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S. 321

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

FEBRUARY 13, 2001

Mr. GRASSLEY (for himself, Mr. KENNEDY, Mr. JEFFORDS, Mr. BAUCUS, Ms. SNOWE, Mr. ROCKEFELLER, Mr. DASCHLE, Mr. BREAUX, Mr. CONRAD, Mr. GRAHAM, Mr. BINGAMAN, Mr. KERRY, Mr. TORRICELLI, Mrs. LINCOLN, Mr. AKAKA, Mr. BAYH, Mr. BIDEN, Mrs. BOXER, Mr. BYRD, Mr. L. CHAFEE, Mr. CLELAND, Mrs. CLINTON, Ms. COLLINS, Mr. CORZINE, Mr. CRAPO, Mr. DAYTON, Mr. DEWINE, Mr. DODD, Mr. DOMENICI, Mr. DORGAN, Mr. DURBIN, Mr. EDWARDS, Mrs. FEINSTEIN, Mr. FRIST, Mr. HARKIN, Mr. HELMS, Mr. INOUE, Mr. JOHNSON, Mr. KOHL, Ms. LANDRIEU, Mr. LEAHY, Mr. LEVIN, Mr. LIEBERMAN, Mr. LUGAR, Ms. MIKULSKI, Mrs. MURRAY, Mr. NELSON of Florida, Mr. REED, Mr. REID, Mr. ROBERTS, Mr. SANTORUM, Mr. SARBANES, Mr. SCHUMER, Mr. SMITH of Oregon, Mr. THOMAS, Mr. THURMOND, Mr. WARNER, and Mr. WELLSTONE) 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,*

1 **SECTION 1. SHORT TITLE; AMENDMENTS TO SOCIAL SECUR-**
 2 **RITY ACT; TABLE OF CONTENTS.**

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

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

12 (c) **TABLE OF CONTENTS.**—The table of contents of
 13 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.

14 **SEC. 2. OPPORTUNITY FOR FAMILIES OF DISABLED CHIL-**
 15 **DREN TO PURCHASE MEDICAID COVERAGE**
 16 **FOR SUCH CHILDREN.**

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

20 (1) **IN GENERAL.**—Section 1902 (42 U.S.C.
 21 1396a), as amended by section 2(a) of the Breast

1 and Cervical Cancer Prevention and Treatment Act
2 of 2000 (Public Law 106–354; 114 Stat. 1381) and
3 section 702(b) of the Medicare, Medicaid, and
4 SCHIP Benefits Improvement and Protection Act of
5 2000 (as enacted into law by section 1(a)(6) of Pub-
6 lic Law 106–554), is amended—

7 (A) in subsection (a)(10)(A)(ii)—

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

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

12 (iii) by adding at the end the fol-
13 lowing new subclause:

14 “(XIX) who are disabled children
15 described in subsection (cc)(1);”;

16 (B) by adding at the end the following new
17 subsection:

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

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

21 “(B) who would be considered disabled under
22 section 1614(a)(3)(C) (determined without regard to
23 the reference to age in that section) but for having
24 earnings or deemed income or resources (as deter-
25 mined under title XVI for children) that exceed the

1 requirements for receipt of supplemental security in-
 2 come benefits; and

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

6 “(i) 300 percent of the income official pov-
 7 erty line (as defined by the Office of Manage-
 8 ment and Budget, and revised annually in ac-
 9 cordance with section 673(2) of the Omnibus
 10 Budget Reconciliation Act of 1981) applicable
 11 to a family of the size involved; or

12 “(ii) such higher percent of such poverty
 13 line as a State may establish, except that no
 14 Federal financial participation shall be provided
 15 under section 1903(a) for any medical assist-
 16 ance provided to an individual who would not be
 17 described in this subsection but for this
 18 clause.”.

