

109TH CONGRESS  
1ST SESSION

# H. R. 1443

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.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 17, 2005

Mr. SESSIONS (for himself, Mr. WAXMAN, Mr. TERRY, Mr. DINGELL, Mr. McHUGH, Mr. McNULTY, Mr. ABERCROMBIE, Mr. BROWN of Ohio, Mr. VAN HOLLEN, Mr. FORD, Mr. KIND, Mr. LANGEVIN, Mr. TOWNS, Mr. ROSS, Mrs. CHRISTENSEN, Mrs. CAPPs, Mr. GRIJALVA, Mr. PALLONE, Mr. PAUL, Mr. MORAN of Virginia, Ms. LEE, Mr. LANTOS, Mr. DOGGETT, Mr. SCHIFF, Mr. ALLEN, Mr. DAVIS of Florida, Ms. SCHAKOWSKY, Mr. STRICKLAND, Mr. GORDON, Mr. ENGEL, Mr. HINCHAY, Mr. COOPER, Ms. BALDWIN, and Mr. McDERMOTT) 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 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,*

1 **SECTION 1. SHORT TITLE.**

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

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

5 (a) AMENDMENTS TO SOCIAL SECURITY ACT.—Ex-  
6 cept as otherwise specifically provided, whenever in this  
7 title an amendment is expressed in terms of an amend-  
8 ment to or repeal of a section or other provision, the ref-  
9 erence shall be considered to be made to that section or  
10 other provision of the Social Security Act.

11 (b) TABLE OF CONTENTS.—The table of contents for  
12 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 alter-  
native to psychiatric residential treatment facilities for chil-  
dren.

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

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

13 **SEC. 3. OPPORTUNITY FOR FAMILIES OF DISABLED CHIL-**  
14 **DREN TO PURCHASE MEDICAID COVERAGE**  
15 **FOR SUCH CHILDREN.**

16 (a) STATE OPTION TO ALLOW FAMILIES OF DIS-  
17 ABLED CHILDREN TO PURCHASE MEDICAID COVERAGE  
18 FOR SUCH CHILDREN.—

19 (1) IN GENERAL.—Section 1902 (42 U.S.C.  
20 1396a) is amended—

21 (A) in subsection (a)(10)(A)(ii)—

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

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

5 (iii) by adding at the end the fol-  
6 lowing new subclause:

7 “(XIX) who are disabled children  
8 described in subsection (cc)(1);”;

9 (B) by adding at the end the following new  
10 subsection:

11 “(cc)(1) Individuals described in this paragraph are  
12 individuals—

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

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

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

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

23 “(B) who would be considered disabled under  
24 section 1614(a)(3)(C) but for having earnings or  
25 deemed income or resources (as determined under

1 title XVI for children) that exceed the requirements  
2 for receipt of supplemental security income benefits;  
3 and

4 “(C) whose family income does not exceed such  
5 income level as the State establishes and does not  
6 exceed—

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

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

12 “(I) any medical assistance provided  
13 to an individual whose family income ex-  
14 ceeds 300 percent of such poverty line may  
15 only be provided with State funds; and

16 “(II) no Federal financial participa-  
17 tion shall be provided under section  
18 1903(a) for any medical assistance pro-  
19 vided to such an individual.”.

20 (2) INTERACTION WITH EMPLOYER-SPONSORED  
21 FAMILY COVERAGE.—Section 1902(cc) (42 U.S.C.  
22 1396a(cc)), as added by paragraph (1)(B), is  
23 amended by adding at the end the following new  
24 paragraph:

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

5           “(i) require such parent to apply for, enroll in,  
6 and pay premiums for such coverage as a condition  
7 of such parent’s child being or remaining eligible for  
8 medical assistance under subsection  
9 (a)(10)(A)(ii)(XIX) if the parent is determined eligi-  
10 ble for such coverage and the employer contributes  
11 at least 50 percent of the total cost of annual pre-  
12 miums for such coverage; and

