

109TH CONGRESS
1ST SESSION

S. 183

To amend title XIX of the Social Security Act to provide families of disabled children with the opportunity to purchase coverage under the medicaid program for such children, and for other purposes.

IN THE SENATE OF THE UNITED STATES

JANUARY 26, 2005

Mr. GRASSLEY (for himself and Mr. KENNEDY) introduced the following bill;
which was read twice and referred to the Committee on Finance

A BILL

To amend title XIX of the Social Security Act to provide families of disabled children with the opportunity to purchase coverage under the medicaid program for such children, 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 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Family Opportunity
5 Act of 2005” or the “Dylan Lee James Act”.

6 **SEC. 2. REFERENCES; TABLE OF CONTENTS.**

7 (a) AMENDMENTS TO SOCIAL SECURITY ACT.—Ex-
8 cept as otherwise specifically provided, whenever in this

1 title an amendment is expressed in terms of an amend-
 2 ment to or repeal of a section or other provision, the ref-
 3 erence shall be considered to be made to that section or
 4 other provision of the Social Security Act.

5 (b) TABLE OF CONTENTS.—The table of contents for
 6 this Act is as follows:

Sec. 1. Short title.

Sec. 2. References; table of contents.

Sec. 3. Opportunity for families of disabled children to purchase medicaid cov-
 erage for such children.

Sec. 4. Demonstration projects regarding home and community-based alternative
 to psychiatric residential treatment facilities for children.

Sec. 5. Development and support of family-to-family health information centers.

Sec. 6. Restoration of medicaid eligibility for certain SSI beneficiaries.

7 **SEC. 3. OPPORTUNITY FOR FAMILIES OF DISABLED CHIL-**
 8 **DREN TO PURCHASE MEDICAID COVERAGE**
 9 **FOR SUCH CHILDREN.**

10 (a) STATE OPTION TO ALLOW FAMILIES OF DIS-
 11 ABLED CHILDREN TO PURCHASE MEDICAID COVERAGE
 12 FOR SUCH CHILDREN.—

13 (1) IN GENERAL.—Section 1902 (42 U.S.C.
 14 1396a) is amended—

15 (A) in subsection (a)(10)(A)(ii)—

16 (i) by striking “or” at the end of sub-
 17 clause (XVII);

18 (ii) by adding “or” at the end of sub-
 19 clause (XVIII); and

20 (iii) by adding at the end the fol-
 21 lowing new subclause:

1 “(XIX) who are disabled children
2 described in subsection (cc)(1);” and
3 (B) by adding at the end the following new
4 subsection:

5 “(cc)(1) Individuals described in this paragraph are
6 individuals—

7 “(A) who are children who have not attained 19
8 years of age and are born—

9 “(i) on or after October 1, 1999 (or, at the
10 option of a State, on or after an earlier date),
11 in the case of fiscal year 2006;

12 “(ii) on or after October 1, 1994 (or, at
13 the option of a State, on or after an earlier
14 date), in the case of fiscal year 2007; and

15 “(iii) after October 1, 1988, in the case of
16 fiscal year 2008 and any fiscal year thereafter;

17 “(B) who would be considered disabled under
18 section 1614(a)(3)(C) but for having earnings or
19 deemed income or resources (as determined under
20 title XVI for children) that exceed the requirements
21 for receipt of supplemental security income benefits;
22 and

23 “(C) whose family income does not exceed such
24 income level as the State establishes and does not
25 exceed—

1 “(i) 300 percent of the poverty line (as de-
 2 fined in section 2110(c)(5)) applicable to a fam-
 3 ily of the size involved; or

4 “(ii) such higher percent of such poverty
 5 line as a State may establish, except that—

6 “(I) any medical assistance provided
 7 to an individual whose family income ex-
 8 ceeds 300 percent of such poverty line may
 9 only be provided with State funds; and

10 “(II) no Federal financial participa-
 11 tion shall be provided under section
 12 1903(a) for any medical assistance pro-
 13 vided to such an individual.”.

14 (2) INTERACTION WITH EMPLOYER-SPONSORED
 15 FAMILY COVERAGE.—Section 1902(cc) (42 U.S.C.
 16 1396a(cc)), as added by paragraph (1)(B), is
 17 amended by adding at the end the following new
 18 paragraph:

19 “(2)(A) If an employer of a parent of an individual
 20 described in paragraph (1) offers family coverage under
 21 a group health plan (as defined in section 2791(a) of the
 22 Public Health Service Act), the State shall—

23 “(i) require such parent to apply for, enroll in,
 24 and pay premiums for such coverage as a condition
 25 of such parent’s child being or remaining eligible for

1 medical assistance under subsection
 2 (a)(10)(A)(ii)(XIX) if the parent is determined eligi-
 3 ble for such coverage and the employer contributes
 4 at least 50 percent of the total cost of annual pre-
 5 miums for such coverage; and

6 “(ii) if such coverage is obtained—

7 “(I) subject to paragraph (2) of section
 8 1916(h), reduce the premium imposed by the
 9 State under that section in an amount that rea-
 10 sonably reflects the premium contribution made
 11 by the parent for private coverage on behalf of
 12 a child with a disability; and

13 “(II) treat such coverage as a third party
 14 liability under subsection (a)(25).

