particularly goals which can be quantified in terms of reaching and providing care. We are trying to develop quarterly operating plans for all of our regions, which would go out every 3 months, so each quarter they would know what they should be focusing on and measure performance in different areas in those regions as to whether they meet those goals.

I have asked Mr. Derzon, who runs the Health Care Financing Administration and this program, to include goals for the EPSDT program in the operating plans we establish. Those goals will be set State by State within each region. I suppose whether we are mandated to set goals or not is really a function of legislative language. I think goals should be set in this area. It is a measurable area. We need yardsticks in a large organization.

So long as it did not include a massive reporting apparatus, which is both aggravating to the States and which I discover more and more often produces reports nobody in HEW reads, I think it would be fine.

With respect to making up lists of available providers, again we are trying to do this. We think this should be done. The provider problem is a very difficult problem. Increasingly in Medicaid it affects this area. It costs more than $6, for example, to do the first workup on a poor child, but in some areas that is what we are paying.

We have to find a way to deal with the provider problem on a large scale. I would think of all the activities of the medical profession, of all the activities the doctors could engage in in terms of volunteering time or efforts or taking a little less money they would otherwise, you would think that dealing with children would give them the greatest personal rewards and the greatest social rewards. I hope that more doctors would do more of this. But we have to solve the provider problem, and I am not sure myself of exactly the way to do it.

Mr. PREYER. Thank you, Mr. Secretary.

Mr. ROGERS. We are pleased to have the chairman of the full committee this morning. We welcome you and wonder if you might have some comment on the question.

Chairman STAGGERS. Thank you. I am delighted to have the opportunity of welcoming our distinguished witness this morning.

I would like first to thank the subcommittee for the job they are doing. We are going to have the full meeting this morning. This is one of the busiest subcommittees, I expect, in the House, and they do a good job. I do want to congratulate you on the job you are doing.

What are we doing in America to teach prevention of disease, to teach prevention of anything happening? Are we doing anything in the schools in the first grade right on through? I think it is the greatest opportunity we have to teach health care in every grade of school, instead of waiting until something happens, then they have to get a doctor, and so forth. I think we can use health personnel to do this. I do not know whether you have thought of this or brought out any suggestions on it or not, but it has occurred to me that we can do a great good here by starting right at the first grade or kindergarten.

Secretary CALIFANO. Mr. Chairman, it is a privilage for me to have you here, and let me respond to your question. I think you are absolutely right. One of the most incredible things I discovered when I got to HEW was that there was virtually no communication between the health people and the education people, despite the tremendous networks they each have at their disposal to do exactly what you are talking about. The immunization crisis of children in this country is in large measure attributable to the fact that the Public Health people and the health people do not talk to the education people in Washington and in the States. We are now actively working to try to develop a program to do exactly what you are suggesting. I think it is one of the most important things we could do.

If it is done well, not only can we teach health care to children but we can bring some of that health care back into the home through those children. It is the most important time of life to teach it, so we are looking at that aspect as well. I hope that we will be coming forward with proposals early, very early in the next session, to the extent we need legislation to move in that area.

I think there is no better way to spend money.

Chairman STAGGERS. I had thought about it. I certainly think it would be a great way not only for the health of America but to save money and everything else if we could teach proper food, the proper way of taking care of the body, and so forth, that we could certainly improve the health of this land, much more than by just waiting for somebody to get sick and curing them.

I believe it would cost far less and would be of far greater advantage to everyone in the land. I hope that you do think about it a little bit and maybe you can work out something that would be practical to use some of our people in teaching in our schools the art of prevention.

Thank you, Mr. Chairman, for allowing me to intervene for a moment.

Mr. ROGERS. We appreciate your suggestion. I think it is excellent. As a matter of fact, this committee has passed a bill which gives authority to the Department to do exactly this, the Health Promotion Act. It really has not been properly implemented, and I would think that the Secretary could look at that and, I believe,

start a very effective movement. It really was the intent to bring a proper program of education to the American people.

Mr. CARTER. Mr. Chairman, I am happy to have introduced that bill. Unfortunately it was not funded until this year for the following year.

Mr. ROGERS. Mr. Waxman.

Mr. WAXMAN. Thank you, Mr. Chairman.

Mr. Secretary, I am also pleased to have you before us and to have your proposal presented to us. I have a few questions.

One is rather parochial, if you will excuse my concern about the State of California, in regard to the CHAP program.

In California we use nurse practitioners ostensibly in the health screening programs in the school and CHAP requires that nurse practitioners be phased out and be replaced by more costly providers such as physicians. This has been disruptive in my own State which has led the way in preventive health programs for children.

I would like you to explain why CHAP excludes nurse practitioners, what their policy reasoning was that it must be applied nationally, not just in the State of California.

Secretary CALIFANO. Let me say, Mr. Waxman, there is no intention to exclude nurse practitioners. In fact every thrust that we have taken has been to put them more and more into the world of medicine. Our physician extender program for rural health and the demonstration projects in urban areas which this committee has moved forward on is designed to move nurse practitioners into the maintstream of health care.

If there is any implication or anybody can read any of the language in our legislation to exclude nurse practitioners, we will correct it and make it clear.

The legislation would phase out over time, over a 3-year period, those centers that simply do screening, and don't do any treatment. That has created some concern on behalf of some of the public health people throughout the country, in terms of States in which, by reason of practice or tradition, or because of the medical association, they are permitted only to do a screening and then must refer the children to doctors. We would like to get it all done in one place, to the extent we can get it done in one place.

Our intention was to look at the whole network that we have available, to try and reach and treat these children, and get more and more comprehensive centers going, which will provide both the screening and the treatment. I think it may simply be a matter of confusion as far as nurse practitioners are concerned, and to the extent that it is, we will correct it.

I understand your concern in that area.

Let me say to you while I am here, how much we appreciate the hearings you held in California on the immunization program during the recess. They were a great help in that area.

Mr. WAXMAN. They were very dramatic hearings, serious dangers of epidemics not just in the L.A. area but throughout the country which were dramatically pointed out. They were excellent hearings. I know the State of California will be relieved to know that the nurse practitioner will still be able to participate as a provider. The CHAP program though does not require the States to provide

mental health care, diagnosis of mental retardation or certain dental services.

What is the reason for these exclusions?

Secretary CALIFANO. We did not require the States to expand their present efforts in the areas. We don't require that they do so. However, States can provide these specialized services if they include them in the State plan. We did that, again, for a combination of reasons here. It was not simply our budget. It was the State budgets, to the extent which the States would actually provide these services or are equipped to provide that kind of care. We don't prohibit it. We just leave it up to the State, either for all recipients, or just those under 21. But we do not mandate it.

Mr. WAXMAN. Aren't we really providing for a false economy if we don't have these kinds of things taken care of at an early age where they can be treated more easily and more successfully, rather than wait until the problem becomes more aggravated?

Secretary CALIFANO. You are absolutely right about that. There are other ways. We have other programs available, such as maternal and child health, community health centers, and some community mental health centers, to treat some of these problems. We did not include it in the CHAP program. We had to make a choice of a series of priorities, as we did in terms of children 7 to 21. It is a series of budgetary decisions. This one, however, I know is complicated by the way States are equipped and traditionally treat this, and at least for the time being it may be well to leave each of them as not a mandated service as far as States are concerned. If we are unsuccessful in the next couple of years in treating more and more of this through our other programs, then we should probably mandate that the States do it through the CHAP program.

Mr. WAXMAN. Even if we don't mandate it, shouldn't we provide the same reimbursement rate that we provide for the kinds of services that the States will provide? Let the State decide whether it wants to have mental health and dental services, and if they so choose, reimburse at the same kind of rate?

Secretary CALIFANO. Our proposed reimbursement rates are again a function of budget priorities, if you will, and our function of selecting those things we felt were the most important and most urgent in the context of those priorities.

Mr. WAXMAN. Thank you very much.

Secretary CALIFANO. Obviously there is no distinction in terms of the need for the care or the importance of the care.

Mr. ROGERS. Mr. Secretary, there was a report from HEW which suggested that a Deputy Assistant Secretary for Child Health Affairs be established. I think you do have an Assistant to the Assistant Secretary for Health.

What is your thinking on upgrading child health programs in the Department?

Secretary CALIFANO. Mr. Chairman, we are looking at how the Public Health Service should be organized at this time. It is the last portion of the Department in which I have looked at the organization. We went through the large organization to get the five operating divisions in functionally coherent shape, and we have been through four of the five operating divisions individually. I note that

in the area of the Office of Human Development Services, we have taken all the children's programs of a social nature, and all the family programs of a social nature, and we created a new Administration of Family and Children; so that in the social arena, I think we have pretty much brought these programs together, to the extent that we have the power to do so without legislation.

I will be happy to and will look at this as we look at how we reorganize the health area, because we are looking at that right now, and we will reorganize within the Public Health Service in the future.

Mr. ROGERS. I think it does warrant your attention, even the President's attention, when you think that there are some 56 programs in 5 departments, 15 agencies and 45 bureaus. We have found that the Department has always been shorthanded as far as health personnel, devoting their time to EPSDT, and many of the States need technical help, which we simply have not been able to provide, mainly because of a shortage of people.

I wonder how many people would be assigned to CHAP. What is the thinking?

Secretary CALIFANO. Let me make a couple of points here. You are absolutely right about our failure to provide technical assistance, and we will put together an adequate number of people to provide that.

Mr. ROGERS. I think it would help.

Secretary CALIFANO. We are presently, in terms of this year, this moment, under very severe personnel ceilings. These have been applied to every department in the Government, of which we are just one. Obviously, if we didn't have those ceilings, I would have more people in the program today, but as we go with CHAP, and as we move out, we have got to provide technical assistance to the States and counties to make this program work.

Mr. ROGERS. Yes, but I think this is the thrust of the administration, and we commend you for it and the President as well as you, Mr. Secretary. But if it is an administration goal, it doesn't do much good to talk about it unless we then are going to do something about it, and I am sure you share that feeling.

Now we would like to have for the record the organizational setup for CHAP. I think it would be good to have a listing of the positions by grade and location going to the office here as well as in the regional offices so that we will have some idea of what we can anticipate.

Secretary CALIFANO. I would like to add to that, Mr. Chairman, if I may, some of the other programs that also affect children in HEW, so you get a sense of where we might hope to come out in terms of reaching these children.

[Testimony resumes on p. 268.]

[The following information was received for the record:]

Attached is a fact sheet on the reorganization of the Public Health Service as approved by the Secretary and announced September 30, 1977. The essential purpose of the reorganization was to strengthen the administrative capacity of the Office of the Assistant Secretary for Health by reducing the number of units reporting directly to him.

The reorganization places the Office of Child Health Affairs within the newly created Office of the Deputy Assistant Secretary for Health Programs.

Attention is invited to this statement on page 6 of the attached fact sheet:

> "A major priority for the Deputy Assistant Secretary for Programs will be to coordinate all PHS health activities directed toward children. Improved child health is a major objective of the Assistant Secretary for Health and the Secretary."

Thus, under the reorganization, instead of the Office of Child Health Affairs being more or less isolated from other offices and bureaus of the Public Health Service that affect child health, it will be integrated into a system whereby ASH and his principal deputy can command their resources and their attention.

It is working this way: The newly created Office of the Deputy Assistant Secretary for Health Policy, Research, and Statistics, working closely with the heads of the Office of Child Health Affairs and the Bureau of Community Health Services, in the Health Services Administration, develops initiatives in child health. The newly created Office of the Deputy Assistant Secretary for Special Health Initiatives is developing a child immunization program, which is a high priority of the Secretary. The Deputy Assistant Secretary for Programs oversees the agencies that deliver the services.

Beyond structure, the Subcommittee should be aware of the commitment of the principals. The Secretary has repeatedly emphasized the high priority he personally places on maintaining and improving the health of children. The Assistant Secretary for Health is a pediatrician who has both the determination and the experience to carry out the Secretary's commitment. The Deputy Assistant Secretary for Programs is a physician and the mother of three children, and she has been a professor of preventive medicine and the director of the Illinois State Department of Health.

Attachment

FACT SHEET ON REORGANIZATION OF

U.S. PUBLIC HEALTH SERVICE

Secretary Joseph A. Califano, Jr., Secretary, Department of Health, Education, and Welfare, has approved the reorganization recommendations of Dr. Julius B. Richmond, Assistant Secretary for Health and Surgeon General of the U. S. Public Health Service, to streamline the operations of the Public Health Service (PHS) and improve the management and delivery of its health programs.

THE PUBLIC HEALTH SERVICE TODAY

	COMPONENT	BUDGET FY 1978 (Million)	NUMBER OF POSITIONS
1.	Office of the Assistant Secretary for Health	24	624
2.	Health Agencies		
	Alcohol, Drug Abuse, and Mental Health Administration	1,010	6,163
	Center for Disease Control	211	3,912
	Health Resources Administration	830	2,135
	Health Services Administration	1,696	18,787
	National Institutes of Health	2,825	11,545
	Food and Drug Administration	283	7,829
3.	Regional Offices	(39)	(1,233)
	TOTAL	6,879	50,995

THE REORGANIZATION

The goal of this reorganization is to strengthen PHS and the leadership role of the Assistant Secretary for Health (Surgeon General) as the nation's chief health officer. The Assistant Secretary for Health constantly faces problems of vast size and complexity, some requiring rapid action to protect the public's health. To cope with these problems and also provide day-to-day leadership, he must delegate major responsibilities as fully as possible to the agency heads and to a small group of deputy assistant secretaries and key policy assistants.

The present and new organization for PHS are depicted in Exibit I, page 3.

The reorganization has four objectives:

A. To simplify program functions of the Office of the Assistant Secretary for Health (OASH) by assigning major leadership roles to three deputy assistant secretaries--one for programs and population affairs, one for special health initiatives, and one for national health insurance. At the present time, program management and oversight is a collection of separate activities and ill-defined lines of responsibility.

B. To link health services research and health statistics activities directly to policy analysis, planning and evaluation functions under a fourth Deputy Assistant Secretary.

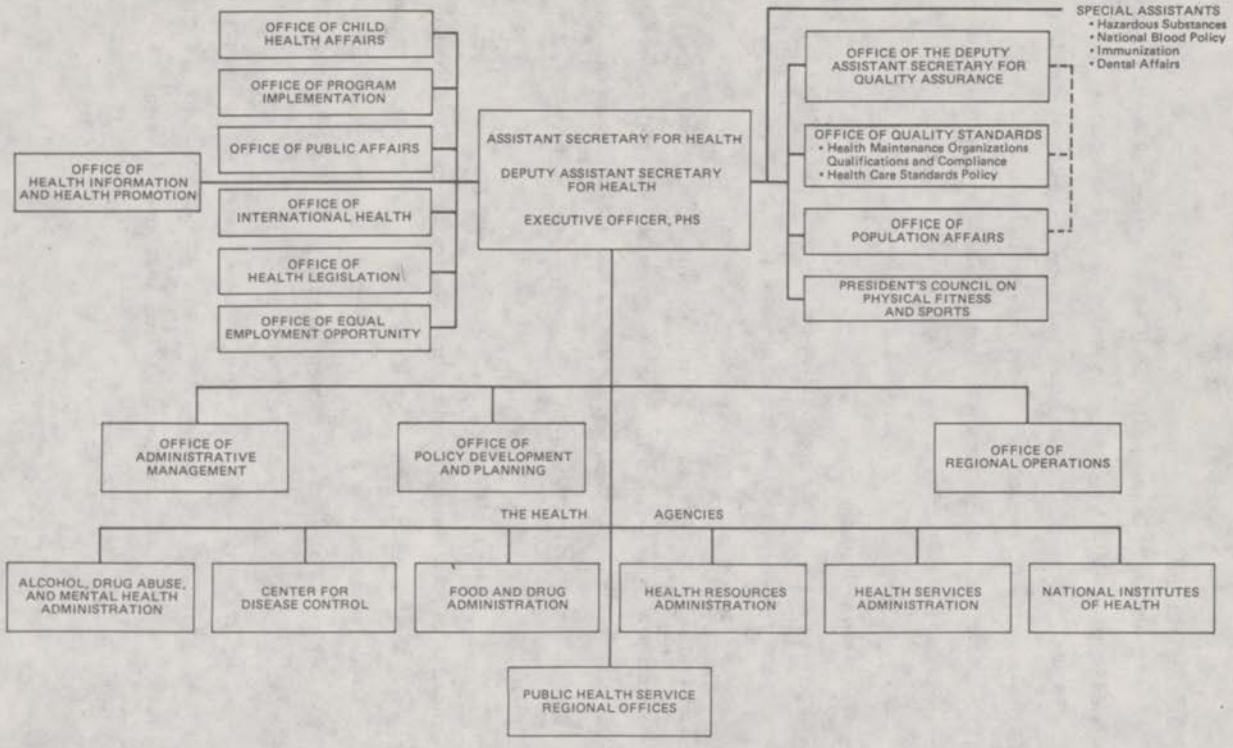
C. To consolidate management activities under the PHS Executive Officer and to redefine selected staff functions to help the Assistant Secretary better manage the PHS and work with outside organizations.

D. To make the PHS regional offices more effective instruments in helping states and local communities develop more equitable and efficient health care systems. The regional offices will also be realigned to conform with other HEW reorganizations.

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

PUBLIC HEALTH SERVICE

PRESENT ORGANIZATION



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NEW ORGANIZATION

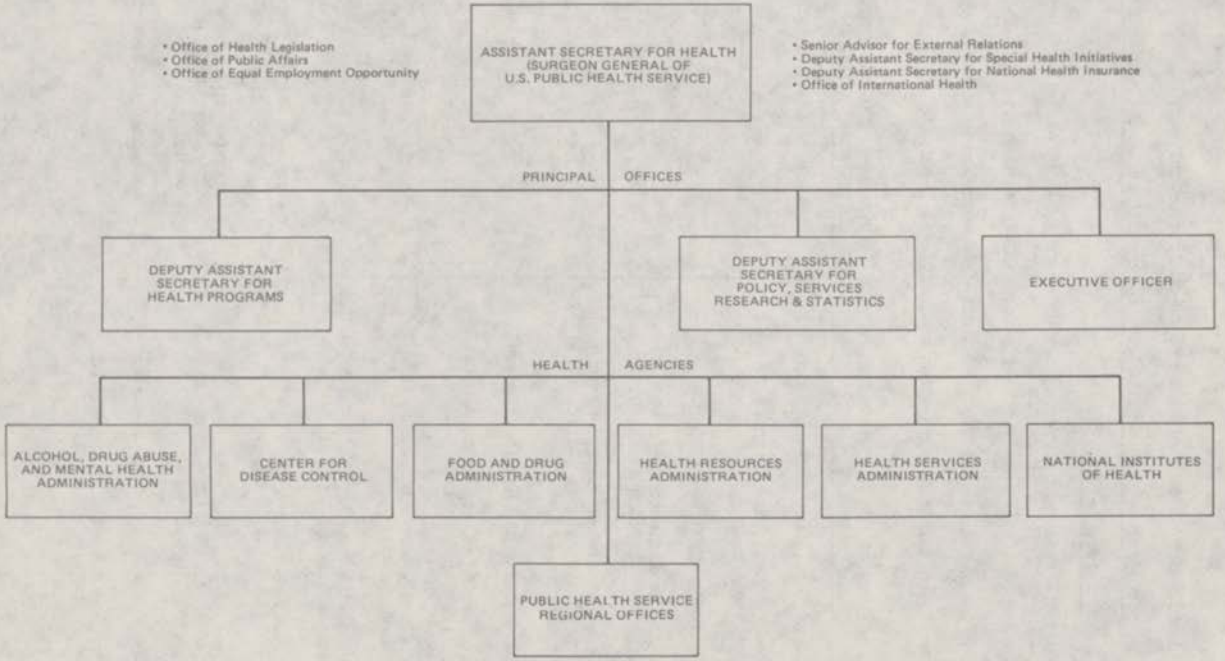


EXHIBIT 1

A description of each of these major objectives follows:

A. Simplify the program functions of the Office of the Assistant Secretary for Health.

Today the Assistant Secretary has an overall Deputy Assistant Secretary and 10 other assistants dealing with program matters. Despite this large staff, he lacks the flexibility to delegate the most important continuing programs responsibilities with which his office is faced.

PROGRAM ACTIVITIES NOW REPORTING TO ASSISTANT SECRETARY	REVISED STRUCTURE REPORTING TO ASSISTANT SECRETARY
1. Deputy Assistant Secretary	1. Deputy Assistant Secretary for Health Programs
2. Deputy Assistant Secretary for Quality Assurance	
3. Office of Quality Standards . HMO Qualification and Compliance . Health Care Standards Policy	
4. Deputy Assistant Secretary for Population Affairs (Office of Population Affairs)	
5. Office of Child Health Affairs	
6. President's Council on Physical Fitness and Sports	
7. Special Assistant for Immunization	2. Deputy Assistant Secretary for Special Health Initiatives
8. Project Manager St. Elizabeths Hospital	
9. Special Assistant for Hazardous Substances	(Transfer to the Center for Disease Control)
10. Special Assistant for Dental Affairs (Chief Dental Officer, PHS)	(Transfer to the Health Resources Administration but remains Special Assistant for Dental Affairs to the Assistant Secretary for Health)
11. Special Assistant for National Blood Policy	(Transfer to NIH)

Not Currently Provided

National Health Insurance	3. Deputy Assistant Secretary for National Health Insurance (and Special Assistant to the Secretary)

The Deputy Assistant Secretary for Health Programs/Population Affairs is the principal deputy to the Assistant Secretary and acts for him in his absence. This Deputy, in addition to assuming responsibility for the functions indicated above, will be responsible for two new objectives assigned by the Secretary:

1. Create a health practices assessment capability to complement the review of health care standards and regulations developed by the Health Care Financing Administration. It will inform doctors and other health professionals of the results of biomedical research and studies of the efficacy of drug and medical procedures and it will integrate scientific and technical findings with ongoing quality assurance activities.

2. Revitalize the Secretary's commitment to Health Maintenance Organizations (HMO) programs as a major health service delivery and cost containment innovation. In addition to administering HMO qualification and compliance activities currently located in the Office of Quality Standards, the Deputy Assistant Secretary for Health Programs will give direct oversight, for the present, to HMO funding activities located in the Health Services Administration.

The Deputy Assistant Secretary for Health Programs will also serve as Deputy Assistant Secretary for Population Affairs, overseeing the activities of the Office of Population Affairs and the implementation of population affairs policy throughout the Department.

A major priority for the Deputy Assistant Secretary for Programs will be to coordinate all PHS health activities directed toward children. Improved child health is a major objective of the Assistant Secretary for Health and the Secretary.

The establishment of the new post of Deputy Assistant Secretary for National Health Insurance is a key step in the development of a National Health Insurance System. This is a major objective of the Administration's domestic policy, and the President has pledged to recommend a plan to the Congress in 1978. Developing HEW recommendations for the President's consideration will be a department-wide effort, involving the Office of the Secretary, the Assistant Secretary for Planning and Evaluation, the Public Health Service, the Health Care Financing Administration and other elements of the Department.

When it becomes clear that the Congress will enact a health insurance plan, the Public Health Service will play a lead role in meshing the new plan with the existing health care delivery and financing systems. Toward this end, the Secretary has appointed a Special Assistant for National Health Insurance (NHI) who will also serve as a Deputy Assistant Secretary for NHI in the Office of the Assistant Secretary for Health. He will coordinate the present Department-wide effort to develop NHI recommendations for the President, and then will be charged with developing plans for integrating NHI with the present system.

Finally, this reorganization initiative provides for the establishment of a Deputy Assistant Secretary for Special Health Initiatives who will provide the capability for immediate, concerted handling of pressing special health initiatives as they arise--such as immunization and the St. Elizabeths Hospital improvement initiative.

B. Link health services research and health statistics activities directly to policy analysis, planning and evaluation functions under a new Deputy Assistant Secretary for Policy, Services Research and Statistics.

Problems and issues in health are taking on social and economic considerations of ever expanding magnitude. Decisions by the Secretary and the Assistant Secretary for Health significantly affect the quality of life of the Nation's people. Decisionmaking requires policy analysis and evaluation support that not only reflect knowledge of the issues but ready access to timely research data, health statistics, and to analytic capability by which these issues are understood, addressed and resolved. An Office of Policy, Services Research and Statistics (OPSRS) headed by a Deputy Assistant Secretary will provide this capability.

The National Center for Health Statistics (NCHS) and the National Center for Health Services Research (NCHSR) are transferred from the Health Resources Administration (HRA) to OPSRS, thereby aligning health policy, statistics, and services research functions under a single official reporting to the Assistant Secretary for Health.

The existing Office of Policy Development and Planning is also transferred to OPSRS, as is the present Office of Health Information and Health Promotion, to provide a close relationship between health strategy and health policy functions, and health information and health promotion functions.

In addition to the advantage of sharpened decisionmaking, elevating NCHS to OASH will result in more effective use of NCHS as the agent responsible for the collection and analysis of general purpose health statistics and for coordinating those statistics that involve cooperation with State and local agencies. Health data collection efforts will become more systematic and uniform and PHS ability to rapidly obtain data needed for policymaking and to resolve data policy issues will be enhanced. The Director, NCHS, will also serve in a dual capacity as Deputy Director, OPSRS.

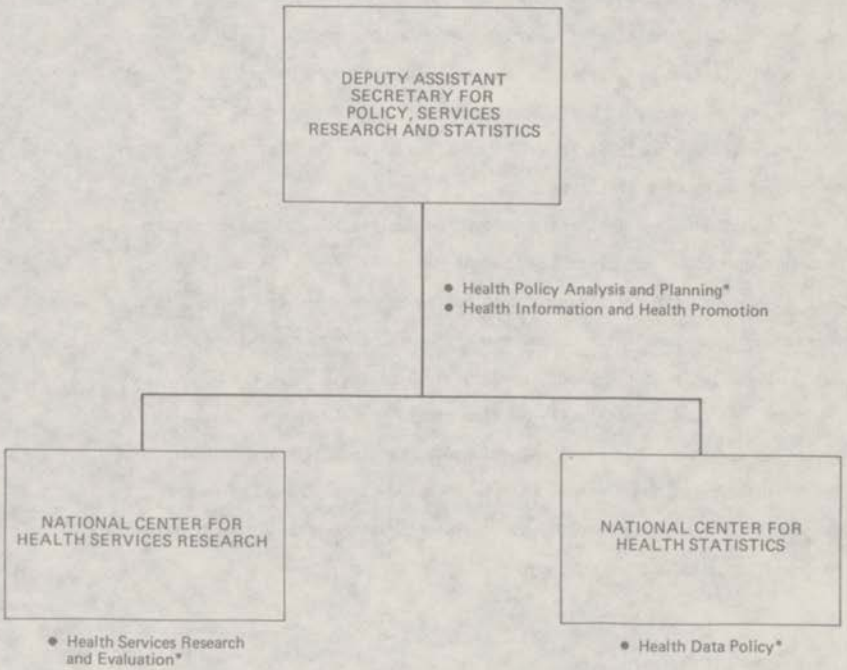
Similarly, NCHSR's cross-cutting responsibilities as the primary source of technical and professional assistance in the area of health policy research and in the development of a national health strategy can be best realized by locating the Center within the principal OASH policy analysis staff. This action will also promote NCHSR as the PHS focus for health services research.

The organization for the Office of Policy, Services Research and Statistics is depicted in Exhibit 2.

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

PUBLIC HEALTH SERVICE

ORGANIZATION FOR OFFICE OF POLICY, SERVICES RESEARCH AND STATISTICS



*Formerly functions of the Office of Policy Development and Planning

EXHIBIT 2

Realignment of Health Resources Administration (HRA).

Elevating the health services research and statistics functions to OASH will allow HRA to focus its efforts on its primary mission of resources development and health planning.

HRA will concentrate on carrying out legislated programs for assuring a health manpower supply adequate to the nation's health care needs and for minimizing geographic and other inequities in the distribution of health professionals. The Assistant Secretary for Health's special assistant for dental affairs, and his staff, will be transferred to HRA in order to relate more closely to dental manpower training activities. The special assistant, however, will retain his title and continue to advise the Assistant Secretary on broader dental health issues.

HRA will also accelerate its efforts to achieve the objectives of the Health Planning and Resources Development Act of 1974, which seeks to assure that adequate health care is available to the Nation's people, while containing increases in the costs of health care, through operation of a nationwide network of local health planning agencies.

HRA will have significantly more people to operate these two vitally important programs. Some will be assigned to programs from the Office of the Administrator, HRA. Others will be recalled to the Bureau of Health Manpower from the regional offices, consistent with recentralization of health manpower programs ordered by Congress.

In the health planning area, HRA will work more closely with the PHS regional offices than it has before. As part of the reorganization, Regional Health Administrators will also serve as the chief federal health planners in the regions. They will become the link between HRA's Bureau of Health Planning and Resources Development and state and local governments, state and local health planning agencies, and the private health sector.

The new organization of HRA is depicted in Exhibit 3, page 12.

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

PUBLIC HEALTH SERVICE

NEW ORGANIZATION FOR HEALTH RESOURCES ADMINISTRATION

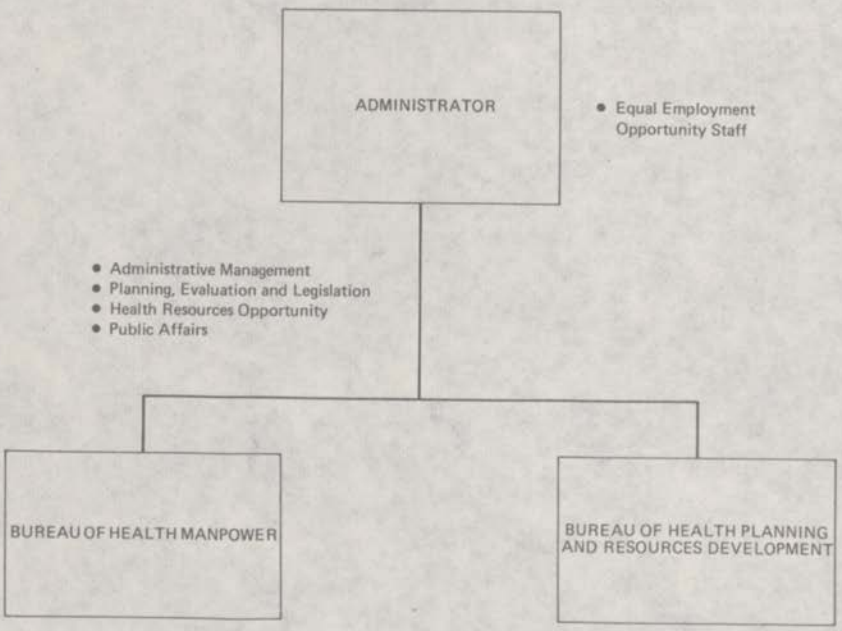


EXHIBIT 3

C. Consolidate management activities under the PHS Executive Officer and redefine selected staff functions to help the Assistant Secretary manage the PHS and work with outside organizations

The remaining functions in the Office of the Assistant Secretary after reorganization will consist of a small number of special staffs and an Office of Management.

1. Special Staffs

The Senior Advisor for External Relations will be responsible for liaison with professional groups and associations and will provide advice and counsel to the Assistant Secretary for Health relative to matters of mutual concern.

A reconstituted Office of International Health will be established as a special staff office. International collaboration and cooperation, now emerging as methodologies for the future, require strengthening in PHS. This need can best be met through expanding the prestigious John E. Fogarty International Center for Advanced Study in the Health Sciences at the National Institutes of Health. Consequently, most operational functions (e.g., AID, Special Foreign Currency, country assessment and progress reports) now in the present OASH Office of International Health, will be reassigned to the Fogarty Center where they will contribute more effectively to the overall international effort. The OASH international health activity will then focus on policy development and guidance for PHS and policy coordination with the various Federal and international organizations, including multilateral and bilateral health programs between the U.S. and foreign countries.

The other special staffs, as at present, are the Office of Health Legislation, the Office of Public Affairs, and the Office of Equal Employment Opportunity (OEEO). OEEO will continue as a special staff Office pending completion of the study of EEO activities being conducted by the Office of the Secretary.

2. Office of Management

An Office of Management (OM), to be headed by the PHS Executive Officer, will be established. It will consolidate the administrative management activities of the existing Office of Administrative Management; the legislative planning implementation system, operational planning system, PHS regulations coordination and review processes, and the executive secretariat functions of the existing Office of Program Implementation; and, the operational liaison and managerial coordination and support functions for PHS regional offices from the existing Office of Regional Operations.

D. Realign PHS Regional Offices.

PHS regional offices will be reorganized pursuant to the Secretary's directive to clarify and revise regional responsibilities and organizations.

This reorganization initiative will primarily strengthen Federal support of State and local health planning efforts by designating the Regional Health Administrator as the chief federal health planner in the region, and establishing an Office of Regional Health Planning (ORHP). ORHP will be responsible

for support of State and local health planning efforts, Cooperative Health Statistics System (CHSS), health facilities planning, operational and strategic plans within the regional office, and evaluations of the effectiveness of regional health programs. Additionally, the regional health administrator will work with PHS agency heads to assure that PHS funded health delivery projects are compatible with local services and needs. This is a major Secretarial initiative. Concurrent with this action, health manpower authorities and functions will be recentralized to HRA, to continue implementation of the Health Professions Educational Assistance Act of 1976.

A significant result of this reorganizational initiative is the reallocation of support positions to regional program functions.

Exhibit 4 depicts this reorganization initiative.

DEPARTMENT OF HEALTH, EDUCATION AND WELFARE

PUBLIC HEALTH SERVICE

NEW ORGANIZATION FOR PHS REGIONAL OFFICES

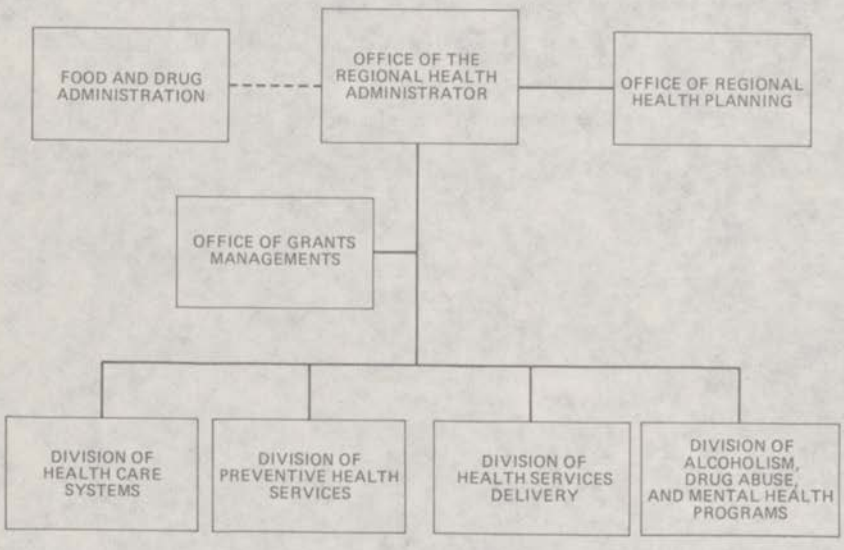


EXHIBIT 4

Accomplishment of the reorganization initiatives will result in a simplified PHS organizational structure. The reorganization will:

- Streamline OASH organizational structure.
- Realign OASH functions and clearly define responsibilities vested in four Deputy Assistant Secretaries, as follows:
  - Deputy Assistant Secretary for Health Programs, responsible for health programs development and oversight, including two new initiatives to create a health practices assessment capability and revitalize the Secretary's commitment to Health Maintenance Organizations Program.
  - Deputy Assistant Secretary for Special Health Initiatives, who will provide the capability for immediate response to urgent issues and problems.
  - Deputy Assistant Secretary for National Health Insurance, who also serves as Special Assistant to the Secretary, on transition to National Health Insurance.
  - Deputy Assistant Secretary for Policy, Services Research and Statistics, responsible for health services research and health statistics activities consolidated with policy analysis, planning and evaluation functions in a new Office of Policy, Services Research and Statistics which includes the National Center for Health Statistics and National Center for Health Services Research.

- Enable the Health Resources Administration to concentrate its efforts on Congressional mandates for assuring an adequate and equitably distributed health manpower supply and effective planning by State and local agencies for meeting health care needs in their respective jurisdictions.
- Consolidate management activities under the PHS Executive Officer and redefine selected staff functions, including the post of a Senior Advisor for external relations and a reconstituted Office of International Health, to assist the Assistant Secretary in PHS management and external relations nationwide.
- Continue essential staff functions for health legislation, public affairs, and equal employment opportunity.
- Realign PHS regional offices and redefine the role of the Regional Health Administrators pursuant to the Secretary's directive to clarify and revise regional responsibilities and organizations.

IMPLEMENTATION

These changes and functional transfers will be implemented within the current PHS manpower ceiling and will result in significantly improved utilization of scarce manpower resources, particularly through reduction of overhead positions and their reallocation to programs. Highlights of personnel reallocations are as follows:

- 60 positions in OASH reallocated to PHS programs.
- 180 positions in PHS regional offices reallocated to BHM, HRA.
- 27 overhead positions in PHS regional offices reallocated to regional program functions.

- 887 NCHS and NCHSR positions in HRA transferred to OASH in support of research and statistics.
- 25 overhead positions in HRA reallocated to BHM and the Bureau of Health Planning and Resources Development, HRA.

This reorganization will significantly reduce the number of persons reporting to the Assistant Secretary for Health. At the present time, the Assistant Secretary for Health works directly with 37 persons in administering PHS. The new organization will reduce this number to 16.

The Public Health Service reorganization will impact many employees. However, no reductions in force involving separations of personnel are anticipated. Maximum use will be made of the recent Civil Service Commission policy regarding the moratorium on downgradings as well as the normal range of administrative remedies, especially concerning a mandatory placement program.

Secretary Califano has directed Dr. Julius B. Richmond, Assistant Secretary for Health (Surgeon General of the U.S. Public Health Service), to implement the headquarters reorganization effective October 30, 1977. It is anticipated that the new PHS regional structure should be in place by January 2, 1978.

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Mr. MAGUIRE. Will the gentleman yield?

Mr. ROGERS. Certainly.

Mr. MAGUIRE. I think the question of coordination with existing other agencies within the Deparmtent and programs which you, yourself, alluded to earlier is critical, and I wonder if we could expand the question to give us some indication of how you are going to relate to the Public Health Service, the Health Care Finance Administration, head start, immunization program, rural health clinics, family planning, et cetera.

Secretary CALIFANO. Absolutely.

Mr. MAGUIRE. May we do that?

Mr. ROGERS. Certainly.

Mr. MAGUIRE. What about maternal and child health, for instance? We are concerned that you ought to be more involved in this whole area. It ought to be, it seems to us, better coordinated.

Secretary CALIFANO. Actually, Mr. Chairman, you sound like me. Yesterday in looking at this, and talking about this, I raised this very issue. When I said we were looking at the EPSDT program, and how it is run, and that we would hopefully be finished within 30 days with all we can do administratively, I should have spoken a little more clearly. We are looking at all the programs that relate to the health care of children, including that program, and they will all be folded into this study, and I would hope to be able to take some actions in about 30 days and have a report back here to this subcomittee.

Mr. MAGUIRE. I think the committee would welcome that and would look forward to working with you in trying to bring about better coordination.

Mr. CARTER. Mr. Chairman.

Mr. ROGERS. And I think this is true at the State level as well. Yes, Dr. Carter.

Mr. CARTER. If you will yield.

Over the years I have seen the Public Health Services in at least some of the States degenerate because of the lack of funds, because the Federal Government was unable to pay physicians to be health officers in different areas and districts. At one time I remember poor mothers came to the health departments for care, prenatal care, and then postnatal care, and the children were looked after from there on up. I regret that we haven't continued this effort over the years. I would hope we can improve and upgrade our public health departments and the services they provide through this legislation.

Then, if we have a child with spinal bifida or other developmental disabilities, he could immediately be referred for treatment.

Does the CHAP program include comparable payment for screening and treatment of developmental disabilities?

Secretary CALIFANO. Doctor, there are two parts to your question.

One, we permit the States to pay for treatment of developmental disabilities, if the State plan includes it, in the context of CHAP. We do not mandate coverage of developmental disabilities in the CHAP program. We do mandate developmental disability assessment, but not treatment. We leave treatment to the State plan.

With respect to the first part of your question, we do expect to use the National Health Service Corps program more vigorously in this area, and we do expect next year to be coming up with requests for expansion of that——

Mr. CARTER. Mr. Chairman, if you will yield for another question——

Secretary CALIFANO. [continuing] To get more doctors to underserved areas.

Mr. CARTER. That is one thing that has really gone awry, as I see it. The National Health Service Corps was developed, as I understand it, to provide physicians to deprived areas, in both urban and rural medically underserved areas. Right now the administrators of our universities are not permitted to grant these scholarships. The decision to the scholarship applicants is made here in Washington. Many of these people come back into the Public Health Service, and are not sent out into rural areas, as was the intent of this legislation to begin with, Mr. Secretary.

Am I not correct in this? You are using it to increase the number of people in the Public Health Service at the present time, as I see it.

Secretary CALIFANO. Well, I will have to look at specific numbers. I would hope that is not the case. I would hope that they are going to the private rural and urban areas, because that is where they are supposed to go.

Mr. CARTER. Yes, sir.

Secretary CALIFANO. It is a relatively new program, and we have had a relatively small number of graduates, a handful so far.

Mr. CARTER. We doubled the authorization last year. I believe the appropriation was doubled too.

Secretary CALIFANO. I understand that, but it takes time for them to work through the mill before they are out there as a doctor. But I will look at this and look at the numbers, and I will get the numbers to you on this.

Mr. CARTER. Yes, sir.

[The following information was received for the record:]

Public Health and National Health Service Corps Scholarship Recipients Providing Obligated Service in PHS Facilities

Section 225 of the Public Health Service (PHS) Act, under which the PHS and NHSC scholarship program was established and from which the NHSC draws personnel, allowed scholarship recipients to fulfill their scholarship obligation by serving internships and residencies in facilities of the PHS, such as PHS hospitals.

With the passage of P.L. 94-484, which restructured the scholarship program the provision for fulfilling scholarship obligations through internship and residency in PHS facilities was removed except for periods of internship and residency served before September 30, 1976.

Because many individuals had accepted scholarships with the understanding and written agreements that they could fulfill their obligation through internships and residency in PHS facilities, the congress found it necessary to amend the PHS act (P.L. 95-83) to allow those individuals who had received a scholarship before enactment of P.L. 94-484 on October 12, 1976 to fulfill their obligations through PHS internship and residency. However, if an individual received a scholarship for the first time from fiscal year 1977 funds, the individual would only receive credit against that one year of scholarship support if he later serves a PHS internship or residency.

Since all internship and residency positions are filled through a national matching system, and since many of the PHS facilities are considered less desirable for internships and residencies by medical school graduates, PHS scholarship recipients who elect PHS internships and residencies as their first choice, are usually matched to them.

Each year under the Section 225 scholarship program an allocation of available graduates has been made between the NHSC, the Indian Health Service (IHS) and the PHS facilities.. This results in a number of internship and residency positions being available in PHS facilities. Under the Section 225 scholarship program, therefore, not all of the graduates were available for NHSC assignment as will be the case under the revised scholarship program.

It should be noted that whether the obligees are receiving internship and/or residency training in PHS facilities or elsewhere, they would nevertheless be unavailable for providing health services during this period of training. The real loss results from the elimination of their obligated service for their period of internship and residency. This will change over the next 3 to 4 years under the legislatively imposed curtailment of this practice and with increasing numbers of obligees becoming available under the PHS and the new NHSC scholarship programs more graduates will be available for service in rural underserved areas. The following is a history and short projection of the deployment of scholarship obligees. It should be noted that these numbers are in addition to the volunter program field strength of 750 persons (490 physicians and 260 nurse practitioners, dentists and others) who are presently all serving in predominately rural underserved areas.

	1975	1976	1977	1978	1979
Scholarship graduates available	44	156	240	455	535
PHS internship and residencies	28	57	51	35	35
Indian Health Service	16	79	69	70	90
NHSC program	-	20	120	350	410

Mr. ROGERS. Mr. Maguire, you have a question?

Mr. MAGUIRE. Thank you, Mr. Chairman.

Mr. Secretary, with respect to the question of outcomes, setting targets, seeing where we are after given periods of time, I wonder if you could tell me what you think a realistic utilization rate under the program might be at the end of the first or second year and at the end of 5 years?

Secretary CALIFANO. I can give you the projections we have as we project out over 5 years with what were last January's budgetary projections for the 5-year period.

We would like to reach 3 million children, this is of a population of 12 million; 3 million in 1978, 4.5 million in 1979, 5.9 million in 1980, 7.4 million in 1981, and about 9 million in 1982.

Mr. MAGUIRE. So a 75 percent rate at the end of 5 years is your target.

Secretary CALIFANO. That is about what it is under the budgetary assumptions, and none of those decisions have been made beyond fiscal 1978 by the administration under the assumptions we had in January or February of this year.

Mr. MAGUIRE. Thank you.

When you quoted the $75 million figure earlier for increased costs, were all children up to 21 to be included? Was that based on a 75 percent utilization rate or some other figure?

Secretary CALIFANO. That is what it would cost to reach a total of 1.5 million children. That is the first year of reaching 1.5 million. We estimate there are slightly more than 1 million such children, and that is the first year cost of reaching them.

Mr. MAGUIRE. The first year cost.

Secretary CALIFANO. Right.

Mr. MAGUIRE. Mr. Secretary, you also made reference in your statement to national health insurance and to your hopes that child health could be an important part of any approach to national health insurance.

Does that mean that we can anticipate that outreach assessment, case management and all of these things we have been talking about today, to assure that poor children receive the diagnosis, treatment, and preventive approaches, that all of that will be included in any approach to national health insurance?

Secretary CALIFANO. I think it is a fair assumption, yes. A lot of that is included in this program now. There seems to be widespread agreement that it is very important to reach children, and the younger the better, as one of the most effective things we can do, both in terms of people as human beings, and also with regard to the preventive point that Dr. Carter has made.

Mr. MAGUIRE. Congressman Moss and some other members of this committee have introduced a bill which relies on a coupon system for services. I wondered if you might have had a chance to look at that, and whether you have any comment on that as a device.

Secretary CALIFANO. I think we would rather not go to the coupon route. There are some portions of the Moss bill that make a great deal of sense to us, and we think would improve our bill. There are

some portions that we disagree with. I think the most effective way might be if I submitted something, an analysis of that bill for the record, if I could do that.

Mr. MAGUIRE. Surely. We would appreciate that.

[The following information was received for the record:]

Analysis of H. R. 7474

H.R. 7474 would:

-- increase the Federal match to 90% for screening/diagnosis.

-- increase the Federal match to 100% for treatment of defects and conditions discovered through screening/diagnosis.

-- provide coupons which identify EPSDT services for which medical assistance is available and which will indicate a child's entitlement to receive EPSDT services.

-- require an annual compilation and publication of a list of providers and institutions that are willing to provide medical services under this program.

The bill has been reviewed by the Department and the following comments are offered:

(1) Separating screening and diagnosis from treatment for a distinct matching rate (90%) is contrary to the thrust which the Department is urging through the CHAP initiative--that is, providing comprehensive care, including assessment, through a primary care provider.

(2) The proposed 100% match "federalizes" Medicaid treatment, but only when it is related to EPSDT screening. Under CHAP, the Federal government would pay a higher match (but not 100%) for all subsequent treatment of an assessed child, except dental or inpatient, regardless of where or how conditions are diagnosed. It would be extremely difficult administratively under H.R. 7474 to determine which treatment would be eligible for the higher Federal match. In addition, federalization of the program (and termination of Federal/State partnership in setting standards, fees, etc.) should be considered on its own merits, not as an adjunct to CHAP.

(3) A coupon system such as that proposed in the bill would be extremely complex and costly to administer, and would give no assurance of delivery of required services. The State of Illinois tried such an approach in 1973 and found that the system was costly (printing alone cost about $1 per book) and not easily understood by recipients.

(4) Publication of an inventory of resources is an excellent idea, but does not require new legislation. It should be pointed out that States are required by current EPSDT regulations to make available to recipients the names of providers of services.

(5) We estimate the Federal cost of this bill in the first year at $468 million above the current EPSDT program, and $288 million above the CHAP program.

Mr. MAGUIRE. Just a concluding comment, Mr. Chairman.

I wonder if maybe sometimes the language we use is indicative or should be indicative of our emphasis, and I would like to see us change the title of this legislation from "assessment" to "assurance," because I think what we are all about here today is assuring health among our children, and that means that we have got to deal as seriously with treatment as with the screening aspects.

Thank you.

Mr. ROGERS. Good thinking.

Mr. Secretary, I have a few questions.

We do have a roll call. I know you need to get away.

What did you say our infant mortality rate was in this Nation?

Secretary CALIFANO. We are 11th among the industrialized nations of the world, although we are the wealthiest nation in the world.

Mr. ROGERS. That is an unexplainable figure, isn't it?

Secretary CALIFANO. Unbelievable.

Mr. ROGERS. Shouldn't we really do something about prenatal care? Should we just pass it by?

Secretary CALIFANO. Oh, no.

Mr. ROGERS. Should we provide prenatal care for first-time mothers?

Secretary CALIFANO. Mr. Chairman, my own view is that we should absolutely treat first-time mothers. Prenatal care is critical.

Mr. ROGERS. If we are really going to get at this problem, we really ought to do it properly. Prenatal care is where we should begin, should we not?

Secretary CALIFANO. Yes, Mr. Chairman, and we should begin for all low income people.

Mr. ROGERS. Yes.

Secretary CALIFANO. We should not limit it to categorically eligible mothers.

Mr. ROGERS. Yes, because I understand that of about 3 million births, 250,000 are low birth weights, and 60,000 of those will die, mainly because the mothers have not had prenatal care, advice, counseling, proper food—60,000 deaths, and it seems to me we might as well recognize this problem and do something about it.

Wouldn't this program be a good vehicle to use?

Secretary CALIFANO. Mr. Chairman, I can speak only for myself on that at this point in time.

Mr. ROGERS. I understand.

Secretary CALIFANO. I think the sooner we deal with the problem, the better. The sooner we cover prenatal care, the better off we will be from every vantage point, both in terms of dealing with the children, in terms of individual human beings, and in terms of the long-run cost implications.

Mr. ROGERS. But the Robert Wood Johnson Foundation did a study in one area of New York City, an area incidentally serviced by four hospitals. They found in 1975-1976 registered mothers, those seeing a physician or getting care from a clinic or the hospital had an infant death rate of 23.9 per 1,000, which is very high, but the unregistered mothers, those that had not had prenatal care, had an infant death rate of 43.1 per 1,000. I think even more shocking in the study, the Harlem Hospital showed that in 1956 the registered infant mortality rate was 18.4 compared to an unregistered mortality rate of 156 per 1,000.

Now that is a national disgrace, to have an infant mortality rate of 156 per 1,000.

Mr. CARTER. Mr. Chairman, I have to agree that 96 percent of women would have their youngsters normally. Only 4 percent would have difficulty according to the figures that I have been told. This is an extremely abnormal incidence of death.

Mr. ROGERS. There is no excuse for this to occur in this Nation.

Secretary CALIFANO. Absolutely. I agree with that 100 percent.

Mr. ROGERS. We will try to address it in this legislation. I think we will expand this program to cover prenatal care for first-time mothers. I am sure, if we can get the Office of Management and Budget to look at it, they will go along.

I don't believe they will recommend that the President veto.

We must recess.

I do have just a few questions and I will come back and we will finish.

The committee stands in recess for 10 minutes.

[Brief recess.]

Mr. ROGERS. The subcommitete will come to order, please.

Mr. Secretary, shouldn't we have a requirement that States maintain at least current efforts?

Secretary CALIFANO. Mr. Chairman, I have no objection to including a maintenance of effort provision in this legislation. I do think we should retain some of the bonuses we provide for good performance here, and I do think we should make sure we get a rational penalty structure. I don't know that the penalty structure that we now have at HEW works.

As you know, because you have been trying to straighten out the long-term care penalty provisions in the Medicaid program, that penalty certainly doesn't work, and here we are again assessing another quarter's worth of utilization control penalties that keep accumulating.

Mr. ROGERS. It just seems that we should require a State, if we give them more money——

Secretary CALIFANO. I have no problem with that, Mr. Chairman.

Mr. ROGERS. I think we will include such.

Now also I don't see anything in the bill that requires provider participation in delivering assessment and treatment services for Medicaid children.

Would you agree that we ought to do something to get better provider participation?

Secretary CALIFANO. We need better provider input and participation, not only here but in other Medicaid services as well. I am not sure I know the right answer to that problem, quite candidly. I do think one of the provisions, for example, in the Moss bill that makes sense to us, that we would suggest you might want to include, is the provision requiring the development of lists of eligible providers and publication of those lists.

Mr. ROGERS. I think Dr. Carter has some feeling that we should build upon public health.

Mr. CARTER. I certainly do. I feel that we should have more public health officials throughout the country, and they should be assisted by nurse practitioners, so that appropriate periodic screening can be done. When disease conditions are found, including poor dental conditions, the children can be referred to practitioners. Really, the public health system is not that bad as far as that is concerned, but we are going to have to build around the Public Health Service Corps, as I see it, to do the examination and the screening, and refer the children to physicians and treatment for correction of defects and so on.

Thank you, Mr. Chairman.

Mr. ROGERS. We will look at that, and I would hope you would as well.

Secretary CALIFANO. We will.

Mr. ROGERS. And that your people will give us some thinking on that before we write the bill.

Secretary CALIFANO. All right, Mr. Chairman.

Mr. ROGERS. Also shouldn't there be some minimum standards for reimbursement? Shouldn't you also have some authority where you could make some judgment on that, for instance, a State like Mississippi vis-a-vis New York?

Secretary CALIFANO. Mr. Chairman, this goes again to the general and one of the serious problems with providers. I guess I have to say in all candor I am not sure of the best way to deal with this problem. What you are suggesting is one way. I would like an opportunity to reflect on that a little, and come back to the committee with some suggestions, because the problem goes beyond the CHAP program and beyond dealing with children in this area.

Mr. ROGERS. In other words I don't think we can really get into this program unless we have given some thought to that, to have requirements and standards for minimum reimbursement while allowing some discretion to the Secretary.

Secretary CALIFANO. There is no question but that some States are not paying enough for the services provided under any standard.

Mr. ROGERS. Some pay——

Secretary CALIFANO. But I would like to come back to you with a special suggestion in that area if I may.

[The following information was received for the record:]

PROVIDER PROBLEMS

We propose to deal with a portion of the provider problem through the additional resource development funds requested to initiate and expand community health centers. These organizations provide the type of continuing primary care which CHAP emphasizes.

The reluctance of private providers to participate in CHAP is, of course, one aspect of their participation in Medicaid generally. Effective solutions for CHAP must deal with the larger issue, and the Department is working on proposals in connection with national health insurance planning.

Consideration was given to the adoption of a minimum fee for assessments, but was abandoned. There is wide variation in rates currently paid. To set a fee high enough to attract reluctant providers would, at the same time cost more for services now available at a lower rate.

A conference, to be sponsored by the Institute for Medicaid Management in mid-December, will develop model State action plans to encourage more provider participation in Medicaid.

Mr. ROGERS. What I want us to do, Mr. Secretary, is assure that we develop an effective program.

Now what about requiring the States to use all qualified providers who are willing to participate?

Secretary CALIFANO. I have absolutely no problem with that. I also think, Mr. Chairman, as I mentioned, in addition to the provider problem, I think we should make sure that there is plenty of flexibility to use every avenue available along the lines Mr. Maguire was suggesting, to reach these children, to identify them, get out and reach them. There are some lessons we are learning in the immunization area that make it important that we have some flexibility here.

Mr. ROGERS. Also what would be your timetable for regulations on CHAP? You know there were continual delays in EPSDT regulations.

Secretary CALIFANO. It was intolerable, a delay of a few years actually. That will not happen here. I hope to announce next week a whole new process for handling all HEW regulations, and I think when you see that, you will recognize that we will get them out.

Mr. ROGERS. That is encouraging. We congratulate you on that.

Now the bill requires States to cover all needy children under the age of 6, even if they are not in an AFDC family. Quite a few States already cover children, as you know, up to 21, who are not in broken families. If they continue that coverage, and I assume they will, would they receive the higher Federal match on the CHAP services?

Secretary CALIFANO. Yes, they would.

Mr. ROGERS. They would.

Now what I want to do is assure that they are covered as well, but I just wondered under your proposal if that was your thinking.

What about paperwork? Can't we get some of these forms down where it is not such a burden?

Secretary CALIFANO. Mr. Chairman, we are trying to do that everywhere. We have had some success in the education area. One of the reasons for combining Medicare and Medicaid in the Health

Care Financing Administration was to reduce paperwork, and I will look at it specifically in this area.

Mr. ROGERS. I think that would be helpful to the committee. Also I think we are finding that uneven rates discourage private doctors from coming in. We ought to look at that problem. I would hope you would address that too. Maybe we really ought to set national goals.

Would it be helpful to have a group come together to set this up or do you think it is sufficient to do it in the legislation with a commitment by the administration?

Secretary CALIFANO. Mr. Chairman, I think there are goals that have to be set in a host of areas, and this is one we can measure. We know the number of children. We can identify them by State. I think this is essentially a management problem of setting up a quarterly operational plan in advance as to the numbers of children that should be reached. I intend to do this as part of a general setting of specific goals for a lot of operational activities of HEW, beginning with the next quarter, I hope, or certainly no later than the first quarter of calendar 1978.

In the sense in which you are thinking about the possibility of mandating goals here, or mandating that we set goals, since we are doing it anyway, I have no objection to your doing that. I don't think we need a commission or group to look at that. I think we can monitor it and report on it. My only hope would be that if that is mandated, in line with your earlier question, that we do it in a way which doesn't create a lot of paperwork.

Mr. ROGERS. Yes.

Finally, I think the administration has testified in the Senate recommending Medicaid coverage for hard-to-place adoptive children.

Secretary CALIFANO. Absolutely.

Mr. ROGERS. I don't think we have had much comment on this side. I wonder about your feeings on that.

Secretary CALIFANO. We proposed in our legislation, which was based on proposals that were being made in the Senate and here, that such coverage should be provided. We think it is preposterous that a family that has a foster child, takes in a foster child that is on AFDC, and loves that child enough to adopt it, instantly has the funds cut off for that child, and has their eligibility for Medicaid cut off. That makes absolutely no sense.

Mr. ROGERS. Once a patient starts treatment, there ought to be a follow-up; would you agree on that?

Secretary CALIFANO. Yes, Mr. Chairman.

Mr. ROGERS. That is not limited to a 6-month period.

Secretary CALIFANO. We put 6 months in. The question we had was the administrative difficulty of going case by case, but I am certainly willing to look at that again.

Mr. ROGERS. I hope you would and let us have your thinking.

Secretary CALIFANO. I will.

Mr. MAGUIRE. Mr. Chairman, just two very quick questions.

In reference to the proposal, Mr. Secretary, that entitles children to health care subsequent to receiving a health assessment, am I correct in assuming that you also intend that problems which arise in between the times that a child is assessed should also be covered?

Secretary CALIFANO. Absolutely.

Mr. MAGUIRE. And on dental care, as I understand it, some 90 percent of children are found to need some kind of care.

In view of that fact, is it not more efficient and practical and sensible not to require assessment, and to allow them to go directly to referrals and treatment?

Secretary CALIFANO. That is fine as far as we are concerned and I would hope they can do that under these circumstances.

Mr. MAGUIRE. Thank you.

Mr. ROGERS. Mr. Secretary, thank you.

Your testimony has been helpful. I believe it is constructive. We commend you on the vigor with which you are pursuing this program and the running of your Department.

Secretary CALIFANO. Thank you, Mr. Chairman.

Mr. MAGUIRE. I concur in that, Mr. Chairman, and express my appreciation.

Mr. ROGERS. The subcommittee will be in recess while the members answer the quorum.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order.

Mr. Maguire.

Mr. MAGUIRE. Thank you, Mr. Chairman.

The next panel is a distinguished panel of experts in the field of dentistry who have come to testify on the need for dental coverage for poor children under CHAP. I share with that a great concern for the health and future of these children. Too often we hear that dental services are too expensive to provide. These statements are often made by individuals who receive the finest care in the country and in the world; they are part of the 10 percent of Americans who consume two-thirds of all dental appointments made in this country.

Those of us who receive regular care often view dental disease as an intermittent annoyance that can be dealt with as problems arise. Dental care is actually the most common disease in the country and like other diseases it varies in its virulence. Many of the children who now qualify for EPSDT have the most violent forms of the disease. They walk around with infections in their mouths that often spread into the bone and through other tissues like muscle and skin. Their teeth break off, their breath is foul, and they often are not able to eat much at all.

These same children often sit in school in pain, with their faces swollen, and they, not infrequently, suffer from malnutrition. How much educational achievement can we expect from these kids? And if education is truly the way to lift onself out of the depths of poverty, do we believe that an individual whose appearance is compromised by broken stumps and empty spaces where teeth should be, will actually be competitive in the employment market? Hardly.

Dental disease is an ugly, physically and mentally debilitating disease. Perhaps those who question the provision of dental services under CHAP can go home, look in the mirror, smile, go eat a good meal and convince themselves that dental services are not really essential. But this is no answer for the millions of children who

desperately need the help that comes almost automatically to those who are not poor.

These distinguished panelists have traveled from all over the country to express their concerns. I thank them for coming, Mr.Chairman, and I look forward to their testimony.

Mr. ROGERS. I am sorry, we are having votes on rules. I see another vote is in progress. Rather than begin the panel, we will vote and then come back. So the committee will stand in recess another 10 minutes. We apologize to those who are waiting to testify. Perhaps the panel could get set up.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order.

We have a distinguished panel of dental care providers.

Welcome to the committee.

Dr. Theordor C. Levitas, past president, American Acamdemy of Pedodontics, on behalf of the American Dental Association.

I might say I am particularly glad to welcome Dr. Theodore C. Levitas here. His brother is a distinguished Congressman and a good friend of this committee, so we are very pleased to have you with us.

Dr. Max Schoen, Professor and Chairman, Preventive Dentistry and Public Health School of Dentistry, University of California, Los Angeles; Dr. Louis Ripa, Professor and Chairman, Department of Children's Dentistry, School of Dental Medicine, State University of New York at Stony Brook; and Ms. Jeri Yunker, who is the Chairperson, Government Relations, American Dental Hygienists Association; and Marilyn Katz, Connecticut Legal Services.

We welcome each of you to the committee.

Your statements will be made a part of the record in full, and you may proceed as you desire. It would be helpful to the committee if you could capsule your remarks in about 5 minutes, if that is possible. You may proceed as you desire.

Dr. Levitas.

STATEMENTS OF THEODORE C. LEVITAS, D.D.S., ON BEHALF OF THE AMERICAN DENTAL ASSOCIATION; LOUIS RIPA, D.D.S., M.S., ON BEHALF OF THE AMERICAN SOCIETY OF DENTISTRY FOR CHILDREN; MAX H. SCHOEN, D.D.S., DR. P.H., PROFESSOR AND CHAIRMAN, PREVENTIVE DENTISTRY AND PUBLIC HEALTH SCHOOL OF DENTISTRY, UNIVERSITY OF CALIFORNIA, LOS ANGELES; JERI YUNKER, R.D.H. CHAIRPERSON, GOVERNMENT RELATIONS, AMERICAN DENTAL HYGIENISTS ASSOCIATION, ACCOMPANIED BY BEN MILLER, WASHINGTON CONSULTANT, ADHA; AND MARILYN KAPLAN KATZ, COUNSEL, CONNECTICUT LEGAL SERVICES

Dr. LEVITAS. Mr. Chairman, I am Ted Levitas of Atlanta, Georgia, and I thank you for your kind remarks.

I might take this opportunity to assure you that my brother reciprocates the high regard for you that you hold for him.

I have had the privilege of speaking to large dental organizations all over this country and abroad, and I must confess that I am a bit more anxious and nervous at this time than standing before 800

people, and it is probabaly a good thing that I am sitting down right now.

I am engaged in the practice of pediatric dentistry in Atlanta. I am past president of the American Academy of Pedodontics which is the organization of specialists in pediatric dentistry and I have been active in the American Society of Dentistry for Children.

Today I am here on behalf of the American Dental Association, which represents more than 110,000 dentists from throughout the country.

As I believe this committee is well aware, the American Dental Association has traditionally placed its highest priority on the dental care of children. The development during childhood of effective regimens of diet, professional treatment, and home care is the foundation for a lifetime of sound oral health.

Dental care for the children of indigent families and families that are minimally self-sustaining is frequently neglected. This occurs for several reasons, but certainly severely limited finances is a significant factor. Because of this situation the Association has long advocated the inclusion of dental services in health care programs aimed at these children and also has promoted the introduction of separate legislation to the same effect.

These efforts have been reviewed in the prepared statement which has been submitted.

The present situation is historically unique for us because it is the first time we have been faced with a bill that proposes incentives to reduce the minimal dental care benefits currently being offered to poor children. In the past our testimony in support of children's dental health bills has been directed toward improving the status quo. Today it appears that we are struggling just to maintain a status quo that everyone admits is grossly deficient.

Before getting into the specifics of our objections to certain provisions of H.R. 6706, I wish to make clear that we recognize the importance of all health care needs of children and support the broadening of the definition of the dependent child.

Mr. Chairman, under the existing EPSDT law and regulations States are required on paper at least, to provide "at least such dental care as is necessary for relief of pain and infection and for restorations of teeth and maintenance of dental health. . ."

Section 7 of CHAP in practical effect would repeal this provision by the following language which requires ". . . the inclusion of all care and services appropriate for individuals under age 21 (but not necessarily including. . .dental care when not for the treatment of conditions discovered during an assessment)."

As Mr. Maguire pointed out earlier this morning, we have cited the statistics showing the need for an effective dental care program I would mention again that some 97 percent of children examined were found to require dental care before age 6.

According to data gathered by the Congressional Budget Office, only 25 percent of children projected to be screened may actually be referred for dental care, because some States are reluctant to "find" dental problems they would be required to treat. This unfortunate state of affairs will become the rule under H.R. 6706 because there is no requirement that persons trained in the detection of dental

disease participate in the child assessment program, an omission that is compounded by the failure to recognize that much dental disease will occur and remain untreated during the intervals between assessments.

Further, we know that much treatment will not even be found by a visual only assessment program examination.

It is for these and other reasons that the dental profession has repeatedly urged State agencies to conserve resources and get to the business at hand by foregoing dental screening in favor of automatic referral to a dentist for diagnosis and treatment. This is the most cost effective way of meeting the dental health needs of the eligible children and we strongly urge that the bill be amended to this effect.

One of the most serious defects in H.R. 6706, and perhaps of more long-range detriment than any other to the provision of needed dental care for poor children, is the exclusion of dental care from the higher Federal matching contribution provided in section 7 of the bill. Under existing law the Federal contribution for dental and other health services ranges from 50 to 78 percent and averages 55 percent. As we understand the proposed formula under H.R. 6706, services "other than dental and inpatient care" would henceforth be matched at a rate between a minimum of 75 percent and a maximum of 84 percent.

This, of course, is an open invitation to the States to reduce even further the inadequate level of dental care now provided to poor children and an encouragement to them to refrain from broadening coverage of such care in the future. Although it would seem difficult to take a step backward from the present EPSDT program under which only one in five eligible children receives any service, the administration has succeeded in designing one of giant-size proportions, insofar as access to dental care is concerned.

The Association strongly recommends that section 7 be amended to include dental care in the higher Federal contribution rate that is proposed.

We are pleased to note that Congressman Maguire has introduced a bill that addresses itself to these specific problems. His choice this morning of the word "assurance" is a welcome one, particularly if it will help assure dental health.

In the message and press releases that accompanied the transmission of H.R. 6706 to Congress, there is strong language in support of the prevention of illness and particularly immunizations which of course, we support wholeheartedly.

Dental caries has been said to be the most prevalent disease afflicting man. Yet no mention is made of community water flouridation which has been recognized for nearly four decades as a safe and effective method of preventing dental disease. For a modest investment in authorizing grants on a voluntary basis to communities wishing to adjust their water supplies, millions of people could be benefited and millions of dollars could be saved.

I would commend Congressman Waxman for his comments on the need to include dental care.

Finally, Mr. Chairman, based upon a considerable number of years of experience, we of ADA anticipate that the Department of

Health, Education, and Welfare will attempt to defend the exclusionary dental care provision of H.R. 6706 on the basis of budgetary considerations. In this regard, the Department's estimates of costs as reported to us are based upon unrealistic assumptions and are significantly inflated. We would be glad to provide our cost projections for the record. In any event, the government should be willing to make a reasonable, humanitarian commitment to the improvement of the dental health of poor children, for general health and dental health are inextricably intertwined. Let me assure you that dental care is too expensive not to be provided.

Most of all, Mr. Chairman, you can see we have some serious concerns with this legislation. At the same time, we support the basic philosophy of the bill which is to improve health care for low income children. We have prepared amendments that would remedy the deficiencies we have described and we would be pleased to submit these and work with the committee toward further improvements in the bill.

In conclusion, let me just comment that the philosopher Goethe said "Little can be done for grownup people. The intelligent man begins with the child."

The American Society of Dentistry for Children has adopted this as its motto. We would urge you to adopt this same motto, and to begin realistically with dental care for children.

Thank you for your time and consideration.

[Dr. Levitas' prepared statement follows:]

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STATEMENT OF
THE AMERICAN DENTAL ASSOCIATION
ON H.R. 6706
THE CHILD HEALTH ASSESSMENT ACT
BEFORE THE
SUBCOMMITTEE ON HEALTH AND THE ENVIRONMENT
COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE
UNITED STATES HOUSE OF REPRESENTATIVES
SEPTEMBER 9, 1977

Mr. Chairman, I am Dr. Theodore C. Levitas of Atlanta, Georgia where I am engaged in the practice of dentistry specializing in Pedodontics. I am a past-President of the American Academy of Pedodontics and have been very active in the American Society of Dentistry for Children. I am here today on behalf of the American Dental Association which represents more than 110,000 dentists from throughout the country.

I am pleased to have this opportunity to present the views of the American Dental Association on H.R. 6706, the Child Health Assessment Act.

As I believe this Committee is well aware, the American Dental Association has traditionally placed its highest priority on the dental care of children. The development during childhood of effective regimens of diet, professional treatment, and home care is the foundation for a lifetime of sound oral health.

Dental care for the children of indigent families and families that are minimally self-sustaining is frequently neglected. This occurs for several reasons, but certainly severely limited finances is a significant factor. Because of this situation the Association has long advocated the inclusion of dental services in health care programs aimed at these children and also has promoted the introduction of separate legislation to the same effect.

With the indulgence of the Committee, I would like briefly to review some of these efforts:

In 1964, when the Association testified on Medicaid, we urged that if resources would not permit coverage of all needy persons, at least dental care for children should be mandated. Such a provision was adopted by the Senate but was dropped in a House-Senate conference with cost cited as the reason.

In 1967, at the urging of the Association, the then Administration submitted to Congress a bill authorizing

among other things pilot dental projects under Title V of the Social Security Act. The bill was passed but no funds were allocated for such projects during fiscal years 1968, 1969 or 1970. In 1971, $500,000 were allocated to seven dental projects serving about 10,000 children. The next year about $860,000 were allocated and by the terms of the law the program was merged into other Title V projects.

The Association vigorously supported the 1967 amendments to the Social Security Act which established EPSDT and included dental care among the mandated benefits. The program languished for more than 2 years until a lawsuit was brought to require HEW to carry out its provisions. Even then and up to the present, progress has been painfully slow, which of course is one of the reasons we are gathered here today.

In 1971, following a comprehensive hearing in the Senate, a Children's Dental Health Act introduced by Senator Warren G. Magnuson and strongly supported by the Association was passed by the Senate by a vote of 88 to 1. It provided grants for children's dental health care projects, fluoridation grants on a one-time voluntary basis, dental health education and other programs to develop effective preventive dental programs for children. The bill was not considered in the House.

In 1975 Senator Magnuson introduced a revised version of the Children's Dental Health Act, again with the Association's support which was designed specifically to augment the floundering EPSDT program by authorizing dental project grants for dental care and services for children of pre-school and school age who qualify for Medicaid. The bill passed the Senate as an amendment to the National Consumer Health Information and Health Protection Act of 1976 but was not included in the final bill reported to the floor of the House.

That brings us down to the present, Mr. Chairman and the situation is historically unique for us because it is the first time we have been faced with a bill that proposes incentives to reduce the minimal dental care benefits currently being offered to poor children. In the past, our testimony in support of children's dental health bills has been directed toward improving the status quo. Today, it appears that we are struggling just to maintain a status quo that everyone admits is grossly deficient.

Before getting into the specifics of our objections to certain provisions of H.R. 6706, I wish to make clear that we recognize the

importance of all health care needs of children, none of which should be neglected. We therefore support the broadening of the definition of "dependent child" and the assurance of continuing care for children whose families' income increases beyond the level of eligibility as provided in Section 2(3) of the bill. The increased emphasis on immunization also is desirable and necessary.

The provisions for outreach appear much improved over EPSDT with federal matching reimbursement tied to these efforts as well as case tracking and follow-up. In this connection, it is our view that inadequate case tracking and outreach are major causes of deficiencies in the EPSDT program. At present there is no information system, no way to identify in a timely manner which children received treatment as a result of referral and as a consequence, no timely way of tracking patients within the system. The new penalty provisions in Section 7(b)(1) appear to be an improvement, but we believe Congress should continue to seek methods of assuring compliance without reducing a state's health care funds. The monetary incentive for good performance also is an important innovation. While Section 6 speaks vaguely to encouraging participation of providers in Medicaid under regulations of the Secretary, the crux of this matter lies in the unrealistic reimbursement schedules that are in effect in many areas, an issue that should be addressed directly.

To turn now to our specific concerns with H.R. 6706, Mr. Chairman, it is our opinion, with all respect to those in the Administration who drafted the bill, that its preamble would more accurately describe its provisions related to dental care if it said "To weaken and emasculate the early, periodic screening, diagnosis and treatment program".

Although the EPSDT program in many respects has been seriously deficient because of faltering and indifferent implementation and underfunding, its weaknesses do not lie in its underlying intent or in the scope of its benefits. CHAP, on the other hand, represents a step backward, if that is possible, in its exclusion of benefits, its disincentives to the provision of comprehensive care and its reliance upon delivery settings that do not exist in many areas or do not lend themselves effectively or economically to meeting the total health needs of the children to be served.

Mr. Chairman, under the existing EPSDT law and regulations States are required on paper at least, to provide "at least such dental care as is necessary for relief of pain and infection and for restorations of teeth and maintenance of dental health..." (CFR 239.10(b)(3)(IV)).

Section 7 of CHAP in practical effect would repeal this provision by the following language which requires "...the inclusion of all care and services appropriate for individuals under age twenty-one (but not necessarily including... dental care when not for the treatment of conditions discovered during an assessment)."

This provision is wholly unrealistic unless its purpose is to deny needed dental care to most of the Medicaid-eligible children in the country. Had the Administration's authors of the bill taken the time and effort, and perhaps they did, to review the information available from their own and other independent sources, they would have discovered from a report on the health status of children of low income families in the Maternal and Child Health Program that in 1969 dental patient visits for all children from families with incomes of $7,000-$10,000 was four times that of children from families with incomes of $3,000-$5,000; that only 40 percent of children under age 17 from low income families had ever been to a dentist; that 97 percent of such children were found to require some dental care before age 6. From a report of the American Academy of Pediatrics on the Delivery of Health Care to Children they would have read that "Dental Disease is nearly universal in children and 50 percent of preschool children have one or more decayed teeth. Poverty intensifies neglect so that children from low income families have five times as many untreated decayed teeth as the average child". From another report they could have found that when black teenagers' health status was examined in Harlem in 1972, dental disease was found to be overwhelmingly the most common problem.

Further they would have found from their own records that in the early days of the Headstart program significant amounts of money were ill-spent, or wasted by requiring dental screenings which many times produced a well-intended chart that collected dust instead of resulting in needed follow-up dental treatment. They also could have found from more recent experience under EPSDT that in states requiring screening by non-dentists as a prerequisite to dental treatment only a small percentage are actually referred for care and those often include only children with the most visible or gross conditions, usually involving severe pain. According to data gathered by the Congressional Budget Office only 25 percent or 500,000 of the 2,000,000 (children) projected to be screened may actually be referred for dental care because some states are reluctant to "find" dental problems they would be required to treat. This unfortunate state of affairs will become the rule under H.R. 6706 because there is no requirement that persons trained in the detection of dental disease participate in the child assessment program, an ommission that is compounded by the failure to recognize that much dental disease will occur and remain untreated during the intervals between assessments.

This litany of the easily discoverable and obvious could be continued to include notice to the Department of Health, Education and Welfare that children with seriously diseased mouths do not perform well in school or in work, that oral disfigurements are handicapping to youths seeking employment, that thousands of man-hours of work per year are lost because of oral disease, and, perhaps most importantly that dental disease is among the most preventable of all maladies.

It is for these and other reasons that the dental profession has repeatedly urged state agencies to conserve resources and get to the business at hand by foregoing dental screening in favor of automatic referral to a dentist for diagnosis and treatment. This is the most cost effective way of meeting the dental health needs of the eligible children and we strongly urge that the bill be amended to this effect.

In this same connection it should be emphasized that the reliance placed in H.R. 6706 upon the utilization of health care centers for assessment and treatment is particularly inappropriate and probably unworkable for dental care since more than three quarters of all dentists practice alone in a private office setting. The American Dental Association believes that the Medicaid eligible population should have the same access to care as the population in general. Emphasizing a delivery mechanism not widely used by the public serves to set the Medicaid eligible children apart, clearly an undesirable effect.

One of the most serious defects in H.R. 6706 and perhaps of more long-range detriment than any other to the provision of needed dental care for poor children is the exclusion of dental care from the higher federal matching contribution provided in Section 7 of the bill. Under existing law the federal contribution for dental and other health services ranges from 50 to 78 percent and averages 55 percent. As we understand the proposed formula under H.R. 6706, services "other than dental and inpatient care" would henceforth be matched at a rate between a minimum of 75 percent and a maximum of 84 percent.

This, of course, is an open invitation to the states to reduce even further the inadequate level of dental care now provided to poor children and an encouragement to them to refrain from broadening coverage of such care in the future. Although it would seem difficult to take a step backward from the present EPSDT program under which only one in five eligible children receives any service, the Administration has succeeded in designing one of giant-size proportions, insofar as access to dental care is concerned.

The Association strongly recommends that Section 7 be amended to include dental care in the higher federal contribution rate that is proposed.

In the message and press releases that accompanied the transmission of H.R. 6706 to Congress, there is strong language in support of the prevention of illness and particularly immunizations which of course, we support wholeheartedly. No mention is made, however, of community water fluoridation which has been recognized for nearly four decades as a safe and effective method of preventing dental disease. For a modest investment in authorizing grants on a voluntary basis to communities wishing to adjust their water supplies, millions of people could be benefited and millions of dollars could be saved. Although the present and previous Administrations have given a great amount of lip-service in support of the water fluoridation procedure, it is regrettable that they all have joined in the groundswell of timidity that has prevented substantive federal action.

Finally, Mr. Chairman, based upon a considerable number of years of experience, we anticipate that the Department of Health, Education and Welfare will attempt to defend the exclusionary dental care provision of H.R. 6706 on the basis of budgetary considerations. In this regard, the Department's estimates of costs as reported to us are based upon unrealistic assumptions and are significantly inflated. We would be glad to provide our cost projections for the record. In any event, the government should be willing to make a reasonable, humanitarian commitment to the improvement of the dental health of poor children.

Mr. Chairman, as you can see we have some serious concerns with this legislation. At the same time, we support the basic philosophy of the bill which is to improve health care for low income children. We have prepared amendments that would remedy the deficiencies we have described and we would be pleased to submit these and work with the Committee toward further improvements in the bill.

Thank you for your time and your consideration.

Mr. ROGERS. Thank you very much, Dr. Levitas, for a very helpful statement.

There is again another call. I think there are going to be two more after this. You will have to bear with us. We will recess for 10 minutes.

I might say for the convenience of other panelists, this will be the last panel before lunch. We will come back at 1:30 to begin the other panels.

[Brief recess.]

Mr. MAGUIRE. The subcommittee will come to order.

Dr. Ripa, I believe your testimony is next.

STATEMENT OF LOUIS RIPA, D.D.S., M.S.

Dr. RIPA. Mr. Chairman and members of the subcommittee: I am Louis Ripa, professor and chairman of the Department of Children's Dentistry, School of Dental Medicine, State University of New York at Stony Brook.

I appreciate the opportunity to appear before you today. I am a member of national organizations promoting dental service, research, and education, including the American Association of Den-

tal Research, and appear here today with the support of the American Society of Dentistry for Children.

I wish to provide the committee with an overview of the magnitude of the problem of dental disease, specifically dental caries, in American children and adolescents. I ask permission to submit for the record a longer referenced and illustrated version of my statement [see p. 290].

The principal disease affecting children and adolescents is dental caries. Dental decay starts early in life, and few individuals are immune. A study of a group of preschool children residing in flouride-deficient midwestern communities revealed that even before the full eruption of the deciduous teeth, teeth were already decaying. In this group of 1 to 3-year olds, one third of the children were diagnosed as having cavities involving 25 percent of their teeth. By age 5, the percentage of children affected by dental decay rises to 75 percent.

A description of caries activity in children is further compounded by the eruption of the permanent dentition, so that, during the 6- to 12-year-old period, both deciduous and pemanent teeth are present together in the mouth. The first permanent teeth to erupt, at age 6, are the first molars. They are believed, by many, to be the most caries susceptible teeth in the mouth. The first permanent molars are the permanent teeth which are most frequently extracted because of decay. The premature loss of a tooth, especially a first permanent molar, usually leads to orthodontic complications.

It is generally acknowledged that in fluoride-deficient communities, children average about 0.75 new lesions a year. Thus, data from the National Health Survey shows that the average 12-year-old child has four carious permanent teeth, while the average 17-year-old has 8.78. Our own data obtained in 1975 on children in our local Long Island community, are consistent with these figures. Since each tooth has five surfaces, the number of decayed surfaces, as opposed to decayed teeth, which must be restored is considerably higher than represented by these figures.

By early adulthood, few individuals enjoy a caries-free status. Only three of every 1,000 new Navy recruits entering the Great Lakes Naval Training Center are caries-free.

The treatment of dental caries is either restoration or extraction with possible replacement. The magnitude of the dental care problem in the young adult is expressed in statistics on treatment needs of new United States Army recruits in 1969. The minimum dental needs resulting from caries, per 1,000 recruits, were:

8,500 tooth surfaces requiring dental restoration, 205 crowns, 582 fixed or removable dentures, and 1,008 tooth extractions.

For these needs, the Army allocates one dentist per 600 to 800 recruits.

It must be emphasized, however, that the receipt of dental care is not uniform throughout the population. While the caries prevalence of high versus low socioeconomic groups is comparable, the amount of dental care that these groups have received is not. The highest number of carious teeth is found among children in low-income families, and the highest number of restored teeth is found among children of high-income families.

Suggested approaches to the national problem of dental decay in children include examination, prevention, and treatment. It must be strongly emphasized that mass, routine dental inspections; i.e., dental screenings, in children is unnecessary. As discussed earlier in this presentation, dental decay is a pandemic. It is, therefore, a waste of resources to conduct mass screenings on a population known to be susceptible to the disease and in which the disease is demonstrably high. Allocation of resources must be directed toward treatment of existing lesions and prevention of future ones. Treatment is necessary, since neglect will lead to pain, infection, and a deterioration of the normal dentition through tooth loss. This, in turn, can be reflected in absenteeism from school or industry, and often limits the possible potential of the child or adolescent.

A course of treatment, however, will not suffice to both resolve the existing dental needs of our children and accommodate the ones that develop each year on so large a scale. The unmet needs of approximately 24 million children in the United States, aged 6 to 11, include 12 million untreated decayed permanent teeth and 33 million untreated deciduous teeth.

Dental caries, however, is a preventable disease. It can be controlled by the widespread application of safe and effective procedures. Prevention is a realistic approach in children since the decay process starts at an early age. In addition, it is generally more economical to prevent a disease than to treat it.

The primary agent for the prevention of caries is fluoride. As of January 1976, 49.4 percent of the U.S. population was consuming optimally fluoridated drinking water, with an expected caries reduction of approximately 50 percent. The fluoridation of community water supplies, however, will not reach the entire population since approximately 23 percent of U.S. residents are not served by central water supplies. Thus, other methods of providing fluoride to children on a communitywide basis have been sought. Reductions of between 20 percent and 50 percent can be expected from a daily regimen of fluoride tablets or from fluoride rinsing. Topical fluoride treatments in the dental office, the application of sealants to the occlusal surfaces by dentists or trained ancillaries, and the routine use of approved fluoride-containing dentifrices have been shown to further reduce the number of decayed teeth.

Currently, two diffeent school-based caries-preventive demonstration programs have been initiated in the United States. One, funded by the National Institute of Dental Research, involves approximately 80,000 school children in the supervised weekly rinsing of a 0.2 percent sodium fluoride solution. The other, under the auspices of the American Fund for Dental Health and supported by the Robert Wood Johnson Foundation, involves several different therapeutic regimens within the schools. This program was initially designed to involve 20,000 elementary school children. I am involved as project director or Dental Examiner in both of these projects. These programs are expected to serve as models for future community caries preventive programs.

There is a very definite need to provide secondary care for children and adolescents in order to restore normal function to diseased mouths. However, primary care through appropriate pre-

ventive modes must be encouraged since it is an unrealistic expectation that dental needs can ever be totally met by treatment alone.

Legislation designed to provide dental care for the underprivileged must provide, at a minimum, a level similar to that already available through EPSDT.

[Testimony resumes on p. 318.]

[Dr. Ripa's prepared statement and attachments follow:]

STATEMENT OF LOUIS W. RIPA, D.D.S., M.S.

TO THE

HOUSE OF REPRESENTATIVES

INTERSTATE AND FOREIGN COMMERCE COMMITTEE

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT

REGARDING

CHILD HEALTH ASSESSMENT ACT

(H.R. 6706)

MR. CHAIRMAN AND MEMBERS OF THE SUBCOMMITTEE, I AM LOUIS RIPA, PROFESSOR AND CHAIRMAN OF THE DEPARTMENT OF CHILDREN'S DENTISTRY, SCHOOL OF DENTAL MEDICINE, STATE UNIVERSITY OF NEW YORK AT STONY BROOK. I AM A MEMBER OF NATIONAL ORGANIZATIONS PROMOTING DENTAL SERVICE, RESEARCH, AND EDUCATION* AND APPEAR HERE WITH THE SUPPORT OF THE AMERICAN SOCIETY OF DENTISTRY FOR CHILDREN. I WISH TO PROVIDE THE COMMITTEE WITH AN OVERVIEW OF THE MAGNITUDE OF THE PROBLEM OF DENTAL DISEASE, SPECIFICALLY DENTAL CARIES, IN AMERICAN CHILDREN AND ADOLESCENTS.

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* MEMBER, AMERICAN DENTAL ASSOCIATION
MEMBER, AMERICAN SOCIETY OF DENTISTRY FOR CHILDREN
MEMBER, NEW YORK STATE SOCIETY OF DENTISTRY FOR CHILDREN
FELLOW, AMERICAN ACADEMY OF PEDODONTICS
DIPLOMATE, AMERICAN BOARD OF PEDODONTICS
MEMBER AND FACULTY DELEGATE, AMERICAN ASSOCIATION OF DENTAL SCHOOLS
MEMBER, INTERNATIONAL ASSOCIATION FOR DENTAL RESEARCH
MEMBER, AMERICAN ASSOCIATION FOR DENTAL RESEARCH

In the interest of time, I ask permission to submit for the record a referenced and illustrated version of my statement.

Dental Caries Prevalence

The principle dental disease affecting children and adolescents is dental caries. Along with the common cold, it is the most prevalent disease which afflicts the American population. Dental decay starts early in life and few individuals are immune. A study of a group of pre-school children residing in fluoride-deficient Midwestern communities revealed that even before the full eruption of the deciduous dentition, teeth were already decaying.[1] In this group of 1- to 3-year-olds, one-third of the children were diagnosed as having cavities involving 25% of their teeth (Table 1). As determined in a review conducted for the National Academy of Sciences, by age 5, the percentage of children affected by dental decay rises to 75%.[2]

Statistics on dental disease in children is well documented after age 5, when the children enter school and are available for examination. Data from the National Health Survey shows that at age 6, the mean number of decayed or filled teeth is 3.5.[3] While the total number of decayed or filled deciduous teeth becomes less due to the normal shedding of the deciduous teeth, the percentage of decayed and filled deciduous teeth remains constant through age 12[4] (Table 2).

A DESCRIPTION OF CARIES ACTIVITY IN CHILDREN IS FURTHER COMPOUNDED BY THE ERUPTION OF THE PERMANENT DENTITION, SO THAT, DURING THE 6- TO 12-YEAR-OLD PERIOD, BOTH DECIDUOUS AND PERMANENT TEETH ARE PRESENT TOGETHER IN THE MOUTH. THE FIRST PERMANENT TEETH TO ERUPT, AT AGE 6, ARE THE FIRST MOLARS. THEY ARE BELIEVED, BY MANY, TO BE THE MOST CARIES SUSCEPTIBLE TEETH IN THE MOUTH. THE FIRST PERMANENT MOLARS ARE THE PERMANENT TEETH WHICH ARE MOST FREQUENTLY EXTRACTED BECAUSE OF DECAY. THE PREMATURE LOSS OF A TOOTH, ESPECIALLY A FIRST PERMANENT MOLAR, USUALLY LEADS TO ORTHODONTIC COMPLICATIONS.

IT IS GENERALLY ACKNOWLEDGED THAT IN FLUORIDE-DEFICIENT COMMUNITIES, CHILDREN AVERAGE ABOUT 0.75 NEW LESIONS A YEAR.[5] THUS, DATA FROM THE NATIONAL HEALTH SURVEY SHOWS THAT THE AVERAGE 12-YEAR-OLD CHILD HAS FOUR CARIOUS PERMANENT TEETH, WHILE THE AVERAGE 17-YEAR-OLD HAS 8.7[6] (TABLE 3). OUR OWN DATA OBTAINED IN 1975 ON CHILDREN IN OUR LOCAL LONG ISLAND COMMUNITY, ARE CONSISTENT WITH THESE FIGURES (FIGURE 1). SINCE EACH TOOTH HAS FIVE SURFACES, THE NUMBER OF DECAYED SURFACES (AS OPPOSED TO DECAYED TEETH) WHICH MUST BE RESTORED IS CONSIDERABLY HIGHER THAN REPRESENTED BY THESE FIGURES.

CONSEQUENCES OF DENTAL CARIES

BY EARLY ADULTHOOD, FEW INDIVIDUALS ENJOY A CARIES-FREE STATUS. ONLY THREE OF EVERY 1,000 NEW NAVY RECRUITS ENTERING THE GREAT LAKES NAVAL TRAINING CENTER ARE CARIES-FREE.[7]

The treatment of dental caries is either restoration or extraction with possible replacement. The magnitude of the dental care problem in the young adult is expressed in statistics on treatment needs of new United States Army recruits in 1969. The minimum dental needs resulting from caries, per 1,000 recruits, were:

8,500 tooth surfaces requiring dental restoration
205 crowns
582 fixed or removable dentures
1,008 tooth extractions

For these needs, the Army allocates one dentist per 600 to 800 recruits.*

It must be emphasized, however, that the receipt of dental care is not uniform throughout the population. While the caries prevalence of high versus low socio-economic groups is comparable, the amount of dental care that these groups have received is not. The highest number of carious teeth is found among children in low income families, and the highest number of restored teeth is found among children of high income families (Figure 2).

