

## Calendar No. 295

108TH CONGRESS }  
*1st Session* }

SENATE

{ REPORT  
108-157

---

### FAMILY OPPORTUNITY ACT OF 2003

---

SEPTEMBER 30 (legislative day, SEPTEMBER 29), 2003.—Ordered to be printed

Mr. GRASSLEY, from the Committee on Finance,  
submitted the following

### R E P O R T

[To accompany S. 622]

The Committee on Finance, to which was referred the bill (S. 622) 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, reports favorably thereon with an amendment in the nature of a substitute and refers the bill to the full Senate with a recommendation that the bill do pass.

#### I. BACKGROUND

Health care research shows that children with significant disabilities face multiple barriers to accessing critical health care services. In their efforts to obtain high quality health care services for their child, parents with children with disabilities often face financial difficulties. Many are forced to stay impoverished, become impoverished, put their children in out of home placements, or simply give up custody of their children—so that their child can maintain eligibility for health coverage through Medicaid.

Not all employer sponsored health plans or State Children's Health Insurance Programs (S-CHIP) cover essential services that children with severe disabilities need to maintain their health status or to prevent deterioration of their health status. Medicaid often provides access to more comprehensive services, including respite care, day treatment services, mental health services, personal care services, and durable medical equipment.

In a health care survey of 20 States, families with special needs children report they are turning down jobs, turning down raises, refusing overtime, and are unable to save money for the future of their children and family—so that they can stay in an income bracket low enough to qualify their child for SSI and/or Medicaid.

The committee bill is intended to address the two greatest barriers preventing families from staying together and staying employed: (1) Lack of access to appropriate health care services, and (2) lack of access to information and resources to help parents navigate the system.

The sponsors of the Family Opportunity Act first introduced the legislation in the second session of the 106th Congress. The bill had wide bi-partisan support in both the House and Senate. By the close of the 106th Congress, the House bill, sponsored by Representatives Pete Sessions (R-TX) and Henry Waxman (D-CA), had 142 co-sponsors and the Senate bill, sponsored by Senators Chuck Grassley (R-IA) and Edward Kennedy (D-MA), had 77 co-sponsors.

The introduction of the Family Opportunity Act (also called the “Dylan Lee James Family Opportunity Act”) was motivated by the circumstance of individual families—the Melissa Arnold family and the Dylan Lee James family. Both families relied on Medicaid health services for their child with disabilities, and both families risked losing eligibility to Medicaid as a result of financial eligibility rules that created disincentives for the parents to work and/or to seek better employment opportunities. Sadly, Dylan Lee James, who suffered from Downs Syndrome, died at young age from complications.

The FY 2001 Budget Resolution included a reserve fund for the Family Opportunity Act, and on July 12, 2000, the Senate Budget Committee held a hearing to examine the Family Opportunity Act. The nature of the hearing was to highlight the need for the Family Opportunity Act. The first panel of witnesses consisted of three elected representatives, including Senator Edward Kennedy (D-MA), Governor Mike Huckabee (R-AR), and Representative Pete Sessions (R-TX). The second panel consisted of health experts and family members, including William Scanlon, Ph.D., Director of Health, Education, and Human Services at the General Accounting Office in Washington, D.C.; Gordon Fay, a staff sergeant in the U.S. Air Force and a parent of a 9-year-old daughter with Angelman’s Syndrome; Rebecca Eichorn, a parent of a teenager with mental health needs from Newberg, Oregon; Tanya Baker-McCue, a parent of a teenager with cystic fibrosis from Albuquerque, New Mexico; and Dr. David Alexander, medical director of Raymond Blank Children’s Hospital in Des Moines, Iowa.

The sponsors re-introduced the Family Opportunity Act in the 107th Congress and again achieved broad bi-partisan support. It was voice voted out of the Finance Committee. The House bill, H.R. 600, had 236 co-sponsors and the Senate bill, S. 321, had 75 co-sponsors.

At the time of the Finance Committee mark up of the Family Opportunity Act in 108th Congress, there were 63 co-sponsors of the Senate bill, S. 622.

For 3 consecutive years, the sponsors of the legislation have secured support from congressional budget committees. The FY 2003 Congressional Budget Resolution includes a \$7.46 billion budget reserve fund for the Family Opportunity Act legislation.