15 “(B) In the case of a parent to which subparagraph
 16 (A) applies, a State, subject to paragraph (1)(A)(iii)(II),
 17 may provide for payment of any portion of the annual pre-
 18 mium for such family coverage that the parent is required
 19 to pay. Any payments made by the State under this sub-
 20 paragraph shall be considered, for purposes of section
 21 1903(a), to be payments for medical assistance.”.

22 (b) STATE OPTION TO IMPOSE INCOME-RELATED
 23 PREMIUMS.—Section 1916 (42 U.S.C. 1396o) is amend-
 24 ed—

1 (1) in subsection (a), by striking “subsection
2 (g)” and inserting “subsections (g) and (h)”; and

3 (2) by adding at the end the following new sub-
4 section:

5 “(h)(1) With respect to disabled children provided
6 medical assistance under section 1902(a)(10)(A)(ii)(XIX),
7 subject to paragraph (2), a State may (in a uniform man-
8 ner for such children) require the families of such children
9 to pay monthly premiums set on a sliding scale based on
10 family income.

11 “(2) A premium requirement imposed under para-
12 graph (1) may only apply to the extent that—

13 “(A) in the case of a disabled child described in
14 that paragraph whose family income—

15 “(i) does not exceed 200 percent of the
16 poverty line, the aggregate amount of such pre-
17 mium and any premium that the parent is re-
18 quired to pay for family coverage under section
19 1902(cc)(2)(A)(i) and other cost sharing
20 charges do not exceed 5 percent of the family’s
21 income; and

22 “(ii) exceeds 200, but does not exceed 300,
23 percent of the poverty line, the aggregate
24 amount of such premium and any premium that
25 the parent is required to pay for family cov-

1 erage under section 1902(cc)(2)(A)(i) and other
 2 cost sharing charges do not exceed 7.5 percent
 3 of the family's income; and

4 “(B) the requirement is imposed consistent with
 5 section 1902(cc)(2)(A)(ii)(I).

6 “(3) A State shall not require prepayment of a pre-
 7 mium imposed pursuant to paragraph (1) and shall not
 8 terminate eligibility of a child under section
 9 1902(a)(10)(A)(ii)(XIX) for medical assistance under this
 10 title on the basis of failure to pay any such premium until
 11 such failure continues for a period of at least 60 days from
 12 the date on which the premium became past due. The
 13 State may waive payment of any such premium in any
 14 case where the State determines that requiring such pay-
 15 ment would create an undue hardship.”.

16 (c) CONFORMING AMENDMENTS.—(1) Section
 17 1903(f)(4) (42 U.S.C. 1396b(f)(4)) is amended in the
 18 matter preceding subparagraph (A), by inserting
 19 “1902(a)(10)(A)(ii)(XIX),” after
 20 “1902(a)(10)(A)(ii)(XVIII),”.

21 (2) Section 1905(u)(2)(B) (42 U.S.C.
 22 1396d(u)(2)(B)) is amended by adding at the end the fol-
 23 lowing sentence: “Such term excludes any child eligible for
 24 medical assistance only by reason of section
 25 1902(a)(10)(A)(ii)(XIX).”.

1 (d) EFFECTIVE DATE.—The amendments made by
 2 this section shall apply to medical assistance for items and
 3 services furnished on or after October 1, 2005.

4 **SEC. 4. DEMONSTRATION PROJECTS REGARDING HOME**
 5 **AND COMMUNITY-BASED ALTERNATIVE TO**
 6 **PSYCHIATRIC RESIDENTIAL TREATMENT FA-**
 7 **CILITIES FOR CHILDREN.**

8 (a) IN GENERAL.—The Secretary of Health and
 9 Human Services (in this section referred to as the “Sec-
 10 retary”) is authorized to conduct, during each of fiscal
 11 years 2006 through 2010, demonstration projects (each
 12 in the section referred to as a “demonstration project”)
 13 in accordance with this section under which up to 10
 14 States (as defined for purposes of title XIX of the Social
 15 Security Act) are awarded grants, on a competitive basis,
 16 to test the effectiveness in improving or maintaining a
 17 child’s functional level and cost-effectiveness of providing
 18 coverage of home and community-based alternatives to
 19 psychiatric residential treatment for children enrolled in
 20 the medicaid program under title XIX of such Act.

