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NINETY-THIRD CONGRESS

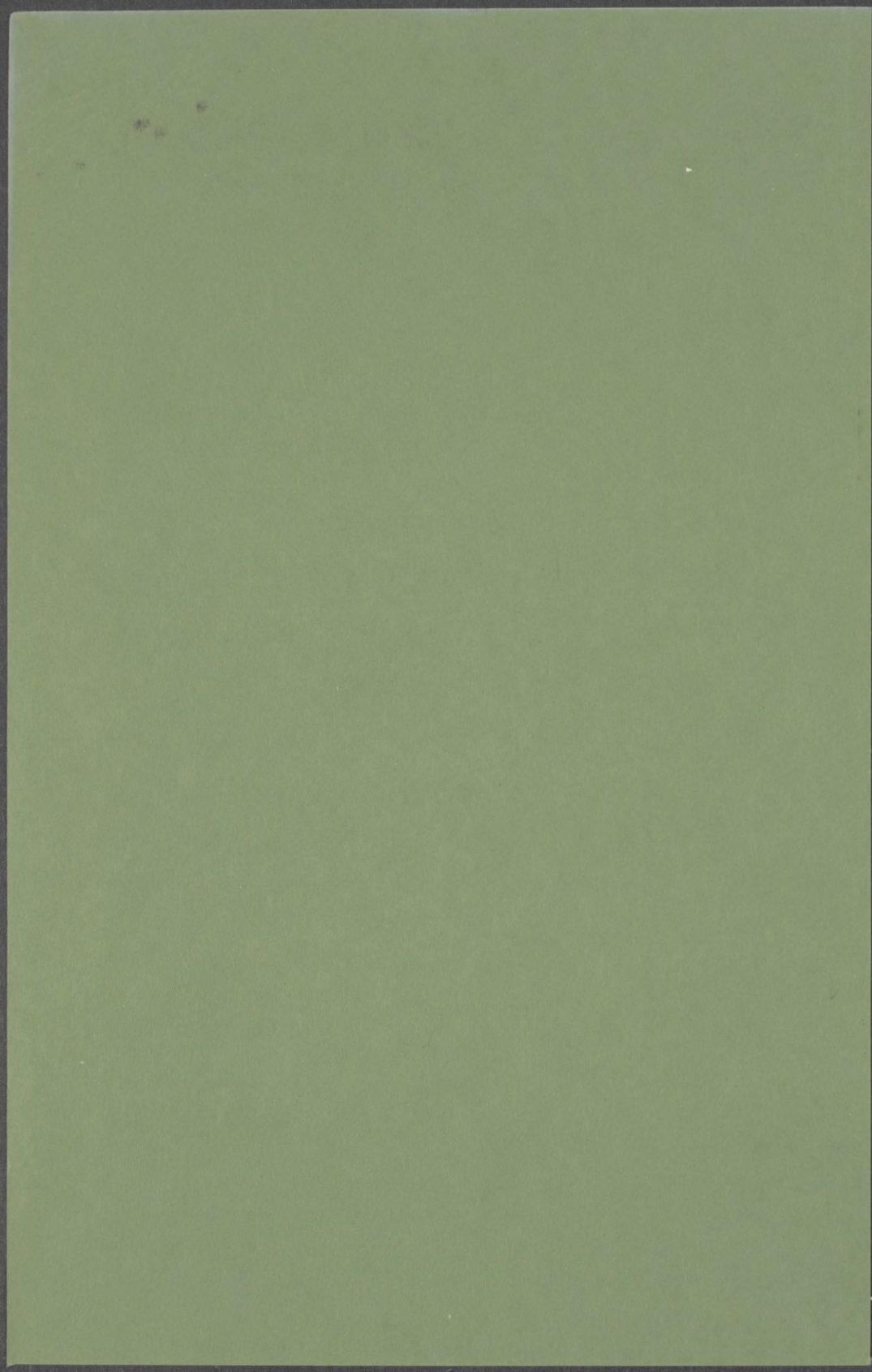
ON

TO PROVIDE ASSISTANCE FOR THE DEVELOPMENTALLY
DISABLED, ESTABLISH A BILL OF RIGHTS FOR THE DE-
VELOPMENTALLY DISABLED, AND FOR OTHER PURPOSES

MAY 1, 1974



AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
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DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT, 1974

HEARING
BEFORE THE
SUBCOMMITTEE ON THE HANDICAPPED
OF THE
COMMITTEE ON
LABOR AND PUBLIC WELFARE
UNITED STATES SENATE
NINETY-THIRD CONGRESS
SECOND SESSION
ON
S. 3378
TO PROVIDE ASSISTANCE FOR THE DEVELOPMENTALLY
DISABLED, ESTABLISH A BILL OF RIGHTS FOR THE DE-
VELOPMENTALLY DISABLED, AND FOR OTHER PURPOSES
AND RELATED BILLS

MAY 1, 1974



Printed for the use of the Committee on Labor and Public Welfare

U.S. GOVERNMENT PRINTING OFFICE

33-979 O

WASHINGTON : 1974

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THE UNITED STATES OF AMERICA

FROM 1776 TO 1876

BY JAMES M. SMITH

IN TWO VOLUMES

VOLUME I

1776-1800

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DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT, 1974

WEDNESDAY, MAY 1, 1974

U.S. SENATE,
SUBCOMMITTEE ON THE HANDICAPPED,
OF THE COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met, pursuant to notice, at 2:35 p.m., in room 4232, Dirksen Office Building, the Honorable Jennings Randolph (subcommittee chairman) presiding.

Present: Senators Randolph, Kennedy, and Stafford.

Committee staff members present: Patria Forsythe, professional staff member; Larry Horowitz, M.D., professional staff member; and Jay Cutler, minority counsel.

Senator RANDOLPH. The members of the Subcommittee on the Handicapped of the full Committee on Labor and Public Welfare are in session this afternoon on Senate bill S. 3378, the "Developmentally Disabled Assistance and Bill of Rights Act".

Other members of the subcommittee, of course, are intensely interested in this legislation, and I am delighted to have sitting during this hearing Senator Stafford, who is the ranking minority member on the subcommittee, and Senator Kennedy, who ably chairs our Subcommittee on Health and cooperates closely with the Subcommittee on the Handicapped in its deliberations.

You will remember that last year on February 8, this subcommittee held hearings and we had, I believe, Senators Stafford and Kennedy, approximately 30 witnesses; is that your memory?

Senator STAFFORD. That is my recollection, Mr. Chairman.

Senator RANDOLPH. At that time we invited the representatives of the Department of Health, Education, and Welfare to present their views on this pending legislation.

They were unable to appear at that time, so we have decided that we wanted the input of administration; that is the reason for our being together today.

One year ago I requested, on behalf of the subcommittee, that the General Accounting Office conduct a full review of the Developmental Disabilities Program.

In January of this year we received a two volume report from GAO which dealt with Public Law 91-517, the "Developmental Disabilities Service and Facilities Construction Amendments of 1970."

The members of the staff of our subcommittee have been meeting with the GAO staff members and there has been careful study of that report.

It discusses in detail the administration of the legislation at the Federal and State levels and the impact and effect on the developmentally disabled.

Our staff members have reviewed the testimony and statements of the more than 30 witnesses that I have mentioned that came before us last year.

S. 3378 is the result; and Senator Stafford and Senator Kennedy know from their association with the drafting of this bill, that we consumed long months of effort in attempting to properly focus the program and assist the States in developing a comprehensive plan which will bring together all the resources available in a coordinated manner so that the developmentally disabled are served and served in the very best way.

[The texts of the bills under consideration follow:]

1 (2) The term "facility for persons with developmental
2 disabilities" means a facility, or a specified portion of a facil-
3 ity, designed primarily for the delivery of one or more serv-
4 ices to persons with one or more developmental disabilities.

5 (3) The terms "nonprofit facility for persons with de-
6 velopmental disabilities", "nonprofit community mental
7 health center", or "nonprofit private institution of higher
8 learning" mean a facility for persons with developmental dis-
9 abilities, and an institution of higher learning which is owned
10 and operated by one or more nonprofit corporations or asso-
11 ciations no part of the net earnings of which inures, or may
12 lawfully inure, to the benefit of any private shareholder or
13 individual.

14 (4) The term "nonprofit private agency or organiza-
15 tion" means an agency or organization which is such a cor-
16 poration or association or which is owned and operated by
17 one or more of such corporations or associations.

18 (5) The term "construction" includes acquisition, ex-
19 pansion, remodeling, and alteration of existing buildings,
20 and initial equipment of any such buildings (including medi-
21 cal transportation facilities) ; including architect's fees, but
22 excluding the cost of offsite improvements and the cost of
23 the acquisition of land.

24 (6) The term "cost of construction" means the amount

1 found by the Secretary to be necessary for the construction
2 of a project.

3 (7) The term "title", when used with reference to a
4 site for a project, means a fee simple, or such other estate
5 or interest (including a leasehold on which the rental does
6 not exceed 4 per centum of the value of the land) as the
7 Secretary finds sufficient to assure for a period of not less
8 than fifty years undisturbed use and possession for the pur-
9 poses of construction and operation of the project.

10 (8) (A) The term "Federal share" with respect to any
11 project means the portion of the cost of construction of such
12 project to be paid by the Federal Government.

13 (B) The Federal share with respect to any project in
14 the State shall be the amount determined by the appropriate
15 State agency designated in the State plan, but, except as
16 provided in paragraph (C) the Federal share for any project
17 under part B of title I may not exceed $66\frac{2}{3}$ per centum of
18 the costs of construction of such project. Prior to the ap-
19 proval of the first such project in the State during any fiscal
20 year, such State agency shall give the Secretary written
21 notification of the maximum Federal share established pur-
22 suant to this paragraph for such projects in such State to
23 be approved by the Secretary during such fiscal year and
24 the method for determining the actual Federal share to be

1 paid with respect to such projects; and such maximum Fed-
2 eral share and such method of determination for such projects
3 in such State approved during such fiscal year shall not be
4 changed after the approval of the first such project in the
5 State during such fiscal year.

6 (C) In the case of any facility or center which provides
7 or will, upon completion of the project for which application
8 has been made under part B of title I, provide services for
9 persons in an area designated by the Secretary as an urban
10 or rural poverty area, the maximum Federal share deter-
11 mined under paragraph (B) may not exceed 90 per centum
12 of the costs of construction of the project.

13 (9) The Federal percentage for any State shall be
14 100 per centum less that percentage which bears the same
15 ratio to 50 per centum as the per capita income of such
16 State bears to the per capita income of the United States,
17 except that the Federal percentage for Puerto Rico, Guam,
18 American Samoa, and the Virgin Islands shall be $66\frac{2}{3}$ per
19 centum.

20 (10) (A) The Federal percentages shall be promul-
21 gated by the Secretary between July 1 and September 30
22 of each even-numbered year, on the basis of the average of
23 the per capita incomes of the States and of the United States
24 for the three most recent consecutive years for which satis-
25 factory data are available from the Department of Com-

1 merce. Such promulgation shall be conclusive for each of the
2 two fiscal years in the period beginning July 1 next succeed-
3 ing such promulgation; except that the Secretary shall pro-
4 mulgate such percentages as soon as possible after the enact-
5 ment of this Act, which promulgation shall be conclusive for
6 the fiscal year ending June 30, 1965.

7 (B) The term "United States" means (but only for
8 purposes of this subsection and subsection (10) the fifty
9 States and the District of Columbia.

10 (11) The term "Secretary" means the Secretary of
11 Health, Education, and Welfare.

12 (12) The term "developmental disability" means a
13 disability—

14 (A) attributable to mental retardation, or cerebral
15 palsy, or epilepsy, or autism, or learning disability; or

16 (B) attributable to any other condition of an in-
17 dividual found to be closely related to mental retarda-
18 tion as it refers to general intellectual functioning or im-
19 pairment in adaptive behavior or to require treatment
20 similar to that required for mentally retarded individuals,
21 which disability (i) originates before such individual attains
22 age eighteen, (ii) which has continued or can be expected
23 to continue indefinitely, and (iii) which constitutes a
24 severe handicap to such individual's ability to function
25 normally in society.

1 (13) The term "services for persons with develop-
2 mental disabilities" means specialized services or special
3 adaptations of generic services directed toward the alleviation
4 of a developmental disability or toward the social, personal,
5 physical, or economic habilitation or rehabilitation of an in-
6 dividual with such a disability, and such term includes diag-
7 nosis, evaluation, treatment, personal care, day care, domi-
8 ciliary care, special living arrangements, training, education,
9 sheltered employment, recreation, counseling of the individ-
10 ual with such disability and of his family, protective and
11 other social and sociolegal services, information and referral
12 services, follow-along services, and transportation services
13 necessary to assure delivery of services to persons with de-
14 velopmental disabilities.

15 (14) The term "regulations" means (unless the text
16 otherwise indicates) regulations promulgated by the Secre-
17 tary.

18 (15) The term "poverty area" means any—

19 (A) such area contains one or more subareas which
20 are characterized as subareas of poverty;

21 (B) the population of such subarea or subareas
22 constitutes a significant portion of the population of such
23 rural or urban area; and

24 (C) the project, facility, or activity, in connection
25 with which such determination is made, does, or (when

1 completed or put into operation) will, serve the needs of
2 the residents of such subarea or subareas.

3 (13) The term "design for implementation" means a
4 document prepared by the appropriate State agency or
5 agencies outlining the implementation of the State plan as
6 developed by the State planning council. The design for im-
7 plementation shall include details on the methodology of
8 implementation, priorities for spending, specific objectives
9 to be achieved, and a listing of those programs and resources
10 to be utilized, and a method for periodic evaluation of its
11 effectiveness in meeting State plan objectives.

12 AUDIT

13 SEC. 3. Each recipient of a grant or contract under this
14 Act shall keep such records as the Secretary may prescribe,
15 including records which fully disclose the amount and dis-
16 position by such recipient of the proceeds of such grant or
17 contract, the total cost of the project or undertaking in con-
18 nection with which such grant or contract is made or funds
19 thereunder used, the amount of that portion of the cost of
20 the project or undertaking supplied by other sources, and
21 such records as will facilitate an effective audit. The Secre-
22 tary and the Comptroller General of the United States, or
23 any of their duly authorized representatives, shall have access
24 for the purpose of audit and examination to any books,
25 documents, papers, and records of the recipient of any grant

1 or contract under this Act which are pertinent to such grant
2 or contract.

3 OFFICE OF DEVELOPMENTAL DISABILITIES

4 SEC. 4. There is established in the Office of the Assist-
5 ant Secretary for Human Development in the Department
6 of Health, Education, and Welfare, an Office of Develop-
7 mental Disabilities headed by a Director to administer this
8 Act.

9 TITLE I—ASSISTANCE FOR THE DEVELOP-
10 MENTALLY DISABLED

11 PART A—DEMONSTRATION AND TRAINING GRANTS FOR
12 UNIVERSITY AFFILIATED FACILITIES AND RENOVA-
13 TION AND MODERNIZATION OF FACILITIES

14 DECLARATION OF PURPOSE

15 SEC. 100. The purpose of this title is to improve the
16 provision of services to persons with developmental disabili-
17 ties through (A) grants to assist the several States in de-
18 veloping and implementing a comprehensive and continuing
19 plan for meeting the current and future needs of persons
20 with developmental disabilities; (B) the renovation and
21 modernization of university-affiliated facilities which aid in
22 demonstrating the provision of specialized services for per-
23 sons with developmental disabilities, through support of
24 demonstration and training programs at institutions of higher
25 education; (C) the development of regional community

1 programs for services to persons with developmental dis-
2 abilities; (D) the support of activities which will contribute
3 to improving the condition of persons with developmental
4 disabilities, including but not limited to grants for demon-
5 strating exemplary services to persons with developmental
6 disabilities who are especially disadvantaged; (E) technical
7 assistance in the establishment of services and facilities for
8 persons with developmental disabilities, including assistance
9 in State and local planning or administration; (F) training
10 of specialized personnel needed for the provision of services
11 for persons with developmental disabilities; (G) developing
12 or demonstrating new or improved techniques for the pro-
13 vision of services to persons with developmental disabilities;
14 and (H) gathering or disseminating information relating to
15 development disabilities.

16 AUTHORIZATION OF APPROPRIATIONS

17 SEC. 101. For the purpose of assisting in the moderniza-
18 tion and renovation (to comply with the provisions of Public
19 Law 90-480, relating to architectural barriers) of facilities
20 which will aid in demonstrating provision of specialized serv-
21 ices for the diagnosis and treatment, education, training, or
22 care of persons with developmental disabilities or in the
23 interdisciplinary training of physicians and other specialized
24 personnel needed for research, diagnosis and treatment, edu-
25 cation, training, or care of persons with developmental dis-

1 abilities, including research incidental or related to any of
2 the foregoing activities, there are authorized to be appro-
3 priated \$5,000,000 for the fiscal year ending June 30, 1975,
4 and a like amount for each of the next four succeeding fiscal
5 years. The sums so appropriated shall be used for project
6 grants for renovation or modernization of public and other
7 nonprofit facilities which are associated with a college or
8 university.

9 DEMONSTRATION AND TRAINING GRANTS

10 SEC. 102. (a) For the purposes of contributing more
11 effectively to the solution of complex health, education, and
12 social problems of children and adults suffering from devel-
13 opmental disabilities, the Secretary may, in accordance with
14 the provisions of this part, make grants to cover costs of
15 administering and operating demonstration facilities and in-
16 terdisciplinary training programs for personnel needed to
17 render specialized services to persons with developmental
18 disabilities, including training in established disciplines as
19 well as new kinds of training to meet critical shortages in the
20 services to persons with developmental disabilities with
21 emphasis upon such programs ability and commitment to
22 provide services not otherwise available under other laws to
23 persons with developmental disabilities in alternative pro-
24 grams of community care as contrasted with such services
25 being provided in institutionalized settings.

1 (b) For the purpose of making grants under this section,
2 there are authorized to be appropriated \$20,000,000 for the
3 fiscal year ending June 30, 1975, and a like amount for each
4 of the four succeeding fiscal years.

5 APPLICATIONS

6 SEC. 103. (a) Applications for grants under this part
7 with respect to the renovation or modernization of any fa-
8 cility may be approved by the Secretary only if the applica-
9 tion contains or is supported by reasonable assurances that—

10 (1) the proposal is consistent with the State plans
11 established pursuant to section 114;

12 (2) the facility will be associated, to the extent pre-
13 scribed in regulations of the Secretary, with a college or
14 university medical centers (including affiliated health
15 or education facilities), or with such other part of a
16 college or university as the Secretary may find appro-
17 priate in the light of the purposes of this part;

18 (3) the plans and specifications are in accord with
19 regulations prescribed by the Secretary under section
20 118;

21 (4) title to the site for the project is or will be
22 vested in one or more of the agencies or institutions filing
23 the application or in a public or other nonprofit agency
24 or institution which is to operate the facility; and

25 (5) adequate financial support will be available

1 for renovation or modernization of the project and for its
2 maintenance and operation when completed.

3 (b) Applications for demonstration and training grants
4 under this part may be approved by the Secretary only if
5 the applicant is a college or university operating a facility of
6 the type described in section 101 or is a public or nonprofit
7 private agency or organization operating such a facility. In
8 considering applications for such grants, the Secretary shall
9 require such applications to demonstrate that the grant appli-
10 cation has been reviewed and approved by the State councils
11 established under section 114 (d), and give priority to any
12 application which shows that the applicant has made
13 arrangements, in accordance with regulations of the Secre-
14 tary for a junior college or community based entity to
15 participate in the programs for which the application is made.
16 (c) Applications for assistance under this part shall
17 demonstrate the ability of the applicant for such assistance
18 to provide to the developmentally disabled population
19 the services and training for manpower in conformity with
20 the State plan established under section 114.

21 (d) Applications for assistance under this part shall
22 establish as priority goals—

23 (1) deinstitutionalization, including prevention of
24 institutionalization, normalization outside of institutions,

1 development of community based programs including
2 placement, and follow-up services;

3 (2) early screening diagnosis and evaluation, on
4 behalf of developmentally disabled infants and preschool
5 children (including maternal care, developmental
6 screening, home care, infant and preschool stimulation
7 programs, and parent counseling and training) ; and

8 (3) normalization of institutional life.

9 AMOUNT OF GRANTS; PAYMENTS

10 SEC. 104. (a) The total of the grants with respect to any
11 project under this part may not exceed 75 per centum of the
12 necessary cost thereof as determined by the Secretary.

13 (b) Payments of grants under this part shall be made in
14 advance or by way of reimbursement, and on such condi-
15 tions as the Secretary may determine.

16 RECOVERY

17 SEC. 105. If any facility with respect to which funds
18 have been paid under this part shall, at any time within
19 twenty years after the completion of construction—

20 (1) be sold or transferred to any person, agency,
21 or organization which is not qualified to file an applica-
22 tion under this part, or

23 (2) cease to be a public or other nonprofit facility
24 for persons with developmental disabilities, unless the

1 Secretary determines, in accordance with regulations,
2 that there is good cause for releasing the applicant or
3 other owner from the obligation to continue such facility
4 as a public or other nonprofit facility for persons with
5 developmental disabilities,
6 the United States shall be entitled to recover from either
7 the transferor or the transferee (or, in the case of a facility
8 which has ceased to be a public or other nonprofit facility
9 for persons with developmental disabilities, from the owners
10 thereof) an amount bearing the same ratio to the then value
11 (as determined by the agreement of the parties or by action
12 brought in the district court of the United States for the
13 district in which the facility is situated) of so much of the
14 facility as constituted an approved project or projects, as
15 the amount of the Federal participation bore to the cost of
16 the construction of such project or projects.

17 MAINTENANCE OF EFFORT

18 SEC. 106. Applications for grants under this part may
19 be approved by the Secretary only if the application contains
20 or is supported by reasonable assurances that the grants will
21 not result in any decrease in the level of State, local, and
22 other non-Federal funds for services for persons with devel-
23 opmental disabilities and training of persons to provide such
24 services which would (except for such grant) be available

1 to the applicant, but that such grants will be used to supple-
2 ment, and, to the extent practicable, to increase the level of
3 such funds.

4 PART B—GRANTS FOR PLANNING, PROVISION OF SERV-
5 ICES, AND CONSTRUCTION AND OPERATION OF
6 FACILITIES FOR PERSONS WITH DEVELOPMENTAL
7 DISABILITIES

8 AUTHORIZATION OF APPROPRIATION

9 SEC. 111. In order to make the grants to carry out the
10 purposes of this part there are authorized to be appro-
11 priated \$40,000,000 for the fiscal year ending June 30,
12 1975, \$55,000,000 for the fiscal year ending June 30, 1976,
13 \$70,000,000 for the fiscal year ending June 30, 1977,
14 \$85,000,000 for the fiscal year ending June 30, 1978, and
15 \$100,000,000 for the fiscal year ending June 30, 1979;
16 and there is further authorized to be appropriated for such
17 purposes for each subsequent fiscal year such sums as may
18 be necessary.

19 STATE ALLOTMENTS

20 SEC. 112. (a) (1) From the sums appropriated pur-
21 suant to section 111 for each fiscal year, other than amounts
22 reserved by the Secretary for projects under subsection (e)
23 of this section, the several States shall be entitled to allot-
24 ments determined, in accordance with regulations, on the
25 basis of (A) the population, (B) the extent of need for

1 services and facilities for persons with developmental disa-
2 bilities, and (C) the financial need, of the respective States;
3 except that the allotment of any State (other than the
4 Virgin Islands, American Samoa, Guam, and the Trust
5 Territory of the Pacific Islands) for any such fiscal year
6 shall not be less than \$100,000 plus, if such fiscal year is
7 later than the fiscal year ending June 30, 1975, and if
8 the sums so appropriated for such fiscal year exceed the
9 amount authorized to be appropriated to carry out such pur-
10 poses for the fiscal year ending June 30, 1975, an amount
11 which bears the same ratio to \$100,000 as the difference
12 between the amount so appropriated and the amount author-
13 ized to be appropriated for the fiscal year ending June 30,
14 1975, bears to the amount authorized to be appropriated for
15 the fiscal year ending June 30, 1975.

16 (2) In determining, for purposes of paragraph (1),
17 the extent of need in any State for services and facilities for
18 persons with developmental disabilities, the Secretary shall
19 take into account the scope and extent of the services speci-
20 fied, pursuant to section 115(b)(5), in the State plan of
21 such State approved under this part.

22 (3) Sums allotted to a State for a fiscal year and desig-
23 nated by it for construction, renovation, or modernization
24 and remaining unobligated at the end of such year shall re-
25 main available to such State for such purpose for the next

1 fiscal year and for such year only, in addition to the sums
2 allotted to such State for such fiscal year: *Provided*, That if
3 the maximum amount which may be specified pursuant to
4 section 115 (b) (13) for a year plus any part of the amount
5 so specified pursuant thereto for the preceding fiscal year and
6 remaining unobligated at the end thereof is not sufficient to
7 pay the Federal share of the cost of construction of a specific
8 facility included in the construction, renovation, or moderni-
9 zation program of the State developed pursuant to section
10 115 (b) (13), the amount specified pursuant to such section
11 for such preceding year shall remain available for a second
12 additional year for the purpose of paying the Federal share of
13 the cost of construction, renovation, or modernization of
14 such facility.

15 (b) Whenever the State plan approved in accordance
16 with section 115 provides for participation of more than one
17 State agency in administering or supervising the administra-
18 tion of designated portions of the State plan, the State may
19 apportion its allotment among such agencies in a manner
20 which, to the satisfaction of the Secretary, is reasonably
21 related to the responsibilities assigned to such agencies in
22 carrying out the purposes of this part. Funds so apportioned
23 to State agencies may be combined with other State or
24 Federal funds authorized to be spent for other purposes,

1 provided the purposes of this part will receive proportionate
2 benefit from the combination.

3 (c) Whenever the State plan approved in accordance
4 with section 115 provides for cooperative or joint effort
5 between States or between or among agencies, public or
6 private, in more than one State, portions of funds allotted
7 to one or more such cooperating States may be combined
8 in accordance with the agreements between the agencies
9 and States involved.

10 (d) The amount of an allotment to a State for a fiscal
11 year which the Secretary determines will not be required by
12 the State during the period for which it is available for the
13 purpose for which it is allotted shall be available for reallocot-
14 ment by the Secretary on such date or dates as he may fix,
15 but not earlier than thirty days after he has published notice
16 of his intention to reallocate in the Federal Register, to other
17 States with respect to which such a determination has not
18 been made, in proportion to the original allotments of such
19 States for such fiscal year, but with such proportionate
20 amount for any of such other States being reduced to the
21 extent it exceeds the sum the Secretary estimates such State
22 needs and will be able to use during such period; and the total
23 of such reductions shall be similarly reallocated among the
24 States whose proportionate amounts were not so reduced.
25 Any amount so reallocated to a State for a fiscal year shall be

1 deemed to be a part of its allotment under subsection (a) for
2 such fiscal year.

3 (e) Of the sums appropriated pursuant to section 111,
4 such amount as the Secretary may determine, but not more
5 than 10 per centum thereof, shall be available for grants by
6 the Secretary to public or nonprofit private agencies to pay
7 up to 90 per centum of the cost of projects which in his judg-
8 ment are of special national significance because they will
9 assist in meeting the needs of persons with developmental
10 disabilities (especially the disadvantaged), or will demon-
11 strate new or improved techniques for provision of services for
12 such persons, or are otherwise specifically significant for
13 carrying out the purposes of this part. Such projects shall
14 include (1) integrated service model projects for services to
15 the developmentally disabled population, (2) public aware-
16 ness and public education programs to assist in the elimina-
17 tion of attitudinal and environmental barriers confronted by
18 individuals with developmental disabilities, and (3) demon-
19 stration projects to coordinate and utilize all available
20 community resources.

21 NATIONAL COUNCIL ON SERVICES AND FACILITIES FOR
22 THE DEVELOPMENTALLY DISABLED

23 SEC. 113. (a) (1) Effective July 1, 1975, there is
24 hereby established, in the office of the Secretary, a National
25 Council on Services and Facilities for the Developmentally

1 Disabled (hereinafter referred to as the "Council"), which
2 shall consist of the Deputy Commissioner of the Bureau
3 of Education for the Handicapped, the Commissioner of
4 the Rehabilitation Services Administration, the Admin-
5 istrator of the Social and Rehabilitation Service, the Di-
6 rector of the National Institute of Child Health and Human
7 Development, the Director of the National Institute of Neu-
8 rological Disease and Stroke, and the Director of the Na-
9 tional Institute of Mental Health, and 15 members, not
10 otherwise in the regular full-time employ of the United
11 States, to be appointed by the Secretary without regard
12 to the provisions of title 5, United States Code, governing
13 appointments in the competitive civil service.

14 (2) The Secretary shall from time to time designate
15 one of the appointed members of the Council to serve as
16 Chairman thereof.

17 (3) The appointed members of the Council shall be
18 selected from leaders in the fields of service to persons with
19 developmental disabilities, including leaders in State or
20 local government, in institutions of higher education, and
21 in organizations which have demonstrated advocacy of con-
22 sumers of such services. At least five members shall be rep-
23 resentatives of State or local public or nonprofit private
24 agencies responsible for services to persons with develop-

1 mental disabilities, and at least five shall be of consumers
2 of such services or their parents, or guardians.

3 (b) Each appointed member of the Council shall hold
4 office for a term of four years, except that any member ap-
5 pointed to fill a vacancy occurring prior to the expiration
6 of the term for which his predecessor was appointed shall
7 be appointed for the remainder of such term, and, of the
8 twenty members first appointed, five shall hold office for a
9 term of three years, five shall hold office for a term of two
10 years, and five shall hold office for a term of one year, as
11 designated by the Secretary at the time of appointment. A
12 former member may only be reappointed to the Council
13 after a period of one year has elapsed from the end of his
14 appointed term.

15 (c) The Council shall meet at least twice a year, and
16 shall hold its initial meeting within ninety days after the
17 date of enactment of this Act.

18 (d) It shall be the duty and function of the Council to
19 (1) advise the Secretary with respect to any regulations
20 promulgated or proposed to be promulgated by him in the
21 implementation of this title, (2) study and evaluate pro-
22 grams authorized by this title to determine their effectiveness
23 in carrying out the purposes for which they were estab-
24 lished, (3) monitor the development and execution of this

1 title and report directly to the Secretary on any delay in
2 the rapid execution of this title, and (4) submit directly to
3 the Congress annually an evaluation of the efficiency of the
4 administration of this title.

5 (e) The Council is authorized to engage such technical
6 assistance as may be required to carry out its functions, and
7 the Secretary shall, in addition, make available to the Council
8 such secretarial, clerical, and other assistance and such
9 statistical and other pertinent data prepared by or available
10 to the Department of Health, Education, and Welfare as it
11 may require to carry out such functions.

12 (f) Members of the Council, while attending meetings
13 or conferences thereof or otherwise serving on the business
14 of the Council, shall be entitled to receive compensation
15 at rates fixed by the Secretary, but at rates not exceeding
16 the daily equivalent of the rate provided for GS-18 of the
17 General Schedule for each day of such service (including
18 travel time), and while so serving away from their homes or
19 regular places of business, they may be allowed travel ex-
20 penses, including per diem in lieu of subsistence, as authorized
21 by section 5703 of title 5, United States Code, for persons
22 in the Government service employed intermittently

23 STATE PLANS

24 SEC. 114. (a) Any State desiring to take advantage
25 of this part shall within 180 days after the date of enactment

1 of this Act have a State plan which is a specific goal oriented
2 plan, submitted to, and approved by the Secretary under this
3 section designed to—

4 (1) reduce and eventually eliminate inappropriate
5 institutional placement of persons with developmental
6 disabilities;

7 (2) improve the quality of care and rehabilita-
8 tion of persons with developmental disabilities for whom
9 institutional care is appropriate;

10 (3) provide early screening, diagnosis and evalua-
11 tion on behalf of developmentally disabled infants and
12 preschool children (including maternal care, develop-
13 mental screening, home care, infant and preschool stimu-
14 lation programs, and parent counseling and training);

15 (4) support the establishment of community pro-
16 grams as alternatives to institutionalization, designed to
17 provide services for the care and habilitation of persons
18 with developmental disabilities, which programs utilize,
19 to the maximum extent feasible the resources and per-
20 sonnel in related community programs to assure full co-
21 ordination with such programs and to assure the provi-
22 sion of appropriate supplemental health, educational or
23 social services for persons with developmental disabilities;

24 (5) protect the human rights of all persons with

1 developmental disabilities, especially those without
2 familial protection;

3 (6) provide for cross disciplinary intervention and
4 training programs for multihandicapped individuals;
5 and

6 (7) coordinate programs of public information
7 and public awareness of the problems faced by persons
8 with developmental disabilities through the use of funds
9 authorized under section 112 (e).

10 (b) In order for a State plan to be approved by the
11 Secretary under this section, its design for implementation
12 must be approved by the State planning council. A State
13 plan for the provision of services and facilities for persons
14 with developmental disabilities shall—

15 (1) designate (A) a State planning council, to
16 be responsible for submitting revisions, the develop-
17 ment of the State plan, and transmitting such reports
18 as may be required by the Secretary; (B) except
19 as provided in clause (C), the State agency or agencies
20 which shall administer and supervise the administration
21 of the State plan, and which shall submit to the State
22 planning council the design to implement the priorities
23 specified by the State planning council in the State
24 plan, including the disbursement of all funds under this
25 part except as otherwise provided; and, if there is

1 more than one such agency, the portion of such plan
2 which each will administer (or the portion the admin-
3 istration of which each will supervise) ; and (C) a single
4 State agency as the sole agency for administering or
5 supervising the administration of grants for construction,
6 renovation, or modernization under the State plan;

7 (2) describe the quality, extent, and scope of serv-
8 ices being provided or to be provided to meet the
9 goals specified in subsection (a) of this section;

10 (3) describe (A) the quality, extent, and scope of
11 services being provided, or to be provided, to persons
12 with developmental disabilities under such other State
13 plans for federally assisted State programs as may be
14 specified by the Secretary, but in any case including
15 education for the handicapped, vocational rehabilitation,
16 public assistance, medical assistance, social services, ma-
17 ternal and child health, crippled children's services, and
18 comprehensive health and mental health plans, and (B)
19 how funds allotted to the State in accordance with sec-
20 tion 112 will be used to complement and augment rather
21 than duplicate or replace services and facilities for per-
22 sons with developmental disabilities which are eligible
23 for Federal assistance under such other State programs;
24 (4) provide for the maximum utilization of all avail-
25 able community resources including volunteers serving

1 under the Domestic Volunteer Service Act of 1973
2 (87 Stat. 394) and other appropriate voluntary
3 organizations;

4 (5) set forth policies and procedures for the ex-
5 penditure of funds under the plan, which, in the judg-
6 ment of the Secretary, are designed to assure effective
7 continuing State planning, evaluation, and delivery of
8 services (both public and private) for persons with de-
9 velopmental disabilities;

10 (6) contain assurances satisfactory to the Secre-
11 tary and the State planning council that (A) the funds
12 paid to the State under this part will be used to make a
13 significant contribution toward strengthening services for
14 persons with developmental disabilities in the various
15 political subdivisions of the State in order to improve the
16 quality, scope, and extent of such services; (B) part of
17 such funds may be made available to other public or
18 nonprofit private agencies, institutions, and organiza-
19 tions; (C) such funds will be used to supplement and,
20 to the extent practicable, to increase the level of funds
21 that would otherwise be made available for the purposes
22 for which the Federal funds are provided and not to
23 supplant such non-Federal funds; and (D) there will be
24 reasonable State financial participation in the cost of
25 carrying out the State plan;

1 (7) (A) provide for the furnishing of services and
2 facilities for persons with developmental disabilities, and

3 (B) describe the quality, extent, and scope of such
4 services as will be provided to persons with develop-
5 mental disabilities;

6 (8) provide that services and facilities furnished
7 under the plan for persons with developmental disabili-
8 ties will be in accordance with standards prescribed by
9 regulations of the Secretary;

10 (9) provide such methods of administration, in-
11 cluding methods relating to the establishment and main-
12 tenance of personnel standards on a merit basis (except
13 that the Secretary shall exercise no authority with re-
14 spect to the selection, tenure of office, and compensation
15 of any individual employed in accordance with such
16 methods), as are found by the Secretary to be neces-
17 sary for the proper and efficient operation of the plan;

18 (10) provide that the State planning council shall
19 be adequately staffed, and shall include representatives of
20 each of the principal State agencies and representatives
21 of local agencies and nongovernmental organizations
22 and groups concerned with services for persons with de-
23 velopmental disabilities: *Provided*, That at least one-
24 third of the membership of such council shall consist of
25 consumers of such services or their parents or guardians;

1 (11) provide that the State planning council will
2 periodically, but not less often than annually, review and
3 evaluate its State plan approved under this section and
4 submit appropriate modifications to the Secretary;

5 (12) provide that the State agencies designated
6 pursuant to paragraph (1) will make such reports, in
7 such form and containing such information, as the Sec-
8 retary or the State planning council may from time to
9 time reasonably require, and will keep such records and
10 afford such access thereto as the Secretary finds neces-
11 sary to assure the correctness and verification of such
12 reports;

13 (13) provide that special financial and technical as-
14 sistance shall be given to areas of urban or rural poverty
15 in providing services and facilities for persons with de-
16 velopmental disabilities who are residents of such areas;

17 (14) describe the methods to be used to assess
18 the effectiveness and accomplishments of the State in
19 meeting the needs of persons with development disabili-
20 ties in the State;

21 (15) specify the per centum of the State's allot-
22 ment (under section 112) for any year which is to be
23 devoted to construction, renovation, or modernization of
24 facilities, which per centum shall be not more than 10
25 per centum of the State's allotment or such lesser per

1 centum as the Secretary may from time to time pre-
2 scribe;

3 (16) if Federal funds are allocated for construc-
4 tion, renovation, or modernization as provided in sub-
5 paragraph (15) of this subsection, outline a program of
6 construction, renovation, or modernization of facilities
7 for the provisions of services for persons with develop-
8 mental disabilities which (A) is based on a statewide in-
9 ventory of existing facilities and survey of need; (B)
10 sets forth the relative need, determined in accordance
11 with the regulations prescribed by the Secretary for the
12 several projects included in the construction, renovation,
13 or modernization program; and (C) assigns priority to
14 the construction, renovation, or modernization of
15 projects, insofar as financial resources available therefor
16 and for maintenance and operation make possible, in the
17 order of relative need taking into account the need for
18 renovation to comply with Public Law 90-480;

19 (17) provide for affording to every applicant for
20 a construction, renovation, or modernization project an
21 opportunity for hearing before the State agency;

22 (18) provide for such fiscal control and fund ac-
23 counting procedures as may be necessary to assure the
24 proper disbursements of and accounting for funds paid
25 to the State under this part;

1 (19) provide for the implementation of an evalua-
2 tion system compatible with the system developed under
3 section 122, within thirty months after the date of en-
4 actment of this Act;

5 (20) provide that all relevant information shall be
6 made available to the State planning council; and

7 (21) contain such additional information and as-
8 surances as the Secretary may find necessary to carry
9 out the provisions and purpose of this part.

10 (c) The Secretary shall approve any State plan and
11 any modification thereof which complies with the provi-
12 sions of subsection (b) of this section. The Secretary shall
13 not finally disapprove a State plan except after reasonable
14 notice and opportunity for a hearing to the State.

15 (d) The State Planning Council described pursuant to
16 clause (1) of subsection (b) of this section shall serve as
17 advocates for persons with developmental disabilities and
18 shall—

19 (1) be appointed by the Governor,

20 (2) plan, develop, and coordinate all programs
21 involving developmental disabilities,

22 (3) prepare the overall State plan,

23 (4) establish priorities for the distribution of funds
24 within the State,

1 (5) approve implementation of the State plan re-
2 quired by this section,

3 (6) monitor the implementation of the State plan,
4 and

5 (7) evaluate the implementation of the State plan.

6 (e) The State planning council described in subsection

7 (b) (1) (A) of this section shall develop and transmit to the
8 State agency or agencies designated under subsection (b)

9 (1) (C) the State plan described in subsection (a). Such
10 State agency or agencies shall then prepare a design for
11 implementation which it shall transmit to the State plan-
12 ning council for approval in accordance with subsection
13 (d) (5).

14 APPROVAL OF PROJECTS FOR CONSTRUCTION, RENOVATION,
15 OR MODERNIZATION

16 SEC. 115. (a) For each project for construction, reno-
17 vation, or modernization pursuant to a State plan approved
18 under this part, there shall be submitted to the Secretary,
19 through the State agency designated pursuant to section
20 114 (b) (1) (C) (hereinafter referred to as the "State
21 Agency"), an application by the State or a political sub-
22 division thereof or by a public or nonprofit private
23 agency. If two or more agencies join in the construction,
24 renovation, or modernization (to comply with Public Law

1 90-480, relating to architectural barriers) of the project, the
2 application may be filed by one or more of such agencies.
3 Such application shall set forth—

4 (1) a description of the site for such project;

5 (2) plans and specifications thereof, in accordance
6 with regulations prescribed by the Secretary;

7 (3) reasonable assurance that title to such site is
8 or will be vested in one or more of the agencies filing
9 the application or in a public or nonprofit private agency
10 which is to operate the facility;

11 (4) reasonable assurance that adequate financial
12 support will be available for the construction, renova-
13 tion, or modernization of the project and for its mainte-
14 nance and operation when completed;

15 (5) a certification by the State agency of the Fed-
16 eral share for the project; and

17 (6) a certification by the State agency that the
18 project will comply with the provisions of Public Law
19 90-480, relating to architectural barriers.

20 (b) The Secretary shall approve such application if
21 sufficient funds to pay the Federal share of the cost of
22 such project are available from the allotment to the State,
23 and if the Secretary finds (1) that the application contains
24 such reasonable assurances as to title, financial support, and
25 payment of prevailing rates of wages and overtime pay, (2)

1 that the plans and specifications are in accord with regula-
2 tions prescribed by the Secretary, (3) that the application
3 is in conformity with the State plan approved under this
4 part, and (4) that the application has been approved and
5 recommended by the State agency and is entitled to priority
6 over other projects within the State in accordance with the
7 State's plan for persons with developmental disabilities and
8 in accordance with regulations prescribed by the Secretary.

9 (c) No application shall be disapproved until the Sec-
10 retary has afforded the State agency an opportunity for a
11 hearing.

12 (d) Amendment of any approved application shall be
13 subject to approval in the same manner as the original
14 application.

15 WITHHOLDING OF PAYMENTS

16 SEC. 116. (a) Whenever the Secretary, after reasonable
17 notice and opportunity for hearing to the State planning
18 council and those State agencies designated pursuant to
19 section 114 (b) (1) finds—

20 (1) that any such State agency or agencies are not
21 complying with the provisions required by section 114

22 (b) to be included in the State plan, or with regula-
23 tions of the Secretary;

24 (2) that any assurance required to be given in an

1 application filed under section 115 is not being or cannot
2 be carried out;

3 (3) that there is a substantial failure to carry out
4 plans and specifications related to construction, renova-
5 tion, or modernization approved by the Secretary under
6 section 116; or

7 (4) that adequate funds are not being provided an-
8 nually for the direct administration of the State plan,
9 the Secretary may forthwith notify such State council and
10 agencies that—

11 (A) no further payments will be made to the State
12 for construction, renovation, or modernization from al-
13 lotments under this part; or

14 (B) no further payments will be made from allot-
15 ments under this part for any project or projects desig-
16 nated by the Secretary as being affected by the action
17 or inaction referred to in paragraph (1), (2), (3), or
18 (4) of this section; as the Secretary may determine to be
19 appropriate under the circumstances; and, except with
20 regard to any project for which the application has al-
21 ready been approved and which is not directly affected,
22 further payments for construction, renovation, or modern-
23 ization projects may be withheld, in whole or in part,
24 until there is no longer any failure to comply (or to carry
25 out the assurance or plans and specifications or to provide

1 adequate funds, as the case may be) or, if such com-
2 pliance (or other action) is impossible, until the State
3 repays or arranges for the repayment of Federal moneys
4 to which the recipient was not entitled.

5 (b) Whenever the State planning council finds that
6 a State agency administering funds pursuant to the imple-
7 mentation design is failing to comply with such design, the
8 State planning council shall notify the Governor and the
9 Secretary of cause to begin proceedings under subsection
10 (a) of this section.

11 PAYMENTS TO THE STATES FOR PLANNING

12 ADMINISTRATION AND SERVICES

13 SEC. 117. (a) (1) From each State's allotments for a
14 fiscal year under section 112, the State shall be paid for
15 the Federal share of the expenditures, other than expendi-
16 tures for construction, renovation, or modernization incurred
17 during such year under its State plan approved under this
18 part. Such payments shall be made from time to time in
19 advance on the basis of estimates by the Secretary of the
20 sums the State will expend under the State plan, except
21 that such adjustments as may be necessary shall be made
22 on account of previously made underpayments or over-
23 payments under this section.

24 (2) For the purpose of determining the Federal share
25 with respect to any State, expenditures by a political sub-

1 division thereof or by nonprofit private agencies, organiza-
2 tions, and groups shall, subject to such limitations and con-
3 ditions as may be prescribed by regulations, be regarded
4 as expenditures by such State.

5 (b) (1) Except as provided in paragraph (2), the
6 "Federal share" with respect to any State for purposes of
7 this section for any fiscal year shall be 70 per centum of
8 the expenditures, other than expenditures for construction,
9 renovation, or modernization incurred by the State during
10 such year under its State plan approved under this part
11 during each of the fiscal years ending June 30, 1975, and
12 for each fiscal year thereafter.

13 (2) In the case of any project located in an area within
14 a State determined by the Secretary to be an urban or rural
15 poverty area, the "Federal share" with respect to such
16 project for purposes of this section for any fiscal year may
17 be up to 90 per centum of the expenditures, other than ex-
18 penditures for construction, renovation, or modernization
19 incurred by the State during such year under its State plan
20 approved under this part with respect to such project for the
21 first twenty-four months of such project, and 80 per centum
22 of such nonconstruction expenditures for each fiscal year
23 thereafter.

24

REGULATIONS

25 SEC. 118. (a) The Secretary of Health, Education,
26 and Welfare, not later than sixty days after the date of

1 enactment of this Act, shall prescribe general regulations
2 applicable to all the States to carry out the purposes of this
3 Act.

4 (b) Regulations promulgated by the Secretary may be
5 waived upon approval of an application by a State for
6 permission to establish a multilevel project to provide
7 services for individuals who are developmentally disabled by
8 combining funds received from other Federal, State, or local
9 programs where such local programs would impede the im-
10 plementation of such program. Such waivers shall be re-
11 viewed annually by the Secretary and issued on an indi-
12 vidual case-by-case basis and for a specified period of time,
13 but in no case longer than thirty-six months. Renewal of
14 such waivers shall only be given following a full evaluation
15 of the impact of such waiver and justification for renewal
16 by the Secretary in a report to the appropriate committees
17 of the Congress.

18 NONDUPLICATION

19 SEC. 119. (a) In determining the amount of any pay-
20 ment for the construction, renovation, or modernization of
21 any facility under a State plan approved under this part,
22 there shall be disregarded (1) any portion of the costs of
23 such construction, renovation, or modernization which are
24 financed by Federal funds provided under any provision of
25 law other than this part, (2) the amount of any non-Federal

1 funds provided under any provision of law other than this
2 part, and (3) the amount of any non-Federal funds required
3 to be expended as a condition of receipt of such Federal
4 funds.

5 (b) In determining the amount of any State's Federal
6 share of expenditures for planning, administration, and serv-
7 ices incurred by it under a State plan approved under this
8 part, there shall be disregarded (1) any portion of such
9 expenditures which are financed by Federal funds provided
10 under any provision of law other than this part, and (2)
11 the amount of any non-Federal funds required to be expended
12 as a condition of receipt of such Federal funds.

13 EVALUATION OF DEVELOPMENTAL DISABILITIES SERVICES

14 SEC. 120. (a) The Secretary of Health, Education, and
15 Welfare shall develop an evaluation system and plan for
16 implementation of such system and report to the appropriate
17 committees of the Congress within eighteen months after
18 the date of enactment of this Act. Such system shall provide
19 a model for the development of State evaluation systems for
20 all services delivered within the States to persons with
21 developmental disabilities.

22 (b) The evaluation system required by subsection (a)
23 shall include an evaluation of an education and training,
24 habilitation, rehabilitation, early childhood, diagnostic and

1 evaluation, or any other services and assistance under all
2 laws administered by the Secretary.

3 (c) In developing the evaluation system required under
4 subsection (a) the Secretary shall insure that such system
5 is consumer oriented and is designed to—

6 (1) evaluate the effects of services on the lives of
7 consumers,

8 (2) evaluate the overall impact of State programs
9 for the developmentally disabled,

10 (3) provide and evaluate the cost-benefit ratios of
11 particular service alternatives, and

12 (4) provide that evaluation of program quality
13 shall be performed by individuals not directly involved
14 in the delivery of such services.

15 (d) The Secretary is authorized to make grants and
16 enter into contracts to conduct feasibility studies with regard
17 to developing the evaluation system required under subsec-
18 tion (a) except that such grants or contracts shall not be
19 entered into with groups or individuals who are directly
20 related to this program.

21 (e) There are authorized to be appropriated to carry
22 out the purposes of this section \$1,000,000 for the fiscal
23 year ending June 30, 1975, and for each succeeding fiscal
24 year thereafter.

1 GRANTS FOR SPECIAL PROJECTS FOR SERVICES TO
2 PERSONS WITH DEVELOPMENTAL DISABILITIES

3 SEC. 121. (a) For the purpose of making grants under
4 this section for special projects and demonstrations (and re-
5 search and evaluation connected therewith), there is au-
6 thorized to be appropriated \$15,000,000 for the fiscal year
7 ending June 30, 1975, \$17,500,000 for the fiscal year end-
8 ing June 30, 1976, \$20,000,000 for the fiscal year ending
9 June 30, 1977, \$22,500,000 for the fiscal year ending June
10 30, 1978, and \$25,000,000 for the year ending June 30,
11 1979.

12 (b) The Secretary after consultation with the National
13 Council established pursuant to section 113 of this Act
14 shall make grants to States and public or nonprofit agen-
15 cies and organizations for paying part or all of the cost
16 of special projects and demonstrations (and research and
17 evaluation in connection therewith) for establishing pro-
18 grams which hold promise of expanding or otherwise im-
19 proving community based services to persons with develop-
20 mental disabilities (especially those who are disadvantaged
21 or multihandicapped). Such projects and demonstrations
22 shall include, but not be limited to, parent counseling and
23 training, early screening and intervention, infant and pre-
24 school programs, seizure control systems and community
25 based counseling, care, housing and other services necessary

1 to maintain a person with developmental disabilities in the
2 community.

3 (c) No funds appropriated pursuant to section 304 (a)
4 of the Rehabilitation Act of 1973 (Public Law 93-112) may
5 be used for carrying out the purposes of this section unless
6 funds are not available under this section.

7 REPEAL OF PRIOR LAW

8 SEC. 122. Effective July 1, 1975, parts B and C of
9 the Developmental Disabilities Services and Facilities Con-
10 struction Act are repealed.

11 TITLE II—BILL OF RIGHTS FOR THE MENTALLY
12 RETARDED AND OTHER INDIVIDUALS WITH
13 DEVELOPMENTAL DISABILITIES

14 SEC. 201. (a) Title II of the Mental Retardation Facili-
15 ties and Community Mental Health Centers Construction
16 Act of 1963 (42 U.S.C. 2681) is redesignated as title III
17 and each section and cross references thereto are redesign-
18 dated as follows: Sections 200 through 207 as 310 through
19 317; sections 220 through 224 as 320 through 324; sections
20 240 through 247 as 340 through 347; sections 251 through
21 256 as 351 through 356; sections 261 through 266 as 361
22 through 366; sections 271 through 272 as 371 through 372.

23 (b) Such Act is further amended by inserting after
24 title I the following new title:

1 "TITLE II—BILL OF RIGHTS FOR THE MENTALLY
2 RETARDED AND OTHER INDIVIDUALS WITH
3 DEVELOPMENTAL DISABILITIES

4 "STATEMENT OF PURPOSE

5 "SEC. 201. The purpose of this title is to establish stand-
6 ards which assure humane care, treatment, habilitation, and
7 protection of the mentally retarded and other individuals with
8 developmental disabilities (as defined in section 3 of the
9 Developmentally Disabled Assistance and Bill of Rights
10 Act) in residential facilities and minimize inappropriate
11 admissions to such residential facilities.

12 "PART A—STANDARDS FOR RESIDENTIAL FACILITIES FOR
13 THE MENTALLY RETARDED AND OTHER INDIVIDUALS
14 WITH DEVELOPMENTAL DISABILITIES

15 "Chapter 1.—ADMINISTRATIVE POLICIES AND
16 PRACTICES

17 "Subchapter I—Philosophy, Location, and Organization

18 "SEC. 210. (a) The ultimate aim of the facility shall
19 be to foster those behaviors that maximize the human qual-
20 ities of the resident, increase the complexity of his behavior,
21 and enhance his ability to cope with his environment.

22 " (b) The facility shall accept and implement the prin-
23 ciple of normalization, defined as the use of means that are
24 as culturally normative as possible to elicit and maintain

1 behavior that is as culturally normative as possible, taking
2 into account local and subcultural differences.

3 "SEC. 211. (a) The names of facilities, the labels ap-
4 plied to their users, and the way these users are interpreted
5 to the public should be appropriate to their purposes and
6 programs and services should not emphasize 'mental retar-
7 dation' or 'deviancy'.

8 "(b) Residents should not be referred to as 'patient'
9 except in a hospital-medical context; as 'kids' or 'children'
10 if they are adults; or as 'inmates'; or as clients.

11 "SEC. 212. (a) The facility should be located within,
12 and conveniently accessible to, the population served, so
13 as to have access to necessary generic community services.

14 "(b) The facility should not be isolated from society
15 or community by factors such as:

16 "(1) difficulty of access, due to distance or lack of
17 public transportation;

18 "(2) architectural features;

19 "(3) socio-cultural or psychological features; and

20 "(4) rules, regulations, customs, and habits.

21 "(c) Protection devices (such as fences and security
22 windows), where necessary, should be inconspicuous, and
23 should preserve as normal an environmental appearance as
24 possible, so as to permit the pursuit of normal activities.

1 “(d) The facility should be in scale with the commu-
2 nity in which it is located.

3 “(e) The facility and the surrounding community should
4 be encouraged to share their services and resources on a
5 reciprocal basis.

6 “(f) The community in which the facility is located
7 should be capable of meeting the needs of the facility's res-
8 idents for generic and specialized services.

9 “(g) The community in which the facility is located
10 should be capable of absorbing, and encouraged to absorb,
11 into its cultural life those residents capable of participation
12 in that life.

13 “(h) The facility shall have available a current descrip-
14 tive directory of community resources.

15 “SEC. 213. (a) Residents should be integrated to the
16 greatest possible extent with the general population. To this
17 end, generic and specialized community services, rather than
18 facility services, should be used extensively or, if possible,
19 completely. The residents should, including but not limited
20 to—

21 “(1) attend (special) classes or programs in regu-
22 lar schools;

23 “(2) attend religious instruction and worship in
24 the community;

1 “(3) utilize medical, dental, and all other profes-
2 sional services located in the community;

3 “(4) use community rather than facility recreation
4 resources, such as bowling alleys, swimming pools,
5 movies, and gymnasias;

6 “(5) shop in community stores, rather than in
7 facility stores and canteens; and

8 “(6) work in as integrated a fashion as possible:
9 sheltered employment should be in regular industry,
10 and among nonretarded workers; sheltered workshops
11 should be in the community; and work that must be on
12 the campus of the facility should afford maximal contact
13 with nonretarded persons.

14 There shall be evidence of professional and public education
15 to facilitate the integration of residents, as above set forth.

16 “(b) The facility should be divided into groupings of
17 program and residence units, based upon a rational plan to
18 meet the needs of the residents and fulfill the purposes of
19 the facility.

20 “SEC. 214. The facility shall to the maximum extent
21 feasible move residents from—

22 “(1) more to less structured living;

23 “(2) larger to smaller facilities;

24 “(3) larger living units to smaller living units;

- 1 “(4) group to individual residence;
2 “(5) dependent to independent living; and
3 “(6) segregated to integrated living.

4 **“Subchapter II—General Policies and Practices**

5 “SEC. 215. (a) The facility shall have a written out-
6 line of the philosophy, objectives, and goals it is striving to
7 achieve, that is available for distribution to staff, consumer
8 representatives, and the interested public, and that shall
9 include but need not be limited to:

10 “(1) its role in the State comprehensive program
11 for the mentally retarded and other individuals with
12 developmental disabilities;

13 “(2) its concept of the rights of its residents;

14 “(3) its goals for its residents;

15 “(4) its concept of its relationship to the parents
16 of its residents, or to their surrogates;

17 “(5) its concept of its relationship to the com-
18 munity, zone, or region from which its residents come;

19 “(6) its concept of its responsibility (through re-
20 search, training, and education) for improving methods,
21 understanding, and support for the mental retardation
22 and developmentally disabled field.

23 “(b) The facility shall have a plan for evaluation and
24 modification to maintain:

25 “(1) the consistency of its philosophy, objectives,

1 and goals with advancements in knowledge and profes-
2 sional practices; and

3 “(2) the consistency of its practices with its phi-
4 losophy, objectives, and goals.

5 “(c) The facility shall have a manual on policies and
6 procedures, describing the current methods, forms, processes,
7 and sequence of events being followed to achieve its objec-
8 tives and goals.

9 “(d) The facility shall have a written statement of poli-
10 cies and procedures concerning the rights of residents that—

11 “(1) assure the civil rights of all residents;

12 “(2) are in accordance with general and special
13 rights of the mentally retarded and other individuals with
14 developmental disabilities as defined by the Secretary in
15 accordance with section 201 of this title; and

16 “(3) define the means of making legal counsel
17 available to residents for the protection of their rights.

18 “Sec. 216. (a) The facility shall have a written state-
19 ment of policies and procedures that protect the financial
20 interests of residents and that provide for—

21 “(1) determining the financial benefits for which
22 the resident is eligible;

23 “(2) assuring that the resident receives the funds
24 for incidentals and for special needs (such as specialized

1 equipment) that are due him under public and private
2 financial support programs; and

3 “(3) when large sums accrue to the resident, pro-
4 viding for counseling of the resident concerning their
5 use, and for appropriate protection of such funds.

6 “(b) Procedures in the major operating units of the
7 facility shall be described in manuals that are current, rele-
8 vant, available, and followed.

9 “(c) The facility shall have a summary of the laws
10 and regulations relevant to mental retardation and other de-
11 velopmental disabilities and to the function of the facility.

12 “(d) The facility shall have a plan for a continuing
13 management audit to insure compliance with State laws
14 and regulations and the effective implementation of its stated
15 policies and procedures.

16 “SEC. 217. (a) A public facility shall have documents
17 that describe the statutory basis of its existence, and describe
18 the administrative framework of the governmental depart-
19 ment in which it operates.

20 “(b) A private facility shall have documents that in-
21 clude its charter, its constitution and bylaws, and its State
22 license.

23 “SEC. 218. (a) The governing body of the facility
24 shall exercise general direction and shall establish policies

1 concerning the operation of the facility and the welfare of
2 the individuals served.

3 “(b) The governing body shall establish appropriate
4 qualifications of education, experience, personal factors, and
5 skills for the chief executive officer. The chief executive
6 officer shall have had training and experience in the admin-
7 istration of human services. The chief executive officer shall
8 have administrative ability, leadership ability, and an under-
9 standing of mental retardation and other developmental dis-
10 abilities. Where the chief executive officer is required also to
11 have had training in a professional service discipline, such
12 training shall be in a discipline appropriate to the facility’s
13 program.

14 “(c) The governing body shall employ a chief execu-
15 tive officer so qualified, and shall delegate to him authority
16 and responsibility for the management of the affairs of the
17 facility in accordance with established policies.

18 “(d) The chief executive officer shall—

19 “(1) designate an individual to act for him in his
20 absence;

21 “(2) make arrangements so that some one individ-
22 ual is responsible for the administrative direction of the
23 facility at all times;

24 “(3) when an assistant chief executive officer is

1 employed, the qualifications required for this position
2 shall be in compliance with those stated above for the
3 chief executive officer; and

4 “(4) there shall be on the premises of the facility
5 at all times a person designated by the chief executive
6 officer, or the person acting for him, to be responsible
7 for the supervision of the facility.

8 “SEC. 1219. (a) The facility shall be administered and
9 operated in accordance with sound management principles.

10 “(b) The type of administrative organization of the
11 facility shall be appropriate to the program needs of its
12 residents.

13 “(c) The facility shall have a table of organization that
14 shows the governance and administrative pattern of the
15 facility.

16 “(d) The table of organization shall show the major
17 operating programs of the facility, with staff divisions, the
18 administrative personnel in charge of the programs and di-
19 visions, and their lines of authority, responsibility, and
20 communication.

21 “(e) The organization shall provide for the judicious
22 delegation of administrative authority and responsibility
23 among qualified members of the staff, in order to distribute
24 the administrative load of the facility and to accelerate its
25 operating efficiency.

1 “(f) The organization shall be such that problems re-
2 quiring ongoing decisionmaking regarding the welfare of
3 the resident are handled primarily by personnel on the lowest
4 level competent to resolve the problem.

5 “(g) The organization shall provide for the utilization
6 of staff with different levels of training by using those with
7 more adequate training to supervise and train those with
8 lesser training.

9 “(h) The organization shall provide effective channels
10 of communication in all directions.

11 “(i) The facility shall have a plan for improving the
12 quality of staff and services that shows how the staff func-
13 tions by programmatic responsibilities in establishing and
14 maintaining standards of quality for services to residents.
15 The plan shall show how the facility's organizational struc-
16 ture enables the following functions:

17 “(1) determination of standards for quality of
18 services to the residents;

19 “(2) establishment of qualifications for personnel:

20 “(3) recruitment of qualified personnel;

21 “(4) initiation of preservice and inservice training
22 and staff development programs;

23 “(5) work with administrators, supervisors, and
24 staff of the administrative units of the facility to secure
25 and assign qualified personnel to such units;

- 1 “(6) annual evaluation of staff performance;
2 “(7) continuous evaluation of program effective-
3 ness; and
4 “(8) development and conduct of appropriate re-
5 search activities.

6 “SEC. 220. (a) The administration of the facility shall
7 provide for effective staff and resident participation and
8 communication. Staff meetings shall be regularly held. Stand-
9 ing committees appropriate to the facility, such as records,
10 safety, human rights, utilization review, research review,
11 and infection and sanitation, shall meet regularly. Commit-
12 tees shall include resident participation, whenever appro-
13 priate. Committees shall include the participation of direct-
14 care staff, whenever appropriate.

15 “(b) Minutes and reports of staff meetings, and of
16 standing and ad hoc committee meetings shall include records
17 of recommendations and their implementation, and shall be
18 kept and filed. Summaries of the minutes and reports of staff
19 and committee meetings shall be distributed to participants
20 and to appropriate staff members. Various forms of com-
21 munication (such as meetings, minutes of meetings, direc-
22 tives, and bulletins) shall be utilized to foster understanding
23 among the staff, among the residents, between staff and resi-
24 dents, and between facility, community, and family.

25 “SEC. 221. (a) The facility shall designate a percentage

1 of its operating budget for self-renewal purposes, including
2 but not limited to:

3 " (1) development of operational data records;

4 " (2) research on its own programs;

5 " (3) evaluation by qualified persons who are not
6 part of the facility;

7 " (4) elicitation of feedback from consumers of the
8 facility's services, or from their representatives; and

9 " (5) staff education.

10 " (b) The findings generated by the foregoing activities
11 shall be actively and broadly disseminated to:

12 " (1) all members of the facility's staff; and

13 " (2) consumer representatives, when appropriate.

14 " (c) The facility shall have a continuing system for
15 collecting and recording accurate data that describe its
16 population, in such form as to permit data retrieval and
17 usage for description, programing of services, and research.

18 Such data shall include, but need not be limited to:

19 " (1) number by age-groups, sex, and race;

20 " (2) number grouped by levels of retardation
21 (profound, severe, moderate, mild, and borderline),
22 according to the appropriate nationally recognized pro-
23 fessional association on mental deficiency's manual on
24 terminology and classification in mental retardation;

25 " (3) number grouped by levels of adaptive be-

1 havior, according to the appropriate nationally recog-
2 nized professional association on mental deficiency classi-
3 fication;

4 “(4) number with physical disabilities;

5 “(5) number ambulatory and nonambulatory (mo-
6 bile and nonmobile);

7 “(6) number with sensory defects;

8 “(7) number with oral and other communication
9 handicaps; and

10 “(8) number with convulsive disorders, grouped
11 by level of seizure control.

12 “SEC. 222. The facility shall have a description of
13 services for residents that is available to the public and that
14 includes information including but not limited to:

15 “(1) groups served;

16 “(2) limitations concerning age, length of residence,
17 or type or degree of handicap;

18 “(3) the plan for grouping residents into program
19 and living units;

20 “(4) preadmission and admission services;

21 “(5) diagnosis and evaluation services;

22 “(6) means for individual programing of residents
23 in accordance with need;

24 “(7) means for implementation of programs for
25 residents, through clearly designated responsibility;

1 “(8) the therapeutic and developmental environ-
2 ment provided the residents; and

3 “(9) release and follow-up services and procedures.

4 “SEC. 223. (a) The facility shall provide for meaningful
5 and extensive consumer-representative and public partici-
6 pation, by the following means :

7 “(1) the policymaking or governing board (if any)
8 shall include consumers or their representatives (for
9 example, parents), interested citizens, and relevantly
10 qualified professionals presumed to be free of conflicts
11 of interest;

12 “(2) when a facility does not have a governing
13 board, its policymaking authority shall actively seek
14 advice from an advisory body composed as described
15 above;

16 “(3) the facility shall actively elicit feedback from
17 those consumers of its services (and their representa-
18 tives) who are not members of the aforementioned gov-
19 erning or advisory bodies;

20 “(4) there shall be an active program of ready,
21 open, and honest communication with the public. In
22 structuring visits to the facility by persons not directly
23 concerned with a resident, however, steps shall be taken
24 both to encourage visiting and to consider the sensibilities
25 and privacy of the residents. Undignified displays or

1 exhibitions of residents shall be avoided, and normal
2 sensitivity shall be exercised in speaking about a resident;

3 “(5) personnel shall be permitted to communicate
4 their views about a resident and his needs and program
5 to his relatives. Personnel shall be trained to properly
6 and competently assume this responsibility;

7 “(6) the facility shall maintain active means of
8 keeping residents’ families or surrogates informed of
9 activities related to the residents that may be of interest
10 to them;

11 “(7) communications to the facility from residents’
12 relatives shall be promptly and appropriately handled
13 and answered;

14 “(8) close relatives shall be permitted to visit at
15 any reasonable hour, and without prior notice. Steps
16 shall be taken, however, so that the privacy and rights
17 of the other residents are not infringed by this practice;

18 “(9) parents and other visitors shall be encour-
19 aged to visit the living units, with due regard for
20 privacy. There shall be facilities for visiting that pro-
21 vide privacy in the living unit (but not special rooms
22 used solely for visiting) ;

23 “(10) parents shall be permitted to visit all parts
24 of the facility that provide services to residents;

25 “(11) frequent and informal visits home shall be

1 encouraged, and the regulations of the facility shall en-
2 courage rather than inhibit such visitations;

3 “(12) there shall be an active citizens’ volunteer
4 program; and

5 “(13) the facility shall acknowledge the need for,
6 and encourage the implementation of, advocacy for all
7 residents.

8 “(b) A public education and information program
9 should be established that utilizes all communication media,
10 and all service, religious, and civic groups, and so forth, to
11 develop attitudes of understanding and acceptance of the
12 mentally retarded and other individuals with developmental
13 disabilities in all aspects of community living.

14 **“Subchapter III—Admission and Release**

15 “SEC. 224. No individual whose needs cannot be met
16 by the facility shall be admitted to it. The number admitted
17 as residents to the facility shall not exceed—

18 “(1) its rated capacity; and

19 “(2) its provisions for adequate programing.

20 “SEC. 225. (a) The laws, regulations, and procedures
21 concerning admission, readmission, and release shall be sum-
22 marized and available for distribution. Admission and release
23 procedures shall—

24 “(1) encourage voluntary admission, upon appli-
25 cation of parent or guardian or self;

1 “(2) give equal priority to persons of comparable
2 need, whether application is voluntary or by a court;

3 “(3) facilitate emergency, partial, and short-term
4 residential care, where feasible; and

5 “(4) utilize the maximum feasible amount of volun-
6 tariness in each individual case.

