

107TH CONGRESS  
1ST SESSION

# H. R. 600

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

FEBRUARY 13, 2001

Mr. SESSIONS (for himself, Mr. WAXMAN, Mr. UPTON, Mr. BARRETT, Mr. BILIRAKIS, Mr. DINGELL, Mr. DREIER, Mr. BROWN of Ohio, Ms. PRYCE of Ohio, Mr. STRICKLAND, Mrs. ROUKEMA, Mr. BALDACCI, Mr. ISAKSON, Mr. DOGETT, Mr. GILCHREST, Mr. MOORE, Mrs. MYRICK, Mr. OBERSTAR, Mr. REYNOLDS, Mr. HINCHEY, Mr. DEFazio, Mr. KENNEDY of Rhode Island, Mr. SANDERS, Ms. KAPTUR, Mrs. JOHNSON of Connecticut, Mr. TOWNS, Mr. STARK, Ms. ESHOO, Ms. BALDWIN, Mr. GALLEGLY, Mr. ABERCROMBIE, Mr. SNYDER, Ms. SCHAKOWSKY, Mr. SHIMKUS, Mr. SCOTT, Mr. PALLONE, Mr. STUPAK, Mr. MARKEY, Mr. WYNN, Mrs. CAPPS, Mr. HALL of Ohio, Mr. KIND, Mr. MATSUI, Mr. GEORGE MILLER of California, Mr. MORAN of Virginia, Mrs. MCCARTHY of New York, Mr. PAYNE, Mr. UDALL of New Mexico, Mr. WATT of North Carolina, Mr. ENGEL, Mr. NADLER, Ms. LEE, Ms. BERKLEY, Mr. MURTHA, Mr. RUSH, Mrs. JONES of Ohio, Mr. KUCINICH, Mr. McNULTY, Ms. DEGETTE, Mr. BOUCHER, Mr. GREEN of Texas, Mr. BECERRA, Mr. ALLEN, Ms. RIVERS, Mrs. LOWEY, Mr. SHAYS, Mr. WELDON of Florida, Mr. OXLEY, Mr. PICKERING, Mr. WHITFIELD, Mr. LAHOOD, Mr. HAYWORTH, Mr. FLETCHER, Mr. SWEENEY, Mr. SHADEGG, Mr. TAUZIN, Mr. GILMAN, Mr. NETHERCUTT, Mr. MORAN of Kansas, Mr. BRADY of Texas, Mr. DEUTSCH, Ms. CAPITO, Mr. WELLER, Mr. SCHAFER, Mr. NUSSLE, and Mr. PAUL) 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 pur-

chase 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; AMENDMENTS TO SOCIAL SECU-**  
 4       **RITY ACT; TABLE OF CONTENTS.**

5       (a) SHORT TITLE.—This Act may be cited as the  
 6       “Family Opportunity Act of 2001” or the “Dylan Lee  
 7       James Act”.

8       (b) AMENDMENTS TO SOCIAL SECURITY ACT.—Ex-  
 9       cept as otherwise specifically provided, whenever in this  
 10      Act an amendment is expressed in terms of an amendment  
 11      to or repeal of a section or other provision, the reference  
 12      shall be considered to be made to that section or other  
 13      provision of the Social Security Act.

14      (c) TABLE OF CONTENTS.—The table of contents of  
 15      this Act is as follows:

- Sec. 1. Short title; amendments to Social Security Act; table of contents.
- Sec. 2. Opportunity for families of disabled children to purchase medicaid coverage for such children.
- Sec. 3. Treatment of inpatient psychiatric hospital services for individuals under age 21 in home or community-based services waivers.
- Sec. 4. Demonstration of coverage under the medicaid program of children with potentially severe disabilities.
- Sec. 5. Development and support of family-to-family health information centers.
- Sec. 6. Restoration of medicaid eligibility for certain SSI beneficiaries.

