

105TH CONGRESS
2D SESSION

S. 1866

To provide assistance to improve research regarding the quality and effectiveness of health care for children, to improve data collection regarding children’s health, and to improve the effectiveness of health care delivery systems for children.

IN THE SENATE OF THE UNITED STATES

MARCH 26, 1998

Mr. DEWINE introduced the following bill; which was read twice and referred to the Committee on Labor and Human Resources

A BILL

To provide assistance to improve research regarding the quality and effectiveness of health care for children, to improve data collection regarding children’s health, and to improve the effectiveness of health care delivery systems for children.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Child Health Care
5 Quality Research Improvement Act”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

1 (1) There is increased emphasis on using evi-
2 dence of improved health care outcomes and cost ef-
3 fectiveness to justify changes in our health care sys-
4 tem.

5 (2) There is a growing movement to use health
6 care quality measures to ensure that health care
7 services provided are appropriate and likely to im-
8 prove health.

9 (3) Few health care quality measures exist for
10 children, especially for the treatment of acute and
11 chronic conditions.

12 (4) A significant number of children in the
13 United States have health problems, and the per-
14 centage of children with special health care needs is
15 increasing.

16 (5) Children in the health care marketplace
17 have unique health attributes, including a child's de-
18 velopmental vulnerability, differential morbidity, and
19 dependency on adults, families, and communities.

20 (6) Children account for less than 15 percent of
21 the national health care spending, and do not com-
22 mand a large amount of influence in the health care
23 marketplace.

24 (7) The Federal government is the major payer
25 of children's health care in the United States.

1 (8) Numerous scientifically sound measures
 2 exist for assessing quality of health care for adults,
 3 and similar measures should be developed for assess-
 4 ing the quality of health care for children.

5 (9) The delivery structures and systems that
 6 provide care for children are necessarily different
 7 than systems caring for adults, and therefore require
 8 appropriate types of quality measurements and im-
 9 provement systems.

10 (10) Improving quality measurement and mon-
 11 itoring will—

12 (A) assist health care providers in identify-
 13 ing ways to improve health outcomes for com-
 14 mon and rare childhood health conditions;

15 (B) assist consumers and purchasers of
 16 health care in determining the value of the
 17 health care products and services they are re-
 18 ceiving or buying; and

19 (C) assist providers in selecting effective
 20 treatments and priorities for service delivery.

21 (11) Because of the prevalence and patterns of
 22 children’s medical conditions, research on improving
 23 care for relatively rare or specific conditions must be
 24 conducted across multiple institutions and practice

1 settings in order to guarantee the validity and gener-
 2 alizability of research results.

3 **SEC. 3. DEFINITIONS.**

4 In this Act:

5 (1) HIGH PRIORITY AREAS.—the term “high
 6 priority areas” means areas of research that are of
 7 compelling scientific or public policy significance,
 8 that include high priority areas of research identified
 9 by the Conference on Improving Quality of Health
 10 Care for Children: An Agenda for Research (May,
 11 1997), and that—

12 (A) are consistent with areas of research
 13 as defined in paragraphs (1)(A) and (2) of sec-
 14 tion 1142(a) of the Social Security Act;

15 (B) are relevant to all children or to spe-
 16 cific subgroups of children; or

17 (C) are consistent with such other criteria
 18 as the Secretary may require.

19 (2) LOCAL COMMUNITY.—The term “local com-
 20 munity” means city, county, and regional govern-
 21 ments, and research institutes in conjunction with
 22 such cities, counties, or regional governments.

23 (3) PEDIATRIC QUALITY OF CARE AND OUT-
 24 COMES RESEARCH.—The term “pediatric quality of
 25 care and outcomes research” means research involv-

1 ing the process of health care delivery and the out-
2 comes of that delivery in order to improve the care
3 available for children, including health promotion
4 and disease prevention, diagnosis, treatment, and re-
5 habilitation services, including research to—

6 (A) develop and use better measures of
7 health and functional status in order to deter-
8 mine more precisely baseline health status and
9 health outcomes;

10 (B) evaluate the results of the health care
11 process in real-life settings, including variations
12 in medical practices and patterns, as well as
13 functional status, clinical status, and patient
14 satisfaction;

15 (C) develop quality improvement tools and
16 evaluate their implementation in order to estab-
17 lish benchmarks for care for specific childhood
18 diseases, conditions, impairments, or popu-
19 lations groups;

20 (D) develop specific measures of the qual-
21 ity of care to determine whether a specific
22 health service has been provided in a technically
23 appropriate and effective manner, that is re-
24 sponsive to the clinical needs of the patient, and
25 that is evaluated in terms of the clinical and

1 functional status of the patient as well as the
2 patient's satisfaction with the care; or

3 (E) assess policies, procedures, and meth-
4 ods that can be used to improve the process and
5 outcomes of the delivery of care.