7 “(b) The determination of legal incompetence shall be
8 separate from the determination of the need for residential
9 services, and admission to the facility shall not automatically
10 imply legal incompetence.

11 “SEC. 226. (a) The residential facility shall admit only
12 residents who have had a comprehensive evaluation, cover-
13 ing physical, emotional, social, and cognitive factors, con-
14 ducted by an appropriately constituted interdisciplinary
15 team.

16 “(b) Initially, service need shall be defined without
17 regard to the actual availability of the desirable options.
18 All available and applicable programs of care, treatment,
19 and training shall be investigated and weighed, and the
20 deliberations and findings recorded. Admission to the resi-
21 dential facility shall occur only when it is determined to be
22 the optimal available plan. Where admission is not the
23 optimal measure, but must nevertheless be recommended or
24 implemented, its inappropriateness shall be clearly acknowl-

1 edged and plans shall be initiated for the continued and
2 active exploration of alternatives.

3 “(c) The intended primary beneficiary of the admis-
4 sion shall be clearly specified as—

5 “(1) the resident;

6 “(2) his family;

7 “(3) his community;

8 “(4) society; and

9 “(5) any combination of the above.

10 “(d) All admissions to the residential facility shall be
11 considered temporary, and, when appropriate, admissions
12 shall be time limited. Parents or guardians shall be coun-
13 seled, prior to admission, on the relative advantages and
14 disadvantages and the temporary nature of residential serv-
15 ices in the facility. Prior to admission, parents or guardians
16 shall, and the prospective resident should, have visited the
17 facility and the living unit in which the prospective resident
18 is likely to be placed.

19 “SEC. 227. (a) A medical evaluation by a licensed
20 physician shall be made within one week of the resident’s
21 admission. Upon admission, residents should be placed in
22 their program groups, and they should be isolated only
23 upon medical orders issued for specific reasons.

24 “(b) Within the period of one month after admission
25 there shall be:

1 “(1) a review and updating of the preadmission
2 evaluation;

3 “(2) a prognosis that can be used for program-
4 ing and placement;

5 “(3) a comprehensive evaluation and individual
6 program plan, made by an interdisciplinary team;

7 “(4) direct-care personnel shall participate in the
8 aforementioned activities;

9 “(5) the results of the evaluation shall be recorded
10 in the resident's unit record;

11 “(6) an interpretation of the evaluation, in action
12 terms, shall be made to:

13 “(A) the direct-care personnel responsible for
14 carrying out the resident's program;

15 “(B) the special services staff responsible for
16 carrying out the resident's program; and

17 “(C) the resident's parents or their surrogates.

18 “(c) There shall be a regular, at least annual, joint re-
19 view of the status of each resident by all relevant personnel,
20 including personnel in the living unit, with program recom-
21 mendations for implementation. This review shall include—

22 “(1) consideration of the advisability of continued
23 residence and alternative programs;

24 “(2) at the time of the resident's attaining major-
25 ity, or if he becomes emancipated prior thereto:

1 “(A) the resident’s need for remaining in the
2 facility;

3 “(B) the need for guardianship of the resident;

4 “(C) the exercise of the resident’s civil and
5 legal rights;

6 “(3) The results of these reviews shall be:

7 “(A) recorded in the resident’s unit record;

8 “(B) made available to relevant personnel;

9 “(C) interpreted to the resident’s parents or
10 surrogates;

11 “(D) interpreted to the resident, when appro-
12 priate; and

13 “(4) parents or their surrogates shall be involved
14 in planning and decisionmaking.

15 “SEC. 228. A physical inspection for signs of injury or
16 disease should be made in accordance with procedures estab-
17 lished by the facility:

18 “(A) within twenty-four hours prior to a resident’s
19 leaving the facility for vacation, placement, or other
20 temporary or permanent release; and

21 “(B) within twenty-four hours following a resi-
22 dent’s return to the facility from such absence.

23 “SEC. 229. (a) At the time of permanent release or
24 transfer, there shall be recorded a summary of findings,
25 progress, and plans.

1 “(b) Planning for release shall include provision for
2 appropriate services, including protective supervision and
3 other followup services, in the resident's new environment.
4 Procedures shall be established so that—

5 “(1) parents or guardians who request the release
6 of a resident are counseled concerning the advantages
7 and disadvantages of such release; and

8 “(2) the court or other appropriate authorities are
9 notified when a resident's release might endanger either
10 the individual or society.

11 “(c) When a resident is transferred to another facility
12 there shall be—

13 “(1) written evidence that the reason for the
14 transfer is the welfare of the resident; and

15 “(2) a transfer process that shall insure that the
16 receiving facility will meet the needs of the resident.

17 “(d) Except in an emergency, transfer shall be made
18 only with the prior knowledge, and ordinarily the consent,
19 of the resident and his guardian.

20 “SEC. 230. (a) In the event of any unusual occur-
21 rence, including serious illness or accident, impending death,
22 or death, the resident's next of kin, or the person who func-
23 tions in that capacity (a guardian or citizen advocate) shall
24 be notified promptly and in a compassionate manner. When
25 appropriate, the wishes and needs of the resident, and of the

1 next of kin, concerning religious matters shall be determined
2 and, insofar as possible, fulfilled.

3 “(b) When death occurs:

4 “(1) with the permission of the next of kin or legal
5 guardian, an autopsy shall be performed;

6 “(2) such autopsy shall be performed by a quali-
7 fied physician, so selected as to be free of any conflict
8 of interest or loyalty;

9 “(3) the family shall be told of the autopsy find-
10 ings, if they so desire; and

11 “(4) the facility shall render as much assistance as
12 possible in making arrangements for dignified religious
13 services and burial, unless contraindicated by the wishes
14 of the family.

15 “(c) The coroner or medical examiner shall be notified
16 of deaths, in accordance with State law.

17 **“Subchapter IV—Personnel Policies**

18 “SEC. 231. (a) Adequate personnel services shall be
19 provided by means appropriate to the size of the facility.
20 If the size of the facility warrants a personnel director, he
21 shall have had several years of progressively more respon-
22 sible experience or training in personnel administration,
23 and demonstrated competence in this area.

24 “(b) The facility’s current personnel policies and prac-
25 tices shall be described in writing:

1 “(1) The hiring, assignment, and promotion of em-
2 ployees shall be based on their qualifications and abilities,
3 without regard to sex, race, color, creed, age, irrelevant
4 disability, marital status, ethnic or national origin, or
5 membership in an organization.

6 “(2) Written job descriptions shall be available for
7 all positions.

8 “(3) Licensure, certification, or standards such as
9 are required in community practice shall be required for
10 all comparable positions in the facility.

11 “(4) Ethical standards of professional conduct, as
12 developed by appropriate professional societies, shall be
13 recognized as applying in the facility.

14 “(5) There shall be a planned program for career
15 development and advancement for all categories of
16 personnel.

17 “(6) There shall be an authorized procedure, con-
18 sistent with due process, for suspension and/or dismissal
19 of an employee for cause.

20 “(7) Methods of improving the welfare and se-
21 curity of employees shall include:

22 “(A) a merit system or its equivalent;

23 “(B) a salary schedule covering all positions;

24 “(C) effective grievance procedures;

1 “(D) provisions for vacations, holidays, and
2 sick leave;

3 “(E) provisions for health insurance and retire-
4 ment;

5 “(F) provisions for employee organizations;

6 “(G) opportunities for continuing educational
7 experiences, including educational leave; and

8 “(H) provisions for recognizing outstanding
9 contributions to the facility.

10 “(c) A statement of the facility's personnel policies
11 and practices shall be available to all its employees.

12 “(d) All personnel shall be initially screened to deter-
13 mine if they are capable of fulfilling the specific job re-
14 quirements. All personnel shall be medically determined
15 to be free of communicable and infectious diseases at the
16 time of employment and annually thereafter. All personnel
17 should have a medical examination at the time of employ-
18 ment and annually thereafter. Where indicated, psychologi-
19 cal assessment should be included at the time of employ-
20 ment and annually thereafter.

21 “(e) The performance of each employee shall be evalu-
22 ated regularly and periodically, and at least annually. Each
23 such evaluation shall be—

24 “(1) reviewed with the employee; and

1 “(2) recorded in the employee’s personnel record.

2 “(f) Written policy shall prohibit mistreatment, ne-
3 glect, or abuse of residents. Alleged violations shall be re-
4 ported immediately, and there shall be evidence that—

5 “(1) all alleged violations are thoroughly investi-
6 gated;

7 “(2) the results of such investigation are reported
8 to the chief executive officer, or his designated repre-
9 sentative, within twenty-four hours of the report of the
10 incident; and

11 “(3) appropriate sanctions are invoked when the
12 allegation is substantiated.

13 “SEC. 232. (a) Staffing shall be sufficient so that the
14 facility is not dependent upon the use of residents or volun-
15 teers for productive services. There shall be a written policy
16 to protect residents from exploitation when they are engaged
17 in productive work. A current, written policy shall en-
18 courage that residents be trained for productive, paid em-
19 ployment. Residents shall not be involved in the care
20 (feeding, clothing, bathing), training, or supervision of
21 other residents unless they—

22 “(1) have been specifically trained in the neces-
23 sary skills;

24 “(2) have the humane judgment required by these
25 activities;

1 “(3) are adequately supervised; and

2 “(4) are reimbursed.

3 “(b) Residents who function at the level of staff in
4 occupational or training activities shall—

5 “(1) have the right to enjoy the same privileges as
6 staff; and

7 “(2) be paid at the legally required wage level
8 when employed in other than training situations.

9 “(c) Appropriate to the size and nature of the facility,
10 there shall be a staff training program that includes:

11 “(1) orientation for all new employees, to acquaint
12 them with the philosophy, organization, program, prac-
13 tices, and goals of the facility;

14 “(2) induction training for each new employee, so
15 that his skills in working with the residents are increased;

16 “(3) inservice training for employees who have not
17 achieved the desired level of competence, and opportuni-
18 ties for continuous inservice training to update and im-
19 prove the skills and competencies of all employees;

20 “(4) supervisory and management training for all
21 employees in, or candidates for, supervisory positions;

22 “(5) provisions shall be made for all staff members
23 to improve their competencies, through means, includ-
24 ing but not limited to—

25 “(A) attending staff meetings;

1 “(B) undertaking seminars, conferences, work-
2 shops, and institutes;

3 “(C) attending college and university courses;

4 “(D) visiting other facilities;

5 “(E) participation in professional organiza-
6 tions;

7 “(F) conducting research;

8 “(G) publishing studies;

9 “(H) access to consultants;

10 “(I) access to current literature, including
11 books, monographs, and journals relevant to mental
12 retardation and developmental disabilities;

13 “(6) interdisciplinary training programs shall be
14 stressed;

15 “(7) the ongoing staff development program
16 should include provision for educating staff members
17 as research consumers;

18 “(8) where appropriate to the size and nature of
19 the facility, there shall be an individual designated to
20 be responsible for staff development and training, and
21 such individual should have—

22 “(A) at least a master's degree in one of the
23 major disciplines relevant to mental retardation or
24 other developmental disability;

25 “(B) a thorough knowledge of the nature of

1 mental retardation and other developmental dis-
2 abilities, and the current goals, programs, and prac-
3 tices in this field;

4 “(C) a knowledge of the educational process;

5 “(D) an appropriate combination of academic
6 training and relevant experience;

7 “(E) demonstrated competence in organizing
8 and directing staff training programs; and

9 “(9) appropriate to the size and nature of the facil-
10 ity, there should be adequate, modern educational media
11 equipment (including but not limited to: overhead,
12 filmstrip, motion picture, and slide projectors; screens;
13 models and charts; and video tape systems) for the con-
14 duct of an inservice training program.

15 “(d) Working relations should be established between
16 the facility and nearby colleges and universities for the fol-
17 lowing purposes:

18 “(1) making credit courses, seminars, and work-
19 shops available to the facility's staff;

20 “(2) using facility resources for training and re-
21 search by colleges and universities; and

22 “(3) exchanging of staff between the facility and
23 the colleges and universities for teaching, research, and
24 consultation.

1 **"Chapter 2.—RESIDENT LIVING**

2 **"Subchapter I—Staff-Resident Relationships and**

3 **Activities**

4 "SEC. 240. (a) The primary responsibility of the liv-
5 ing unit staff shall be to devote their attention to the care
6 and development of the residents as follows:

7 "(1) each resident shall receive appreciable and
8 appropriate attention each day from the staff in the
9 living unit;

10 "(2) living unit personnel shall train residents in
11 activities of daily living and in the development of self-
12 help and social skills;

13 "(3) living unit personnel shall be responsible for
14 the development and maintenance of a warm, family-
15 or home-like environment that is conducive to the
16 achievement of optimal development by the resident;

17 "(4) appropriate provision shall be made to en-
18 sure that the efforts of the staff are not diverted from
19 these responsibilities by excessive housekeeping and cler-
20 ical duties, or other non-resident-care activities; and

21 "(5) the objective in staffing each living unit
22 should be to maintain reasonable stability in the assign-
23 ment of staff, thereby permitting the development of
24 a consistent inter-personal relationship between each
25 resident and one or two staff members.

1 “(b) Members of the living unit staff from all shifts
2 shall participate with an interdisciplinary team in appropriate referral, planning, initiation, coordination, implementation, followthrough, monitoring, and evaluation activities relative to the care and development of the resident.

6 “(c) There shall be specific evaluation and program
7 plans for each resident that are—

8 “(1) available to direct care staff in each living
9 unit; and

10 “(2) reviewed by a member or members of the
11 interdisciplinary program team at least monthly, with
12 documentation of such review entered in the resident's
13 record.

14 “(d) Activity schedules for each resident shall be available to direct care staff and shall be implemented daily as
15 follows:
16

17 “(1) such schedules shall not permit ‘dead time’
18 of unscheduled activity of more than one hour continuous duration; and

20 “(2) such schedules shall allow for individual or
21 group free activities, with appropriate materials, as specified by the program team.

23 “(e) The rhythm of life in the living unit shall resemble
24 the cultural norm for the residents’ nonretarded or nondevelopmentally disabled age peers, unless a departure from this
25

1 rhythm is justified on the basis of maximizing the residents'
 2 human qualities. Residents shall be assigned responsibilities
 3 in the living unit commensurate with their interests, abilities,
 4 and developmental plans, in order to enhance feelings of
 5 self-respect and to develop skills of independent living. Mul-
 6 tiple-handicapped and nonambulatory residents shall—

7 “(1) spend a major portion of their waking day out
 8 of bed;

9 “(2) spend a portion of their waking day out of
 10 their bedroom areas;

11 “(3) have planned daily activity and exercise
 12 periods; and

13 “(4) be rendered mobile by various methods and
 14 devices.

15 “(f) All residents shall have planned periods out of
 16 doors on a year-round basis. Residents should be instructed
 17 in how to use, and, except as contraindicated for individual
 18 residents by their program plan, should be given opportunity
 19 for, freedom of movement—

20 “(1) within the facility's ground; and

21 “(2) without the facility's grounds.

22 Birthdays and special events should be individually
 23 observed. Provisions shall be made for heterosexual inter-
 24 action appropriate to the residents' developmental levels.

25 “(g) Residents' views and opinions on matters con-

cerning them should be elicited and given consideration in
defining the processes and structures that affect them.

“(h) Residents should be instructed in the free and
unsupervised use of communication processes. Except as
denied individual residents by team action, for cause, this
should typically include—

“(1) having access to telephones for incoming and
local outgoing calls;

“(2) having free access to pay telephones, or the
equivalent, for outgoing long distance calls;

“(3) opening their own mail and packages, and
generally doing so without direct surveillance; and

“(4) not having their outgoing mail read by staff,
unless requested by the resident.

“(i) Residents shall be permitted personal possessions,
such as toys, books, pictures, games, radios, arts and crafts
materials, religious articles, toiletries, jewelry, and letters.

“(j) Regulations shall permit normalized and normaliz-
ing possession and use of money by residents for work pay-
ment and property administration, as for example, in
performing cash and check transactions, and in buying
clothing and other items, as readily as other citizens. In
accordance with their developmental level—

“(1) allowances or opportunities to earn money
shall be available to residents; and

1 “(2) residents shall be trained in the value and
2 use of money.

3 “(k) There shall be provision for prompt recognition
4 and appropriate management of behavioral problems in the
5 living unit. There shall be a written statement of policies
6 and procedures for the control and discipline of residents
7 that is—

8 “(1) directed to the goal of maximizing the
9 growth and development of the residents;

10 “(2) available in each living unit; and

11 “(3) available to parents or guardians.

12 “(1) Residents shall participate, as appropriate, in
13 the formulation of such policies and procedures. Corporal
14 punishment shall not be permitted. Residents shall not dis-
15 cipline other residents, except as part of an organized self-
16 government program that is conducted in accordance with
17 written policy.

18 “(m) Seclusion, defined as the placement of a resident
19 alone in a locked room, shall not be employed.

20 “(n) Except as provided in subsection (p), physical
21 restraint shall be employed only when absolutely necessary
22 to protect the resident from injury to himself and to others,
23 and restraint shall not be employed as punishment, for the
24 convenience of staff, or as a substitute for program. The
25 facility shall have a written policy that defines the uses of

1 restraint, the staff members who may authorize its use, and
2 a mechanism for monitoring and controlling its use. Orders
3 for restraints shall not be in force for longer than twelve
4 hours. A resident placed in restraint shall be checked at
5 least every thirty minutes by staff trained in the use of
6 restraints, and a record of such checks shall be kept. Me-
7 chanical restraints shall be designed and used so as not to
8 cause physical injury to the resident, and so as to cause the
9 least possible discomfort. Opportunity for motion and exer-
10 cise shall be provided for a period of not less than ten min-
11 utes during each two hours in which restraint is employed.
12 Totally enclosed cribs and barred enclosures shall be con-
13 sidered restraints.

14 “(o) Mechanical supports used in normative situations
15 to achieve proper body position and balance shall not be
16 considered to be restraints, but shall be designed and
17 applied—

18 “(1) under the supervision of a qualified profes-
19 sional person; and

20 “(2) so as to reflect concern for principles of good
21 body alinement, concern for circulation, and allowance
22 for change of position.

23 “(p) Chemical restraint shall not be used excessively,
24 as punishment, for the convenience of staff, as a substitute

1 for program, or in quantities that interfere with a resident's
2 habilitation program.

3 “(q) Behavior modification programs involving the
4 use of time-out devices or the use of noxious or aversive
5 stimuli shall be:

6 “(1) reviewed and approved by the facility's re-
7 search review and human rights committees;

8 “(2) conducted only with the consent of the affected
9 resident's parents or surrogates;

10 “(3) described in written plans that are kept on
11 file in the facility;

12 “(4) restraints employed as time-out devices shall
13 be applied for only very brief periods, only during con-
14 ditioning sessions, and only in the presence of the
15 trainer; and

16 “(5) removal from a situation for time-out purposes
17 shall not be for more than one hour, and this procedure
18 shall be used only during the conditioning program, and
19 only under the supervision of the trainer.

20 “Subchapter II—Food Services

21 “SEC. 241. (a) Food services shall recognize and
22 provide for the physiological, emotional, religious, and cul-
23 tural needs of each resident, through provision of a planned,
24 nutritionally adequate diet. There shall be a written state-
25 ment of goals, policies, and procedures that—

1 “(1) governs all food service and nutrition activ-
2 ities;

3 “(2) is prepared by, or with the assistance of, a
4 nutritionist or dietitian;

5 “(3) is reviewed periodically, as necessary, by the
6 nutritionist or dietitian;

7 “(4) is in compliance with State and local
8 regulations;

9 “(5) is consistent with the facility's goals and
10 policies; and

11 “(6) is distributed to facility personnel.

12 “(b) When food services are not directed by a nu-
13 tritionist or dietitian, regular, planned, and frequent con-
14 sultation with a nutritionist or dietitian should be available.
15 Records of consultations and recommendations shall be main-
16 tained by the facility and by the consultant. An evaluation
17 procedure shall be established to determine the extent of
18 implementation of the consultant's recommendations.

19 “(c) A nourishing, well-balanced diet, consistent with
20 local customs, shall be provided all residents. Modified diets
21 shall be—

22 “(1) prescribed by the resident's program team,
23 with a record of the prescription kept on file;

24 “(2) planned, prepared, and served by persons
25 who have received adequate instruction; and

1 “(3) periodically reviewed and adjusted as needed.

2 “(d) Dietary practices in keeping with the religious
3 requirements of residents' faith groups should be observed
4 at the request of parents or guardians. Denial of a nutri-
5 tionally adequate diet shall not be used as a punishment. At
6 least three meals shall be served daily, at regular times,
7 with—

8 “(1) not more than a fourteen-hour span between
9 a substantial evening meal and breakfast of the follow-
10 ing day, and

11 “(2) not less than ten hours between breakfast
12 and the evening meal of the same day.

13 “(e) Resident's mealtimes shall be comparable to those
14 normally obtaining in the community. Provision should be
15 made for between meal and before bedtime snacks, in keep-
16 ing with the total daily needs of each resident. Food shall be
17 served—

18 “(1) as soon as possible after preparation, in order
19 to conserve nutritive value;

20 “(2) in an attractive manner;

21 “(3) in appropriate quantity;

22 “(4) at appropriate temperature;

23 “(5) in a form consistent with the developmental
24 level of the resident; and

25 “(6) with appropriate utensils.

1 When food is transported, it shall be done in a manner that
2 maintains proper temperature, protects the food from contam-
3 ination and spoilage, and insures the preservation of nutritive
4 value.

5 “(f) All residents, including the mobile nonambulatory,
6 shall eat or be fed in dining rooms, except where contraindi-
7 cated for health reasons, or by decision of the team respon-
8 sible for the resident’s program. Table service shall be pro-
9 vided for all who can and will eat at a table, including
10 residents in wheelchairs. Dining areas shall—

11 “(1) be equipped with tables having smooth, im-
12 pervious tops or clean table coverings may be used;

13 “(2) be equipped with tables, chairs, eating uten-
14 sils, and dishes designed to meet the developmental needs
15 of each resident;

16 “(3) promote a pleasant and home-like environ-
17 ment that is attractively furnished and decorated, and is
18 of good acoustical quality; and

19 “(4) be designed to stimulate maximum self-devel-
20 opment, social interaction, comfort, and pleasure.

21 “(g) Dining arrangements shall be based upon a rational
22 plan to meet the needs of the residents and the requirements
23 of their programs. Dining and serving arrangements should
24 provide for a variety of eating experiences (for example,
25 cafeteria and family style), and, when appropriate, for the

1 opportunity to make food selections with guidance. Unless
2 justified on the basis of meeting the program needs of the
3 particular residents being served, dining tables should seat
4 small groups of residents (typically four to six at a table),
5 preferably including both sexes.

6 “(h) Dining rooms shall be adequately supervised and
7 staffed for the direction of self-help eating procedures, and to
8 assure that each resident receives an adequate amount and
9 variety of food. Staff members should be encouraged to eat
10 with those residents who have semi-independent or inde-
11 pendent eating skills. For residents not able to get to dining
12 areas, food service practices shall permit and encourage maxi-
13 mum self-help, and shall promote social interaction and en-
14 joyable experiences.

15 “SEC. 242. (a) Residents shall be provided with sys-
16 tematic training to develop appropriate eating skills, utilizing
17 adaptive equipment where it serves the developmental
18 process.

19 “(b) Residents with special eating disabilities shall be
20 provided with an interdisciplinary approach to the diagnosis
21 and remediation of their problems, consistent with their de-
22 velopmental needs.

23 “(c) Direct-care staff shall be trained in and shall utilize
24 proper feeding techniques. Residents shall eat in an upright
25 position. Residents shall eat in a manner consistent with their

1 developmental needs (for example, infants should be fed in
2 arms, as appropriate). Residents shall be fed at a leisurely
3 rate, and the time allowed for eating shall be such as to per-
4 mit adequate nutrition, to promote the development of self-
5 feeding abilities, to encourage socialization, and to provide a
6 pleasant mealtime experience.

7 “(d) Effective procedures for cleaning all equipment
8 and all areas shall be followed consistently. Handwashing
9 facilities, including hot and cold water, soap, and paper
10 towels, shall be provided adjacent to work areas.

11 “Subchapter III—Clothing

12 “SEC. 245. (a) Each resident shall have an adequate
13 allowance of neat, clean, fashionable, and seasonable
14 clothing.

15 “(b) Each resident shall have his own clothing, which
16 is, when necessary, properly and inconspicuously marked
17 with his name, and he shall use this clothing. Such clothing
18 shall make it possible for residents to go out of doors in
19 inclement weather, to go for trips or visits appropriately
20 dressed, and to make a normal appearance in the community.

21 “(c) Nonambulatory residents shall be dressed daily in
22 their own clothing, including shoes, unless contraindicated
23 in written medical orders.

24 “(d) Washable clothing shall be designed for multi-

1 handicapped residents being trained in self-help skills, in
2 accordance with individual needs.

3 “(e) Clothing for incontinent residents shall be de-
4 signed to foster comfortable sitting, crawling and/or walk-
5 ing, and toilet training.

6 “(f) A current inventory should be kept of each resi-
7 dent's personal and clothing items.

8 “(g) Residents shall be trained and encouraged to:

9 “(1) select and purchase their own clothing as
10 independently as possible, preferably utilizing commu-
11 nity stores;

12 “(2) select their daily clothing;

13 “(3) dress themselves;

14 “(4) change their clothes to suit the activities in
15 which they engage; and

16 “(5) maintain (launder, clean, mend) their cloth-
17 ing as independently as possible.

18 “SEC. 246. Storage space for clothing to which the
19 resident has access shall be provided. Ample closet and
20 drawer space shall be provided for each resident. Such space
21 shall be accessible to all, including those in wheelchairs.

22 “SEC. 247. The person responsible for the facility's
23 resident-clothing program shall be trained or experienced
24 in the selection, purchase, and maintenance of clothing, in-
25 cluding the design of clothing for the handicapped.

1 **"Subchapter IV—Health, Hygiene, and Grooming**

2 "SEC. 250. (a) Residents shall be trained to exercise
3 maximum independence in health, hygiene, and grooming
4 practices, including bathing, brushing teeth, shampooing,
5 combing and brushing hair, shaving, and caring for toenails
6 and fingernails.

7 "(b) Each resident shall be assisted in learning normal
8 grooming practices with individual toilet articles that are
9 appropriately available to that resident.

10 "(c) Teeth shall be brushed daily, with an effective den-
11 tifice. Individual brushes shall be properly marked, used,
12 and stored. Dental care practices should encourage the use of
13 newer dental equipment, such as electric toothbrushes and
14 water picks, as prescribed.

15 "(d) Residents shall be regularly scheduled for hair
16 cutting and styling, in an individualized, normalized manner,
17 by trained personnel.

18 "(e) For residents who require such assistance, cutting
19 of toenails and fingernails by trained personnel shall be sched-
20 uled at regular intervals.

21 "(f) Each resident shall have a shower or tub bath at
22 least daily, unless medically contraindicated. Resident's bath-
23 ing shall be conducted at the most independent level possible.
24 Residents' bathing shall be conducted with due regard for

1 privacy. Individual washcloths and towels shall be used. A
2 bacteriostatic soap shall be used, unless otherwise prescribed.

3 “(g) Female residents shall be helped to attain maxi-
4 mum independence in caring for menstrual needs. Menstrual
5 supplies shall be of the same quality and diversity available
6 to all women.

7 “(h) Every resident who does not eliminate appropri-
8 ately and independently shall be engaged in a toilet train-
9 ing program. The facility’s training program shall be applied
10 systematically and regularly. Appropriate dietary adapta-
11 tions shall be made to promote normal evacuation and
12 urination. The program shall comprise a hierarchy of pro-
13 cedures leading from incontinence to independent toileting.
14 Records shall be kept of the progress of each resident receiv-
15 ing toilet training. Appropriate equipment shall be provided
16 for toilet training, including equipment appropriate for the
17 multiply handicapped. Residents who are incontinent shall
18 be immediately bathed or cleansed, upon voiding or soiling,
19 unless specifically contraindicated by the training program
20 in which they are enrolled, and all soiled items shall be
21 changed. Persons shall wash their hands after handling an
22 incontinent resident.

23 “(i) Each living unit shall have a properly adapted
24 drinking unit. Residents shall be taught to use such units.
25 Those residents who cannot be so taught shall be given the

1 proper daily amount of fluid at appropriate intervals adequate
2 to prevent dehydration. There shall be a drinking unit
3 accessible to, and usable by, residents in wheelchairs. Spe-
4 cial cups and noncollapsible straws shall be available when
5 needed by the multiply handicapped. If the drinking unit
6 employs cups, only single-use, disposable types shall be
7 used.

8 “(j) Procedures shall be established for:

9 “(1) monthly weighing of residents, with greater
10 frequency for those with special needs;

11 “(2) quarterly measurement of height, until the
12 age of maximum growth;

13 “(3) maintenance of weight and height records;
14 and

15 “(4) every effort shall be made to assure that resi-
16 dents maintain normal weights.

17 “(k) Policies and procedures for the care of residents
18 with infections and contagious diseases shall conform to
19 State and local health department regulations.

20 “(l) Orders prescribing bed rest or prohibiting residents
21 from being taken out-of-doors shall be reviewed by a physi-
22 cian at least every three days.

23 “(m) Provisions shall be made to furnish and maintain
24 in good repair, and to encourage the use of, dentures, eye-

1 glasses, hearing aids, braces, and so forth, prescribed by
2 appropriate specialists.

3 **"Subchapter V—Grouping and Organization of Living**
4 **Units**

5 "SEC. 255. (a) Living unit components or groupings
6 shall be small enough to insure the development of meaning-
7 ful interpersonal relationships among residents and between
8 residents and staff. The resident-living unit (self-contained
9 unit including sleeping, dining, and activity areas) should
10 provide for not more than sixteen residents. Any deviation
11 from this size should be justified on the basis of meeting
12 the program needs of the specific residents being served.
13 To maximize development, residents should be grouped
14 within the living unit into program groups of not more than
15 eight. Any deviation from this size should be justified on
16 the basis of meeting the program needs of the specific resi-
17 dents being served.

18 "(b) Residential units or complexes should house both
19 male and female residents to the extent that this conforms
20 to the prevailing cultural norms. Residents of grossly dif-
21 ferent ages, developmental levels, and social needs shall not
22 be housed in close physical or social proximity, unless such
23 housing is planned to promote the growth and development
24 of all those housed together. Residents who are mobile-non-
25 ambulatory, deaf, blind, or multihandicapped shall be inte-

1 grated with peers of comparable social and intellectual de-
 2 velopment, and shall not be segregated on the basis of their
 3 handicaps.

4 “(c) The living unit shall not be a self-contained pro-
 5 gram unit, and living unit activities shall be coordinated with
 6 recreation, educational, and habilitative activities in which
 7 residents engage outside the living unit, unless contraindi-
 8 cated by the specific program needs of the particular residents
 9 being served. Each program group should be assigned a
 10 specific person, who has responsibility for providing an orga-
 11 nized, developmental program of physical care, training, and
 12 recreation.

13 “(d) Residents shall be allowed free use of all living
 14 areas within the living unit, with due regard for privacy and
 15 personal possessions. Each resident shall have access to a
 16 quiet, private area where he can withdraw from the group
 17 when not specifically engaged in structured activities.

18 “(e) Outdoor active play or recreation areas shall be
 19 readily accessible to all living units.

20 **“Subchapter VI—Resident-Living Staff**

21 “SEC. 256. (a) There shall be sufficient, appropriately
 22 qualified, and adequately trained personnel to conduct the
 23 resident-living program, in accordance with the standards
 24 specified in this section. Resident-living personnel shall be
 25 administratively responsible to a person whose training and

1 experience is appropriate to the program. The title applied
2 to the individuals who directly interact with residents in the
3 living units should be appropriate to the kind of residents
4 with whom they work and the kind of interaction in which
5 they engage. The personnel who staff the living units may be
6 referred to by a variety of terms, such as attendants, child
7 care workers, or cottage parents. The term 'psychiatric aid'
8 may be appropriate for a unit serving the emotionally dis-
9 turbed, but not for a cottage of well-adjusted children. The
10 title of "child care worker" may be appropriate for a nursery
11 school group, but not for an adult unit. Nurses' aides are
12 appropriate for units serving sick residents but not well ones.

13 “(b) The attire of resident-living personnel should be
14 appropriate to the program of the unit in which they work,
15 and consistent with attire worn in the community.

16 “(c) When resident-living units are organized as recom-
17 mended in subchapter V, and designed as stipulated in sub-
18 chapter VII, the staff-resident ratios for twenty-four-hour,
19 seven-day coverage of such units by resident-living personnel,
20 or for equivalent coverage, should be as follows:

21 “(1) for medical and surgical units, and for units
22 including infants, children (to puberty), adolescents
23 requiring considerable adult guidance and supervision,
24 severely and profoundly retarded or developmentally
25 disabled moderately and severely physically handi-

1 capped, and residents who are aggressive, assaultive, or
2 security risks, or who manifest severely hyperactive or
3 psychotic-like behavior—

4 “(A) first shift, 1 to 4;

5 “(B) second shift, 1 to 4;

6 “(C) third shift, 1 to 8; and

7 “(D) overall ratio (allowing for a five-day
8 workweek plus holiday, vacation, and sick time),
9 1 to 1;

10 “(2) for units serving moderately retarded or de-
11 velopmentally disabled adolescents and adults requiring
12 habit training—

13 “(A) first shift, 1 to 8;

14 “(B) second shift, 1 to 4;

15 “(C) third shift, 1 to 8; and

16 “(D) overall ratio, 1 to 1.25;

17 “(3) for units serving residents in vocational train-
18 ing programs and adults who work in sheltered employ-
19 ment situations—

20 “(A) first shift, 1 to 16;

21 “(B) second shift, 1 to 8;

22 “(C) third shift, 1 to 16; and

23 “(D) overall ratio, 1 to 2.5.

24 “(d) Regardless of the organization or design of resi-
25 dent-living units, the overall staff-resident ratios should be

1 as stipulated above. Regardless of the organization or design
2 of resident-living units, the overall staff-resident ratios for
3 the categories defined above shall not be less than 1 to 2,
4 1 to 2.5, and 1 to 5, respectively.

5 **"Subchapter VII—Design and Equipage of Living Units**

6 "SEC. 257. (a) The design, construction, and furnish-
7 ing of resident-living units shall be—

8 "(1) appropriate for the fostering of personal and
9 social development;

10 "(2) appropriate to the program;

11 "(3) flexible enough to accommodate variations in
12 program to meet changing needs of residents; and

13 "(4) such as to minimize noise and permit com-
14 munication at normal conversation levels.

15 "(b) The interior design of living units shall simulate
16 the functional arrangements of a home to encourage a per-
17 sonalized atmosphere for small groups of residents, unless it
18 has been demonstrated that another arrangement is more
19 effective in maximizing the human qualities of the specific
20 residents being served. There shall be a minimum of eighty
21 square feet of living, dining, or activity space for each
22 resident. This space shall be arranged to permit residents to
23 participate in different kinds of activities, both in groups
24 and singly. Furniture and furnishings shall be safe, appro-
25 priate, comfortable, and homelike.

- 1 “(c) Bedrooms shall:
- 2 “(1) be on or above street grade level;
- 3 “(2) be outside rooms;
- 4 “(3) accommodate from one to four residents;
- 5 “(4) provide at least sixty square feet per resident
- 6 in multiple sleeping rooms, and not less than eighty
- 7 square feet in single rooms;
- 8 “(5) partitions defining each bedroom shall extend
- 9 from floor to ceiling;
- 10 “(6) doors to bedrooms—
- 11 “(A) should not have vision panels;
- 12 “(B) should not be lockable, except where
- 13 residents may lock their own bedroom doors, as
- 14 consistent with their program;
- 15 “(7) there shall be provision for residents to mount
- 16 pictures on bedroom walls (for example, by means of
- 17 pegboard or cork strips), and to have flowers, artwork,
- 18 and other decorations;
- 19 “(8) each resident shall be provided with—
- 20 “(A) a separate bed of proper size and height
- 21 for the convenience of the resident;
- 22 “(B) a clean, comfortable mattress;
- 23 “(C) bedding appropriate for weather and
- 24 climate;
- 25 “(9) each resident shall be provided with—

1 “(A) appropriate individual furniture, such as
2 a chest of drawers, a table or desk, and an individ-
3 ual closet with clothes racks and shelves accessible
4 to the resident;

5 “(B) a place of his own for personal play
6 equipment and individually prescribed prosthetic
7 equipment; and

8 “(10) space shall be provided for equipment for
9 daily out-of-bed activity for all residents not yet mobile,
10 except those who have a short-term illness, or those very
11 few for whom out-of-bed activity is a threat to life.

12 “(d) Suitable storage shall be provided for personal
13 possessions, such as toys, books, pictures, games, radios,
14 arts and crafts materials, toiletries, jewelry, letters, and
15 other articles and equipment, so that they are accessible to the
16 residents for their use. Storage areas shall be available for
17 off-season personal belongings, clothing, and luggage.

18 “(e) Toilet areas, clothes closets, and other facilities
19 shall be located and equipped so as to facilitate training to-
20 ward maximum self-help by residents, including the severely
21 and profoundly retarded or developmentally disabled and the
22 multiple handicapped as follows:

23 “(1) water closets, showers, bathtubs, and lava-
24 tories shall approximate normal patterns found in homes,
25 unless specifically contraindicated by program needs;

1 “(2) toilets, bathtubs, and showers shall provide
2 for individual privacy (with partitions and doors), un-
3 less specifically contraindicated by program needs;

4 “(3) water closets and bathing and toileting appli-
5 ances shall be equipped for use by the physically
6 handicapped;

7 “(4) there shall be at least one water closet of
8 appropriate size for each six residents;

9 “(A) at least one water closet in each living
10 unit shall be accessible to residents in wheelchairs;

11 “(B) each water closet shall be equipped with
12 a toilet seat;

13 “(C) toilet tissue shall be readily accessible at
14 each water closet;

15 “(5) there shall be at least one lavatory for each
16 six residents and one lavatory shall be accessible to and
17 usable by residents in wheelchairs;

18 “(6) there shall be at least one tub or shower for
19 each eight residents;

20 “(7) there shall be individual racks or other drying
21 space for washcloths and towels; and

22 “(8) larger, tilted mirrors shall be available to resi-
23 dents in wheelchairs.

24 “(f) Provisions for the safety, sanitation, and comfort
25 of the residents shall comply with the following requirements:

1 “(1) each habitable room shall have direct outside
2 ventilation by means of windows, louvres, air-condition-
3 ing, or mechanical ventilation horizontally and vertically;

4 “(2) each habitable room shall have at least one
5 window, and the window space in each habitable room
6 should be at least one-eighth ($12\frac{1}{2}$ per centum) of the
7 floor space;

8 “(A) each resident unit of eight shall have at
9 least one glazed area low enough so that a child in
10 normal day activities has horizontal visual access to
11 the out of doors;

12 “(B) the type of glass or other glazing material
13 used shall be appropriate to the safety needs of the
14 residents of the unit;

15 “(3) floors shall provide a resilient, comfortable,
16 attractive, nonabrasive, and slip-resistant surface. Car-
17 peting used in units serving residents who crawl or
18 creep shall be nonabrasive;

19 “(4) temperature and humidity shall be main-
20 tained within a normal comfort range by heating, air
21 conditioning, or other means. The heating apparatus
22 employed shall not constitute a burn hazard to the
23 residents;

24 “(5) the temperature of the hot water at all taps
25 to which residents have access shall be controlled, by

1 the use of thermostatically controlled mixing valves or
2 by other means, so that it does not exceed 110 degrees
3 Fahrenheit. Mixing valves shall be equipped with safety
4 alarms that provide both auditory and visual signals of
5 valve failure;

6 “(6) emergency lighting of stairs and exits, with
7 automatic switches, shall be provided in units housing
8 more than fifteen residents;

9 “(7) there shall be adequate clean linen and dirty
10 linen storage areas for each living unit. Dirty linen and
11 laundry shall be removed from the living unit daily;
12 and

13 “(8) laundry and trash chutes are discouraged,
14 but if installed, such chutes shall comply with regula-
15 tions proscribed by the Secretary.

16 **“Chapter 3.—PROFESSIONAL AND SPECIAL**
17 **PROGRAMS AND SERVICES**

18 **“Subchapter I—Introduction**

19 “SEC. 258. (a) In addition to the resident-living serv-
20 ices otherwise detailed in this title, residents shall be provided
21 with the professional and special programs and services de-
22 tailed in this section, in accordance with their needs for such
23 programs and services.

24 “(b) The professional and special programs and serv-
25 ices detailed herein may be provided by programs main-

1 tained or personnel employed by the residential facility, or
2 by formal arrangements between the facility and other agen-
3 cies or persons, whereby the latter will provide such pro-
4 grams and services to the facility's residents as needed.

5 “(c) In accordance with the normalized principle, all
6 professional services to the mentally retarded and other indi-
7 viduals with developmental disabilities should be rendered
8 in the community, whenever possible, rather than in a resi-
9 dential facility, and where rendered in a residential facility,
10 such services must be at least comparable to those provided
11 the nonretarded in the community.

12 “(d) Programs and services provided by the facility
13 or to the facility by agencies outside it, or by persons not
14 employed by it, shall meet the standards for quality of serv-
15 ice as stated in this section. The facility shall require that
16 services provided its residents meet the standards for quality
17 of services as stated in this section, and all contracts for the
18 provision of such services shall stipulate that these stand-
19 ards will be met.

20 “SEC. 259. (a) Individuals providing professional and
21 special programs and services to residents may be identified
22 with the following professions, disciplines, or areas of service:

23 “(1) audiology;

24 “(2) dentistry (including services rendered by li-

- 1 censed dentists, licensed dental hygienists, and dental
- 2 assistants) ;
- 3 “ (3) education ;
- 4 “ (4) food and nutrition (including services rendered
- 5 by dietitians and nutritionists) ;
- 6 “ (5) library services ;
- 7 “ (6) medicine (including services rendered by licensed
- 8 physicians, whether doctors of medicine or doctors
- 9 of osteopathy, licensed podiatrists, and licensed
- 10 optometrists) ;
- 11 “ (7) music, art, dance, and other activity therapies ;
- 12 “ (8) nursing ;
- 13 “ (9) occupational therapy ;
- 14 “ (10) pharmacy ;
- 15 “ (11) physical therapy ;
- 16 “ (12) psychology ;
- 17 “ (13) recreation ;
- 18 “ (14) religion (including services rendered by
- 19 clergy and religious educators) ;
- 20 “ (15) social work ;
- 21 “ (16) speech pathology ;
- 22 “ (17) vocational rehabilitation counseling ; and
- 23 “ (18) volunteer services.
- 24 “ (b) Interdisciplinary teams for evaluating the resident's

1 needs, planning an individualized habilitation program to
2 meet identified needs, and periodically reviewing the resi-
3 dent's response to his program and revising the program
4 accordingly, shall be constituted of persons drawn from, or
5 representing, such of the aforementioned professions, disci-
6 plines, or service areas as are relevant in each particular case.

7 “(c) Since many identical or similar services or func-
8 tions may competently be rendered by individuals of dif-
9 ferent professions, the standards in the following subsec-
10 tions shall be interpreted to mean that necessary services
11 are to be provided in efficient and competent fashion, with-
12 out regard to the professional identifications of the persons
13 providing them, unless only members of a single profes-
14 sion are qualified or legally authorized to perform the stated
15 service. Services listed under the duties of one profession
16 may, therefore, be rendered by members of other profes-
17 sions who are equipped by training and experience to do so.

18 “(d) Regardless of the means by which the facility
19 makes professional services available to its residents, there
20 shall be evidence that members of professional disciplines
21 work together in cooperative, coordinated, interdisciplinary
22 fashion to achieve the objective of the facility.

23 “SEC. 260. Programs and services and the pattern of
24 staff organization and function within the facility shall be

1 focused upon serving the individual needs of residents and
2 should provide for—

3 “(1) comprehensive diagnosis and evaluation of
4 each resident as a basis for planning programing and
5 management;

6 “(2) design and implementation of an individual-
7 ized habilitation program to effectively meet the needs
8 of each resident;

9 “(3) regular review, evaluation, and revision, as
10 necessary, of each individual's habilitation program;

11 “(4) freedom of movement of individual residents
12 from one level of achievement to another, within the
13 facility and also out of the facility, through training,
14 habilitation, and placement; and

15 “(5) an array of those services that will enable
16 each resident to develop to his maximum potential.

17 **“Subchapter II—Dental Services**

18 “SEC. 261. (a) Dental services shall be provided all
19 residents in order to maximize their general health by—

20 “(1) maintaining an optimal level of daily oral
21 health, through preventive measures; and

22 “(2) correcting existing oral diseases.

23 “(b) Dental services shall be rendered—

24 “(1) directly, through personal contact with all

1 residents by dentists, dental hygienists, dental assistants,
2 dental health educators, and oral hygiene aides, as ap-
3 propriate to the size of the facility; and

4 “(2) indirectly, through contact between dental
5 staff and other personnel caring for the residents, in
6 order to maintain their optimal oral health.

7 “(c) Dental services available to the facility should
8 include—

9 “(1) dental evaluation and diagnosis;

10 “(2) dental treatment;

11 “(3) comprehensive preventive dentistry programs;

12 “(4) education and training in the maintenance of
13 oral health;

14 “(5) participation, as appropriate, by dentists and
15 dental hygienists in the continuing evaluation of indi-
16 vidual residents by interdisciplinary teams, to initiate,
17 monitor, and follow up individualized habilitation pro-
18 grams;

19 “(6) consultation with, or relating to—

20 “(A) residents;

21 “(B) families of residents;

22 “(C) other facility services and personnel;

23 “(7) participation on appropriate facility commit-
24 tees; and

25 “(8) planning and conducting dental research;

1 cooperating in interdisciplinary research; and interpret-
2 ing, disseminating, and implementing applicable research
3 findings.

4 “(d) Comprehensive diagnostic services for all resi-
5 dents shall include—

6 “(1) a complete extra and intraoral examination,
7 utilizing all diagnostic aids necessary to properly eval-
8 uate the resident’s oral condition, within a period of
9 one month following admission;

10 “(2) provision for adequate consultation in dentist-
11 ry and other fields, so as to properly evaluate the ability
12 of the patient to accept the treatment plan that results
13 from the diagnosis; and

14 “(3) a recall system that will assure that each resi-
15 dent is reexamined at specified intervals in accordance
16 with his needs, but at least annually.

17 “(e) Comprehensive treatment services for all residents
18 shall include—

19 “(1) provision for dental treatment, including the
20 dental specialties of pedodontics, orthodontics, periodon-
21 tics, prosthodontics, endodontics, oral surgery, and oral
22 medicine, as indicated; and

23 “(2) provision for emergency treatment on a
24 twenty-four-hour, seven-days-a-week basis, by a quali-
25 fied dentist.

1 “(f) Comprehensive preventive dentistry programs
2 should include—

3 “(1) fluoridation of the facility’s water supply;

4 “(2) topical and systemic fluoride therapy, as pre-
5 scribed by the dentist;

6 “(3) periodic oral prophylaxis, by a dentist or
7 dental hygienist, for each resident;

8 “(4) provisions for daily oral care, as prescribed
9 by a dentist or dental hygienist, including:

10 “(A) Toothbrushing and toothbrushing aids,
11 such as disclosing wafers;

12 “(B) tooth flossing;

13 “(C) irrigation;

14 “(D) proper maintenance of oral hygiene
15 equipment;

16 “(E) monitoring the program to assure its
17 effectiveness; and

18 “(5) provision, wherever possible, of diets in a
19 form that stimulates chewing and improvement of oral
20 health.

21 “(g) Education and training in the maintenance of oral
22 health shall include:

23 “(1) continuing inservice training of living-unit
24 personnel in providing proper daily oral health care for
25 residents;

1 “(2) providing dental health education to direct-
2 care personnel;

3 “(3) a dental hygiene program that includes:

4 “(A) discovery, development, and utilization
5 of specialized teaching techniques that are effective
6 for individual residents;

7 “(B) imparting information regarding nutri-
8 tion and diet control measures to residents and
9 staff;

10 “(C) instruction of classroom teachers and/or
11 students in proper oral hygiene methods;

12 “(D) motivation of teachers and students to
13 promote and maintain good oral hygiene;

14 “(E) instruction of residents in living units in
15 proper oral hygiene methods; and

16 “(4) instruction of parents or surrogates in the
17 maintenance of proper oral hygiene, where appropriate
18 (as in the case of facilities having day programs, or in
19 the case of residents leaving the facility).

20 “(h) A permanent dental record shall be maintained
21 for each resident. A summary dental progress report shall
22 be entered in the resident's unit record at stated intervals.
23 A copy of the permanent dental record shall be provided a
24 facility to which a resident is transferred.

25 “(i) When the facility has its own dental staff, there

1 should be a manual that states the philosophy of the dental
2 service and describes all dental procedures and policies.
3 There shall be a formal arrangement for providing qualified
4 and adequate dental services to the facility, including care
5 for dental emergencies on a twenty-four hour, seven-days-a-
6 week basis. A dentist, fully licensed to practice in the State
7 in which the facility is located, shall be designated to be
8 responsible for maintaining standards of professional and
9 ethical practice in the rendering of dental services to the
10 facility. Where appropriate, the facility should, in addition,
11 have available to it, and should utilize, the program-develop-
12 ment consultation services of a qualified dentist who has ex-
13 perience in the field of dentistry for the retarded and other
14 individuals with developmental disabilities.

15 “(j) There shall be available sufficient, appropriately
16 qualified dental personnel, and necessary supporting staff, to
17 carry out the dental services program. All dentists providing
18 services to the facility shall be fully licensed to practice in
19 the State in which the facility is located. All dental hygienists
20 providing services to the facility shall be licensed to practice
21 in the State in which the facility is located. Dental assistants
22 should be certified by an appropriate nationally recognized
23 professional association or should be enrolled in a program
24 leading to certification. Dental health educators shall have
25 a thorough knowledge of—

1 “(1) dental health; and

2 “(2) teaching methods.

3 “(k) Oral hygiene aides, who may supplement and
4 promote the proper daily oral care of residents, through actual
5 participation and development of new methods in the tooth-
6 brushing program, or in the dissemination of oral hygiene
7 information, should be—

8 “(1) thoroughly trained in current concepts and
9 procedures of oral care; and

10 “(2) trained to recognize abnormal oral conditions.

11 “(l) Supporting staff should include, as appropriate to
12 the program—

13 “(1) receptionists;

14 “(2) clerical personnel to maintain current dental
15 records;

16 “(3) dental laboratory technicians certified by the
17 appropriate nationally recognized professional associa-
18 tion;

19 “(4) escort aides; and

20 “(5) janitorial or housekeeping personnel.

21 “(m) All dentists providing service to the facility shall
22 adhere to the code of ethics published by the appropriate
23 nationally recognized professional association.

24 “SEC. 262. (a) Appropriate to the size of the facility, a
25 continuing education program shall be provided that is de-

1 signed to maintain and improve the skills and knowledge of
2 its professional dental personnel, through means including but
3 not limited to:

4 “(1) preceptor or other orientation programs;

5 “(2) participation in seminars, workshops, confer-
6 ences, institutes, or college or university courses, to the
7 extent of at least sixty clock hours annually for each
8 dental professional, in accordance with the standards of
9 the nationally recognized professional dental association
10 and its component societies;

11 “(3) study leave;

12 “(4) participation in the activities of professional
13 organizations that have as their goals the furtherance of
14 expertise in the treatment of the handicapped;

15 “(5) access to adequate library resources, including
16 current and relevant books and journals in dentistry,
17 dental hygiene, dental assisting, mental retardation, and
18 developmental disabilities;

19 “(6) encouragement of dentists to qualify them-
20 selves for staff privileges in hospitals; and

21 “(7) sharing of information concerning dentistry in
22 its relationship with mental retardation and develop-
23 mental disabilities as by publication.

24 “(b) To enrich and stimulate the facility’s dental pro-
25 gram, and to facilitate its integration with community serv-

1 ices, the facility should affiliate with, and provide educational
 2 experiences for the dental-career students of, dental schools,
 3 universities, colleges, technical schools, and hospitals, when-
 4 ever the best interests of the facility's residents are thereby
 5 served.

6 “(c) There shall be adequate space, facilities, and equip-
 7 ment to meet the professional, educational, and administra-
 8 tive needs of the dental service. General anesthesia facilities
 9 for dental care shall be available. The services of a certified
 10 dental laboratory shall be available. Appropriate dental con-
 11 sultation shall be employed in the planning, design, and
 12 equipage of new dental facilities, and in the modification
 13 of existing facilities. All dental facilities shall be free of
 14 architectural barriers for physically handicapped residents.

15 **“Subchapter III—Educational Services**

16 “SEC. 263. (a) Educational services, defined as de-
 17 liberate attempts to facilitate the intellectual, sensorimotor,
 18 and effective development of the individual, shall be avail-
 19 able to all residents, regardless of chronological age, degree
 20 of retardation, or accompanying disabilities or handicaps.
 21 There shall be a written statement of educational objec-
 22 tives that are consistent with the facility's philosophy and
 23 goals. The principle that learning begins at birth shall be
 24 recognized, and the expertise of early childhood educators

1 shall be integrated into the interdisciplinary evaluation and
2 programing for residents.

3 “(b) Educational services available to the facility
4 shall include but not be limited to—

5 “(1) establishment and implementation of individ-
6 ual educational programs providing:

7 “(A) continuous evaluation and assessment of
8 the individual;

9 “(B) programing for the individual;

10 “(C) instruction of individuals and groups;

11 “(D) evaluation and improvement of instruc-
12 tional programs and procedures;

13 “(2) participation in program development serv-
14 ices, including those relating to:

15 “(A) resident habilitation;

16 “(B) staff training;

17 “(C) community activities;

18 “(3) consultation with, or relating to:

19 “(A) other programs for residents and staff;

20 “(B) parents of residents;

21 “(C) administration and operation of the
22 facility;

23 “(D) the community served by the facility;

24 and

25 “(4) research relating to educational programs,

1 procedures, and techniques; and the interpretation, dis-
2 semination, and application of applicable research
3 findings.

4 “(c) Where appropriate, an educator shall be a mem-
5 ber of the interdisciplinary teams or groups concerned
6 with—

7 “(1) the total programing of each resident; and

8 “(2) the planning and development of the facility’s
9 programs for residents.

10 “(d) Individual educational evaluations of residents
11 shall:

12 “(1) commence with the admission of the resident;

13 “(2) be conducted at least annually;

14 “(3) be based upon the use of empirically reliable
15 and valid instruments, whenever such tools are avail-
16 able;

17 “(4) provide the basis for prescribing an appro-
18 priate program of learning experiences for the resident;

19 “(5) provide the basis for revising the individual
20 prescription as needed;

21 “(6) the reporting and dissemination of evalua-
22 tion results shall be done in such a manner as to—

23 “(A) render the content of the report mean-
24 ingful and useful to its intended recipient and user;
25 and

1 “(B) promptly provide information useful to
2 staff working directly with the resident.

3 “(e) There shall be written educational objectives for
4 each resident that are—

5 “(1) based upon complete and relevant diagnostic
6 and prognostic data;

7 “(2) stated in specific behavioral terms that permit
8 the progress of the individual to be assessed; and

9 “(3) adequate for the implementation, continuing
10 assessment, and revision, as necessary, of an individually
11 prescribed program.

12 “(f) There shall be evidence of educational activities
13 designed to meet the educational objectives set for every
14 resident. There shall be a functional educational record for
15 each resident, maintained by, and available to, the educator.

16 “(g) There shall be appropriate programs to implement
17 the facility's educational objectives. Wherever local resources
18 permit and the needs of the resident are served, residents
19 should attend educational programs in the community. Edu-
20 cable and trainable residents shall be provided an educational
21 program of a quality not less than that provided by public
22 school programs for comparable pupils, as regards:

23 “(1) physical facilities;

24 “(2) qualifications of personnel;

25 “(3) length of the school day;

1 “(4) length of school year;

2 “(5) class size;

3 “(6) provision of instructional materials and sup-
4 plies; and

5 “(7) availability of evaluative and other ancillary
6 services.

7 “(h) Educational programs shall be provided severely
8 and profoundly retarded or developmentally disabled resi-
9 dents, and all other residents for whom educational provisions
10 may not be required by State laws, irrespective of age or
11 ability.

12 “(i) Appropriate educational programs shall be pro-
13 vided residents with hearing, vision, perceptual, or motor
14 impairments, in cooperation with appropriate staff.

15 “(j) Educational programs should include opportunities
16 for physical education, health education, music education,
17 and art education, in accordance with the needs of the
18 residents being served.

19 “(k) A full range of instructional materials and media
20 shall be readily accessible to the educational staff of the
21 facility.

22 “(l) Educational programs shall provide coeducational
23 experiences. Learning activities in the classroom shall be
24 coordinated with activities of daily living in the living units
25 and with other programs of the facility and the community.

1 The facility shall seek reciprocal services to and from the
2 community, within the bounds of legality and propriety. An
3 educational program operated by a facility shall seek con-
4 sultation from educational agencies not directly associated
5 with the facility.

6 "SEC. 264. (a) There shall be available sufficient,
7 appropriately qualified educational personnel, and necessary
8 supporting staff, to carry out the educational programs.
9 Delivery of educational services shall be the responsibility of
10 a person who is eligible for—

11 "(1) certification as a special educator of the men-
12 tally retarded or other individuals with developmental
13 disabilities; and

14 "(2) the credential required for a comparable
15 supervisory or administrative position in the community.

16 "(b) Teachers shall be provided aides or assistants,
17 as needed. The facility's educators shall adhere to a code of
18 ethics prescribed by the Secretary. Appropriate to the nature
19 and size of the facility, there shall be an ongoing program
20 for staff development specifically designed for educators.
21 Staff members shall be encouraged to participate actively in
22 professional organizations related to their responsibilities.

23 "(c) To enrich and stimulate the facility's educational
24 program, and to facilitate its integration with community
25 services, opportunities for internships, student teaching, and

1 practicum experiences should be made available, in coopera-
2 tion with university teacher-training programs, whenever the
3 best interests of the residents are thereby served.

4 **"Subchapter IV—Food and Nutrition Services**

5 "SEC. 265. (a) Food and nutrition services shall be
6 provided in order to—

7 "(1) insure optimal nutritional status of each resi-
8 dent, thereby enhancing his physical, emotional, and
9 social well-being; and

10 "(2) provide a nutritionally adequate diet, in a form
11 consistent with developmental level, to meet the dietary
12 needs of each resident.

13 "(b) There shall be a written statement of policies and
14 procedures that—

15 "(1) describes the implementation of the stated ob-
16 jectives of the food and nutrition services;

17 "(2) governs the functions and programs of the
18 food and nutrition services;

19 "(3) is formulated and periodically reviewed by
20 professional nutrition personnel;

21 "(4) is prepared in consultation with other profes-
22 sional staff;

23 "(5) is consistent with the facility's goals and
24 policies;

- 1 “(6) is distributed and interpreted to all facility
2 personnel; and
3 “(7) complies with State and local regulations.
4 “(c) Whenever appropriate, the following services
5 should be provided—
6 “(1) initial and periodic evaluation of the nutri-
7 tional status of each resident, including—
8 “(A) determination of dietary requirements
9 and assessment of intake and adequacy through—
10 “(i) dietary interview;
11 “(ii) clinical evaluation;
12 “(iii) biochemical assessment;
13 “(B) assessment of food service practices;
14 “(C) assessment of feeding practices, capabili-
15 ties, and potential;
16 “(2) maintenance of a continuing and periodically
17 reviewed nutrition record for each resident;
18 “(3) incorporation of recommendations drawn from
19 the nutrition evaluation into the total management plans
20 for the resident;
21 “(4) periodic review of implementation of recom-
22 mendations and of need for modification;
23 “(5) participation in the continuing interdiscipli-
24 nary evaluation of individual residents, for the purposes

1 of initiation, monitoring, and followup of individualized
2 habilitation programs;

3 “(6) provision of—

4 “(A) counseling services to the individual resi-
5 dent;

6 “(B) reciprocal consultation services with fa-
7 cility staff and students;

8 “(C) counseling service to residents’ families
9 or their surrogates;

10 “(D) nutrition education, on a continuing basis,
11 for residents, families or surrogates, staff, and stu-
12 dents, and development of such programs in co-
13 ordination with various education programs within
14 the facility and the community;

15 “(7) coordination of nutrition programs between
16 the facility and the community, including—

17 “(A) development of awareness of available
18 programs in nutrition;

19 “(B) development of needed nutrition pro-
20 grams;

21 “(C) encouragement of participation of profes-
22 sionals and students in nutrition programs for the
23 mentally retarded and developmentally disabled; and

24 “(8) development, coordination, and direction of

1 nutrition research, as well as cooperation in interdisci-
2 plinary research.

3 “(d) Food services shall include—

4 “(1) menu planning;

5 “(2) initiating food orders or requisitions;

6 “(3) establishing specifications for food purchases,
7 and insuring that such specifications are met;

8 “(4) storing and handling of food;

9 “(5) food preparation;

10 “(6) food serving;

11 “(7) maintaining sanitary standards in compliance
12 with State and local regulations; and

13 “(8) orientation, training, and supervision of food
14 service personnel.

15 “(e) The food and nutrition needs of residents shall
16 be met in accordance with the recommended dietary allow-
17 ances of the food and nutrition board of the national research
18 council, adjusted for age, sex, activity, and disability, through
19 a nourishing, well-balanced diet. The total food intake of
20 the resident should be evaluated, including food consumed
21 outside of as well as within the facility.

22 “(f) Menus shall be planned to meet the needs of
23 the residents in accordance with subsection (e). Menus shall
24 be written in advance. The daily menu shall be posted in
25 food preparation areas. When changes in the menu are

1 necessary, substitutions should be noted and should provide
2 equal nutritive values. Menus shall provide a sufficient va-
3 riety of foods served in adequate amounts at each meal,
4 and shall be: (1) Different for the same days of each week;
5 (2) Adjusted for seasonal changes. Records of menus as
6 served shall be filed and maintained for at least thirty days.
7 At least a one-week supply of staple foods and a two-day
8 supply of perishable foods shall be maintained on the
9 premises. Records of food purchased for preparation shall
10 be filed and maintained for at least thirty days. A file of
11 tested recipes adjusted to appropriate yield should be
12 maintained.

13 “(g) Foods shall be prepared by methods that—

14 “(1) conserve nutritive value;

15 “(2) enhance flavor; and

16 “(3) enhance appearance.

17 “(h) Food shall be prepared, stored, and distributed in
18 a manner that assures a high quality of sanitation. Effective
19 procedures for cleaning all equipment and work areas shall
20 be followed consistently. Dishwashing and panwashing shall
21 be carried out in compliance with State and local health
22 codes. Handwashing facilities, including hot and cold water,
23 soap, and paper towels, shall be provided adjacent to work
24 area.

25 “(i) When food is transported, it shall be done in a

1 manner that maintains proper temperature, protects the food
 2 from contamination and spoilage, and insures the preserva-
 3 tion of nutritive value. Food storage procedures shall meet
 4 State and local regulations. Dry or staple food items shall be
 5 stored at least twelve inches above the floor, in a ventilated
 6 room not subject to sewage or waste water backflow, or
 7 contamination by condensation, leakage, rodents, or vermin.
 8 Perishable foods shall be stored at the proper temperatures
 9 to preserve nutritive values. Food served to residents and
 10 not consumed shall be discarded.

11 “(j) There shall be a sufficient number of competent
 12 personnel to fulfill the objectives of the food and nutrition
 13 services, including—

14 “(1) nutritionists or dietitians;

15 “(2) other food service personnel;

16 “(3) clerical personnel;

17 “(4) depending upon the size and scope of the
 18 facility, food and nutrition services shall be directed by
 19 one of the following—

20 “(A) a dietitian who is eligible for member-
 21 ship in the appropriate professional dietetic associa-
 22 tion, and preferably eligible for registration by such
 23 association, or a nutritionist who has a master’s
 24 degree in foods, nutrition, or public health nutrition,
 25 who is eligible for membership in the appropriate

1 professional dietetic association, and preferably
2 eligible for registration by the association, and who,
3 unless employed by a facility that also employs a
4 dietitian, has had experience in institutional food
5 management;

6 “(B) a food service manager who has a bache-
7 lor’s degree in foods, nutrition, or a related field, and
8 who receives consultation from a dietary consultant;

9 “(C) a responsible person who has had training
10 and experience in meal management and service,
11 and who receives consultation from a dietary con-
12 sultant; and

13 “(D) the person responsible for food and nu-
14 trition services should have had training or experi-
15 ence in providing services to the mentally retarded,
16 and other individuals with developmental disabilities
17 and should be sensitive to their needs;

18 “(5) the dietary consultant shall—

19 “(A) be eligible for membership in the appro-
20 priate professional dietetic association, and prefer-
21 ably eligible for registration by such association;

22 “(B) serve on a regularly scheduled and fré-
23 quent basis when no full-time dietitian is available;
24 and

25 “(6) every person engaged in the preparation and

1 serving of food in the facility shall have a valid food
2 handler's permit, as required by State or local regu-
3 lations. No person who is afflicted with a disease in a
4 communicable stage, or who is a carrier of a com-
5 municable disease, or who has an open wound, shall
6 work in any food service operation. Every person en-
7 gaged in the preparation and serving of food in the
8 facility shall annually be medically determined to be
9 free of any disease in a communicable stage. All dieti-
10 tians and nutritionists shall adhere to the code of ethics
11 of the appropriate professional dietetic association.

12 “(k) Appropriate to the size of the facility, an ongo-
13 ing inservice training program shall be conducted that is
14 designed to improve and maintain the skills of its food and
15 nutrition services staff, through means such as—

16 “(1) seminars, workshops, conferences, and insti-
17 tutes;

18 “(2) college and university courses;

19 “(3) participation in professional organizations;

20 “(4) participation in interdisciplinary groups;

21 “(5) visitations to other facilities; and

22 “(6) access to adequate library resources, including
23 current and relevant books and journals in nutrition and
24 mental retardation.

25 “(l) Opportunities should be provided, in cooperation

1 with university and other training programs, for students to
 2 obtain practical experience, under appropriate supervision,
 3 whenever the best interests of the residents are thereby
 4 served.

5 “(m) There shall be adequate space, facilities, and
 6 equipment to fulfill the professional, educational, administra-
 7 tive, operational, and research needs of the food and nutri-
 8 tion services. Dining areas and facilities for food storage,
 9 preparation, and distribution shall be—

10 “(1) designed in cooperation with a dietitian and,
 11 when appropriate, with assistance from a qualified food
 12 service and equipment consultant;

13 “(2) adequate for the storage and preservation of
 14 food;

15 “(3) in compliance with State and local sanitation
 16 and other requirements;

17 “(4) adequate for the preparation and serving of
 18 food; and

19 “(5) adequate for sanitary storage for all dishes
 20 and equipment.

21 “Subchapter V—Library Services

22 “SEC. 266. (a) Library services, which include the
 23 location, acquisition, organization, utilization, retrieval, and
 24 delivery of materials in a variety of media, shall be available
 25 to the facility, in order to support and strengthen its total

1 habilitation program by providing complete and integrated
2 multimedia information services to both staff and residents.
3 Library services shall make available to the facility the
4 resources of local, regional, State, and National library
5 systems and networks. Library services shall be available to
6 all residents, regardless of chronological age, degree of
7 retardation, level of communication skills, or accompanying
8 disabilities or handicaps.

9 “(b) Library services to residents shall be rendered—

10 “(1) directly, through personal contact between
11 library staff and residents;

12 “(2) indirectly, through contact between librarians
13 and other persons working with the residents, designed
14 to—

15 “(A) maintain an atmosphere that recognizes
16 the rights of the resident to access to information
17 and to personal use of library materials appropriate
18 to his level of development in communication skills
19 or to his desire to conform to peer groups; and

20 “(B) enhance interpersonal relationships be-
21 tween direct-care workers and residents, through the
22 mutual enjoyment of written, recorded, or oral
23 literature appropriate to the resident’s level of
24 development and preference.