1 **SEC. 2. OPPORTUNITY FOR FAMILIES OF DISABLED CHIL-**  
2 **DREN TO PURCHASE MEDICAID COVERAGE**  
3 **FOR SUCH CHILDREN.**

4 (a) STATE OPTION TO ALLOW FAMILIES OF DIS-  
5 ABLED CHILDREN TO PURCHASE MEDICAID COVERAGE  
6 FOR SUCH CHILDREN.—

7 (1) IN GENERAL.—Section 1902 (42 U.S.C.  
8 1396a), as amended by section 2(a) of the Breast  
9 and Cervical Cancer Prevention and Treatment Act  
10 of 2000 (Public Law 106–354; 114 Stat. 1381) and  
11 section 702(b) of the Medicare, Medicaid, and  
12 SCHIP Benefits Improvement and Protection Act of  
13 2000 (as enacted into law by section 1(a)(6) of Pub-  
14 lic Law 106–554), 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:

22 “(XIX) who are disabled children  
23 described in subsection (cc)(1);”; and

24 (B) by adding at the end the following new  
25 subsection:

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

3               “(A) who have not attained 18 years of age;

4               “(B) who would be considered disabled under  
5 section 1614(a)(3)(C) (determined without regard to  
6 the reference to age in that section) but for having  
7 earnings or deemed income or resources (as deter-  
8 mined under title XVI for children) that exceed the  
9 requirements for receipt of supplemental security in-  
10 come benefits; and

11              “(C) whose family income does not exceed such  
12 income level as the State establishes and does not  
13 exceed—

14                      “(i) 300 percent of the income official pov-  
15 erty line (as defined by the Office of Manage-  
16 ment and Budget, and revised annually in ac-  
17 cordance with section 673(2) of the Omnibus  
18 Budget Reconciliation Act of 1981) applicable  
19 to a family of the size involved; or

20                      “(ii) such higher percent of such poverty  
21 line as a State may establish, except that no  
22 Federal financial participation shall be provided  
23 under section 1903(a) for any medical assist-  
24 ance provided to an individual who would not be

1 described in this subsection but for this  
2 clause.”.

3 (2) INTERACTION WITH EMPLOYER-SPONSORED  
4 FAMILY COVERAGE.—Section 1902(cc) (42 U.S.C.  
5 1396a(cc)), as added by paragraph (1), is amended  
6 by adding at the end the following new paragraph:  
7 “(2)(A) If an employer of a parent of an individual  
8 described in paragraph (1) offers family coverage under  
9 a group health plan (as defined in section 2791(a) of the  
10 Public Health Service Act), the State may—

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

19 “(ii) if such coverage is obtained—

20 “(I) subject to paragraph (2) of section  
21 1916(h), reduce the premium imposed by the  
22 State under that section (if any) in an amount  
23 that reasonably reflects the premium contribu-  
24 tion made by the parent for private coverage on  
25 behalf of a child with a disability; and

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

3           “(B) In the case of a parent to which subparagraph  
4 (A) applies, if the family income of such parent does not  
5 exceed 300 percent of the income official poverty line (re-  
6 ferred to in paragraph (1)(C)(i)), a State may provide for  
7 payment of any portion of the annual premium for such  
8 family coverage that the parent is required to pay. Any  
9 payments made by the State under this subparagraph  
10 shall be considered, for purposes of section 1903(a), to  
11 be payments for medical assistance.”.

12           (b) STATE OPTION TO IMPOSE INCOME-RELATED  
13 PREMIUMS.—Section 1916 (42 U.S.C. 1396o) is  
14 amended—

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

17           (2) by adding at the end the following new sub-  
18 section:

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

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

3 “(A) the aggregate amount of such premium  
 4 and any premium that the parent is required to pay  
 5 for family coverage under section 1902(cc)(2)(A)(i)  
 6 does not exceed 5 percent of the family’s income;  
 7 and

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

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

20 (c) CONFORMING AMENDMENT.—Section 1903(f)(4)  
 21 (42 U.S.C. 1396b(f)(4)), as amended by section 710(a)  
 22 of the Medicare, Medicaid, and SCHIP Benefits Improve-  
 23 ment and Protection Act of 2000 (as enacted into law by  
 24 section 1(a)(6) of Public Law 106–554), is amended in  
 25 the matter preceding subparagraph (A) by inserting

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

3 (d) TECHNICAL AMENDMENTS.—

4 (1) Section 1902 (42 U.S.C. 1396a), as amend-  
5 ed by section 702(b) of the Medicare, Medicaid, and  
6 SCHIP Benefits Improvement and Protection Act of  
7 2000 (as enacted into law by section 1(a)(6) of Pub-  
8 lic Law 106–554), is amended by redesignating the  
9 subsection (aa) added by such section as subsection  
10 (bb).