21 (b) APPLICATION OF TERMS AND CONDITIONS.—

22 (1) IN GENERAL.—Subject to the provisions of
 23 this section, for the purposes of the demonstration
 24 projects, and only with respect to children enrolled
 25 under such demonstration projects, a psychiatric res-

1 idential treatment facility (as defined in section
 2 483.352 of title 42 of the Code of Federal Regula-
 3 tions) shall be deemed to be a facility specified in
 4 section 1915(c) of the Social Security Act (42
 5 U.S.C. 1396n(c)), and to be included in each ref-
 6 erence in such section 1915(c) to hospitals, nursing
 7 facilities, and intermediate care facilities for the
 8 mentally retarded.

9 (2) STATE OPTION TO ASSURE CONTINUITY OF
 10 MEDICAID COVERAGE.—Upon the termination of a
 11 demonstration project under this section, the State
 12 that conducted the project may elect, only with re-
 13 spect to a child who is enrolled in such project on
 14 the termination date, to continue to provide medical
 15 assistance for coverage of home and community-
 16 based alternatives to psychiatric residential treat-
 17 ment for the child in accordance with section
 18 1915(c) of the Social Security Act (42 U.S.C.
 19 1396n(c)), as modified through the application of
 20 paragraph (1). Expenditures incurred for providing
 21 such medical assistance shall be treated as a home
 22 and community-based waiver program under section
 23 1915(c) of the Social Security Act (42 U.S.C.
 24 1396n(c)) for purposes of payment under section
 25 1903 of such Act (42 U.S.C. 1396b).

1 (c) TERMS OF DEMONSTRATION PROJECTS.—

2 (1) IN GENERAL.—Except as otherwise pro-
3 vided in this section, a demonstration project shall
4 be subject to the same terms and conditions as apply
5 to a waiver under section 1915(c) of the Social Se-
6 curity Act (42 U.S.C. 1396n(c)), including the waiv-
7 er of certain requirements under the first sentence
8 of paragraph (3) of such section but not applying
9 the second sentence of such paragraph.

10 (2) BUDGET NEUTRALITY.—In conducting the
11 demonstration projects under this section, the Sec-
12 retary shall ensure that the aggregate payments
13 made by the Secretary under title XIX of the Social
14 Security Act (42 U.S.C. 1396 et seq.) do not exceed
15 the amount by which the Secretary estimates would
16 have been paid under that title if the demonstration
17 projects under this section had not been imple-
18 mented.

19 (3) EVALUATION.—The application for a dem-
20 onstration project shall include an undertaking to
21 provide for such interim and final evaluations of the
22 demonstration project by independent third parties,
23 and for such interim and final reports to the Sec-
24 retary, as the Secretary may require.

1 (d) PAYMENTS TO STATES; LIMITATIONS TO SCOPE
2 AND FUNDING.—

3 (1) IN GENERAL.—Subject to paragraph (2), a
4 demonstration project approved by the Secretary
5 under this section shall be treated as a home and
6 community-based waiver program under section
7 1915(c) of the Social Security Act (42 U.S.C.
8 1396n(c)) for purposes of payment under section
9 1903 of such Act (42 U.S.C. 1396b).

10 (2) LIMITATION.—In no case may the amount
11 of payments made by the Secretary under this sec-
12 tion for State demonstration projects for a fiscal
13 year exceed the amount available under subsection
14 (f)(2)(A) for such fiscal year.

15 (e) SECRETARY'S EVALUATION AND REPORT.—The
16 Secretary shall conduct an interim and final evaluation of
17 State demonstration projects under this section and shall
18 report to the President and Congress the conclusions of
19 such evaluations within 12 months of completing such
20 evaluations.

21 (f) FUNDING.—

22 (1) IN GENERAL.—For the purpose of carrying
23 out this section, there are appropriated, from
24 amounts in the Treasury not otherwise appropriated,

for fiscal years 2006 through 2010 a total of
\$218,000,000, of which—

(A) the amount specified in paragraph (2)
shall be available for each of fiscal years 2006
through 2010; and

(B) a total of \$1,000,000 shall be available
to the Secretary for the evaluations and report
under subsection (f).

(2) FISCAL YEAR LIMIT.—

(A) IN GENERAL.—For purposes of para-
graph (1), the amount specified in this para-
graph for a fiscal year is the amount specified
in subparagraph (B) for the fiscal year plus the
difference, if any, between the total amount
available under this paragraph for prior fiscal
years and the total amount previously expended
under paragraph (1)(A) for such prior fiscal
years.