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

23 “(2)(A) If an employer of a parent of an individual
 24 described in paragraph (1) offers family coverage under

1 a group health plan (as defined in section 2791(a) of the
2 Public Health Service Act), the State may—

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

11 “(ii) if such coverage is obtained—

12 “(I) subject to paragraph (2) of section
13 1916(h), reduce the premium imposed by the
14 State under that section (if any) in an amount
15 that reasonably reflects the premium contribu-
16 tion made by the parent for private coverage on
17 behalf of a child with a disability; and

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

20 “(B) In the case of a parent to which subparagraph
21 (A) applies, if the family income of such parent does not
22 exceed 300 percent of the income official poverty line (re-
23 ferred to in paragraph (1)(C)(i)), a State may provide for
24 payment of any portion of the annual premium for such
25 family coverage that the parent is required to pay. Any

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

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

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) the aggregate amount of such premium
20 and any premium that the parent is required to pay
21 for family coverage under section 1902(cc)(2)(A)(i)
22 does not exceed 5 percent of the family’s income;
23 and

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

1 “(3) A State shall not require prepayment of a pre-
2 mium imposed pursuant to paragraph (1) and shall not
3 terminate eligibility of a child under section
4 1902(a)(10)(A)(ii)(XIX) for medical assistance under this
5 title on the basis of failure to pay any such premium until
6 such failure continues for a period of not less than 60 days
7 from the date on which the premium became past due.
8 The State may waive payment of any such premium in
9 any case where the State determines that requiring such
10 payment would create an undue hardship.”.

11 (c) CONFORMING AMENDMENT.—Section 1903(f)(4)
12 (42 U.S.C. 1396b(f)(4)), as amended by section 710(a)
13 of the Medicare, Medicaid, and SCHIP Benefits Improve-
14 ment and Protection Act of 2000 (as enacted into law by
15 section 1(a)(6) of Public Law 106–554), is amended in
16 the matter preceding subparagraph (A) by inserting
17 “1902(a)(10)(A)(ii)(XIX),” after “1902(a)(10)(A)
18 (ii)(XVIII),”.

19 (d) TECHNICAL AMENDMENTS.—

20 (1) Section 1902 (42 U.S.C. 1396a), as amend-
21 ed by section 702(b) of the Medicare, Medicaid, and
22 SCHIP Benefits Improvement and Protection Act of
23 2000 (as enacted into law by section 1(a)(6) of Pub-
24 lic Law 106–554), is amended by redesignating the

1 subsection (aa) added by such section as subsection
2 (bb).

3 (2) Section 1902(a)(15) (42 U.S.C.
4 1396a(a)(15)), as added by section 702(a)(2) of the
5 Medicare, Medicaid, and SCHIP Benefits Improve-
6 ment and Protection Act of 2000 (as so enacted into
7 law), is amended by striking “subsection (aa)” and
8 inserting “subsection (bb)”.

9 (3) Section 1915(b) (42 U.S.C. 1396n(b)), as
10 amended by section 702(c)(2) of the Medicare, Med-
11 icaid, and SCHIP Benefits Improvement and Pro-
12 tection Act of 2000 (as so enacted into law), is
13 amended by striking “1902(aa)” and inserting
14 “1902(bb)”.

15 (e) EFFECTIVE DATE.—

16 (1) IN GENERAL.—The amendments made by
17 subsections (a), (b), and (c) shall apply to medical
18 assistance for items and services furnished on or
19 after January 1, 2002.

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

1 **SEC. 3. TREATMENT OF INPATIENT PSYCHIATRIC HOS-**
2 **PITAL SERVICES FOR INDIVIDUALS UNDER**
3 **AGE 21 IN HOME OR COMMUNITY-BASED**
4 **SERVICES WAIVERS.**

5 (a) IN GENERAL.—Section 1915(c) (42 U.S.C.
6 1396n(c)) is amended—

7 (1) in paragraph (1)—

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

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

15 (2) in paragraph (2)(B), by striking “or serv-
16 ices in an intermediate care facility for the mentally
17 retarded” each place it appears and inserting “,
18 services in an intermediate care facility for the men-
19 tally retarded, or inpatient psychiatric hospital serv-
20 ices for individuals under age 21”;

21 (3) by striking paragraph (2)(C) and inserting
22 the following:

23 “(C) such individuals who are determined to be
24 likely to require the level of care provided in a hos-
25 pital, nursing facility, or intermediate care facility
26 for the mentally retarded, or inpatient psychiatric

1 hospital services for individuals under age 21, are
 2 informed of the feasible alternatives, if available
 3 under the waiver, at the choice of such individuals,
 4 to the provision of inpatient hospital services, nurs-
 5 ing facility services, services in an intermediate care
 6 facility for the mentally retarded, or inpatient psy-
 7 chiatric hospital services for individuals under age
 8 21;” and

9 (4) in paragraph (7)(A)—

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

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

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

20 **SEC. 4. DEMONSTRATION OF COVERAGE UNDER THE MED-**
 21 **ICAID PROGRAM OF CHILDREN WITH POTEN-**
 22 **TIALLY SEVERE DISABILITIES.**

23 (a) STATE APPLICATION.—A State may apply to the
 24 Secretary of Health and Human Services (in this section
 25 referred to as the “Secretary”) for approval of a dem-

1 onstration project (in this section referred to as a “dem-
2 onstration project”) under which up to a specified max-
3 imum number of children with a potentially severe dis-
4 ability (as defined in subsection (b)) are provided medical
5 assistance under the State medicaid plan under title XIX
6 of the Social Security Act (42 U.S.C. 1396 et seq.).

7 (b) CHILD WITH A POTENTIALLY SEVERE DIS-
8 ABILITY DEFINED.—

9 (1) IN GENERAL.—In this section, the term
10 “child with a potentially severe disability” means,
11 with respect to a demonstration project, an indi-
12 vidual who—

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

14 (B) has a physical or mental condition,
15 disease, disorder (including a congenital birth
16 defect or a metabolic condition), injury, or de-
17 velopmental disability that was incurred before
18 the individual attained such age; and

19 (C) is reasonably expected, but for the re-
20 ceipt of medical assistance under the State
21 medicaid plan, to reach the level of disability
22 defined under section 1614(a)(3) of the Social
23 Security Act (42 U.S.C. 1382c(a)(3)), (deter-
24 mined without regard to the reference to age in
25 subparagraph (C) of that section).

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

6 (c) APPROVAL OF DEMONSTRATION PROJECTS.—

7 (1) IN GENERAL.—Subject to paragraph (3),
8 the Secretary shall approve applications under sub-
9 section (a) that meet the requirements of paragraph
10 (2) and such additional terms and conditions as the
11 Secretary may require. The Secretary may waive the
12 requirement of section 1902(a)(1) of the Social Se-
13 curity Act (42 U.S.C. 1396a(a)(1)) to allow for sub-
14 State demonstrations.

15 (2) TERMS AND CONDITIONS OF DEMONSTRA-
16 TION PROJECTS.—The Secretary may not approve a
17 demonstration project under this section unless the
18 State provides assurances satisfactory to the Sec-
19 retary that the following conditions are or will be
20 met:

21 (A) INDEPENDENT EVALUATION.—The
22 State provides for an independent evaluation of
23 the project to be conducted during fiscal year
24 2006.

1 (B) CONSULTATION FOR DEVELOPMENT
2 OF CRITERIA.—The State consults with appro-
3 priate pediatric health professionals in estab-
4 lishing the criteria for determining whether a
5 child has a potentially severe disability.

6 (C) ANNUAL REPORT.—The State submits
7 an annual report to the Secretary (in a uniform
8 form and manner established by the Secretary)
9 on the use of funds provided under the grant
10 that includes the following:

11 (i) Enrollment and financial statistics
12 on—

13 (I) the total number of children
14 with a potentially severe disability en-
15 rolled in the demonstration project,
16 disaggregated by disability;

17 (II) the services provided by cat-
18 egory or code and the cost of each
19 service so categorized or coded; and

20 (III) the number of children en-
21 rolled in the demonstration project
22 who also receive services through pri-
23 vate insurance.

24 (ii) With respect to the report sub-
25 mitted for fiscal year 2006, the results of

1 the independent evaluation conducted
2 under subparagraph (A).

3 (iii) Such additional information as
4 the Secretary may require.