11 (2) Section 1902(a)(15) (42 U.S.C.  
12 1396a(a)(15)), as added by section 702(a)(2) of the  
13 Medicare, Medicaid, and SCHIP Benefits Improve-  
14 ment and Protection Act of 2000 (as so enacted into  
15 law), is amended by striking “subsection (aa)” and  
16 inserting “subsection (bb)”.

17 (3) Section 1915(b) (42 U.S.C. 1396n(b)), as  
18 amended by section 702(c)(2) of the Medicare, Med-  
19 icaid, and SCHIP Benefits Improvement and Pro-  
20 tection Act of 2000 (as so enacted into law), is  
21 amended by striking “1902(aa)” and inserting  
22 “1902(bb)”.

23 (e) EFFECTIVE DATE.—

24 (1) IN GENERAL.—The amendments made by  
25 subsections (a), (b), and (c) shall apply to medical



1 assistance for items and services furnished on or  
 2 after January 1, 2002.

3 (2) TECHNICAL AMENDMENTS.—The amend-  
 4 ments made by subsection (d) shall take effect as if  
 5 included in the enactment of section 702 of the  
 6 Medicare, Medicaid, and SCHIP Benefits Improve-  
 7 ment and Protection Act of 2000 (as enacted into  
 8 law by section 1(a)(6) of Public Law 106–554).

9 **SEC. 3. TREATMENT OF INPATIENT PSYCHIATRIC HOS-**  
 10 **PITAL SERVICES FOR INDIVIDUALS UNDER**  
 11 **AGE 21 IN HOME OR COMMUNITY-BASED**  
 12 **SERVICES WAIVERS.**

13 (a) IN GENERAL.—Section 1915(c) (42 U.S.C.  
 14 1396n(c)) is amended—

15 (1) in paragraph (1)—

16 (A) in the first sentence, by inserting “, or  
 17 inpatient psychiatric hospital services for indi-  
 18 viduals under age 21,” after “intermediate care  
 19 facility for the mentally retarded”; and

20 (B) in the second sentence, by inserting “,  
 21 or inpatient psychiatric hospital services for in-  
 22 dividuals under age 21” before the period;

23 (2) in paragraph (2)(B), by striking “or serv-  
 24 ices in an intermediate care facility for the mentally  
 25 retarded” each place it appears and inserting “,

1 services in an intermediate care facility for the men-  
2 tally retarded, or inpatient psychiatric hospital serv-  
3 ices for individuals under age 21”;

4 (3) by striking paragraph (2)(C) and inserting  
5 the following:

6 “(C) such individuals who are determined to be  
7 likely to require the level of care provided in a hos-  
8 pital, nursing facility, or intermediate care facility  
9 for the mentally retarded, or inpatient psychiatric  
10 hospital services for individuals under age 21, are  
11 informed of the feasible alternatives, if available  
12 under the waiver, at the choice of such individuals,  
13 to the provision of inpatient hospital services, nurs-  
14 ing facility services, services in an intermediate care  
15 facility for the mentally retarded, or inpatient psy-  
16 chiatric hospital services for individuals under age  
17 21;”;

18 (4) in paragraph (7)(A)—

19 (A) by inserting “, or inpatient psychiatric  
20 hospital services for individuals under age 21,”  
21 after “intermediate care facility for the men-  
22 tally retarded”; and

23 (B) by inserting “, or who would require  
24 inpatient psychiatric hospital services for indi-  
25 viduals under age 21” before the period.

1 (b) EFFECTIVE DATE.—The amendments made by  
 2 subsection (a) apply with respect to medical assistance  
 3 provided on or after January 1, 2001.

4 **SEC. 4. DEMONSTRATION OF COVERAGE UNDER THE MED-**  
 5 **ICAID PROGRAM OF CHILDREN WITH POTEN-**  
 6 **TIALLY SEVERE DISABILITIES.**

7 (a) STATE APPLICATION.—A State may apply to the  
 8 Secretary of Health and Human Services (in this section  
 9 referred to as the “Secretary”) for approval of a dem-  
 10 onstration project (in this section referred to as a “dem-  
 11 onstration project”) under which up to a specified max-  
 12 imum number of children with a potentially severe dis-  
 13 ability (as defined in subsection (b)) are provided medical  
 14 assistance under the State medicaid plan under title XIX  
 15 of the Social Security Act (42 U.S.C. 1396 et seq.).