1 “(c) Library services available to residents should
2 include—

3 “(1) assistance in team evaluation and assessment
4 of the individual's level of development in communica-
5 tion skills, such as listening, comprehension, reading,
6 and ability to respond to stimuli in a wide range and
7 variety of media;

8 “(2) provision of informational, recreational, and
9 educational materials appropriate to individual residents
10 at all stages of development in communication skills,
11 including media to stimulate sensory development, both
12 in the library and in the living unit. Such materials
13 should include, but need not be limited to—

14 “(A) books, including picture, juvenile, adult,
15 high interest-low vocabulary, large print, and talk-
16 ing books;

17 “(B) magazines, including juvenile, adult pic-
18 torial, and magazines on talking books;

19 “(C) newspapers;

20 “(D) audiovisual media, including films, film-
21 strips, slides, video tapes, audio tapes, and records,
22 and appropriate equipment;

23 “(E) graphics;

1 “(F) experient materials, such as manipula-
2 tive materials, toys and games, realia, and animals;

3 “(3) development of programs for individual or
4 group enjoyment, for development of communication
5 skills, for encouragement and satisfaction of natural hu-
6 man curiosity about anything, including sex and the facts
7 of life, and for general enhancement of self-image. These
8 programs should include, but need not be limited to—

9 “(A) storytelling, with listener participation
10 through games or other activities;

11 “(B) reading aloud, including ‘reading’ pic-
12 tures;

13 “(C) film or filmstrip programs;

14 “(D) listening to recorded media;

15 “(E) media discussion groups;

16 “(F) library clubs;

17 “(G) touching, browsing, exploring, or naming
18 sensory stimuli;

19 “(H) creative writing, including group compo-
20 sition through dictation, tape recording, etc.;

21 “(I) puppetry, including the making of pup-
22 pets;

23 “(J) creative dramatics;

24 “(4) opportunities to visit, and make use of, com-
25 munity library services and facilities in the same manner,

1 and on the same terms, as any resident of the com-
 2 munity;

3 “(5) referral services to the community library
 4 most convenient to place of residence or employment,
 5 when the resident leaves the facility; and

6 “(6) active participation in, and encouragement
 7 of, library programs related to the educational and habili-
 8 tative services of the facility, including the supplementa-
 9 tion, support, and reinforcement of school programs.

10 “(d) Librarians providing service to residents should
 11 act as advocates on their behalf if facility policies or com-
 12 munity library policies interfere with the retarded or develop-
 13 mentally disabled person's freedom to read materials of his
 14 own choosing or if they deny or abrogate his right to infor-
 15 mation or access to library services of any kind, in accordance
 16 with the standards adopted by the appropriate professional
 17 library association.

18 “(e) Library services to staff should include—

19 “(1) selection, acquisition, organization, classifica-
 20 tion, cataloging, procurement through interlibrary loan,
 21 and dissemination of informational, educational, and in-
 22 structional library materials and audiovisual equipment;

23 “(2) provision of reference and bibliographic mate-
 24 rials and services, literature searches, bibliography com-
 25 pilation, indexing and abstracting services, and other

1 guides to the literature relevant to mental retardation
2 and developmental disabilities;

3 “(3) acquisition of material for evaluation for pur-
4 chase;

5 “(4) provision of a current awareness program to
6 alert staff to new materials and developments in their
7 fields;

8 “(5) orientation to library services and functions,
9 including continuing instruction and assistance in the use
10 of informational sources, and participation in general
11 orientations to the facility;

12 “(6) provision of written and oral translation serv-
13 ices; and

14 “(7) cooperation in inservice training programs by
15 working with subject specialists and by recommending,
16 providing, or producing materials in various media.

17 “(f) Library services to the facility may include—

18 “(1) provision of informational materials about the
19 facility and mental retardation developmental disabilities
20 in general, through an organized collection of resources;

21 “(2) assistance with such public relation functions
22 as preparing brochures, program statements, annual re-
23 ports, writing news releases and feature stories, and of-
24 fering editorial and research assistance to staff preparing
25 professional books and papers; and

1 “(3) assistance in preparing grant applications and
2 report writing.

3 “(g) When library services are provided in the facility—

4 “(1) there shall be a written statement of objectives
5 that make possible a well-conceived, comprehensive,
6 long-range program of library development, consistent
7 with the overall goals of the facility, adapted to the needs
8 and aptitudes of the residents, and designed to be modi-
9 fied as the program of the facility changes;

10 “(2) there shall be a separate budget, adequate to
11 carry out the program in accordance with stated goals
12 and objectives;

13 “(3) library services shall be placed within the
14 organizational structure of the facility in such a way as
15 to be available to, and maximally utilized by, all relevant
16 services and programs;

17 “(4) there shall be written policies covering the
18 library's day-to-day activities, and the coordination of
19 these activities with those of other services of the facility
20 and with related activities in the community;

21 “(5) there shall be available sufficient, appropri-
22 ately qualified staff, and necessary supporting personnel,
23 to carry out the program in accordance with stated goals
24 and objectives;

25 “(6) a qualified librarian shall be responsible for all

1 library services. Where the level of need for services
2 does not require the full-time employment of a pro-
3 fessional librarian, coverage may be through the use of
4 consultant service or supervisory personnel, through the
5 pooling of resources and the sharing of services by two
6 or more facilities in a geographic area, or through serv-
7 ice supplied through a regional library system;

8 “(7) the librarian shall participate, when appro-
9 priate, in the interdisciplinary planning, development,
10 and evaluation of facility programs;

11 “(8) the librarian should coordinate the purchasing
12 of all print and nonprint materials for the facility, and
13 act as the facility’s informed agent in initiating the
14 purchase of print and nonprint materials, and the library
15 should serve as clearing house for such holdings;

16 “(9) librarians should participate in—

17 “(A) educating appropriate members of the
18 community, concerning the library needs of resi-
19 dents;

20 “(B) planning, with community librarians, the
21 utilization of library resources to optimize resident
22 adjustment;

23 “(C) developing appropriate expectancies and
24 attitudes within community libraries that residents
25 will use;

1 “(10) appropriate relationships with other libraries
2 and community agencies shall be established to more
3 effectively accomplish the library’s service functions;

4 “(11) appropriate to the size of the facility, there
5 should be a staff development program designed to main-
6 tain and improve the skills of library services staff
7 through means such as—

8 “(A) staff meetings and inservice training;

9 “(B) seminars, workshops, conferences, and
10 institutes;

11 “(C) college and university courses;

12 “(D) professional organizations;

13 “(E) participation in interdisciplinary groups;

14 “(F) visits to other facilities;

15 “(G) access to relevant professional literature;

16 “(12) whenever appropriate, the library should
17 provide training for beginning librarians, further the
18 orientation and training of library assistants, technicians,
19 or volunteers, and serve as a training center for library
20 institutes or workshops;

21 “(13) library services should be located so as to
22 be convenient and accessible to all users;

23 “(14) all library functions should be integrated
24 within a centralized location, whenever this does not act
25 as a barrier to accessibility for any group;

1 “(15) space, physical facilities, and equipment shall
2 be adequate to carry out the program, and shall comply
3 with the standards for library services in health care
4 institutions published by the appropriate professional
5 library association of hospitals and institutions of the
6 appropriate professional library association;

7 “(16) the hours during which the library is open
8 should meet the requirements of the majority of the
9 library’s users, and should be as generous as possible;
10 and

11 “(17) users of library services shall participate in
12 the planning and evaluation of library programs, by
13 means such as advisory committees.

14 “(h) If library services are provided outside the facility,
15 there shall be a formal agreement that stipulates lines of com-
16 munication, areas of responsibility, and kinds of service.

17 “(i) The individual responsible for maintaining stand-
18 ards of professional and ethical practice in the rendering of
19 library services to the facility—

20 “(1) shall have a master’s degree in library science
21 from a school accredited by the recognized national
22 professional library association; and

23 “(2) should have preparation in a field relevant to
24 work with the mentally retarded and other individuals
25 with developmental disabilities.

1 “(j) Individual rendering library services, including
 2 librarians, media specialists, library and media technicians,
 3 supportive staff, and volunteers, shall have qualifications
 4 appropriate to their responsibilities and duties.

5 **“Subchapter VI—Medical Services**

6 “SEC. 267. (a) Medical services shall be provided in
 7 order to—

8 “(1) achieve and maintain an optimal level of
 9 general health for each resident;

10 “(2) maximize normal function and prevent dis-
 11 ability; and

12 “(3) facilitate the optimal development of each
 13 resident.

14 “(b) Medical services shall be rendered—

15 “(1) directly, through personal contact between
 16 physicians and residents; and

17 “(2) indirectly, through contact between physi-
 18 cians and other persons working with the residents,
 19 which is designed to maintain an environment that rec-
 20 ognizes and meets the health, hygiene, sanitary, and
 21 nutritional needs of the residents.

22 “(c) Medical services available to the residential facil-
 23 ity should include—

24 “(1) evaluation and diagnosis;

25 “(2) treatment;

1 “(3) program development services, including
2 those relating to—

3 “(A) resident habilitation;

4 “(B) staff training;

5 “(C) community participation;

6 “(4) consultation with, or relating to—

7 “(A) residents;

8 “(B) families of residents;

9 “(C) the administration and operation of the
10 facility;

11 “(5) medical and ancillary staff training; and

12 “(6) preventive health services for residents and
13 staff.

14 “(d) The services of medical and surgical hospitals that
15 are accredited by the recognized national appropriate joint
16 commission on accreditation of hospitals shall be available
17 to residents. Only pathology, clinical laboratory, and radio-
18 logic services that meet the hospital accreditation standards
19 of such joint commission on accreditation of hospitals
20 shall be utilized. Electroencephalographic services shall be
21 available as necessary. There shall be evidence, such as may
22 be provided by a record of the deliberations of a utilization
23 review committee, that such hospital and laboratory services
24 are utilized in accordance with proper professional standards.

25 “(e) Physicians shall participate, when appropriate—

1 “(1) in the continuing interdisciplinary evaluation
2 of individual residents, for the purposes of initiation,
3 monitoring, and followup of individualized habilitation
4 programs; and

5 “(2) in the development for each resident of a de-
6 tailed, written statement of—

7 “(A) case management goals, encompassing
8 the areas of physical and mental health, education,
9 and functional and social competence; and

10 “(B) a management plan detailing the various
11 habilitation or rehabilitation modalities that are to
12 be applied in order to achieve the specified goals;
13 with clear designation of responsibility for imple-
14 mentation.

15 “(f) The management plan shall ordinarily include, but
16 not necessarily be limited to—

17 “(1) the resident's day-to-day activity program;

18 “(2) physical rehabilitation to prevent and correct
19 deformity, to enhance mobility, and to facilitate train-
20 ing in self-help skills;

21 “(3) provision for adaptive equipment necessary
22 to the rehabilitation plan;

23 “(4) an educational program;

24 “(5) a vocation and occupational program;

1 “(6) stated intervals for review of the manage-
2 ment plan; and

3 “(7) short- and long-term goals, including criteria
4 for release.

5 “(g) Statement of treatment goals and management
6 plans shall be reviewed and updated—

7 “(1) as needed, but at least annually; and

8 “(2) to insure continuing appropriateness of the
9 goals, consistency of management methods with the
10 goals, and the achievement of progress toward the goals.

11 “(h) Special attention shall be given those residents
12 who, without active intervention, are at risk of further loss
13 of function, by means that include—

14 “(1) early diagnosis of disease;

15 “(2) prompt treatment in the early stages of
16 disease;

17 “(3) limitation of disability by arresting the dis-
18 ease process;

19 “(4) prevention of complications and sequelae;
20 and

21 “(5) rehabilitation services to raise the affected
22 individual to his greatest possible level of function, in
23 spite of his handicap, by maximizing the use of his
24 remaining capabilities.

1 “(i) Preventive health services to residents shall
2 include—

3 “(1) means for the prompt detection and referral
4 of health problems, through adequate medical surveil-
5 lance, periodic inspection, and regular medical examina-
6 tion;

7 “(2) annual physical examinations, that include—

8 “(A) examination of vision and hearing;

9 “(B) routine screening laboratory examina-
10 tions, as determined by the physician, and special
11 studies when the index of suspicion is high;

12 “(3) maintenance of a graphic record of height
13 and weight for each resident, in a form that permits
14 ready reference to standardized norms;

15 “(4) immunizations, using as a guide the recom-
16 mendations of the United States Public Health Service
17 Advisory Committee on Immunization Practices and of
18 the appropriate committee on the control of infectious
19 diseases of the appropriate medical specialty association;

20 “(5) tuberculosis control, in accordance with the
21 recommendations of the appropriate medical specialty
22 association as appropriate to the facility's population;
23 and

1 “(6) reporting of communicable diseases and in-
2 fections in accordance with law.

3 “(j) Preventive health services to staff shall include—

4 “(1) preemployment physical examinations; and

5 “(2) surveys for the detection and prevention of
6 communicable diseases.

7 “(k) There shall be a formal arrangement for qualified
8 medical care for the facility, including care for medical
9 emergencies on a twenty-four-hour, seven-days-a-week basis.
10 A physician, fully licensed to practice medicine in the State
11 in which the facility is located, shall be designated to be
12 responsible for—

13 “(1) maintaining standards of professional and
14 ethical practice in the rendering of medical services in
15 the facility; and

16 “(2) maintaining the general health conditions
17 and practices of the facility and/or system of health
18 services.

19 Each resident shall have a personal (primary) physician,
20 who maintains familiarity with his state of health and with
21 conditions within the residential living unit that bear on his
22 health. Qualified medical specialists of recognized profes-
23 sional ability shall be—

24 “(1) available for a broad range of specialized
25 care and consultation; and

1 “(2) appropriately used.

2 “(1) Appropriate to the size of the facility, an ongoing
3 inservice training program shall be conducted that is de-
4 signed to maintain and improve the medical skills of its phy-
5 sicians and their knowledge of developmental disabilities,
6 through methods such as staff seminars, outside speakers,
7 attendance at professional medical meetings, and informa-
8 tional exchanges with universities and teaching hospitals.

9 “(m) There shall be adequate space, facilities, and
10 equipment to fulfill the professional, educational, and ad-
11 ministrative needs of the medical service.

12 **“Subchapter VII—Nursing Services**

13 “SEC. 268. (a) Residents shall be provided with nurs-
14 ing services, in accordance with their needs, in order to—

15 “(1) develop and maintain an environment that
16 will meet their total health needs;

17 “(2) foster optimal health;

18 “(3) encourage maximum self-care and independ-
19 ence; and

20 “(4) provide skilled nursing care as needed.

21 “(b) There shall be a written statement of nursing phi-
22 losophy and objectives that are consistent with the purpose
23 of the facility and that give direction to the nursing pro-
24 gram. Nursing personnel shall be responsible for the formu-

1 lation, review, and revision of the philosophy and objectives.

2 The philosophy and objectives shall be—

3 “(1) distributed to all nursing personnel; and

4 “(2) made available and interpreted to all other
5 personnel.

6 “(c) Nursing services should be provided through—

7 “(1) direct nursing intervention;

8 “(2) instruction and supervision of facility staff
9 rendering nursing care;

10 “(3) supporting, counseling, and teaching the resi-
11 dent, his family, and his direct-care staff, at the facility
12 or in the home;

13 “(4) consultation and followthrough in the interest
14 of the resident; and

15 “(5) participation on appropriate facility com-
16 mittees.

17 “(d) Nursing services to residents shall include, when
18 appropriate—

19 “(1) professional nurse participation in—

20 “(A) the preadmission evaluation study and
21 plan;

22 “(B) the evaluation study, program design,
23 and placement of the resident at the time of admis-
24 sion to the facility;

1 “(C) the periodic reevaluation of the type, ex-
2 tent, and quality of services and programing;

3 “(D) the development of discharge plans;

4 “(E) the referral to appropriate community
5 resources;

6 “(2) services directed toward the promotion of
7 health, including—

8 “(A) observation and assessment of the devel-
9 opmental function of the resident, within his
10 environment;

11 “(B) training in habits of personal hygiene;

12 “(C) family life and sex education;

13 “(D) safety education;

14 “(E) control of communicable diseases and
15 infections, through—

16 “(i) identification and assessment;

17 “(ii) reporting to medical authority;

18 “(iii) implementation of appropriate pro-
19 tective and preventive measures;

20 “(F) development of a written plan for nursing
21 action, in relation to the total habilitation program;

22 “(G) modification of the nursing plan, in terms
23 of the resident's daily needs, at least annually for
24 adults and more frequently for children, in accord-
25 ance with developmental changes;

1 “(3) participation in the prevention of disability for
2 all residents, with special attention to those residents who
3 exhibit the lowest level of functional development,
4 including—

5 “(A) nursing assessment of the functional level
6 of development;

7 “(B) development, implementation, and coor-
8 dination of a plan to maintain and encourage optimal
9 level of function, with written provision for direct
10 and indirect nursing intervention; and

11 “(4) planned, intensive nursing care for every resi-
12 dent who is medically determined to be acutely ill.

13 “(e) A professional nurse shall participate, as appropri-
14 ate, in the planning and implementation of training of facility
15 personnel. Direct-care personnel shall be trained in—

16 “(1) detecting signs of illness or dysfunction that
17 warrant medical or nursing intervention;

18 “(2) basic skills required to meet the health needs
19 and problems of the residents; and

20 “(3) first aid in the presence of accident or illness.

21 “(f) Qualified nurses shall be encouraged to become in-
22 volved in—

23 “(1) initiating, conducting, and evaluating nursing
24 research;

1 “(2) evaluating and applying relevant research
2 findings for the benefit of residents;

3 “(3) formulating the policies governing research
4 in the facility; and

5 “(4) serving as resource persons to schools of nurs-
6 ing, and to public health nursing and related agencies.

7 “(g) There shall be available sufficient, appropriately
8 qualified nursing staff, which may include currently licensed
9 practical nurses and other supporting personnel, to carry out
10 the various nursing service activities. A registered profes-
11 sional nurse shall be designated as being responsible for
12 maintaining standards of professional, legal, and ethical
13 practice in the delivery of nursing services according to the
14 needs of the residents. The individual responsible for the
15 delivery of nursing services—

16 “(1) should have at least a master's degree in
17 nursing; and

18 “(2) shall have knowledge and experience in the
19 field of developmental disabilities.

20 “(h) Nursing service personnel at all levels of experi-
21 ence and competence shall be—

22 “(1) assigned responsibilities in accordance with
23 their qualifications;

1 “(2) delegated authority commensurate with their
2 responsibility; and

3 “(3) provided appropriate professional nursing
4 supervision.

5 “(i) Organized nursing services and professional nurse
6 practitioners should have recourse to qualified and appro-
7 priate consultation as needed. All professional nurses shall
8 be familiar with, and adhere to, the code of ethics published
9 by the appropriate nationally recognized professional nurses’
10 association.

11 “(j) Appropriate to the size of the facility, there shall
12 be an educational program designed to enhance the clinical
13 competencies and the knowledge of developmental disabili-
14 ties of its professional nursing staff, through means, including
15 but not limited to—

16 “(1) staff meetings and inservice training;

17 “(2) seminars, workshops, conferences, and insti-
18 tutes;

19 “(3) college and university courses;

20 “(4) participation in professional organizations;

21 “(5) participation in interdisciplinary groups;

22 “(6) visits to other facilities; and

23 “(7) access to relevant professional literature.

24 “(k) To enrich and stimulate the facility’s nursing pro-
25 gram, and to facilitate its integration with community serv-

1 ices, educational experiences for students of all types of
 2 professional and vocational nursing schools shall be encour-
 3 aged and defined by a contractual agreement, whenever the
 4 best interests of the residents are thereby served.

5 “(1) There shall be adequate space, facilities, and equip-
 6 ment to fulfill the professional, educational, and administra-
 7 tive needs of the nursing service. Professional nursing con-
 8 sultation shall be included in the design and modification of
 9 areas and facilities that will be used by the ill and the
 10 physically handicapped.

11 **“Subchapter VIII—Pharmacy Services**

12 “SEC. 269. (a) In order to contribute to improved
 13 resident care and to promote optimal response to drug ther-
 14 apy by the residents, through the full utilization of the
 15 knowledge and skills of the pharmacist, pharmacy services
 16 shall be provided under the direction of a qualified pharma-
 17 cist. There shall be a formal arrangement for qualified phar-
 18 macy services, including provision for emergency service, by
 19 means appropriate to the facility. Such means may include
 20 the services of a pharmacist in a local community or hospital
 21 pharmacy that meet the standards listed herein, as well as
 22 the operation of its own pharmacy by the facility. There
 23 shall be a current pharmacy manual that—

24 “(1) includes policies and procedures, and defines

1 the functions and responsibilities relating to pharmacy
2 services; and

3 “(2) is revised annually to keep abreast of current
4 developments in services and management techniques.

5 “(b) There shall be a formulary system, approved by
6 the responsible physician and pharmacist, and by other ap-
7 propriate facility staff. Copies of the facility’s formulary and
8 of the nationally recognized American hospital formulary
9 service shall be located and available, as appropriate to the
10 facility.

11 “(c) Upon admission of the resident, a medication his-
12 tory of prescription and nonprescription drugs used shall be
13 obtained, preferably by the pharmacist, and this information
14 shall be entered in the resident’s record for the information
15 of the staff. The pharmacist shall—

16 “(1) receive the original, or a direct copy, of the
17 physician’s drug treatment order;

18 “(2) review the drug regimen, and any changes,
19 for potential adverse reactions, allergies, interactions,
20 contraindications, rationality, and laboratory test modi-
21 fications, and advise the physician of any recommended
22 changes, with reasons and with an alternate drug
23 regimen;

24 “(3) maintain for each resident an individual record

1 of all medications (prescription and nonprescription)
2 dispensed, including quantities and frequency of refills;

3 “(4) participate, as appropriate, in the continuing
4 interdisciplinary evaluation of individual residents, for
5 the purposes of initiation, monitoring, and followup of
6 individualized habilitation programs;

7 “(5) participate in any of the following activities
8 that are undertaken in the facility:

9 “(A) drug research;

10 “(B) drug utilization review;

11 “(C) infection and communicable disease com-
12 mittee;

13 “(D) safety committee;

14 “(E) patient care incident review; and

15 “(6) establish quality specifications for drug pur-
16 chases, and insure that they are met.

17 “(d) The pharmacist should—

18 “(1) prepare a drug treatment plan, as prescribed
19 by the attending physician, for inclusion in the resident’s
20 record and for use by the staff, that includes—

21 “(A) the drug product, dosage form, route of
22 administration, and time of administration, includ-
23 ing, when appropriate, the time with respect to
24 meals, other drugs, and activities;

1 “(B) a schedule of laboratory tests necessary to
2 detect adverse reactions;

3 “(C) nothing of any potential adverse reactions
4 for the staff's information;

5 “(2) regularly review the record of each resident
6 on medication, and have contact with selected residents
7 with potential problems, noting in the residents' records
8 and reporting to physicians any observations of response
9 to drug therapy, and of adverse reactions and over or
10 underutilization of drugs;

11 “(3) provide instructions and counseling on the
12 correct use of his drugs, as prescribed by the attending
13 physician, to each resident on home visit and discharge,
14 and/or to this parents;

15 “(4) provide education and counseling to residents
16 in independent living units on the correct use of their
17 drugs, as prescribed by the attending physician, and
18 on the results expected from correct use and from
19 over or underuse;

20 “(5) participate in programs for sex education and
21 drug abuse education;

22 “(6) provide information on the resident's drug
23 regimen to the receiving facility pharmacist, when the
24 resident is transferred, and, with the approval of the
25 resident or his guardian, to the resident's community

1 pharmacist, his private physician, and/or the com-
2 munity mental retardation or developmental disability
3 service when the resident is discharged from the facility,
4 so as to insure continuity of care;

5 “(7) participate in inservice education programs
6 for professional and direct-care staff;

7 “(8) orient and teach students in pharmacy and
8 other professions, regarding pharmacy’s services to the
9 residents and regarding drugs and their uses; and

10 “(9) participate in public educational and informa-
11 tional programs on mental retardation and develop-
12 mental disabilities.

13 “(e) Where appropriate to the facility, there shall be
14 a pharmacy and therapeutics committee, that includes one
15 or more pharmacists, to develop policy on drug usage in the
16 facility, and to develop and maintain a current formulary.
17 This committee shall meet not less than once every three
18 months. Minutes of the committee meetings shall be kept
19 on file.

20 “(f) Written policies and procedures that govern the
21 safe administration and handling of all drugs shall be devel-
22 oped by the responsible pharmacist, physician, nurse, and
23 other professional staff, as appropriate to the facility. The
24 compounding, packaging, labeling, and dispensing of drugs,
25 including samples and investigational drugs, shall be done

1 by the pharmacist, or under his direct supervision, with
2 proper controls and records. Each drug shall be identified
3 up to the point of administration. Procedures shall be estab-
4 lished for obtaining drugs when the pharmacy is closed.

5 “(g) The unit dose or individual prescription system
6 of drug distribution should be used. Wherever possible,
7 drugs that require dosage measurement shall be dispensed
8 by the pharmacist in a form ready to be administered to
9 the patient.

10 “(h) There shall be a written policy regarding the ad-
11 ministration of all drugs used by the residents, including
12 those not specifically prescribed by the attending practitioner.
13 There shall be a written policy regarding the routine of
14 drug administration, including standardization of abbrevia-
15 tions indicating dose schedules. Medications shall not be used
16 by any resident other than the one for whom they were is-
17 sued. Only appropriately trained staff shall be allowed to
18 administer drugs.

19 “(i) There shall be a written policy governing the self-
20 administration of drugs, whether prescribed or not.

21 “(j) Drugs shall be stored under proper conditions of
22 sanitation, temperature, light, moisture, ventilation, segre-
23 gation, and security. All drugs shall be kept under lock and
24 key except when authorized personnel are in attendance.
25 The security requirements of Federal and State laws shall be

1 satisfied in storerooms, pharmacies, and living units. Poisons,
2 drugs used externally; and drugs taken internally shall be
3 stored on separate shelves or in separate cabinets, at all lo-
4 cations. Medications that are stored in a refrigerator con-
5 taining things other than drugs shall be kept in a separate
6 compartment with proper security. A perpetual inventory
7 shall be maintained of each narcotic drug in the pharmacy,
8 and in each unit in which such drugs are kept, and inventory
9 records shall show the quantities of receipts and issues and
10 the person to whom issued or administered. If there is a
11 drug storeroom separate from the pharmacy, there shall be
12 a perpetual inventory of receipts and issues of all drugs by
13 such storeroom.

14 “(k) The pharmacist should review the drugs in each
15 living unit monthly, and should remove outdated and de-
16 teriorated drugs and drugs not being used. Discontinued and
17 outdated drugs, and containers with worn, illegible, or miss-
18 ing labels, shall be returned to the pharmacy for proper
19 disposition.

20 “(l) There shall be automatic stop orders on all drugs.
21 There shall be a drug recall procedure that can be readily
22 implemented. Medication errors and drug reactions shall be
23 recorded and reported immediately to the practitioner who
24 ordered the drug. There shall be a procedure for reporting
25 adverse drug reactions to the Federal Food and Drug Ad-

1 ministration. The pharmacist shall be responsible for the stor-
2 age and dispensing of investigational drugs. The pharmacist
3 shall provide the residential staff with pharmacological and
4 other necessary information on investigational drugs, includ-
5 ing dosage form, dosage range, storage, adverse reactions,
6 usage, and contraindications.

7 “(m) There shall be an emergency kit—

8 “(1) readily available to each living unit; and

9 “(2) constituted so as to be appropriate to the needs
10 of its residents.

11 “(n) Pharmacy services shall be—

12 “(1) directed by a professionally competent and
13 legally qualified pharmacist who is a graduate of a
14 school of pharmacy accredited by the American Council
15 on Pharmaceutical Education, or its equivalent, and who
16 serves on a full-time or part-time basis, as the activity
17 of the service requires;

18 “(2) staffed by a sufficient number of competent
19 personnel, consistent with the facility’s needs, and in-
20 cluding—

21 “(A) pharmacists necessary to provide com-
22 prehensive pharmacy services;

23 “(B) technicians and clerical personnel to re-
24 lieve the pharmacist of nonprofessional and clerical
25 duties;

1 “(3) pharmacists should have had training and/or
2 experience in providing services to the mentally retarded
3 and other individuals with developmental disabilities, and
4 should be sensitive to their needs; and

5 “(4) all pharmacists shall be familiar with, and ad-
6 here to, the code of ethics of the nationally recognized
7 professional pharmaceutical association.

8 “(o) Appropriate to the size of the facility, there should
9 be a staff development program, designed to maintain and
10 improve the skills of its pharmacy staff through means, in-
11 cluding but not limited to:

12 “(1) staff meetings and inservice training;

13 “(2) seminars, workshops, conferences, and insti-
14 tutes;

15 “(3) college and university courses;

16 “(4) participation in professional organizations;

17 “(5) participation in interdisciplinary groups;

18 “(6) visits to other facilities; and

19 “(7) access to relevant professional literature.

20 “(p) The pharmacy serving the facility shall—

21 “(1) have sufficient space for necessary compound-
22 ing, dispensing, labeling, and packaging functions;

23 “(2) have the equipment necessary for compound-
24 ing, dispensing, issuing, storing, and administrative
25 functions;

1 “(3) be clean and orderly; and

2 “(4) contain current pharmaceutical reference ma-
3 terial to provide adequate information concerning drugs.

4 “(q) Space for the storage of drugs in the storeroom,
5 pharmacy, and living units shall be sufficient to prevent
6 crowding of the drugs. There shall be adequate drug prepa-
7 ration areas, that are—

8 “(1) properly secured;

9 “(2) well lighted; and

10 “(3) located so that personnel will not be inter-
11 rupted when handling drugs.

12 “(r) If the facility operates its own pharmacy, there
13 should be—

14 “(1) an office for the pharmacist; and

15 “(2) a private area for instructing and counseling
16 residents and/or parents on the correct use of drugs.

17 **“Subchapter IX—Physical and Occupational Therapy**

18 **Services**

19 “SEC. 270. (a) Although this subsection combines
20 standards for physical and occupational therapy, each is a
21 discrete service that complements the other in a manner
22 similar to their relationship with all other health and med-
23 ically related services. Both services, therefore, shall be pro-
24 vided, or made available to, residents on a continuing basis,

1 as needed. Physical and occupational therapy services shall
2 be provided in order to—

3 “(1) prevent abnormal development and further
4 disability;

5 “(2) facilitate the optimal development of each
6 resident; and

7 “(3) enable the resident to be a contributing and
8 participating member of the community in which he
9 resides.

10 The facility shall have a written statement of its physical
11 therapy and occupational therapy objectives for its residents,
12 consistent with—

13 “(1) the needs of the residents;

14 “(2) currently accepted physical therapy and occu-
15 pational therapy theories, principles, and goals;

16 “(3) the philosophy and goals of the facility; and

17 “(4) the services and resources provided.

18 Physical and occupational therapy services shall be pro-
19 vided—

20 “(1) directly, through personal contact between
21 therapists and residents;

22 “(2) indirectly, through contact between therapists
23 and other persons involved with the residents, to:

24 “(A) create and maintain an atmosphere that

1 recognizes the physical and psychosocial needs of
2 residents and is conducive to the development and
3 maintenance of optimal physical and psychosocial
4 functioning;

5 “(B) maximize the effectiveness of all pro-
6 grams for residents, through the application of
7 knowledge concerning the development and main-
8 tenance of motor performance and behaviors; and

9 “(C) implement programs for the improvement
10 of physical and psychosocial functioning in all en-
11 vironmental settings.

12 Physical and occupational therapists shall have a
13 responsibility for organizing and implementing programs to
14 achieve physical and occupational therapy goals throughout
15 the resident's daily activities.

16 “(b) Physical and occupational therapy services avail-
17 able to the facility should include—

18 “(1) screening and evaluation of residents;

19 “(2) therapy with individuals and groups;

20 “(3) program development services, including those
21 relating to—

22 “(A) resident habilitation;

23 “(B) inservice training of professional, direct-
24 care, and other staff;

25 “(C) community participation;

1 “(4) consultation with, or relating to—

2 “(A) residents;

3 “(B) families of residents;

4 “(C) medical, dental, psychological, educa-
5 tional, nursing, and other services;

6 “(D) the administration and operation of the
7 facility;

8 “(E) the community served by the facility;

9 “(5) training of therapy staff;

10 “(6) training of physical and occupational therapy
11 graduate and/or undergraduate students, interns, sup-
12 portive staff, and volunteer workers;

13 “(7) assessment of program effectiveness; and

14 “(8) conduct of, or participation in, research, and
15 dissemination and appropriate application of research
16 findings.

17 “(c) Therapists should screen residents, in order to—

18 “(1) determine the characteristics of the facility’s
19 population;

20 “(2) identify resident needs and establish program
21 priorities; and

22 “(3) determine the administrative, budgetary, and
23 personnel requirements of the service.

24 “(d) Evaluation of individual residents by physical and
25 occupational therapists should include—

1 “(1) observing and testing performance and mo-
2 tivation in sensorimotor, perceptual, behavioral, and self-
3 care activities;

4 “(2) assessment and analysis of findings, to deter-
5 mine level of function and to identify deviations from
6 accepted norms;

7 “(3) providing information for interdisciplinary
8 staff use, in determining diagnosis, functional capacities,
9 prognosis, and management goals; and

10 “(4) physical and occupational therapists shall par-
11 ticipate, when appropriate, in the continuing interdisci-
12 plinary evaluation of individual residents, for the pur-
13 poses of initiation, monitoring, and followup of individual-
14 ized habilitation programs.

15 “(e) Physical therapy and occupational therapy staff
16 shall provide treatment-training programs that are designed
17 to—

18 “(1) preserve and improve abilities for independ-
19 ent function, such as range of motion, strength, toler-
20 ance, coordination, and activities of daily living;

21 “(2) prevent, insofar as possible, irreducible or
22 progressive disabilities, through means such as the use
23 of orthotic and prosthetic appliances, assistive and
24 adaptive devices, positioning, behavior adaptations, and
25 sensory stimulation;

1 “(3) the therapist shall function closely with the
2 resident’s primary physician and with other medical
3 specialists;

4 “(4) treatment-training progress shall be—

5 “(A) recorded regularly;

6 “(B) evaluated periodically; and

7 “(C) used as the basis for continuation or
8 change of the resident’s program.

9 “(f) Evaluation results; treatment objectives, plans,
10 and procedures; and continuing observations of treatment
11 progress shall be—

12 “(1) recorded accurately, summarized meaning-
13 fully, and communicated effectively;

14 “(2) effectively used in evaluating progress; and

15 “(3) included in the resident’s unit record.

16 “(g) Consumers and their representatives, including
17 residents, families, other disciplines, and community groups,
18 shall be utilized in the planning and evaluation of physical
19 therapy and occupational therapy services. There shall be
20 available sufficient, appropriately qualified staff, and sup-
21 porting personnel, to carry out the various physical and
22 occupational therapy services, in accordance with stated
23 goals and objectives. Physical and occupational therapists
24 shall be—

1 “(1) graduates of a curriculum accredited by the
2 appropriate nationally recognized association;

3 “(2) if a physical therapist, eligible to practice in
4 the State in which the facility is located; and

5 “(3) if an occupational therapist, eligible for regis-
6 tration by the appropriate nationally recognized asso-
7 ciation.

8 “(h) A physical therapist and an occupational thera-
9 pist shall be designated as being responsible for maintaining
10 standards of professional and ethical practice in the render-
11 ing of their respective therapy services in the facility. Each
12 such therapist shall be qualified as in subsection (g) and,
13 in addition, shall—

14 “(1) have had three years of professional experi-
15 ence, two years of which should have been in working
16 with the mentally retarded and other individuals with
17 developmental disabilities;

18 “(2) have demonstrated competence in adminis-
19 tration and supervision, as appropriate to the facility's
20 program; and

21 “(3) preferably have a master's degree, in an area
22 related to the program.

23 “(i) Therapy assistants shall—

24 “(1) be certified by the nationally recognized pro-
25 fessional occupational therapy association or be gradu-

1 ates of a program accredited by the nationally recog-
2 nized professional physical therapy association; and

3 “ (2) work under the supervision of a qualified
4 therapist.

5 “ (j) Therapy aides shall—

6 “ (1) be provided specific inservice training; and

7 “ (2) work under the supervision of a qualified
8 therapist or therapy assistant.

9 “ (k) Physical and occupational therapy personnel shall
10 be—

11 “ (1) assigned responsibilities in accordance with
12 their qualifications;

13 “ (2) delegated authority commensurate with their
14 responsibilities; and

15 “ (3) provided appropriate professional direction
16 and consultation.

17 “ (1) Physical and occupational therapy personnel shall
18 be familiar with, and adhere to, the ethical codes and
19 standards of practice promulgated by their respective nation-
20 ally recognized professional organizations.

21 “ (m) Physical-therapy and occupational therapy serv-
22 ices operated by a facility shall seek consultation, at periodic
23 intervals, from experts in physical therapy and occupational
24 therapy who are not directly associated with the facility.
25 Appropriate to the nature and size of the facility and to the

1 physical and occupational therapy services, there shall be a
2 staff development program that is designed to maintain and
3 improve the skills of physical and occupational therapy per-
4 sonnel, through methods, including but not limited to:

5 " (1) regular staff meetings;

6 " (2) an organized inservice training program in
7 physical and occupational therapy;

8 " (3) visits to and from the staff of other facilities
9 and programs;

10 " (4) participation in interdisciplinary meetings;

11 " (5) provision for financial assistance and time for
12 attendance at professional conferences;

13 " (6) provisions for encouraging continuing educa-
14 tion, including educational leave, financial assistance,
15 and accommodation work schedules;

16 " (7) career ladders and other incentives to staff
17 recruitment and development;

18 " (8) workshops and seminars;

19 " (9) consultations with specialists; and

20 " (10) access to adequate library resources, which
21 include current and relevant books and journals in phys-
22 ical and occupational therapy, mental retardation, de-
23 velopmental disabilities, and related professions and
24 fields.

1 “(n) Space, facilities, equipment, supplies, and re-
2 sources shall be adequate for providing efficient and effective
3 physical and occupational therapy services, including, but not
4 necessarily limited to—

5 “(1) facilities for conducting administrative aspects
6 of the program;

7 “(2) facilities for conducting screenings and eval-
8 uations;

9 “(3) facilities for providing treatment and training
10 for individuals and groups;

11 “(4) such other space, staff, and services as are
12 essential to support and maintain effective programs;
13 and

14 “(5) appropriate physical and occupational therapy
15 consultation shall be employed in the design, modifica-
16 tion, and equipage of all physical and occupational ther-
17 apy areas and facilities required to meet the specific goals
18 of physical and occupational therapy services.

19 **“Subchapter X—Psychological Services**

20 “SEC. 271. (a) Psychological services shall be pro-
21 vided, in order to facilitate, through the application of
22 psychological principles, techniques, and skills, the optimal
23 development of each resident. Psychological services shall be
24 rendered—

1 “(1) directly, through personal contact between
2 psychologists and residents;

3 “(2) indirectly, through contact between psycholo-
4 gists and other persons involved with the residents,
5 designed to—

6 “(A) maintain an atmosphere that recognizes
7 the psychological needs of residents and that is con-
8 ducive to the development and maintenance of con-
9 structive interpersonal relationships; and

10 “(B) maximize the effectiveness of all pro-
11 grams for residents, through the application of
12 knowledge concerning the understanding and change
13 of behavior.

14 “(b) Psychological services available to the residential
15 facility should include but not be limited to:

16 “(1) evaluation and assessment of individuals and
17 programs;

18 “(2) therapy with individuals and groups;

19 “(3) program development services, including those
20 relating to—

21 “(A) resident habilitation;

22 “(B) staff training;

23 “(C) community participation;

24 “(D) resident, staff, and community motiva-
25 tion;

1 “(4) consultation with, or relating to—

2 “(A) residents;

3 “(B) parents of residents;

4 “(C) the administration and operation of the
5 facility;

6 “(D) the community served by the facility;

7 “(5) psychology staff training; and

8 “(6) conduct of research, consultation on research
9 design, and dissemination of research findings.

10 “(c) Psychologists shall participate, when appropriate,
11 in the continuing interdisciplinary evaluation of individual
12 residents, for the purposes of initiation, monitoring, and
13 followup of individualized habilitation programs—

14 “(1) psychologists shall conduct evaluations neces-
15 sary to—

16 “(A) meet legal requirements;

17 “(B) meet research needs; and

18 “(C) provide data for biostatistical reporting;

19 “(2) methods of data collection employed in evalua-
20 tion and assessment shall include, as appropriate—

21 “(A) standardized tests and techniques;

22 “(B) observations in natural and experimental
23 settings, using standardized or generally accepted
24 techniques;

25 “(C) interviews with—

1 “(i) the resident (or prospective resi-
2 dent) ;

3 “(ii) members of the resident’s family and
4 other informants; and

5 “(D) review of all pertinent records, including
6 the comparison of current and previous status;

7 “(3) collation, analysis, and interpretation of data
8 shall—

9 “(A) be performed in accordance with stand-
10 ards generally acceptable in professional psychology;

11 “(B) provide, as appropriate, both intra- and
12 interindividual comparisons, by reference to norma-
13 tive data; and

14 “(C) utilize appropriate equipment, which is
15 made available for the purpose;

16 “(4) the reporting and dissemination of evaluation
17 results shall be done in such a manner as to—

18 “(A) render the content of the report mean-
19 ingful and useful to its intended recipient and user;

20 “(B) enhance clinical understanding of the in-
21 dividual;

22 “(C) promptly provide information useful to
23 staff working directly with the resident;

24 “(D) facilitate use of data for research and pro-
25 fessional education;

1 “(E) facilitate use of data for statistical re-
2 porting; and

3 “(F) maintain accepted standards of confiden-
4 tiality;

5 “(5) there shall be developed and maintained for
6 each resident a continuing evaluation record that is fre-
7 quently updated and that includes, but is not limited to,
8 psychometric data.

9 “(d) Psychologists shall participate, when appropriate,
10 in the development of written, detailed, specific, and indi-
11 vidualized habilitation program plans that—

12 “(1) provide for periodic review, followup, and up-
13 dating;

14 “(2) are designed to maximize each resident’s de-
15 velopment and acquisition of—

16 “(A) perceptual skills;

17 “(B) sensorimotor skills;

18 “(C) self-help skills;

19 “(D) communication skills;

20 “(E) social skills;

21 “(F) self direction;

22 “(G) emotional stability;

23 “(H) effective use of time (including leisure
24 time) ;

25 “(I) basic knowledge;

1 “(J) vocational-occupational skills; and

2 “(K) socioeconomic values relevant to the
3 community in which he lives.

4 “(e) Psychologists should provide individual, and/or
5 groups of, residents with therapy designed to develop, mod-
6 ify, and maintain behavior and attitudes that are rewarding
7 and effective in meeting the demands of their intrapersonal
8 and interpersonal situations. Psychologists should provide
9 consultation and training services to program staff con-
10 cerning:

11 “(1) principles and methods of understanding and
12 changing behavior, to the end of devising maximally ef-
13 fective programs for residents;

14 “(2) principles and methods of individual and pro-
15 gram evaluation, for the purposes of assessing resident
16 response to programs and of measuring program ef-
17 fectiveness;

18 “(3) psychologists should participate in the devel-
19 opment of incentive systems designed to maximize mo-
20 tivation and to optimize, by means of provision for feed-
21 back, performance, and learning on the part of—

22 “(A) residents enrolled in habilitation pro-
23 grams;

24 “(B) staff engaged in resident habilitation pro-
25 grams; and

1 “(C) personnel involved in resident habilita-
2 tion resources in the community.

3 “(f) Psychologists should provide assistance and/or
4 consultation relative to—

5 “(1) developing and conducting evaluations de-
6 signed to select and maintain appropriate and effective
7 staff;

8 “(2) developing job analyses;

9 “(3) psychological problems of staff, including the
10 making of appropriate referrals;

11 “(4) data concerning staff, and reports of evalua-
12 tions of staff, shall—

13 “(A) be provided in appropriate form, and
14 only to clearly appropriate supervisory staff;

15 “(B) enable data to be used for classification
16 and reporting purposes;

17 “(C) enable data to be used for research pur-
18 poses; and

19 “(D) maintain acceptable standards of confi-
20 dentiality.

21 “(g) Psychologists should participate in—

22 “(1) educating appropriate members of the com-
23 munity, concerning the domiciliary, vocational, and
24 recreational needs of residents who return to the
25 community;

1 “(2) planning with community officials the adap-
2 tation of domiciliary, vocational, and recreational re-
3 sources, to optimize resident adjustments; and

4 “(3) developing appropriate expectancies and at-
5 titudes within the community into which residents go.

6 “(h) There shall be available sufficient, appropriately
7 qualified staff, and necessary supporting personnel, to carry
8 out the various psychological service activities, in accord-
9 ance with the needs of the following functions:

10 “(1) psychological services to residents, including
11 evaluation, consultation, therapy, and program develop-
12 ment;

13 “(2) administration and supervision of psycholog-
14 ical services;

15 “(3) staff training;

16 “(4) research;

17 “(5) the facility should have available to it the
18 services of at least one doctoral-level psychologist who
19 is—

20 “(A) a diplomate of the nationally recognized
21 board of professional psychology, or is licensed or
22 certified by a State examining board, or is certified
23 by a voluntary board established by a qualified State
24 professional psychological association;

25 “(B) knowledgeable and experienced in the

1 area of mental retardation or developmental dis-
2 abilities;

3 “(6) a psychologist, qualified as specified in sub-
4 section (h) (5) shall be designated as being responsible
5 for maintaining standards of professional and ethical
6 practice in the rendering of psychological services in the
7 facility;

8 “(7) all psychologists providing service to the
9 facility shall—

10 “(A) possess the educational and experiential
11 qualifications required for membership in the na-
12 tionally recognized professional psychological as-
13 sociation;

14 “(B) have demonstrated knowledge in the area
15 of mental retardation and developmental disabilities;

16 “(8) all psychological technicians, assistants, and
17 clerks employed by the facility shall work under the
18 direct supervision of a psychologist who is qualified as
19 specified in subsection (h) (8) ;

20 “(9) all members of the psychological services staff
21 shall have and be familiar with, the ethical standards
22 of psychologists and the nationally recognized casebook
23 on ethical standards of psychologists, published by the
24 nationally recognized appropriate professional psycho-

1 logical association, and all shall adhere to the ethical
2 standards stated therein;

3 “(A) all new psychology service employees
4 shall receive this material, and be familiarized with
5 it, as a part of their orientation; and

6 “(B) the application of the ethical standards
7 to practice with the mentally retarded and develop-
8 mentally disabled in residential facilities shall be
9 emphasized.

10 “(i) Appropriate to the size of the facility, an ongoing
11 inservice training program shall be conducted that is de-
12 signed to maintain and improve the skills of its psychology
13 staff, through methods, including but not limited to—

14 “(1) staff seminars;

15 “(2) outside speakers;

16 “(3) visits to and from the staff of other facilities;

17 “(4) attendance at conferences;

18 “(5) participation in interdisciplinary groups;

19 “(6) informational exchanges with universities,
20 teaching hospitals, community mental health and men-
21 tal retardation centers, and other community resources;
22 and

23 “(7) adequate library resources, including current
24 and relevant books and journals in psychology and men-

1 tal retardation and developmental disabilities shall be
2 available.

3 “(j) The training of interns and graduate students in
4 psychology shall be encouraged, and appropriate supervi-
5 sion shall be provided. There shall be appropriate space
6 and equipment for psychological services, including—

7 “(1) offices for professional and clerical staff;

8 “(2) testing and observation rooms;

9 “(3) interviewing, counseling, and training/treat-
10 ment rooms;

11 “(4) play therapy rooms;

12 “(5) access to conference rooms; and

13 “(6) access to research and data analysis facilities.

14 **“Subchapter XI—Recreation Services**

15 “SEC. 272. (a) Recreation services should provide
16 each resident with a program of activities that—

17 “(1) promotes physical and mental health;

18 “(2) promotes optimal sensorimotor, cognitive, af-
19 fective, and social development;

20 “(3) encourages movement from dependent to in-
21 dependent and interdependent functioning; and

22 “(4) provides for the enjoyable use of leisure time.

23 “(b) The facility shall have a written statement of its
24 recreation objectives for residents, consistent with—

1 “(1) the needs of its residents;

2 “(2) currently accepted recreation principles and
3 goals;

4 “(3) the philosophy and goals of the facility; and

5 “(4) the services and resources the facility offers.

6 “(c) Recreation services available to the residential
7 facility should include—

8 “(1) recreation activities for the residents;

9 “(2) recreation counseling;

10 “(3) individual and group instruction of residents
11 in recreation skills, to achieve maximum proficiency and
12 develop leadership potential;

13 “(4) therapeutic recreation;

14 “(5) education and consultation; and

15 “(6) research and evaluation.

16 “(d) Recreation activities available to the residents
17 should include, as appropriate to the size and location of the
18 facility, and as adapted to the needs of the residents being
19 served—

20 “(1) excursions, outings, and other trips to famil-
21 iarize the residents with community facilities;

22 “(2) spectator activities, such as movies, television,
23 sports events, and theater;

24 “(3) participation in music, drama, and dance, such
25 as rhythmic, folk dancing, community sings, group

1 music sessions in the living units, performance in music
2 or dramatic productions, performance in choral or in-
3 strumental groups, and informal listening to records or
4 tapes;

5 “(4) outdoor and nature experiences, including
6 activities such as camping, hiking, and gardening;

7 “(5) team sports and lead-up activities;

8 “(6) individual and dual sports, such as bowling,
9 archery, badminton, horseshoes, miniature golf, bicy-
10 cling, and shuffleboard;

11 “(7) hobbies, such as collecting, photography,
12 model building, woodworking (including use of power
13 tools) cooking, and sewing;

14 “(8) social activities, such as clubs, special inter-
15 est and discussion groups, social dancing, cookouts,
16 parties, and games;

17 “(9) service clubs and organizations, such as lead-
18 ers clubs, scouting, 4-H, Junior Red Cross, Junior
19 Chamber of Commerce, Hi-Y, Tri-Hi-Y, resident coun-
20 cils, and senior citizens clubs;

21 “(10) aquatics, including waterplay, swimming,
22 and boating;

23 “(11) arts and crafts, including a wide range of
24 activities from simple to complex, from reproductive to

1 creative, and consistent with activities found in the
2 community;

3 “(12) physical fitness activities designed to develop
4 efficient cardiovascular and cardiorespiratory functions,
5 strength, endurance, power, coordination, and agility,
6 sufficient for both usual and extra demands;

7 “(13) library services for reading, listening, and
8 viewing, such as looking at books, listening to records
9 and tapes, and viewing film strips and slides;

10 “(14) celebration of special events, such as holidays
11 and field days;

12 “(15) winter activities, including snow sculpture,
13 snowplay, games, and sports;

14 “(16) opportunities to use leisure time in activities
15 of the resident's own choosing in an informal setting
16 under minimal supervision, such as a ‘drop-in center’;

17 “(17) frequent coeducational experiences, to pro-
18 mote acceptable social behavior and enjoyment of social
19 relationships; and

20 “(18) activities for the nonambulatory, including
21 the mobile and nonmobile.

22 “(e) Maximum use should be made of all community
23 recreation resources. Recreation counseling should be a con-
24 tinuous process that provides for—

25 “(1) modification of resident's recreation behaviors;

1 “(2) guidance to residents on how to find, reach,
2 and utilize community recreation resources;

3 “(3) family counseling in relation to recreation
4 activities; and

5 “(4) interpretation of residents’ needs and abilities
6 to community agencies.

7 “(f) Therapeutic recreation, defined as purposive inter-
8 vention, through recreation activities, to modify, ameliorate,
9 or reinforce specific physical, emotional, or social behaviors,
10 should include, as appropriate—

11 “(1) participation on an interdisciplinary team, to
12 identify the habilitation needs and goals of the resident;

13 “(2) determination of appropriate recreation inter-
14 vention, to achieve the stated habilitation goals;

15 “(3) a written plan for implementing the thera-
16 peutic recreation objectives, consistent with the recom-
17 mendations of the evaluation team; and

18 “(4) evaluation of the effectiveness of such inter-
19 ventions, and subsequent redefinition of the resident’s
20 habilitation needs and goals.

21 “(g) Education and consultation services should
22 include—

23 “(1) provision of stimulation, leadership, and as-
24 sistance with recreation activities, conducted by the di-
25 rect-care staff;

1 “(2) staff training and development;

2 “(3) orientation and training of volunteers;

3 “(4) training of interns and students in recreation;

4 “(5) consultation to community agencies and orga-
5 nizations, to stimulate the development and improvement
6 of recreation services for the retarded; and

7 “(6) public education and information, to encour-
8 age acceptance of the retarded in recreation activities.

9 “(h) Recreational services shall be coordinated with
10 other services and programs provided the residents, in order
11 to make fullest possible use of the facility's resources and to
12 maximize benefits to the residents. Activities in health,
13 music, art, and physical education shall be coordinated with
14 recreation activities relevant to these areas.

15 “(i) Records concerning residents should include—

16 “(1) periodic surveys of their recreation interests;

17 “(2) periodic surveys of their attitudes and opin-
18 ions regarding recreation services;

19 “(3) the extent and level of each resident's partici-
20 pation in the activities program;

21 “(4) progress reports, as appropriate;

22 “(5) reports on relationships among peers, and
23 between residents and staff; and

24 “(6) evaluations conducted by personnel at all

1 levels and, where appropriate, by staff from other
2 services.

3 “(j) Established procedures for evaluating and research-
4 ing the effectiveness of recreation services, in relation to
5 stated purposes, goals, and objectives, should include—

6 “(1) utilization of adequate records concerning resi-
7 dents’ interests, attitudes, opinions, participations, and
8 achievements;

9 “(2) time schedules for evaluation that are appro-
10 priate to the service or program being evaluated;

11 “(3) provision for using evaluation results in pro-
12 gram planning and development;

13 “(4) provision for disseminating evaluation results
14 in professional journals and in public education and
15 information programs; and

16 “(5) encouragement of recreation staff to initiate,
17 conduct, and participate in research studies, under the
18 supervision of qualified personnel.

19 “(k) There shall be sufficient, appropriately qualified
20 recreation staff, and necessary supporting staff, to carry out
21 the various recreation services in accordance with stated
22 goals and objectives.

23 “(1) Scheduling of staff shall provide—

1 “(A) coverage on evenings, weekends, and holi-
2 days; and

3 “(B) additional coverage during periods of peak
4 activity.

5 “(2) Recreation personnel shall be—

6 “(A) assigned responsibilities in accordance with
7 their qualifications;

8 “(B) delegated authority commensurate with their
9 responsibility; and

10 “(C) provided appropriate professional recreation
11 supervision.

12 “(3) Personnel conducting activities in recreation pro-
13 gram areas should possess the following minimum educa-
14 tional and experiential qualifications:

15 “(A) a bachelor's degree in recreation, or in a spe-
16 cialty area, such as art, music, or physical education; or

17 “(B) an associate degree in recreation and one
18 year of experience in recreation; or

19 “(C) a high school diploma, or an equivalency cer-
20 tificate; and two years of experience in recreation, or
21 one year of experience in recreation plus completion of
22 comprehensive inservice training in recreation; or

23 “(D) demonstrated proficiency and experience in
24 conducting activities in one or more program areas.

25 “(4) Personnel performing recreation counseling or

1 therapeutic recreation functions should possess the follow-
 2 ing minimum education and experiential qualifications, and
 3 should be eligible for registration with the appropriate na-
 4 tionally recognized therapeutic recreation society at the ap-
 5 propriate therapeutic recreation specialist level:

6 “(A) a master’s degree in therapeutic recreation
 7 and one year of experience in a recreation program serv-
 8 ing disabled persons; or

9 “(B) a master’s degree in recreation and two years
 10 of experience in a recreation program serving disabled
 11 persons; or

12 “(C) a bachelor’s degree in recreation and three
 13 years of experience in a recreation program serving dis-
 14 abled persons; or

15 “(D) a combination of education and experience in
 16 recreation serving disabled persons that totals six years.

17 “(5) Education and consultation functions in recreation
 18 should be conducted by staff members, in accordance with
 19 their education, experience, and role in the recreation pro-
 20 gram.

21 “(1) Appropriate to the size of the recreation program,
 22 there shall be a staff development program that provides
 23 opportunities for professional development, including—

24 “(1) regular staff meetings;

1 “(2) an organized inservice training program in
2 recreation;

3 “(3) access to professional journals, books, and
4 other literature in the fields of recreation, therapeutic
5 recreation, rehabilitation, special education, and other
6 allied professions;

7 “(4) provisions for financial assistance and time for
8 attendance at professional conferences and meetings;

9 “(5) procedures for encouraging continuing educa-
10 tion, including educational leaves, direct financial assist-
11 ance, and rearrangement of work schedules;

12 “(6) provision for workshops and seminars relating
13 to recreation, planned by the recreation and other pro-
14 fessional and administrative staff; and

15 “(7) provision for staff consultation with special-
16 ists, as needed, to improve recreation services to res-
17 idents.

18 “(m) Recreation areas and facilities shall be designed
19 and constructed or modified so as to—

20 “(1) permit all recreation services to be carried out
21 to the fullest possible extent in pleasant and functional
22 surroundings;

23 “(2) be easily accessible to all residents, regardless
24 of their disabilities;

25 “(3) appropriate recreation consultation shall be

1 employed in the design or modification of all recreation
2 areas and facilities;

3 “(4) toilet facilities, appropriately equipped in ac-
4 cordance with the needs of the residents, should be easily
5 accessible from recreation areas; and

6 “(5) appropriate and necessary maintenance serv-
7 ices shall be provided for all recreation areas and facili-
8 ties.

9 “(n) Indoor recreation facilities should include, as ap-
10 propriate to the facility—

11 “(1) a multipurpose room;

12 “(2) a quiet browsing room;

13 “(3) access to a gymnasium;

14 “(4) access to an auditorium;

15 “(5) access to suitable library facilities;

16 “(6) access to kitchen facilities;

17 “(7) adequate and convenient space for storage of
18 supplies and large and small equipment; and 81

19 “(8) adequate office space for the recreation staff 81

20 “(o) Outdoor recreation facilities should include, as ap-
21 propriate to the facility— 81 periodic (8) 12

22 “(1) access to a handball court, a lawn tennis court, and 82

23 “(2) access to gardening and other (12) activity areas 82

24 “(3) access to an adequately equipped recreation 82

25 areas; and 82 tion for music therapy; and 25

1 “(4) the facility’s residents should have, as appro-
2 priate and feasible, access to year-round swimming and
3 aquatic facilities.

4 “(p) Adequate transportation services for recreation
5 programs shall be provided. Recreation equipment and sup-
6 plies in sufficient quantity and variety shall be provided to
7 carry out the stated objectives of the activities programs.
8 Toys, games, and equipment shall be—

9 “(1) selected on the basis of suitability, safety,
10 durability, and multiplicity of use; and

11 “(2) adapted as necessary to the special needs of
12 the residents.

13 “(q) If a music therapy program is provided, it should
14 include—

15 “(1) participation by the music therapist, when
16 appropriate, on an interdisciplinary evaluation team to
17 identify the resident’s needs and ways of meeting them;

18 “(2) determination of music therapy goals for the
19 resident and development of a written plan for achieving
20 them;

21 “(3) periodic progress reports, reevaluations, and
22 program changes as indicated;

23 “(4) direction by a therapist eligible for registra-
24 tion with the appropriate nationally recognized associa-
25 tion for music therapy; and

1 “(5) appropriate space, facilities, and equipment,
2 with special consideration of the acoustical characteristics
3 of rooms used for performing and listening.

4 **“Subchapter XII—Religious Services**

5 “SEC. 273. (a) Religious services shall be made avail-
6 able to residents, in accordance with their needs, desires,
7 capabilities, and in accordance with their basic right to free-
8 dom of religion, in order to—

9 “ (1) develop and enhance their dignity ;

10 “ (2) provide for the most meaningful and relevant
11 practice of their religion ; and

12 “ (3) provide spiritual programs designed to aid
13 their development and growth as persons.

14 “ (b) Implementation of religious services should utilize
15 community resources, whenever and wherever this is possible
16 and in the best interests of the residents. The objectives of
17 the facility’s religious services for its residents shall be di-
18 rected toward full integration into, and membership in, their
19 faith, and should include—

20 “ (1) upholding the dignity and worth of the indi-
21 vidual ;

22 “ (2) building moral and ethical standards of be-
23 havior ;

24 “ (3) preparing for religious growth in their faith
25 groups ;

1 “(4) establishing healthy self, world, and God
2 concepts;

3 “(5) establishing constructive value systems;

4 “(6) giving direction toward greater personal
5 maturity;

6 “(7) strengthening interpersonal relationships; and

7 “(8) contributing to growth in personal adequacy
8 and happiness.

9 “(c) Religious services shall be made available to all
10 residents, regardless of their degree of retardation. Participa-
11 tion in religious programs shall be voluntary, in accordance
12 with the wishes of the resident, if he expresses them, or with
13 the wishes of his parent or guardian.

14 “(d) Religious services to residents should include—

15 “(1) worship opportunities, sacraments, and reli-
16 gious rites, according to the needs and abilities of the
17 residents and consonant with the practices of their re-
18 spective faiths;

19 “(2) religious education programs geared to the
20 needs and abilities of the residents;

21 “(3) observation of dietary practices in keeping
22 with the religious requirements of residents' faith groups;

23 “(4) observation of religious holidays and holy
24 days in keeping with the religious requirements of resi-
25 dents' faith groups;

1 “(5) pastoral counseling, both individual and group,
2 to residents and their families;

3 “(6) pastoral visits to residents, with special em-
4 phasis on the care of the troubled, the sick, and the
5 dying;

6 “(7) pastoral consultation with persons concerned
7 with the resident's welfare; and

8 “(8) referral and communication between religious
9 workers in the facility and in the community.

10 “(e) Those who serve the religious needs of the resi-
11 dents, including clergy, religious educators, and volunteers,
12 should whenever possible—

13 “(1) assert and safeguard the full human and civil
14 rights of the residents;

15 “(2) participate, as appropriate, in team and other
16 interdisciplinary planning regarding programs for indi-
17 vidual residents, as well as in facility-wide or com-
18 munity programs;

19 “(3) keep appropriate records of significant reli-
20 gious events in the lives of each resident;

21 “(4) participate in training programs for facility
22 personnel, including orientation of direct-care personnel
23 in how they may help to further the religious programs
24 for residents;

1 “(5) participate in training programs for commu-
2 nity clergy, theological students, and others;

3 “(6) become involved with community clergy, and
4 with religious and other groups, in their concerns for
5 the spiritual care of the retarded;

6 “(7) promote public understanding and accept-
7 ance of the retarded; and

8 “(8) participate in their own faith group meetings,
9 as required to maintain their standing.

10 “(f) There shall be available sufficient, appropriately
11 qualified personnel, which may include clergy or religious
12 leaders, religious educators, volunteers, and clerical and sup-
13 porting personnel, to carry out the various religious pro-
14 grams—

15 “(1) religious services to residents shall be under
16 the direction of a person who, in keeping with the size
17 and nature of the facility, may be one of the following:

18 “(A) a chaplain certified for work with the
19 mentally retarded or other individuals with devel-
20 opmental disabilities by a recognized certifying
21 agency;

22 “(B) a clergyman or religious leader in good
23 standing in his religious body;

24 “(C) a religious educator; or

25 “(D) a responsible person, who secures the

- 1 services of qualified persons in carrying out the
2 worship and education aspects of the program; .
3 “(2) chaplains serving residential facilities for the
4 retarded, on a full- or part-time basis, should—
5 “(A) be clergymen or religious leaders in good
6 standing in their religious bodies; or
7 “(B) be endorsed or assigned by their recog-
8 nized religious bodies; or
9 “(C) have B.A. and B.D. degrees, or their
10 equivalents; and
11 “(D) be certified for work with the mentally
12 retarded or other individuals with developmental
13 disabilities by a recognized certifying agency;
14 “(3) professional religious educators serving resi-
15 dential facilities for the retarded or other individuals
16 with developmental disabilities, on a full- or part-time
17 basis, should—
18 “(A) be endorsed or assigned by their recog-
19 nized religious bodies; or
20 “(B) have a bachelor’s degree, or its equiva-
21 lent; and
22 “(C) be certified for work with the mentally
23 retarded or other individuals with developmental
24 disabilities by a recognized certifying agency;

1 “(4) nonprofessional religious services personnel,
2 including volunteers, should—

3 “(A) be screened for ability to perform their
4 assigned duties;

5 “(B) be oriented to, and trained for, their as-
6 signments; and

7 “(C) be provided ongoing supervision by a
8 clergyman, religious leader, or religious educator
9 of the respective faith.

10 “(g) Appropriate to the size of the facility, there shall
11 be an educational program designed to enhance the competen-
12 cies of religious services personnel, through means such as:

13 “(1) staff meetings and inservice training;

14 “(2) seminars, workshops, conferences, and insti-
15 tutes;

16 “(3) college and university courses;

17 “(4) participation in professional organizations;

18 “(5) participation in interdisciplinary groups;

19 “(6) visits to other facilities;

20 “(7) access to relevant professional literature; and

21 “(8) religious services personnel should have access
22 to qualified and appropriate consultation, as needed.

23 “(h) Religious services personnel should be encouraged,
24 when possible, to involve themselves in activities such as—

25 “(1) offering clinical pastoral education programs;

1 “(2) providing educational experiences for stu-
2 dents;

3 “(3) developing innovative religious education
4 materials;

5 “(4) developing innovative worship services;

6 “(5) conducting specific research and development
7 projects; and

8 “(6) exploring and expanding citizen advocacy
9 programs.

10 “(i) Residents shall have access to places appropriate
11 for worship and religious education that are adequate to
12 meet the needs of all. Religious services personnel shall be
13 provided with office and other space, equipment, and supplies
14 adequate to carry out an effective program.

15 **“Subchapter XIII—Social Services**

16 “SEC. 274. (a) Social services shall be available to all
17 residents and their families, in order to foster and facilitate—

18 “(1) maximum personal and social development of
19 the resident;

20 “(2) positive family functioning; and

21 “(3) effective and satisfying social and community
22 relationships.

23 “(b) Social services shall be provided, directly and in-
24 directly, to—

25 “(1) the resident;

1 “(2) his family;

2 “(3) individuals or groups who represent different
3 aspects of the social environment of the resident; and

4 “(4) the community.

5 “(c) Consumers and their representatives, including
6 residents, families, other disciplines, and community groups,
7 shall participate in the planning and evaluation of social
8 service programs. Social services, as part of an interdis-
9 plinary spectrum of services, shall be provided through the
10 use of social work methods directed toward—

11 “(1) maximizing the social functioning of the resi-
12 dent;

13 “(2) enhancing the coping capacity of his family;

14 “(3) modifying environmental influences leading
15 to, or aggravating, mental retardation or developmental
16 disabilities;

17 “(4) increasing public understanding and accept-
18 ance of mental retardation or developmental disabilities
19 and its associated problems;

20 “(5) creating a favorable climate to assist each re-
21 tarded person to achieve as nearly normal living as is
22 possible for him;

23 “(6) asserting and safeguarding the human and
24 civil rights of the retarded and other individuals with
25 developmental disabilities and their families; and

1 “(7) fostering the human dignity and personal
2 worth of each resident.

3 “(d) Social services available to the facility should in-
4 clude, as appropriate—

5 “(1) preadmission evaluation and counseling, with
6 referral to, and use of, other community resources, as
7 appropriate;

8 “(2) psychosocial assessment of the individual resi-
9 dent and his environment, as a basis for formulating an
10 individual treatment plan;

11 “(3) implementation of an individual social work
12 treatment plan for the resident and his family;

13 “(4) planning for community placement, discharge,
14 and followup;

15 “(5) participation in policy and program develop-
16 ment within the facility in relation to—

17 “(A) the resident's psychosocial needs and de-
18 velopment;

19 “(B) serving the families of the resident;

20 “(C) use of community supportive and habili-
21 tative services;

22 “(D) staff training and development;

23 “(6) consultation with, or in relation to—

24 “(A) programs offered by other disciplines;

1 “(B) administration and operation of the fa-
2 cility;

3 “(C) agencies and individuals in the commu-
4 nity served by the facility;

5 “(7) collaboration with other service delivery sys-
6 tems in planning and implementing programs for resi-
7 dents; and

8 “(8) participation in social work and interdiscipli-
9 nary program evaluation and research.

10 “(e) During the evaluation process, which may or may
11 not lead to admission, the resident and his family should be
12 helped by social workers to—

13 “(1) know the rights and services to which they
14 are entitled, including the means of directing their ap-
15 peals to the proper sources;

16 “(2) obtain advocacy on their behalf if rights and
17 services are denied them; and

18 “(3) consider alternative services, based on the re-
19 tarded or developmentally disabled person's status and
20 salient family and community factors, and make a re-
21 sponsible choice as to whether and when residential
22 placement is indicated.