Approaches to the Caries Problem

Suggested approaches to the national problem of dental decay in children include examination, prevention, and treatment. It must be strongly emphasized that mass, routine dental inspections; i.e.,

DENTAL SCREENINGS, IN CHILDREN IS UNNECESSARY.[9] AS DISCUSSED EARLIER IN THIS PRESENTATION, DENTAL DECAY IS A PANDEMIC. IT IS, THEREFORE, A WASTE OF RESOURCES TO CONDUCT MASS SCREENINGS ON A POPULATION KNOWN TO BE SUSCEPTIBLE TO THE DISEASE AND IN WHICH THE DISEASE IS DEMONSTRABLY HIGH. ALLOCATION OF RESOURCES MUST BE DIRECTED TOWARD TREATMENT OF EXISTING LESIONS AND PREVENTION OF FUTURE ONES. TREATMENT IS NECESSARY, SINCE NEGLECT WILL LEAD TO PAIN, INFECTION, AND A DETERIORATION OF THE NORMAL DENTITION THROUGH TOOTH LOSS. THIS, IN TURN, CAN BE REFLECTED IN ABSENTEEISM FROM SCHOOL OR INDUSTRY, AND OFTEN LIMITS THE POSSIBLE POTENTIAL OF THE CHILD OR ADOLESCENT.

A COURSE OF TREATMENT, HOWEVER, WILL NOT SUFFICE TO BOTH RESOLVE THE EXISTING DENTAL NEEDS OF OUR CHILDREN AND ACCOMMODATE THE ONES THAT DEVELOP EACH YEAR ON SO LARGE A SCALE. THE UNMET NEEDS OF APPROXIMATELY 24 MILLION CHILDREN IN THE UNITED STATES, AGED 6 TO 11, INCLUDE 12 MILLION UNTREATED DECAYED PERMANENT TEETH AND 33 MILLION UNTREATED DECIDUOUS TEETH.[5,10]

DENTAL CARIES, HOWEVER, IS A PREVENTABLE DISEASE. IT CAN BE CONTROLLED BY THE WIDESPREAD APPLICATION OF SAFE AND EFFECTIVE PROCEDURES. PREVENTION IS A REALISTIC APPROACH IN CHILDREN SINCE THE DECAY PROCESS STARTS AT AN EARLY AGE. IN ADDITION, IT IS GENERALLY MORE ECONOMICAL TO PREVENT A DISEASE THAN TO TREAT IT.

The primary agent for the prevention of caries is fluoride. As of January, 1976, 49.4% of the U. S. population was consuming optimally fluoridated drinking water,[11] with an expected caries reduction of approximately 50% (Table 4). The fluoridation of community water supplies, however, will not reach the entire population since approximately 23% of U. S. residents are not served by central water supplies. Thus, other methods of providing fluoride to children on a community-wide basis have been sought. Reductions of between 20% and 50% can be expected from a daily regimen of fluoride tablets (Table 5A and B) or from fluoride rinsing (Table 6).[12,13] Topical fluoride treatments in the dental office (Table 7A, B, and C), the application of sealants to the occlusal surfaces by dentists or trained ancillaries (Table 8), and the routine use of approved fluoride-containing dentifrices (Table 9A and B) have been shown to further reduce the number of decayed teeth.[14,15,16]

Currently, two different school-based demonstration programs have been initiated in the United States. One, funded by the National Institute of Dental Research, involves approximately 80,000 school children in the supervised weekly rinsing of a 0.2% sodium fluoride solution. The other, under the auspices of the American Fund for Dental Health and supported by the Robert Wood Johnson Foundation, involves several different therapeutic regimens within the schools (Figure 3). This program was initially designed to involve 20,000 elementary school children. (I am

INVOLVED AS PROJECT DIRECTOR OR DENTAL EXAMINER ON BOTH OF THESE PROJECTS.) THESE PROGRAMS ARE EXPECTED TO SERVE AS MODELS FOR FUTURE COMMUNITY CARIES PREVENTIVE PROGRAMS.

RECOMMENDATIONS

THERE IS A VERY DEFINITE NEED TO PROVIDE SECONDARY CARE TO CHILDREN AND ADOLESCENTS IN ORDER TO RESTORE NORMAL FUNCTION TO DISEASED MOUTHS. HOWEVER, PRIMARY CARE THROUGH APPROPRIATE PREVENTIVE MODES MUST BE ENCOURAGED SINCE IT IS AN UNREALISTIC EXPECTATION THAT DENTAL NEEDS CAN EVER BE TOTALLY MET BY TREATMENT ALONE.

LEGISLATION DESIGNED TO PROVIDE DENTAL CARE FOR THE UNDER-PRIVILEDGED MUST PROVIDE, AT A MINIMUM, A LEVEL SIMILAR TO THAT ALREADY AVAILABLE THROUGH EPSDT.

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TABLE 5A: CARIES-PREVENTIVE EFFECTS OF FLUORIDE TABLETS ON DECIDUOUS TEETH: A SUMMARY.

TABLE 5B: CARIES-PREVENTIVE EFFECTS OF FLUORIDE TABLETS ON PERMANENT TEETH: A SUMMARY

SOURCE: INTERNATIONAL WORKSHOP ON FLUORIDES AND DENTAL CARIES REDUCTIONS, D.J. FORRESTER & E.M. SCHULZ, JR. (EDS.), BALTIMORE, 1974.

TABLE 6: SELF-ADMINISTRATION OF TOPICAL FLUORIDE BY MOUTH RINSING.

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TABLE 7A: STUDIES EMPLOYING TOPICAL NaF IN PERMANENT TEETH: NON-FLUORIDE AREAS.

TABLE 7B: STUDIES EMPLOYING TOPICAL SnF_2 IN PERMANENT TEETH: NON-FLUORIDE AREAS.

TABLE 7C: STUDIES OF TOPICALLY-APPLIED ACIDULATED PHOSPHATE-FLUORIDE SYSTEMS IN PERMANENT TEETH: NON-FLUORIDE AREAS.

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TABLE 8: Results of Clinical Sealant Studies.

SOURCE: Ripa, L.W.: Properties and Uses of Dental Materials in Pedodontics, chapter in Clinical Pedodontics, S. Finn (ed.), 5th Edition of book in preparation for W.B. Saunders, Philadelphia.

TABLE 9A: Dentifrice Studies Using Stannous Fluoride with a Compatible Calcium Phosphate Abrasive System (North American studies only).

TABLE 9B: Dentifrice Studies Using Sodium Monofluorophosphate as the Active Therapeutic Agent.

SOURCE: Ripa, L.W.: The Effectiveness of Oral Hygiene Methods in the Control of Dental Caries, chapter 9, In Oral Hygiene in Oral Health, H.J.V. Goldberg & L.W. Ripa (eds.), C.C. Thomas, Springfield, 1977, pp. 283-308.

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TABLE I

Caries Prevalence in Preschool Children

Age of children (yrs.)	Number of children	Percent with caries	def teeth all children	def teeth children with caries
1	48	8.3	0.13	1.50
2	708	35.3	1.36	3.85
3	159	57.2	2.66	4.65

TABLE 2

Mean annual caries incidence rates (new decayed and filled surfaces) per 100 primary tooth surfaces at risk

	Age 7-9		Age 8-10		Age 9-11		Age 10-12		All ages	
	M	F	M	F	M	F	M	F	M	F
Upper										
Second molar	5·42	8·25	6·11	7·50	6·52	7·39	6·90	5·12	6·18	7·07
First molar	4·80	4·79	3·78	4·75	3·83	4·85	2·99	0·99	4·01	4·62
Canine	1·67	0·93	1·66	0·81	0·74	0·62	1·58	0·53	1·42	0·79
Lower										
Second molar	7·02	6·59	6·21	4·85	7·52	6·65	7·82	2·73	6·91	5·56
First molar	3·71	3·85	2·62	2·41	2·04	1·14	2·91	1·54	2·87	2·72
Canine	0·90	1·00	0·57	0·16	1·44	1·50	0	0	0·78	0·67
All teeth	3·67	4·45	3·39	3·60	3·65	4·06	3·87	2·32	3·59	3·89

TABLE 3

Average number of decayed (D), missing (M), and filled (F) teeth per person among youths 12-17 years, with standard errors of the estimates, by age, sex, and race: United States, 1966-70

Age and sex	All DMF teeth			D teeth			M teeth			F teeth		
	Total[1]	White	Negro	Total[1]	White	Negro	Total[1]	White	Negro	Total[1]	White	Negro
	Number of teeth											
Both sexes												
12-17 years	6.2	6.3	5.6	1.7	1.5	3.2	0.7	0.6	1.3	3.8	4.2	
12 years	4.0	4.0	3.7	1.2	1.1	2.3	0.4	0.4	0.7	2.3	2.6	(
13 years	4.7	4.8	4.4	1.5	1.3	2.6	0.5	0.4	1.0	2.8	3.1	0.8
14 years	5.9	5.9	5.6	1.8	1.5	3.3	0.6	0.6	1.2	3.5	3.8	1.2
15 years	7.0	7.1	6.0	1.9	1.6	3.5	0.8	0.8	1.4	4.2	4.7	1.1
16 years	7.4	7.4	7.2	1.9	1.6	4.0	0.8	0.7	1.7	4.6	5.1	1.4
17 years	8.7	8.9	7.4	2.0	1.7	3.8	1.1	1.0	1.9	5.6	6.2	1.7
Male												
12-17 years	5.8	6.0	5.2	1.7	1.5	3.0	0.7	0.6	1.4	3.5	3.8	0.8
12 years	3.6	3.6	3.6	1.2	1.0	2.3	0.4	0.3	0.7	2.1	2.3	0.6
13 years	4.4	4.5	3.8	1.3	1.2	2.2	0.5	0.4	1.1	2.6	2.9	0.5
14 years	5.5	5.6	5.1	1.8	1.6	3.1	0.6	0.5	1.3	3.1	3.4	0.8
15 years	6.6	6.7	5.5	1.8	1.6	3.0	0.8	0.7	1.7	4.0	4.4	0.8
16 years	7.0	7.0	6.7	1.9	1.6	4.0	0.9	0.8	1.7	4.2	4.7	1.1
17 years	8.6	8.8	7.1	2.2	2.0	3.8	1.2	1.1	1.8	5.2	5.7	1.4
Female												
12-17 years	6.5	6.6	6.0	1.7	1.4	3.4	0.7	0.6	1.2	4.1	4.5	1.4
12 years	4.3	4.4	3.7	1.3	1.2	2.4	0.4	0.4	0.6	2.6	2.8	0.7
13 years	5.1	5.1	5.0	1.6	1.4	3.0	0.5	0.4	0.8	3.0	3.3	1.1
14 years	6.3	6.3	6.1	1.7	1.4	3.4	0.7	0.6	1.0	3.8	4.2	1.6
15 years	7.4	7.5	6.6	2.0	1.7	4.0	0.9	0.8	1.2	4.5	5.0	1.4
16 years	7.8	7.8	7.6	1.8	1.5	4.1	0.8	0.7	1.7	5.1	5.6	1.7
17 years	8.8	9.0	7.7	1.8	1.4	3.8	1.0	0.9	1.9	6.0	6.6	2.0

TABLE 4

COMPARISON OF DMF TEETH* PER CHILD BEFORE AND AFTER FLUORIDATION**

Community	Age	DMF Teeth	% Difference
Brantford, Ontario			
Before F., 1944-45	8	2.4	54.2
After F., 1955	8	1.1	
Newburgh, New York			
Before F., 1944-45	9	3.1	51.6
After F., 1954	9	1.5	
Grand Rapids, Michigan			
Before F., 1944-45	10	4.9	53.1
After F., 1954	10	2.3	
Marshall, Texas			
Before F., 1945	10	4.3	67.4
After F., 1956	10	1.4	
Evanston, Illinois			
Before F., 1946	12-14	9.0	48.9
After F., 1959	12-14	4.6	

* DMF teeth includes permanent teeth decayed, missing or filled

** Adapted from United States Public Health Service statistics

TABLE 5-A

Caries-Preventive Effects of Fluoride Tablets on Deciduous Teeth: A Summary

Study	F Compound	Daily Dosage (mg)	Initial Age of Subjects In Years	No. of Subjects	Years of F Intake	Caries Reduction	
Arnold et al. 1960	NaF	0.5-1	Birth-6	121	1-12	"Comparable to water F" (deft)	[5]
Pollak 1960	NaF+V[$]	1	3	100	2	80% (dmft)	[3]
	NaF+V	1	4	111	2	20% (dmft)	[3]
Ziemnowicz-Glowaka 1960	NaF	0.8* (4x0.2)[$]	3	139	2	26% (dmfs)	[1]
Lutomska & Koninska 1962	NaF	0.6 (3x0.2)	3-4	154	2	"No significant effect"	[3]
Kamocka et al. 1964	NaF	0.75* (3x0.25)	3	64	3	0% (dmft)	[2]
	NaF	0.75* (3x0.25)	4	79	3	0% (dmft)	[2]
Leonhardt 1965	NaF+V (liquid)	1*	3	?	2	38% (dmft)	[3]
	NaF+V (liquid)	1*	4	?	2	30% (dmft)	[3]
Hennon et al. 1966, 1967, 1970	NaF+V	0.5-1	Birth-5½	85	3	63% (dmfs)	[1]
	NaF+V	0.5-1	Birth-5½	54	4	68% (dmfs)	[1]
	NaF+V	0.5-1	Birth-5½	60	5	66% (dmfs)	[1]
Margolis et al. 1967	NaF+V	0.5-1	Birth	91	5	70% (deft)	[3]
Hoskova 1968	NaF	0.25-1 (1-4x0.25)	Prenatal	78	4	93% (deft)	[1]
	NaF	0.25-1 (1-4x0.25)	Birth-1	151	4	54% (deft)	[1]
Kailis et al. 1968	NaF	?	Prenatal	50	4-6	82% (deft)	[1]
	NaF	?	Birth	92	4-6	56% (deft)	[1]
Stolte 1968	?	1	3	130	3	11% (dmft)	[3]
Prichard 1969	NaF	?	Prenatal	176	6-8	70% (deft)	[1]
	NaF	?	Birth	282	6-8	40% (deft)	[1]

TABLE 5-A (CONTINUED)

Caries-Preventive Effects of Fluoride Tablets on Deciduous Teeth: A Summary

Study	F Compound	Daily Dosage (mg)	Initial Age of Subjects In Years	No. of Subjects	Years of F Intake	Caries Reduction	
Hamberg 1971	NaF+V (drops)	0.5	Birth	342	3	57% (decayed teeth)	[3]
	NaF+V (drops)	0.5	Birth	342	6	49% (decayed teeth)	[3]
Hennon et al. 1971	NaF+V	0.5	<1	458	3	78% (defs)	[3]
Kraemer 1971	CaF_2	1	4	170	2	22% (dmft)	[3]
	CaF_2	1	5	82	2	18% (dmft)	[3]
Schutzmann-sky 1971	NaF	1	Prenatal	100	<1	13% (dmft)	[1]
	NaF	0.25-1 (1-4x0.25)	Prenatal	100	9	30% (dmft)	[1]
	NaF	0.25-1 (1-4x0.25)	Birth	100	9	14% (dmft)	[1]
Hennon et al. 1972	NaF+V	1	$1\frac{1}{2}$-3	182	1	57% (defs)	[1]
	NaF	1	$1\frac{1}{2}$-3	165	1	55% (defs)	[1]
	NaF+V	1	$1\frac{1}{2}$-3	95	2	66% (defs)	[1]
	NaF	1	$1\frac{1}{2}$-3	91	2	63% (defs)	[1]
Aasenden & Peebles 1974	NaF+V‡‡	0.5-1	Birth	87	8-11	80% (dfs, 2nd molars)	[1]

‡ V=Vitamins

‡‡ A NaF+V combination was given up to 3 years of age. Beyond this age some children received NaF+V while others received only NaF.

* Tablets given only on school days.

ø Four 0.2 mg. F tablets given daily.

[1] Statistically significant

[2] Not statistically significant

[3] No statistical test reported

TABLE 5-B

Caries-Preventive Effects of Fluoride Tablets on Permanent Teeth: A Summary

Study	F Compound	Daily Dosage (mg)	Initial Age of Subjects in Years	No. of Subjects	Years of F Intake	Caries Reduction	
Stones et al. 1949	NaF	1.5	6-14	125	2	0% (caries intensity)	[2]
Bibby et al. 1955	NaF (pill)	1	5-14	133	1	Tentative finding: no reduction (new carious areas)	[3]
	NaF (lozenge)	1	5-14	119	1	Tentative finding: possible reduction (new carious areas)	[3]
Niedenthal 1957	NaF	1* (2x0.5)$^{\phi}$	6-7	251	3	22% (DMFT)	[3]
Wrzodek 1959	NaF	1*	6-9	8381	3	21% (DMFT)	[3]
	NaF	1*	6-9	13585	4	22% (DMFT)	[3]
Arnold et al. 1960	NaF	0.5-1	Birth-6	121	1-15	"Comparable to water F" (DMFT)	[3]
Krusic 1960	CaF_2	?	8-15	480	1-3	70% (?)	[3]
Pollak 1960	NaF+V$^{\phi}$	1	6-7	300	2	38% (DMFT)	[3]
Ziemnowicz-Glowaka 1960	NaF	0.8* (4x0.2)	3-6	704	2	33% (DMFS)	[1]
	NaF	0.8* (4x0.2)	5-6	204	3	28% (DMFS)	[1]
Jez 1962	CaF_2	?	7-11	7200	$2\frac{1}{2}$	0% (?)	[3]
Krychalska-Karwan & Laskowska 1963	NaF	?	grammar school	134	4	5% (DMFS)	[3]
Minoguchi et al. 1963	NaF+V	0.25	Birth-6	75	6	36% (DMFT)	[3]
Binder 1964, 1967	NaF	1*	6	?	4	35% (DMFT)	[3]
Grissom et al. 1964	NaF	1*	6-11	178	2	34% (DMFS)	[1]

TABLE 5-B (CONTINUED)

Caries-Preventive Effects of Fluoride Tablets on Permanent Teeth: A Summary

Study	F Compound	Daily Dosage (mg)	Initial Age of Subjects in Years	No. of Subjects	Years of F Intake	Caries Reduction	
Kamocka et al. 1964	NaF	0.75* (3x0.25)	3	64	3	17% (DMFT)	[2]
	NaF	0.75* (3x0.25)	4	79	3	60% (DMFT)	[1]
Leonhardt 1964	NaF	1	6	398	4	32% (DMFT)	[3]
	NaF	1	7	429	3	25% (DMFT)	[3]
Hippchen 1965	?	1	6	500	3	32% (DMFT)	[3]
Schutzmann-sky 1965	NaF	0.75* (3x0.25)	6	580	4	25% (DMFS)	[3]
	NaF	0.75* (3x0.25)	6	197	6	27% (DMFS)	[3]
Berner et al. 1967, 1968	NaF	0.5-1*	5-7	105	3	84% (DMFS, except 1st molar) 33% (DMFS, 1st molar)	[3]
	NaF	1*	7-9	158	4	16% (DMFT)	[3]
	NaF	1*	7-9	160	6	20% (DMFT)	[3]
	NaF	1*	7-9	109	7	24% (DMFT)	[3]
DePaola & Lax 1968	APF	1*	6-8	130	2	23% (DFS)	[1]
Girardi-Vogt 1968	NaF	1	1st grade	?	3	31% (?)	[3]
Stolte 1968	?	1	3	150	3	69% (DMFT)	[3]
Marthaler 1969	NaF	0.5-1* (2-4x0.25)	6-7	450	1-8	36% (DMFT) 47% (DMF sites)	[1]
Hamberg 1971	NaF+V (drops)	0.5	Birth	342	7	70% (decayed teeth)	[3]
Schutzmann-sky 1971	NaF	1	Prenatal	100	<1	6% (DMFT)	[2]
	NaF	0.25-1 (1-4x0.25)	Prenatal	100	9	43% (DMFT)	[1]
	NaF	0.25-1 (1-4x0.25)	Birth	100	9	39% (DMFT)	[1]

TABLE 5-B (CONTINUED)

Caries-Preventive Effects of Fluoride Tablets on Permanent Teeth: A Summary

Study	F Compound	Daily Dosage (mg)	Initial Age of Subjects in Years	No. of Subjects	Years of F Intake	Caries Reduction	
Aasenden et al. 1972	APF (liquid)	1*	8-11	109	3	30% (DFS)	[1]
	NaF (liquid)	1*	8-11	114	3	27% (DFS)	[1]
Plasschaert & Konig 1973	NaF	1	7	190	2	32% (DMFS)	[1]
Aasenden & Peebles 1974	NaF+V‡‡	0.5-1	Birth	100	8-11	80% (DFS, all teeth) 77% (DFS, 1st molars)	[1]
Driscoll et al. 1974	APF	1*	6-7	202	$2\frac{1}{2}$	6% (DMFS)	[2]
	APF	2* (2x1)	6-7	197	$2\frac{1}{2}$	27% (DMFS)	[1]

‡ V=Vitamins
‡‡ A NaF+V combination was given up to 3 years of age. Beyond this age some children received NaF+V while others received only NaF.
* Tablets given only on school days.
ø Two 0.5 mg. F tablets given daily.

[1] Statistically significant
[2] Not statistically significant
[3] No statistical test reported

TABLE 6

SELF ADMINISTRATION OF TOPICAL FLUORIDE BY MOUTH RINSING

Study	Initial Age (yrs.)	Agent	Applications/ Duration	% Reduction DMFS
Torrell & Ericsson[95]	11	0.05% NaF	Daily/2 yrs.	49
	11	0.2% NaF	2x month/2 yrs.	21
Horowitz et al.[96]	6	0.2% NaF	1x week/20 mo.	16
	11	0.2% NaF	1x week/20 mo.	44
Frankl et al.[97]	14	APF(0.02% F), pH 4.0	Daily/2 yrs.	25
Radike et al.[98]	8-13	0.1% SnF_2	Daily/20 mo.	33,43*

* 2 independent examiners

TABLE 7-A

STUDIES EMPLOYING TOPICAL NaF IN PERMANENT TEETH: NONFLUORIDE AREAS

Study	Initial Age	% F Conc.	No. Applications	Years After Initial Application	% Reduction DMFT	% Reduction DMFS
Bibby[1]	10-13	0.1	3	1		45.9
			6	2		27.6
Galagan & Knutson[6]	7-15	2	2	1	21.7	13.5
			4	1	40.7	33.7
			6	1	41.0	28.3
Bergman[8]	11-12	2	4	3		43.0
Law et al.[7]	7-13	2	4	1	35.2	35.8
Torell & Ericsson[4]	10	2	4	2		19.8

TABLE 7-B

STUDIES EMPLOYING TOPICAL SnF_2 IN PERMANENT TEETH: NONFLUORIDE AREAS

Study	Initial Age	% SnF_2 Conc.	No. Applications	Years After Initial Application	% Reduction DMFT	% Reduction DMFS
Mercer & Muhler[18]	6-14	8	1	1	50	51
Gish et al.[17]	7	8	1	8 mos.	21*	26*
Gish et al.[15]	7	8	1	1	59*	56*
Gish et al.[20]	7	8	1	1	31*	31*
	7	8	2	2	17*	24*
	7	8	3	3	35*	39*
	7	8	4	4	32†	30†
Gish et al.[21]	7	8	2	2	28*	26*
	7	8	3	3	30*	23*
	7	8	4	4	20†	25†
	7	8	5	5	30†	35†
Peterson & Williamson[22]	9-13	8	2	2	26.2	24.2
Harris[23]	7-12	8	6	3	23.3	—
Law et al.[7]	7-13	8	1	3	23.6	—
Cartwright et al.[24]	6-19	8	4	2	—	37
Horowitz & Lucye[25]	8-10	8	2	2	8	8
Wellock et al.[26]	8-12	8	1	1	9	0
		1.23% (NaF + HF),		1	1 55	71
Salter et al.[27]	6-7	8	1	1	64.7	55.8
			2	1	29.4	29.5

* = Compared to 4 applications of 2% NaF.
† = Compared to 2 series of 4 applications of 2% NaF spaced at 3-yr. intervals.

TABLE 7-C

STUDIES OF TOPICALLY APPLIED ACIDULATED PHOSPHATE-FLUORIDE SYSTEMS IN PERMANENT TEETH: NONFLUORIDE AREAS

Study	Initial Age	Agent	No. Applications	Years After Initial Appointment	% Reduction DMFT	% Reduction DMFS
Wellock & Brudevold[23] ..	8-11	1.23% (NaF + HF) 0.1 M H_3PO_4, pH approx. 3	1	1	55	71
			2	2	67	70
Pameijer et al.[29]	4-10	2% NaF, 0.15 M H_3PO_4, pH 3.6	4	3-15 mos.		51*
Wellock et al.[28]	8-12	1.23% (NaF + HF) 0.1 M H_3PO_4, pH 3.0-3.5	1	1	44	46
			2	2	44	52
Cartwright et al.[24]	6-9	1.23% (NaF + HF) 0.1 M H_3PO_4, pH 2.8	4	2	49	
Muhler et al.[40]	6-13	8% SnF_2 + 8% NaH_2PO_4, pH 3.0	2	1	65.5	67.0
		3.6% NaF + 1.8% K_2HPO_4, pH 6.0	2	1	51.2	51.5
Averill et al.[44]	7-11	2% NaF, 0.1 NaH_2PO_4 + H_3PO_4, pH 4.4	4	2	11.6	+2.3
Cons et al.[42]	6-11	1.23% (NaF + HF) 0.1 M H_3PO_4, pH 3	3	3	16	+1
Ingraham & Williams[39] ..	6-10	1.23% (NaF + HF)	2	2	18.2	10.9
		0.1 M H_3PO_4, pH 3	2	2	23.9†	13.1†
Horowitz[41]	10-12	1.23% (NaF + HF)	1	1	17.0	22.4
		0.1 M H_3PO_4, pH 3	2	1	28.3	27.1
Horowitz[43]	10-12	1.23% (NaF + HF)	2	2	25.7	33.0
		0.1 M H_3PO_4 pH 3	4	2	32.9	35.9
Horowitz[43]	10-12	1.23% (NaF + HF)	3	3	26.8	30.0
		0.1 M H_3PO_4, pH 3	6	3	40.3	42.6
De Paola et al.[45]	6-8	1% NaF, 0.1 M H_3PO_4, pH 3.8	3	1	23	21
		0.25% NaF, 0.03 M H_3PO_4, pH 3.8‡	6	2	6	11
			9	3	1	3

* Compared to half-mouth treatments with 2% NaF.

† Agent changed during 2nd and 3rd years of study.

‡ Acidulated phosphate fluoride solution applied in rubber trays with paper liners.

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TABLE 8

RESULTS OF CLINICAL SEALANT STUDIES

Investigator(s)	Time (mos.)	% Retained Sealant*	% Caries Reduction**
Autopolymerizing Systems			
Wilson et al.[137]	6	74	78
Rock[138]	12	52	81
Thylstrup & Poulsen[139]	12	73	70
Rock[140]	24	52	65
Ultraviolet Light Polyermized Systems			
Luoma et al.[141]	6	99	92
Buonocore[142]	12	99	100
McCune et al.[143]	12	83	81-85‡
Rock[144]	12	54	65
Rock[138]	12	86	100
Gourley[145]	12	87	65
Risager & Poulsen[146]	12	69	§
Stiles et al.[147]	12	51	§
Meurman et al.[148]	18	95	88
Buonocore[135]	24	87	99
Horowitz et al.[149]	24	73	67
Rock[140]	24	80	99
Gourley[150]	24	78	58
Burt et al.[136]	24	27	14
Higson[151]	24	3	23
Rock[152]	36	70	68
Going[153]	36	56	47
Horowitz et al.[134]	48	50	41
Leake & Martinello[154]	48	20	21

* completely covered teeth only

** permanent teeth only

‡ two investigators

§ caries data not presented in a manner that allows tabulation

TABLE 9-A

DENTIFRICE STUDIES USING STANNOUS FLUORIDE WITH A COMPATIBLE CALCIUM PHOSPHATE ABRASIVE SYSTEM (NORTH AMERICAN STUDIES ONLY)

Study	Dentifrice	Initial Age	Supervision	Duration	% Reduction DMFT	% Reduction DMFS
Muhler et al.[42]	SnF_2-$Ca_3P_2O_8$	5-15	No	6 mos.	53.4	71.5
Muhler et al.[42]	SnF_2-$Ca_3P_2O_8$	5-15	No	1 yr.	50.6	49.3
Muhler et al.[43]	SnF_2-$Ca_3P_2O_8$	5-15	No	6 mos. 1 yr.	45.4 33.9	44.7 36.0
Muhler et al.[43]	SnF_2-$Ca_3P_2O_8$	17-36	No	6 mos. 1 yr.	55.0 53.7	50.4 41.6
Muhler et al.[38]	SnF_2-$Ca_3P_2O_8$	17-36	No	24 mos.	30.0	34.0
Muhler[44]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	6-18	No	6 mos. 1 yr. 18 mos. 2 yrs. 3 yrs.	42.2 28.2 31.4 24.5 23.7	25.8 18.5 24.3 19.2 22.4
Gish and Muhler[45]	SnF_2-$Ca_3P_2O_8$,$Sn_3P_2O_8$†	6-14	No	12 mos.	15.8 (28.6)*	38.3 (31.1)*
Gish and Muhler[45]	SnF_2-$Ca_3P_2O_8$,$Sn_3P_2O_8$†	6-14	No	24 mos.	23.1 (25.7)*	35.4 (29.5)*
Muhler[47]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	5-17	No	6 mos. 12 mos.		37.1 33.0
Kyes et al.[48]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	17-24	No	1 yr. 2 yrs.	+31 14	.5 14
Zacherl and McPhail[49, 50]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	Approx. 6- 8	No	10 mos. 18 mos. 30 mos.	36.3 36.4 35.5	39.2 42.1 40.4
		Approx. 11-13	No	10 mos. 18 mos. 30 mos.	22.7 34.8 37.3	34.1 38.7 43.5
Horowitz et al.[51]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	6-10	No	1 yr. 2 yrs. 3 yrs.	+8.8 9.1 16.7	+5.1 2.1 16.9
			Supervised 1x/day in school plus unsupervised home brushing	1 yr. 2 yrs. 3 yrs.	10.8 13.1 16.3	9.9 11.8 20.9
Jordon and Peterson[52]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	8-11	Supervised 1x/day in school plus unsupervised home brushing	1 yr.	35.5	33.9
Jordon and Peterson[53]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	8-11	Supervised 1x/day in school plus unsupervised home brushing	2 yrs.	15.8	20.5
			No	2 yrs.	15.9	12.4
Pelley and Muhler[54]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	10-19	Semisupervised 3x/day in military school	5 mos. 10 mos.	103 93	58.4 57.0
Bixler and Muhler[55]	SnF_2-$Ca_3P_2O_8$, $Sn_3P_2O_8$	11-18	Semisupervised 3x/day in military school	8 mos.	55 (46)*	52 (38)*

(Continued on next page)

TABLE 9-A (CONTINUED)

Study	Dentifrice	Initial Age	Supervision	Duration	% Reduction DMFT	% Reduction DMFS
Bixler and Muhler[46]	SnF_2-$Ca_2P_2O_7$, $Sn_2P_2O_7$	11-23	Semisupervised 3x/day in military and boarding schools	8 mos. 19 mos.		60 54
Thomas and Jamison[48]	SnF_2-$NaPO_3$, $CaHPO_4$	7-16	Semisupervised 2-3x/day in orphanages	24 mos.	38.8	30.6
	SnF_2-$Ca_2P_2O_7$, $Sn_2P_2O_7$	7-16	Semisupervised 2-3x/day in orphanages	24 mos.	22.8	30.4

* = 2 examiners.
† = Fluoridated community.
SnF_2 = Stannous fluoride.
$Ca_2P_2O_7$ = Calcium pyrophosphate.
$Sn_2P_2O_7$ = Stannous pyrophosphate.
$CaHPO_4$ = Dicalcium phosphate.

TABLE 9-B

DENTRIFICE STUDIES USING SODIUM MONOFLUOROPHOSPHATE AS THE ACTIVE THERAPEUTIC AGENT

Study	Dentifrice	Initial Age	Supervision	Duration	% Reduction DMFT	% Reduction DMFS
Mergele[36]	MFP-IMP-SNLS	9-13	No	3 yrs.	8.8	17.4
	SnF_2-$Ca_2P_2O_7$				6.4	13.2
	SNLS-$CaHPO_4$*				+1.0	3.5
Naylor & Emslie[37]	MFP-$CaHPO_4$-SNLS	11-12	No	3 yrs.	8.4	14.5
	SnF_2-IMP				13.9	18.1
Fanning et al.[38]	MFP-IMP-SNLS	11-13	No	2 yrs.		20.2
	SnF_2-IMP					21.9
Muller et al.[39]	MFP-IMP-SNLS	10-12	1x/day	30 mos.		18.9
Thomas & Jamison[47, 48]	MFP-IMP-SNLS	8-16	2x/day	2 yrs.	37.1	34.1
Mergele[40]	MFP-IMP-SNLS	7-21	3x/day	22 mos.	19	21
	SnF_2-IMP				12	9

* F area (Houston, 1 ppmF).
MFP-IMP-SNLS = sodium monofluorophosphate, insoluble sodium metaphosphate, sodium N-lauroyl sarcosinate.
MFP-$CaHPO_4$-SNLS = sodium monofluorophosphate, dicalcium phosphate, sodium N-lauroyl sarcosinate.
SnF_2-$Ca_2P_2O_7$ = stannous fluoride, calcium pyrophosphate.
SnF_2-IMP = stannous fluoride, insoluble sodium metaphosphate.
SNLS-$CaHPO_4$ = sodium N-lauroyl sarcosinate, dicalcium phosphate.

PERMANENT DENTITION: MEAN DMFT / CHILD
COMPARISON OF 3-VILLAGE POPULATION TO NATIONAL SURVEY FIGURES
FOR MALE AND FEMALE WHITE CHILDREN

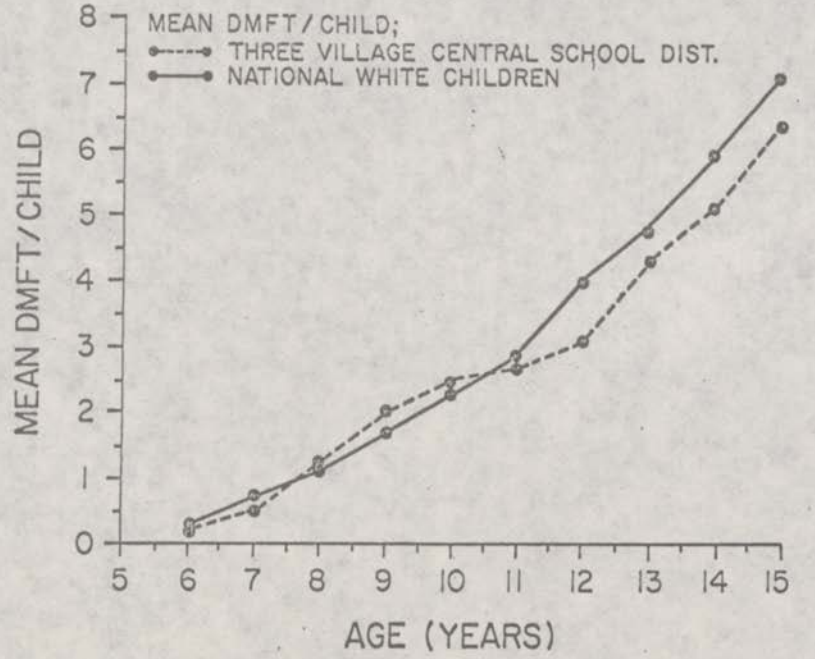

FIGURE 2

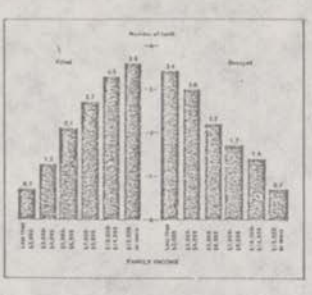

Figure . Average numbers of filled and of decayed primary and permanent teeth per child, by family income.

FIGURE 3

PREVENTIVE PROCEDURES USED IN THE NATIONAL PREVENTIVE DEMONSTRATION PROGRAM

First, second, and fifth grade children will receive various combinations of five proven preventive procedures:

- Application of fluoride by several different methods to protect the teeth from decay.
- Removal of plaque by brushing and flossing to prevent disease of gums and bone supporting teeth.
- Application of sealants to the chewing surfaces of new permanent teeth to protect them from decay.
- Modification of school lunch programs to reduce the consumption of sugar.
- Education to improve health knowledge and habits.

Mr. MAGUIRE. We will proceed with Dr. Schoen's statement after a brief recess. We will be back shortly.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order, please.

Dr. Schoen, you may proceed.

STATEMENT OF MAX H. SCHOEN, D.D.S., DR. P.H.

Dr. SCHOEN. Thank you, Mr. Chairman. My name is Max Schoen and I am Professor and Chairman of the Section of Preventive Dentistry and Public Health of the UCLA School of Dentistry. I am also Assistant Dean for Academic Affairs. The bulk of my 34 year professional career has been spent as a practicing dentist who has participated in the design of dental care programs and the administration of group practice. My testimony today represents my individual views.

As you have heard, the vast majority of children in the United States suffer from dental caries. This disease, if untreated, causes

considerable pain and suffering and eventually tooth loss. In addition, aside from the hazards of untreated infection, there may be untoward effects on nutrition, learning and appearance, leading to personality problems. Particularly tragic is the fact that much caries is either directly preventable or that once started its eventual harmful effects can be eliminated or minimized by early treatment.

The legislative proposal being considered by this committee unfortunately considers dental care as an optional benefit not subject to the improved Federal cost sharing available for compliance related to most other health care. Presumably, one major reason for the omission of dentistry as a mandated benefit is concern for cost. However, in fiscal year 1976 dental expenditures under Medicaid—including EPSDT—were only 2.7 percent of the total, while for the general population they were 6.2 percent of health costs. Per capita general medical care costs for Medicaid recipients were similar to that for the total population, but dental expenditures were much less. The current proposal would continue and actually tend to increase this inequity by shortchanging attention to a disease category where primary and secondary prevention have proven to be effective.

In addition, because of its high prevalence and continuous attack rate the usual screening or assessment process and proposed intervals are not applicable to dental decay. The disease can and must be dealt with, but not in the same manner as many other health problems.

It is not my purpose to discuss legislative specifics but rather to present the broad outlines, with supporting data, of a workable program to control this disastrous disease entity at a not unreasonable cost.

The plan should include two concurrent and interdependent components: one for prevention and the other for therapy.

PREVENTION

The prevention portion, in order to reach the maximum number of children should be carried out in the schools for grades kindergarten through twelfth grade. At present, the most cost/effective service, other than fluoridated water, is a regular weekly fluoride mouth rinse which can be performed by the children under supervision of non-dental personnel. Since it would be both impractical and illogical to provide such service only to eligible children, all school children should be encouraged to participate on a voluntary basis. However, those whose family incomes were above the economic limits of the CHAP program would be required to pay for the service.

In addition, an annual prophylaxis should be provided by either an expanded function assistant or a dental hygienist, depending on the age of the child and the presence of calculus. This service should be coupled with radiographs as necessary. Each child shall receive an epidemiologic examination by a dental hygienist and all children shall be referred to a dentist of their choice for definitive diagnosis, treatment planning and therapy. Any radiographs shall

be forwarded to the dentist after retention of a duplicate set with the child's school dental health record.

At the time of the prophylaxis, individual oral health education shall be provided to each child as a personalized supplement to ongoing classroom and parent centered programs throughout the year.

Preschool children and those between 18 and 21 years of age—not in high school—could participate voluntarily.

The regulations must be flexible enough to encourage changes in the prevention package as studies reveal the various techniques and combinations which are most cost/effective. For example, the Robert Wood Johnson Foundation has funded a large scale project to measure the cost/effectiveness of several different combinations of school based prevention programs.[1] However, some recent work by Lindhe and Axelsson in Scandinavia has not been included.[2] Their research indicated that a frequent prophylaxis accompanied by topical fluoride may reduce the incidence of periodontal disease and dental caries to almost zero. If these results can be replicated in the United States, and if the approach is cost effective, this legislation and the ensuing regulations should not become barriers to the changed techniques.

THERAPY

No fees should be payable to dentists for those services available at the schools—application of preventive agents, prophylaxis and radiographs. However, payment of a fee for diagnosis and treatment planning should be allowed once a year if performed. Comprehensive services, including orthodontics for major handicaps, should be covered.

Medicaid and other welfare programs tend to pay the dentist too little for restorative care. The CHAP program must provide a mechanism for payment of a reasonable fee, preferably a negotiated fixed fee for each type of service.

It also should encourage alternate forms of delivery and payment for dental services such as a group practice capitation or an HMO type of approach. Where resources are lacking governmental and consumer cooperative agencies should be encouraged. However, since dentistry has been historically a separate segment of the health delivery system, it should be permitted to make separate arrangements for these alternate delivery mechanisms, as well as the conventional ones. This does not mean that joint ventures should be discouraged.

EVALUATION

My experiences as a consultant and evaluator of dental care and dental care programs—currently as an auditor of the California Dental Services' performance under Denti-Cal—have convinced me

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[1] American Fund for Dental Health. National Preventive Dentistry Demonstration Program, Information and Guidelines for Sponsoring Agency. The Fund, Lexington, 1976.

[2] Ahlberg, J. The Lindhe, Axelsson, Tollskog Study: "The Effect of Proper Oral Hygiene on the Oral Health of School Children." Presented at Colloquium" International Dental Care Delivery Systems" May 6, 1977. Washington, D.C. Sponsored by LOM and PAHO.

that adequate quality and performance control cannot be accomplished by claim form review alone. The previously mentioned annual epidemiologic examination of children by dental hygienists, followed up by the staff dentists as aberrations are noted, can serve as a relatively ideal monitoring mechanism for both technical quality and the discovery of fraud. It could also evaluate the effectiveness of the prevention program. Costs would be minimal since the professional contact with each child would be a routine part of the entire plan—not just a special audit visit.

COSTS AND UTILIZATION

At present the California Dental Service is the agency which administers the program for most of the Medi-Cal children in the State. It is now in the fourth year of its contract. The children's program is quite comprehensive, covering virtually all dental services except orthodontics. Average annual costs per user for children through age 20 have been $82 in 1974, $75 in 1975 and $77 in 1976. The costs of the preventive and diagnostic component have ranged from $22-$27 per user of such services—28-32% of total costs—while those for the restorative component have ranged from $71-$72 per user of such services (53-56% of total costs). All other services account for about 15% of costs.

Since CDS has administered the program, average annual utilization of one or more services has been estimated to have risen to 35-40 percent of eligibles[3]. Earlier studies had shown use rates of under 20 percent[4].

California is a good model for this crude estimate since it represents about 10 percent of the population, has a comprehensive children's dental program, represents the high side of fees for service, has large populations not covered by fluoridation and has good data. Therefore, use of its statistics is not likely to yield low estimates. For example, Dr. Naham Cons, Director of the Bureau of Dental Health of New York State, estimates that the average annual cost of dental care per Medicaid child in New York City, which has had fluoridated water for 12 years, would be about $60 after a 30 percent upward adjustment of grossly inadequate fees[5].

A 5-year treatment program in an area around Chattanooga, which provided care to children age 5-15, averaged $55.80 per child per year[6]. Costs tended to decrease over the 5-year period despite inflation, probably due to increased maintenance care.

California has a number of fluoride rinse, examination and dental health education programs which range in cost from $1.43 to $8.55 per child per year depending on age, location and the mix of components. The average cost is $3.81 per child. Even with the addition of an annual prophylaxis and appropriate radiographs, at an estimated cost of $6 per child, total cost per child for the preventive component would not exceed $10. More than this

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[3] Personnel communications from California Dental Service and California Department of Health administrative personnel. Based on average monthly eligibility.

[4] California Department of Health Care Services. Medi-Cal Report No. 68-7. Sacramento, December 1968.

[5] Cons, Naham. Personnel Communication.

[6] Doherty, Neville and Sandra Vivian. Expenditures for the dental care of indigent children in the Chattanooga Project, 1971-1975. J. of Pub. Hlth. Dent. 37:209-216. Summer 1977.

amount would be deducted from the $22-$27 current preventive and diagnostic costs incurred by payment to dentists for preventive and diagnostic services, although increased use rates would balance out these savings.

The savings in therapy are difficult to estimate, but would be considerable. If it is assumed that the national average increment of new decayed teeth per year in children is 0.75, a one-third reduction would decrease the number of teeth requiring restorative care by 0.25. Since fillings do not last indefinitely and untreated caries leads to increased need for endodontics, extractions, space maintainers and bridgework, the savings may be doubled by elimination of some of this additional therapy. At $15 per restoration per tooth, at least $7.50 per child per year would be saved. If utilization for restoratirve services would reach 50 percent of the eligible children after a few years, and 14 million were eligible, the therapy savings alone would be over $50 million per year based on conservative estimates. Savings derived from use of fluoridated water are easier to project and several studies are available.

ADMINISTRATIVE CONSIDERATIONS

The administrative agency for the preventive and evaluation component should be the best governmental agency or agencies available in each State. For large schools, permanent personnel could be stationed at each site. Mobile teams could be used for smaller schools. Space availability would determine whether fixed installations or mobile trailers would be used.

The therapy component could be administered directly by the State, by a service corporation or an insurance company.

Where necessary, Federal legislation might have to override State dental practice acts, although many States now include the suggested functions for auxiliaries.

Projects and studies both recent and those conducted many years ago have demonstrated the acceptability of school-based programs, even where they include treatment, so this should create no real problems.[7, 8]

SUMMARY

This testimony has proposed that dental care be included as one of the basic services covered by the CHAP program. Since screening or assessment procedures are not applicable in the usual sense, regular ongoing treatment should be covered. In order to be cost effective, a combinaion of two interacting components has been suggested. One, a school-based preventive and evaluation plan, utilizing non-professional and auxiliary dental personnel in the main; and two, a treatment component to be performed by dentists in private practice if available and accessible. These joint programs administered by appropriate local and State, public and private

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[7] Waterman, George F. and John W. Knutson. Studies on dental care services for school children—third and fourth treatment series. Richmond Indiana. Public Health Reports 69:247-254. March 1954.

[8] Jenny, Joanna et al. Measuring satisfaction and dental health status to assess quality in dental care delivery systems. Presented at the Annual Meeting of the American Association for Dental Research, Las Vegas, Nevada. June 24, 1977.

agencies under strict Federal guidelines and/or regulations can control this major disease problem in the eligible population at a cost which will have but a small impact upon total costs.

In order to bolster my statement I have submitted to the committee several reprints of data [may be found in subcommittee's files] and have included several references[9] with this testimony so you can see what studies have been covered in this and in other countries.

I thank you very much for allowing me time to present my views.

[The following tables were attached to Dr. Schoen's statement:]

TABLE I

DENTI-CAL SERVICES, COSTS AND USE

Ages 0-20

1974-1976

	1974		1975		1976	
	No	%	No	%	No	%
Total pd 0-20	34,586,958	100%	34,500,593	100%	36,121,099	100%
prev & diag	10,912,881	31.6	9,721,839	28.2	9,990,199	27.7
restorative	18,270,337	52.8	19,198,840	55.6	20,236,978	56.0
Total number of users	422,061	100%	459,244	100%	467,213	100%
prev & diag	406,877	96.4	437,266	95.2	442,653	94.7
restorative	254,774	60.4	268,597	58.5	284,231	60.8
Total cost per user	82.08		75.13		77.31	
prev & diag*	26.82		22.23		22.65	
restorative*	71.82		71.48		71.20	

Source: Unpublished, Data provided to California Department of Health by California Dental Service

*These figures are for the users of the particular service, and not for all users of any service.

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[9] *Additional General References:*

Carlos, James P. (Ed) Prevention and Oral Health. Fogarty International Center Series on Preventive Medicine. Volume I. DHEW Pub. No (NIH) 74-707 U.S. Govt. Print. Off. Washington, D.C. 1975.

National Institute for Dental Research, U.S. Department of HEW. Preventing Tooth Decay: A guide to implementing self-applied fluoride programs in schools. DHEW Publ. No. (NIH) 77-1196. U.S. Govt. Print. Off. Washington, D.C. 1977.

TABLE II

DENTAL DISEASE PREVENTION PROGRAMS SUPPORTED BY THE DENTAL HEALTH SECTION FOR 1977-1978 FISCAL YEAR

Agency	Objectives	Funded by DHS	Total Funding	Cost/ Child
1. Tulare County Schools	6,000 children (K-3) participate in comprehensive dental and nutrition education program, including daily plaque control, weekly fluoride rinse, screening and referral services.	$ 7,500	$ 22,216	$3.70
2. Tuolumne County Schools	2,850 children (K-12) participate in multifaceted, comprehensive dental health program including brushing, flossing, fluoride rinse and OHI inspection.	$ 8,000	$ 12,803	$4.49
3. Colusa County	1,800 children (K-8) of four unified school districts will be provided disclosing and plaque control instructions, nutrition education and flossing.	$ 3,051	$ 7,625	$4.24
4. Child Development and Education Council, Inc.	8,000 students in all or a portion of dental health and nutrition education, daily brushing and flossing, weekly flossing instruction and fluoride rinse, annual dental screening (pre and post). Implement dental health education into regular classroom activities.	$ 6,053	$ 22,813	$2.85
5. Northern Sacramento Valley Rural Health Project	10,000 children (K-6), daily brushing and flossing, weekly fluoride rinse, instruction in dental hygiene and nutrition for plaque avoidance and control.	$ 9,000	$ 14,338	$1.43
6. Contra Costa County	3,000 low income children (K-3) will receive consultative, educational and screening services and materials, dental health and nutrition education. Teacher and nurse in-service education, plaque control instruction, daily brushing and flossing, weekly fluoride rinse, annual screening and referral.	$11,000	$ 18,974.20	$6.32
7. Salud-East Yolo	1,700 children (Preschool-5) will be furnished dental health disease and nutrition education, daily brushing and flossing, weekly fluoride rinse, annual screening and referral, program evaluation to continue program growth.	$ 8,000	$ 10,354	$6.09

Mr. ROGERS. Thank you very much. We appreciate your statement, which is excellent.

Ms. Yunker.

STATEMENT OF JERI YUNKER, R.D.H.

Ms. YUNKER. Mr. Chairman, I am Jeri Younker, a registred dental hygienist from Dallas, Texas, and currently the Chairperson of the Committee on Governmental Relations of the American Dental Hygienists' Association. With me is Mr. Ben Miller, the Association's Washington consultant. On behalf of the members of ADHA, may I thank you for the opportunity to participate in this dental panel discussion and to present testimony of ADHA on the "Child Health Assessment Program."

The Association certainly supports the emphasis which the bill places on the importance of establishing State child health asessment programs, but without dental care the program is unacceptable to our members. We believe that a much higher priority should be placed on preventive children's dental health programs and that the dental components of State health assessment programs should receive the same average of 75 percent Federal matching funds which are recommended for other health care services.

Dental disease is the problem which affects more of the school-age population than any other health problem. Studies among children have indicted that the most effective solution to meeting this problem is through preventive dental care: regular examinations, cleaning, fluoride treatments and dental education. We have shared responsibility of seeing that such care reaches our children, especially those from needy and disadvantaged families.

A poverty study among third-grade children conducted in a Midwestern city revealed that those from low socioeconomic status families were more likely to have incurred cavities than children from higher status. Furthermore, few of these children received the necessary treatment to halt the cause of the disease. The implications for their future is obvious; dental disease is not something outgrown. This fact is substantiated by published reports from a New York City study which showed that audits from low-income areas lost more teeth, had higher levels of untreated decay and periodontal disease. It cannot be overemphasized that providing dental care at an early age is a lifetime benefit to the individual who receives it. Preventive dental care can be expected to pay dividends in the long run, not only in better health for more members of society but also in reduced expenditures in the total area of oral health.

The Association recognizes that concerns over costs to include dental care in early periodic screening, diagnosis and treatment programs have been a major factor in the slow establishment of dental programs for children. However, the fact is that preventive dental care is reaching children through innovative programs which have proven effective both in terms of cost and care.

Dental team concepts, full roles for dental hygienists, broad delivery settings—all have been successfully put into practice by

individuals in government and the dental profession who are actively committed to improved oral health. One State program in Vermont has collected data to show that initial cost per patient for preventive dental care declines as much as 21 percent in the second or third year of the program. While time permits only citing a few examples of dental health programs, in general they consist of two major components: delivery of preventive dental care inspections, fluoride treatments, cleaning, and dental health education activities.

The importance of regular dental inspections was clearly demonstrated by a comparative study of two school systems in Denver with differing approaches to dental health. The better oral health conditions of students in one system was attributed to sequential dental health programs, which included inspections and educational projects, that had been conducted by the program's dental hygienists. A study by the Indian Health Service has determined that a 1-year recall program to be the most effective for prevention of dental diseases of children ages 5 to 9.

In North Carolina it was determined that two-thirds of the population did not receive dental care. All in the dental community cooperated to implement a statewide 10-year program to turn these statistics around. As found in other cost-effective programs, the success of the North Carolina project is considered to be in the combination of the dental consultant team and teachers. One goal of the 10-year program is to have at least one dental hygienist in each of the 100 counties of North Carolina to work with teachers in instructing their pupils on routine home care.

Lastly, I would like to cite one more example to demonstrate that cost and care effective programs do not have to be on such scales or involve large staffs. The city of Englewood, New Jersey, determined that its citizens were in the highest 5 percent of the Nation in need of dental treatment. The city health department, in an attempt to serve the total comnmunity, instituted a city-wide prevention program aimed at the school population. Employing a part-time dental hygienist, the program enables children to receive regular inspections, cleaning and dental health instruction, as well as any necessary further treatment through local participating dentists.

The programs which I have briefly cited and which are discussed in the written testimony that is being submitted will demonstrate to the subcommittee that cost-effective, quality preventive care can be provided to children. We urge that the "child health assessment program" be amended to include support for dental care programs at parity with other health services identified in this legislation. Today's children cannot accept responsibility for the oral health of tomorrow's adults—we must.

Mr. Chairman, with your permission I would like to submit for the record a list of references pertaining to my oral statement.

[The list referred to follows:]

LIST OF REFERENCES

1. *Effect of Preventive Program on Dental Plaque, Gingivitus and Caries.* Gothenberg; Sweden. *Journal of Clinical Periodontology.* Volume 1, pp. 126-138, 1974.

2. *Impact of Teacher-Student Dental Health Education.* Freidman, Lawrence A., DDS; *Journal of School Health.* Volume XLIV, Number 3, March 1974.

3. *Comparison of Three Methods of Teaching Oral Hygiene to School Children.* Koch, Douglas M., DDS; Koch, Gorann, DDS; Tynelius, Gunilla M. *Journal of Dental Education,* March 1970.

4. *Preventive Dental Behavior in Children.* Bragramian, Robert A., DDS, DR. PH; Gochman, David S., PhD. *Journal of Michigan Dental Association.* Volume 55, January 1973.

5. *Oral Hygiene Performance of Elementary School Children Following Dental Health Education.* Podshadley, Arlon G., DDS; Shannon, Jean H., BA. *Journal of Dentistry for Children.* Volume 37, pp. 298-300, July-August 1970.

6. *Comparative Findings in School Systems With Differing Approaches to Dental Health Education.* Meyer, Sharon, RDH, MPH; Downs, Robert A., DDS, MSPH. *Journal of School Health.* Volume 38, pp. 604-610, November 1968.

7. *Effect on Oral Cleanliness Produced by Dental Health Instruction and Brushing Teeth in Classroom.* McCauley, H. Berton, DDS; Davis, Lillian B., SC.D; Frazier, Todd M., A.B. *Journal of School Health.* Volume 25, pp. 250-254, November 1955.

8. *Elementary School Program in Preventive Health.* Cusato, James L., DDS; Kaplan, David E., Ed.M. *Journal of Massachusetts Dental Society.* Volume 23, pp. 256-259, Fall 1974.

[Testimony resumes on p. 348.]

[The ADHA's prepared statement follows:]

American Dental Hygienists' Association

"Statement on Child Health Assessment Program" (H.R. 6706)

to the

Subcommittee on Public Health and Environment

of the

Committee on Interestate and Foreign Commerce

United States House of Representatives

September 9, 1977

97-633 O - 77 - 22

Introduction

The American Dental Hygienists' Association is pleased to submit a record statement to the House Subcommittee on Public Health and Environment stating its views on the Child Health Assessment Program (CHAP) (H.R. 6707), as proposed by the Carter Administration. In its present form, the Association would not be able to support this legislative proposal because of the low priority assigned to the provision of dental services for poor and needy children. The thrust of this statement will suggest that projects for dental health of children and youth should be included in this bill, and that dental care needs of children, whose parents are eligible for care under Title XIX, Medicaid should be on parity with other health care needs.

For the Subcommittee's information, and for publication in the record of its September 9, 1977 hearings, a brief statement describing the dental hygiene profession and the dental hygienists' role in the delivery of oral health care is appended to this statement (See Exhibit I).

Goals of Title V of the Social Security Act

It is the Association's understanding that the Child Health Assessment Program (H.R. 6706) is intended by the Administration to be the successor program to Title XIX, Medicaid, Early Periodic Screening, Diagnosis and Treatment (EPSDT) program, administered by the Department of Health, Education and Welfare. The EPSDT program was initially authorized by Congress in 1967, for

implementation in 1969. Between then and now, implementation at federal and state levels of EPSDT programs have been disappointing to those who provide dental care.

Since the Administration has featured CHAP as a direct descendent of the EPSDT plan, and as an improvement of this plan as well, the Association can logically assume that H.R. 6706 also is intended as a program which will fulfill the goals of Title V of the Social Security Act,[1] which read as follows:

> To provide quality health service for prospective mothers, infants and children, particularly in urban and/or low income areas where access to quality care is otherwise limited.

In its belief that the dental hygiene profession has a vital role to play in the delivery of oral health care, the American Dental Hygienists' Association 1976 House of Delegates has repeatedly affirmed its agreement with American Dental Association policies on the development of programs which would provide comprehensive dental services for children. The Association believes that such comprehensive dental health programs--especially for children whose parents are economically disadvantaged--should have the highest priority among all federally supported dental health programs which may eventually be enacted into law by the Congress.

The current Association policy on children's dental health programs recommends that:

> All children who have had an initial year in a national health program should be re-examined diagnosed, and treated if necessary, on at least an annual basis in subsequent years. In addition, the individual oral hygiene habits

of these children should be re-evaluated, with preventive skills being reinforced. Qualified dental hygienists should be utilized to carry out the periodic re-examinations and review of preventive practices, referring to a dentist whose patients with treatment needs beyond the capability of the hygienist.[2]

Projects for Health of Children and Youth

In April, 1975, the Association sent a strongly supportive statement to the HEW Assistant Secretary for Health on proposed amendments to the Code of Federal Regulations involving "Maternal and Child Health and Crippled Children's Services Programs and Projects" (Subpart A of Part 51(a) of Title 42, CFR). The proposed amendments to the 1975 Code were designed to encourage states to implement dental health care plans for disadvantaged children in connection with their in-place EPSDT medical programs.

We call the Subcommittee's attention to the Thursday, November 20, 1975 Federal Register (Volume 40, No. 225, pp. 54102-54107 inclusive), to assist Committee members in recalling that the Department of Health, Education and Welfare did, in fact, publish Rules and Regulations relating the development of dental health programs for children by the states, as an additional element of their EPSDT programs. These Regulations suggest programs which are similar to those which the Association urges the Subcommittee to add to the "Child Health Assessment Act", to make this legislation more acceptable. In our view, the Department of Health, Education and Welfare already has done its homework in planning to include childrens dental health

programs in state plans.

In an April 2, 1975 statement to the HEW Assistant Secretary for Health, the Association commented, in part, as follows:

> The Association concurs with the criteria in this section recommended by the Assistant Secretary for Health, specifying that programs or projects for the health of children and youth should provide for: 'medical and dental care, including screening, diagnosis, preventive services, treatment, correction of defects and after-care must include thorough medical and dental examinations and indicated laboratory tests and specialty examiniations; treatment must include services of medical and dental paramedical practitioners.' In addition, the Association supports the Assistant Secretary's recommendations that state plans provide assurances 'that screening, diagnosis and preventive services should be available without charge to all children and youth within the area.'[3]

General Comments

The Association has stated previously that it does not support H.R. 6706, as introduced by the Subcommittee chairman. On the other hand, the ADHA is urging that this bill should be modified to include preventive dental care programs for children. Not only would such a change in H.R. 6706 make the bill more acceptable to the dental profession, but also to the general public and to the Administration as well. The Administration's advance publicity on CHAP states that this program will currently extend, and eventually replace, the former EPSDT program of the prior administration. Apparently, the Administration also believes that the development of

comprehensive health assessment centers, with an increase in federal matching funds from an average of 55 percent to 75 percent, will substantially improve the existing EPSDT program.

The Association might agree with this publicity, if a dental component, placing dental care in parity with the medical care, could be added to the "Child Health Assessment Program."

As previously noted, the Association supports the goals of Title V of the Social Security Act. The Association also supported HEW regulations (Federal Register, Thursday, Nobember 10, 1975), which modified the Title XIX, EPSDT programs and encouraged development by states of dental health programs for disadvantaged and needy children. The Association policy, which places the highest priority on development and implementation of comprehensive, preventive dental care programs for children, especially children from needy and disadvantaged families, is still in effect. However ineffectual they may have been in encouraging states to develop EPSDT dental programs, the HEW regulations are also still in effect.

Estimated Costs of an EPSDT Dental Program

The Association recognizes that estimated costs, to include dental care in state EPSDT programs, have been a major deterrent among many states to slow the process of establishing dental health programs for children. According to the Children's Defense Fund Study, "EPSDT: Does it Spell Health Care for Poor Children?",[4] estimated costs of various EPSDT services in state plans would approximate the totals provided in Table 1 below.

Table 1

Estimated Costs of EPSDT

Component	Per Capita Cost of Component	Total Project Cost
Outreach	$1.00 per eligible child	$13,000,000 (FY 1976 Cost)
Screening	$21.00 per child screened	$42,000,000
Follow-up	$10.40 per child with referral	$13,000,000
Treatment (Includes diagnosis and Immunization)		
Medical	$35.00 per child treated	$21,000,000
Dental	$90.00 per child treated	$27,000,000 (300,000 cases, FY 197
TOTAL		$136,000,000
Estimated Federal Share at 55%		$74,800,000
Average Cost Per Child in EPSDT		$68.00

As far as the Association can determine, the $90.00 per child estimate for dental treatment was supplied to HEW by the Congressional Budget Office. While this estimate undoubtedly reflects actual costs for existing state programs, it does not provide analysis of age and income groups, estimates of "covered population" and "utilizing population." Further, the CBO (HEW) figures do not show cost-per-patient and total dollar costs to be shared by the federal and state governments.

Using 1975 data published by the American Dental Association's Bureau of Economic Research and Statistics, these differentiating

factors can be supplied (See Tables 2 and 3 below).[5]

Table 2

Age/Income Class	Covered Pop.	Util. Pop.	Cost/Patient	Cost of Program
2-17 (under $5,000)	10.9	4.0	$65.00	$260.00

Table 3

			(75-25) Fed.	State	(75-25) Fed.	State
2-17 (under $5,000)	10.9	4.0	$49	$16	$196	$64

CBO (HEW) total dollar cost figures in Table 1 ($27,000,000) vary sharply and on the low side, compared with Table 2 ADA estimates ($260,000,000). However, the differences can be explained, as follows:

1. CBO (HEW) figures use $90 as the cost-per-patient unit and reflect an actual utilizing population of 300,000; and

2. ADA figures use $65 as a cost-per-patient unit and assume a utilizing population of 4 million (an unrealistically high utilization rate).

Thus, available price and cost data are confusing and misleading. We are confronted with an "peaches and apples" comparison, so that quantifying the cost of childrens dental health programs appears to be hazardous at best.

The Association believes that efforts to quantify utilization rates and dollar costs should, if possible, be realistically stated. From the available data, it does not appear that the initial cost of providing dental care will be low. High initial costs can be

expected, because the eligible population will include a majority of children who have never received dental care or care for emergencies only. Rather, the impact of initial dental treatment for these children must be viewed "down the line" somewhere--possibly in three to five years. Preventive program costs, however high the initial cost-per-patient may be, can be expected to decline after routine dental treatment is provided.

Between 1974 and 1976, the state of Vermont implemented a totally state subsidized Tooth Fairy Program (TFP)--a Children's Comprehensive Dental Health Program--for the children of low and middle income families. An evaluation of the Vermont TFP has been published by the Vermont Public Interest Research and Education Fund.[6] Comments and quotations which follow reflect experiences and findings presented in this Tooth Fairy Evaluation report.

It is significant that the total cost of the Vermont program was $480,000, $450,000 of which represented payment to dentists for dentalcare (80,000 services for 12,000 children). Only $20,173 was spent for program administration. The total annual cost of the TFP was equal to 0.3 of one percent of the state budget.

The program was considered successful by the families of enrollees (97 percent recommended continuation of the TFP) and also by Vermont dentists (88 percent provided support). In a state with a preponderance of rural towns and villages, the need for dental care was substantial (48 percent of the enrollees had never received dental care or had experienced only emergency care; 32 percent of the enrollees had never received dental care).

Cost-Benefits of the TFP

The program demonstrated that dental expenditures decrease after the initial year. In the TFP, third year enrollees consumed an average of $54 in dental services. The same group used $69 in dental services in the previous or second year (an average of 21 percent reduction of expenditures after two years enrollment in the TFP). Further, the program demonstrated that the rate of school referrals declined from 40 percent in 1975, to less than 20 percent in 1976.

The following table from the Evaluation report provides a study of annual, cost-per-patient of dental treatment in the Vermont program.

Average Annual Costs*

Group	1974	1975	1976
Group A (most needy families)	$68.69	$80.14	$58.89
Group B (middle income families)	52.54	62.50	51.00
State		34.00	30.00

*55 percent of the claims from Group A; 45 percent of the claims from Group B

The Evaluation report authors make this observation about cost-benefits of a comprehensive children's dental health program, such as the Vermont TFP, which is quoted below:

> Initially high costs for dental care in the earliest period of a new Tooth Fairy Program enrollment are followed by significant declines in costs, as the backlog of unmet needs are remedied.....Inidividual patient costs go down after major needs have been met. But the benefits for the child will last a lifetime. With broadly conceived state programs in preventive health, unmet needs will at some point stop accumulating and thus, large initial costs will be less frequent.

The Vermont Tooth Fairy Program Evaluation report offers evidence in support of the view that initial costs of a children's dental care program should not be a deterrent to the support and implementation of such programs. As will be noted later in this statement, it is apparent that the Vermont TFP may be used a model for as many as 30 other states to establish and improve their children's dental program.

Recommendations

The Association believes that costs of children's dental care programs can be held to reasonable levels, if the following practices and procedures are included during their planning and implementation:

1. initial screening responsibilities should be assigned only to dental or dental auxiliary personnel, as determined by each state;

2. dental hygienists services should be fully utilized in both screening and treatment of CHAP patients; physicians and nurses are not appropriately trained or experienced to screen or treat eligible dental enrollees;

3. Expanded Function Dental Auxiliaries (EFDA's) should be utilized on both screening and treatment of eligible patients, when permitted by the state dental practice acts or state board regulations; (2416 dental hygienists have already received expanded function training); and

4. special definitions of "supervision" by the dentist of hygienists and EFDA's should be developed for remote and dental manpower shortage area programs; if necessary, dental practice acts and state dental board regulations should be appropriately modified to accommodate local and regional needs for dental care.

State EPSDT Dental Programs

The Association would like to point out that state dental health departments and dental organizations are accepting the challenge under Title XIX, Medicare to establish EPSDT programs. As members of the Subcommittee may know, however, there has been a significant road block in the design of the initial screening of EPSDT eligible recipients for dental care.

In part at least, an obstacle preventing EPSDT dental program start-ups may be explained in the quotation below, taken from A Guide To Dental Care, EPSDT-Medicaid.[7]

> Screening Personnel and Methods
>
> Screening for dental defects should be a part of total health screening and the personnel should be those involved with the overall responsibility for screening for health defects. As indicated by the previous section, the screening personnel may vary with the age of the child. In the younger

years this should be done by trained health personnel such as physicians or nurses.

Better than others, members of the Subcommittee can appreciate that the exclusion of dentists or dental hygienists in the initial screening process of EPSDT--Medicaid recipients does, in all probability, lead to few referrals of Medicaid-eligible children to dental offices. Despite this deterrent, however, several state dental health departments, in cooperation with the state dental societies, have established state EPSDT dental programs.[8]

Alabama. In October, 1972, this state started out to provide care for eligible children under age 12. Remaining age groups were phased-in as budgets permitted. At the outset, dental procedures included in the state plan were limited, but new procedures have since been added. Of 240,000 eligible recipients in the state, some 35,000 or about 16 percent have received dental treatment. The dental EPSDT program cost over a period of 29 months, was in excess of $3 million.

Michigan. This program was initiated in 1973. Michigan established a $25+ million budget to serve the 450,000 eligible population in the state. Within its first year, Michigan dentists screened all eligible children and treated gross dental defects.

New York. The state population of eligible recipients was estimated at 1.4 million children. Only three percent of this population had been served by 1975, although the program was initiated in 1972. In 1975, the state dental health department was considering a reorganization of this plan.

Other States. The Illinois Department of Dental Health reported children have been served, but the Illinois plan is still in an early stage of development. Wisconsin, Oregon and Minnesota are in the active planning stages of establishing EPSDT programs.

The fact that more states have not initiated EPSDT programs can be attributed to a variety of reasons, but the principle reasons for a less-than-impressive beginning of dental programs, among the 30 states which included some dental care, were concerns about costs, ineffective screening and need for liaison between state medical and dental departments; i.e., the extent to which state dental health departments were involved in the design and planning of the program and involved directly in the screening process.

The Association believes that continuing efforts by the states to initiate EPSDT dental programs should not be allowed to languish. Dental hygienists are professionally qualified to serve as a valuable resource to states in planning and administering such programs. The Association strongly supports a plan to extend EPSDT programs into the CHAP, provided that dental care is viewed as an essential component of medical care--which it actually is in most of the state plans which have recently begun to function.

Conclusion

An informal survey conducted by the staff of the Vermont Tooth Fairy Program, in September, 1976, included fifty state health departments. Forty responses were received which affirmed that 30 states offer EPSDT dental services under Title XIX, Medicaid. A

majority of the states offered, or plan to offer, a range of dental services comparable to those included in the Vermont program. It appears that all states use a mix of state and federal funds as determined by the EPSDT regulations. Some states, notably Tennessee, Texas and North Dakota, are currently planning to expand their children's dental care programs.

The CHAP bill proposes that the federal/state match for dental programs not be increased from an average of 55 percent to the 72-25 percent formula recommended for medical programs. If this provision remains unchanged as the CHAP bill recommends, there is a strong likelihood that an already effective start-up of dental programs under EPSDT will be adversely affected. Either programs which are now in operation or planning will not be expanded, or many may eventually be discontinued. Congress cannot expect that all states will emulate the Vermont model, which does not thus far use Title XIX Medicaid funds. The Association is confident, however, that Congress will want to continue to encourage all states to develop or maintain and improve existing comprehensive preventive dental health programs for children.

The Association urges the Subcommittee to give serious consideration to these recommendations and to revise H.R. 6706, or to prepare a new bill which would encompass dental programs, as well as other types of health care programs and services. If only four percent of the 13 million estimated EPSDT Medicaid eligible children have been treated--and probably less than two precent of these have received dental care--the new "Child Health Ass essment Program".

should become a focal point to make a substantial overall improvement in the health of our disadvantaged children.

The Association is prepared and willing to make its resources available at both state and federal levels to provide dental health care and treatment to all Mediciad-eligible children who need and deserve such care. The Association believes that there is sufficient documentation at hand which establishes that early preventive health measures will pay significant dividends in treatment savings over a patient's life span. The presence of dental disease (caries) in the mouth of a child is not self-curing, as many childhood sicknesses may be. Dental disease is cumulative. Untended dental caries become larger and more serious in time. No dollar value can be placed on the lifetime benefits to the child who receives preventive dental care when he most needs to have it.

References

1. Social Security Act, Title 5.

2. Association Policy Manual, American Dental Hygienists' Association, January, 1977, page 15.

3. American Dental Hygienists' Association statement, transmitted to Dr. Theodore Cooper, HEW Assistant Secretary for Health, April 2, 1975.

4. "EPSDT: Does It Spell Health Care for Poor Children", Children's Defense Fund, Washington Research Project Incorporated, 1977.

5. Dental Care Data, submitted by the American Dental Association to the Subcommittee on Health, House Ways and Means Committee, November 18, 1975.

6. "Tooth Fairy Evaluation, Vermont Children's Comprehensive Dental Health Program", Vermont Public Interest Reserach and Education Fund, Montpelier, Vermont, 1977.

7. A Guide to Dental Care EPSDT-Medicaid, DHEW, Social and Rehabilitation Service, in cooperation with the American Society of Dentistry for Children and the American Academy of Pedodontics; (SRS) 74-24515, 1974.

8. "Whatever Happened to EPSDT?", Jamie Binder Murray, MS, Chicago, Journal of the American Dental Association, Volume 90, March, 1975.

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Exhibit I, ADHA Record Statement
Subcommittee on Public Health and Environment
June 1977 Hearings, "Child Health Assessment Program"

AMERICAN DENTAL HYGIENISTS' ASSOCIATION

WASHINGTON, D.C. OFFICE
1101 17TH STREET N.W.
SUITE 1006
WASHINGTON, D.C. 20036
(202) 833-3024

American Dental Hygienists' Association

The American Dental Hygienists' Association is the official agency of the dental hygiene profession in the United States. Dental hygienists, under the direction of their dentist employers, provide important preventive patient care and oral health education services to the public. In 1977, the Association is composed of 30,000 members, a total which includes approximately 9,800 student members.

The Association participates in the program of the Commission on Accreditation of Dental and Dental Auxiliary Educational Programs of the American Dental Association, in administering an educational system which includes 183 accredited dental hygiene programs in colleges and universities throughout the nation. Upon completion of standardized educational requirements, the graduate dental hygienist must satisfactorily pass both national and state board examinations in order to obtain a license to practice dental hygiene.

There are currently in excess of 34,000 full-and part-time dental hygienists in private dental offices and public health agencies, school systems, in the federal and military dental health servies, and research. The American Dental Hygienists' Association conducts its many activities in full cooperation with the dental profession and shares the common goals of providing dental health services to meet the ever-growing demands of the American people for adequate oral health care.

The Association has cooperated in developing accreditation of dental hygiene programs, achievement and aptitide testing procedures, licensure in all States, and national board examination in dental hygiene. Working relationships have been established with the American Dental Association, American Dental Assistants' Association, and many other related organizations, thereby strengthening the role of the dental hygienist on the oral health care team.

The concept of preventive dentistry is not a new idea. Dentists have advocated and taught effective oral hygiene habits to prevent tooth decay since the invention of the tooth-

brush, but the idea of turning over to a dental auxiliary the primary responsibility for maintenance and instruction of oral hygiene for patients was not formalized until the early 1900's.

Today, dental hygienists are trained for a minimum of 2 years, and are engaged in much more than the polishing and cleaning of teeth, although this remains one of their primary duties. They prepare dental X-rays, and instruct patients in proper techniques for the cleaning of teeth, gum treatment, and the role of nutrition in oral health. Working under the supervision of dentists, many dental hygienists have expanded their functions in the treatment of periodontal disease and administering anesthesia, as well.

As dental hygienists have become more involved in organizational efforts to make the public more aware of their role in providing dental care, the ADHA has expanded to operate on various levels. A Washington Office was established in 1971 to maintain liaison with federal health programs affecting dental hygiene practice and education, as well as make known the Association's views on significant items of health legislation.

Educating the public to good oral health as an integral part of total physical well-being continues to be a major concern of the profession, as well as encouraging the continuing education of dental hygienists and setting standards for implementing innovative dental hygiene techniques in keeping with State practice acts.

It is apparent, then, that dental hygienists have established themselves as an indispensible part of the dental health team by relieving the dentist of those responsibilities for which the hygienist is specially trained, thereby increasing dentists' productivity, and by offering the patients professional expertise to aid establishment of a good oral health regimen.

Although dental hygiene has come into its own as a profession in recent years, it has by no means reached a static stage. ADHA's constant innovation and continuous involvement with dental health concerns at every level--educational, legislative, and direct care delivery--are evidence that the Association is still striving to fulfill its goals and thereby, better address the Nation's oral health needs.

Mr. ROGERS. Thank you for your excellent statement.
Ms. Katz.

STATEMENT OF MARILYN KAPLAN KATZ

Ms. KATZ. Thank you. I appreciate the opportunity to testify before you today. I am not a provider and do not represent a provider group. I represent, as an attorney, the intended beneficiaries of this act, the low-income children and their parents who look to you to provide them with better health care. In this capacity I have become familiar with the EPSDT program as it operates on the local level in Connecticut.

In its current form, the dental portion of the CHAP legislation aspects, would be very detrimental to the interests of my clients in two ways. First, it is important to know that children and parents care about dental care. It is important to them. It is one of the few universal services that all my clients and their children can benefit from. There are many very highly specializd items that are being considered in the screening and treatment package. It is certainly important for the one child who may suffer from a rare disease to have that discovered in time. But dental care is something each and every one of them can benefit from and appreciate it. It is the kind of thing, as Congressman Maguire said, that most Americans take for granted but that they cannot.

Secondly, from a legal point of view as an attorney trying to help clients achieve their goals in this area, the CHAP proposal would make our legal position worse than it now is under the current law. It would remove the support we now have to build on in order to make the current requirement for this a reality.

Dealing first with the problems of my clients, in their nonlegal aspects, you have heard that a dental assessment is unnecessary because nearly all children will need dental care at any rate. I would suggest to you it is really more than unnecessary. An assessment can be a significant barrier to receiving care. We have seen this happen in Connecticut in two ways.

First of all, you lose children in the process between the assessment and the treatment, between the diagnosis and child care and the referral. The rate of children who complete each step goes down. Given the difficulties of transportation and the difficulties of knowledge and communication, I think that the simpler we can make the program, the fewer stops, and the fewer different providers the children get shuttled to, the greater the chance of success.

Secondly, the assessment process as it now operates in Connecticut leads to very, very few children being referred for dental problems. The latest HEW statistics show that only 6 percent of the children screened were identified as having dental problems, and presumably were referred on to a dentist. This is very serious. Not only for the dental problems but for the other health care problems that these children have. For many of them a dentist may be the only real primary care provider that they see. Unfortunately, despite EPSDT most of our children rely on emergency room care for their physician services. This means that many of their general health conditions are never looked at by a medical doctor.

I have had two clients just in the last year who had serious health problems that were first detected by dentists. One was a boy about 16 years old who was observed in a dental office to have a smell of acetone breath, rampant cavities and unexplained abcesses in his teeth. The dentist learned that he had frequent urination at night. Suspecting a medical problem the dentist referred the boy to a doctor. The child had juvenile diabetes, which can be very serious and dangerous. It might well have not been detected if the boy had not seen a dentist.

Another child we had was an 11-year-old girl who was observed by her dentist to have a large swelling in her jaw that was not painful to her and that she had not noticed. The dentist referred her to a surgeon who removed a giant cell. Without this intervention she would have sufffered a broken jaw.

These cases and the statistics on the low number of children now receiving care are not a reflection of lack of concern on the part of parents. Parents recognize that their children need dental care but often have great difficulty in getting it.

One of my clients called 25 dentists and was unable to find one who would treat her child. This is a combination of inadequate fee schedules and, I think, lack of education on the part of the State about the availability and need for dental care.

Mr. ROGERS. Thank you so much.

Ms. KATZ. I have one other thing to say. Shall I continue?

Mr. ROGERS. Yes.

Ms. KATZ. I would like to point out that the legal difficulties we are trying to overcome now are to get the fee structures raised and to get adequate referrals. We think that under the current law, which mandates at least what dental care is necessary for the relief of pain and infection and to maintain teeth, we might be able to make some progress. In fact, just last year we were able to use the current provisions to stop some intended cutbacks in the dental program in Connecticut by pointing out these were mandatory services the State had to deliver. I am afraid under this CHAP bill as now proposed we would not have that much to build on. We would have to limit ourselves to children who had been assessed and then only to those conditions found in the assessment.

Given the irrationality the dentists have told us is inherent in an assessment predicated system, there would be some equal protection problems that I do not think the Congress would want to create in such legislation.

I was just made aware of the bill that Congressman Maguire introduced yesterday. I think the provisions in his bill would take care of our concerns. First of all, as I read the bill, it would eliminate the exception of dental care from required services. Second, it would provide that an assessment need not be required before dental treatment is covered; and third, it would provide that when a dental assessment is made part of a State plan it must be done by trained dental personnel.

I would like to strongly urge you to report the Maguire dental proposal instead of the current CHAP proposal.

[Testimony resumes on p. 358.]

[Ms. Katz prepared statement follows:]

STATEMENT OF MARILYN KAPLAN KATZ, CONNECTICUT LEGAL SERVICES

My name is Marilyn Katz. As an attorney for Connecticut Legal Services, I represent low income children and their parents in efforts to secure better health services for children. In this capacity I have become familiar with the Medicaid program and with the Early Periodic Screening, Diagnosis and Testing (EPSDT) program as it operates at the local level in my state.

I appreciate the opportunity to testify before you today.

I would like to briefly comment on the proposed Child Health Assessment (CHAP) Act of 1977. Although there are many aspects of the bill which deserve close consideration, I would like to confine my remarks today to those provisions which affect dental care.

First I would like to invite you to look at dental care from the perspective of my clients. Everyone is concerned about rising Medicaid costs. I am sure this concern is shared by your committee, as it looks at the types of services that could be covered in a preventive care program for children. The reaction to the testimony you have heard thus far today may be: "Surely dental care can be useful to children, but there are more crucial items to be covered, such as tests

which will discover debilitating diseases and make their treatment possible." From our clients' point of view, it is of course important to discover any condition that may affect a particular child, even if that child's malady is rare. However, my clients are most concerned about getting the very basic health services - what most people in this country take for granted.

This includes dental care. For example Connecticut has a $300 million dollar a year Medicaid program. All but $25 million of this goes to institutions, nursing homes and hospitals. Therefore each person on Medicaid averages only about $125 a year for all non-institutional medical care. This is a very small amount and the dental portion is even smaller - less than 1% or $10 per person average per year.

Our clients believe that the already small amount spent for their basic health and dental needs should not be eliminated in moves for cost control. Our clients care about dental care. One client of mine called 25 dentists in and around the town where she lives, trying to find one who would treat her children under Medicaid. She was unable to find one dentist who would see them.

It is not lack of parental concern but other problems which account for the small amount of dental services

currently provided poor children. The problems for our clients are learning what care is available and convincing someone to treat them despite the low fees that will be paid for the services. We are relying on the law in its current state to try to correct these problems.

Current law requires the states to provide for the treatment of conditions discovered in screening children as long as such treatment is one of the services ordinarily provided by the state under its state plan (the state may be providing the service because it is required by the Medicaid Act or because the state has chosen it from the list of optional services covered by Medicaid). In addition the states are required to provide "at least such dental care as is necessary for relief of pain and infection and for restoration of teeth and the maintenance of dental health, whether or not otherwise included under the state plan..." 45 C.F.R. §249.10(a)(3)(iv). This regulation has been read in a rational manner by many states including Connecticut to require dental care within the limits of the definition for all Medicaid eligible children regardless of whether or not they have undergone what is formerly called "an assessment" under EPSDT. Thus in Connecticut, less than 6% of the Medicaid eligible children who receive screening assessments under EPSDT were identified

as having dental problems. Yet approximately 20% of all Medicaid eligible children - including many unscreened children - receive dental services under Medicaid because of the present EPSDT program requirements.

The sources of these statistics provides another illustration of the effect of the present law. They were learned through discovery in the case of Robinson v. Maher where I was counsel. The lawsuit grew out of an attempt by Connecticut to cut back on services. The state was going to withdraw dental care services from adults but not from children because of its understanding that the EPSDT regulation required them to provide dental services to all Medicaid eligible children. We are now relying on the present requirement in an affirmative effort to make the requirement more meaningful. We are urging the state to inform our clients of the availability of dental care through personal and mail contacts and to insure the availability of the care by setting reasonable fees.

The current law which requires certain dental services to be provided regardless of whether the child has been assessed embodies a recognition of two unique aspects of dental problems: one, their incidence, i.e., the fact that all children need dental treatment; and two, the difficulty of detection, i.e., the fact that one cannot usually identifycavities just by looking in a child's mouth.

As HEW has stated in its own Medical Assistance Manual for the states, "Unlike other health needs, dental problems are so prevalent that most individuals will need diagnostic evaluation and some treatment. This examination, diagnosis and treatment planning must be the responsibility of legally qualified dental practitioners and their auxiliary personnel." Medical Assistance Manual, §5-70-20 F(4).

Thus, on the one hand, HEW has itself stated, you cannot expect ordinary dental problems to be discovered in a regular screening process. The Connecticut statistics referred to previously illustrated this: less than 6 percent of the children who received screening assessments were identified as having dental problems. On the other hand, we know that all children need dental treatment and in Connecticut - even with the lack of information and the low fees - 20 percent of all Medicaid eligible children get such care.

The situation I have described is the reason we are opposed to the dental care provision of the proposed CHAP bill. This bill has been introduced "to assure that more low-income children receive regular high-quality primary and preventive care," (from President Carter's message of April 25, 1977, announcing the legislation), and Section 3(G)(ii) of the bill broadens the responsibilities of the state to provide other kinds of care whether discovered

in an assessment or not. However, this section makes an exception for dental services by requiring only "the treatment of conditions discovered during an assessment." Especially without a concurrent provision which would mandate a professionally conducted dental assessment, this language if enacted could virtually eliminate the treatment of dental problems for poor children. For without such a proper dental examination by a dentist or equally trained professional, not even conditions such as simple cavities will be discovered by a person simply looking into a child's mouth.

There are other dangers to interposing an assessment before a child is examined by a dental professional. I have had several clients within the past year who had other serious health problems that were first detected by dentists. One, a 16 year old boy, was observed in a dental office to have a smell of acetone breath, rampant cavities, and unexplained abscesses in his teeth. When the dentist questioned him he learned that the boy had frequent urination at night. The dentist referred him to a physician and the expected diagnosis of diabetes was confirmed. Juvenile diabetes can be a very serious and dangerous disease and it might not have been detected until the boy had to be hospitalized were it not for his visit to the dentist. Another child we had, an 11 year

old girl, was observed during a routine dental visit to have an unexplained hard lump swelling in her jaw. The dentist referred her to a surgeon who removed a giant cell. Without the dentist's finding she would have eventually suffered a broken jaw.

Perhaps under a very thorough and effective child health assessment program, these symtoms might have been recognized by trained personnel without the dentist's participation. However, the health care provider for many of the children who are our clients is an emergency room where only the grossest disorders are diagnosed and treated. Thus a regular dental examination may be the best chance they have for their general health as well as that of their teeth.

Therefore, an "assessment" to be meaningful must be done by a dental professional. Ordinarily what is now done is that a child goes to the dentist's office and "the assessment" is done by the dentist in the course of his examination prior to treatment. Such an assessment might also take place through the services of a trained dental hygienist who could do the preliminary examination, cleaning, and X-rays at another location, possibly the school, and then refer the children to the dentist for further treatment.

However, this points up the other problem with the bill as currently drafted. If a provision is added to the statute or imposed by regulationfor a specific dental assessment to be carried out by a trained dental professional, then all conditions will be "discovered during an assessment" and the purpose of the language as a limitation on treatment would have no meaning. We believe that given its importance to clients and its proven effectiveness as a cost control item of preventive care all dental services should be included,as all medical services will now be included,under the proposed act. But if limitations on dental services are to be imposed, they should be ones rationally related to the efficacy and need for the services, which the language of the current regulation recognizes and mandates, not to some artificial cut-off point.

As an attorney, I would also ask the committee to give its attention to the possible additional legal consequences of enacting the bill as it now reads. I believe that the program being proposed which would provide for dental treatment to be provided to children only after an assessment, when that assessment would clearly not lead to the discovery of situations to be treated, is wholly irrational. I cannot believe that the Congress would want to enact a program that would raise such serious equal protection problems.

Therefore, we would urge you to amend the bill to make clear that dental care services are to be covered regardless of whether or not they are "discovered during an assessment." In the alternative, we would urge you to amend the bill to require meaningful professionally conducted dental assessments. Thirdly, if dental care is tied to assessments, we would urge you to require that such assessments be made for all children every year. Without such changes, we would urge you not to enact the current proposed language on dental care but to leave the situation as it presently exists so that the regulation pertaining to dental care which currently discriminates between the required and non-required dental services based on their need and efficacy can remain intact.

Mr. ROGERS. Thank you so much.

We will have to ask you to bear with us once more. We will recess for ten minutes.

[Brief recess.]

Mr. ROGERS. The subcommittee will come to order.

Why is dental care always considered more expensive than just medical care? Is there any validity to that?

Dr. SCHOEN. I will take it, if I may, Mr. Chairman.

It isn't more epxensive than medical care, because in the United States in fiscal 1976, I believe in all medical care, $139 billion was spent and in dental care $8.6 billion was spent. So while $8.6 billion is a considerable sum of money, it represents a rather small proportion of the total expenditures.

Mr. ROGERS. Yes, but did you treat all the people who needed it?

Dr. SCHOEN. No, but even if we——

Mr. ROGERS. What would it have been if you had done that?

Dr. SCHOEN. If we had treated all of the people?

Well, if you treat them all at once, and this is a wild guess, it might have gone up to maybe $16 billion or $20 billion, but you never have 100 percent utilization on anything, and some of us have estimated that if you would get all people to a regular level, the cost would not be any higher than $8.6 billion.

Mr. ROGERS. How did you dentists ever let it get to the stage where when people talk about medical care, dental care is never included?

Dr. SCHOEN. Do you want to take that?

Dr. LEVITAS. Mr. Chairman, I don't think anyone can give you an answer as to how it got that way, but so much of dental care is an elective procedure, or has been put in the viewpoint of being an elective procedure. A lot of it is of a technical, and if you will permit me, mechanical nature, not taking anything away from the scientific application of very sound principles that go into that. There is a great cartoon that shows a lady looking in her mouth and says "$350 for something you can't even see."

Well, this is the attitude that the public has had, and unfortunately I think that perhaps part of the blame for the very thing that you have asked about must be placed on my dear good close friends and some of my best friends are physicians. I feel that they don't have the understanding and the appreciation of the intertwining and the very complete relationship of dental care as related to medical care.

Mr. ROGERS. You know you can go get your ears looked at, your eyes looked at, your nose, but not your teeth. It has all got to be separate. I would think the Dental Association ought to start a drive to include dental health as a part of the health care of everybody.

Dr. SCHOEN. I think we have, Mr. Chairman, but we are educated in different shools with different degrees, and that separation, which started in about 1840 or so, seems to have perpetuated itself, so that we are considered a separate and distinct profession, rather than a specialty of medicine.

Ms. KATZ. Could I say something to that?

Mr. ROGERS. Yes.

Ms. KATZ. Addressing your first point about the cost of dental care, if we look at the Medicaid budget in a State like Connecticut we see the evidence that recipients don't have a lot of input into what kinds of care are provided.

The institutions do frankly, the nursing homes and the hospitals, and to some extent the physicians. Three quarters of the Connecticut Medicaid budget goes for institutional care for a very small portion of the Medicaid population. The amount spent on dental care in Connecticut is less than 2 percent of the total Medicaid budget. That is less than $10 per person, and that is not even distributed equally. The children don't get as much of that as the adults do. The adults get unfortunately the more extensive care, because we are correcting years of neglect. The children get an almost infinitestimal amount. So even if in a State like Connecticut we tripled the expenditures, it would still be less than 3 percent of the budget, and very small amounts of money in dollars compared to the whole thing amount—less than $10 million.

Mr. ROGERS. Dr. Levitas, you have something further?

Dr. LEVITAS. I do.

I was going to make the observation, because I have believed this, and I say this in keeping with the statement that you have just made about examinations, if the pediatrician were to require a dental examination of every child at a proper age level, before he would sign a health certificate for that child, I believe that this would do as much as anything else that we could possibly institute to first help correct, and most important and secondly, to prevent

dental problems in children, because parents, the mothers particularly, place a tremendous degree of confidence and trust in their pediatricians, and would take the children, if the pediatricians insisted upon this type of examination.

