

111TH CONGRESS
1ST SESSION

H. R. 1117

To amend title XIX of the Social Security Act to establish a State plan option under Medicaid to provide an all-inclusive program of care for children who are medically fragile or have one or more chronic conditions that impede their ability to function.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 23, 2009

Ms. BALDWIN (for herself, Mr. BROWN of South Carolina, and Mr. SPRATT) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend title XIX of the Social Security Act to establish a State plan option under Medicaid to provide an all-inclusive program of care for children who are medically fragile or have one or more chronic conditions that impede their ability to function.

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 “Medically Fragile Chil-
5 dren’s Act of 2009”.

1 **SEC. 2. ESTABLISHMENT OF PROGRAM OF ALL-INCLUSIVE**
2 **CARE FOR MEDICALLY FRAGILE CHILDREN**
3 **AS A MEDICAID STATE OPTION.**

4 (a) IN GENERAL.—Title XIX of the Social Security
5 Act is amended—

6 (1) in section 1902(a)(10)(A)(ii) (42 U.S.C.
7 1396b(a)(10)(A)(ii))—

8 (A) in subclause (XVIII) by striking “or”
9 at the end;

10 (B) in subclause (XIX), by adding “or”
11 after the semicolon; and

12 (C) by inserting after subclause (XIX) the
13 following:

14 “(XX) who are medically fragile
15 children described in section 1942;”;

16 (2) in section 1905(a) (42 U.S.C. 1396d(a)), in
17 the matter preceding paragraph (1)—

18 (A) in clause (xii), by striking “or” at the
19 end;

20 (B) in clause (xiii), by adding “or” after
21 the comma; and

22 (C) by inserting after clause (xiii) the fol-
23 lowing:

24 “(xiv) medically fragile children de-
25 scribed in section 1942;”;

26 (3) by adding at the end the following:

1 “PROGRAM OF ALL-INCLUSIVE CARE FOR MEDICALLY
2 FRAGILE CHILDREN

3 “SEC. 1942. (a) STATE OPTION TO ESTABLISH ALL-
4 INCLUSIVE CARE FOR MEDICALLY FRAGILE CHIL-
5 DREN.—

6 “(1) STATE PLAN AMENDMENT.—

7 “(A) IN GENERAL.—A State may elect
8 through a State plan amendment to provide
9 medical assistance and other services described
10 under this section by means of a program of
11 all-inclusive care described in subsection (b) for
12 eligible children described in paragraph (2). In
13 the case of an eligible child enrolled with an all-
14 inclusive care program pursuant to such an
15 election—

16 “(i) the child shall receive benefits
17 under the plan, as well as items and serv-
18 ices described in section 1905(r) solely
19 through such programs; and

20 “(ii) program providers shall receive
21 an all-inclusive payment in accordance with
22 a program agreement for the provision of
23 such care that meets the requirements of
24 this section.

1 “(B) OPTION TO LIMIT ENROLLMENT.—A
2 State may establish a numerical limit on the
3 number of eligible children who may be enrolled
4 in an all-inclusive care program under a pro-
5 gram agreement under this section.

6 “(2) DEFINITION OF ELIGIBLE CHILD; PRO-
7 GRAM PROVIDER.—In this section,

8 “(A) ELIGIBLE CHILD.—The term ‘eligible
9 child’ means an individual who—

10 “(i) has not attained age 25;

11 “(ii) is—

12 “(I) determined by the State to
13 be medically fragile based on health
14 status and related indicators (such as
15 medical diagnoses and measures of ac-
16 tivities of daily living, instrumental
17 activities of daily living, and cognitive
18 impairment); or

19 “(II) diagnosed as having 1 or
20 more chronic conditions;

21 “(iii) requires daily monitoring of a
22 significant medical condition necessitating
23 overall care planning in order to achieve or
24 maintain optimum health and develop-
25 mental status, achieve community integra-

1 tion to the maximum extent possible, and
2 requires both medical assistance and at
3 least 2 additional services furnished under
4 an all-inclusive program as a result of
5 functional deficits;

6 “(iv) resides in the service area of a
7 program provider with a program agree-
8 ment under this section; and

9 “(v) meets such other eligibility re-
10 quirements (including eligibility standards
11 related to family income and resources) as
12 the State may establish pursuant to sec-
13 tion 1902(r)(2).

