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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

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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.

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

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Medically Fragile Children's Act of 2009''.

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

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

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

(A) in subclause (XVIII) by striking ''or'' at the end;

(B) in subclause (XIX), by adding ''or'' after the semicolon; and

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

''(XX) who are medically fragile children described in section 1942;'';

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

(A) in clause (xii), by striking ''or'' at the end;

(B) in clause (xiii), by adding ''or'' after the comma; and

(C) by inserting after clause (xiii) the following:

''(xiv) medically fragile children described in section 1942;''; and

(3) by adding at the end the following:

"PROGRAM OF ALL-INCLUSIVE CARE FOR MEDICALLY FRAGILE CHILDREN

"SEC. 1942. (a) STATE OPTION TO ESTABLISH ALL-INCLUSIVE CARE FOR MEDICALLY FRAGILE CHILDREN.—

"(1) STATE PLAN AMENDMENT.—

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

"(i) the child shall receive benefits under the plan, as well as items and services described in section 1905(r) solely through such programs; and

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

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

"(2) DEFINITION OF ELIGIBLE CHILD; PROGRAM PROVIDER.—In this section,

"(A) ELIGIBLE CHILD.—The term 'eligible child' means an individual who—

"(i) has not attained age 25;

"(ii) is—

"(I) determined by the State to be medically fragile based on health status and related indicators (such as medical diagnoses and measures of activities of daily living, instrumental activities of daily living, and cognitive impairment); or

"(II) diagnosed as having 1 or more chronic conditions;

"(iii) requires daily monitoring of a significant medical condition necessitating overall care planning in order to achieve or maintain optimum health and developmental 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) COMPREHENSIVE BENEFITS.—The program shall provide items, benefits, and services to eligible children enrolled in the program through an all-inclusive and comprehensive, multidisciplinary health and social services delivery system. Each participating system in a State shall have the demonstrated ability to undertake the following:

"(A) MEDICAL ASSISTANCE.—Furnish or arrange for the items and services described in section 1905(r) (early and periodic screening, diagnostic, and treatment services), as well as any other item or service for which Federal financial participation may be available under this Act.

"(B) ADMINISTRATIVE ACTIVITIES TO ASSURE ACCESS TO PREVENTIVE, ACUTE, PRIMARY, SPECIALIZED, AND LONG TERM CARE AND MEDICALLY APPROPRIATE UTILIZATION OF CARE.—The administration activities described in section 1902(a)(43) (related to administrative activities to assure receipt of services described in section 1905(r)) and section 1905(a)(19) (related to medical assistance case management services).

"(C) ADDITIONAL SERVICES.—Social work services, transportation services, family support services, care coordination, coordination of program services with educational, and social services for which the child is eligible, nutrition assessment and counseling, personal care services, respite care, and home and vehicle modification services.

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

"(3) QUALITY ASSURANCE; PATIENT SAFEGUARDS.—At a minimum—

"(A) for each enrolled child, a written plan of quality assurance and improvement that is periodically reviewed and updated, and procedures for implementing such plan and monitoring and reviewing the quality of care;

"(B) coverage of emergency services described in section 1932(b)(2);

"(C) the provision of information to families whose children are enrolled in the program in easily understood form; and

"(D) written safeguards regarding the rights of enrolled eligible children (including a

patients bill of rights and written procedures for grievances and appeals, which shall be no less stringent than procedures applicable to entities participating in a State plan for medical assistance pursuant to section 1932 of the Act).

"(4) VOLUNTARY ENROLLMENT AND DISENROLLMENT.—Voluntary enrollment and disenrollment without cause at any time.

"(5) TRANSITION ASSISTANCE.—In the case of a child who is enrolled under the program under this section and whose enrollment ceases for any reason (including that the child no longer qualifies as an eligible child), assistance to the child in obtaining necessary transitional care through appropriate referrals and making the child's medical records available to new providers.

"(c) PROVIDER AGREEMENTS; USE OF ALL-INCLUSIVE PAYMENT METHODOLOGY.—

"(1) IN GENERAL.—

"(A) PROVIDER AGREEMENTS.—A State that elects the option under this section shall enter into an agreement with a program provider that has agreed to provide a program of all-inclusive care in accordance with the provisions of this section for eligible children who re-

side in the geographic area served by the provider (and specified in such agreement) and elect to enroll with the provider.

"(B) CHOICE AND COMPETITION.—To the extent feasible, the State shall enter into agreements with multiple providers in a single geographic area, and enter into agreements that provide coverage to as much of the State as is practicable.

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

"(i) Service utilization data.

"(ii) Expenditures.

"(iii) Quality and health status measures (as identified by the Secretary).

"(2) PAYMENT.—

"(A) The State may utilize a negotiated, all-inclusive payment method that reflects the full range of medical assistance and related administrative activities recognized under section

1903 of the Act for which the provider will assume responsibility.

"(B) Such payment method shall provide for payment in an all-inclusive amount (using such methods as a per-member-per month or case payment arrangement) that shall assures quality, efficiency in relation to an all-inclusive approach to payment methods, access to necessary care to achieve the purposes of this section, and to the greatest degree possible, the integration of care, services, and activities described in this section with other funding related to the educational, social and other services that an enrolled child may receive.

"(3) AUTHORITY TO CONTRACT.—The State may enter into an agreement under this section with a program provider that is not a Medicaid managed care organization (as defined in section 1903(m)(1)(A)) so long as the provider demonstrates the health care expertise and infrastructure necessary to support the delivery of a program of all-inclusive care in accordance with the provisions of this section and satisfies such other criteria as the State specifies in the State plan amendment filed under this section.

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

"(1) preventing a program provider from entering into contracts with other governmental or non-governmental payers for the care of eligible children enrolled with the provider; or

"(2) affecting the option of a State to offer services to medically fragile children under a demonstration or waiver.".

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

(c) STUDY AND REPORT.—

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

(A) the information submitted to the Secretary under subsection (c)(1)(C) of such section 1942; and

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

(2) REPORT.—Not later than 2 years after the date of the enactment of this Act, and annually thereafter, the Secretary of Health and Human Services shall submit a report to Congress on the results of the study required under paragraph (1) that includes such recommendations for legislative or administrative action as the Secretary determines appropriate.

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