Mr. ROGERS. Maybe we should require dental screening before payment is made. We need to do something, and I think you have brought to the committee a great many facts about cost. Any additional statistics you have, and I think you said you had some, Dr. Levitas, would be helpful to the committee.

Also, if you could state for us what services ought to be covered, if that is possible, so that we do what should be done to improve the health of young people, I think that would be helpful to the committee.

Mr. Maguire, I wonder if you could take over the committee?

Mr. MAGUIRE. Thank you, Mr. Chairman.

Mr. ROGERS. Thank you for your presence.

Mr. MAGUIRE. [presiding]. Thank you very much.

Dr. Levitas, I thought your statement was excellent. I want to compliment you on it. It was extremely thoughtful. You didn't hesitate to challenge assumptions that you felt were faulty, and I am grateful, as I know the whole committee is, for your offer to provide your own cost estimates, which I think we will need as we proceed.

Clearly, this is going to be a key issue, and if you could supply at your convenience those estimates, it would be very much appreciated.

Dr. LEVITAS. I am sure that the ADA office here will see that that is made available to you.

Mr. MAGUIRE. Thank you very much, sir.

Doctor, the question of adequate participation by potential providers has been touched on by a number of witnesses in these 2 days of hearings, that is participation in the Medicaid type of program, specifically in this case, of course, the child health assessment program.

How can we promote more provider participation?

Dr. LEVITAS. I am speaking of course as a private practitioner, and can give you my impressions. I am involved in Medicaid in that I see Medicaid children and I am happy to be able to do so and I make no bones about it. I have seen them since the inception of the program at home.

There are three factors that it is my experience most of my colleagues take exception to. One is the tremendous amount of red tape involved in trying to get cases approved, treatment plans approved, prior to actual treatment.

To take just a moment of your time, I have a case right now that is pending of a severely retarded young girl who is waiting for treatment, who is to listen to her mother, in severe pain. This has been going on for weeks and weeks, simply trying to cut through red tape in the Medicaid program to get an okay to render her treatment.

The second factor I think is the laundry listing, or the tendency to eliminate and not permit the doctor to do comprehensive dental care, but to say you can't do this, you can only do that. You can't use these things and you must use that. That is resented.

And, of course, then, to be very mundane about it, is the matter of fees, where in almost all instances in most States, dentists who are participating in these programs are asked to take reduced fees for their services. It seems peculiarly strange to me that people in other fields are not asked to take reduced fees to construct hospitals or roads or school buildings or whatever it is, and yet the professional in health care, in dentistry certainly, is asked to take a reduced fee to treat children, and adults for that matter, in the Medicaid programs. I think it is those three things.

Mr. MAGUIRE. Do you think there is a basis in some instances to make a distinction between what would or would not be permitted and covered.

Dr. LEVITAS. I do. It is a very tough question to answer.

Mr. MAGUIRE. Could a better job be done, or is it intrinsically a situation which is not amenable to being ameliorated?

Dr. LEVITAS. In dentistry, dental services, and I hope these gentlemen and ladies will take issue if they disagree with me, there are many ways to render certain types of treatment.

What has happened is that, to use a phrase, Cadillac dentistry has been provided for people who could not afford Ford dentistry, and perhaps this is where some of the monies have gone. So to answer your question, and maybe you had better put all this down as just plain old me speaking and not the ADA because I don't know how they feel about this, but I am just talking for myself.

Yes, there probably should be some restrictions on how things are done, but the dentist must have the leeway to render needed services without having to half way treat a mouth, to treat an individual, to treat certain teeth.

Mr. MAGUIRE. That is very helpful. I want to again express my appreciation for your fine statement, particularly points that you have made about the cost effectiveness, diagnosis and treatment approach as opposed to a screening approach. And the fact that the administration bill as at least presently drawn appears to invite States to reduce their effort in this area. I think those are extremely important points and I am glad that you underlined them in your statement.

Dr. Ripa, what comments might you have on the effect if we proceed as the administration recommend, of treating children up to age 6 but not beyond age 6?

Dr. RIPA. Well, one of the main problems with that approach is that the permanent teeth do not begin to erupt until age 6, and so by limiting care to only children from birth to 6, we would really eliminate any treatment to the permanent dentition at all. Certainly one can say the same thing about providing preventive care to children from birth to 6. While we could provide some systematic flouride benefits, even these benefits would slowly dissipate if we stopped that particular care at age 6, so it seems to be an inappropriate age to stop dental care.

Mr. MAGUIRE. Thank you.

Dr. Schoen, your testimony is most thought-provoking in its laying out of an alternative approach to what is usually assumed to be the way that people are going to be treated, and the use of the schools in particular it seems to me is thoughtful and innovative. I

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am wondering though about the denial of payment to dentists for certain kinds of services, for example, fluoride rinsing, et cetera.

Can you expand on that a little bit, as to why you make that recommendation?

Dr. SCHOEN. Mr. Maguire, I had made the recommendation because for a dentist to conduct a fluoride rinse program would be almost impossible since it has to be repeated at a regular interval. And the only way that such a program can be cost effective is to do it for the vast majority of the children on a regular basis, and the only way that you can get to those children on a regular basis is in the schools.

Also it is the type of a service which can be provided or supervised by nonprofessionals, teachers' aides, teachers and so on, who can be trained to supervise the provision of this service. It then becomes extremely inexpensive.

If this is done, that would provide the bulk of the benefit. If someone voluntarily then wished their dentist to apply additional fluoride, I think they could do so, but would have to pay for it. But when the dentist does it in the dentist's office, it becomes a rather expensive procedure because the prophylaxis and fluoride together as we found in head start, for example, and as in the figures I gave here, the prophylaxis-fluoride-X-ray diagnosis chews up around $20 to $25, and that can be done for a much smaller rate at the schools, with the dentists doing restorative care. Again this approachis much more cost effective. The dentist only sees a fraction of the children anyway.

Mr. MAGUIRE. What about X-rays?

Dr. SCHOEN. Well, the X-rays. I am now a consultant or an auditor for the State of California reviewing dentists' performance under Medicaid, and the level of the quality of the X-rays leaves a lot to be desired for possibly, and this is a guess, close to 50 percent of the X-rays. And also in many of the situations, there are too many X-rays taken. In other situations there are too few X-rays taken.

Mr. MAGUIRE. And it is easier to control that in a school environment.

Dr. SCHOEN. It is easier to control it in a school environment where part of the system would be to take the X-rays and then send them to the dentist. In an emergency situation, obviously the dentist could take the X-ray for that emergency, and in addition the keeping of a copy of the X-ray in the school environment would permit one to evaluate the success of the program very easily, which now is an impossible problem in auditing.

Mr. MAGUIRE. Dr. Levitas, would you care to comment on those points, first with respect to the rinsing, and second with respect to the X-rays?

Dr. LEVITAS. What was the second part?

Mr. MAGUIRE. Second, with respect to the X-rays.

Dr. LEVITAS. The rinsing program is probably a very fine adjunct to an overall preventive concept of dentistry. The thing that disturbs me is that most children do not enter school until they are 6 years old, and, if that is the case, they are not going to get the benefit of this type of thing.

Mr. MAGUIRE. Although head start or other preschool programs could, I think, operate that?

Dr. LEVITAS. Right; if they had the people trained and willing to take the time that needs to be done. I think that would probably be a fine adjunct to this type of program.

As to the matter of X-rays—I relate to it as a private practitioner—I have a little difficulty. I think the taking of X-rays particularly for young children at times can be difficult. To do it on a mass production basis with a lot of kids around and with someone who is not for the most part probably exquisitly trained in the field of dental radiography and of making some judgments as to the effectiveness of the pictures that have been made, I would be inclined to feel this should be a function of the dentist in the dental office. I am not altogether sure about the importance of keeping records in the school of dental X-rays. If they wanted to get information, the films could be duplicated and sent out from the private offices. I feel that part probably should be retained at the dental office.

Mr. MAGUIRE. Thank you.

Ms. Yunker, what type of role can the hygienists play in underserved rural areas? Would you expand on that? It is a subject which keeps coming up. How do we deal with the underserved area? How do we provide the services?

Ms. YUNKER. The dental hygienist can perform many functions in all sorts of settings. In most State practice acts there is a special clause that allows the dental hygienist to work in community settings, in rural settings, school settings.

The hygienist can do all of the primary preventive services which would be the traditional duties, the prophylaxis, the cleaning, the X-rays. Also to add that dental hygienists do meet all accreditation standards set by the ADA to take X-rays and settings.

The hygienist can do the fluoride treatments, can do numerous procedures that would be an adjunct to the preventive treatments. Some can do sealants. So it is a very wide amount of functions that can be performed. They can also be in an administrative role, in an educational role.

Mr. MAGUIRE. What does your statement imply when you say some can and some cannot? What are the criteria?

Ms. YUNKER. The criteria would be what the State practice act allows the dental hygienist to perform. There is a great deal of variation from State to State. In many States there is a wide range of traditional functions performed by all dental hygienists. There is a varied amount of functions performed in other States.

Mr. MAGUIRE. Thank you.

Ms. Katz, I very much appreciate your statement. I am wondering, though, if you were hit with what is admittedly a difficult question of having limited resources, what kind of care you would feel ought first to be provided to children if we actually face that dilemma and we cannot do everything?

Ms. KATZ. As I indicated, I think that, representing all my clients, I would have to go for those kinds of care that are the most universal and the most desired by them. Those are the primary care and preventive care functions. It just hits everyone that way, that a

lot of other services do not, dental care and primary physician care. Those are things my clients lack more than anything else.

Mr. MAGUIRE. Are you saying you would include dental care and sacrifice some other things?

Ms. KATZ. I think I would have to say yes.

I would have to place it near the very top of the list of what should be provided under CHAP. I mentioned that dental care is of universal applicability. Even more important, preventive care is one of the most universally effective health services. The proven benefits of routine dental care contrast with the unfortunately less certain efficacy of many other medical treatments.

Not only does dental care cause a measurable improvement in childrn's health, but it is an improvement which is immediate and visible. The children—and their parents—directly experience the value of teeth which look and feel better and they can readily understand the connection between the treatment and the benefit. This experience is a good thing in and of itself and is also an excellent lesson in the value of regular health care in general.

The lesson continues because dental care involves the recipients as active participants—and in a way that is within their resources to perform. Many necessary medical treatments are administered to children and others which require participation are unfortunately beyond the means of my clients. For example, I currently have a client whose child is suffering from muscular dystrophy. Because of this ailment the child needs a special formula for food which costs almost $20 per week. This is beyond the financial resources of her family to provide. Ironically because of the inability to secure this $20 a week diet treatment, the child is currently in the hospital at a far greater costs which will be borne under Medicaid. Other kinds of medical treatment similarly tax the resources of our clients beyond their abilities in both financial and non-financial ways, including special living arrangements and regular appointments which require transportation and time.

But dental care requires only inexpensive and easily performed acts on the part of our clients. A toothbrush and some dental floss are the only tools necessary and, after proper instruction, they can be used by a child.

All of these aspects make dental treatment the ideal service to include and emphasize in any child health program interested in comprehensiveness of coverage and in prevention.

If I may comment on one question you asked before in terms of engaging providers, I think there are several things in the current regulations and statutes that could be useful. The subcommittee might want to consider either keeping or expanding such provisions to elicit more provider participation in the program.

I think the current regulation that limits dental care to those items which are necessary for the relief of pain and the maintenance of dental health is a good place to start. It may be you want more particularity about which services meet this definition, but I think that is a good definition that would exclude most elective work.

We have been trying to work within that definition to get certain items that are now excluded on our State laundry list, as Dr.

Levitas said, included, because we think they are services which go to prevention and maintenance of dental health. I would like to see that language either kept or expanded.

Secondly, prior authorization is responsible for some of the red tape he was talking about. But the regulations provide that prior authorization cannot be used to unduly burden the provision of services. It is not to be used as a dodge to deny services. A couple of things that can be done in that regard are to have a certain monetary limit where, for example, anything under $50 does not require prior authorization by the State, so there is no red tape and that dollar amount is the State's safeguard to getting things done.

In the cavities, there is some question of whether or not X-rays can show or not show whether the work was needed to be done. Then it will probably be authorized anyway. We could have the situation, though, where the dentist assumes the risk. This is something we are working on in Connecticut. There is no prior authorization but if on a double check it seems the work cannot be done, the dentist assumes the risk of having done that work and not being compensated. I think as a tradeoff many dentists would be willing to put up with the fact they might not be reimbursed once in a while in return for the fact they would be able to do the work for their clients while they are there.

If you have someone in the dentist's office and you tell them "I will call you in 6 weeks; maybe I will get to treat you but maybe I won't," a lot of clients are lost and never receive treatment.

Mr. MAGUIRE. Are there any dentists on the panel who agree with that statement?'

Dr. SCHOEN. In California, even though I am critical of some parts of the program, for most of the Medicaid dental services for children—and they are quite comprehensive—there is no prior authorization and the costs over 3 years were actually a little lower in the third year than the first year so there was no inflation that took place. The utilization rate had gone up. So there is an example where prior authorization was not necessary.

Ms. KATZ. The third point I wanted to make concerns fees. The regulations now provide that the fee levels have to be set by the States so as to elicit the participation of a sufficient number of providers so that a recipient gets the same services as the general population. The fees are too low in many instances to insure that sufficient numbers of providers participate. I am not an advocate of high fees from a provider point of view. I am interested in keeping the costs down so more people can get more care. But it does create a second-class system if you only have $6 to pay for a dental cleaning because that is what the Medicaid rate is though dentists regularly receive $12 from those who can afford to pay. I would suggest we look to a standard that is not whatever the dentist would charge but something like the reimbursement rate used by Blue Cross or other medical insurance systems that would more closely approximate the real cost than what is now being charged.

Dr. LEVITAS. Mr. Maguire, would it be fair for me to ask you a question?

Mr. MAGUIRE. You could try.

Dr. LEVITAS. Suppose in this same program you had a question of fees or availability of funds, as you have raised the issue. Would you go to the physicians and say, "We have only x numbers of dollars. What are we going to eliminate from your treament of these children?" That is what you are asking us. We have only so many dollars so we are going to say we cannot treat everything, but what would you like us to treat? I do not think that question would be put to a group of physicians. You cannot treat that rash or sore because we have only x number of dollars.

We must be given the privilege of rendering comprehensive dental care to children who need it. Certain types of cosmetic dentistry might be as important to the well-being of an individual as anything else that could be done for a particular patient. Yet, if there are strict limitations put into law, then there is no way that we can do it unless we go about it doing it for free, which other people are not asked to do—and plenty of us do for free anyway, as I am sure you are aware.

I think it is wrong to ask us what would we eliminate. We want to do comprehensive dental care for children so that we eliminate future needs which will become of even greater expense to the child and apparently to the Federal Government.

Mr. MAGUIRE. Thank you.

Are there any additional comments?

Dr. RIPA. Obviously the priority in terms of care gets down to the costs involved, and again obviously to reduce the costs one has to initially prevent the disease. That is why all of us have really emphasized prevention, because dental caries, which is what we are primarily talking about in children, can be prevented, and community approaches to prevention are the most cost effective. That rationale is what does lead us into the community fluoride rinsing programs, which can be done almost entirely with lay personnel and teachers, which, as Dr. Schoen has indicated, can significantly reduce the cost per recipient.

In addition, for head start children, while they may not be able to use a rinsing technique, certainly they would be able to use a fluoride tablet to gain systemic fluoride preventive benefits. Ultimately one should have a reduction in dental costs by these community approaches to the problem.

Mr. MAGUIRE. Thank you very much, members of the panel. We apprciate your testimony very much.

We will recess and reconvene at 1:30.

[Whereupon, at 1:10 p.m., the subcommittee recessed, to reconvene at 1:30 p.m. of the same day.]

AFTER RECESS

[The subcommittee reconvened at 1:45 p.m., Hon. Paul G. Rogers, presiding.]

Mr. ROGERS. The subcommittee will come to order.

Our next panel will consist of Dr. C. Arden Miller, past President of the American Public Health Association; Dr. Fred Seligman, Director of Division of Comprehensive Health Care, Associate Professor of Pediatrics, University of Miami Medical School, Miami,

Florida; Georgia L. McMurray, who is Director, Department of Public Affairs, Community Service Society; Anne-Marie Foltz, Associate in Research, Yale School of Medicine, New Haven, Connecticut; and Rebecca Andrade, who is Executive Director of the Tri-City Citizens Union for Progress, Newark, New Jersey.

We welcome each of you to the committee, and your statements will be made a part of the record. If you can confine your remarks to about 5 minutes, it will help the committee. We are delighted to welcome you.

STATEMENTS OF C. ARDEN MILLER, M.D., PAST PRESIDENT, AMERICAN PUBLIC HEALTH ASSOCIATION; FRED SELIGMAN, M.D., M.P.H., ON BEHALF OF THE ASSOCIATION OF CHILDREN AND YOUTH PROJECT DIRECTORS, AND THE AMERICAN PUBLIC HEALTH ASSOCIATION; ANNE-MARIE FOLTZ, M.P.H., ASSOCIATE IN RESEARCH, YALE SCHOOL OF MEDICINE; REBECCA DOGGETT ANDRADE, EXECUTIVE DIRECTOR, TRI-CITY CITIZENS UNION FOR PROGRESS; AND GEORGIA McMURRAY, DIRECTOR, DEPARTMENT OF PUBLIC AFFAIRS, COMMUNITY SERVICE SOCIETY

Mr. ROGERS. You may proceed.

Dr. MILLER. Thank you, Mr. Chairman.

I am Dr. C. Arden Miller, representing the American Public Health Association.

It has been my privilege to listen to your hearings for the past day and a half, and I have found much in them that is reassuring.

I am particularly reassured by many of the comments and questions that have come from you and your committee. I am reassured by Dr. Carter's interest in strengthening health departments and the public health capability within this program. I am reassured by your interest in wishing to place the whole EPSDT and CHAP endeavor in a broader context of maternal and child health and prenatal services. I am reassured by Mr. Maguire's interest in wanting to make this a program that assures services rather than provides only assessments.

In the testimony that the Association has prepared, we deal with a number of issues that have been dealt with I think to good advantage previously, and I won't repeat that. These issues include extension of eligibility to 21 years of age, providing for broader definitions and continuity of eligibility, inclusion of dental care, inclusion of children suffering from mental disabilities, and improving the Federal match of funds. What I do wish to dwell on at some length are two issues; one having to do with the principle of assuring services, and the other having to do with what Secretary Califano referred to as the provider problem.

In regard to assuring services, I am aware, as I think all of us are, that it is currently an official part of this government's policy to be concerned about human rights. We applaud that concern and believe that it is a domestic issue as well as a foreign one. I think it is a domestic issue that is represented in consideration of CHAP.

We construe that EPSDT provides poor children of this country with an entitlement; an entitlement to screening, an entitlement to

accurate diagnosis and to accurate treatment. I think that it is government's responsibility not only to define that entitlement and that right but to fulfill it. It is in that spirit that I wish to address the whole matter of assurance of services.

Mr. Califano this morning expressed an intention to assure services to 75 percent of all eligible children within a 5-year period. I must say I am disappointed at the limitation of that objective. The same Department plans to immunize 90 percent of children within a much shorter period of time, and I submit that the outreach efforts for immunizing 90 percent of children are not vastly different from the outreach problems of screening those same children for dental disorders, anemia and problems of hearing and vision. I think we can do better about assurances.

I am especially concerned that the constraints on providing improved services and incorporating more children with expanded eligibilities and benefits are all fiscal constraints. What concerns me about that is that it is really a measly amount of money that we are talking about. A very modest increase in money would extend eligibility and would extend benefits. The problem is that it is so easy once again to neglect children. They don't complain very much. We spend vast sums of money on other kinds of programs where the complaints are louder. I hope this is an instance where we do extend eligibility and benefits to the maximum. I think we must provide assurances that the entitlement for the health of America's children are fulfilled.

The provider problem. I agree with statements that many people have made that CHAP should be written in such a way as to allow and encourage a full range of providers and that contracts should be written with providers wherever they are qualified and wherever they are willing to offer these services. But I submit that among those providers, there is one that is unique, and that is the provider that has the responsibility to assure services to those children who are not reached by anyone else. Those are the health departments.

I think that this country does not possess the models whereby it is possible for government to regulate private and voluntary providers in such a way that we can assure that they can equitably fulfill entitlements to services.

The one delivery system that we can regulate, that we can control sufficiently to guarantee that everyone can be reached, are the official agencies of health, State and local health departments. Regrettably enough they are not all highly qualified either, and I submit that it should be a component of this bill to see to it that they are qualified.

A word about health departments. I know that you are aware that they are the only provider available for large numbers of children. There are census tracts in this country, particularly in inner cities, where as many as 80 percent of all children make use of medical care and health services as provided by health department clinics, school clinics. In our own State it is estimated that 50 percent of all children, insofar as they get any medical care at all except at the time of illness, get it from their local health departments.

The record of EPSDT, in relation to local health departments, is interesting. Local health departments are responsible for 60 percent

of all the assessments that were done, and those States that relied on health departments for doing the assessments succeeded in reaching larger proportions of children than those States which used mix providers.

There is no evidence that those States that used health departments as the providers were any less successful in providing diagnosis and treatment than those who used mixed providers.

I think that health departments can do a good job. Many of them are doing an excellent job. We have recently completed a survey of all health departments in the country, and those results soon will be published.

I was reassured at the many departments which have potential for reaching large numbers of children and for providing them with primary care services. Right now one out of four Americans is reached by some direct personal heatlh service that is provided by local health departments. I suggest that that is an access system that we can't ignore when writing legislation about personal health services.

Furthermore, it is perhaps worthwhile to point out that a number of times, at least three that I can count readily within recent years, it has been a matter of national policy to establish some kind of provision for broad personal health services with the intention of reaching everyone. That was true of family planning services. It was true of immunizations for swine influenza, and though that program had many problems which I won't dwell on, it was an expectation that ultimately fell as a responsibility of health departments. That was also true of EPSDT.

I think that insofar as those programs have failed, they represent failures of logic and thinking that those health departments can expand their services without also expanding their resources and facilities. I think it is necessary, in order for CHAP to be adequately implemented for the health departments to be improved.

One of the speakers this morning, perhaps yesterday, emphasized that CHAP should be written in such a way that we emphasize outputs. I subscribe to that empahsis. But I would remind the committee and others, that if we have learned anything in this country about improving health services, it should be that we don't improve outputs necessarily by adding to incomes. We improve outputs by improving services, and I think services need to be expanded and improved in the sense that health departments serve as the residual guarantor of all essential health services for a population.

I have some specific recommendations about the CHAP proposal.

No. 1, I would propose that there be specific pass-through financing of Federal funds to local health departments wherever those departments are not adequate to provide services, and wherever other providers either are not qualified or are unwilling to provide mandated services.

No. 2, I would like to say a word about the penalties that should be imposed for States who do not meet specified outputs. The new proposal I think is an improvement over EPSDT, in that it attacks administrative costs rather than funds available to poor people. And yet I recoil at the idea that when States don't provide services

that are mandated, we really penalize the States by withdrawing money from poor people's programs.

I would suggest that a good place to look for penalizing the States is to withdraw part of their revenue sharing money. That money was provided to States at a time when we were cutting back many Federal initiatives for health services specifically earmarked for poor people. Part of the justification for curtailing those programs was that the States would now take care of them and Federal Government would give them the money to do it through revenue sharing.

Insofar as the States haven't done that, shared revenue seems to me a fair target for penalities.

The third emphasis that I would like to make is the requirement that within a 3-year period, all providers provide comprehensive care. I am an enthusiastic subscriber to the concept of comprehensive care, but I really think in this instance it is retrogressive. It is retrogressive in the sense that I see no likelihood that all children within the 3-year period can be provided all of the services under one roof.

In fact, it imposes an unfair penalty on health departments to require this, because no one expects other providers, such as privately practicing physicians to take care of the dental, the ear problems and the eye problems all under one roof. They use referral systems too. They assure access to services and I think that the same assurances can be provided by a majority of health departments.

A fourth item is the desirability that the program be administered not by welfare agencies but by health departments. It is a health service program, and even though there are income factors associated with eligibility, it seems to me it ought primarily to be administered as a health service program.

My last point is that wherever there are populations of children who could qualify for services as defined by the C&Y and the MIC projects which demonstrate so effectively a cost effective model of comprehensive care, then I certainly think States should be required to expand their programs of special projects to provide new projects for such eligible populations.

Let me conclude by saying that I am aware that there are a number of people who look upon CHAP and EPSDT as something that we need to do until national health insurance comes along. I really think it is much more important than that.

I think it may be possible to write national health insurance in such a way that children won't benefit substantially. The record is very good that when children are thrown into financing and service programming along with their elders that children get pushed to the end of the line, and I think unless we put in place a solid health delivery service system for children before we have national health insurance, I think they will suffer terribly.

Thank you very much, Mr. Chairman.

[Testimony resumes on p. 384.]

[Mr. Miller's prepared statement follows:]

TESTIMONY BEFORE

SUBCOMMITTEE ON HEALTH AND ENVIRONMENT

OF THE

COMMITTEE ON INTERSTATE AND FOREIGN COMMERCE

HOUSE OF REPRESENTATIVES

September 9, 1977

In Consideration of

The Child Health Assessment

Act of 1977

Presented on Behalf of

The American Public Health Association

by

C. Arden Miller
Professor, Maternal and Child Health
University of North Carolina School of Public Health
Chapel Hill, North Carolina 27514

This testimony is presented on behalf of the American Public Health Association. I am Dr. C. Arden Miller, a pediatrician, and Professor of Maternal and Child Health at the School of Public Health, University of North Carolina; I speak for the Association as a past President. The Association, with affiliates in all 50 states, comprises a total membership through the National Association and its affiliates of about 50,000 people. Most of them are health professionals: nurses, physicians, social workers, environmentalists, administrators, nutritionists, health educators, podiatrists, technicians, and a number of new professionals such as health aides and community outreach workers. Consumers are welcome members of the Association.

Although I take responsibility for the contents of this testimony, I wish to acknowledge important assistance from statements that were prepared by the Children's Defense Fund, the Coalition for Children and Youth, the American Academy of Pediatrics, and colleagues in the American Public Health Association.

Since November of 1976 a strong theme for our nation has emerged in defense of human rights. The American Public Health Association applauds that emphasis and invokes it today in consideration of the Child Health Assessment Act of 1977 (HR6706/S1392).

Programs that address the needs of poor people are predominantly addressing the needs of children. The majority of poor people in the United States are children, and there are more of them raised in poverty today than in 1970.(1) About forty percent of all minority children and about fifteen percent of all white children are raised in poverty. Their

rights to health services have been well defined for nearly a decade under the entitlements of the Early Periodic Screening Diagnosis and Treatment Program of the Medicaid amendments. Medicaid eligible children are entitled to services that screen for health problems, and are further entitled to accurate diagnoses and treatment of any problems that are identified. These entitlements -- these human rights -- have been upheld repeatedly in litigation that has attended implementation of EPSDT.

The need for such a program is great. More than half of the children who have been screened have been found to suffer one or more health problems. Only about forty percent of those problems have been treated even though the most conspicious of them - dental disease, nutritional anemia, hearing disorder and visual defect - are readily correctible. This circumstance is especially tragic because without treatment all of these conditions can be expected to lead to lifelong disabilities. But, most tragic of all, about three out of every four children who are entitled to the services of EPSDT have not been reached by it.

Poor children are the most vulnerable and perhaps the most neglected people in our society. Their rights to health care continue to be largely unfulfilled. The full scope of children's health problems is superbly documented in the first twenty pages of, "A Proposal for New Federal Leadership in Maternal and Child Health in the U.S.", Office of Child Health Affairs, Office of Assistant Secretary for Health, DHEW, November 1, 1976.

The probable advent of national health insurance in the years immediately ahead requires that prior attention be given to strengthening health services for children. Unless special provision is made for children, they

will get pushed to the end of the queue when they are incorporated into service or financing systems along with their elders.

But more than delay is involved; the nature and scope of health services that children require are different from what their elders expect and require.(2)

The experience of other nations is relevant. When universal health insurance was introduced in Quebec, the number of physician visits per person each year remained constant but were shifted from those in high to those in lower income groups. But disturbingly enough there was a decline of about seven per cent in physician visits for ages under 17 years. Enterline concludes that the decline "may reflect inability of the age group to compete for services".(3) Children in another province of Canada (Newfoundland and Labrador) were protected from such crowding out. A children's health service was established there in 1958. Later when a health insurance program was established for all ages, special benefits for children were retained.(4)

Recent experience in Britain is even more compelling. When the National Health Service was enacted in 1948 preventive services, consisting most conspicuously of primary health care to mothers and children, were separately maintained under the Local Health Authority. A much admired feature of this service was the work of specially trained nurses, known as Health Visitors. In 1974 all health services were merged under a unified authority for the sake of integrating preventive and curative medicine and providing a single door of access through the offices of general practitioners. A report published in December, 1976 by a government committee on Child Health Services states that since unification "... families with

young children have had less than their previous share of the health visitor's time, and this is a development we should like to see reversed".(5) Special provision must be for health services to children; the report urges that those provisions be made once again in Britain.

In this country we are obliged to develop systems of care that legitimately derive out of American institutions; but we are not obliged to repeat the mistakes of others nor of our own past. Special provision must be made for health services to children.

The CHAP program as currently proposed is not an adequate response to the health problems of children. The APHA supports the concept underlying CHAP; the most timely avenue for improving health services to children rests with extending and improving EPSDT. It represents a powerful entitlement for children. Its failures of implementation are correctable under stronger federal support, technical assistance, standard setting and enforcement.

CHAP should state explicitly that its purpose is stronger than health assessment; it should seek to introduce every child into a community based health care system - public or private - that will provide continuing primary and preventive health care, and access to a full range of diagnostic, curative and rehabilitative health services as may be required.

CHAP eases some eligibility requirements now existing under EPSDT for children under six years of age, but discriminates against the school age population and fails to cover medically needy children. We urge that eligibility be modified to include all children and youth up to 21 years of age who meet the financial requirements for cash assistance. Children should not be excluded if family income falls within the levels of welfare

eligibility even if they fail to meet other state welfare requirements. Eligibility once achieved should be continued for at least twelve months after a health assessment. Even with these revisions eligibility is seriously limited; plans should be laid to expand eligibility to the 23 million children living in families that are supported at less than 150 percent of poverty levels. And even this step should be regarded as an interim measure towards the eligibility of all children and youth. The health needs of all people over 65 years of age, regardless of their economic resources, were addressed under Medicare; children are the next population group whose health needs should be met under public responsibility.

The benefits provided under CHAP, as it is now proposed, exclude certain kinds of treatment, and exclude care for children suffering from certain diagnoses, namely mental illness, mental retardation, and developmental disabilities. Treatment for these disorders, as well as all appropriate preventive health services including prevention of dental caries, should be restored. Dental care should be provided. Efforts to disqualify certain conditions or diseases will foster circumventions in some instances, and discriminatory practices in others, and will impose expensive and unnecessarily complicated administrative conditions. Many children will suffer needless neglect. Unsatisfactory early experience with administration of Crippled Children's services in some states that required eligible children to be "of sound mind" is relevant. When eligibility requirements were liberalized, the "adjustments" of I.Q. scores became less urgent.

There should be no limit on the number of medically indicated visits; data do not support an expectation that children will visit health service providers unnecessarily.

Uniform federal standards of care should be adopted, similar to those which have been recommended by the American Academy of Pediatrics. Performance standards should be adopted to assure that a reasonable proportion of eligible children in each state are reached by services that conform to defined standards. A state's failure to meet standards of performance with minimally acceptable outcomes should be penalized not as now proposed, by withholding funds that are specifically identified with services to poor people, but by withholding a portion of the state's revenue sharing funds. Rationale can be developed for this action on the basis that a number of federally financed programs, many of them targeted as health services for poor people, were curtailed in favor of revenue sharing in expectation that states would assume and extend services that had previously been sponsored by federal government. Where health services are demonstrably deficient the states may rightfully be considered to have failed an obligation that was implicit in the principle of revenue sharing.

CHAP should provide 90 per cent federal reimbursement of state expenditures for services. Precedent for this level of matching derives from some other aspects of Medicaid. Additional federal funds should be made available to develop resources that are required to implement CHAP.

The American Public Health Association's greatest emphasis with regard to CHAP concerns resource development, especially in the agencies of government at the local level that carry greatest responsibility for implementing the program. Nearly 60% of all health assessments that were performed under EPSDT were rendered by local health departments. Those states, 25 of them in 1975, which relied exclusively on health departments for screening reached a higher proportion of eligible children than those

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states that relied on multiple providers.(6) Many children who were found to have health problems by EPSDT screenings were not subsequently enrolled in programs of adequate diagnosis and treatment. Evidence has not been presented to suggest that these failings occurred any more commonly after screening in health departments than in private physicians' offices or in hospital clinics.

Certainly any child who receives health care from a qualified provider - be it neighborhood health center, physician, or special project of Title V - should not have the care interrupted in order to participate in the services of a health department clinic where there has been no previous contact. But large numbers of poor children receive no services, and their care ultimately fall as a responsibility of the local health department. Regulatory models simply do not exist to assure that private and voluntary providers can be made equitably to honor the entitlements of all children to health services. The fulfillment of those entitlements - the guarantees that human rights will be honored - falls ultimately as an obligation of government. In matters of health service that obligation is best fulfilled by the public health service agency that functions closest to most people - local health departments.

At least three times within recent years federal government has attempted to implement massive programs of personal health service without developing the resources of implementation. Family planning, immunization against influenza, and health screening for children all made appropriate and extensive use of private and voluntary providers. But ultimately the guarantor for those services - the assurance that everyone would be reached - rested with local health departments. In all of these programs health departments carried the greatest burden of service. Insofar as the programs failed the failures should be attributed to a false expectation that local

health departments can expand performance without expanding facilities and staff. In aggregate health departments represent the potential for an effective health service infrastructure that can assure that every person is reached with essential primary care.

In an excellent recently published book on primary health care (Lewis, Mechanic and Fein) the statement is made that adequate first contact care requires at a minimum: insuring necessary immunization, providing prenatal and child care, and monitoring overall health needs. These requirements are well within the capability of at least ¼ of this nation's 1,700 local health departments.(7) CHAP should be used as a device for resource development that would enable other health departments to develop such a capability wherever there are children who are not adequately served by existing health care providers.

Some data on health services for children is timely.

- In 1975 one out of every four Americans received some personal health service from local health departments. By far the largest population served was children.(8)

- In some census tracts as many as 80% of all children receive their personal health care from well child stations or school health clinics that function as programs of local health departments.(9) In at least one state 50% of all children receive whatever health care they get, except at times of hospitalization which is rare among children, at the clinics of local health departments.(10)

- Although the availability of Medicaid reduced the economic barriers between poor people and health care - and increased the number of their visits to health care providers - it did not substantially alter the sources of health care for children.(11)

- Only about 30% of practicing physicians will see Medicaid patients(6); in at least one state for which a recent report is available 60% of pediatricians refuse to see Medicaid enrolled children.(12)

- The most effective public initiatives during the past two decades for improving health services to children were included in the Neighborhood Comprehensive Health Centers and in the Children and Youth and Maternal and Infant Care projects of Title V. The Department of HEW has curtailed the growth of the neighborhood health centers and has reassigned the Child and Youth and Maternal and Infant Care projects to the states for inclusion in their Programs of Special Projects. By all available measures these programs have affirmed their effectiveness in maintaining health and in reducing unnecessary hospitalization, surgery, laboratory tests and x-rays. The per capita cost of such programs of comprehensive care, including all administrative costs, is substantially less than more traditional fragmented forms of health service. These projects remain little more than token demonstrations of what might be done to improve health services to children. In 1974 an estimated 550,000 children were served by the Children and Youth projects, and an estimated 7,000,000 additional children would have qualified for such comprehensive care.(1) Similarly in 1975 only an estimated 145,000 out of total need of 500,000 were served in the Maternal and Infant Care projects.(1) The constraints were fixed by policy and funding at the federal level of government.

For most of this century the prevailing public policy for improvement of health services has been to develop at public expense the resources that are incorporated in private and voluntary health service systems. These resources include hospitals, technological development, training of manpower

including physicians, and direct reimbursement for services. The benefits of this emphasis have been enormous; it represents a commitment that needs to be continued. But at the same time our nation needs to strengthen and expand those agencies of health service that perform in the public sector and which are obligated to fill the gaps in our piece-meal laissez-faire system of health care.

Providers of personal health services under public authority are important for children and are important for the whole spectrum of maternal and child health services. The importance is most critical for children and families who are in greatest need: minority groups and poverty level families. The populations for whom public providers render extensive services present a disproportionate burden of diseases, disability and neglect.

Assumption that all health care now provided under public authority can be transferred to private providers is not justified. Models for regulating private and voluntary providers are not available to reassure that maldistribution will be corrected or that entitlements will be equitably honored. Many advantages of health care under public authority are not transferrable to private systems. For example, the valuable work of new professionals is most conspiciously developed in public agencies. Support systems such as outreach, counselling, education and transportation more readily characterize public systems of care than private ones. Efforts to force all poor people into private and voluntary health care systems, while retaining public responsibility for transportation and outreach, will result in even greater fragmentation of programs and will place unfair burdens on children and on all health care agencies and providers.

Critics of public provision of health services sometimes raise the specter of a monolithic public program. We run a contrary kind of risk - sacrificing the well-being of children to a monolithic health service system that assures private professional prerogatives. So long as a substantial portion of our population lives in poverty, I submit that we must provide the special support systems that impoverished people require. Arguments in favor of a single system of health care - a subsidized private one which minimizes public health provider systems - monopolizes resources, favors a special privilege, and fosters a narrow concept of health care.

The credentials of private and voluntary health service delivery systems are strong in the interest of children's health. They deserve to be further strengthened, but if concurrent efforts are not made to strengthen health services which are rendered by official agencies of government, then another generation of children will suffer blighted health.

It is urgent that CHAP be strengthened as a device to provide federal funds, facilities, technical assistance, and standards to assist organized providers of limited services in order that they may do a more adequate job of assesment, diagnosis and treatment of all children. Local health departments represent the greatest need and greatest potential for expansion of health provider systems on behalf of children. CHAP should incorporate provision for pass through funding of federal money for local health departments to develop the services necessary to implement CHAP according to uniform national standards. Federal funds that pass through state and local government for support of local health departments should not substitute for present funding from local sources. Under these provisions local health departments would not be placed under federal authority; they

would be strengthened in order equitably to achieve specified national health goals and objectives.

These recommendations should not invite criticism that local health departments, or a public system of care, will supplant private providers or compete unfairly with them. Where children are adequately served by qualified providers - or where that potential exists - contracts should be written as now recommended by CHAP to continue and extend that care. But greatest concern attaches to the many children where there are no providers, or where there are few who will see poor children. For those children our public system of primary health care needs to be improved and expanded; CHAP should provide the facilities, staff support, and technical assistance for that important purpose.

In locales where population groupings and other circumstances are conducive, provision should be made to expand a state's Program of Special Projects according to well known models of comprehensive health service (comprehensive neighborhood health centers and special projects of Title V of the Social Security Act).

We urge that administration of CHAP be established in State Health Departments. Although eligibility for the program is tied to eligibility for welfare support the program is in fact a health service, predominately implemented even now through health departments.

Title V of the Social Security Act provided authorization for government to respond to the unmet health needs of children. In the intervening forty years many children benefited from this authority, but many were missed, due largely to the wide discretion allowed states in implementation of Title V. EPSDT in part corrected this circumstance by uniformly providing poor children with a strong entitlement to health services. CHAP should now fulfill that entitlement by providing the mandate and the resources to assure that every child in this country participates, under public auspices to the extent that may be necessary, in a program of health care that emphasizes primary and preventive services and access to accurate diagnosis and treatment as individually required.

C. Arden Miller, M.D.

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Mr. ROGERS. Dr. Seligman.

STATEMENT OF FRED SELIGMAN, M.D., M.P.H.

Dr. SELIGMAN. Thank you, Mr. Chairman.

It is a pleasure to be here from Florida. I am Dr. Fred Seligman, Associate Professor of Pediatrics and Psychiatry at the University of Miami Medical School. I hold a masters degree in maternal and child health from the University of California at Berkeley. I am also Director of the University of Miami Comprehensive Health Care Program, a children and youth project, financially supported by Title V of the Social Security Act.

I am speaking on behalf of the Association of Children and Youth Project Directors of which I am immediate past president, and also on behalf of the American Public Health Association of which I am an Action Board Member. The responsibility for this testimony is

mine alone. However, I have received important inputs from the Children's Defense Fund, the Coalition for Children and Youth, and colleages of the American Academy of Pediatrics, American Public Health Association, and the Ambulatory Pediatric Association.

CHAP IS A FIRST STEP

The CHAP proposal is an improvement over current Medicaid legislation. The proposal, however, is only a first step, and is not adequate as now proposed. It does address the needs of our Nation's young and poor, and for this, my colleagues in the field are grateful because all too often our Nation's young do not receive the priority of health and social needs they so rightfully deserve and infrequently attain.

It does not, however, clarify the issues that have made the current Medicaid program for children a failure. It still reinforces the concept that the health of our children is welfare oriented and primarily under the auspices of welfare rather than stipulating that our children's health services must be under the leadership of health administrators and health professionals.

It does little to clarify the interagency relationships between the administrators of title XIX and title V, and may in fact compound the already existing rivalry. It was not until about 1973 that the Medical Service Administration was clarified as the agency to administer the Medicaid program, thereby forcing the maternal and child health service, once the leader of our health programs to our Nation's young, to assume a consultative and secondary relationship to the Medicaid program.

TITLE V IS THE FRAMEWORK OF A NATIONAL HEALTH POLICY FOR CHILDREN

As a result, the title XIX program today tries to serve more children less effectively and at greater cost than does the title V program. Yet the latter program, the title V program, is the framework upon which a national health service and a national health policy for children can and should be built.

STATE HEALTH DEPARTMENTS SHOULD BE THE RESPONSIBLE STATE AGENCIES

As such, the State health departments should be the responsible State agency to administer the CHAP program. A qualified pediatrician with an M.P.H. should be the State director. There should be a State advisory committee which includes consumers.

C & Y AND OTHER COMMUNITY BASED PROGRAMS SHOULD BE MORE EFFECTIVELY UTILIZED

Since the middle 1960's, title V programs have developed in all States effective comprehensive programs for mothers and children. I am particularly referring to the MIC programs, and especially the children and youth projects. The accomplishments of these programs have been well documented elsewhere. They are cost effec-

tive, preventively-oriented primary care centers for children that emphasize comprehensiveness and continuity of service.

I have run one for 9 years now, and I can assure you, Mr. Chairman, that these programs work.

They are the types of centers this legislation addresses. I urge you to expand this concept, and specifically include language in the legislation specifying children and youth projects as the prototype program this Nation is trying to develop.

Further, I urge you to include language so that these programs and similar community-based programs are utilized by the States to accomplish the goals which CHAP seeks.

COORDINATION OF CHAP

Section 6 should be modified so that the coordination be not only with the community health programs of section 330 of the Public Health Service Act, but also with all Federal, State and local health care programs, particularly title V formula grants.

RESTORATION OF EXCLUSIONS FOR MENTAL ILLNESS, MENTAL RETARDATION, AND DEVELOPMENTAL DISABILITIES

I am particularly concerned with the provisions in section 3, which exclude care for mental illness, mental retardation, and developmental disabilities. For too long these diagnostic categories have been separated from physical health. This provision only perpetuates the notion that those in these categories are not entitled to the same treatment as others.

As a medical educator—and I am sure Mr. Chairman, that in some of your conversations with Dr. Manny Papper you have talked about this—I have spent so much of my time trying to convince trainees and graduate health professionals to assess the whole child.

Now Congress supports legislation that tells health professionals that he or she evaluate and treat only the physical side of a child because only this is reimbursable. Yet 85 percent of a pediatrician's time is spent in managing and guiding the psychological and developmental aspects of a child's well-being. You are telling health professionals to evaluate and care for the problems they rarely see and exclude those conditions that confront them daily; namely, developmental problems, learning disorders, troubled behavior, mental retardation and neurological malfunctions.

I submit to the distinguished members of this subcommittee that pain and suffering, particularly of mental illness and mental retardation, is as great or greater than the pain of any physical disability. My Hippocratic oath tells me to alleviate pain and suffering whatever the cause.

This definition of exclusions in coverage by diagnostic category is open to the interpretation that children with the above mentioned conditions need not be covered for any treatment related to such conditions. This provision will provide States a financial incentive to label and over classify children in these categories as a cost saving device.

The greatest disability among our Nation's young, other than dental problems, is mental illness and mental retardation. This is particularly the case among our poor, impoverished children.

In Miami I am working with the State Medicaid program in attempting to develop improved methods of screening for mental and developmental disabilities. We are using a screening device that is currently identifying about 45 out of every 100 inner city children as suspects for these categories.

Recently I personally evaluated 45 suspect children from a total of 100 that were screened. My clinical judgment was that 20 children fell in the diagnostic categories described above. Of these 20, 10 were mentally retarded, 7 had adjustment reactions, 5 had significant sleeping disorders, 4 were suffering various degrees of depression, 3 had evidence of brain disfunction, and 2 had potentially serious psychiatric problems. All these children are at high risk. These are the children who, in the future, I can assure you will fill our Nation's prisons. This is the population of children who will be drug pushers and the perpetuators of violent crimes.

I thought I should share this information with you, which is sponsored by current title XIX monies, and let you decide whether these categories should be excluded.

RESTORATION OF DENTAL EXCLUSIONS

The provision which only allows for dental restoration based on a prior screening is another mechanism to exclude from coverage dental pathology, which is the most common health defect in our Nation's young. Experience in my own program in Miami is such that 75 to 80 percent of children seen by a dentist for screening require dental care and the remaining 20 to 25 percent require preventive dental services. For this reason dental screening as a prerequisite to dental care is unnecessary and uneconomical. Tying dental care to a referral from an assessment is needless duplication of effort and precludes preventive dental services and treatment for acute conditions that may arise following screening.

CHILDREN RARELY OVER UTILIZE HEALTH SERVICES

If exclusions are required for cost control, exclusions should be on the basis of the type and quality of services which States may not be required to pay for. However, it has been well substantiated that there is rarely overusage through abuse in regards to children's services. If anything, the reverse is true, that in a freely competing system utilization by children decreases at the expense of increased utilization by other age categories.

STANDARD SETTING

I endorse the concept in section 5, whereby Federal regulations will define the content and frequency of periodic assessments. These standards should be the same in all child health programs. The minimal standard of care should be that of the Academy of Pediatrics, and the periodicity schedule should tie in closely with the required immunization schedule.

Further, the periodicity schedule should be defined in time intervals, recognizing that the population served is frequently difficult to motivate to entry into the health care system, a system that often has not been responsive, attentive, empathic nor knowledgeable of the needs and concerns of young families who must cope with the environmental stress of poverty and who often evidence unique race-ethnic attitudes to health care when interfacing with the orthodox often foreign American medical system.

INCENTIVES SHOULD BE PARTICULARLY CONSUMER ORIENTED

My descriptive language of the service population has been intentional, because we must take into account the demographic characteristics of the population to be served. The legislative language emphasizes bureaucratic organization including penalties to State providers for noncompliance, penalties which are ultimately passed on in one way or another to the consumer. I advocate increased focus on consumers by deemphasizing penalties which are frequently not enforced anyway, and emphasizing instead incentives, not only to State agencies and providers, but particularly incentives to consumers.

I would have you consider a universal system of incentives to families, whereby a family would receive a bonus for each dependent child who successfully completed a health screening and whose immunizations was up to date. This could be in the form of an increase in the income tax deduction for the dependent or alternatively a health bonus allowing the family additional health service benefits. I would submit that such a system would more effectively deal with recalcitrant States and ineffective providers and reduce the number of so-called unmotivated families.

THE SECRETARY SHOULD HAVE MULTIPLE TOOLS OF ENFORCEMENT

At the same time, however, the Secretary must have multiple tools to assure State compliance, particularly explicit authority to take appropriate remedial actions when compliance is lacking.

CONCLUSION

In the brief time allotted to me for the oral testimony, I have attempted to emphasize certain portions of the proposed legislation whereby meaningful improvements can be achieved. Consumer-oriented incentives, standard setting taking the characteristics of the population into account, realistic enforcement, technical assistance, bureaucratic responsibility residing with health professionals who are expert in child health services, focusing State responsibility within State health departments, including the private sector as viable providers, assuring a Federal mandate for minimal reimbursement by States, and stronger Federal support, particularly so that programs can provide comprehensive health services, will minimize previous failures and will more closely achieve the purpose of the CHAP program, which is to introduce the child and his family into a health care system that will provide the child with comprehensive continuing primary and preventive health care.

I have additional written comments which concern seven points.

First, that all children under age 21 who fall below 150 percent of Federal poverty guidelines should be included.

Second, that there should be resource allocation and standard setting for adolescent health, including pregnancy management, screening for V.D., and unwanted parenthood. Adolescents really get left out of our health care system.

Three, loss of Medicaid eligibility is effectively considered in CHAP now.

Four, because of the importance of a newborn visit a single home visit at 10 to 14 days of age should be included in the minimum standard schedule.

Five, that public health departments should not expand to become primary providers of care since this compromises the standard setting and enforcement functions.

Six, private physicians should be encouraged to participate as CHAP providers.

Lastly, that reimbursement rates should be realistic.

[Additional comments of Dr. Seligman follow:]

ADDITIONAL COMMENTARY:

Medically Needy Children Should Be Included

Section 3 does not go far enough in including all children under age 6 years who are AFDC eligible. Since health care is most meaningful when family focused, all children under age 21 years who are members of such families should, at a minimum, be included. This section does not address the medically needy, who are frequently the children with most difficulty in obtaining health services. Section 3 should therefore be expanded to include all children under age 21 years who are members of families who fall below 150% of federal poverty guidelines.

Resource Allocation and Standard Setting for Adolescent Health

Specific resources should be allocated for the development of comprehensive primary care programs which focus special attention in providing preventively oriented pregnancy coverage to women under age 21, including aggressive outreach, case-finding, and health education. Standard setting in regards to health screening of adolescents must include assessment of risk to VD, treatment of VD, health education to prevent VD, and methods of case-finding which include outreach. Adolescent health screening should include assessment of the risk of unwanted parenthood for all teenagers, and methods of primary prevention instituted including health education and the provision of contraceptive materials where desired.

Loss of Medicaid Eligibility

Section 5 addresses a problem frequent under current EPSDT; namely, loss of Medicaid eligibility during health assessment or before treatment can be completed. The increase of eligibility to 6 months after loss of eligibility is a good one.

Standards Should Include Newborn Visit and Home Visit

The standards set for periodicity of visits should be considered as minimal, recognizing that in many instances it is appropriate and necessary for more frequent visits. The initial assessment should be conducted at the same time as the newborn exam since this is the time that early problems

may be detected. It is also a time when the family is most highly motivated to the health needs of their infant. A single home visit at 10-14 days by a professional nurse or other health visitor under the aegis of a physician, or health department, should be part of the schedule, since this is a time that the home environment can be optimally assessed, and an effective time for the infant to enter the health care system. Each of our Nation's infants deserve by right an assessment that his environment meets minimal requirements for his development.

Public Health Departments Should Not Become Expanded Primary Care Providers

While I have stressed the need for State health departments to have administrative control for CHAP, I do not support the concept of public health departments expanding to become primary providers of health care, except in medically underserved areas. The major role of local health departments is consultative. Health departments should set standards and enforce them. In far too many instances, health departments have their standard setting and enforcement abilities compromized when they themselves operate programs, frequently of necessity, that only marginally meet standards. In some instances, health departments attempt to be primary care providers as a means of generating profits which can subsidize their standard setting and enforcement functions. Health Departments should be assured of adequate federal finances to support their standard setting and enforcement functions and not have to depend on financing from direct primary care.

Private Physicians Should Be Participants

Technical language should be strenthened in Section 5 to assure that physicians in private practice may participate

as CHAP providers. I am sure that the Chairman of this Subcommittee, Congressman Paul Rogers, knows that private physicians cannot now be EPSDT providers in Florida. There must be federal assurance that this does not repeat.

Reimbursement Rates Should Be Realistic

Further, reimbursement rates must be realistic. My own Title V program in Florida receives $8.00 for each EPSDT screening which barely covers the cost of the laboratory work. We participate in this program and lose money for each child screened. Removing the financial contraints to practitioners would help, but there must be more elaboration regarding the steps that will be taken to remove obstacles to participation by physicians in private practice.

Mr. ROGERS. Thank you very much, Doctor. Your suggestions will be gone over carefully by the committee.
Mrs. Foltz.

STATEMENT OF ANNE-MARIE FOLTZ, M.P.H.

Mrs. FOLTZ. My name is Anne-Marie Foltz., a researcher at the Yale School of Medicine.

My testimony is based on the research my colleagues and I have carried out since 1972 on Federal child health policy, particularly Medicaid and title V.

I have with me some of the publications which have come from our project. In doing this research I have had the opportunity to talk with Federal, State, local and regional officials charged with the implementation of EPSDT and with other maternal child health services.

It is reassuring that so much attention at this hearing is being paid to child health. When the EPSDT amendments were considered back in 1967, they were only part of the social security amendments, which amounted to some 3,000 pages of testimony of which only 8 pages were devoted to child health.

The intent of EPSDT was to make available preventive health services to needy children eligible for Medicaid. Prior to 1967, only seven States paid for such services.

EPSDT, however, as others have said earlier in the hearings, was ambiguous in intent, and never clearly defined. Therefore, it became a screening program rather than comprehensive preventive care program.

EPSDT is a case in which during the past 10 years the political environment really became inhospitable to the congressional laws.

Medical care for children costs far less than for adults, and it is a very small amount of Medicaid expenditures. Even in States where the most active and successful EPSDT programs, preventive care expenditures for children comprise less than 1 percent of all State Medicaid expenditures.

The EPSDT program, passed nearly 10 year ago has been dubbed a failure by the press, by another congressional subcommittee, and by the States. I do not share this opinion.

I think the program has been enormously successful, perhaps unintentionally, in two ways. First, it has documented, as has no other program in American history, the health needs of poor children. Second, it has uncovered the present system's inability to provide comprehensive and preventive care to poor children, even when a financing mechanism is provided.

The reasons for this failure can be attributed to four major problems which are mainly administrative and are remediable. I shall discuss each of these, and show how new legislation can remedy them.

The first problem has been the inability of Federal and State agencies to monitor and follow children under care. After 10 years, adequate case management systems are still lacking in most areas.

EPSDT was a new type of program. It required HEW to monitor quality and quantity of care. That requires major staffing. However, that program, both in HEW and in the regional offices, has been continuously understaffed.

I was glad to hear the chairman request just such information on how a new CHAP program would be staffed, because that has been one of the continuing problems in monitoring the present program.

The present legislation does not address directly the need for better information, for better reporting systems from the States, and for staffing. It also includes a paragraph requiring medical case management. That is in section 1912(b)(4), and this is a very narrow definition of what we would expect every comprehensive care provider to provide. I concur with Dr. Seligman's remarks, that children should be followed in their whole and all of their development, not just for their medical care as narrowly defined.

The second problem in the health system has been the Federal inability to enforce its own regulations in the States. Unlike Medicare, Medicaid is a State responsibility. Eligibility levels and services vary from State to State.

The Federal matching rates to the States were designed to encourage poorer States to provide federally-mandated services, but as I have shown in a table accompanying my formal testimony, when States were under Federal mandate to provide preventive health services, only some States such as Michigan and South Carolina increased their financial commitment to children compared to adults.

The greatest danger with this legislation, as with any EPSDT legislation, is that States required to carry out new services will compensate by decreasing services. Between 1972 and 1976, one large western State decreased by 9 percent the children receiving dental services while increasing by 81 percent the adults seeking dental services. The children's services were mandated, but the adult's services were not.

If the present laws or if the new legislation is to encourage States to increase services, it should require the States to maintain their effort in children's Medicaid expenditures in ambulatory care, at least at the levels of fiscal 1975.

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The third problem in administration is confusion among Federal and State agencies as to which of them is responsible for child health. This problem has been amply treated by others earlier. Let me just say that the provision of 6-month extension in eligibility following screening is a small improvement, but a year's grace period, although more costly, would provide more continuity of care. The issue of coordination begins at the Federal level, and a Federal agency charged with coordinating the care should be mandated rather than leaving it up to the States to sort things out for themselves.

The fourth problem has been unwillingness of public and private health professionals to participate. We should note that particularly in the matters of outreach, follow-up and coordination, private providers have already said that they have trouble handling those services unless they are going to be paid for them. The present law does not specify what kind of payment will go to the providers for these services.

I want to comment on Congressman Maguire's proposal which solves some of these problems. It does increase eligibility up to the age of 21. By broadening the scope of acceptable providers, it provides greater continuity of care and handles some of the outreach problems, particularly if the community organizations will be reimbursed for providing outreach and follow up.

Since we are short of time, I will leave the rest of my remarks, which have been submitted formally, to the record.

[Testimony resumes on p. 434.]

[Mrs. Foltz prepared statement and attachment follows:]

STATEMENT OF ANNE-MARIE FOLTZ, M.P.H., RESEARCHER,
YALE UNIVERSITY SCHOOL OF MEDICINE

My name is Anne-Marie Foltz. I am a researcher at the Yale University School of Medicine. My testimony on H.R. 6706, the Child Health Assessment Act (CHAP), is based on the research my colleagues and I have carried out since 1972 on federal child health policy, particularly Medicaid and Title V. In doing this research I have had the opportunity to talk extensively with federal, regional, state, and local officials charged with implementation of EPSDT and other maternal and child health services, as well as with the health care providers. The present CHAP legislation before you is based on the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) amendments of 1967.

The intent of the EPSDT legislation was to make available preventive health services to needy children eligible for Medicaid. Prior to 1967, only seven states provided such services in their Medicaid programs. In other states, poor children received care only when acutely ill. No funds were provided for the basic immunizations and check-ups which are considered a routine part of normal pediatric care.

The EPSDT legislation was however, ambiguous in intent, as noted in my article on the EPSDT program, "The Development of Ambiguous Federal Policy," which I am submitting for the record. The contribution of H.R. 6706 would be to clarify and dispel some of these ambiguities.

The EPSDT program, never clearly defined, became in many states a screening program rather than a comprehensive preventive care program. HEW, faced with the prospect of administering over 50 jurisdictions, was unable to demand the type of information that would enable it to evaluate not only the screening component, but also the child's entry into the

health care system. Hence the screening component became the largest part of the program. If the program sought to provide full preventive care, it would have to enroll every child with a comprehensive care provider who would have responsibility for overseeing such care. Then, care would not be episodic as it is now, with screenings carried out by one group and treatment by another. The H.R. 6706, with its emphasis on comprehensive care providers, goes at least part way to meet this need and to improve on the EPSDT program.

The cost of prevention is low and the returns are high. Medical care for children costs far less than care for adults. In 1975 Medicaid expended over $1000 per elderly recipient, while it expended less than $200 per child.

The issue then is to put a relatively small amount of money into preventive care for children. The amounts requested for comprehensive child health care are extraordinarily small, amounting to less than 25 per cent of the Medicaid budget. At present, even in states with the most active and successful EPSDT programs, preventive care expenditures comprise less than one per cent of state Medicaid funds (see Table 1).

As a member of a municipal legislature in Connecticut, I, like you, am constantly reminded by my constituents that there is no free lunch. The challenge, then, is for the Congress to set priorities and put our money, however limited, where it will do the most good. In this case, that good is for preventive care for poor children under an expanded CHAP program.

Table 1. Health services under Medicaid in selected states during period of EPSDT implementation.

	Michigan	Texas	South Carolina	California	Indiana
EPSDT expenditures as a percentage of total Medicaid expenditures 1976	0.6	0.1	0.4	0.05	0.8
Percent change in adult Medicaid expenditures 1972-1976	112.6	216.8	207.8	76.2	92.2
Percent change in children's Medicaid expenditures 1972-1976	215.5	189.1	400.3	29.6	4.7
Percent change in adult Medicaid recipients 1972-1976	60.9	6.8	199.8	-22.2	10.7
Percent change in child Medicaid recipients 1972-1976	112.6	77.2	192.7	-18.0	10.0

Source: National Center for Social Statistics, Department of Health, Education and Welfare

The EPSDT program passed by this Congress nearly ten years ago has been dubbed a failure by the press, by another Congressional committee, and by the states. I do not share this opinion. Unintentionally, it has been most successful in two significant ways. First, it has documented, as has no other program in American history, the health needs of poor children. The EPSDT program, by bringing Medicaid-eligible children into early screening and into contact with providers of care, has revealed, for example, that half of those children were inadequately immunized and one quarter of them had severe dental problems. In demonstration projects, more than half the cases discovered were previously unknown and untreated.

EPSDT's second significant contribution in the field of child health has been to uncover the present health system's inability to provide comprehensive and continuous health services for poor children, even given a financing mechanism. The reasons for this failure in our present health system are mostly administrative and are remediable. The proposed H.R. 6706 before your committee helps remedy a number of these failures.

Specifically, the administrative failures can be attributed to four problems. I shall discuss each of these under the present EPSDT program and will show how the H.R. 6706 solves these problems, or can be amended to solve them.

The first problem has been the inability of federal and state agencies, health as well as welfare departments, to monitor and follow the children under their care. Adequate case management systems are

still lacking in most areas ten years after EPSDT's passage.

EPSDT was a new type of program. It was not a pure Medicaid vendor-payment program. HEW had to monitor the quality and quantity of care. Effective monitoring requires major staffing in both the HEW central offices and the regional offices. However, this new type of program has been continuously understaffed. A program overseeing potentially two billion dollars of child medical care was for many years operated by a staff of less than ten persons. For example, when states fail to report data, like one northeastern state which by mid-1977 had still not filed its fiscal 1975 reports, HEW rarely can spare the staff to follow-up.

H.R. 6706 does not address directly the need for better information systems. It does provide, however, incentives for good management. States will only put such systems into practice if better financial incentives can be provided for installing these systems.

The second problem has been federal inability to enforce its own regulations in the states. Unlike Medicare, Medicaid is a state responsibility. No state in the history of the program has lost funds for failure to comply with federal regulations.

The federal matching rates to the states were designed to ease the burden on the poorer states of providing federally mandated services and to encourage them to participate. However, they have not worked as intended. Typically, under Medicaid, poor persons in rich states were favored to the detriment of poor persons in poor states. In 1970, for example, federal Medicaid grants were $281 per poor person in Massachu-

setts compared to only $7.50 per poor person in Mississippi. Under H.R. 6706, states such as Mississippi would be required to add new eligible children to their rolls, the needy children under six, as well as to expand services for those already eligible. The present legislation should be amended to decrease this discrepancy and provide special incentives for the poorest states.

As Table 1 shows, during the period 1972 to 1976 when states were under federal mandate to provide preventive health services to Medicaid recipients, only some states, such as Michigan and South Carolina, increased their financial commitment to children compared to their commitment to adults. In other states, such as California and Indiana, expenditures for children did not even keep pace with expenditures for adults.

The greatest danger, however, with this legislation as with the earlier EPSDT legislation, is that states required to carry out new services will compensate by decreasing their services and expenditures in other non-mandated areas, or they may decrease services in mandated areas if they are not closely supervised. For example, even though EPSDT mandated dental services for children under 21, states did not always comply. Between 1972 and 1976 one large western state decreased by 9 per cent the children receiving dental services while increasing by 81 per cent adult dental services which were not mandated. H.R. 6706, by increasing federal matching payments, will permit states to maintain the same level of services as before while spending less of their own funds. The new legislation should do more. It should encourage the

states to increase services. Therefore, it is essential that the legislation specifically require the states to maintain their effort in children's Medicaid expenditures in ambulatory care at at least the levels of fiscal 1975. This maintenance of effort should apply both to the level of expenditures and to the numbers of recipients.

The third problem is confusion among federal and state agencies as to which of them is responsible for child health. The lessons of EPSDT indicate that it is difficult, if not impossible, to coordinate equal agencies without sufficient financial incentives. Both the 1965 and 1967 Medicaid amendments required cooperation and agreements among state health and welfare agencies, but states reported that, although agreements were signed, little coordination took place. In one state, the Office of Child Development-Head Start personnel refused to have anything to do with EPSDT programs. In other states, health and welfare were unable to coordinate their EPSDT services. The program was basically one of health services but it was usually administratively assigned to a welfare agency. Part of the problem lies in the fact that health and welfare agencies have different ideologies, goals, clientele, professionals, and structures which tend to increase tensions between the two agencies. Within the states a single agency can be responsible, but it then must also be given the financial authority to buy the cooperation it needs.

The conflict between health and welfare is underlined by the statement of an exasperated health worker who said, referring to Medicaid children: "What do we do? Catch them when they're eligible?" The com-

plex Medicaid eligibility laws thwart the orderly process of maintenance of health care. The ultimate solution is to make these health services available to all children regardless of income. Meanwhile, the best we can do is catch them when they are eligible. The H.R. 6706 provision of a six month extension of eligibility is an improvement over EPSDT. However, a year's grace period, although more costly, would provide more continuity of care and might be more workable administratively.

The issue of coordination, however, begins at the federal level. Only a strong federal agency for child health services which has the full backing of the Congress and the President can lean on other health and welfare agencies. Such an agency could be located in the health services financing agency of HEW, but must be given sufficient authority to command cooperation.

The fourth problem for EPSDT and Medicaid has been the unwillingness of public and private health professionals to participate in a public health system unless adequate financial incentives are provided and bureaucratic disincentives are removed. In many states Medicaid payments lag behind established fee schedules of other third party payers. Lack of providers has been a continuous problem in ghetto and rural areas.

The purpose of H.R. 6706 is to make one person or organization responsible for the continuous health care of a child. Clearly, it is unreasonable to require that such a comprehensive care provider furnish all services which might be desired for the maintenance of the health of

the child. The experience of EPSDT indicates that the crucial element is not so much whether or not the provider has the ability to deliver the necessary services, but whether the child who needs those services actually is brought to the right place, and then whether all the appropriate and available services are in fact provided. This task of follow-up and coordination, as well as outreach, has already proved to be more than most private physicians can handle. Both private practitioners and clinic supervisors have told me that under EPSDT the coordination, outreach, and follow-up is a massive administrative job whose cost is not met under present Medicaid-EPSDT fee schedules. Thus, such administration to monitor child care must be clearly stated as part of state agency responsibility, which may be delegated, but for which the person who carries out the work is reimbursed.

If Congress still means what it stated in the EPSDT legislation in 1967, then the issue is to establish the administrative networks and financing to deliver services to the needy children already identified. EPSDT promised much to poor children; it has delivered little. It has, however, provided a foundation for more effective legislation. The present H.R. 6706 builds upon this earlier foundation. EPSDT has shown that merely providing laws does not provide services. Strengthened administrative provisions in CHAP can help get health care to those children who need it most.

The Development of Ambiguous Federal Policy: Early and Periodic Screening, Diagnosis and Treatment (EPSDT)

ANNE-MARIE FOLTZ

This paper examines why Congress's first major program for comprehensive health care to needy children took five years to begin even partial operation. An examination of the 1967 program's legislative history reveals that Congress paid little attention to EPSDT's implications: it was left ambiguous whether health (Title V) or welfare (Title XIX) would administer; costs were never clearly stated; eligibility and scope of services to be provided were left vague. Despite pressure from welfare rights interest groups, these ambiguities delayed the preparation of regulation and guidelines which never did succeed in resolving the question of overlapping jurisdiction and costs. In addition, many states' resistance to paying for the program further held up implementation.

The paper concludes that: (1) Congress's and HEW's unwillingness to face up to the real costs of health programs threatens long-term public and state support for such programs; (2) division of responsibility between health and welfare lessens the impact of a program; (3) grant-in-aid programs give states the power to distort the intent of federal health policies; and (4) where states fail to implement such policies, initiatives may pass to consumer advocacy groups.

In late 1967, the United States Congress passed the Early and Periodic Screening Diagnosis and Treatment (EPSDT) programs of the Social Security Act, potentially the most comprehensive child health care program the government had ever undertaken. However, this program was not implemented immediately; regulations emerged from the Department of Health, Education, and Welfare (HEW) only in November 1971; final guidelines were issued in 1972, and full implementation was deferred until July 1973. Even before that date, it was clear that most states would not comply with HEW's regulations and guidelines,[1] and as of December 1973, HEW (1974) reported that only half the states could be said to be implementing the program state-wide without problems.

[1]For example, in March 1973, the National Welfare Rights Organization in a letter to Caspar Weinberger, Secretary of HEW, cited "Massive non-compliance," based on HEW's own reports. See also Tolchin (1973) and Georgetown Law Journal (1971: 976).

This paper will analyze what went on at the federal level to explain why these federal initiatives took so long to be carried out. Issues such as the cost of the program, the administering agency, and the extent of services and children to be served were not clarified in the legislation. The resulting ambiguities left the Department of Health, Education, and Welfare with the difficult, if not impossible, task of drawing up a set of regulations and guidelines which could satisfy administrators, state officials, interest groups, and Congress.

Background: Health Care for Children Through Government Programs

Part of the ambiguity lay in the almost reluctant way in which the federal government had gotten into the business of providing health services to children. Programs had gradually been added to the federal responsibility and they varied greatly according to their emphasis. Some were concerned with preventive services, others with comprehensive care, still others with diagnosis and treatment of specific crippling diseases.

As Schlesinger (1967) has noted the first federal program to provide care for mothers and children through grants-in-aid to the states was the Sheppard-Towner Act of 1921. Its broad provisions for "promoting the welfare and hygiene of maternity and infancy" did not clarify what services were to be provided. Meanwhile the states and localities had developed on their own preventive care to limited groups of children through well-child conferences run by both voluntary and public agencies.

Screening as a federal policy goal appeared in the 1935 Social Security Act Title V legislation establishing a program for Crippled Children (CC). It sought to enable each state to extend and improve:

> such state services for locating crippled children, and for providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling. . . . (Section 511)

To locate such children, some sort of screening procedure is im-

plied. Locating crippled children or children with conditions which might lead to crippling could have taken one of two forms: either a broadly conceived interpretation to set up state-wide screening procedures, or a more narrowly defined one to set up registries of crippled children. The former, today known as "outreach," was not attempted by the states under this program. With the encouragement of the Children's Bureau, which administered the CC program, each state created registries of crippled children to demonstrate how many had been found. These registries proved to be more activity reports than reports on the health status of children and eventually most states dropped the registries.

Preventive care and screening were implicit in an equally important section of Title V, Maternal and Child Health Services, which was a successor to the Sheppard-Towner Act. In many states the legislation's goal of "promoting the health of mothers and children" was understood to mean not only the supervision of maternity clinics and hospitals, but also the promotion of well-child conferences. Thus, two types of screening developed from Title V: through MCH, the well-child conference; and through CC, registries of crippled children. Preventive care was provided by the MCH services through supervision of maternity clinics, through consultations with local health officials, and through the establishment of well-child conferences. Diagnosis and treatment were provided by the crippled children's program. However, by 1955 only 6.5 percent of the nation's children under 21 were reached by these programs (refer to Table 1).

During World War II, the Emergency Maternity and Infant Care program (EMIC) gave the states funds to carry out both curative and preventive services for wives and children of armed forces personnel in the lower pay grades. The well-child conferences of the Title V programs were expanded to care for the additional mothers and children. Despite the program's apparent success, it was nonetheless abandoned after the war with all the other emergency wartime programs (Sinai and Anderson, 1948).

The sixties saw the burgeoning of federally funded health programs for children as well as other age groups. The Title V programs were expanded to include federal grants for local projects: in 1963 the Maternity and Infant Care Projects provided funds for localities to carry out comprehensive maternity and infant care; in 1965 the Children and Youth Projects provided similarly to

TABLE 1

Children Served by Title V Maternal and Child Health and Crippled Children's Programs and the Title XIX Program as a Percentage of U.S. Population Under 21, 1940, 1955, and 1970 (based on data drawn from sources cited below)

	Percentage of U.S. Population Under 21		
	1940	*1955*	*1970*
Maternal and Child Health	3.0	5.8	6.9
Crippled Children	.5[a]	.4	.6
Total Title V Programs	3.5	6.2	7.5
Title XIX Program	—	—	9.4[b]

[a]Data are for 1939 since statistics were not collected for 1940.

[b]Children served by this program may also have received services through Title V programs.

Source: HEW (1957:7; 1971a:7; 1971b: Tables 7-9, 11; 1972c:1); U.S. Department of Commerce (1940: Table 2; 1956: Table 19; 1970: Table 50); U.S. Department of Labor (1941:40).

selected localities for comprehensive health services for children and youth; in 1968 dental care and intensive infant care projects were also authorized. Localities were also helped to establish health services through the OEO programs which funded neighborhood health centers and provide health services for head start programs.[2]

Medicaid, or Title XIX of the Social Security Act, although not a program aimed specifically at children, rapidly became their largest public medical program after its establishment in 1966. By 1970, expenditures for children under Title XIX were $968 million compared to $328 million spent by the Title V programs (Cooper and McGee, 1971: 9). Title XIX of the Social Security Act reimbursed the states for providing health care to welfare recipients and, if the states elected to have such a program, to those who were "medically needy." Each state set its own standards for medical need just as it set standards for eligibility for welfare, but it was intended to include those who were categorically eligible and who

[2]For a list of federal, state, and local government health programs for children in 1966, see HEW (1966: Table A-1). Health services administered by the federal government in 1972 are presented in Minnesota Systems (1972: 3-10).

faced high medical expenses although they were not poor enough to receive welfare payments. Children under 21 could also be included in any state's Medicaid program regardless of categorical eligibility, but only 17 states chose this option. Services provided under the 1965 Title XIX legislation included inpatient and outpatient hospital services, and physician's and other remedial services. Preventive care or screening services were not spelled out in the legislation (Social Security Act, Section 1905a). They could be provided, but in practice, most states did not reimburse for them.

Administration of the federal programs were assigned to different federal agencies. All the Title V programs had been assigned to the Children's Bureau and although this bureau moved from one federal agency to another over the years, it remained intact until 1969. In the states, Title V programs were usually administered by health officials. Title XIX, which became the major federal program for health services for children, was administered by a division within the Bureau of Family Services which grew into the Medical Services Administration (MSA) of the Social and Rehabilitation Service (SRS).[3] Most states placed the administration of the program in their welfare departments, although Mississippi set up an independent agency and five states placed it in the health department (HEW, 1970: 395-398).

All federal programs were to be directed toward children who did not have access to regular medical services. In the Title V legislation of 1935 this took the form of directing aid to areas suffering from "economic distress," or to rural areas where no medical care was available (Section 511). The provisions of health services through Title XIX (Medicaid) of the Social Security Act which were expanded by the 1967 amendments to include EPSDT, were directed only to those children eligible through the AFDC Program (Title IV), or classified as "medically needy" by the states (Sections 401-410 and 1905). At no time was the federal law interpreted as having legislated health services for all children. When Congress discussed the Emergency Maternity and Infant Care (EMIC) Act of 1943, it rejected the Children's Bureau's first request for funds

[3]Strictly speaking, MSA does not administer Title XIX. It is considered to be a federally assisted state-administered program. However, MSA's duties of monitoring the states' programs and sending policy directives make it look as if it is administering the program, even though states have in the past ignored some of the directives without losing federal funding.

because "there was no requirement of lack of financial ability as prerequisite to the benefits" U.S. Congress, House of Representatives, Report of Committee on Appropriations, February 24, 1943:6, as cited in Sinai and Anderson (1948: 113).[4] Only when Congress was reassured that the program was restricted to needy children did it appropriate the funds. This federal decision to focus programs on poor children rather than on all children was to complicate the administration and implementation of health programs, because it established a two-class system of health care: private for the haves and public for the have-nots, even though well-child conferences had traditionally been open to anyone who wanted to use them without a means test.[5]

The Beginnings of EPSDT

By 1967 health services for needy children were being carried out by many different federal, state, and local agencies, as well as by voluntary groups and parent-teacher associations. Standards were set by those agencies as well as by the American Academy of Pediatrics, committees of state medical societies, and the American Public Health Association. The time was ripe for a comprehensive plan for preventive health services which would include screening and treatment for children, most particularly those who did not receive care through the private sector. Evidence had been accumulating for years that preventive services would decrease infant and child mortality and lessen the likelihood of crippling diseases, but no government program had yet attempted to provide these services in a comprehensive fashion.

The establishment of a program of preventive services for children confronted the federal government with four major ques-

[4]Various other proposals have been heard from time to time. For example, in 1972, Senator Ribicoff of Connecticut was considering a "kiddycare" bill which would have provided national health insurance for all children the way that Medicare provided a national health insurance for those over 65 regardless of need. Several other members of Congress during its 93rd and 94th sessions were known to have child health insurance bills "in the wings."

[5]The "Bureau of Child Hygiene has been opening child heath centers in various parts of the state where *children of all classes* may be brought for free monthly examination and inspection" (Ingraham, 1926: 115). Emphasis added.

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tions which had to be resolved in the course of legislation, administration, and implementation of the program. These questions were: (1) Which children were to be reached? (2) What would be the extent and quality of health services offered? (3) How much could or should be spent on the program? and (4) Through what administering agency was the program to be implemented? The cost would, of course, affect both the extent and quality of care and the numbers of children to be reached. These four questions do not seem to have been addressed in an orderly or exhaustive fashion by those planning the program. As a result, the program that has became known as EPSDT created considerably more controversy during the five years after it was signed into law by President Johnson in 1968 than it did during its eight-month legislative gestation.

The idea for federally sponsored periodic screening for low-income children first appeared in 1966 in a program analysis prepared in the Secretary's Office of HEW. The case finding was to lift a burden from the population by saving children from handicapping conditions. Three possible programs for the screening and treatment of low-income children were suggested: one program would serve an estimated one million newborn children in health-depressed areas at a cost of nearly $30 million; another would serve five million children including newborns and those aged one, five, and nine who live in health-depressed areas at a cost of $150 million; and finally the third would serve all the nation's 104,000 premature infants at a cost of a mere $5.3 million (HEW, 1966: III, 22). This was the first and last time a federal document put a specific price tag on a specific nationwide screening or preventive care program for specified child populations. As for the administration of this program, it was suggested that "it could be organized as an extension of the present Crippled Children's Program. Funds for such a program could come through the Title XIX 'Medicaid' program. . . ." (HEW, 1966: III, 18), with the suggestion that Title XIX be amended to include diagnostic examinations. The seeds of administrative ambiguity were thus planted in this first report.[6] The

[6]Title XIX was barely under way at the time the Program Analysis was written, and its authors may have wanted to hedge their bets since its scope, administration, and direction were unclear. At least one author has said that it was their intention that the program should be administered by Title V with Title XIX acting as a pass-through mechanism (personal communication, George A. Silver, M.D., June 3, 1974).

scope of services was not discussed in any detail.

President Johnson, in his address to Congress on the Welfare of Children on February 8, 1967 (U. S. Congress, 1967a) recommended that increased funds for the care of needy children be doubled to a total of $221 million. He also asked that the number of needy children being seen and treated under the Crippled Children's program be doubled to one million. Whether these increased appropriations and expanded legislation were aimed at the same populations was not clear from the President's message.

EPSDT Legislation—H.R. 5710

Some clarification appeared eight days later when the President's ideas were incorporated in legislation introduced by Representative Wilbur Mills. The Social Security Amendments of 1967, or H.R. 5710, provided broad-ranging changes in the Social Security Act programs, of which the child health provisions formed only a small part. When the House Ways and Means Committee invited comment from interested parties, the bill was described as including "revisions in the Old-Age, Survivors and Disability Insurance; provisions relating to health care for the aged and others (Title XVIII and Title XIX); provisions relating to public assistance; tax provisions relating to senior citizens, etc." (U. S. Congress, 1967b). Only those who already knew that nearly half of those eligible for care under Title XIX were under 21 would have noticed that the hearing could have anything to do with children.

The provisions for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) of needy children consisted of three amendments: two to Title XIX and one to Title V, of the Social Security Act. The major amendment to Title XIX (now frequently referred to as the EPSDT amendment) was worded as follows:

> . . . effective July 1, 1969, such early and periodic screening an diagnosis of individuals who ar eligible under the plan and are under the age of 21—to ascertain their physical or mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby, as may be provided in regulations of the Secretary. [Sec. 301 (b) (1)]

The intent of this legislation was to encourage staes to extend their coverage of care for children to preventive ervices. At the time,

only seven states specifically provided for this care in their state plans (HEW, 1967: 44).

The other amendment to Title XIX called for cooperation between the Title XIX and the CC and MCH programs of Title V. This amendment provided for the state Title XIX agency to enter into agreements with any agency receiving payment for part or all of its costs under Title V; that it use such an agency in furnishing care and services; and that it make provision for reimbursing such an agency for the care and services furnished. This agreement of cooperation was not new to Title XIX. When Medicaid was passed in 1965, it had included a provision for the state Title XIX agencies to enter into agreements with the state agencies responsible for administering or supervising health services and vocational rehabilitation. The novelty was that the Title V agencies were specifically mentioned, the agreement was to include reimbursement and the Secretary of HEW would write regulations clarifying the scope of the relationship [Section 1902 (a) (11) (A) and (B); (A) was the original statement; (B) was the 1967 addition].

The third amendment, an amendment to Title V, said that state health plans with regard to the Crippled Children's program must:

> . . . effective July 1, 1967, provide for early identification of children in need of health care and services, and for health care and treatment needed to correct or ameliorate defects or chronic conditions discovered thereby, through provision of such periodic screening and diagnostic services, and such treatment, care, and other measures to correct or ameliorate defects or chronic conditions as may be provided in regulations of the Secretary. [Section 301 (a) (2)]

This mandate to carry out preventive care replaced the weaker langage in the earlier Crippled Children's provisions for locating crippled children. Authorizations for the program were to be increased from $55 to $65 million (U. S. Congress, 1967b: 93). In its explanations of the act's provisions, HEW said that the amendment to Title XIX plus the "proposed increase of $15 million [sic] in the authorization for 'Crippled Children's Services' and the requirement . . . that such services include periodic screening and diagnosis would greatly strengthen the nation's programs for children" (U. S. Congress, 1967b: 26). HEW had not mentioned how the program was to be administered or how many children were to be served.

These three amendments constituted what has become known

as EPSDT, the Early and Periodic Screening, Diagnosis and Treatment Program. EPSDT went through three phases in its legislative history: as H.R. 5710 when it was discussed in hearings before the House Ways and Means Committee in March and April 1967; as H.R. 12080 when in August it emerged from the Ways and Means Committee Report; and still as H.R. 12080 in hearings before the Senate Finance Committee during August and September of the same year. During each phase, the issues of program cost and administration were taken up while the questions of scope of services and eligible population were more frequently ignored.

The First Public Discussion—H.R. 5710 Hearings

Hearings on H.R. 5710, held before the Ways and Means Committee during March and early April 1967, extended for nearly 3,000 pages of testimony of which child health amendments formed only a small part. More individuals or organizations commented on the costs of the program than on any of the other three issues that would determine the shape of the future program. However, those testifying were confused as to who was to foot the bill, Title V or Title XIX. HEW had suggested $100 million extra for Title XIX earmarked for children and $15 million extra for Crippled Children under Title V. Some of the Title XIX money (or perhaps much of it) was supposed to go toward encouraging states to expand their programs to include any kind of services to children, not just the preventive ones (U. S. Congress, 1967b: 125-126). George Meany welcomed the President's proposals for "an increase of $100 million in federal financial participation for needy children," but added that the amounts authorized for child health were the "absolute minimum required" (U. S. Congress, 1967b: 584-585). The American Parents Committee (U. S. Congress, 1967b: 2006) and the American Academy of Orthopedic Surgeons (U. S. Congress, 1967b: 2351) supported the $10 million increase (presumably for crippled children), which would pay for additional case finding and increased medical costs. Other organizations were less certain that the amounts asked for would be adequate to carry out the additional case finding and payment for increasing medical costs. The American Cerebral Palsy Association (U. S. Congress, 1967b: 2237) said that $18 million extra was needed. The Founda-

tion for the Blind (U. S. Congress, 1967b: 2242) and the State of Illinois Commission on Children (U. S. Congress, 1967b: 2416) both objected that CC is closed-ended funding and would limit the kinds of services that could be provided. Title XIX funding is open-ended. The strongest request for additional support for the CC program came from those who administered it, the Association of State and Territorial Health Officers. Under a 1965 law the CC programs would have to pay "reasonable cost" for hospital services and without the provision of additional federal funds, this "greatly increased cost is working a tremendous hardship on these programs. . . . There is every possibility that they will result in a reduced amount of care given" (U. S. Congress, 1967b: 2263).

The concerns for the funding of this new program stemmed from confusion over whether it was a Title V or Title XIX program, or rather, whether it was a health or a welfare program. At the federal level, Title XIX was administered by the Medical Services Administration (MSA) of the Social and Rehabilitation Service (SRS); Title V by the Children's Bureau, which at the time was part of SRS but was soon to be dismantled and transferred to the newly created Health Services and Mental Health Administration (HSMHA). This separation was paralleled at the state level, where the Title XIX programs were usually administered by welfare departments and Title V programs by health departments. The confusion was not clarified in commentary on the administrative framework for the program. HEW Secretary John Gardner (U.S. Congress, 1967b: 98) called for agreements between the Title XIX and Crippled Children (Title V) agencies. Martha M. Eliot (U. S. Congress, 1967b: 2267), former head of the Children's Bureau, "heartily" approved of this relation. The American Nursing Association (U. S. Congress, 1967b: 2229) felt that the purpose of the legislation was to broaden the base of the Children's Bureau Title V programs, and ignored the role of the Title XIX agency. Representative James A. Burke (U. S. Congress, 1967b: 1964) of Massachusetts was the only one to comment on the ambiguity, saying: "it is a program that should be administered by the Department of Public Health. . . . It is not a welfare program. It is a health program." The issue of whether health or welfare should implement a health program for welfare children was not resolved during these or subsequent hearings; it has continued to plague all those charged with implementing the program.

The issue of which children were to be served or which ones were eligible for the proposed program also received scant attention and produced conflicting points of view. Secretary Gardner (U. S. Congress, 1967b: 190), like the President, had suggested that 500,000 additional children would be screened furing the first year of operation, and within three to five years, the program would extend to five million children.[7] Whether these were children to be served under the CC or the Title XIX program was not clear. The American Parents Committee (U. S. Congress, 1967b: 2007) also picked up this 500,000 children figure and assumed the case finding for these low-income or medically indigent children would take place within the context of the CC program. Not only was there question of how many children would or could be served, but who would be eligible for the new program. There was pressure to expand state CC services to include children with vision or hearing problems and there was concern that specialized services not available through the private sector would no longer be available to middle-income families if the present program were carried out. Under the Title XIX program economic eigibility was the only criterion. The repercussions of this unresolved conflict would be felt down to the implementation of the programs within the state.

Except for the comment that vision and hearing screening should be included, no one testified at these or at later hearings on the scope or extent of screening or preventive care to be carried out in the proposed program. These details were to be prescribed by the Secretary.

Phase 2—Same Provision; New Bill

The three EPSDT amendments remained essentially unchanged when the Social Security amendments of 1967 were incorporated into H.R. 12080, which was reported out of the Ways and Means Committee in August 1967. The many major changes which affected the rest of the Social Security Act affected EPSDT only in-

[7]During 1968 before EPSDT, the CC program served 475,000 children while Medicaid served 5,574,000 children. The CC program had been serving over 400,000 children since 1964. No data are available on the children served by Medicaid during its first two years, 1966 and 1967 (HEW, 1971a: Table 1; HEW, n.d.: Table 2).

directly.[8] One of the changes was to consolidate all the funding for Title V into one authorization of $250 million, of which half was to go for Maternal and Child Health and Crippled Children's Services combined. If the shares were divided equally, the CC program would receive an authorization of $62.5 million, a few million dollars less than had been proposed in H.R. 5710.[9]

The date on which screening was to become effective, July 1, 1967, was removed from the EPSDT amendment to Title V because the date was already past. July 1, 1969, remained as the effective date for the program in the Title XIX amendment. With the EPSDT amendment to Title V written into a new consolidated Title V, the two EPSDT amendments to Title XIX were called "conforming amendments.[10]

The question of administrative authority was immediately raised in the Ways and Means Committee's report which emphasized that the EPSDT provisions were to bring about more aggressive case-finding by the CC programs; however, the committee then obscured its intent: (U. S. Congress, 1967c: 127)

> Organized and intensified case-finding procedures will be carried out in well baby clinics, day care centers, nursery schools, Headstart centers in cooperation with the Office of Economic Opportunity, by periodic screening of children in schools, through follow-up visits by nurses to the homes of newborn infants, by checking birth certificates for the reporting of congenital malformation and by related activities. Title XIX (Medical Assistance) would

[8]One major issue debated throughout the 1967 Social Security Amendments was whether the eligibility levels for medically needy should be limited to 133 ⅓ percent of the public assistance levels under the categorical programs. Both the states and the federal government were anxious to cut Medicaid costs by limiting the number of people who would be eligible for the medically needy category. Congress decided to apply this limitation only to the AFDC program. Consequently the number of children eligible for EPSDT through Title XIX was curtailed by this action.

[9]In fact, the MCH and CC shares, as they were allocated by the HEW Secretary, were not quite equal. The CC program received slightly more than the MCH program.

[10]SRS administrators later, when writing regulations for Title XIX, wondered whether the Title V amendment took precedence because the Title XIX amendments were "conforming." They were reassured by HEW General Counsel that juridically this had no meaning and they could proceed with regulations for Title XIX.

> be modified to conform to this requirement under the formula grant program.

The legislative mandate was only for the CC and Title XIX programs, but the committee was suggesting that all other federal, state, and local programs be asked to cooperate as well, with neither the funding nor the administrative framework provided for them. Much of the screening work around the country was at the time being supported by the MCH program, but it was not mentioned in the commentary.

Although administration was to be in the hands of the CC program, case finding would also be carried out by the Title XIX program. A dual system of administration was being proposed, with the Title XIX agency expected to provide reimbursement to the Title V agency (U. S. Congress, 1967c: 195). CC's funding for this massive expanded program was limited to about $7.5 million more than its previous authorization, while there was no mention of the funding to be availble to Title XIX for the program. Thus the program was not likely to open the way for increased services by the MCH and CC programs (usually the health departments) in the states. The open-ended funding of Title XIX gave that program greater flexibility.

Finally, the committee did not mention the number of children to be helped by this expanded program nor the extent of services to be provided.

When H.R. 12080 passed the House in August and was sent to the Senate, the cost of EPSDT, the eligible population, the extent of care and how the program was to be administered, had not been clarified. The latter two questions were left for the Secretary of HEW to prescribe in regulations. Presumably, the Senate hearings would provide insight into the intent of the legislation, but this was not to be.

Phase 3—Senate Hearings and Passage

Hearings were held before the Senate Finance Committee during August and September 1967. The EPSDT provisions were unchanged from the hearings before the Ways and Means Committee on H.R. 5710, so most of those who testified did so on other controversial issues without reference to EPSDT. No special mention

of EPSDT was made by either HEW Secretary Gardner or Under-Secretary Wilbur Cohen. Nor did senators raise questions. Among the hundreds of witnesses and communications that were incorporated into these hearings, only one witness, Dr. Donald C. Smith of the American Academy of Pediatrics, stressed the need for preventive health measures in childhood and asked that the high quality of CC programs be maintained. He therefore recommended an amendment that would *require* cooperation between state agencies administering Crippled Children's Programs and those administering Title XIX programs (U. S. Congress, 1967d: I, 201). No such requirement was added. Congress retained the more ambiguous wording of the amendment that state Title XIX agencies provide for "entering into agreements" with Title V and other agencies.

H.R. 12080 was a complex bill with titles relating to Public Assistance, Medicare, Medicaid, and Child Welfare. The Child Health Act of 1967 was only eight and a half of the 112 pages, and EPSDT took up only the three paragraphs described earlier. Provisions on AFDC stimulated the most comment. Early periodic screening and treatment, if not ignored, at least was not uppermost in people's minds. In retrospect, this lack of concern seems odd because so much time and energy during these hearings were devoted to restricting the costs of Medicaid. This new program would greatly increase Medicaid costs. Perhaps those who proposed the program were aware of its high potential cost and also of the jurisdictional dispute it would engender and therefore deliberately underplayed financing and administration.