5 (3) LIMITATIONS ON FEDERAL FUNDING.—

6 (A) APPROPRIATION.—

7 (i) IN GENERAL.—Out of any funds in
8 the Treasury not otherwise appropriated,
9 there is appropriated to carry out this
10 section—

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

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

15 (ii) BUDGET AUTHORITY.—Clause (i)
16 constitutes budget authority in advance of
17 appropriations Acts and represents the ob-
18 ligation of the Federal Government to pro-
19 vide for the payment of the amounts ap-
20 propriated under clause (i).

21 (B) LIMITATION ON PAYMENTS.—In no
22 case may—

23 (i) the aggregate amount of payments
24 made by the Secretary to States under this
25 section exceed \$100,000,000;

1 (ii) the aggregate amount of payments
 2 made by the Secretary to States for ad-
 3 ministrative expenses relating to the eval-
 4 uations and annual reports required under
 5 subparagraphs (A) and (C) of paragraph
 6 (2) exceed \$2,000,000 of such
 7 \$100,000,000; or

8 (iii) payments be provided by the Sec-
 9 retary for a fiscal year after fiscal year
 10 2010.

11 (C) FUNDS ALLOCATED TO STATES.—

12 (i) IN GENERAL.—The Secretary shall
 13 allocate funds to States based on their ap-
 14 plications and the availability of funds. In
 15 making such allocations, the Secretary
 16 shall ensure an equitable distribution of
 17 funds among States with large populations
 18 and States with small populations.

19 (ii) AVAILABILITY.—Funds allocated
 20 to a State under a grant made under this
 21 section for a fiscal year shall remain avail-
 22 able until expended.

23 (D) FUNDS NOT ALLOCATED TO STATES.—

24 Funds not allocated to States in the fiscal year
 25 for which they are appropriated shall remain

1 available in succeeding fiscal years for alloca-
2 tion by the Secretary using the allocation for-
3 mula established under this section.

4 (E) PAYMENTS TO STATES.—The Sec-
5 retary shall pay to each State with a dem-
6 onstration project approved under this section,
7 from its allocation under subparagraph (C), an
8 amount for each quarter equal to the Federal
9 medical assistance percentage (as defined in
10 section 1905(b) of the Social Security Act (42
11 U.S.C. 1395d(b))) of expenditures in the quar-
12 ter for medical assistance provided to children
13 with a potentially severe disability.

14 (d) RECOMMENDATION.—Not later than October 1,
15 2005, the Secretary shall submit a recommendation to the
16 Committee on Commerce of the House of Representatives
17 and the Committee on Finance of the Senate regarding
18 whether the demonstration project established under this
19 section should be continued after fiscal year 2007.

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

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

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

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

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

19 “(A) assist families of children with disabilities
20 or special health care needs to make informed
21 choices about health care in order to promote good
22 treatment decisions, cost-effectiveness, and improved
23 health outcomes for such children;

24 “(B) provide information regarding the health
25 care needs of, and resources available for, children
26 with disabilities or special health care needs;

1 “(C) identify successful health delivery models
2 for such children;

3 “(D) develop with representatives of health care
4 providers, managed care organizations, health care
5 purchasers, and appropriate State agencies a model
6 for collaboration between families of such children
7 and health professionals;

8 “(E) provide training and guidance regarding
9 caring for such children;

10 “(F) conduct outreach activities to the families
11 of such children, health professionals, schools, and
12 other appropriate entities and individuals; and

13 “(G) are staffed by families of children with
14 disabilities or special health care needs who have ex-
15 pertise in Federal and State public and private
16 health care systems and health professionals.

17 “(3) The provisions of this title that are applicable
18 to the funds made available to the Secretary under section
19 502(a)(1) apply in the same manner to funds made avail-
20 able to the Secretary under paragraph (1).”.

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 “or who are” and inserting “,
2 (bb) who are”; and

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

10 (b) EFFECTIVE DATE.—The amendments made by
11 subsection (a) shall apply to medical assistance for items
12 and services furnished on or after the first day of the first
13 calendar quarter that begins after the date of enactment
14 of this Act.

○