23 “(f) During the preadmission process, the resident and
24 his family should be helped by social workers to—

1 “(1) cope with problems of separation inherent in
2 placement;

3 “(2) initiate planning for the resident's return to
4 his family and/or community;

5 “(3) begin involving themselves as partners with
6 the residential facility staff in developing a treatment/
7 habilitation plan;

8 “(4) become oriented to the practices and pro-
9 cedures of the facility; and

10 “(5) share information about themselves that will
11 provide the facility's staff with maximum understanding
12 of their situation, so that effective services can be
13 delivered.

14 “(g) Social workers shall participate, when appropriate,
15 in the continuing interdisciplinary evaluation of individual
16 residents for the purposes of initiation, monitoring, and fol-
17 lowup of individualized habilitation programs.

18 “(h) During the retarded or developmentally disabled
19 person's admission to, and residence in, the facility, or while
20 he is receiving services from the facility, social workers shall
21 provide liaison between him, the facility, the family, and the
22 community, so as to:

23 “(1) help the resident to—

1 “(A) cope with problems accompanying separation from family and community;

2 “(B) learn the roles and use the resources that will enable him to maximize his development;

3 “(C) participate in programs, in accordance with his individual treatment plan, that will maximize his ability for independent living, in or out of the residential facility;

4 “(2) help the staff to—

5 “(A) individualize and understand the needs of the resident and his family in relation to each other;

6 “(B) understand social factors in the resident's day-to-day behavior, including staff-resident relationships;

7 “(C) prepare the resident for changes in his living situations;

8 “(3) help the family to develop constructive and personally meaningful ways to support the resident's experience in the facility through—

9 “(A) counseling concerned with problems associated with changes in family structure and functioning;

10 “(B) utilization of the family's and the resident's own strengths and resources;

1 “(C) referral to specific services, as appro-
2 priate; and

3 “(4) the family to participate in planning for
4 the resident’s return to home or other community place-
5 ment.

6 “(i) After the resident leaves the facility, social work-
7 ers shall provide systematic followup, including—

8 “(1) counseling with the resident;

9 “(2) counseling with family, employers, and other
10 persons significant to the resident’s adjustment in the
11 community; and

12 “(3) referral to appropriate community agencies.

13 “(j) Social services shall help to integrate residential
14 and other community services, through—

15 “(1) providing liaison between the residential
16 facility and the community;

17 “(2) providing consultation to community agencies
18 to facilitate the identification of needed resources for the
19 retarded and other individual with developmental dis-
20 abilities and his family;

21 “(3) interpreting the residential facility and its pro-
22 gram to relevant sectors of the community;

23 “(4) collaborating with other disciplines to help
24 the community develop appropriate resources; and

25 “(5) involvement with social policy issues that

1 affect the retarded and other individuals with develop-
2 mental disabilities.

3 “(k) Social services shall develop and maintain com-
4 prehensive, current records, useful for its own programs and
5 those of other services. There shall be available sufficient,
6 appropriately qualified staff and necessary supporting per-
7 sonnel to carry out the various social service activities.

8 “(1) The facility should have available to it a social
9 worker who—

10 “(A) has a master’s or doctoral degree from an
11 accredited school of social work;

12 “(B) has had three years of post-master’s ex-
13 perience in the field of social welfare;

14 “(C) meet the educational and experiential
15 qualifications for certification by the appropriate
16 nationally recognized academy of certified social
17 workers; and

18 “(D) is knowledgeable and experienced in
19 mental retardation.

20 “(2) A social worker having the qualifications
21 specified in subsection (k) (1) shall be designated as
22 being responsible for maintaining standards of profes-
23 sional practice in the rendering of social services to the
24 facility, and for staff development.

1 “(3) Social workers providing service to the facility
2 shall—

3 “(A) have a master’s degree from an accredited
4 school of social works; or

5 “(B) meet the educational qualifications required
6 for full membership in the appropriate nationally recognized
7 professional association of social
8 workers and shall have had three years of experience
9 in the field of social welfare.

10 “(4) Social work assistants or aides employed by
11 the facility shall work under the supervision of a social
12 worker having the qualifications specified in subsection
13 (k) (3).

14 “(5) Social service personnel, at all levels of experience
15 and competence, shall be—

16 “(A) assigned responsibilities in accordance
17 with their qualifications;

18 “(B) delegated authority commensurate with
19 their responsibilities; and

20 “(C) provided appropriate professional social
21 work supervision.

22 “(6) A full-time supervisor should be responsible
23 for the direct supervision of not more than six staff
24 members, plus related activities.

1 “(7) All social service personnel shall be familiar
2 with, and adhere to, the code of ethics of the National
3 Association of Social Workers.

4 “(1) Appropriate to the size of the facility’s social serv-
5 ice program, an ongoing program of staff development shall
6 be provided to improve the skills of the social work staff
7 through such means as—

8 “(1) inservice training;

9 “(2) affiliation with schools of social work;

10 “(3) staff consultation with specialists, as needed,
11 to improve social services to residents;

12 “(4) conference attendance, and other educational
13 opportunities and forms of professional exchange; and

14 “(5) career ladders and other incentives to staff re-
15 cruitment and development.

16 “(m) Space, facilities, equipment, supplies, and re-
17 sources shall be adequate for providing effective social serv-
18 ices, including—

19 “(1) offices for social service and clerical staff;

20 “(2) private interviewing rooms;

21 “(3) rooms suitable for conferences and group ac-
22 tivities;

23 “(4) dictating and transcribing equipment;

24 “(5) telephone service;

25 “(6) travel provisions;

1 “(7) provision for recordkeeping and information
2 retrieval; and

3 “(8) library services.

4 **“Subchapter XIV—Speech Pathology and Audiology**
5 **Services**

6 “SEC. 275. (a) Speech pathology and audiology serv-
7 ices shall be available, in order to—

8 “(1) maximize the communication skills of all resi-
9 dents; and

10 “(2) provide for the evaluation, counseling, treat-
11 ment, and rehabilitation of those residents with speech,
12 hearing and/or language handicaps.

13 “(b) The specific goals of speech pathology and audiol-
14 ogy services shall be—

15 “(1) appropriate to the needs of the residents
16 served;

17 “(2) consistent with the philosophy and goals of
18 the facility;

19 “(3) consistent with the services and resources of-
20 fered by the facility; and

21 “(4) known to, and coordinated with, other services
22 provided by the facility.

23 “(c) Speech pathology and audiology services shall be
24 rendered through—

1 “(1) direct contact between speech pathologists and
2 audiologists and residents;

3 “(2) participation with administrative personnel in
4 designing and maintaining social and physical environ-
5 ments that maximize the communication development of
6 the residents; and

7 “(3) working with other personnel, such as teach-
8 ers and direct-care staff, in implementing communication
9 improvement programs in environmental settings.

10 “(d) Speech pathology and audiology services available
11 to the facility shall include, as appropriate—

12 “(1) audiometric screening of—

13 “(A) all new residents;

14 “(B) children under the age of ten, at annual
15 intervals;

16 “(C) other residents at regular intervals;

17 “(D) any resident referred;

18 “(2) speech and language screening of—

19 “(A) all new residents;

20 “(B) children under the age of ten at annual
21 intervals;

22 “(C) all residents, as needed;

23 “(3) comprehensive audiological assessment of resi-
24 dents, as indicated by screening results, to include tests
25 of pure-tone air and bone conduction, speech audiometry,

1 and other procedures, as necessary, and to include assess-
2 ment of the use of visual cues;

3 “(4) assessment of the use of amplification;

4 “(5) provision of procurement, maintenance, and
5 replacement of hearing aids, as specified by a qualified
6 audiologist;

7 “(6) comprehensive speech and language evalua-
8 tion of residents, as indicated by screening results, in-
9 cluding appraisal of articulation, voice, rhythm, and
10 language;

11 “(7) participation in the continuing interdisdisci-
12 plinary evaluation of individual residents for purposes of
13 initiation, monitoring, and followup of individualized
14 habilitation programs;

15 “(8) treatment services, interpreted as an extension
16 of the evaluation process, that include—

17 “(A) direct counseling with residents;

18 “(B) speech and language development and
19 stimulation through daily living activities;

20 “(C) consultation with classroom teachers for
21 speech improvement and speech education activ-
22 ities;

23 “(D) direct contact with residents to carry on
24 programs designed to meet individual needs in com-
25 prehension (for example, speech reading, auditory

1 training, and hearing aid utilization) as well as ex-
 2 pression (for example, improvement in articula-
 3 tion, voice, rhythm, and language) ;

4 “(E) collaboration with appropriate educators
 5 and librarians to develop specialized programs for
 6 developing the communication skills of multiple
 7 handicapped residents, such as the deaf, retarded,
 8 and the cerebral palsied;

9 “(9) consultation with administrative staff regard-
 10 ing the planning of environments that facilitate com-
 11 munication development among residents in—

12 “(A) living areas;

13 “(B) dining areas;

14 “(C) educational areas;

15 “(D) other areas, where relevant;

16 “(10) participation in inservice training programs
 17 for direct-care and other staff;

18 “(11) training of speech pathology and audiology
 19 staff;

20 “(12) training of speech pathology and audiology
 21 graduate and/or undergraduate students, interns, sup-
 22 portive staff, and volunteer workers;

23 “(13) consultation with, or relating to—

24 “(A) residents (for example, self-referral);

25 “(B) parents of residents;

1 “(C) medical (otological, pediatric, and so
2 forth), dental, psychological, educational, and other
3 services;

4 “(D) the administration and operation of the
5 facility;

6 “(E) the community served by the facility;
7 and

8 “(14) program evaluation and research.

9 “(e) Comprehensive evaluations in speech pathology
10 and audiology shall consider the total person and his environ-
11 ment. Such evaluations should—

12 “(1) present a complete appraisal of the resident’s
13 communication skills;

14 “(2) evidence concern for, and evaluation of, con-
15 ditions extending beyond observed speech, language,
16 and hearing defects;

17 “(3) consider factors in the history and environ-
18 ment relevant to the origins and maintenance of the
19 disability;

20 “(4) consider the effect of the disability upon the
21 individual and the adjustments he makes to the prob-
22 lem as he perceives it; and

23 “(5) consider the reaction of the resident’s family,
24 associates, and peers to the speech and/or hearing
25 problem.

1 “(f) Evaluation and assessment results shall be re-
2 ported accurately and systematically, and in such manner
3 as to—

4 “(1) define the problem to provide a basis for for-
5 mulating treatment objectives and procedures;

6 “(2) render the report meaningful and useful to its
7 intended recipient and user;

8 “(3) where appropriate, provide information use-
9 ful to other staff working directly with the resident;

10 “(4) conform to acceptable professional standards,
11 provide for intraindividual and interindividual compari-
12 sons, and facilitate the use of data for research and
13 professional education; and

14 “(5) provide evaluative and summary reports for
15 inclusion in the resident's unit record.

16 “(g) Treatment objectives, plans, and procedures
17 shall—

18 “(1) be based upon adequate evaluation and as-
19 sessment;

20 “(2) be based upon a clear rationale;

21 “(3) reflect consideration of the objectives of the
22 resident's total habilitation program;

23 “(4) be stated in terms that permit the progress
24 of the individual to be assessed;

25 “(5) provide for periodic evaluation of the resi-

1 dent's response to treatment and of treatment effective-
2 ness;

3 “(6) provide for revision of objectives and proce-
4 dures as indicated; and

5 “(7) provide for assistance or consultation when
6 necessary.

7 “(h) Continuing observations of treatment progress
8 shall be—

9 “(1) recorded accurately, summarized meaning-
10 fully, and communicated effectively; and

11 “(2) effectively utilized in evaluating progress.

12 “(i) There shall be established procedures for evaluat-
13 ing and researching the effectiveness of speech pathology
14 and audiology services, including but not limited to:

15 “(1) utilization of adequate records concerning resi-
16 dents' response and progress;

17 “(2) time schedules for evaluation that are appro-
18 priate to the service being evaluated;

19 “(3) provision for using evaluation results in pro-
20 gram planning and development;

21 “(4) encouragement of speech pathology and au-
22 diology staff to participate in research activities; and

23 “(5) provision for dissemination of research results
24 in professional journals.

25 “(j) There shall be available sufficient, appropriately

1 qualified staff, and necessary supporting personnel, to carry
2 out the various speech pathology and audiology services,
3 in accordance with stated goals and objectives—

4 “(1) A speech pathologist or audiologist, who is
5 qualified as specified in paragraph (2) of this subsection,
6 and who, in addition, has had at least three years of
7 professional experience, shall be designated as being re-
8 sponsible for maintaining standards of professional and
9 ethical practice in the rendering of speech pathology and
10 audiology services in the facility.

11 “(2) Staff who assume independent responsibilities
12 for clinical services shall possess the educational and
13 experiential qualifications required for the appropriate
14 certificate of clinical competence issued by the appro-
15 priate nationally recognized professional speech and
16 hearing association in the area (speech pathology or
17 audiology) in which they provide services.

18 “(3) Staff not qualified for such association certifi-
19 cation shall be provided adequate, direct, active, and
20 continuing supervision by staff qualified for certification
21 in the area in which supervision is rendered.

22 “(A) Supervising staff shall be responsible for
23 the services rendered by uncertified staff under their
24 supervision.

25 “(B) Adequate, direct, and continuing super-

1 vision shall be provided nonprofessionals, volunteers,
2 or other supportive personnel utilized in providing
3 clinical services.

4 “(4) Students in training and staff fulfilling experi-
5 ence requirements for such appropriate nationally recog-
6 nized professional speech and hearing association certifi-
7 cation shall receive direct supervision, in accordance with
8 the requirements of the appropriate nationally recog-
9 nized professional boards of examiners in speech pathol-
10 ogy and audiology.

11 “(5) All speech pathology and audiology staff
12 shall be familiar with, and adhere to, the code of ethics
13 published by the appropriate nationally recognized pro-
14 fessional speech and hearing association.

15 “(k) Appropriate to the nature and size of the facility
16 and to the speech pathology and audiology service, there shall
17 be a staff development program that is designed to maintain
18 and improve the skills of speech pathology and audiology
19 staff, through methods, including but not limited to—

20 “(1) regular staff meetings;

21 “(2) an organized inservice training program in
22 speech pathology and audiology;

23 “(3) visits to and from the staff of other facilities
24 and programs;

25 “(4) participation in interdisciplinary meetings;

1 “(5) provision for financial assistance and time for
2 attendance at professional conferences;

3 “(6) provisions for encouraging continuing educa-
4 tion, including educational leave, financial assistance, and
5 accommodation of work schedules;

6 “(7) workshops and seminars;

7 “(8) consultations with specialists; and

8 “(9) access to adequate library resources, which in-
9 clude current and relevant books and journals in speech
10 pathology and audiology, mental retardation, and related
11 professions and fields.

12 “(1) Space, facilities, equipment, and supplies shall be
13 adequate for providing efficient and effective speech pathol-
14 ogy and audiology services, in accordance with stated ob-
15 jectives, including—

16 “(1) adequate and convenient evaluation, treat-
17 ment, counseling, and waiting rooms;

18 “(2) specially constructed and sound-treated suites
19 for audiological services, meeting appropriate standards;

20 “(3) design and location such as to be easily ac-
21 cessible to all residents, regardless of disability;

22 “(4) specialized equipment needed by the speech
23 pathologist;

24 “(5) specialized equipment needed by the audi-
25 ologist, including an audiometer, with provisions for

1 sound field audiometry, and equipment capable of per-
2 forming at least the following procedures: hearing
3 screening, pure-tone air and bone conduction with con-
4 tralateral masking, speech audiometry, site-of-lesion
5 battery, nonorganic hearing loss battery, and hearing
6 aid evaluation;

7 “(6) provisions for adequate maintenance of all
8 areas, facilities, and equipment, including—

9 “(A) electroacoustic calibration of audiometers
10 at regular, at least quarterly, intervals;

11 “(B) calibration logs on all audiometers; and

12 “(7) appropriate speech pathology and audiology
13 consultation shall be employed in the design, modifica-
14 tion, and equipage of all speech pathology and audiology
15 areas and facilities.

16 **“Subchapter XV—Vocational Rehabilitation Services**

17 “SEC. 276. (a) The facility shall provide all its resi-
18 dents with habilitation or rehabilitation services, which in-
19 cludes the establishment, maintenance, and implementation
20 of those programs that will insure the optimal development
21 or restoration of each resident, physically, psychologically
22 socially, and vocationally—

23 “(1) The facility shall have a written, public state-
24 ment of its rehabilitation objectives for its residents,
25 consistent with—

1 “(A) the needs of its residents;

2 “(B) currently accepted rehabilitation princi-
3 ples and goals;

4 “(C) the facility’s philosophy and goals; and

5 “(D) the services and resources the facility
6 offers.

7 “(2) While the habilitation/rehabilitation concept
8 and process embrace all efforts to achieve the optimal
9 development of each resident, specific habilitation/reha-
10 bilitation services shall focus on the maximum achieve-
11 ment of—

12 “(A) self-help skills;

13 “(B) social competence, including communica-
14 tion skills;

15 “(C) vocational competence; and

16 “(D) independent living.

17 “(b) The ultimate objective of vocational rehabilitation
18 services shall be to assist every resident to move as far as
19 he can along the continuum from vocational afunction to
20 remunerative employment and entry into the mainstream
21 of society as an independent citizen and worker. Vocational
22 rehabilitation services shall be rendered—

23 “(1) directly, through personnel contact between
24 vocational rehabilitation personnel and residents; and

25 “(2) indirectly, through contact between voca-

1 tional rehabilitation personnel and other persons work-
2 ing with residents, designed to enhance and facili-
3 tate the development and maintenance of a rehabilita-
4 tive environment.

5 “(c) Vocational rehabilitation services available to the
6 residents, in accordance with their needs, shall include—

7 “(1) vocational evaluation;

8 “(2) the formulation of written vocational objec-
9 tives for each resident;

10 “(3) the formulation of a written plan to achieve
11 the stated objectives;

12 “(4) implementation of the vocational plan
13 through—

14 “(A) individual counseling;

15 “(B) prevocational programs;

16 “(C) vocational training;

17 “(D) vocational placement;

18 “(E) referral to appropriate sources for other
19 services; and

20 “(F) followup.

21 “(d) Vocational evaluation of each resident shall—

22 “(1) be initiated within one month after admission
23 to the facility;

24 “(2) arise out of a written comprehensive interdis-
25 ciplinary evaluation (medical, psychological, social, and

- 1 educational) that generates data relevant to vocational
- 2 objectives and goals, such as information concerning—
- 3 “(A) aptitudes and abilities;
- 4 “(B) self-help and independent living skills;
- 5 “(C) interests;
- 6 “(D) self and vocational perception;
- 7 “(E) sensorimotor coordination;
- 8 “(F) communication skills;
- 9 “(G) current social adjustment;
- 10 “(H) educational history; and
- 11 “(I) vocational and avocational history;
- 12 “(3) be adequate for the formulation of vocational
- 13 goals and of a detailed plan for the achievement of such
- 14 goals;
- 15 “(4) be adequate for the assessment of current voca-
- 16 tional status and for the prediction of possible future
- 17 status; and
- 18 “(5) provide for periodic, but at least semiannual
- 19 reevaluation, consistent with the progress of the resident
- 20 toward the stated goals.
- 21 “(e) The written vocational plan for each resident
- 22 shall—
- 23 “(1) be consistent with the vocational evaluation;
- 24 “(2) specify the program to be undertaken to
- 25 achieve his vocational objectives;

1 “(3) indicate the order in which the program is to
2 be undertaken;

3 “(4) provide for the implementation of the evalua-
4 tion team's recommendations; and

5 “(5) assign the responsibility to carry out the plan.

6 “(f) The resident shall be fully involved in his voca-
7 tional evaluation, and in the formulation of his program
8 plan. Prevocational services shall contribute to the develop-
9 ment of work readiness in the resident, and shall provide—

10 “(1) vocationally relevant academic instruction;

11 “(2) instruction in the self-help and social skills
12 necessary for vocational success;

13 “(3) instruction and practice in the social skills
14 necessary for maximally independent functioning in the
15 community, such as travel, handling of money, and use
16 of community resources;

17 “(4) an orientation to the world of work;

18 “(5) development of work attitudes needed for
19 vocational success;

20 “(6) rotated exploration and try-out of job tasks;

21 “(7) continuous evaluation of vocational potential;

22 and

23 “(8) any necessary supportive services, including
24 physical and mental restoration.

25 “(g) Vocational training programs shall meet all ap-

- 1 plicable legal requirements, and shall be provided through
2 means such as:
- 3 “(1) work training stations;
 - 4 “(2) work activity centers;
 - 5 “(3) transitional sheltered workshops;
 - 6 “(4) work-study programs;
 - 7 “(5) on-the-job training;
 - 8 “(6) trade training, in the classroom or on the
9 job;
 - 10 “(7) vocational training programs shall—
 - 11 “(A) provide for an evaluation of training
12 progress at least every three months;
 - 13 “(B) make maximum use of job training
14 resources—
 - 15 “(i) within the facility;
 - 16 “(ii) within the community;
 - 17 “(8) facilities conducting vocational training pro-
18 grams shall have vocational training personnel assigned,
19 in such numbers and for such times as are necessary and
20 appropriate to the situation, to supervise the training in
21 each training area; and
 - 22 “(9) written, detailed training guides and curricula
23 shall be available for all vocational training area.
 - 24 “(h) Job placement services shall assist the individual
25 to enter into appropriate kinds of employment, such as:

- 1 “(1) competitive, remunerative employment;
- 2 “(2) trade training programs;
- 3 “(3) transitional or extended sheltered workshops;
- 4 “(4) sheltered employment;
- 5 “(5) homebound employment;
- 6 “(6) homemaker; and
- 7 “(7) in conjunction with job placement services,
- 8 the individual shall be provided assistance related to off-
- 9 the-job needs, activities, and resources, such as—
- 10 “(A) living arrangements;
- 11 “(B) social and recreation activities;
- 12 “(C) medical services;
- 13 “(D) educational resources;
- 14 “(E) religious activities;
- 15 “(F) transportation;
- 16 “(G) legal affairs;
- 17 “(H) financial affairs; and
- 18 “(I) counseling.
- 19 “(i) Systematic follow-up services shall be provided
- 20 that—
- 21 “(1) continue to be available to the individual for
- 22 at least one year following placement;
- 23 “(2) involve contact with—
- 24 “(A) the individual;

1 “(B) the individual’s family or family-substi-
2 tute; and

3 “(C) the individual’s employer, if appropriate;
4 ate;

5 “(3) generate data concerning vocational outcomes
6 to evaluate and improve the effectiveness of vocational
7 rehabilitation programs.

8 “(j) There shall be a clearly designated person or team
9 responsible for the implementation, evaluation, and revision
10 of the facility’s vocational rehabilitation program.

11 “(1) There shall be available to each resident in a
12 vocational rehabilitation program a counselor who is
13 responsible for seeing that the resident’s vocational
14 rehabilitation program is effectively carried out.

15 “(2) A vocational rehabilitation counselor shall—

16 “(A) have a master’s degree in rehabilitation
17 counseling, or a master’s degree in a related area
18 plus training and skill in the vocational rehabilitation
19 process; or

20 “(B) have a bachelor’s degree and work under
21 the direct supervision of a person qualified as in (A).

22 “(3) Vocational rehabilitation personnel providing
23 training to residents in vocational areas shall be—

24 “(A) vocational instructors certified by the
25 appropriate state agency; or

1 “(B) tradesmen who have attained at least
2 journeyman status.

3 “(k) Appropriate to the nature and size of the facility,
4 provisions shall be made for vocational rehabilitation staff
5 developments, through such means as—

6 “(1) inservice training;

7 “(2) short-term workshops;

8 “(3) seminars;

9 “(4) attendance at conferences; and

10 “(5) visits to other facilities.

11 “(1) Every facility that has a vocational rehabilitation
12 program shall seek to establish working relationships with
13 public and private rehabilitation agencies in the community.
14 Each facility should have working relationships with univer-
15 sity training programs in rehabilitation, including provision
16 for—

17 “(1) research opportunities;

18 “(2) practicum experiences;

19 “(3) internship; and

20 “(4) consultation.

21 **“Subchapter XVI—Volunteer Services**

22 “SEC. 277. (a) Volunteer services shall be provided
23 in order to enhance opportunities for the fullest realization of
24 the potential of each resident by—

1 “(1) increasing the amount, and improving the
2 quality, of services and programs; and

3 “(2) facilitating positive relationships between the
4 facility and the community which it serves.

5 “(b) The facility shall have a written statement of the
6 goals and objectives of its volunteer services program that
7 are—

8 “(1) appropriate to the needs of the residents;

9 “(2) consistent with the philosophy and goals of
10 the facility;

11 “(3) developed in collaboration with the facility’s
12 staff;

13 “(4) specific and measurable; and

14 “(5) continuously assessed and periodically revised.

15 “(c) Volunteers shall provide services, which may be
16 direct or indirect, that are based on resident needs, staff re-
17 quests, and volunteer skills, and that enhance programs, de-
18 velop social competence, and build self-esteem—

19 “(1) volunteer services shall supplement, but shall
20 not be used in lieu of, the services of paid employees;

21 “(2) volunteer participation shall comply with
22 State laws, such as those relating to labor and insurance;

23 “(3) volunteer participation shall be open to per-
24 sons of both sexes, and of all ages, races, creeds, and
25 national origins; and

1 “(4) volunteer services shall be available to all resi-
2 dents, regardless of age, ability, or handicaps.

3 “(d) Direct services provided to residents by volun-
4 teers, as appropriate to the facility’s program and in coopera-
5 tion with its staff, may include, but are not limited to—

6 “(1) physical, occupational, and music therapy as-
7 sistance;

8 “(2) psychological testing assistance;

9 “(3) behavior modification and programed in-
10 struction assistance;

11 “(4) teacher or classroom assistance;

12 “(5) religious instruction;

13 “(6) recreation and leisure time activities;

14 “(7) social skills development;

15 “(8) library services;

16 “(9) nursing services;

17 “(10) transportation and escort assistance;

18 “(11) visits, vacations, and trips;

19 “(12) job and home findings; and

20 “(13) citizen advocacy.

21 “(e) Indirect services provided by volunteers, as ap-
22 propriate to the facility’s program and in cooperation with
23 its staff, may include, but are not limited to—

24 “(1) conducting tours;

25 “(2) clerical and laboratory assistance;

1 “(3) gift shop and canteen operation;

2 “(4) public relations and community education;

3 and

4 “(5) contributions.

5 “(f) Volunteer services staff should provide the follow-
6 ing services—

7 “(1) to the facility’s staff—

8 “(A) orientation in the need for, and philoso-
9 phy of volunteer services;

10 “(B) identification of how and where volun-
11 teers can be utilized; and

12 “(C) assistance in developing training for vol-
13 unteers;

14 “(2) to the volunteers—

15 “(A) orientation, training, and placement;

16 “(B) opportunities to participate in planning
17 and evaluating their experiences; and

18 “(C) appropriate recognition of their services
19 and contributions.

20 “(g) Volunteer services staff functions shall include—

21 “(1) development and implementation of a plan for
22 recruitment, selection, deployment, orientation, training,
23 supervision, evaluation, recognition, advancement, and
24 separation of volunteers;

1 “(2) development in collaboration with appro-
2 priate staff, of job descriptions for volunteers;

3 “(3) maintenance of complete and accurate rec-
4 ords, including, but not necessarily limited to—

5 “(A) hours of volunteer service rendered;

6 “(B) individuals and organizations providing
7 services;

8 “(C) materials and moneys received; and

9 “(D) operational budget.

10 “(h) The staff members responsible for facility programs
11 utilizing volunteers shall be responsible for providing such
12 volunteers with on-the-job training, supervision, and con-
13 sultation.

14 “(i) The cooperation and involvement of staff and
15 community, which is essential to a successful volunteer serv-
16 ices program, should be achieved by means such as—

17 “(1) a standing staff committee on volunteer serv-
18 ices, to foster communications and cooperation, to evalu-
19 ate and coordinate existing programs, and to stimulate
20 new programs;

21 “(2) a volunteer services advisory committee, com-
22 posed of representatives of appropriate community orga-
23 nizations;

24 “(3) encouragement of, and involvement with,
25 parents groups;

1 “(4) collaboration with appropriate agencies and
2 community groups; and

3 “(5) recruiting volunteers representative of the
4 community served by the facility, in respect of age, sex,
5 socioeconomic, religious, racial, and ethnic groups.

6 “(j) There shall be available sufficient, appropriately
7 qualified staff, and necessary supporting personnel, to carry
8 out the volunteer services program, in accordance with
9 stated goals and objectives.

10 “(1) A facility staff member shall be designated to
11 be responsible and accountable for volunteer services—

12 “(A) where the size of the facility and scope
13 of the program warrant, the person responsible for
14 volunteer services shall devote full time to this area;

15 “(B) volunteer services shall be organized
16 within the administrative structure of the facility
17 in such a way as to be available to, and maximally
18 utilized by, all relevant services and programs:
19 therefore, the staff member responsible for volunteer
20 services should report to an individual with facility-
21 wide administrative responsibility; and

22 “(C) the staff member responsible for volun-
23 teer services should have the same relationship to
24 volunteers as a personnel officer has to paid em-
25 ployees.

1 “(2) The staff member responsible for volunteer
2 services shall have—

3 “(A) the necessary interpersonal, consultative,
4 leadership, and organizational and administrative
5 skills and abilities;

6 “(B) demonstrated ability to identify, mobilize,
7 and deploy volunteer resources to meet the needs
8 of residents;

9 “(C) knowledge of community organization;

10 “(D) knowledge of current practices and con-
11 cepts in mental retardation; and

12 “(E) training and/or experience in organizing
13 and administering volunteer services, as appropriate
14 to the nature and size of the facility, and preferably—

15 “(i) a baccalaureate degree in a behav-
16 ioral science; and

17 “(ii) three years of experience in volun-
18 teer services or related area.

19 “(k) Appropriate to the size of the facility, there
20 should be a staff development program designed to maintain
21 and improve the skills of volunteer services staff, through
22 means such as—

23 “(1) seminars, workshops, and conferences;

24 “(2) college and university courses;

25 “(3) participation in professional organizations;

1 “(4) participation in interdisciplinary groups;

2 “(5) visits to other facilities; and

3 “(6) access to relevant professional literature.

4 “(1) There shall be adequate and accessible space, fa-
5 cilities, equipment, and supplies for providing efficient and
6 effective volunteer services. If a canteen is operated by the
7 facility, it shall—

8 “(1) be operated for the benefit of the residents;

9 “(2) be open to residents, staff, families, and
10 visitors, without segregation by space or hours of use,
11 so as to facilitate interaction;

12 “(3) provide opportunities for residents to purchase
13 items for their personal needs;

14 “(4) provide opportunities for the training of resi-
15 dents; and

16 “(5) be operated so that any profits derived are
17 utilized for the benefit of residents.

18 **“Chapter 4.—RECORDS**

19 **“Subchapter I—Maintenance of Residents’ Records**

20 “SEC. 278. (a) A record shall be maintained for each
21 resident that is adequate for—

22 “(1) planning and continuous evaluating of the
23 resident’s habilitation program;

24 “(2) providing a means of communication among

1 all persons contributing to the resident's habilitation
2 program;

3 "(3) furnishing documentary evidence of the resi-
4 dent's progress and of his response to his habilitation
5 program;

6 "(4) serving as a basis for review, study, and
7 evaluation of the overall programs provided by the fa-
8 cility for its residents;

9 "(5) protecting the legal rights of the residents,
10 facility, and staff; and

11 "(6) providing data for use in research and edu-
12 cation.

13 "(b) All information pertinent to the above-stated
14 purposes shall be incorporated in the resident's record, in suf-
15 ficient detail to enable those persons involved in the resi-
16 dent's program to provide effective, continuing services. All
17 entries in the resident's record shall be—

18 "(1) legible;

19 "(2) dated; and

20 "(3) authenticated by the signature and identifica-
21 tion of the individual making the entry.

22 "(c) Symbols and abbreviations may be used in record
23 entries only if they are in a list approved by the facility's
24 chief executive officer and a legend is provided to explain

1 them. Diagnoses should be recorded in full and without the
2 use of symbols or abbreviations.

3 **"Subchapter II—Content of Records**

4 "SEC. 279. (a) The following information should be
5 obtained and entered in the resident's record at the time of
6 admission to the facility:

7 "(1) name, date of admission, date of birth, place
8 of birth, citizenship status, marital status, and social se-
9 curity number;

10 "(2) father's name and birthplace, mother's maiden
11 name and birthplace, and parents' marital status;

12 "(3) name and address of parents, legal guardian,
13 and/or next of kin;

14 "(4) sex, race, height, weight, color of hair, color
15 of eyes, identifying marks, and recent photograph;

16 "(5) reason for admission or referral problem;

17 "(6) type and legal status of admission;

18 "(7) legal competency status;

19 "(8) language spoken or understood;

20 "(9) sources of support, including social security,
21 veterans' benefits, and insurance;

22 "(10) provisions for clothing and other personal
23 needs;

24 "(11) information relevant to religious affiliation;

1 “(12) report(s) of the preadmission evalua-
2 tion(s); and .

3 “(13) reports of previous histories and evaluations.

4 “(b) Within the period of one month after admission
5 there shall be entered in the resident's record—

6 “(1) a report of the review and updating of the
7 preadmission evaluation;

8 “(2) a statement of prognosis that can be used for
9 programing and placement;

10 “(3) a comprehensive evaluation and individual
11 program plan, designed by an interdisciplinary team;
12 and

13 “(4) a diagnosis based on the appropriate na-
14 tionally recognized professional association on mental
15 deficiency's manual on terminology and classification in
16 mental retardation and, where necessary, the diagnostic
17 and statistical manual of mental disorders, most recent
18 edition, published by the appropriate nationally recog-
19 nized professional psychiatric association.

20 “(c) Records during residence should include—

21 “(1) reports of accidents, seizures, illnesses, and
22 treatments thereof, and immunizations;

23 “(2) record of all periods of restraint, with justifica-
24 tion and authorization for each;

1 “(3) report of regular, at least annual, review and
2 evaluation of the program, developmental progress, and
3 status of each resident;

4 “(4) observations of the resident’s response to his
5 program, recorded with sufficient frequency to enable
6 evaluation of its efficacy;

7 “(5) record of significant behavior incidents;

8 “(6) record of family visits and contacts;

9 “(7) record of attendance and leaves;

10 “(8) correspondence;

11 “(9) periodic updating of the information recorded
12 at the time of admission; and

13 “(10) appropriate authorizations and consents.

14 “(d) At the time of discharge from the facility, a dis-
15 charge summary shall be prepared that should—

16 “(1) include a brief recapitulation of findings,
17 events, and progress during residence, diagnosis, prog-
18 nosis, and recommendations and arrangements for future
19 programing:

20 “(2) be completed and entered in the resident’s
21 record within seven days following discharge; and

22 “(3) with the written consent of the resident or his
23 guardian, be copied and sent to the individual or agency
24 who will be responsible for future programing of the
25 resident.

1 “(e) In the event of death—

2 “(1) a copy of the death certificate should be placed
3 in the resident’s record; and

4 “(2) when a necropsy is performed, provisional
5 anatomic diagnoses should be recorded within seventy-
6 two hours, where feasible, and the complete protocol
7 should be made part of the record within three months.

8 **“Subchapter III—Confidentiality of Records**

9 “SEC. 280. (a) All information contained in a resi-
10 dent’s records, including information contained in an auto-
11 mated data bank, shall be considered privileged and
12 confidential—

13 “(1) the record is the property of the facility,
14 whose responsibility it is to secure the information
15 against loss, defacement, tampering, or use by unauthor-
16 ized persons;

17 “(2) the record may be removed from the facility’s
18 jurisdiction and safekeeping only in accordance with a
19 court order, subpoena, or statute;

20 “(3) there shall be written policies governing ac-
21 cess to, duplication of, and dissemination of information
22 from the record; and

23 “(4) written consent of the resident or his guardian
24 shall be required for the release of information to
25 persons not otherwise authorized to receive it,

1 **“Subchapter IV—Central Record Service**

2 “SEC. 281. (a) The facility shall maintain an orga-
3 nized central record service for the collection and dissemina-
4 tion of information regarding residents. A centralized or
5 decentralized system of recordkeeping may be used in ac-
6 cordance with the needs of the facility—

7 “(1) there shall be a unit record that contains all
8 information pertaining to an individual resident for all
9 admissions to the facility;

10 “(2) where particular professional services require
11 the maintenance of separate records, a summary of the
12 information contained therein shall be entered in the unit
13 record at stated intervals;

14 “(3) records shall be readily accessible to author-
15 ized personnel;

16 “(4) where a centralized system is used, appro-
17 priate records shall also be available in the resident-
18 living units; and

19 “(5) a periodic review of the content of the records
20 should be made by—

21 “(A) record personnel, to assure that they are
22 current and complete; and

23 “(B) a committee of appropriate staff, in-
24 cluding the record librarian, to assure that they
25 meet the standards set forth in section 278;

1 “(6) there shall be a master alphabetical index of
2 all residents admitted to the facility; and

3 “(7) records shall be retained for the period of
4 time specified by the facility, but at least for the period
5 of time consistent with the statute of limitations of the
6 State in which the facility is located.

7 **“Subchapter V—Statistical Records**

8 “SEC. 282. (a) While the type and amount of sta-
9 tistical information will depend upon the facility’s particu-
10 lar needs, such information should include at least the fol-
11 lowing:

12 “(1) number of residents by age groups, sex, race,
13 and place of residence;

14 “(2) number of residents by level of retardation,
15 according to the appropriate nationally recognized pro-
16 fessional association on mental deficiency classification;

17 “(3) number of residents by level of adaptive be-
18 havior, according to the appropriate nationally recog-
19 nized professional association of mental deficiency
20 classification;

21 “(4) number of residents with physical disabilities;

22 “(5) number of residents who are ambulatory and
23 nonambulatory (mobile and nonmobile);

24 “(6) number of residents with sensory defects;

1 “(7) number of residents with convulsive disorders,
2 grouped by level of seizure control;

3 “(8) number of residents by etiological diagnoses,
4 according to the appropriate nationally recognized pro-
5 fessional association and, where necessary, the DSM-II
6 classifications;

7 “(9) movement of residents into, out of, and with-
8 in the facility; and

9 “(10) length of stay.

10 “(b) Data shall be reported to appropriate Federal and
11 other agencies as requested.

12 **“Subchapter VI—Records Personnel**

13 “SEC. 283. (a) There shall be available sufficient, ap-
14 propriately qualified staff, and necessary supporting person-
15 nel, to facilitate the accurate processing, checking, indexing,
16 filing, and prompt retrieval of records and record data.

17 “(b) The record system should be supervised on a full-
18 or part-time basis, according to the needs of the facility, by
19 an individual who—

20 “(1) is a registered record librarian; or

21 “(2) is an accredited record technician; or

22 “(3) has demonstrated competence and experience
23 in administering and supervising the maintenance and
24 use of records and reports.

25 “(c) Record personnel should—

1 “(1) be involved in educational programs relative
2 to their activities, including orientation, on-the-job train-
3 ing, and regular inservice education programs; and

4 “(2) participate in workshops institutes or cor-
5 respondence education courses available outside the
6 facility.

7 “(d) There shall be adequate space, facilities, equip-
8 ment, and supplies for providing efficient and effective record
9 services.

10 **“Chapter 5.—RESEARCH**

11 **“Subchapter I—Encouragement of Research**

12 “SEC. 284. (a) Recognizing that the understanding,
13 prevention, and amelioration of mental retardation and other
14 developmental disabilities ultimately depends upon knowl-
15 edge gained through research, the administration and staff
16 of the facility (and, in the case of public facilities, the ap-
17 propriate governmental agency) shall encourage research
18 activity.

19 “(1) opportunities and resources should be made
20 available to members of the staff who are equipped by
21 interest and training to conduct applied and/or basic
22 research. Research resources and/or necessary research
23 assistance should be made available to all staff members
24 who have identified researchable problems related to
25 the programs for which they are responsible;

1 “(2) research by qualified investigators who are
2 not staff members of the facility shall be encouraged.
3 There shall be a written policy concerning the conduct
4 of research in the facility by investigators who are not
5 staff members. Outside researchers shall fulfill the same
6 obligations relative to staff information and feedback
7 as do facility staff members. Consideration should be
8 given to the assignment of a facility staff member to
9 each research project conducted by outside investigators;
10 and

11 “(3) where feasible, there shall be ongoing, coop-
12 erative programs of research and research training with
13 colleges, universities, and research agencies.

14 “(b) The administration of the facility shall make pro-
15 vision for the design and conduct, or the supervision, of re-
16 search that will objectively evaluate the effectiveness of pro-
17 gram components and contribute to informed decisionmak-
18 ing in the facility.

19 **“Subchapter II—Review of Research Proposals**

20 “SEC. 285. (a) An interdisciplinary research committee
21 shall review all proposed studies to insure—

22 “(1) adequacy of research design; and

23 “(2) implementation of ethical standards in the
24 design.

25 “(b) Facility staff members shall be consulted regard-

1 ing the planning of research and the utilization of research
2 findings in their areas of competence and interest.

3 **"Subchapter III—Conduct of Research**

4 "SEC. 286. (a) The facility shall follow, and comply
5 with the statement of assurance on research involving human
6 subject required by the United States Department of Health,
7 Education, and Welfare for projects supported by that
8 Agency or any appropriate more stringent such statement,
9 as appropriate.

10 "(b) Investigators and others directly involved in the
11 research shall—

12 "(1) adhere to the ethical standards of their pro-
13 fessions concerning the conduct of research; and

14 "(2) have access to the record of informed consent.

15 **"Subchapter IV—Reporting Research Results**

16 "SEC. 287. (a) The principal investigator of each re-
17 search project shall be responsible for communicating to the
18 staff of the facility the purpose, nature, outcome, and possible
19 practical or theoretical implications of the research. Copies
20 of the reports resulting from research projects shall be main-
21 tained in the facility.

22 "(b) Where research findings are made public, care
23 shall be taken to assure the anonymity of individual residents
24 and parents.

25 "(c) Clearly defined mechanisms shall exist for inform-

1 ing staff members of new research findings that have ap-
2 plicability to the programs and administration of the facility.
3 There shall be evidence that currently applicable research
4 results are being implemented in the facility's programs.

5 **"Chapter 6.—SAFETY AND SANITATION**

6 **"Subchapter I—Safety**

7 SEC. 288. (a) The requirements of the Secretary
8 shall be met, with specific reference to the following—

9 " (1) provision of adequate and alternate exits and
10 exit doors;

11 " (2) provision of exit ramps, with nonskid surface
12 and slope not exceeding one foot in twelve; and

13 " (3) provision in handrails on stairways.

14 " (b) There shall be records that document strict com-
15 pliance with the regulations of the State or local fire safety
16 authority that has primary jurisdiction over the facility—

17 " (1) aisles and exits shall be free from all encum-
18 brances and floors shall be uncluttered;

19 " (2) flammable materials shall be properly stored
20 and safeguarded;

21 " (3) attics and basements shall be kept orderly and
22 free of rubbish; and

23 " (4) there shall be records of periodic fire safety
24 inspections and reports.

25 " (c) There shall be a written staff organization plan and

1 detailed, written procedures, which are clearly communicated
2 to, and periodically reviewed with staff, for meeting all
3 potential emergencies and disasters pertinent to the area, such
4 as fire, severe weather, and missing persons.

5 “(1) The plans and procedures should include—

6 “(A) plans for the assignment of personnel to
7 specific tasks and responsibilities;

8 “(B) instructions relating to the use of alarm
9 systems and signals;

10 “(C) information concerning methods of fire
11 containment;

12 “(D) systems for notification of appropriate
13 persons;

14 “(E) information concerning the location of
15 firefighting equipment; and

16 “(F) specification of evacuation routes and
17 procedures.

18 “(2) the plans and procedures shall be posted at
19 suitable locations through the facility.

20 “(d) Evacuation drills shall be held at least quarterly,
21 for each shift of facility personnel and under varied condi-
22 tions, in order to—

23 “(1) insure that all personnel on all shifts are
24 trained to perform assigned tasks;

25 “(2) insure that all personnel on all shifts are famil-

1 iar with the use of the firefighting equipment in the
2 facility;

3 “(3) evaluate the effectiveness of disaster plans
4 and procedures;

5 “(4) evacuation drills shall include actual evacua-
6 tion of residents to safe areas during at least one drill
7 each year, on each shift. There shall be special provisions
8 for the evacuation of the physically handicapped, such as
9 fire chutes and mattress loops with poles; and

10 “(5) there shall be a written, filed report and
11 evaluation of each evacuation drill.

12 “(e) An active safety program shall be maintained by
13 a multidisciplinary safety committee that investigates all
14 accidents and makes recommendations for prevention. Rec-
15 ords of the activities of the safety committee shall be kept.
16 There shall be adequate safety shields on the moving parts
17 of all dumb waiters, elevators, and other machinery, as pro-
18 vided for in applicable standards and codes.

19 “(f) All buildings and outdoor recreation facilities con-
20 structed after 1971 shall be accessible to, and usable by, the
21 nonambulatory and shall meet standards of the Secretary
22 for making building accessible to, and usable, by the physi-
23 cally handicapped—

24 “(1) all existing buildings and outdoor recreation
25 facilities shall be modified so as to conform to the above
26 standards by December 31, 1976; and

1 “(2) existing facilities shall provide—

2 “(A) entrance ramps wide enough for wheel-
3 chairs, not exceeding a rise of one foot in twelve,
4 with nonslip surfaces, and with rails on both sides;

5 “(B) doorways and corridors wide enough for
6 wheelchairs; and

7 “(C) grab bars in toilet and bathing facilities.

8 “(g) Paint used in the facility shall be lead free. Old
9 paint or plaster containing lead shall have been removed,
10 or covered in such manner that it is not accessible to resi-
11 dents.

12 “(h) Appropriate provisions shall be made for emer-
13 gency auxiliary heat by means of alternate sources of electric
14 power, alternate fuels, and/or standby equipment.

15 **“Subchapter II—Sanitation**

16 “SEC. 289. (a) There shall be records that document
17 strict compliance with the sanitation, health, and environ-
18 mental safety codes of the State or local authorities having
19 primary jurisdiction over the facility. Written reports of
20 inspections by State or local health authorities, and records
21 of action taken on their recommendations, shall be kept on
22 file at the facility.

23 “(b) The holding, transferring, and disposal of waste
24 and garbage shall be done in a manner that will not create
25 a nuisance, nor permit the transmission of disease, nor create
26 a breeding place for insects or rodents—

1 “(1) waste that is not disposed of by mechanical
2 means shall be—

3 “(A) kept in leakproof, nonabsorbent contain-
4 ers with close-fitting covers; and

5 “(B) disposed of daily.

6 “(2) containers shall be thoroughly cleaned inside
7 and out, each time they are emptied; and

8 “(3) impervious plastic liners should be used.

9 “(c) Handwashing facilities shall be available in, or
10 immediately adjacent to—

11 “(1) bathrooms;

12 “(2) toilet rooms;

13 “(3) sleeping areas; and

14 “(4) kitchens.

15 “(d) There shall be adequate insect screens on all
16 windows and doors where needed and adequate janitorial
17 equipment and storage space in each unit of the facility.

18 **“Chapter 7.—ADMINISTRATIVE SUPPORT**

19 **SERVICES**

20 **“Subchapter I—Functions, Personnel, and Facilities**

21 “SEC. 290. (a) Adequate, modern administrative sup-
22 port shall be provided to efficiently meet the needs of, and
23 contribute to, program services for residents, and to facilitate
24 support of a variety of resources, which may include, but need
25 not be limited to, the following kinds of services: clerical,

1 communication, dietary, financial, housekeeping, laundry,
2 personnel, physical plant, records, safety and security, and
3 supply and purchasing.

4 “(b) Administrative support functions should be di-
5 rected by a qualified administrator, trained and experienced
6 to provide skilled and efficient coordination of these services,
7 to adequately meet the facility’s program objectives. In
8 larger facilities, provision may be made for both executive
9 direction, via a chief executive officer (superintendent, di-
10 rector, and so forth), and administration of support services
11 (via a business manager, and so forth). In smaller facilities,
12 a single person may provide both program direction and
13 administration of support services—

14 “(1) the administrator of support services should—

15 “(A) have at least a baccalaureate degree; or

16 “(B) have completed formal graduate educa-
17 tion in health administration or its equivalent.

18 “(2) all administrative support personnel shall have
19 sufficient understanding and appreciation of the nature
20 and behavior of the mentally retarded and developmen-
21 tally disabled resident, to assure that each employee’s
22 work and his relations to the residents contribute posi-
23 tively to their welfare.

24 “(c) There shall be adequate office space, facilities,

1 equipment, and supplies for the efficient conduct of all
2 administrative support functions.

3 **"Subchapter II—Fiscal Affairs**

4 "SEC. 291. (a) Funds shall be budgeted and spent in
5 accordance with the principles and procedures of program
6 budgeting.

7 "(1) the budget requests submitted by the facility
8 shall—

9 "(A) adequately reflect the program needs of
10 the residents, as developed by program staff; and

11 "(B) be adequately documented and inter-
12 preted.

13 "(2) budget preparation shall be the product of
14 team management;

15 "(3) budget preparation and implementation shall
16 include active participation of professional team mem-
17 bers;

18 "(4) budget development shall include incorpora-
19 tion of effectiveness measures; and

20 "(5) there shall be sufficient latitude to permit re-
21 budgeting of funds in response to changing program
22 needs, and in accordance with the principles and proce-
23 dures of program budgeting.

24 "(b) Individuals acting on the facility's budget requests
25 (board members, State budget officials, members of appro-

1 priations committees, and so forth) should have firsthand
2 knowledge of its operations and needs, obtained by regular
3 visitation and observation of its programs.

4 “(c) Budget performance reports shall be prepared at
5 appropriate intervals and submitted to those individuals par-
6 ticipating in budgeting and management responsibilities.

7 “(d) Funds for community (that is, nonresidential)
8 programs and services shall not be included in computing the
9 per capita (that is, per resident) cost of operation. The per
10 capita expenditure for residential services, divided by the cost
11 of living index for the State or area, should compare favor-
12 ably with the same ratio for the Nation as a whole, that is,
13 come within 90 per centum of the Nation as a whole or,
14 preferably, exceed 100 per centum. Maintenance expendi-
15 tures should be at least the same as would be required by
16 age peers in the community.

17 “(e) There shall be a formal system of internal control
18 in handling the fiscal affairs of the facility. The facility shall
19 have an adequate ‘responsibility’ accounting system.

20 “(f) A full audit of the facility’s fiscal activities shall be
21 performed regularly, preferably annually, by a qualified ac-
22 countant independent of the facility.

23 “(g) Fiscal reports shall be prepared and communicated
24 to the facility’s public at least annually.

25 “(h) Facilities charging for services shall have a written

1 schedule of rates and charge policies, which shall be available
2 to all concerned.

3 “(i) Where the size of the facility’s operation warrants
4 a fiscal officer, he shall have appropriate training and experi-
5 ence in accounting and auditing. Sufficient accountants, ac-
6 count clerks, and clerk-typists shall be provided to assure
7 maximum support to the efforts of personnel directly involved
8 in service to resident.

9 **“Subchapter III—Purchase, Supply, and Property**

10 **Control**

11 “SEC. 292. (a) There shall be written purchasing poli-
12 cies regarding authority and approvals for supplies, services,
13 and equipment.

14 “(b) There shall be adequate documentation of the pur-
15 chasing process, including, where appropriate, requisitions,
16 bids from a number of suppliers, purchase orders, and receiv-
17 ing reports.

18 “(c) The inventory control system and stockroom op-
19 eration shall be adequate for—

20 “(1) receiving supplies;

21 “(2) issuing supplies as needed in programs;

22 “(3) maintaining necessary stock level;

23 “(4) establishing responsibility for stocks; and

24 “(5) there shall be appropriate storage facilities
25 for all supplies and surplus equipment.

1 “(d) Where the size of the facility’s operation warrants,
2 the person responsible for directing purchase, supply, and
3 property control should have had several years of progres-
4 sively more responsible experience in these fields, and/or
5 related training. There shall be sufficient trained and experi-
6 enced personnel to accomplish the necessary purchase, sup-
7 ply, and property control functions.

8 **“Subchapter IV—Communications**

9 “SEC. 293. (a) There shall be adequate communica-
10 tion service, including adequate telephone service, whenever
11 residents are in the facility.

12 “(b) The communication system shall assure—

13 “(1) prompt contact of on-duty personnel; and

14 “(2) prompt notification of responsible personnel
15 in the event of emergency.

16 **“Subchapter V—Engineering and Maintenance**

17 “SEC. 294. (a) The facility shall have an appropriate
18 and written preventive maintenance program.

19 “(b) Where the size of the facility warrants, engineer-
20 ing and maintenance shall be directed by an engineer who—

21 “(1) has had at least three years of progressively
22 more responsible experience in institutional engineering
23 and maintenance;

24 “(2) is licensed or certificated, as appropriate to the
25 nature of the facility; and

1 “(3) there shall be sufficient trained and experi-
2 enced personnel to accomplish the required engineering
3 and maintenance functions.

4 **“Subchapter IV—Housekeeping Services**

5 “SEC. 295. Appropriate to the size and nature of the
6 facility, the person responsible for directing housekeeping
7 services should have had—

8 (1) several years of progressively more responsi-
9 ble experience in this field, and/or related training;

10 (2) formal training in short courses or vocational
11 schools; and

12 (3) experience and training in supervision and
13 management.

14 **“Subchapter VII—Laundry Services**

15 “SEC. 296. (a) Laundry services shall be managed
16 so that—

17 (1) daily clothing and linen needs are met with-
18 out delay; and

19 (2) there is a minimum loss and damage to clothing.

20 “(b) Appropriate to the size and nature of the facility,
21 the person responsible for directing laundry services should
22 have had several years of progressively more responsible
23 experience in this field, and/or related training. The person
24 responsible for directing laundry service shall have the
25 ability to supervise residents who work in the laundry.

"Chapter 8.—DEFINITIONS

2 "SEC. 297. As used in this part the term—

3 "(1) 'Advocacy' means that which is done by an
4 advocate.

5 "(2) 'Advocate' means an individual, whether a pro-
6 fessional employed by a private or public agency, or a
7 volunteer (a citizen advocate), who acts on behalf of a
8 resident to secure both the services that the resident requires
9 and the exercise of his full human and legal rights.

10 "(3) 'Ambulatory' means able to walk independently,
11 without assistance.

12 "(4) 'Chief executive officer' means the individual ap-
13 pointed by the governing body of a facility to act in its
14 behalf in the overall management of the facility. Job titles
15 may include, but are not limited to, superintendent, director,
16 and administrator.

17 "(5) 'Developmental disability' means a disability—

18 "(A) attributable to mental retardation, or cerebral
19 palsy, or epilepsy, or autism, or learning disability; or

20 "(B) attributable to any other condition of an
21 individual found to be related to mental retardation as
22 it refers to general intellectual functioning or impairment
23 in adaptive behavior or to require treatment similar to
24 that required for mentally retarded individuals,

25 which disability (i) originates before such individual attains

1 age eighteen, (ii) which has continued or can be expected
2 to continue indefinitely, and (iii) which constitutes a severe
3 handicap to such individual's ability to function normally in
4 society.

5 “(6) ‘Direct-care staff’ means individuals who conduct
6 the resident-living program; resident-living staff.

7 “(7) ‘Facility’ means a residential facility for the men-
8 tally retarded.

9 “(8) ‘Generic services’ means services offered or avail-
10 able to the general public, as distinguished from specialized
11 services intended only for the mentally retarded.

12 “(9) ‘Governing board’ means a group of individuals
13 that constitutes the governing body of a facility; one form
14 of a governing body. A governing board may be called
15 a board of trustees, board of directors, or board of governors.

16 “(10) ‘Governing body’ means the policy-making au-
17 thority, whether an individual or a group, that exercises
18 general direction over the affairs of a facility and estab-
19 lishes policies concerning its operation and the welfare of
20 the individual it serves.

21 “(11) ‘Guardian’ means an individual who has legal
22 control and management of the person, or of the property
23 or estate, or of both the person and the property, of a resi-
24 dent. A natural guardian is a parent lawfully in control of
25 the person or his minor child; natural guardianship termi-

1 nates when the child attains his majority. A legal guardian
2 is one appointed by a court. A guardian of the person is one
3 appointed to see that the resident has proper care and pro-
4 tective supervision in keeping with his needs. A guardian
5 of the property is one appointed to see that the financial
6 affairs of the resident are handled in his best interests. A
7 guardian ad litem is one appointed to represent a resident
8 in a particular legal proceeding, without control over either
9 the resident's person or his estate. A public guardian is a
10 public official empowered to accept court appointment as a
11 legal guardian. A testamentary guardian is one designated
12 by the last will and testament of a natural guardian.

13 “(12) ‘Legal incompetence’ means the legal determi-
14 nation that a resident is unable to exercise his full civil and
15 legal rights, and that a guardian is required.

16 “(13) ‘Living unit’ means a resident-living unit that
17 includes sleeping, dining, and activity areas.

18 “(14) ‘Mobile nonambulatory’ means unable to walk
19 independently or without assistance, but able to move from
20 place to place with the use of devices such as walkers,
21 crutches, wheelchairs, wheeled platforms, and so forth.

22 “(15) ‘Nonambulatory’ means unable to walk inde-
23 pendently, without assistance.

24 “(16) ‘Nonmobile’ means unable to move from place to
25 place.

1 “(17) ‘Normalization principle’ means the principle of
2 letting the mentally retarded and other individuals with
3 developmental disabilities ‘obtain an existence as close to
4 the normal as possible,’ making available to them ‘patterns
5 and conditions of everyday life which are as close as possible
6 to the norms and patterns of the mainstream of society.’
7 Specifically, ‘the use of means that are as culturally normative
8 as possible to elicit and maintain behavior that is as culturally
9 normative as possible.’

10 “(18) ‘Public financial support programs’ include, but
11 are not limited to, services for crippled children; aid to the
12 disabled, old age, survivors, and disability insurance, and
13 other benefits available under the Social Security Act;
14 and benefits administered by the Veterans’ Administration.

15 “(19) ‘Resident’ means the general term used in the
16 standards to refer to an individual who receives service from
17 a residential facility, whether or not such individual is actu-
18 ally in residence in the facility. The term thus includes in-
19 dividuals who are being considered for residence in a fa-
20 cility, individuals who were formerly in residence in a facility,
21 and individuals who are receiving services other than dom-
22 iciliary from a facility. (A residential facility, on the other
23 hand, may use the term ‘resident’ to refer only to those
24 individuals actually in residence, and may thus distinguish
25 between resident and nonresident recipients of its services.)

1 “(20) ‘Resident-living’ means pertaining to residential
2 or domiciliary services provided by a facility.

3 “(21) ‘Residential facility’ means a facility that provides
4 twenty-four-hour programing services, including residential
5 or domiciliary services, directed to enhancing the health, wel-
6 fare, and development of individuals classified as mentally
7 retarded. While the facility must provide twenty-four-hour
8 programing for residents, in accordance with their needs, it
9 need not itself operate any programs or services other than
10 residential or domiciliary.

11 “(22) ‘Rhythm of life’ means relating to the normal-
12 ization principle, under which making available to the men-
13 tally retarded and other individuals with developmental dis-
14 abilities ‘patterns and conditions of everyday life which
15 are as close as possible to the norms and patterns of the main-
16 stream of society’ means providing a normal rhythm of the
17 day (in respect to arising, getting dressed, participating in
18 play and work activities, eating meals, retiring, and so
19 forth), normal rhythm of the week (differentiation of daily
20 activities and schedules), and normal rhythm of the year.

21 “(23) ‘Surrogate’ means an individual who functions
22 in lieu of a resident’s parents or family.

23 “(24) ‘Time out’ means time out from positive rein-
24 forcement. A behavior modification procedure in which,

1 contingent upon the emission of undesired behavior, the
2 resident is removed from the situation in which positive re-
3 inforcement is available.”.

4 **“Chapter 9.—REVISION OF STANDARDS**

5 **“SEC. 299. (a)** It shall be the duty and function of the
6 Council established under section 133 (a) of this Act to (1)
7 advise the Secretary with respect to any regulations promul-
8 gated or proposed to be promulgated by him in the imple-
9 mentation of the standards established under part A of this
10 Act, (2) study and evaluate such standards authorized by
11 this Act through site visits and other appropriate methods
12 with a view of determining their effectiveness in carrying
13 out the purposes for which they were established, and (3)
14 based upon site visits or other studies, evaluations, or reviews
15 recommend to the Secretary any changes, revisions, modifi-
16 cations, or improvements in the standards established under
17 part A of this Act, which will strengthen or upgrade such
18 standards.

19 **“(b)** Nothing herein shall limit the authority of the
20 Secretary to seek and receive advice and respect to the above
21 matters from any source he deems appropriate, including but
22 not limited to the national accrediting body for facilities and
23 programs for the mentally retarded, and other individuals
24 with developmental disabilities.

1 “PART B—INSTITUTIONAL ASSISTANCE

2 “GRANTS TO ASSIST INSTITUTIONS FOR INDIVIDUALS
3 WITH DEVELOPMENTAL DISABILITIES

4 “SEC. 300. For the purpose of assisting States in meet-
5 ing the expenses, directly or indirectly, for bringing publicly
6 operated facilities and publicly assisted facilities into con-
7 formity with the standards established under part A of this
8 title, which seek to assure the humane care, protection, habili-
9 tation, and treatment of individuals with developmental dis-
10 abilities in residential facilities, there are authorized to be ap-
11 propriated such sums as are necessary to enable the Secre-
12 tary to make grants under this title.

13 “STATE PLANS

14 “SEC. 301. (a) Any State desiring to receive a grant
15 under this title shall submit a plan to the Secretary—

16 “(1) setting forth a schedule for compliance with
17 the standards established under part A of this title for
18 each facility for which assistance is requested;

19 “(2) assuring reasonable State financial participa-
20 tion in the cost of carrying out the plan to comply with
21 the standards set forth in this title and how the resi-
22 dential facility for individuals with developmental
23 disabilities will complement and augment rather than
24 duplicate or replace other community services for in-

1 dividuals with development disabilities or meet the
2 requirements of part A of this title;

3 “(3) setting forth a schedule of costs to achieve com-
4 pliance with the standards established under part A
5 of this title; and

6 “(4) designating how placement in residential facil-
7 ities shall be minimized through alternative regional and
8 community programs and services for individuals with
9 developmental disabilities, and be in coordination with
10 the plan established under title I of this Act.

11 “(b) The Secretary shall approve a plan which sets
12 forth a reasonable time for compliance with the standards
13 established under this title, and he shall not finally disapprove
14 a plan except after reasonable notice and opportunity for a
15 hearing to such State.

16 “AMOUNT OF GRANTS; PAYMENTS

17 “SEC. 302. (a) The total of the grants with respect to
18 any project under this part may not exceed 75 per centum of
19 the necessary cost thereof as determined by the Secretary.

20 “(b) Payments of grants under this part shall be made
21 in advance or by way of reimbursement, and on such condi-
22 tions as the Secretary may determine.

23 “MAINTENANCE OF EFFORT

24 “SEC. 303. Applications for grants under this part may
25 be approved by the Secretary only if the application con-

1 tains or is supported by reasonable assurances that the grants
2 will not result in any decrease in the level of State, local, and
3 other non-Federal funds for services for individuals with de-
4 velopmental disabilities which would (except for such grant)
5 be available to the applicant, but that such grants will be
6 used to supplement, and, to the extent practicable, to increase
7 the level of such funds.

8 "WITHHOLDING OF GRANTS

9 "SEC. 304. (a) Five years after the date of enactment of
10 this title, no residential facility for individuals with develop-
11 mental disabilities shall be eligible to receive payments either
12 directly or indirectly under any Federal law, unless such
13 facility meets the standards promulgated under part A of
14 this title.

15 "(b) The funds to which any individual would other-
16 wise be entitled to have paid on his behalf to any vendor of
17 residential services, public or private, shall be reserved for
18 him and administered by the Social Security Administra-
19 tion in the same manner as benefits under title II of the
20 Social Security Act would be administered on his behalf were
21 he entitled to same."

93^d CONGRESS
2^d SESSION

S. 3011

IN THE SENATE OF THE UNITED STATES

FEBRUARY 18, 1974

Mr. JAVITS (by request) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

A BILL

To amend the Public Health Service Act, the Developmental Disabilities Services and Facilities Construction Act, and the Comprehensive Alcohol Abuse and Alcoholism Prevention, Treatment, and Rehabilitation Act of 1970, to revise and extend programs of health services, and for other purposes.

- 1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*
3 That this Act may be cited as the "Health Services Amend-
4 ments of 1974".

II

1 TITLE I—COMPREHENSIVE PUBLIC HEALTH
 2 SERVICES, AND HEALTH SERVICES DEVEL-
 3 OPMENT

4 REPEAL OF MENTAL HEALTH ALLOCATION

5 SEC. 101. Section 314 (d) (7) of the Public Health
 6 Service Act is amended to read as follows:

7 “(7) ALLOCATION OF FUNDS WITHIN THE
 8 STATES.—At least 70 per centum of a State’s allotment
 9 under this subsection shall be available only for the pro-
 10 vision under the State plan of services in communities
 11 of the State.”

12 EXTENSION OF STATE FORMULA GRANTS

13 SEC. 102. Section 314 (d) (1) of such Act is amended
 14 by striking out “and” after “1973,” and inserting imme-
 15 diately after “1974” the following: “, and such sums as may
 16 be necessary for each of the next three fiscal years”.

17 EXTENSION AND REVISION OF PROJECT GRANTS

18 SEC. 103. Section 314 (e) of such Act is amended to
 19 read as follows:

20 “(e) (1) There are authorized to be appropriated such
 21 sums as may be necessary for the fiscal year ending June
 22 30, 1975, and each of the next two fiscal years, for grants
 23 to any public or nonprofit private entity to pay part of the
 24 cost of—

25 “(A) providing services (including related train-

1 ing) to meet health needs of limited geographic scope
2 or of specialized regional or national significance;

3 “(B) preventing or treating alcoholism;

4 “(C) providing or operating centers to make avail-
5 able comprehensive health services (as defined by the
6 Secretary) ;

7 “(D) providing or operating health service clinics
8 for domestic agricultural migratory workers or for
9 projects in improving health care or conditions of these
10 workers or their families, or to encourage and cooperate
11 in programs to improve their health services or condi-
12 tions, including the support of services to seasonal agri-
13 cultural workers when it contributes to improving the
14 health conditions of migratory workers; or

15 “(E) providing services (including related train-
16 ing) in the field of family planning.

17 “(2) With respect to a facility or center, or portion
18 thereof, used or to be used for a purpose enumerated in the
19 preceding paragraph, the Secretary may provide, upon such
20 terms as he deems necessary to protect the financial interest
21 of the United States, that a grant under this subsection shall
22 be available to pay the cost (in addition to any cost for which
23 it may otherwise be made available under that paragraph)
24 of—

25 “(A) in the case of a facility or center in existence

1 prior to January 1, 1974, amortizing the principal of,
2 or paying the interest on, a loan for the facility's or
3 center's acquisition, construction, expansion, alteration,
4 or remodeling (including a facility or center acquired
5 from, or constructed in connection with, any program
6 or project transferred to the Secretary from the Office
7 of Economic Opportunity), including architects' fees
8 and the cost of acquiring land; or

9 " (B) its minor remodeling or minor alteration, in-
10 cluding architects' fees."

11 CONSOLIDATION OF ADVISORY COUNCILS

12 SEC. 104. (a) Section 316 of the Public Health Service
13 Act (establishing a National Advisory Council on Compre-
14 hensive Health Planning Programs) is repealed, and there is
15 enacted a new section 316 to read as follows:

16 "NATIONAL ADVISORY COUNCIL ON HEALTH SERVICES

17 "SEC. 316. (a) The Secretary shall appoint, without
18 regard to the provisions of title 5 of the United States Code,
19 governing appointments in the competitive service, and with-
20 out regard to the provisions of chapter 51 and subchapter III
21 of chapter 53 of that title relating to classification and Gen-
22 eral Schedule pay rates, a permanent body to be known as
23 the National Advisory Council on Health Services. The
24 Council shall consist of the Secretary or his designee, who
25 shall be the Chairman, and not to exceed twenty members,

1 not otherwise in the regular full-time employ of the United
2 States, who are (1) leaders in health care administration or
3 the provision of health services, or (2) representatives of
4 consumers of health care. At least one-third of the appointed
5 members shall be individuals representing the consumers of
6 health care. Insofar as practicable, the members shall be ap-
7 pointed from different geographic areas of the United States
8 and, in the aggregate, shall be representative of all areas
9 within the United States in which health services are pro-
10 vided, or their provision assisted, under this Act.