The three amendments which became known as EPSDT passed the Senate unchanged from the House version. After a Senate-House conference, they then passed the two houses as part of the Social Security Amendments of 1967 or PL 90-248, and were signed into law by President Johnson on January 2, 1968.

The United States had just enacted its first policy mandating preventive health services for needy children, a kind of health insurance for the poor. All states with Title XIX programs[11] would have to provide such services for all eligible children. In addition, the Crippled Children's Program would also have to carry out early periodic screening for those who were eligible under its plans. Yet, despite the broad mandate, during its eight-month legislative his-

[11]By 1970, this would include all states but Alaska and Arizona.

tory, EPSDT's details were scarcely touched on. The scope of screening and the eligible population were hardly mentioned. Estimates of cost were applied separately for the CC and Title XIX programs with no public discussion on how these costs would be worked out. Nor was it discussed whether health or welfare agencies were to be responsible for this health-welfare program. Thus, the Secretary's office was faced with a formidable task in understanding legislative intent when it came to writing regulations.

Development of Regulations and Guidelines[12]

Although the EPSDT provisions had become law in January 1968 with the stipulation that they be implemented by July 1, 1969, final regulations and guidelines did not appear for four and a half years. Proposed regulations were issued in December 1970; after lengthy discussions final regulations appeared in November 1971 and final guidelines in June 1972. Meanwhile, the final implementation date for all age groups had been deferred until July 1, 1973. This four-and-a-half-year period was filled with discussions within HEW as to what direction rule making should take. Many people were involved—administrators and planners for the Title V and Title XIX programs in Washington, senators, representatives, Congress as a whole, the state Title XIX and Title V agencies, which were for the most part welfare and health departments, the HEW regional offices, the National Welfae Right Organization (NWRO), the Medical Assistance Advisory Council (MAAC), and professional groups such as the American Optometric Association. The law was interpreted and reinterpreted; the scope of services under EPSDT was broadened, narrowed, and then broadened again. Opposing forces used HEW as a battleground for issues which had not been resolved during the program's legislative history. The administrative framework, costs, eligibility, and scope of the program all had to be clarified before regulations and guidelines could be published and the program implemented.

[12]I am grateful to the many officials of the Social and Rehabilitation Service and the Maternal and Child Health Services who generously gave of their time to provide much of the information upon which the following pages are based. Their generosity should not be confused with responsibility for the way their information has been used.

Regulations and Guidelines—Administering Agency

Congress had given EPSDT both to Title XIX and to the CC program of Title V, without clarifying which agency was to administer the progrm. The CC program which was administered by the Maternal and Child Health Services (MCHS) was not asked by HEW Secretary Wilbur Cohen to develop regulations, even though the legislation called for them. This charge was giveninstead to Medical Services Administration (MSA) in the summer of 1968.[13] Even though MSA wondered at first what the implication was of the dual administration in the legislation, it worked out a draft whereby the state agencies would make firm agreements with one another, and this approach was coordinated with Dr. Arthur Lesser, the director of MCH Services. MSA proceeded to draft regulations and assume its role as the administrator for the EPSDT program, while using MCHS as consultants.

After proposed regulations for the EPSDT program were published in December 1970, states began to question how this cooperation would work.[14] The Medicaid program was to provide for (U. S. Federal Register, 1970b: 18879):

> . . . identification of those eligible individuals who are in need of medical or remedial care and services furnished through Title V grantees, and for assuring that such individuals are informed of such services and are referred to Title V grantees for proper care and services, as appropriate.

In most states, Title V agencies were in health departments while Title XIX agencies were in welfare departments. The greatest con-

[13]Writing regulations was a new procedure for MSA. Prior to 1968, Title XIX programs had provided all guiding material to the states through its *Handbook of Medical Assistance—Supplement D*. Since these guidelines gave no way for the public or interested parties to be heard, and since several different agencies had been placed together during the 1968 reorganization of HEW, their policies were standardized and regulations had to be written. H.R. 12080 required that regulations be written for use of skilled nursing homes as well as for EPSDT, and both these regulations were several years aborning.

[14]Proposed regulations for cooperation between Title V and Title XIX agencies had been published earlier that year but had elicited little comment from the states, possibly because the states did not know what the scope of the program would be (U. S. Federal Register, 1970a: 8664).

cern was duplication of effort between the two agencies, but one state official pointed out that this relation would result in more competition and misunderstanding between the programs than already existed. Neither Congress nor HEW had taken into account that these two agencies might not work well together on the state level. The MCHS pressed for greater details on the relationship in the guidelines, while state and regional officials asked why other agencies, such as Visiting Nurses Associations and home health agencies, had not been mentioned.

The question of reimbursement provided the major conflict and source of confusion for the Title XIX and Title V agencies. Early in 1970, MSA had received the legal opinion that the regulations called for total reimbursement for all Title V services and the Title XIX agency would have no control over the numbers of children screened, or the amount of reimbursement except as these items might be covered in the written agreements, nor could reimbursement be limited to children referred by the Title XIX agency. But the confusion persisted, perhaps because the state Title XIX agencies were not happy that they would be paying for Title V services which hitherto had been free to recipients. The following year MSA had to issue another clarification, slightly weakened by this time, that Title XIX payment could include both diagnostic and treatment services "as appropriate." It noted that responsibilities for payment were program decisions rather than those of legal prerogative. MSA was trying to force the states to work out their own relationships, but the state Title V and Title XIX agencies kept appealing to their respective HEW agencies for support. The next year another memorandum reiterating the previous position was sent out. The reimbursement issue was particularly difficult because in many states the Title V programs provided the major public screening services through child health conferences, and the major public diagnostic and treatment services through the Crippled Children's program. However, their funding had not increased and consequently they had trouble maintaining their programs.

Between 1968 and 1972, MSA gradually clarified its role as the sole administrator of the EPSDT program, while MCHS took a more and more consultative role.[15] MSA's involvement in its new

[15]Regulations for the Title V EPSDT amendment were finally issued in 1974 (U.S. Federal Register, 1974).

role of providing for health services was so strong that by 1973 it was letting contracts for EPSDT program evaluations and for the development of screening standards. These contracts, which were part of MSA's surveillance and evaluation responsibility, did not differ much from contracts which were let by MCHS for evaluation of its programs. Meanwhile, the MCHS were not entirely pleased to see MSA moving into the field of health services. This tension at the federal level was reflected within the state agencies, either because of the existence of an MSA and an MCHS encouraged their state counterparts to square off against one another, or because the two federal agencies could not control them. One MSA administrator wondered at the time whether MSA had a policy of encouraging interagency relations, because the guidelines did not reflect this. The issue always came to a head over whether Title XIX would reimburse Title V for its services. States were hard hit by inflation and were looking for ways to avoid spending money. When these issues had to be settled, Title V agencies (usually the health department) and Title XIX agencies (usually the welfare department) would buck the issue up to the federal level. The administrative issue had been resolved in one sense, but as soon as the states began implementing the program, all the tension between a health agency and a welfare agency which was running a health program erupted, and this ambiguity continued to plague all those charged with implementation.

Regulations and Guidelines—Costs and Funding

The administrative decision which made EPSDT a Title XIX program resolved the issue of who was to pay for it. Title XIX reimburses from 50 to 83 percent of states' costs. Theoretically no limits existed for the development of the EPSDT program, but experience with Title XIX had shown that generally states like California and New York took advantage of the program, while smaller, poorer states did not.[16] As Stevens and Stevens noted (1970: 365-378), when states did spend a great deal of money, as New York and California did in the early years of Medicaid, then Congress got upset because costs were too high.

[16]In 1969, these two states alone accounted for 45 percent of Medicaid expenditures (HEW, 1972b: Table 7).

During the first two years of regulation drafting, cost estimates were not made because, according to MSA and state officials, available data were so poor. However, by August 1970 someone had come up with a first-year cost of $45 million. This large sum must have alarmed HEW, for by December of that year it had advised the Senate Finance Committee that it had delayed issuance of regulations for EPSDT because of the "great cost" it would entail for both the federal and state governments. HEW then asked Congress for legislation to phase in the program slowly (U. S. Congress, 1970: 169), but Congress refused. Meanwhile, Senator Abraham Ribicoff and the Medical Assistance Advisory Council (MAAC) continued to press for regulations.

When proposed regulations were published in December 1970, the states responded vehemently and very rapidly on the question of cost. Eighteen out of the 22 states responding said the program would place a financial burden on the state beyond its capacity. In case HEW should miss the point, one southern state had its entire congressional delegation send letters of alarm. Part of the reason states could not estimate costs was that the federal guidelines were still not available.[17]

During the spring of 1971, the Nixon administration had committed itself to a reduction of federal Medicaid costs for fiscal 1972,[18] and by May HEW, following suit, decided it would allow states to implement the program in phases starting first with children under six in order to soften the financial impact on the states. The softened financial impact on the federal government was implicit. Costs continued to concern HEW; one official estimated EPSDT would cost $400 million by 1973 and this would create a sizable drain on the Treasury. HEW decided to narrow the scope of services and also to concentrate on slowly phasing in children by age groups. In September, HEW decided that the program would cost only $25 million the first year. When this sum was approved by the Office of Management and Budget in the fall of 1971, the final regulations could be published.

[17]One small midwestern state which had looked more carefully at costs than others estimated they would have 15 to 20 children eligible for kidney dialysis at $30,000 each.

[18]The administration was at the time proposing the ill-fated Family Health Insurance Plan (FHIP), and EPSDT was held up while HEW studied how they fit together. Officials in the secretary's office even considered getting legislation to eliminate EPSDT altogether.

The states through their concern for their own costs had managed to stave off for nearly three years the implementation of a law passed by Congress.[19] The power of the states in this case illustrated the limitations of federal aid programs. Since the incentive was not great enough, and since financial needs were sufficiently pressing, the states did what they could to hinder implementation. HEW was caught between the congressional groups which had favored EPSDT and the state welfare agencies who were its clients. HEW deferred making a choice by offering the states a few years' respite by phasing in the program slowly. This respite was only temporary, and eventually the states would have to come to terms with the financial burden of EPSDT, unless they could convince Congress to repeal it completely.

Regulations and Guidelines—Eligibility

The eligibility issue was also resolved when EPSDT became solely a Title XIX program. Under Title XIX any child who was eligible under the state plan was eligible for EPSDT. However, state plans varied considerably. By 1971, 48 states had Medicaid programs under which all children receiving AFDC welfare payments were eligible. In addition, 25 states offered Medicaid services to any low-income child who fell within the income guidelines (HEW, 1971c: 2-3). Arizona and Alaska had no Medicaid services. However, states varied considerably in their eligibility requirements. For example, in 1968 while New York was providing medical payments for 206 children per 1,000 inhabitants, South Carolina was providing for only two per 1,000 (HEW, n.d.: Table A). In all it was estimated that approximately 10 million children would have been eligible for EPSDT, or 12 percent of the United States child population of 80 million.

During the development of regulations and guidelines restrictions on eligibility arose from the need to cut back costs and one way to do this was to cut down on the eligible population and to allow states to serve first children under six years and not serve older children until 1973. This phasing-in approach met at first with some skepticism from the HEW general counsel, but it was finally ac-

[19]Two states, Virginia and Mississippi, were exceptions and had supported the program and were implementing the program before February 1972.

cepted. The eligibility restriction was supposed to be temporary but states were in fact slow to phase in the over-six population.

Regulations and Guidelines—Scope of Services

From the earliest drafts of the regulations, MSA understood that the amount, duration, and scope of services was to be comprehensive and this thinking was reflected in the proposed regulations published in 1970 (U. S. Federal Register, 1970b: 18879; emphasis added).

> Effective January 1, 1971 (or earlier at the option of the State), that early and periodic screening and diagnosis to ascertain physical and mental defects, and treatment of conditions discovered *regardless of the limits otherwise imposed under the State plan* on the type and amount of such care and services. . . . will be available to all eligible individuals under 21 years of age.

In the 48 states with Medicaid programs at the time, state plans were by no means comprehensive. All states included the five basic services: inpatient care, outpatient care, laboratory and X-ray services, skilled-nursing home services for those over 21, and physician services, but here the similarity ended. One state, Minnesota, provided the full range of services available; others like Kansas, Nebraska, North Dakota, and New York provided all but one or two services; still others like Mississippi and Missouri offered only three additional services. Eighteen states did not provide dental services and 18 did not provide eyeglasses; eight states did not provide prescribed drugs (HEW, 1971d). In fact, in five states the content of Medicaid programs was determined by state statutes, and since screening for eye defects or provision of eyeglasses, as well as other services, were not included, the above regulation would require a change in law. Thus to be comprehensive any federal regulation would have to go outside the bounds of state plans.

The states objected vigorously to providing unlimited amounts of services for unlimited periods regardless of the limits of the state plan. They said the regulations were contrary to the intent of Title XIX and federal-state grant programs because they took away from the state control over the scope of their programs. Some state officials also said that the state simply did not have the medical

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manpower to carry out such a comprehensive plan, implying that government should not try to provide services to low-income people until resources are available. Another state official suggested more directly that periodic screening was an outmoded concept largely abandoned by public health and the medical profession.

Strong support for the regulations came from the director of the National Legal Program on Health Problems of the Poor, who also lobbied effectively with other groups, particularly welfare rights groups, to support the EPSDT program. He asked that the regulations specify the types of care included, such as eyeglasses and hearing aids, and dental fillings.

During the long period between the proposed and final regulations, state and federal concern for EPSDT costs was rising. The result was that MSA regretfully curtailed the scope of services required of the states under EPSDT. The final regulations asked the states to provide EPSDT "within the limits of the state plan on the amount, duration and scope of care and services" (U. S. Federal Register, 1971: 21410). This constituted a major blow to the comprehensiveness of the treatment segments of the EPSDT services. As mentioned before, states were uneven in their provisions for treatment. The welfare rights lobby had had some effect, however, for the regulations included three treatment services which had to be included by states regardless of the limits of state plans:

> . . . eyeglasses, hearing aids, and other kinds of treatment for visual and hearing defects, and at least such dental care as is necessary for relief of pain and infection and for restoration of teeth and maintenance of dental health. . . .

These three treatment services, plus early and periodic screening, thus became the EPSDT program as it emerged from the federal regulations.

In writing guidelines, MSA tried to help states develop as comprehensive a program as possible. The MCHS which over the years had developed a body of information on quality health services for children provided valuable consultation. Other groups like the American Optometric Association, speaking in the interests of its own profession, asked specifically that visual screening and restorative services be included. The final guidelines reflected these interests, and detailed the case-finding procedures, screening tests to be performed, and diagnosis, treatment, and therapeutic services to be made available to eligible children (HEW, 1972a).

All these services, however, had to be carried out within the limits of the state plan.

To those who had viewed EPSDT as a major innovative comprehensive health program for needy children, the regulations were a disappointment. Treatment was not comprehensive. To those with a "toe-in-the-door" philosophy of federal policy making, it was an encouraging first step for the care of children. Certainly more poor children would get more types of care under this program than they had before. In one state, where the scope of the program had the potential of being comprehensive, an official commented wryly that the same services were not available to middle-income children.

Conclusion

The advent of EPSDT legislation provided the United States with the first major federally sponsored program for comprehensive health services for 12 percent of America's children. It could have been a prototype for health insurance for all children, but congressional intent for the program was so ambiguous that considerable energy had to be exerted to resolve the questions it posed. During the development of regulations and guidelines interest groups used what leverage they could to accomplish their ends. These conflicting interests used HEW as a battleground and compounded the task of program implementation. Some individuals and groups, such as community organizations, the MAAC, and the National Legal Program on Health Problems gave fairly steady, general support to the program, but factions tended to cluster around particular issues: administration, costs, and scope of services.

MSA emerged as the administrator of the EPSDT programs and found itself providing for health services for children, something that had been the province of MCH services. The factions within HEW managed to adjust to these new roles, but implementation of the program would create new tensions between health and welfare agencies at the state level. Ambiguity in legislative intent gave no one federal or state agency full responsibility for carrying out the program. Thus, the administering agencies were unable to build a bureaucratic constituency behind the program. Responsibility was divided between health and welfare agencies

with most going to the latter. On the federal level, MSA showed yet greater commitment than MCHS. In the states, neither health nor welfare agencies could become committed and build up the solidarity needed to carry out the program.

Costs were another issue which brought several factions into conflict over a program variously described as costing anywhere from $15 to $400 million. President Nixon had pledged not only to reform the welfare system, but also to cut costs, yet he had inherited one of the most far-reaching health programs the nation had ever undertaken. Congress, although also committed to lowering welfare costs, and particularly Title XIX costs, managed to live with its ambivalence toward the EPSDT program and mandated its implementation while attempting to cut back on other programs. The states were the hardest hit by the program's staggering potential (though never defined) costs. During the development of regulations and guidelines they tried to discourage HEW from asking them to carry out the program, and when they had to implement, they moved very slowly. States were angered by the heavy costs and lack of lead time they had been given. One state official suggested that states should have been given the same amount of time for implementation as HEW had had to write regulations.

While most of those who grouped around the issue of costs wanted to cut back or eliminate the program, those concerned with the eligible population and scope of services strongly favored the program's development. County and national welfare rights organizations, with the support of MCH services, had shown their strength by the well-thought-out and comprehensive array of tests and screening mechanisms that became available to low-income children (at least those eligible for Title XIX under state plans). However, the states and federal government in their concern for costs succeeded in cutting back the scope of services available under the program.

The absence of discussion surrounding EPSDT's intent is not unique in the history of federal health policy. Title V when presented to Congress in 1935, received scant notice because attention was drawn to the major provisions of the Social Security Act. EPSDT's predecessor and umbrella program, Medicaid, slipped into the 1965 Social Security Amendments to fill the gaps left by Medicare. When it was passed, it was called the "sleeper" of the Amendments because no one had foreseen that the costs of this

program would rise from $2 billion to nearly $9 billion in a few years and that by 1971 it would be serving nearly 20 million people.

The experience of Title V, Medicaid and EPSDT exemplify the toe-in-the-door procedures of federal policy making. Congress seems to assume that once a worthy policy is passed, its implications can be worked out later, and the program expanded when necessary or desirable. This had not always been the case. Title V was never expanded. Its funds were increased over time, but the program never became a national program for child health services. Since the sixties other programs such as Head Start and Neighborhood Health Centers and, of course, EPSDT have been added to supplement Title V rather than integrated. Medicaid was viewed as a stop-gap measure for those not eligible for Medicare. It did expand, but its unexpected high costs did little to endear to the American public the principle of publicly financed medical care. To compound the problem of poorly thought-out policy, EPSDT was added to Medicaid before its implications were studied.

What can one learn about ambiguous toe-in-the-door policy making from the experience of EPSDT and its four-and-a-half-year delay in implementation? First, that Congress and the executive agencies are unable or unwilling to come up with reliable cost estimates for health and welfare programs. One wonders whether accurate cost estimates were actually unavailable to Congress or whether no one in Congress or HEW was willing to face the costs the program would entail. At any time Congress or HEW could have gone back to the 1966 Program Analysis and discovered that the cost of screening five million children was $150 million. It may be true that no politician can sell an expensive health program to his constituents, but unrealistic costing leads to a public that may become increasingly disenchanted with federal health programs which cannot live up to the expectation placed on them by Congressional and Executive rhetoric.

Second, ambiguity in administrative assignment lessens bureaucratic solidarity and thereby a program's chances for success. Had Congress given responsibility for EPSDT to one single agency, it would have been easier to build bureaucratic solidarity behind the program to smooth its implementation. The division of responsibility between health and welfare split the program between agencies with differing philosophies and goals.

Third, establishing federal child health policies through the mechanism of federal-state grant-in-aid programs increases the am-

biguity of the final policy. Medicaid and EPSDT are officially state programs. And the states can put up formidable barriers to their implementation. They can protest vigorously to HEW as they did when the proposed EPSDT regulations were issued. In addition, they can refuse to implement the program at all; they can limit eligibility; or they can limit the scope of the state plan. Since states in fact have used all of these ways to limit the economic impact of the Medicaid and EPSDT programs, it is not an encouraging precedent. Even the threat of lawsuits and federal penalty have failed to move some states.

Finally, the role of health and welfare interest groups in urging HEW to carry out EPSDT should be noted. The welfare rights groups lobbied to get regulations to emerge from HEW. The continued role of these groups in bringing lawsuits against states for failure to implement EPSDT indicates that such groups may be taking the leadership which states have been unwilling to exercise in implementing federal policy.

Congressional intent in EPSDT legislation, as in much legislation which is born in compromise, had resulted in ambiguity. If Congress was ambiguous in its intent for EPSDT in 1967-68, it continued to be so. While trying to cut welfare and Medicaid costs on the one hand, in 1972 it reaffirmed its intent to maintain the EPSDT program by adopting a penalty for states which failed to carry out the program. This ambiguity encouraged many groups to work for the program's early demise. Compromises made during the development of regulations and guidelines placated, at least temporarily, the states, interest groups, and administering agencies, and thereby assured the program of a continued, albeit tenuous and unsatisfactory existence.

Anne-Marie Foltz, M.P.H.
Yale University
School of Medicine
Department of Epidemiology and Public Health
60 College Street
New Haven, Connecticut 06510

Valuable suggestions and criticisms of an earlier draft of this paper were provided by James W. Bjorkman, Jean Hoodwin, Lucille Reifman, George A. Silver, Rosemary Stevens, and Robert Stevens. Research was made possible through Department of Health, Education and Welfare Grant #5-RO1-HS-00900.

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THE MILBANK MEMORIAL FUND QUARTERLY

Volume 53 · Number 1
Winter · 1975

Health and Society

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Mr. MAGUIRE. Thank you very much.

We will have another bell, and I think rather than beginning your testimony at this point, Ms. Andrade, we will recess briefly and come back, if we may impinge upon your time.

We stand recessed for 10 minutes.

[Brief recess.]

Mr. MAGUIRE. The committee will come to order.

Our next statement will be from Dr. Andrade, Excutive Director, Tri-City Citizens Union for Progress, Newark, New Jersey.

STATEMENT OF REBECCA DOGGETT ANDRADE

Ms. ANDRADE. Thank you, Mr. Chairman. My name is Rebecca Doggett Andrade. I am Executive Director of Tri-City Citizens Union for Progress, which is a private, non-profit community development organization in the city of Newark, New Jersey.

In 1972 we added a health component to our child care program to ensure that each child was physically capable of learning.

That component was expanded into a neighborhood child health station to serve the 3,000 families in our 12-square block neighborhood.

I am probably here today because our organization was drawn into health advocacy as a result of trying to provide health care for all of the children in our neighborhood.

We learned about EPSDT through a child health project run by the Rutgers Newark Law School. They had started to look into New Jersey's EPSDT/Medicaid program and had some alarming facts. These statistics became all the more real to us as our organization, as well as other child care centers in Newark, tried to bring health care into our communities by way of EPSDT.

For example, the community groups requested that outreach services be a reimbursable expense under EPSDT.

OUTREACH

Statistics showed that less than 5 percent of the Medicaid children were receiving EPSDT care.

However, community recommendfations for community-sponsored outreach to be a reimbursable expense under Medicaid were denied.

Already overworked caseworkers in the county welfare systems were expected to do outreach to clients.

PROVIDER SHORTAGE

Figures showed that a large number of private physicians in the State did not participate in the Medicaid program.

Pediatric clinics at hospitals charged under the regular Medicaid program at the highest possible rates.

City or county health departments were all not involved in the EPSDT program. In fact, many of them had not heard of EPSDT either.

Local public schools were not involved in EPSDT although the Medicaid program declared that eligible children were getting equivalent care.

Neither community health centers nor potential community health centers were reimbursed at a reasonable rate.

Our recommendations were that a full-scale effort be launched to recruit more providers at all levels (1) by offering a reasonable rate, (2) by providing startup funds in cases where non-profit organizations were involved, and (3) by streamlining the certificate of need procedure in the department of health, and (4) by providing technical assistance to willing community organizations.

QUALITY OF CARE

There did not appear to be a mechanism for colleting data on whether or not the full range of EPSDT services were performed before providers were reimbursed.

Advocates recommended a per-child rate with the full package of services required.

The Regional Office of HEW publicly admitted that New Jersey has met statutory requirements but has never been in programmatic compliance with the spirit and purpose of EPSDT coordintion with existing health agencies.

Before our advocacy work began, few private or public providers had ever heard of EPSDT. There was no public education effort nor attempts to orient providers as to what their service responsibilities were.

City and county health departments were not recruited as part of the delivery system. No attempts were made to upgrade those services.

Public school health programs had been surveyed and were known to provide less than 50 percent of the EPSDT services required. However, the Medicaid children were deemed to be receiving "equivalent care." Therefore, no outreach efforts were done through public schools nor was there any attempt to upgrade the public school health program.

The net results of our efforts have been relatively minor. A State advisory committee was established but it has no prospects of creative work because there is no Federal mandate or requirement for programmatic compliance.

We support the Congress' attempts to improve on child health with the passage of CHAP. I am very glad to see that the name of the program is now being proposed to be Child Health Assurance Program. In that regard we would like to make the following recommendations and comments:

1. Incentives should be included for upgrading public school as well as city and county child health programs. EPSDT service standards are comprehensive and should be the model for child health.

2. Incentives should be included for increasing the number of providers available to clients.

3. Start-up funds for community-based non-profit corporations should be authorized.

4. Outreach programs sponsored by community groups should be reimbursable at 90 percent FFP. The 10 percent should be provided with State funds.

5. A comprehensive State plan should be prepared. Some components of that plan should include:

(a) Public meetings and comment period be required.

(b) Identification of EPSDT services in the total Medicaid package.

(c) Plan for recruitment of providers in underutilized areas.

(d) Plan for coordination and upgrading of child health services with all responsible State agencies (i.e. State departments of education and health).

6. Some CHAP funds should be set aside for innovative projects that will promote higher levels of parent participation, provider recruitment or public education.

We think there is a great deal more effort that can be done at a local level but there will have to be some level of funding and incentive for that to take place.

7. Administrative orders or directives from the HEW Secretary should be used before penalties are imposed.

8. Penalties should cover all areas of compliance, not just reporting requirements.

9. The penalty proposed by CHAP will be a more effective and fair measure than the present EPSDT legislation proposes.

10. CHAP must permit services to children with developmental needs. Without this component, the whole impact of preventive health care is lost. This is especially crucial in light of the fact that low income women give birth to children with more developmental deficiencies and risks.

11. Public school aged children—ages 7-18—must also be included under CHAP.

12. Dental care needs are at crisis proportion in the poverty communities. A comprehensive program of dental education—prevention—and treatment is crucial.

Screenings are only effective if they are part of an educational and orientation program for parent and child.

Our own experience in community health is that local people need a great deal of resources at their disposal.

We presently do not have a delivery system for preventive health care in this country. We are trying to use a delivery system that is designed for sick people to meet the demands of keeping people well.

Our hope is that this is just a first small step in providing our nation's children with everything they need to grow.

Mr. MAGUIRE. Thank you, Ms. Andrade. I might say I am very proud as a Representative of the State of New Jesey to have in our own State the kind of leadership that you have shown in the Newark case. It gives us a case study which will certainly help us to draft Federal legislation. I want to compliment you on your statement, not only its analytic quality in terms of identifying where problems arose, but also the very specific and lengthy list of recommendations which will be very helpful to the committee.

Our next panelist is Ms. Georgia L. McMurray, Director, Department of Public Affairs, Community Service Society, New York.

STATEMENT OF GEORGIA L. McMURRAY

Ms. McMURRAY. Thank you, Mr. Chairman. My name is Georgia McMurray. I am Director of the Department of Public Affairs of the Community Service Society.

I have a long history of professional and personal concern with children, having served as Commissioner of the Agency for Child Development of the city of New York and in another capacity, having directed an evaluation of the head start/EPSDT collaborative effort for HEW in 1976. The Community Service Society has for nearly 130 years of its history, represented the interests of the poor and disadvantaged of New York City. I am here today representing the position of the CSS Committee on Health in regard to the Child Health Assessment Act—H.R. 6706—the Carter administration's proposed replacement of the EPSDT program.

The EPSDT program originated in 1967 when the Social Security Act was amended to require States to provide for early and periodic screening diagnosis and treatment for all Medicaid eligible children under the age of 21. After 10 years, 15 lawsuits, another amendment to the Social Security Act to strengthen EPSDT enforcement, and the promulgation of numerous regulations, only 16 percent of the eligible children nationwide have been screened. Of those screened who required treatment, 22 percent did not get care (U.S. DHEW, FY-76 National Statistical Summary EPSDT). In New York State, the performance record is even worse. We have 11 percent of the Nation's Medicaid eligible children, yet only 12 percent of these 1.4 million children—60 percent of whom live in New York City—were screened as of 1976.

The proposed Child Health Assessment Act (CHAP) is an attempt to improve the EPSDT program. However, it is our opinion that CHAP, while appearing to offer improvements to the existing law, in fact retains the same structural defects and would neither improve the health care of poor children nor remedy the flaws inherent in EPSDT. Even HEW estimates that CHAP would only increase screening of Medicaid eligible children from the current 16 percent to 22 percent by the end of 1978. We believe that there are important lessons that have been learned from the EPSDT program. Before formulating any plans to improve the health care of poor children, we should consider some of the following points.

1. A dual system of care should be avoided.

CHAP would maintain a separate program for the poor, which we oppose because of the means test requirement and associated administrative costs. The old axiom that "medicine for the poor is poor medicine" is too often still true and is substantiated by the small percentage of providers participating in EPSDT and the abuse documented in Medicaid mills. In addition, the near poor—those beyond the expanded eligibility requirements of CHAP—are still excluded. This is particularly serious in New York City. Due to the fiscal crisis, severe cutbacks in services provide by city child health stations and pediatric clinics have cut off the source of care for those who cannot afford to pay out-of-pocket. Most critically, the comprehensive scope of "free" benefits—those not usually covered under private insurance—for the poor will surely incur middle-class

resentment. Unless there is a broad base of constituent and political support, there will not be the leadership at all levels of government needed to make the program work. CHAP retains the 2-track system of care by focusing on the very poor and thus eliminates the possibility of any such broad-based support.

2. A health program should be administratively workable.

Maero Systems, Inc., studied the implementation of EPSDT in selected counties in New York State for HEW in 1976 and found that in each county, administrative costs were greater than either screening, diagnosis, or treatment. In one county, administration was 410 percent of screening costs. This is largely due to the administratively complex problems associated with identifying and recertifying eligible children. (The turnover in eligibility is about 30 percent per year.) The cost-effectiveness of the program is undermined, as much of the screening is done on children who are already in the mainstream of health care, rather than those in most need. Case management and tracking is also complex and costly, and these procedures raise serious questions about safeguarding individual privacy, especially when they are only used for poor populations. As a "welfare medicine" program, CHAP does not, and probably cannot, simplify this administrative complexity.

3. A health program should not be tied to a welfare system.

In New York and numerous States, EPSDT is part of an already overburdened welfare system which lacks expertise in delivering health care. A health program should be independent from considerations of eligibility. CHAP does not address this problem.

4. Organized resources must be in place to serve the health needs of children.

A major structual defect in EPSDT was the implicit assumption that the delivery system had the capacity and willingness to serve the health needs of poor children. Such a system was not then in place and is not in place now. A recent finding of CSS Committee on Health demonstrates the insensitivity of the system to the health needs of the poor. In order to get free immunization through the skeletal remains of city child health stations, we discovered that Chinatown residents had to take their children two long bus rides across Manhattan. Throughout the city, there are many low-income neighborhoods where more than 40 percent of the children have not been adequately immunized.

A massive commitment to integrated health and related services (e.g. transportation, community-based outreach, health education) is needed to make care available and accessible. There should be incentives to encourage providers to accept other than fee-for-service reimbursement that is appropriate to required standards for participation. We acknowledge that the CHAP proposal recognizes the need for resource development. However, the total amount—$25 million—proposed nationwide would hardly meet the needs for New York City alone.

CHAP does not contain the necessary ingredients to trigger the structural changes in the health care delivery/financing system which would make it responsive to the health needs of poor children. Further, the program is limited in population coverage to low-income children. Isolated categorical programs do not aggregate

sufficient health care dollars and constituent support to move the system in desired directions.

CSS proposes that a national system of maternal and child health services be substituted for the CHAP proposal now being considered by this subcommittee. Rather than attempting to refashion the EPSDT program, which has been both wasteful and ineffective, we advocate adopting a program for pregnant mothers and children which would serve as a first stage in incrementally implementing a comprehensive national health care program for all the population.

Dr. Eveline Burns, the eminent economist consultant to CSS, testified before this body at its hearing last year on the Scheuer bill.[1] While pointing out the weaknesses in that bill, Dr. Burns cited many good reasons for the United States to establish a health care program for children as a first step for a national comprehensive program serving all age groups.

Despite the advances in medical knowledge and technical capability, we know that the health needs of children in this country are not being met. High perinatal mortality and neo-natal death rates indicate the need for medical intervention during pregnancy and at birth. For example, in New York City the infant mortality rate per 1,000 live births was 19.3 in 1975, but for non-white babies it was almost 50 percent greater than for white babies.

But infant mortality rates tell only part of the story. Even if children survive, there is no guarantee that they will receive adequate health care either for prevention or for treatment.

In a 1965 study of 18 year olds rejected by the U.S. Selective Service it was found that 15.2 percent were rejected because of chronic handicapping conditions and that 33 percent of those conditions could have been prevented or corrected if discovered before the individual reached age 9.

A recent report of the Medical Services Administration of HEW indicated that between 20 percent and 40 percent of children in low income families suffered from one or more chronic conditions and that only 40 percent of the conditions were being treated.

HEW has also reported that while 97 percent of children under 6 require some dental care, only 40 percent of children under age 17 in low income families have ever seen a dentist.

Of all children from age 6 to 11, 10 percent have vision problems but only 40 percent of the children with such problems in low income families in that age bracket have had their vision handicaps corrected.

Clearly the unmet health needs of children must be addressed aggressively and thoroughly. The children cannot wait.

To devise a program which selects children as the initial category to be covered is both logical and in the public interest. This represents an investment in our Nation's future; healthy children are likely to become healthy and economically productive adults. Also implicit in such a public policy objective is the potential savings to be realized in lowered medical care expenditures for a population which has benefited from preventive health care. Early

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[1] In June 1976 on H.R. 12937, the Maternal and Child Health Care Act, introduced by Representative James Scheuer.

detection and treatment of illness, augmented by health education for mothers and children to promote good health habits in regard to smoking, alcohol consumption and nutrition, should help to avoid or alleviate many future health complications.

The costs of directing such a program largely to children would be relatively low. Expenditures for personal health care are far lower for persons under age 19 than for persons 65 or older or even for those in the intermediate age group.

The costs of directing such a program largely to children would be relatively low. Expenditures for personal health care are far lower for persons under age 19 than for persons 65 or older or even for those in the intermediate age group. In 1975 the average health care bill for the aged was $1,360; for those 19-64 years old, $472 and for the young, $212. Clearly children in general require the least costly care of the age cohorts. They are less likely than the aged to have chronic illnesses or require costly hospitalization or long-term care. The average amount spent for different types of health care varies widely with age. For example, in 1975 of the total health care dollar for children under 19, only 33.6 percent was expended for hospital care and 1.5 percent for nursing home care. In contrast, the 19-64 age group spent 48.7 percent for hospitalization and 2 percent of the average health care bill of $472 for nursing home care. For persons 65 years and over, 69.5 percent of their health care dollar was spent for hospitalization (44.3 percent) of nursing home care (25.2 percent).

We believe that this country has the necessary health resources. Given the less expensive health needs of children and youth, we can implement the first phase of a national health program with a relatively small investment and provide incentives to redistribute and better use existing resources.

Launching a program with this population focus will provide the opportunity to finance needed health care for children. Such an approach will also build a foundation and test a system which has potential for expanding to the whole population. The present health care delivery system is costly and unresponsive to the needs of many people. We have a maze of public and private financing mechanisms for meeting health costs, costs which have been continually escalating. A federally financed maternal and child health program can provide the financial leverage to create an administrative framework that might begin to control the unprecedented increase in the costs of health care. At the same time, this program could reshape the health care delivery system and gear it to prevention rather than treatment.

Finally, I welcome CHAP's intent to improve a program that has been frought with problems since its inception. However, instead of trying to correct EPSDT, an unsuccesssful program, I urge this subcommittee to consider developing a new far-reaching maternal and child health program, embodying the essential principles that are truly needed if we are to address the structural defects in our health care system. These principles are: service benefits without cost sharing; universal entitlement for covered population; comprehensive and continuous care; emphasis on delivery of care through groups of providers with capacity to directly or indirectly—through

referral—provide full range of services; strong incentives for capitation arrangements with the Government; strict public accountability—fiscal and performance—through Government administration; funding for development of new resources, and redistribution of existing resources should be determined in conjunction with State and local health planning bodies.

In the months ahead our Committee on Health will be developing a detailed proposal for a maternal and child health program. We look forward to working with members of this subcommittee and staff.

Mr. MAGUIRE. Thank you very much.

The bill to which you referred is a bill which I co-sponsored. I very much endorse the overall approach that you have outlined as an ideal way that we ought to be proceeding. Unfortunately, we sometimes have to do something less than that in order to actually move a piece of legislation that involves obviously a need for support both at the executive offices and here in the Congress. Therefore, while I agree with many of the points that you have made so forcefully in your statement, I think we ought to recognize that we now have this proposal which I hope we can make a good proposal. We are not, unfortunately, likely to get that objective of yours and mine met as quickly, so perhaps we can take a step forward here. Nevertheless I appreciate very much your comments.

Mrs. MCMURRAY. On the community services side we certainly recognize the political realities. We thought there should be a statement before the Congress of our concern there is a need to look toward this as far as our children are concerned.

Mr. MAGUIRE. I agree with that. We are very grateful to you for asserting that very worthy objective.

Dr. Miller, I was not here when you read your statement but I have since read it and I want to compliment you on what I think is a most humane and learned contribution to the discussion, particularly the comparative data with respect to what has been and what has not been accomplished in other countries and what the particular need of our own country ought to be. It is a very helpful addition to the record. We will rely on it very heavily. Your reputation, of course, precedes you, so it was no surprise to members of the subcommittee that we had such testimony.

You indicated that health departments are one useful way to serve the children we are trying to reach. There are other people who have expressed the view that local health departments have not done such a terrific job by and large. I wonder if you could tell us of any particularly successful programs that you may know of that have been implemented by local health departments and what would be the basis for your hope that the general record might be transformed.

Dr. MILLER. I think that is a fair question and fair observation. Everybody knows dismally inadequate local health departments. It may seem it requires an act of faith to program that local health departments can serve as the guarantor of services on behalf of everyone. But I think the truth is there is pathetically little information available about local health departments.

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I might point out, to my knowledge the government does not even maintain a central depository of information concerning local health departments, has no registry of them, no knowledge of where they are. There was such a registry until 1971 when in an economy measure in HEW the registry was discontinued.

I think there are some local health departments. Congressman Preyer comes from a district where there is one of the best. It is an area in which the local director of health asserted against much opposition there were 18,000 children in that community receiving no care whatsoever, and a project was started to provide care and it has been done superbly.

I think some studies are beginning to emerge from the State and Territorial Health Officers and from research groups, including our own, that will soon publish information about local health departments. I think there is much in those studies that can be found to be reassuring. Under congressional mandate a group is at work now attempting to establish minimal performance standards for all local health departments, which I think is actually essential. Hopefully within a year those can be made available or can be made operative.

I just reiterate that, as poor as they are in many areas, I think in many others they are excellent. They represent the only device I know by which it is possible for government to guarantee that certain services will be delivered. I think there are not the regulatory models that exist that you can redistribute private and volunteer services in such a way to guarantee entitlements.

Mr. MAGUIRE. Thank you.

I notice our chairman is here.

Mr. ROGERS. I agree this has been a very helpful panel to the committee.

Dr. Seligman, you suggested, I think, funding go directly to the department of health of the State?

Dr. SELIGMAN. Let me clarify that. Yes, the State health department should have administrative authority over these programs. Now, I also did make a point regarding health departments and I want to clarify it. In regard to health departments being service providers, I was saying public health departments should not expand as primary providers of care. This is a touchy issue. In the children and youth projects one third of the programs have been operated by medical schools, one-third by hospitals and one-third by health departments. There has been extensive data done on this to see the performance standards among the three groups. Although there have been some different characteristics among the three, basically they have all been pretty equal in performance, which does suggest if health departments operate programs that have adequate funding they can do as good a job as voluntary hospitals and medical schools. I think sometimes all too often health departments are not supported adequately with funds and they have to try to operate service programs with reduced funding, and I think that this ultimately gets some health departments a poor service reputation and also compromises their ability to enforce service standards when they themselves are functioning at reduced capacity.

Mr. MAGUIRE. [presiding]. Dr. Carter.

Dr. CARTER. Thank you, Mr. Chairman.

I am particularly glad to see this panel and Dr. Miller who took care of me in a debate in Miami sometime ago. I am very thankful to see him here.

I am sympathetic to greater funding of our Public Health Service. Actually, I believe that the major portion of this program should be carried out so far as the screening is concerned, by the different health departments and their assistants, nurse practitioners, dental hygienists, and so on. It is so necessary that we find and treat the difficult incipient diseases that many of our youngsters have. Of course, one of the problem areas which we should focus on is dental caries. Mental illness is another. When we see it in youngsters it is usually rather intractible in many cases. I hope that we do not find too much of that. It would be particularly helpful to spot and treat these problems early, especially for children who have dyslexia.

Do you agree, Dr. Miller?

Dr. MILLER. Yes. I think there is every reason to be optimistic that early care will be helpful.

Mr. CARTER. Do you know what part of our prison population now is composed of dyslectics?

Dr. MILLER. No, I do not know that.

Mr. CARTER. No less than 10 percent. If we could find these youngsters who go to school and cannot read or learn and then become "turned off" and drop out and become criminals, perhaps we could help them. If we diagnose this condition in the early stage, and then could teach these youngsters slowly and patiently, we would not only produce better citizens but also lessen the population within our criminal institutions.

Do you agree that the health departments throughout our country should be the core of this program?

Dr. MILLER. I am sympathetic to that view. The expression I use, they need be the guarantor for the program. I think it is appropriate that all kinds of qualified and willing providers be utilized if they are available and if they are willing, but if not, there is a substantial core of children that I think are served in no other way than health departments.

Mr. CARTER. You do have an organization that has been weakened over the years from lack of funds. I have seen the number of health officers drop in my State from 120 to perhaps 20 or 30. We have nurse practitioners who are very helpful, but we do not have enough of them. Do you think you should do most of the screening? Perhaps it should start with prenatal care. Head start could also assist in screening any child, whether he is poor or not, and in giving immunizations as early as possible.

Dr. MILLER. Yes. I subscribe to your views in this matter and, further, would suggest that obligations continue during the school years. I think any child who experiences school problems, a failure, truancy, whatever they may be, deserves a very careful and thorough health evaluation.

Mr. CARTER. When you evaluate them, then you might want to refer them to other health professionals if you thought it necessary; is that correct?

Dr. MILLER. Yes, indeed.

Mr. CARTER. As a health official, does your program have venereal disease clinics?

Dr. MILLER. Indeed.

Mr. CARTER. You do give treatments in many cases for venereal diseases; is that correct?

Dr. MILLER. That is true.

Mr. CARTER. It is extremely helpful that you do that. You have this capability. In other areas they may not have the capacity, but at least you can detect the disease and refer the patient to other people for treatment.

Dr. MILLER. That is true.

Mr. CARTER. If we depend only upon practitioners throughout our country—and of course I have been one of them—it would be very difficult to cover all of the youngsters in our country, even those in the poverty group; is that not true?

Dr. MILLER. I think that is true. I think it is going to take many, many different systems of service to make sure we reach all children.

Mr. CARTER. Yes, sir. I feel that you are the "finders" and "preventers." You should give the immunizations, and so on, and then perhaps the system which has been mentioned by Mr. Maguire and also by the gentleman from California, probably should be considered. Certainly as I see it, I believe that our Public Health Service must be rebuilt. We have let it go down too long over a long period of time.

Thank you, Mr. Chairman.

Mr. MAGUIRE. Thank you, Dr. Carter.

Ms. Andrade, I wonder if you can explain a little more for us how your outreach program actually operates and what percentage of children you succeeded in reaching in the area that you addressed yourself to. Outreach again and again in this testimony comes up as the absolutely necessary but illusive goal, and I wondered if you could elaborate on that having worked effectively in your area in that.

Ms. ANDRADE. Yes. In our particular program we have a 12-square-block target area on which we work, which covers about 3,000 families. Through private foundation monies we were able to hire six part-time community people whom we call health block workers, who do door-to-door visitation, talk with parents about whether or not the children have immunizations, whether they have had an annual checkup, if the chldren have any other kinds of health problems.

We feel this door-to-door contact or person-to-person contact is very much needed because the majority of preschool-age children in particular are not enrolled in any organized program. There is head start, there is child care, but in the city of Newark, for example, less than 10 percent of the children under the age of 6 are enrolled in any kind of organized program, so that most of the preschool-age children—this is the age group when we talk about prevention is most crucial—are at home with their parents or someone else. So you really need a system that will reach the parent or care giver at home.

Mr. MAGUIRE. Were the health community workers, persons who came themselves from the community?

Ms. ANDRADE. Yes, these are persons who live in that particular neighborhood. In our proposal to the Medicaid office we proposed that particular functions be reimbursed under EPSDT, but that was denied. We have been able to finance that through a private foundation for 3 years.

Mr. MAGUIRE. Do you have any statistical measures of effectiveness?

Ms. ANDRADE. We have to measure effectiveness in several ways in outreach because outreach is more than just contact. Outreach is also a determination as to whether that person that you talked to at the door actually came to our clinic or some other clinic and actually got the health checkup including immunization done.

Also in child health to get a complete checkup for a child requires more than one visit to a health station or to an office, so that outreach also has to be willing to do followup to make sure that parents bring the children back for two or three or five or six visits, especially if the children are in the process of being immunized, so that we have found, for example, that at the present time our effectiveness in terms of the numbers of people who are contacted, who make appointments and actually show up on the first visit are about 70 percent.

We do not consider that to be effective. It is only 70 percent effective. That means 30 percent of the people in that neighborhood have not shown, and that requires second visits, sometimes as many as four and five visits because we are talking about prevention primarily under EPSDT.

Mr. MAGUIRE. It is only about five more times effective than the program nationally, so by some relative criterion it ought to be deemed effective.

Do you use the health community workers also for the followup?

Ms. ANDRADE. Yes, they do followup. People who miss appointments are revisited. We have an ideal situation because these are people who live in the neighborhood, so they even catch people on the street or supermarket. It is very hard to escape them.

Mr. MAGUIRE. Do they feel their civil rights are being violated as a result of this close observation?

Ms. ANDRADE. No. I think because we are not a welfare caseworker or someone tied to their chance of getting a check. We find that the response is getting better, that this year we had more parents come in for the annual checkup on their own than we did last year. We have not been able yet to really collate the exact statistics on it.

The other indices we use are whether or not people will respond to the reminder postcard that we send that it is time for the annual checkup and whether they come in on their own in response to that card or whether it does require a personal contact, a phone call or visit.

We think outreach is also public education, that because we are talking about children who are probably well and most of us are crisis oriented, we do not see a doctor until there is an ache or pain, that it is very difficult to convince people it is important to get an

annual checkup. Unfortunately, most parents wait until it is time for children to go to public school and immunizations are required before they will actually bring the child to a physician or a clinic for any kind of checkup.

Mr. MAGUIRE. I have a number of questions I want to try to deal with very quickly since we have other panels waiting.

Do you use pediatric nurse practitioners in your clinic?

Ms. ANDRADE. Yes.

Mr. MAGUIRE. Will you tell us quickly how that works.

Ms. ANDRADE. Yes. Unfortunately, New Jesey does not reimburse them. We also have a consulting physician, M.D. The pediatric nurse practitioner does the complete physical checkup, is certified to do immunizations, also does the counseling of parents on any particular matters that come up, they are bilingual, they explain to parents what kinds of tests and examinations they are giving the children.

If the problem is detected in any of the examinations we do, that child is referred to a physician for diagnosis and treatment. The practitioner is a person that we feel is a legitimate part of the preventive health care system because they are RN's, in our case, who receive specialized training in pediatric health care. Their whole orientation is towards counseling and compliance on the part of parents, so that we think under CHAP and EPSDT pediatric nurse practitioners are key persons on the health care team.

I might also add that we feel a nutritionist is a very key person on a health care team, especially in our community in Newark, where iron deficiency is very high, high blood pressure is very high, and other nutrition-related problems are very high in an urban community. We think extra counseling and assistance is needed for families in terms of their particular health problems.

Mr. MAGUIRE. Thank you.

Mrs. Foltz, what will happen to medically needy individuals under the proposed legislation? Do you read the legislation as including them or not?

Mrs. FOLTZ. The legislation proposed both the administration bill and your bill, does not make any mention of medically needy. Therefore, it would be the same as in the present medication legislation, that is it is optional with the States as to whether medically needy persons are included. At present medically needy are included in the State plans in 32 jurisdictions and they would continue to be covered. In the other 18, medically needy children would not be covered.

Mr. MAGUIRE. You mean we should cover them?

Mrs. FOLTZ. Yes. The implication is that families with a sudden high medical expense or continuing high medical expenses, but are not eligible for Medicaid even though they may spend down to the level of eligibility. Therefore, children in those families would not be eligible for preventive care or treatment.

Mr. MAGUIRE. Dr. Seligman, I am wondering how you think the provisions will respond to a standard-setting exercise by the Government which you indicated was extremely important. How are we going to get enthusiastic cooperation from professionals?

Dr. SELIGMAN. I think okay. I referred to the standards of the American Academy of Pediatrics, and cetainly in the professional

fields for children this is very widely accepted as an acceptable standard not only among pediatricians but nurses and all other people who serve children.

Mr. MAGUIRE. Mrs. Foltz, how would yo suggest providers insure follow-up care when they themselves cannot do it or cannot assure the followup?

Mrs. FOLTZ. If the providers cannot assure followup care, then it will have to be undertaken by another organization; for example, the State would have to be responsible for providing the followup care. Providers would refer, but if providers cannot assure the followup has taken place, then another administrative organization should assure there has been followup.

Mr. MAGUIRE. Thank you all very much for very helpful testimony.

The next panel is composed of Dr. Morris Dixon and Ms. Donna Nativio and L. Jerome Ashford.

Let me again remind the panelists we have a time problem and to the extent you can summarize your testimony it will be helpful. We will include, of course, the entire written text in the record, but we will try to limit everybody to 5 minutes.

STATEMENTS OF MORRIS S. DIXON, JR., M.D., ON BEHALF OF THE AMERICAN ACADEMY OF PEDIATRICS; DONNA NATIVIO, R.N., MEMBER OF EXECUTIVE COMMITTEE, MATERNAL CHILD HEALTH DIVISION OF PRACTICE, AMERICAN NURSES' ASSOCIATION; AND L. JEROME ASHFORD, EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Dr. DIXON. Mr. Chairman, I am Morris Dixon, Jr., Assistant Professor of Pediatrics at Case Western Reserve University School of Medicine in Cleveland, Ohio, today I am representing the American Academy of Pediatrics.

The Academy has long recognized the importance of EPSDT as the largest program for preventive child care in the country, and in fact formed a committee in 1972 addressed specifically to the EPSDT program. I was chairman of that committee for 3 years. The Academy's State chapters have also had EPSDT committees which have met with a mixture of success and failure in working with the EPSDT programs.

Through that mechanism I have also been a consultant to the Ohio EPSDT program since 1972.

Congress should be commended for its farsightedness in passing the legislation making EPSDT possible. That was EPSDT's finest hour. The implementation of EPSDT at the Federal level and in most States, however, has been a disaster. The Secretary this morning reaffirmed this judgment.

One of the chief reasons for its downfall is that a clear direction was not given that the purpose of EPSDT should be to develop a source of comprehensive and continuing preventive and primary health care for all eligible children.

The absence of a clear purpose has led to much confusion and has led commonly to an overwhelming amount of attention to screening and increased fragmentation of care. This mistake must not be

repeated if CHAP is enacted. The purpose must be clearly spelled out by Congress so that Federal and State administrators understand the intent of the law.

The proposed CHAP program is a health care program for children and requires medical leadership. Again we need to learn from the experience of EPSDT and make sure that there is health direction in its administration.

We recommend that a medical director be appointed who understands the delivery of health care and who can orchestrate outreach health care and outcome measures to make CHAP a successful program for the health care of eligible children. In the entire Medicaid program, not just EPSDT at the Federal level, there has been only one physician, and that physician has been on loan as a consultant. Consequently MSA has been unable to give technical assistance to the States, and its major effort in recent years has been to write penalty regulations and check for fraud.

CHAP is a huge health care program and requires the combined efforts of all possible providers, both public and private. The CHAP proposal addresses this by stating that the State will encourage participation by physicians and health care providers.

The Academy urges Congress to give stronger direction to the Secretary of HEW, and through him to the States, to make sure this is required in each State plan. The administrators of CHAP must not only encourage the participation of private physicians, but investigate why they may not be participating, if that is the case.

The Academy conducted a survey for MSA in 1976 which demonstrated that private pediatricians did not participate in EPSDT screening in many States because of the degree and quality of communication between them and the responsible administration as well as problems with forms and fees. It is disappointing to note that there has not been one move of corrective action by the Department as a result of this report.

In this report, the Academy identified 22 States which do not provide for the utilization of private providers for screening exams. In order that eligible children under this program receive appropriate care, the Academy recommends that the Secretary of HEW establish a broad-based national child health advisory board, with representatives of major health provider groups as well as government bodies to oversee and insure a coordinated approach to CHAP.

We further recommend that each State be required to have a child health board to advise them on the administration and implementation of this program. Such a board could address the more controversial issues which are best handled at the local level. Such issues might include alternative care planning for children with mental illness or developmental disabilities not covered under a CHAP program, assurances that children are not intentionally receiving fragmented care, and maximizing the use of existing local health care resources.

There is an absolutely indefensible situation at present. Programs having existed at this level of expenditure throughout the Nation are literally devoid of data with which to prepare plans for this new legislation, or to engage in an appropriate discussion with facts. Thus more deliberate attention must be given to data collection, and an informatin system on an ongoing basis.

Funds should be earmarked in this program for a formal evaluation of the program, and less attention, less emphasis being given to fraud control as the only apparent orientation that is now receiving preeminence.

Congress may wish to formulate or direct the Secretary to formulate desired outcome measures for CHAP, both quantitative and qualitative, upon which the Secretary should respond annually. Such measures should include the number of children actively enrolled in CHAP-sponsored primary care, the health outcome as a result of that care, and the number of children unserved and the reasons why they are unserved, as all such measures are essential to its evaluation and cost effectiveness.

In conclusion, the American Academy of Pediatrics, in pursuit of its objective that all children receive comprehensive health care of high quality, recommends that any revision of the EPSDT program receive careful scrutiny by this committee and the Congress. The issues I have raised today are essential ingredients of a health care program for children.

If it is in fact the intention of the Congress to provide for such a program, the Academy pledges its continued cooperation in its efforts to improve the quality of programs for children.

Mr. Chairman, I have deliberately made this testimony brief. Many important issues of outreach eligibility and program content are in my written report, and I shall be glad to discuss them with you.

[Testimony resumes on p. 460.]

[Dr. Dixon's prepared statement follows:]

Testimony of the

American Academy of Pediatrics

Before the
Subcommittee on Health and the Environment

of the
Committee on Interstate and Foreign Commerce

September 9, 1977

Presented by Morris S. Dixon, Jr., M.D.

Mr. Chairman, I am Dr. Morris S. Dixon, Jr. here today representing the American Academy of Pediatrics, in response to H.R. 6706, the "Child Health Assessment Act." You and members of your Committee are to be commended for your efforts toward revising EPSDT from its current emphasis on screening to a more extensive comprehensive health care program for children and the Academy is pleased to have this opportunity to offer comments and suggestions on the various aspects of this bill.

Historical Backdrop to the EPSDT Program

EPSDT had its origin in the 1967 Amendment to Title XIX of the Social Security Act, and required that each state ensure minimum, basic health care to all children eligible to receive assistance under the federal Medicaid program. Its intent was to stress the importance of preventive health services, along with early detection and treatment of disease in Medicaid-eligible children from birth to age twenty-one. The program's services were mandated to consist of "no less than early and periodic screening" for potential and existent health problems, appropriate diagnostic and follow-up treatment services for all eligible children on a voluntary basis.

At the time the EPSDT legislation was passed, the following observations characterized the relationship between the health status of poor children and the existing nature of the Medicaid program:

- The Medicaid program was largely reaching only those who were already ill. With the exception of children covered under Medicaid by virtue of recieving Aid to Families with Dependent Children or as members of families covered under other categorical assistance programs, the eligibility guidelines for Medicaid required that one prove "medical neediness" in order to be eligible for the program. Thus, non-categorical eligibility rested upon both financial and medical need.

- Medicaid, as a health care financing program based on the presumption of illness, did little to encourage the seeking of preventive health care for children.

- There existed unevenness in both the quantity and quality of health care received by children in low-income families throughout the country.

- It could be assumed, based on these factors, that potentially handicapping conditions among low income children were undoubtedly going unnoticed and untreated.

As a response to such weaknesses in the Medicaid program's response to the health needs of children, EPSDT could be viewed as a first major comprehensive federal health policy for children in need. By design, its intent has been both fiscal coverage and the provision of minimal standards of preventive health care for children.

Current Assessment of EPSDT

To date, the EPSDT program has not adequately fulfilled its objective of introducing children into the medical care system existing in their communities to provide for their immediate and future health needs. It is difficult to determine the adequacy of health care provision to eligible children within the states, as the data derived from EPSDT frequently provides counts by numbers of screenings performed and conditions referred or reaching treatment, rather than numbers of children screened and receiving treatment for referred problems; the two types of data do not tell us the same thing. Estimates suggest that the numbers of children screened under the existing program varies enormously by state, hence pointing to the inequities between states in outreach and follow-up efforts and provision of services. National estimates, taking into consideration the periodicity schedule for screening children according to age, suggest that 30% of eligible children have been screened at one time or another. The program, however, has failed to establish goals to increase its effectiveness each year, either in regard to increasing practitioner participation or increasing the proportion of eligible children actually receiving services.

The Academy has endeavored for many years to cooperate with and assist those responsible for the EPSDT Program and the history of our efforts will document our good faith. However, at this point in time we only sumarize the program successes as being philosophic achievements: the basic recognition of the value of preventive health care for the future of children; verbal homage to the notion of continuity of care which, if practiced, would immeasurably improve the health status of children; recognition of the necessity of outreach activities to inform and assure access to care to a population unaccustomed to making use of preventive health resources.

From the Medicaid program which did not address children's needs, to the EPSDT Program which has not fulfilled its objective, we now turn to CHAP, a program designed to modify and improve the EPSDT Program. If CHAP is to make a significant improvement in EPSDT, then the goal and purpose of CHAP must more clearly state the program's intent to introduce this nation's poor children into a health care system within their communities that will provide that each child with comprehensive, continuing preventive and primary health care.

In addition, the following concerns and recommendations reflect issues perceived by the American Academy of Pediatrics as requiring further interpretation, clarification or revision in the legislation.

I. Issues of Eligibility

It is recommended that the following groups receive purposeful attention in the CHAP program:

A. Attention should be focused on pregnant teenagers who become eligible for Medicaid and the CHAP Program only at the birth of their children. Exclusion of the "pre-eligible" pregnant teenager may be a cost-containment measure, but is intenable in light of the increased risks to the young mother and the fetus-newborn. The infant's need for health care begins before birth; preventive care cannot begin with extra-uterine life.

Young teenagers experience higher rates of obstetric complications during pregnancy and delivery, higher rates of premature delivery and are at greater risk of giving birth to low birth-weight infants than are women in any other age group. They require closer medical attention, yet 70% of girls under 15 get no prenatal care at all or delay care until the end of pregnancy. Low birth-weight infants are at high risk of sensory, neurological, developmental and physical disorders and the association between receipt of prenatal care and positive health outcomes for both mother and infant have been well documented.

Currently, twenty-two states do not consider low income women eligible for public assistance until after the birth of the child. This has acted as a deterrent to the receipt of adequate prenatal care and cash benefits necessary to obtain nutritional supplementation for many poor adolescents not living in AFDC households. Approximately 250,000 girls seventeen and under, 13,000 of whom are less than fifteen, give birth each year. Presumably a small, but unknown, proportion of these are not already eligible for care under Medicaid.

If the fact of pregnancy would entitle a poor adolescent to care under the CHAP program, she would be more likely to come into early contact with the health care system capable of providingher and her infant the needed care from early stages of pregnancy; this inclusion would apply the resources of the CHAP program in a truly preventive fashion.

B. As proposed children ages 7 to 21 years who are living in families financially eligible but excluded from Medicaid by reason of not meeting other welfare program criteria are to be included in CHAP at the option of individual states. Their exclusion from mandated services appears to be based on economic reasons, and cannot be defended on either a biological or social basis. The fact that the recommended periodicity of examinations may be less frequent for children ages 7 to 21 by no means lessens the likelihood of their need for health care or their essential need for continuity of care.

The program's proposed exclusive focus on children six years and younger may in fact serve to fragment the provision of

health care to young families. Inclusion of 7 to 21 year olds would increase the ease of program implementation, as record-keeping and tracking are frequently done on a family basis, including all children in a family, rather than attempting to reach individual children, and impose upon families the difficult task of maneuvering multiple separate health systems for their children, dependent upon age, other health services for which this age group may be eligible, such as school health services, are not intended to be health care programs, and thus will not provide care for children when ill.

C. Children with a diagnosis of mental illness, mental retardation or developmental disabilities which are frequently poorly defined, appear to be excluded from services beyond the initial assessment. The apparent concern has been that CHAP not become responsible for the expensive and often life-long financing of the total care for such children. States must be obligated, nontheless, to assure that arrangements for all care these children need following assessment be met, rather than simply doing nothing, as the current language seems to allow. By labeling children with such ill-defined diagnoses, states may conceivably exclude them from the care program. The states must be required to refer these children to the appropriate programs designed to meet their particular needs. Medical advisory bodies should oversee the coordination of all available health resources to assure comprehensive care for these diagnosed children. As writen, H.R. 6706 fails to address alternative care planning or the assurance of adequate program funding to guarantee care. It must be clarified whether Medicaid is to be the first dollar spent to provide care to these children.

II. Issues of Program Content and Coverage

There is a need to spell out in the program's regulations the minimum range of diagnostic and treatment services that will be required to be available in all states.

A. Periodicity and Content of Examinations

Each child eligible for the CAHP program must receive an initial comprehensive examination as spelled out in the 1972 guidelines. One of the major commendations of the Academy is that the initial assessment be conducted at the time of the newborn examination for children entering the program from birth. The periodicity schedule and procedures for continued preventive health care are stated to meet the Academy's "Recommendations for Preventive Health Care of Children and Youth." This represents the best opinions and information available in this country at this time as to minimal care needs. The ages suggested for visits are based on characteristics that make health care at these specific times more important. It should be emphasized that this minimal scheduling and content of care guidline may require that services needed by a given child be given with greater frequency or intesity, as determined by his/her health care provider's assessment of the child's individual needs.

B. Dental Care

The requirement that children be screened for dental care is inappropriate, as the need for dental care among the CHAP-eligible population can be anticipated to be practically universal. The reality is that children in the age group being served accrue dental needs that require attention in the interim between assessments, which may be spaced as far apart as every three years. Routine dental care should be viewed as part of any comprehensive health package for children.

C. Duration of Eligibility for Care

It is recommended that the provision in the legislation to provide a six month period in which assessed children who become financially ineligible for CHAP continue to receive needed services be extended to one year. It is further recommended that the state plan require an administrative arrangement between Title XIX and Title V agencies to assure the continuance of care for children delcared financially ineligible for CHAP. It is necessary that a federal reporting mechanism be created to delineate those children going off CHAP and document plans for their ongoing care.

III. Provider Issues

This program is too large to overlook any source of health care, either public or private. Attaining the program's goals necessitates the more active participation of all health resources, both at the level of administrative involvement and in the provision of health care at the community level. There are some 20,000 pediatricians caring for children in this country; and they, along with general practitioners and family practice physicians who care for children, must be viewed as potential partners in the active processes of providing the care mandated by the program and in planning, administering and evaluating the program's efforts.

B. Provider Participation

It is felt that the relatively poor participation by private practitioners in the current EPSDT Program should provoke must stronger language and incentives than are found in the current bill. There are currently 22 states in which private practitioners do not play a role in the screening aspect of EPSDT. In fact, states are conscientiously excluding practitioners in private practice from participating in the screening of children. States should be required to show cause for not having private provider participation. The absence of one provider sector runs the grave risk of labeling this health care system as one for poor children, thus perpetuating a seperatist system.

The less than adequate attempt to include the private providers appears to be rationalized on the basis of a perceived need to develop additional provider settings across the country.

States are developing comprehensive clinic arrangements, often without regard to whether their need is addressed to populations where providers do not exist or may exist but have failed to participate in the program. Nothing in the bill appears to address the reasons that private providers do not currently participate in the program. The bill's lack of attention to these issues leaves us concerned that the program has an inplicit purpose of institutionalizing publicly sponsored and operated clinics for poor children. The Academy is most interested in seeing that private providers participate in CHAP.

A nationwide survey of pediatricians by the Academy has revealed that major deterrents to effective provider participation in the current EPSDT program are the degree and quality of communication between private physician providers and the responsible state agencies, and the issues surrounding forms and fees. With regard to communication, all provider input to the program should be viewed as essential and originating with the planning of policy, procedures and development of regulations, with continuing involvement imperative if increased provider participation and expansion of provider resources to the program are desired.

At present, forms vary in content and complexity from state to state. This lack of equivalence between states with regard to records and paperwork impedes continuity of care. Attention must be directed to the development of guidelines for medical records and reimbursement-reporting forms. The Academy is on record with the Department regarding our availability to assist in the development of forms and record guidelines.

B. Provider Agreements with States

All providers, whether individuals or institutions, will be required to enter into agreements with the state agency responsible for the program's administration. The content of these anticipated agreements must be elaborated upon. The agreement obligates providers to responsibilities for patient advocacy, outreach, follow-up, as well as for direct care services. All of these are to be regarded as elements of quality health care and are vigorously endorsed by the Academy, but details of how resources will be made available to finance and support of such services are not addressed in the bill. To date the Administration has been unable to identify the nature and content of these agreements. Such requirements appear, again, to foster institutionalized arrangements for the provision of health care to poor children and may mediate against participation of all care providers. We must reiterate our concern that lack of private provider participation promotes the development of government run clinics as the sole mechanism to provide health care to the poor, and runs counter to the concept of a pluralistic system of health care involving multiplicity of provider resources and freedom of choice for the consumer as to his/her provider of care. The reality is that all providers are necessary to accomplish the task. We can assure the Subcommittee that there is no resistance on the part of the majority of members of the Academy to participate

with the government in the care of children through programs which focus on the health of children, adopt administratively sound procedures, and provide for reasonable and timely reimbursement for services.

C. Reporting Uncovered Services

It is recommended that Congress receive from the Secretary of DHEW an annual report of care and services needed by children under CHAP which are not covered financially under the program; e.g., prosthetic devices for amputees, medications. This is necessary information which would be essential in subsequently amending CHAP.

VI. Issues of Outreach, Tracking and Supporting Services

The lack of outreach services or the existence of ineffective means of outreach has been one of the greatest downfalls of the EPSDT program. Under the present proposal, the state is permitted but not sufficiently obligated to develop adequate services to complement those likely to be found at present in the private provider sector. There is clearly a need to define and develop an intensive system of outreach and tracking support services. Simple written notification as to the availability of services has repeatedly proven to be an ineffective means of reaching a population; outreach requires manpower. Tracking requires an organized data system. Aggressive outreach and support services are viewed as antithetical to welfare programs and without the mandatory inclusion and financial support for such services, there is no basis for expecting their achievement. The anticipated increase in matching funds should, in part, be directed toward adequate outreach and follow-up staffing to assure comprehensive follow-up.

V. Issues of Administrative Organization of CHAP

The proposed CHAP program is a Federal-State shared funding approach to health care of children with the Federal share being reasonably open-ended to accommodate the percentage of contribution of the various states. A single state agency is proposed to administer the program, but interagency agreements encourage that state health agencies administer the definitive services.

The Academy is concerned that CHAP, as a health care program, has not been assigned to the Health Administration portion of DHEW or under the Assistant Secretary for Health. Several arguments have been offered as rationale for not assigning CHAP to a Health Administration: There is a difference in funding arrangements between this health program and existing programs found within the PHS, which use a more traditional categorical approach to eligibility; secondly, the role of the Health Administration is perceived as being restricted to resource development, innovation in health delivery methods, standards development and research in health care.

The Academy is persuaded, however, that CHAP should be administered by a health-oriented agency for the following reasons:

a. It remains a health care program regardless of its method of funding.

b. A primary orientation in financing or welfare orientation does not reflect adequate familiarity with health care providers and accessibility to their services.

c. Cost containment methods run the risk of permitting health care practices under the present agency to be compromised; e.g., discontinuity of eligibility, elimination of critical components of health cares, such as prescription medications and prosthetic devices or physical therapy.

d. There appears to be preoccupation under the present agency with fraud and penalty arrangements, and lack of attention to efforts to evaluate the value of the program.

e. The record of poor participation by the private provider sector promotes the development of a series of government-run state and local clinics. This, in turn, risks the possibility that poor children will be deprived access to a more pluralistic system of care involving the range of provider groups.

f. Recruitment of health care professionals to administer the program is impeded under the current arrangement. At present, only one physician, at a consultant rather than a line function, exists in the Medicaid program.

g. A welfare-oriented agency has little experience with outreach, as this concept is antithetical to the welfare program. In contrast, outreach and follow-up are familiar and critical elements of a health care program, particularly if attempting to provide services to a population generally unfamiliar with the use of organized and preventive health care systems.

h. MSA has done little to address or correct these obstacles.

For the above reasons, it is our conviction that CHAP absolutely requires a health mentality in its execution. What we fail to see in the proposal is any delineation of the role of the Assistant Secretary for Health who is the person to whom health providers relate on the issue of health care programs.

VI. Issues of Health Input to CHAP and Technical Assistance

A. Adequacy of Health Expertise in the Program

A high level of technical talent is needed at the Federal an Regional levels to offer administrative expertise to the program and consultation to the states. The use of consultants on an ad hoc basis, lacking line authority, impedes formulation of program regulations that will be responsive to the needs of both health care consumers and providers. Obstacles must be eliminated which limit access to the necessary expert health talent, whether they be in those of authorization, budgetary allocation for positions or perceived availability of those

with appropriate skills. Traditionally, there has been minimal involvement of health experts in formulating and/or reviewing regulations before they are issued. Review in this sense, has usually been conducted with the help of staff or consultants inside DHEW, with less reliance on outside expertise.

B. Technical Assistance to the States

Attention and technical assistance to the staffs drawing up the plans are needed to determine areas that need specification or new legislative approaches. State plans remain very general in scope, paralleling what is contained in the EPSDT legislation and regulations. It has not been required that state plans address the issue of how to screen the never-screened eligible children into the program. There is clearly a need for more assurance than is apparent in the CHAP proposal that competent and adequate technical assistance to all states be made available through this program.

C. Medical Advisory Boards

Nationally, as well as the state levels, advisory boards are not required beyond the mandated advisory body required under the generic Title XIX legislation. The Academy proposes, however, that advisory bodies are necessary to ensure that state program content and implementation include appropriate translations of regulatory requirements and maximum use of existing local health care resources.

It should be within the purview of a state's advisory board to determine if a facility providing care is the best that can be attained in the state or locale at the time. The advisory board is seen as the mechanism with which to address the reasons for the existence of non-comprehensive care providers in an area or the lack of care resources.

A state's Child Health Advisory Board would be responsible for the review and approval of program regulations, assessment of long-range planning needs for the state, mediation of state-local jurisdiction disputes, and advisement of the governor as to the conduct of the program. The board is suggested to consist of approximately nine members providing expertise from various discipline; including local health officers, pediatricians, other physician practitioners, nurses, representatives of a child advocacy organizations and parents of CHAP-eligible children.

VII. Penalties

The emphasis on penalties in the program, particularly as would be passed upon those attempting to implement the program, can only be viewed as destructive. Other techniques that might be recommended to encourage adherence to guidelines and achievement of program goals are: 1) orders of the Secretary; 2) program audits (not neccessarily financial) or other means of conducting surveys of program activities.

VIII. Resource Development

Provisions of the bill addressing the resource development issue are painfully meager. Attention should be given to the fact that aggressive and comprehensive development of resources must be directed toward all potential sources of health care.

IX. Data Collection, Evaluation and Research Issues

A striking paucity of data characterizes the present EPSDT program situation, making it difficult to develop plans for this new legislation. Appropriate data is urgently needed to evaluate the current program in on-going fashion and prepare for the future legislative changes.

Ongoing evaluation of the effectiveness of CHAP in attaining its goal of providing a "medical home" for this nation's population of poor children requires not only that the plan for evaluation be developed prior to the program's implementation, but more importantly, that the orientation and approach to evaluation encompass sound scientific conceptualization and methodologies which can be clearly set forth in formal field research proposals. Evaluation must be viewed as an ongoing process, requiring methods for periodic assessment of health impact once the program is in progress.

Assessment of the program's impact should provide for carrying out baseline studies, including baseline health assessments on representative samples of children, current medical use patterns among assessed children, current costs and factors influencing current use patterns. These baseline studies would provide a basis of comparison with ongoing assessments, once CHAP is implemented, to permit determination of the health and economic impact of the program. It is essential that efforts to distinguish the merit and benefits of the program be clearly separated from monitoring and surveillance activities whose purposes are to assure conformity to regulations and detect fradulent or abusive practices.

Annual Medicaid expenditures for children total approximately $3 billion, with the estimated combined federal and state cost for EPSDT being about $250 Million. We need to identify Medicaid monies going to support women for care during pregnancy; and Medicaid expenditures for children need to be broken down into specifics of care and providers. At present, it is not always possible to distinguish numbers of children from numbers of screenings in the data, nor to identify program efforts for children by age and conditions.

A. We strongly urge the allocation of some percentage of funds for a formal and ongoing evaluation of the EPSDT Program, with less emphasis being given to fraud control as the orientation being given attention in attempts to assess the program.

B. Data gathering, system development and analysis must be federally funded activities.

C. States should be required to set outcome standards and goals in their state plans, and should further be required to report their progress in relation to their goals to the Congress. What we seek from the state in such a requirements is a data base, providing not only gross numbers of children assessed and treated, but an accounting of what happened to those numbers in the program system. This then becomes a means of state accountability.

D. We further urge a provision in the law requiring the Secretary to report to Congress on the progress of the program, annually. Such a report should contain data of a nature entailing cost-effectiveness, analyses of program components, assessment of program goal-attainment, and clarification of problems inherent in the program. This requirement would allow revisions and changes to improve the program, eliminate problems and pave the way for future child health legislation.

E. We are told that computer monitored tracking systems to assure follow-up diagnosis and treatment after screening. are to be installed in every state. While the data base to be forthcoming from this system has not been specified, information as to utilization patterns and costs that can be derived from this system are required for the development of any future financing plans.

X. Financial Incentives

The Academy supports the financial incentive as proposed by H.R. 6706 but must express doubts as to whether it is sufficient to expect a meaningful increase in state participation in the program. Other fiscal problems faced by a state may remain as constant, underlying determinants of participation. The legislation must clarify further whether the higher match was intended for care relevant to conditions detected at the screening examination, or whether it is to be provided for all ambulatory services to an assessed child.

Mr. ROGERS. Thank you, Doctor.
Ms. Nativio.

STATEMENT OF DONNA NATIVIO, R.N.

Ms. NATIVIO. Thank you.

I am Donna Nativio, a pediatric nurse practitioner working at the University Health Center in Pittsburgh, Pa., and I am here today representing the Executive Committee of the Maternal Child Health Division of Practice of the American Nurses' Association.

Our national association represents nearly 200,000 professional nurses.

Thank you for the opportunity to present the views of the American Nurses' Association on H.R. 6706.

In the interests of preserving your time, I will submit a detailed written statement for the record and just present the highlights at this point.

We support your efforts, as evidenced in this legislation, to continue and to expand programs of health care for children.

We have a number of comments and suggestions which we believe would help to assure access to the primary care services included in

this proposal. I will comment specifically on several aspects of the bill.

The first of those is eligibility. As proposed, H.R. 6706 covers 700,000 children whose families meet State financial income requirements for welfare but not other welfare requirements. Children in these families from 7 to 21 years of age are not included. Therefore for these children there is the abrupt interruption of health care services after age 7 years. This not only means discrimination in care among children of different ages in the same family, but it tends to nullify the effectiveness of care received in the early years.

We believe these health services should be available through age 21. The proposal would allow a 6-month extension of Medicaid services beyond cessation of eligibility. We believe a more realistic time frame would be at least 1 year.

Section 3(G) states that services may not necessarily include those individuals under age 21 with mental illness, mental retardation and developmental disabilities from treatment. An estimated 30 percent of children entering first grade have identified behavioral and emotional problems. We strongly urge that provision of mental health services be mandatory.

H.R. 6706 should provide for regular health assessments at times or intervals defined by the regulations.

Twenty-five percent of the children screened in the EPSDT program had severe dental problems. H.R. 6706 only covers dental treatment for conditions diagnosed during an assessment. Instead of improving and expanding, it would cut back on dental benefits. Prophylactic dental care as well as emergency dental care should continue to be covered.

The American Nurses' Association shares the concern expressed in this bill to increase immunization levels of children. We believe there should be a national program of childhood immunization. A copy of ANA's position statement on this issue is attached.

Under "outreach," financial incentives should be provided to encourage States to provide personalized outreach. Records show that with personal contacts, only 1 percent refused EPSDT services. Without outreach workers to explain the value of the program, service refusals jumped to 15 percent.

An evaluation of the EPSDT program conducted by the Office of the Regional Director-HEW, Region 5, recognizes that "personal outreach and case management improve implementation levels." In other words, when procedures such as notification, screening arrangements, referral appointments and treatment follow-ups are performed personally by agency staff, screening percentages are substantially higher. We strongly believe outreach incentives are an essential part of this program.

Item 4 under "Providers," the proposal requires States to encourage participation by physicians and health care centers. Providers of child health care assessments and primary health care systems should include nurses at all levels of their expertise. In most cases today it is the public health nurses practicing in clinics, schools and in the field who obtain the complete health history, perform the visual, hearing and anemia tests, measure height and weight, do

physical evaluations and assessments of oral health. Community-based nurses are the ideal professionals to do case finding and follow-up care. School nurses and school nurse practitioners are in a strategic place to deliver the care called for in H.R. 6706.

These nurses frequently are the child's first contact with the health care system. The school nurse or school nurse practitioner has daily access to the children who will be recipients of health services under this bill. Health education, counseling, and guidance are aspects of the comprehensive continuous care for children called for. The delivery of this care can best be facilitated by utilizing an existing structure—the school system.

The nurse practitioner can be utilized in her area of expertise. The nurse practitioner, as defined by the American Nurses Council of Family Nurse Practitioners and Clinicians, is a primary care provider prepared to give continuous, personalized care to the patient-client at the point of entry into the health care system, and to continue as the individual's care provider.

Nurse practitioners are prepared to provide prenatal, postnatal, and well-child care; guidance regarding nutrition and immunization; assistance in coping with illness and crises throughout the developmental cycle; supervision of treatment; and physical and psychological comfort.

Mr. ROGERS. May I interrupt, and I hate to do this, but there are people who do have planes tonight and I am going to try to hear them all. So if you could help us by maybe summarizing the additional points on page 6.

Ms. NATIVIO. I have perhaps 2 minutes left.

The EPSDT legislation held the potential for becoming one of the most comprehensive and ambitious health care programs the government has ever undertaken but it was severely hampered by delay in implementation.

We urge inclusion in the proposal of a realistic date for ths program to be implemented by the States.

Federal standards should require the States to include a quality assurance program. The program should set it to assure quality of care by qualified providers whose services are reimbursable by the States.

We had several recommendations for changes in terminology which are in the complete report.

Finally we would like to take a moment to acknowledge Congressman Maguire's proposed amendments to the Child Health Assessment Act. These would address many of the concerns that we have presented today.

Thank you.

[Testimony resumes on p. 471.]

[Ms. Nativio's prepared statement and attachment follow:]

STATEMENT OF

AMERICAN NURSES' ASSOCIATION

TESTIMONY PRESENTED

BY

DONNA NATIVIO

MATERNAL CHILD HEALTH DIVISION OF PRACTICE
AMERICAN NURSES' ASSOCIATION

I am Donna Nativio, a member of the Executive Committee of the Maternal Child Health Division of Practice of the American Nurses' Association. The American Nurses' Association is the national professional association of registered nurses with a membership of approximately 200,000.

Thank you for the opportunity to present the views of the American Nurses' Association on HR 6706, a bill to strengthen and improve the early and periodic screening, diagnosis, and treatment program. We see this legislation as one step toward a national health policy calling for comprehensive health care services for children.

We support your efforts to continue and expand the availability of health care to children, to increase the numbers of children eligible, to assure continuity of care, to increase immunization levels of children and to provide further incentives to states to arrange for and encourage quality health care for children.

"Health care" is not synonymous with "medical care." While the term "medical care" emphasizes the curing of illness, the term "health care" incorporates the meaning of medical care and also emphasizes the preserving of wellness. "Health care" requires the planning and services of a variety of health providers - the collaboration of a variety of health care

practitioners. Nurses work collaboratively with the physician and other health care practitioners to provide improved quality care more economically.

Primary health care is defined in the report of the HEW Secretary's Committee to Study Extended Roles for Nurses, Extending the Scope of Nursing Practice, as having two dimensions, "a person's first contact in any given episode of illness with the health care system that leads to a decision of what must be done to help resolve his problem; and the responsibility for the continuum of care, i.e. maintainance of health, evaluation and management of symptoms, and appropriate referrals." Implied in this definition are services by professionals capable of recognizing illness, deciding what must be done, and assuming responsibility for helping clients prevent illness and maintain health. The Child Health Assessment Act includes primary health care services.

We suggest the following changes in HR 6706 to help assure access to primary health care services.

1. Eligibility: As proposed, HR 6706 covers 700,000 children whose families meet state financial income requirements for welfare but not other welfare requirements. Children in these families from 7-21 years of age are not included. Therefore for these children there is the abrupt interruption of health care services after age 7 years. Children from birth through 21 years of age who meet state financial requirements for welfare should be eligible for HR 6706 for adequate health care services in order to reach the most needy poor children and avoid discrimination among children of different ages in the same family.

The proposal will allow a six-month extension of Medicaid services beyond cessation of eligibility. This is an arbitrary and unrealistic limitation of a course of treatment and recovery. A more realistic time frame is one year.

Section 3(G) states that services may not necessarily include those individuals under age twenty-one with mental illness, mental retardation and developmental disabilities from treatment. An estimated 30% of children entering first grade have identified behavioral and emotional problems. Their growth and development would be hampered by this provision. We strongly urge that provision of mental health services be mandatory.

2. Coverage (benefits): In addition to statements already discussed concerning primary care coverage, H.R. 6706 should provide for regular health assessments at times or intervals defined by regulation.

Twenty-five percent of the children screened in Early Periodic Screening, Diagnosis and Treatment had severe dental problems. Prophylactic dental care as well as emergency dental care should continue to be covered. H.R. 6706 only covers dental treatment for conditions diagnosed during an assessment. H.R. 6706 instead of improving and expanding, would cut back on dental benefits. What is the rationale for discontinuing a service which meets a documented need?

The American Nurses' Association shares the concern expressed in this bill to increase immunization levels of children. We believe there should be a national program of childhood immunization. An immunization program is an integral part of comprehensive health care. A copy of ANA's statement on this is attached.

3. Outreach: Financial incentives should be provided to encourage states to provide personalized outreach. According to Early Periodic Screening, Diagnosis and Treatment, The Possible Dream, published by HEW, "Personal contacts with outreach workers were responsible for 75% of the children screened during a three year period in one Pennsylvania county. South Carolina, which has enrolled 85% of its eligible children, sees its transportation contact with the local Community Action Program as a major factor in its high rate of participation. In Maine, 1200 people were contacted over a three month period. With personal contacts, only 1% refused EPSDT services; without outreach workers to explain the value of the program, service refusals jumped to 15%." An evaluation of the EPSDT program conducted by the Office of the Regional Director, HEW, Region V, recognizes that "Personal outreach and case management improves implementation levels." In other words, when procedures such as notification, screening arrangements, referral appointments and treatment follow-up are performed personally by agency, staff, screening percentages are higher... Personal outreach was felt to be a major positive factor affecting implementation. Local programs indicated that when they adopted this approach, both higher screening and treatment levels resulted.

4. Providers: Many states have not used the full range of qualified providers in their health care delivery programs. The proposal requires states "to encourage participation by physicians and health care centers." Providers of child health assessments and primary care systems should include nurses at all levels of their expertise. In most cases today it is the Public

Health Nurses practicing in clinics, schools and in the field, who obtain a complete health history, including a developmental history and a history of immunization; performs vision, hearing and anemia tests; measured height and weight; does a physical evaluation; and an assessment of oral health. Community based nurses are the ideal health professionals to do case finding and follow-up care.

School nurses and school nurse practitioners are in strategic places to deliver the care called for in H.R. 6706. These nurses frequently are the child's first contact with the health care system. The school nurse or school nurse practitioner has daily access to the children who will be recipients of this bill. Health education, counseling and guidance are aspects of the comprehensive, continuous care for children called for in H.R. 6706. The delivery of this care can best be facilitated by utilizing an existing structure - the school system.

The nurse practitioner can be utilized in her area of expertise. The nurse practitioner, as defined by the American Nurses' Council of Family Nurse Practitioners and Clinicians, is a primary care provider prepared to give continuous, personalized care to the patient/client at the point of entry into the health care system, and to continue as the individual's care provider.

Nurse practitioners are prepared to provide prenatal, postnatal, and well-child care; guidance regarding nutrition and immunization; assistance in coping with illness and crises throughout the developmental cycle; supervision of treatment; and physical and psychological comfort.

A nurse practitioner's preparation consists of a specialized program of study beyond that required for R.N. licensure. It must meet the American Nurses' Association's Guidelines for Short Term Continuing Education Programs and a certification mechanism to insure quality of care to the consumer by the provider. To date more than one thousand nurses have initiated the certification process. The process includes a peer review mechanism.

5. Implementation: The EPSDT legislation held the potential for becoming one of the most comprehensive and ambitious health care programs the government had ever undertaken. However, HEW did not issue regulations until July, 1973. Five years elapsed from the time legislation was passed until the program was implemented. This delay lessened the potential effectiveness of the program. We urge inclusion in the proposal of a realistic date for the program to be implemented by the states.

6. Federal Standards: Federal standards should require the states to include a quality assurance program. This program should set standards to assure quality of care by qualified providers whose services are reimbursable by the state.

7. Changes in Terminology: Much of the care needed by this population does not need to be given by a physician. Statistics from Wisconsin state that only one out of every 5 children screened in the EPSDT program required referral to a family physician. If 80% of the children served in the EPSDT program did not require medical care, it seems illogical to make physicians

the only care provider identified in the bill. We suggest the following changes:

a. Sec. 4(A), Section 1902 (a) (C): strike out "medical assistance" and replace with "health services."

b. Sec. 5, Section 1912B (4): "medical care" should be changed to "health care," and "medical services" should be changed to "health service."

c. Sec. 5, Section 1912B (5): change "medical care" to "health care."

d. Sec. 6, Section 1902 (37): should read "provide that the state will encourage participation by physicians, nurses, and health care centers in the program."

e. Sec. 7 (a), Section 1903 (b)(3): should have "medical care" changed to "health care."

In summary, the American Nurses' Association would support H.R. 6706 with the recommended changes. To do less would be a denial of meeting the known needs of the children who qualify for services under the Medicaid program.

We appreciate the opportunity to appear here today. We will be happy to supply any additional information and assistance that would be helpful to the committee.

9/8/77

AMERICAN NURSES' ASSOCIATION

DIVISION ON COMMUNITY HEALTH NURSING PRACTICE
AND
DIVISION ON MATERNAL AND CHILD HEALTH NURSING PRACTICE

STATEMENT TO NATIONAL IMMUNIZATION CONFERENCE

BETHESDA, MARYLAND

APRIL 4, 5, 6, 1977

The Divisions on Community Health and Maternal Health Nursing Practice of the American Nurses' Association are aware of the need for a national program of immunization against communicable diseases for all children.

A childhood immunization program is an integral part of comprehensive health care. In order to reach the greatest population effectively, a variety of sources should be utilized for administration in the immunization process. However, whenever possible the immunization process should be either a component of a continuing primary provider-client relationship or the entry to such an ongoing relationship.

Nursing has long manifested a strong commitment to primary preventive care. Today, because of their practice with children and families in a variety of settings, nurses are in a key position not only to contribute to planning for childhood immunization, but also to engage in identification of populations at risk, provision of services, follow-up care, control and surveillance activities which are essential components of a sustained childhood immunization program.

Because the need for such a sustained childhood immunization program is crucial, varied approaches to education for health care providers and the public must be developed, promoted, and implemented. The program should be easily accessible to families and should not be a financial burden to individuals. The costs of vaccine administration and follow-up care should be met by existing public and private sources of reimbursement. A uniform immunization record keeping system should be developed and utilized by all states.

Provision should be made for the compensation of those clients who may demonstrate vaccine-related injuries. Professionals and health personnel who administer vaccines should not be held liable for adverse reactions which occur through no fault of the procedure.

The Divisions on Community Health Nursing and Maternal Child Nursing Practice of the ANA believe adults must share the responsibility for immunization of children against preventable communicable diseases. Both the public and health care providers must learn to expect, demand, and provide an efficient system for a sustained immunization program for all children in the United States.

Mr. ROGERS. Thank you so much.

I am going to ask witnesses, if they will summarize in 5 minutes. We got off track for a while here, and I think we are going to have to get back on track if we are to give everyone an opportunity to be heard. People have come here from all over the United States and are entitled to be heard.

Our next witness is Mr. L. Jerome Ashford.

STATEMENT OF L. JEROME ASHFORD

Mr. ASHFORD. I am L. Jerome Ashford, Executive Director of the National Association of Community Health Centers.

Mr. ROGERS. It is good to see you back before the committee.

Mr. ASHFORD. It is a pleasure to be here.

We represent more than 800 community and migrant health programs serving more than 10 million citizens in urban and rural communities across the United States.

As the principal provider of primary health care services to American Citizens, especially its medically underserved and medically indigent, we are deeply concerned about the health of our Nation's most valuable resource—our children.

We know, Mr. Chairman, that you and your fellow subcommittee members share this concern and we commend you for your expedient action on this important legislative proposal.

The administration has made it clear that community and migrant health centers are expected to play a major role in providing continuing primary and preventive health care, through the proposed CHAP program, to medically unserved and underserved children throughout the United States. Accordingly, there are some recommendations and concerns I would like to share with the subcommittee for your consideration.

RECOMMENDATIONS

A. Eligibility.

1. The proposed legislation would require States to provide Medicaid coverage for all children under 6 years of age whose families meet the States income test for AFDC, but whose family structure currently makes them ineligible for AFDC. There is ample evidence which demonstrates that older children, ages 7-21, are often found to have as many, if not more, health problems than younger children. Therefore, we would support inclusion of all individuals under age 21 who meet the established financial need criteria.

2. With respect to the migrant farmworker, we have supported for some time now, legislation that would remove State "intent to reside" requirements. This would enable migrant farmworkers and their dependents who are otherwise eligible for medical assistance under title XIX to receive such assistance in the State in which they are physically located at the time medical assistance is needed. The present situation is totally unfair to the migrant population who by nature of their employment are mobile.

It is my understanding the administration is considering recommending legislation that would remove State "intent to reside" requirements for migrant families.

Mr. Chairman, we recommend that at this time you consider an amendment that would allow children under 21 of migrant farmworker families to participate in the CHAP program. Otherwise, most of these children, who are in deep need, will be excluded from CHAP.