13           “(ii) if such coverage is obtained—

14           “(I) subject to paragraph (2) of section  
15 1916(h), reduce the premium imposed by the  
16 State under that section in an amount that rea-  
17 sonably reflects the premium contribution made  
18 by the parent for private coverage on behalf of  
19 a child with a disability; and

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

22       “(B) In the case of a parent to which subparagraph  
23 (A) applies, a State, subject to paragraph (1)(A)(iii)(II),  
24 may provide for payment of any portion of the annual pre-  
25 mium for such family coverage that the parent is required

1 to pay. Any payments made by the State under this sub-  
2 paragraph shall be considered, for purposes of section  
3 1903(a), to be payments for medical assistance.”.

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

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

9 (2) by adding at the end the following new sub-  
10 section:

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

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

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

21 “(i) does not exceed 200 percent of the  
22 poverty line, the aggregate amount of such pre-  
23 mium and any premium that the parent is re-  
24 quired to pay for family coverage under section  
25 1902(cc)(2)(A)(i) and other cost sharing

1 charges do not exceed 5 percent of the family's  
2 income; and

3 “(ii) exceeds 200, but does not exceed 300,  
4 percent of the poverty line, the aggregate  
5 amount of such premium and any premium that  
6 the parent is required to pay for family cov-  
7 erage under section 1902(cc)(2)(A)(i) and other  
8 cost sharing charges do not exceed 7.5 percent  
9 of the family's income; and

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

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

22 (c) CONFORMING AMENDMENTS.—(1) Section  
23 1903(f)(4) (42 U.S.C. 1396b(f)(4)) is amended in the  
24 matter preceding subparagraph (A), by inserting

1 “1902(a)(10)(A)(ii)(XIX),” after  
2 “1902(a)(10)(A)(ii)(XVIII),”.

3 (2) Section 1905(u)(2)(B) (42 U.S.C.  
4 1396d(u)(2)(B)) is amended by adding at the end the fol-  
5 lowing sentence: “Such term excludes any child eligible for  
6 medical assistance only by reason of section  
7 1902(a)(10)(A)(ii)(XIX).”.

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

11 **SEC. 4. DEMONSTRATION PROJECTS REGARDING HOME**  
12 **AND COMMUNITY-BASED ALTERNATIVE TO**  
13 **PSYCHIATRIC RESIDENTIAL TREATMENT FA-**  
14 **CILITIES FOR CHILDREN.**

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

1 psychiatric residential treatment for children enrolled in  
2 the medicaid program under title XIX of such Act.

3 (b) APPLICATION OF TERMS AND CONDITIONS.—

4 (1) IN GENERAL.—Subject to the provisions of  
5 this section, for the purposes of the demonstration  
6 projects, and only with respect to children enrolled  
7 under such demonstration projects, a psychiatric res-  
8 idential treatment facility (as defined in section  
9 483.352 of title 42 of the Code of Federal Regula-  
10 tions) shall be deemed to be a facility specified in  
11 section 1915(c) of the Social Security Act (42  
12 U.S.C. 1396n(c)), and to be included in each ref-  
13 erence in such section 1915(c) to hospitals, nursing  
14 facilities, and intermediate care facilities for the  
15 mentally retarded.

16 (2) STATE OPTION TO ASSURE CONTINUITY OF  
17 MEDICAID COVERAGE.—Upon the termination of a  
18 demonstration project under this section, the State  
19 that conducted the project may elect, only with re-  
20 spect to a child who is enrolled in such project on  
21 the termination date, to continue to provide medical  
22 assistance for coverage of home and community-  
23 based alternatives to psychiatric residential treat-  
24 ment for the child in accordance with section  
25 1915(e) of the Social Security Act (42 U.S.C.

1 1396n(c)), as modified through the application of  
2 paragraph (1). Expenditures incurred for providing  
3 such medical assistance shall be treated as a home  
4 and community-based waiver program under section  
5 1915(e) of the Social Security Act (42 U.S.C.  
6 1396n(c)) for purposes of payment under section  
7 1903 of such Act (42 U.S.C. 1396b).