(B) FISCAL YEAR AMOUNTS.—The amount
specified in this subparagraph for—

(i) fiscal year 2006 is \$21,000,000;

(ii) fiscal year 2007 is \$37,000,000;

(iii) fiscal year 2008 is \$49,000,000;

(iv) fiscal year 2009 is \$53,000,000;

and

1 (v) fiscal year 2010 is \$57,000,000.

2 **SEC. 5. DEVELOPMENT AND SUPPORT OF FAMILY-TO-FAM-**
 3 **ILY HEALTH INFORMATION CENTERS.**

4 Section 501 (42 U.S.C. 701) is amended by adding
 5 at the end the following new subsection:

6 “(c)(1)(A) For the purpose of enabling the Secretary
 7 (through grants, contracts, or otherwise) to provide for
 8 special projects of regional and national significance for
 9 the development and support of family-to-family health in-
 10 formation centers described in paragraph (2)—

11 “(i) there is appropriated to the Secretary, out
 12 of any money in the Treasury not otherwise appro-
 13 priated—

14 “(I) \$3,000,000 for fiscal year 2006;

15 “(II) \$4,000,000 for fiscal year 2007; and

16 “(III) \$5,000,000 for fiscal year 2008; and

17 “(ii) there is authorized to be appropriated to
 18 the Secretary, \$5,000,000 for each of fiscal years
 19 2009 and 2010.

20 “(B) Funds appropriated or authorized to be appro-
 21 priated under subparagraph (A) shall—

22 “(i) be in addition to amounts appropriated
 23 under subsection (a) and retained under section
 24 502(a)(1) for the purpose of carrying out activities
 25 described in subsection (a)(2); and

1 “(ii) remain available until expended.

2 “(2) The family-to-family health information centers
3 described in this paragraph are centers that—

4 “(A) assist families of children with disabilities
5 or special health care needs to make informed
6 choices about health care in order to promote good
7 treatment decisions, cost-effectiveness, and improved
8 health outcomes for such children;

9 “(B) provide information regarding the health
10 care needs of, and resources available for, such chil-
11 dren;

12 “(C) identify successful health delivery models
13 for such children;

14 “(D) develop with representatives of health care
15 providers, managed care organizations, health care
16 purchasers, and appropriate State agencies a model
17 for collaboration between families of such children
18 and health professionals;

19 “(E) provide training and guidance regarding
20 caring for such children;

21 “(F) conduct outreach activities to the families
22 of such children, health professionals, schools, and
23 other appropriate entities and individuals; and

24 “(G) are staffed—

1 “(i) by such families who have expertise in
 2 Federal and State public and private health
 3 care systems; and

4 “(ii) by health professionals.

5 “(3) The Secretary shall develop family-to-family
 6 health information centers described in paragraph (2) in
 7 accordance with the following:

8 “(A) With respect to fiscal year 2006, such cen-
 9 ters shall be developed in not less than 25 States.

10 “(B) With respect to fiscal year 2007, such
 11 centers shall be developed in not less than 40 States.

12 “(C) With respect to fiscal year 2008, such cen-
 13 ters shall be developed in all States.

14 “(4) The provisions of this title that are applicable
 15 to the funds made available to the Secretary under section
 16 502(a)(1) apply in the same manner to funds made avail-
 17 able to the Secretary under paragraph (1)(A).

18 “(5) For purposes of this subsection, the term ‘State’
 19 means each of the 50 States and the District of Colum-
 20 bia.”.

21 **SEC. 6. RESTORATION OF MEDICAID ELIGIBILITY FOR CER-**
 22 **TAIN SSI BENEFICIARIES.**

23 (a) IN GENERAL.—Section 1902(a)(10)(A)(i)(II) (42
 24 U.S.C. 1396a(a)(10)(A)(i)(II)) is amended—

25 (1) by inserting “(aa)” after “(II)”;

1 (2) by striking “) and” and inserting “and”;

2 (3) by striking “section or who are” and insert-
3 ing “section), (bb) who are”; and

4 (4) by inserting before the comma at the end
5 the following: “, or (cc) who are under 21 years of
6 age and with respect to whom supplemental security
7 income benefits would be paid under title XVI if
8 subparagraphs (A) and (B) of section 1611(c)(7)
9 were applied without regard to the phrase ‘the first
10 day of the month following’ ”.

11 (b) EFFECTIVE DATE.—The amendments made by
12 subsection (a) shall apply to medical assistance for items
13 and services furnished on or after January 1, 2006.

○