For the 27 States which include "medically needy" in their Medicaid program and in which migrants work and reside during the year, 24,000 infants, children and youth—under 21—would potentially benefit by removal of existing "intent to reside" restrictions imposed by many States. Such action is preferable to forcing these families into a situation whereby they are either forced to lie or suffer.

3. The proposed legislation extends Medicaid eligibility for all children who have been assessed, for 6 months following the date when a family no longer qualifies for welfare.

We feel eligibility for all children should be extended for at least 1 year following a health assessment or until such time as a condition is found and corrected. Health centers serving largely indigent populations encounter numerous administrative problems with families who are eligible one month and not the next. Moreover, the time lag between initial screening to diagnosis and treatment of a health problem, including broken appointments, may well exceed the 6-month period. Also, there are conditions, scoliosis—curvature of spine—or a seizure disorder, for example, which may take 6 months or longer to bring to an optimal state of management. Our concern here is that the child receives the care and treatment he or she needs.

B. Health Benefits Covered.

1. We strongly agree that health assessments at regular intervals should be provided rather than periodic screening. With respect to establishing standards, a uniform national health assessment should be required by regulation. The assessment guidelines proposed by the American Academy of Pediatrics are quite good and should serve as the basis for a uniform assessment procedure. A developmental assessment should be included—not separate.

2. Complete health services should be provided following an assessment. As you know, State limitations in coverage are often defined in terms of the scope and amount of services such as limiting the number of visits, specific types of procedures, or the reimbursement rate. The end result could be exclusions from treatment coverage.

For example, in North Carolina, a screening visit is covered, but if eyeglasses or corrective lenses are needed, they are not covered. In this instance, we can only hope the Commission for the Blind can come through. In Mississippi, dental services are limited to $154. In many instances, this is adequate, however, a number of the children we see have severe conditions with all teeth rotten to the gums and secondary infection of the gums and bone tissue. Obviously, $154 cannot cover the cost of treatment in this case.

Therefore, we would argue that no limitations should be placed on coverage of the treatment needed by children. Quite frankly, Mr. Chairman, we would favor federalization of the Medicaid program so that it would be uniform throughout and hopefully would include

all financially needy children without regard to categorical qualification or limitation on treatment.

3. Routine as well as emergency dental care should be provided. Screening for dental problems should not be a mandatory prerequisite for treatment. The objective of this program is to correct health problems. Between the time of initial screening and treatment, a child may well develop another cavity or gum infection that was not present at the time screening was conducted. Does this mean the additional work should not be done, or the individual be recycled by further screening at additional cost?

4. Outreach.

Mr. Chairman, if this program is to be effective, I cannot overemphasize the importance of outreach in terms of both case finding and case tracking. I feel that community and migrant programs have amply demonstrated the importance of effective outreach efforts. Moreover, I feel the experience of the EPSDT program cleary indicates the need for more out-effective outreach.

An effective outreach program must include the capacity for extensive and continuing personal contact between the provider of services and the target population. To bring previously unserved children into the proposed service delivery program will require substantial modification to existing personal behavior patterns, as well as the development of ongoing relationships with other private and public instituions in the community such as schools, churches, et cetera. None of this can be accomplished without adequate outreach components.

Billings must be made through the individual physician and signed over to the health center. We find this an unacceptable situation and encourage the subcommittee to rectify this problem through whatever legislative mechanisms.

I will dispose the remainder of my comments and will submit the balance of the text for the record.

[The text referred to follows:]

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BALANCE OF MR. ASHFORD'S PREPARED STATEMENT

- We feel very strongly that outreach services should be a reimbursable service when performed by public or private non-profit community-based organizations. This is especially important in light of decreasing federal support for such services under sections 330 and 319. Moreover, reimbursement should be reasonably related to cost and include costs for both case-finding and case-tracking. I would hope the Subcommittee realizes the importance of outreach for this program to be effective.

5. Transportation

The problem of transportation is especially significant for the poor in rural areas--and if a child is screened but cannot receive treatment, what does the program accomplish? Transportation should be a reimbursable service for public or private non-profit community-based organizations.

C. Provider Participation

As I believe you are aware, Mr. Chairman, there still exist today State Medicaid programs that do not recognize community and migrant health centers as providers of health care. In those instances, billings must be made through the individual physician.

We feel the proposed legislation is weak in that it "encourages" participation by physicians and health care centers and to "monitor" contracts with providers.

This language should be strenghtened as follows:

1. States should be required to indentify and offer contracts to all qualified providers, and

2. States should have an obligation to arrange for and provide reasonable contracts with providers of CHAP services.

7. With respect to reasonableness, criteria should be established by regulation. However, as a minimum, we would strongly urge report language or an amendment that would spell out such "reasonable contracts" include an adequate rate of reimbursement related to actual cost and timely payment of claims.

D. Administration

We feel there should be established one clear set of requirements for the program including "minimum" federal standards dealing with program performance, administration and quality of care. One measure of performance should be outcome measures of the extent to which children are provided assessments and follow-up care.

In addition, reporting requirements should be kept relatively simple. The New York program, I am told, has experienced difficulty in this area, as a result, many providers are discouraged from participating in the program. While reporting is essential to the evaluation and monitoring of program activities, it should not be burdensome or too costly.

E. General

Additional points addressed by other groups with which we concur are as follows:

1. States should at least maintain their current level of financial commitment in the program. The proposed bill includes no maintenance effort provisions.

2. States should be required to include as part of their Medicaid plan, a complete explanation of how CHAP requirements will be carried out.

3. Public participation in development of the CHAP part of the State Title XIX plan should be required.

4. With respect to enforcement, we would urge the Secretary be given authority to issue an order for the State to provide requisite services.

Mr. Chairman, on behalf of the Members of the National Association of Community Health Centers, I thank you for this opportunity to share with you our thoughts on this proposed legislation. I assure that the community and migrant health centers of this nation strongly support this proposal and stand ready to exert every possible effort to make it successful once it is implemented.

Thank you, Mr. Chairman. If you have any questions, I shall be pleased to respond to them at this time.

Mr. ROGERS. Thank you for your helpful statement and the committee will check into these points raised.

Might I just ask this, Dr. Dixon? Do you think that the private physicians will participate in this program?

Dr. DIXON. Yes, they are participating now, Mr. Chairman.

Mr. ROGERS. But at a rather low level, are they not?

Dr. DIXON. We don't know what level. We really don't know at what level there is participation. We do know however, that there are 22 States which discourage private practitioners from participating and that there really are barriers for participation in the screening process. For instance, barriers might be refusal to pay for the screenings. This is documented information in our study for MSA last year. So I think with encouragement, with dialogue, with the thrust toward a comprehensive care program, private practitioners will participate.

Mr. ROGERS. Do you think it is wise though to direct the funding to public health units?

Dr. DIXON. Yes. In my testimony I stated that we need all health resources, and I think all resources that can give quality care for children should participate in this program.

The thing that has bothered me during these hearings is the misconception of the words "screening" and "assessment." This bill is a child health assessment program, and yet in the testimony commonly screening and assessment are used interchangeably. I think this is a mistake. We screen for disease. We assess children. We integrate the whole process in the assessment, and I think this needs to be clarified in the minds of the committee.

Mr. ROGERS. Thank you so much.

We are grateful to each of the panel members for being here. Your testimony has been helpful, and the committee will carefully consider what you have said. Thank you for your presence today and for your patience.

The next witness will be Una Haynes, who is a consultant, pediatric nursing, on behalf of United Cerebral Palsy Associations, Inc., The Epilepsy Foundaton of America, The National Association for Retarded Citizens, The National Society for Autistic Children.

We welcome you and your associates to the table. We also appreciate the fact that one spokesman can speak for those who have similar interests and so we salute you.

STATEMENT OF UNA HAYNES, CONSULTANT, PEDIATRIC NURSING, ON BEHALF OF THE EPILEPSY FOUNDATION OF AMERICA, THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS, THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN, AND THE UNITED CEREBRAL PALSY ASSOCIATIONS, INC.; ACCOMPANIED BY VINCENT GRAY, EXECUTIVE DIRECTOR, THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN; AND LAURA LEVINE, ASSISTANT DIRECTOR, GOVERNMENTAL AFFAIRS, UNITED CEREBRAL PALSY ASSOCIATIONS, INC

Ms. HAYNES. Thank you.

On my left is Mr. Vincent Gray, the Executive Director of The National Association for Retarded Children here in Wshington, D.C., who will be available to answer such technical questions as may arise; and on my right, Laura Levine, who is the Assistant Director of United Cerebral Palsy, Governmental Affairs, here in Washington.

We are deeply concerned about the exclusion of the retarded and developmentally disabled children in the CHAP proposal because the lack of service early on, as I am sure you know, may very well exacerbate what is originally a disability into a true handicap by the time they are adults.

Another point that is germane I think to our interests is that these individuals will indeed be candidates for Medicare when they reach their majority, and therefore it would seem patent that neglecting their health needs as little children will make them much more severely disabled and they will need much greater services when they grow older.

It has been my personal experience in the past 6 years to be the director of a collaborative infant project in which we have served 10,000 disabled babies in the 0 to 3 age range in 65 centers sponsored by various agencies located in 26 differnt States, including Hawaii. And I can testify to you that their health needs are there, and they are great, and many can be resolved without their becoming so desperatey ill in the first place or so severely disabled.

While many individuals erroneously assume that the mentally retarded and the developmentally disabled children will get these health services that they need through other auspices, such as those of the developmental disability, this is not necessarily so, and this does not mean that DD is not a good program in itself. It is merely that in somc instances the States are choosing, and often wisely, to use these monies for good, astute, long-range planning. The monies are not there for delivering services when they are needed.

The same thing is true with crippled children services. They are there. They are extremely useful. I don't know how they would do without them, but the eligibility requirements for crippled children's services are quite different from one State to another.

I was interested to hear that there was a public health nurse speaking here about the role of the public health nurse, and I would

like to submit to your attention that in one of our units, for instance, I will cite the one in Stockton, California, 40 percent of the babies referred to the program had been found by the screening of the public health nurses.

I was thinking what will happen to these public health nurses and the families who share the concerns for a child who is not developing normally, is at the Medicaid level but is distinctly excluded then from receiving the kind of assessment that he or she would need. The concern is a great one.

Unfortunately human beings being what they are, the pressures of finance being what they are, it is unfortunately possible that there may be a tendency to label children as mentaly retarded and/or developmentally disabled when they come to attention for the purpose of taking advantage of the possible exclusion that is available through this testimony. It is unfortunate to say this out loud but I think it does happen.

It also goes against what I think all of us and I think you very particularly, Mr. Chairman, have done, to stop disabling by the label as it were, but we will categorize these children almost immediately as either retarded or disabled within the broad group within which they may fall, because it may be a little easier to avoid the services to them.

We would like to avoid the categorical approach. I feel proud of the agencies which I am here representing, that they have not fought in a chauvinistic way only for the population which is their primary concern but rather for all children. We must remember that the disabled children overall do have major needs but it is not necessarily so. As a matter of fact, our data are beginning to suggest from the baby programs, if these disabled children are provided the services they need, they do not require long-term institutional care.

Of the first 500 babies we served, only four needed care out of their homes. This was not really due to the depth of disability of the children, but I hate to say some of the mothers of these babies are only 15 and not able to be parents of a child, much less than a disabled child. Foster care parents are much more willing to take on the care of a child when they know the services are there to help them.

We have read earlier the bill submitted by Mr. Maguire. We think within the provisions therein some of our concerns will be resolved. I feel that I have been very short. If I have failed to present the depth and the extent of our concern, it is a personal failure really and not the lowered level of their needs.

[Ms. Haynes' prepared statement follows:]

STATEMENT

ON BEHALF OF

THE EPILEPSY FOUNDATION OF AMERICA

THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS

THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

Introduction

The four national voluntary agencies representing persons with developmental disabilities have been historically supportive of comprehensive health care programs for children as a primary mechanism for preventing and reducing the incidence of these handicapping conditions. Programs such as the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) initiative provided under Medicaid have been welcomed by our organizations as major federal commitments to assuring and increasing the continuity, quality, and availability of such efforts.

The Child Health Assessment Program (CHAP) is another such potentially valuable tool for implementing a national strategy of health promotion and prevention for low-income children, a population statistically at high risk for long-term, permanently disabling conditions. For this reason our organizations are particularly distressed by the flagrantly discriminatory categorical exception made in providing treatment services to mentally retarded and developmentally disabled children under Section 3(G) of the proposed legislation. By rendering the provision of care and treatment services to mentally retarded and developmentally disabled children optional under each state's Medicaid program, Section 3(G) effectively excludes such children from receiving those same health services available on a routine basis to their nondisabled peers, services which they unquestionably require and to which they would otherwise be entitled by virtue of their financial status.

Need for Early Intervention

Of all child population groups, low-income children are at greatest risk of experiencing developmental disability or delay as the result of inadequate prenatal care, poor nutrition, environmental hazards such as lead-based paint poisoning and mercury toxicity, and, above all, lack of early diagnosis and treatment of various disorders due to insufficient utilization or availability of health services.

In his address to the White House Conference on the Handicapped on May 23rd of this year President Carter enunciated his administration's commitment to insuring the health of financially disadvantaged children:

> As I look across this tremendous auditorium, with many different kinds of handicaps represented here, I know that many of them could have been prevented in your early life...within just a few years we will multiply five times the number of poor, young children who have a chance to see a doctor early in their lives so their potential handicap or affliction might be prevented or corrected.[1]

This preventive emphasis has already been endorsed by this committee and by the Congress as a whole in such legislation as the Health Promotion and Disease Prevention Act of 1976 (P.L. 94-317) and the Health Professionals Educational Assistance Act (P.L. 94-484), which seek to insure the adequacy and availability of preventive services and primary care professionals to deliver them. We are thus particularly dismayed at the exclusion from such services of precisely that population which has a demonstrable need for them: mentally retarded and developmentally disabled low-income children.

It has been abundantly documented that disabling conditions occur with greater frequency among the low-income population which Medicaid is designed to serve.[2] Those disabling physical and mental conditions which are not the result of prenatal problems often first manifest themselves during infancy or the preschool years. Without immediate and ongoing therapeutic intervention these conditions can become permanently disabling. With many low-income children in need of treatment for medical conditions related specifically to problems of growth and development,[3] it becomes particularly essential that individuals so identified be eligible to receive the full range of referral, treatment and follow-up services available under Medicaid auspices, so as to insure the amelioration of their condition before damage or degeneration becomes irreversible.

Current regulations under EPSDT require states to arrange for treatment of conditions discovered during routine screening, either by providing such services themselves or by referring children appropriately. There is little doubt that the de facto exclusion under CHAP of mentally retarded and developmentally disabled children from even this basic referral function will create even more severe impediments to attaining appropriate services than these children already face as the result of inadequate parental information or preventive education, and the inherent difficulties which lay consumers--and particularly the poor--continually experience in attempting to access health services.

Moreover, the few federal programs providing some medical or health-related services to children with mental retardation and developmental disabilities are so fragmented, condition/region specific, and hedged with varying eligibility requirements and application procedures that tracking appropriate services within such a "non-system" becomes a confusing and frustrating process; and it goes almost without saying that under these conditions continuity of services is impossible to guarantee.

In short, it had been our understanding that the Child Health Assessment Program was designed to expand, not restrict, the scope of the EPSDT mandate. Clearly the new program as drafted contravenes that goal as articulated in Section 2 of the proposed legislation (Appendix).

Exclusionary Rationale: Fact and Fallacy

Cost. The Administration's failure to require follow-up treatment services for mentally retarded and developmentally disabled children appears to be motivated primarily by a concern that the cost of providing such services will be prohibitive to states. An unstated but implicit assumption appears to be that mentally retarded and developmentally disabled children are at high risk for long-term institutional care.

Such an assumption is not warranted. The overwhelming number of mentally retarded and developmentally disabled children do not require institutional care. Even among the more severely involved institutional care is only rarely called for and need not be long-term. Equally important is the recognition that early intervention and follow-up can prevent the development of some forms of developmentally disability (such as mental retardation caused by inborn errors of metabolism); can dramatically reduce the severity of the disability (as in many seizure disorders which, if untreated, can significantly increase in frequency and intensity of occurrence); can compensate for disability-produced impairments (as in the case of children with cerebral palsy who, with appropriate therapy, can be helped to reduce or compensate for communication and motor difficulties); and can reverse symptoms (as in the case of those autistic children whose cognitive and behavioral functioning has improved significantly as a result of neurological intervention). Early intervention, in other words, is a significant factor in reducing the need for long-term institutional care among the mentally retarded and developmentally disabled child population; and any legislation inhibiting the provision of such care as early as possible not only fails to save money, but virtually assures additional public expense throughout the life of the child, expense which might otherwise have been avoided.

In assessing cost it must also be remembered that severely mentally retarded or developmentally disabled children eligible for Medicaid as SSI recipients or as AFDC children will in most cases become eligible for Medicaid as adults on the basis of their disability. Nondisabled AFDC children, in contrast, will generally lose eligibility for Medicaid when they reach their majority. Thus the disabled Medicaid child will also be Medicaid's responsibility as an adult. If these children are not reached in childhood--when the possibility of reversing or reducing disability is greatest--the long-term cost to Medicaid will be dramatically increased.

The Developmental Disabilities Act. A second and equally specious rationale for excluding mentally retarded and developmentally disabled children from the program is the putative availability of treatment services for them under the Developmental Disabilities Act (P.L. 94-103). The legislative mandate of P.L. 94-103 is that of planning and coordination of services, and not service delivery. P.L. 94-103 is equipped to provide neither the funding nor the administrative apparatus necessary to deliver services, except as the provider of last resort in certain limited instances. Even then, current appropriations ($30 million) could not possibly absorb the burden of providing in full those referral and treatment services currently available to mentally retarded and developmentally disabled children under the EPSDT mandate. Clearly it is unrealistic to expect that, given its current structure and funding levels, P.L. 94-103 could provide the scope and volume of services which the Medicaid apparatus is already organized to deliver.

Consequences of Exclusion

Perhaps the gravest danger inherent in the exclusion of mentally retarded and developmentally disabled children from services under CHAP is the very real likelihood of

its acting as an incentive to states to reclassify many otherwise eligible children as mentally retarded or developmentally disabled in order to lessen state financial involvement in the provision of screening, referral and treatment. Such a response on the part of the states will delay or deny treatment to many children for whom immediate therapeutic attention is critical if permanent damage is to be avoided. Yet it is evident from the preliminary response by many states to programs such as P.L. 94-142, the "Education for All Handicapped Children Act," that additional state administrative and/or fiscal commitments to comprehensive new programs, even with the incentive of a matching provision, tend often to be viewed in terms of the most expedient rather than the most equitable implementation route.

In the case of the CHAP program categorical exclusion is regressive as well as obstructive. During the past few years Congress has been moving away from defining basic social needs such as health in categorical terms, preferring to emphasize functional capabilities and the specific types of services an individual might require in order to optimize his/her physical and mental competencies. At the same time there has been a trend toward the individualization of services provided under many federal programs, and a concentration upon developing programs whose balance of components reflects each person's unique needs. In this context it becomes readily apparent that a policy of blanket categorical exclusion is at best outdated, at worst insensitive, and in any event contradictory to the health needs of low-income mentally retarded and developmentally disabled children.

Finally, such a policy is clearly incompatible with Medicaid's long-standing reluctance to authorize a more circumscribed set of services to one group of eligible recipients than to another on the basis of diagnosis (Section 1902(a)(10).

The EPSDT system was originally conceived as a mechanism for coordinating referral and treatment services for all eligible children under a centralized administrative rubric. By providing clients with a central locus through which they could be assured of receiving treatment, the program was to minimize the haphazard and discontinuous service delivery which generally characterizes an individual's attempts to receive health care from more than one agency or program. The EPSDT model is, of course, only a model; and many flaws exist in the way the system currently operates. But despite its many failures of implementation, we believe that the philosophical underpinnings of the program--the provision of centralized, comprehensive health care to all low-income-children, including those mentally retarded and developmentally disabled--remain sound and ought to be perpetuated.

We therefore urge you to remove from the CHAP proposal as drafted that language which denies to mentally retarded and developmentally disabled children their right to receive the health care necessary to insure their maximum participation as adults in American society. To this end we respectfully suggest the following revision of Section 3(G):

> "effective October 1, 1977, in the case of any individual under the age of twenty-one who has received his periodic assessment pursuant to section 1912(b)(1), for the inclusion of all care and services appropriate for individuals under age twenty-one ~~(but not necessarily including (i) those for the treatment of mental illness, mental retardation, or developmental disabilities, and (ii) dental care when not for the treatment of conditions discovered during an assessment)~~

for which payment is available under this title, whether or not under the State plan for the State such care and services are provided to individuals who have not been periodically assessed pursuant to section 1912(b)(1);"

Thank you for permitting us this opportunity to express our concerns. We look forward to the day when we can unreservedly express our support for a revised and expanded program of comprehensive health care for all low-income children. To that end we will be happy to cooperate with your staff in providing any further information or assistance the Subcommittee may require.

NOTES

1. "President Carter Gives Hope to Handicapped Individuals," Congressional Record, Vol. 123, No. 99, June 9, 1977, pp. H5690-H5691.

2. e.g., National Center for Health Statistics, HRA/PHS/DHEW, Selected Vital and Health Statistics in Poverty and Nonpoverty Areas of 19 Large Cities, United States, 1969-71. (DHEW Pub. No. (HRA) 76-1904); The Children's Defense Fund, EPSDT: Does It Spell Health Care for Poor Children? (Washington, D.C.: The Washington Research Project, Inc., June, 1977).

3. Children's Defense Fund, op. cit., p. 109.

APPENDIX

H.R. 6706

DECLARATION OF PURPOSE

SEC. 2. The purpose of this Act is to modify the early and periodic screening, diagnosis, and treatment program and broaden medicaid eligibility--

(1) to continue and expand the availability of health care to children whose families do not have adequate resources to cover the cost of such care and to strengthen efforts to assure adequate child health assessments, diagnosis, treatment, and periodic reassessment of all eligible children;

(2) to increase the number of children eligible for such care;

(3) to assure the continuity of care for a period after a child would on account of income become ineligible for medical care under title XIX of the Social Security Act;

(4) to increase immunization levels of children; and

(5) to provide further incentives to States to arrange for and encourage quality health care for children.

Mr. ROGERS. Thank you. I think you have expresed very deep regard and concern.

In your experience how many of the children had to be institutionalized?

Ms. HAYNES. We would be glad to submit some written testimony from our statistial data. I can say only in the first group that a little over 500. They were not institutions as such. I would be glad to submit this.

Mr. ROGERS. I think that would be helpful if you could submit it for the record.

[The information requested was not available to the subcommittee at the time of printing.]

Mr. ROGERS. Can we find out for our own interests how the developmental disabilities are funds being administered?

Mr. GRAY. First of all, I think in considering the Development Disability Act as a potential resource for these youngsters that would be excluded under this program, we need to return to the real intent of the act. That is essentially planning and coordination and, to some extent, to protect the rights of developmentally disabled citizens. We look, for example, at the financial resources coming into the District of Columbia, and the entire act provides only $150,000 for the entire population.

Forty thousand dollars of that money is used for planning staff, which leaves about $100,000 to $110,000 for projects in the District of Columbia. Without going into a great deal of explanation, it is

pretty clear that is meager and certainly would not nearly meet the needs of developmentally disabled citizens of the District.

The entire intent of the act is to pull together a service delivery system from a planning point of view that would bring together services that would meet the myriad needs of developmentally disabled citizens. I think to saddle the DD program with that kind of responsibility would be contrary to the intent and far beyond the resources that would be available under the development disabilities program.

Mr. ROGERS. I just wondered how it was being applied here.

Thank you. Your suggestions are helpful and we certainly will consider them. We are grateful to you for being here.

We now have a panel of Dr. John B. Nelson, President, American Association of Psychiatric Services for Children; Dr. Allan Barclay, Department of Psychology, St. Louis University, on behalf of the American Psychological Association and the Association for the Advancement of Psychology; Dr. Joseph D. Noshpitz, Past President, American Academy of Child Psychiatry; Jonas V. Morris, Governmental Affairs Consultant, National Council of Community Mental Health Centers; and Ms. Julia Oliver, Department of Public Welfare, Member, Board of Directors, Mental Health Association.

It is my understanding Dr. Barclay has to catch a plane, so if we could let him go first—may I say that each of your statements will be made a part of the record in full without objection and if each could make his or her remarks in five minutes it would be appreciated.

STATEMENTS OF ALLAN G. BARCLAY, Ph.D., ON BEHALF OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION, AND THE ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY, ACCOMPANIED BY CLARENCE J. MARTIN, EXECUTIVE DIRECTOR AND GENERAL COUNSEL, ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY; JULIA OLIVER, MEMBER, BOARD OF DIRECTORS AND COMMITTEE ON LEGISLATION AND SERVICES, MENTAL HEALTH ASSOCIATION; JOHN B. NELSON III, M.D., PRESIDENT, AMERICAN ASSOCIATION OF PSYCHIATRIC SERVICES FOR CHILDREN, ACCOMPANIED BY DEBORA KRAMER, EXECUTIVE DIRECTOR; JOSEPH D. NOSHPITZ, M.D., ON BEHALF OF THE AMERICAN PSYCHIATRIC ASSOCIATION AND THE AMERICAN ACADEMY OF CHILD PSYCHIATRY, ACCOMPANIED BY VIRGINIA Q. BAUSCH, EXECUTIVE DIRECTOR, AMERICAN ACADEMY OF CHILD PSYCHIATRY; AND JONAS V. MORRIS, GOVERNMENTAL AFFAIRS CONSULTANT, NATIONAL COUNCIL OF COMMUNITY MENTAL HEALTH CENTERS

Dr. BARCLAY. Thank you for the courtesy of offering first. Mr. Chairman, members of the House Subcommittee on Health and the Environment of the Interstate and Foreign Commerce Committee, I wish to express my appreciation for the opportunity to be here today to testify on the proposed child health assessment program (CHAP) on behalf of the American Psychological Association and the Association for the Advancement of Psychology. My name is Allan G. Barclay, I am Professor of Psychology at St. Louis Univer-

sity and Director of the Child Development Center, St. Louis University School of Medicine. I am accompanied here today by Clarence Martin, Executive Director and General Counsel of the Association for the Advancement of Psychology, an advocacy group for psychologists concerned with public issues and their impact on psychology and the government.

I would like to offer my written statement for the record and, with the permission of the chair and for the sake of brevity, summarize my statement.

We support the spirit of the CHAP bill in its attempt to strengthen and improve the previous program, early and periodic screening, diagnosis and treatment (EPSDT). The provision of "comprehensive, continuing primary and preventive health care" is a commendable goal, one with which we wholeheartedly agree. The insufficiencies of the EPSDT program have been extensively and thoughtfully documented by the report of the Children's Defense Fund, and need not be reiterated in our testimony.

The current bill, however, may constitute a step backward even from the currently existing EPSDT requirements, which obligate States to at least arrange for, but not necessarily pay for, all treatment following assessment. If the aim of the proposed CHAP bill is to establish a comprehensive, coordinated, high quality program for poor, high risk and disadvantaged children, it fails seriously in this respect by excluding obligatory treatment for "mental illness, mental retardation, and the developmental disabilities." We must recognize that the problems of these children are often more psychological and behavioral than medical in nature and medical treatment alone may simply be wasted if we do not get to the root cause of the problem.

"The difficulties existing under the current EPSDT program in terms of linking together the assessment, screening and treatment process has been thoroughly documented, and we believe the CHAP bill would present even more significant difficulty in this respect. We strongly believe that it is both a professional as well as an ethical responsibility to provide treatment resources for developmental problems identified through screening and assessment.

A second major area of concern for us, as psychologists, is the developmental screening aspect of the bill. Screening is a poor term for the complicated process involved in separating those experiencing problems from those with normal development. Assessment, or developmental review, would be a term more reflective of the complexity of the process. As has been reiterated repeatedly by professionals involved in this area, recognizing the cultural and ethnic diversity of our pluralistic society, no single instrument can be used for developmental assessment for all ages and all functions, or in all environments. A variety of assessment procedures, of adequate reliability and validity are available, depending upon the age of the child and the dimensions to be assessed. However, few of these instruments have been developed and standardized with the population of children in question; that is, high risk, poor and disadvantaged children, especially those from minority populations.

The American Psychological Association stands firmly behind the concept of prevention of emotional and developmental disorders,

both from a humanitarian point of view and from a concern for reducing the increasing large sums of money which we Americans pay for medical care. In Missouri, for instance, we estimate a mentally retarded or severely emotionally disturbed child or adolescent who must be institutionalized will cost the State in excess of $13,000 for each year he remains institutionalized.

The concept of assessment of developmental problems, and their treatment at an early stage, holds considerable promise, but is an extremely complicated undertaking. The state of the art is such that fully adequate instruments for this kind of assessment are only in rudimentary stage of development. Certainly, as a first step, a high priority for this program should be the funding of research with the primary aim of development techniques for, to name only a few areas, the assessment of psychosocial, cognitive, emotion, and linguistic functioning in children from culturally and socially diverse backgrounds.

In summary, the CHAP bill has enormous potential for improving the health and welfare of poor and disadvantaged children in our country and holds promise in the long run for minimizing the cost of more extensive interventions at a later point in the individual's life. The stated intent of the program and many of its provisions are extremely hopeful. Provisions should, however, be built into the bill which allow for thorough evaluation of the effectiveness of the program in behavioral, observable terms. The American Psychological Association supports the gradual phasing-in of a comprehensive, high-quality health assessment and treatment program for all Medicaid children which includes concern for social, emotional, intellectual and developmental functioning. We offer our resources and expertise to assist in any way possible to insure that a significant national health program of assessment and treatment for high-risk poor and disadvantaged children can be developed and effectively implemented.

[Testimony resumes on p. 496.]

[Dr. Barclay's prepared statement follows:]

TESTIMONY OF

ALLAN G. BARCLAY, PH.D.
AMERICAN PSYCHOLOGICAL ASSOCIATION

ACCOMPANIED BY

CLARENCE J. MARTIN
EXECUTIVE DIRECTOR AND GENERAL COUNSEL
ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY

MR. CHAIRMAN, MEMBERS OF THE HOUSE SUBCOMMITTEE ON HEALTH OF THE INTERSTATE AND FOREIGN COMMERCE COMMITTEE, I WISH TO EXPRESS MY APPRECIATION FOR THE OPPORTUNITY TO BE HERE TODAY TO TESTIFY ON THE PROPOSED CHILD HEALTH ASSESSMENT PROGRAM (CHAP) ON BEHALF OF THE AMERICAN PSYCHOLOGICAL ASSOCIATION AND THE ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY. MY NAME IS ALLAN G. BARCLAY, I AM A PROFESSOR OF PSYCHOLOGY AT ST. LOUIS UNIVERSITY AND DIRECTOR OF THE CHILD DEVELOPMENT CENTER, ST. LOUIS UNIVERSITY SCHOOL OF MEDICINE. I AM ACCOMPANIED HERE TODAY BY CLARENCE MARTIN, EXECUTIVE DIRECTOR AND GENERAL COUNSEL OF THE ASSOCIATION FOR THE ADVANCEMENT OF PSYCHOLOGY, AN ADVOCACY GROUP FOR PSYCHOLOGISTS CONCERNED WITH PUBLIC ISSUES AND THEIR IMPACT ON PSYCHOLOGY AND THE GOVERNMENT.

THE AMERICAN PSYCHOLOGICAL ASSOCIATION REPRESENTS OVER 45,000 PSYCHOLOGISTS THROUGHOUT THE NATION --- MANY OF WHOM SPECIALIZE IN DEVELOPMENTAL PSYCHOLOGY, AND CLINICAL CHILD PSYCHOLOGY, AND WHO ARE ACTIVELY INVOLVED IN CLINICAL SERVICE, CLINICAL RESEARCH AND BASIC RESEARCH WITH CHILDREN. AMONG THE MANY ROLES OF PSYCHOLOGISTS, TWO PRIMARY ONES ARE: 1) THE DEVELOPMENT AND USE OF INSTRUMENTS DESIGNED TO ASSESS DISORDERS OF SOCIAL/EMOTIONAL, INTELLECTUAL, LEARNING, AND NEUROPSYCHOLOGICAL NATURE; AND 2) THE DEVELOPMENT AND IMPLEMENTATION OF HIGH QUALITY REMEDIAL AND THERAPEUTIC PROGRAMS FOR OPTIMAL GROWTH AND DEVELOPMENT OF THE CHILD.

The purposes of the APA Division on Child and Youth Services are 1) to provide a recognized, major organizational entity within the American Psychological Association to be concerned specifically with clinical and scientific issues relative to services, and service structures for children and youth and 2) to develop preventive and corrective measures to deal with the developmental problems of children and youth.

We support the spirit of the CHAP bill in its attempt to strengthen and improve the previous program, Early and Periodic Screening, Diagnosis and Treatment (EPSDT). The provision of "comprehensive, continuing primary and preventive health care" is a commendable goal, one with which we wholeheartedly agree. The insufficiencies of the EPSDT program have been extensively and thoughtfully documented by the report of the Children's Defense Fund, and need not be reiterated in our testimony. It is clear that the intent of an act, and its actual implementation, are two very distinct issues, and that much needs to be done within the Medicaid program to improve the assessment and treatment of needy children. Testimony of the Children's Defense Fund, the American Association of Psychiatric Services for Children, the American Orthopsychiatric Association, and the Coalition for Children and Youth has thoroughly specified changes which would be advisable in the current proposal to make it a more optimally functioning system.

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As mental health care providers, we are particularly concerned with those aspects of the program which deal with the assessment of children's behavioral, emotional, mental, and developmental problems, and their treatment. The Report of the Children's Defense Fund in June 1977, on the EPSDT documents the fact that developmental problems are among the most common conditions that affect children -- particularly, poor, high risk and disadvantaged children. The Report states that "the combined group of mentally retarded, seizure disorders, neuromotor disabilities, school learning problems and emotional disturbances exceed 17% of all children a percentage that is higher than most other conditions such as anemia, or tuberculosis" (William K. Frandenburg and A. Frederick North, A Guide to Screening for EPSDT Program Under Medicaid, prepared by the American Academy of Pediatrics, Washington, D.C., Social and Rehabilitation Service, U.S. Department of Health, Education and Welfare June 1974, P. 141).

The Report of the Children's Defense Fund also cites data gathered by Haggerty, et.al., which states that "the most prominent of the child health problems that have emerged in the past decade or two are the behavioral and schooling problems found in children of all ages. Between 20-30% of children entering first grade have been identified as having behavioral and emotional problems. (p.95) The prevalence of pre-school behavioral problems in various populations varies from 8-50% (p.99); and 10-30% of school children experience significant learning problems or behavioral difficulties." (Robert Haggerty, et.al., Child Health and the Community, New York John Wiley & Sons, 1975, p.101).

CANDIDLY, HOWEVER, THE PRESENT PROVISIONS OF THE PROPOSED BILL WOULD HAVE AN ADVERSE EFFECT FROM OUR POINT OF VIEW. IT HAS BEEN CLEARLY DOCUMENTED THAT A LARGE PROPORTION OF CHILDREN HAVE EMOTIONAL, BEHAVIORAL, AND PHYSICAL PROBLEMS RELATED TO GROWTH AND DEVELOPMENT, AND THAT THERE EXISTS A GREAT NEED FOR TREATMENT AVAILABILITY AND FOLLOW-UP TREATMENT FOR THESE DEVELOPMENTAL PROBLEMS. THE CURRENT BILL, HOWEVER, DOES NOT OBLIGATE STATES TO PROVIDE FOR THE TREATMENT OF THESE DISORDERS. THIS IS A STEP BACKWARD EVEN FROM THE CURRENTLY EXISTING EPSDT REQUIREMENTS, WHICH OBLIGATE STATES TO AT LEAST ARRANGE FOR, BUT NOT NECESSARILY PAY FOR, ALL TREATMENT FOLLOWING ASSESSMENT. IF THE AIM OF THE PROPOSED CHAP BILL IS TO ESTABLISH A COMPREHENSIVE, COORDINATED, HIGH QUALITY PROGRAM FOR POOR HIGH RISK AND DISADVANTAGED CHILDREN, IT FAILS SERIOUSLY IN THIS RESPECT BY EXCLUDING OBLIGATORY TREATMENT FOR "MENTAL ILLNESS, MENTAL RETARDATION, AND THE DEVELOPMENTAL DISABILITIES." WE MUST RECOGNIZE THAT THE PROBLEMS OF THESE CHILDREN ARE OFTEN MORE PSYCHOLOGICAL AND BEHAVIORAL THAN MEDICAL IN NATURE AND MEDICAL TREATMENT ALONE MAY SIMPLY BE WASTED IF WE DO NOT GET TO THE ROOT CAUSE OF THE PROBLEM.

"THE DIFFICULTIES EXISTING UNDER THE CURRENT EPSDT PROGRAM IN TERMS OF LINKING TOGETHER THE ASSESSMENT, SCREENING AND TREATMENT PROCESS HAS BEEN THOROUGHLY DOCUMENTED, AND WE BELIEVE THE CHAP BILL WOULD PRESENT EVEN MORE SIGNIFICANT DIFFICULTY IN THIS RESPECT. WE STRONGLY BELIEVE THAT IT IS BOTH A PROFESSIONAL AS WELL AS AN ETHICAL RESPONSIBILITY TO PROVIDE TREATMENT RESOURCES FOR DEVELOPMENTAL PROBLEMS IDENTIFIED THROUGH SCREENING AND ASSESSMENT.

CONCERN HAS ALSO BEEN EXPRESSED THAT THE CHAP BILL WILL PROVIDE INCREASED INCENTIVE FOR DIAGNOSING CHILDREN IN THESE CATEGORIES, WHERE THE PROVISION OF TREATMENT IS NOT OBLIGATORY, IN ORDER TO SAVE STATE FUNDS. THIS IS A HIGHLY UNDESIRABLE AND POTENTIALLY VERY DESTRUCTIVE SIDE EFFECT OF THE CHAP BILL AS IT NOW STANDS. THE PSYCHOLOGICAL LITERATURE IS REPLETE WITH EXAMPLES OF THE EFFECT OF CLASSIFICATION AND LABELING UPON FUTURE BAHAVIORS OF A CHILD AFFECTING THE PERCEPTIONS OF OTHERS, SUCH AS PARENTS AND TEACHERS. EXPECTATIONS CREATED BY THE LABELING PROCESS ITSELF, WITH OR WITHOUT TREATMENT RESOURCES BEING MADE READILY AVAILABLE, ARE BAD ENOUGH AND A SOURCE OF CONCERN TO US -- BUT WITHOUT MANDATED TREATMENT TO ACCOMPANY SUCH LABELING WE MUST STRENOUSLY OBJECT TO THIS ASPECT OF THE CHAP BILL.

THE GOAL OF PROVIDING PREVENTION, AND EARLY DETECTION, OF EMOTIONAL AND DEVELOPMENTAL DISORDERS IS A LAUDABLE ONE. WE KNOW THAT THE EARLIER A DISORDER IS TREATED, THE MORE SUCCESSFUL THE OUTCOME AND THE LESS LIKELIHOOD THAT IT WILL CAUSE OTHER PROBLEMS IN THE DEVELOPMENT OF THE CHILD. HOWEVER, THE CHAP BILL SHOULD GO FARTHER, NOT ONLY OBLIGATING THE STATE TO PAY FOR THE TREATMENT FOR DISORDERS DISCOVERED UNDER THE CHAP PROGRAM, BUT ALSO PROVIDING FOR ADDITIONAL FUNDS FOR THE DEVELOPMENT OF TREATMENT RESOURCES IN COMMUNITIES WHERE SUCH RESOURCES ARE LIMITED OR NONEXISTENT AT THIS TIME. THIS, AGAIN, IS ANOTHER DOCUMENTED PROBLEM OF THE IMPLEMENTATION OF THE EPSDT PROGRAM. THE PROVISION IN THE CHAP BILL WHICH PROVIDES FOR A CONTINUITY OF CARE AND CONTINUATION OF NEEDED TREATMENT FOR 6 MONTHS AFTER A CHILD HAS LOST MEDICAID ELIGIBILITY IS A SIGNIFICANT STEP TOWARD REMEDIATING SOME OF THE PROBLEMS OF THE EPSDT, ALTHOUGH WE WOULD URGE CONTINUED TREATMENT

UNTIL THE PROBLEM IS REMEDIATED.

A SECOND MAJOR AREA OF CONCERN FOR US, AS PSYCHOLOGISTS, IS THE DEVELOPMENTAL SCREENING ASPECT OF THE BILL. SCREENING IS A POOR TERM FOR THE COMPLICATED PROCESS INVOLVED IN SEPARATING THOSE EXPERIENCING PROBLEMS FROM THOSE WITH NORMAL DEVELOPMENT. ASSESSMENT, OR DEVELOPMENTAL REVIEW, WOULD BE A TERM MORE REFLECTIVE OF THE COMPLEXITY OF THE PROCESS. AS HAS BEEN REITERATED REPEATEDLY BY PROFESSIONALS INVOLVED IN THIS AREA, RECOGNIZING THE CULTURAL AND EHTNIC DIVERSITY OF OUR PLURALISTIC SOCIETY, NO SINGLE INSTRUMENT CAN BE USED FOR DEVELOPMENTAL ASSESSMENT FOR ALL AGES AND ALL FUNCTIONS, OR IN ALL ENVIRONMENTS. A VARIETY OF ASSESSMENT PROCEDURES, OF ADEQUATE RELIABILITY AND VALIDITY ARE AVAILABLE, DEPENDING UPON THE AGE OF THE CHILD AND THE DIMENSIONS TO BE ASSESSED. HOWEVER, FEW, OF THESE INSTRUMENTS HAVE BEEN DEVELOPED AND STANDARDIZED WITH THE POPULATION OF CHILDREN IN QUESTION -- THAT IS, HIGH RISK, POOR AND DISADVANTAGED CHILDREN ESPECIALLY THOSE FROM MINORITY POPULATIONS.

THE AMERICAN PSYCHOLOGICAL ASSOCIATION STANDS FIRMLY BEHIND THE CONCEPT OF PREVENTION OF EMOTIONAL AND DEVELOPMENTAL DISORDERS, BOTH FROM A HUMANITARIAN POINT OF VIEW AND FROM A CONCERN FOR REDUCING THE INCREASINGLY LARGE SUMS OF MONEY WHICH WE AMERICANS PAY FOR MEDICAL CARE. IN MISSOURI, FOR INSTANCE WE ESTIMATE A MENTALLY RETARDED OR SEVERELY EMOTIONALLY DISTURBED CHILD OR ADOLESCENT WHO MUST BE INSTITUTIONALIZED WILL COST THE STATE IN EXCESS OF $13,000 FOR EACH YEAR HE REMAINS INSTITUTIONALIZED. THE CONCEPT OF ASSESSMENT OF DEVELOPMENTAL PROBLEMS, AND THEIR TREATMENT AT AN EARLY STAGE, HOLDS CONSIDERABLE PROMISE, BUT IS

AN EXTREMELY COMPLICATED UNDERTAKING. THE STATE OF THE ART IS SUCH THAT FULLY ADEQUATE INSTRUMENTS, FOR THIS KIND OF ASSESSMENT ARE ONLY IN RUDIMENTARY STAGE OF DEVELOPMENT. CERTAINLY, AS A FIRST STEP, A HIGH PRIORITY FOR THIS PROGRAM SHOULD BE THE FUNDING OF RESEARCH WITH THE PRIMARY AIM OF DEVELOPING TECHNIQUES FOR TO NAME ONLY A FEW AREAS, THE ASSESSMENT OF PSYCHOSOCIAL, COGNITIVE, EMOTIONAL, AND LINGUISTIC FUNCTIONING IN CHILDREN FROM CULTURALLY AND SOCIALLY DIVERSE BACKGROUNDS.

GIVEN THE STATE OF THE ART AS IT NOW EXISTS, THE ASSESSMENT OF MENTAL ILLNESS, MENTAL RETARDATION, AND DEVELOPMENTAL DISABILITIES IS A COMPLEX TASK, REQUIRING THE SENSITIVITY AND JUDGMENT OF A TRAINED PROFESSIONAL. WHILE MEDICAL SCREENING AND TREATMENT FOR MEDICAL DISORDERS LENDS ITSELF TO A UNIDIMENSIONAL SCREENING TEST WHICH CAN BE READILY ADMINISTERED BY A TECHNICIAN WITH A PASS/FAIL OUTCOME, SCREENING FOR DEVELOPMENTAL PROBELMS PRESENTS A QUITE DIFFERENT PROBLEM. SECURING THE INVOLVEMENT AND COOPERATION OF THE PARENTS, EFFECTIVELY INTERVIEWING AND, WHEN APPROPRIATE, TESTING THE CHILD, AS WELL AS OBSERVING THE CHILD IN THE NATURAL ENVIRONMENT, ARE ALL PROCEDURES WHICH MAY BE REQUIRED AS PART OF THE DEVELOPMENTAL REVIEW AND/OR ASSESSMENT, AND WHICH REQUIRE THE ABILITIES OF A HIGHLY SKILLED PROFESSIONAL. ALTHOUGH THERE MAY BE SOME FUNCTIONS WHICH COULD BE PERFORMED BY A PARAPROFESSIONAL UNDER THE SUPERVISION OF A PROFESSIONAL, THESE WOULD NEED TO BE DETERMINED ESPECIALLY IN LIGHT OF THE SERIOUSNESS OF DECISIONS MADE FROM SUCH DATA, BY THE NEEDS OF THE APPROPRIATE RESEARCH. THE PROCEDURES TO BE USED IN EACH CASE MUST BE DETERMINED BY THE NEEDS OF THE INDIVIDUAL, AND CONCLUSIONS DRAWN MUST BE TEMPERED

BY A KNOWLEDGE OF WHAT IS NORMAL FOR THE CHILD WITHIN THEIR OWN CULTURE, AS WELL AS AN UNDERSTANDING OF THE EMOTIONAL AND MOTIVATIONAL CONDITIONS AFFECTING THE ASSESSMENT, AND THE AVAILABILITY OF SUPPORT FROM THE FAMILY AND COMMUNITY STRUCTURE. THESE ARE MOST DIFFICULT JUDGEMENTS TO MAKE, AND MOST CRITICAL ONES, SINCE LABELING THE CHILD AT AN EARLY AGE MAY ADVERSELY AFFECT SUBSEQUENT DEVELOPMENT FAR INTO THE FUTURE. MOREOVER, THE ABILITY TO INVOLVE THE PARENTS AND SCHOOLS, AND ENLIST THEIR COOPERATION, IS CRITICAL TO THE OUTCOME OF ANY ASSESSMENT OR TREATMENT PROCEDURE, SINCE A CHILD MUST FUNCTION WITHIN THE HOME AND SCHOOL ENVIRONMENTS AND ANY MEANINGFUL CHANGE TO HELP THE CHILD MUST OCCUR IN THE CONTEXT OF SUCH ENVIRONMENTS.

WE FURTHER SUGGEST THAT FUNDS BE MADE AVAILABLE FOR THE TRAINING OF PROFESSIONALS AND PARAPROFESSIONALS FOR APPROPRIATE UTILIZATION IN THIS DEVELOPMENTAL ASSESSMENT PROCESS. EPSDT HAS BEEN HAMPERED BY THE LACK OF ADEQUATELY TRAINED PERSONNEL AS WELL AS BY THE LACK OF TREATMENT RESOURCES. AS THE SITUATION EXISTS AT THIS CURRENT TIME, THE ABILITY AND SENSITIVITY OF THE PERSON PERFORMING THE ASSESSMENT IS MORE CRUCIAL THAN THE SPECIFIC INSTRUMENTS USED.

IN SUMMARY, THE CHAP BILL HAS ENORMOUS POTENTIAL FOR IMPROVING THE HEALTH AND WELFARE OF POOR AND DISADVANTAGED CHILDREN IN OUR COUNTRY AND HOLDS PROMISE IN THE LONG RUN FOR MINIMIZING THE COST OF MORE EXTENSIVE INTERVENTIONS AT A LATER POINT IN THE INDIVIDUAL'S LIFE. THE STATED INTENT OF THE PROGRAM AND MANY OF ITS PROVISIONS ARE EXTREMELY HOPEFUL. PROVISIONS SHOULD,HOWEVER, BE BUILT INTO THE BILL WHICH ALLOW FOR THOROUGH EVALUATION OF THE EFFECTIVENESS

OF THE PROGRAM IN BEHAVIORAL, OBSERVABLE TERMS. THE AMERICAN PSYCHOLOGICAL ASSOCIATION SUPPORTS THE GRADUAL PHASING-IN OF A COMPREHENSIVE, HIGH-QUALITY HEALTH ASSESSMENT AND TREATMENT PROGRAM FOR ALL MEDICAID CHILDREN WHICH INCLUDES CONCERN FOR SOCIAL, EMOTIONAL, INTELLECTUAL AND DEVELOPMENTAL FUNCTIONING. WE OFFER OUR RESOURCES AND EXPERTISE TO ASSIST IN ANY WAY POSSIBLE TO INSURE THAT A SIGNIFICANT NATIONAL HEALTH PROGRAM OF ASSESSMENT AND TREATMENT FOR HIGH RISK POOR AND DISADVANTAGED CHILDREN CAN BE DEVELOPED AND EFFECTIVELY IMPLEMENTED.

Mr. ROGERS. Thank you very much, Dr. Barclay. We understand you do have to go. We will excuse you at this time.

Mr. Martin is here and can answer any questions. We welcome you, Mr. Clarence Martin, Executive Director and General Counsel of the Association for the Advancement of Psychology. Also the committee is pleased to have Mr. Jay Cutler, who for so many years worked on legislation so effectively.

I understand Ms. Oliver has a time problem on transportation. Is there anyone else?

Ms. Oliver, we would be pleased to receive your statement. It will be made a part of the record.

STATEMENT OF JULIA OLIVER

Ms. OLIVER. Mr. Chairman and members of the subcommittee: My name is Julia Oliver and I reside in Tallapoosa County, Alabama. I am appearing today in behalf of the Mental Health Association, of which I am a member of the Board of Directors and on the Committee on Legislation and Services. In addition, I am a social worker who has worked in Bryce Mental Hospital. I am the former Commissioner of Public Welfare in Alabama and am now an administrator in the Department of Pensions and Security and I am familiar with the administration of the early, periodic screening, diagnosis, and treatment (EPSDT) program.

The Mental Health Association is the national citizens' voluntary organization, with membership approaching one million, representing consumers of mental health services. Our goals are to work for improved methods in the research, prevention, detection, diagnosis and treatment of mental illness, as well as the promotion of good mental health.

Mr. Chairman, we are very grateful for this opportunity to present our views to the Subcommittee on Health and the Environment.

The Mental Health Association believes that it is just as important for CHAP to provide treatment for the mentally ill as for the physically ill. We, therefore, urge the House Subcommittee on

Health and the Environment to delete the discriminatory and inequitable language in H.R. 6706 that states: "...but not necessarily including those for the treatment of mental illness, mental retardation, or developmental disabilities." This language is contained on page 3, section 3, subparagraph G, lines 9, 10, and 11 of the Child Health Assessment Act (CHAP).

The Mental Health Association has consistently been an advocate for improved programs and services for mentally ill children. The Association believes that a total system of care must be available for children suffering from mental illness, and treatment programs for children from all income levels are essential. The CHAP proposal clearly discriminates against low-income mentally ill children and will be another barrier to equal opportunity for treatment.

Unless CHAP mandates the treatment services for the mentally ill, many children will be deprived of these necessary and important services. This discrimination would compound an existing practice whereby the Medicaid program has consistently and arbitrarily discriminated against one segment of the population—the mentally ill people: only 29 States, as of June 1, 1976, were providing the Medicaid option to cover care for patients under 21 in psychiatric hospitals. Not all States provide outpatient care.

To mandate the screening and diagnosis of eligible children and then not make provisions for the recommended treatment seems inconsistent with the goals of H.R. 6706. Those stated goals are to strengthen and improve the EPSDT program for children whose families do not have adequate resources to cover the cost of such care and to provide further incentives to States to arrange for—and encourage—quality health care for children. Authorizing treatment for physical but not for mental illness is rather like saying that under CHAP children can be treated from the neck down but not from the neck up. Why is it necessary to make this unfair, arbitrary distinction?

Gentlemen, one example of the value of early diagnosis and treatment is the story of a child with whom we have had a personal experience who did not come to the attention of authorities until he was 12 years of age. All of his life he exhibited behavioral problems. Because of his acting out behavior his mother was unable to cope, placed him in foster care and immediately deserted. His father refused to accept responsibility for his son's behavior. Although some treatment was given while in foster care this was shortlived. His behavior finally culminated in expulsion from school and he eventually went on the streets—drugs led to institutionalization and later his criminal behavior resulted in being imprisioned. Perhaps early diagnosis and treatment would have helped this boy and he would have led a useful life.

Mental illness affects at least 10 percent of our population including children and youth and it has been said by the American Medical Association to be the country's number one health problem. Yet there still remains discrimination, inadequate financial support, and stigma for those who suffer from mental illness. Partially because of recent successful court cases of litigation, especially in right to treatment cases, and legislation, such as the Education for All Handicapped Children Act—Public Law 94-142—

the historical neglect of mentally ill persons is changing. Surely treatment services for the mentally ill children should be included in such an important health program as envisaged in H.R. 6706.

The incidence of mental illness is increasing, and services that focus on prevention, early detection, and treatment are essential. Children who are mentally ill are grossly underserved. In a 1976 U.S. Office of Education report, it was estimated that 55 percent of the Nation's 7.8 million handicapped children are served by educational programs. The emotionally disturbed children were the most unserved; only 13 percent of those suffering such handicaps were served. The CHAP proposal is continuing to view mentally ill children as ones who will be served only after the needs of others are met.

Delay in treatment compounds the problems of the mentally ill child and increases the chances that long-term, expensive hospitalization will be necessary for them. In addition, treatment for emotional problems is interrelated with physical health. Some studies, including the 1975 California Psychological Health Plan, have shown low costs for the treatment of physical illness when adequate mental health services are available. According to Kaiser-Permanente and other studies, more than half the complaints in doctor visits have a significant psychological basis or component.

It seems logical and cost effective to invest in services that focus on prevention, early detection, and treatment for high-risk children. These services could help increase future earning capability, prevent institutionalization, and prevent chronic dependency. The CHAP program has potential for being an important means of prevention. The treatment services could prevent the problems from being compounded and made more complex. These services could help a child develop to his/her maximum potential.

By not mandating coverage of critically needed treatment services, progress will be further delayed in meeting the needs of children whose mental and physical health is adversely affected due to the effects of poverty. The Joint Commission on the Mental Health of Children in 1969 listed some facts that indicated a need for priority attention to physical and mental health needs of poor children. These facts included:

"Analysis of head start children showed that at least 10 percent were judged to be crippled in their emotional development by the age of 4 years. In some cities, this figure is estimated at 20 to 25 percent."

"The early results of current study of mental and emotional disorders among children in Manhattan show that rates are much higher for poor children and for children who are members of oppressed minority groups."

Treatment of mentally ill children is not more expensve than many of the conditions covered in CHAP. In 1973 Blue Cross-Blue Shield Federal high option had only 2.7 percent of its admissions for mental conditions for patients under 18 years of age. Without adequate diagnosis and treatment, the costs of mental illness to society are great, because the highest proportion of the cost is due to decreased productivity because of mental illness—not treatment costs. Of the [NIMH, 10/75, Division of Biometry and Epidemiology]

$37 billion estimated costs, $14½ billion is for direct care, and $19 billion is because of decreased productivity and related indirect costs. All of which could have been decreased if services had been available to individuals at an earlier age.

The CHAP proposal will not resolve the serious lack of programs serving the children who have—or could—potentially have emotional problems. The actions taken regarding the treatment of mental illness in this legislation could have a major impact on how national insurance proposals are drafted.

Community Mental Health Centers cannot continue to serve children and youth unless other Federal programs such as CHAP become part of the case of continued financial support created by the Federal seed money for these centers.

Mr. Chairman, with the current wording of the legislation, the rights and priorities of the mentally ill, mentally retarded, and developmentally disabled continue to be neglected. The Mental Health Association believes that this capricious and arbitrary discrimination against low-income mentally ill children can—and should—be eliminated by striking lines 9, 10, and 11 of Section 3, subparagraph G of H.R. 6706 . Under the provisions as they now exist, there is a possibility that Some states would label children—mentally ill, developmentally disabled, or mentally retarded—as a means of avoiding providing otherwise mandated services. You are able to remove the obstacles put forth in the legislation and allow all of these children to have an equal opportunity to receive assistance in overcoming their handicaps at an early stage in their growth and development. We thus urge you not to allow these children to go without treatment and that you mandate this treatment for mentally ill as well as physically ill children. Without prevention and treatment the costs are high—in terms of human life, usefulness to society—and in extremely high fiscal costs.

Mr. Chairman, some children who are mentally ill will either be relieved from their pain or their suffering will continue. Their fate rests largely in your hands and the action by this committee.

Thank you for the opportunity of presenting the views of the Mental Health Association.

Mr. ROGERS. Thank you for a most helpful statement and for your presence here. We understand your time element and we will excuse you. Thank you for your presence.

Dr. Nelson.

STATEMENT OF JOHN B. NELSON III, M.D.

Dr. NELSON. Mr. Chairman, the hour is late and fatigue is setting in.

Mr. ROGERS. I understand you are accompanied by Debora Kramer, who is Executive Director of your Association. We welcome you.

Dr. NELSON. I will make a very short statment in recognition of the lateness of the hour.

We want to cover five areas that we believe require attention. The first is the inclusion of mental health treatment; the second, an effective outreach component in the program; third, increasing

initiatives for participation of qualified providers; fourth, mandating State performance criteria; and fifth, developing the States' capacity to deliver CHAP services.

We will be submitting testimony and data that will support these areas. Thank you.

[Testimony resumes on p. 594.]

[Dr. Nelson's prepared statement and appendixes follow:]

STATEMENT OF JOHN B. NELSON III, M.D., PRESIDENT

AMERICAN ASSOCIATION OF PSYCHIATRIC SERVICES FOR CHILDREN

Mr. Chairman, distinguished colleagues;

It is indeed a pleasure to appear before you today to present our views on so important a piece of legislation as HR 6706, the Child Health Assessment Act of 1977. My name is John Nelson. I am a child psychiatrist by training, the medical director of the Brookline Mental Health Center in Brookline, Mass., and the current president of the American Association of Psychiatric Services for Children. Accompanying me today, is Mrs. Debora Kramer, Executive Director of AAPSC. As the largest organization of children's mental health services in the country, The AAPSC, whose member services employ over 8,000 child mental health professionals from all the disciplines, wishes to commend the stated intent of this legislation.

It is unnecessary for us to reiterate the declaration of purpose contained in Sec. 2 of the Bill. We certainly agree on the goal of making quality health care available to those children whose families do not have such care. In many respects the CHAP bill does improve and expand upon the Early Periodic Screening Diagnosis and Treatment program. In fact the legislation appears to be responsive to many of the criticisms that have been leveled against EPSDT in the few years it has been operational. It adds to the Medicaid and EPSDT eligible population, those children under the age of six (although we would like to see this amended also to include children from 6 to 21) whose family structure presently makes them ineligible for services. It speaks to the issue of continuity of care by continuing eligibility for medical assistance for six months after the family is no longer Medicaid eligible because of higher income. It increases the financial incentives for the States by augmenting the Federal match. It attempts to improve upon the quality and continuity of care by asking the

States to enter into agreements with comprehensive care providers for health resource development in areas with a shortage of comprehensive care providers. And it mandates treatment for all conditions found in the assessment of children with certain notable and shortsighted exceptions; namely, mental illness, mental retardation, developmental disabilities, and for certain kinds of dental care.

1. Non-Mandatory Coverage of Treatment for Mental Illness

The limitation on the treatment of mental illness poses an obvious problem to those of us engaged in the provision of mental health services to this group of particularly vulnerable children. The bill as written in fact takes a regressive step from the original enabling legislation for EPSDT, which, although not mandating federal financial participation in the treatment of mental illness, did mandate referral for treatment services. As the present legislation reads, only treatment services presently available in the individual State's Medicaid plans would be covered by CHAP. Since inpatient services are now a State option, as are clinic services, mental health treatment services will not be available to the CHAP children in those states that do not include clinic and inpatient services in their Medicaid plans. Only 29 States presently include inpatient services: 42 include clinic services, but not all of the 42 include mental health clinic services.

The AAPSC has questioned many of the DHEW officials who participated in the drafting of the HR 6706. We were told that the exclusion of mental health treatment services from the mandatory provisions of the Bill was due to the lack of available data on cost and utilization of mental health treatment services by persons under 21 years of age. We find this reasoning untenable. In fact, we would like to suggest that it places us in a "Catch 22" situation. AAPSC has attempted to get data from the Medical Services Administration about the current experience with mental health services to individuals under 21 in the Title XIX

program for many years. We have asked: "How many children are being served in the inpatient program and what are the costs? How many children are being served on an outpatient basis through clinic, outpatient, hospital, and individual provider services and what are those costs?" What we have been told in the past is that HEW doesn't know, that the data are not broken down this way. Up until July of 1977, we were also told that HEW didn't care about collecting such data, that there were too many other concerns about the operation of the Medicaid program to bother with taking a look at the experience in the mental health area. When the inpatient option became law we even suggested to the Department , that it would be relatively simple to collect the inpatient data on mental health services to individuals under the age of 21 at the time of the initial implementation of the program, but our requests always fell on deaf ears. In July, 1977, we received from the acting director of the Medicaid Bureau, written assurance that the collection of outpatient cost and utilization data would become a high priority in their FY'78 Evaluation plan. This assurance comes a little late for us to answer HEW's insistence that the reason for the exclusion of mental health treatment is the fact that so little is known about the costs of treating mental illness in children. Actually, not a great deal of data are available, but that is only because no one has been interested in funding studies that would permit the collection of such data. A policy paper prepared by a Public Health Analyst on the staff of the Assistant Secretary for Planning and Evaluation cites the lack of research resources as one of the primary reasons for the scarcity of prevalence studies in the area of children's handicapping conditions (John Dempsey, "Handicapped Children and Disability: A Policy Overview Paper,"October 1976). In fact, this same paper states that there is very little accurate data on the entire population of handicapped children in the nation, but that data in the area of the mentally ill are most lacking. One can take

the argument outlined in Dr. Dempsey's paper one step further: there have been no resources available for the collection of prevalence data and there have been no resources available for collecting cost and utilization data.

The AAPSC has attempted to gather, both from its own membership and from other sources known to us, what prevalence and cost/utilization data we could, given the resources we could muster to collect it. What we have found are contained in the tables appended to this statement. What little is available does confirm what we have been saying for many years based on our own humanitarian instincts, namely, that emotional disabilities are widespread among the high risk children served by the EPSDT program, that the bulk of these children can be served by relatively short term intervention, and that for the very small percentage who need the lengthier and more costly inpatient and residential care, the utilization and cost experience in the small sampling of States participating in the program, does not merit HEW's decision to remove treatment of mental illness from the mandatory provisions of the Bill (see Appendix I).

In fact, we would suggest to the distinguished members of this Committee, that HR 6706 as presently constituted provides an incentive to those States who are not presently participating in the inpatient and clinic options to place children who have been assessed by the program in the diagnostic categories where States need not be financially responsible for treatment. This categorical approach to what is heralded to be a program promoting "more comprehensive, continuing primary and preventive health care," is contradictory to the stated purpose of the legislation. It would appear to us that it would be far more rational to consider the CHAMPUS (Civilian Health and Medical Program of the Uniformed Services) experience of limiting costs through quality assurance measures such as peer review and standard setting, rather than artibrarily delegating the health services relative to emotional disabilities as unnecessary

and too costly components for inclusion in a comprehensive health care program. The exclusion makes no sense to us either from a humanitarian or from a cost effective point of view.

Our experience in the field, our participation in preventive as well as diagnostic and treatment activities have led us to conclude that for any illness it is far more costly in the long run not to treat it when it is first uncovered through screening assessment and diagnosis. Good mental health is a part of good comprehensive health care. To consider it as a separate and distinct entity from the entire spectrum of health is to contradict what has become a truism today: that in dealing with prevention, primary and comprehensive health care for any individual, you must deal with the whole person. To be a little facetious, this Bill attempts to separate the head from the body. Our experience has demonstrated the devastating impact emotional disability in a family member has on an entire family. If the resources were made available to collect such data, we would be able to demonstrate that mental illness in a child leads to loss of productivity in an entire family. Parents miss days from work because school systems cannot deal with disruptive children and someone must be home to supervise the child.

Untreated disabilities can lead to severe acting out problems in the adolescent years, problems which can tie up the juvenile justice system for months, even years on end. The average cost of a one year's stay in a juvenile detention facility in the State of New York is $20,000 a year. Society is bearing the cost of those placements, now. Many future placements could be avoided if the children were given access to treatment resources at an early age.

We pay a lot of lip service to the fact that children are our most precious resource and that the guardianship of their health is one of the most important activities we as a society can pursue. To say then, as this Bill as presently

written appears to say, that we don't care about their mental health, is tantamount to saying that we care about our most precious resource only so long as we don't have to deal with the uncomfortable fact that we may have to channel some of our fiscal resources in new directions if we are to insure the future health of our nation.

We would suggest, then, that this Committee drop the present exemptions for mandatory treatment services from this legislation. We would like to see Federal reimbursement available for all health services for problems uncovered through screening and assessment.

There are several other areas of the Bill to which we would like to call your attention.

2. Strengthening the Outreach Component of the Program

Our own experience in providing services to the low-income population has taught us that an effective outreach program is one of the most important pieces in insuring access to care. Currently, States must inform families with Medicaid eligible children about EPSDT and encourage and help them to utilize services. However, inadequate outreach is demonstrated by the extremely low rates of participation in EPSDT. Approximately 25 percent of eligible children were screened in the last year. Few states use the method of outreach known to be most effective in reaching low-income facilies: personal contact by those people in their communities known and trusted by them. For a relatively small cost, the CHAP program could be greatly strengthened by: a) establishing performance standards for outreach which require States to assess a reasonable proportion of eligible children; b) providing financial incentives for outreach by increasing the Federal match to 90 percent to States for outreach services performed by private, non-profit organizations or individuals with strong community ties (e.g. Head Start programs, community clinics, etc.); c) requiring States to earmark a small

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proportion of funds for public education and for efforts to enroll children in the program. Those States which fail to attract to the program a reasonable proportion of eligible children should be required to develop a new outreach program that mandates the use of workers and/or organizations from the local communities.

3. Encouraging Qualified Providers to Participate in CHAP

One of the problems identified in the studies of the operation of the EPSDT program is that many of the qualified providers have chosen not to participate in the program. The reasons for this are varied but HR 6706 as written provides few incentives to participation. The AAPSC recommends that CHAP be amended to require States to identify qualified providers, including child mental health practitioners and to encourage their participation in CHAP by offering satisfactory administrative arrangements such as adequate reimbursement rates and prompt claims payment. We would urge that the Secretary be required to review each State's performance in this area on an annual basis.

The criteria in the bill defining CHAP providers should be modified to clarify the fact that providers such as Head Start programs, mental health clinic programs, etc. which can assure that children receive CHAP services do qualify, even though they themselves do not provide all services.

4. Requiring Performance Criteria

CHAP should be amended to establish performance criteria that States be expected to meet. The criteria should include the enrollment of a reasonable proportion of eligible children in the program and the provision of the required assessment and treatment services. The Secretary should be required to gather data on an annual basis in order to assess States' performance in enrolling eligible children in CHAP and in providing a reasonable proportion of eligible children with health assessments and treatment services. CHAP should require

that all States meet all program requirements and that the sanctions available to the Secretary be used for any lapse in program responsibility.

5. Developing State's Capacity to Deliver CHAP Services

The CHAP provisions of Title XIX can be distinguished from the rest of the Medicaid program by the fact that States are charged with seeing that children are served by the program. If the program is to be effective, then States must see to it that the requisite services are in place for the children in need. This requires a planning and administrative component which is not adequately addressed in HR 6706. States should be required to submit to HEW an annual plan, developed with the opportunity for substantial public input, that indicates how the requirements of CHAP are to be met. It should be required that this plan be utilized by the State Health Planning Agency to facilitate the integration of planning for adequate health services for children with the planning for the State population as a whole.

We realize that Medicaid in general and CHAP in particular are reimbursement mechanisms and not what are usually considered to be health service programs. Nevertheless, we submit that with this requirement, CHAP can become an effective vehicle for identifying shortage areas, and with proper and adequate administrative support and monitoring can be utilized in conjunction with other health delivery and health planning programs to aid States in identifying and filling gaps in the delivery system.

We would like at this point to call the Committee's attention to an already identified gap in the service delivery system, and that is in the area of children's community mental health services. If the Congress should accept our recommendation that mental health treatment services be a mandatory component of the program, then it would be wise to bear in mind that a greatly strengthened children's mental health program must be part of the Community Mental Health

Centers' renewal legislation that will be considered by this Committee later this year.

We would like to conclude our statement by affirming our support for the intent of the CHAP legislation. As one of the participants in the AAPSC Conference on Developmental Screening and Assessment in the EPSDT program observed in a working paper prepared for the Conference, one of "EPSDT's significant contribution[s] to the field of child health has been to uncover the present health system's inability to provide comprehensive and continuous health service for poor children, even given a financing mechanism." (Anne-Marie Foltz, "The Policy Dilemma, Screening and Cost-Effectiveness," Feb. 1977). Many of the reasons for this failure can be dealt with if the Committee accepts our suggestions for modification of HR 6706.

As AAPSC has emphasized in the Prologue to its report on Developmental Review in the EPSDT program, a copy of which is appended to this statement (Appendix II),

> "The legislation authorizing EPSDT (CHAP) makes it national policy that the development of our children, our future citizens, be safeguarded so as to insure that each child reaches maturity functioning at a maximum level of development. This goal is more than the finding, the study, and the treatment of disease. The guardianship of the health of children is in the national interest as well as in the interest of the individuals; this is the essence of EPSDT (CHAP)."

Mr. Chairman, this Committee has the opportunity to translate this statement into reality. It is our hope that you will do so on behalf of all children and youth in need. Thank you very much.

APPENDIX

I

TITLE XIX STATE INPATIENT DATA

Wisconsin

State and County Mental Health Inpatient $'s (1976)

	Total	Federal
Increase County Hospitals	1,600,000	960,000
State Hospitals	1,531,700	919,020
Prior Plan	3,766,200	2,259,720
Total Title XIX	6,897,900	4,138,740

Pennsylvania

12 State-owned and operated hospital (1 specifically for children and adolescents)

March, 1977 - *300* children and adolescents in the hospitals projected annually - $6,500,000 Federal assistance *($21,666.67/child)*

Eastern State Hospital (Trevose) - average length of stay:

3 months - 1 year:	25%
1 - 2 years:	50%
2 + years:	25%

Reference: Correspondence to AAPSC from State Departments of Public Welfare

AAPSC SURVEY OF MEMBER SERVICES (1975 STATISTICS)
(Data Based on 70 Respondents)

Setting	Children Seen					
	Total Number	% By Sex		% By Age		
		Boys	Girls	0-5	6-13	14-18
Outpatient	43,707	62.1	37.9	9.9	54.7	35.4
Partial Hosp/Day Care	2,001	69.1	30.9	26.2	62.5	11.3
Residential Care	704	77.8	22.2	.5	55.1	44.4
Inpatient Care	1,621	61.3	38.7	3.7	34.6	61.7
Total	48,033	62.6	37.4	10.2	54.4	35.4

INCOME OF CASELOAD (by Percent)

	Percent		Percent
$3,000 & Under	16.8	$10,001 to $13,000	16.8
$3,001 to $7,000	23.9	$13,001 to $20,000	13.1
$7,001 to $10,000	21.9	More than $20,000	7.4

AAPSC Survey (contd.)

Number of Visits Required for Diagnosis

1-4	65.3%
5-8	33.3%
9+	1.4%

Length of Treatment

		% Served In	% Terminated After
A. Outpatient	Hours		
	1-6	20.2	20.2
	7-12	20.2	40.4
	13-30	26.7	67.1
	30-90	25.2	92.3
	90+	7.8	100.0
B. Daycare	Months		
	0-3	11.0	11.0
	3-6	12.2	23.2
	6-12	37.4	60.6
	12-24	32.2	92.8
	24+	7.2	100.0
C. Inpatient Hospital	Weeks		
	0-1	11.3	11.3
	1-3	25.4	36.7
	3-12	29.9	66.6
	12+	33.4	100.0
D. Residential Center	Months		
	0-3	10.0	10.0
	3-6	13.6	23.6
	6-12	23.5	47.1
	12-24	44.0	91.1
	24+	8.9	100.0

Needed Services (in decreasing order)

	All Ages	0-5	0-12	13-18
Residential	1	1	1	1
Day Treatment	2	2	2	2
Parent Education	3	4	4	3
Hospital	4	3	3	4
Special Education	5	5	6	5
Outpatient	6	6	5	6

AAPSC Survey (contd.)

Concerns (Top 5 in decreasing order)

1. Finances
2. Program Evaluation
3. Quality Assurance
4. Staff Salaries
5. Training

Sources of Funds to Agencies

	Percent
Voluntary (United Way, etc.)	12.0
Fees: Patient, self pay	9.7
Patient, insurance	12.2
Fees: Contract for Services (Consult. & Ed. etc.)	9.5
Local Tax Levy	9.5
State Allocation	26.1
County and City	3.0
Federal Funds:	
Staffing Grant	3.3
Part F, Children's Services	2.1
Research	.7
Title XIX	1.5
Title XX	.4
Endowment Funds	1.9
CHAMPUS	1.8
Other	6.3

Allocation of State Monies

A) Directly 35%*
Via Local Government Body 75%*

B) Difficulties with restrictions placed on funds

Yes	58%
No	42%

*Some get monies both ways, hence percentage totals greater than 100.

Reed - Table 13

Blue Cross/Blue Shield Federal, High Option (1973)
Hospital Care for Mental Disorders as % of Care for all Conditions

Age	All Conditions	Mental	Mental as % of all	
0-18	50.5	1.3	2.7%	Admission rates/1000
all	118.5	4.9	4.2%	
0-18	249.4	34.4	13.8	Days of Care rate/1000
all	926.3	86.9	9.4	
0-18	$25.33	2.42	9.6%	Covered Charges/person
all	89.61	5.95	6.6	

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Blue Cross/Blue Shield-Federal (1974)

High option-basic
5.9 Claims/1000 covered population for mental disorders
1.7% of total claims
benefits paid $1.45/person covered (3.6% total benefits)

High option-supplemental (non-member hospitals)
1.2 claims/1000 population 18.3% total
$1.28/covered persons 65.2% total

High option-supplemental (physicians)
20.8/1000 (18.7% total)
$3.75/per 53.4 total (after deductible and coinsurance)

Reference: Louis S. Reed, Ph.D
Coverage & Utilization of Care for
Mental Conditions under Health Insurance
Various Studies, 1973-74
American Psychiatric Association, 1975

TABLE 12

Blue Cross and Blue Shield Plan for Federal Employees, High Option, 1973
Basic Inpatient Hospital Benefits for Mental Disorders,
by Age and Sex (in General Hospitals and Member Mental Hospitals)

Age	Male	Female	Total		Male	Female	Total	
	Admissions–Rate per 1,000				*Average Length of Stay (Days)*			
Under 19	1.3	1.4	1.3	27% of	27.3	23.8	26.5	145%
19-34	7.1	9.2	8.3	avg.	21.0	17.7	19.0	of avg.
35-44	6.3	10.7	8.6	rate	13.6	15.8	15.1	rate
45-54	7.6	10.1	8.9		13.5	16.4	15.2	
55-64	6.7	6.9	6.8		15.0	18.1	16.5	
65 and over	3.5	4.0	3.8		17.3	18.4	17.9	
All ages	4.2	5.6	4.9		17.5	17.7	17.6	
	Days of Care–Rate per 1,000				*Average Covered Charges per Covered Person*			
Under 19	34.7	34.1	34.4	40% of	$2.39	$2.45	$2.42	41%
19-34	149.4	163.3	157.2	avg.	10.47	11.62	11.11	of avg.
35-44	86.4	169.5	130.0	rate	5.82	11.46	8.77	rate
45-54	103.4	166.7	134.7		7.08	11.39	9.24	
55-64	100.0	125.6	112.5		6.90	9.16	8.00	
65 and over	60.9	74.4	66.0		2.66	2.75	2.71	
All ages	73.3	100.1	86.9		4.98	6.90	5.95	

TABLE 14

Blue Cross and Blue Shield Plan for Federal Employees,
High Option, 1973
Basic Hospital Outpatient Benefits for
Mental Disorders, by Age and Sex

Age	Male	Female	Total	
	Admissions–Rate per 1,000			
Under 19	0.1	0.2	0.2	33% of
19-34	0.8	1.1	1.0	avg.
35-44	0.6	1.6	1.1	rate
45-54	0.7	1.6	1.1	
55-64	0.5	1.3	0.9	
65 and over	0.4	1.0	0.7	
All ages	0.4	0.8	0.6	
	Covered Charges per Covered Person			
Under 19	*	*	*	
19-34	$0.02	$0.03	$0.02	
35-44	0.02	0.04	0.03	
45-54	0.02	0.04	0.03	
55-64	0.01	0.03	0.02	
65 and over	0.01	0.01	0.01	
All ages	0.01	0.02	0.01	

*Less than one half of one cent.

TABLE 15

Blue Cross and Blue Shield Plan for Federal Employees,
High Option, 1973
Basic Surgical-Medical Benefits for
Mental Disorders, by Age and Sex

Age	Male	Female	Total	
	In-Hospital Medical Claims per 1,000			
Under 19	1.3	1.5	1.4	27%
19-34	7.7	9.7	8.8	of avg.
35-44	6.6	11.8	9.3	rate
45-54	7.4	11.4	9.4	
55-64	6.4	7.9	7.2	
65 and over	3.3	4.3	3.8	
All ages	4.2	6.2	5.2	
	Visit Days per 1,000			
Under 19	24.5	26.2	25.4	39%
19-34	103.7	123.9	115.0	of avg.
35-44	70.4	131.4	102.4	rate
45-54	76.8	125.7	101.3	
55-64	70.4	94.4	82.2	
65 and over	35.7	51.8	44.1	
All ages	52.7	76.1	64.6	
	Benefits Paid per Covered Person			
Under 19	$0.45	$0.50	$0.47	37%
19-34	2.14	2.52	2.35	of avg.
35-44	1.39	2.72	2.09	rate
45-54	1.49	2.61	2.05	
55-64	1.36	1.85	1.60	
65 and over	0.50	0.72	0.62	
All ages	1.02	1.52	1.28	

Reference: Louis S. Reed, PhD
Coverage & Utilization of Care for Mental Conditions under Health Insurance Various Studies, 1973-74
American Psychiatric Association, 1975

TABLE 16

Blue Cross and Blue Shield Plan for Federal Employees, High Option, 1973
Supplemental Benefits for Mental Disorders, by Age and Sex

Age	Males	Females	Total		Males	Females	Total	
	Hospital Cases per 1,000 Population				*Hospital Charges per Person Covered*			
Under 19	0.8	0.6	0.7	54% of avg.	$0.98	$0.74	$0.87	64% of avg.
19–34	2.9	2.4	2.6		3.76	2.28	2.93	
35–44	1.2	2.1	1.7		0.92	1.55	1.25	
45–54	1.2	2.2	1.7		1.02	1.92	1.47	
55–64	1.1	1.5	1.3		1.02	1.60	1.30	
65 and over	0.8	1.0	0.9		1.02	1.29	1.16	
All ages	1.2	1.4	1.3		1.34	1.36	1.35	
	Physicians' Services—Cases per 1,000 Population				*Physicians' Charges per Person Covered*			
Under 19	7.1	4.8	6.0		$1.61	$1.10	$1.36	
19–34	44.9	59.1	52.8		13.85	15.95	15.02	
35–44	32.7	44.0	38.8		9.38	10.64	10.04	
45–54	17.3	26.3	21.8		3.78	5.50	4.65	
55–64	8.7	13.7	11.1		1.82	2.70	2.15	
65 and over	3.2	5.7	4.5		0.37	0.53	0.46	
All ages	18.1	21.8	19.0		4.26	5.27	4.77	

Total Supplemental Benefits Paid by Program per Person Covered

	Males	Females	Total	
Under 19	$2.45	$1.71	$2.08	38% of avg.
19–34	15.01	15.80	15.45	
35–44	8.78	10.77	9.82	
45–54	4.14	6.83	5.49	
55–64	2.33	3.91	3.10	
65 and over	1.42	2.30	1.88	
All ages	4.90	5.93	5.42	

TABLE 17

Blue Cross and Blue Shield Plan for Federal Employees,
High Option, 1973
All Benefits Paid for Mental Disorders per
Person Covered, by Age and Sex

Age	Male	Female	Total	
Under 19	$5.29	$4.67	$4.98	39% of avg.
19–34	27.63	29.96	28.93	
35–44	16.01	24.99	20.71	
45–54	12.73	20.87	16.82	
55–64	10.60	14.95	12.73	
65 and over	4.59	5.79	5.22	
All ages	10.91	14.37	12.67	

Reference: Louis S. Reed, Ph.D
Coverage & Utilization of Care
for Mental Conditions under Health
Insurance Various Studies, 1973-74
American Psychiatric Association, 1975

DATE FROM QUEBEC HEALTH INSURANCE BOARD

TABLE 6

Number and Cost of Psychiatric Services per 1,000 Beneficiaries, by Age and Sex, 1973

	Male		Female		Total	
Age	Number	Cost	Number	Cost	Number	Cost
0-1	4	$45	3	$45	3	$45
1-4	10	120	6	84	8	103
5-9	27	396	17	225	22	313
10-14	36	551	25	373	30	464
15-24	96	1,435	154	2,549	125	1,987
25-34	190	3,160	373	6,379	281	4,770
35-44	180	2,871	361	5,834	270	4,352
45-54	164	2,446	285	4,207	226	3,345
55-64	144	2,048	215	2,957	181	2,521
65+	83	1,092	127	1,633	108	1,401
Total	110	$1,700	191	$3,030	161	$2,370

Number
Avg: ages 0-14 = 16
Avg: ages 0-24 = 38

Cost
Avg: ages 0-14 = $231.00
Avg. ages 0-24 = $582.00

TABLE 7

Average Cost of Psychiatric Service (Cost per Service), by Age and Sex, 1973

Age	Male	Female	Total
0-1	$10.99	$16.57	$13.17
1-4	11.85	13.31	12.39
5-9	14.53	13.14	14.01
10-14	15.27	15.12	15.21
15-24	14.94	16.53	15.91
25-34	16.63	17.12	16.95
35-44	15.92	16.17	16.09
45-54	14.87	14.77	14.81
55-64	14.23	13.75	13.93
65+	13.16	12.83	12.94
Total	15.39	15.83	15.67

Age 0-14 Avg: $ 13.70
Age 0-24 Avg: $ 14.14

Reference: Louis S. Reed, Ph.D.
Coverage & Utilization of Care for Mental Health Conditions under Health Insurance Various Studies, 1973-74
American Psychiatric Association, 1975

CHAMPUS

1) less than 2% utilization of mental health services for past 3 years
   (1.82% in FY'75)
2) per user/per year cost for mental health services in FY'75 = $1,181 less
   coinsurance and deductible
   on per capita basis: mental health services/person = $20.90
3) mental health services used 17.7% of total health benefit fund

Average duration of hospital stay (all conditions) = 8.6 days
childhood behavior disorder: Average duration = 47.4 days
personality disorders: all age average duration = 20.4
age 5-14 average duration = 53.

diagnosis of schizophrenia and aged 1-14
4% of all admissions in diagnosis
18% of hospital days (58. days average 1-14)
(12.1 days average all ages)

Personality Disorder

	Admissions	Hospital Days	Average Stay
Age 5-14	12%	31%	53
All ages	100%	100%	20.4

Reference: Draft of Paper by Herbert Dorken, PhD
Langley Porter Institute,
University of California
San Francisco, CA 94143
2/10/77

Statistical Note #92

Patient Care Episodes, 1971 - All Facilities

	Total			Inpatient			outpatient		
	#	%	rate*	#	%	rate*	#	%	rate*
All Ages	4,038,143	100	1967.8	1,721,389	42.6	838.8	2,316,754	57.4	1129.0
under 18	771,874	100	1090.6	139,658	18.1	197.3	632,216	81.9	893.3

* rate per 100,000 total population

Reference: Statistical Note #92
DHEW/ Public Health Services ADAMHA/NIMH
Div. of Biometry & Epidemiology
Survey & Reports Branch
Rockville, MD
August, 1973, DHEW Pub. # (ADM) 73-158

TABLE 1. NUMBER AND PERCENT DISTRIBUTION OF TOTAL PATIENT CARE EPISODES, AND NUMBER, PERCENT DISTRIBUTION AND PERCENT CHANGE IN PATIENT CARE EPISODES UNDER 18 YEARS OF AGE, BY TYPE OF PSYCHIATRIC SERVICE, UNITED STATES 1966, 1969 and 1971

Type of Psychiatric Service	Number of Psychiatric Services 1971	1971					1969				
		Total Patient Care Episodes-All Ages		Patient Care Episodes - Under 18 Years of Age			Total Patient Care Episodes-All Ages		Patient Care Episodes - Under 18 Years of Age		
		Number	Percent	Total	Percent	Percent of All Episodes	Number	Percent	Number	Percent	Percent of All Episodes
Total-All Psychiatric Services[a/]	4,053	3,861,343	100.0	771,874	100.0	20.0	3,585,909	100.0	647,690	100.0	19.1
Inpatient Psychiatric Services[a/]	1,774	1,564,589	40.0	139,658	18.1	9.0	1,491,458	44.0	105,585	16.3	7.1
State & County Mental Hospitals	334	745,259	19.3	39,196	5.1	5.3	767,115	22.7	35,287	5.4	4.6
Private Mental Hospitals	158	97,963	2.5	7,668	1.0	7.8	102,510	3.0	7,275	1.1	7.1
Genl.Hosp.Inpt.Psych.Units	653	542,642	14.1	46,065	6.0	8.5	535,493	15.8	38,808	5.7	6.9
Residential Treatment Centers for Emotionally Disturbed Children	344	28,617	0.7	28,617	3.7	100.0	21,340	0.6	21,340[b/]	3.3	100.0
Community Mental Health Centers	295	130,088	3.4	18,092[b/]	2.3	13.9	65,000	1.9	4,875[b/]	0.8	7.5
Outpatient Psychiatric Services	2,279	2,316,754	60.0	632,216	81.9	27.3	1,894,451	56.0	541,905	83.7	28.6
Community Mental Health Centers	295	622,906	16.1	196,877[b/]	25.2	31.3	291,148	8.6	76,281[b/]	11.8	26.2
All Other Outpatient Psychiatric Services	1,984	1,693,848	43.9	437,339	56.7	25.8	1,603,303	47.4	465,624	71.9	29.0

Type of Psychiatric Service	1966[c/]					Percent Change in Number of Patient Care Episodes Under 18 Years of Age		
	Total Patient Care Episodes-All Ages		Patient Care Episodes - Under 18 Years of Age					
	Number	Percent	Number	Percent	Percent of All Episodes	1966-1969	1969-1971	1966-1971
Total-All Psychiatric Services[a/]	2,649,000	100.0	485,700	100.0	18.3	33.3	19.2	58.9
Inpatient Psychiatric Services[a/]	1,463,000	55.2	86,700	17.8	5.9	21.8	32.2	61.1
State & County Mental Hospitals	802,000	30.3	36,900	7.6	4.6	-4.4	11.1	6.1
Private Mental Hospitals	104,000	3.9	7,800	1.6	7.5	-6.7	5.4	-1.7
Genl. Hosp. Inpt. Psych. Units	549,000	20.7	34,000	7.0	6.2	8.3	25.1	35.5
Residential Treatment Centers for Emotionally Disturbed Children	8,000	0.3	8,000	1.	100.0	166.8	[illegible]	258.0
Community Mental Health Centers	N.A.	N.A.	N.A.	N.A.	N.A.	-	[illegible]	-
Outpatient Psychiatric Services	1,186,000	44.8	399,000	82.2	33.6	35.8	[illegible]	58.5
Community Mental Health Centers	N.A.	N.A.	N.A.	N.A.	N.A.	-	[illegible]	-
All Other Outpatient Psychiatric Services	1,186,000	44.8	399,000	82.2	33.6	16.7	-6.1	9.6

a/ Excludes inpatient psychiatric services of Veterans Administration hospitals.

b/ Data are for under 20 year age group.

c/ Figures shown for 1966 represent revisions of the 1966 data as shown in earlier NIMH publications.

N.A. - not applicable -- only a few of these facilities began functioning in this year and reporting was not requested.

Reference: Statistical Note #90 DHEW/ Pub. Health Services ADAMHA/NIMH Div. of Biometry & Epidemiology Survey & Reports Branch / Rockville, MD July, 1973, DHEW Pub. # (ADM) 73-158

TABLE 2. NUMBER, PERCENT DISTRIBUTION, RATE PER 100,000 POPULATION AND PERCENT CHANGE IN RATE OF PATIENT CARE EPISODES IN PSYCHIATRIC SERVICES,[a/] BY TYPE OF PSYCHIATRIC SERVICE, BY AGE, UNITED STATES, 1966 and 1971

	Total - All Ages		Under 18		18-24		25-44		45-64		65 and Over	
	1971	1966[b/]	1971	1966[b/]	1971	1966[b/]	1971	1966[b/]	1971	1966[b/]	1971	1966[b/]
						Number						
Total-All Psych.Services[a/]	4,038,147	2,772,089	771,876	685,729	681,[illegible]	334,422	1,433,133	959,959	888,231	678,985	263,266	113,014
All Inpatient Services..	1,721,389	1,386,089	139,658	86,729	245,106	134,086	614,901	560,825	512,378	515,900	209,345	288,551
State & Cnty Men.Hosps.	745,259	807,716	39,196	36,902	97,285	53,748	236,337	239,060	238,710	283,985	133,731	188,521
Private Mental Hosps..	97,963	103,973	7,668	7,794	14,095	11,154	34,253	41,361	29,525	30,486	12,422	13,178
Res.Tx.Ctrs/Children..	28,637	8,000	28,637	8,000	-	-	-	-	-	-	-	-
Genl.Hosp.Psych.Serv..	562,642	548,921	46,065	34,033	94,569	66,968	231,376	216,826	132,863	166,872	37,769	64,224
VA Hospitals.....	176,800	122,979	-	-	20,967	2,214	59,738	63,580	79,885	34,557	16,210	22,628
CMHC's.....	130,088	N.A.	18,092*	N.A.	18,190**	N.A.	93,197	N.A.	31,396	-	9,213	N.A.
All Outpatient Services.	2,316,754	1,386,000	632,216	399,000	436,535	200,338	818,232	399,134	375,852	163,065	53,919	24,463
CMHC's.....	622,906	N.A.	196,877*	N.A.	92,609**	N.A.	221,796	N.A.	95,412	N.A.	18,212	N.A.
All Other Services....	1,693,848	1,386,000	437,339	399,000	343,926	200,338	596,436	399,134	280,440	163,065	35,707	24,463
						Percent Distribution						
Total-All Psych.Services[a/]	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
All Inpatient Services..	42.6	57.2	18.1	17.9	36.9	40.1	42.9	58.4	57.7	76.0	79.5	92.2
State & Cnty Men.Hosps.	18.5	28.9	5.1	7.7	14.3	16.1	16.5	24.9	26.9	41.8	50.8	80.3
Private Mental Hosps..	2.4	3.8	1.0	1.6	2.1	3.3	2.4	4.3	3.3	4.5	4.7	4.2
Res.Tx.Ctrs/Children..	0.7	0.3	3.7	1.6	-	-	-	-	-	-	-	-
Genl.Hosp.Psych.Serv..	13.4	19.8	6.0	7.0	13.9	20.0	16.1	22.6	15.0	24.6	14.3	20.5
VA Hospitals.....	4.4	4.4	-	-	3.0	0.7	4.2	6.6	9.0	5.1	6.2	7.2
CMHC's.....	3.2	-	2.3	-	2.7	-	3.7	-	3.5	-	3.5	-
All Outpatient Services.	57.4	42.8	81.9	82.1	64.0	59.9	57.1	41.6	42.3	24.0	20.5	7.8
CMHC's.....	15.4	-	25.2	-	13.6	-	15.5	-	10.7	-	6.9	-
All Other Services....	42.0	42.8	56.7	82.1	50.4	59.9	41.6	41.6	31.6	24.0	13.6	7.8
						Rate per 100,000 Population[c/]						
Total-All Psych.Services[a/]	1997.8	1433.2	1090.6	695.7	2862.8	1709.2	2964.7	2095.6	2105.0	1718.8	1310.2	1671.8
All Inpatient Services..	838.8	820.0	197.3	124.2	1029.4	653.3	1272.0	1224.2	1214.3	1306.0	1041.9	1541.2
State & Cnty Men.Hosps.	363.2	414.8	55.4	52.9	408.6	274.7	488.9	521.9	565.7	718.9	665.6	1006.9
Private Mental Hosps..	47.7	53.8	10.8	11.2	59.2	57.0	70.9	90.3	70.0	77.2	61.8	70.4
Res.Tx.Ctrs/Children..	14.0	4.1	40.5	11.5	-	-	-	-	-	-	-	-
Genl.Hosp.Psych.Serv..	264.4	283.8	65.1	48.7	397.2	342.3	478.6	473.3	314.9	422.4	188.0	343.0
VA Hospitals.....	86.2	63.6	-	-	88.1	11.3	123.6	138.8	189.3	87.5	80.7	120.9
CMHC's.....	63.4	-	25.6	-	76.4	-	110.0	-	74.4	-	45.9	-
All Outpatient Services.	1129.0	613.2	893.3	571.5	1833.4	1023.9	1692.7	871.3	890.7	412.8	268.3	130.7
CMHC's.....	303.5	-	275.3	-	389.0	-	458.8	-	226.1	-	90.6	-
All Other Services....	825.4	613.2	618.0	571.5	1444.4	1023.9	1233.8	871.3	664.6	412.8	177.7	130.7
						Percent Change in Rates 1966-1971						
Total All Psych.Services[a/]	37.3%		56.8%		67.5%		41.5%		22.5%		-21.6%	
All Inpatient Services..	2.7		58.9		57.6		3.9		-5.9		-32.4	
State & Cnty Men.Hosps.	-12.4		4.7		48.7		-6.3		-21.3		-33.9	
Private Mental Hosps..	-11.3		-3.8		3.9		-21.5		-9.3		-12.2	
Res.Tx.Ctrs/Children..	241.5		252.2		-		-		-		-	
Genl.Hosp.Psych.Serv..	-6.8		33.7		16.0		1.1		-25.4		-45.2	
VA Hospitals.....	35.5		-		679.6		-11.0		116.3		-33.3	
CMHC's.....	-		-		-		-		-		-	
All Outpatient Services.	84.1		56.3		79.1		94.3		115.8		105.3	
CMHC's.....	-		-		-		-		-		-	
All Other Services....	34.6		8.1		41.1		74.7		61.0		36.0	

a/ See footnote 2 of text for psychiatric services excluded from this table

b/ Some figures shown represent revisions of 1966 data presented in earlier NIMH publications.

c/ Sources of base populations used to compute rates were as follows: 1966 - U.S. Bureau of the Census, Current Population Reports, Series P-25, No.483; 1971 - U.S. Bureau of the Census, Current Population Reports, Series P-20, No.225 (Tables 1 and 3).