11 “(b) Each appointed member of the Council shall hold
12 office for such term as the Secretary shall prescribe.

13 “(c) Appointed members of the Council, while attend-
14 ing meetings or conferences thereof or otherwise serving on
15 the business of the Council, shall be entitled to receive com-
16 pensation at rates fixed by the Secretary, but at rates not
17 exceeding the daily equivalent of the rate specified at the
18 time of service for GS-18 of the General Schedule (as lim-
19 ited by section 5308 of title 5 of the United States Code), in-
20 cluding traveltime, and while so serving away from their
21 homes or regular places of business they may be allowed
22 travel expenses, including per diem in lieu of subsistence, as
23 authorized by section 5703 (b) of title 5 of the United States
24 Code for persons in the Government service employed inter-
25 mittently.

1 “(d) The Council shall advise the Secretary as to mat-
 2 ters of policy arising with respect to the financing and de-
 3 livery of health services under this Act.”

4 (b) (1) Section 217 (a) of the Public Health Service
 5 Act is amended—

6 (A) in the first sentence thereof, by striking out
 7 “the National Advisory Mental Health Council, the Na-
 8 tional Advisory Council on Alcohol Abuse and Alcohol-
 9 ism”;

10 (B) in the second sentence thereof—

11 (i) by striking out “the National Advisory
 12 Mental Health Council, the National Advisory
 13 Council on Alcohol Abuse and Alcoholism, and”,
 14 and

15 (ii) by striking out “psychiatric disorders,
 16 alcohol abuse and alcoholism, and dental diseases
 17 and conditions, respectively” and inserting “and
 18 dental diseases” in lieu thereof; and

19 (C) in the fourth sentence thereof—

20 (i) by striking out “(other than the members
 21 of the National Advisory Council on Alcohol Abuse
 22 and Alcoholism)”; and

23 (ii) by inserting “and” before “(2)”; and

1 (iii) by striking out “; and (3)” and the re-
2 mainder of clause (3) preceding the period.

3 (2) Section 217 (b) of such Act is amended, in the
4 second sentence thereof, by striking out “mental health,
5 alcohol abuse, and alcoholism,”.

6 (3) Section 217 of such Act is further amended by
7 striking out subsection (c) and (d) thereof, and redes-
8 ignating subsection (e) as subsection (c).

9 (c) (1) Section 303 (b) of such Act is amended by
10 striking out “may be made only upon recommendation of
11 the National Advisory Mental Health Council. Such grants”.

12 (2) Section 303 of such Act is amended by adding a
13 new subsection (c) to read as follows:

14 “(c) The National Advisory Council on Health Services
15 shall advise the Secretary on matters of policy arising in
16 the administration of this section.”

17 (d) Section 329 (e) (1) (E) of such Act is amended
18 by striking out “National Advisory Council on Compre-
19 hensive Health Planning” and inserting “National Advisory
20 Council on Health Services” in lieu thereof.

21 (e) Section 223 of the Community Mental Health
22 Centers Act is amended by striking out “, after consultation

1 with the National Advisory Mental Health Council (ap-
2 pointed pursuant to the Public Health Service Act),”.

3 (f) Section 266 of such Act is repealed.

4 TITLE II—EXTENSION OF ALCOHOLISM FORMULA

5 GRANTS

6 SEC. 201. Section 301 of the Comprehensive Alcohol
7 Abuse and Alcoholism Prevention, Treatment, and Rehabili-
8 tation Act of 1970 is amended by striking out “each of the
9 next two fiscal years” and inserting in lieu thereof “each
10 of the next five fiscal years”.

11 TITLE III—DEVELOPMENTAL DISABILITIES

12 SHORT TITLE; REFERENCES TO SECTIONS

13 SEC. 301. (a) This title may be cited as the “Develop-
14 mental Disabilities Amendments of 1974”.

15 (b) Unless the context otherwise requires, whenever
16 in this title an amendment or repeal is expressed in terms
17 of an amendment to, or repeal of, a section or other provi-
18 sion, the reference shall be considered to be made to a section
19 or other provision of the Developmental Disabilities Services
20 and Facilities Construction Act.

21 EXTENSION OF AUTHORIZATIONS

22 SEC. 302. (a) Section 122 (b) is amended by striking
23 out “and” before “\$9,250,000” and by inserting before the
24 period at the end thereof “, and such sums as may be neces-

1 sary for the fiscal year ending June 30, 1975, and for each
2 of the next two fiscal years”.

3 (b) Section 131 is amended by striking out “and”
4 before “\$32,500,000” and by inserting before the period
5 at the end thereof “, and such sums as may be necessary for
6 the fiscal year ending June 30, 1975, and for each of the
7 next two fiscal years”.

8 MINIMUM ALLOTMENT FOR TERRITORIES

9 SEC. 303. Section 132(a) (1) is amended by striking
10 out “any State (other than the Virgin Islands, American
11 Samoa, Guam, and the Trust Territory of the Pacific Is-
12 lands)” and inserting in lieu thereof “the Virgin Islands,
13 American Samoa, Guam, and the Trust Territory of the
14 Pacific Islands for any such fiscal year shall not be less
15 than \$50,000, and the allotment of each other State”.

16 ELIMINATION OF REQUIREMENTS OF FEDERAL APPROVAL 17 OF EACH CONSTRUCTION PROJECT

18 SEC. 304. (a) (1) Sections 135 and 136 are stricken,
19 and sections 137, 138, and 139 are redesignated as sections
20 135, 136, and 137, respectively.

21 (2) Section 123(a) (2) is amended by striking out
22 “139” and inserting in lieu thereof “137”.

23 (3) Section 134(b) is amended by striking out “and”
24 after the semicolon at the end of paragraph (17), by re-

1 designating paragraph (18) as paragraph (20), and by
2 inserting the following new paragraphs after paragraph
3 (17) :

4 “(18) provide reasonable assurance that adequate
5 financial support will be available to complete the con-
6 struction of, and to maintain and operate when such
7 construction is completed, any facility, the construction
8 of which is assisted by funds made available pursuant
9 to section 132;

10 “(19) provide reasonable assurance that all labor-
11 ers and mechanics employed by contractors or subcon-
12 tractors in the performance of work on any construc-
13 tion project assisted with funds made available pursuant
14 to section 132 will be paid wages at rates not less than
15 those prevailing on similar construction in the locality
16 as determined by the Secretary of Labor in accordance
17 with the Davis-Bacon Act, as amended (40 U.S.C.
18 276a-276a-5) ; and the Secretary of Labor shall have
19 with respect to the labor standards specified in this
20 paragraph the authority and functions set forth in Re-
21 organization Plan Numbered 14 of 1950 (15 F.R. 3176;
22 5 U.S.C. 133z-15) and section 2 of the Act of June
23 13, 1934, as amended (40 U.S.C. 276c) ; and”.

24 (4) The heading of the section redesignated as section

1 135 by paragraph (1) of this subsection is amended by
2 inserting "CONSTRUCTION," after "PLANNING,".

3 (5) The heading of the section redesignated as section
4 136 by paragraph (1) of this subsection is amended by in-
5 serting "CONSTRUCTION," after "PLANNING,".

6 (6) The section redesignated as section 135 (a) (1) by
7 paragraph (1) of this subsection is amended by striking
8 out ", other than expenditures for construction,".

9 (7) Section 140 is amended by striking out so much
10 thereof as precedes subsection (b) (other than the section
11 heading), by striking out "(b)" and inserting in lieu thereof
12 "SEC. 138.", and by inserting "construction," after "plan-
13 ning,".

14 (8) Section 142 (a) (2) (A) is amended by inserting
15 "which was used by the State in which the facility is located"
16 before "to assist in financing the construction of the facility".

17 (b) (1) Section 401 (h) (1) of the Mental Retardation
18 Facilities and Community Mental Health Centers Construc-
19 tion Act of 1963 is amended by striking out "part C of title
20 I or".

21 (2) Section 401 (h) (2) of such Act is amended by
22 striking out "(A) for any project under part C of title I may
23 not exceed 66 $\frac{2}{3}$ per centum of the costs of construction of
24 such project; and (B)".

1 (3) Section 401 (h) (3) of such Act is amended by
2 striking out "under part C of title I or".

3 (4) Section 403 (a) of such Act is amended by striking
4 out "section 134 in the case of a facility for the mentally
5 retarded or persons with other developmental disabilities, or"
6 and by striking out "section 136 or" and "as the case may
7 be," from clause (2) thereof.

8 (5) Section 403 (b) of such Act is amended by striking
9 out "135 or".

10 (6) Section 404 of such Act is amended by striking
11 out "135 or" and "136 or" from the first sentence thereof.

12 (7) Section 405 of such Act is amended by inserting
13 "or, section 135" after "section 403".

14 (8) Section 405 (1) of such Act is amended by striking
15 out "135 or" from clause (A) thereof and by inserting "(in
16 the case of a community mental health center)" after "205"
17 in such clause.

18 AMENDMENTS TO FEDERAL SHARE PROVISION

19 SEC. 305. The section redesignated as section 135 (b)
20 by section 304 (a) (1) of this Act is amended to read as
21 follows:

22 “(b) The ‘Federal share’ with respect to any State for
23 purposes of this section shall be 70 per centum for the fiscal
24 year ending June 30, 1975; 60 per centum for the fiscal

1 year ending June 30, 1976; and 50 per centum for the
2 fiscal year ending June 30, 1977.”

3 INCLUSION OF LAND ACQUISITION COSTS

4 SEC. 306. Section 401 (e) of the Mental Retardation
5 Facilities and Community Mental Health Centers Construc-
6 tion Act of 1963, is amended by inserting “, for purposes
7 of title II of this Act only,” before “the cost of the acqui-
8 sition of land.”.

9 INCLUSION OF AUTISM

10 SEC. 307. Section 401 (1) of the Mental Retardation
11 Facilities and Community Mental Health Centers Construc-
12 tion Act of 1963 is amended by inserting “(including
13 autism)” after “condition of an individual”.

14 INCREASING EMPHASIS ON DEINSTITUTIONALIZATION AS 15 A PROGRAM OBJECTIVE

16 SEC. 308. (a) Section 130 is amended (1) by striking
17 out “and” in clause (e), (2) by striking out the period at
18 the end of clause (f) and inserting “; and” in lieu thereof,
19 and (3) by inserting a new clause (g) as follows:

20 “(g) grants to assist in the elimination of inappro-
21 priate placement of persons with developmental dis-
22 abilities in institutions.”

23 (b) Section 134 (b) (1) (4) is amended by redesignig-
24 nating clauses (C) and (D) as clauses (D) and (E),

1 respectively, and by inserting the following new clause (C) :
2 “(C) part of such funds will be made available for the
3 elimination of the inappropriate placement of persons with
4 developmental disabilities in institutions;”.

5 TITLE IV—EFFECTIVE DATE

6 SEC. 401. This Act is effective with respect to appro-
7 priations for fiscal years beginning after June 30, 1974,
8 except that section 104 is effective upon its enactment.

Senator RANDOLPH. It has been agreed that this program be moved to the Office of Human Development so that the coordination of the agencies that have been included in the program will have this opportunity and responsibility for an input, and so that the planning can be carried forth more effectively.

I think it is important to say that the need for the National Council to have a more active role in the administration of this effort prompted the decision to place the Council in the Office of the Secretary. It is our hope, I think shared by members of the subcommittee, that this move will provide the thrust by the Council to make this program effective.

As set forth in a publication distributed through the Office of the Assistant Secretary for Human Development, there was established the Department's planning and resources program, which recognized that there are groups of people who have certain special needs.

Now, based on statement of purpose for the Office of Human Development the Subcommittee on the Handicapped has determined that this was, indeed, the logical place for this new act to be administered.

During the hearings last February there was much testimony supporting the broadening of the definition of developmental disability. Included in the statement of the Chairman of the National Advisory Council on Services to the Developmentally Disabled was a recommendation to the Secretary that the definition be broadened.

After consideration of this testimony the subcommittee agreed on the definition in our new legislation, Senate 3378. There are other major components of this bill which are designed to insure quality, humane care and treatment and protection of the developmentally disabled within residential facilities.

Now, we are very happy that the Assistant Secretary for Legislation of the Department of Health, Education, and Welfare is present and accompanied by others from that Department.

Senator STAFFORD, would you make such comments as you would like at this time?

Senator STAFFORD. Well, thank you very much, Mr. Chairman, and I welcome Mr. Kurzman's presence here in front of the subcommittee with his associates.

You stated the position of the subcommittee so fully and so ably that I simply would like to be associated with your opening remarks, and I will forebear any further comment at this time.

Senator RANDOLPH. Thank you, Senator Stafford.

For the record I want to reemphasize your close attention to the subject matter, your expertise in the drafting of the bill, and your continued commitment to programs of this kind to help persons who are in need.

Senator Kennedy, we are delighted that you have joined us this afternoon for this hearing. We would be helped by your statement.

Senator KENNEDY. Thank you very much, Mr. Chairman.

The subcommittee completes its hearings on the extent to revise developmental disability legislation which expires June 30, and on November 16, 1971, President Nixon established two national goals; first, to reduce by half the occurrence of mental retardation in the United States before the end of the century; second, to enable one-third of the more than 200,000 retarded persons in public institutions to return to useful lives in the community.

Today largely through the unwillingness of the administration to back up its rhetoric with positive action those goals are far from being achieved. The administration's budget requests have been far below authorization figures and far below the level necessary to provide for the full implementation of the developmental disability legislation.

For the university affiliated facilities, the administration is requesting only \$4.2 million, the same amount that Congress has appropriated every year since 1972.

Yet, it is at these very centers that the new and innovative interdisciplinary training programs would have to be developed if significant progress is to be made to meet the President's goals.

In his 1971 message the President placed heavy emphasis on research and improved prevention through widespread application of biomedical research advancements.

Yet when one looks at the budget for the two research institutes at NIH which are responsible for research into the cause and prevention of mental retardation, one finds the budget request for one, the National Institute of Child Health and Human Development is \$5 million less than what was appropriated last year in the budget. The other, the National Institute of Neurological Diseases and Stroke is budgeted at \$5 million less than last year's appropriation.

This is in spite of the fact that Congress has repeatedly made it clear that the war on cancer shall not be at the expense of but rather in addition to the efforts of the other research institutes.

As a result of President Kennedy's efforts, Congress established some 12 mental retardation centers in medical centers and universities across the country and they were assigned a 20-year mission to attack problems that surrounded the multiple causes of mental retardation and to explore treatment alternatives. These centers are now in place.

The National Institute of Child Health and Human Development, caught in the budgetary crisis facing NIH, has never had to budget to adequately develop the possibilities afforded by these centers. The problem of appropriate financial support becomes even more important in light of legislative changes currently being contemplated by the subcommittee.

I support S. 3378, but I want to point out to my colleagues that many of the changes contained in this bill will require a concentrated, concerted effort to increase appropriations.

This legislation enlarges the population of eligibles under the act, but enlarged eligibility without expanded appropriations would result in inadequate programs for all recipients.

Last year in earlier testimony on this legislation, Geraldo Rivera showed the committee portions of his documentary on Willowbrook, and if anyone needed convincing of the need for the establishment of institutional standards that film provided it.

This legislation provides for the establishment of such standards, and I want to commend Senator Javits for agreeing to incorporate his bill of rights for the mentally retarded into S. 3378.

My one concern is that the establishment of standards in institutions without the establishment of comparable standards in community facilities would result in the abandonment of the institutions in favor of facilities that would need no standards at all.

Thus, I am delighted to cosponsor with Senators Randolph and Stafford an amendment to establish community facilities standards.

President Kennedy said:

The manner in which our Nation cares for its citizens, conserves its manpower resources, is more than an index to its concern for the less fortunate. It is the key to its future.

I believe that this legislation, if enacted and fully implemented, will go a long way toward brightening that future.

Senator RANDOLPH. Thank you very much, Senator Kennedy.

We appreciate your active cosponsorship of the measure. There is a considerable number of members who are intensely interested in bringing about the changes incorporated in S. 3378. We have the cosponsorship of Senator Williams, chairman of the parent committee, Senator Javits, Senator Cranston, Senator Mondale, Senator Pell, and Senator Schweiker, and Senator Taft.

As I understand what you said, Senator Kennedy, it is our feeling that full funding for our authorizations would provide for planning for services needed; however, increased appropriations will be needed to deliver those services.

Senator KENNEDY. That is correct, Mr. Chairman.

Senator RANDOLPH. Now, Mr. Secretary, we appreciate your cooperation with the subcommittee. I will say, even before you start, that we have an important rollcall in the Senate which is at 3 p.m. That is the hour decided for the rollcall, and I can only say to you that I am not certain of our ability to return, with the Senate picture as it is today; but I authorize, if agreeable with you and Senator Stafford, that our staff members continue so that we do not have an inordinate delay. Is that agreeable, Senator Stafford?

Senator STAFFORD. That is agreeable.

Senator RANDOLPH. Mr. Secretary, if you would identify yourself and those who sit with you.

Mr. KURZMAN. Thank you very much.

STATEMENT OF STEPHEN KURZMAN, ASSISTANT SECRETARY FOR LEGISLATION, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE; ACCOMPANIED BY JAMES DWIGHT, ADMINISTRATOR OF THE SOCIAL AND REHABILITATION SERVICE, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE; AND FRANCIS LYNCH, DIRECTOR OF THE DIVISION OF DEVELOPMENTAL DISABILITY, SOCIAL AND REHABILITATION SERVICE

Mr. KURZMAN. Mr. Chairman, thank you very much.

I'm Stephen Kurzman, Assistant Secretary for Legislation, Department of Health, Education, and Welfare; and with me are Mr. James Dwight, Administrator of the Social and Rehabilitation Service; and Mr. Francis Lynch, Director of the Division of Developmental Disability of the SRS/RSA.

Mr. Chairman, and members of the subcommittee, we very much welcome this opportunity to appear today to testify on the progress that has been made under the Developmental Disability Act since its enactment on October 30, 1970, and on the proposals for its extension now under consideration by this subcommittee.

Although the developmental disabilities program was enacted only 4 years ago it has already become an effective means of integrating certain services for a needy population.

Its achievements are primarily due to the comprehensiveness of its approach to the problem of the developmentally disabled, which represents a significant change from the specialized approach of the mental retardation legislation it replaced. The commitment of the administration to the program is demonstrated in our bill, S. 3011, which was introduced at our request by Senator Javits.

Before addressing the provisions of S. 3011 and S. 3378, the bill introduced by Mr. Chairman and members of the subcommittee as described, I should like to state briefly the goals of the DD program, as we see it, and give an outline of its accomplishments during the administration's implementation of this important initiative.

First, the Developmental Disabilities Act stresses that the development of planning capacity at the State and local levels to utilize effectively all available resources to meet the needs of the developmentally disabled.

An estimated \$800 million in Federal funds will be obligated by HEW in fiscal year 1974 on programs for this group from such agencies as the Office of Education, the Social and Rehabilitation Service, and the National Institute of Mental Health.

Much more is provided by State, local, and private agencies and the important need is for the development of a coherent strategy to utilize all these resources to reduce the dependency of the developmentally disabled.

The planning capacity of the State and local agencies which has been derived from our developmental disabilities program has enabled these agencies to begin to draw together available resources in a coherent way.

The second principle underlying the program is that Federal money is to be used, not to duplicate existing resources, or to substitute for them, but as a catalyst to bring about new service resources in areas where none had previously existed. This emphasis on the catalyst effect of Federal funds has stimulated the growth of programs serving the developmentally disabled.

Third, in developing service programs at the delivery level, the primary goal is to establish an integrated network of services for the developmentally disabled. Much emphasis has been placed by the States, for example, on information and referral services and centers to link the recipient with the services he needs.

Finally, the program has emphasized the authority of the States to determine their own goals and the methods to achieve them. This flexibility has enabled the States to manage the program effectively.

Of the 56 States and territories eligible to participate in the formula grant program, 54 have designated State planning and advisory councils and agencies to administer planning, services, and construction activities under this program.

In fiscal year 1974 \$30,875,000 has been distributed in the basic formula grant program. Of this 1 percent went to program evaluation, 5.2 percent to projects of national significance, and 93.8 percent to States and territories. States have indicated, on the average, that they will use 73 percent of their funds for services, 22 percent for planning and administration, and 5 percent for construction.

Senator RANDOLPH. May I interrupt, Mr. Secretary?

Have we had evidence from the States that the amount of money in fiscal year 1974, \$30,875,000, was the sum that they could use effectively, or was it a sum that was insufficient to do the job, or what? Would you give us a response of the feelings from the States, since you have spoken of the responsibility of the States?

Mr. KURZMAN. Mr. Chairman, I'd like to turn to my colleagues—perhaps Mr. Lynch—for the answer to that question. I do not happen to know the specific reaction to it.

Mr. LYNCH. Thank you, Mr. Secretary.

Mr. Chairman, yes, we have every indication from the States that every bit of the money is being used, and none has been allowed to lapse, and they have found that they have been able to put it into action very readily.

Senator RANDOLPH. Now, the second portion of my question was have the States indicated that they could use more money, and use it effectively?

Mr. LYNCH. In the development of this, yes, Mr. Chairman, they indicated that. There have been indications from the States plans that they could use more money if they had these resources.

Senator RANDOLPH. Will you try to reflect that, Secretary Kurzman, in your presentation today, if I may anticipate? I haven't had the opportunity to read your statement.

Mr. KURZMAN. I think this deals not only with that question, Mr. Chairman, but the question raised by Senator Kennedy's opening comments too, and it is that in our view this is a catalytic program, and clearly it is important from this point of view to avoid looking at it as if it were designed to meet all the needs of the developmentally disabled. It could not possibly, in view of the scale of the program, even as authorized by the authorizing legislation totally apart from the appropriation request.

Instead, it is designed to be essentially a gap-filling program integrating services to individuals whose basic service needs, medical, rehabilitative and educational, are met by Federal, State and local programs such as the medicaid program, which deals with the medical needs of the poor and which comprises a massive portion of the \$800 million that we have identified as the total Federal expenditure for the developmentally disabled. Of course, there is State matching for Medicaid on a roughly 50-50 basis.

Another basic service program is the vocational rehabilitation program, which has a specific set aside for mental retardation—again matched by State and local moneys—and which comprises a very substantial additional portion of that \$800 million.

Senator RANDOLPH. Mr. Secretary, have you felt that there is enough money to do the job of planning this program?

Mr. KURZMAN. Our understanding of the levels is that they have grown commensurately with the growth of the capacity of the States and localities to undertake the kind of planning and service integration that we're talking about here.

I should point out that the appropriations have not been level from the beginning. In 1971 the appropriations were at the level of \$34,790,000 and they have now grown to the level of \$53,625,000, and that is including \$12.5 million from the vocational rehabilitation program specifically.

I think our answer would have to be yes, we think our appropriations are growing commensurate with our capacity to use them. Now, that does not mean if you go out and ask any service provider if they would like more money, and this is true for all HEW's grantees, that they will say no. What has to be done is what we do in constructing the HEW budget proposal with the Office of Management and Budget, and what they must do in proposing the entire Federal budget, and what what the Appropriations Committees in Congress must do, which is to balance all these demands for additional funds.

Senator RANDOLPH. Certainly it would not be desirable just giving more money if that money could not be efficiently used; and so insofar as the chairman speaks, he wants always the moneys to be within the realm of realism. That is why I asked you that question specifically. Can the money be used to advantage, and is the money needed and what is your feeling about it?

Off the record.

[Discussion off the record.]

[Mrs. Forsythe acting chairman.]

[Committee members departed the room for rollcall vote.]

Mr. KURZMAN. A significant trend in the operation of the program has been the increased efforts by many States to deinstitutionalize developmentally disabled persons. North Carolina, Wisconsin, Washington, and California, in particular, have all emphasized this goal with success.

California plans to convert all of its long-term residential State hospitals into high specialized treatment and service facilities. Mentally retarded persons who can benefit from new community-provided care are being discharged to permit the evolution of these hospitals into specialized service centers.

It is generally agreed that returning the institutionalized individual to the community has in the majority of cases had a good effect on his rehabilitation.

It is the policy of HEW to encourage deinstitutionalization where such a program is consistent with the capacities of the individuals concerned and where the home community can provide alternative services.

We plan to continue this policy in our future administration of programs for the developmentally disabled.

Turning to university affiliated facilities, title I, part B of the act provides for Federal support for interdisciplinary training in institutions of higher learning, as well as for the construction of facilities to house these programs. Grants may be made to cover the costs for administering and operating demonstration facilities and training programs for personnel needed to render specialized services to persons with developmental disabilities. In fiscal year 1973, \$4,250,000 was made available for this program.

Among the professional disciplines trained in these facilities are medical personnel, dentists, nurses, speech and hearing therapists, nutritionists, physical therapists, occupational therapists, rehabilita-

tion specialists, special educators, psychologists, social workers, recreational specialists.

Each facility is encouraged to conduct a comprehensive program so that each discipline involved in the habilitation and rehabilitation of the developmentally disabled may be fully familiar with the contributions of the other disciplines.

Dr. HOROWITZ. Could you submit for the record how many people have been trained in each category, and what your target numbers are and how many we need?

Mr. KURZMAN. I would be happy to do that.

Mrs. FORSYTHE. If I can say something else, Doctor Horowitz, Mr. Secretary—you mentioned the university affiliated facilities; can you submit for us any criteria used to achieve the goals of the university affiliated facilities, and any reports of interaction among the university affiliated facilities for some kind of comprehensive planning to evidence that there is not duplication of activities in the various UAF's; and lastly is there a followup study of some kind that indicates that interdisciplinary training is indeed needed?

Mr. KURZMAN. We will be happy to do that.

[The information referred to and subsequently supplied may be found in the appendix on p. 311.]

Mr. KURZMAN. With this background before us, I would like to address the legislation under consideration by this subcommittee, S. 3011 and S. 3378.

Dealing with title I of S. 3378, Mr. Chairman, I stated earlier that we are in accord with our goals of improving the provisions of providing alternative living arrangements for individuals with developmental disabilities. The similarity between the legislation introduced last week, S. 3378, and the administration's proposal, S. 3011, is striking.

We are in agreement that the offering of the interdisciplinary training through a university affiliated facility is helpful in demonstrating the provision of specialized services to persons with developmental disabilities. It can be a focal point within the State for technical assistance, the dissemination of information on improved techniques and new models for public and private agencies who serve this population.

The main emphasis of S. 3011, now that the UAF's have been operating for some time, is on administration and operation of these useful models. Therefore, we have not proposed continued authorization for construction.

On the State planning council, S. 3378 would continue the dominant role of the State planning and advisory council, although it would be redesignated as a State planning council only. Appointment by the Governor should insure that the most appropriate agency officials, as well as representatives of private organizations and consumers, are involved in this program.

The planning council will have broad authority to oversee the construction, renovation, or modernization of service facilities, and to specify the amount, up to 10 percent of the State allotment to be spent on such projects. This oversight by the council should be helpful in matching the need for facilities by a number of State agencies with the program direction outlined in the State plan.

S. 3378 would continue the National Council on Services and Facilities for the Developmentally Disabled, place it organizationally in the Office of the Secretary of the Department of Health, Education, and

Welfare, and include as members representatives of certain Federal agencies involved in developmental disabilities programs.

We view the involvement of such agencies as important although it may not be most effectively accomplished through such advisory groups. While we are pleased with the assistance of this particular council, we view with some alarm, as you do, Mr. Chairman, the proliferation of advisory groups in general.

I should point out too that the bill would add as I understand four representatives or four agencies to the count, so—but it would not include all the agencies that in our view should be included, if agency representatives are to be added.

Mrs. FORSYTHE. We would be glad to consider, Mr. Secretary, the addition of members. This was done by the staff here with the information we had from your Department as to who was involved in the implementation of the Developmental Disability Act.

Mr. KURZMAN. We would be happy to supply additional agencies, Mrs. Forsythe.

[The information referred to and subsequently supplied may be found in the appendix on p. 316.]

Dr. HOROWITZ. Are all the positions on the current National Advisory Council filled?

Mr. KURZMAN. No, they are not. As I understand it there are some vacancies that have not as yet been filled.

Dr. HOROWITZ. Have they been filled at any time since the act was first passed?

Mr. KURZMAN. I can't answer that.

Mr. DWIGHT. Yes, the act as it presently operates calls for staggered expirations of terms. This is the second year, as of the end of December, where certain terms expire. I think there are five member vacancies which need to be reappointed and there are several factors which have caused us to move with some caution in terms of reappointing those memberships, upon the fact that just last week the RSA Commissioner, which appointed the management and the works for some time we felt he should have an opportunity to participate in that process of selection; and second, the overall consideration of the role of advisory groups and—in fact, the administration will have, as I understand it, a proposal on all advisory committees shortly;— and third, the fact that this legislation that we're here speaking to today would alter the composition of this Board if it is enacted, and it would seem unwise to make appointments when, in fact, those appointments could easily be canceled within the next month or two.

Dr. HOROWITZ. But of course even knowing until recently that this legislation was going through.

Mr. DWIGHT. Those are the factors which would influence this.

Dr. HOROWITZ. How long did it take to get the National Advisory Council up to full complement, and for how long a period did it function under full complement? It's my understanding that as recently as January or February there were some problems getting full council membership established, is that incorrect?

Mr. DWIGHT. I am not familiar with that. Mr. Lynch might want to comment on that.

Mr. LYNCH. The National Council was at full complement for two full terms, and it hasn't since December when five members went off. It has been at a 15 member level rather than a 20 member level.

Dr. HOROWITZ. OK.

Mrs. FORSYTHE. One additional thing, Mr. Kurzman, you referred to this as an Advisory Council, and the bill specifically states that this is a National Planning Council and does not serve in an advisory role, but a planning role.

I wanted to make that point, because it was very important when we discussed this legislation.

Mr. KURZMAN. Well, I think the remarks we have all made recognize that, Mrs. Forsythe, and what we were really describing was the evaluation under the act that Congress passed, of which Chairman Randolph was one of the principal sponsors, to rationalize throughout the Federal executive branch all of these councils, whether they are advisory or planning, or policymaking, or whatever the appellations applied to them, which consist of nongovernmental members and which are given a role of one sort or another. In many statutes they differ, but in HEW, as you know, we've had upwards of 360 councils of non-HEW personnel, and clearly the Congress in what was called the Advisory Council Act, for want of a more comprehensive name, agreed that this kind of proliferation of councils is not helpful. There comes a point where there are diminishing returns.

Mrs. FORSYTHE. I think I can speak for the chairman and say that he viewed this as a very necessary council made up of Government as well as outside consultants, or members, with an extremely important function.

Mr. KURZMAN. Yes.

Well, the administration fully supports the idea of continuing this council, and that is why our bill proposed to continue it.

Probably the most complex problem under title I of S. 3378 is the definition of developmental disabilities. From the inception of the act there has been a great deal of controversy concerning the appropriate definition. Questions have arisen as to the coverage of the primary groups, such as the one specifically named—disability, as the nature of substantial handicaps, the terms used in the act, and the intended relationship between mental retardation and other conditions.

The major issue is well known, and it concerns the inclusion in the definition of neurological conditions requiring treatment similar to that required for mental retardation.

For the first 3 years, coverage under the act has not been extended beyond the three categories specifically enumerated by Congress—mental retardation, cerebral palsy, and epilepsy. While the act allows the Secretary to make findings concerning other neurological conditions which are closely related to mental retardation or which require treatment similar to the treatment required for mental retardation, no additional categories have yet been named.

A great deal of effort has been devoted to attempting to define such other conditions. Requests have been received recommending the inclusion of autism, learning disabilities, dyslexia, spina bifida, childhood schizophrenia and minimal cerebral dysfunction.

Since such a laundry list approach to defining the target population under the act seemed to the Department to be unworkable, the administration sought advice from others to develop a functional definition to be promulgated in regulations.

The National Advisory Council on Services and Facilities for the Developmentally Disabled did not recommend inclusion of other groups because of their own disagreement as to whether certain con-

ditions could be classified as neurological. A majority of State council members advised against the extension of the definition until they had more experience in planning and providing services for the enumerated groups. The views of the major private associations representing autistic children, children with learning disabilities and other handicapped persons were heard and considered at the National Conference for State Planning and Advisory Councils for the Developmentally Disabled. However, there was no consensus as to the inclusion of additional groups.

The reaction of other expert groups such as the National Academy of Sciences and the National Advisory Committee on the Classification of Exceptional Children indicated to us that the question of enumerating other conditions was extremely complex and required much more time for study than was available in the period remaining for implementation under the present act.

Therefore, our policy has been, in view of all this disagreement about the issue, to continue the current policy of administering the definition of developmental disabilities without reference to other conditions to be included.

We do feel, however, that there is one category that needs to be included in the definition because of its unique character and that is autism. Although the autistic comprise a small segment of the population (approximately 80,000 persons) we believe that if this group is not included, in many instances no mechanism would be available for providing comprehensive and systematic services to them.

Dr. HOROWITZ. Mr. Secretary, how many people do you estimate are eligible for treatment under the developmental disabilities program?

Mr. KURZMAN. Well, I understand, Doctor Horowitz, that this is the \$64,000 question. It is almost impossible to answer unless you are very clear about what the definition does and does not include.

So I will turn to Mr. Lynch, if I may, to make the guestimates, if he can.

Mr. LYNCH. In terms of eligible services under the caveat of substantially handicapped in the former definition or severely handicapped in the Randolph Bill, we are assuming that it is that segment of the mentally retarded population, the cerebral palsy population, the population of epilepsy, and those other groups under other diagnoses who requires similar services as the mentally retarded.

We are dealing with in the range of 6 to 10 million maybe.

Dr. HOROWITZ. 6 to 10 million?

Mr. LYNCH. That is right.

Dr. HOROWITZ. How many received services last year under the program, would you estimate?

Mr. LYNCH. Well, in terms of the data received we show in the neighborhood of, I think, about 300,000 people who have directly received some kind of service.

Now, quite honestly to separate that figure out as an individual service delivery factor is something that we have not been called upon to do since our mandate is not to BEH or VR with individual entitlement to service, but to put in place an array of services by program integration, coordination, and finally gap filling.

Dr. HOROWITZ. What accounts for the discrepancy between the number of people eligible for these services versus the number of people being served? Is it a question of money or what?

Mr. LYNCH. Well, the discrepancy occurs in that the number that are served we are assuming that they are being served under the gap filling provision of this bill.

In other words, the money that the State councils provide to fill the gaps in services, we are attempting to account the numbers who have been more broadly serviced by the program integration that has occurred through the effect of State councils' planning and coordination efforts.

Dr. HOROWITZ. Well, I guess I should rephrase my original question. What is the eligible group which you think need the services mandated by this legislation? What is the target population; that would be somewhat less than 6 to 10 million?

Mr. LYNCH. That is right.

Dr. HOROWITZ. Do you have any guess as to what that would be?

Mr. LYNCH. Well, I am trying to discern, doctor, between the eligible group for total service under the State plan where forms of program integration are bringing the rain to fall on even those who are not in the target population definition of substantially handicapped or severe disability, and that population who meet the definition of the developmentally disabled in law.

The object of our legislation is to provide for those, who are not being served under another authority. For example, we can assume that in some instances in some States that there are children who would be served in the educational system, and in another State would be ineligible for services under that educational system because that educational system may not be sufficiently sophisticated to serve a more severely disabled population.

Dr. HOROWITZ. I understand that, but what I do not get is how you measure what your goals are to achieve a coverage of the certain population under this legislation.

For example, we are expanding the current definition to include autism and learning disabilities, so it is important to know how many more people will be treated under that expanded definition.

Mr. LYNCH. Yes, sir, and that relates in part to something that I wish I had followed up when Senator Stafford asked me the original question, do the States indeed indicate that they need more money, and yes, indeed, they do.

Our point here is to point out clearly to them by providing them technical assistance and help from the regional offices and planning skillfully with the existing resources that are mandated in legislation that they can provide an array of services, and then our assessment of the eligible population who are not receiving services in already mandated areas, we can come up with a more intelligent answer to the Senator's question, in terms of what other people are falling between the cracks, this will vary from State to State, depending on the sophistication of the program, and depending upon such variables as the availability of transportation to a service.

For example, it—

Dr. HOROWITZ. I understand what you are saying. It is awfully hard to pinpoint the number of people who would be primarily served under this developmental disabilities legislation, which is the gap filling legislation.

Mr. LYNCH. That is right.

Dr. HOROWITZ. So that when we add new groups we really do not know the number that we are adding them to, and we do not know how many we are adding, therefore, we do not have a realistic assessment, perhaps, as to what we need to put into the program.

Mr. LYNCH. We have a pretty good fix on one thing, for example, in our agreement to include autism, but because lack of agreement on the part of the pediatricians, neurologists and psychiatrists in terms of what autism is that these children are probably not being served in other programs for example mental health and I do not think there is any question about it. They are not being served under any clear-cut authority. Consequently in order to take this group out of limbo, so to speak, and since many require services similar to the mentally retarded, we have agreed to include them.

We recognize, of course, that a large number of these youngsters who are classified as "MR" functioning at the mental retardation level, are in DD programs.

Dr. HOROWITZ. What is required to get the data that we now do not have, what needs to be done?

Mr. LYNCH. I think, sir, that what we are attempting to do is to gain the experience to clearly delineate in a number of areas those groups that are not being served by the developmental disabilities program integration of services and I think that is what we are struggling for, to get a fix on those kind of numbers, and when we are dealing with nine State and Federal programs; we are dealing with varying eligibility requirements based on disability in some cases and based on poverty in other cases, based on medical indigency in other cases, and to provide the States with a where with all to assess through a matrix in terms of age grouping as well as severity of disability, it is a job that takes indeed statesmanship and craftsmanship, and that is what we are about in the States.

Dr. HOROWITZ. Well, I have just one more question on this subject. If we are including autism and learning disabilities, what additional funding would be necessary for the Department to fully cover these new populations and not reduce services to those who are currently eligible?

In other words, how would that alter your budget request, for example, if learning disabilities were included?

Mr. KURZMAN. Doctor Horowitz, we are not proposing to change the funding request by virtue of the fact that we are adding autism. We are trying to resolve uncertainty in the States as to who they can deal with.

Dr. HOROWITZ. I understand that.

Mr. KURZMAN. Our view on this is again, I think, and the same question arises with learning disabilities, that this coverage is necessary because persons with learning disabilities which are so severe that they meet the existing definition of the developmentally disabled are not being included in the program.

Dr. HOROWITZ. Currently?

Mr. KURZMAN. Currently, and as you see, if I could get to the next paragraph, we really do not have any big problem with including, nor with dropping the term neurological. Largely to avoid conflict over very narrow technical questions that is what we are trying to insure—and I think that the Randolph bill helps in this respect by being clear

about what truly constitutes a severe handicap which cannot adequately be dealt with in the context of some other kind of institution.

For example, in the case of learning disabilities clearly the major source of Federal funding for that is the Bureau of Education of the Handicapped in the Office of Education, and most youngsters with learning disabilities can be served through the public schools with that kind of assistance, which has a stimulating effect on State private and local funding.

There is always the need beyond the level of which it ever is at any given point, but that is the major source of treatment of the problem, and of remedial services, special education services.

In the case of some children who have learning disabilities of such great severity that a particular school system simply cannot handle it, then we would expect and hope that the developmental disabilities program would provide that kind of service to fill that gap.

Dr. HOROWITZ. Any guess on how many that is?

Mr. KURZMAN. Again I would leave it to the experts here to make a judgment on that. As I say, in many cases I am told by program people that that is what is happening now, the more severely disabled and learning disabilities are already being handled by DD funded operations rather than by BEH funded operations, so that by changing the definition you do not automatically create a larger service burden for the developmental disabilities agency. That is basically why, I think, we are not saying we need to increase the budget request.

Mr. CUTLER. Are you saying that the educable mentally retarded and the trainable mentally retarded that are handled in the special educational system are not covered in the Developmental Disabilities Act?

Mr. DWIGHT. Yes, that is what we are saying.

Mrs. FORSYTHE. May I just ask one question. On page 8, Mr. Secretary, you say in your last sentence: "Therefore, the Secretary will continue", and there is a blank, "the current policy of administering the definition of developmental disabilities without reference to other conditions to be included under the act". Could you explain that please?

Mr. KURZMAN. That sentence refers to our policy that is in effect until the act is extended and changed. If the act were to stay as it is right at the moment, we would be constrained, we feel, to continue the policy we have had for the first 3½ years, which is to leave the definition to the three enumerated categories.

Mrs. FORSYTHE. And when this act is passed you will be expanding your activity into the other areas?

Mr. KURZMAN. Yes, of course.

Now, a phrase was deleted there because this portion of our testimony was written when you first called us to testify in this matter about a year ago. That phrase was "until June 30, 1974," and it was deleted only because we were revising the statement to testify today. It is kind of anomalous to discuss the question of current policy. We only have 2 more months to administer the current act.

If I may continue?

Mrs. FORSYTHE. Please do, Mr. Secretary.

Mr. KURZMAN. S. 3378 also includes autism but goes further by deleting the term "neurological" and by including individuals with learning disabilities who also meet the other criteria within the definition of developmental disability.

As I have indicated we would expect that most children with this disability are already included in public school programs, assisted by the Bureau of Education of the Handicapped.

We recognize, however, that there are individuals with severe learning disabilities who cannot be adequately served through public educational programs and therefore need the specialized assistance provided by the developmental disability program. Many such persons are already being served under the DD program. Therefore, we would not object to the inclusion of this group in the definition provided they meet the three requirements listed:

That the disability originate before age 18, that it can be expected to continue indefinitely, and that it constitute a severe handicap as newly and more explicitly defined by S. 3378.

We understand that under this definition individuals that cannot be served under the public educational system would receive priority for the services to the developmentally disabled.

At this point, I would like to address an issue that has caused increasing concern in our Department, and that is the legislating of organizational requirements. The chairman's bill would administratively change the location of the Division of Developmental Disabilities from the Rehabilitation Services Administration to the Office of Human Development. Such a provision restricts the flexibility of the Secretary to group programs serving similar populations or dealing with similar State agencies. The present location of this Division in the Social and Rehabilitation Service is the most appropriate since approximately 80 percent of the HEW funded programs for the developmentally disabled are in SRS. The recent experience of sharing staff in developing regulations for intermediate care facilities is a good example of a program interrelationship that is critical.

The Medical Services Administration and the Rehabilitation Services Administration are both in SRS.

This brings me to title II. While we are very much sympathetic to the objectives of this title, which is essentially a modification of the bill introduced by Senator Javits some time ago, we question the need for putting it into statute and would object to its approach.

In view of the fact that we do have regulations on that subject—

Mr. CUTLER. Excuse me, Mr. Kurzman. Senator Javits was curious to know how your regulations, if you will, cover many of the principles enunciated by his bill, incorporated as Title II of S. 3378?

Mr. KURZMAN. We would be glad to give you a comparison, Mr. Cutler, of the two, and I think as we go through this, the portion of the testimony, I will be hitting most of those, and I will be happy to give you a chart for them as well.

Mr. CUTLER. I would like that section by section showing each provision in title II, and the specific authority for your regulations.

Mr. KURZMAN. I would be happy to do that.

[The information referred to and subsequently supplied may be found in the appendix on p. 319.]

Mr. KURZMAN. Now, as you know from what I was about to say, there are some things we do not address. We try to deal with our reasons for that in the text, and I am coming to that now.

We are very much concerned that the program authorized in that title would overlap, duplicate, and confuse the authority that we already have. We would note that formula grants under the Develop-

mental Disabilities Act can be used by States for their deinstitutionalization efforts.

Additionally, title I of this bill would specifically earmark funds for services to persons with developmental disabilities for whom institutional care is appropriate.

Mr. CUTLER. Excuse me, Mr. Kurzman, but under the definition of a formula grant do you exclude from the population the educable mentally retarded and the trainable mentally retarded? As you know the law says developmentally disabled, and then goes on to define developmentally disabled as mentally retarded, et cetera.

Mr. DWIGHT. I think Mr. Cutler, you are addressing again, the gap filling proposition which is the underbidding of the developmentally disabled legislation, and those persons for the most part are provided with education and training opportunities in the public school system.

Mr. CUTLER. That does not answer my question. Do you or don't you to the extent that they are otherwise available?

Mr. DWIGHT. We do not.

Mr. CUTLER. You do not include them?

Mr. KURZMAN. If they are not otherwise available we would include them.

Mr. CUTLER. Could you give me a breakdown on a State-by-State basis of your criteria showing all mentally retarded in the State and the number you have counted in for the purposes of this act?

Mr. DWIGHT. I am not sure that I completely understand the gist of your question.

Mr. CUTLER. Let me read you section 132 of the act as it now exists.

Mr. KURZMAN. I think perhaps Mr. Schwartz has pointed out something that may not be on the same wavelength, but I think title II and our ICF regulations are direct toward the—

Mr. CUTLER. I am in title I.

Mr. KURZMAN. I am sorry you are talking about title I. That distinction is relevant to title II.

Mr. CUTLER. Right I am asking about title I.

Mr. DWIGHT. This is in the manifestation of the actual calculation of the amount awarded to any particular State?

Mr. CUTLER. That is correct, section 1 is formula distribution and allocation.

Mr. DWIGHT. Mr. Lynch would have to speak to that.

Mr. CUTLER. For example, could you tell me how many New York State mentally retarded citizens there are and how many you have counted in for the purpose of this act in your distribution formula?

Mr. LYNCH. I think we have to, Mr. Cutler, give you an estimation of the number of mentally retarded citizens in New York State. We have no census identification of them.

Mr. CUTLER. Well, how do you come out with those that are being served in the public school system which you have obviously eliminated from the necessity of receiving services under this act?

Mr. LYNCH. Well, those who are—in terms of your question, sir, who are in the classes for the educable mentally retarded for the most part are not considered severely handicapped.

Mr. CUTLER. Right.

Mr. LYNCH. And most of their service needs are being met either—in terms of their education in the EMR classes for the most part.

The thrust is to integrate this population into the programs of the community, such as recreation.

A good number of these folks are VR eligibles, so they are eligible for the vocational rehabilitation program. Some of them in terms of receiving mental health services would receive them through the usual community channels of developing community mental health services.

Now, in terms of the training of mentally retarded there are education needs that are being met by the education system by providing classes for the training of mentally retarded persons and are met under provisions of the Education Act, and we intend that, of course, their service needs be met with education dollars.

Mr. CUTLER. So you are prepared to give me a breakdown on a State by State basis showing the need, let us say, that is limited for the purpose of our discussion, the need for the mentally retarded being served by the public school system and those that are not. You obviously had to make some computation somewhere.

Mr. LYNCH. Right. Those that are severely handicapped developmentally disabled who are not receiving services under the public school system, either for trainable classes or for eligible classes, and particularly those other needs than education needs that they may have may well be provided for by developmental disabilities.

Mr. CUTLER. But you will be able to furnish this committee with the breakdown of how you made your decision?

[The information referred to and subsequently supplied may be found in the appendix on p. 374.]

Mr. LYNCH. Because the formula allocations—

Mr. CUTLER. Because the formula allocations compilations extended to meet the services for evidently developmental disabilities. Now you have clearly decided that developmental disabilities are different within the framework of the definition in the law. The definition did not separate out educables and trainable mentally retarded. The definition says mentally retarded, and you have made a value judgment somewhere that I do not know that you have the authority at all to do.

Mr. LYNCH. I don't think we considered that we had authority to separate people out.

Mr. CUTLER. But you did. You just told us that you don't include them.

Mr. LYNCH. Because our authority is in terms of gap filling and supplementing, not supplanting services, sir.

And as I indicated previously, there are some States, for example, that do not provide any classes for the trainable mentally retarded.

Now, if the money is used in that area, where there are no State classes for the trainable mentally retarded, and it is used in a stimulatory way to achieve this goal in the State, then we certainly applied that kind of effort.

If the money is there, in New York State, and the authority is in New York State for the provision for classes for trainable mentally retarded youngsters, we applied that and we applied the broadening of that under the appropriate Federal-State funding plan—and their other needs, the other needs of these youngsters, if there are recreation needs, transportation needs, or social service, social legal services, they can be appropriately funded as gap filling where there is not an appropriate need for them.

Now, your primary objective, as you know, sir, in this act, is to put in array—put in place an array of services for the developmentally disabled.

Certainly, if this beneficial rain falls on youngsters who are not as severely handicapped, we consider that a blessing as well.

In other words, if a child who is in the educable mental retardation classes, and one of his other service needs is met by a service that is put in place by this legislation, like a group home, for example—let us just a moment take a youngster who doesn't have an adequate home or community support in his home.

And he can be placed in a group home that is designated to serve the target population, those youngsters who are more severely handicapped. If he can benefit by these services, and there is an opening, he certainly is then eligible.

Mr. CUTLER. I think it is time the families, if you will, of educable and trainable mentally retarded children understood that they are not covered by this act 9 times out of 10.

Mr. LYNCH. I am sorry if that is the image that is being created in terms of 9 times out of 10. I don't think that that is the case.

I think that in the State planning, the development of the State planning—and one of the unique provisions of the act was that those very people that you refer to, the consumer interest groups, at least one-third of the representation of that group was in the State council—that they have had, we feel, from our discussions with the State planning chairman, a very valuable input to the development of the plan and the establishment of the priorities for funding the program, gap filling programs.

And they have also felt, according to their reports to us, that they have had a major role in program integration, that they didn't feel existed prior to this time when we were limited to a project grant authority.

Mr. KURZMAN. If I may return, we were discussing the provisions of the pending bills and of existing law which deal with this question of enforcement of standards for institutions housing the mentally retarded. Federal funds for necessary improvements in the quality of care provided to developmentally disabled persons in residential settings are already authorized under existing programs, most notably the medicaid program established under title XIX of the Social Security Act.

Mr. CUTLER. Does that only apply to medicaid recipients, though?

Mr. KURZMAN. Yes.

We agree that the general quality of care in residential facilities for the developmentally disabled must be improved. However, we urge that this be done administratively under the authority granted by existing legislation. In January of this year, in accordance with the Department's obligation to establish standards under the medicaid program for intermediate care facilities for the mentally retarded and persons with other developmental disabilities, and in keeping with the concern I have discussed today that standards for such facilities be improved, the Department issued new regulations for intermediate care facilities which were effective in March.

These regulations establish a two-phase process for upgrading the quality of care. By March 18, 1975, all institutions for the mentally retarded which receive title XIX funding under the intermediate

care facility program must be certified under the interim standards. These standards require facilities to establish an overall plan of care for each resident and provide supervision of that plan by a qualified mental retardation professional; to provide all necessary resident living services, including training and guidance in activities of daily living and development of self-help skills for maximum independence, as well as dental, physical, and occupational therapy, speech pathology and audiology, psychological and social services needed by the resident; and to comply with fire safety and sanitation requirements and requirements for physical comfort of residents. Care must be directed toward attainment of the optimal physical, intellectual, social, or vocational functioning of each resident. This accords with the emphasis which the regulations place on active treatment. If a facility has deficiencies, it may be certified for a maximum of 12 months if it submits an acceptable plan of correction and if the deficiencies do not jeopardize the health and safety of residents and do not impair the facility's ability to provide adequate care. If all deficiencies are not corrected within the time period approved for correction, it cannot be recertified for participation in the title XIX program. Of course, any facility with deficiencies that do jeopardize the health and safety of residents or which impair its ability to provide adequate care is not eligible for certification to receive title XIX funds in the first place.

Mr. CUTLER. Excuse me.

What has happened to those institutions that have been in violation of the life safety codes?

Are they still in operation, those that were in operation before this was promulgated?

Mr. KURZMAN. The Department has already begun the action, as you may know, of terminating the eligibility of institutions which do not meet the fire safety code.

We have taken action in Pennsylvania, in the case of somewhere between 30 and 40 nursing homes, earlier this year, and in the process of requiring recertification throughout the country.

Mr. CUTLER. How many nursing homes throughout the country did not meet the life safety codes by the day certain?

Mr. KURZMAN. I would have to get that for you.

[The information referred to and subsequently supplied may be found in the appendix on p. 364.]

Mr. DWIGHT. These are skilled nursing facilities.

The information that we had was the States were certifying as of—and we will have to furnish the date for the record—that there were provider agreements, and implicit in the provider agreements was the fact that the facility either met all requirements or was in an acceptable plan of correction so that those standards would be met.

In several States we have through independent action by the various regional offices of the Department, determined that that is not the case, and we have commenced to identify those facilities and refused to continue to allow them to participate in the program.

Mr. CUTLER. But a day certain has passed—by the time of which they were supposed to be in compliance with the life safety code, correct?

Mr. KURZMAN. Initially the requirements of our regulations which required compliance by skilled nursing home with those provisions have passed; that is correct.

Mr. CUTLER. Have any of them been paid and withheld, having been in violation after a day certain?

Mr. DWIGHT. Yes.

Mr. CUTLER. Could you supply us, for the record, how many were in violation and how many have payments suspended?

Mr. KURZMAN. We will be happy to supply information on the status of that.

[The information referred to and subsequently supplied may be found in the appendix on p. 364.]

Mr. KURZMAN. As you may know, this is a major effort of enforcement that the Department has undertaken, under the personal direction of the Under Secretary.

In fact, we have made an enormous effort to pull together all the agencies within the Department who are responsible for making sure that these requirements are met, and a new system with specific responsibility in regional directors, to pull all those agencies together, region by region, has been instituted.

So this is a very important program from our point of view.

Mr. DWIGHT. It might be well if we were to go on to expand slightly in the area which relates to intermediate care facilities which are facilities which provide care to the mentally retarded.

Those standards provide a phasing with some enforcement and followable plans in order that that facility continue to participate.

And I think Mr. Kurzman is going to cover this point in his testimony.

But it seems to me that that is a major difference between the plan that the Department had as it related to the enforcement of the standards in skilled nursing facilities, and the plans which we have prospectively, not only for intermediate care facilities, but also for skilled facilities.

In other words, we have a capacity to follow the progress the facilities are making toward meeting those standards, one, and two, we are in a position, through the consolidation of resources in the regional offices, to identify problems in States and concentrate our resources where the problems are the greatest.

Mrs. FORSYTHE. I believe some of the staff members have questions to ask.

Would you care to summarize the rest of your testimony?

Mr. KURZMAN. I would be happy to.

The second phase of the Department's program for upgrading the quality of care in intermediate care facilities for the retarded requires that facilities participating in the medicaid program must meet additional standards by March 18, 1977. These second-phase standards are based in large measure on the standards for residential facilities for the mentally retarded formulated by the Council for Facilities for the Mentally Retarded of the Joint Commission Accreditation of Hospitals and are essentially the same as the requirements which would be imposed under title II. However, they would not be imposed 5 years from enactment of S. 3378—as title II proposes—which at the earliest would be 1979—but, as I mentioned, in 1977.

Before any intermediate care facility for the mentally retarded can be certified under the interim standards, it must submit a plan—including a timetable—for achieving compliance with the 1977 stand-

ards. The plan for compliance must describe in detail the extent to which the facility currently meets the 1977 standards and the specific steps it must take to fully meet compliance with the 1977 standards.

The plan must include the number, titles and qualifications of personnel, structural changes on renovations, and programs and services provided. This plan for compliance must be approved by the Department and the facility must submit semiannual reports documenting its progress. If a facility does not progress in accordance with its plan, it cannot be certified for continued participation in the medicaid program.

We would note that some of the requirements with which the States must comply by 1977 are most stringent than those in title II. For example, title II would require provision of at least 60 square feet per resident in multiple sleeping rooms and not less than 80 square feet in single rooms, while the Department's regulations require at least 80 square feet in multiple sleeping rooms and not less than 100 square feet in single rooms.

Mr. CUTLER. You will also supply the analysis of the different personnel staffing requirements between the regulations and the bill?

Mr. KURZMAN. Yes.

[The information referred to and subsequently supplied may be found in the appendix on p. 365.]

Mr. KURZMAN. As you may know, the Notice of Proposed Rule Making which the Department issued in March 1973, would have established second-phase standards virtually identical to those in title II—because it would have required intermediate care facilities to meet by 1976 the provisions in the JCAH's 1971 Standards for Residential Facilities for the Mentally Retarded. However, as a result of careful consideration following receipt of many comments on the Notice of Proposed Rule Making, we chose not to adopt the JCAH requirements in toto. I would like to indicate the major differences between the 1971 JCAH standards, which are incorporated in title II, and the Department's regulation, and the reasons for those differences.

The JCAH Standards and title II contain a considerable amount of admonitory material—sections telling the facility what it should do, rather than what it must do. On advice of our General Counsel, this material was not inserted in the regulation, since it is unenforceable; however, we anticipate that most of it will be placed in the guidelines we will be issuing to advise the public regarding implementation of the regulations.

Additionally, the JACH Standards and title II contain sections dealing with subjects for which funding is available under acts other than title XIX—vocational rehabilitation, education, and research. In order to avoid duplication, provisions on these topics were not included in the Department's ICF regulations.

The use of medicaid money for leverage in upgrading quality of care has proven successful in our skilled nursing facility program, and we believe it will be equally effective in this situation.

The Department estimates that \$490 million in Federal funds will be spent in fiscal year 1975 under the medicaid program for care of over 100,000 individuals in public institutions for the mentally retarded. The new ICF regulations will affect every large institution for the mentally retarded in those States which have elected to provide such coverage under medicaid, thereby accomplishing the purposes of title II of S. 3378.

We anticipate that additional States will extend medicaid coverage to institutions for the mentally retarded to take advantage of Federal financial assistance. In order to assure that Federal dollars will expand services and improve settings, rather than simply replace State dollars, Federal law requires States to maintain their fiscal efforts for such facilities until January 1, 1975.

Title II would interfere with the standardized certification procedures for institutional services under the medicaid program by mandating a different approach for institutions serving the mentally retarded. Medicaid certification procedures already in effect for skilled nursing facilities require annual onsite surveys, disclosure of deficiencies and written plans—including timetables—to correct deficiencies. The new regulations extend these requirements to ICF's for the mentally retarded.

Additionally, we would caution against the inclusion of requirements as specific as those in Title II in legislation. There have been many recent advances in the field of residential services to the developmentally disabled, including the establishment of new modes of care such as the group home and halfway house. We anticipate that progress in this area will continue to occur. New developments will require modifications in existing standards. If detailed standards are set in statute, it may be difficult to make necessary changes promptly. We believe that the administrative mechanism is better suited to adjusting details to meet changed circumstances.

To summarize, we concur in the desirability of standards, but we must differ with the approach to the problem which title II would have us take. We believe the ICF regulations will result in the goal we all seek: Treatment and care for mentally retarded individuals which is humane, safe, healthful and appropriate.

Mr. CUTLER. Do you have at this point in time something from the Department of Justice assuring the Department of Health, Education, and Welfare that their proposed regulations or regulation met the constitutional minimums?

Mr. DWIGHT. Yes.

We worked directly with the Department of Justice.

Mr. CUTLER. My question is, do you have in your files a letter that overturns prior correspondence from the Department of Justice indicating to you that your regulations did not meet the constitutional minimums?

Mr. DWIGHT. I don't believe we ever got anything like that in writing.

But the Department of Justice was satisfied with those regulations before they were finally issued.

Mr. CUTLER. If I furnish you a copy of a letter from the Department of Justice to the Department of Health, Education, and Welfare, can you show me a final letter indicating from the Department of Justice that they were satisfied that you met the constitutional minimums?

Mr. DWIGHT. I don't believe there is a letter in the file to that effect.

But there were conversations had with the persons who wrote that letter that satisfied them that the concerns that they expressed in the letter, I assume you were referring to, were not valid.

Mrs. FORSYTHE. Do you want to continue?

Mr. KURZMAN. In conclusion, I would like to emphasize that we

share a common objective with the committee: Improving the lives of the developmentally disabled. We believe that continuing the developmental disabilities program with the changes we have discussed and issuing regulations setting improved standards for facilities for the mentally retarded will make major steps toward this objective. We look forward to working with this subcommittee on this important matter.

Mrs. FORSYTHE. Thank you very much, Mr. Secretary.

Dr. HOROWITZ. Senator Kennedy, in his opening statement, quoted from the statement of 1971 on mental retardation, summarizing the two goals the President had enunciated with regard to reducing the occurrence of mental retardation and deinstitutionalization. He talked about that component of the President's statement which indicated that there needed to be a priority on research and the dissemination of preventive techniques.

Why is it that the institutes at NIH responsible for research in these areas are being proposed to get \$5 million apiece less next year than they had appropriated this year, if the administration gets its way?

And what component of the research activities in these two institutes is directed at mental retardation research and developmental disability research?

Mr. KURZMAN. I have to supply an answer to you on that, Dr. Horowitz.

The budget at NIH, as you know, has been discussed by Dr. Edwards, and others, from the health side, in the Health Subcommittee, on several occasions, and will be discussed again before the Appropriations Committee.

Dr. HOROWITZ. Does it seem inconsistent to you to ask for less money in these institutes at the same time that you establish a goal that relies on some of the work of these institutes?

Mr. KURZMAN. It seems to me you are not looking at the specifics of what is going on at those institutes.

My understanding of it is that if you look at the specifics of the applications you are receiving and the priorities they are setting for activity, and of course balance it across the board, which has to be done by both the Department and the Office of Management and Budget in the creation of the whole budget, and in the Congress itself, in appropriating you have to compare one with the other, and we think, as we do go from subcommittee to subcommittee, and subject to subject, and each one is for the day of that subcommittee hearing the highest priority of that subcommittee—but when putting together a budget all of these have to be put together in one place.

Dr. HOROWITZ. Can we infer from that that it is a policy of the administration, for example, to support research and developing a cure for cancer with a higher priority than doing research on the problems surrounding mental retardation?

Would that be a correct inference from the budget figures, for example?

Mr. KURZMAN. I would say that the only correct inference would be that in our proposed budget for the National Institutes of Health in general, heart and cancer clearly have a higher priority than all the other research activities at NIH.

That clearly is a policy judgment, a proposal made to the Congress which, by the way, it seems to me, the Congress has in many ways accepted both in the 1974 Labor-Health, Education, and Welfare appropriations bill, and in various enactments, most particularly in the enactment of the Cancer Act which makes that kind of priority very clear by setting up a very special administrative arrangement for that program just to assure that priority.

Dr. HOROWITZ. I think it is a very high priority.

I think the principle I am trying to illustrate is whether or not you think it would be fair to equate the amount of money that the administration requests in a particular category, for an item, with the importance that the administration views the particular problem.

Mr. KURTZMAN. No, I don't, Dr. Horowitz.

As I say, first you have to—you are making a lot of assumptions when you do that, it seems to me.

You are assuming that the amount of money spent is a reflection necessarily of its relative importance. It may not be. You have to look at what each institute is doing across the board, and NICHD is doing many other things as well as mental retardation.

I don't know the relative priority within that institute.

Dr. HOROWITZ. Do we know how many approved and recommended but unfunded grants are pending now in this area, in these two institutes?

Mr. KURTZMAN. I would be happy to supply it.

Dr. HOROWITZ. It's our understanding that the numbers will be quite surprising.

Mr. KURTZMAN. But I suspect, Dr. Horowitz, and I would like to supply this, too, that this is the case in every institute and with regard to every subject.

Dr. HOROWITZ. That's right.

And so one has to eventually decide what is most important. And one puts one's money, it seems to me, on the things that one considers most important.

Mr. KURTZMAN. I think there other considerations, too.

There are also considerations of quality.

And, of course, a great deal of this is done, you know, within the Institutes by rankings given to applications by advisory councils of outside experts.

Now, that is where most of your advisory councils are. They are the NIH Advisory Councils. And very often these are experts in the field.

They rank the applications primarily in terms of their scientific merit and the kind of contribution they can be expected to make, as well as the capacity of the individual and the institution to bring off the research successfully.

And that goes into the judgement as well as the availability of funds and the priorities the institute puts on various fields.

Dr. HOROWITZ. When you mentioned earlier that the Department was reconsidering all of its positions with regard to advisory councils—now you said that the greatest number of advisory councils is in the National Institutes of Health setting—is it fair to infer that the struc-

Cost-benefit analysis

ture of the current NIH Advisory Council system is under review in the Department?

Mr. KURZMAN. No—that we have carved out and said we will continue as it has in the past.

Secretary Weinberger said that repeatedly.

And we have also indicated that in the case of this Advisory Council for Developmental Disabilities in our bill, we call for its continuation.

I think the point I was making with Mrs. Forsythe is that we are trying very hard to avoid proliferation and additions to the system, and wherever we can eliminate councils that don't serve an important function, we are certainly going to do so.

Dr. HOROWITZ. Thank you.

Mrs. FORSYTHE. Mr. Kurzman, what happens to recommendations of the National Advisory Council on Developmental Disabilities after they are presented to the Secretary, and what action has been taken on recommendations that have been made to date for this program to the Secretary?

Mr. KURZMAN. Well I can answer that in part.

Clearly our bill reflects very heavily the recommendations.

I know the Chairman of the Advisory Council met with then Secretary Richardson and in the preparation of our legislation it was a major element.

Indeed, in our consideration of our testimony today, what the Council recommended is a major consideration.

Mrs. FORSYTHE. The reason for the inquiry is that when the statement of the National Advisory Council was presented last February there was a strong recommendation to revise the definition of developmental disability which would have broadened it.

I heard that statement again at the last meeting of the Council on Developmental Disabilities where I heard and I think I saw disappointment expressed on the part of the members of the Council that the definition and several other recommendations that have been made have not been implemented.

Mr. KURZMAN. Well, I would be happy to indicate by submission which of the recommendations were accepted and which were not.

But I think my statement just now will be borne out.

Most of them were.

As you know, on the definition, as my statement indicated, the Council was divided and had as much difficulty with the subject as just about every other expert group that has looked at it has had.

They did make a recommendation which, as you know, was in two parts. Essentially, they made a recommendation No. 1, and said that if you don't like that that they would make a recommendation No. 2, as a second alternative.

I think the inclusion of autism essentially reflects, as I understand it, their secondary recommendation.

It was not their primary one. It was their secondary one.

Senator Randolph's bill incorporates in some sense their first one.

Neither really goes to precisely the point they were making, which is that the functional definition would be better than adding any listing of specific diseases.

And neither of our definitions will do that.

So, as far as accepting the Advisory Council's recommendation, I think where we are today and what we are saying, the subcommittee

and we, are as close as you can come to doing that and still satisfy the many interest groups who would like to see, particularly with the history of this program, their particular etiology mentioned by name.

So I think we are doing pretty well in taking a valued group's recommendations into account.

Mrs. FORSYTHE. Mr. Cutler.

Mr. CUTLER. I just wanted to get back to a question I asked Mr. Dwight about a letter, a letter of December 21, addressed to Frank Carlucci, with regard to the edited version, edited JCAH standard and you indicated there was no letter of transmittal. In fact, it is strange because the reason for the response by Assistant Attorney General Pottinger is the fact that the Justice Department was sent a copy of the proposed plan.

In regard to that, I could read you from this letter—and that is why I asked if there had been any final letter of signoff.

With respect to the edited JCAH standards which we understand to be incorporated in the ICH regulations as a result of the requirements, we are concerned that the date for full compliance has been extended to 1978, and that the editing of the standards has resulted in numerous omissions or amendments which raise serious constitutional questions similar to those outlined in my previous letter of October 25, 1973, and November 15, 1973.

The closing paragraph reads—

I remain confident that working together we can agree on a version of the ICH regulations which meets this Division's concerns.

I am asking you now again, is there any letter from the Department of Justice to either Mr. Carlucci or Secretary Weinburger that indicates their approval, if you will, of the proposed regulation.

Mr. DWIGHT. I would repeat my previous answer.

I am not aware of any letter which is subsequent to the one—

Mr. CUTLER. You are not aware of this letter, obviously.

Mr. DWIGHT. Yes, I was.

I made reference to it earlier in my comments.

As indicated, I had several subsequent meetings with Mr. Pottinger to resolve the concerns he and his associates had that are set forth in that letter. However, I do not believe that he ultimately responded in writing to those meetings that we had with him.

Mr. CUTLER. So there is a final verbal signoff, if you will, by the Department of Justice, Mr. Pottinger agreeing that the proposed regulations had met all his concerns.

Mr. DWIGHT. I think I would put that a little bit differently.

And that is that the Department, including the Department's General Counsel, took into consideration all the concerns he raised, and satisfied ourselves that there were no major deficiencies, no deficiencies in the final regulations along the lines that he had set forth—

Dr. HOROWITZ. Satisfied yourselves or him?

Mr. DWIGHT. Satisfied ourselves.