8 (c) TERMS OF DEMONSTRATION PROJECTS.—

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

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

1           (3) EVALUATION.—The application for a dem-  
2           onstration project shall include an undertaking to  
3           provide for such interim and final evaluations of the  
4           demonstration project by independent third parties,  
5           and for such interim and final reports to the Sec-  
6           retary, as the Secretary may require.

7           (d) PAYMENTS TO STATES; LIMITATIONS TO SCOPE  
8           AND FUNDING.—

9           (1) IN GENERAL.—Subject to paragraph (2), a  
10          demonstration project approved by the Secretary  
11          under this section shall be treated as a home and  
12          community-based waiver program under section  
13          1915(e) of the Social Security Act (42 U.S.C.  
14          1396n(c)) for purposes of payment under section  
15          1903 of such Act (42 U.S.C. 1396b).

16          (2) LIMITATION.—In no case may the amount  
17          of payments made by the Secretary under this sec-  
18          tion for State demonstration projects for a fiscal  
19          year exceed the amount available under subsection  
20          (f)(2)(A) for such fiscal year.

21          (e) SECRETARY'S EVALUATION AND REPORT.—The  
22          Secretary shall conduct an interim and final evaluation of  
23          State demonstration projects under this section and shall  
24          report to the President and Congress the conclusions of

1 such evaluations within 12 months of completing such  
2 evaluations.

3 (f) FUNDING.—

4 (1) IN GENERAL.—For the purpose of carrying  
5 out this section, there are appropriated, from  
6 amounts in the Treasury not otherwise appropriated,  
7 for fiscal years 2006 through 2010 a total of  
8 \$218,000,000, of which—

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

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

15 (2) FISCAL YEAR LIMIT.—

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

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

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

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

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

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

7 and

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

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

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

13 “(c)(1)(A) For the purpose of enabling the Secretary  
14 (through grants, contracts, or otherwise) to provide for  
15 special projects of regional and national significance for  
16 the development and support of family-to-family health in-  
17 formation centers described in paragraph (2)—

18 “(i) there is appropriated to the Secretary, out  
19 of any money in the Treasury not otherwise appro-  
20 priated—

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

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

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

1           “(ii) there is authorized to be appropriated to  
2           the Secretary, \$5,000,000 for each of fiscal years  
3           2009 and 2010.

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

6           “(i) be in addition to amounts appropriated  
7           under subsection (a) and retained under section  
8           502(a)(1) for the purpose of carrying out activities  
9           described in subsection (a)(2); and

10           “(ii) remain available until expended.

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

13           “(A) assist families of children with disabilities  
14           or special health care needs to make informed  
15           choices about health care in order to promote good  
16           treatment decisions, cost-effectiveness, and improved  
17           health outcomes for such children;

18           “(B) provide information regarding the health  
19           care needs of, and resources available for, such chil-  
20           dren;

21           “(C) identify successful health delivery models  
22           for such children;

23           “(D) develop with representatives of health care  
24           providers, managed care organizations, health care  
25           purchasers, and appropriate State agencies a model

1 for collaboration between families of such children  
2 and health professionals;

3 “(E) provide training and guidance regarding  
4 caring for such children;

5 “(F) conduct outreach activities to the families  
6 of such children, health professionals, schools, and  
7 other appropriate entities and individuals; and

8 “(G) are staffed—

9 “(i) by such families who have expertise in  
10 Federal and State public and private health  
11 care systems; and

12 “(ii) by health professionals.

13 “(3) The Secretary shall develop family-to-family  
14 health information centers described in paragraph (2) in  
15 accordance with the following:

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

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

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

22 “(4) The provisions of this title that are applicable  
23 to the funds made available to the Secretary under section  
24 502(a)(1) apply in the same manner to funds made avail-  
25 able to the Secretary under paragraph (1)(A).

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

4 **SEC. 6. RESTORATION OF MEDICAID ELIGIBILITY FOR CER-**  
5 **TAIN SSI BENEFICIARIES.**

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

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

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

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

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

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

○