N.A.--not applicable--only a few centers had begun functioning in this year and reporting was not requested.

* Under 20 years

** 20-24 years

Statistical Notes 86, 126
DHEW/Public Health Service
Div. of Biometry & Epidemiology
ADAMHA/NIMH - Rockville, MD
June, 1973 &
1976: DHEW Pub. # (ADM) 76-158

COMMUNITY MENTAL HEALTH CENTERS

1971 (Sample of 69 CMHC's)

38.44% of total population in 69 catchment areas are under 20 years
patient additions under 20 are 26.1% of total additions

0.61% of total population under 20 are additions
0.90% of total population all ages are additions

	0-19	All Ages
Population	3,609,047 (38.4%)	9,388,619 (100%)
Patient Additions	21,929 (26.1%)	84,192 (100%)

All Centers - 1971:

Age group under 20 form 27.4% of total additions (118,748/432,640)

	0-19		All Ages	
	#	%	#	%
All Services	118,748	100	432,640	100
Inpatient	10,413	8.8	75,900	17.5
Outpatient	102,669	86.4	335,648	77.6
Partial	5,666	4.8	21,092	4.9

1973 (261 Centers)

Population under 15 is 28.6% of total catchment population and forms 16.7% of patient additions
Population under 25 is 46.8% of catchment population and forms 43.7% of patient additions

	Catchment Pop.	CMHC additions	Add. as % of total pop.
All ages	39,172,222	419,107	1.07
under 15	11,264,606	70,004	.62
under 25	18,343,669	182,985	1.00

97-633 O - 77 - 34

NUMBER AND PERCENT DISTRIBUTION OF PATIENT CARE EPISODES UNDER 18 YEARS BY TYPE OF MENTAL DISORDER, BY TYPE OF PSYCHIATRIC SERVICE, UNITED STATES 1971

Type of Mental Disorder	Total--All Psychiatric Services[a]	%	Total Inpatient Services[a]	%	Total Outpatient Services	%
Total All Mental Disorders. . .	743,237	100	111,021	100	632,216	100
Mental Retardation.	55,264	7.4	5,835	5.3	49,429	7.8
Organic Brain Syndromes (excl. alcohol & drug). . .	19,128	2.6	3,649	3.3	15,479	2.4
Schizophrenia	42,035	5.7	21,341	19.2	20,694	3.3
Depressive Disorders (psychotic & neurotic). . .	24,250	3.3	8,657	7.8	15,593	2.5
Other Psychotic Disorders . .	2,408	0.3	1,199	1.1	1,209	0.2
Alcohol Disorders	2,373	0.3	870	0.8	1,503	0.2
Disorders Assoc. w/drug abuse	13,072	1.8	7,357	6.6	5,715	0.9
All Other Disorders	584,707	78.6	62,113	55.9	522,594	82.7

[a]Includes state and county MH, PMH, GHIPU, CMHCs; excludes VA hospitals and residential treatment centers for emotionally disturbed children.

NUMBER AND PERCENT DISTRIBUTION OF DISCHARGES UNDER 18 YEARS BY TYPE OF MENTAL DISORDER, BY TYPE OF PSYCHIATRIC SERVICE, UNITED STATES 1971

Type of Mental Disorder	Inpatient Psychiatric Discharges	%	Outpatient Psychiatric Discharges	%
Total	70,085	100	293,474	100
Mental Retardation.	4,427	6.3	23,778	8.1
Organic Brain Syndromes (excl. alcohol & drug).	2,170	3.1	6,820	2.3
Schizophrenia	9,835	14.0	8,522	2.9
Depressive Disorders (psychotic & neurotic) . .	6,553	9.4	5,847	2.0
Other Psychoses	723	1.0	382	0.1
Other Neuroses.	4,277	6.1	8,861	3.0
Personality Disorders	6,357	9.1	23,772	8.1
Alcohol Disorders	750	1.1	275	0.1
Disorders Associated with Drug Abuse.	3,743	5.3	2,092	0.7
Transient Situational Disturbance	16,926	24.2	89,337	30.5
All Other Disorders	14,324	20.4	123,788	42.2

Reference: Statistical Note # 90
DHEW/Public Health Service
ADAMHA/NIMH
Div. of Biometry, Survey & Reports Br.
Rockville, MD
July 1973, DHEW Pub. No. (ADM) 73-158

ADDITIONS TO 69 SELECTED COMMUNITY MENTAL HEALTH CENTERS BY AGE, COLOR AND SEX, U.S. 1971: NUMBER

Color and Sex			Age													
	Total	% of Pop.	0-4	% of Pop.	5-14	% of Pop.	15-19	% of Pop.	20-24	% of Pop.	25-44	% of Pop.	45-64	% of Pop.	65+	% of Pop.
Total.....	84,192	.90	855	.11	10,411	.55	10,633	1.15	12,146	1.48	30,846	1.41	15,912	.87	3,359	.36
White male	34,576	.85	455	.13	5,532	.67	4,105	1.00	4,582	1.28	11,791	1.23	6,894	.87	1,217	.34
White female....	37,860	.90	287	.09	3,331	.42	5,053	1.29	5,919	1.62	14,391	1.46	7,194	.84	1,685	.34
Black male.....	5,581	1.04	69	.12	933	.71	584	.93	630	1.35	2,174	1.89	970	1.12	221	.66
Black female....	6,175	1.06	44	.08	615	.47	921	1.52	1,015	2.02	2,490	1.85	854	.83	236	.51

POPULATION OF CATCHMENT AREAS SERVED BY 69 SELECTED COMMUNITY MENTAL HEALTH CENTERS BY AGE, COLOR AND SEX, UNITED STATES 1970

Color and Sex	Age							
	Total	0-4	5-14	15-19	20-24	25-44	45-64	65+
Total.....	9,388,619	795,690	1,885,735	927,622	820,146	2,193,675	1,837,157	928,594
White male.....	4,064,570	350,221	830,127	411,918	358,850	958,887	794,718	359,849
White female.....	4,209,108	333,508	792,536	392,130	364,286	984,843	852,966	488,639
Black male.....	534,145	56,608	131,941	62,987	46,765	115,355	86,772	33,697
Black female.....	580,796	55,353	131,131	60,587	50,225	134,590	102,701	46,209

Reference: Statistical Note #86
DHEW/Public Health Service
ADAMHA/NIMH
Div. of Biometry, Survey & Reports Branch
Rockville, MD
June 1973, DHEW Pub. No. (ADM) 73-158

ADDITIONS TO 69 SELECTED COMMUNITY MENTAL HEALTH CENTERS BY AGE, COLOR AND SEX, UNITED STATES 1971: PERCENT DISTRIBUTION BY AGE*

Color and Sex	Age							
	Total	0-4	5-14	15-19	20-24	25-44	45-64	65+
Total.....	100.0%	1.0	12.4	12.7	14.4	36.6	18.9	4.0
White male.....	100.0%	1.3	16.0	11.9	13.3	34.1	19.9	3.5
White female.....	100.0%	0.8	8.8	13.3	15.6	38.0	19.0	4.5
Black male.....	100.0%	1.2	16.7	10.5	11.3	39.0	17.4	4.0
Black female.....	100.0%	0.7	10.0	14.9	16.4	40.3	13.8	3.8

* Where percents do not add up to totals shown, discrepancies are due to rounding error

COMPARISON OF PATIENT ADDITIONS BETWEEN ALL AND 69 SELECTED COMMUNITY MENTAL HEALTH CENTERS BY AGE, UNITED STATES 1971

Age	Number		Percent Distribution by Age*									
			Total		White Male		White Female		Black Male		Black Female	
	All Centers	69 Selected Centers	All Centers	69 Selected Centers	All Centers	69 Selected Centers	All Centers	69 Selected Centers	All Centers	69 Selected Centers	All Centers	69 Selected Centers
Total.....	411,149	84,192	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
0-4.....	4,299	855	1.0	1.0	1.3	1.3	0.7	0.8	1.5	1.2	1.0	0.7
5-14.....	54,938	10,411	13.4	12.4	17.0	16.0	8.9	8.8	21.4	16.7	11.8	10.0
15-19.....	53,602	10,663	13.0	12.7	13.1	11.9	13.1	13.3	12.4	10.5	13.4	14.9
20-24.....	63,314	12,146	15.4	14.4	14.8	13.3	15.7	15.6	15.3	11.3	16.5	16.4
25-44.....	151,105	30,846	36.8	36.6	33.6	34.1	39.5	38.0	34.9	39.0	39.0	40.3
45-64.....	69,011	15,912	16.8	18.9	16.9	19.9	18.0	19.0	11.8	17.4	14.5	13.8
65+.....	14,880	3,359	3.6	4.0	3.3	3.5	4.1	4.5	2.7	4.0	3.7	3.8

* Where percents do not add up to totals shown, discrepancies are due to rounding error

DISTRIBUTION OF ADDITIONS TO FEDERALLY FUNDED COMMUNITY MENTAL HEALTH CENTERS BY AGE AND DIAGNOSIS
UNITED STATES, 1970

Diagnosis	Number								%							
		Age at admission								Age at admission						
	Total	0–4	5–14	15–19	20–24	25–44	45–64	65+	Total	0–4	5–14	15–19	20–24	25–44	45–64	65+
Total	334,760	3,420	48,201	42,245	48,995	121,116	57,655	13,128	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Mental retardation	10,036	506	4,035	1,671	1,085	1,824	693	222	3.0	14.8	8.4	4.0	2.2	1.5	1.2	1.7
Organic brain syndromes (excluding alcoholism and drug abuse)	9,739	136	974	550	665	1,783	2,154	3,477	2.9	4.0	2.0	1.3	1.4	1.5	3.7	26.5
Schizophrenia	50,597	92	1,040	4,173	8,850	24,062	11,049	1,331	15.1	2.7	2.1	9.9	18.1	19.9	19.2	10.1
Affective disorders (including psychotic depressive and depressive neurosis)	52,545	60	1,017	3,760	8,352	22,696	13,796	2,864	15.7	1.7	2.1	8.9	17.1	18.7	23.9	21.8
Other psychotic disorders	5,994	1	145	596	895	2,331	1,650	376	1.8	(*)	.3	1.4	1.8	1.9	2.9	2.9
Alcoholism (including alcoholism associated with organic brain syndromes)	19,756	11	114	429	1,589	9,743	7,209	661	5.9	.3	.2	1.0	3.2	8.0	12.5	5.0
Drug abuse (including drug abuse associated with organic brain syndromes)	10,539	9	181	2,428	3,398	3,778	636	109	3.1	.3	.4	5.7	6.9	1.1	1.1	.8
Behavior disorders of childhood and adolescence (including Adj. Reaction of Infancy, Childhood and Adolescence)	33,018	994	17,303	11,091	1,437	1,588	486	119	9.9	29.1	35.9	26.3	2.9	1.3	.8	.9
All other mental disorders	60,283	399	6,889	7,183	10,775	24,673	8,636	1,728	18.0	11.7	14.3	17.0	22.0	20.4	15.0	13.2
Unknown or undiagnosed mental disorder	70,367	1,133	15,362	8,932	9,335	23,357	10,200	2,048	21.0	33.1	31.9	21.1	19.1	19.3	17.7	15.6
Social maladjustments without manifest psychiatric disorder and no mental disorder	11,886	79	1,141	1,432	2,614	5,281	1,146	193	3.6	2.3	2.4	3.4	5.3	4.4	2.0	1.5

* Less than 0.05.

SOURCE: Based on data from the January 1971 Inventory of Federally Funded Community Mental Health Centers, Biometry Branch, National Institute of Mental Health.

Reference: Financing Mental Health Care in the United States - DHEW Pub. No. (HSM) 73-9117 Printed 1973

State and County Mental Hospitals - 1972

Additions

6.1% of all additions are under 18 years old

16.3/100,000 population under 18 are additions
197.2/100,000 general population are additions
(under 18 rate is 8.2% of regular rate)

Resident Population

Rate per 100,000 for resident population decreased each year from 1969 to 1973 for under 18 age group: from 18.4 in 1969 to 15.5 in 1973

Reference: Statistical Notes # 115, 116
DHEW/ Public Health Service
ADAMHA/NIMH
Div. of Biometry, Survey & Reports Br.
Rockville, MD
1975, DHEW Pub. No. (ADM) 75-158

Table 3. Number and percent distribution of additions under 18 years of age to State and county mental hospitals by age, sex, and diagnosis, United States 1973

Sex and Diagnosis	Total Under 18		Under 5		5-9		10-14		15-17	
	#	%	#	%	#	%	#	%	#	%
Both Sexes	25,830	100.0	208	100.0	1,796	100.0	7,695	100.0	16,131	100.0
Mental Retardation	2,878	11.1	122	58.6	473	26.3	955	12.4	1,328	8.2
OBS Associated with Drug Abuse	370	1.4	0	-	1	0.1	28	0.4	341	2.1
Other OBS	1,045	4.1	7	3.4	135	7.5	353	4.6	550	3.4
Schizophrenia	3,996	15.5	25	12.0	198	11.0	906	11.8	2,867	17.8
Depressive Disorders	1,045	4.1	1	.5	12	.7	202	2.6	830	5.1
Personality Disorders	2,104	8.1	4	1.9	15	.8	476	6.2	1,609	10.0
Drug Dependence	1,443	5.6	0	-	0	-	94	1.2	1,349	8.4
Adjustive Reaction	6,723	26.0	16	7.7	348	19.4	2,258	29.3	4,101	25.4
Behavioral Disorders	3,864	15.0	26	12.5	452	25.2	1,708	22.2	1,678	10.4
Other	2,362	9.1	7	3.4	162	9.0	715	9.3	1,478	9.2

Table 5. Number and percent distribution of resident patients under 18 years of age in State and county mental hospitals by age, sex, and diagnosis, United States 1973

Sex and Diagnosis	Total Under 18		Under 5		5-9		10-14		15-17	
	#	%	#	%	#	%	#	%	#	%
Both Sexes	10,576	100.0	74	100.0	1,136	100.0	4,145	100.0	5,221	100.0
Mental Retardation	2,494	23.6	48	64.9	360	31.7	861	20.8	1,225	23.5
Organic Brain Syndromes	822	7.8	7	9.5	123	10.8	358	8.6	334	6.4
Schizophrenia	2,386	22.5	11	14.9	203	17.9	872	21.0	1,300	24.9
Personality Disorders	611	5.8	0	-	6	.5	203	4.9	402	7.7
Adjustive Reaction	1,701	16.1	2	2.7	153	13.5	696	16.8	850	16.3
Behavioral Disorders	1,775	16.8	5	6.7	246	21.6	927	22.5	597	11.4
Other	787	7.4	1	1.3	45	4.0	228	5.5	513	9.8

Reference: Statistical Note #115
DHEW/Public Health Service ADAMHA/NIMH
Div. of Biometry & Epidemiology Survey & Reports Branch
Rockville, MD
April, 1975, DHEW Pub. # (ADM) 75-158

ADMISSIONS TO STATE & COUNTY MENTAL HOSPITALS, UNITED STATES, 1969-73

Year Both Sexes	Total Under 18			Under 5			5 - 9			10 - 14			15 - 17		
	Number	Rate[a]	%	Number	Rate[a]	%	Number	Rate[a]	%	Number	Rate[a]	%	Number	Rate[a]	%
1969	27,973	40.1	100	410	2.4	1.5	1,999	9.9	7.1	8,503	41.2	30.4	17,061	148.3	61.0
1970	27,189	39.0	100	155	0.9	0.6	1,685	8.5	6.2	7,840	37.6	28.8	17,509	148.2	64.4
1971	28,029	40.3	100	268	1.6	1.0	1,776	9.2	6.3	7,643	36.3	27.3	18,342	152.4	65.4
1972	27,133	39.3	100	245	1.4	0.9	1,633	8.7	6.0	7,984	38.0	29.4	17,271	140.4	63.7
1973	25,830	37.9	100	208	1.2	0.8	1,796	9.9	6.9	7,695	36.9	29.8	16,131	129.1	62.5

[a]Rate per hundred thousand population.

RESIDENT PATIENTS IN STATE & COUNTY MENTAL HOSPITALS, UNITED STATES, 1969-73

Year Both Sexes	Total Under 18			Under 5			5 - 9			10 - 14			15 - 17		
	Number	Rate[a]	%	Number	Rate[a]	%	Number	Rate[a]	%	Number	Rate[a]	%	Number	Rate[a]	%
1969	12,841	18.4	100	84	.5	.7	1,600	7.9	12.5	5,067	24.5	39.4	6,090	53.1	47.4
1970	12,844	18.7	100	53	.3	.4	1,560	7.8	12.1	4,952	23.8	38.6	6,279	53.3	48.9
1971	12,519	18.0	100	133	.8	1.1	1,408	7.3	11.2	4,838	23.0	38.6	6,140	51.2	49.1
1972	11,269	16.3	100	85	.5	.8	1,284	6.9	11.4	4,398	21.0	39.0	5,502	44.9	48.8
1973	10,576	15.5	100	74	.4	.7	1,136	6.3	10.7	4,145	19.9	39.2	5,221	41.9	49.4

[a]Rate per hundred thousand population.

Reference: Statistical Note #115
DHEW/ Public Health Service ADAMHA/NIMH
Div. of Biometry & Epidemiology Survey & Reports Branch
Rockville, MD
April, 1975, DHEW Pub. #(ADM) 75-158

Residential Treatment Centers for Children (1973)

As of January, 1974:

There were 340 RTC's w/ 19,023 beds

27.9 RTC beds per 100,000 population under 18

1973

29,726 children received care, amounting to 6,337,926 days

average residence/day = 17,624, at end of 1973, 17,697 in residence

12,029 discontinuations, 12,179 additions

average of 92.6% beds occupied daily

Expenditures: Total: 242,348,000 (approx)
$38 per patient day
$20,389 per discontinuation

Reference: Statistical Note #130
DHEW/ Public Health Service
ADAMHA/NIMH
Div. of Biometry & Epidemiology
Survey & Reports Branch
Rockville, MD
April, 1976, DHEW Pub. # (ADM) 76-158

Table 1. Comparisons of selected data on residential treatment centers and psychiatric hospitals for children: United States, 1973

Selected Measures for 1973	Residential Treatment Centers (N=340)	Psychiatric Hospitals for Children (N=26)
Predominant Type of Ownership.....	Private Nonprofit	State and County
Average (mean) Size (in beds).....	56	90
Most Frequent Minimum Admission Age....	6 years	6 years
Most Frequent Maximum Admission Age....	18 years	18 years
Average Caseload per Facility [6/]		
Annual Additions.....	36	84
Annual Discontinuations.....	35	85
Resident Patients as of December 31, 1973	52	79
Addition Indices [6/]		
Additions per 100 Beds.....	64	94
Additions per 100 Average Res. Patients	69	107
Additions per 100 Discontinuations.....	101	99
Additions per 100,000 U.S. Resident Population Under 18 Years.....	18	3
Full-Time Equivalent Staff [8/] per 100 Residents		
Total Patient Care Staff.....	77	143
Professional.....	50	67
Other.....	27	76
Expenditures		
Annual Total Expenditures per Facility.	$712,788	$2,208,724
Annual Salary Expenditures per Facility	$425,847	$1,870,902
Percent Salaries are of Total.....	60 percent	80 percent
Average Total Expenditure per Patient Day.....	$38	$82
Average Total Expenditures per Discontinuation.....	$20,389	$25,561

Reference: Statistical Note #130
DHEW/ Public Health Service
ADAMHA/NIMH
Div. of Biometry & Epidemiology
Surevey & Reports Branch
Rockville, MD
April, 1976, DHEW Pub. # (ADM) 76-158

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Table 2. Comparisons of selected data on residential treatment centers: United States, 1971 and 1973

Selected Measures	1971	1973	Percent Change 1973 vs. 1971
Number of Facilities	344	340	- 1.2
Average (mean) Size (in beds)	57	56	- 1.8
Average Caseload per Facility[6/]			
Annual Additions	32	36	+12.5
Annual Discontinuations	29	35	+20.7
Resident Patients at End of Year	51	52	+ 2.0
Additions Indices[6/]			
Additions per 100 Beds	56	64	+14.3
Additions per 100 Resident Patients	63	69	+ 9.5
Additions per 100 Discontinuations	110	101	- 8.2
Additions per 100,000 U.S. Civilian Population Under 18 Years[7/]	16	18	+12.5
Full-Time Equivalent Staff per 100 Average Daily Residents[8/]			
Total Patient Care Staff	64	77	+20.3
Professional	38	50	+31.6
Other	26	27	+ 3.8
Expenditures			
Annual Total Expenditures per Facility	$573,000	$712,788	+24.4
Annual Salary Expenditures per Facility	$348,000	$425,847	+22.4
Percent Salaries are of Total	61%	60%	+ 1.6
Average Total Expenditures per Patient Day	$ 31	$ 38	+22.6
Average Total Expenditures per Discontinuation	$ 19,654	$ 20,389	+ 3.7

Table 3. Number and percent distribution of residential treatment centers; average number of beds per group and beds per 100,000 resident population of the United States under 18 years, by selected facility characteristics: United States, 1974

Selected Facility Characteristics	Residential Treatment Centers		Inpatient Beds			Beds per 100,000 U.S. Resident Population Under 18 [3]
	Number	Percent	Number	Percent	Average Number per Group	
All RTC's	340	100.0	19,023	100.0	56	27.9
Size (Based on Number of Beds)						
Under 25 Beds	88	25.8	1,472	7.7	17	2.2
25-49 Beds	129	38.2	4,588	24.1	36	6.7
50-74 Beds	69	20.4	4,033	21.2	58	5.9
75-99 Beds	26	7.5	2,251	11.8	87	3.3
100 Beds and Over	28	8.1	6,679	35.2	239	9.8
Ownership						
Private/Nonprofit	330	97.1	18,543	97.5	56	27.2
State & County Government	10	2.9	480	2.5	48	0.7
Geographic Region [4]						
Region I	41	12.1	1,779	9.4	43	46.4
Region II	36	10.6	3,039	16.0	84	38.3
Region III	24	7.1	2,291	12.0	95	30.3
Region IV	15	4.4	1,022	5.4	68	9.3
Region V	104	30.5	4,447	23.3	43	29.7
Region VI	22	6.5	1,840	9.7	84	25.3
Region VII	20	5.9	759	4.0	38	20.7
Region VIII	15	4.4	534	2.8	36	27.1
Region IX	47	13.8	2,645	13.9	56	34.6
Region X	16	4.7	667	3.5	42	30.4

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Table 6. Patient movement and annual volume of services in inpatient service of residential treatment centers by size (based on number of beds) and geographic region: United States, 1973

Size (based on number of beds) & Geographic Region	Patient Movement During Year[6/]				Annual Volume of Service[6/]		
	Residents at Beginning of Year	Additions During Year	Discontinuations During Year	Residents at End of Year	Patients Under Care	Average Resident Patients	Number of Patient Days
All RTC's.....	17,547	12,179	12,029	17,697	29,726	17,624	6,337,926
Size (Based on number of beds)							
Under 25 beds....	1,354	1,145	1,205	1,294	2,499	1,324	457,836
25-49 beds.....	4,231	3,199	3,142	4,288	7,430	4,260	1,514,614
50-74 beds.....	3,691	3,079	2,989	3,781	6,770	3,736	1,333,683
75-99 beds.....	2,084	1,874	1,877	2,081	3,958	2,083	739,866
100 beds & over..	6,187	2,882	2,816	6,253	9,069	6,220	2,291,927
Geographic Region[4/]							
Region I.....	1,617	958	907	1,668	2,575	1,643	580,907
Region II.....	2,820	1,676	1,589	2,907	4,496	2,864	1,012,828
Region III.....	2,331	850	866	2,315	3,181	2,323	824,187
Region IV.....	800	685	563	922	1,485	861	350,086
Region V.....	4,004	3,120	3,076	4,048	7,124	4,026	1,436,597
Region VI.....	1,826	1,067	1,210	1,683	2,893	1,755	642,283
Region VII.....	661	668	649	680	1,329	671	240,812
Region VIII.....	445	422	342	525	867	485	163,095
Region IX.....	2,439	2,203	2,295	2,347	4,642	2,393	875,120
Region X.....	604	530	532	602	1,134	603	212,011

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Table 15. Number and percent distribution of expenditures, residential treatment centers, by type of expenditure and size (based on number of beds): United States, 1973

Size (based on number of beds)	Total Expenditures	Operating Expenditures			Capital Expenditures
		Total Operating Expenditures	Salaries	Other Operating Expenditures	
	Annual Expenditures in Thousands of Dollars				
All Sizes.....	$242,348	$222,550	$144,788	$77,762	$19,798
Less Than 25 Beds	21,365	20,862	13,801	7,061	504
25-49 Beds.....	57,349	52,549	35,730	16,819	4,800
50-74 Beds.....	52,067	50,094	32,415	17,679	1,973
75-99 Beds.....	24,812	23,707	14,726	8,981	1,105
100 Beds & Over..	86,754	75,338	48,116	27,222	11,416
	Percent Distribution of Expenditures				
All Sizes.....	100.0	91.8	59.7	32.1	8.2
Less Than 25 Beds	100.0	97.6	64.6	33.0	2.4
25-49 Beds.....	100.0	91.6	62.3	29.3	8.4
50-74 Beds.....	100.0	96.2	62.2	34.0	3.8
75-99 Beds.....	100.0	95.5	59.3	36.2	4.5
100 Beds & Over..	100.0	86.8	55.4	31.4	13.2

Table 16. Average expenditures per patient day and per discharge in residential treatment centers, by type of expenditure and size (based on number of beds): United States, 1973

Size (based on number of beds)	Total Expenditures	Operating Expenditures			Capital Expenditures
		Total Operating Expenditures	Salaries	Other Operating Expenditures	
	Average Expenditures per Patient Day				
All Sizes.....	$38	$35	$23	$12	$ 3
Less Than 25 Beds	46	45	30	15	1
25-49 Beds.....	39	36	24	12	3
50-74 Beds.....	39	37	24	13	2
75-99 Beds.....	34	32	20	12	2
100 Beds & Over..	38	33	21	12	5
	Average Expenditures per Discontinuation				
All Sizes.....	$20,389	$18,795	$12,198	$6,597	$1,594
Less Than 25 Beds	18,341	17,932	11,834	6,098	409
25-49 Beds.....	18,922	17,420	11,817	5,603	1,502
50-74 Beds.....	17,088	16,476	10,634	5,842	612
75-99 Beds.....	13,437	12,872	7,974	4,898	565
100 Beds & Over..	31,133	27,239	17,351	9,888	3,894

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Table 17. Distribution of residential treatment centers by response to specific items on the 1973 Inventory of Mental Health Facilities [10/]

Data Item and Group	Number of RTC's Surveyed	Response		Nonresponse	
		Number of RTC's	Percent	Number of RTC's	Percent
Number of Beds	340	314	92.4	26	7.6
RTC's by Geographic Region [11/]	340	314	92.4	26	7.6
Type of Ownership	340	314	92.4	26	7.6
Type of Service Modes					
By Bed Size	340	314	92.4	26	7.6
By Geographic Region	340	314	92.4	26	7.6
Region I	41	37	90.2	4	9.8
Region II	36	33	91.7	3	8.3
Region III	24	24	100.0	-	-
Region IV	15	15	100.0	-	-
Region V	104	97	93.3	7	6.7
Region VI	22	20	90.9	2	9.1
Region VII	20	18	90.0	2	10.0
Region VIII	15	15	100.0	-	-
Region IX	47	41	87.2	6	12.8
Region X	16	14	87.5	2	12.5
Patient Movement & Volume of Service					
By Bed Size	340	292	85.9	48	14.1
By Geographic Region	340	292	85.9	48	14.1
Region I	41	32	78.0	9	22.0
Region II	36	29	80.6	7	19.4
Region III	24	21	87.5	3	12.5
Region IV	15	15	100.0	-	-
Region V	104	92	88.5	12	11.5
Region VI	22	20	90.9	2	9.1
Region VII	20	17	85.0	3	15.0
Region VIII	15	13	86.7	2	13.3
Region IX	47	40	85.1	7	14.9
Region X	16	13	81.3	3	18.7
Number of Staff & Hours Worked					
By Bed Size	340	312	91.8	28	8.2
Expenditures					
By Bed Size	340	285	83.8	55	16.2
By Geographic Region	340	297	87.4	43	12.6
Region I	41	36	87.8	5	12.2
Region II	36	31	86.1	5	13.9
Region III	24	24	100.0	-	-
Region IV	15	14	93.3	1	6.7
Region V	104	92	88.5	12	11.5
Region VI	22	18	81.8	4	18.2
Region VII	20	18	90.0	2	10.0
Region VIII	15	14	93.3	1	6.7
Region IX	47	37	78.7	10	21.3
Region X	16	13	81.3	3	18.7
Expenditures per Patient Day & per Discontinuation					
By Bed Size	340	285	83.8	55	16.2

Reference: Morton Kramer
"Some Perspectives on the Role of Biostatistics and Epidemiology in the Prevention and Control of Mental Disorders"
Health & Society, Summer, 1975

TABLE 3

Extent to Which Needs for Psychiatric Services Would Be Met in Relation to Various Assumptions of Need: Assuming 1971 Use Rates Only, by Age, United States, 1975 and 1980

Age	Estimated Gen. Pop. g/ (in 000's) (1)	Estimated Pt. Care Episodes (2)	Estimated No. Persons Recv'g Care (3)	Estimated number of persons needing care, assuming 2% in need (4)	10% in need (5)	20% in need (6)	Number in need not receiving care, assuming 2% in need (7)	10% in need (8)	20% in need (9)	Percent unmet need, assuming 2% in need (10)	10% in need (11)	20% in need (12)
1975												
Total, All ages	213,334	4,237,576	3,340,061	4,306,468	21,532,400	43,064,800	1,066,310	18,162,329	39,076,739	24.8	84.3	92.3
Under 18.....	68,109	809,377	643,580	1,362,180	6,810,900	13,621,800	718,678	6,165,398	12,976,298	52.5	90.5	95.2
18-24.....	27,780	716,150	572,930	555,600	2,778,000	5,556,000	0	2,205,080	4,983,080	0.0	79.4	89.7
25-44.....	53,835	1,306,340	1,102,471	1,076,700	5,383,500	10,767,000	0	4,280,029	9,563,329	0.0	77.6	88.8
45-64.....	43,430	931,267	745,814	868,600	4,343,000	8,686,000	122,786	3,597,184	7,940,184	14.1	82.8	91.4
65+.....	22,170	373,442	320,334	443,400	2,217,000	4,434,000	222,846	1,998,644	4,313,644	50.3	90.1	95.0
1980												
Total, All Ages	228,676	4,380,344	3,600,273	4,573,520	22,867,600	45,735,200	1,030,038	19,367,325	42,134,925	22.3	84.3	92.1
Under 18.....	69,844	829,364	587,453	1,396,880	6,984,400	13,939,200	702,267	6,278,947	13,261,267	50.6	90.1	95.1
18-24.....	29,134	760,334	606,444	582,120	2,913,600	5,831,200	0	2,387,134	5,223,334	0.0	79.1	89.6
25-44.....	61,332	1,397,822	1,178,093	1,266,640	6,333,200	13,466,400	0	4,933,103	11,188,303	0.0	79.5	89.7
45-64.....	43,489	988,034	793,061	869,780	4,348,900	8,697,800	77,719	3,334,839	7,905,739	8.9	81.8	90.9
65+.....	24,853	393,322	234,018	497,960	2,485,200	4,810,600	247,943	2,171,302	4,356,582	51.4	90.3	95.1

g/ U.S.Bureau of the Census,Series D projection of the U.S.population(Current Population Reports - Series P-25, No. 493)

Derivation of columns 2 through 12:

Col.2 - Total patient care episodes obtained by applying 1971 patient care episode rate per 100,000 population (1,968 per 100,000) to the projected 1975 and 1980 total U.S. population. Age distributions of patient care episodes obtained by applying 1971 percentage distribution of patient care episodes by age to the 1975 and 1980 estimated total patient care episodes.

Col.3 - Represents a conversion of patient care episodes into number of persons accounting for these episodes by multiplying patient care episodes by a factor of 80. This factor was derived from findings of the Maryland Psychiatric Case Register that every person in that register had an average of 1.3 episodes of care per year.

Col.4 = Col.1 x .02
Col.5 = Col.1 x .10
Col.6 = Col.1 x .20
Col.7 = Col.4 - Col.3 (NOTE: For this column negative values were assumed to be zero,i.e.,the need for services would be met. Also the total is the sum of the parts.)

Col. 8= Col.5 - Col.3
Col. 9= Col.6 - Col.3
Col.10= Col.7 ÷ Col.4
Col.11= Col.8 ÷ Col.5
Col.12= Col.9 ÷ Col.6

FY '76: 48% of Medicaid eligibles under 21; 18.4% expenditures for services to under 21's.

Mental Health Services

1. 28 States currently cover children under 21 for inpatient psychiatric care. 24 provide other services, e.g., clinic, outpatient, evaluations.

2. In FY 76, 11.1 million children under 21 received services under Medicaid. It is estimated that only 7,000 received covered services in mental hospitals. (.063% received services in mental hospitals.)

3. Children receiving inpatient psychiatric care in mental hospitals accounted for an estimated 6.4% of all recipients of mental hospital care under Medicaid in FY 76.

4. In FY 76, $503 million were expended for mental hospital care; it is estimated that $45.8 million (roughly 9%) was expended on children under 21.

APPENDIX II

DEVELOPMENTAL SCREENING AND ASSESSMENT

in the

EARLY and PERIODIC SCREENING, DIAGNOSIS and TREATMENT PROGRAM

FINAL REPORT

April, 1977

Supported by U.S. Department of Health, Education and
Welfare Contract No. SRS-500-76-0510

The American Association of Psychiatric Services for Children, Inc.
1701 Eighteenth Street, N.W.
Washington, D.C. 20009

ACKNOWLEDGEMENTS

This report was prepared by Dorothy S. Huntington, Ph.D. It represents a synthesis of material supplied by various position papers, conference proceedings, and helpful suggestions made by those who responded to the initial draft of the report. The American Association of Psychiatric Services for Children wishes to express its gratitude to all of those who are listed on the following page who generously gave of their time and counsel.

We must be held solely responsible for all errors of omission or commission. Nevertheless this project could never have been accomplished without the tireless and invaluable participation of Dorothy S. Huntington, Ph.D., Chief, Child and Family Services, Community Mental Health Center, Peninsula Hospital and Medical Center, Burlingame, California, who participated in the original planning for the project, synthesized one of the original working papers, chaired the conference itself, and prepared all versions of this report. Special thanks also must go to the following people who authored the original working papers: Allan G. Barclay, Ph.D., Thomas Coleman, M.D., Anne-Marie Foltz, M.P.H., M.Phil., Frances Degan Horowitz, Ph.D., L. Wendell Rivers, Ph.D. And finally thanks must go to Jane R. Mercer, Ph.D., from whose research and publications the sixth working paper was synthesized.

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American Association of Psychiatric Services for Children
Conference on
Developmental Screening and Assessment
held in San Diego, California
February 10-12, 1977

Conference Participants

Robert S. Adams, M.D.
Allan G. Barclay, Ph.D.
Thomas J. Boll, Ph.D.
Harold Boverman, M.D.
Richard J. Bonnie, L.L.B.
Thomas Coleman, M.D.
Marcene Erickson, R.N.
Anne-Marie Foltz, M.P.H., M. Phil.
Martin E. Glasser, M.D.
Fernando A. Guerra, M.D.
Frances Degan Horowitz, Ph.D.
Dorothy S. Huntington, Ph.D.
Conference Chairman
Harold Ireton, Ph.D.
Sydney Koret, Ph.D.
LuVern A. Kunze, Ph.D.
Harryetta B. Matthews, R.N.
Jane R. Mercer, Ph.D.
L. Wendell Rivers, Ph.D.
Carlos J. Sanchez, M.D.
Henry R. Shinefield, M.D.
Sheila Swaiman
Judith Humphreys Weitz

Observors

Karl Banks
Rudolf Hormuth, M.S.W.
Beatrice D. Moore, M.S.W.
Laurence J. Platt, M.D.
Linda Randolph, M.D.
Robert S. Thompson, M.D.
Elsie M. Tytla, M.D.
Charles Wilkinson, M.D.

Conference Staff

Debora D. Kramer
Ruth Ann McGrail
Monica G. Noether
Marietha J. Slade

EXECUTIVE SUMMARY

I. PROLOGUE

Developmental assessment is an extraordinarily complex topic, but one which holds enormous promise for all children. Attempting to make recommendations about developmental assessment perhaps approaches the level of a Herculean task.

> In view of the work ahead of this group I am reminded of a story which appeared in the Washington Post supplement. The story was set on an ancient Roman galley and the Hortator, the one who bangs on the drum to keep the oarsmen in cadence, says - "I got some good news and some bad news! You all get steaks tonight!" "Yea!" "Yea!" from the rowing benches. "And now the bad - the Captain wants to go water skiing tomorrow!" I get the feeling that the organizers of this conference are avid water skiers. (Hurt, 1974)

The Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT) became a mandated service under the Medicaid Program through an amendment in 1967 to the Social Security Act, Title XIX, Section 1905(a)(4)(B). Effective July 1, 1969, it required

> ...such early and periodic screening and diagnosis of individuals who are eligible under the plan or are under the age of 21 to ascertain their physical and mental defects, and such health care, treatment, and other measures to correct or ameliorate defects and chronic conditions discovered thereby as may be provided in regulations of the Secretary.

We recommend that a major shift in emphasis and conceptualization be made with reference to EPSDT and developmental issues. These recommendations flow from a consideration of a wide variety of salient points, the most basic of which is that development is not a disease which yields a judgment of present or absent. We are basically concerned with the concept of competence - how well has a child met, and how well does he now meet, the expectations implicitly and explicitly set by his society for an individual of his/her age and sex group.

The legislation authorizing EPSDT makes it national policy that the development of our children, our future citizens, be safeguarded so as to insure that each child reaches maturity functioning at a maximum level of development. This goal is more than the finding, the study, and the treatment of disease. The guardianship of the health of children is in the national interest as well as in the interest of the individuals; this is the essence of EPSDT.

Parents must be accepted as full partners with the professionals who plan and staff the services provided for children. If responsible parenthood is to be encouraged, then parental involvement must be fostered. No single department or unit of the Federal government nor of local governments, and no single profession, has "the key" alone to promoting childrens' development. Only through coordinated service delivery as proposed herein is this possible.

We must develop a system of health care that treats the person rather than the disease or dysfunction. We are urging the development of a system for the protection of child development, a system of developmental review.

No single test or instrument is recommended because none could possibly be used for the adequate accomplishment of a developmental review for all ages and functions. Each review must include multiple assessment procedures tied to the age of the child and the dimensions to be assessed.

Any system of review must be predicated upon parental and child involvement in the review.

Any review must be oriented to the discovery of developmental strengths as well as weaknesses, not to the exclusive search to rule in or rule out pathology.

Every attempt must be made to voluntarily engage and utilize parents in the entire process of continuity of care and developmental review.

We recommend this system for all our child citizens. We encourage the recognition that the current law as specifically written is inadequate, undesirable and almost impossible to implement, but if the welfare of children is the goal, this proposed system should be set in its place.

There must be an integration into the EPSDT program of payment for all services which are needed by a child or family as a result of developmental review, including special education costs.

Our basic message is that developmental review is much more complicated than it appears when it is labeled "developmental screening" but yet the system of developmental review holds out enormous promise. We are, in this program, at a point of crisis; it is instructive to note that the word crisis in Chinese calligraphy is the blending of the two symbols for danger and opportunity.

National and individual interests may or may not coincide in a screening operation; indeed they may sometimes be in conflict, but they will always coincide with regard to the guardianship of the development of our future citizens. Thus the issues are more complicated and more relevant to both national and individual interests than the critical incident style of assaying or analyzing for specific fixable defects. The issues are more in the realm of a periodic review of a process, that of development. They are relevant to all children. Further, they are more relevant to a synthesis of function, supports, and developmental needs than to analysis and fragmentation.

Once this departure from the former conceptual model is accepted, we can go on to the details. To state it most concretely, we believe with reference to developmental and psychological issues, that the national mandate for EPSDT may better be stated by a change in name to EPRDT; the "R" representing a developmental review rather than a screen. The function of the review is to assess the ways in which development is occuring, the form that it is taking.

It then follows that national and individual needs and priorities will determine the processess to be used for the review and the resources available. The process and the resources will in turn determine the level of review, the ages served, and the backup treatments to be made available. It is at this final level of conceptualization where specific methods of review may be suggested, and specific ways of delivering services involved in this review may be proposed.

It is apparent that the present legislative language, which states that there shall be screening "...for mental defect...", is clearly inappropriate. The proper emphasis, in our opinion, is upon a process of developmental review, with the object being to identify strengths and competencies as well as weaknesses and defects.

It is assumed that the legislative intent of the EPSDT Program was to establish a national policy such that the development of the child be safeguarded in order to insure that, as with any other national resource, the resource is available to the nation. To that end, it is assumed that the *raison d'etre* for the program must be the husbanding of our child resources, from both a humanitarian and an economic point of view, and that the EPSDT Program must not have a narrow focus upon defect, but must look as well toward the optimization of the development of the child.

The policy surrounding the fuller implementation and development of the Early and Periodic Screening, Diagnosis and Treatment Program should be based on three principles:

1. a national commitment to the well-being of all children
2. a fostering of parental involvement
3. a pooling of professional and parental knowledge.

A policy for children must give practical recognition to the fact that they are the citizens of the future. Their development determines the fabric of tomorrow's society. At a time when resources are limited, there is a case for concentrating them where they can do the most good, in the area of well-being of children and families.

II. RECOMMENDATIONS

A. Our first recommendation is that the EPSDT mandate be broadened to apply to all children in this country so that a system of developmental review and protection might be planned for comprehensive implementation. It is also urged that funds be made available for the development of health care resources, including manpower, facilities, and research and development.

B. In the interest of pooling resources, consolidating efforts, and effecting maximum impact, we recommend that the currently existing extensive overlap in functions and goals of existing Federal programs be eliminated. The Maternal and Child Health program, the Education for All Handicapped Children Act (PL 94-142), and other programs sponsored by NIMH, NICCHD, BEH and OCD/Children's Bureau have significant duplication of effort with EPSDT; a thorough review of existing programs and agencies serving children should be undertaken, with the goal of effecting such mergers as would improve our services to children and reduce duplication.

C. The establishment of an EPSDT Coordinating Office at the local level is recommended; the function of this local coordinator will be to insure that the review, referral, treatment, information dissemination and follow-up resources of the community be utilized in carrying out the goals of the "merged", coordinated EPSDT program. Also recommended is the establishment of EPSDT Community Coordinating Councils to include the schools and all service agencies, as well as representatives of parents and service providers.

D. These support systems are being recommended in order to enable and facilitate planning on the local level; identification of gaps and needs in the service resources; coordination and stimulation of services relevant to achieving goals of EPSDT, and cooperation and contribution to the external evaluation of EPSDT. We clearly are recommending multiple models of service delivery depending on the characteristics of individuals and agencies available as support systems.

E. We recommend a new approach to the discovery of "handicapping conditions" or "mental defects". Developmental review is seen as the first step in engaging children and parents in an ongoing concern with their health and well-being. We see it as a way of promoting strengths, as a way of engaging parents with their children, of strengthening these parent/child ties, and of reducing the anxiety so prevalent in our society today regarding issues in parenting and child rearing. This is a true system of health care versus specific medical care.

F. As the individual with primary responsibility for the care of the child and for the facilitation of development, it is vital that the parent or other caregiver be meaningfully involved in the process of developmental review.

G. Such developmental review should, to the maximum extent possible, avoid coercion such as mandating that the developmental review be a condition for a survival need such as a welfare payment. Vigorous efforts should be made to insure voluntary participation by the parent in the developmental review.

H. Such developmental review should, to the maximum extent possible, provide significant benefit from participation, in the form of a better understanding of the child, with the aim being to provide assistance to the parent in coping with developmental issues, and facilitating future development.

I. Such developmental review should, to the maximum extent possible, recognize, respect and incorporate ethnic, cultural, social and linguistic differences that exist in a pluralistic and culturally and ethnically diverse nation such as the United States.

In a free, pluralistic society, there are clear boundaries on the scope of legitimate inquiry into personal and familial concerns. Therefore a mass government financed screening program should be limited to:

1) those measures of organic functioning and basic, adaptive coping skills which enjoy a high degree of consensus within the health professions and effected communities, and

2) those behavioral factors especially associated with learning, language and speech development, motor skills and perceptual abilities.

Specific assessment of emotional and behavioral adjustment and parent/child interactions should be left to parental initiative and sensitive clinical observation (Stage Three as herein proposed.)

As an integral part of the initial outreach phase of a developmental review effort, parents should be provided in the language most appropriate to them, a written description of the nature and purpose of the proposed procedures, including adequate assurances of its quality, confidentiality and benefits to the child and family. At the time the parent personally appears, he or she should be verbally informed of the nature and purpose of all developmental review procedures, and should be notified that selective participation is possible. A refusal to authorize any given procedure must not jeopardize the child's access to any other aspects of the program. Parental consent should then be obtained for each procedure and for any proposed transfer of records or information upon completion of the developmental review. Each child being served should be informed of the nature and purposes of the procedures and their results to the maximum extent possible consistent with his or her level of intellectual and emotional maturity.

Any transfer of developmental information between and among systems is recommended only when the information would be helpful in identifying

those conditions under which a child functions best, so as to enable, for example, optimal school placement. It is our recommendations that only diagnostic (Stage Three) information that is pertinent to educational prescription for the child be communicated to the schools, subject always to informed parental consent.

J. It is strongly recommended that no single instrument for development assessment be mandated nationally. There is no one single instrument, inventory or assessment tool that is totally satisfactory.

Any instruments, materials and methods for developmental review within the EPSDT program must be normed for the minority group with whom they are to be used. They must also be interpreted by persons who are familiar with the economic and cultural background of the populations being assessed.

K. The system for developmental review must be clearly recognized as a system, not a piecemeal approach.

We recommend research and development or demonstration projects to develop measurement and evaluation standards appropriate to the assessment of children and their environments. There should also be research into the methodology of developmental review with emphasis on a variety of assumptions and theories related to age and ethnicity.

There must be the development of strategies for the simultaneous selection of measurement variables and the identification of program needs, for the establishment of research, development and evaluation priorities. There must be an emphasis on the overlap between research and consumer priorities. In addition, there must be provision for taking into account family needs and values in the conceptualization of measurement related problems, and in the development, selection and application of any measurement or other instruments. Parents and those directly responsible for the welfare of the children must be involved in all decision making processes in this area.

The focus in interpretations of assessment must always be on individual differences that will lead to appropriate intervention for each specific child, as opposed to a focus on group difference and comparisons.

There should be a collection of multi-measure, multi-domain, multi-function measures from which instruments may be selected at a local level, by local option for Stage Two and Stage Three reviews.

L. Adequate developmental review would include factors from these areas:

1) biological dimensions
2) psychological dimensions
3) family dimensions
4) environmental/social/cultural elements

M. The review should be carried out in three stages:

1) Stage One

a. The biological dimensions would be reviewed within the framework of the pediatric physical examination, which would be expanded to include an opportunity for the child and family to discuss, if they so wish, any stresses or problems with which they would like help, or to identify strengths and support systems that could be engaged to provide for furthering development.

b. An assessment of the child's functioning would be done based upon the parents' report in the areas of development of skills and emotional and behavioral status.

2) Stage Two

Direct observation of the child's functioning, utilizing a variety of broader developmental screening inventories or instruments.

3) Stage Three

This stage of developmental review would include detailed aspects of the four domains: biological, psychological, family, and environmental/social cultural. The psychological domain would include a wide variety of functions - cognitive development, coping strategies, social development, emotional development, language and speech development, auditory perception, visual perception and physical functions.

This extensive review of a child's development, this clinical assessment, must be done with great clinical sensitivity by people highly skilled both in child development and in working with parents.

N. It is clearly necessary that we develop appropriate instruments in order that all stages of developmental review be carried out most adequately. There is not at the present time a single, universally acceptable tool for developmental review although there is a multiplicity of such instruments appropriate in differing situations and for differing developmental problems.

It is strongly recommended that the Medical Services Administration take a leadership role in establishing task forces and demonstration projects to develop further review procedures relative to acceptability, standardization norms, instrument reliability, instrument validity, concurrent validity, use by paraprofessionals, cost effectiveness and availability. In developing parent questionnaires, concerning their child's development, it is obvious that the questionnaires must not be trivial. must have developmental implications, and must have cross-cultural validity.

O. It is also recommended that a separate task force be appointed to supply a list of tests currently available, with information on how well they meet these criteria (section N above) of appropriateness, and in what areas of psychological, family and environmental review.

In connections with this, it is strongly recommended that there be constructive use made of data already available from past projects such as the collaborative studies, in order that we may become much more sophisticated about issues of longitudinal prediction.

After two years, no standardized procedure should be utilized in the program until it has been approved pursuant to regulations adopted by the Secretary. In the interim period, this Task Force shall review standardized procedures currently in use to determine their compliance with these above mentioned criteria, and shall recommend appropriate regulations to the Secretary.

P. It is recommended that a separate task force be developed that would collate and make available to local communities the varying models of parent based "treatment" programs that have been developed, and also make available the wealth of parent education materials that currently exist in many scattered places. This particular use of parent education materials holds within it a truly exciting and innovative approach to health care in this country.

Q. Any developmental review system initiated under EPSDT should clearly reflect the important distinction between the disease recognition and prevention model, and the cultural diversity model. Screening may legitimately utilize the "disease model" during the years of infancy and early childhood development when the child's primary social group is the family; in doing so, however, developmental review must focus primarily on the child's "physiological" development. Conversely, as children enter the mandated school system, when their behavior is evaluated with reference to the expectations of the social group, developmental assessment necessarily encompasses behavioral measures, and policies must therefore be formulated within the normative framework of the "cultural diversity" model.

R. It is recommended that specific guidelines concerning program evaluation be developed by a task force of experts who have specific competency in this area. We caution that this must be done quite soon, so that elements considered essential to proper program evaluation be included in those programs now in the process of implementation. Evaluation of EPSDT should be done in relation to specific, predetermined process and outcome measurements.

One of the most important issues in evaluation must be the inclusion of a search for possible positive and negative side effects of any system of developmental review on children and their families. This would include an investigation of any problems associated with potential "labelling" as a consequence of the administration and implementation of any of the aspects of developmental review herein recommended.

Research must be set up to provide answers to cost issues, and to develop appropriate systems for collection of data to estimate costs and benefits of publicly financed child health programs.

S. The proper implementation of EPSDT across the country will require the development of training programs in order to increase the sophistication of professionals in the area of normal development, developmental review, and opportunities for the developmental protection of children. Therefore, we recommend that there be an expansion of existing sources of funding so that training programs necessary for existing professionals who will contribute to the achievement of the goals of EPSDT be made available. We include in the group of eligible professionals: physicians, nurses, teachers, psychologists, social workers, school counselors, and speech pathologists and audiologists. Training programs should be carried out by existing accredited training resources and institutions (for example, universities, state colleges, community colleges). Training could be offered in the form of workshops, courses, seminars, and inservice training programs. We also recommend that training funds for paraprofessional personnel be made available on the assumption that Stage One and perhaps Stage Two of the developmental review process will be carried out by such personnel, and on the assumption that a great deal of the parent support work will also be carried out ultimately by paraprofessionals.

We urge increased effort to sensitize health professionals to the problems of parents, to the issues of ethnic diversity within this pluralistic society, and we urge that health professionals be trained to offer increased support and counseling to all families.

In order to acheve the goals of EPSDT, special resources for developmental review need to be created to supplement the kinds of assessments typically done by physicians. The nature of these special resources are largely specially trained personnel. Such personnel should have extensive skills in using developmental evaluation techniques, should know something about the arena in which physicians operate and similarly should have some familiarity with the nature and requirements of effective educational settings. They must also know about parents, about families, their ethnic and economic diversity and the realities in which they live in our society.

RATIONALE AND ELABORATION

1. What is Developmental Review?

It is evident that the development of a child is a process, requiring periodic review to insure that development is proceeding adequately. Thus the term "screening", with its connotation of searching for a defect, is less appropriate than is the term "developmental review" which implies a process orientation rather than a simple cross-sectional view. While it may be difficult to change the present legislative language, it is urged that the process of developmental review be strongly encouraged, and that the concept of developmental screening, which is more appropriate to medical or disease oriented conceptual models, be avoided.

Developmental review in the context of a health program has three goals:

1. The promotion of strengths of a child and family to cope with the various tasks of living
2. The prevention of specific developmental disabilities
3. Early case finding.

At this time we are recommending an entire reconceptualization of developmental assessment within the EPSDT program. This "Operation Rethink" demands the acceptance of new ideas. It is appropriate here to quote the various steps a new idea must go through:

Evolution of Reaction to a New Idea

1. indignant rejection
2. reasoned objection
3. qualified opposition
4. tentative acceptance
5. qualified endorsement
6. judicious modification
7. cautious adoption
8. impassioned espousal
9. proud parenthood
10. dogmatic propagation. (Lade, 1965)

The elements of Operation Rethink involve a reassessment of what "mental defects" are; what mental health and development are; the role of the family in child development; the orientation of a screening, diagnosis and treatment program around the integration of the family within the system; and finally, how one produces developmental gains via various support systems.

Under the proposed system of conceptualization there is no way in this field to identify precise tests to distinguish between "normal" and "abnormal" children; there are dozens of crucial functions subsumed under the concept of development, since development is not one thing. Developmental review would thus consist of an assessment of these functions rather than the specific diagnostic of a condition. A functional assessment, a profile of strengths and weaknesses, or assets and liabilities, describes the transactions between the child and the world around him in terms of the tasks asked of him and the people significant to his life, in the context of the particular settings in which the child is found and at the particular time of every developmental review. The outline of assets and liabilities, strengths and weaknesses, is clearly not related solely to the functioning of the child but is defined specifically in relation to the expectations of the important people and institutions in a child's life: family, school, friends, whatever is uniquely and individually important to any one particular child.

The effects of early life experiences as well as the effects of recent experiences such as a divorce in the family, the loss of a parent or other significant person via death, situational issues such as a fear of the procedures, all have a powerful effect on the ability of a child to demonstrate the quality of his functions during any specific review. Developmental review would thus assume that the child and his environment (including significant caregivers) are a unit and are not divisible. One does not exist without the other. One cannot be reviewed adequately without consideration of the other. Developmental review concerns itself with what goes on between the child and this environment on the biological, psychological, social and cultural levels.

It is just as foolish to search for a single method of observing a child's development as it is to tell a physician that he must use only one method (using a stethoscope versus using a thermometer versus visual inspection, for example) to complete an entire physical examination. However, it is obvious that a combination of methods will allow the observation of a set of significant functions. It must be stressed repeatedly that development is not a disease which yields a judgment of present or absent. We are basically concerned with the concept of competence - how well has this child met, and how well does he now meet, the expectations implicitly and explicitly set by his society for an individual of his/her age and sex group?

This approach raises a host of questions and issues. To be addressed are such considerations as the difference between medical and psychological screening, diagnosis and treatment; the difference between an individual problem of a child and the matrix of social problems that might be reflected in a child. Also to be addressed are issues such as primary

prevention as the detection of disease in non-symptomatic persons versus the newer concept of promoting strengths and promoting health. One must also consider health care in general versus medical care; this is a particularly prominent issue since EPSDT is essentially a medical care system.

With all the foregoing in mind, we recommend a new approach to the discovery of "handicapping conditions" or "mental defects". We do not see developmental screening only as a quick, simple procedure to identify those in need of further study but rather we see it as the first step in a way of engaging children and parents in an ongoing concern with their health and well being. We see it as a way of promoting strengths, as a way of engaging parents with their children, of strengthening these parent/child ties and of reducing the anxiety so prevalent in our society today regarding issues of parenting and child rearing. This is a true system of health care versus specific medical care.

We run the danger within developmental review of the fallacy of misplaced concreteness. There has been in the past an almost obsessive concern with the number of false positives and false negatives that each specific test yields. This is not truly the issue; the issue is what a parent thinks of his child, how he perceives the child, and how the child thinks of himself/herself. In addition it must be noted that this obsessive concern makes it sound as if there were a magical treatment available once the case is "diagnosed" according to this single all powerful instrument. That this is not the case will be reviewed in the following section. Again, we see the screening process and the diagnostic process themselves as the first order "treatment", through the engagement process by helping a parent think about the child's emotional and developmental status in a new way, in the context of a relationship with a helping person, a health professional in the broadest sense who is interested, who cares, is supportive and listens.

Engaging the Parents

In order to accomplish the goal of assessing a child's growth, strengths and weaknesses, one must as a prerequisite engage the cooperation of his parent or caregiver. Although logical, this process is at times ignored. This leaves the parent non-engaged, virtually sabotaging any cooperative effort on the part of an "outsider" to assess the function of a child. In actual practice this also leads to a very low number of return visits for diagnosis and treatment, when referral is made without parental engagement.

The parent is the only true observer of a child's rate of growth from birth until school age. Health professionals are not predictably involved in any consistent manner. When the child enters school, a new observer is identified, the teacher. Therefore, the parent must be engaged early in the infant's life in order to utilize his observational skills in a developmental review. The teacher likewise can be a valuable adjunct with parental approval to give information about the rate of growth the child. The exclusion, however, of the parent when the teacher's observations are sought, can lead once again into a sabotage of future attempts to assess the child.

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All parents, whether single or "coupled", have some fears about outsiders observing their child, and indirectly their "parenting". These fears can be stated as a "fear of labeling: good parent - bad parent" with a further extension of such, "good child - bad, defective child". Since parenting is frequently filled with ambivalent feelings of whether or not the "effort is enough", the fear of intrusion from an outsider is constant. On the other hand, the assistance and clarification of areas of concern are greatly welcomed and invited.

A further fear is that if any defect is discovered, there will be in fact no assistance or treatment for the correction of such. With these considerations, the following suggestions for engagement are made:

1. Every attempt should be made to voluntarily engage the parents and the child. Coercion by mandating an exam, or by attaching the exam to a survival need (money from welfare), immediately raises resistance and anger.

2. In order to have the parents cooperate, they must understand the benefits of participation. A model allowing for parents to evaluate the child first (parental inventory) with the opportunity to discuss areas of concerns as well as strengths, allows parents to look forward to assistance, rather than to fear "criticism."

3. The process of engagement should follow the stages of the parents' assessment of their child's development, and the parents' participation with a health worker to talk about areas of concern. (This also offers the opportunity for direct observation.) It would, in addition, be important at this stage to have a health worker who is bicultural and bilingual.

4. Although there may be a period of time from the initial contact to the definitive "diagnosis", the process of engagement with parents will enable the review to proceed. The failure to follow this engagement process could negate the opportunity to proceed to the desirable goals of treatment, remediation and facilitation of growth and development.

5. The definitive diagnosis, even though confirmed by criteria and norms, must be shared with the parents by a health professional with high sensitivity, expertise and knowledge of the parents.

6. The earlier the engagement process takes place, the earier it will be to have an accurate assessment of the child. Once rapport has been established at an early age, ideally birth, the review can take place with ease.

2. Some Considerations in Developmental Screening, Diagnosis and Treatment: Strengths versus Weaknesses

We must think very clearly about the implications of the difference in concept between screening oriented to promotion of strengths and prevention of disorders, and screening oriented to defects, damage, dysfunction, illnesses and weaknesses. We select tests partially on the basis of what use is going to be made of the results. The emphasis on defects and weaknesses leads to many ethical, social and psychological problems. In order to be concerned with success rather than failure, we need to establish a non-pathological model. As Brazelton (1976) has said,

> A new model is needed in pediatrics - a non-pathological model. With such a model that identifies the strengths of parents and children, the pediatrician would present himself as an advocate rather than a labeler. The Hawthorn effect would be great - expectations that they would succeed might reinforce their sense of dignity, of their own coping capacities, instead of the kind of expectancy to fail which, too often, they find now.

This viewpoint is especially important if we are to screen for mental retardation where, without ignoring pathology, we must be concerned with positive adaptive, coping capacities and not just with "defective" scores or failures on formal I.Q. testing.

The Nature of Intelligence and the Concept of Development

> A radical redefinition of intelligence is emerging from a growing number of studies that regard the specific capabilities measured by I.Q. tests as an important, but trainable, pattern of intellectual skills. These studies lead to the conclusion that I.Q. tests do not measure innate intellectual capacity, but rather a group of learned skills that can be taught in the classroom or in the home. (Whimbey, 1974)

The traditional assumption is that mental retardation is a chronic handicap that exists in a person as an individual characteristic, unrelated to the circumstances of that individual's life. There are two models, then, of retardation: the pathological and the statistical. The pathological model is based on a disease model that views mental retardation as a biological dysfunction typified by particular biological symptoms. The statistical models states that a person is abnormal if he falls into the tails of the statistical distribution of the population on whatever measure is being used for diagnosis. Both models imply a relatively simple conception of a developmentally constant and pervasive factor of general intelligence, yet this conception is no longer tenable as a model for "mental" development. A statement by Mercer (1972a) is particularly apt here:

> First, we concluded that a one dimensional diagnosis for retardation in which only an intelligence score is systematically used as the basis for evaluation is not equitable for persons from non-Anglo backgrounds. There is a real need for a standardized measure of adaptive behavior. Second, we concluded that pluralistic assessment procedures which take the socio-cultural characteristics of the individual's background into account when evaluating the meaning of a particular intelligence test score or adaptive behavior score, would produce greater convergence between clinical diagnosis and social system definitions. Such procedures would eliminate the ethnic disproportions which result from present clinical procedures.
>
> The medical model is transcultural. It assumes that socio-cultural factors are irrelevant to diagnosis and that similar patterns of symptoms will appear in persons of all cultures. If socio-cultural factors are considered at all, they tend to be studied in an etiological (causal) context as factors producing the organic pathology. Implied in a medical pathological classification system is the assumption that the sympyoms are biologically determined and that action to prevent, ameliorate, or cure a pathology will be focused on treating the biological organism. It is assumed that diagnosis and treatment can proceed without reference to the individual's socio-cultural background.
>
> The transcultural assumptions of the medical pathological model, when dealing with biological characteristics, are not an issue in the discussion. A child with a chromosomal anomaly, such as Down's Syndrome, can be identified and labeled in any cultural setting. His social milieu is not relevant to classification. For this reason, the discussion in this paper addresses only those cases in which there are no biological signs of deviance and classification rests entirely on behavior. In my opinion, it is the classification of the "normal-bodied" child which is the central problem facing the committee and the central issue in the current controversy. (Meier, 1973)
>
> The traditional statistical model assumes that there is one normal curve and this single distribution can be used to classify all children. This one 'standard norm' is based on the behavior of persons in the Anglo-American mainstream and, consequently, produces relatively accurate predictions concerning those who will 'succeed' in that mainstream. It institutionalizes the culture of the Anglo mainstream as the single, monocultural frame of reference for 'normal'. (Meier, 1973)

Intelligence is clearly a matter of basic endowment, health status, environmental expectations and experience, learning and definition. The pathological model fails when one refers to psychological functions: development is not a disease that yields a judgment of present or absent. There is an enormously wide range of what is "normal" or "average" in

developmental processes, and an equally wide range in the variant rates at which different functions develop in different children. One frequently wishes that this were not so, but it must be stressed that "development is not a single unfolding of more complicated behavior from infancy to maturity, but a process of learning and interaction." (Boelsche, 1969)

The Model of Medical Screening versus Developmental Assessment

The nature of developmental phenomena discussed above leads to very different models of screening and assessment.

Medical screening is a sophisticated concept; such screening is usually simple, quick, capable of "pass or fail" interpretation; it is applied once to each subject to minimize non-cooperation, and lends itself to evaluation in terms of sensitivity, specificity and repeatability.

Developmental assessment of psychological functions on the other hand, is a clinical procedure to which "pass or fail" interpretation should not be applied, repeated examinations are essential and it is not amenable to detailed quantitative evaluation (Rogers, 1971). The essentially clinical nature of developmental assessment must never be overlooked; screening cannot be a "one-shot" attempt on a parameter that is developmental.

Developmental assessment involves a description of the child's adaptive functioning in the major areas of development of skills (motor, language, self-help, etc.) and adjustment, including behavioral and emotional characteristics. Such description of development and adjustment may be based on parental report, clinical observation and possibly direct testing of the child.

Preliminary interpretation of functioning in relation to the expectable range for children of the same age, sex and cultural group then defines a developmental profile of the child's strengths and weaknesses. This developmental profile may be used to define needs for further evaluation or other intervention.

There are marked differences in the personnel required, also, for medical and developmental screening: for medical screening tests, suitable training in procedure is necessary but no previous clinical experience is necessary or even desirable. Developmental assessment, on the other hand, should only be performed by personnel having broad experience in the children of the age being assessed, and having specific training and experience in the field.

If one uses the analogy of screening oranges for size as an appropriate one for medical screening, then it is easy to see that the appropriate method for screening is the use of some sort of size sorting equipment - screens with progressively finer mesh.

> Of course there may be numerous other standard characteristics against which any given orange must be assessed, such as juiciness, sweetness, resistance to bruising, color, thickness of skin, peeling ease, general esthetic appearance, etc. Some of these characteristics are more difficult to mechanically screen and assess than others, thus requiring the informed, relatively subjective assessment of trained interpreters to differentiate and classify them. (Meier, 1973)

This seems an appropriate analogy to developmental screening and assessment. Because we use the same word - "screening" - we seem to have confused the concepts of medical screening for the presence or absence of disease with developmental screening, which might more appropriately be called review of developmental status.

The distinctions between the two models complicate the generation of a comprehensive, nation-wide screening system. The dangers of over-generalizing a model which may be relatively satisfactory in one realm to other, inappropriate realms cannot be overstressed.

The Appropriate Target for Screening: Society/family/child

The issue to be considered here is whether to screen on the basis of population statistics to identify high risk groups or whether to screen the individual. In addition, we cannot over-emphasize the importance of assessing not only the individual child but also the context within which he is growing and developing, in order to arrive at a contextual and therefore more valid prediction of whether or not the child stands some risk of developmental disability.

If we really mean preventive health care, we are focusing on family issues, not just the child. Medical care and health care are not synonymous. We therefore must look at the issues of prevention of disabilities in children by health care and nutritional programs for the mothers, who have been completely left out of the EPSDT program, for example. If prevention is really the goal, why not screen pregnant women and help them with the many viral and nutritional diseases that may lead to severe mental retardation in their children?

In addition, parental motivation to take advantage of "intervention opportunities" effects the outcome of that treatment/intervention with the child. The screening should therefore be done on the parents as well as the child, if one follows this model. A host of ethical issues are involved here.

Screening for child abuse, as has frequently been suggested, also implies that abuse is purely an individual issue. The questions of extreme violence depicted on TV and the encouragement of abuse in our society must also be discussed in terms of "screening the society". Prevention of abuse may dictate a totally different approach in this case.

Not only might parents (and families in general) be "targets" for screening, but parents might well do the first level screening. Parental questionnaires have proven highly effective; a simple question of the type "do you think all is well?" releases torrents of information. "If physicians could approach a program like EPSDT with an attitude to parents of 'what do you think you and your baby need?', the physician could then offer his expertise in predicting to the child's future potential and determine with the parents how 'we' can best work together to help their child realize it." (Brazelton, 1976)

Problems of Determining Causation

A crucial issue on treatment approaches is the frequently made, but always incorrect assumption that screening or detection gives evidence of causation. Treatment programs are frequently designed on the basis of these assumptions. As Friedlander (1975) has commented in terms of language screening,

> I know of no existing, validated instrument by which it is possible to make a reasonably clean differentiation between central integrative dysfunction, low adaptive intelligence and inadequate environmental support for language learning in the cases of children below the age of five whose language development is disappointing.

The same might be said for the vast majority of psychological functions in young children.

State Behavior

The physiological and psychological state of the infant and child at the time of testing, that is, the degree of wakefulness, alertness, anxiety and attention is an important confounding factor in all screening and assessment efforts and frequently has been overlooked. Thus it is possible that a low score on some screening or assessment procedures may not be a function of some deficiency, but rather a function of the child being in a state inappropriate for that assessment at the time. The issue of the strange surroundings must also be carefully considered in relation to the child's degree of comfort, and therefore test-taking ability.

Developmental Issues

Screening cannot be a one-shot testing session on a parameter that is developmental. There is a great deal of misunderstanding about developmental issues in children, and about the constant change in their developmental capacities. In addition, infants and very young children are difficult to screen and assess definitively because of the wide range of normal inter-and intra-individual variations as they rapidly grow and develop.

Lack of Predictive Validity

Developmental screening in the traditional sense cannot be used to predict future potential, because of the nature of "intelligence", because of the limited number of items on such screening devices, and because of the difficulty of standardization using different ethnic, socio-economic and educational backgrounds of children and families. Such procedures should be used only as observational descriptions, by thoroughly trained examiners, which would then lead to plans for educational and remedial intervention for each child. Stability of intellectual functions is very probably in large part a function of environmental stability, and in no way may one predict how an individual might do when the environment is radically modified toward greater enrichment or deprivation. The predictive validity of developmental screening devices is thus very poor, based on issues of environmental stimulation or interference.

Problems of Personnel

Since children of pre-school age are frequently shy with strangers, in a new setting and with strange tasks, the skill of the examiners is an especially important issue. In many cases, bilingual competence will be crucial, as will be a thorough knowledge of the expectations of each ethnic group for their children. Programs to develop personnel with such skills, and to train, re-train, do periodic proficiency checks and constant supervision are extremely costly.

The "Treatment"/intervention System

The basic question of having a detection system when no "treatment" is available must be faced. If screening and then full scale assessment do not guide some form of "teaching" process or intervention system, why do it? Improvement in the health status of poor children requires meeting a large volume of unmet need for health care as well as changes in environmental, social and other factors that affect health status, but are outside the scope of a reimbursement and support system related solely to health services delivery. This is a crucial point, particularly in the area of "mental defects". Many developmental "defects" are social, educational or nutritional. Unfortunately the required services are not eligible for reimbursement under the current Medicaid system. The Federal appropriation for Medicaid does not include, and State Medicaid agencies do not have, funds that can be directed toward development of health care resources, whether manpower, facilities, or equipment, or toward research and demonstration efforts, specifically for the purposes of EPSDT.

When a satisfactory comprehensive developmental screening system has been field tested and thoroughly debugged, it is only useful if it plugs into practical intervention programs. The implementation of early childhood intervention through EPSDT has enormous potential for impact on the health, mental health and welfare of the entire country.

Yarrow (1975) states that cognitive - motivational characteristics in infancy and early childhood are significantly influenced by the early environment and in turn are related to later intellectual performance.

> A crucial issue with regard to intervention programs is pointed up by our findings. The issue is not simply whether we can increase the child's intelligence quotient or capacity to make perceptual discriminations, but whether we can modify the child's basic arousal level so that he becomes and continues to be more receptive to stimulation and learns to respond adaptively to people and objects in his environment.

Any sort of attempt to do this implies an "ecological intervention" - "a major transformation of the environment for the child and the persons principally responsible for his care and development" (Bronfenbrenner, 1975).

3. An Approach to Developmental Review

Given that the process of developmental review is more appropriate than that of screening, it becomes apparent that such developmental reviewers must, of necessity, engage the parent or other caregiver as a significant aspect of the review process. Thus, in order to accomplish the goal of reviewing the development of the child and the concomitant strengths and weaknesses, the assistance of the parent, or other caregiver must be engaged. As the individual with primary responsibility for the care of the child and for the facilitation of development, it is vital that the parent or other caregiver be meaningfully involved in the process of developmental review. Any such review process must make vigorous efforts not only to engage the caregiver in the review process, but must also be alert to the psychological dynamics of the review process, such as the natural ambivalence to intrusion into the family and consequent concern about adequacy as a parent or caregiver. In order to provide some areas of discussion relative to the "engagement" of the parent or caregiver in the developmental review process, it is felt that the following points must enter into any consideration of the developmental review process:

1. Such developmental review should, to the maximum extent possible, avoid coercion, such as mandating that the developmental review be a condition for a survival need, such as a welfare payment. Vigorous efforts should be made to insure voluntary participation by the parent in the developmental review.

2. Such developmental review should, to the maximum extent possible, provide for significant benefit participation in the form of a better understanding of the child, with the aim being to provide assistance to the parent in coping with developmental problems, rather than the anticipation of criticism for inadequate parenting.

3. Such developmental review should, to the maximum extent possible, recognize the ethnic, cultural, social, and linguistic differences that exist in a pluralistic, and culturally and ethnically diverse nation such as the United States. The developmental review process, especially the interpretation of the findings of such a review, must make a vigorous effort to insure that such differences are recognized, respected and incorporated appropriately in the total developmental review process.

4. Such developmental review should, to the maximum extent possible, insure that there is adequate provision for an interpretation and review of the findings of the developmental review to the parent, taking into account the strengths, as well as the weaknesses, of the child, and insuring that the interpretation is, to the maximum extent possible, of practical benefit to the child and parent in the facilitation of future development.

Thus, the process of parent "engagement" is viewed as a primary prerequisite for any adequate developmental review, and as a sine qua non of the adequate implementation of such a program.

Developmental Review

Given an extensive review of currently available materials, it is strongly recommended that no single instrument for developmental assessment be mandated nationally. There is no one single instrument, inventory, or assessment tool that is totally satisfactory. Any instruments used must meet the criteria discussed below. At the current time there is no one instrument that meets such criteria. There are a number of assessment tools that might serve as prototypes of approaches to the adequate conduct of a developmental review, and the criteria for such exemplars are discussed in the following section. It is also strongly recommended that the system of developmental review herein discussed be clearly recognized as a system for developmental review, not simply a piecemeal approach. We strongly urge that this system of review be adopted and implemented, and that appropriate guidelines and regulations be developed for its implementation.

In essence the system of developmental review proposes the following. An adequate review would include factors for these areas:

1. biological dimensions
2. psychological dimensions
3. family dimensions
4. environmental/social/cultural elements.

The review should be carried out in three stages:

Stage One

The biological dimensions would be reviewed within the framework of the pediatric physical examination. The basic sampling from the biological domain would be conducted as set forth in the guidelines for the pediatric examination of the American Academy of Pediatrics. It is further proposed, however, that the pediatric examination be slightly expanded to include an opportunity for the child and family to discuss, if they so wish, any characteristics of the family situation that they identify as causing stress and problems, as well as to identify strengths and support systems that assist the family in its coping behaviors. Some sample questions that might be added in the course of the pediatric examination and health history are:

Who is in the family unit?

How are the key relationships functioning (parent/child, couple, child/child)?

Are there health and/or social or emotional problems that are of concern to the family?

This opening of an opportunity to review problems and assess strengths and support systems with the health personnel allows for further engagement and child/family development.

The second area to be covered in Stage One review is an assessment of the child's functioning based upon the parent's report. This would provide an opportunity for the parent, alone or in interaction with the health personnel, to comment on the child's developmental progress and on issues relating to behavioral adjustment, temperament, coping capacities and the like. This would involve two sub-sections:

1. A parent report (interview or inventory) of the child's development of skills (motor, language, etc.) that would provide a developmental profile of the child's functioning.

2. A parental report (interview or inventory) of the child's adjustment and emotional and behavioral status.

Both of these reports may, according to local option, be developed as structured inventories which would permit review of changes over time as the child is followed in the health care system. The use of structured inventories would also allow paraprofessionals a key role in gathering this information.

Stage Two

On the basis of the informal observations of the person doing the health examination, and on the material from the parent questions, the parent inventory covering developmental areas and the parent inventory covering behavior, it would be decided if there were a need to refer a specific child to Stage Two. In Stage Two there would be direct structured observation of the child's functioning. This might be accomplished using a variety of broader developmental screening inventories or instruments that are currently available. Paraprofessionals might then be trained to administer these screening inventories, if interpretation of results and constant monitoring of reliability were the responsibility of more highly trained professionals.

Stage Three

Based on the findings from Stage Two a child might be referred to a Stage Three assessment of functioning. This stage of the developmental review would include aspects of the four domains listed above: biological, psychological, family and environmental/social/cultural.

In the biological domain, one might envision a child being referred for careful neurologic assessment, or for an extensive physical examination and review of health history. The health history, as specified in the guidelines of the American Academy of Pediatrics will also yield a great deal of pertinent information on development.

In the psychological domain, the recommendation is that an adequate developmental review cover behavior representative of a wide variety of functions:

Cognitive Development

Cognitive Skills
Judgment and reasoning processes (as opposed to outcome)
Memory
Interest and skill at gaining information
Information about the world
Integration and organization
Attention, persistence

Coping Strategies

Characteristic patterns of dealing with tasks
Motivation

Social Development

Relation to adults
Relation to children

Self-help adaptive skills
Concepts of responsibility and moral dictates

Emotional Development

Affect expression and control
Self-concept, self esteem
Body image
Separation
Concept of competence

Language and Speech Development

Receptive language; language comprehension
Expressive language
Articulation
Fluency

Auditory Perception

Discrimination
Auditory memory

Visual Perception

Visual
Visual motor
Visual memory
Visual integration
Visual sequencing and reasoning

Physical Functions

Movement, mobility
Gross motor
Fine motor

In the family domain, one might use any number of currently available family stress inventory outlines. One would, in addition, be investigating the issue of what familial factors are available to support the health development of the child. One would like to know about parenting issues such as: do the parents feel they understand the child, do they accept the child as he is, do the parents feel in control of the child or is he "beyond" their control, and do they essentially trust the child. A variety of economic, historic, and human relationship issues might be reviewed for their strength-giving aspects in child development.

It must be emphasized that the identification of emotional and behavioral difficulties, and problems with social development on parent/child interaction, should be left to parental or child initiative and sensitive clinical observation. Clinical inquiry as it is normally carried out with parents and children by a

skilled professional must be employed at this stage. The use of a systematized standardized procedure inquiring into these issues is ethically unacceptable.

In the environmental/social/cultural area, one is essentially again looking for the factors to support the health development of a child and family. Particularly pertinent here would be the support of community institutions such as schools, hospitals, churches, recreational facilities, and the entire childcare/day care system.

It should be emphasized that at every point in the developmental review, the orientation is toward the child's competencies and forces which are facilitating or could facilitate the child's development. The basic questions which must be added to the center around the areas of significant problems in development, manifested in social, emotional or intellectual functioning at home, in school or in the community. What are the biologic, familial, social and intra-psychic roots of the difficulties, and what maintains them?

Is Intervention Necessary?

The final question, of course, is "is intervention necessary?". The entire developmental review is a process of attempting to understand, in successively finer terms, the situation of the child and family that would lead to positive action.

> Developmental advances and irregularities are understood as the result of forces that are internal (generic, physiologic, and psychologic) and external (familial, educational, and communal). Or, more precisely, the child is seen as a "psychosomatically integrated" person - a member of a complex ecologic system whose endowment and physiologic experiences are in constant interaction with environmental provisions. (Cohen, 1976)

Numerical results of test items are only one very small part of the picture. The process by which a child arrives at a result is crucial.

One must observe with all clinical skill issues, such as working method, attitude, motility, interest span, curiosity, how a child understands his environment, those around him and his own relationships to them. The ethical dilemma of reviewing a child's development, without reviewing the parent/child totality when this is intrusive, but crucial to adequate investigation, must always be raised. It is in this area that some of the basic disagreements of the group were raised. What is clear, is that this clinical assessment must be allocated to people highly skilled both in child development and in working with parents, having a very high sensitivity to what is appropriate and what is inappropriate with any specific person. It is for this reason that any extensive review of a child's development must be done by someone with

great clinical sensitivity. A true comprehension of what the clinical process is must be conveyed to all people involved in developmental review so that a very clear understanding of the difference between Stage One and Stage Two material as contrasted with Stage Three, the usual diagnostic stage, is available. "Screening" is not just faster and simpler; it involves an entirely different process of understanding.

As will be noted, no specific list of tests, instrument or observation schema have been included. It was the feeling of the group that no such list should be made available since it would automatically signify to people seeing the report that these instruments were "acceptable". Two points need to be made: first, that one of the basic areas of disagreement covered the use of instruments acknowledged to be inadequate, simply to have an instrument, and second, that it is clearly necessary that we do develop instruments in order that the developmental review may be carried out most adequately. The recurrent theme in reports and discussions is that while it is earnestly desired that there be a uniformly acceptable set of review procedures, relative to psychometric validity, norms, cultural/ethnic validity, etc., there simply is no such set of procedures currently available. It is the hope that such a set of procedures might be developed, and it is strongly urged that the Medical Services Administration take a leadership role in establishing task forces and demonstration projects to do just that.

It has been noted earlier that while there is not, at the present time, one single fully acceptable tool for developmental review of the psychological domains of cognition, emotion, perceptual-motor functions, or parenting, there are procedures that have reasonable utility to selected aspects of the developmental review process and are acceptable in certain situations. Any tool must meet acceptable criteria for use. The following criteria are proposed for instruments to be used in the different stages of the developmental review process, whether the review is direct, with the child, or indirect, through the parent or caregiver:

1. Acceptability of the instrument, and its content, to parent, child and professionals;

2. Standardization norms appropriate to the population to be reviewed; to include at least the following: age, sex, race, socio-economic status, and geographic area;

3. Demonstrated instrument reliability;

4. Demonstrated instrument validity, thorough standard correlation techniques, and through false positive/false negative rates for functions assessed;

5. Demonstrated concurrent validity;

6. Amenability of the instrument to administration, and scoring, by trained paraprofessionals;

7. Cost effectiveness;

8. Instrument must be published, and widely available.

Given that the instruments to be used are in conformity with these criteria, and with appropriate consideration for cultural, ethnic, racial, and socio-economic factors that may influence interpretation of the findings from the developmental review process, this proposed system of developmental review has the following desirable characteristics:

1. It does not attach a label, or categorize, a child prior to a much more extended review, referred to as a Stage III developmental review;

2. It makes a dedicated effort to engage the primary caregiver, the parent, as a collaborator in the developmental process, and attempts to insure that the interpretation of the findings of the developmental review are culturally relevant, as well as psychologically sound;

3. It establishes definitive criteria for any developmental review instrument to be used, recognizing that the present state of the art does not admit of a singly universally acceptable instrument that is applicable to all of the culturally diverse, and pluralistic, populations involved in the EPSDT program, some twelve million American children;

4. It attempts to establish a brief, workable system of developmental review, that is functionally effective, both in terms of cost and benefits, with, hopefully, a reasonable guarantee of acceptability to both parents and professionals; and

5. It recognizes that there is not, at the present time, a single, universally acceptable tool for developmental review, while at the same time pointing out that there are a multiplicity of such instruments that have practical utility in differing situations, oriented toward review of individual and specific developmental functions.

It should be constantly emphasized that everyone is strongly opposed to any effort to attach "labels", or to make a diagnosis of the child during the first two stages of developmental review. The purposes of the initial review are to engage the parents in a collaborative effort to assess the process of the child, and to identify areas in which process has been perhaps problematic or, alternatively, to identify areas of special gifts that might be enhanced through facilitate efforts. The first two stages of review would not attempt to categorize or "label" children; rather, the system of developmental review would be devoted primarily to determining whether, in fact, there is cause for concern and if so, what

further efforts must be made to determine whether the concern is valid or merely reflects transient and not continuing problems. Given this orientation, the question of false positives/false negatives is moot.

The relevant question might be posed as follows: "Is there sufficient consensus between the developmental reviewer, the parent, and the child (in the case of older children) that there is need for further review?" If the answer is affirmative, then the recommendation would be that of referral for Stage Three review. It is to be noted that the assumption is that Stage One review (other than the health examination in some locations) will be done by paraprofessionals, while Stage Two would be most likely a combination of professional/paraprofessional efforts, i.e. the administration but not the interpretation of the developmental review instruments will be conducted by paraprofessional personnel at this stage. Stage Three must be carried out by experienced and skilled professional clinicians. On a concrete level, it is recommended that whenever the performance of a given child at Stage Two deviates by more than 20% either above or below what would be expected for chronological age norms for that particular developmental review instrument, then the findings from the developmental review for that child should be assessed to determine whether a Stage Three referral should be made, or in the case of a child who has special gifts, to make special efforts to assist parents in seeking out means to facilitate the special talents. It is to be stressed that this proposed method of identification of children who may be at risk for developmental difficulties is both empirical and objective, and does not "label" or diagnose a child. Rather, it simply indicates that optimum developmental progress is either not occuring or is occuring at an accelerated rate. Thus, the system of developmental review as proposed recognizes that there may be strengths as well as weaknesses, and moderates the search for pathology that is the hallmark of other systems of developmental review.

It should be pointed out that the areas of basic disagreement were four:

1. Any review of the adequacy of parenting skills was an anxiety provoking area for many. This is discussed in fuller detail in the section on legal and ethical considerations.

2. Using instruments that are acknowledged to be inadequate, simply to have an instrument, was a further area of disagreement.

3. The absolute need not to be make up lists of "approved" tests was felt strongly by many. It is suggested, however, that it would be possible to supply a list of tests currently available with information on how they meet the criteria of appropriateness reviewed above. A separate task force could do this in a brief time, making the point always that that situation is much more complicated than many people believe.

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4. In terms of the content of screening instruments, the question of whether we are ready to move from small scale to country-wide on any available instruments was an issue. The vast social implications of what we do were constantly before us.

4. The Role of the Parent

Clearly underlying the approach to developmental review suggested herein is the premise that a child's cognitive and emotional functions do not develop in vacuo. Although this appears to be a truism, it is unfortunately also true that this "truism" rarely informs the development of program.

Health care is often delivered without the involvement of the parent. Our belief in the importance of the "engagement" of the parent in the system, in the use of information from the parent in the developmental review, and in the involvement of the parent in the full-scale treatment programs should be stressed.

> Relationships between parent characteristics and child health and child development and the greater long-term effectiveness of parent centered as contrasted to child-centered early education programs suggests that child health programs should have a major goal of supporting family care of the child. A comparison of major characteristics of parental as contrasted to professional interaction with the child--priority, duration, continuity, amount, extensity, intensity, pervasiveness, consistency, responsibility, and interfamily variability--suggests the need for a major focus on the role of the parent in the EPSDT program. Traditionally parents have had primary responsibility for the integration of screening, diagnosis, and treatment services for their children. Parental cooperation with health workers is essential in order to make EPSDT services available to their children. Therefore, a major component in planning State and local EPSDT programs will be to develop communication and collaboration with parents and with parent groups.
>
> To achieve the needed collaboration between health and welfare professionals and parents will require training of both parents and professionals. Health and welfare professionals should understand the role of the family in child health and should have skills in strengthening and supporting as well as supplementing family care of the child. Workshops and inservice training programs for health and welfare workers on the conceptualization of family care, on variables

> that influence family care, on the relationships of parental care to child health and child development, and on new methods by which professionals and paraprofessionals can strengthen and support parental care of the child are needed. The programs should motivate increased collaboration with parents in providing for the needs of children. Programs that train and motivate parents to become involved with review of developmental progress and with diagnosis and treatment through outreach programs, followup programs and continuing home visitors programs are essential to insure early and continuing care of the child. (Schaefer, 1974)

It is of interest to note that in the extensive National Infant Collaborative Project, the parents are seen as astute at understanding their infants; they intuitively feel when their child is not developing normally. "Parents may well be the best observers and diagnosers of early problems. This possibility suggests that professionals need to listen carefully and with respect to what parents say about their infant". (Meisel, 1974)

There is at the current time only one full-scale health screening program in place in another country, this being the screening program for four year old children in Sweden. In this program information on the child's mental development is obtained in three ways: a parent questionnaire, a nurse interview, and observation by the screening staff. A series of questions in the parent questionnaire inquires as to the child's level of general development, speech development, level of play and coordination, independence in dressing, eating, washing, etc. and toileting abilities. While it had originally been intended that all four year olds in Sweden have an identical nurse interview, this plan has been modified by experience. In Uppsala an analysis based on data gathered in 1969 and 1970 showed that 93% of the children considered to need further consultation because of mental problems could have been identified on the basis of the questionnaire and screening staff observation. This observation and questionnaire approach is identical to what is being recommended here as Stage One of the developmental review. The physicians' observations include the child's behavior during his examination, ability to undress and dress self, ability to follow instructions, ability to concentrate and pay attention. Again in the Swedish study, information on the child's emotional development, including the possibility of behavioral difficulties, is also obtained via parent questionnaire and observation by the screening staff. A series of questions in the parent questionnaire inquires into the child's behavior: anxiety, sleep difficulties, lack of independence, aggressiveness, lack of concentration, overactivity, difficulties in interacting with others and listlessness. The parents are asked to rate any behavior problems listed as minor or major, and they are also asked if they feel that outside help is needed. The child's emotional and behavioral development is observed by the screening staff. These observations include:

level of security of the child during the examination (secure and certain, apprehensive and tense or negativistic, very anxious); level of activity of the child during the examination (calm and collected, fidgity with lack of concentration, very fidgity, divided attention, confused or apathetic). (Wagner, 1975)

In developing a parent questionnaire, it is obvious that the questionnaire must not be trivial, must have developmental implications, but most importantly, must have cross-cultural validity. There are in the United States a number of such parent questionnaires currently being used.