Dr. HOROWITZ. Can we have the committee write a letter to Mr. Pottinger and ask him for a written response to this?

Mr. CUTLER. Certainly.

Mr. DWIGHT. I would say that the conversations that I had with Mr. Pottinger indicated that he would be reasonably comfortable with the conclusions we reached.

And we did make modifications to those final rules as a consequence of the concern he expressed in that letter.

Mr. CUTLER. I have nothing further.

Mrs. FORSYTHE. I think that we have completed the questions.

I would like to say before we close the hearing that I would like to remind Mr. Kurzman and the staff that the major thrust of this program is comprehensive planning—and just to go over the points that the chairman, Senator Randolph, outlined, in order to reach the goals that we hope will be developed from the comprehensive planning: that we need to have a broadened definition of developmental disabilities; that we need to have a working Council; and most importantly, that the Office of Human Development, where as the Senator put it, from the information in your own publication on that Office, is the logical place to assign this program for Americans with special concerns.

At this time I order printed as an appendix statements submitted by persons unable to attend this hearing and other pertinent material submitted for the record.

Thank you very much for your testimony.

Mr. KURZMAN. Thank you.

[Whereupon, at 4:10 p.m., the hearing was adjourned subject to the call of the Chair.]

APPENDIX

(HEW responses to questions raised at the Developmental Disabilities Hearing on May 1, 1974)

1. Number of people trained in UAF's, categorized by discipline.
2. Target numbers for people trained in UAF's, and the difference between target numbers and actual numbers trained.

In 1974, approximately 50,000 trainees representing some 60 disciplines received some exposure to the classroom and clinical training programs of the UAFs. Of these, 2436 will receive long-term training (160 to 500 hrs.) The great majority received short-term training.

During 1975, the UAFs will strive to increase the number of trainees, especially of technicians and paraprofessionals (below AB degree level) who provide on-going, direct care services to the developmentally disabled, with special emphasis on staff needed to facilitate deinstitutionalization.

There are no specific targets set for the numbers of people to be trained in UAF's.

3. Information regarding the goals of UAF's.

4. Information regarding interaction among UAF's.

The amount of \$4,250,000 requested for university-affiliated facilities for the developmentally disabled is the same amount appropriated in 1974. These funds provide support for the costs of administration and operation of a total of 33 centers. These grants provide "core" (administrative and operational) support in these centers which, in turn, impact on the UAF by providing a base for support from other sources for (1) interdisciplinary training, (2) demonstration of new, specialized, and exemplary services, (3) research related to improve the areas of training and services, and (4) technical assistance or consultation to State councils and agencies to help reach objectives in the delivery of services to the developmentally disabled. Training of personnel is the central function of UAFs, but it has a special approach, i.e., it is interdisciplinary, being service based and problem centered, encompassing a full range of disciplines, including medical, education, social and rehabilitation specialists, and consisting of supportive and allied professional personnel, all needed to cope with the medical and behavioral complexities of developmental disabilities. Most UAF are regional (multi-state) in geographical coverage; some UAFs are even national in scope since they offer special training or services not offered elsewhere. Each UAF has unique program features, thus none is exactly alike. Some UAFs collaborate in providing training and special services for a regional area, e.g., the two UAFs in New England provide combined support for six states. The UAFs have a further impact value in the ripple effect of extending their capacities into the community, including junior colleges in the training of direct care personnel, as well as community services and technical assistance. During FY 1973, a special survey and analysis revealed that a total of 52,854 personnel were trained in 32 UAFs, and well over 19,702 clients were served in 28 facilities.

5. Studies, if available, showing that interdisciplinary training is needed.

The need for interdisciplinary UAF studies is evidenced by the Association of UAF, a national organization of UAF consortium, supported by a grant from DDD. The AUAF has (1) conducted and completed a study under contract in May, 1973, under the direction of Tadashi Mayeda, entitled "Data Collection and Utilization in UAF," indicating in the Recommendations of the Project Report a follow-up and continuing interdisciplinary UAF study; (2) prepared and submitted in February, 1974 a proposal for a pre-evaluation interdisciplinary UAF study, to develop criteria and measures useful for assessing the effectiveness of UAF interdisciplinary training and associated programs; (3) currently preparing a formal application for a project grant to conduct the pre-evaluation study; (4) met with HEW staff at the Office of the Assistant Secretary for Planning and Evaluation on supporting an interagency (HEW: including DDD, MCH, and BEH) evaluation study with use of UAF set-aside funds and based in part on the AUAF pre-evaluation study; (5) coordinated activities in joint AUAF meetings with the UAF Committee of the National Advisory Council for DD, which is strongly

interested in stimulating interdisciplinary UAF studies. The one percent set-aside allowed from DD-UAF appropriations, amounting to \$42,500 per annum, has been too small an amount to launch the kind of interdisciplinary UAF study necessary to assess on a longitudinal basis in an integrated manner the effectiveness, both impact and strategies, of this complex program, involving multiple, interacting variables, located in a variety of UAF models, with differing capabilities and responsiveness based on varying resources and geographical manpower requirements. Aside from program evaluation, funds are not available to conduct other types of studies.

The DD center at Temple University has published a 116 page book entitled, Manpower Projections for DD in the 1980's, June, 1973, which includes some essential concepts for training in DD, and which further documents the need for a variety of studies in the subject area. (The cited above book is enclosed as a reference with this Question and Answer.)

Other programs besides DD are supportive of interdisciplinary training. The VR program supports some 19 Research and Training Centers which utilize the

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concept of interdisciplinary training for the training of personnel vocational and medical rehabilitation. The interdisciplinary concept is also being used in research in the 12 NICHD Mental Retardation Research Centers. Even non-DD programs foster the interdisciplinary concept for training, e.g., George Washington University, Department of Medical and Public Affairs, "Communicating Scientific Information for Education and Research."

The interdisciplinary concept has been promoted by the President's Committee on Mental Retardation. PCMR was established on October 17, 1961. The periodical PCMR reports are supportive of training e.g., MR-68, designates "Manpower to Serve the Retarded" as a priority area, and MR-69, indicates need for improved manpower training programs. The need for training is evident.



COMMUNICATING
SCIENTIFIC
INFORMATION FOR
EDUCATION AND
RESEARCH

DEPARTMENT OF
MEDICAL AND PUBLIC AFFAIRS
THE GEORGE WASHINGTON UNIVERSITY
MEDICAL CENTER

INFORMATION PROFILE
DEPARTMENT OF MEDICAL AND PUBLIC AFFAIRS
THE GEORGE WASHINGTON UNIVERSITY
MEDICAL CENTER

Chairman: Murdock Head, M.D.
Executive Officer: Richard H. Ross

ORIGIN AND MISSION

The Department of Medical and Public Affairs was established after more than a decade of experimentation and study toward joining biomedicine and related interdisciplinary interests in the environment and human ecology. The Department, to our knowledge, is the only one of its kind in the United States, devoted entirely to communications research and programming in the biomedical and environmental sciences.

The Department is chaired by Dr. Murdock Head, recognized professionally in biomedical communication; he holds degrees in medicine, law and dentistry.

Four elements of communication are included in the Department:

Interpersonal Dialogue between the Disciplines

The Department has access to an unusual conference facility, where representatives of numerous specialties have met for conferences, workshops, and seminars related to man's environment. Representatives of governments, industries, the professions, and academia have gathered and discussed related matters during the past 12 years. A number of resources have resulted -- human, economic, published reports and audiovisual studies -- which are available to the Department. No other department in this country has conducted this diversity of programming.

The Media Component

The utilization of knowledge normally develops from the spoken to the written word. These concepts may be transmitted via audiotape, videotape, film, publication, or other media. The choice of a vehicle for transmission

communication through mass media, whether monographs, professional journals, magazines, or newspapers, provides merely supportive techniques for a final communication effort. The Department, again, has a unique history in the development and use of media in man's environment, and their dissemination.

The Data Processing and Information Retrieval Component

The Department of Medical and Public Affairs has, as one of its major efforts, developed a large operational unit devoted to abstracting scientific literature, along with the use of computers for data storage and information retrieval.

Accredited Courses

Forensic Medicine is offered, on a continuing basis, to students of the Schools of Law and Medicine. Associate professors and physicians within this Department provide courses in the fields of medicine and law and in the interrelated roles of the physician, the patient, and the public.

DIVISIONS

The two divisions comprising the Department of Medical and Public Affairs, Airlie Division and the Science Communication Division, are unique in their interrelationships as well as the additional interrelated resources that each can offer.

Airlie Division

The Airlie Division is devoted to the production and distribution of educational and public affairs programming and has available several photographic units which move freely with personnel and equipment. There are recording studios, editing rooms, film studios, and screening rooms, in addition to technical personnel, writers, and specialists which allow for the mobility and flexibility necessary for filming specialized programs.

Documentaries produced by the Airlie Division have been awarded a number of emmys, as well as national and international film festival awards.

Science Communication Division

The Science Communication Division (SCD) occupies a unique status among the world's scientific information-oriented activities through its position in a university medical center. The establishment of SCD reflected the Department's concern for encouraging the development of a systematic, professional function for organizing and disseminating biomedical information to both scientific and public communities through various media. Thus, the two components of the Department -- the Airlie Division and SCD -- jointly and individually address their capabilities to the problems of communicating essential information appropriately packaged, to many sectors of the scientific community and to the public.

The capabilities and services of SCD have been developed over a period of 11 years, during which the Division has been actively engaged in science communication and information technology. The scope of SCD programs includes a variety of research projects focused on improvement of communications in the life sciences, emphasizing literature collection, analyses, abstracting and indexing, and the development of information centers for processing and disseminating life sciences information. With its departmental status, SCD communicates freely with all segments of the George Washington University and is able to call upon specialists in other schools and departments. In addition, communication is maintained with American University, The Catholic University, Georgetown University, and Howard University, all members of the Consortium of Universities of the Washington, D.C. area.

The availability of academic specialists provides the Division with the capability to extend its information handling programs into a number of scientific disciplines, with the assurance of adequate technical support.

The SCD has a staff of 40 together with a number of specialist participants whose services are required from time to time. Collectively, this interdisciplinary team represents an aggregate of expertise in such disciplines as medicine, biology, chemistry, social sciences, engineering, information systems development, management science, and library science.

The principal resources which enable SCD to act successfully upon special information requirements within the life sciences community include:

- The availability of academic specialists, information scientists, and librarians.

- Access to a wide variety of information systems and internally maintained data bases.

- Flexibility in the management of tasks and in the development of products and services.

Clearly, the major asset in the approach to literature and scientific information must be personnel knowledge and experience. The fact that SCD is integrated with the University Medical Center has enabled the Division to develop a high level of biomedical and professional support which substantially increases the reliability of its efforts. SCD products, which may be continuing services from information center facilities or prepared on an ad hoc basis, are developed to meet the special needs of individual research groups or widely diverse communities of users.

In performing science information projects the SCD has built up a recognized capability based on the combined resources mentioned above, the skills of its staff, and extensive, in-house collections. All these are utilized to provide comprehensive information support which considerably exceeds the generalized "first cut" capability of a mechanized bibliographic reference system. In effect, the effort of SCD begins with the outputs of computer

searches from such systems as MEDLARS, NASA, SIE, DDC, and others.

Each of the large, general-purpose machine systems contains a segment of the material needed for single project. However, each yields from different kinds of sources. But even in the aggregate, these combined outputs are inadequate until supplemented by numerous additional sources which remain outside their files. As an illustration, it is significant to note that 50 percent of the literature collected on Prostaglandins does not appear in the established biomedical literature services of the U.S. and Western Europe. As a preliminary step toward any analytical effort, the SCD staff has two essential tasks: (1) to identify and procure additional literature that did not appear through searches of secondary sources and information systems; (2) to eliminate (often in major portions) material which does not relate to the needs and objectives of a particular research project.

The verification and evaluation of each document against the requirements of a user community is the fundamental difference which distinguishes preliminary research from routine bibliographic reference service. This task, which requires professional knowledge, is essential to make certain that literature support is comprehensive in coverage and at the same time provides material that is known to bear directly on the topic under study....

Dissemination of abstracts as a current awareness service is performed for several biomedical topics. These programs require a continuing literature search, preparation of abstracts when none is already available, regular distribution to interested individuals, and preparation of cumulative indexes at longer intervals. Computer facilities are available at the University for projects requiring data tabulation and summaries. The SCD maintains card punch and verifier equipment for generating machine-readable records when required. When substantial computer time or special programming capabilities are needed, ad hoc services are procured to work with SCD staff for developing

file generation, output reports, and summaries in a format appropriate to the user's requirements.

DEPARTMENTAL SERVICES

Departmental services are available only to its sponsors and to individuals and institutions specifically authorized under the terms of a contract, grant, or award. Such agreements are established both by solicitation from the Department through proposals and by requests from agencies, institutions, foundations, societies, and industry.

DATA COLLECTION

AND

UTILIZATION

IN

UNIVERSITY

AFFILIATED

FACILITIES

**DATA COLLECTION AND UTILIZATION
IN UNIVERSITY AFFILIATED FACILITIES**

Tadashi Mayeda

Ontario, California

May 1973

Prepared under contract to the Nisonger Center of the Ohio State University on behalf of the Association of University Affiliated Facilities, Washington, D.C. as part of a grant from the Division of Developmental Disabilities, Rehabilitation Services Administration, Social and Rehabilitation Service of the Department of Health, Education, and Welfare.

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II. RESULTS OF FOUR DATA SURVEYS

Summary

Twelve data sheets are included in this section. These sheets list all the data collected from four surveys so that directors, data coordinators, and others, who will be working with data in the future, might familiarize themselves with the details of the system and the benefits and problems associated with it.

Highlights have been extracted from the data sheets and author's comments have been added in some cases. These are meant to guide readers through the sheets and not necessarily to influence them on their content.

The following is an overall summary of the four data surveys:

Mailings and response

Thirty six University Affiliated Facilities were solicited for data. All were accounted for and all, except one, have submitted or agreed to submit data. Thirty two facilities responded in part or completely to the four data surveys. Twenty five data coordinators, representing 29 facilities, were appointed.

Trainees and clients

A total of 52,854 persons were trained in 32 facilities during a twelve month period of time. This figure includes data from 3 facilities that reported on training for 3 and 6 month periods only. Twenty percent of these trainees were private practitioners not enrolled in degree or board certification programs. Over 8 percent were students at a level lower than the Associate of Arts degree.

A total of 19,702 clients were served through 28 facilities. This figure does not include many of the special education clients of the UAF's

Approvals and accreditation

The UAF's are most frequently accredited as hospitals or as medical residency programs; next as K-12 primary grade schools. There appears to be some inclination showing toward pre-school and day care.

Academic affiliations

Pediatric and speech pathology affiliations appear most frequently followed closely by psychology and social work. Special education, nursing, audiology, occupational therapy, and physical therapy, in addition to the first four, appear to comprise the "core" of most frequent academic affiliations. Psychiatry and dentistry follow

this group in two thirds of all facilities. More than 60 discipline affiliations were reported.

Community affiliations

All facilities reported community ties. Affiliations with schools, state hospitals, and child development centers appeared most frequently. Affiliations with State Developmental Disabilities Councils and non-profit associations appeared in the majority of facilities. There were fewer junior college affiliations than the author expected.

Physical characteristics

Fourteen facilities have more than 50,000 net square feet; 9 have 25,000 to 49,999 square feet; 5 have 10,000 to 24,999 square feet; and three less than 10,000 square feet. Total staff and trainee-in-residence capacity for all reporting facilities is 4,560.

Functional characteristics

The broad variation in original design concepts are revealed by the functional characteristics of each of the UAF's. Most provide for medical diagnosis and classroom teaching of young children, however, the facility-by-facility capacity for each varies considerably.

Discipline of trainees

Training for the 52,854 trainees ranged from short orientation sessions to full time involvement. Special education led with 8,132 trainees followed by nursing with 7,131. Psychology ranked first as the discipline taught by the greatest number of facilities.

Medium to long term trainees

Of the 52,854 trainees, 2,436 were in training for more than 160 contact hours. The broad variations in the numbers of medium and long term trainees in the various facilities is interesting and should be investigated further through later surveys.

Levels of trainees

More than half of the total number of trainees (29,441) were candidates for degrees or board certification. Approximately 20% (10,155) were private practitioners. More than 8% (4,371) were students at a level lower than the Associate of Arts level.

6. List all Federal organizations which should be included among the DD Advisory Council Membership

National Institute of Mental Health

Health Services Administration

Medical Services Administration

Bureau of Education for Handicapped

Community Services Administration

Rehabilitation Services Administration

Assistance Payments Administration

7. A section-by-section analysis comparing ICF-MR regulations with Title II of S.3378, and discussion of the legal authorities for the ICF regulations

The attached table is a section-by-section comparison of S.3378, Title II, and the intermediate care facility-mental retardation (ICF-MR) regulations. The latter comprise two sections of the Code of Federal Regulations: 45 CFR 249.12, establishing standards with which intermediate care facilities must currently comply, and 45 CFR 249.13, establishing standards with which intermediate care facilities for the mentally retarded must comply by March 18, 1977.

For summary purposes, the comparison seeks to emphasize major differences. It will be noted that many provisions of S. 3378 are identified as suggestions or recommendations which are not specified in the regulations. The regulations generally encompass only actual requirements, since they are rules to be enforced. Much of the philosophical, admonitory and explanatory material contained in the non-mandatory language in S. 3378 will be used in guidelines to be issued by SRS. This division of mandatory and admonitory material was made on the advice of HEW Office of the General Counsel. In large part, this difference in approach accounts for the briefer character of the ICF-MR regulations.

Another factor accounting for the less detailed character of the ICF-MR regulations is the use in the regulation of requirements which apply to a number of sections, rather than the repetition in each section of parallel requirements (as in many sections of S. 3378). This applies particularly to personnel policies, as in the repetition of provisions on in-service training and maintenance of professional standards of ethics.

Legal Authority for Intermediate Care Facility Regulations

The regulations cited in the chart are based primarily on Sections 1905(a)(14) and (15), and 1905(c) and (d) of the Social Security Act, authorizing intermediate care facility services (including such services in a public institution for the mentally retarded) as an optional service under Title XIX of the Act, and Section 1102 of the Act, directing the Secretary of Health, Education and Welfare to make and publish rules and regulations as necessary for the efficient administration of his responsibilities under the Act.

Additional enactments relating to intermediate care facility services upon which regulations pertaining to intermediate care facility services are based include Section 1902 (a)(31), which mandates a regular program of independent professional review and a written plan of service prior to admission or authorization of benefits in an intermediate care facility (basis for 45 CFR 250.24), Section 1903(g)(1), Section 1903(h)(1), Section 1903(j)(2).

5. SECTION-BY-SECTION COMPARISON OF ICF-MR REGULATIONS
AND TITLE II OF S.3378 (PROPOSED JCAH STANDARDS) WITH
EMPHASIS ON IDENTIFYING MAJOR DIFFERENCES

S.3378

45 CFR 249.13

TITLE II - Bill of Rights for the
Mentally Retarded and Other Individuals
with Developmental Disabilities

Intermediate Care Facility Services in
Institutions for the Mentally Retarded or
Persons with Related Conditions

(with appropriate references to
 45 CFR 249.12, Standards for
 Intermediate Care Facilities

Chapter 1. Administrative Policies and Practices

Subchapter I. Philosophy, Location, and Organization

Sec. 210-214. Largely written as
 recommendations rather than require-
 ments.

No comparable section; advisory
 material does not appear in regulation.

Subchapter II-General Policies and Practices

Sec. 215

(a) Requires written outline of
 philosophy, objectives, goals
 specific minimum content.

249.13(a) (1) (i) Similar; omits less
 concrete goals

(b) Requires plan for evaluation
 and modification to maintain
 consistency of philosophy.

Not specified

(c) Requires manual on plans and
 procedures

249.12(a) (1) (ii) Requires written
 policies and procedures governing
 all areas of service; these must
 be available to staff, residents and
 the public

(d) Requires written statement of
 policies and procedures on
 residents' rights

249.13(a) (1) (ii) Similar; omits
 reference to special rights of MR,
 definition of means of making legal
 counsel available to residents;
 requires that civil rights of residents
 be assured

S. 3378ICF-MR REGULATIONSSec. 216

- (a) Requires written statement of policies and procedures to protect residents' financial interests, specifies content

249.13(a)(1)(iii) Similar; omits determining resident's eligibility for benefits, assuring he receives special needs due him under public, private programs.

Adds requirement for policy permitting normalizing possession and use of money by residents.

- (b) Requires manuals describing facility procedures

(b) 249.13(a)(1)(iv) Same

- (c)(d) Requires plan for continuing management audit; summary of MR laws

249.13(a)(1)(v) Same, except no summary MR laws

Sec. 217

- Requires facility to have legal documents (charter)

No comparable section

Sec. 218

- (a) Requires governing body to direct facility and establish policies

249.13(a)(1)(vi) Same

- (b) Specifies qualifications of chief executive officer.

249.12(c)(2) Requires licensed nursing home administrator or, QMRP, or, in case of hospital, hospital administrator

- (c) Requires his employment by governing body

249.13(a)(1)(vii) Governing body sets qualifications for chief executive

- (d) Requires coverage in absence of chief executive officer

249.13(a)(1)(viii) Similar

Sec. 219

- (a) Requires adherence to sound management principles

Not specified

- (b) Requires use of appropriate organization

Not specified

- (c)-(d) Table of organization

249.13(a)(1)(ix) Similar

- (e)-(h) Specifies in detail principles of organization

Not specified

S 3378ICF-MR REGULATIONS

- | | |
|---|---|
| <p>Sec. 220</p> <p>(a) Requires effective staff and resident participation and communication; specifies certain meetings</p> <p>(b) Specifies details on staff and committee meetings</p> | <p>249.13(a) (i) (x) (A) Virtually identical</p> <p>249.13(a) (i) (x) (B) Similar; not as detailed</p> |
| <p>Sec. 221</p> <p>Requires percentage of budget to be used for "self-renewal" purposes, specifies minimum content and use of results</p> | <p>No comparable section</p> |
| <p>Sec. 222</p> <p>Requires description of facility services that is available to public, specifies minimum content</p> | <p>249.12(a) (i) (ii) Requires written policies and procedures governing all areas of service to be made available to staff, residents and the public</p> |
| <p>Sec. 223</p> <p>(a) Requires consumer-representative s and public participation, specifies means</p> <p>(b) Suggests public education and information program</p> | <p>Not as detailed: 249.13(a) (i) (xi) emphasizes communication with families and surrogates, relatives' visits, residents' visits home</p> <p>Not specified; advisory material does not appear in regulation</p> |

Subchapter III-Admission and Release

- | | |
|---|---|
| <p>Sec. 224</p> <p>Limits admission to those whose needs can be met by facility</p> | <p>249.13(a) (2) (i) Same</p> <p>249.12(a) (i) (ii)</p> |
| <p>Sec. 225</p> <p>(a) Admission, release, readmission requirements must be summarized, available for distribution. Specifies objectives</p> <p>(b) Requires determination of legal incompetence to be separate from determination of need for services, states admission does not imply legal incompetence</p> | <p>249.13(a) (2) (ii) Same; but omits objectives</p> <p>Not specified</p> |

S.3378ICF-MR REGULATION

Sec. 226

- (a) Requires comprehensive evaluation of residents
- (b) Specifies considerations regarding admission
- (c) Specifies who shall be named as intended primary beneficiary of care
- (d) All admissions considered temporary, time-limited. Parents to be counseled on merits, temporary nature of services. Parents or guardians required to visit facility before resident is admitted

249.13(a) (2) (iii) Same

249.13(a) (2) (iv) Same

Not specified

249.13(c) (11) Social workers assist family in considering alternative services and making responsible choice during evaluation period

Sec. 227

- (a) Requires medical evaluation within one week of admission

45 CFR 250.24(a) (1) (i) Requires comprehensive medical, social psychological evaluation prior to admission

(b)-(c) Very similar to-----

249.13(a) (2) (v)-(vii)

Sec. 228

Suggests physical inspection before leaving and after returning to facility

Not specified; regulation does not include advisory material

Sec. 229

Procedures for handling permanent release or transfer

249.13(a) (2) (viii)-(x) Similar; omits required notice to court in certain cases, assurance that receiving facility will meet resident's needs

Sec. 230

Procedures in the event of unusual occurrence, including death

249.13(a) (2) (xi) and (xii) Similar; omits requirement for helping family arrange religious services and burial, notifying coroner or medical examiner as required by law

S.3378ICF-MR REGULATIONSubchapter IV. Personnel Policies

Sec. 231

- | | |
|--|--|
| (a) General statement on personnel services, qualifications of personnel director when one is needed | Not specified |
| (b) Prescribes personnel policies coverage | 249.13(a) (3) (i)-(v) Similar; omits planned program for career development, methods of improving employee welfare and security. |
| (c) Requires statement of personnel policies available to employees | 249.13(a) (3) (vi) Requires personnel policies to be in writing and available to all employees |
| (d) Pre-hiring procedures | 249.13(a) (3) (xi) Not specified, except for procedures to assure employees free of communicable, infectious disease |
| (e) Requires periodic performance rating | Not specified |
| (f) Same essentially as | 249.13(a) (3) (vii) |

S. 3378ICF-MR Regulations

Sec. 232 (a) and (b) Policy on use of Residents or volunteers for productive services

249.13(a) (3) (viii) Similar; not as detailed.

(c) Prescribes staff training program, minimum content

249.13(a) (3) (ix) Similar, not as detailed.

(d) Suggests working relationships with nearby colleges for training purposes

Not specified; advisory material is not included in the regulation

Chapter 2. Resident Living

Subchapter I. Staff-Resident Relationships and Activities

Sec. 240 (a) State primary responsibility of living unit (IU) staff as care and development of residents, prescribes elements

249.13(b) (1) (i) Similar, does not require family-like atmosphere; advisory material is not included in the regulation.

(b) Requires IU Staff to participate with interdisciplinary professional team in patient care

249.13(b) (1) (ii) Same

(c) Requires specific evaluation and program plans for each resident

249.13(b) (1) (iii) Same

(d) Requires activity schedule for each resident, prescribes implementation

249.13(b) (1) (iv) Same, except permits unscheduled activity of three hours rather than one.

Sec. 240 (e) General statement on "rhythm of life" in living unit, regimen for multi-handicapped and non-ambulatory residents

249.13(b) (1) (v). Same, except no statement on "rhythm of life".

(f) Requires planned periods outdoors year-round for all patients. Suggests how residents should be given freedom of movement

249.13(b) (1) (vi) Same, except for suggestions on freedom of movement, similar activities.

ec. 240

S.3378ICF-MR Regulation

(g) and (h) Suggests eliciting residents' views, instructing them in communication

Not specified, regulation does not include advisory material

(i) Requires residents be allowed personal possessions

249.13(b) (1) (vii) Same

(j) Requires facility to permit patients to have use of money

249.13(a)(1) (iii) Similar with fewer details

(k) Requires written policies, procedures for control and discipline of residents

249.13(b) (1) (viii) Similar

(l) Corporal punishment

249.13(b) (1) (ix) Same

(m) Seclusion

249.13(b) (1) (x) Same

(n) and (o) Physical restraints
(p) Chemical restraints

249.13(b) (1) (xi) and
249.12(a) (1) (ii) (a) (2) Same
249.13(b) (ii) (xii)

(q) Behavior modification programs

249.13(b) (1) (xiii) Same, except that programs may be reviewed and approved by Qualified Mental Retardation Professional as well as facility's human rights committee.

Subchapter II Food Services

ec. 241

(a) Statement of general purpose. Requires written statement of goals, indicates content

249.13(a) (i) Facility shall have written outline of objectives and goals.

(b) When food services not directed by nutritionist or dietitian suggests that consultants must be obtained, and consultations evaluated.

249.13(c) (4) (xiii). In facilities of 20 beds or more, food services must be directed by dietitian meeting requirements of Medicare (20 CFR 405.1101); (c) (4) (xiv): Less than 20 beds, direction by designated staff members suited by training and experience.

249.12(a) (7) (iii) For individuals needing medically prescribed special diets, menus planned by qualified dietitian, or reviewed and approved by physician.

S.3378

- Sec. 241 (c) Requires nourishing diet. prescribes requirements for modified diets.
- (d) Suggests dietary practices in keeping with religious requirements of residents
- Specifies 3 meals daily, indicates intervals
- (e) Suggests pre-bedtime snacks
- (f) Specifies how food shall be served
- (f) Requires feeding all residents in dining rooms, specific arrangements
- (g) More on dining arrangements, largely written as recommendations rather than requirements
- (h) Requires adequate supervision, staffing of dining rooms; suggests staff eat with residents, requires encouragement of selfhelp for those unable to get to dining areas.

ICF-MR. REGULATION

- 249.13(c) (4) (ii) Same
- 249.13(c) (4) (iii) food and nutrition needs shall be met in accordance with the recommended dietary allowances of the Food and Nutrition Board of the National Research Council, National Academy of Sciences
- Not specified, Regulation does not include advisory material
- 249.13(c) (4) (iv). Same
- Not specified; Regulation does not include material which is advisory.
- 249.13(c) (4) (vi) Similar;
- 249.12(a) (7) (vi) All food is distributed and served under sanitary conditions
- 249.13(c) (4) (viii) Generally similar, fewer details
- Not specified, regulation does not include advisory material
- 249.13(e) (4) (ix). Similar, limited to basic adequacy of staffing, supervision; regulation does not include advisory material

S.3378ICF - MR Regulations

Sec. 242

249.13(c) (4) (x) Same

(a) Requires residents be trained in eating skills

(b) Requires interdisciplinary approach to problems of residents with special eating disabilities

Not specified

(c) Requires training of direct care staff in feeding techniques, specifies feeding practices

249.13(c) (4) (xi) Similar; omits some detail

(d) Requires procedures for cleaning all areas and equipment

249.13(c) (4) (vii) same; also 249.12(a) (1) (vi) facility must be in conformity with Federal, State and local laws, codes and regulations pertaining to health and safety.

S.3378ICF - MR RegulationsSubchapter III - Clothing

Sec. 245

- | | |
|---|--|
| (a) General statement on each resident's clothing allowance | 249.13(b) (2) (i). Basically same
Adds requirement that clothing be <u>suitable</u> |
| (b) Each resident to have own clothing, prescribes its nature | 249.13(b) (2) (ii) Similar, less detail |
| (c) Requires nonambulatory residents to be dressed in own clothing, with some exceptions. | 249.13(b) (2) (iii) Requirement applied to <u>all</u> residents |
| (d) (e) (f) Requirements for washable clothing, incontinent patients, inventories | 249.13(b) (2) (i) Resident clothing must be suitable |
| (g) Requires residents be trained in certain clothing activities | 249.13(b) (2) (iv). Similar, less detail |

Sec. 246

Requires storage space for each resident's clothing

249.13(b) (2) (v) Similar

*Sec. 247

Specifies qualifications of staff person responsible for resident - clothing program

Not specified

Subchapter IV - Health, Hygiene, and Grooming

Sec. 250

249.13(b) (3) (i)

(a) Requires resident training in health, hygiene and grooming

Same

(b) (c) (d) (e) (f) (g), Prescribes specific procedures: teeth hygiene, hair care, toenail and fingernail care, bathing, female menstrual needs

Not specified

(h) Residents' toilet problems and habits

249.13(b) (3) (ii) Similar: less detail

(i) Requires drinking unit in each living unit

Not specified

(j) Prescribes practices on weighing, measuring residents

249.13(b) (3) (ii) Same

(k) Requires procedures on care of infections and contagious diseases to conform to State and local health regulations

249.12(a) (1) (vi) Facility must be in conformity with Federal, State and Local laws, codes and regulations pertaining to health and safety

(l) Prescribes review of orders on bed-rest, etc.

249.13(b) (3) (iv). Same

(m) Requires provisions for furnishing and care of dentures, eyeglasses, etc.

249.13(b) (3) (v). Same

S.3378ICF MR Regulations- Grouping and Organization of Living Units

- | | |
|--|--|
| sec. 255(a) (b) (c) (d) (e) Prescribes conditions as to intermingling of developmental levels, ages, needs, coordination with activities, use of living areas, accessibility of outdoor recreation areas | 249.13(b) (4) Contains language in §255(b) of S.3378 dealing with intermingling; 249.12(a) (4) (i) (e) requires overall plan of care prescribing an integrated program.
249.13(c) (10) (v) Requires easy accessibility to residents of recreation areas and facilities. |
|--|--|

Subchapter V.- Resident - Living Staff

- | | |
|---|--|
| sec 256 (a) General statement on adequacy of staff, leadership, job titles,

(b) <u>Suggests</u> staff dress policy

(c) <u>Recommends</u> resident - staff ratios when resident living-units organized as recommended in subchapter V and designed as in sub-VII, by severely retarded moderately retarded, others, with overall limits regardless of organization design
(d) <u>Requires</u> certain resident-staff ratios | 249.13(b) (5) (i), Similar; no reference to titles.

Not specified; Regulation does not include advisory material

Not specified; regulation does not include advisory material

249.13(b) (5) (ii) similar, same ratios but slight differences in group definitions |
|---|--|

Subchapter VI - Design and Equipage of Living Units

- | | |
|---|---|
| sec. 257 (a) General objectives

(b) Objectives of interior design Requires minimum (80 square feet of living, dining, activity space for each resident | Not specified

249.12(a) (6) Resident living areas are designed and equipped for comfort and privacy; there are areas for dining, divisional and social activities; there is sufficient space for activities in multi-purpose rooms not to interfere with each other. |
|---|---|

S,3378

ICF - MR Regulations

Sec. 257

- (c) Requirements for bedrooms including at least 60 square feet per resident in multiple sleeping rooms, 80 square feet in singles

249.13(b) (6) (i), (ii) and (iii) Similar; requires 80 square feet and 100 square feet respectively; adds requirement of no more than 4 residents per room, unless justified by resident's program needs; omits details on partitions, doors, room decoration, personal play equipment, space.

- (d) Requires suitable storage space

249.13(b) (6) (iv) Similar

- (e) Requirements on location of toilet areas, closets, other facilities

249.13 (b) (6) (v) and (vi), Requires individual privacy in toilets, tubs, showers, special equipment for handicapped; 249.12(a) (6) (i) requires toilet and bathing facilities appropriate in number, size and design to meet residents' needs; omits drying racks, mirrors

- (f) provisions for safety, sanitation, comfort of residents

249.13(b) (6) (vii) - (xiii). similar but not as detailed, no auditory and visual signals on mixing valves; glazing material requirements.

Chapter 3. Professional and Special
Programs and Services

Subchapter I. Introduction

Sec. 258

- | | |
|---|--|
| (a) General statement | 249.13 (c)(1) Same |
| (b) Programs and services may be provided by own staff or outside agencies. | 249.12 (a)(3)(i) Requires outside arrangement for service when facility cannot provide with own staff. |
| (c) Recommends all services to MIs to be rendered in community rather than facility when possible | Not specified; advisory material is not included in regulation. |
| (d) All services and programs must meet standards for quality set in this section | 249.13 (c)(1)(i) Same |

Sec. 259

- | | |
|--|---------------------------------------|
| (a) Specifies identifications for professions, areas, or disciplines of persons which may provide professional services | Not specified |
| (b) Requires interdisciplinary teams for evaluating, planning for individual's needs to be drawn from professions listed | 249.13 (c)(1)(ii) Virtually identical |
| (c) Permits services listed under duties of one profession to be performed by persons of other professions who are properly equipped | Not specified |
| (d) Requires evidence that members of different professions work together | Not specified |

Sec. 260 - Requires programs, staff to focus on individual needs of residents, identifies recommended activities

Not specified; advisory material is not included in regulation; however, regulations provide for regular review and evaluation of resident's program 45 CFR 250.24, 249.10 (d)(1)(v)(d), 249.12 (c)(3), and individual plan of care requirements (defined in 249.10 (d)(v)(b)), 249.13 (c)(ii)

Subchapter II - Dental Services

Sec. 261

- | | |
|--|---|
| (a) General purpose statement | Not specified |
| (b) Specifies how rendered (directly and indirectly) | Not specified |
| (c) Recommends certain dental services | Not specified; advisory material is not included in regulation |
| (d) Specifies content of comprehensive diagnostic services | 249.13(c)(2)(i) Similar; Requires comprehensive diagnostic services; omits consultation and waives exam within one month of admission if resident had one within 6 months and it meets certain conditions |
| (e) Specifies content of comprehensive treatment services | 249.13(c)(2)(ii) Similar; Requires comprehensive treatment services, omitting specific reference to dental specialties |
| (f) Suggests content of comprehensive preventive dentistry program | Not specified; regulation does not include advisory material |
| (g) Specifies content of education and training in oral health maintenance | 249.13(c)(2)(iii) Similar; omitting some details |
| (h) Requires permanent dental record for each resident | 249.13(c)(2)(iv) Same |
| (i) Requires formal arrangement for providing dental services to facility, including emergency care round-the-clock; designation of dentist to maintain standards; makes other recommendations | 249.13(c)(2)(v) Same with respect to formal arrangements for providing care; omits advisory material |
| (j) Specifies dental staff requirements, makes other recommendations | 249.13(c)(2)(vi) Similar; omits mention of dental health educators, and omits advisory material |
| (k) Suggests qualifications of oral hygiene aides | Not specified; advisory material is not included in regulation |
| (l) Suggests supporting staff | Not specified; advisory material is not included in regulation |
| (m) Requires dentists to adhere to professional code of ethics | Not specified |

Subchapter II - Dental Services

Sec. 262

- | | |
|--|--|
| (a) Requires continuing education program for dental personnel, specifies content | 249.13(a)(3)(ix)(B) Requires continuous inservice training to update and improve the skills and competencies of all employees |
| (b) Suggests facility affiliate with school training programs | Not specified; regulation does not include advisory material |
| (c) Requires adequate space, facilities, equipment, anesthesia facilities, certified dental lab, dental consultation, freedom from physical barriers for handicapped | 249.12(a)(6)(vi) Areas for therapy are of sufficient size and design to accommodate necessary equipment, conduct examinations and provide treatment.

249.13(f)(1)(iv) Accommodations are made to meet the needs of persons with disabilities. |

Subchapter III - Education Services

Sec. 263

- | | |
|---|---|
| (a) Defines "educational services" requires their availability to all residents. Requires written statement of objectives | 249.13(c)(3) "Training and habilitation services" 249.13(c)(3)(i). Uses same definition for "training and habilitation services." Omits statement of objectives and required recognition of principle that learning begins at birth |
| (b) Lists minimum services | Not specified |
| (c) Requires educator as member of interdisciplinary team, where appropriate | Not specified |
| (d) Prescribes method and nature of individual evaluations | 249.13(c)(3)(ii) Similar; omits some detail |
| (e) Requires written objectives for each resident | 249.13(c)(3)(iii). Similar; omits some detail |
| (f) Requires evidence of activities to meet objectives set for each resident | 249.13(c)(3)(iv). Virtually identical |
| (g) Requires appropriate programs to implement educational objectives of facility | Not specified |
| (h) Requires educational programs for all developmentally disabled for whom such are not required by State laws | Not specified |

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- | | |
|--|--|
| (i) Requires educational programs for residents with hearing, vision, perceptual, or motor impairments | 249.13(c)(3)(v) Same |
| (j) Suggests additional kinds of educational programs | Not specified; regulation does not include advisory material |
| (k) Requires "a full range" of instructional material to be accessible to staff | Not specified |
| (l) Requirements re: coeducation, coordination with other facility activities and the community | Not specified; 249.13(c)(1) (12) requires interdisciplinary team to review and revise residents' program |

Sec. 264

- | | |
|---|---|
| (a) Requires sufficient qualified staff, specifies qualifications of supervisor | 249.13(c)(3)(vi) Similar; requires supervision by a Qualified Mental Retardation Professional as defined in 45 CFR 249.12(c)(3) |
| (b) Staff development program required; requires provision of assistants as needed; active encouragement of participation in professional organizations | 249.13(a)(3)(ix) Requires staff development program for all employees; no requirement of encouraging participation in professional organizations;

249.13(c)(3)(vi) requires sufficient staff |
| (c) Suggests opportunities for internships, etc. through arrangement with universities | Not specified; regulation does not include advisory material |

Subchapter IV - Food and Nutrition Services

Sec. 265(a)	Statement of objectives	Not specified
(b)	Written statement of procedures and policies required	249.12(a)(1)(ii) Requires written policies and procedures governing all areas of service
(c)	<u>Suggests</u> services that should be provided when appropriate	Not specified; regulation does not include advisory material
(d)	Prescribes content of food services	249.13(c)(4)(i). Same
(e)	Requires food and nutrition needs to be met in accord with recommendations of food and nutrition board	249.13(c)(4)(iii) Substantially the same
(f)	Prescribes planning, content of menus, records of menus	249.13(c)(4)(v). Substantially the same
(g)	Prescribes food preparation methods	Not specified
(h)	Deals with preparation, storage, distribution of food, compliance with State and local health codes	249.13(c)(4)(vii); also 249.12(a)(7)(vi) All food is procured, stored, prepared, distributed and served under sanitary conditions; 249.12(a)(1)(vii) compliance with health laws
(i)	Storage requirements for dry and perishable foods	249.13(a)(4)(vii); Also see 249.12(a)(7)(vi); 249.13(a)(4)(vi).
(j)	Requires sufficient competent personnel, specifies categories	249.13(c)(4)(xi). Similar, no specific listing of categories
(k)	Requires appropriate inservice training program	249.13(a)(3)(ix). Requires inservice training for all employees
(l)	Recommends internship opportunities	Not specified; regulation does not include advisory material
(m)	Requires adequate space, facilities, equipment for food services.	Not specified

Subchapter V - Library Services

Sec. 266 Consists largely of recommendations . Not included

Subchapter VI - Medical Services

Sec. 267

- | | |
|---|--|
| (a) States purpose of providing medical services | 249.13(c)(5) and 249.12(b)(6)
249.13(a)(1)(i) facility shall have a written outline of philosophy, objectives and goals it is trying to achieve |
| (b) States methods of rendering service | 249.13(c)(5)(i). Same |
| (c) List <u>recommended</u> kinds of medical activities | Not specified; Regulation does not include advisory material |
| (d) Requires services of Medical and surgical hospitals accredited by JCAH to be available to residents; limits pathology, clinical lab and radiologic services to those that meet JCAH standards, EEG's available as necessary | 249.12(a)(2) Requires transfer agreement with nearby hospital.
249.12(a)(1)(ii)(A)(ii) Requires that, if residents condition changes so that care is needed which the facility cannot provide, resident is promptly transferred to hospital, skilled nursing facility or other appropriate facility. Also see 249.13(c)(5)(ii). |
| (e) Requires physician participation in planning resident's care | 249.13(c)(5)(iii) Same |
| (f) Suggests detailed content of management plan | Not specified; Regulation does not include advisory material |
| (g) Requires review and update of treatment goals and management plan | 249.13(c)(5)(iv) Same |
| (h) Requires special attention to residents who, without active intervention, risk further loss of function; list minimum detailed content of such attention | Not specified |

Sec. 267 (cont'd.)

- (1) Establishes preventive health service requirements

249.13(c)(5)(v) and 249.13(b)(3)(iii) establish virtually identical requirements, except that 249.13(c)(5)(v)(c) and (D) specify use of immunization recommendations of Committee on control of Infectious Diseases of the American Academy of Pediatrics; and use of TB control recommendations of American College of Chest Physicians and/or section on diseases of the chest, American Academy of Pediatrics.

- (j) Specifies minimum content of preventive health services to staff

249.13(a)(3)(xi). Personnel with communicable disease symptoms are not allowed to work; 249.12(a)(1)(vii) facility meets health requirements re communicable diseases

- (k) Requires each resident to have personal (primary) physician; and availability and use of qualified medical specialists

249.12(b)(6) Requires each resident's health care to be under continuing M.D. care; M.D. sees resident at least every 60 days unless justified and documented otherwise by attending M.D.

- (l) Requires, appropriate to size of facility, an ongoing inservice training program for its physicians, suggests methods

249.13(a)(3)(ix)(B) requires inservice training for all employees

249.13(c)(5)(vii) Adds requirement of effective arrangements through which medical and remedial services not regularly provided within the facility can be obtained promptly when needed.

Subchapter VII. Nursing Services

Sec. 268

- | | |
|---|--|
| (a) States detailed purposes of nursing services | No statement of general purposes |
| (b) Nursing personnel to develop written statements of nursing philosophy and objectives, prescribes its distribution. | 249.13(a) (1) (i) requires facility to state its philosophy, goals and objectives |
| (c) Recommends kinds of activities through which nursing services shall be provided | Not specified; regulation does not contain advisory material |
| (d) Specifies content of nursing services to include: | 249.13(c) (6) (ii) Virtually same; |
| (1) <u>Professional</u> nurse activities | (A) Same activities, but <u>registered nurse</u> required |
| (2) Health promotion activities, including assessment of development function and safety education | (B) Same, except does not include assessment of development function, safety education, <u>but additionally requires family planning and VD counseling</u> |
| (3) Participation in prevention of disability | Not specified |
| (4) Intensive nursing care for the acutely ill | Not specified
249.12(a) (1) (ii) (A) (1) (ii) and 249.12(a) (2) establish provisions for transfer of acutely ill persons; |
| (e) Requires <u>professional</u> nurse to participate in training facility personnel; specifies training of direct care personnel | (c) (6) (iii) Same, but <u>registered</u> nurse required |
| (f) Details activities that qualified nurses are to be <u>encouraged</u> to become involved in | Not specified |

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Sec 268

- (g) Requires sufficient staff; requires designation of registered professional nurse to be responsible for maintaining nursing standards

(1) Requires nursing supervisor to have at least an M.A. in nursing

- (h) Specifies approach to assigning nursing personnel duties

- (i) Recommends nursing service have recourse to appropriate consultants, requires professional nurses to adhere to appropriate code ethics

- (j) Requires appropriate educational program on clinical competences and development disabilities for nursing staff, prescribes minimum content

- (k) Requires encouragement for internships for nursing students in the community

- (l) Requires adequate space, facilities and equipment for nursing service

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249.13(c) (6) (iv) Similar; does not require M.A. in nursing;

249.12(a) (9) (i) Requires health services to be under supervision of RN or LPN employed full time on day shift seven days of week, except that where LPN is used, there must be contract with RN for consultation at least four hours per week; 249.13(c) (6) (v) assigning nursing duties same.

Not specified; Regulation does not include advisory material; 249.13(a) (3) (iv) requires recognition of ethical standards of professional societies

249.13(a) (3) (ix) orientation and inservice training required for all facility personnel

Not specified

249.12(a) (6) (vi) Requires areas for therapy services to be of size and design to accommodate necessary equipment, conduct examinations and provide treatment

Subchapter VIII. Pharmacy Services

Sec. 269 (a)

Licensing not specified for director of pharmacy. Requires arrangements for pharmacy services, pharmacy manual

- (b) Requires formulary system;

- (c) Requires pharmacist to carry out certain duties, including review of each patient's drug regimen and recommending changes to physician

249.13(c) (7) (i) requires director of pharmacy services to be licensed; otherwise is similar

249.13(c) (7) (iii) Same

249.13(c) (7) (v) Same, except requires pharmacist or RN to make periodic review of patient's drug regimen for potential adverse reactions; does not list activities for pharmacist comparable to §269(c) (5)

Sec 269

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ICF-MR REGULATION

- | | |
|--|---|
| (d) Recommends certain activities for pharmacist, including
(2) regular reviews of each resident's medication record and adverse reactions to drugs | No such suggestions, but
249.13(c) (7) (v) <u>requires</u> regular review of each patient's medication record |
| (e) Requires pharmacy and therapeutic committee, where appropriate

Requires written policies and procedures governing administration and handling of drugs | Not specified

249.13(c) (7) (vi) Similar; omits mention of procedure for obtaining drugs when pharmacy is closed |
| (g) <u>Recommends</u> use of unit dose or individual prescription system | Not Specified |
| (h) Requires written policy on administration of all drugs used by residents, and on the routine of drug administration | 249.13(c) (7) (vi) and (vii) Similar; does not mention standardization of drug abbreviations |
| (i) Requires written policy on self administration of drugs | 249.13(c) (7) (vi) same |
| (j) Specifies requirements for drug storage | 249.13(c) (7) (viii) Similar; no explicit mention of perpetual inventory of narcotics but 249.12(a) (1) (vi) requires conformity with Federal, state and local laws and regulations relating to medications and controlled substances |
| (k) Recommends pharmacist review drugs in each living unit monthly, and remove drugs outdated, deteriorated, or not being used; Requires return of discontinued drugs | 249.13(c) (7) (ix) Same, except pharmacist review not included; regulation does not include advisory material |
| (l) Requires automatic stop orders, drug recall procedures recording of medication errors, and that pharmacist be responsible for storing and dispensing investigational drugs | 249.13(c) (7) (x) Similar; does not include pharmacist responsibility for storing and dispensing investigational drugs; 249.12(a) (1) (vi) requires conformity with laws relating to medications and controlled substances |

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Sec. 269

- (m) Requires emergency kit to be available

249.13(c) (7) (d) Same

Requires pharmacy services to be

249.13(c) (7) (i) Similar; requires direction by qualified licensed pharmacist;

- (1) directed by professional graduate of school of pharmacy accredited by American Council on Pharmaceutical Education or its equivalent

- (2) Staffed by sufficient competent personnel

249.13(a) (3) requires sufficient staff; recognition of professional ethics requirements

- (3) Recommends pharmacists be trained in serving developmentally disabled

- (4) Requires them to adhere to professional ethics

- (o) Recommends staff development program for pharmacists, suggests minimum content

249.13(a) (3) (ix) Requires orientation and inservice training for all employees

- (p) Prescribes general requirements for adequate space, equipment, orderliness, reference material

Not specified

- (q) Prescribes general requirements for drug preparation and storage areas

Not specified

- (r) Recommends areas for pharmacist, resident counseling

Not specified; regulation does not include advisory material

S.3378PT-OT REGULATIONSubchapter IX. Physical and Occupational Therapy Services

Sec. 270

- | | |
|--|--|
| (a) General statement of purpose; requirement for written objectives, specifies general responsibilities of P and OTS; requires certain methods to be used | 249.13(c) (8) (i) does not include general PT/OT objectives statement-249.13(a)(1) (i) requires objectives for facility; does require use of methods as in §270(a) (4) |
| (b) Recommends P and OT services that should be available to facility | Not specified; regulation does not include advisory material |
| (c) Suggests purposes of screening by therapists | Not specified; regulation does not include advisory material |
| (d) Suggests content of evaluations of residents by therapists | Not specified; regulation does not include advisory material |
| (e) Requires certain PT and OT programs | 249.13(c) (8) (ii-iii) same |
| (f) Prescribes use of evaluation results | 249.13(c) (8) (iv) same |
| (g) Requires use of consumers and their representatives in planning and evaluating therapy services; requires availability of adequate staff; P and OT therapists shall be <ol style="list-style-type: none"> (1) graduates of curriculum accredited by appropriate national association (2) If a PT, eligible to practice in the state (3) if an OT, eligible for registration by the appropriate national association | 249.13(c) (8) (v) Similar; does not include use of consumers; P and O therapists must meet requirements of Medicare (20 CFR 405.1101) |

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Sec. 270 (h) A/P and OT must be responsible for maintaining professional and ethical standards. In addition to qualifications in (g) must

- (1) Have had 3 years professional experience, 2 years of which should include working with developmentally disabled,
- (2) demonstrated competence in administration and supervision
- (3) preferably have M.A.

Not specified, except as required under Medicare (see above); 249.13(a) (3) professional ethics must be recognized

(l) Therapy assistant must be certified by national professional association or be graduate of a program accreditation by such association

249.13(c) (8) (v) (B) Must meet Medicare requirements (20 CFR 405.1101)

(j) Specifies training, supervision required for therapy aides

Not specified

(k) Specifies authority and responsibilities of PT and OT personnel

249.13(c) (3) (v) (C) Same

(l) P and OT personnel must adhere to ethical codes of national professional organizations

249.13(a) (3) requires recognition of professional ethics

(m) P and OT services must seek periodic consultation from outside P and OT experts. Requires staff development program

Periodic consultation not specified; 249.13(a) (3) (ix) requires inservice training for all employees

(n) Details minimum needs for space, facilities equipment, supplies, resources for P and OT.

249.12(a) (6) (vi) areas for therapy services are of size and design to accommodate necessary equipment, conduct examinations, and provide treatment

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ICF-MR REGULATION

Subchapter X. Psychological Services

Sec. 271

- | | |
|---|---|
| (a) General statement of purpose; methods of rendering services | 249.13(c) (9) (i) Similar, does not include general statement of purposes |
| (b) Details recommended content of psychological services | Not specified; regulations do not include advisory material |
| (c) Details required content of psychological component of interdisciplinary evaluation of individual residents | 249.13(c) (9) (ii),(iii) Similar, not as detailed |
| (d) Requires psychologists to help develop individualized habilitation plans, specifies details | 249.13(c) (9) (iv) Same except does not require inclusion of steps to maximize individual's acquisition of basic knowledge, vocational-occupational skills, and socio-economic values |
| (e) Recommends therapy psychologists should provide to maintain and modify behavior and attitudes; recommends providing consultation and training for program staff | Not specified; regulation does not include advisory material |
| (f) Recommends areas in which psychologists should provide assistance and/or consultation | Not specified; Regulation does not include advisory material |
| (g) Recommends areas in which psychologists should participate regarding work with members of the community | Not specified; regulation does not specify advisory material |
| (h) Requires sufficient staff to perform certain prescribed functions; | 249.13(c) (9) (v)-(vi) Similar, omits research function, and has different staff qualifications: |
| Recommends availability of doctoral-level psychologist knowledgeable in MR or DD; | 249.13(c) (9) (vi) Psychologist must have at least M.A. in accredited program and experience or training in MR |
| Ph.D. psychologist shall be responsible for maintaining professional and ethical standards in the facility; | |

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Sets forth certain other
requirements of psychology
staff

- (1) Requires inservice training
program for psychology staff,
sets minimum content
- (2) Requires facility to encourage
training of intern and
graduate students in psychology,
sets minimum requirements for
space and equipment

ICF-MR REGULATION

Not specified

249.13(a) (3) (ix) Inservice training
required for all facility employees

249.12(a) (6) (vi) Therapy areas must be
adequate in size and design; no require-
ment for encouragement of training

S.3378ICF-MR REGULATIONSubchapter XI. Recreation Services

Sec. 272

- | | |
|---|--|
| (a) <u>Suggests</u> purpose of recreation services | 249.13(c) (10) Not specified; regulation does not include advisory material |
| (b) <u>Requires</u> written statement of recreation objectives | Not specified |
| (c) <u>Recommends</u> kinds of recreation services | Not specified; regulation does not include advisory material |
| (d) <u>Recommends</u> kinds of recreation activities | Not specified; regulation does not include advisory material |
| (e) <u>Urges</u> maximum use of community recreation resources, suggests content of recreation counseling | Not specified; regulation does not include advisory material |
| (f) <u>Suggests</u> content of desirable therapeutic recreation | Not specified; regulation does not include advisory material |
| (g) <u>Suggests</u> content of education and consultation services | Not specified; regulation does not include advisory material |
| (h) <u>Requires</u> that recreational services be coordinated with other services provided residents | 249.13(c) (10) (i) Same, except omits reference to health, music, art, and physical education |
| (i) <u>Recommends</u> contents of records kept on each resident's recreation interest and participation | 249.13(c) (10) (ii) <u>Requires</u> certain records be kept, but not as extensive as those recommended under S.378 |
| (j) <u>Recommends</u> content of procedures for evaluating and researching effectiveness of recreation services | Not specified; regulation does not include advisory material |
| (k) <u>Requires</u> sufficient recreation staff at all time; recommends minimum qualifications for staff conducting recreation program; | 249.13(a) (3) <u>Requires</u> sufficient staff

249.13(c) (10) (iv) <u>Requires</u> qualifications recommended by S.3378 §272 (k) (3); regulation does not include other advisory material |

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|---|--|
| (l) Requires staff development program, prescribes minimum content | 249.13(a) (3) (ix) Requires staff development program for all employees |
| (m) Prescribes requirements for design and construction of recreation areas and facilities | 249.13(c) (10) (v) Same, except omits reference to surroundings, use of consultants, access to toilet facilities |
| (n) Recommends indoor recreation facilities | Not specified; 249.13(c) (10) (v) requires accessible recreation facilities |
| (o) Recommends outdoor recreation facilities | Not specified; 249.13(c) (10) (v) requires accessible recreation areas and facilities |
| (p) Require adequate transportation services for recreation programs. Prescribes how toys, games, equipment shall be selected, adapted. | Not specified |
| (q) Recommends content of music therapy program if it is provided | Not specified; regulation does not include advisory material |

Subchapter XII. Religious ServicesSec. 273

- | | |
|---|--------------|
| Requires religious services to be made available to residents; personnel available to carry out religious programs; requires provision of space for religious services programs | Not included |
|---|--------------|

Subchapter XIII. Social ServicesSec. 274

- | | |
|----------------------------------|---------------------------------|
| (a) General statement of purpose | 249.13(c) (11)
Not specified |
| (b) Identifies beneficiaries | Not specified |

Sec 274

S.3378ICF-MR REGULATION

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|--|--|
| <p>(c) Requires inclusion of consumers and their representatives in planning and evaluation of social service programs;</p> <p>Identifies specific objectives of social work methods</p> | <p>Not specified</p>

<p>249.13(c) (11) (i) Same, except omits "modifying environmental influences", "increasing public acceptances of mental retardation", "creating a favorable climate" "fostering human dignity and personal worth"</p> |
| <p>(d) Recommends minimum content of social services available to facility</p> | <p>Not specified; regulations do not include advisory material</p> |
| <p>(e) Recommends objectives of social workers during evaluation process</p> | <p>(c) (11) (ii) Same, except states these as required objectives and excludes helping resident and his family to know their rights and obtain advocacy assistance. 249.13(a) (1) (ii) requires facility policies and procedures that assure the civil rights of residents</p> |
| <p>(f) Recommends objectives of social workers during pre-admission process</p> | <p>Not specified; regulation does not include advisory material</p> |
| <p>(g) Requires social worker participation in interdisciplinary evaluation</p> | <p>249.13(c) (11) (iii) same</p> |
| <p>(h) Requires social workers to provide liaison between resident and others during admission and residence, identifies ways in which various parties must be helped</p> | <p>249.13(c) (11) (iv) Same, except not as detailed</p> |
| <p>(i) Requires social workers to provide systematic followup after resident leaves facility, specifies minimum steps</p> | <p>(c) (11) (v) Same, except does not specify minimum steps aside from referral to community agencies</p> |

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|--|---|
| (j) Identifies how social services shall help integrate residential and other community services | Not specified |
| (k) Requires sufficient social service records | Not specified; 249.12(a)(4)(i) requires entries in resident's record describing treatments and services rendered, social history, plans of care, progress notes |
| (1-2) Facility should have available to it a social worker who has M.A. or Ph.D., has had 3 years of post-master's experience, meets qualifications for certification by national academy of certified social workers, and is knowledgeable and experienced in mental retardation; must have social worker so qualified responsible for standards of professional practice | Not specified |
| (3) Social workers providing service to facility must have M.A. or meet educational requirements for membership in national association and three years experience in social welfare. | 249.13(c)(11)(vi) Must meet requirements for social workers under Medicare (20 CFR 405.1101) |
| (4) Social work assistants or aides must be supervised by social worker | 249.13(c)(11) Similar; social worker must meet 20 CFR 405.1101 requirements |
| (5) Requires appropriate assignment, supervision requirements for social worker | Not specified |
| (6) Recommends supervisor: staff ratio for social workers | Not specified; regulations does not include advisory material |

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Sec. 274

- (7) Requires social service personnel to adhere to ethics code of NASW

ICF-MR REGULATION

Not specified; 249.13(a)(3) requires recognition of professional ethics

- (l) Requires staff development program for social work staff, suggests content

249.13(a)(3)(ix) requires staff development program for all personnel

- (m) Requires adequate space, facilities, equipment, supplies resources, specifies minimum content

Not specified

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ICF-MR. REGULATIONS

Subchapter III. Speech Pathology and Audiology Services

Sec. 275	(a) Statement of general purposes	249.13(c) (12) Not specified
	(b) Identification of goals	Not specified
	(c) Prescribes modes of rendering services	249.13(c) (12) (i) Same, except omits reference to participation in design and maintenance of environment
	(d) Prescribes what services shall include, as appropriate	249.13(c) (12) (ii) Similar, condenses requirements
	(e) Recommends content of evaluations	Not specified, regulation does not include advisory material
	(f) requires evaluation and amendment results to be reported accurately, specifies manner	249.13(c) (12) (iii) Similar; not as many directions for reporting
	(g) Prescribes treatment objectives, plans and procedures	Not specified
	(h) Requires accurate recording and utilization of observations of progress	249.13(c) (12) (iv) Same
	(i) Requires procedures for evaluating and researching effectiveness of speech pathology and audiology service	Not specified.
	(j) (1) and (2) Requires sufficient staff; staff who assume independent responsibilities for clinical services shall have qualifications for certification by national professional speech and hearing association. One such person who has at least 3 years professional experience shall be responsible for maintaining ethical standards	249.13(c) (12) (v) Similar; such staff shall meet Medicare requirements (20 CFR § 5.1101)

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(3) Requires staff in (1) and (2) to supervise staff not so certified.

(4) Requires direct supervision of students and staff working for professional certification

(5) Requires all staff to adhere to professional ethics

(1) specifies minimum of space facilities, equipment supplies, but in general terms

ICF-MR REGULATIONS

249.13(c) (12) (v) Requires adequate direct and continuing supervision of personnel, volunteers or supportive personnel

249.13(c) (12) (v) same as above

249.13(a) (3) (iv) requires recognition of professional ethics

249.13(c) (12) (vi) Similar; does not have list of rooms, equipment, supplies

Subchapter XVVocational Rehabilitation Services

Sec. 276

Not included; is covered by other programs

Subchapter XVIVolunteer Services

Sec. 277 Requires provision of volunteer services

Not included; regulation contains references to volunteers, e.g.

249.13(c) (12) (v) Records

Chapter 4

Sec. 278 Maintenance

249.13(d) (i) Similar; omits certain purposes

(a) Prescribes purposes of records

(b) General requirements as to how information shall be kept in records

249.13(d) (i), (ii) Similar; omits some general language

(c) Suggests conditions of using symbols and abbreviations

249.13(a) (1) (iii) Prescribes conditions, but in less detail

Sec. 279 Content

249.13(d) (2) (i) Same list, but requires it

(a) Suggest details of information to be entered at admission

(b) Prescribes information to be entered in record

249.13(d) (2) (ii) same, except omits diagnosis as found in manual of national association

Sec. 279(2)

- (c) Recommends certain records during residence
- (d) Requires discharge summary; recommends contents
- (e) Recommends records in event of death

249.13(d)(2)(iii) Same, but requires records

249.13(d)(2)(iv) Same, omits contents; advisory material is not included in regulation

Not specified; regulation does not contain advisory material

Subchapter III - Confidentiality of Records

Sec. 280

- (a) All information in resident record shall be considered privileged and confidential; specifies responsibilities for safekeeping, requirements for release of information

249.13(d)(3)(i)-(iv) Similar; omits mention of privilege, and limitation of removal of record from facility to situation in which there is court order, subpoena or statute

Subchapter IV - Central Record Service

Sec. 281

- (a) Requires central record service, unit record, accessibility of records to authorized personnel, master alphabetical index, retention of record for at least State Statute of Limitation; Recommends periodic review of records

249.13(d) (3) Same, except does not require unit record, does not authorize decentralized record system, requires record retention in accordance with State Statute of Limitations and HEW regulation; omits advisory material

Subchapter V - Statistical Records

Sec. 282

- (a) Recommends content of minimum statistical information
- (b) Requires reporting of data to appropriate Federal and other agencies

Not specified; regulation does not include advisory material

See § 1902(a) (27) Social Security Act, implementing regulations

Subchapter VI - Records Personnel

Sec. 283

- (a) Requires sufficient, qualified staff to handle records

249.13(a) (3) (viii) Requires sufficient facility personnel

S.3378ICF-MR REGULATIONSec. 283 Records Personnel

(b) Suggests qualification of supervisor

Not specified; regulation does not include advisory material

(c) Suggests in-service training activities

Not specified; regulation does not include advisory material

Chapter 5 ResearchSec. 284 Encouragement of research

249.13(e) Omits all references to research except requirement that all research must comply with statement on assurance on research involving human subjects required by DHEW for projects supported by it (found in S.3378 at section 286(a).)

Chapter 6 Safety and SanitationSubchapter I SafetySec. 288

(a) Specifies Secretary's requirements that must be met on exits and doors, ramps, handrails

249.12(a) (1) (vii) requires conformity with Federal, State and local laws, codes and regulations on health and safety; 249.12(a) (6) (ix) requires conformity with ANSI standards

(b) Requires documentation of strict compliance with State or local fire safety authority

249.12(a) (5) requires institution to meet provisions of Life Safety Code of NFPA (1967 ed) as applicable to institutional occupancies, with certain narrow exceptions

(c) Requires written plan and procedures to meet all potential emergencies and disasters, suggests content

249.13(f) (1) (i) Similar, but omits suggested content

(d) Requires evacuation drills

249.13(f) (1) (iii) Similar

(e) Requires multidisciplinary safety committees to investigate all accidents, make recommendations

249.13(f) (1) (iii) Omits such committee but requires facility to investigate accidents; adds requirement that facility take corrective action

S.3378ICF-MR REGULATION

- | | |
|---|---|
| (f) Requires all buildings and outdoor recreation facilities built after 1971 to meet Secretary's standards for making buildings accessible to physically handicapped | 249.13(f) (1) (iv) Requires facilities to meet ANSI standards, subject to waiver in existing buildings by survey agency |
| (g) Requires lead-free paint | 249.13(f) (1) (v) Same |
| (h) Requires appropriate provisions for alternate heat source for emergencies | Not specified |

Subchapter II Sanitation

Sec. 289

- | | |
|---|--|
| (a) Requires strict compliance with certain codes; reports of inspections by health authorities on file at facility | 249.13(f) (2) Same |
| (b) (c) (d) Prescribes practices with regard to waste and garbage, handwashing facilities, insect screens | Not specified; 249.12(a) (1) (vii) requires compliance with Federal, State and local laws, codes and regulations pertaining to health and safety |

Chapter 7 Administrative Support ServicesSubchapter I Functions, personnel, facilities

Sec. 290

- | | |
|---|--|
| (a) Requires adequate support services, with list | 249.13(g) (1) Same except for list |
| (b) Requires qualified administrator
(1) Suggests he have at least a B.A. or have completed formal graduate education in health administration or the equivalent | 249.12(c) (2) Requires person licensed in the State as a nursing home administrator or QMPP, or, in case of a hospital, requires hospital administrator. |
| (2) Requires all support personnel to understand, appreciate nature of mentally retarded | Not specified |

S.3378ICF-MR REGULATION

- | | |
|---|---------------|
| (c) Requires adequate office space, facilities, equipment, supplies for support functions | Not specified |
|---|---------------|

Subchapter II Fiscal Affairs

Sec. 291

- | | |
|--|--|
| (a) Requires program budgeting | Not specified |
| (b) Suggests persons acting on budget requests have first hand knowledge of its operations, needs | Not specified; regulation does not include advisory material |
| (c)-(i) Sets forth requirements on budget performance reports, internal expenditure control, audits, reports | Not specified |

Subchapter III Purchase, Supply and Property Control

Sec. 292

- | | |
|--|---|
| (a) Requires written purchasing policies | 249.13(a) (iv) Policies and procedures in the major operating units of the facility shall be described in manuals |
| (b) Requires documentation of purchasing process | 249.13(g) (1) (i) Same |
| (c) Establishes requirements for inventory control system | 249.13(g) (1) (ii) Similar, condensed |
| (d) Suggests qualification for purchasing director in large facility | Not specified; regulation does not include advisory material |

Sec. 293 Subchapter IV Communications 249.13(g) (2) IdenticalSubchapter V Engineering and Maintenance

Sec. 294

- | | |
|---|---|
| (a) Requires preventive maintenance program | 249.13(g) (3) (i) Same |
| (b) Prescribes qualifications for engineering director in large facility; requires sufficient personnel | 249.13(g) (3) (ii) Similar; requires sufficient trained and experienced personnel, no prescription of engineering director's qualifications |

Subchapter VI Housekeeping Services

- Sec. 295 Prescribes qualifications for housekeeping director in large facility Not specified

Subchapter VII Laundry Services

- Sec. 296
- (a) Requires management of services to meet daily linen needs, minimize clothing loss/damage 249.13(g) (4) Similar, omits mention of clothing loss and damage
 - (b) Prescribes qualifications for laundry service director in large facility Not specified

Chapter 8 Definitions

- Sec. 297 Defines terms used in Title II 249.13(h) (i)-(x) Similar; fewer terms but same definitions of those terms; 45 CFR 249.10(d) (1) (vi) defines "persons with related conditions"; 45 CFR 249.10(d) (1) (iv) defines "resident of an intermediate care facility"

8. State-by-State breakdown of mentally retarded children that are served by school system and the number of these who are not.