6 (4) PROVIDER-BASED RESEARCH NETWORKS.—

7 The term “provider-based research network” refers
8 to 1 of the following which exist for the purpose of
9 conducting research:

10 (A) A hospital-based research network that
11 is comprised of a sufficient number of children's
12 hospitals or pediatric departments of academic
13 health centers.

14 (B) A physician practice-based research
15 network that is comprised of a sufficient num-
16 ber of groups of physicians practices.

17 (C) A managed care-based research net-
18 work that is comprised of a sufficient number
19 of pediatric programs of State-licensed health
20 maintenance organizations or other State cer-
21 tified managed care plans.

22 (D) A combination provider-based research
23 network that is comprised of all or part of a
24 hospital-based research network, a physician

1 practice-based research network, and a man-
 2 aged care-based research network.

3 (5) SECRETARY.—The term “Secretary” means
 4 the Secretary of Health and Human Services.

5 **SEC. 4. EXPANSION OF THE HEALTH SERVICES RESEARCH**
 6 **WORKFORCE.**

7 (a) GRANTS.—The Secretary shall annually award
 8 not less than 10 grants to eligible entities at geographi-
 9 cally diverse locations throughout the United States to en-
 10 able such entities to carry out research training programs
 11 that are dedicated to child health services research train-
 12 ing initiatives at the doctoral, post-doctoral, and junior
 13 faculty levels.

14 (b) ELIGIBILITY.—To be eligible to receive a grant
 15 under subsection (a), an entity shall—

16 (1) be a public or nonprofit private entity; and

17 (2) prepare and submit to the Secretary an ap-
 18 plication, at such time, in such manner, and contain-
 19 ing such information as the Secretary may require.

20 (c) LIMITATION.—A grant awarded under this sec-
 21 tion shall be for an amount that does not exceed \$500,000.

22 (d) AUTHORIZATION OF APPROPRIATIONS.—There
 23 are authorized to be appropriated to carry out this section,
 24 \$5,000,000 for each of the fiscal years 1999 through
 25 2003.

1 **SEC. 5. DEVELOPMENT OF CHILD HEALTH IMPROVEMENT**
 2 **RESEARCH CENTERS AND PROVIDER-BASED**
 3 **RESEARCH NETWORKS.**

4 (a) GRANTS.—In order to address the full continuum
 5 of pediatric quality of care and outcomes research, to link
 6 research to practice improvement, and to speed the dis-
 7 semination of research findings to community practice set-
 8 tings, the Secretary shall award grants to eligible entities
 9 for the establishment of—

10 (1) not less than 10 national centers for excel-
 11 lence in child health improvement research at geo-
 12 graphically diverse locations throughout the United
 13 States; and

14 (2) not less than 5 national child health pro-
 15 vider quality improvement research networks at geo-
 16 graphically diverse locations throughout the United
 17 States, including at least 1 of each type of network
 18 as described in section 3(4).

19 (b) ELIGIBILITY.—To be eligible to receive a grant
 20 under subsection (a), an entity shall—

21 (1) for purposes of—

22 (A) subsection (a)(1), be a public or non-
 23 profit entity, or group of entities, including uni-
 24 versities, and where applicable their schools of
 25 Public Health, research institutions, or chil-
 26 dren's hospitals, with multi-disciplinary exper-

tise including pediatric quality of care and outcomes research and primary care research; or

(B) subsection (a)(2), be a public or non-profit institution that represents children's hospitals, pediatric departments of academic health centers, physician practices, or managed care plans; and

(2) prepare and submit to the Secretary an application, at such time, in such manner, and containing such information as the Secretary may require, including—

(A) in the case of an application for a grant under subsection (a)(1), a demonstration that a research center will conduct 2 or more research projects involving pediatric quality of care and outcomes research in high priority areas; or

(B) in the case of an application for a grant under subsection (a)(2)—

(i) a demonstration that the applicant and its network will conduct 2 or more projects involving pediatric quality of care and outcomes research in high priority areas;

1 (ii) a demonstration of an effective
 2 and cost-efficient data collection infra-
 3 structure;

4 (iii) a demonstration of matching
 5 funds equal to the amount of the grant;
 6 and

7 (iv) a plan for sustaining the financ-
 8 ing of the operation of a provider-based
 9 network after the expiration of the 5-year
 10 term of the grant.

11 (c) LIMITATIONS.—A grant awarded under sub-
 12 section (a)(1) shall not exceed \$1,000,000 per year and
 13 be for a term of more than 5 years and a grant awarded
 14 under subsection (a)(2) shall not exceed \$750,000 per
 15 year and be for a term of more than 5 years.

16 (d) AUTHORIZATION OF APPROPRIATIONS.—There
 17 are authorized to be appropriated—

18 (1) to carry out subsection (a)(1), \$10,000,000
 19 for each of the fiscal years 1999 through 2003; and

20 (2) to carry out subsection (a)(2), \$3,750,000
 21 for each of the fiscal years 1999 through 2003.