A second area of important contribution of parents to developmental review is the review of the family environment. The purpose of this is to describe the characteristics of the family and the social and economic circumstances in which it finds itself, in order to identify the stresses and the strengths and support systems available to the child. Some questions which might be added to the physical examination have been discussed in Stage One screening. In addition to this there is the possibility that, with parental approval, a local group might choose to add considerations of a more extensive sort in understanding the family support system. Under these circumstances, an approach such as that suggested by Mercer in discussing measures of sociocultural modality might be accepted:

1. family structure
2. Anglization
3. occupation of head-of-household
4. family size
5. parent/child relationship
6. sense of efficacy
7. source of income
8. urbanization
9. community participation.

Some local areas may choose to focus on a "problem list" such as economic stress, marital discord, parent depression, and the like. There are several family stress questionnaire currently available.

It is clearly essential that parents understand their children's abilities and assets as well as their disabilities and deficiencies. What a child can do is far more important than what a child cannot do. Parental involvement in every step of developmental review is essential. The dialogue which brings parents and children into a true health care system is vital. We must also think seriously about developing parent-based treatment models right at the beginning of the programs. This crucial aspect of health care is frequently ignored. Treatment in this area of development frequently involves educational programs for parents on how to work with their children, and educational materials about life styles and health impact on family organization. "Treatment" may be education of the parent to support the child's strengths.

A recently published review of intervention strategies for high risk infants and young children (Tjossem, 1976) reviews an entire series of parent projects. In assessing the availability of treatment resources in local communities, most frequently the most obvious resource is omitted - the parents. It is possible to help parents learn to work with their own children in a way that has been highly productive not only for the children but also for the parents themselves. It is recommended that a separate task force be developed that would collate and then make available to local communities the varying models of parent based "treatment" programs that have been developed, and also make available to these local communities the wealth of parent education material that currently exists in many scattered places. This particular use of parent education materials holds within it a truly exciting and innovative approach to health care in this country.

5. The Delivery System

Our first recommendation is that the EPSDT mandate be broadened to apply to all children in this country so that a system of developmental review and of developmental protection, might be planned for comprehensive implementation. This will undoubtedly require the establishment of guidelines for eligibility of families who will qualify to receive these services paid for by Federal funds and for sliding fee scales for other families, but we believe that the service delivery systems contributing to the goals of EPSDT ought to serve the needs of all children in our society. Primary prevention and early intervention programs should be available to all children and youth. The identification of EPSDT as being available only to poor children is detrimental to the poor and non-poor alike, as well as to the long-term viability of the program. It also detracts from the potential of our efforts to conserve our most valuable resources for the future - our children.

There is extensive overlap in functions and goals of several existing Federal programs. In the interest of pooling resources, consolidating efforts, and effecting maximum impact, we recommend that such overlap be eliminated, possibly through mandated merger.

It is premature to say whether actually merging programs is possible or desirable, or whether EPSDT should have the key coordinating role, described below. We need to know a great deal more about how each of these programs operates, how they are administered, what services they can provide, to whom, and in what kind of setting, which are most acceptable to families and can best reach them, etc., before any decision can be made regarding the most reasonable and effective relationship of each to the other. Nonetheless, intensive efforts at coordination, collaboration and linkages must be continued and strengthened immediately.

Specifically, the Maternal and Child Health program and the Education for All Handicapped Children Act (PL 94-142) are programs having significant duplication of effort with EPSDT. A thorough review of existing programs and agencies serving children should be undertaken, with a goal of effecting such mergers as would improve our services to children and reduce duplication. Added to such a review should be programs sponsored by NIMH, NICCHD, BEH and OCD/Children's Bureau. Care must be taken, however, that existing services provided by current Federal programs must not be lost if and when a consolidation of effort should occur. For example, it would be unfortunate if the services now funded by Crippled Children's Services were lost in the "merger".

Interface of the Medical and Educational Settings for Achieving the Goals of EPSDT (hereafter EPSDT refers to a merged program)

In order to facilitate the interface of medical and educational settings and, as well, social service delivery systems for the purpose of achieving the goals of EPSDT, we are recommending the establishment of an EPSDT Coordinating Office at the local level to be staffed by an EPSDT local Coordinator and supporting personnel. It will be the function of the Coordinator to insure that the screening, diagnosis, referral, treatment, information dissemination, and follow-up resources of the community be brought to bear upon carrying out the goals of EPSDT. It will be the function of the Coordinator to relate to the medical, educational, and service agency settings so that each contributes its competence in providing developmental review and protection for all children in the community and for individual children who need special services.

Developmental review and protection of the child begins during the prenatal period. Pregnant teenagers and pregnant non-teenagers need to be provided with a health delivery system that offers both medical and educational services. Through information dissemination and by relating to the schools, physicians, clinics, county health offices, welfare agencies, and individual families, the EPSDT local coordinator should work to insure that every pregnant woman is entered into the health delivery system as soon after the onset of pregnancy as possible.

Initial developmental review becomes possible in the first few days of life in the hospital setting. Because of presenting conditions, some infants will be classified as high risk for normal development, some will be classified as suspected risk, and some as normal. Developmental delay and disorder may be expected from all of these groups in the differing percentages. The normal pediatric exam needs to be supplemented by an additional screening instrument. None presently exists that can be conveniently implemented. However, we are recommending that, subject to parental consent, each newborn infant in a community or designated EPSDT district be entered on to a birth registry and slated for periodic home visits by an EPSDT home visitor.

The home visitor would be expected to make contact with the parents prior to the infant's dismissal from the hospital, to conduct or arrange for subsequent metabolic and/or blood screens that can be done in the home at 10-14 days and to offer the parents pertinent information concerning early child development and resources available in the community including clarification of the full range of services available from the EPSDT Program. If developmental problems are observed by the home visitor (as the result of general observations, parental concerns, or the application of a Stage Two developmental screening test) referral to appropriate medical or developmental services for Stage Three evaluation would be made if the parents are agreeable. With parental consent the home visitor would facilitate communication with the child's physician if the child is being served by a physician or would refer the child and his/her family to appropriate services. Home visitors' work should be under the supervision of the EPSDT Coordinator and be assigned in accordance with neighborhood or community EPSDT districts. However, flexibility in program requirements should be maintained; if lodging the home visitors with an existing community service agency rather than in the office of the Coordinator makes more sense for a particular community or neighborhood, such arrangements should be permitted.

The frequency of visits would be determined by a needs assessment by the home visitor. Visits to the home will continue until the child has engaged a health care system that provides health care over time. The home visitor's role would serve educational goals, permitting developmental review to take place; would facilitate referral and follow-up. At any time, upon parental request, the home visits would be discontinued.

Public health nurses, pedicatric nurse assistants, developmental psychologists, and other professionals with special training might serve as home visitors for the purpose of providing special services to the family (e.g., home based developmental programs for young infants).

At the end of the preschool period and just prior to entrance into the public school, the question of the interface with the public schools for purposes of information transfer will need to be faced. Children identified by the EPSDT program as having been recipients of services may or may not be served by having information communicated to the public schools. It will be the responsibility of the EPSDT Coordinator to arrange for service agency personnel providing services to the child to meet with the parents of the child for the purpose of making a decision concerning information transfer. Such developmental information transfer is recommended only when the information would be helpful in identifying the conditions under which a child functions best, so as to enable optimal school placement. It is our recommendation that only diagnostic information that is pertinent to educational prescription for the child be communicated to the schools, subject, always, to informed parental consent. We are assuming that normal medical information typically

required by school systems at the time of public school entrance for all children would continue. As the child moves across systems or within systems, information transfer should only occur when the parent and service provider agree that it is in the best interests of the child. With due consideration of age and maturity the child's consent should be included as a condition for information transfer.

During the years in which the child is enrolled in the public school, the teacher and parent are always the first line of information for developmental review. Special training programs will be recommended which will enhance the developmental surveillance and protection role of the teacher. It is in relation to the entrance into public school that the recommendation for the close collaboration or merger of PL 94-142 and EPSDT is most relevant. This "merger" of the mandates of PL 94-142, Maternal and Child Health and EPSDT will maximize the resources available for developmental protection of children during the school years. We recommend leaving to each State the implementation of goals of these "merged" mandates via interagency agreements and local coordination of services and agencies. Such implementation should result in developmental review and protection of children through the school years meeting the American Academy of Pediatrics' standards for periodic health supervision (this includes physical as well as psychological developmental surveillance with due consideration of the development of life style habits that foster health). Identification of individual educational needs should be part of an ongoing program, to be followed up by the provision of relevant services. During the adolescent years, educational or direct experiences which contribute to developmental readiness for parenthood and adulthood should be made available.

In an attempt to insure that services are made available, states should be required to outline a phasing plan for EPSDT implementation beginning with outreach and covering start up and activation of the full range of EPSDT services and providing for multiple entry points. Local EPSDT Coordinating Councils should be established with representation from the schools, health services and other appropriate agencies; parental representatives must also be included.

Recommendations Concerning Support Systems for EPSDT

Two major support systems were mentioned in the preceding section. Recommended is the creation of an EPSDT Coordinator, and EPSDT office and support personnel for EPSDT districts. Where feasible, these districts should be formed to be coincident with local school districts, or to be larger or smaller than existing school districts depending upon population density. Also recommended is the establishment of EPSDT Community Coordinating Councils (as noted above) to include the schools and all service agencies as well as including representatives of parents and service providers.

These support systems are being recommended in order to enable and facilitate 1) planning on the local level; 2) identification of

gaps and needs in the service resources; 3) coordination and stimulation of services relevant to achieving goals of EPSDT; and 4) cooperation and contribution to the external evaluation of EPSDT.

As is obvious from the foregoing recommendations, there is an absolute necessity to examine any local situation prior to initiating a program. Questions involved in a health needs assessment of a community would give answers to "who is there to do it", "what are the supportive institutions", and "what facilities are available to work with parents in developing the fullest treatment programs".

The manpower issues involved in training, consultation, and technical assistance are primary. To be carefully reviewed, again in each local situation, are issues of qualifications of personnel involved in each stage of developmental review, cultural appropriateness of these personnel, and their training and education. Each natural system on a local level would include not only the professional system but the highly valuable, and indeed critical, sources of information and support, the parents. The characteristics of each natural system need to be defined for each locality. We clearly are recommending multiple models of service delivery depending on the characteristics of individuals and agencies available as support systems. The local coordinating councils may decide on resource centers with transportation to these centers, on the use of mobile units, on the use of community college personnel, on a multitude of other mechansims for obtaining services. Again, improvement in the health status of children requires meeting a large volume of unmet needs for health care as well as for changes in environmental, social and other factors that clearly affect health status but are outside the scope of a reimbursement and support system related only to health services delivery. For this reason our emphasis on coordination of program and payment mechanism must be taken seriously.

Existing programs which hold enormous potential are not adequately meeting the needs of America's children and families. Federal programs are scattered among dozens of departments and agencies.

> This fragmentation creates problems of coordination at best and conflict among programs at worst. At the state and local level the situation is even more confused. A wide range of services to families and children is currently being provided in an essentially haphazard fashion from many different government agencies and private organizations. Despite the sporadic attempts at community and regional planning and coordination, the result has been inadequate coverage in many localities and duplication of effort in others.

> Categorical, single strategy programs, while effective in meeting some of the specific needs of many families have failed to provide the support required by many families with multiple needs. In addition to programs specifically directed toward families and children, public policies in many areas have effects, both positive and negative, on the welfare of families. Despite this fact, little explicit attention is given to the impact on families and children of welfare, health, housing, transportation, environmental regulation, criminal justice, recreation, consumer protection, and other programs, both old and new. (Toward a National Policy for Children and Families, 1976)

The Parent and Support Systems

To be emphasized repeatedly in this approach toward coordination of services at a Federal and local level is the role of the parent.

> Support not intervention for parents of young risk children has emerged as the most promising available approach for producing developmental gains. Findings show that parents are effective teachers of risk children if given appropriate support. Their success in enhancing their child's development rests largely upon their motivation, involvement and acceptance of responsibility. The early relationship established between mother and infant is given as a fundamental determinant of the child's later course. With acceptance of these principles and the family as the object for support, communities can organize supportive services that enable families to enhance their risked child's development.
>
> Ideally, the approach begins in the newborn nursery. Here, both physicians and nurses are alert to sounds of early risk and show concern for the child's developmental well-being as well as health. In their appraisal, signs of risk in the early mother-infant relationship are not ignored. With evidence of risk and need for support, mother and child are discharged with an accompanying referral to be community health services for nurse support and observations in the home.
>
> In her home visit, the nurse first gives expression of the community's interest and support for the future well-being of the risk infant and family. While observant of total family needs as well as the health of both mother and child, the nurse is supportive of the mother's beneficial child care behaviors. She continues her periodic visits until, after exchanges with the child's physician, determination is made that no risk or continued risk is present. With this determination, she maintains her visits and relationship with the risk child and family and terminates service to the child and family that are doing well.

In the continuing supportive relationship, the nurse extends her knowledge of child care and training to the child through the mother. For family and child requirements beyond her command, she draws upon her knowledge of community or area resources to bring them into family service. In this manner, referral of the family is made to the community's educational resource upon evidence of the risk child's needs for educational assistance in mastering the developmental tasks of childhood.

The transition from nurse and physician to education services brings with it a comprehensive understanding of the child's health and developmental status and the family's needs and strengths. Upon educational evaluation and acceptance for service, the child and family enter into the home-based training program offered by the educational resource. The individualized training program is implemented by the parents with the guidance and support of the educator. Continuing, as needed, into the preschool years, the educator monitors the family's and child's needs for adjunctive community services and assists in bringing their support to the family.

The parent approach outlined in the foregoing is but one of many models a community might develop to provide services to risk children. To the extent that other models capture the basic principles involved, they should be effective programs. These principles restated are:

1. supportive services are initiated early
2. are offered on the basis of perceived risk and need, not diagnosis
3. are family oriented
4. support and enhance the mother-child interaction system, and
5. are sustained.

The requirements of the basic program are modest and can be met. They exist as medical, nursing, and early educational services provided in most communities, or, in their absence, can be developed through existing agency organizations. The resources and technology are, or can be, available. The task, now, is to make them work. (Tjossem, 1976, pp. 24-25)

6. Payments and Eligibility

The coordination of services and programs discussed in the preceding section obviously dictates coordination of payment and eligibility issues. It is a strong recommendation of this group that

the "merged" EPSDT Program be available to all children and families in the United States. It is also urged that funds be made available for development of health care resources, including considerations of manpower, facilities, and research and development.

In the current situation, EPSDT turnover in eligibility negates the periodic aspect of EPSDT and may deny treatment found necessary as a result of developmental review. There are lapses in eligibility and these lapses are a clearly demonstrated problem. Patients may not be eligible for services long enough to receive treatment for identified developmental problems, or their treatment may be interrupted on the basis of eligibility issues. Currently, eligibility for EPSDT depends in most states on eligibility for welfare services, and health care needs do not necessarily correspond to welfare status. EPSDT reconfirms the limitation of "means-tested medicine", and the need for a more continuous and comprehensive method of assuring the right to treatment for people whose incomes often vary widely from month to month.

7. Ethical and Legal Considerations

General Ethical/Legal Premises

In developmental review, ethical evaluations must be viewed against the backdrop of two different normative models: 1) the disease recognition and prevention model and 2) the cultural diversity model. The former emphasizes identifiable organic pathologies which imply some type of medical treatment. Within this model, the basic assumption is that false positives carry no risk aside from those associated with further diagnostic procedures, while failing to detect pathology could lead to serious and possible irreversible consequences.

On the other hand, the "cultural diversity" normative model focuses on behaviors which deviate from the expectations of the social group. In this case, the basic assumption is that false positives are more serious than false negatives in screening because labeling a child as deviant tends to trigger social responses such as labeling, tracking into special programs, institutionalization, changed perceptions and expectations, etc., which in themselves may have irreversible consequences. For this reason, emerging law in the area of mental retardation and juvenile justice clearly rests on this assumption.

Thus, any developmental review system initiated under EPSDT should clearly reflect this important distinction. In our view, screening may legitimately utilize the "disease model" during the years of infancy and early childhood development when the child's primary social group is the family in doing so, however, developmental review must focus primarily on the child's "physiological" development. Conversely, as children enter the mandated school

system, when their behavior is evaluated with reference to the expectations of the social group, developmental assessment necessarily encompasses behavioral measures, and policies must therefore be formulated within the normative framework of the "cultural diversity" model.

The Scope of Developmental Review

In a free, pluralistic society, there are clear boundaries on the scope of legitimate inquiry into personal and familial concerns. Therefore a mass goverment financed screening program should be limited to 1) those measures of organic functioning and basic, adaptive coping skills which enjoy a high degree of consensus within the health professions and affected communities, and 2) those behavioral factors especially associated with learning, language and speech development, motor skills and perceptual abilities. Specific assessment of emotional and behavioral adjustment and parent/child interactions should be left to parental initiative and sensitive clinical observation (Stage III as herein proposed).

Relationship Between Developmental Review and the Remainder of the Health Care Delivery System

1. Programs should not be instituted without careful attention to their place in the full service delivery system: coordination of services as recommended in Section E is vital.

2. A top priority is the identification of gaps in diagnostic and treatment services in each community as an integral part of health services needs assessment.

3. There must be some mechanism for assuring the quality and equivalency of all developmental review and treatment services in the community.

Relationship Between Developmental Review and Unavailability of Follow-up Services

It is not ethically mandatory to limit the scope of review by precluding a specific review procedure because treatment is unavailable for the identified condition. This is true whether or not there be known treatment at all, or treatment is not available in the community, or if available, is too costly. Reasons offered for this position include:

1. without such data, the need for the development of treatment capabilities may never become apparent;

2. the information may be useful to the provider in counseling the parent about managing the problem, and in developing parent oriented treatment programs;

3. treatment may later become available.

However, in many individual cases, it is likely that the cost of Stage Three review would be unjustified by its likely benefits to the child.

Informing Parents of Results of Screening

If the developmental review program suggests that the child is in developmental difficulty, the health professional should inform the parent of the general area of concern, being careful to avoid arousing undue parental anxiety, before recommending referral for diagnostic (Stage III) evaluation. If the diagnosis is positive, the clinician should inform the parents fully of the child's developmental status and discuss the treatment alternatives. If treatment (or perhaps even diagnostic) services are not available in the community, then the diagnosing clinician should counsel the parent, utilizing his/her own clinical judgment in determining what information to disclose. It is, of course, also important to inform parents when no indications of difficulty are found during any of the stages of developmental review.

Criteria Governing Use of Standardized Procedures

1. We accept the view that American society is heterogeneous. Therefore, standardization of all procedures used in screening or diagnosis which are correlated with sociocultural factors must be done with appropriate sociocultural norms, and all testing must be administered in language appropriate to the language spoken by the child. Further criteria for appropriateness of instruments are spelled out in Section 3.

   After two years, no standardized procedure should be utilized in the program until it has been approved pursuant to regulations adopted by the Secretary. In the interim period, a task force appointed by the Medical Services Administration shall review standardized procedures currently in use, with the advice of appropriate professional and consumer groups, to determine whether they are correlated with sociocultural factors.

2. Each standardized procedure should have predictive validity for the behavior or conditions which they purport to measure. They must have predictive validity for children of each of the sociocultural groups with whom the procedure is to be used. After two years, no standardized procedure should be utilized in the program until it has been approved pursuant to regulations adopted by the Secretary. In the interim, the task force appointed by the Medical Services Administration shall review the predictive validity of standardized procedures currently in use for compliance with this standard.

The Ethical Relevance of Cost

Cost becomes an ethical issue when government, with limited resources, must finance services for large numbers of children and must choose to what extent which children can and will be served.

Although reliable cost estimates are presently not available for screening, diagnosis and treatment for EPSDT children, it is clear that such procedures should be as low cost as possible with the highest return.

Considering these premises, we suggest the following guidelines for priorities for the EPSDT Program:

1. Priority for care should be targeted to the prenatal, infancy and early childhood periods until the child reaches the mandated school entry age.

2. Stage I and Stage II review procedures should be as quick, brief and simple as possible without sacrificing quality so that as high a proportion of funds as possible can be put toward treatment.

Informed Consent

1. Parents

   a. As an integral part of the initial outreach phase of a developmental review effort, parents should be provided with a written description of the nature and purpose of the proposed procedures, including adequate assurances of quality, confidentiality and benefits to the child and family. Any written notification should include information in a language appropriate for that particular family.

b. At the time the parent personally appears, he or she should be verbally informed of the nature and purpose of all developmental review procedures, and should be notified that selective participation is possible. A refusal to authorize any given procedure must not jeopardize the child's access to any other aspects of the program. Parental consent should then be obtained for each procedure and for any proposed transfer of records or information upon completion of the developmental review.

2. Informing the Child

Each child being served should be informed of the nature and purposes of the procedures and their results to the maximum extent possible consistent with his or her level of intellectual and emotional maturity.

Records and Confidentially

All patient records should be created and maintained in accord with the customary practices of the health professions. Confidentiality should be carefully preserved and no information should be released without parental consent.

At the time of the mandated school entry screening, all records of earlier developmental review at time of birth, during infancy, or at time of pre-school entry would be consolidated by the EPSDT Coordinator. It will be the responsibility of this Coordinator to arrange for service agency personnel providing services to the child to meet with the parents of the child for the purpose of making a decision concerning information transfer. Such developmental information transfer is recommended only when the information would be helpful in identifying the conditions under which a child functions best so as to enable optimal school placement. It is our recommendation that only diagnostic information that is pertinent to educational prescription for the child be communicated to the schools, subject always to informed parental consent.

1. Under no circumstances should Stage One and Stage Two information be transferred to the school system.

2. "Medical" information from these records may be disclosed to authorized persons in the educational system with parental consent in accord with usual procedures.

3. "Screening information" *per se* should not be disclosed at all.

4. Additional information from the records may be disclosed to authorized persons with parental consent only after the EPSDT Coordinator has consulted with the parent and

> they have made an independent determination that the disclosure is in the child's best interests. With due consideration of age and maturity, the child's consent should be included as a condition of information transfer.

Ethical Aspects of Developmental Review and Assessment After Mandated School Entry

Many of these ethical and legal concerns about the purpose and scope of developmental assessment, informed consent, parental and child roles and confidentiality of records are especially acute after the child has entered the school system. This committee recognizes the school as a major point of impact on the child's development at this stage of his life. We also recognize our mutual concern with the critical aspects of a child's development at this point, since much of this development affects school adjustment and learning ability. There are some safeguards built into the education system to address our concerns for safeguarding the child's rights (such as the Buckley admendment) and more will doubtless come with implementation of PL 94-142. Nonetheless, the EPSDT Program should not abdicate nor delegate its responsibility for the children because they have entered the educational system. It requires instead that the criteria outlined interface with the safeguards in the education system, and buttress it when there are gaps. In fact, the "merged" EPSDT with its concern for the over-all health and well-being of the child, should feel that its responsibilities may supercede the requirements of the education system whenever safeguards for the child's rights in these processes are concerned.

The Dangers of Labeling

> "It would be unconscionably myopic to entirely overlook some of the larger societal issues inherent in any national massive screening system. The legal ethical and ethnic ramifications of labeling humans are to be carefully considered and respected, especially in light of the recommendations forthcoming from the 1971 President's Commission on Mental Retardation in Monte Corona, California which severely criticized current labeling practices and their subsequent dehumanizing effects. For example, the determination of cutoff points separating normal development from abnormal development is extremely controversial and the Boston conference focused much discussion and debate on this crucial issue (PCMR, 1973.)" (Meier, 1973)

In a working paper prepared for the National Advisory Committee on Classification of Exceptional Children, Mercer addresses this normality issue:

> "The classification of exceptional children has become a critical social problem because those ethnic and cultural

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> groups disadvantaged by present classification systems are protesting the taken-for-granted value frame within which psychologists, educators, and test makers have been operating. The classification of exceptional children did not become an issue because psychologists, educators and medical practitioners were dissatisfied with the present system. This fact has great importance to the deliberations of this committee. It signifies that the central issues are conceptual and ethical rather than technical and empirical. It means that basic assumptions are being challenged. The committee must be willing to examine basic assumptions and to address the fundamental value of questions being raised by those who take issue with present policies and procedures. If, instead, the committee treats its task as merely setting guidelines for establishing the reliability and validity of measurement techniques in their traditional sense, its work will have little relevance to the current controversy because it will have misunderstood the nature of the controversy. The value issues must first be clarified and the implications of adopting a particular value frame explored." (Mercer, 1972b)

We would call attention to the crucial nature of this statement for implementing the provisions of EPSDT, for beyond the ethical issues lie the dangers of legal action. Test results are used for making far-reaching decisions about children. In recent years, a growing controversy regarding the use of tests has blossomed. It has become increasingly apparent that the large scale use of tests for placing persons in social, educational and ecomomic niches has serious social consequences, particularly in light of the growing realization that standardized tests are unfair not only to the culturally different and the socio-economically disadvantaged, but also to the bright unorthodox person and the naive individual who lacks experience in taking them. There are potentially biasing effects of ethnicity, language, socio-economic level, and conditions of test administration on test performance. "Increasing social demands seek to modify existing uses of tests that are inappropriate and unfair, particularly with minority group children. Social pressure in this regard takes various forms, and principally includes litigation, action by professional and other types of organizations, and legislation." (Laosa and Oakland, 1974)

The messages that a child receives about himself from his environment determine to a great extent his feelings about who he is, what he can do, and how he should behave. Thus, if parents or teachers perceive children as different in some way, they will treat the child differently and may thereby encourge him to become as he is perceived. Teachers give the least acceptance and support

to children they perceive as having the least promise and the least backing from parents. Teacher contacts with "low assessment" children tend to be significantly more directive and discouraging of initiative and spontaneity. When adults believe a child to be incompetent, they may protect him from exposure to experiences from which he may learn greater competence. Learning is heavily involved with the expectation that one is able to learn.

Specific Minority Issues

There is a prevailing attitude, based on economic considerations in many minority groups, that one ignores all conditions which do not cause pain. One of the major issues in any comprehensive system of developmental review is: what form of outreach must be designed and employed which will impact upon the pattern of health facility non-utilization which is so firmly established within poor minority families, and which interferes with the early detection of factors which may potentially lead to poor intellectual and emotional functioning.

Again, the issue of parent and teacher expectations is crucial. In the past many programs for the "disadvantaged" are really programs that have retarded a child's development, even though they were designed to overcome the deprivation. Because "less" is expected from them "less" is observed to come from them.

It must be repeatedly stressed that any instruments, materials and methods for developmental review within the "merged" EPSDT program must be normed for the minority group with whom they are to be used. They must also be interpreted by persons who are familiar with the economic and cultural background of the population being assessed.

Why Our Fears Will Not Be Stilled

The perhaps repetitious insistence on the appropriateness of instruments and the inappropriateness of labels comes from the experience throughout the country of harm that has been done to children under the guise of "doing good". Children have been tracked and labeled, excluded from school, on the basis of the use of psychological instruments. In addition to this, the issue of parental and teacher expectation is a daily consideration. Children taunt each other, and guilt and anxiety are easily aroused in both children and families. The basic rights of children must be considered in any program of developmental review. The motto must always be "first do no harm". In the EPSDT system, there is the potential for enormous good.

8. Evaluation

Program evaluation is a highly specialized field; it is recommended that specific guidelines concerning program evaluation be developed by a task force of experts who have specific competency in this area. We caution that this must be done quite soon, so that elements considered essential to proper program evaluation be included in those programs now in the process of implementation.

Evaluation of EPSDT should be done in relation to specific, predetermined process and outcome measurements. An effort should be made, however, to insure that the evaluation of the developmental review segments of EPSDT does not itself become the controlling factor in the operation of the EPSDT program where such control would deflect the program from achieving its goals. Any evaluation program to be implemented must be done so with a minimum of paperwork and with the least distortion or interference in the operation of the program.

Process evaluation would be relatively easy to implement since it involves such matters as utilization, cost issues, volume of service and so forth. Outcome evaluation is much more difficult and more demanding, but must be done since the issue of long-term predictability of any aspect of developmental review is one that is crucial for the future of the children.

9. Cost Effectiveness

Any publicly financed health program begins with the assumption that it provides benefits which are an adequate return on the investment of public funds. Otherwise, the government need not institute a program at all. It could let the market place regulate health care without interference. During the past forty years in the United States the government has gradually increased its share of payment for personal health services. In child health, the government paid out 3.5 billion dollars in 1973 for welfare recipients and the medically needy, which has thereby become the major governmental child health program in both numbers of recipients and dollars expended.

The history of the federally and state financed Early and Periodic Screening, Diagnosis and Treatment Program of Medicaid indicates that it was established on the overall assumption that early detection and treatment of disease will save lives, save suffering and save the costs of life-long crippling conditions. Further, it was assumed that screening and early detection of disease can alter the natural history and course of a disease and that the benefits of this alteration can be quantified in dollar amounts. These cost-benefit assumptions were never fully documented so it is difficult to know precisely what were Congress's expectations when it passed the law in 1967 (P.L. 90-248). Thus, an evaluation of the program based on congressional goals is not possible simply because these goals were never clear.

In actual fact, despite the grandiose title of the program, it was planned and implemented in such a way that prevention and screening have been the focus, while diagnosis and treatment have been secondary if not neglected. Continuity of care has remained a distantly hoped for goal.

It was hoped that the burden of handicapping conditions would be removed by providing preventive care services for children. The Department of Health, Education and Welfare thereby thrust itself in the midst of a major debate in the field of medicine and public health which has been described as medicine's great schism: prevention versus cure.

Not only has there been no discussion of exactly what was to be prevented through the new program, there was no commentary on how effective a preventive program might be. Given this imprecision of purpose, it is no wonder that costs of these programs were even less clearly stated.

One way of controlling costs in implementation is to limit the extent of services that states are required to provide. In monitoring the programs in the states, HEW decided to focus its attentions on EPSDT and not to look at the overall care rendered under Medicaid to welfare and medically needy children.

The efficacy of disease management through screening rests on three necessary conditions: a knowledge of the natural history of the disease; the efficacy or efficiency of the treatment; and agreement on a large number of social and individual benefits which may accrue from the screening procedures. For screening to be efficacious, there must be a consensus on the social and individual benefits of the treatment procedures, and it is here that the developmental screening aspects are most vulnerable.

Few cost estimates have been made of the developmental screening components of the EPSDT program, particularly in relation to benefits. In the past, the issue of quality of care as measured by appropriate utilization has been constantly confused with the issue of costs. Sometimes costs are evaluated; sometimes costs are noted only in terms of the substitution of expensive services for less expensive services into contrasting organizations of health care. Costing out the EPSDT program and assessing cost effectiveness has received far less attention than studies for the Medicaid population as a whole. As in the case of developmental screening, the state of the art of cost effectiveness is not far advanced. Almost no work has been done on cost effectiveness for any system of developmental review; cost effectiveness itself may not be highly relevant if the goal is to provide children with relevant and promotive access to health care. A "merged" EPSDT, seen as a comprehensive care program, provides a basic package of health services which should be available to any child in the United States regardless of his economic status.

One does not need cost benefit analyses to prove that poor children should have access to the same health benefits as rich ones. Nor does or should one need cost benefit analyses to decide that children with crippling conditions deserve care. The analyses become useful, however, when, given limited resources, policy makers must decide how much of what sort of care can be given to how many people.

EPSDT's significant contribution to the field of child health has been to uncover the present health system's inability to provide comprehensive and continuous health services for poor children, even given a financing mechanism. The reasons for this failure are diverse:

1. The state of the art of preventive health services, particularly with reference to developmental review: disagreement among health professionals as to what is required and what is needed.

2. The inability of organized systems (state health or welfare departments) to monitor and follow all children under their care: the lack of case management systems.

3. The unwillingness of private health professionals to participate in a public health system unless adequate financial incentives are provided and bureaucratic dis-incentives are removed.

4. Confusion among federal and state agencies as to which group is responsible for child health (for example, Maternal and Child Health, Medical Services Administration, the Office of Child Development, etc.).

Research must be continued to provide answers to cost issues, and to develop appropriate systems for collection of data to estimate costs and benefits of publicly financed child health programs. The goal is, obviously, to determine the most economically feasible methods to deliver services without sacrificing quality.

The field of policy is extraordinarily important. If Congress meant what was stated in the EPSDT legislation, to make comprehensive care available for every poor child, then it must follow through on its promises and abandon cost effective approaches which subvert the intent of the policy.

10. Training, Research and Demonstration Projects

The proper implementation of EPSDT across the country will require the development of training programs in order to increase the sophistication of professionals in the area of normal develop-

ment, developmental review, and opportunities for the developmental protection of children. Therefore, we recommend that there be an expansion of existing sources of funding so that training programs necessary for existing professionals who will contribute to the achievement of the goals of EPSDT may be made available. We include in the group of eligible professionals: physicians, nurses, teachers, psychologists, social workers, school counselors, and speech pathologists and audiologists. Training programs should be carried out by existing accredited training resources and institutions (for example, universities, state colleges, community colleges). Training could be offered in the form of workshops, courses, seminars, and inservice training programs. We also recommend that training funds for paraprofessional personnel be made available on the assumption that Stage I and perhaps Stage II of the developmental review process will be carried out by such personnel, and on the assumption that a great deal of the parent support work will also be carried out ultimately by paraprofessionals.

We urge increased effort to sensitize physicians and other health professionals to the problems of parents, to the problems of ethnic diversity within this pluralistic society, and we urge that health professionals be trained to offer increased support and counseling to all families.

It is also crucial that members of different professional groups be sensitized to the ways that their colleagues in other professions view the world. The training of any "bridge" person must include knowledge not only of the procedures used in the various professions that are being bridged, but also the institutions in which they are embedded and the professional culture that surrounds them. Some of this can be acquired by exposure to other professionals but the understanding of it that is essential to effective collaboration probably depends on a more explicit examination of it during training.

We will gain little if we establish new bureaucratic structures without careful consideration of the qualities of the people who will make up that structure.

In order to achieve the goals of EPSDT, special resources for developmental review need to be created to supplement the kinds of assessments typically done by physicians. The nature of these special resources are largely trained personnel. Such personnel should have a very firm grounding in normal child development, should have extensive skills in using developmental evaluation techniques, should know something about the arena in which physicians operate and similarly should have some familiarity with the nature and requirements of effective educational settings. They must also know about parents, about families, their ethnic and economic diversity, and the realities in which they live currently in our society.

Data Available

It is strongly recommended that there be constructive use made of data already available from past projects such as the collaborative studies, in order that we may become much more sophisticated about issues of longitudinal prediction.

As has been noted repeatedly in this report, we recommend research and development or demonstration projects to develop measurement standards appropriate to the assessment of young children and their environments. There should also be research into the methodology of developmental review of young children with emphasis on the variety of assumptions and theories related to age and ethnicity.

There must be the development of strategies for the simultaneous selection of measurement variables and the identification of program needs, for the establishment of research, development and evaluation priorities. There must be an emphasis on the overlap between research and consumer priorities. In addition, there must be provision for taking into account family needs and values in the conceptualization of measurement related problems, and in the development, selection and application of any measurement or other instruments. Parents and those directly responsible for the welfare of the children must be involved in all decision making processes in this area.

The focus in interpretations of assessment must always be on individual differences that will lead to appropriate intervention for each specific child, as opposed to a focus on group differences and comparisons.

Any instruments that are developed must describe capabilities and limitations for which some form of intervention, including parent education, may be prescribed, as opposed to tests or instruments that are interpreted only in normative terms.

There should be selection of a multi-measure, multi-domain, multi-function collection of measures from which instruments may be selected at a local level, by local option.

One of the most important issues in evaluation must be the inclusion of a search for possible positive and negative side effects of any system of developmental review on children and their families. This would include an investigation of any problems associated with potential "labeling" as a consequence of the administration of any of the aspects of developmental review herein recommended.

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Mr. ROGERS. That is very helpful and very concise.

Let me ask the whole panel this. Does anybody know what the costs are for delivering ambulatory mental health care to children? What is an estimated cost of delivering ambulatory care?

Ms. KRAMER. Mr. Chairman, if you will refer to the 29 pages of tables which accompany the written statement the AAPSC is submitting for the record, you will see there are several statements which speak to estimates of ambulatory cost. A survey we have done of our own membership, based on 70 responses of child mental health services, most of which are ambulatory services, some of which also provide inpatient care, indicates that better than 60 percent of all the children seen by community child mental health services can be served in under 30 outpatient treatment hours.

There are a variety of cost figures that can be attached to these 30 hours but the 30 hours is the better than average number of treatment hours required for intervention with the mentally ill child on an ambulatory basis.

Mr. ROGERS. Thank you so much.

Dr. NOSHPITZ. The American Academy of Child Psychology also has made a study in which colleagues in a committee have gone to private practitioners in the community and tried to find out what it costs to deal with a particular diagnosis on an outpatient basis. The figures are not all in. If the comnmittee is interested, we will try to get this for you.

Mr. ROGERS. It would be most helpful to have those figures and the committee would be grateful if they could be supplied.

Dr. Noshpitz, if you would like to give your statement, please proceed.

STATEMENT OF JOSEPH D. NOSHPITZ, M.D.

Dr. NOSHPITZ. Thank you, Mr. Chairman and members of the subcommittee. My name is Joseph D. Noshpitz, M.D. I am past President of the American Academy of Child Psychiatry, and I am here to present the joint testimony of the Academy and the American Psychiatric Association regarding H.R. 6706.

I am here with Mrs. Virginia Bausch, the Executive Director of the Academy.

Mr. ROGERS. We welcome you.

Dr. NOSHPITZ. There is a clause in this bill limiting the need to make provisions for mental illness, mental retardation, or developmental disabilities. Unless that clause is deleted, both of these organizations oppose H.R. 6706.

Mr. ROGERS. May I get that ultimatum once more?

Dr. NOSHPITZ. Yes. Unless the clause is deleted, the parenthetical statement that it is optional to the States—I believe the language states "except that." Since the chairman has indicated that the statements will be included in the record, I would like to make the rest of my remarks merely a summary of the written statement.

Mr. ROGERS. That would be fine.

Dr. NOSHPITZ. These are just a few points I would like to make. One, the language of the bill as much as encourages States not to provide treatment to cases of mental illness, mental retardation or developmental disabilities. Two, it does so while mandating assessment of these children. If this mandate is indeed carried out, the consequences bring us to point three, that parents will have their children evaluated, they will be told—and we are talking of millions of cases—"Your child has been found to have problems, no State services are available, the rest is up to you."

I predict they will not be happy, and with good reason. The pain associated with the identifying of such conditions is a dreadful thing. When you are poor and deprived, it does not make it easier.

Four, the notion that someone else will care for this, like the community mental health center program or the developmental disabilities program, is a cop-out. What has happened in this bill happens elsewhere. No one wants to pay for or deliver the care to this group of children. The real question is this. If you do decide to mandate these services to such children as we request, will you put the language in terms strong enough so that the services will indeed be forthcoming?

Essentially, the bill deals with preventive mental health. One of the most staggering burdens we face in this country is the consequence of inadequate prevention. This is parceled out among the education system, the welfare system and the penal system. The cost is in billions, tens of millions every day, and the mass of pain, frustration and depression among the people involved beggars description. This program should offer treatment, and if that treat-

ment did no more than prevent 1 child in every 10 served from becoming a social burden and a troubled human being as a youth and adult, it will more than have paid for itself.

In fact, I think we can do a great deal better than that, and at a very small fraction of the later cost.

In the light of these considerations I plead with you: Delete the parenthetical statement that makes such treatment optional. State, and with vigor, that treatment of mental illness, retardation and developmental disabilities is mandated. The children, the families, and the country need it.

[Dr. Noshpitz' prepared statement follows:]

American Psychiatric Association

1700 Eighteenth Street, N.W., Washington, D.C. 20009 • Telephone: (202) 797-4900

Testimony of the
AMERICAN PSYCHIATRIC ASSOCIATION
and the
AMERICAN ACADEMY OF CHILD PSYCHIATRY

on H.R. 6706
The Child Health Assessment Act

Before the
Subcommittee on Health and the Environment
Committee on Interstate and Foreign Commerce
United States House of Representatives

by
Joseph D. Noshpitz, M.D.

Mr. Chairman, and members of the Subcommittee, my name is Joseph D. Noshpitz, M.D. I am past President of the American Academy of Child Psychiatry, and am here to present joint testimony regarding H.R. 6706 on behalf of the Academy and the American Psychiatric Association.

Unless the clause limiting the need to provide mental illness, mental retardation, or developmental disabilities is deleted from the bill, both of these organizations oppose H.R. 6706.

We all know that children tragically afflicted by mental illness, mental retardation or developmental disabilities are difficult to treat. They have been traditionally excluded from service programs. In the past, however, discrimination has taken place regrettably through an act of omission. But this bill is unconscionable. The legislation explicitly authorizes the denial of treatment to children suffering with mental illness, mental retardation, or developmental disabilities.

Let there be no mistaking what the provision authorizing optional treatment for these children in this legislation means. It is tantamount to exclusion. HIstorically, optional coverage for mental illness has meant no coverage.

While the bill's declaration of purpose says one thing, the legislation per se is to the contrary. The bill says if you are a poor child whose health assessment is mentally ill, mentally retarded, or developmentally disabled, care and services need not be provided.

This bill represents a confusing message from the new Administration and a strange departure from its heralded leadership in the fight against mental illness. It's OK to treat mental illness but not mentally ill or mentally retarded children! And, if the Congress accepts these provisions, it will reverse its leadership role and the sensitivity to the needs of these special children.

Under existing law many states presently feel constrained to provide treatment for these disabilities. Yet this legislation explicitly makes this coverage optional. H.R. 6706 states, in effect, that a 3-year-old will be treated for diabetes or kidney disease, while he will be labeled and not treated for psychosis, neurosis, or depression.

Failure to diagnose and treat mental and emotional illness among children, the first-line of prevention, will have severe consequences in future years. If mental and emotional illness, mental retardation, and developmental disability is attended to as close to its inception as possible, the result will be thousands more who will be able to function in society as productive adults. Neglect at this early age is not only unconscionable. It is also counterproductive from the standpoint of a healthy and productive society.

We as a society are presently underserving our mentally ill children. There are approximately 88 million children in the United States, constituting about 40% of the population, and if one uses the commonly acknowledged figure of 10% of the population requiring services for mental or emotional illness, we would estimate that close to nine (9) million children have demonstrable psychiatric problems. Only about 10% of this population, or about 900,000 children, receive

any treatment at all. The number of Medicaid eligible children is dramatically lower than that.

This program offers the potential to Congress to provide a system of active treatment to these children who are presently being seriously neglected.

Proponents of this bill are operating under the delusion that these children are adequately served through other programs, such as those in Community Mental Health Centers. One can only seriously question child advocates who offer this as a solution. The CMHC system is a service plan that has historically omitted children's services entirely, or phased them in only after a Congressional mandate (P.L. 94-63). Regrettably hereto it has been very sporadic and in a disorganized fashion.

The CMHC catchment areas serve 40% of the population. The Mental Health Association has estimated consertively that there are at least 5 million disturbed children in this country; 2,000,000 of them fall within catchment areas. In 1975, however, only 300,000 children were seen in the CMHC system. The rest were not seen because of lack of staff, lack of funding, not enough specifically trained clinicians, inappropriate facilities, etc. From these figures, it is all too obvious that the program does not serve the children in need.

Another argument given by the Medical Services Administration of DHEW is that there are no adequate cost controls and that treatment is too costly. This fallacious argument is a strange reason to deny treatment to mentally ill and mentally retarded children.

Fallacious because the National Institute of Mental Health statistics show a sever under-utilization of services compared with estimates of need and we ask how were these conclusions arrived at? In point of fact, MSA has stated repeatedly it does not have data on the cost of treatment of the mental or emotional disturbances of medicaid children.

The American Academy of Child Psychiatry and American Psychiatric Association

urge the Congress to eliminate all language that makes such treatment optional. In addition, we strongly recommend that the CHAP program be charged specifically with assessing child health and mental health needs, and then mandating all subsequent active treatment that may be necessary.

I hope that the Committee will favorably consider our recommendation to delete the limitation on providing active treatment services for mentally ill, mentally retarded, or developmentally disabled children. I respectfully request that the attached article, "Toward a National Policy for Children," be included in the record. I will be pleased to answer any questions.

Mr. ROGERS. Thank you very much, Doctor.

What would be your thinking if where it now says " . . . but not necessarily including those" we inserted " . . . institutional services for the treatment of mental illness, mental retardation or development disabilities"?

Dr. NOSHPITZ. Right offhand that sounds to me like it might be ambiguous. I would worry about the language and have it rather precise as to what is, and what is not included.

Mr. ROGERS. Did you have a comment? I was thinking of the concept. I think that very expensive institutional services is what has been the concern.

Ms. KRAMER. Institutional services are indeed expensive, but if you will examine the data that we have been able to obtain from a selected number of States who do have inpatient services available for the title XIX population under 21, it is very clear that the increased Federal costs are not overwhelming.

For instance, in the State of Pennsylvania there were in 1976, 300 children in State and county mental institutions. The Federal share for the care of those children amounted to $6 million. The costs are very high but, as Dr. Noshpitz says, it is a very small percentage of children. It is only 300 children in one of our major urban States.

We have data, inpatient data, from the State of Wisconsin. The Federal share for approximately 200 children in the State of Wisconsin is $4 million. The data that we have from the Medical Services Administration estimates that 6.4 percent of all Medicaid recipients of mental hospital care were children under the age of 21, and only 9 percent of costs for mental hospital care was expended on children.

Approximately 27 States do cover inpatient services for children, and only 9 percent of the costs are going for those 27 states.

Mr. ROGERS. Thank you. That is very helpful.

I share your concern regarding classifying illness as not being a health problem. This seems to indicate, that mental health is not a health concern. So I have concern about that too. Thank you.

Now you have another old friend of the committee, or I will say young friend, Jonas Morris.

STATEMENT OF JONAS V. MORRIS

Mr. MORRIS. I have nothing to add at this time to the statement that I will submit for the record on behalf of the National Council of Community Mental Health Centers.

[Testimony resumes on p. 609.]

[Mr. Morris' statement and attachment follows:]

NATIONAL COUNCIL OF COMMUNITY MENTAL HEALTH CENTERS
2233 Wisconsin Avenue, N.W., Washington, D.C. 20007

Statement Concerning Child Health Assessment Program

Presented to

Health and Environment Subcommittee

Committee on Interstate and Foreign Commerce

U.S. House of Representatives

by

Jonas V. Morris, Governmental Affairs Consultant, NCCMHC

September 9, 1977

This statement is presented on behalf of the National Council of Community Mental Health Centers, representing 686 members, 609 of whom are comprehensive community mental health center programs or agencies developing such programs or having a direct interest in community mental health services.

The Administration's proposal to revise the Early Periodic Screening, Diagnosis and Treatment program and replace it with a Child Health Assessment Program could, if effectively implemented, have a significant effect on improving the health of Medicaid-eligible children. By the Administration's own estimates EPSDT reaches only 30 percent of those currently eligible and about 22% of those screened and found in need of treatment do not get the service they require.

Unfortunately, the CHAP proposal will not have the effect of improving the mental health of these children as it is currently designed. Unlike EPSDT, the Administration's CHAP proposal would specifically exclude treatment for mental illness, mental retardation, and developmental disabilities from the

requirement that services found needed by the screening program must be provided.

The rationale for excluding treatment for the mentally ill is apparently twofold: concern about uncontrolled increases in costs of services and the fact that the network of federally-funded community mental health centers is available to provide the necessary services.

In terms of costs, there have been numerous studies over recent years which all demonstrate the practicality of covering mental health services under insurance plans and clearly show that as a percentage of the total, the costs of mental health services and the utilization rates for mental health services do not become excessive. This Committee is, of course, familiar with much of this data, which has been collected from the Federal Employees Program, from United Auto Workers plans, the Canadian Health Insurance System and other major plans. A summary of some of these data is also attached to this statement.

Furthermore, there are studies from both Health Maintenance Organization settings and from insurance plans which show that providing mental health services has a positive benefit on the costs of other services. Many individuals in need of treatment for a mental health problem become frequent users of medical services, but once mental health services are available this use is drastically cut back, showing overall savings to the program even after allowing for the cost of the new mental health benefit.*

It is also important to realize that with CHAP we are talking about providing treatment services to children. These services therefore could prevent many mentally ill, mentally retarded or developmentally disabled youngsters from

*Health Model as Entree to Human Services Model in Psychotherapy, Cummings, Nicholas, Clinical Psychologist, Fall 1975; and Effects of Outpatient Psychiatric Utilization on the Costs of Providing Third Party Coverage, Blue Cross of Western Pa., Dec. 1976

growing up into seriously handicapped adults. This in itself can be cost effective for society, as well as extremely important to these children and their families.

The concept that CHAP need not require provision of services and thereby ensure funding for such services through Medicaid, because the community mental health centers are available is very disturbing to NCCMHC. Already, the CMHCs are finding themselves caught in a squeeze play in attempting to collect appropriate federal funds for services. PL 94-63 specifically requires centers to collect all available third-party payments, and mentions in the law collections from Medicaid and Medicare. As CMHC grants are reduced, and now as they are terminating for many programs, these payments are crucial if the centers are to survive. Yet the federal statutes for Medicaid and Medicare set up barriers to the collection of these payments to CMHCs. NCCMHC has been trying for the last several years to attempt to rectify this situation so that Medicare and Medicaid will not work at cross purposes to the CMHC Act, but to date we have not been very successful. Although this Committee and the Ways and Means Committee have just reported a bill to authorize a demonstration project to test the feasibility of covering CMHC services under Medicare, there has been no action taken to ensure that centers are able to collect appropriate reimbursements from Medicaid.

Thus the CHAP program, by providing a specific exclusion for services to the mentally ill, is making a very difficult situation worse for the CMHCs. Unless amendments are made to either the federal third-party payment programs (either by changing Medicare and Medicaid or by covering CMHC services under a new national health insurance plan) the number of CMHC programs virtually folding up; reverting to offering only those services for which reimbursement

is available; or cutting back innovative services such as outreach, C&E, and day care so that all that is available in the community are the services which were in place before the CMHC was ever initiated, will increase year by year.

Data already show that centers in their last few grant years begin to show a change in the patients they treat, with a greater emphasis on those able to pay or in the low-income range (eligible for reimbursement through public programs). This trend is disturbing; clearly individuals with no coverage and without the ability to pay for service are the very people who most need a program such as a CMHC in their community.

Thus, NCCMHC is generally supportive of the concept of CHAP, but only if the discrimination against the mentally ill, mentally retarded, and developmentally disabled is removed and treatment services for these children are required to be provided, as is the case for other services.

THE COSTS OF COVERAGE OF MENTAL HEALTH CARE UNDER INSURANCE PROGRAMS

With a new emphasis on community based treatment, particularly outpatient and other services which are less intensive than 24 hour inpatient care, the feasibility of covering mental health services under health insurance programs has increased.

A study by Louis S. Reed, to be published shortly by the American Psychiatric Association* includes data from several health insurance plans which indicate the feasibility in terms of costs of covering extensive mental health services, particularly outpatient care and other alternatives to hospitalization. Cited below are data from this study, which reviewed the following plans:

- Federal Employee Blue Cross/Blue Shield High Option Plan
- United Auto Workers health insurance plan
- Canadian Health Insurance System

Blue Cross/Blue Shield for Federal Employees: Considerable data is now available on the federal employees high option plan, which covers about 4.5 million people and is the largest private health insurance plan in the world. This plan provides extensive benefits: full coverage for 365 days per admission is provided for hospital care; physicians' in-hospital charges are covered in full; under supplemental benefits the plan pays 80% of physicians outpatient charges, subject to a $100 deductible.

As the high option plan for mental health benefits was initiated, utilization rates increased. This could be expected in any program as new benefits are added. However, over recent years the rate of utilization has stabilized at around 7% of all benefits under the plan. (See table below)

FEDERAL EMPLOYEES HEALTH BENEFIT PLAN -- BLUE CROSS/BLUE SHIELD
BASIC BENEFITS, HIGH AND LOW OPTIONS COMBINED

	Benefits Paid for Mental Disorders	Total Benefits Paid	Percent
1960-65	$40.2	$1,040.4	3.9
1966	13.2	277.2	4.8
1967	18.1	336.8	5.4
1968	24.8	405.0	6.1
1969	30.4	480.9	6.3
1970	41.1	601.9	6.8
1971	49.1	698.9	7.0
1972	54.3	760.4	7.1
1973	61.6	848.2	7.3
1974	70.1	979.1	7.2

SOURCE: Office of the Actuary, U.S. Civil Service Commission (9/12/74).

Data from this plan also reveal that 80% of persons receiving inpatient care for nervous and mental disorders were released within 30 days, and accounted for 45% of the total charges. The 89% who were released within 45 days accounted for 62% of charges, the 97% released within 90 days accounted for 84% of charges and the 99% released within 120 days accounted for 91% of the charges.

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* Louis S. Reed, "Coverage and Utilization of Care of Mental Conditions Under Health Insurance: Various Studies", American Psychiatric Association, 1975.

(11)

With regard to outpatient care, in 1973 persons with claims for mental illness constituted 0.6% of the total covered population. Of all persons incurring mental health charges, 62.2% had charges of less than $400 and their charges amounted to 15.3% of the total. Another 28.5% had charges of between $500 and $1,999, their charges amounting to 38.3% of the total. Another 7.2% had charges between $2,000 and $5,000 during the year, their charges amounting to 29.1% of the total. Finally, 2% had charges of over $5,000, amounting to 17.4% of the total.

UAW Plan: The United Auto Workers plan provides up to $400 a person a year in outpatient mental health coverage, and 45 days of inpatient care. There are no deductibles, and provided the patient receives care from an accredited group facility there is no copayment.

A recent study of utilization of UAW members in Baltimore,* shows the cost per enrollee increased from $2.71 in 1967 to $5.41 in 1970, but was less than 50¢ per enrollee per month.

The study compared utilization rates between those who visited a private practitioner and those who visited the Johns Hopkins clinic. The hospitalization rate was much higher among the patients seen through fee-for-service financing (52% of patients) compared with those using the clinic (4%).

Canadian Health Insurance Programs: The Reed study included a review of the Canadian federal-provincial programs of hospital and medical insurance, which provide care for mental conditions to the same extent as for other conditions.

In 1971, hospital separations with a diagnosis of mental illness comprised 3.7% of all separations, and patient days for mental illness were 5.7% of days for all conditions.

In 1971, 1972 and 1973, payments for outpatient psychiatric services ranged from 43¢ to $3.15 per covered person and constituted 1.4% to 5.4% of total payments for all medical services.

Finally, the Reed study shows the extent to which employees in a cross section of American industry are covered for mental illness under their employee health plans.

Data provided by the Department of Labor's Digest of Selected Health and Insurance Plans, shows in 1974, that 68% of plans studied provided the same hospital benefits for mental conditions as for other conditions, the remaining 32% had reduced benefits. 41% of the plans provided the same outpatient care, 45% had reduced benefits for mental conditions, 8% had no outpatient coverage for either mental or other conditions and 5% provided greater benefits for mental than other conditions.

Other data on costs of inpatient and outpatient mental health care under a wide range of plans are shown in the following tables extracted from Health Insurance and Psychiatric Care: Utilization and Cost**

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* H. R. Spiro, G. M. Crocettie and I. Siassi: "Fee-for-Service Insurance versus Cost Financing: Impact on Mental Health Care Systems", American Journal of Public Health 65: 139-143, February 1975.

** L. S. Reed, E. S. Myer, and P. L. Scheidemandel: Health Insurance and Psychiatric Care: Utilization and Cost. American Psychiatric Association, Washington, D.C. 1972

(111)

HOSPITAL CARE FOR MENTAL ILLNESS -- COST RATES BY BENEFIT PERIOD, 1968-1969

Benefit Period	Cost per covered person (mental illness)	Percent of cost for all conditions	Average length of stay (mental)
Less than 30 days			
GHI (NY) Federal, Low Option (10 days)	$0.34	0.8%	4.3
Group Health Assn. Federal (10 days +)	0.65	1.2	12.5
Kaiser Hawaii (20 days)	0.74	2.3	2.7
N.Y. City Blue Cross (21 days + 9 half days)	1.47	3.0	16.3
30-31 days			
Hawaii Medical Service, Federal	0.40	1.1	7.9
Tennessee Blue Cross	0.89	1.6	10.5
Federal Blue Cross-Blue Shield, Low Option	1.11	3.5	10.7
New York (Syracuse) Blue Cross	1.60	3.8	13.4
Postmasters Benefit Plan	1.70	2.2	75.3
GHI (NY) Federal, High Option	1.74	2.6	11.1
Kentucky Blue Cross	1.81	4.2	11.8
Connecticut Blue Cross	1.84	4.4	12.7
Maryland Blue Cross	1.93	3.0	14.1
Western Pennsylvania Blue Cross	1.94	2.8	10.8
Philadelphia Blue Cross	1.98	3.1	15.2
National Assn. of Letter Carriers	2.14	4.2	20.3
National Postal Union	2.18	3.2	15.8
St. Louis Blue Cross	3.42	6.5	14.5
45-50 days			
Kaiser Oregon (45 @ 80%) Federal	0.17	0.5	4.3
Washington Physicians Service (45)	00.89	2.8	7.5
Kaiser Southern California (45)	1.36	3.1	15.4
Mail Handlers (45)	1.73	3.5	17.5
Rural Carriers (45)	1.93	3.7	17.9
United Federation of Postal Clerks (50 days/lifetime)	2.23	3.3	18.9
70 days and over			
HIP Federal, Low Option (70)	1.22	2.5	5.8
Delaware Blue Cross (120)	1.45	3.2	23.6
Ohio (Cincinnati) Blue Cross (70+)	2.64	4.5	16.0
Federal Blue Cross/Blue Shield, High Opt (365)	3.23	5.0	16.3
HIP Federal, High Option (365)	3.43	6.2	24.7
American Federation of Govt. Employees (200)	3.63	4.0	22.6
Virginia Blue Cross (70)	3.96	5.8	18.5
Govt. Employees Hospital Assn. ($2,000 + 80% thereafter)	5.70	6.9	31.0

COST OF PHYSICIANS' SERVICES FOR MENTAL ILLNESS UNDER PRIVATE HEALTH INSURANCE, 1968-1969

Plan	Cost Per Covered Person	Percent of Cost of Physicians' Services for all Illness	Benefits for Mental Illness
National Postal Union	$0.27	1.8%	80% of 1st 10 visits, then 50% to $400*
Group Health Assn., Transit Workers	0.56	-	$15/visit to 16 visits/yr. (excl. Long-term care)
Postmasters Benefits Plan	0.66	2.3	50%, $100 deductible*
Hawaii Medical Service, Federal	0.69	1.0	$300/yr, 1st visit deductible*
Washington Physicians Service, Federal	0.71	-	75% to 20 visits/yr*
Mail Handlers	0.79	9.4	75% to $300/yr; 20 visits/yr.*
Rural Carriers	0.92	6.8	80% to $1,500 yr, $50 deductible*
Group Health Assn., Federal	1.02	-	$15/visit to 16 visits/yr. (excl. long-term care)
United Federation of Postal Clerks	1.12	5.6	50 visits/lifetime @ $25
National Assn. of Letter Carriers	1.32	9.3	80% to $400, then 50% to $3,000*
Group Health Insurance, Fed., Low Option	1.37	3.5	$300/yr for adults; $500/yr for children
Michigan Blue Cross/Blue Shield	1.43	-	1st 5 visits in full; coinsurance
Kaiser Oregon, Federal	1.43	3.5	80% to $400
Group Health Assn., General Enrollees	1.48	-	$15/visit to 16 visits/yr. (excl. long-term care)
Group Health Insurance, Fed., High Option	1.66	3.5	$300/yr for adults; $500/yr for children
St. Louis Labor Health Institute	1.69	8.0	Unlimited
Maryland Blue Cross/Blue Shield	1.94	-	1st 5 visits in full; coinsurance
Govt. Employees Hospital Assn.	2.32	9.2	30 visits/yr*
American Federation of Govt. Employees	2.40	7.2	50% to 50 visits/yr., $50 deductible*

* Includes physicians' services in and out of hospital.

(v)

HMO Experience

Studies of group practice organizations demonstrate that mental health services can be provided without utilization rates and costs becoming excessive (5 per cent of HMO premiums for mental health services). Further HMO studies indicate that patients treated by mental health providers reduce their non-psychiatric physician usage within the HMO by a significant percentage and that providing mental health services through the HMO results in savings in subsequent years up to $240 per case or 20c per enrollee per month.**

Conclusion

The cost of mental illness is now conservatively measured as around $30 billion per annu the direct cost of services (including the expense of pre-payment through insurance) is $10.4 billion, equivalent to 14% of all health care expenditures in the nation.

Data indicate the feasibility of covering mental health services under insurance plans without severe restrictions or limitations:

- The costs of essentially unlimited mental health coverage in the Federal Employees Program has plateaued at around 7% of all health benefits
- HMOs estimate five per cent of their premium for the provision of limited mental health services
- In CHAMPUS program, which has been critized for escalating mental health costs, mh costs constitute 19% of all health benefits (high because CHAMPUS covers care not available in military hospitals, which most prominently excludes mental health services)
- More than two-thirds of the employees in the plans studied by Louis Reed have nondiscriminatory inpatient coverage, and more than two-fifths have nondiscriminatory outpatient coverage -- large groups of American workers clearly already have substantial mental health coverage where utilization rates and costs have not proved to be a problem

** Goldberg, Irving D. et al "Effect of a Short-term Outpatient Psychiatric Therapy Benefit on Utilization of Medicare Services in a Prepaid Group Practice Medical Program" Medicare Care 8:419-428 (September-October 1970) and Follette, William and Cummings, Nicholas A. "Psychiatric Services and Medical Utilization in a Prepaid Health Plan Setting" Medical Care 5: 25-35 (January-February 1967)

Mr. ROGERS. Thank you.

We will look at any other figures you may have for us. It will be appreciated because it is difficult for us to get estimated costs in these areas from HEW, and yet they continue to say it is too expensive. Anything you can do to help us in that regard will be appreciated.

I believe this completes the panel. Thank you for your patience. We are sorry we had such a difficult day with so many roll calls. Your testimony has been helpful. The committee plans to take action on this bill.

The committee stands adjourned.

[The following letters and statements were received for the record:]

LINDY (MRS. HALE) BOGGS, M.C.
2D DISTRICT, LOUISIANA
COMMITTEE:
APPROPRIATIONS

WASHINGTON OFFICE:
1524 LONGWORTH BUILDING
WASHINGTON, D.C. 20515
BARBARA RATHE
ADMINISTRATIVE ASSISTANT

Congress of the United States
House of Representatives
Washington, D.C. 20515

November 11, 1977

Honorable Paul G. Rogers
Chairman, Subcommittee on
Health and the Environment
2415 Rayburn Building
Washington, D. C.

Dear Mr. Chairman:

I understand that your Subcommittee conducted hearings on September 8 and 9 on H.R. 6706, the Child Health Assessment Act.

I have received a letter from the Honorable Edwin Edwards, Governor of the State of Louisiana, commenting on the position of the State with regard to CHAP. In view of the concerns expressed by the Governor, I would appreciate your including this letter in the hearing records. I hope that you and the Subcommittee staff will carefully consider the points expressed by Governor Edwards in your mark-up sessions on this legislation.

My kindest regards and best wishes.

Sincerely,

Lindy

Lindy (Mrs. Hale) Boggs, M. C.

LB:nm

State of Louisiana

EXECUTIVE DEPARTMENT

Baton Rouge

EDWIN EDWARDS
GOVERNOR

November 3, 1977

Honorable Lindy Boggs
1524 Longworth House Office Building
Washington, D. C. 20515

Dear Congresswoman Boggs:

RE: Louisiana's Position on Child Health Assessment Program (CHAP) H.R. 6706

The Department of Health, Education and Welfare has proposed the expansion of the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program of Title XIX by adopting the Child Health Assessment Program (CHAP). Prior to this Program's adoption, I feel it is vital to inform you of the Program's intent and the problems which state officials foresee with its enactment.

Attached for your review and consideration is a position paper on the Child Health Assessment Program.

Thank you for your time and cooperation.

Sincerely,

Edwin Edwards

EDWIN EDWARDS

EE:bsa
Attachment

THE STATE OF LOUISIANA'S POSITION ON
THE CHILD HEALTH ASSESSMENT PROGRAM (CHAP)

H.R. 6706

The Department of Health, Education, and Welfare (DHEW), through the guidelines advocated by the Carter Administration, proposes to improve health services for poor children by expanding the existing program under Title XIX, that is, the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program. DHEW's proposal is the Child Health Assessment Program (CHAP). The Administration anticipates that the new program could broaden Medicaid eligibility and strengthen EPSDT in several ways:

(1) It emphasizes comprehensive health care by increasing the federal matching rate to states from an average of 55 percent to 75 percent for health assessments and ambulatory services provided by comprehensive health care centers, or by private physicians willing and able to assure comprehensive care.

(2) It emphasizes prevention by assuring immunizations for all eligible children.

(3) It provides for a national rate for costs of health assessments and assures follow through treatment for at least one year after identification of problem, regardless of continued eligibility.

(4) A capitation rate will be available to primary care providers who are willing to become comprehensive care providers for families choosing a single source of care. The increased matching rate and the capitation fee are intended to encourage the use of comprehensive health care centers and providers where the full component of health care can be provided - the assessment, diagnosis and treatment. It is expected that this will shift care from more costly emergency rooms and hospitals to primary care settings.

(5) There will be an increase in expenses to $180 million in the fiscal year 1978 for the new provisions of the proposal. This increase will be in addition to the anticipated expenditure of $165 million under EPSDT in that year plus $6 million for immunizations.

Furthermore, the Carter Administration feels justified in its recommendation of expanding and improving the current medical services rendered to its eligible children because of inefficiences that have developed in the existing EPSDT Program.

(1) There are 12 million children currently eligible for Medicaid; EPSDT reaches only 30 percent of these children.

(2) There are an estimated 700,000 children under six not reached by EPSDT because their families have incomes which meet state financial requirements for Medicaid but their family structure

(father being present, for example) makes them ineligible for Medicaid.

(3) There are 1.1 million health problems identified annually during screening but only 60 percent received follow-up care and as many as 500,000 conditions remained untreated.

(4) Children with developmental problems were rarely helped even though large numbers were found to have perceptual, motor and cognitive difficulties.

(5) Half of the states chose to provide screening through health departments. Providing routine care to children on a continuing basis is difficult for health departments because of inadequate staff and improper facilities.

Because of the potential for a measurable increase in Title XIX expenditures if this Program is adopted, it is important for us to point out that this proposal has met with unfavorable reaction. The State of Louisiana feels that the future success of CHAP was based on assumptions by DHEW that cannot be totally justified. More specifically, they are:

(1) DHEW assumes that comprehensive care providers are readily available in the state in sufficient numbers to effectively carry out our program. In Louisiana, the local health departments have taken the load of providing screening services while the bulk of diagnosis and treatment has been provided by the private sector.

(2) The demand for EPSDT has been met through the efforts of State's Medical Societies, the Medical Assistance and the Social Services Programs of the Office of Family Services, and the Health Department of DHHR. It would be unrealistic to project that the majority of these health units could be expanded to qualify as comprehensive care providers. The State Medical Practice Act could further prohibit health departments from providing diagnosis and treatment services in some areas of the State.

(3) What will happen to our local health departments if such centers are developed? If comprehensive health care centers cannot be established, it seems likely that the program would create a situation more detrimental to the children who need to be screened and referred. Starting over with a new program would delay progress that improvements on EPSDT have just recently secured.

(4) The anticipated cooperation of private physicians as possible comprehensive care providers is very slight. Private physicians would have to be willing to become case managers. This would involve extensive paper work which is already the main complaint of the physicians currently providing services. Recruiting and maintaining providers for medical services are time consuming jobs for states at the present time.

(5) Louisiana is basically a rural state and these rural areas are especially limited in private physician resources. The inadequate number of participating providers available for screening is a primary reason for contracting with the Health Department. It is highly recommended that the problem of lack of adequate medical resources throughout the state should be addressed before we attempt to impose a CHAP system.

(6) Violation of the free choice of the provider is another issue refuting the implementation of CHAP. Requiring clients to receive diagnostic and treatment services at the screening site is in disagreement with the provisions regarding free choice of provider under 45 CFR 249.20.

While Louisiana supports the overall goal of CHAP, improving health care for poor children, we cannot fully support the program as proposed for the reasons cited above.

ARLAN STANGELAND
7TH DISTRICT, MINNESOTA

COMMITTEES:
GOVERNMENT OPERATIONS
PUBLIC WORKS AND
TRANSPORTATION

Congress of the United States
House of Representatives
Washington, D.C. 20515

OFFICES:
1516 LONGWORTH HOUSE OFFICE BUILDING
WASHINGTON, D.C. 20515
(202) 225-2165

M-F BUILDING
403 CENTER AVENUE
MOORHEAD, MINNESOTA 56560
(218) 233-3631

July 26, 1977

Honorable Harley O. Staggers
Chairman
Interstate and Foreign Commerce
2125 Rayburn House Office Building
Washington, D. C. 20515

Dear Chairman Staggers:

I received the enclosed material from the Minnesota Department of Public Welfare regarding H.R. 6706. I would appreciate your making their comments a part of the record on this legislation.

With best wishes, I am

Sincerely,

Arlan Stangeland

Arlan Stangeland
Member of Congress

Enclosure

STATE OF MINNESOTA
DEPARTMENT OF PUBLIC WELFARE
CENTENNIAL OFFICE BUILDING
ST. PAUL, MINNESOTA 55155

OFFICE OF THE COMMISSIONER
612/296-2701

GENERAL INFORMATION
612/296-6117

July 7, 1977

Honorable Arlan Stangeland
House of Representatives
1610 Longworth Office Building
Washington, D.C. 20515

Dear Congressman Stangeland:

Attached is the Minnesota Department of Public Welfare's response to the Child Health Assessment Act which has been introduced in the House (H.R. 6706) and is being heard by the Subcommittee on Health and the Environment of the Interstate and Foreign Commerce Committee. The bill, which would replace the Early and Periodic Screening, Diagnosis and Treatment Program, contains many provisions which we feel would strengthen and improve the current EPSDT Program. However, the bill also contains provisions which would have a serious impact on our ab lity to administer a comprehensive child assessment program in Minnesota. We are especially concerned with the sections relating to screening provider participation in the program. It is our opinion that, if these sections remain unchanged, few current or potential screening providers in the state would be willing or allowed to provide screening services to children eligible for Medical Assistance.

Your consideration of our response to the bill would be most appreciated as would any efforts you can make to see that our concerns are reflected in the bill's final form. We will be happy to supply any additional information you may desire on Minnesota's EPSDT Program. Thank you for your attention to this matter.

Very truly yours,

Vera J. Likins

Vera J. Likins
Commissioner

VJL/NJF/ld

Attachment

MINNESOTA DEPARTMENT OF PUBLIC WELFARE RESPONSE TO

PROPOSED CHILD HEALTH ASSESSMENT ACT

Being the single state agency which administers both the Medical Assistance and the Early and Periodic Screening, Diagnosis and Treatment Programs in Minnesota, we have reviewed the proposed Child Health Assessment Act with great interest. While the CHAP Program incorporates many features which Minnesota EPSDT staff have been advocating for some time, it also contains provisions which, if implemented, have grave implications for the future of the program in the state. In order to explain our position more fully, a section-by-section analysis of the bill follows.

1. Eligibility

We are very pleased that eligibility will be expanded to children who are currently not covered under the EPSDT Program. However, Minnesota and other states which currently provide coverage under the Medical Assistance-only provision will be unaffected by this change since coverage is already provided to these children, up to the age of 21. While the expansion of coverage is commendable, it only begins to attack the problems of health care for children of the working poor who cannot afford preventive health care and who do not qualify even under this expanded coverage.

2. Covered Services

The extension of covered treatment services also would not affect Minnesota's Program since these services are covered under the current Title XIX State Plan. In states where coverage is not so broad, the requirement for expanded coverage is good. We do feel, however, that there are problems with the limitations included in this section.

A. The exclusion of treatment for mental illness, mental retardation and developmental disabilities does a great disservice to children found to have problems in these areas. States should either have to provide treatment for children with such problems or arrange for such treatment as the present EPSDT regulations require. Unless such a requirement exists, either problems will be found for which no treatment is offered, or states will stop requiring that these problems be screened for, in which case the comprehensive nature of the program will be seriously undermined.

B. Treatment of dental problems should be required, regardless of whether the condition was or was not discovered during an assessment. In Minnesota, as is probably true in many other states, in-depth dental screening is not done during the assessment and "conditions" are not usually uncovered. Rather, a cursory examination is made for gross dental abnormalities. For children who have no such gross abnormalities, referral for dental care is made routinely for those children who have not seen a dentist within the past year. This policy is followed because of numerous studies which have shown that from 90 to 95% of all children need some dental care before the age of 5. The current EPSDT regulations which require "at least such dental care as is necessary for relief of pain and infection and for restoration of teeth and maintenance of dental health" are far preferable to this revision.

3. Provider Participation

Our strongest objections relate to this section of the bill. If the requirements for provider participation are implemented, the net effect in Minnesota would be to virtually eliminate all of our screening providers. Proposed Section 1912(b)(1)(2) would eliminate our nurse-run screening clinics which currently serve approximately 15% of the Title XIX children who are screened. Proposed Section 1912(b)(3)(4)(5)(6) would likely cause the vast majority of our private providers, who screen the remainder of the Title XIX children, to decline participation in the CHAP Program. These sections would likely ensure, whatever our intentions, that we could not implement a screening program for Title XIX children in Minnesota. We will deal with the issues affecting each type of provider separately.

A. The requirement that screeners provide a minimum of diagnosis and treatment services within three years would eliminate the nurse-run screening clinics which are currently operating in Minnesota under the approval and supervision of the Department of Health. These clinics are usually operated by a county nurse's service or health department and provide comprehensive screening services through a limited schedule of clinics held three or four times monthly in a county. These clinics provide needed services in areas around the state where physicians are not available or do not want to participate in the EPSDT Program. The clinics also operate in areas where they are a supplement to physicians who are participating in the EPSDT Program. The clinics refer all children who need diagnosis and treatment to the proper sources and follow them up to ensure that needed services have been obtained. We do not understand the necessity of limiting the screening portion of the program to providers who can provide some unspecified minimum range of diagnosis and treatment services. Nurses have been authorized by the Minnesota Legislature to provide screening services to Title XIX children and we have found that they have both the ability and desire to do so. We feel it is not only appropriate for nurses to provide screening services, but that such a policy allows for the most sensible use of scarce and expensive health care resources. We also do not understand what would constitute a minimum range of diagnosis and treatment services. Children who are screened may require a vast array of services including physical, dental, optometry, audiology, psychiatry, family counseling, physical rehabilitation, nutrition counseling, and services for developmental disabilities or mental retardation. Only a small fraction of the health care providers in Minnesota can begin to provide this variety of diagnosis and treatment services. Because of this fact, good referral and follow-up procedures will be required regardless of which providers do the screening. Nurses who provide screening services in Minnesota are specially trained in referral procedures, including the community resources available. We therefore feel that limiting the sources where children may recieve screening services will not solve the follow-up problem and will seriously impede our ability to provide screening services on a statewide basis.

B. The requirements that providers perform follow-up and medical case management for children who are screened would virtually guarantee that the vast majority of private providers who currently screen Title XIX children would not participate in the CHAP Program if such participation were voluntary. We make this strong statement based on actual experience in Minnesota. As a result of a lawsuit brought by Legal Aid of Minneapolis

against this Department, an out-of-court settlement was signed. One of the provisions of this settlement was that the Department would sign EPSDT Provider Agreements with all screening providers and that such agreements would require providers to meet minimum screening standards and to use a separate EPSDT billing invoice. These requirements fall far short of the follow-up and case management responsibilities included in the CHAP legislation. Nevertheless, we have had some extremely vocal opposition to even these requirements. The attached letter from the Hennepin County Medical Society is an example of how some physicians feel about having even minimum requirements placed on their participation in the EPSDT Program. It should be pointed out that Hennepin County is the largest county in Minnesota and contains approximately 40% of the physicians in the state. Of course not all physicians in Hennepin County or around the state agree with the position of the Hennepin County Medical Society. We have received letters from physicians all over the state supporting our development of screening standards and EPSDT Provider Agreements. However, if these physicians were required to provide follow-up and case management services along with the medical screening components, it seems likely that a substantial percentage of them would choose not to participate in the program. Instead, physicians would continue and expand their current practice of seeing Title XIX children for preventive health care and billing these services on the regular Medical Assistance Practitioner Invoice with no notification to the EPSDT Program that these children have been screened. If these requirements are not changed, then some provision must be added that would require physician participation in the CHAP Program in order to receive Medicaid reimbursement for other patients. If such a requirement is not added, the state will be placed in the untenable position of being required to operate a CHAP Program on the one hand and being unable to secure provider participation in the Program on the other hand. If such a situation develops, Minnesota will be unable to implement the CHAP Program.

4. Extension of Eligibility

The provision to extend Medical Assistance eligibility to children who have been screened for six months after grant status terminates is a great improvement in the program. The limitations to the program because of its tie-in to welfare eligibility would still exist, but this provision would at least lessen some of the negative impacts.

5. Additional State Plan Requirements - Section 6

A. Our ability to encourage participation by physicians and health care centers will be extremely limited if the requirements for physician provision of follow-up and case management are adopted. See section above on Provider Participation.

B. We are puzzled by the brief mention of outreach in this section and throughout the entire bill. We feel that good outreach is crucial to the success of a program like CHAP or EPSDT which depends on voluntary participation and which involves a concept not understood by many people. A state can have an excellent "on paper" program and still screen very few children because few people choose to participate. Our experience and that of most other states has shown that person-to-person contact is the best way to assure participation in the program. A provision should be added which requires such outreach efforts and then provides higher Federal Financial

Participation in order to encourage the employment of staff to perform these outreach activities. No matter how it is done, some strengthening of outreach requirements should be included in the legislation.

6. Increased Federal Financial Participation for Medical Services

Increasing the FFP for medical services provided under CHAP is an improvement since it could provide an incentive for states to screen more children. Determining which children are receiving medical services because of screening will continue to be a problem. Even with MMIS, (Medicaid Management Information System), we have been unable to devise a system which will accurately tie diagnosis and treatment invoices received to a previous screening.

7. Penalty Provision

The provisions for invoking a fiscal penalty against states which do not implement an adequate child health assessment program are a great improvement over current EPSDT penalty provisions. Penalizing Medicaid administrative funds instead of AFDC grant funds is an improvement since the loss will occur in the Medicaid Program and will penalize administrative instead of grant funds. Giving states a chance to correct their programs before the penalty is imposed is also a marked improvement over the current ambiguous requirements. However, it is very important that the penalty requirements be clear and that the review standards be specific and enforced uniformly across the country. It has been our experience that such is not the case with the current EPSDT penalty provisions. At the present time we do not know what standards our program is being measured against or what specific failures we may be penalized for. It has been our experience that review standards change from review to review and that we do not receive a clear statement after the reviews on whether or not our program is in compliance with federal regulations. Also, the documentation requirements are very important and should relate directly to the health status of children in a given state. Current documentation requirements relate strictly to process rather than outcome and rely almost completely on case record entries. We have found that it is entirely possible for a state or county to operate an EPSDT Program which fulfills all the paperwork documentation requirements and which still screens almost no children. A state's success or failure in program implementation should be measured by the program's goal--are Title XIX children in that state receiving needed health care?

8. Incentive Provision

The provision to increase the federal share of Medicaid administrative reimbursement if a state meets criteria for good performance is excellent. This provision will provide state administrators with a real incentive to develop a comprehensive program rather than simply to meet minimum federal requirements. However, the entire usefulness of this provision will depend on the performance criteria which are developed by HEW. We agree that such criteria should include measurements of the percentage of children screened and treated, but they should also include other state efforts that are not so easily measured. Efforts by state to coordinate with other programs, to seek consumer and provider input into the program, and to develop innovative outreach methods should also be included as measurements of superior efforts at program implementation. Also, states like Minnesota which have implemented a Medicaid Management Information System are currently receiving 75% FFP for a large percentage of Medicaid administrative costs. These states will not receive a comparable incentive to states not having MMIS. We feel that the incentive FFP for states with MMIS should be higher so they will receive a benefit comparable to non-MMIS states.

9. Implementation Date

We are assuming, even though the bill specifies an implementation date of October 1, 1977, that a phase-in schedule will be developed for the various requirements. Some of the provisions, (i.e., the requirement for the signing of Provider Agreements) will take some time to implement.

10. Screening Standards

The omission of a clear requirement for screening standards in the bill appears to us to be a serious oversight. In Minnesota, the development of screening standards has been very difficult and has required much imput from all individuals with an interest in the program. Yet we feel the development of standards is essential. If uniform standards do not exist, then children screened at one site may receive a far less comprehensive assessment than children screened elsewhere and yet both children are "counted" as having been screened. We would suggest that the development of standards be left to the individual states with approval from HEW required, and with provisions for provider and consumer input specified. In this way, some guarantee will exist that all children screened receive the service which was promised to them.

HENNEPIN COUNTY MEDICAL SOCIETY
Suite 401, 20 Washington Avenue South
Minneapolis, Minnesota 55401
612/333-3231

JUN 1977
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ASSISTANCE

June 14, 1977

Nancy J. Feldman
EPSDT Supervisor
Department of Public Welfare
Centennial Office Building
St. Paul, Minnesota 55155

Dear Ms. Feldman:

We are writing in response to the recently drafted EPSDT Screening Standards and EPSDT Provider Agreement. We would like to take this opportunity to comment on the organizational concept of the EPSDT program, as well as the specific materials distributed from your office on April 13, 1977.

First, with regard to the organizational structure for implementation of the EPSDT program, we would call your attention to the HEW publication - "A Guide to Screening/EPSDT-Medicaid: (p. 29)*:

> "Ideally, each child should receive all of the screening services he requires as an integral part of continuous preventive health maintenance and illness care. The ideal setting is in a physician's office or clinic which provides comprehensive health care for children regardless of their economic situation or their source of care."

The authors of the publication cited above further note (pp. 19-20) that:

> "The effectiveness of an EPSDT program will depend as much on how the component activities are organized into a total program as on how well each separate activity is performed." Several "priorities" for EPSDT program development are suggested by the authors:
>
> 1. The organizational plan should ensure that all health problems discovered through screening receive treatment. Unless treatment is ensured, all other activities...become largely worthless.
>
> 2. Arrangements must encourage and support the continued participation of physicians...in the EPSDT program.

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* "A Guide to Screening/EPSDT-Medicaid", U.S. Department of Health, Education, and Welfare in cooperation with the American Academy of Pediatrics, by William K. Frankenburg, M. D. and A. Frederick North, Jr., M. D., 1974.

3. The activities should be organized in a manner that keeps total program costs, not just costs of the screening program, to a level that is compatible with an effective program.

4. The organization of activities should support and contribute to, rather than compete or interfere with, good patterns of comprehensive health care.

In striving for a single standard of excellence in the medical care available to all children, we concur totally with the organizing framework suggested in the HEW publication. Utmost attention must be given to the development of systems which promote continuity of care, and which, conversely, avoid fragmentation of services (and records) or the disruption of existing relationships between patient and physician. Optimally, Minnesota's primary care physicians will comprise the nucleus for providing EPSDT services.

With regard to the proposed EPSDT Screening Standards and Provider Agreement, we offer the following comments and suggestions:

1. We feel strongly that the types of procedures to be included in screening exams, and the schedule or frequency for performing such procedures, should be left to the discretion of the attending physician. To quote again from the HEW publication on EPSDT screening (p. 53):

   "The precise age at which each visit is scheduled and each procedure is carried out is not critical. It is more important that the general pattern of screening...be incorporated into a pattern of preventive and therapeutic health care that is appropriate to the needs of each individual child."

   We suggest instead that the EPSDT Screening Standards be relabeled as Screening Guidelines for reference and use by the attending physician as appropriate. Rather than adopt a rigid schedule applicable to all patients, which may not be cost effective, DPW should monitor the scope of care actually being rendered and institute educational efforts or corrective action as deficiencies are documented.

2. We are also concerned that you are proposing yet another form to be filled out by the physician's office - the EPSDT Invoice (DPW 1973-10/75). More specifically, we are concerned that the scope of this "invoice" extends far beyond the reporting necessary to compute reimbursements for health services rendered. The proposed invoice has taken on the form of a quasi-medical record, asking for definitive information on pulse, respiration, blood pressure, etc., as well as an indication of whether there are developmental or medical problems in over forty areas (e.g. heart, lungs, nutrition, hemoglobin).

   Again, in the interest of cost consciousness, we would suggest an alternative to the EPSDT Invoice. The existing Practitioner Invoice (DPW 1497-6/74), now in general use by physician's offices throughout Minnesota, should be considered an acceptable means of reporting EPSDT screening exams, and for reporting follow-up care and treatment.

   If it is felt that the Practitioner Invoice will not provide sufficient information to assess the actual scope of screening completed during exams,

or to determine referral patterns for suspected medical problems, then supplemental studies should be completed using a sampling of physicians. The EPSDT Invoice should not be adopted as part of the protocol for the EPSDT program.

3. Last, we disagree with the need for an EPSDT Agreement, separate and distinct from the regular Title XIX Agreement signed by physicians. The proposed schedule of procedures to be performed during screening exams and the additional burden and cost of complying with new reporting requirements may well make it untenable for many physicians to sign this Agreement. Moreover, you may place many primary care physicians in a "catch 22", where, due to their reluctance to sign the EPSDT Provider Agreement, they will be unable to participate in early periodic screening, but as a participating Title XIX physician can serve the same children for diagnosis and treatment upon referral. No one will be well served by creating such a dilemma.

   We request in conjunction with the other suggestions in this letter, that the Department of Public Welfare accept any licensed physician who has submitted a Title XIX Agreement, as eligible to participate fully in the EPSDT program. The objective, of course, is to expand the base of qualified persons eligible to provide needed services to children, not further restrict it.

Our comments are intended to be constructive, as our interest is truly in achieving a single standard of excellence in the medical care available and rendered to the children in Minnesota. We hope you will carefully consider our recommendations, and would look forward to exploring ways of mobilizing the resources available through the physician members of the Hennepin County Medical Society in both implementing and operating an effective EPSDT program.

Sincerely yours.

Frank E. Johnson, M. D.
President

cc: Minnesota State Medical Association
Ramsey County Medical Society
Hennepin County Welfare Department
Minnesota Department of Health

Members of the Hennepin County Medical Society Ad Hoc EPSDT Committee

William D. Bevis, M. D.
George W. Lund, M. D.
Stuart V. Thorson, M. D.
Walter L. Wilder, M. D.
Duane L. Orn, M. D.

ARLAN STANGELAND
7TH DISTRICT, MINNESOTA

COMMITTEES:
GOVERNMENT OPERATIONS
PUBLIC WORKS AND
TRANSPORTATION

Congress of the United States
House of Representatives
Washington, D.C. 20515

OFFICES:
1518 LONGWORTH HOUSE OFFICE BUILDING
WASHINGTON, D.C. 20515
(202) 225-2165

M-F BUILDING
403 CENTER AVENUE
MOORHEAD, MINNESOTA 56560
(218) 233-8631

August 22, 1977

Honorable Harley O. Staggers
Chairman
Interstate and Foreign Commerce
2125 Rayburn House Office Building
Washington, D. C. 20515

Dear Chairman Staggers:

I received the enclosed letter from Mrs. Helen E. Benshoof, Director of the Multi-County Nursing Service, Detroit Lakes, Minnesota, regarding H.R. 6706. I would appreciate your making her comments a part of the record on this legislation.

With best wishes, I am

Sincerely,

Arlan Stangeland

Arlan Stangeland
Member of Congress

P.S. Enclosed also is a copy of a letter from Dr. Warren R. Lawson, Commissioner of Health, Minnesota Department of Health, and I would appreciate your giving his comments every consideration.

Multi-County Nursing Service

Mahnomen County
County Building, Box 227
Mahnomen, Minnesota 56557
Phone 935-2646 2527

~~Hubbard County~~
~~Courthouse~~
~~Park Rapids, Minnesota 56470~~
~~Phone 732-3341 2247~~

Becker County - 518 Summit
~~222 Washington~~ Box 701
Detroit Lakes, Minnesota 56501
Phone 847-9237

August 8, 1977

The Honorable Arlan Stangeland
House of Representatives
1518 Longworth House Office Building
Washington, D.C. 20515

Dear Mr. Stangeland:

I understand that a new program--Comprehensive Health Assessment and Primary Care for Children Program (CHAP)--which will modify and expand the Early and Periodic Screening, Diagnosis and Treatment Program (EPS/DT) is to be considered in Congress soon.

We have an excellent Early and Periodic Screening Program (EPS) currently functioning in our agency. Because of this, I have some concerns about the CHAP program. Our program is nurse administered with close ties to the family physician. We provide outreach, screening, interpretation/education, referral and follow-up to assure diagnosis and treatment. We feel that we have a very comprehensive health service program for children.

Based upon our experience, I would like to offer for your consideration my comments on the CHAP proposal and the ways in which it will strengthen the EPS/DT program.

Extension of Eligibility: I strongly support the extension of eligibility to include children from families below poverty level which do not qualify for Medicaid for reasons other than income. I believe that this extension proposal affirms an intent to improve the availability of health services for low income children.

Comprehensive Care Centers: I am pleased with the new, stronger emphasis on comprehensive health care. Certainly, the adequate provision for diagnosis and treatment is an essential component of an early identification/prevention program. In proposing that CHAP favor health centers and private providers that can assure comprehensive care, the definition of "comprehensive" must be carefully considered and developed with maximum flexibility to insure that the entire spectrum of health, social services, and special education services can be arranged as necessary to serve the needs of the individual. Since virtually no agency or provider directly provides the entire array of needed services, the level of comprehensiveness assured to the child is dependent upon the quantity and quality of arrangements made with numerous other agencies and providers. In northwestern Minnesota we are very fortunate in the resources we have available to us. From experience I know that other areas are not so fortunate. I would suggest that in the Bill consideration should be given to local public health agencies which have developed appropriate linkages through the years.

Extended Eligibility for Treatment: The assurance that program eligibility will be maintained until the completion of diagnosis and treatment is a significant improvement. I have been concerned for the children who are screened in EPS but were removed from Title XIX eligibility before their diagnostic and treatment services could be completed.

Evaluation: From what I've read of the CHAP proposal, it does not appear that program evaluation has been included. I believe that program evaluation must be addressed in the policy formation process for CHAP. Evaluation of CHAP programs must address outcomes as well as process and output. Until and unless an evaluation mechanism is established which measures outcome, we will not be able to assess the value of this preventive health service delivery system in terms of the effect on the health status of children or its current effectiveness. This would defeat one of the purposes of CHAP, which is to focus the nation's attention on the value of providing comprehensive health assessments and primary care for children. I thank you for your consideration of my comments and concerns in further CHAP policy development.

Sincerely,

Helen E. Benshoof

(Mrs.) Helen E. Benshoof, PHN
Director
Multi-County Nursing Service
Detroit Lakes, Minnesota

HEB:alh

minnesota department of health
717 s.e. delaware st. minneapolis 55440

August 10, 1977

The Honorable Arlan Stangeland
House of Representatives
1518 Longworth Office Building
Washington, D.C. 20515

Dear Mr. Stangeland:

The purpose of this letter is to inform you of the position of the Minnesota Department of Health relative to legislation proposed for a new Child Health Assessment Program - CHAP. The CHAP legislation is intended to replace Early and Periodic Screening, Diagnosis and Treatment (EPSDT) and proposes to extend eligibility to expand the provision of primary care by utilizing "comprehensive care providers". While we are certainly supportive of comprehensive preventive child health services, we have some serious concerns regarding the CHAP legislation. We have expressed these concerns to Dr. Keith Weikel, Director, Medical Services Administration, Department of Health, Education and Welfare, and are attaching a copy of our correspondence to Dr. Weikel for your consideration.