The attached table based on services under Title VI-A of the Elementary, Secondary Education Act, indicates that of a total of 1,697,500 mentally retarded children, 872,213 are presently served by public institutions and public education agencies, leaving 825,287 that are not.

Estimated Number of Mentally Retarded Children Served Under ESEA, Title VI-A 1/

	TRAINABLE	EDUCABLE	TOTAL	5/10/74
TOTALS	148,466	723,747	872,213	
1. Alabama	2,170	7,438	9,608	
2. Alaska	110	850	960	
3. Arizona	925	5,322	6,247	
4. Arkansas	1,346	5,303	6,649	
5. California	12,807	55,000	67,807	
6. Colorado	0-	10,595	10,595	
7. Connecticut	3,172	8,246	11,418	
8. Delaware	621	2,361	2,982	
9. District of Columbia	423	1,747	2,170	
10. Florida	5,573	27,238	32,811	
11. Georgia	1,711	23,060	24,771	
12. Hawaii	717	2,591	3,308	
13. Idaho	458	1,300	1,758	
14. Illinois	11,335	32,450	43,785	
15. Indiana	4,876	18,688	23,564	
16. Iowa	2,258	7,978	10,236	
17. Kansas	1,233	6,982	8,215	
18. Kentucky	1,765	10,661	12,427	
19. Louisiana	3,513	11,250	14,763	
20. Maine	625	2,718	3,343	
21. Maryland	3,892	20,944	24,836	
22. Massachusetts	2,540	14,000	16,540	
23. Michigan	7,457	43,640	51,097	
24. Minnesota	3,014	11,900	14,914	
25. Mississippi	585	6,870	7,455	
26. Missouri	1,766	23,774	25,540	
27. Montana	343	1,500	1,843	
28. Nebraska	1,292	5,782	7,074	
29. Nevada	300	1,872	2,172	
30. New Hampshire	565	1,605	2,170	
31. New Jersey	5,579	23,402	28,981	
32. New Mexico	593	4,388	4,981	
33. New York	8,371	36,472	44,843	
34. North Carolina	4,500	30,093	34,593	
35. North Dakota	297	1,281	1,578	
36. Ohio	14,140	50,289	64,429	
37. Oklahoma	1,072	8,554	9,626	
38. Oregon	600	4,670	5,270	
39. Pennsylvania	10,987	47,287	58,274	
40. Rhode Island	900	2,500	3,400	
41. South Carolina	1,050	17,534	18,584	
42. South Dakota	330	1,067	1,397	
43. Tennessee	2,798	14,701	17,499	
44. Texas	7,186	49,452	56,638	
45. Utah	1,395	3,415	4,810	
46. Vermont	270	1,100	1,370	
47. Virginia	1,780	15,645	17,425	
48. Washington	3,838	13,287	17,125	
49. West Virginia	831	5,625	6,456	
50. Wisconsin	4,216	18,655	22,871	
51. Wyoming	340	665	1,005	
52. American Samoa	1/ Based on estimates from States and BEH offices.			
53. Guam	Primarily represent children served in public in-			
54. Puerto Rico	stitutions and public education offices.			
55. U.S. Territory	October 1971	BEH,OE		
56. Virgin Islands		DEW		
TOTAL:	148,466	723,747	872,213	

(1971-1972)

	(A) HANDICAPPED CHILDREN 5 - 19	(B) HANDICAPPED CHILDREN 0 - 4	(C) HANDICAPPED CHILDREN 0 - 19	(D) HANDICAPPED CHILDREN SERVED	(E) CHILDREN STILL UNSERVED
SPEECH IMPAIRED	2,112,600	327,900	2,440,500	1,360,203	1,080,297
EMOTIONALLY DISTURBED	1,207,200	180,800	1,388,000	156,486	1,231,514
MENTALLY RETARDED	1,388,300	309,200	1,697,500	872,213	825,287
LEARNING DISABLED	603,600	93,700	697,300	166,534	530,766
HARD OF HEARING	301,800	46,800	348,600	43,915	304,685
DEAF	45,300	7,000	52,300	35,624	16,676
CRIPPLED & OTHER HEALTH IMPAIRED	301,800	46,800	348,600	182,636	165,964
VISUALLY IMPAIRED	60,400	9,400	69,800	30,630	39,170
MULTI- HANDICAPPED	35,800	5,100	40,900	9,310	31,590
TOTALS	6,056,800	1,026,700	7,083,500	2,857,551	4,225,949

ESTIMATES COMPILED FROM MULTIPLE STUDIES OF INCIDENCE AND FROM STATE DEPARTMENT OF EDUCATION SPECIAL EDUCATION STAFF. SOURCE MATERIAL AVAILABLE FROM THE OFFICE OF PROGRAM PLANNING & EVALUATION, BUREAU OF EDUCATION FOR THE HANDICAPPED, U.S. OFFICE OF EDUCATION, WASHINGTON, D.C. 20202.

AS OF JULY 1, 1968, THERE WERE APPROXIMATELY 75,000,000 CHILDREN IN THE UNITED STATES BETWEEN THE AGES OF 0-19 YEARS, OF WHICH, AN ESTIMATED 7,083,500 ARE HANDICAPPED.

ESTIMATED NUMBER OF HANDICAPPED CHILDREN IN THE UNITED STATES
(1971-1972)

COLUMN A

INCIDENCE LEVELS HAVE BEEN DERIVED FROM A NUMBER OF SOURCES AND THESE SOURCE REFERENCES ARE AVAILABLE BY CATEGORY FROM THE PLANNING AND EVALUATION STAFF OF THE BUREAU OF EDUCATION FOR THE HANDICAPPED. INCIDENCE LEVELS REFER TO SCHOOL-AGE POPULATION, 5-19, FOR THE YEAR 1969.

CATEGORIES OF HANDICAPS

. SPEECH IMPAIRED	3.5%
. FUNCTIONALLY DISTURBED	2.0%
. MENTALLY RETARDED	2.3%
. LEARNING DISABLED	1.0%
. HARD OF HEARING	0.5%
. DEAF	0.075%
. CRIPPLED AND OTHER	
. HEALTH IMPAIRED	0.5%
. VISUALLY IMPAIRED	0.1%
. MULTIHANDICAPPED	0.06%

THE TOTAL NUMBER OF HANDICAPPED CHILDREN IN THE ABOVE CATEGORIES REPRESENTS 10.03% OF ALL SCHOOL-AGE CHILDREN FROM 5-19.

COLUMN B

FIFTY PERCENT OF THE INCIDENCE LEVEL OF HANDICAPPED CHILDREN WAS APPLIED TO CHILDREN BETWEEN THE AGES OF 0-4 TO DETERMINE THE NUMBER. THE RATIONALE IS BASED ON THE FACT THAT HANDICAPPING CONDITIONS OFTEN FAIL TO APPEAR PRIOR TO AGE 4 - THUS, AN ESTIMATE HAS BEEN MADE BASED ON 50% OF NATIONALLY RECOGNIZED INCIDENCE LEVELS OF HANDICAPPED CHILDREN FROM AGES 5-19.

COLUMN C

TOTAL OF COLUMNS A AND B.

COLUMN D

NUMBER OF HANDICAPPED CHILDREN AS ESTIMATED BY STATE SPECIAL EDUCATION STAFF AND REI PERSONNEL. PRIMARILY INCLUDES CHILDREN SERVED IN LOCAL PUBLIC EDUCATION AGENCIES AND BY STATE OPERATED SCHOOLS FOR THE HANDICAPPED. CHILDREN SERVED IN NONPUBLIC SCHOOLS WERE EXCLUDED TO THE GREATEST EXTENT POSSIBLE BECAUSE COMPREHENSIVE, COMPLETE DATA ON THIS POPULATION IS DIFFICULT TO OBTAIN. NOTE: MANY STATES COMBINE FIGURES FOR THE DEAF AND HARD OF HEARING. THEREFORE, THE FIGURES IN THESE TWO CATEGORIES INCLUDE BOTH TYPES OF CHILDREN AND THE ACTUAL NUMBER OF A PARTICULAR TYPE OF HANDICAPPED CHILD IS UNKNOWN FOR THESE TWO CATEGORIES.

COLUMN E

COLUMN C MINUS COLUMN D.

PREPARED BY THE BUREAU OF EDUCATION FOR THE HANDICAPPED, U.S. OFFICE OF EDUCATION, DEPARTMENT OF HEALTH, EDUCATION AND WELFARE, WASHINGTON, D.C. 20202.

NOVEMBER, 1971

9. How many SNFs did not meet the Life Safety Code (LSC)?

A survey conducted by the Office of Nursing Home Affairs (ONHA) in the fall of 1973 produced the latest data available. It shows that:

- there were 7,318 SNFs in the Medicare and Medicaid programs
- 6,684 of these had complete LSC surveys
- 4,307 of the 6,684 had Code deficiencies
- an additional 2,120 had been given waivers for conditions which, while not meeting LSC requirements, were not considered a threat to patients' health and safety.

As indicated there is no later data available on the LSC status of these facilities. ONHA is currently conducting a further survey.

11. An analysis of the personnel and staffing requirements in the ICF regulations and in Title II.

The attached table compares the requirements with respect to numbers and qualifications of personnel. Only requirements are included, not recommendations or suggestions. The focus is on minimum numbers and qualifications, not on functions performed or organizational considerations. The latter are described and compared in the table responding to question 7

As in the other table, the ICF-MR requirements are found in two regulations: 45 CFR 249.12, effective on March 18, 1974, and 45 CFR 249.13, effective not later than March 18, 1977. The former establish the requirements for all ICFs, which, with exceptions noted, apply to MR facilities as well as the geriatric facilities.

COMPARISON OF STAFFING REQUIREMENTS: NUMBER AND QUALIFICATIONS
TITLE II, S.3378 AND ICF-MR REGULATIONS

S. 3378ICF-MR REGULATIONS

Sec. 218

- (a) Governing body sets qualifications of chief executive officer: training and experience in administration of human services, administrative ability, leadership ability, understanding of developmental disabilities
- (d)(3) When assistant chief executive is employed, same qualifications apply as for chief executive

249.13(a)(1)(vii) Governing body establishes appropriate qualifications of education, experience, personal factors, skills

249.12(c)(2) Facility is administered by licensed nursing home administrator or hospital administrator or by a Qualified Mental Retardation Professional (see below)

Not specified

Sec. 256

- (c) Staff-resident ratios required:
- (1) for medical-surgical units, units including infants, children to puberty, adolescents requiring considerable adult guidance and supervision, severely and profoundly retarded--1 to 2.
 - (2) for units serving moderately retarded--1 to 2.5
 - (3) for units serving residents in vocational training programs--1 to 5

249.13(b)(5)(ii) Staff-resident ratios same as S.3378 "unless program needs justify otherwise"

Sec. 258

- (b) Professional and special programs and services may be provided by personnel hired by facility or by formal arrangements with outside agencies or persons

249.12(a)(3)(i) ICF must maintain effective arrangements for required services through written agreement with outside resource where facility does not employ qualified professional to render required service

S.3378ICF-MR REGULATIONS

Sec. 259

- (c) Services listed in chapter on Professional and Special Programs and Services under duties of one profession may be rendered by members of other professions who are equipped by training and experience to do

No such provision

Sec. 261

- (j) Requires availability of sufficient qualified dental personnel and supporting staff. All dentists and dental hygienists shall be fully licensed in State

249.13(c)(2)(vi) Same

Sec. 264

- (a) Requires availability of sufficient qualified educational personnel and supporting staff. Supervision by person eligible for certification as special educator of developmentally disabled and the credential required for comparable supervisory or administrative position in the community

249.13(c)(3)(vi) Same, but under heading Training and Habilitation & Supervision by Qualified Mental Retardation Professional* as defined in 249.12(c)(3)

Sec. 265

- (j) Requires availability of sufficient number of competent personnel to fulfill food and nutrition services objectives. Direction shall be by one of following who must have had training or experience in serving developmentally disabled:
- (1) a dietitian or nutritionist (with special qualifications spelled out)
 - (2) a food service manager with B.A. in foods, nutrition, or related field and who receives consultation from dietary consultant

249.13(c)(4)(xii) Requires availability of sufficient number of competent personnel to fulfill food and nutrition needs of resident

(c)(4)(xiii) In facilities of 20 beds or more, direction by dietitian who meets Medicare-Medicaid requirements for skilled nursing facility service (20 CFR 405.1101)

(c)(4)(xiv) In smaller facilities, direction by designated staff member suited by training or experience in food management or nutrition

S.3378

- (C) person with experience in meal management and service, who receives consultation

Dietary consultant must be eligible for professional dietetic association and serve on regularly scheduled basis when no full-time dietitian is available

Sec. 267

- (k) Requires formal arrangement for qualified medical care, including emergencies 24 hours a day, 7 days per week. Fully licensed physician responsible for maintaining medical standards and general health conditions.

Each resident must have personal physician

Sec. 268

- (g) Requires availability of sufficient qualified nursing staff, which may include LPNs. An RN shall be responsible for nursing standards. Supervising nurse must have knowledge and experience in DDs.

ICF-MR REGULATIONS

249.13(c)(5)(vi) Same, re: formal arrangement, medical standards

Facility must have effective arrangements to obtain medical, remedial services required by residents but not regularly provided by facility

249.12(b)(6) Facility assures each resident's health care is under continuing supervision of a physician who sees him as needed and no less than every 60 days unless justified otherwise

249.13(c)(6)(iv) Same, but omits reference to maintenance of nursing standards

249.12(a)(9)(i) and (iii) Requires supervision of health services by RN or LPN employee full time on day shift; except where LPN is used, must receive consultation from RN at least 4 hours each week; also in facilities of 15 beds or less, this requirement may be met if physician certifies residents do not need professional nurse and facility has contract for visits by RN or public health nurse

S.3378

Sec. 269

- (a) Requires pharmacy services to be directed by qualified pharmacist, and formal arrangement for pharmacy services
- (n) Specifies director must be legally qualified and graduate of accredited school of pharmacy

Sec. 270

- (g) Requires availability of sufficient qualified staff to carry out physical and occupational therapy services. Paid OTs must be (1) graduates of a curriculum accredited by national association, (2) if a PT, eligible to practice in the State, and (3) if an OT, eligible for registration by national association
- (h) A PT and OT shall be responsible for maintaining respective professional standards. Each such therapist must (1) have had 3 years professional experience, 2 years of which were in work with DDS, (2) have demonstrated administrative competence.
- (i) Therapy assistant qualifications also stated

Sec. 271

- (h) Requires availability of sufficient qualified staff to carry out psychological service activities
- (7) All psychologists must (A) have qualifications for membership in national professional association, (B) have demonstrated knowledge in MR and DDS

ICF-MR REGULATIONS

249.13(c)(7)(i) Same, except specifies qualified licensed pharmacist

249.13(c)(8) Same, except P and OTs must meet Medicaid-Medicare qualifications for SNF P and OTs (20 CFR 405.1101)

Therapy assistants must meet Medicaid-Medicare qualifications for SNF TAs (20 CFR 405.1101)

249.13(c)(9)(v) Same, except all psychologists must have at least an M.A. from accredited program and experience or training in MR

S.3378

Sec. 272

- (k) Requires availability of sufficient qualified recreation staff to carry out recreation services

No minimum qualifications required

Sec. 273

- (f) Requires availability of sufficient qualified personnel to carry out religious programs. Requires services to be under direction of chaplain, clergyman or religious leader, religious educator, or responsible person who secures services of qualified persons

Sec. 274

- (k) Requires availability of sufficient qualified staff to carry out social services
- (2) Social worker responsible for maintaining professional standards and staff development. Must have (A) M.A. or Ph.D. from accredited school, (B) 3 years post-M.A. experience, (C) qualifications for certification by professional academy, (D) knowledge and experience in MR
- (3) Social workers in facility must (A) have M.A. from accredited school, or (B) meet educational qualifications for membership in national association and 3 years of experience in social welfare

ICF-MR REGULATIONS

249.13(c)(10)(iii) Same, except requires all recreational personnel to have (A) B.A. in recreation or a specialty area, or (B) an associate degree in recreation and one year recreation experience, or (C) high school diploma, or equivalency certificate, and 2 years recreation experience, or one year experience plus in-service training, or (D) demonstrated proficiency in conducting activities in one or more program areas

Religious services not included in regulation

249.13(c)(11)(vii) Same

Not specified

(c)(11)(vi)(A) Social workers must meet definition of Medicaid-Medicare requirement in SNFs (20 CFR 405.1101)

S. 3378ICF-MR REGULATIONS

Sec. 275

- (j) Requires availability of sufficient qualified staff to carry out speech pathology and audiology services
- (1) Speech pathologist or audiologist responsible for maintaining professional standards shall have qualifications for certificate of clinical competence issued by appropriate national association, and at least 3 years professional experience
- (2) Staff with independent responsibility for clinical services must have qualifications as in (1), except for experience.

249.13(c)(12)(v) Same

Not specified

Sec. 276

- (j) Requires person on team responsible for vocational rehabilitation program
- (1) Requires VR counselor available for each resident
- (2) Specifies qualifications for VR counselor
- (3) and for VR personnel giving training to residents

Not included

Sec. 283

- (a) Requires availability of sufficient qualified staff for records processing, checking, indexing, filing, retrieval

249.13(d)(5)(i) Same

Sec. 290

- (a) Adequate administrative support required

249.13(g)(1) Same

(g)(iv) Requires sufficient trained, experienced personnel to accomplish purchase, supply, property control functions

S.3378ICF-MR REGULATIONS

(b)(2) All support personnel shall have sufficient understanding, appreciation of MR and DD resident to assure that he furthers their welfare

Sec. 294

(a)(3) Requires sufficient qualified personnel for engineering and maintenance functions

Not specified

Not specified

249.13(g)(3)(ii) Same

249.12(b)(5)(i) Requires staff member qualified in directing group activity (to direct activities program)

249.12(c)(3) Requires Qualified Mental Retardation Professional (QMRP) responsible for supervising implementation of each resident's plan of care, integrating program, recording progress, initiating periodic review of each plan of care. QMRP means:

(i) A psychologist with at least an M.A. from accredited program and specialized training or 1 year experience in treating MR

(ii) A physician licensed in medicine or osteopathy and specialized training or 1 year experience in treating MR

(iii) An educator with an education degree and specialized training or 1 year experience in treating MR

(iv) A social worker with B.A. in social work, or B.A. in another field and at least 3 years social work experience under supervision of qualified social worker, and with specialized training or 1 year experience in working with MR

(v) A physical or occupational therapist as defined in 20 CFR 405.1101 (m) or (g) and who has specialized training or 1 year experience in treating MR

(vi) A speech pathologist or audiologist as defined in 20 CFR 405.1101 (t) and who has specialized training or 1 year experience in treating MR

ICF-MR REGULATIONS

(vii) A registered nurse who has specialized training or 1 year experience in treating MR

(viii) A therapeutic recreation specialist who is graduate of accredited program and where applicable, is licensed or registered in the State, and who has specialized training or 1 year experience in working with MR

MSA/OC 5/15/74

15. Recommendations of the National Advisory Council on DD which were accepted and those which were not.

The following material Tab (1) represents the recommendations and departmental responses on actions by the Council to March of 1973. This represents the recommendations from 5 of the 7 meetings held at that time.

Tab (2) represents the action and recommendations of the last three meetings. Some of the very latest are now being considered by the Secretary.

-2-

(1) Five year extension of the Developmental Disabilities Act with progressive increments in authorization levels.

The Department proposed a five year extension of the program. However, in keeping with Administration policy, we would authorize the appropriation of "such sums", rather than specifying dollar limitations.

(2) Revise the allotment formula so that each State gets an allotment of \$75,000, with the remainder distributed on the basis of population and need. Retain the required minimum allotment of \$100,000 for each State, but add a minimum of \$50,000 for each territory.

The Department proposed a \$50,000 minimum for each territory, but maintained the current State formula of allotting all funds to States on a population/need basis, with a \$100,000 minimum.

(3) Increase the Federal share with respect to any State from 70 per centum to 80 per centum and eliminate the 90 per centum limitation with respect to projects in poverty areas under the formula grant program.

The Department proposed eliminating the 90 per centum limitation with respect to projects in poverty areas, but proposed a declining Federal share with respect to any State (70 per centum in FY 74 and FY 75, 65 per centum in FY 76 and FY 77, and 60 per centum in FY 78).

(4) Eliminate the 75 per centum maximum Federal share for construction under the project grant program, but maintain it for demonstrations and training.

This was proposed by the Department.

(5) Consolidate all project grant authorities administered by the Division of Developmental Disabilities.

This was not contained in the Department's draft bill.

(6) Eliminate Federal review of construction projects under the State plan.

This was proposed by the Department.

(7) Include advance funding provision.

This was proposed by the Department.

(8) Revise definition of "developmental disability".

The Department did not propose the substantially revised definition suggested by the Council. However, we did propose eliminating the requirement that the disability be neurologically based, which was the major concern of the Council.

(9) Legislative initiatives in the area of reform of and improved conditions in mental retardation facilities.

The Department intends to encourage reform through regulation. Proposed standards for mental retardation facilities assisted under title XIX of the Social Security Act were published in the Federal Register on March 5, 1973.

(10) Include cost of land acquisition in the definition of cost of construction.

This was proposed by the Department.

- 1) NAC then reconsidered the Council's advice in 1972 to the Secretary regarding a definition of developmental disabilities. It was approved by a vote of 9 to 3 to reaffirm the NAC 1972 recommendation for a definition to the Secretary.
- 2) It was unanimously approved that the Secretary recommend that a request for funds be more appropriately addressed to the authorization that Congress has set forth in the legislation since the need is there.
- 3) Recommended to the Secretary that a request for funds to be appropriated correspond to the amount authorized by Congress because the need is evident.
- 4) The Council recommend to the Secretary that a provision in the new legislation include the requirement that 30% match be made by the State with the provision that they may set their own matching requirements relative to local funding of local programs.
- 5) NAC supports the administration's position opposing the earmark of the 10-30% of the formula grant for deinstitutionalization and recommended to the Secretary that the regulations require a deinstitutionalization component of the State Plan. Vote approval 13-1.
- 6) National Advisory Council advise that an administration bill on Developmental Disabilities should stand as a separate bill, not as a title or part of another bill or omnibus bill.

NATIONAL SOCIETY FOR AUTISTIC CHILDREN

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518/489-7375

May 1, 1974

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Ruth Christ Sullivan, Director

The Honorable Jennings Randolph, Chairman
Subcommittee on the Handicapped
United States Senate
Washington, D.C. 20510

Dear Senator Randolph:

Once again the National Society for Autistic Children is impressed by and grateful for your concern for autistic persons. The inclusion of autism in the definition of developmental disabilities in S. 3378 is a very practical reflection of that concern. We also support the inclusion of "severe learning disabilities"; however, these specific additions, welcome as they are, do raise concerns for eligible disabilities not mentioned, in particular spina bifida. We hope this omission can be rectified during the Subcommittee's deliberations.

Because there will not be public hearings on S. 3378, we are enclosing a copy of our testimony to the House Subcommittee on Public Health and Environment on H.R. 11511. It contains material not available to us during last spring's Senate hearings on the renewal of the Developmental Disabilities Act, material which we hope will be helpful to your committee. Of particular interest to you will be Appendices 3A and 4F; both were prepared by Ruth Sullivan, and the latter deals specifically with West Virginia.

Because S. 3378 contains several major changes in the Act, the enclosed statement is not as specific as we would like. The statement of the Consortium Concerned with the Developmentally Disabled, to which we belong, will, however, address these issues. We would like to just mention here our support of the administrative change proposed; i.e., placing the Developmental Disabilities program in the Office of Human Development, and of the change in the composition of the National Advisory Council. NSAC believes the mandated addition of representatives of appropriate federal agencies is a very positive step towards better service planning and delivery.

NSAC respectfully requests that this letter and the enclosed statement be made part of the record of testimony on S. 3378. Thank you.

Sincerely yours,
Mary B. Akerley
Mary B. Akerley, 1st V.P.
Chmn., Ntl. Aff. Comm.

Dedicated to the education and welfare of children with severe disorders of communication and behavior

Association of University Affiliated Facilities

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WASHINGTON, D.C. 20007
(202) 333-7880

May 1, 1974

Senator Jennings Randolph
Chairman, Subcommittee on the
Handicapped
United States Senate
Washington, D.C. 20510

Re: S.3378, Developmentally Disabled Assistance and Bill of Rights Act

Dear Mr. Chairman:

The Association of University Affiliated Facilities (AUAF) is pleased to provide comments with respect to S.3378, the Developmentally Disabled Assistance and Bill of Rights Act. Our comments will be limited to those provisions of Title I of the bill which bear directly on the UAF program.

(1) Length of extension of act

AUAF supports a 5-year extension of the Developmental Disabilities Act, as would be provided by S.3378. The planning emphasis of this legislation calls for a reasonably long authorization period. The measure recently reported out by the House Public Health Subcommittee (H.R. 14215) would extend the Developmental Disabilities Act for two years. This seems inadequate in terms of encouraging continuity and stability, and would probably not serve to encourage the States' to effectively utilize the Developmental Disabilities program.

(2) Review mechanism for demonstration and training
(UAF) grants

We suggest several changes with respect to section 103 (b) of S.3378. Of great concern is the language in that section which would "require such applications to demonstrate that the grant application has been reviewed and approved by the State councils established under section 114 (d). . . ."

Such a requirement — that State councils "sign off" on UAF administrative support grants — has been considered and rejected by the National Advisory Council on Developmental Disabilities. The reasons for the proposal's rejection are persuasive:

— The University Affiliated Facilities program does not conform to state lines. It is a national program with regional responsibilities.

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Many UAFs are located in cities which border more than one state (New York, Washington, Philadelphia, Cincinnati, Louisville, Memphis, St. Louis, Omaha, Kansas City, Portland). Several relate strongly to entire geographical regions. For example, the two UAFs in Massachusetts serve the neighboring New England States and work closely with the State councils in those States. The John F. Kennedy Child Development Center in Denver relates strongly to ten states in the Rocky Mountain region through joint planning efforts with those States' councils and by providing interdisciplinary evaluation and treatment planning for children throughout the region. A requirement in the law that one State council authorize the regional functions of a UAF is illogical. It would, in fact, possibly destroy the regional concept of the UAF program.

— Such a role for the State planning councils is inconsistent with their overall function. The Developmental Disabilities Act support for UAFs is "to cover costs of administering and operating" the facilities and programs; not to provide program funds.

(3) Clarification of mission of University Affiliated Facilities program

The University Affiliated Facilities concept offered the first major interdisciplinary approach to meeting the pressing needs of all mentally retarded and other developmentally disabled persons. The program provides for comprehensive and interdisciplinary training of a broad range of professional and paraprofessional persons to work with the developmentally disabled.

A key mission of University Affiliated Facilities is also to provide model systems incorporating a full range of services such as comprehensive and interdisciplinary screening, evaluation, treatment planning and educational programming.

Closely intertwined is the operation of a program which translates the results of current clinical research into improved services for the developmentally disabled and for improved training of professionals to work in the field.

Another important feature of the University Affiliated Facilities program is its commitment to help strengthen and improve services for the developmentally disabled in the various states, regions and communities. This can range from a brief telephone consultation to planning and conducting activities in actual community settings. This role of the program has resulted in significant liaison with State planning councils in many states, and increasing joint efforts to upgrade services in those states.

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In the context of these comments as to the mission of the University Affiliated Facilities, sections 103 (c) and (d) of S.3378 would impose certain inappropriate requirements upon UAFs seeking assistance for DD funding.

Additionally, certain appropriate expectations of the UAF program might properly be set forth in these sections. For example, section 103 (c) could require specification of geographical areas of primary impact and major areas of competence of the applicant UAF, while correctly identifying the primary mission of the program to be that of interdisciplinary preparation of personnel.

We suggest the following wording of this section:

Sec. 103 (c) Applications for assistance under this part shall specify the geographical areas of primary impact and major areas of competence of the applicant, and shall demonstrate the ability of the applicant for such assistance to contribute to training for manpower in the primary service areas in the States of its primary impact.

We suggest the substitution of the words "give preference to" for the word "establish", in section 103 (d), and the addition of language which would include reference to the need for improved services and greater concern for the adult developmentally disabled in the community.

Consistent with the above references to sections 103 (c) and (d), we strongly urge the deletion of the wording which would "... require such applications to demonstrate that the grant application has been reviewed and approved by the State councils established under section 114 (d). . . ."

(4) Matching requirement for UAF administrative support grants

Section 104 (a) of S.3378 would continue an unnecessary and unproductive 25 percent matching requirement for UAF grants. The funds provided by the Developmental Disabilities Act have contributed significantly to the UAFs' need for operating funds; however, the funding levels thus far have been far from adequate. Reasonable authorization figures have not been followed by adequate budget requests or appropriations. The 25 percent matching requirement merely detracts from the utility of the support provided by the DD act. The provision in the law does not bear upon the UAFs' efforts to supplement their budgets with state and other funds since these efforts are at a maximum in any event.

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The requirement which would be continued by section 104 (a) should be deleted.

(5) National Council on Services and Facilities
for the Developmentally Disabled

We suggest the establishment of the National Council, to replace the present National Advisory Council, be effective July 1, 1974, rather than July 1, 1975. Such a change would permit the Council to hold its initial meeting within ninety days after the date of enactment of the law, as would be required by section 113 (c) of S.3378, and would avoid a one-year lag in continuity with the existing Council.

AUAF appreciates this opportunity to comment on this important legislation, and commends the Subcommittee for its efforts on behalf of the developmentally disabled and handicapped.

Sincerely,

Robert P. McNeill

Robert P. McNeill
Executive Director

Donald E. McNamee

Donald E. McNamee
Chairman
AUAF Legislative Committee
Administrator
Eunice Kennedy Shriver Center
Waltham, Massachusetts

STATEMENT
ON
THE DEVELOPMENTALLY DISABLED ASSISTANCE
AND
BILL OF RIGHTS ACT
(S. 3378)

Respectfully Submitted to:

The Subcommittee on the Handicapped
Of The
SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE

Presented By:

THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS

May 7, 1974

The National Association for Retarded Citizens is pleased, once again, to have an opportunity to comment on the extension of the Developmental Disabilities Act. Since 1970, this Act has provided for meaningful, state-wide planning activities, as well as service gap-filling and construction of facilities, for a segment of our country's severely disabled population which has been neglected for such a long time.

Senate Bill S.3387, the Developmentally Disabled Assistance and Bill of Rights Act, contains many provisions that will greatly strengthen this program. There are also a few provisions contained in the bill that we feel will not serve in the best interest of developmentally disabled people.

The National Association for Retarded Citizens is deeply concerned that this bill will broaden the definition of developmental disabilities to include autism and learning disabilities. We oppose this broadening, not because persons with autism or learning disabilities do not deserve services or that their needs are not similar to those of the mentally retarded, but because there is clear indication in every state that the needs of the developmentally disabled population, as currently defined in the Developmental Disabilities Act, are nowhere near met by this and other programs. To broaden the definition at this time will either seriously dilute the services and planning efforts currently under way, or become a hoax to the autistic and learning disabled, since there will really be no funds to provide additional services to them.

When there is evidence that those disabled persons currently meeting the Developmental Disabilities definition are receiving adequate services, the National Association for Retarded Citizens will be the first to advocate for a broadening of the definition.

It should be made clear that the needs of the autistic and learning disabled population are already well known in many states, since the Planning and Advisory Councils must review the State Plans of other agencies that are currently providing services or are aware of the service needs.

Additionally, representatives of autism and learning disabilities consumer groups already hold positions on some Developmental Disabilities Planning and Advisory Councils.

The authorization levels for the formula grants to states will still not allow states to fill any substantial gaps in services and still maintain adequate planning levels. We suggest the following authorizations:

FY 1975	\$50 million
FY 1976	\$60 million
FY 1977	\$70 million
FY 1978	\$85 million
FY 1979	\$100 million

We strongly support the five-year extension provision. This will help to provide for well thought out planning activities and program stability and continuity.

We also support the Special Projects Grant Authority. We are concerned, however, that the language in Sec. 121(c) may be interpreted to prohibit the use of Sec. 304(e) of the Rehabilitation Act of 1973 by developmentally disabled persons. Developmentally disabled persons should be able to use this section of the Act for the purposes for which it was intended.

The National Association for Retarded Citizens recommends that a uniform matching formula of 75 percent federal support be utilized in all appropriate sections of this Act. This would include the formula grants to states, special projects, construction, U.A.F. demonstration and training grants, and U.A.F. architectural barrier elimination.

We further recommend that the minimum allocation to states under the formula grants be raised to \$200,000.

More than 20 percent of the states currently receive \$100,000 annually. They have had to work with this allocation since 1970. As the appropriations for this program has risen since 1970, only the larger states have received increased allocations. No one will argue that \$100,000 today will not buy what \$100,000 did four and five years ago. We strongly urge the committee to consider giving the smaller states an opportunity to increase services.

The State Plan requirements found in Sec. 114(a) are laudable, except that sub-sections (3) and (6) seem to be too specific and fall within the scope of the other sub-sections. We recommend that sub-sections (3) and (6) be deleted and incorporated in the report language accompanying the bill.

We also believe there will be problems in the states in their efforts to comply with the development of a new State Plan within 180 days of the enactment of this Act. Depending upon the date of passage, many states may be mid-way in the process of completing their goals contained in their FY '74 State Plan. We agree that the provisions contained in this Act should be incorporated as soon as possible, but not to the disadvantage and hinderance of on-going activities.

Two specific sections of the Bill (Sec. 114(c)(2) and Sec. 120(b)) broaden the scope of planning and evaluation considerably, usurping responsibilities of existing state agencies given them by other federal programs. These sub-sections should be rewritten to conform more closely to the intent of the Developmental Disabilities Program.

The National Association for Retarded Citizens is pleased to see a broadening of the National Advisory Council on Developmental Disabilities to include representatives of federal agencies. We recommend that the Assistant Secretary for Human Development (DHEW) and a high level person representing the Social Security Administration be appointed to the Council. Additionally, the Assistant Secretary for Housing for the Elderly and the Handicapped should also be considered, even in an ex-officio capacity.

The language which appoints the citizen members of the Council is somewhat confusing. We recommend that some provision be included to provide continued service on the Council for those members whose terms have not yet expired. This will assure continuity. We also suggest a limit of two consecutive terms on the Council before a member cannot be reappointed.

The changes in the role of the State Councils will be greatly strengthened by the passage of this bill. One concern is the dropping of the term "Advisory" from the title of the State Councils. We assume this was done to give increased importance to the planning role. We support the added weight to the planning effort, but we believe the Councils' advisory role to the Governor is also most important. We recommend that the term "Advisory" be re-instated in the title.

The limitation of 10 percent of the state's allocation for construction seriously impedes the efforts of the states, particularly the small states, to carry out meaningful construction plans. We agree that planning and services is more important than construction, particularly in the Developmental Disabilities Program. However, in some localities, facilities must be constructed or renovated in order to provide necessary services. NARC recommends a maximum of 30 percent of the formula grants to states may be used for construction purposes.

The new section of the bill which calls for an evaluation system to be used by states is strongly supported.

The National Association for Retarded Citizens continues its strong support of the U.A.F. program. We support the authorization levels for Demonstration and Training Projects in the U.A.F.'s. We are concerned with the provision that the state councils review and approve the U.A.F. grant applications. This will lead to many problems. Some U.A.F.'s serve regions, thereby necessitating 5 or 6 states to review their applications. This could create bureaucratic nightmares. We suggest that the U.A.F.'s grant applications take into consideration the needs of the states which they service and that the states then review the applications. We do not recommend, however, that the states be given sign-off authority.

We also support the provision for modernization and renovation of U.A.F.'s to better enable these facilities to serve the developmentally disabled population.

The National Association for Retarded Citizens is sympathetic to the standards for residential facilities and community agencies developed by the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals (ACF/MR). NARC is a member of the Accreditation Council and has actively participated in the development of these standards. We are painfully aware of the inadequate and all too often degrading, dehumanizing conditions which prevail in many of our institutions for the mentally retarded, and are irrevocably committed to their obliteration. We are convinced that the imposition of standards is a critical element of any reform strategy. However, we believe that a statutory approach to standard-setting is both unwise and impractical.

The manner in which we think about retarded people and how best to provide them with the services they need has changed profoundly over the last decade, and will continue to do so. The turning away from institutional, custodial modes of care to normalized community living is an accelerating process; our continuing experience with it will surely have implications for both institutional and non-institutional standards. We are very concerned that the legislative process is too cumbersome to permit timely, rapid revision of the standards to reflect the best and most current thinking in the field.

As an alternative approach, we respectfully request that the Subcommittee consider amending the bill under consideration to require the Secretary of the Department of Health, Education, and Welfare to publish the standards through the regulatory process, to

be applied to all facilities and agencies serving the mentally retarded and receiving Federal funds. A second approach would be to retain the standards in the bill, but with the inclusion of a carefully limited waiver authority for the Secretary.

The standards included in this bill incorporate the ACFMR standards in toto, including those standards which ACFMR itself considers desirable, but not mandatory, for accreditation. These "soft" standards state that a facility "should" do this or "should not" do that. We believe this language is unenforceable and recommend deletion of the nonmandatory standards.

While the ACFMR standards for residential facilities do require compliance with the Life Safety Code, specific emphasis is placed only on a small portion of the Code's requirements. In this respect, the ACFMR standards appear somewhat less forceful than the standards for intermediate care facilities in institutions for the mentally retarded published by the Department of Health, Education and Welfare. We believe the Life Safety Code, in its entirety, is critical in large institutions and recommend its application to any facility with more than thirty residents. We are particularly concerned that HEW's will to enforce the Code in Medicaid facilities not be weakened by a less emphatic requirement in S. 3378.

Another major difference between S. 3378 and the Medicaid intermediate care facility regulations lies in the period allowed for achieving compliance with the standards. Where Medicaid permits only three years, S. 3378 would give facilities five years to meet the ACFMR standards. As in the case of the Life Safety Code, we believe it is important not to undercut HEW's efforts at enforcement. We suggest that only three years be allowed for achieving compliance.

The system for certifying facilities in compliance appears to be somewhat vague. It bypasses both the ACF/MR accreditation process and the Medicaid/State licensing agency system. The licensing agency in most states is the Health Department, and we recognize that a Health Department is inappropriate for non-medical facilities. In addition, we believe it is unwise to ask a state agency to survey its own institutions. We realize also that the federal government cannot delegate its authority and responsibility for standards enforcement to a private group, such as the ACF/MR. However, we are concerned with both the costs and bureaucratic difficulties involved in setting up yet another system of surveying, certification, and enforcement.

We recommend a system similar to that used under Medicare for facilities with more than thirty residents. Under such a system, the Secretary would contract with ACF/MR to survey facilities and make recommendations regarding certification. However, the final decision on whether or not to certify a facility in compliance would be vested with the Secretary and performed in the Regional HEW offices. The Secretary would be required to perform validation surveys of ACF/MR using federal personnel on a set percentage of facilities. The percentage should be established in law; we would recommend that 10 percent of all ACF/MR surveys be validated by the Regional Offices. The ACF/MR should be subsidized for a portion of the costs associated with training qualified personnel and performing the actual surveys.

For community agencies and facilities serving less than thirty residents, we recommend requiring the Secretary to contract with

the State agency responsible for administering the developmental disabilities program to perform the survey and certification function. The state agencies should be reimbursed for 100 percent of their costs.

We believe this system has several advantages:

1. It draws on the experience of the ACFMR, while still vesting overall responsibility for the certification with the Secretary;
2. It avoids duplication of scarce professional surveyor resources;
3. It may be more rapidly implemented, since it utilizes organizational structures already partly in place.

Our most overwhelming concern, however, is the inadequate provision in this bill for assisting States, facilities, and agencies in achieving compliance with the standards. The bill, by imposing the ACFMR standards, contemplates a very major reform of the entire provider system; it is absolutely critical that specific and sufficient sums be authorized to support the cost of this reform. Otherwise, the job will be done shoddily and superficially, if at all.

We support the amendment cosponsored by Senator Randolph, Senator Stafford, and Senator Kennedy to include the ACFMR standards for community agencies. While we have the same general reservations concerning statutory standard-setting for community agencies, as we expressed earlier in this statement, we believe that the establishment of standards (whether in law or by regulation) should be comprehensively approached. Establishing standards for residential facilities alone will surely result in a distortion of State priorities and expenditures if States are forced to turn all their

attention to upgrading institutions at the expense of community services, in order to avoid loss of Federal funds. The only insurance against this occurring is to approach standard-setting for services for the mentally retarded from a comprehensive service-delivery perspective rather than in a fragmented manner. It is equally important to safeguard the quality and adequacy of services provided to persons living in the community as it is for persons living in institutions. This is particularly critical at a time when more and more mentally retarded persons are returning to the community environment. We must assure that deinstitutionalization (which will be accelerated by the imposition of the residential facility requirements) does not fail because of inadequate supervision of community services.

Finally, the National Association for Retarded Citizens supports the transfer of the Developmental Disabilities Program from the Rehabilitation Services Administration to the Office of Human Development. This shift should assist in focusing the program on the full system of care required throughout the lifetime of a developmentally disabled person, rather than the narrow focus of the Rehabilitation Services Administration.

The National Association for Retarded Citizens congratulates the members of the Subcommittee on the Handicapped for their intense interest in this legislation and pledges to assist them in making the lives of our developmentally disabled citizens happier and more productive.

STATEMENT

ON

THE DEVELOPMENTAL DISABILITIES ASSISTANCE

AND BILL OF RIGHTS ACT

(S. 3378)

Respectfully Submitted to:

THE SUBCOMMITTEE ON THE HANDICAPPED

Of the

COMMITTEE ON LABOR AND PUBLIC WELFARE

UNITED STATES SENATE

On Behalf Of:

THE CONSORTIUM CONCERNED WITH THE DEVELOPMENTALLY DISABLED

Mr. Chairman:

The Consortium Concerned with the Developmentally Disabled is happy to present a consensus in support of the extension of the Developmental Disabilities Act as projected in S. 3378; its members look forward to implementing many of the creative provisions included in this pending legislation.

We hope for early enactment.

EXTENSION FOR FIVE YEARS

In reviewing the legislation, members of the Consortium were particularly heartened by the five year extension proposed in S. 3378. The five year extension is especially critical in the case of the formula grants to states. We commend the Subcommittee for recognizing that states must have long range perspective and a long-range assurance of funding in order to carry out the comprehensive planning mandate which the Act lays upon them.

SCHEDULE

Because the state plans for FY 1975 were due in the Department of Health, Education, and Welfare regional offices on May 1st, the Consortium recommends that the provisions of the present Act, with certain exceptions noted below, be extended for fiscal year 1975 with authorizations for the formula grant at \$50 million, and for the University Affiliated Facilities demonstration and training program at \$20 million. The new provisions in S. 3378 would then become effective on July 1, 1975. Such an approach will enable the Department of Health, Education, and Welfare to promulgate regulations implementing the new legislation in advance of the actual effective date of such legislation, thereby considerably simplifying the administrative problems in the states. This recommendation is

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consistent with the provision of S. 3378 which calls for repeal of parts B and C of the present Act on July 1, 1975, at which time the newly constituted National Council would come into being.

The Consortium recommends that the following provisions become effective upon enactment:

Sections 3 (Audit), 4 (Office of Developmental Disabilities), 100 (Declaration of Purpose), and 121 (Special Projects) Section 2 (Definition), with the exception of the following subsections: 8B, 8C, 9, and 10A. These subsections should be deleted.

UNIVERSITY AFFILIATED FACILITIES

The Consortium continues its strong support of the University Affiliated Facilities program and endorses the authorization levels established in S. 3378 for demonstration and training projects. However, we would recommend deletion of the language in Section 103(b) which would require that the University Affiliated Facilities grant applications be "reviewed and approved by the state councils." We believe this provision will create bureaucratic delays and difficulties in the case of University Affiliated Facilities serving multi-state regions, where as many as 5 or 6 states would be given sign-off authority.

We also recommend deletion of Section 104(a) which limits the federal share to a maximum of 75 percent in project grants for demonstrations and training in University Affiliated Facilities; we call the Committee's attention to the fact that no such limitation is proposed in the Section 121 program of special project grants for demonstrations made to agencies other than University Affiliated Facilities.

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AUTHORIZATIONS

In addition to the authorizations proposed for the one-year extension mentioned above, we propose somewhat higher authorization levels for the fiscal years 1976-1979. Specifically we propose:

for FY 1976 the sum of \$85 million
for FY 1977 the sum of \$90 million
for FY 1978 the sum of \$95 million
for FY 1979 the sum of \$100 million.

Our reasons for creating a substantial increase in 1976 lie in the increased responsibility which the legislation would place upon the state councils with respect to both mandated activities and the enlarged population to be served.

ALLOTMENTS

The Consortium concurs with the Administration that the territories should be permitted to enjoy a minimum allotment of \$50,000 each.

In addition, we believe that states which have isolated populations or population areas of low density are faced with extraordinary costs and difficulties. We therefore recommend that Section 112 (a)(1)(B) be amended by deleting the present language and inserting the words "the special needs of persons with developmental disabilities in isolated areas or areas of low population density."

MATCHING

The Consortium prefers a uniform 75 percent block match for all purposes in lieu of complicated special matches for construction and poverty areas. With a block match, states are free to vary the local match which they may require of their grantees, and thus may provide up to 100 percent of cost to poverty areas, if circumstances so require.

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THE NATIONAL COUNCIL ON DEVELOPMENTAL DISABILITIES

The Consortium appreciates the attention which the Subcommittee has given the role and composition of the National Council. It is suggested that the federal membership of the council should include a representative of the programs for the elderly and the handicapped administered by the Department of Housing and Urban Development. In addition, we suggest that the federal contingent include three additional members, to be appointed by the Secretary, who represent as nearly as possible, the federal/state programs enumerated in Section 114(b) (3). We are also concerned that the public members of the Council be provided with an opportunity for somewhat greater continuity of service. This is particularly important in view of the fact that S. 3378 would reduce the number of public representatives to 15. We must also consider the recently experienced situation in which delays in appointment have reduced the complement of the Council. We therefore respectfully suggest that public members be permitted to serve not more than two consecutive terms. It is critical that a high turnover in the membership not jeopardize the long-term thrust of the program. We also recommend that the members be appointed for the designated terms or "until their successors have qualified" so as to cover those periods where there may be delays in nominating replacements.

STATE PLANS

The Consortium recognizes and appreciates the efforts of the Subcommittee to make state plan objectives more specific. We respectfully submit, however, that it is contrary to the spirit of the Developmental Disabilities Act to require the State Plan to "provide" any special service. The freedom and flexibility which the State Council has to

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fund direct services for developmental disabilities money is based on a recognition that the major service areas can and should be "provided" by other existing agencies; developmental disabilities money should serve a gap filling function. For this reason we recommend that the word "provide" in Section 114 (a) (3) and (a) (6) be removed and the word "promote" used instead.

We also recommend that the state-federal program "housing for the elderly and handicapped" should be included in the list of programs reviewed by the state council in accordance with Section 114(b) (3).

We recommend elimination of items 7 (A) and (B) in Section 114 (b), as these provisions are now superfluous.

CONSTRUCTION

We recommend adoption of the Administration's modifications as found in S.3011 regarding Construction. This change calls for delegating the authority to approve individual construction projects to the states, in accordance with the state plan and with federal specifications. Concurrent with this, we recommend maintaining the 50 percent limitation on the amount of the total allotment which may be spent on construction, rather than 10 percent contained in S. 3378. It is true that nationwide the average amount used for construction is less than 6 percent; however, in those states which have made use of Developmental Disabilities' funds for construction purposes the 10 percent limitation may jeopardize current efforts.

DUTIES OF THE STATE PLANNING COUNCILS

The Consortium respects the efforts of the Subcommittee to strengthen the role of the Council. The Consortium nevertheless considers that the State Council should not be given administrative powers in contravention of

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state law or gubernatorial prerogatives. We therefore recommend that the phrase in Section 114 (d) (2) be rewritten to "promote the coordination of all programs involving developmental disabilities."

SPECIAL PROJECTS

The need for a special projects authority peculiar to the Developmental Disabilities Act, including funds which may be delegated for administration at the regional level, has become acutely apparent in recent weeks as a result of the withdrawal of funds previously made available to the Developmental Disabilities Division under special language in Section 4(a) (1) of the former Vocational Rehabilitation Act. We therefore concur in the House language which consolidates authorities for a broad variety of activities not limited to direct service. We also concur with the House language which consolidates the projects of national significance into the general project grant authority and reserves 30 percent out of this total for projects of national significance.

We recommend that authorizations for the fiscal year ending June 30, 1975 be raised to \$20 million and that each of the subsequent authorizations be raised by \$2.5 million over the previous year. The purpose of this change is to make sure that approximately the same level will be authorized in 1975 as has already been requested in the President's budget for fiscal year 1975 and that small increments be available thereafter.

The Consortium believes it is not desirable to imply that the National Council should serve as a study section or grant review body. Instead, we recommend that the National Council advise the Secretary

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concerning the priorities to be used in awarding grants under this section. For example, Section 121(b) might be restructured to read "In accordance with priorities set forth after consultation with the National Council, established pursuant to Section 113 of this Act, the Secretary shall make grants to states and public or non-profit organizations ..."

We also suggest that the purposes for which these grants may be made should be broadened to include all of the purposes set forth in Section 100 (except the first and second, which are elsewhere specifically funded). The new authority should encompass any purpose for which special project grants were being funded under authorities delegated to the Division of Developmental Disabilities from the Public Health and Rehabilitation Acts. These go beyond direct services. For example, certain multi-state backup activities supported through the regional offices have been exceptionally helpful to state councils. Moreover, it is understood that the National Council is interested in decentralizing technical assistance activities to qualified universities and other agencies within the respective HEW regions.

For reasons mentioned above, we do not believe that any particular type of project or demonstration should be mandated. We therefore suggest deletion of the language "shall include" in Section 121 (b).

We are concerned that the language in Section 121 (c) may be capable of misconstruction. To the extent that projects initiated under the old Section 4 (a) (1) or the new Section 304 of the Rehabilitation Act were planned to extend beyond FY 1975, we would urge that they be so

continued wherever possible under that authority until their normal termination. In the event that the Developmental Disabilities office is separated from Rehabilitation Services Administration, there may arise an inference that developmentally disabled people are no longer eligible for any services under the Rehabilitation Act. The Developmental Disabilities Act requires that eligible individuals secure their entitlements under the more generic state-federal plans whenever possible. Denial of any entitlements under the Rehabilitation Act would negate this thrust. We therefore recommend inclusion of language to the effect that "nothing in this Act shall be construed to prohibit any person who is developmentally disabled from receiving benefits to which he might be entitled as a severely handicapped individual under the Rehabilitation Act of 1973."

BILL OF RIGHTS FOR THE MENTALLY RETARDED IN RESIDENTIAL FACILITIES

The Consortium is deeply concerned with the quality of care and treatment provided to developmentally disabled people in public and private institutions of all kinds throughout the country. We are sympathetic to the objectives of the Subcommittee and Senator Javits as regards Title II. However, Consortium members continue to question the wisdom of enacting any detailed standards, however good, into law.

We note that the standards incorporated in Title II of S. 3378 contain language not consistently susceptible to concrete measurement. While such language may be appropriate to regulations, we believe it is not appropriate to legislated standards. We are concerned that facilities threatened with the loss of Federal funds may successfully

bring suit against the standards, on the basis of unconstitutionally vague language.

We also believe that no set of standards is more efficacious than the compliance mechanism which is established in insure its implementation; we are concerned that the compliance mechanism proposed in Title II may prove inadequate to the task.

For these reasons, we believe that the objective of Title II should not be pursued through statutory action. We believe this is also true in the case of the community standards, should they be amended to the bill.

The Consortium concerned with the Developmentally Disabled is most appreciative of this opportunity to share our views with the Subcommittee.

STATEMENT

Respectfully Submitted

to

The Subcommittee on the Handicapped

of the

Senate Labor and Public Welfare Committee

on

S. 3378, "The Developmentally Disabled
Assistance and Bill of Rights Act"

In Behalf Of

United Cerebral Palsy Associations, Inc.

66 East 34th Street

New York, New York 10016

by

E. Clarke Ross

Federal Programs Consultant

UCPA Washington Office

May 1, 1974

To United Cerebral Palsy Associations, Inc., the Developmental Disabilities legislation is absolutely essential to the eventual satisfactory programming for severely and multiply handicapped individuals. The present departmentalized delivery systems have for the most part chosen to ignore the severely and multiply handicapped and to relegate them in their thinking, planning, and service development to some pattern of institutionalized existence out of the mainstream of society.

The DD Act with its targeting of this population for planning and services, its mandate for coordinating service programs across department lines, and its involvement of consumers in the process of planning and decision-making has taken a giant step in helping our most severely disabled citizens move toward achieving their human and civil rights.

SPECIFIC COMMENTS ON S. 3378

(1) Definition

UCPA certainly looks with favor on the addition of "autism" to the definition of developmental disability. We have always supported the broadest interpretation of the term "developmental disabilities" so long as efforts are targeted on the most severely and substantially handicapped individuals. Because of the necessity for interrelating DD programs with other state-federal programs such as social services, Medicaid, and Supplemental Security Income, it seemed wise to us to have all of these programs use the same definition for "disabled." UCP opted to support a slightly modifies version of the definition used presently by the Social Security Administration. This definition was also recommended by the National Developmental Disabilities Advisory Council:

An individual is considered to be disabled "if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months (or, in the case of a child under the age 18, if he suffers from any medically determinable physical or mental impairment of comparable severity.)"

On further study, UCP's Medical Director has suggested the following further modified version:

"A Developmental Disability means a disability which (1) is attributable to a physical and/or a mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial, normal activities."

UCPA has some concern over the addition of "learning disability" to the definition. We firmly believe that the Developmental Disabilities

(2)

legislation must be limited to the severe learning disabled as Part G, Specific Learning Disabilities, of the Education of the Handicapped Act offers opportunities to the less severe learning disabled. UCPA also believes specific coordination between the Division on Developmental Disabilities and the Bureau for the Education of the Handicapped must occur, especially in services to the learning disabled.

(2) State Plan Goals

While the specific goal orientation of State Plans proposed by S. 3378 is laudible and the goals listed are necessary ones, the proposal seriously limits States' need for flexibility. To develop comprehensive service systems, States must operate under only general regulatory guidelines and not earmarked goals. The broad initiatives of deinstitutionalization and institutional reform are sufficient goals for States to operate under. All goals proposed by S. 3378 may easily be accomplished under these two initiatives.

UCPA is extremely pleased by S. 3378's mention of cross disciplinary intervention and training programs for multihandicapped individuals. Three years ago, with the aid of a grant from the Division of Developmental Disabilities, UCPA developed and trained mini - teams for getting bedfast, multiply handicapped individuals from back wards in institutions, out of bed and into supportive wheeled equipment so that they could leave the wards and participate in institutional programs. Though a subject close to our hearts, we believe it need not be listed as a specific goal in the text of S. 3378. Such goals are better suited for committee report language.

UCPA is pleased with the emphasis placed upon early screening, diagnosis, and evaluation as a State Plan goal in S. 3378. It is an area of UCPA involvement which has received considerable State DDA funding support. But adult services, neglected for years, desperately requires attention and visibility. Services for non - employed severely handicapped adults is one of the highest priorities of the IHF Plan, the Individual With Cerebral Palsy and His Family, the major program thrust of UCPA in the 1970's. UCPA encourages the Subcommittee on the Handicapped to emphasize adult services as well as early intervention in its committee report.

(3) Strengthening State DD Councils

UCPA is highly supportive of the necessity of the mechanism of the Developmental Disabilities Advisory Councils in planning, coordinating, and accessing services for the developmentally disabled across departmentalized lines and in serving in an advocacy capacity. As such, UCPA endorses the strengthening of State DD Councils as proposed by S. 3378.

(4) Evaluation of State DD Services

The proposed requirement for a State evaluation system, especially with its emphasis on consumers, is worthwhile. UCPA favors improved evaluation techniques, ones that can adequately evaluate the development and accessing of resources. However we are very concerned that such evaluations not develop into simple head counting of individuals served.

(3)

(5) Transfer of DDD to OHD

UCPA believes the proposed transfer of the Division on Developmental Disabilities to the Office for Human Development will provide increased visibility, focus, and leadership on behalf of the developmentally disabled. Recognition within HEW of the Division's responsibilities will be increased by such a transfer.

(6) State Construction Allotments

The requirement that no more than 10% of a State's allotment each year may be spent on construction, renovation, and modernization is, it appears to UCPA, too limiting. A State with an annual allotment of \$100,000 would only have \$10,000 available for construction and related activities. Though UCPA does not endorse preoccupation with brick and mortar when so many services are lacking, neither would we favor strict limitations under all situations.

(7) Residential and Community Standards

UCPA, as an integral part of the evolution of both the residential and community standards developed by the Accreditation Council for Facilities for the Mentally Retarded (ACFMR) of the Joint Commission on Accreditation of Hospitals (JCAH), is both very comfortable with and supportive of the standards proposed by S. 3378. However, any standards required by federal statute must have a mechanism for review and response to changing situations. New information and new conditions must be taken into account and the possibility of change and flexibility must be provided for - UCPA recommends that the exact standards not be listed in the text of S. 3378. We suggest that S. 3378 make particular reference to the ACFMR standards. UCPA feels very strongly that since ACFMR is already in the business of accreditation, it would be advisable to designate this group as the primary surveyor for compliance, with appropriate procedures for an additional independent survey if the National Advisory Council on Developmental Disabilities wishes to validate the findings of the ACFMR survey team.

CONCLUSION

UCPA is extremely pleased with the success of the Developmental Disabilities program to date. Realizing its multi-facet purposes of planning, resource developing, coordinating, gap-filling, and service delivery, UCPA believes the future strength of the program will lie in its planning and coordinating responsibility. UCPA believes in the necessity for program stability and, as such, supports the five year extension proposed by S. 3378.

CALIFORNIA SOCIETY FOR AUTISTIC CHILDREN

A CHAPTER OF THE NATIONAL SOCIETY FOR AUTISTIC CHILDREN

Dedicated to the education, welfare and cure of children with severe disorders of communication and behavior



February 17, 1974
15 Chenin Court
Pleasant Hill, Ca. 94523

Hon. Yvonne Brathwaite Burke
Room 507, Cannon House Office Bldg.
Washington, D.C. 20515

ATTENTION: Mr. Ronald D. Rosen RE: Problems with DDA in California

Dear Mr. Rosen,

The problems of the implementation of PL 91-517 in California are perhaps unique because of the geographic size of the state, and the variable distribution of population. The state is divided into thirteen areas, each of which is governed by an area board, and served by a Regional Center.

In area boards consisting of more than one county (in some instances as many as nine counties), each county may develop their own annual action plan. Counties and area boards are free to develop their plans fairly independently, following only sketchy regulations presently provided by federal and state guidelines. To add to the discrepancies in services from area to area, four California area boards had been given special state permission to serve the developmentally disabled, not just the mentally retarded.

Of the nine remaining areas, some have elected during the past couple of years to serve a more broad target population than just the retarded. Examples of this are the Santa Clara, Santa Cruz, San Benito, Monterey Counties Area Board, the Orange County Area Board, The San Diego-Imperial Counties Area Board, and the Santa Barbara, San Luis Obispo, Ventura Counties Area Board. In effect, these areas are operating under the original intent of PL 91-517, that is, serving those who have a substantial handicap similar to and requiring similar treatment to mental retardation. We who act as advocates for services to autistic children are deeply grateful for the support and assistance already extended to families of autistic children by these centers who have not been offered additional funding, yet offer service to them. We are certain that their enlightened and humanitarian assistance policies have literally saved many individual substantially handicapped children and their families from crisis and physical and financial ruin.

In the absence of clearly definitive action by Congress or HEW to clarify the definition of the DD target population, we in California began to work towards obtaining the official inclusion of autism as a developmental disability at the first State Planning and Advisory Council meeting in 1972.

The DD State Planning and Advisory Council voted unanimously in January, 1973, to recommend that autism and neurological impairments be recognized as developmental disabilities in California (attachment 1, page 3). Our Secretary, Earl Brian, acknowledged this in a letter to HEW Secretary Weinberger in August, 1973 (attachment 2), and the administrative directive to Regional Centers advising them of their responsibility to serve all of the developmentally disabled was promulgated in November, 1973 (attachment 3). The Lanterman Act, AB 846, which became effective January, 1974, amended the old state mental retardation services act, replacing the term "mental retardation" with "developmentally disabled" wherever it appeared in the wording of the original law.

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Hon. Yvonne Brathwaite Burke

RE: Problems with DDA in California page 2.

We are advised that extra money has been appropriated for this expansion of the target population, some of which is scheduled to be disbursed during the remainder of this fiscal year. Despite these definitive developments, some area boards, specifically Area Board Five, which is made up of the five San Francisco Bay Area Counties, still chose not to make any provision for either the neurologically impaired or the autistic in their area board plans for 1975-76.

At the Area Board Five meeting held in January, 1974, this 1975-76 plan was presented to the component counties prior to its formal adoption. Representatives of the local chapter of the National Society for Autistic Children questioned the continued absence of any mention of services for autistic and neurologically handicapped children for that fiscal year planning. The response of the Board was that until Congress took a firm and legally definitive stand on the definition of developmental disabilities, they would proceed to develop their area board plan as they wished; in fact, they said that a vote had been taken by members of various regional centers, and that a decision had been reached to exclude autism from services provided by the regional centers. I have been unable to substantiate this statement with members from other regional center staffs.

Confronting the Board with the November, 1973, memo from Don Miller's Office (attachment 3), which clearly defined the DD target population that was henceforth to be served, the Board stated that they regarded this as an informational memo that they might either follow or ignore as they wished. They continued, stating that they were very busy serving just the retarded, and that they had a waiting list of retarded that needed services, which was their number one priority.

When the Lanterman Act was mentioned, however, the Board said that when they received some allocation "specific for that category of handicapped", they would begin to consider setting up services for them. At a subsequent meeting, a provisional section was added to the plan, outlining some basic statistics and financial provisions on autism and neurological impairments. So, at least, we have a beginning on the negotiations for services.

In these dealings with Area Board Five, three things seemed clear; (1) that this Regional Center was reluctant, even in light of state directives, to expand their target population until they had in their hands a very clear and legally definitive law from Congress mandating such action; (2) The governing area board of Region Five was opposed to the concept of the inclusion of autism in DD "because they felt that this category consisted of a group of such grossly handicapped individuals that it would cause the Board financial disaster to provide them with services"; (3) That any mention of autism or neurological impairment would never have been made in the final Area Board Plan for 1975-76 if our Society's representatives had not attended the meeting armed with pertinent recent legislative and departmental documents and demanded to be heard.

These are not problems unique to the San Francisco area; our Los Angeles chapter has encountered similar opposition in their dealings with that area board, but I do not have access to the details of that or other situations in California.

Their reluctance to provide services to autistic children is another example of an agency (such as a public school system) excluding a group of individuals who desperately need its services. The excuses employed are routine; (1) lack of clear mandate to provide such services; (2) lack of financial resources to establish and maintain a service; (3) lack of trained manpower to implement such programs.

If these valid-sounding excuses did represent actual insurmountable obstacles, how have some area boards managed to do what a few of our area boards have maintained is an impossible task? Too much money spent maintaining expensive full-time professional

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page 3.

staffs whose main function is the re-diagnosis of children that have already been diagnosed by accredited agencies or professionals? Too much money spent maintaining a large physical plant for regional center staff offices? When confronted with inexplicable differences in services available from center to center, we consumers wonder about such things.

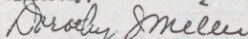
A regional Center may use a diagnostic label to exclude a client from its services in the absence of a clearly written mandate. In the past, some California centers have routinely re-diagnosed all cases being considered for eligibility for services, regardless of the availability of thorough and legitimate diagnostic work-ups already available on a child. This "re-evaluation" diagnosis was sometimes used by a center to deny a multi-handicapped "autistic-retarded" individual service on the technical grounds that the diagnostic team's finding was that the child's primary handicap was autism, with mental retardation a secondary handicap. Such arbitrary "chicken-or-the-egg-first" rulings have denied many severely handicapped needy individuals any kind of service beyond a diagnosis. With lack of schooling and comprehensive community care or service of any kind available, the only course of action open to many families is state hospital placement. This placement, however, usually involves regional center participation, which again brings up the question of eligibility, a center's priorities, and waiting lists. A real "Catch-22" for some families!

With new state legislation and directives mentioned in this letter, hopefully such practices have come to an end in California. This has not been achieved, however, without considerable work by our organization and others here in the state. We hope that the regional centers' efficiency will improve so that present lengthy waiting lists some have can be shortened or abolished, and that the lapse of time between determination of eligibility and actual delivery of services can be significantly diminished. I am sure there are extenuating circumstances that influence these administrative circumstances; I hear only of the problems from the consumer's standpoint, and of the crises that occur in some families caught in the bureaucratic maze.

The area served by the Golden Gate Regional Center, Area Board Five, is perhaps the most sophisticated cosmopolitan area in the state of California. We boast several prestigious colleges, a major medical school-hospital complex, and, next to the Los Angeles area, are the most densely populated region in the state. If the discrimination and opposition to progress and change can occur here, it can certainly occur anywhere in the United States.

It is obvious, from our experiences here in California, that until Congress itself passes into law a clear and uncompromising definition of the DD target population, such discriminatory and tragic practices of "playing God" will continue, using Congress' continuing procrastination and ambivalence as an excuse. We urge you to pursue the adoption of a renewal act that lists autism as a separate category within DD, leaving no room for agency interpretation, which, as we have seen, results in denial of service to many needy handicapped individuals.

Sincerely,



Dorothy J. Miller

President, East Bay Chapter, NSAC, CSAC
Secretary, CSAC, CSAG Liason for DD

DM

cc: Mary Akerley, Chairman, NSAC Nat'l Affairs Committee
Kimberley Gund, President, CSAC

HEALTH AND WELFARE AGENCY



MINUTES

California State Developmental Disabilities
Planning and Advisory Council

San Francisco

January 24, 1973

Council Members Present:

Wilbert C. Bradshaw
George S. Dolim
Rose D. Jenkins, M.D.
Betts Jensen
William E. Mayer, M.D.
Doris B. Meyer

John P. Morris, M.D.
George S. Roche, Ph.D., Chairman
Juanita W. Shaffer
H. David Sokoloff
Gwendolyn W. Stephens
Rolf R. Williams

Alternates Present:

William H. Clark, M.D., representing Frederick B. Hodges, M.D.
Les Brinegar, representing Wilson C. Riles
Ken Nelson, representing Alan C. Nelson (non-voting alternate)

Absent:

Robert B. Carleson
Dwight M. Geduldig

Also Present:

Mr. Ed Wheeler, Deputy Secretary, Health and Welfare Agency
J. M. Stubblebine, M.D., Director, Department of Health Planning
William J. Kurtz, Assistant Secretary, Special Services

Chairman George S. Roche called the meeting to order at 10:00 a.m. Minutes of the meeting of November 29, 1972, were approved as distributed.

Health Department Plans

Mr. Ed Wheeler, Deputy Secretary of the Health and Welfare Agency, spoke about the establishment of a single Department of Health, and the gradual change toward greater use of community-based treatment programs for both the mentally ill and the mentally retarded. Mr. Wheeler stated that during 1973-74 the Council and the Office of Developmental Disabilities would continue in the Health and Welfare Agency, and that Dr. Gregovich's office would be adding necessary staff.

J. M. Stubblebine, M.D., Director, Department of Health Planning, described the progress being made in organizing the new Department of Health, particularly in increasing coordination and reducing the number of levels of responsibility. Licensing will be consolidated in one department, and there will be a separate program unit for developmental disabilities. Details on the new organization are being prepared and will be presented to the Legislature.*

Mr. Sokoloff asked whether the purpose of reorganization was to improve services or to save money, and whether there has been adequate planning for the change from institutional care toward community care systems, with proper standards for services and facilities, and the availability of alternatives and an advocacy system. Will there be a method of evaluating services so the Council can make judgments?