22 **SEC. 6. RESEARCH IN SPECIFIC HIGH PRIORITY AREAS.**

23 (a) ADDITIONAL FUNDS FOR GRANTS.—From
 24 amounts appropriated under subsection (c), the Secretary
 25 shall provide support, through grant programs authorized

1 on the date of enactment of this Act, to entities deter-
 2 mined to have expertise in pediatric quality of care and
 3 outcomes research. Such additional funds shall be used to
 4 improve the quality of children's health, especially in high
 5 priority areas, and shall be subject to the same conditions
 6 and requirements that apply to funds provided under the
 7 existing grant program through which such additional
 8 funds are provided.

9 (b) ADVISORY COMMITTEE.—

10 (1) IN GENERAL.—To evaluate progress made
 11 in pediatric quality of care and outcomes research in
 12 high priority areas, and to identify new high priority
 13 areas, the Secretary shall establish an advisory com-
 14 mittee which shall report annually to the Secretary.

15 (2) MEMBERSHIP.—The Secretary shall ensure
 16 that the advisory committee established under para-
 17 graph (1) includes individuals who are—

18 (A) health care consumers;

19 (B) health care providers;

20 (C) purchasers of health care;

21 (D) representative of health plans involved
 22 in children's health care services; and

23 (E) representatives of Federal agencies in-
 24 cluding—

- 1 (i) the Agency for Health Care Policy
- 2 and Research;
- 3 (ii) the Centers for Disease Control
- 4 and Prevention;
- 5 (iii) the Health Care Financing Ad-
- 6 ministration;
- 7 (iv) the Maternal and Child Health
- 8 Bureau;
- 9 (v) the National Institutes of Health;
- 10 and
- 11 (vi) the Substance Abuse and Mental
- 12 Health Services Administration.

13 (3) EVALUATION OF RESEARCH.—The advisory
 14 committee established under paragraph (1) shall
 15 evaluate research in high priority areas using cri-
 16 teria that include—

- 17 (1) the generation of research that includes
- 18 both short and long term studies;
- 19 (2) the ability to foster public and private
- 20 partnerships; and
- 21 (3) the likelihood that findings will be
- 22 transmitted rapidly into practice.

23 (c) AUTHORIZATION OF APPROPRIATIONS.—There
 24 are authorized to be appropriated to carry out this section,

1 \$12,000,000 for each of the fiscal years 1999 through
2 2003.

3 **SEC. 7. IMPROVING CHILD HEALTH DATA AND DEVELOP-**
4 **ING BETTER DATA COLLECTION SYSTEMS.**

5 (a) SURVEY.—The Secretary shall provide assistance
6 to enable the appropriate Federal agencies to—

7 (1) conduct ongoing biennial supplements and
8 initiate and maintain a longitudinal study on chil-
9 dren’s health that is linked to the appropriate exist-
10 ing national surveys (including the National Health
11 Interview Survey and the Medical Expenditure Panel
12 Survey) to—

13 (A) provide for reliable national estimates
14 of health care expenditures, cost, use, access,
15 and satisfaction for children, including unin-
16 sured children, poor and near-poor children,
17 and children with special health care needs;

18 (B) enhance the understanding of the de-
19 terminants of health outcomes and functional
20 status among children with special health care
21 needs, as well as an understanding of these
22 changes over time and their relationship to
23 health care access and use; and

1 (C) monitor the overall national impact of
2 Federal and State policy changes on children's
3 health care; and

4 (2) develop an ongoing 50-State survey to gen-
5 erate reliable State estimates of health care expendi-
6 tures, cost, use, access, satisfaction, and quality for
7 children, including uninsured children, poor and
8 near-poor children, and children with special health
9 care needs.

10 (b) GRANTS.—The Secretary shall award grants to
11 public and nonprofit entities to enable such entities to de-
12 velop the capacity of local communities to improve child
13 health monitoring at the community level.

14 (c) ELIGIBILITY.—To be eligible to receive a grant
15 under subsection (b), an entity shall—

16 (1) be a public or nonprofit entity; and

17 (2) prepare and submit to the Secretary an ap-
18 plication, at such time, in such manner, and contain-
19 ing such information as the Secretary may require.

20 (d) AUTHORIZATION OF APPROPRIATIONS.—There
21 are authorized to be appropriated to carry out this section,
22 \$14,000,000 for each of the fiscal years 1999 through
23 2003, of which—

24 (1) \$6,000,000 shall be made available in each
25 fiscal year for grants under subsection (a)(1);

1 (2) \$4,000,000 shall be made available in each
2 fiscal year for grants under subsection (a)(2); and

3 (3) \$4,000,000 shall be made available in each
4 fiscal year for grants under subsection (b).

5 **SEC. 8. OVERSIGHT.**

6 Not later than after the date of enactment
7 of this Act, The Secretary shall prepare and submit a re-
8 port to Congress on progress made in pediatric quality of
9 care and outcomes research, including the extent of ongo-
10 ing research, programs, and technical needs, and the De-
11 partment of Health and Human Services' priorities for
12 funding pediatric quality of care and outcomes research.

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