16 (b) CHILD WITH A POTENTIALLY SEVERE DIS-  
 17 ABILITY DEFINED.—

18 (1) IN GENERAL.—In this section, the term  
 19 “child with a potentially severe disability” means,  
 20 with respect to a demonstration project, an indi-  
 21 vidual who—

22 (A) has not attained 21 years of age;

23 (B) has a physical or mental condition,  
 24 disease, disorder (including a congenital birth  
 25 defect or a metabolic condition), injury, or de-

1            velopmental disability that was incurred before  
 2            the individual attained such age; and

3            (C) is reasonably expected, but for the re-  
 4            ceipt of medical assistance under the State  
 5            medicaid plan, to reach the level of disability  
 6            defined under section 1614(a)(3) of the Social  
 7            Security Act (42 U.S.C. 1382c(a)(3)), (deter-  
 8            mined without regard to the reference to age in  
 9            subparagraph (C) of that section).

10          (2) EXCEPTION.—Such term does not include  
 11          an individual who would be considered disabled  
 12          under section 1614(a)(3)(C) of the Social Security  
 13          Act (42 U.S.C. 1382c(a)(3)(C)) (determined without  
 14          regard to the reference to age in that section).

15          (c) APPROVAL OF DEMONSTRATION PROJECTS.—

16            (1) IN GENERAL.—Subject to paragraph (3),  
 17            the Secretary shall approve applications under sub-  
 18            section (a) that meet the requirements of paragraph  
 19            (2) and such additional terms and conditions as the  
 20            Secretary may require. The Secretary may waive the  
 21            requirement of section 1902(a)(1) of the Social Se-  
 22            curity Act (42 U.S.C. 1396a(a)(1)) to allow for sub-  
 23            State demonstrations.

24            (2) TERMS AND CONDITIONS OF DEMONSTRA-  
 25            TION PROJECTS.—The Secretary may not approve a

1 demonstration project under this section unless the  
2 State provides assurances satisfactory to the Sec-  
3 retary that the following conditions are or will be  
4 met:

5 (A) INDEPENDENT EVALUATION.—The  
6 State provides for an independent evaluation of  
7 the project to be conducted during fiscal year  
8 2006.

9 (B) CONSULTATION FOR DEVELOPMENT  
10 OF CRITERIA.—The State consults with appro-  
11 priate pediatric health professionals in estab-  
12 lishing the criteria for determining whether a  
13 child has a potentially severe disability.

14 (C) ANNUAL REPORT.—The State submits  
15 an annual report to the Secretary (in a uniform  
16 form and manner established by the Secretary)  
17 on the use of funds provided under the grant  
18 that includes the following:

19 (i) Enrollment and financial statistics  
20 on—

21 (I) the total number of children  
22 with a potentially severe disability en-  
23 rolled in the demonstration project,  
24 disaggregated by disability;

1 (II) the services provided by cat-  
2 egory or code and the cost of each  
3 service so categorized or coded; and

4 (III) the number of children en-  
5 rolled in the demonstration project  
6 who also receive services through pri-  
7 vate insurance.

8 (ii) With respect to the report sub-  
9 mitted for fiscal year 2006, the results of  
10 the independent evaluation conducted  
11 under subparagraph (A).

12 (iii) Such additional information as  
13 the Secretary may require.

14 (3) LIMITATIONS ON FEDERAL FUNDING.—

15 (A) APPROPRIATION.—

16 (i) IN GENERAL.—Out of any funds in  
17 the Treasury not otherwise appropriated,  
18 there is appropriated to carry out this  
19 section—

20 (I) \$16,666,000 for each of fiscal  
21 years 2002 and 2003; and

22 (II) \$16,667,000 for each of fis-  
23 cal years 2004 through 2007.

24 (ii) BUDGET AUTHORITY.—Clause (i)  
25 constitutes budget authority in advance of

1 appropriations Acts and represents the ob-  
2 ligation of the Federal Government to pro-  
3 vide for the payment of the amounts ap-  
4 propriated under clause (i).