Dr. Stubblebine indicated that standards, licensing and quality are major concerns. Programs for licensing and certification and for standards development will be a prominent part of the new organization.

Closure of MR Hospitals

Dr. Stubblebine was asked from the floor about administration plans described in newspapers concerning the future of MR Hospitals. The chairman noted receipt of correspondence on this subject from Area Board 7, Porterville State Hospital Parents Group, Parents Hospital Association of Sonoma State Hospital, and Mrs. Gail Sifford.

Dr. Stubblebine asked Dr. Mayer to respond. Dr. Mayer stated that the objective has not been to close state hospitals to save money, but rather to develop better alternatives in the community so that there will be less need for state institutions. Mr. Kurtz reported that the budget process allows for this, and pointed out that \$1.5 million is currently being shifted from hospital care to community care, as part of the plan to have the money follow the patients.

In a general discussion of the current planning process, some Area Board Chairmen and others expressed concern about not being informed of state plans until so late that there could be no participation or input into the plans. Much of the discussion centered on newspaper reports that state hospitals would be closed. During the discussion, it was stated by Dr. Mayer that there has been no change in the state policy. Individuals will not be discharged from state hospitals without advance planning with the family and the Regional Center, and then, only if the new situation is equal to or better than state hospital care. The state concept is to utilize community care; state hospitals are now vendors of service to the Regional Centers, with the Centers controlling the disposition of cases. Both the State hospitals and Regional Centers will be in separate units under one organizational system within the new Department of Health. The state wants as much input as possible from the public and from the Council and Area Boards, particularly now when the Boards will have planning funds and a more appropriate timetable for the submission of area plans.

*Since the time that Dr. Stubblebine made his remarks, a document describing the general organization was distributed. This document is currently being revised and will be sent out at a later date.

- 3 -

Inclusion of Autism and Neurological Handicaps with Developmental Disabilities

The request to include autism and neurological handicaps within the definition of developmental disabilities to be served under the Lanterman Act was discussed.

This was set over from the previous council meeting on November 29.

It was noted that the Federal Secretary of Health, Education, and Welfare had not acted on similar requests to include these disabilities under the Federal Developmental Disabilities Act.

MOVED by Dolim and seconded by Jensen and Sokoloff, it was subsequently amended that the Council ask the Secretary of the Health and Welfare Agency to find that autism and minimal cerebral dysfunction are developmental disabilities under the Lanterman Act and to seek funds in an amount which is sufficient to provide planning and services for those covered under other neurological handicapping conditions. Motion carried.

Community Residential Facilities

Lois C. Lillick, M.D., Deputy Director, Chief, Health Facilities and Resources Program, described a spread sheet she had prepared showing the different types of facilities and the licensing requirements. The information is appended. Additional information on numbers of facilities, residents, etc., will be detailed in future reports. Dr. Mayer indicated that board and care homes must now be licensed and the necessary regulations have just been published. At least 400 such facilities will be covered.

Mr. Bradshaw described some of the problems facility operators were having in trying to conform to various requirements.

MOVED by Stephens, seconded by Dolim, that the Council establish an ad hoc committee on licensing of facilities. Carried. The chairman appointed Bradshaw (chairman) and council members Carlson, Hodges and Mayer; and Dr. Stubblebine; and will appoint two additional members to be suggested by Bradshaw.*

Hunt for the Handicapped Child.

Russell Herron, President of California Association for the Retarded, described a multi-organization effort to establish a registry of all handicapped children, using volunteers to gather names.

MOVED by Sokoloff, seconded by Meyer, that this Council endorses the principle behind the "Hunt" to find those people who are not now receiving services. Carried. Dr. Roche was authorized to attend a January 27 meeting announced by Dr. Herron to continue development of plans for the "Hunt".

*Those appointed subsequently were Mrs. Rhoda Pearson and Mrs. Marcia C. Buck.

Federal Funds

The effects of recent federal social security amendments and the implications of revenue sharing were discussed by Mrs. Schuster and Mr. Best of the Department of Social Welfare. (Mrs. Shuster's presentation is attached to the minutes.) Concerns were expressed about reduced federal funds for ACSU, Regional Centers, and for workshops, as well as the effects on welfare assistances.

MOVED by Stephens and seconded by Williams, that the chairman appoint, at a later date, a committee to report on the new federal regulations and how they will affect California.

1974-75 State Plan

Dr. Morris presented the report of the State Plan Committee, which is appended.

MOVED by Morris and seconded by Jenkins, that the Secretary of the Health and Welfare Agency be asked to contract with the firm of Kramer, Miller and Associates to assist the committee with its work. Carried.

University Affiliated Facilities

Dr. Jenkins reported on a preliminary meeting of the UAF Committee with representatives of the three facilities in California. She requested and it was the consensus that the committee should be extended by the chairman appointing a person from each facility to the committee. The report is appended.

Assessment of Prevention Potentials

The Committee on Prevention is not ready at this time to make a report. An interim report will be submitted at the next meeting.

Evaluation

Mrs. Meyer reported that the Office of Developmental Disabilities is currently obtaining reactions from State Departments and others on guidelines for an evaluation of DD services. The committee will review the guidelines and report to the Council.

Special Education Plan

Chairman of the Committee on Relationships, Mrs. Stephens, presented a written report on the meeting of the Commission on Special Education. A copy is attached.

DD Special Project Funds

Dr. Charles R. Gardipee, Chief, Bureau of Mental Retardation and Disabilities Services, stated that Developmental Disabilities project grant applications were being evaluated and a priority listing will be submitted to the Office of Developmental Disabilities' Office in a few days.

Flow of Federal Funds

Mr. Williams, Chairman of the Committee on Federal Funds, presented tables regarding federal funds currently being received by departments. The tables are appended.

He made the comment that these may be obsolete because of changes made by HR-1. The Committee was thanked and relieved of its duties with the understanding that more information about HR-1 would be forthcoming in future meetings.

Area Board 7 Letter

The Council took up the January 23, 1973, letter of Area Board 7, consideration of which had been set over when it was presented as part of discussion about hospital closing.

MOVED by Sokoloff, seconded by Shaffer, that the Secretary is requested to take affirmative action to cure communications shortcomings between State Departments and Area Boards described in the January 23 letter and that he report to the Council on the action taken. Carried.

New Business

Mrs. Meyer reported that federal funds appropriated for the Department of Agriculture's supplemental feeding program were not being spent; the Bay Area Dietetic Association letter (attached) states this program helped prevent mental retardation.

MOVED by Morris, seconded by Jenkins, that the Secretary be asked to find out why the appropriated funds were returned instead of being spent on the program.

Service Delivery System

The chairman stated that recent changes involving the Regional Centers and Mental Hygiene's Alternate Care Services Unit made it advisable to look at the services delivery system, the heart of which is intended, by statute, to be the Regional Center and to find out if this role is being accomplished.

With the approval of the Council, the chairman appointed an ad hoc committee on Delivery System consisting of Dolim (chairman), Meyer, Dr. Neil Brooks of Area Board 12 and Mr. Nathan Edwards of Area Board 8.

A preliminary report was requested at the next meeting.

The next meeting of the Council will be held in Fresno on April 12; the following meeting will be held in Sacramento on May 10.

Adjournment was at 4:25 p.m.

Georgiana Allan
Recorder

STATE OF CALIFORNIA

ATTACHMENT 2

RONALD REAGAN, Governor

HEALTH AND WELFARE AGENCY

915 Capitol Mall, Room 200 - Sacramento 95814 (916) 445-6951

DEPARTMENTS OF THE AGENCY

Corrections
Health
Human Resources Development
Rehabilitation
Social Welfare
Youth Authority



EARL W. BRIAN, M.D.
Secretary

August 13, 1973

Robert L. Miller, D.D.S.
President
National Society for Autistic Children
621 Central Avenue
Albany, New York 12206

Dear Dr. Miller:

Thank you for your recent letter concerning the National Society for Autistic Children. I am enclosing a copy of my letter to Secretary Caspar Weinberger of Health, Education and Welfare in Washington.

As you may be aware, the Department of Health is planning to include services for autistic children under the Developmental Disabilities Program.

Again, thank you for taking the time to write and for your concern in working for this group of disabled children.

Sincerely,

EARL BRIAN, M.D.
Secretary

Enclosure

DEPARTMENT OF HEALTH
714 P STREET
SACRAMENTO, CALIFORNIA, 95814

GOLDEN GATE
REGIONAL CENTER

ATTACHMENT 3

November 19, 1973

TO: Regional Center Directors
Area Board Chairmen
Developmental Disabilities Planning and Advisory Council
Hospital Advisory Boards
Hospital Medical Directors
Community Services Section Area Supervisors

FROM: *Don Z. Miller*
Don Z. Miller, Chief
Developmental Disabilities Program

As a result of the Lanterman Bill, AB 846, we are now a program for the developmentally disabled. This makes it necessary that operational definitions be developed.

The State of California has accepted responsibility for the provision of essential and required services to the developmentally disabled citizens who are substantially handicapped. This includes individuals with mental retardation, cerebral palsy, epilepsy, autism and neurological handicaps. Such conditions must have originated before the age of 18.

The following are draft copies of definitions which shall be used, but I would welcome any suggestions for improvement during the next 60 days.

DEFINITIONS:

Substantially Handicapped - Describes a developmentally disabled individual whose needs cannot be met from participating in and benefiting from those social, economic, educational, recreational or other opportunities which generally are or expected to be available to his peers in his community who are not handicapped.

Mental Retardation - Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior (a general guideline is an IQ which is more than two standard deviations below the norm).

Autism - (1) A syndrome described as consisting of withdrawal, very inadequate social relationships, exceptional object relationships, language disturbances, and monotonously repetitive motor behavior; many children with autism will also be seriously impaired in general intellectual function; (2) this syndrome usually appears before the age of six and is characterized by severe withdrawal and inappropriate response to external stimuli.

November 19, 1973

Epilepsy (Convulsive disorder) - Clinical disorder involving impairment of consciousness, characterized by single or recurring attacks of loss of consciousness, convulsive movements, or disturbances of feeling or behavior. These transient episodes are associated with excessive neuronal discharge occurring diffusely or focally in the brain. The sites of the neuronal discharges determine the clinical manifestations of the seizure.

Cerebral Palsy - A disorder dating from birth or early infancy, non-progressive, although if not treated, there is marked regression in functioning, characterized by examples of aberrations of motor functions (paralysis, weakness, uncoordination) and often other manifestations of organic brain damage such as sensory disorders, seizures, mental retardation, learning difficulty and behavioral disorders.

Neurological Handicap - A syndrome characterized by learning, perceptual, and/or behavioral disorders of an individual whose IQ is not less than two standard deviations below the norm. These characteristics exist as a result of brain disfunction (any disorder in learning or using the senses), neurological disorder, or any damage to the central nervous system - whether due to genetic, hereditary, accident, or illness factors.

DZM:gi

NATIONAL SOCIETY FOR AUTISTIC CHILDREN

621 Central Avenue, Albany, New York 12206

518/489-7375

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Ruth E. Dyer

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STATEMENT

to

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on

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on

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 10609 Glenwild Road
 Silver Spring, Maryland 20901

February 21, 1974

Dedicated to the education and welfare of children with severe disorders of communication and behavior

The National Society for Autistic Children appreciates this opportunity to present testimony to the Subcommittee on Public Health and Environment on H.R. 11511, particularly Title IV, "The Developmental Disabilities Amendments of 1973."

Autism is a developmental disability characterized by the absence of normal communication skills (verbal and non-verbal) and by the inability to develop normal interpersonal relationships. A formal definition and list of symptoms is appended to our statement for your information (Attachment #1).

The National Society for Autistic Children (NSAC) is an organization of parents, professionals and other interested citizens dedicated to improving the welfare of the estimated 80,000 autistic persons in the United States. Because they are so small a minority (only 4 in 10,000), they have not received the legislative and administrative attention necessary for their habilitation. Even so, one-third recover sufficiently to function independently as adults and another third make sufficient progress to avoid institutionalization - provided, of course, there is an alternative at hand. One can only imagine what the prognosis would be if adequate therapeutic resources were available.

For this reason, we are concerned with both Titles II and IV of H.R. 11511. To save the Subcommittee's time, we are combining our remarks into a single statement. Our organization works closely with the National Association for Mental Health, and we support fully their testimony on Title II, especially the reordering of service priorities in favor of children and the elderly. The concept of Community Mental Health Centers is an important component of the deinstitutionalization program and, as such, deserves the full support of Congress.

NSAC is a member of the Consortium Concerned with the Developmentally Disabled and endorses fully the Consortium's statement, presented earlier this afternoon. We wish as an individual organi-

zation to emphasize the need for a longer renewal period for DDA and to suggest that the appropriate classification for this legislation is "Planning" rather than "Service." We are aware of the Subcommittee's concern with three specific areas in the DDA program and will speak to these.

I. The first, deinstitutionalization, is a concept we wholeheartedly support, and we feel the provisions of H.R. 11511 will strengthen national and local efforts in this regard. We do feel somewhat limited in our ability to speak to this issue, however, as to date there has been no public effort to apply this concept to autistic persons.

II. The same limitations are operating relative to the second area; i.e., how effectively DDA monies have been spent to date. Nevertheless, we would like to suggest that no evaluation of expenditures can be used as an accurate index of program effectiveness. To do so would be analogous to assessing the track record of a thoroughbred race horse which had been half-starved. The DDA has not received anything close to the sums which its drafters authorized and which must be considered an integral part of the conceptualization as well as of the administration of the program.

We have examined the Executive Secretary's Report, presented to the National Advisory Council at its November (1973) meeting, and would like to make the following observations:

1. the majority of projects, both planning and service, are directed toward the mentally retarded (see especially the section, "Institutional Reform and Deinstitutionalization Plan," pp. 47 - 52 of the report). While this is not surprising in view of the legislative history, it does suggest that some priorities for future projects be spelled out, in order to insure services for other eligible populations; and
2. in spite of the narrowly technical use of "neurological" relative to the eligibility of autism, populations have been served which can in no way be construed to be suffering from neurological impairments:
 - A. Prevention of mental retardation in "high-risk" (i.e., poverty) areas in Plainville, Conn. (p. 3 of report); and
 - B. Child Advocacy Models for ethnic, inner city, rural, handicapped, infant pre-school, family, and institutional populations (emphasis added) in twelve projects, jointly funded with other federal agencies (pp. 11-13 of report).

III. The definition is an area in which we do feel well qualified to testify. That some changes are needed for the sake of clarification is apparent from the amount of controversy and confusion over who may or may not be planned for and served. For example, in Maryland there has been a consumer representative for autism on the State Council since its formation: at first the legality of his appointment was questioned; more recently, his position has been used to demonstrate that autism is included even though not one autistic person in Maryland has been planned for and/or served under DDA. Similar merry-go-rounds are operating in all areas of the country; some specific examples are appended to this statement, including a letter from the Chairman of the National Advisory Council to the Secretary, protesting his appointment of the parent of an autistic child to the Council before a finding had been made on the eligibility of autism (Attachments 3 and 4A - 4F).

There really are two issues here:

1. The inclusion of autism as an eligible disability, and
2. The optimal wording of the definition to insure that all eligible persons are served.

Several reasons have been given for excluding autistic persons from the benefits of DDA. One is that NSAC had done nothing to get the legislation passed - that we were coming in at the tail-end to reap the benefits. This position, which might be termed "The Little Red Hen Syndrome", is not without merit: it is perfectly true that we didn't plant the wheat, haul it to the mill, or make the dough; and it is equally true that we wanted a small slice of the loaf. Our failure was due entirely to ignorance (in general and about the proposed legislation itself) and inexperience. We are a relatively young organization and small by comparison: our total annual national budget, for example, is less than the Heart Fund allocates for fund-raising in the Washington Metropolitan Area alone! Until this past September we had no paid staff; we now have an Executive Director with part-time secretarial and clerical help. We still have no Washington staff; our National Affairs Committee is composed en-

tirely of volunteers, none of whom are able to devote full time to its activities. Last year the Committee's total budget was \$100. Please understand - this is not a plea for sympathy; it is an attempt to acquaint the Subcommittee with some of the less obvious realities of the situation.

Another reason offered for the exclusion of autism is that there is not enough money to serve even the three named categories, much less any of the so-called "wastebasket groups." Again, the merits of such a position can hardly be denied. One need only look at pictures of Willowbrook or walk through Rosewood to know that we have a long way to go in treatment of the mentally retarded. Listen to the story of an epileptic's troubles in getting a job or a driver's license, then ask yourself if any group is more cruelly discriminated against. Look at the multiple handicaps of a cerebral palsied child - often mental as well as physical, and ask if any effort to help can be too great.

But with all their pathological and ethical merits, neither of the above reasons for exclusion has any legal credibility. The determination of who is covered by DDA is a medical one; it has - or should have - nothing to do with politics or finances.

It has also been suggested that autism is not neurological and therefore cannot be covered by DDA. We realize that the old myth of psychogenic causation dies hard and therefore submitted considerable scientific and medical evidence of organic causation. I am a layman, so my discussion of this area must be superficial; I offered to bring a neurologist to the hearing but was told the Subcommittee would not have time to hear him. I can say that efforts to cure autism or alleviate its symptoms by methods traditionally used in mental illness (e.g., psychotherapy) have failed, and that researchers in physical medicine are finding more and more abnormalities in the metabolic and neural systems of autistic children.

At a conference on Severe Psychopathologies of Childhood held in New York in December (1973), members of many disciplines (educa-

tion, psychology, psychiatry, neurology) shared their recent work on autism and childhood schizophrenia. The paper presented by Dr. Jovan Simeon of the University of Missouri (Dr. Simeon is a psychiatrist.) would be of particular interest to the Subcommittee because one factor which has operated against a neurological classification of autism has been the so-called "normal" EEG's of autistic children. They have appeared normal, according to Dr. Simeon, because the differences between the electrical activity in an autistic child's brain and that in a normal child's are so slight, that the usual visual analysis of an EEG cannot detect them. However, comparative analysis by digital computer has shown these slight but consistent differences in autistic children: fewer alpha waves, more slow and fast frequency waves, and shorter latency periods between responses to an aural stimulus, none of which are likely to be caused by poor parenting!

We therefore maintain that autism is a neurological impairment with service needs similar to those of the mentally retarded, and is therefore an eligible developmental disability as defined in the Act.

It might seem then that we favor the definition of the target population in Title IV. We believe it was the Subcommittee's intention to specifically include autism; we respectfully suggest that the Administration's definition, incorporated into H.R. 11511, will not insure planning and services for autistic persons. It will solve the "neurological-or-not" problem, but it still leaves the inclusion of autistic persons up to the Secretary. The present Secretary has followed his predecessor's pattern of equivocation on this; conflicting directives and "buck-passing" have been the Administration's chosen techniques for dealing with inquiries from states and regions, citizen groups, and even members of Congress. (Please see Attachment 4B, ^{also 4A, Illinois} Connecticut, for an example of this.)

Nor do we see the addition of "autism" immediately after "epilepsy" as the best possible solution, although it is vastly

superior wording to the Administration's. Every disability added to those specifically covered makes the implied exclusion of those not named even stronger. We do not believe anyone, no matter what his position, has the right to decide which handicapped people will be helped and which will not. The whole point of DDA is efficient, economical and effective delivery of services to a very special population: those who never have been and never will be normal because of a major interference in development. Dr. Elizabeth Boggs has explained the differences between DDA and traditional approaches this way:

1. The target population is determined by functional level, evidenced by developmental lags, rather than by etiology;
2. Clients need an individualized package drawn from the entire human resource system.

The first point is the more germane one here. How can anyone look at two children propped up, side by side, in the same day program, neither of whom has control of his arms and legs, and say, "This one gets help because his handicap comes from brain damage, but the other one doesn't because his disability is the result of damage to his spine"? Yet that is exactly what happens when we say that DDA is for the child with cerebral palsy but not for his peer with spina Bifida. Including the autistic child but not the one with severe developmental aphasia or some other major learning disability is the same thing.

We are therefore not going to request the inclusion of autism by name in the definition. We do not seek service at the expense of other equally deserving disabled people. We are very grateful to Congresswoman Burke for her support; we feel her wording has pointed up technical difficulties in both the present and proposed definitions. We are also grateful to the more than seventy other members of Congress who have gone on record as supporting the inclusion of autism in DDA (see Attachment #2). And we appreciate the supportive remarks of Drs. Charles Edwards and Bertram Brown in testimony to this Subcommittee last week.

Nevertheless, we feel the best possible approach would be a non-categorical definition of the target group. Such a definition received wide endorsement last year when the renewal legislation was being considered. The National Advisory Council endorsed the definition in a memo to Secretary Richardson; the relevant sections of that memo follow:

8. The definition of developmental disabilities should be revised to eliminate etiological factors, to focus on the most substantially handicapped and to define the target population based on objective characteristics. The new definition should be consistent with and referable to legal definitions which set forth eligibility criteria for services and payments to disabled persons in other

established federal programs. The following language would meet this criterion.

Developmental Disabilities means a disability which (1) is attributable to a medically determinable physical or mental impairment, (2) originates before the individual attains the age eighteen and has continued or can be expected to continue indefinitely, and (3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under age eighteen a handicap of comparable severity).

As an alternative sub-paragraph (1) above could read:

"(1) is attributable to mental retardation, cerebral palsy, epilepsy, or other medically determinable physical or mental impairments."

In addition to a revised definition, the Developmental Disabilities Act should provide for service eligibility for all substantially handicapped persons who can benefit from a service being provided for persons with developmental disabilities as defined in the primary target group. The following language is suggested:

"A person" means a person with a developmental disability or a person with another substantial handicap who has similar service needs and who is considered eligible for such similar services by an agency or a facility which is providing services primarily intended for persons with developmental disabilities.

Rationale: From the inception of the Developmental Disabilities Act, there has been a great deal of controversy as to the basic question, "Who are the developmentally disabled?" Questions arose as to the coverage of the primary groups, the nature of substantial handicap and the intended relationship between mental retardation and other conditions. The major issue concerns the inclusion or exclusion of other neurological conditions. The Council has considered a wealth of testimony on this issue and heard from various groups supporting and opposing changes in the definition. While there is little agreement on proper interpretation of the present law and on specific language for a new law, there is widespread support for a functional definition as opposed to a definition which relies on diagnostic labels. There is also agreement that regardless of the legal definition, service eligibility should be based on similar service needs.

The Council's suggested definition builds upon these areas of agreement and incorporates language used in the definition of disability under the Social Security Amendments of 1972 (P.L. 92-603⁴) and anticipates new definitions for "severely handicapped" under the new Rehabilitation Act (HR 8395). The shift from the concept of "condition" (neurological or otherwise) to the concept of physical or mental impairment provides the definition with a functional basis which has been used in the Social Security disability insurance program, and which will be further developed (especially in regard to children) as DHEW prepares to implement H.R. 1. The existing statutory linkages to social services and rehabilitation services in the supplementary income program make it important to develop common approaches to the definition wherever possible.

Inasmuch as blindness is defined separately in all Social Security Act titles, the possibility of excluding blindness per se from the above definition should be considered.

The Council recognizes the complexity of the definitional issue and the near impossibility of developing a solution satisfactory to all. However, the Council urges that the suggested approach be given serious consideration as a way to begin to rationalize our services and payments programs for the developmentally disabled within the context of the other major service systems.

Other supporters of this non-categorical definition were: an Ad Hoc Coalition on Developmental Disabilities (composed of the National Association for Retarded Children, United Cerebral Palsy Associations, Epilepsy Foundation of America, Association of University Affiliated Facilities, National Association of State Mental Health Program Directors, and National Association of Coordinators of State Programs for the Mentally Retarded), National Association for Mental Health, Association for Children with Learning Disabilities, Easter Seal Society, Spina Bifida Association of America, and our own organization.

Such a definition would seem as well to be consistent with the Hobbs Study on the effects of labelling, which concluded that the process does more harm than good. This study was ordered and funded by HEW; the thought that the Administration might now disregard it is both frustrating and infuriating.

The alternatives to a non-categorical definition are the so-called "laundry list" - a demeaning term on the same level as "wastebasket group" - or separate legislation and separate programs for each disability. Contemplation of just the administrative costs of the latter is frightening, yet justice demands that equal provision be made for all.

We understand that enumerating all the eligible disabilities is cumbersome and has fiscal implications upsetting to many people. However, the decision rendered in *Mills v. the D.C. Board of Education* articulated a principle which is equally applicable here: no person may be denied services because of lack of funds; whatever monies are available must be shared among all eligible persons. While NSAC does not favor this type of definition, we find it preferable to one which would exclude any eligible group.

We respectfully suggest that today's hearing format of separate statements from each of the "wastebasket groups" could have the effect of reinforcing the fear that there are masses "out there" clamoring for inclusion and fighting one another for first place in line. We

NSAC STATEMENT ON H.R. 11511

PAGE 10

hope our remarks have shown the Subcommittee that this is not the case. We are talking today about that small percentage of the handicapped who are developmentally disabled - but we are talking about all of them.

In conclusion, the National Society for Autistic Children urges that the Subcommittee consider H.R. 11511 favorably, but with changes that reflect our concerns relative to Titles II and IV, and expresses its sincere appreciation for the Subcommittee's attention and interest.

Working Definition* of Autistic Children as Adopted by the
NATIONAL SOCIETY FOR AUTISTIC CHILDREN Board and
Approved by the NSAC Professional Advisory Board
January 14, 1973

General Definition:

The term "autistic children" as used by the National Society for Autistic Children shall include persons, regardless of age, with severe disorders of communication and behavior whose disability became manifest during the early developmental stages of childhood. "Autistic children" includes, but is not limited to, those afflicted with infantile autism (Kanner's syndrome), profound aphasia, childhood psychosis, or any other condition characterized by severe deficits in language ability and behavior and by the lack of ability to relate appropriately to others. The autistic child appears to suffer primarily from a pervasive impairment of his cognitive and/or perceptual functioning, the consequences of which are manifested by limited ability to understand, communicate, learn, and participate in social relationships.

Specific Characteristics:

Such children are typically multihandicapped in their abilities to receive and communicate information, resulting in behavior inappropriate to physical and social demands of their environment. As in aphasia, the dominant communication disorder or learning disability appears to result from the inability to use and to understand language appropriately. The difficulty is often accompanied by impairment in motor, visual, and auditory perception. The behavior of an autistic child is typically improved by the application of appropriate educational procedures. A combination of some or all of the following behaviors characterize the autistic child. These behaviors vary from child to child and time to time in severity and manner.

1. Severely impaired speech or complete lack of speech.
2. Impaired or complete lack of relatedness and social inaccessibility to children, parents, and adults.
3. Extreme distress for no discernible reason due to minor changes in the environment.
4. Lack of intellectual development or retardation in certain areas, sometimes accompanied by normal or superior abilities in other areas.
5. Repetitive and peculiar use of toys and objects in an inappropriate manner, and/or similar repetitive and peculiar body motions, such as incessant rocking.
6. Unusual reaction to perceptual stimuli, such as seeming not to hear certain sounds and over-reacting to others (e.g., holding hands over ears) or "looking-through" objects, poor eye contact, or unable to perform certain gross and/or fine motor activities (walking with peculiar gait, limpness in fingers, inability to hold a pencil appropriately).
7. Onset of disorder at birth or apparent normal early development followed by deterioration in functioning.
8. Hyperactivity or passivity.
9. Apparent insensitivity to pain.

* It is anticipated that this working definition of autism will be changed and made more specific with new research knowledge.

NATIONAL SOCIETY FOR AUTISTIC CHILDREN
PROFESSIONAL ADVISORY BOARD
JANUARY 1973

- ERIC SCHOPLER, Ph.D., CHAIRMAN, Co-Director, Division TEACCH, Psychiatry Dept., UNC Medical School, Chapel Hill, N.C. 27514
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- ERIC SCHOPLER, Ph.D., Co-director, Division TEACCH, Psychiatry Dept., UNC Medical School, Chapel Hill, N.C. 27514
- LUKE WATSON, Ph.D., Director, Columbus Community Behavior Modification Program, Columbus State Institute, 1601 Broad St., Columbus, Ohio 43223
- LORNA WING, M.D., President, British Society for Autistic Children, c/o 1-a Golders Green Rd., London N.W. 11, England

INCLUSION OF AUTISM IN DD DEFINITION GAINING SUPPORT

ATTACHMENT
#2

72 Members of Congress have now sponsored bills to modify the definition of dd by including autism among the "other neurological conditions" which may be found by the Secretary "to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals..." These Members of Congress are:

Representatives

Harley O. Staggers (D, W.Va.) (Admin. bill)
Samuel Devine (R, Ohio) (Admin. bill)

Representatives

Bella Abzug (D, N.Y.)
Joseph Addabbo (D, N.Y.)
Herman Badillo (D, N.Y.)
Jonathan Bingham (D, N.Y.)
Corrine Boggs (D, La.)
Frank Brasco (D, N.Y.)
John Breaux (D, La.)
George Brown (D, Calif.)
John Buchanan (R, Ala.)
Clair Burgener (R, Calif.)
Yvonne Burke (D, Calif.)
Phillip Burton (D, Calif.)
Hugh Carey (D, N.Y.)
Charles Carney (D, Ohio)
Shirley Chisholm (D, N.Y.)
William Clay (D, Mo.)
Harold Collier (R, Ill.)
John Conyers (D, Mich.)
James Corman (D, Calif.)
Paul Cronin (R, Mass.)
Ron de Lugo (D, V.I.)
Robert Drinan (D, Mass.)
Ronald Dullums (D, Calif.)
Don Edwards (D, Calif.)
Bill Frenzel (R, Minn.)
Harold V. Froelich (R, Wis.)
Ella Grasso (D, Conn.)
Edith Green (D, Oregon)
Orval Hansen (R, Idaho)
Michael Harrington (D, Mass.)
Augustus Hawkins (D, Calif.)
Floyd Hicks (D, Wash.)
Lawrence Hogan (R, Md.)
Barbara Jordan (D, Texas)
Peter Kyros (D, Maine)
Spark Matsunaga (D, Hawaii)

Senators

Jacob Javits (R, N.Y.) (Admin. bill)
Mike Gravel (D, Alaska)

Senators

Harold Hughes (D, Iowa)
Hubert Humphrey (D, Minn.)
Daniel Inouye (D, Hawaii)
Mike Mansfield (D, Mont.)
John Pastore (D, R.I.)
Charles Percy (R, Ill.)
Ted Stevens (R, Alaska)
John Tunney (D, Calif.)

Representatives (Continued)

Lloyd Meeds (D, Wash.)
John Melcher (D, Mont.)
Ralph Metcalf (D, Ill.)
Parren Mitchell (D, Md.)
Robert Mollohan (D, W. Va.)
Frank Moss (D, Utah)
Wayne Owens (D, Utah)
Charles Rangle (D, N.Y.)
Thomas Rees (D, Calif.)
Henry Reuss (D, Wis.)
Robert Roe (D, N.J.)
Benjamin Rosenthal (D, N.Y.)
Edward Roybal (D, Calif.)
Paul Sarbanes (D, Md.)
John Seiberling (D, Ohio)
Fortney Stark (D, Calif.)
Alan Steelman (R, Texas)
Louis Stokes (D, Ohio)
Gerry Studds (D, Mass.)
William Whitehurst (R, Va.)
Charles Wilson (D, Calif.)
Antonio B. Won Pat (D, Guam)
Cus Yatron (D, Pa.)
Andrew Young (D, Ga.)



NATIONAL ADVISORY COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

ATTACHMENT

#3

Room 3062, HEW South Building
Washington, D.C. 20201
(202) 962-7355

October 25, 1973

The Honorable Caspar W. Weinberger
The Secretary of Health, Education, and Welfare
Washington, D.C. 20201

Dear Mr. Secretary:

Section 401(1) of P.L. 91-517 enacted in 1970 and extended by P.L. 93-45 calls for a Secretarial "finding." No such finding has yet been issued. A marked copy of the relevant sections of the Act and the regulations as finalized is attached. The language of this section as the Administration proposed six months ago to amend it is also attached. The failure to close on this issue in regulations, when looked at currently in the context of statements made by you before the House Sub Committee on Health and Environment last March, and your recent appointment of the immediate past President of the National Society for Autistic Children - who is the father of an autistic child, as a consumer member of the National Advisory Council, is, in my opinion, increasingly and unnecessarily placing the Department, the Division of Developmental Disabilities, and the National Advisory Council in an untenable position.

I urge you very respectfully to request of the DDD-RSA-SRS a proposal for an amendment to the regulations which would constitute a Secretarial finding under the existing statute; if the language as proposed is substantially acceptable to you, I would further urge that it be submitted to the National Advisory Council for its advice and comment (as required by law) not later than November 16, 1973 which is the date of the next meeting.

A resolution of this small but contentious issue would, I am sure, be welcomed on the Hill, by the State Advisory Councils and by the administering components of HEW.

UNSUBJ 1070

Sincerely yours,

Elizabeth M. Boggs, Ph.D.
Chairman

Enclosures

ELIZABETH M. BOGGS, Ph.D.
Chairman
Hampton, New Jersey

CHARLES D. BARNETT, Ph.D.
Columbia, South Carolina

MR. DILL BECKMAN
Columbia, South Carolina

LOUIS A. BRANSFORD, Ed.D.
Albuquerque, New Mexico

HONORABLE DALE M. ENGSTROM
Chattanooga, Tennessee

DORIS S. FRASER, Ph.D.
Boston, Massachusetts

LEONARD J. GANSER, M.D.
Madison, Wisconsin

MRS. VIRGINIA GOULD
Camarillo, California

MR. GEORGE V. GRAY
Albany, New York

MR. DENNIS HAGGERTY
Philadelphia, Pennsylvania

MRS. JEWEL B. HAMILTON
Pasadena, Texas

MR. MARTIN T. KELP
Rocky River, Ohio

MRS. MARGARET O. MURRAY
Shawnee Mission, Kansas

PAUL H. PEARSON, M.D.
Omaha, Nebraska

MRS. MARCILE L. PERRIN
Omaha, Nebraska

RAYMOND R. REMBOLT, M.D.
Iowa City, Iowa

MR. EDWARD L. TAYLOR
Philadelphia, Pennsylvania

MISS CLARA F. TUBBY
Belmont, Massachusetts

MR. RAYMOND W. VOWELL
Austin, Texas

ARTHUR WARD, JR., M.D.
Seattle, Washington

FRANCIS X. LYNCH
Executive Secretary
Washington, D.C.

ATTACHMENT #
3-a
(3 pages)
NATIONAL

101 Richmond Street
Huntington, W.Va. 25702

February 5, 1971

Dr. Edward Newman
Commissioner of the Rehabilitative Service Admin.
Washington, D.C. 20201

Dear Dr. Newman:

It has come to my attention that part of the 11.2 million dollars appropriated for PL91-517 for FY71 may be ear-marked for special projects. It is this portion of the appropriation that I am writing about. As you probably know, the mentally ill child in the United States is, without any doubt, the most handicapped, discriminated against, of all citizens. He is excluded from virtually every public school in the country, often is not admitted to state hospitals even those with children's wards, is excluded from special classes, does not fit under services as rendered at most community mental health centers. Private schools are scarce and the fees out of reach of most families. Parents often spend more money than they have just getting a diagnosis. The next battle is trying to find where there is help, and it is for this service that I am suggesting our Society might be eligible for a special project.

For almost a decade I have been collecting information about the mentally ill child and have been serving informally until June, '70 as the center of Information and Referral Service for Mentally Ill Children in the United States. I am now officially the Director of this Service which is a part of the National Society for Autistic Children, Inc.

We have practically no funds for this desperately needed service. I am operating out of my home with 12 hours a week of secretarial help and all the volunteers I can get. Letters pour in from around the country asking "where in the United States can I find a school or a residential center for my child." Several national organizations refer such inquiries to me. I feel sure the information that I have in my files is, to my knowledge, more up-to-date and more detailed than can be found in any other source.

Bro
1/2 p. 2 of 123 draft proposal
Exempt of letter from note
to, prepared by
E. Gibson

copy to
Mr. Cronin
Reg III
H. Redmond

3-a

Dr. Edward Newman
February 5, 1971, p.2

Would it be possible for you to consider this very important Service for funding as a Special Project under P191-517? It is my understanding that since we are a "low incidence" group that we are eligible. In the original Senate Bill one of the categories under "service" actually was for Information and Referral.

We are an all-volunteer organization. I work almost day and night on this project with, of course, no pay. With some funding I could make a much better effort to collect much more information and could disperse it much more efficiently. This Service could (has) saved parents and their children precious years of looking for help.

I will look forward to hearing from you.

Sincerely,

Ruth C. Sullivan, Director
NSAC-Information & Referral Service

RCS:msg.

30

RS
 from [unclear]

bcc: Dr. Palmquist &

enclosure, as
 listed below

101 Richmond Street
 Huntington, W.Va. 25702

February 12, 1971

Mr. William Crunk, Regional Commissioner
 Region III
 Rehabilitative Services
 P.O. Box 12900
 Philadelphia, Pa. 19108

Dear Mr. Crunk:

Request
 denied

In speaking to Mr. James Brew recently,
 he suggested that I send to you the enclosed
 letter which proposes a special project of
 national significance regarding funding of the
 only national information and referral service
 specifically ^{monthly} for children. I hope that you will
 be interested in my proposal and would
 appreciate any comments or suggestions you might
 have to give.

Sincerely,

Ruth C. Sullivan, Director
 ERAC-Information & Referral Service

RCS:msg

Enclosure

cc: Mr. James Brew & Mr. L. D. Newman
 C. G. [unclear] - [unclear]
 with [unclear]

STATE OF ILLINOIS
DEPARTMENT OF MENTAL HEALTH
ALBERT J. GLASS, M.D., Director



ATTACHMENT 4A (4 pages)
GENERAL OFFICE

401 SOUTH SPRING STREET
SPRINGFIELD, ILLINOIS 62706

DDSA

June 14, 1972

Ms. Rosalind C. Oppenheim, Director
Rimaldn School for Autistic Children
1224 Dempster Street
Evanston, Illinois 60202

Dear Ms. Oppenheim:

May we take this means to acknowledge that your FY 1971 DDSA grant application received March 23, 1972 has been considered inappropriate for DDSA funding for the following reasons:

1. The Governor's Advisory Council for Developmental Disabilities thought that autism in children was not a disability that could be included within the definition(s) of the developmentally disabled.
2. The Grant Evaluation Committee of the Governor's Advisory Council determined that low priority existed for these proposals planning to provide service to individuals categorized as having a "neurological condition closely related to mental retardation".

This decision was the consensus of the Governor's Advisory Council on Developmental Disabilities, the Department of Mental Health Regional Staff and DDSA General Office.

Please feel free to contact this office for further clarification of this matter. We shall be happy to work with you concerning program development for developmentally disabled individuals in your community and/or any specific project you have in mind. We know that the Department of Mental Health Regional Staff in your locale are anxious to do the same.

Naturally, we are sorry that your proposal could not be funded; we can only hope that this disappointment will not deter you from carrying on your fine purpose with other funding sources.

Please contact us if you have any further question regarding your FY 1971 DDSA application disposition.

Sincerely,

Eugene R. Kelly
Eugene R. Kelly
Director
Developmental Disabilities

ERK:rig

STATE OF ILLINOIS
DEPARTMENT OF MENTAL HEALTH
ALBERT J. GLASS, M.D., Director



44
GENERAL OFFICE

401 SOUTH SPRING STREET
SPRINGFIELD, ILLINOIS 62706

June 19, 1972

Mr. Joseph E. Oppenheim
President, Greater Chicago Chapter
National Society for Autistic Children, Inc.
8224 North Ridgeway Avenue
Skokie, Illinois 60076

Dear Mr. Oppenheim:

This is in response to your letter of April 22, 1972, which was addressed to Lieutenant Governor Paul Simon, in which you indicated that the Developmental Disabilities Services and Facilities Construction Act of 1970 (P. L. 91-517) is omitting the Autistic Child because lack of funds necessitates the omission of a fourth category of the developmentally disabled--namely the "neurological condition of an individual found by the Secretary to be closely related to mental retardation".

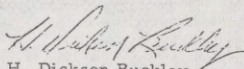
It is true that currently this State has received information from D/H, E. W. that "other neurological conditions" will not be included within the "substantially handicapped" definitions of the developmentally disabled for FY 1972. Whether this is because of lack of funds actually appropriated by Congress to the States or a difficulty with the definition of the Autistic Child is an open question at the present time. The majority of persons on the Illinois Governor's Advisory Council on Developmental Disabilities think the Autistic cannot be considered mentally retarded because of the causal factors relevant to the condition. Most assume that the causal factors are primarily associated with emotional dysfunction at an early age and therefore do not fall within the purview of P. L. 91-517--which currently defines the developmentally disabled as individuals with "substantial handicap" within the areas of Mental Retardation, Cerebral Palsy and Epilepsy.

We think it is unfortunate that the Autistic Child seems to be "left out" although other sources of funding within the Illinois Department of Mental Health are available for program services to assist these children. Should a changed posture regarding this matter occur at a Federal level, I am sure the Governor's Advisory Council for Developmental Disabilities will reconsider the implications of the Autistic Child's inclusion within "other neurologic condition" area of definition.

Mr. Joseph E. Oppenheim
June 19, 1972
Page 2

Your interest in this matter is appreciated and we hope this clarification has been of some assistance to you. If we can be of further service to you, please feel free to contact us.

Sincerely,


H. Dickson Buckley
Legislative Liaison
Office of the Director

HDB:mh

cc: Lt. Governor Simon

4A

September 21, 1972

State of Illinois
Department of Mental Health
401 South Spring Street
Springfield, Illinois

ATTENTION: Mr. Eugene R. Kelly
Director, Developmental Disabilities

Dear Mr. Kelly:

In a telephone conversation in August, 1972 with Arlen Gould of the Governor's Office of Human Resources, we apprised him of the denial of our application for DBSA funding for Fiscal Year 1971. Mr. Gould at that time advised us that there was to be a change in policy and priorities for grants under the terms of DDSA for fiscal years subsequent to 1971; and he urged us to write you at once for Grant Application forms, so that we might apply for funding for Fiscal Year 1972.

As you know, we did write you for the forms; and subsequently received them from you. The accompanying instructions indicated an August 21st deadline for the filing of DBSA grant applications for Fiscal Year 1972; but when we telephoned Mr. Birky's office in September to question this deadline date, we were advised that the deadline had been extended to October.

On September 18th, we telephoned you in Springfield to ask some questions about the instructions for completing the grant application. During that conversation, you told us that there had been no change in policy and priorities for grants under the terms of DDSA for Fiscal Year 1972; and that, in fact, autistic children were eligible for funding under the Developmental Disabilities Act, and any DBSA application we filed for funds for services for autistic children for Fiscal Year 1972 would be denied.

Accordingly, we are not filing a fiscal application for a DBSA grant for Fiscal Year 1972. However, we want our letter to file for a DBSA grant for Fiscal Year 1972 to be a matter of record. That is the purpose of the attached Letter of Intent.

Sincerely,

THE REHAB CENTER FOR AUTISTIC CHILDREN

Harold C. O'Connell,
Director

cc: Birky

Benhaven

Established 1967

A school for autistic and brain-damaged children
9 St. Roman Terrace • New Haven, Conn. 06511 • 624-9819

ATTACHMENT

4B

(5 pages)

(CONNECTICUT)

Amy L. Lettlick
Director

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July 6, 1973

Mr. David D. Berdon, Chairman
State Planning and Advisory Council
70 Livingston Street
New Haven, Conn. 06511

Dear Mr. Berdon:

Enclosed you will find a copy of a letter which Secretary of HEW, Caspar Weinberger, wrote to Sen. Weicker. In carrying out the recommendations made by both men, I am now writing to you to inquire whether Benhaven is now in any better position to receive funds through the Developmental Disabilities Act.

I would appreciate knowing whether our grants now can come under consideration in as much as the category of autism has been included in the definition of those with developmental disabilities. As Senator Weicker states, I realize that Connecticut will be the one to decide this, and that is why I am writing to you.

Please let me know what our position is at this particular point.

Sincerely,

Mrs. Birney A. Lettlick,
Director

BAL/gb
Encs.

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 STAFF DIRECTOR AND GENERAL COUNSEL

United States Senate

SELECT COMMITTEE ON SMALL BUSINESS
 (CREATED PURSUANT TO S. RES. 22, 81ST CONGRESS)
 WASHINGTON, D.C. 20510

June 20, 1973

Mrs. Birney A. Lettick, Director
 Benhaven School
 720 Edgewood Avenue
 New Haven, Connecticut 06515

Dear Mrs. Lettick:

Attached you will find a copy of a letter that I received from Secretary Caspar Weinberger of the Department of Health, Education and Welfare.

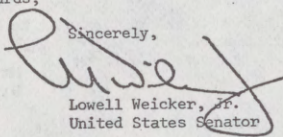
Based on Mr. Weinberger's letter, it appears that the final decision as to how the Developmental Disabilities Act funds will be allocated rests with the individual states involved.

Accordingly I certainly think it would be in order for you to contact Mr. David D. Berdon, as Mr. Weinberger has suggested.

If I can be of any further assistance with regard to this or any other matter, please don't hesitate to contact my Bridgeport office at 915 Lafayette Boulevard, Bridgeport, Connecticut.

With kind regards,

Sincerely,


 Lowell Weicker, Jr.
 United States Senator

LW:hkf
 Enclosure

4B



THE SECRETARY OF HEALTH, EDUCATION, AND WELFARE
WASHINGTON, D.C. 20201

JUN 19 1968

Honorable Lowell P. Weicker, Jr.
United States Senator
915 Lafayette Boulevard
Bridgeport, Connecticut 06603

Dear Senator Weicker:

Thank you for your letter of May 23 in behalf of Mrs. Mirney Lottick who is asking whether the extension of the Developmental Disabilities Act will enable states to serve the autistic and others with neurological disorders.

It is true that the language of the extension of the Act now includes the autistic by category as one of the "other neurological disorders associated with mental retardation or needing similar services." However, the decision to serve this group will rest with the individual state; it is not mandatory.

Your constituent should once again approach the Connecticut Developmental Disabilities Council with her proposal. It is this Council's decision whether or not such construction is the top priority for the use of 50 percent of Connecticut's Developmental Disabilities formula grant. We suggest that Mrs. Lottick contact the Council regarding her continuing interest in the developmentally disabled in Connecticut. She should direct her inquiry to Mr. David D. Bordon, Chairman, State Planning and Advisory Council, 70 Livingston Street, New Haven, Connecticut 06511.

We hope this information will be helpful in responding to your constituent.

Sincerely,

JOSEPH P. HAINES

Secretary



STATE OF CONNECTICUT
STATE DEPARTMENT OF HEALTH

79 ELM STREET

HARTFORD, CONNECTICUT 06115



OFFICE OF MENTAL RETARDATION

DEVELOPMENTAL DISABILITIES PROGRAM

February 1, 1974

Mrs. Amy L. Lettick, Director
Benhaven
9 St. Ronan Terrace
New Haven, Connecticut 06511

Dear Mrs. Lettick:

I am writing in response to your letter of January 14, 1974, in which you explored the possibility of applying for Developmental Disabilities funds.

Upon receipt of your letter I was particularly struck by the copy of the June 19, 1973 letter to Senator Lowell Weicker from Secretary Caspar Weinberger in which it was stated that it is the responsibility of the State Developmental Disabilities Council to decide whether or not to fund programs for the autistic. Most certainly this was not our understanding of the Developmental Disabilities Act and I have very carefully explored this issue before responding to your request.

I have presented this question to Robert Briggs, Coordinator of the Developmental Disabilities Program in the Boston Regional Office of Health, Education and Welfare. This question has also been presented to the office of Mr. Fran Lynch, National Director of the Developmental Disabilities Division, Rehabilitation Services Administration, Washington. Both offices agree that current legislation limits the use of Developmental Disabilities funds to the three categories of mental retardation, cerebral palsy, and epilepsy.

In addition, the National Conference on Developmental Disabilities has outlined the proposed bill (HR 11511) which would broaden the definition of Developmental Disabilities to include autism and other neurological conditions. I am sending you the synopsis and status report of that proposed legislation which indicates that hearings on this bill shall be held in late January or early February of 1974. Even if the proposed legislation were enacted, I doubt if it would be effective during this fiscal year which ends on June 30, 1974.

Because of all of the above, I find that I am currently unable to evaluate your proposal requesting Developmental Disabilities funds for your program.

Mrs. Amy L. Lettick

-2-

February 1, 1974 4B

I shall keep your material on file in this office, however, and contact you personally if we are advised at any time in the future that the definition of Developmental Disabilities has been broadened to include autism.

Very truly yours,

Daniel J. O'Connell
Daniel J. O'Connell, A.C.S.W.
Director

DJO:jc
encs.

cc: Mr. David Berdon
Mr. Robert Briggs

PC 91-517
 Dr. D. A.

MARY STEWART GOODWIN, M. D.
 T. CAMPBELL GOODWIN, M. D.
 COOPERSTOWN, NEW YORK 13326
 PHONE 607 547-8192

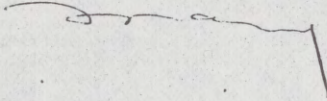
ATTACHMENT 4C
 New York
 (4 pages)

Dec. 29, 1971

Dear Ruth:

Here is some more material about the Developmental Disabilities Act. As you can see it has been grossly misused in New York State. I am sending copies of the enclosed to various legislators and others and also to Sheridan Meimark. Any additions and corrections will be appreciated, after the holidays, of course.

Love to all, yours,



DEVELOPMENTAL DISABILITIES ACT PL 91-517
NEW YORK STATE 1971

- October 30, 1970 - Developmental Disabilities Services and Facilities Construction Act signed by President Nixon. PL 91-517.
- fiscal Year 1971 - New York State allotted \$750,000 to implement the Act.
- April 8, 1971 - Sole responsibility for expenditure of funds assigned to The New York Department of Mental Hygiene without notice to concerned public.
- April - November, 1971 - Many requests for information about expenditure of funds under the Act and about requirements for project support, addressed to Dr. Frederic Grunberg, Department of Mental Hygiene, by parents and others interested in handicapped children. Answers to the requests suggested that plans for expenditure of funds were still under advisement, presumably deferred pending the announcement of the Advisory Council, defined in terms of DDA.
- June 4, 1971 - Developmental Disabilities Act State Plan submitted to Region II of the Department of Health, Education and Welfare by New York State Department of Mental Hygiene.
- September 12, 1971 - Developmental Disabilities Act State Plan FY approved without condition by the Regional Commissioner (Region II) of the Department of Health, Education and Welfare.
- October, November 1971 - Repeated inquiries addressed to Dr. Grunberg's office regarding the membership of the State Advisory Council, required by PL-91-517. "appointments under consideration".
- November, 1971 - Letters of inquiry regarding the Council addressed to Senator James Buckley and Senator Jacob Javits.
- November 24, 1971 - Personal communications from the Department of Mental Hygiene stating that all funds under the DDA fiscal year 1971 had been appropriated.

Dec. 25, 1971

RECOMMENDATIONS

- the legality of assigning the funds from the Developmental Disabilities Act PL 91-517 to be administered by the Department of Mental Hygiene.
- the needs of the recipients of the projects approved for 1971.
- the personal qualifications of the members of the Advisory Council of the Developmental Disabilities Act as announced on November 26, 1971.

LESSONS LEARNED

- the assignment of the funds for disabilities originating before the age of eighteen to a Department staffed by physicians trained in adult psychiatry and inexperienced in child care.
- the assignment of funds to a Department which has failed in the past to provide appropriate services for mentally handicapped children with developmental disabilities.
- the failure of the Governor to announce the membership of the Advisory Council before grant money had been assigned to specific service and construction projects.
- the failure to provide citizens with adequate preliminary information in time for grant applications to be presented during 1971.
- the failure to have adequate representation on the Council from the disciplines best equipped to provide services for children with developmental disabilities (i.e. Learning Disability Centers, Speech and Hearing Centers, Communications Disorders Clinics and Clinics for the Blind and Visually Impaired).
- the failure to disburse the funds towards small, effective community projects in many parts of the State where such expenditures could result in maximum benefits for minimum outlay.
- the failure to support innovative projects, especially for children with gynecia, challenged autism and similar developmental disabilities who have been excluded from many services in the past.
- the cost of administration (\$90,000) in a department already heavily staffed with administrative personnel and with an annual departmental budget of over \$500,000,000.
- the assignment of funds for projects already in existence and supported by or eligible for support by the Department of Mental Hygiene, private or quasi-public organizations.
- the expenditure for construction of nearly one-half of the available funds (construction - \$300,000; services - \$361,407; administration - \$90,000).

-2-

November 26, 1971

- Announcement in Mental Hygiene News of that date, of nineteen members of the State Advisory Council; membership included representatives from the State Department of Health and Education, respectively; local government agencies, medical centers, and representatives from private agencies including Rockefeller Center. The last nine members were categorized as "consumers". By the terms of the DDA, one-third of the members of the State Council must represent consumers.

December 12, 1971

- Article in the Times-Union newspaper of Albany, New York, that Mr. Alton Marshall had been named as Chairman of the State Advisory Council, under terms of the Developmental Disabilities Act. Mr. Marshall was formerly Secretary to Governor Nelson Rockefeller and is presently President of Rockefeller Center.

ATTACHMENT 4D (2pgs)
MASSACHUSETTS

Thursday's Children



VOL. I, NO. 2 DECEMBER, 1971

PUBLISHED BY ASSOCIATION FOR MENTALLY ILL CHILDREN OF MASS. (AMIC)
continues on page 2

Disabilities Act a question

Asked to comment on the exclusion of autistic children from provisions of the Developmental Disabilities Act passed by the Massachusetts Council, Dr. Doris Fraser, director of the Bureau of Developmental Disabilities said, "You are...pounding on the wrong door."

"Congress passed legislation granting 20 million dollars for these children (mentally ill and/or seriously disturbed) as an amendment to the 1970 amendment to the Mental Health Act. The money is not going after everybody to get this money," she said. You should be going after everybody to get this money."

Dr. Fraser pointed out that the 1970 amendment was almost double the \$11 million states in the first year for the children presently under

Disabilities Act, an amendment to the Mental Retardation Act. "And statistics show that there are seven to eight million retarded and under one million seriously ill. You should fight for this 20 million," she said.

Approached for information on this federal appropriation by an AMIC member, Dr. R.F. Hutchison, Massachusetts Assistant, Mental Health Commission for Children's Services, said that the Bureau of the Budget due to the fiscal crisis.

"It is \$10 million, not \$20 million," Dr. Hutchison said. He said that the information relative to the possible use of the money and he offered no comment on plans for its use.

Richardson's reply (Oct. 5) stated, "The question you raised is being carefully examined as part of the development of regulations and policies to Disabilities Program. We plan to complete preparation of the regulations in proposed rule continued on page 2

ATTACHMENT 4D (2pgs)
MASSACHUSETTS

Disabilities Act still a question

continued from page 1

making form soon. Prior to the adoption of these proposed regulations, consideration will be given to all comments submitted to the Department."

On Oct. 27, Harrington read into the Congressional Record a report, which started out:

"Mr. Speaker, one of the most difficult and least understood of all childhood diseases is autism, a handicap which causes untold anguish to families. Children afflicted with autism require special treatment and care. Many are unable to speak or relate to other individuals. When a child has autism, he is legitimately handicapped and the long years of care are an acute and unending expense for their parents."

"There is a great deal of controversy about whether autism is a physical or emotional illness, or both. Whatever the cause, the effect is that an autistic child has little chance of ever leading a normal life, or even a somewhat sheltered life unless proper treatment is available. But proper treatment is prohibitively expensive..."

The Development Disabilities Council for Massachusetts was sworn into office Sept. 30 by Governor Sargent.

In England

Editor's note: It is interesting to compare the highly important but individual attempt of Rep. Harrington to introduce the concept of autism to the Congress of the United States with a presentation or "debate" in the House of Lords in England, reported from the "Hansard," or House record, of Feb. 17, 1970. The June, 1970 Newsletter of the English National Society for Autistic Children (in Golders Green Rd., London, NW11) has a 14-page (legal size, single space) report of the discussion about autism between four Lords and two Baronesses. Replete with references to the writings of Drs. Jorma Wing and Michael Rutter, the discussion highlights history of diagnosis and importance of education in treatment.

Excerpts:

Quoting Wing, "They are

tone deaf to any kind of language... They are also unable to entertain concepts and to work out causal connections."

Quoting Rutter: "It has been suggested that we do not at the moment know the best way to educate autistic children, and that therefore it is difficult to lay down the regulations or to know what the result of them would be... But one thing seems clear: and that is expressed better than I could by (Rutter) in his book, 'Schooling and the Autistic Child.' "In our present state of knowledge education probably constitutes the most important aspect of treatment and it is to the school in one form or another that we must look for the greatest hope of bringing about improvement in the child."

'My Lords...'

Lord Bishop: "My Lords... Like the last speaker, I must confess with some shame that until this matter was brought to my notice recently, I was quite ignorant of this particular group of children... What has been stated, elsewhere seems to put these children, so far as they can be diagnosed, in a very peculiar category of their own... They have the ordinary organs for receiving through their senses, the experiences of the world out of which we build our personalities; but, somehow or other, they lack entirely a capacity to co-ordinate, assess and build these up into a framework of like which can be theirs."

'Alas!'

Baroness Elliot: (She cites statistics which estimate some 3,049 autistic children in England that year) "If this is compared with blind children, where the United Kingdom is 1,427, or with deaf children, totalling 3,356, it shows that autistic children are, alas! in a very high category indeed. The special provision for them nowhere compares with the special provision for deaf or blind children."

have recently defined education as a right; they have stated that it must no longer be considered a privilege but a right.

We are the advocates for our children. If we do not speak they will be forgotten. We must not allow our ability to speak for our children to be belittled by bureaucrats who stand between us and the programs our children need.

At a recent meeting of the Council for the Vocational Education of the Handicapped (of which we are a member), I was impressed by the representatives of various disabled groups. Who represented the physically disabled? A man in a wheelchair. The deaf? One who was deaf, etc.

We are the logical advocates for our children because we daily see the need. For those unable to communicate, we are perhaps best able to interpret their needs.

Our recent two day conference on Child Advocacy (sponsored jointly by the Department of Mental Health, McLean Institutes for Education and Mental Health, and AMIC) stressed the need for people in the field to advocate effectively for children and to prevent further institutionalization of children.

We are supported in our role as moral activists for children by the Coalition for Children and the Task Force on Children Out of School. We have recently been asked to serve on that Task Force and we are now working with that group on a review of 750.

Regional Conferences to review 750 will be held throughout the State. We intend to present our views at every one of them.

When and where there are opportunities, let us all speak up for our handicapped children. If we don't we may find the years make little difference, and children in 1981 will still be looking for help.



THURSDAY'S CHILDREN
Published by AMIC
Association for Mentally
III Children in Massachusetts,
7 Tuxedo Circle,
Arlington, Mass. 02074
President: Barbara Cutler
Editor: Barbara Lillard Powers



JOHN J. GILLIGAN
GOVERNOR
Kenneth D. Gaver, M.D.
Director

OF
MENTAL HYGIENE AND CORRECTION

OHIO DEPARTMENTS BUILDING
65 SOUTH FRONT STREET
COLUMBUS, OHIO 43215

April 26, 1972

ATTACHMENT #
4E

See also OHIO
reference in

4F

RECEIVED MAY 3 1972

Lorine M. Reid
Executive Director - Lucas County M.H. & M.R. Board
Community Services Building
1 Stranahan Square
Toledo, Ohio 43604

Dear Miss Reid:

The Developmental Disabilities Planning and Advisory Council at its meeting on April 21st, 1972, recommended that project grant application number 1971-46-02, entitled "Program for Autistic Children" for a state grant under P.L. 91-517 be disapproved.

It will not be possible for your project grant application to be funded. P.L. 91-517 affirms categorically those types of programs eligible for funding and not fundable under other state or federal auspices. The 1972 State Plan for Developmental Disabilities sets forth a priority system as well as its objectives to serve the needs of the developmentally disabled. May we encourage you to continue seeking funds for your project as other state and federal programs may be more amenable to your needs.

Should you have any questions in relation to your project application, a project review may be requested by contacting the Office of Developmental Disabilities, Division of Mental Retardation, (614) 469-3002.

Sincerely yours,

Baird A. Krueger

Baird A. Krueger
Director
Developmental Disabilities Section

BAK/pf

NATIONAL SOCIETY FOR AUTISTIC CHILDREN

621 Central Avenue, Albany, New York 12206

518/489-7375



February 18, 1974

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Ruth Christ Sullivan, Director

Mrs. Mary Akerley
 10609 Glenwild Road
 Silver Spring, Maryland 20901

Dear Mary:

I hope the enclosed copies of letters I've received or sent over the last few years will be of some help in documenting the exclusion of autistic children from DDA funds.

When, as NSAC's Legislative Chairman, I began to work on DDA, I was told (by Mrs. Elizabeth Schoenfield of the Philadelphia HEW office) that at a meeting where the DDA definition of handicap was being discussed, someone from NIMH objected to autism being included because "there's 10 million dollars over at NIMH for autistic children." As we now know, that \$10 million was for "child mental health" and was earmarked for "prevention". Since there is no known way to prevent autism, this meant that autism was excluded from DDA and from the NIMH program.

As you see from my letters to Russell McQuain, Director of W.Va.'s Commission of Mental Retardation, my requests for funds were denied.

I have asked Barbara Cutler of AMIC to send you an article from their news letter, Thursday's Child, in which they report being turned down for DDA funds in Mass.

I have also asked Mr. Thomas M. Wernert, Executive Director of the Lucas County Mental Health and Mental Retardation Board, to send you a copy of the letter which disapproved their request for funds for an autism project. I asked him for some documents that reported DDA funds being withdrawn from an ongoing DDA autism project, but he could find nothing in writing. We all know, however, that the autism program had been in existence for one year when DDA funds were withdrawn because someone decided autism could not qualify under the definition.

* Toledo, Ohio

Dedicated to the education and welfare of children with severe disorders of communication and behavior

ATTACHMENT 4F
 WEST VIRGINIA (789906)

MASS.

OHIO.

Page 2
 Mary Akerley
 February 18, 1974

At one point soon after the DDA guidelines were published, Sheridan Neimark, Past Legislative Chairman, and an attorney, questioned the legality of denying services to handicapped persons who so clearly fit the definition. In fact, a much larger percentage of autistic children fit the present DDA definition than do mentally retarded, epilepsy, or cerebral palsy. Also, it would be interesting to have someone on the Committee holding the hearings to give a definition of mental retardation. Could they give one that could exclude autistic children?

Daniel and Connie Torisky of our Pittsburg chapter have organized all the handicapped groups in their area into the Combined Parents Legislative Action Committee, representing 26,000 (!) parents of handicapped children--including mentally retarded, epilepsy and cerebral palsy. Their Committee adamantly supports the inclusion of autism as a separate category.

The best solution to the present dilemma, it seems, would be to eliminate all categories and let the description be the guidelines--e.g. "substantially handicapped", "severely developmentally disabled", "originated before age 18", "can be expected to continue indefinitely", and "constitutes a substantial handicap".

It is surprising that there is such a fuss over the idea that autism may not be neurological, when even the most analytically oriented now admit that there is at least some organic impairment. Dr. Edward Ornitz of UCLA said in an article for California Medicine* that hypotheses based on psychogenic causation of autism "are no longer accepted by the majority of serious investigators... and are now only of historical interest".

I hope some of this will be of help.

Best wishes,

Ruth

Ruth C. Sullivan, Director
 NSAC - Information and Referral Service
 306 31st Street
 Huntington, West Virginia 25702

RCS:bf

* April, 1973

101 Richmond Street
Huntington, West Va.
25702

January 12, 1972

Mr. Russel H. McQuain, Acting Executive Director
Commission on Mental Retardation
State Capitol Building
Charleston, West Virginia 25305

Dear Mr. McQuain:

I am trying to get some funding for this Information and Referral Service, the only one of its kind serving the entire nation. As you probably know, West Virginia comes in for a good share of the service that I give. It occurs to me that it might be possible under the Developmental Disabilities Act to work out a project that might be mutually beneficial.

I would like to propose a special national project sponsored under the West Virginia DDA. I don't know how this would work out, and if you are interested, perhaps we could discuss this on the phone. Since I am located in West Virginia, it would probably be more expedient for you to receive the Federal funds for the project. I believe that there is a special wording of the Act which speaks of "special projects of national interest".

This is the only national Information and Referral Service for mentally ill children, and judging from the mail I get daily, and how our service is expanding, I judge that it is filling an urgent need, not only for West Virginia but for the entire country. I will enclose some material which I hope

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Mr. Russell McQuain

January 12, 1972

Page 2

will give you some idea of what we are doing. The operation is almost completely volunteer. I have two part-time secretaries, two days a week. I think that we could work out something which would be a unique project under the DDA. I look forward to hearing from you.

Sincerely,

Ruth C. Sullivan, Director
ESAC - Information & Referral
Service

RCS/lm

Enclosures

cc: Mr. John D. Twinn, Administrator
Social and Rehabilitation Service
Department of Health, Education and Welfare

copy to Dr. Francis X. Lynch



COMMISSION ON MENTAL RETARDATION

1704 WASHINGTON STREET, E.
CHARLESTON, WEST VIRGINIA 25305

February 7, 1972

Mrs. Ruth C. Sullivan, Director
NSAC-Information and Referral Service
101 Richmond Street
Huntington, West Virginia 25702

Dear Mrs. Sullivan:

This will acknowledge receipt of your recent letter of January 31, 1972, and of your previous communication of January 12, 1972, the latter dealing with your proposed information and referral service for mentally ill children.

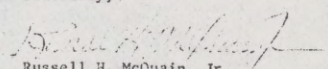
As the situation presently exists, the state service program is involved with mentally retarded, cerebral palsied, and epileptic, all of substantial handicap. The national planning and advisory council, recently meeting, attempted to deal with "substantially handicapped," and, we understand, with "another neurological condition" and other terminology.

I am planning to meet soon with our regional consultant from Philadelphia with regard to your idea of submission of a proposal under the "special projects of national interest" concept.

In the meantime, I am forwarding you material on the Developmental Disabilities Act, including guidelines for services, tentative federal register, etc.

I will be in touch with you by the end of the month after talking with the Region III DDA consultant.

Sincerely,


Russell H. McQuinn, Jr.
Acting Executive Director

Enclosures

*in Charleston
that -
him 12/22/72
Elizabeth Huntington
Huntington, West Va.
University of West Virginia*

RC's Huntington 7'

101 Richmond Street
Huntington, West Va.
25702

February 10, 1972

Mr. Russell H. McQuasin, Jr.
Acting Executive Director
Commission on Mental Retardation
1704 Washington Street, East
Charleston, West Virginia 25305

Dear Mr. McQuasin:

*Request
denied.*

Thank you for your letter. Since there seems to be some question about the inclusion of mentally ill children under DDA, I am enclosing for you some recent correspondence concerning inclusion of autistic-like children. There is no question that they fit under the DDA terminology. They are certainly neurologically impaired, are substantially handicapped, and are among the most severely developmentally disabled. Perhaps the enclosed material will help you in your discussions with your regional consultant from Philadelphia. Best wishes. I look forward to hearing from you.

Sincerely,

Ruth C. Sullivan, Director
NSAC - Information & Referral
Service

RCS/lm

Enclosures

Mr. McQuasin: I never received a reply to the enclosed letter. Could you give me some up-to-date information? For instance, who serves on the Advisory Council, their backgrounds, what plans are being made for DDA spending in West Virginia, etc.?



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WEST VIRGINIA DEPARTMENT OF MENTAL HEALTH
CHARLESTON 25305

M. MITCHELL-BATEMAN, M.D.
DIRECTOR

January 4, 1972

ADDRESS ALL REPLIES
TO THE DIRECTOR

Mrs. Ruth Sullivan, Director
National Society for Autistic Children
Information and Referral Service
101 Richmond Street
Huntington, West Virginia 25702

Dear Mrs. Sullivan:

Concerning the possibility of state support for an Information and Referral Service for Mentally Ill Children, I have been informed that Developmental Disabilities Act (DDA) funds may be applicable.

May I suggest that you contact Mr. Russell McQuain for details, however, before submitting a formal written request for DDA support:

Russell H. McQuain, Jr., Acting Executive Director
Commission on Mental Retardation
State Capitol Building
Charleston, West Virginia 25305
Telephone: 348-2963

Sincerely,

A handwritten signature in cursive script, appearing to read "Hillel Liebert".

Hillel Liebert
Program Consultant

cc: M. Mitchell-Bateman, M.D.
Mr. Russell H. McQuain, Jr.
Mr. Robert E. Marshall

○