Recently, the Region V Office of Health, Education and Welfare convened two meetings in Minnesota with participants from state and local welfare, health and education agencies, county commissioners and some private providers, to discuss and comment on CHAP. The concerns expressed at these meetings were essentially the same as those expressed in our letter to Dr. Weikel.

We hope this transmittal will be helpful to you as you discuss and consider the CHAP bill. If you need additional information, we will be pleased to be of assistance. Please feel free to call upon Mrs. Sheila Swaiman, Supervisor, Comprehensive Child Health Screening Unit, (612/296-5286).

Respectfully yours,

Warren R. Lawson, M.D.
Commissioner of Health

April 19, 1977

M. Keith Weikel, Ph.D., Director
Medical Services Administration
Department of Health, Education and Welfare
Washington, D.C. 20201

Dear Doctor Weikel:

The Minnesota Department of Health was pleased by the opportunity to review your recent letter to the State Medical Assistance Program Administrators and its accompanying information memorandum regarding the proposed Comprehensive Health Assessments and Primary Care for Children Program (CHAP), which will modify and expand the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT).

We have considerable interest and expertise in this regard through our Early and Periodic Screening Program (EPS) which was developed collaboratively with the State Title XIX SEA Agency, in part to meet the requirements of the Federal EPSDT Program and also to meet the needs of all Minnesota children by extending services to non-medical assistance eligible children. The Minnesota Department of Health approved programs are primarily nurse-administered local screening activities within a county public health nursing service or local health department. The local EPS program combines the activities of outreach, screening, interpretation/education, referral and follow-up to assure diagnosis and treatment, into a comprehensive health service program for children.

Based upon our experience in Minnesota we offer for your consideration our comments on the CHAP proposal and the ways in which it will strengthen the EPSDT Program.

Expansion of Eligibility

We support the proposed expansion of eligibility to include children from families below poverty level which do not qualify for Medicaid for reasons other than income. We believe that this expansion proposal affirms an intent to improve the availability of health services for low income children. However, the proposed expansion will not affect Minnesota, as these children are already eligible for EPSDT services in this State under the "Medical Assistance"only" category which is not tied to other categorical aids.

Comprehensive Care Centers

We are pleased with the new stronger emphasis on comprehensive health care. Certainly, the adequate provision for diagnosis and treatment is an essential component of an early identification/prevention program. In proposing that CHAP favor health centers and private providers that can ensure comprehensive care, the definition of "comprehensive" must

be carefully considered and developed with maximum flexibility to ensure that the entire spectrum of health, social services, and special education services can be arranged as necessary to serve the needs of the individual. Since virtually no agency or provider directly provides the entire array of needed services; the level of comprehensiveness assured to the child is dependent upon the quantity and quality of arrangements made with numerous other agencies and providers. We assume that the number of comprehensive care centers and providers that can achieve this goal is quite limited. Therefore, it will be necessary also to consider those local public health agencies which have extensively developed the appropriate linkages through active efforts in recent years. We believe that our local EPS programs have been quite successful in this regard and through the use of our tracking system, we are able to assure that referrals for further evaluation and treatment are completed as planned.

Our EPS programs have also been increasingly successful in establishing linkages with schools. This liaison which cannot be attained by many health centers and providers is an important one. Schools have a unique access to all children and hence, are almost ideal for assisting with outreach. They have accessibility to the child population through the school census and preschool screening programs. Increasingly, they will be involved in screening activities and treatment services due to the mandate of PL 94:142. In this regard schools are particularly involved in the planning and provision of developmental screening services, which at this time are poorly developed in many health settings. Thus, there should be a plan to integrate the two provider settings via formal linkages where this is possible.

National Cost Figure

We strongly support the proposal for national guidelines for cost of health assessment as a far more equitable and cost effective system for effective providers of services. It also is to assure program cost continuity.

Extended Eligibility for Treatment

The assurance that program eligibility will be maintained until the completion of diagnosis and treatment, is a significant improvement. We have been significantly concerned for the children who were screened in EPSDT but were removed from Title XIX eligibility before their diagnostic and treatment services could be completed.

Evaluation

We would like to direct your attention to an important area which has apparently not been addressed in the proposal for Comprehensive Health Assessments and Primary Care for Children Program. Evaluation of the program seems not to have been included. We believe that program evaluation must be addressed in the policy formulation process for CHAP. Evaluation of CHAP Program must address outcomes as well as process and outputs. Unless, and evaluation mechanism is established which measures outcomes, we will not be able to assess the value of this preventive health service delivery system in terms of its effect on the health status of children, or its cost effectiveness. This would defeat one of the purposes of CHAP, which is to focus the nation's attention on the value of providing comprehensive health assessments and primary care for children.

We thank you for your consideration of our comments and concerns in further CHAP policy development. We are pleased to have the opportunity to comment on this new child health initiative.

Sincerely yours,

Warren R. Lawson, M.D.
Commissioner of Health

SS/dj

State of Rhode Island and Providence Plantations
EXECUTIVE CHAMBER, PROVIDENCE

J. Joseph Garrahy
Governor

September 23, 1977

The Honorable Paul G. Rodgers
Chairman
Subcommittee on Health and the
Environment
House Interstate and Foreign Commerce
2407 Rayburn House Office Building
Washington, DC 20510

Dear Congressman Rodgers:

On behalf of the National Governors' Association, I welcome your invitation to present my views on the President's Child Health Assessment Act (CHAP) proposal.

This proposal represents an admirable and worthwhile attempt to improve the level and availability of health care to eligible children and to broaden the coverage to include additional children ineligible for the existing Medicaid program. There is no question about the advantages to be derived by the individual and society as a whole from the utilization of proper medical care throughout the childhood years. While the benefits are recognized, pitfalls in establishing and administering such a program must also be examined and avoided wherever possible.

The proposal, which would require the extension of eligibility for the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) to all children under six years who meet the income and resources eligibility requirements, but do not possess the federal Aid for Dependent Children (AFDC) characteristic, has merit. Inasmuch as states are currently straining to meet current commitments to provide existing Medicaid services, we welcome the proposed increase in matching payments. However, we question whether these funds will adequately support the higher costs of the proposal, which will obviously increase program costs by mandating not only expanded eligibility, but also more comprehensive and extensive services for

all eligible children. To simply mandate this as an extension of the existing Medicaid program would place an unfair fiscal burden on the states.

In a state such as Rhode Island, which has voluntarily extended the EPSDT program to include not only AFDC recipients but also all Medicaid eligible recipients under 21 years of age, the proposed increase in the Federal Financial Participation under this Act is indeed welcome. However, rather than adherence to the complicated formula envisioned to determine the exact percentage of federal financial participation, it is recommended that the program be funded by 90 percent federal monies. There is precedent for establishing such a federal reimbursement rate; currently, the states are reimbursed for ninety percent of all expenditures incurred for Family Planning Services. It cannot be denied that medical care for those children born is of at least the same or greater importance.

The provision of a bonus for good performance under the Act is an excellent method of inducing states to comply fully with the program. The use of positive stimuli such as an increase from 50 percent to 75 percent in federal reimbursement for general state administrative costs for the Medicaid program should help to make full compliance a priority goal.

The proposed Child Health Assessment Act also contains a provision for fiscal sanctions for noncompliance. I feel this section should be examined carefully. Fiscal sanctions have often proven to be counterproductive, as in the area of Long Term Care. When a state is penalized and loses money, it very often is forced to reduce services in order to compensate for the loss of federal funds. The patient, therefore, is penalized. In lieu of penalizing a state for noncompliance, we recommend giving a state a specified amount of time to correct specific deficiencies before a penalty would be imposed.

Rhode Island has long enjoyed high physician participation and excellent relationships between the Medicaid agency, recipients, and private

physicians. Children who are eligible for the EPSDT program and who are having their ongoing medical needs met by private physicians are receiving the same high quality care that is available to private patients. We take pride in the fact that over 70 percent of EPSDT eligible children do, in fact, receive their medical care from physicians in private practice.

This excellent relationship will be severely strained by the Act as it is currently written. I seriously question the wisdom of proposals to require private physicians to take increasing responsibility for providing a "minimum range of diagnostic and treatment services, (including immunization against childhood diseases) as required by regulations of the Secretary," assume case management responsibility, and make reports as required. Such requirements would be placing an onerous and unnecessary burden on the private practitioner and will indeed have a detrimental effect on continued availability of health care for EPSDT eligible children. Further, it would prevent needed state flexibility to mold the program to parochial needs.

In order to derive maximum benefits from this proposal and to avoid some of the many problems created by the EPSDT program, I strongly recommend that this section (Section 19, 12b) be made more flexible in order to allow each of the various states to determine where the responsibilities for these areas most properly belong in the interests of administrative efficiency and the assurance of quality health care for the children to be served.

The concept of the Child Health Assessment Act is an excellent one. However, unless changes are made in the proposal, I fear that the results will be detrimental not only to the states responsible for administering the program, but also, and more importantly, to those children it is designed to help. I strongly hope such changes will assure the flexibility which will allow each of the states to utilize innovative approaches in order to assure that necessary medical care is available. It is the prevailing feeling that this lack of federal flexibility and its unrelenting adherence to the implementation of stereotyped programs and activities in the area of EPSDT have served as a negative force in the effective organization and implementation of the programs.

Sincerely,

J. Joseph Garrahy
GOVERNOR

September 16, 1977

Congressman Paul G. Rogers, Chairman
Subcommittee on Health and the Environment
House Committee on Interstate and Foreign Commerce
2415 Rayburn House Office Building
Washington D.C. 20515

Dear Congressman Rogers:

I would like to take this opportunity to express to you some of my concerns regarding the proposed CHAP legislation.

Having spent the last 2½ years as EPSDT Coordinator in Ramsey County, I have become increasingly aware of some of the problems on the local level which I will share with you in the hope that the CHAP legislation can be designed to prevent problems which have been identified as a result of EPSDT. (The total population of Ramsey County is 500,000 and St. Paul alone has a population of 300,000.)

Ramsey County Health Providers, public and private, have worked very hard attempting to coordinate various screening programs including the Child Find (PL 94-142), Maternal Infant Project (Title V), the Family Planning Program (Title X) and Head Start Screening. All of these programs offer more of the same components, many of which are for early identification of problems, as the EPSDT Program and are often reaching the same clientele.

We have become discouraged because there aren't equivalencies from one program to the next. Coordination becomes next to impossible especially with the money for the programs coming from different Federal programs and the regulations don't allow for the flexibility needed to coordinate locally, thus efforts and services or parts of services are duplicated. Equivalencies would decrease the duplication considerably.

Early detection is extremely important for all age groups, but the diagnosis and treatment must be available and accessible. Why find a problem and not be able to treat the problem? There must be money available to low income (working poor) for the diagnosis and treatment. I would like to see the eligibility expanded to include more working poor. Many of these people have coverage through their employment which covers only acute medical problems (In-Hospital Coverage). The Minnesota Dept. of Health, through Public Health agencies, has implemented screening for all children on a sliding fee. Many of the children seen don't pay anything because the family gross income is so low, but yet are above Medicaid eligibility.

The exclusion of treatment for mental illness, mental retardation and developmental disabilities causes great concern. There aren't necessarily programs for these children. We are finding a fair number of children with behavior problems. The problems aren't severe enough for hospitalization, yet they need counselling. Children with other handicapping conditions also need service when the disability is identified. The schools in Minnesota are responsible for four year olds on up, but what about the 2 or 3 year old with Congenital Hip, Cerebal Palsy, etc.

Excluding dental is another weakness in the proposed program. So many children are in dire need of dental services. Dental problems can cause so many more problems, poor nutrition, infections, etc.

It seems to me, if we are serious about preventive health programs, we have to include screening diagnosis and treatment as in the EPSDT Program.

One section of the CHAP Program which needs serious consideration is the section on provider participation. If we look at the client and the comprehensiveness of the health screening, we must look at more than physicians as comprehensive providers. Comprehensive providers are non-existent. Comprehensive provider must mean the whole system - Public Health, education system, particularly Special Education, mental health centers, social workers, nurses, doctors and nutritionists. The problems which are being identified are often inappropriate referrals to a physician such as a speech problem which must be diagnosed and treated by a speech pathologist, the need for nutritional counselling referred to a nutritionist, a behavior problem may be referred to the school, Public Health Nurse, social worker, psychologist - depending on the magnitude of the problem.

Minnesota has nurse run clinics. Nurses are specially trained to do the screening components. Children are then referred for diagnosis and treatment. The child health clinics in Ramsey County were converted to EPS Clinics. If comprehensive provider means physician, this will wipe out the nurse run clinics and the screening which is presently being done by nurses in the school systems. Having Public Health Nurses trained to do screening make the service more accessible to clients. The Public Health Nurse is aware of the appropriateresources available for referral and can certainly assist the family in using the resources. Case management is extremely important so people don't get discouraged and give up trying to get through our complex health "system".

One of the problems with EPSDT is that it was placed in the welfare system. This is a problem in a state like Minnesota where we have local control and not don't have Public Health Departments in every locality. Having a health program administered by welfare is difficult because welfare agencies simply do not understand health programs, especially preventive programs and continuity of care. The regulations have never been concerned with the quality of the screening, what components must be given, was diagnosis and treatment ever received and was it satisfactory. The regulations have been concerned with the proper notification and assist-

ance. This certainly is necessary and important, especially outreach, (individual contact with clients) but the quality of the screening service and the diagnosis and treatment is equally as important. It is also necessary to have enough providers of screening services available. We had to substantially increase the number of clinics as we began a personal outreach effort to all the clients who requested EPSDT.

The fear I have is that even though we have outreach, transportation and neighborhood clinics, many children who really need screening aren't getting it. We have a "no-show" rate in clinics of 30 - 50%. The client is always called the day before the clinic appointment and yet there is a high "no-show" rate. Obviously there isn't any incentive for the client to accept screening and thus follow through with necessary diagnosis and treatment. I really have no answer or suggestion on how to reach the high-risk client.

In looking at health and human service programs, I prefer to look at a family or community and build the system to meet the families needs rather than the problem we have run into with specific catagorical programs.

Thank you for your concern for the health and welfare of the nations people.

Sincerely,

Elaine Saline

Elaine Saline
EPSDT Coordinator

ES/jal

cc

AMERICAN ASSOCIATION OF DENTAL SCHOOLS
1625 MASSACHUSETTS AVENUE, N.W.
WASHINGTON, D.C. 20036
202/667-9433

September 19, 1977

The Honorable Paul G. Rogers
Chairman, Subcommittee on Health
and Environment
2415 Rayburn House Office Building
Washington, D.C. 20515

Dear Mr. Chairman:

The American Association of Dental Schools would like to record its strong opposition to current Administrative efforts to weaken the dental health provisions of the Early, Periodic Screening, Diagnosis and Treatment Program (EPSDT). These efforts are contained in HR 6706, "The Child Health Assessment Act (CHAP)", now before your Subcommittee.

We have reviewed the testimony offered on this subject by the American Dental Association on September 9, 1977. We strongly support this testimony and the amendments which that Association has developed to improve dental health care for low income children.

Mr. Chairman, we recognize that budgetary considerations are always important considerations. However, we also think that the childhood development of effective regimens of diet, professional treatment, and home care is the foundation for a life-time of sound oral health. To this end we think that dental health programs for children - particularly low income children - should be strengthened, not weakened.

Thank you for considering our position on this issue and we respectfully request that this letter be made a part of the hearing record on HR 6706.

Sincerely yours,

Harry W. Bruce, Jr., D.D.S.
Executive Director

HWB/jf

The American
Occupational Therapy Association, Inc.

September 20, 1977

The Honorable Paul G. Rogers
Chairman, Subcommittee on Health
and the Environment
Committee on Interstate and Foreign
Commerce
2415 Rayburn Office Building
United States House of Representatives
Washington, D.C. 20515

Dear Mr. Chairman:

The American Occupational Therapy Association is pleased to submit this statement on H.R. 6706, the "Child Health Assessment Act," which strengthens and improves the early and periodic screening diagnosis and treatment program (EPSDT).

For 60 years this association has represented independent health professionals who specialize in alleviating the suffering and increasing the independence and productivity of the aged, the physically or mentally disabled, and the economically or culturally disadvantaged. Occupational therapy practitioners are trained in curricula involving developmental psychology, anatomy, neurophysiology, and the social sciences. This training is followed by field work experience in areas such as psychiatry, rehabilitation, developmental disabilities, and gerontology.

Occupational therapists are among the few non-physician mental health professionals who are trained in the medical and biological sciences. They provide services in general and psychiatric hospitals, nursing homes, community mental health and mental retardation centers, rehabilitation agencies and home health settings, and public and private school systems.

Of the occupational therapists engaged in direct service to clients, twenty-five percent work exclusively with persons under the age of twenty. Many of these therapists perform developmental screenings, such as the Denver Developmental Screening Test, on children up to age six to discover any developmental deficits which could hinder their performance in school or at work. The Association and the 23,000 members which it represents, therefore, have a direct interest in legislation which improves the provision of screening, diagnosis and treatment services to Medicaid-eligible children.

The Association is pleased that H.R. 6706 expands the eligibility of children for Medicaid services and provides incentives to the states to encourage the provision of quality health care services to eligible children within those states. However, we believe that there remain several problem areas in the Child Health Assessment Program (CHAP) which need to be addressed before this legislation is enacted.

The Association is concerned that H.R. 6706 gives states the option of including or excluding care and services, for individuals under age twenty-one, for the "treatment of mental illness, mental retardation, or developmental disabilities,..." We believe that if the coverage for these services remains optional and not mandatory, many states will not provide treatment services for these individuals.

The Association strongly believes that the growth and development of Medicaid-eligible children will suffer if problems discovered by the screening of the developmentally disabled, mentally retarded, and emotionally disturbed are not treated or at least referred for treatment. Therefore, we recommend the deletion of the following underlined wording in H.R. 6706, Section 3(G): "but not necessarily including (i) those for the treatment of mental illness, mental retardation, or developmental disabilities,..."

The expansion of Medicaid-eligibility to children under six years old whose families meet the state's income test for Aid to Families with Dependent Children (AFDC) but whose family structure make them ineligible for AFDC, is a noteworthy provision of CHAP. However, individuals aged 6-21 who meet the same criteria are equally in need of coverage for health services. Many children in this age group need further treatment after screening and would be arbitrarily denied this treatment based on the cutoff at age six. The Association recommends that eligibility for Medicaid should be extended to AFDC financially eligible children under 21.

The Association is also concerned that the proposed bill does not address in sufficient detail the problems of outreach programs for children eligible for screening, diagnosis and treatment services. The small percentage of Medicaid-eligible children screened under the EPSDT program is at least partially due to the existing problems of informing families of eligible children of the availability of such services and assuring that these children take advantage of such services.

The provisions of H.R. 6706 or its regulations should require the development of community education programs which notify the public of the availability of EPSDT services and explain the necessary role these services play in identifying present health problems and preventing future ones. These requirements should also mandate, if possible, increased one-to-one contacts regarding the availability of services between health officials and Medicaid families. Unless the families of eligible children are actively involved in the screening and treatment programs for their children, follow-up treatments and continuing preventive measures may not materialize for children covered under CHAP.

The Association believes that regulations which provide for the implementation of CHAP should also address the accessibility of treatment services once a child has been assessed under this program. Under the current EPSDT program, children are often assessed for specific health problems at one physical location but referred to one or more different locations for treatment. Follow-up and treatment services may be discouraged or underutilized if children and their families are routed to many different localities in order to take advantage of these services. CHAP regulations should provide for a system of assuring assessment and treatment services in an efficient manner with the participants experiencing a minimum of bureaucratic entanglements.

It is the understanding of the Association that Mr. Andrew Maguire has recently introduced H.R. 8974, the "Child Health Assurance Act," which addresses many of our concerns with the CHAP bill. We encourage the Subcommittee to examine Mr. Maguire's bill closely and incorporate those provisions which assure the delivery of quality assessment and treatment services for children.

The Association appreciates this opportunity to submit our comments on the Child Health Assessment Program and stands ready to offer our assistance in the implementation of this much needed legislation.

Sincerely,

James J. Garibaldi
Executive Director

JJG:RSWI:jlr

AMERICAN SPEECH AND HEARING ASSOCIATION
10801 ROCKVILLE PIKE
ROCKVILLE MARYLAND 20852
(301) 897-5700

September 22, 1977

The Honorable Paul G. Rogers
Chairman, Subcommittee on Health
and the Environment
House Interstate and Foreign
Commerce Committee
2415 Rayburn House Office Building
United States House of Representatives
Washington, D.C. 20515

Dear Mr. Rogers:

Thank you for providing us this opportunity to comment on H.R. 6706, legislation which we consider to be of the utmost importance in providing the deserved federal commitment to the EPSDT program.

We commend you and the Administration for invigorating such a commendable program, and hope that the Subcommittee will proceed to mark up the legislation in the near future.

During mark-up, we respectfully request that the Subcommittee consider a bill by another of its members, Rep. Andrew Maguire's H.R. 8974. That bill would retain the mandatory provision of services under EPSDT to the mentally retarded, mentally disturbed, and developmentally disabled. Mr. Maguire believes, and we agree, that denying these categories of children needed health and supplemental services would, in many cases, leave them with no other program from which to receive help. Removing these categories of children from the EPSDT program would diminish the significance of this legislation. Other provisions of Mr. Maguire's bill, especially those assuring adequate follow-up and federal monitoring are laudatory and deserving of the Subcommittee's consideration during mark-up.

The EPSDT program has always been one of great promise. Your legislation renews that promise. We would hope that the Subcommittee, during its consideration of the final version of the bill, will renew that promise to all the children.

Sincerely,

Vivian Dempsey, Esq., Director
Federal Affairs Division

Attachment:

STATEMENT OF
THE AMERICAN SPEECH AND HEARING ASSOCIATION

The American Speech and Hearing Association endorses the intent of HR 6706, the Child Health Assessment Act, to increase the effectiveness and accessibility of the Early, Periodic, Screening Diagnosis and Treatment (EPSDT) Program. We must do this with reservation, as we are opposed to the provision in HR 6706 which would exclude mentally retarded and developmentally disabled children from needed treatment. We would also respectfully request addition of a tracking mechanism, to ensure adequate diagnosis and treatment, by category of disorder, and to ensure referral for treatment to the appropriate health professional.

We are the national, scientific, professional and educational association of 26,000 speech-language pathologists and audiologists. Our speech-language pathologists render their services in a wide variety of health and education settings to children and adults with speech or language disorders. Our audiologist members determine the extent of hearing loss and work with the hearing impaired to maximize residual hearing in people of all ages. Together, our members comprise the nonphysician health specialists who work most closely with the communicatively handicapped.

In General. On the whole, the American Speech and Hearing Association endorses Mr. Rogers' legislation and hope that this legislation signals a renewed commitment with the Department of Health, Education and Welfare to implement EPSDT.

Developmental Disabilities. We are particularly heartened by Mr. Rogers' concern for the 0-6 age category. We believe this accurately reflects the purpose of the EPSDT program, to provide, to the greatest extent possible, appropriate help with health problems for the nation's

poor children. The provision in Mr. Rogers' bill to increase availability of EPSDT to the 0-6 age bracket can only reflect a philosophy that these children can be helped most by getting help to them as soon as possible. The sooner health problems are addressed and ameliorated, the sooner the child can get on to a normally developing life and education. This is particularly true with communicative disorders, since communication forms the basis for our educational system.

Therefore, we cannot support the language in Section 3(G) of HR 6706, which would make discretionary a state's use of EPSDT funds in treating children with developmental disabilities.

One must take care when drawing lines between covered and uncovered services that one does not create a chasm. Some of those we call the communicatively impaired are in danger of falling into the chasm that Section 3(G) would create. There are 20 million children and adults who are communicatively handicapped. Of these, 8.5 million are hearing impaired. Approximately 5 million children and adults have significant speech and language difficulties generally unrelated to learning disorders. Another 3 million have learning disabilities severe enough to interfere with communication and the development of speech and language. Speech and language problems also frequently accompany other primary disabilities, such as mental retardation, emotional disorders, neuromotor defects, perceptual handicaps, epilepsy and learning disabilities.

Regardless of the source of the problem, children in these groups are communicatively handicapped. Regardless of the source of the problem, these children will need help of a speech-language pathologist and, if they are hearing impaired, an audiologist as well.

Which of these children will not receive services under EPSDT because of a definition?

We respectfully submit that the exclusion of development disabilities from EPSDT would be difficult of administration, would violate the nondiscrimination on the basis of disability provision of EPSDT, and would impair the ability of some children to receive the supplemental health services of EPSDT which can help them to lead a normal, healthy life.

Appropriate Screening Mechanisms. Although not in the numbers in which they exist, children with hearing impairment are being discovered during screening and appropriately referred. Unfortunately, we cannot make the same statement for children with speech or language disorders. One problem is that the EPSDT program does not use a test designed to pick up speech or language disorders; the Denver Developmental Screening Test, administered in the 0-6 age bracket has some capability to uncover speech or language problems, but minimally. Michigan has received funding from the Bureau of Community Health Service, Division of Maternal and Child Health, to use experimentally another screening instrument, the Physician's Developmental Quick Screen for Speech Disorders (the PDQ), which takes five minutes to administer and is reported to have a false negative rate of only 3%. We have attached an article about this screening technique to this testimony for your information.

You can be assured that we will watch with interest the number of children in Michigan found to have speech or language problems, and the follow-up treatment they receive.

Data Collection. This leads directly into our next point: There is no adequate data-collection taking place within HEW to monitor the

disabilities uncovered by the EPSDT screening, nor a method of ensuring referral to appropriate health professionals for treatment. As EPSDT increases its use of nurse practitioners to screen and refer children, it is essential that they not only have the proper screening tools to identify disorders, but that they are aware of the health professionals most able to help children with the problems they uncover.

Therefore, we respectfully request the Subcommittee to consider the addition of a section in HR 6706 which would require the Medical Services Administration in the Department of Health, Education and Welfare to collect data on disorders uncovered through EPSDT screening which track diagnosis and treatment by disorder.

We thank the Subcommittee for this opportunity to express our views on HR 6706, and our members look forward to working with the Department of Health, Education and Welfare in implementing EPSDT to the fullest extent of its promise.

Special Reports

SCREENING FOR SPEECH AND LANGUAGE DISORDERS: A TRAINING PROGRAM FOR PHYSICIANS AND ALLIED HEALTH PROFESSIONALS

Physicians are frequently the first professionals to see children with communicative disorders (Court and Harris, 1965a; Court and Harris, 1965b; Godfrey and Ward, 1962; Light and Wolski, 1969; Mullendore, 1965; Richardson, 1964; Schaye and Ruben, 1971; Shank, 1964). They are in critical positions for identifying and referring such children to speech pathologists for further evaluation. It is highly desirable, therefore, to educate medical students about the need to screen children for speech and language disorders and to equip them with the ability to perform such screening functions.

During the past few years, the medical school clinical curriculum has been condensed and attenuated by such trends as increases in class size and decreases in the length of clerkships (Cooper, 1973; Levine, 1973; Talbert and Bishop, 1973). These changes offer an extraordinary challenge to speech pathologists based in teaching hospitals to make use of the most effective and efficient teaching methods to educate the most students regarding speech and language disorders.

This Special Report describes how a system of instruction (Figure 1) is employed in the Department of Pediatrics at The University of Texas Medical Branch at Galveston to teach medical students, residents, practicing physicians, and allied health professionals to screen for speech and language disorders (Kibler, Barker, and Miles, 1970; Levine et al., 1974).

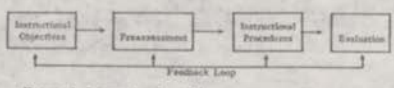

FIGURE 1. Instructional model.

SHARON G. KULIG, Ph.D., assistant professor in the Department of Pediatrics at The University of Texas Medical Branch at Galveston and communicative disorders director of the Child Development Division; KATHRYN ANN BAKER, M.A., speech pathologist on the staff of the Child Development Division at The University of Texas Medical Branch at Galveston; and HAROLD G. LEVINE, M.P.A., director of the Office of Research in Medical Education and associate professor in the Department of Preventive Medicine and Community Health at The University of Texas Medical Branch at Galveston prepared this Special Report.

The model of instruction on which this approach to medical education is based has long been endorsed by educational specialists (Kibler et al., 1970). It is employed to make certain that departmental resources for learning are coordinated and made available to students through the most effective means.

Four steps in the planning of instruction are differentiated in this approach: (1) stating educational objectives in terms of the behaviors to be demonstrated by the student following instruction, (2) appraising how far the student has already moved toward accomplishing each of the objectives, (3) selecting various procedures for accomplishing the desired learning, and (4) gathering information from the student, which enables him to demonstrate that he has reached the objectives (Levine et al., 1974).

DEFINING EDUCATIONAL OBJECTIVES

Educational objectives tell the learner what he will learn to do and how well he must learn to do it (Johnson and Johnson, 1973; Levine et al., 1974). Objectives may relate to the acquisition of knowledge, attitudes, or skills (Johnson and Johnson, 1973; Levine et al., 1974). They usually range in level of abstraction from general goals to rather specific descriptions of actual behaviors. The process of arriving at the specific behaviors desired, based on the overall instructional goals of the educational institution, is difficult and time consuming but extremely valuable in assuring student learning.

Teachers typically teach cognitive educational objectives (Johnson and Johnson, 1973); that is, teachers are most often concerned with objectives related to thinking and analyzing. It was, therefore, not difficult for the speech pathologists of the Child Development Division to agree on the type of factual knowledge of speech and language disorders that should be demonstrated by a medical student rotating through the Department of Pediatrics. For example, it was determined that the learner would be able to list five categories of communicative disorders.

Consensus was similarly achieved on the selection of attitudinal objectives. The medical student's preoccupation with acutely or chronically ill children, for example, is well known and understandable. Therefore, inculcating a willingness in the medical student

to adopt speech and language screening as a routine health maintenance procedure was selected as a specific attitudinal objective.

Once the facts and attitudes needed by the student were defined, it became possible to define how the student should combine these into observable behaviors that could serve as performance objectives related to speech pathology. It was decided that as an initial goal, the medical student should be able to screen children aged six months to six years for speech and language disorders. This goal was further refined through field testing to state that medical students should identify with 90% accuracy, children (aged six months to six years) in need of additional evaluation by a speech pathologist.

ASSESSMENT OF THE LEARNER'S PRIOR KNOWLEDGE

Assessment of the learner's prior knowledge was next considered. Given the nature of the knowledge and skills to be taught, most clinicians agreed that medical students did not possess appreciable previous knowledge of speech and language disorders. Discussion with departmental residents and a survey of the curriculum underscored the fact that the average student's previous course work and clinical experience would contribute little to his ability to screen for speech and language disorders.

The subject of speech and language disorders has been accorded less priority in the medical school curriculum because of the overwhelming amount of knowledge and skills that must be acquired through the student's undergraduate medical education. Although it was certainly conceivable that the student's previous encounters with pediatric patients might have helped him to establish rapport with children, even so, it was anticipated that not all students would possess such skills.

ESTABLISHING SPECIFIC PERFORMANCE OBJECTIVES

The development of specific performance objectives which would provide evidence that the goal was being achieved was the fourth step undertaken in planning the educational experience. It was decided that following instruction, the student should be able: (1) to determine if the language of children aged six months to six years is significantly deviant; (2) to determine if the articulation of children aged six months to six years is significantly deviant; (3) to relate such factors as dentition, tongue mobility, respiration, and palatal function to speech production; and (4) to determine if the child's voice is significantly deviant in regard to pitch, intensity, or quality. In addition, it was determined that the student should be able to discuss nonfluency in children aged 19 to 47 months whose parents volunteered concern about "stuttering."

SELECTION OF INSTRUCTIONAL METHODS

The selection of instructional methods was the next decision to be made. Completion of a self-instructional package and practice in clinical situations were the activities chosen to enable learners to achieve the stated performance objectives.

Self-instruction can be defined as teaching oneself in the absence of an instructor (Holcomb and Sandifer, 1972). Self-instructional techniques can be improved greatly by listing specific objectives and providing practice opportunities within the teaching device. An especially designed screening test, The Physician's Developmental Quick Screen for Speech Disorders (the PDQ) (Kulig and Baker, 1973a), a programmed text, *Screening for Speech Disorders in Pediatric Practice* (Kulig and Baker, 1973b), and a videotape cassette (Kulig and Baker, 1973c), comprised the multimedia self-instructional package (Figure 2) designed for this learning experience.

FIGURE 2. An especially designed screening test, a programmed text, and a videotape cassette comprised the multimedia self-instructional package designed for the learning experience.

The PDQ is a screening instrument designed for use with children aged six months to six years. Disorders involving language, articulation, voice, rhythm of speech, and the speaking mechanism are considered by the test. The 10 age-graded PDQ test forms are self-instructional for administration and scoring. The PDQ kit also contains stimulus and parent counseling materials. The PDQ is predicated on the assumption that unless a screening device can be administered comfortably and quickly in office practice, it will not be employed by allied health professionals as a routine health maintenance procedure. Average administration time for the PDQ is five minutes.

VALIDATION OF THE PDQ

The PDQ was validated at three sites on the Galveston campus of The University of Texas Medical Branch: the Child Development Division, the Pediatric Outpatient Clinic, and the Division of Family Medicine.

Children between the ages of six months and six years were eligible to participate in this study. One hundred and five subjects were obtained in three ways: (1) They were volunteered by their parents in response to local newspaper articles which described the project and invited participation at no cost; (2) They were patients of the Pediatric Outpatient Clinic; or (3) They were patients of the Division of Family Medicine of The University of Texas Medical Branch at Galveston.

The non-speech-pathologist screeners who participated in this project by administering the PDQ were representative of a number of disciplines. Pediatric and family medicine residents administered 25 PDQs; medical students, 27; physician assistant trainees, 10; registered nurses, 14; licensed vocational nurses, 5; pediatric nurse practitioners, 1; and social workers, 23. The speech pathologists who used the battery of back-up instruments were clinicians with master's degrees.

Each subject received two screening evaluations of the adequacy of his speech and language skills. The initial screening involved administration of the PDQ by a nonspeech pathologist. The second speech and language screening was conducted by a speech pathologist who was unaware of the results obtained through PDQ testing.

RESULTS AND IMPLICATIONS

Statistical analysis revealed agreement between non-speech-pathologist screeners using the PDQ and speech pathologists employing a battery of back-up instruments in 90% of the 105 children tested. Chi-square analysis revealed this agreement to be significant beyond the 0.001 level of confidence (Table 1). The validity of the PDQ is implicit in this finding.

The overreferral rate was 7% and the underreferral rate was 3%. This finding was in the hoped-for direction.

TABLE 1. Agreement and disagreement between speech pathologists and non-speech pathologists on adequacy of speech and language skills of 105 children.

	Medical Personnel	
Speech Pathologists	*No. of Subjects Passed*	*No. of Subjects Failed*
Number of subjects passed	78	7
Number of subjects failed	3	17

$\chi^2 = 49.842$.
$p < 0.001$.

Ninety percent agreement existed between non-speech pathologists and speech clinicians on the area of language ($p < 0.001$), 100% agreed on rhythm of speech ($p < 0.001$), 94% agreed on articulation ($p < 0.001$), 98% agreed on speaking mechanism examinations ($p < 0.005$), and 91% agreed on the screening of voice ($p < 0.005$).

The efficacy of non-speech pathologists employing the PDQ with children aged six months to six years is supported by the foregoing study. Additional studies regarding the validity and reliability of each form of the test are currently in progress.

The physician who employs the PDQ in his practice can expect to miss no more than 3% of the speech and language problems exhibited by his pediatric patients under the age of six. The screening instrument is now being used by faculty, house staff, and allied health professions of the University of Texas Medical Branch at Galveston (Figure 3).

FIGURE 3. Pediatrician Bobbye Rouse administering the PDQ to an 18 month old while speech pathologists Sharon Kulig and Kathryn Ann Baker observe.

THE PROGRAMMED TEXT

The stated intention of the programmed text is to introduce the non-speech pathologist to screening for speech and language disorders using the PDQ. Operational definitions of language, the rhythm of speech, articulation, voice, and the speaking mechanism are presented by relating these concepts to the manner in which they are considered by this screening instrument.

For example, the student is told in the text that deviant articulation, as considered by the PDQ, involves misproductions or omissions of the sounds of the language and decreased intelligibility in running conversational speech. The student is cautioned to view deviations in articulation in light of developmental milestones, and he is assured that norms for

articulatory performance are built into each of the age-graded test forms.

Feedback concerning the student's learning is obtained by presenting him with questions to which he is asked to respond in writing in the programmed text. For example, several fill-in-the-blank questions are designed to reinforce the student's understanding of the major categories of communicative disorders: "The seven-year-old child who typically says 'wed' for 'red' may exhibit a disorder of _____" (articulation).

While the PDQ and the programmed text are the primary information carriers of the self-instructional package, a videotape enables the learner to practice his clinical judgment of speech and language disorders. The teaching tape permits the student to see and hear children who illustrate normal and disordered speech and language skills. The use of videotape also contributes to the learning experience what has been described as "a sense of the immediate ('this is happening now')" (Engel, 1972).

Observation of the videotape is further guided by the narrative of the programmed text. As the videotape shows a practicing physician administering the PDQ, the student is asked to record on the test form reproduced in his programmed text his own impressions of the simulated patient. The student is then provided immediate feedback as to the extent of agreement between his clinical judgment and that of a speech pathologist as the text provides him with the speech clinician's written impressions of the same child. The student is then asked to record any discrepancies between his impressions and those of the speech pathologist presented in his text. He is encouraged to discuss such discrepancies subsequently with departmental speech pathologists following his completion of the packet.

The student is similarly taught by text and videotape to counsel parents of children ranging in age from 19 to 47 months when the parents volunteer concern that their youngster "might be stuttering." The student is taught that he might elect to send home with such parents the PDQ handout entitled "Normal Nonfluency—Another Stage in Growing Up," to make this developmental phase of the language learning process less anxiety arousing for parent and child. The student is cautioned, however, that referral of such cases to a speech pathologist for follow-up is indicated should parental concern in this regard persist beyond six weeks despite his counseling. Students are encouraged to refer all children 48 months of age and older to speech pathologists for further evaluation whenever a parent voluntarily expresses concern about "stuttering."

EVALUATION

Evaluating the successfulness of the self-instructional package in accomplishing the educational objectives was the final step undertaken. First, data were gathered concerning students' impressions of the adequacy of the instruction.

Those data were gathered by asking groups of students to complete a structured evaluation form. They were asked to record their impressions of the instructional methods employed according to 19 bipolar scales (for example, objectives inappropriate/objectives appropriate, questions helpful/questions distracting, assumed information I didn't know/written at my level).

In designing the material, several students served as a trial group. Their reactions were generally quite positive. Further administrations to students have elicited continual highly positive responses. Some suggestions offered by those reviewing the materials will be utilized in subsequent editions of the instructional material.

CONCLUSIONS

The creation of a specially designed self-instructional package resulted in the development of a screening test of speech and language sufficiently economical in administration time to be employed by physicians and allied health professionals as a routine health maintenance procedure. Students were taught to screen children aged six months to six years for speech and language disorders with 90% accuracy.

Advantages of the self-instructional approach accrued to departmental speech pathologists as well. Student perceptions of speech pathologists' teaching as well as their consultative roles were enhanced (Levine, 1973). Time was freed to permit speech pathologists to work more frequently with medical students on an individual basis (Holcomb and Sandifer, 1973).

ACKNOWLEDGMENT

This study was funded in part by Bureau of Maternal and Child Health Project 240, Maternal and Child Health Services, Department of Health, Education, and Welfare. The authors wish to express their appreciation to A. Yonovitz, Speech and Hearing Institute, The University of Texas Health Science Center at Houston, for his help with data analysis. The authors also express their appreciation to the faculty, residents, medical students, and allied health professionals of The University of Texas Medical Branch at Galveston who cooperated in the validation of *The Physician's Developmental Quick Screen for Speech Disorders.*

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STATE OF CALIFORNIA—HEALTH AND WELFARE AGENCY EDMUND G. BROWN JR., Governor

DEPARTMENT OF HEALTH
714-744 P STREET
SACRAMENTO, CALIFORNIA 95814
(916) 322-4780

September 28, 1977

Honorable Paul G. Rogers
The House of Representatives
Rayburn House Office Building, Room 2407
Washington, DC 20515

Dear Mr. Rogers:

I would like to commend you for offering new legislation, HR 6706, to improve the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. The provisions of the legislation take important steps toward meeting some of the deficiencies of that program. The increased federal financial participation provided by your bill should increase the availability of the program. Even more important, children who start in the program will have six extra months to get treatment after screening if the family is found ineligible for the Medical Assistance Program.

Although your bill provides coverage for additional children in other parts of the country, we are already including this group in California. We are concerned that this is not enough to bring early and continuing care to all poor children. The California Health and Welfare Agency is studying the need for and feasibility of extending these services beyond the group covered in your bill and would like to share with you the findings of this study when it is ready. In general, it can be said that to meet the needs of poor working families, greater participation in their care by the Federal Government is needed. With the rising cost of food and shelter, the health needs of these children are being neglected.

As the Child Health Assessment Program (CHAP) bill is now presented, there would be problems in implementing it in California. I urge you to consider the following amendments so that maximum program development will be assured.

1. Child Health Assessment Program

   Section 5, Section 1912 (b)(2), should be amended by striking out "during the period beginning October 1, 1977 and ending September 30, 1978" in subparagraph (A) and all of subparagraphs (B) and (C).

   The bill, as now written, implies that periodic assessments with follow-up to diagnosis and treatment by another provider comprises a second class service and will not be allowed or get 75 percent support after 3 years. These are the services that are given throughout California by the public health departments and also by public schools, both of which provide outreach and follow-up by trained nursing personnel. The public health clinics have been encouraged for years and supported by Title V public health money. It is well known that this is the only way to reach many hard-to-reach families. If the

CHAP program is to be successful in its declared objective of reaching hard-to-reach families, this provision should be changed so that all assessment programs with adequate outreach and follow-up are supported to the same extent as comprehensive care providers.

At present in California, only about three percent of the eligible population is being given EPSDT services by comprehensive care providers. There is no area that could adequately serve the children without using public health and school programs. In addition, it should be recognized that these programs which use trained nurses and other support persons to reach out into the community are more expensive than services to people who will come in and get them from a private doctor or centrally located clinic. Since these programs are also more successful in reaching hard-to-reach children, they should receive the higher federal financial participation.

2. Federal Reimbursement

Section 7 (a), Section 1903 (a), Paragraph 6, should be amended by striking out "other than dental and inpatient care", thereby giving at least 75 percent federal reimbursement for all diagnostic and treatment services indicated by the assessment.

The increased federal reimbursement is needed to assure maximum administrative support in all the states for expanding this program to all children. The most needy children will be the ones who have serious problems. Dental care is a most neglected service and one which with increased support may become more available.

3. Penalty Assessment

Section 7 (a), Section 1903 (b) (1), should be amended to change 20 percent on page 10, line 4, to 10 percent. In a cooperative venture between the federal and state governments, it is better to have a penalty more reasonably and fairly applied. This penalty of 20 percent of administrative monies for Title XIX is actually twice as severe for California as the present penalty.

To eliminate previously imposed EPSDT penalties, Section 8 of the bill should be amended to change the repeal date of Section 403 (g) of the Act from September 30, 1977 to July 1, 1974. This will remove the statutory basis for the earliest penalty and, therefore, all penalties.

California is very concerned about the prosecution of the penalties assessed over two years ago. They are taking up much professional time of state program personnel to research and prepare documents for reevaluation and appeal. At the same time much progress has been made throughout the State in meeting the goals of the program. If the repressive nature of the penalty system is to be removed, the states must be given credit for the changes that have taken place.

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4. Other Changes Recommended

a. Section 2 (3), page 2, line 7, compared with Section 4, Section 1912 (c), page 7, line 10 -- Clarify whether eligibility would be based on income only or income and resources.

b. Section 4, Section 1912 (b) (4) -- Allow the provider to work cooperatively with the state program to assure adequate follow-up. In this manner in California the private physician is assisted by workers in the health and welfare departments to keep in touch with hard-to-reach families.

c. Other penalty concerns:

Section 7 (a), Section 1903 (b) (1)

Page 10, line 12 -- Six months should be the minimum period allowed for program changes to bring about compliance. For more serious problems a longer time should be allowed.

Page 10, lines 17 through 22 -- Department of Health, Education, and Welfare should not be allowed to concentrate their audits on some states and not audit others. Either a random sample should be selected or all states audited.

A provision for the penalty process to follow "due process" should be added.

Finally, I would like to assure you that the Administration in California fully supports adequate health care for all children and youth on Medical Assistance and that the Child Health and Disability Prevention Program, in cooperation with the State Division of Social Services, is expanding services to these families as rapidly as possible.

Therefore, I urge you to continue your efforts to improve this program, and I am certain that the changes suggested here would help to provide a better and more effective program in California.

Sincerely,

Jerome A. Lackner, M.D.
Director of Health

AAMD
FOUNDED 1876

AMERICAN ASSOCIATION ON MENTAL DEFICIENCY
5101 Wisconsin Avenue, N.W., Washington, D.C. 20016
202/686-5400

September 30, 1977

The Honorable Paul Rogers
Subcommittee on Health and the Environment
2415 Rayburn Building
Washington, D.C. 20515

Dear Congressman Rogers:

I am writing to express AAMD's position on the CHAP proposal. As you may know, AAMD is the only interdisciplinary professional and scientific organization dedicated to meeting the needs of persons who are mentally retarded.

A key provision of this legislation would act to reduce services to children who are developmentally disabled or mentally ill. By making certain services a matter of discretionary decision-making for each state this provision represents a giant step backwards under the current law. All states are required at a minimum to arrange for treatment of conditions discovered during routine screening. By making even these services optional in the cases of developmentally disabled children the new proposal effectively denies them even the most minimal benefits under the new program.

The position of AAMD is to maintain the mandatory treatment for developmentally disabled children discovered during routine screening. I hope this position is favorably considered during the subcommittee mark-up of H.R. 6707.

Your cooperation will be greatly appreciated.

Yours truly,

Albert J. Berkowitz, Ed.D., FAAMD
Executive Director

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STATEMENT OF

THE AMERICAN SOCIETY OF DENTISTRY FOR CHILDREN

The American Society of Dentistry for Children is pleased to present this testimony. During its fifty years of existence, the Society has striven to promote dentistry for children to elevate the level of dental health of the youngest segment of our population.

In its early history, the Society sought to require the teaching Dentistry for Children as an integral part of the curriculum of accredited schools of dentistry in the United States. Since that successful effort ASDC has spawned other significant activities to promote more and better dental service to our children. We firmly believe in the provision of the highest standards of care to be a large dentally neglected portion of our population.

It may be redundant to state dental disease has an accumulative effect on the health of children and adults. The ravages of the disease to the hard and soft tissues of the oral cavities of children carries over into the permanent dentition creating a favorable environment for the complete loss of teeth necessitating expensive prosthetics devises. Primarily for this reason we support a program which recognizes the need to emphasize dental care at an early age for the children in our society. We do support the intent of H.R. 6706 to include children in the less fortunate socio-economic segment of our society not now eligible for services. We do think, however, the proposed legislation requires modification if this is to be effective.

We see the Child Health Assessment Act as a step backward from the dental benefits now available under the Early and Periodic, Screening,

Diagnosis and Treatment Program (EPSDT). Under the current EDSDT legislation children eligible for the program may receive a broader range of services than proposed in H.R. 6706. On the one hand the bill attempts to permit more children to be covered but on the other hand they will be restricted in the service they may receive. This approach appears to be in conflict with Sec. 2 (1) in the Declaration of Purpose which states the purpose of the program is "to continue and expand the availability of health care to children whose families do not have adequate resources to cover the cost of such care and to strengthen efforts to assure adequate child health assessment, diagnosis, treatment, and periodic reassessment of all eligible children."

By contractual arrangement the American Society of Dentistry for Children was pleased to develop the dental guidelines for EPSDT for the Department of Health Education and Welfare. A copy of these guidelines is attached as an appendix to this testimony. We take the position the guidelines are still useful and meaningful for a program of quality dental care for children. Again, we see a shift to the dental component of the CHAP program as a backward step in the dental care for eligible children.

By limiting treatment only to those dental conditions discovered at the screening period there is a cut back in services. Additionally the screening is not required to be accomplished by anyone with a knowledge of dental conditions. We would support the utilization of screening personnel knowledgeable in dentistry and would strongly urge a continuity of service by permitting the rendering of necessary treatment between screenings for those already eligible who have been treated in the program.

We in ASDC fear the program for dentistry as suggested in H.R. 6706 will be percieved by others as a "quality program" as implied in Sec. 2 (5) of the Declaration of Purpose when in fact it is not. We urge you to maintain the level of services now permitted under the EPSDT program.

One of the key concerns about the current health care delivery system is the efficiency with which care is provided. We in ASDC are aware of the need to make care accessible and to provide it in the most efficient manner. The requirement limiting dental treatment to that discovered during an assessment appears to interpose an additional obstacle for those eligible who seek continuing care and who require additional access to the program. Under the current wording should a child have an emergency problem, that child would not be eligible for care unless previously assessed for that problem, and referred for treatment. Such a requirement would appear not to be in the best interest of the patient or the program.

We also strongly urge the Federal reimbursement for dental care to be dealt with on an equatible basis with all other parts of the health care program. If the purpose of the Act is "To provide further incentives to the States to arrange for and to encourage quality health care for children," it appears worthwhile to create an environment to assure the delivery of the care. By reimbursing one segment of the health care of children differently from the others appears to imply it is not important and therefore a "disincentive" is created. Such a plan also implies that is the way a "quality" program should exist. On that point we take issue for disease in one portion of the body is as important to treat as disease in any other portion of the body. We also see this as setting up a fragment-

ation of services to children whereby children in more affluent states receive more comprehensive care. Thus is set up a program without uniform benefits among the States.

Finally we would like to emphasize the need for the prevention of dental disease. Clearly the proposed Child Health Assessment Act recognizes the importance of prevention as there is a specific reference to increase immunization levels of children. In our Manual for Children's Dental Care Programs (see Appendix) we clearly state our position on the need for prevention with emphasis on the fluoridation of public water supplies. If we are to provide a favorable environment for our children's dental health a more beneficial method cannot be found. There are also possibilities for school water fluoridators in those communities where it is not feasible to fluoridate a common water supply. Additionally there should be a planned program of dental health education in the classrooms for all children coupled with the topical application of flourides. Your consideration for incentives to utilize these methods to develop a positive impact on the dental health of children would be welcomed. Such an incentive program would not only be sensible from a preventive point of view, but would lower program costs in the long view.

We in the American Society of Dentistry for Children are pleased to support the Child Health Assessment Act with the modifications suggested. We are for more and better dental care for the children of our nation. We sincerely hope you will keep the dental provision of the EPSDT program in H.R. 6706 by making the appropriate amendments to the Act.

We thank you for the opportunity to present this testimony.

STATEMENT

of the

AMERICAN MEDICAL ASSOCIATION

Submitted to the
Subcommittee on Health and the Environment
Committee on Interstate and Foreign Commerce
United States House of Representatives

September 23, 1977

Re: H. R. 6706 - The Child Health Assessment Act

The American Medical Association takes this opportunity to submit its views on H.R. 6706, legislation that would modify the current Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program under the Social Security Act.

BACKGROUND ON PROPOSED LEGISLATION

This proposed legislation would amend Title XIX (Medicaid) of the Social Security Act to provide for a Child Health Assessment Program. The stated purposes of enacting this new Child Health Assessment Program are to modify the current EPSDT program and to extend Medicaid EPSDT eligibility to those children whose families are of low income but who do not otherwise qualify for Medicaid because of family structure.

H.R. 6706 would require states to offer through their Medicaid programs the provision of child health assessments and primary care to all children under six years of age whose family meets the state's income test for Aid to Families with Dependent Children (AFDC), but whose family structure makes them ineligible for AFDC. In addition, the state would be required to provide child health assessments and primary care to children under the age of twenty-one

whose families are receiving aid or assistance under certain state welfare programs.

An individual under the age of twenty-one who has received a health assessment under the Child Health Assessment Program would continue to be eligible for medical care for six months after eligibility for medical assistance would otherwise terminate because his family exceeded the eligibility limits to continue in the Medicaid program.

Child health assessment could be provided only by a health care provider who entered into an agreement with the state agency responsible for administering the state Medicaid program to provide to eligible children services including: periodic health assessments, a minimum range of diagnostic and treatment services, and when indicated, referral to appropriate providers for needed treatment.

To be eligible to participate in the program a health care provider would have to assume responsibility for the management of the medical care of each individual assessed to assure that all medical services which are offered under the state plan and which are found to be necessary pursuant to an assessment are made available in a timely manner and that reassessments are performed as required in regulations to be promulgated by the Secretary.

As an incentive to states to enroll eligible children with health care providers participating in the program, the federal matching contribution would be increased. For any state, this incentive rate would be 1/2 of the sum of the state's current Medicaid matching rate and 90% (but not less than 75%) for sums expended during each quarter which are attributable to child health assessments, diagnosis, treatment, follow-up and medical care management of individuals who have been assessed under an approved child health assessment program.

Federal reimbursement under the Medicaid program would be contingent upon a state meeting such standards as the Secretary may determine for the purpose of (a)informing families of children eligible under the program of the availability of child health assessment services; (b) assuring the provision of child health assessments in a timely manner; (c) assuring the provision of any medical care or service, the need for which is disclosed by assessments; and (d) assuring compliance with terms of agreements it has with providers of services under a state's child health assessment program. Failure to comply with these stated requirements would subject the state to a 20% reduction in the federal matching rate under the Medicaid program.

In addition, where the Secretary determines that a state has met the criteria (pursuant to regulations) for good performance under the Child Health Assessment Program, a 25% federal matching rate "bonus" for administration of the program would be made to the state.

COMMENTS

The American Medical Association expresses its strong support for the goal of expanding the availability of quality health care to children, particularly those children from medically indigent families who should benefit most from health care services such as those currently provided under the EPSDT program. Physicians, perhaps more than anyone else,appreciate the importance of adequate health assessment and care for our young people. It is in the formative years of growth and development of the individual, both physically and intellectually, that such services are the most crucial. The importance of adequate health assessment and care cannot be emphasized too strongly, and the medical profession is most pleased to support the formul-

ation of legislation to expand access to America's health care delivery system to meet more adequately the needs of our nation's children and young people.

The early and periodic screening, diagnosis, and treatment (EPSDT) program has come under increasing scrutiny recently. There is little question that improvement in the EPSDT program is needed. In President Carter's health initiatives message to the Congress last spring, he pointed out that the EPSDT program reaches only 30% of the 12 million children currently eligible for Medicaid; that approximately 22% of the children screened under EPSDT and found to need treatment do not receive the service required; and that the present program does not reach an estimated 700,000 children under six years of age who are in families whose income meets state financial requirements for Medicaid but whose family structure makes them ineligible for Medicaid.

While we recognize the weaknesses of the present program, we believe that the EPSDT program under the Medicaid law is fulfilling a needed service and deserves continued support but only with appropriate modification. However, we are concerned that the modifications proposed by this legislation would detract from assuring full access to quality care.

First, the federal government is already deeply involved in a large number of health care programs, each addressed to various segments of the population. Accordingly, the approach to meeting the health care needs of our citizens has often been fragmentary. For example, in attempting to assure maternal and child health, two special programs exist, the Maternal and Child Health Care provisions under Title V of the Social Security Act and the current EPSDT program under Title XIX of the Social Security Act. While these two programs are in many instances complementary, they are also duplicative in other instances. We believe that each of these programs

has a function and should be retained, and in many respects expanded, to assure quality health care to eligible children and their mothers. Yet, we would urge that these programs must be viewed together. Neither program was intended nor can reach all deserving potential beneficiaries.

Another reason why we believe that the legislation as it is proposed is not an adequate approach to assuring full access to the health needs of our nation's children is that the Child Health Assessment Program would continue to be administered under the present Medicaid program. Under present law, a state having a Medicaid program is required to provide EPSDT services to all children eligible for Medicaid, yet the program has failed to do so. We recognize that the proposed legislation does provide increased incentives to a state to provide child health assessment services. Nevertheless, we fail to understand how increased incentives alone will provide assurance that the health services will, in fact, be provided under the respective state Medicaid programs. The Medicaid program has left gaps in the provision of "mandated" services by the respective states, and the bill would not eliminate this potential for leaving gaps.

Furthermore, the Child Health Assessment Program does not address the health needs of pregnant women and mothers of young children who are themselves not eligible for Medicaid. Certainly the health of the unborn and the newborn cannot be separated from the health of the mother. It is for this reason that we emphasize the continuing need for a program to provide not only for the health of young children, but as well for pregnant women and mothers of very young children.

As to specific provisions of the Child Health Assessment Program, we have several strong concerns. First, we note the requirement under the bill that child health assessments under the program may be provided only by a health care provider who enters into an agreement with the state agency responsible

for administering or supervising the administration of the state Medicaid plan. This provision is undesirable, and could result in the receipt of levels of health care for those individuals receiving care under the CHAP program different from those individuals receiving care through other health care providers. To require a health care provider to enter into a health care agreement is not only onerous for the provider, but could tend to concentrate CHAP beneficiaries around a limited range of providers, such as in special CHAP clinics. This provision in itself could lead to curtailment of the individual family's right to select a physician or other health care provider and may in fact effectively deny a beneficiary desired medical attention by restricting the medical resources available to such CHAP beneficiary.

By requiring only health care providers that have contracted with the state Medicaid agency to be permitted to provide CHAP services could result in the evolvement of special "clinics" for the provision of CHAP services and thus preclude any participation by health care providers or physicians who might otherwise desire to provide such services. This could result not only in severely restricting the availability of medical services but failure to take advantage of the broad range of medical services now readily available through the private health care sector. The establishment of a "mini-health delivery system" analogous to a government health service under an expanded EPSDT program will limit access to many of the available medical resources in our present system and may well limit the scope and quality of services to CHAP beneficiaries.

In addition, under the bill a health care provider participating in the Child Health Assessment Program would be required to take responsibility for the management of the medical care of each individual assessed to assure that all medical services which are offered under the state's

Medicaid program are made available in a timely manner and the reassessments are performed as required in regulations to be issued by the Secretary.

The provider would be required to refer individuals to other appropriate providers for any corrective treatment which is not available directly from the participating provider. The health care provider would be required to follow-up this referral to assure the provision of such treatment.

While it is desirable for a patient to have a primary physician on whom that patient may rely for the coordination of his medical care, we must take strong exception to any specification in the law that requires the health care provider to assume responsibility for assuring that a patient received specific follow-up treatment. We need only point out that the physician-patient relationship is a voluntary one and as such a physician maintains no control over whether a patient will return for follow-up treatment and/or consultation. The physician cannot command the patient to return for follow-up treatment, even though he realizes that such follow-up is necessary to insure the effectiveness of earlier treatment. To mandate by law that a health care provider is responsible for a patient over whom the provider has no control once that patient leaves the office or institution is at best a gratuitous requirement incapable of fulfillment, but at its worst, is a condition which may well deter participation by physicians in the program because of ostensible legal implications.

We believe that the requirement in the bill that the health care provider follow up such referrals to assure the provision of the indicated treatment is inappropriate for another reason. When a patient is referred to a specialist for treatment, the medical specialist is responsible for the patient's specialized care. Accordingly, the provisions as stated in the bill should be modified to reflect the applicable law.

The bill would require a participating health care provider in the Child Health Assessment Program to provide to individuals receiving benefits under the program "a minimum range" of diagnostic and treatment services. However, no further definition is provided for what specific services will be deemed "minimum." Because the success of the Child Health Assessment Program will depend in large part on the scope of services made available to beneficiaries, we believe that it is crucial that any legislation not limit access to physicians.

We believe that the use of the phrase "a minimum range" could be construed in such a manner as to preclude physicians and other health care providers who may not have specific equipment and facilities in their offices from providing certain services (e.g., laboratory services, certain diagnostic equipment, or certain treatment facilities). A lack of such facilities does not, however, in any manner necessarily affect an individual physician's ability to provide the appropriate assessment and care needed for beneficiaries under the Child Health Assessment Program. A strict definition could thus remove ready access to such assessment and care and should not be encouraged nor permitted under the bill.

Our concerns over the use of the phrase "a minimum range" are even stronger when we consider other language of the bill in relation to "health care centers." The bill would require that a State plan for medical assistance must provide that a State will encourage participation by physicians and health care centers in the Child Health Assessment Program. Success of the program will of necessity require wide participation by physicians. As the principal health care provider, the physician provides, and will continue to provide, the basic structure around which any Child Health Assessment Program must be fashioned.

To require that a state encourage participation by "health care centers"

in the Child Health Assessment Program raises several questions with respect to assuring full access to quality health care. The principal purpose of the CHAP program is to increase access to care. However, requiring "health care centers" unduly emphasizes a particular point for receiving health care and overlooks the health care available to most children at other than centers. No definition is provided of what will constitute a "health care center." The undesirable reference to "health care centers" should be removed.

We see the desirability for Congress to express its concern over the scope of benefits. If done through an expression in Committee reports, greater flexibility would result without freezing into statutory language the specific scope of benefits desired. At the same time, unless some specification is provided, a mere legislative shell may be created without substance.

Another concern we have with the legislation is that there is no provision to assure fullest participation by physicians in the CHAP program. Presently the EPSDT program is under the Medicaid program and reimbursement is determined under that program. However, reimbursement is restricted in many states to insufficient levels. While under the statute no reimbursement can exceed what Medicare would pay (itself set at an arbitrary level), Medicaid is generally lower. Retention of such levels will accentuate current problems facing the Medicaid program and with an artificially restricted payment mechanism physicians will be discouraged from participating in such programs. Any such impediments to physician participation in the program will prevent full access by individuals to intended benefits of the program. To encourage full participation and access, reimbursement should be at usual and customary levels.

The bill also requires that a health care provider rendering services under the Child Health Assessment Program must make such reports as the state

or the Secretary of HEW may require to assure compliance with the requirements of the program. However, no specific guidance is provided with respect to the content of these reports nor the extent of data which might be required in such reports. Again, while we do believe that the law should not spell out all details as are normally under taken in regulations, we do believe that the law should provide reasonable guidance to the agency responsible for drawing up specific guidelines or regulations for the administration of the program. Therefore, we would urge that greater information be provided with respect to material that would be required to be included in such reports as well as under what circumstances such reports would be required to be made. At the same time, the Subcommittee should weigh carefully the creation of burdensome paperwork and administrative impediments deterring program participation.

The concerns expressed above with respect to specific provisions in H.R. 6706 should not be taken as an overall criticism of the proposed legislation. On the contrary, as we have expressed earlier, we fully support the provision of health care services as are envisioned under the present early and periodic screening, diagnosis,and treatment program. Our major concern is not that the program should not be improved, but rather that any changes be made so as not to discourage full opportunity of patients to have access to care and that any changes be made in conjunction with an evaluation of other related programs. We are concerned, as is the Subcommittee, with health care costs, with efficiency in health care delivery, and with the quality of health care services provided. It is with these concerns in mind that we raise these issues with respect to the expansion of the EPSDT program as proposed in H.R. 6706.

We believe that any re-evaluation and revision in the current EPSDT program requires a concurrent re-evaluation of the maternal and child

health care program as provided in Title V of the Social Security Act. In fact the American Medical Association, in conjunction with the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists, is developing revisions in the Maternal and Child Health program that would expand the program to address more adequately the spirit and intent of providing maternal and child health care services. After completing final development of these amendments we would be pleased to share with you our recommendations for amending the Maternal and Child Health program.

CONCLUSION

In conclusion we would like to point out that in addition to needed changes in Title V of the Social Security Act and to changes in the Child Health Assessment Act, some of the issues of access, free choice, and quality care would with greater efficiency and cost effectiveness be handled through a comprehensive health insurance proposal such as is set forth in H.R. 1818--a health insurance program that the AMA supports. One of the advantages to be gained by such legislation is that the health care of all members of families of all economic levels is taken into account, not just the health care of a particular member of certain families. As you might well agree, oftentimes the health of one family member has a significant bearing on the health of other family members. Accordingly, consideration must not be lost of a holistic approach as the most appropriate manner of assuring quality health care to all needy individuals.

We wish to reiterate our support for the current EPSDT program. We believe that this program is fulfilling a vital need and providing certain health services to children of low income families. Yet, while we support the present EPSDT program, we believe that this program should not be viewed

as addressing the total health care problems of our nation's children. As we pointed out earlier, EPSDT services are required to be provided under existing state Medicaid plans. Yet, EPSDT services have not been provided to all eligible Medicaid beneficiaries. We suspect that many of the basic problems with the EPSDT program may not be in the scope of benefits but rather in the administration of the program. Therefore, we do not believe that the reforms suggested in this proposed legislation would accomplish the achievement of effectively providing increased quality health care services to children.

We urge that the Subcommittee consider our specific concerns with the proposed legislation to modify the current EPSDT programs. While we support the general concept embodied in the Child Health Assessment Program legislation, we urge that the Subcommittee not adopt this proposed legislation without modifications reflecting our concerns.

Joint Statement of the

Blue Cross Association

and

Blue Shield Association

Mr. Chairman and Members of the Subcommittee, the Blue Cross Association and Blue Shield Association appreciate this opportunity to share with you our thoughts on H. R. 6706 related to improving the health of financially needy children.

We support the intent of this Administration proposal to strengthen the Early and Periodic Screening Diagnoses and Treatment (EPSDT) program.

We share your hope that states will find the proposed increases in federal reimbursement rates attractive enough to significantly expand their present level of activity in child health assessments. We also agree that the expansion of benefits to include all services paid for by Medicaid and the extension of eligibility requirements makes eminent sense, as does the revision of existing penalty provisions.

MEDICAID IN A NATIONAL HEALTH PLAN

Both of our organizations have long supported strengthening and improving the Medicaid program. We have testified to that effect at numerous Congressional hearings. Specifically, we have recommended that an essential step toward a rational and efficient national health insurance system should be improvement in the delivery and financing of health care services for the poor and near-poor. We still support that approach.

As major national organizations with a signficant stake in the health status of the country, we find it difficult to rationalize the uneven patterns of availability of Medicaid health services and the uneven levels of program effectiveness that currently exist. We share your concern with the shortcomings in the

present way children of the poor get health care under Medicaid. It is no revelation that the health of our poor and near-poor children is all too often being neglected. The result is that many times ailments which could have been avoided with early diagnosis and treatment become serious and require expensive long-term care.

PROBLEM OF ACCESS TO CARE

After reviewing the provisions of H. R. 6706, we believe this legislation will help significantly in reducing the uneven patterns of care which characterize the current EPSDT program. The bill appears to go a long way toward eliminating some of the inequities under EPSDT which came as a result of poorly coordinated provisions and complex Medicaid eligibility standards.

We would, however, like to offer an observation regarding Section 5 of the bill which describes the phasing-in of agreements with health care providers. The definition of health care provider might be clarified. It appears to be directed only to clinics. It does not seem to address practitioners and other types of providers nor does it deal with the question of what happens if there aren't any providers who are willing to enter into agreement with the state.

While the CHAP proposal recognizes that in some areas there won't be enough providers to extend adequate care to eligible children it does not come to grips with that problem. Removing the financial barriers to care and enrolling children in the program, unfortunately, will not result in either improved quality of care or improved accessibility to health care. The problem in many states, as we see it, is not so much to identify and enroll children in the program, but to coordinate the provision of the different services through a variety of sources and providers. We believe that the CHAP proposal may fall short of its intended

mark unless it includes provisions to insure that the facilities and providers are available at the local community level to dispense appropriate care. The utilization of community non-profit groups, nurse practitioners where appropriate, and public health service facilities as proposed by several members of the Subcommittee appears to us to be a reasonable addition to the bill.

At this point, we would like also to express our agreement with the view, as stated by Subcommittee Chairman Rogers at the recent hearings on the CHAP proposal, that children's health care benefits should begin at conception and continue throughout the formative years. The Chairman's suggestions to provide pre-natal benefits under the program would in our view be well advised.

HEALTH EDUCATION NEEDS EMPHASIS

A further suggestion, emphasizing the preventive aspects of care, would be to include as an added benefit health education directed at both the child and his family to help build good health practices. There is a growing awareness that the goals of better health must be sought not only through improved access or financing of care for the ill or injured but through sustained programs aimed at persuading and motivating individuals to accept responsibility for their own health and providing the information they need to stay well. Improving health care services and health education for children has the greatest potential for an ultimate pay-off. The success of the CHAP program might well depend on educating not only those eligible for the services but also on making children and their parents aware of the need for the services and the advantages of maintaining good health habits. Some positive steps toward that goal might include:

- improving immunization programs
- improving preventive testing of hearing, vision and dental care

- improving nutrition and diet through improved subsidies to luncheon programs
- offering more information and counseling on the effects of alcohol and mood-inducing drugs.

SUMMARY

Health care for children, especially children living in poverty, is an issue often clouded by emotion. We must not lose sight of the fact that healthy children cannot be obtained merely by providing adequate medical services. The criteria for judging results and compliance with federal regulations should not be merely the number of children served but rather whether the health of children has improved. Improving the quality of health services or adding more health services should not be viewed as a panacea. Rather, we must continue to strive for a long-range solution which goes beyond medical care and recognizes housing, nutrition, income, etc. as major determinants of health. Providing more health care services without looking at underlying factors ignores the basic problems of health care.

The Blue Shield and Blue Cross organizations share the goals of the Children's Health Assessment Program and support the expansion of health care services for financially needy children. We emphasize the need to begin looking at all determinants of health (housing, nutrition, income, environment) as well as the need for improved health education programs. The CHAP initiative will fall short of resolving the health problems facing our nation today, but when viewed as a step toward NHI, and blended with other Congressional initiatives, it is a worthy beginning. We thank you for the opportunity to share our views on this important subject.

STATEMENT OF ANDREW J. BIEMILLER, DIRECTOR, DEPARTMENT OF LEGISLATION
AMERICAN FEDERATION OF LABOR AND CONGRESS OF INDUSTRIAL ORGANIZATIONS
SUBMITTED TO THE HEALTH SUBCOMMITTEE OF THE
HOUSE INTERSTATE AND FOREIGN COMMERCE COMMITTEE
ON THE CHILD HEALTH ASSESSMENT ACT
H.R. 6706

September 13, 1977

The AFL-CIO appreciates the opportunity to present its views with respect to H.R. 6706 the Child Health Assessment Program (CHAP), the Administration proposal to improve the Early and Periodic Screening, Diagnosis and Treatment (EPSDT) program which was included in the amendments to the Medicaid program in 1967.

Among the weaknesses of the EPSDT Program are:

* Because of the categorical nature of current welfare programs, including Medicaid, some poor children are not eligible for screening.

* For the 13 million children who are eligible, EPSDT has provided only about one-fourth of the health assessments needed and very few children have had a periodic rescreen as Congress intended.

* Only about 60 percent of the health problems identified through screening have received follow-up care. Often, if treatment was instituted, it was not completed because more than one-third of the children lost eligibility after treatment had begun.

* EPSDI rarely has helped children with developmental problems such as perceptual, motor and cdgitative difficulties.

* The EPSDT has made little progress in dealing with mental health problems of children because emotional disorders are difficult to screen and because of the program's limitations in informing and counseling families.

* A major defect is that the screening rarely linked children to an ongoing and continuing source of primary care.

The Administration's bill addresses some, but not all, of these problems. It would require the states to provide Medicaid coverage for all children under six years of age whose families meet the state's income test for Aid to Families With Dependent Children (AFDC). This is a major improvement over present law since eligibility, based on an income test, is extended to all children under six regardless of family structure. Those previously not covered under EPSDT but now eligible under CHAP include, mainly, children in poor families under six with two parents whether working or not.

On the other hand, children up to the age of 21 may now be covered under Medicaid at the option of the state. Many states have chosen to do so. All children need the care CHAP would provide. Therefore, the AFL-CIO favors covering under CHAP all children under 21 who meet the states' financial criteria for AFDC.

H.R. 6706 extends eligibility for Medicaid benefits to children who have been screened for six months following the date when a families' income exceeds the state's income test and the family becomes ineligible for Medicaid. The AFL-CIO strongly urges this period be extended to one full year in order to assure that treatment which has been initiated will be continued without interruption.

Health Benefits

The CHAP program proposes to provide more comprehensive health assessments for children than has been done in the past. Screening has been successful in detecting many physical problems. However, it is not always possible to accurately diagnose a child who is hyperactive, disturbed or retarded by relatively simple tests. Such problems require a physician to pull together information from screening, physical examinations, health history, observation of the child and consultation with the parents.

Surprisingly, while H.R. 6706 provides all health services following a health assessment, it does not necessarily require treatment of mental illness, mental retardation, developmental disabilities or dental care when not for treatment of conditions discovered by an assessment. A toothache hardly needs an assessment; it needs to be treated.

Therefore, CHAP should provide all necessary health, mental health and dental care services whether discovered through assessment or not.

Provider Participation

States are required to encourage participation by physicians and health care centers in the program. After the first year of the program, a screening agency would be required to have a formal agreement with a provider for treatment. After the third year, the provider's responsibility would include assessment, diagnosis and treatment of problems, referral for specialized care and either undertaking or arranging for case management.

While Section 6 of the bill specifically mentions Community Health Centers as potential participants, it does not specifically mention HMOs. In particular, the prepaid group practice form of HMOs would be an ideal participant in the program since such plans assess and treat all patients, rich or poor, with a single medical staff thereby assuring continuity of care. Priority consideration should, therefore, be required by the states to promote participation in CHAP of HMOs as well as other organized settings such as maternal and child health centers and multispeciality group practice clinics.

Payment to such organized settings should (to the maximum extent possible) be by capitation to assure continuity of care, effective case management and efficiency.

Resource Development

The bill would increase the fiscal year 1978 authorization for resource development of the Community Health Center Program by about $25 million. Resource development funds should also be made available for the initial development or expansion, not only of Community Health Centers, but also for all organized settings such as prepaid group practice plans and maternal and child health clinics which should be used in the CHAP program. The authorization for resource development should be substantially increased.

Federal Standards

The bill provides that standards for an assessment and standards of performance will be defined by regulation. Minimum federal standards should uniformly deal with program performance, administration, quality of care and eligibility.

Financing

CHAP would increase federal assistance to states and localities for the cost of medical and other services given by providers, but not for state administration costs except for the states that perform especially well. The AFL-CIO believes that increased financial assistance should be provided in order that all states may improve their program performance, particularly in their outreach activities to enroll all eligible children. One weakness of the bill is that it does not require any maintenance of effort by the states. The primary purpose behind increasing the federal share of the screening and treatment of children should be to encourage the states to strengthen and expand their programs.

But in order for the increased federal share to result in program improvement, states should maintain at least their current level of financial commitment. Otherwise, the new federal money may only result in replacing state funds rather than increasing benefits for children.

Conclusion

The AFL-CIO strongly endorses the CHAP Program, particularly if the improvements we have suggested are included in the bill enacted by Congress. Improved health services for children should be an important element in creating a health system that will meet priority health needs. They also constitute an important step toward a comprehensive national health insurance program for all of the American people as a matter of right.

STATEMENT OF HENRIETTA MARSHALL
CHAIRMAN, PLANNED PARENTHOOD FEDERATION OF AMERICA

On behalf of the Planned Parenthood Federation, I would like to extend our appreciation for the leadership and concern that members of the Subcommittee have demonstrated in developing legislation to strengthen and improve the Early and Periodic Screening, Diagnosis and Treatment program. We have been pleased and encouraged by the efforts to establish a more specific legislative framework that will make the states, the Administration and the health care system accountable to the goal Congress established ten years ago of identifying and treating conditions which, when left unrecognized, endanger the health, social development, education, future productivity and happiness of young Americans.

We have been particularly interested in the program because of its potential for upgrading health care for adolescents--many of whom are no longer under the care of a pediatrician but have not yet located a point of entry to the larger health care system. Organized family planning programs, including Planned Parenthood, constitute one of the largest networks currently serving as such an entry point, providing more than one million adolescents with routine health services each year, including physical examinations, venereal disease tests, gynecological diagnosis and treatments, cancer screening, family planning services, counseling, blood pressure and sickle cell anemia tests, medical and other referrals.

Almost one-third of the organized family planning caseload is under the age of 20. So we appreciate the opportunity to offer suggestions based on our experience and knowledge.

We have found that the extent to which serious health risks go unrecognized and untreated among adolescents is, at the very least, sobering. Young persons from poor families are particularly likely to have serious, unmet medical needs. Despite this, a significant number of these youngsters are ineligible for Medicaid services simply because they live in

families that are "categorically" ineligible, meaning that both parents are living at home, for example, or that the family head is not disabled or blind. As a result, young persons not able to afford private medical services still are not able to benefit from the Medicaid program.

We certainly want to commend the Chairman and the members of the Subcommittee who have recognized the inequity and the long-term damage resulting from this situation. We strongly support efforts to expand eligibility to include all persons 21 and under who would qualify on the basis of financial need. We agree that expanded eligibility ought not be confined to youngsters under age six, as the Administration suggests. Evidence from the present EPSDT program indicates that as many, if not more, older youngsters are in need of treatment following a health assessment as are small children.

In short, expanded eligibility for youngsters of all ages is essential. As beneficial as such a change would be, however, the record of the old EPSDT program demonstrates that additional changes are also required if teenagers are to be reached and served adequately.

However delinquent EPSDT has been on an overall basis, it must be emphasized that the program's response has been particularly dismal and discouraging in regard to teenagers. EPSDT has been mandated, since its inception, to serve Medicaid-eligible persons up to age 21. But there has been a pervasive tendency among child health advocates, physicians, DHEW personnel and the responsible state officials to view EPSDT as a program for infants and children. Although lip service is given to improved health care for adolescents--and Chairman Rogers and the Subcommittee should certainly be commended in recognizing this as an essential obligation of the program--almost no progress has been made toward encouraging appropriate outreach, requiring necessary services, or involving health care providers

with special experience and knowledge of teenage needs. The federal regulations implementing the EPSDT program are inexplicably silent about contraceptive screening, services and supplies. Program guidelines for screening omit mention of pregnancy tests, contraceptive services or medical assessments and referrals for pregnant adolescents.

A further indication of the program's indifference to adolescents' needs is the continued failure to produce any guidelines specifically concerned with EPSDT providers' responsibilities toward teenagers. For more than two years, such guidelines have been under preparation, but there is no identifiable timetable nor any apparent priority on their completion. A draft of the proposed guidelines was circulated in DHEW this fall. Unfortunately, they seemed to us to be so inappropriate in their tone, so misleading in various factual areas and so contradictory in the guidance provided that we have, in fact, viewed the present delays--as counterproductive as they are-- to be preferable to immediate action.

In view of the nonleadership among administrators at the federal level, perhaps it is not surprising that we simply do not know just how poorly EPSDT is serving adolescents. EPSDT statistics are not collected for any age group within the category "children over six." This age grouping includes youngsters with vastly different kinds of medical needs, and it tends to blur the inadequacy of services to older youngsters. In South Carolina, a state where more detailed information is available, a recent study of the Children's Defense Fund reported that youngsters 16 and over received about 43 percent fewer screening services than the state's screening schedule had targeted. Screenings for youngsters aged six to 15 exceeded the state target by about 34 percent. When both age groups are lumped together, the variations cancel each other, of course, and hide the fact that adolescents are not getting help they need.

Failure to reach adolescents results from two problems at the local level. First, outreach efforts are conducted primarily through welfare offices, frequently with notices sent to the family head. Teenagers are not approached directly nor informed that screening and treatment is available for conditions--like venereal disease, drug abuse or pregnancy--they are particularly concerned about. Second, the program has not involved provider agencies experienced with adolescents and equipped to serve them. Family planning agencies, high school health clinics, drug abuse centers and other facilities serving large numbers of teenagers are seldom even considered when state EPSDT programs are being planned.

Correcting the shortcomings of the old EPSDT program requires us to consider the nature of adolescent health needs. For the most part, their needs are sharply different than those of small children. The three leading causes of death among teenagers, for example, are accidents, homicide and suicide. While babies and gradeschoolers require immunizations and early treatment for hearing problems and congenital defects, adolescents are more likely to require professional attention to social or environmental risks. Unwanted pregnancy, drug abuse, venereal disease, alcoholism and smoking are tragically common among junior and senior high school students.

The Administration and the American public are rightfully concerned by unwanted teenage childbearing which affects millions of families in all parts of the country, especially those without adequate medical care. It is increasingly difficult to ignore the fact that more cases of gonorrhea are recorded each year by the Public Health Service than all other reported communicable diseases combined. Like problems resulting from drugs, smoking and drinking, these are problems that professionals trained to treat children are often not prepared to meet.

If the only child health assessment center in a community is located in a Headstart Center, there is little realistic hope that the program will be able to attract or to adequately serve teenagers. If outreach is aimed solely at mothers and ignores the special concerns of adolescents, information about the program's benefits simply cannot be expected to reach teenagers.

Unfortunately, these circumstances are typical under EPSDT. And it is safe to predict that such policies will persist unless there is specific legislative attention to the needs of teenagers.

In order to adequately serve low-income teenagers under the CHAP program, we believe the legislation must:

1. Expand Medicaid eligibility to include all youngsters under 21 who qualify on the basis of financial need. Denying coverage to needy adolescents because they do not meet a "categorical" requirement is arbitrary and self-defeating.

2. Expand Medicaid eligibility to include low-income women experiencing a first pregnancy. This change is particularly important for adolescents because many of those currently excluded from coverage are under the age of 21. Whatever her age, however, it is consistent with CHAP's goals and the program's commitment to improved infant health to make all low-income women eligible for medical care during a first pregnancy.

3. Require the Secretary to establish regulations setting appropriate standards for health services provided to adolescents as distinguished from standards applicable to babies and children. Many health agencies would be able to fulfill both sets of standards, but others would not and should not be expected to do so. In addition to community health centers and child-oriented agencies, facilities serving large numbers of adolescents--including family planning clinics, drug abuse centers and high school health clinics--should be identified as eligible providers.

4. Provide incentives for outreach to adolescents, especially by people and organizations who have rapport with young persons.

5. Require the states to offer providers reimbursement that can reasonably be expected to elicit the participation of those capable of serving adolescents. Payments to clinics and other nonhospital providers should be sufficient to cover the cost of the medical services and education provided.

6. Provide for the preservation of patient privacy in regard to highly personal services such as venereal disease screening and treatment, pregnancy-related services, drug and alcohol abuse treatment and mental health services. H.R. 3, "The Medicare-Medicaid Anti-Fraud and Abuse Amendments," wisely addresses this problem by prohibiting the mailing of patient statements on such sensitive services. Enactment of such a protection is particularly necessary for protecting adolescent patients under CHAP.

7. Identify family planning as a minimum treatment which, like immunizations for children, providers must be able to deliver at the time an adolescent is screened. Perhaps more than any other preventive service, contraceptive care for sexually active adolescents has great potential for reducing the need for long-term medical and social service support. A pelvic examination, necessary laboratory tests and a thorough medical history are already viewed as integral parts of a health assessment for a sexually active girl . Federal legislation should be revised to require the immediate provision of needed contraceptive services where appropriate. Such an approach not only eliminates delays and inconvenience for the teenager, it avoids duplicative examinations and interviews at another clinic or office.

Mr. Chairman, it is important that the law be deliberate and unambiguous in addressing the needs of adolescents. Currently, the EPSDT program is failing our young persons and it shows no real hope of changing. Your Subcommittee has a chance to reverse this situation and to direct the CHAP program toward substantive action. Your actions would contribute enormously to the health and welfare of young Americans and their prospective offspring.

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Statement

By
Judith Kellogg Barber
Social Services Director
Combined Community Child Development Services, Inc.
Starkville, Mississippi

We appreciate this opportunity to express our concerns regarding the Child Health Assessment Act Section 3. EPSDT and CHAP are the most important health resources available to poor children at this time because they focus on preventive care and on identifying minor health problems before they produce pain and crippling conditions. The CHAP proposal makes a variety of changes in EPSDT and Medicaid which affect individuals under the age of 21 --- changes in eligibility, benefits covered, financing of services, and in the administration and enforcement of the EPSDT program. While there are many features of CHAP with which we are concerned, such as the broadening of eligibility to children under age 6 who are not currently on welfare because they have two parents at home, we have chosen to focus on dental care out of our many Mississippi experiences with unmet dental needs. We are very concerned with the CHAP provision which limits dental care to conditions discovered during an assessment.

Nearly all poor children need routine dental care. Their teeth hurt, they avoid any nutritious food that is difficult to chew, and they cannot concentrate in school while the main fact of their lives is pain. In school, we don't even know they hurt. We call them inattentive. Much tooth decay is not evident from a nurse's visual inspection. Many children get lost

in a maze of state agency screening policies, like the one that issues appointments alphabetically. Most children must wait many months for a dental treatment appointment. During that time their dental referral slips may expire or they may lose their Medicaid status if their mother gets a job or their father comes home.

As a social worker with a day care program in Oktibbeha County, Mississippi which serves 150 children, I am keenly aware of the personal problems of families seeking health care for their children. In Oktibbeha County, over half of our families are poor. Only 44% of the children below the poverty level are Medicaid eligible, around 3,000 children. 1,014 of these children received EPSDT screening last year with 752 of them receiving dental referrals. Less than half of the children referred were treated by a dentist for reasons which range from lack of provider participation in Medicaid to rigid tying of dental treatment to screening assessments.

Receiving Dental Care Under CHAP

We agree whole-heartedly with the Children's Defense Fund's recommendation that "Routine as well as emergency dental care should be provided as needed to children eligible for Medicaid, at least to the same extent under CHAP as now available under EPSDT." Dental services should be matched at the same level as all other services under CHAP. Existing regulations should be

clarified to assure that any eligible child can receive dental care regardless of whether the child has received dental screening or been referred by an assessment provider.

I am troubled by what CHAP has to say about the tying of dental treatment to screening because of the many personal experiences I have had with children who have had to wait a long time for screening and then an even longer time for treatment when its obvious to the child and his family that he hurts and needs immediate treatment without the delay of screening.

In Mississippi, since June 1976, all children over the age of three have received dental referrals based on experience that showed almost universal need for dental care. Prior to that time referrals were only given when cavities were identified during screening. Only 1/3 of eligible children in Oktibbeha County are screened annually and thus received referrals. The 375 children who did receive some treatment survived a major obstacle course. I know of 30 children who waited 4-6 months for a dental appointment. 10 other children had EPSDT referral slips which expired while they were waiting, despite valiant attempts by their social worker to get them moved up the list. Now they must wait their turn at the health department for re-screening before they can again go on a dental waiting list. When a Medicaid mother placed calls to all six local dentists from our office, four dentists told her to call the other two. One dentist gave her an appointment for four months from now.

The other said he would put her on the waiting list, which we know takes from 5-6 months. When I called the same dentists, as a middle-class client, I could receive dental service in 5 weeks. It is the rigid policies like requiring that the problem has to be found in screening before children can get dental care that stand between the child and the treatment he needs.

One Oktibbeha County social worker had the following experience. She helped one mother who received dental referrals for her four children to get appointments after a four-month wait. The day of the appointment, the social worker was contacted by the mother and informed that two of the children had tests at school and couldn't go to the dentist. The dentist, when called, told the social worker to bring the other two children. When they arrived at 11:05 for an 11:00 appointment, they were told that the dentist had an emergency and because they were late, he had left. When the social worker requested another appointment, she was told that the dentist had seen all of the Medicaid patients during this period that he could and the family could not have another appointment for another four months (by which time the referral slips will have expired.) 20,340 Mississippi children who were referred to a dentist last year never received treatment.

Prior to mandatory dental referral for all children over age three in Mississippi, some children passed through cursory

mouth inspections at the health department and did not receive referrals but later were discovered to have dental problems. If CHAP requires that treatment be tied to conditions identified during screening, many children like Carlos will have to wait a full year or more to be re-screened before they can be eligible to wait in line for treatment.

Carlos, who was born in December 1971, entered our day care program in August of 1972. As a result of a group day care appointment, he received his first EPSDT screening in November 1974, a service he should receive annually. His dental evaluation was marked "OK." In January 1976, he was referred by his day care teacher to a learning resource center at the state university for a speech evaluation of his "funny speech." The learning center identified the speech problem as caused by an "open bite" dental problem. The learning center paid for an evaluation by a children's dentist. The dentist verified the problem and referred the child to the county health department for EPSDT screening and dental referral because the last screening did not show dental problems and therefore Medicaid could not be billed. In February, the county health department gave an appointment to the child to see the health department physician. The social worker was told that no re-screening could be done as the child had been screened within the year but that anyway Medicaid does not pay for wires on a child's baby teeth. Nothing was done. In March, the child was x-rayed at a dental

hygiene clinic (at the mother's expense.) Cavities were found. For treatment of the tooth decay, the child must be rescreened at the county health department and referred to the dentist by EPSDT. He will then have to wait at least four months for treatment of cavities. By the time he enters first grade this fall, nothing will have been done on either of his problems. CHAP must address the dental needs of children by not tying treatment rigidly to conditions discovered during an assessment.

Mississippi has made great improvements in its dental program. CHAP could see that all children have dental eligibility without screening. Mississippi now gives universal dental referral to all children who are screened. If treatment is limited to conditions which can be identified visually by a public health nurse, our program will suffer a major set-back.

Assuring That Dental Care Is Available

By making this one change in CHAP, you would go a long way to making conditions better for children, but there still remains the problem of getting treatment. In 1976, 58 of 82 Mississippi counties were considered critical dental shortage areas. A ratio of more than 4,000 patients to one dentist is the definition of a shortage area. 10 Mississippi counties had a patient ratio in excess of 1:10,000 for dental care and three had no dentist at all. It's hard for everyone to get dental care in rural areas, but its most difficult for Medicaid children.

If we take Carlos to the next semi-monthly Medicaid screening, he will get a mandatory dental referral slip, but we have no assurance that he will get treated. CHAP would merely "encourage participation by physicians and health care centers." The whole question of assuring provider participation in the treatment aspects of EPSDT needs careful attention. There has been little focus on giving states explicit responsibility for insuring treatment. States have too often had reimbursement rates and procedures that discourage participation by providers, or that at least give providers an excuse for limiting their service to Medicaid recipients. States could develop programs of reimbursement for services either on an individual need basis or through contracting for blocks of time that would make it attractive for providers to participate. In discussing the block-purchase option with a State Health Department Administrator in Mississippi, we have become convinced that all states need to create such an option is a mandate from Congress to establish a plan for assuring that dental care is available.

Mississippi leads the list of states in dental referrals but has a long way to go in attracting enough dental service to meet the needs identified. Dentists give many reasons for not participating in Medicaid including too much paperwork, broken appointments, delayed reimbursement, and low fee scales. We do believe that it is important to enforce the federal law which requires states to establish reimbursement rates high enough to assure sufficient

providers in the program so that eligible persons can receive services to the same extent that they are available to the general public. The Secretary of HEW should review what states are doing about accepting the responsibility for setting reasonable fee levels, attractive enough to providers to promote their participation.

Assuring adequate fee levels will help accomplish CHAP's intent. During the past four years, Mississippi has had three upward revisions of its fee scale and now has the highest reimbursement rates in the Southeast. Maximum payments for one child per year has moved from $55 to $100 to $150 to $200. Individual fee scale costs show an increase for a one-surface amalgam from $7 to $10 to $12. Dental fees now appear to be competitive with the prevailing market. This has achieved important gains for children. While the total number of dentists who do some Medicaid work has only moved up slowly in four years from 335 to 418, there has been a dramatic increase in the number of dentist receiving over $10,000 per year in Medicaid payments... from a total of 4 in 1973 to 86 in 1976. Those dentists who do participate in the program have found that it is good business. Mississippi's fee scale is certainly one factor in encouraging their participation. And yet in Oktibbeha County where Carlos lives, only two of six dentists participate in the Medicaid program. We need a better service delivery system if we are ever to meet the EPSDT treatment needs. Possibilities might include mobile vans manned by public health service dentists, purchase of blocks of time from a dentist several times a month, or pre-payment plans. States should be charged with coming up with a state plan to meet the dental needs of children, recognizing that conditions vary from community to community. We must all learn that it pays to take care of all children; that all children are our children.

[Whereupon, at 4:25 p.m., the subcommittee adjourned.]

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