

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-

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

“(iv) resides in the service area of a program provider with a program agreement under this section; and

“(v) meets such other eligibility requirements (including eligibility standards related to family income and resources) as the State may establish pursuant to section 1902(r)(2).

“(B) PROGRAM PROVIDER.—The term ‘program provider’ means an organization with an agreement with the State to provide a program of all-inclusive care for eligible children enrolled with the organization in accordance with this section and the terms of such agreement.

“(b) PROGRAM REQUIREMENTS.—In order to satisfy the requirements of this section, a program of all-inclusive care for eligible children shall include, subject to subsection (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.

○