14 “(B) PROGRAM PROVIDER.—The term
15 ‘program provider’ means an organization with
16 an agreement with the State to provide a pro-
17 gram of all-inclusive care for eligible children
18 enrolled with the organization in accordance
19 with this section and the terms of such agree-
20 ment.

21 “(b) PROGRAM REQUIREMENTS.—In order to satisfy
22 the requirements of this section, a program of all-inclusive
23 care for eligible children shall include, subject to sub-
24 section (d), the following:

1 “(1) COMPREHENSIVE BENEFITS.—The pro-
2 gram shall provide items, benefits, and services to el-
3 igible children enrolled in the program through an
4 all-inclusive and comprehensive, multidisciplinary
5 health and social services delivery system. Each par-
6 ticipating system in a State shall have the dem-
7 onstrated ability to undertake the following:

8 “(A) MEDICAL ASSISTANCE.—Furnish or
9 arrange for the items and services described in
10 section 1905(r) (early and periodic screening,
11 diagnostic, and treatment services), as well as
12 any other item or service for which Federal fi-
13 nancial participation may be available under
14 this Act.

15 “(B) ADMINISTRATIVE ACTIVITIES TO AS-
16 SURE ACCESS TO PREVENTIVE, ACUTE, PRI-
17 MARY, SPECIALIZED, AND LONG TERM CARE
18 AND MEDICALLY APPROPRIATE UTILIZATION OF
19 CARE.—The administration activities described
20 in section 1902(a)(43) (related to administra-
21 tive activities to assure receipt of services de-
22 scribed in section 1905(r)) and section
23 1905(a)(19) (related to medical assistance case
24 management services).

1 “(C) ADDITIONAL SERVICES.—Social work
2 services, transportation services, family support
3 services, care coordination, coordination of pro-
4 gram services with educational, and social serv-
5 ices for which the child is eligible, nutrition as-
6 sessment and counseling, personal care services,
7 respite care, and home and vehicle modification
8 services.

9 “(2) AVAILABILITY OF SERVICES.—Access to
10 necessary medical care for acute conditions 24 hours
11 per day, every day of the year.

12 “(3) QUALITY ASSURANCE; PATIENT SAFE-
13 GUARDS.—At a minimum—

14 “(A) for each enrolled child, a written plan
15 of quality assurance and improvement that is
16 periodically reviewed and updated, and proce-
17 dures for implementing such plan and moni-
18 toring and reviewing the quality of care;

19 “(B) coverage of emergency services de-
20 scribed in section 1932(b)(2);

21 “(C) the provision of information to fami-
22 lies whose children are enrolled in the program
23 in easily understood form; and

24 “(D) written safeguards regarding the
25 rights of enrolled eligible children (including a

1 patients bill of rights and written procedures
2 for grievances and appeals, which shall be no
3 less stringent than procedures applicable to en-
4 tities participating in a State plan for medical
5 assistance pursuant to section 1932 of the Act).

6 “(4) VOLUNTARY ENROLLMENT AND
7 DISENROLLMENT.—Voluntary enrollment and
8 disenrollment without cause at any time.

9 “(5) TRANSITION ASSISTANCE.—In the case of
10 a child who is enrolled under the program under this
11 section and whose enrollment ceases for any reason
12 (including that the child no longer qualifies as an el-
13 igible child), assistance to the child in obtaining nec-
14 essary transitional care through appropriate refer-
15 rals and making the child’s medical records available
16 to new providers.