5 (B) LIMITATION ON PAYMENTS.—In no  
6 case may—

7 (i) the aggregate amount of payments  
8 made by the Secretary to States under this  
9 section exceed \$100,000,000;

10 (ii) the aggregate amount of payments  
11 made by the Secretary to States for ad-  
12 ministrative expenses relating to the eval-  
13 uations and annual reports required under  
14 subparagraphs (A) and (C) of paragraph  
15 (2) exceed \$2,000,000 of such  
16 \$100,000,000; or

17 (iii) payments be provided by the Sec-  
18 retary for a fiscal year after fiscal year  
19 2010.

20 (C) FUNDS ALLOCATED TO STATES.—

21 (i) IN GENERAL.—The Secretary shall  
22 allocate funds to States based on their ap-  
23 plications and the availability of funds. In  
24 making such allocations, the Secretary  
25 shall ensure an equitable distribution of

1 funds among States with large populations  
2 and States with small populations.

3 (ii) AVAILABILITY.—Funds allocated  
4 to a State under a grant made under this  
5 section for a fiscal year shall remain avail-  
6 able until expended.

7 (D) FUNDS NOT ALLOCATED TO STATES.—  
8 Funds not allocated to States in the fiscal year  
9 for which they are appropriated shall remain  
10 available in succeeding fiscal years for alloca-  
11 tion by the Secretary using the allocation for-  
12 mula established under this section.

13 (E) PAYMENTS TO STATES.—The Sec-  
14 retary shall pay to each State with a dem-  
15 onstration project approved under this section,  
16 from its allocation under subparagraph (C), an  
17 amount for each quarter equal to the Federal  
18 medical assistance percentage (as defined in  
19 section 1905(b) of the Social Security Act (42  
20 U.S.C. 1395d(b))) of expenditures in the quar-  
21 ter for medical assistance provided to children  
22 with a potentially severe disability.

23 (d) RECOMMENDATION.—Not later than October 1,  
24 2005, the Secretary shall submit a recommendation to the  
25 Committee on Commerce of the House of Representatives



1 and the Committee on Finance of the Senate regarding  
 2 whether the demonstration project established under this  
 3 section should be continued after fiscal year 2007.

4 (e) STATE DEFINED.—In this section, the term  
 5 “State” has the meaning given such term for purposes of  
 6 title XIX of the Social Security Act (42 U.S.C. 1396 et  
 7 seq.).

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

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

12 “(c)(1) In addition to amounts appropriated under  
 13 subsection (a) and retained under section 502(a)(1) for  
 14 the purpose of carrying out activities described in sub-  
 15 section (a)(2), there is appropriated to the Secretary, out  
 16 of any money in the Treasury not otherwise appropriated,  
 17 for the purpose of enabling the Secretary (through grants,  
 18 contracts, or otherwise) to provide for special projects of  
 19 regional and national significance for the development and  
 20 support of family-to-family health information centers de-  
 21 scribed in paragraph (2), \$10,000,000 for each of fiscal  
 22 years 2002 through 2007. Funds appropriated under this  
 23 paragraph shall remain available until expended.

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

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

6           “(B) provide information regarding the health  
7           care needs of, and resources available for, children  
8           with disabilities or special health care needs;

9           “(C) identify successful health delivery models  
10          for such children;

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

16          “(E) provide training and guidance regarding  
17          caring for such children;

18          “(F) conduct outreach activities to the families  
19          of such children, health professionals, schools, and  
20          other appropriate entities and individuals; and

21          “(G) are staffed by families of children with  
22          disabilities or special health care needs who have ex-  
23          pertise in Federal and State public and private  
24          health care systems and health professionals.

1 “(3) The provisions of this title that are applicable  
 2 to the funds made available to the Secretary under section  
 3 502(a)(1) apply in the same manner to funds made avail-  
 4 able to the Secretary under paragraph (1).”.

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

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

- 9 (1) by inserting “(aa)” after “(II)”;
- 10 (2) by striking “or who are” and inserting “,  
 11 (bb) who are”; and
- 12 (3) 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 the first day of the first  
 22 calendar quarter that begins after the date of enactment  
 23 of this Act.