17 “(c) PROVIDER AGREEMENTS; USE OF ALL-INCLU-
18 SIVE PAYMENT METHODOLOGY.—

19 “(1) IN GENERAL.—

20 “(A) PROVIDER AGREEMENTS.—A State
21 that elects the option under this section shall
22 enter into an agreement with a program pro-
23 vider that has agreed to provide a program of
24 all-inclusive care in accordance with the provi-
25 sions of this section for eligible children who re-

1 side in the geographic area served by the pro-
2 vider (and specified in such agreement) and
3 elect to enroll with the provider.

4 “(B) CHOICE AND COMPETITION.—To the
5 extent feasible, the State shall enter into agree-
6 ments with multiple providers in a single geo-
7 graphic area, and enter into agreements that
8 provide coverage to as much of the State as is
9 practicable.

10 “(C) REPORTING REQUIREMENT.—An
11 agreement entered into under subparagraph (A)
12 shall require that a program provider submit to
13 the Secretary, in a form and manner specified
14 by the Secretary and for each eligible child who
15 is enrolled with the program provider under
16 such an agreement, the following:

17 “(i) Service utilization data.

18 “(ii) Expenditures.

19 “(iii) Quality and health status meas-
20 ures (as identified by the Secretary).

21 “(2) PAYMENT.—

22 “(A) The State may utilize a negotiated,
23 all-inclusive payment method that reflects the
24 full range of medical assistance and related ad-
25 ministrative activities recognized under section

1 1903 of the Act for which the provider will as-
2 sume responsibility.

3 “(B) Such payment method shall provide
4 for payment in an all-inclusive amount (using
5 such methods as a per-member-per month or
6 case payment arrangement) that shall assures
7 quality, efficiency in relation to an all-inclusive
8 approach to payment methods, access to nec-
9 essary care to achieve the purposes of this sec-
10 tion, and to the greatest degree possible, the in-
11 tegration of care, services, and activities de-
12 scribed in this section with other funding re-
13 lated to the educational, social and other serv-
14 ices that an enrolled child may receive.

15 “(3) AUTHORITY TO CONTRACT.—The State
16 may enter into an agreement under this section with
17 a program provider that is not a Medicaid managed
18 care organization (as defined in section
19 1903(m)(1)(A)) so long as the provider dem-
20 onstrates the health care expertise and infrastruc-
21 ture necessary to support the delivery of a program
22 of all-inclusive care in accordance with the provisions
23 of this section and satisfies such other criteria as the
24 State specifies in the State plan amendment filed
25 under this section.

1 “(d) RULES OF CONSTRUCTION.—Nothing in this
2 section shall be construed as—

3 “(1) preventing a program provider from enter-
4 ing into contracts with other governmental or non-
5 governmental payers for the care of eligible children
6 enrolled with the provider; or

7 “(2) affecting the option of a State to offer
8 services to medically fragile children under a dem-
9 onstration or waiver.”.

10 (b) CONFORMING AMENDMENT.—Section 1903(f)(4)
11 of such Act (42 U.S.C. 1936b(f)(4)) is amended in the
12 matter preceding subparagraph (A) by inserting “, 1942,”
13 after “1905(p)(1)”.

14 (c) STUDY AND REPORT.—

15 (1) STUDY.—The Secretary of Health and
16 Human Services, in consultation with State Med-
17 icaid agencies, annually shall conduct a study of the
18 quality and cost of providing medical assistance for
19 a program of all-inclusive care for eligible children
20 under section 1942 of the Social Security Act (as
21 added by subsection (a)). Such study shall include
22 an analysis of—

23 (A) the information submitted to the Sec-
24 retary under subsection (c)(1)(C) of such sec-
25 tion 1942; and

1 (B) the extent to which the provision of
2 such assistance resulted in improved quality
3 and health status measures for eligible children.

4 (2) REPORT.—Not later than 2 years after the
5 date of the enactment of this Act, and annually
6 thereafter, the Secretary of Health and Human
7 Services shall submit a report to Congress on the re-
8 sults of the study required under paragraph (1) that
9 includes such recommendations for legislative or ad-
10 ministrative action as the Secretary determines ap-
11 propriate.

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