## II. DESCRIPTION OF THE BILL

The legislation reported by the Finance Committee consists of the following provisions:

*Section 1. Short title*

*Section 2. Opportunity for families of disabled children to purchase medicaid coverage for such children*

### PRESENT LAW

(a) State Option To Allow Families of Disabled Children To Purchase Medicaid Coverage for Such Children.—Federal law establishes the categories or groups of individuals that can be covered under Medicaid and, in many cases, defines specific eligibility rules for these categories. Some groups must be covered under Medicaid (called mandatory groups), while others may be covered at state option. In general, Medicaid is available to low-income persons who are aged, blind or disabled, members of families with dependent children, and certain other pregnant women and children. Applicants' income and resources must be within certain limits, most of which are determined by States, again within Federal statutory parameters. States have considerable flexibility in defining countable income and assets for determining eligibility.

For disabled children, there are several potentially applicable Medicaid eligibility groups, some mandatory but most optional. Some of these children could qualify for Medicaid through more than one pathway in any given State. There are four primary coverage groups for which disability status or medical need is directly related to eligibility.

First, subject to one important exception, States are required to cover all children receiving Supplemental Security Income (SSI). Because SSI is a Federal program, income and resource standards do not vary by . In determining financial eligibility, parents' income is deemed available to noninstitutionalized children (but the need of household members is taken into account). If family income is higher than the SSI threshold, the child will not qualify for SSI or Medicaid.

The major exception to the required coverage under Medicaid of SSI recipients occurs in so called "209(b)" States. Such states can apply more restrictive income and resources standards and/or methodologies in determining Medicaid eligibility than the standards applicable under SSI. States that offer State Supplemental Payments (SSP) may also offer Medicaid coverage to SSP recipients who would be eligible for SSI, except that their income is too high.

Second, States may offer medically needy coverage under Medicaid. The medically needy are persons who fall into one of the other categories of eligibility (e.g., is a dependent child) but whose income exceeds applicable financial standards. Income standards for the medically needy can be no higher than 133 $\frac{1}{3}$  percent of the State's former Aid to Families with Dependent Children (AFDC) payment standard in effect on July 16, 1996. Individuals can meet these financial criteria by having income that falls below the medically needy standard, or by incurring medical expenses that when subtracted from income, result in an amount that is lower than the medically needy income standard. Resource standards correspond

to those applicable under SSI. Older children or those with very large medical expenses may qualify for medically needy coverage. (Other eligibility pathways for younger children are described below.)

Third, States may extend Medicaid to certain disabled children under 18 who are living at home and who would be eligible for Medicaid via the SSI pathway if they were in a hospital, nursing facility, or intermediate care facility for the mentally retarded, as long as the cost of care at home is no more than institutional care. (This group is called the “Katie Beckett” category.) The law allows States to consider only the child’s income and resources when determining eligibility for this group. That is, States may ignore parents’ income.

Fourth, States have an option to cover persons needing home and community based services, if these persons would otherwise require institutional care covered by Medicaid. These services are provided under waiver programs authorized by Section 1915(c) of Title XIX of the Social Security Act. Unlike the Katie Beckett option, which requires all disabled children within a State to be covered, such programs may be limited to specific geographic areas, and/or may target specific disabled groups and/or specific individuals within a group. States may apply institutional deeming rules which allow them to ignore parents’ income in determining a child’s eligibility for waiver services.

Disabled children can also qualify for Medicaid via other eligibility pathways for which disability status and medical need are irrelevant. These additional pathways cover children at higher income levels than those applicable to most of the disability-related eligibility categories described above. For example, States are required to provide Medicaid coverage to children under age 6 (and pregnant women) in families with incomes below 133 percent of the Federal poverty level (FPL), and in FY2002, for children between ages 6 and 18 in families with income below 100 percent of FPL. States may cover infants under age one (and pregnant women) in families with income between 133 and 185 percent of FPL. Similarly, under the State Children’s Health Insurance Program (SCHIP), States may extend Medicaid (or provide other health insurance) to certain children under age 19 who are not otherwise eligible for Medicaid in families with income that is above the applicable Medicaid standard but less than 200 percent of FPL, or in States that already exceed the 200 percent of FPL level for Medicaid children, within 50 percentage points over that existing level.

(b) Interaction With Employer Sponsored Family Coverage.— States may require Medicaid eligibles to apply for coverage in certain employer-sponsored group health plans (for which such persons are eligible) when it is cost-effective to do so. This requirement may be imposed as a condition of continuing Medicaid eligibility, except that failure of a parent to enroll a child must not affect the child’s continuing eligibility for Medicaid.

If all members of the family are not eligible for Medicaid, and the group health plan requires enrollment of the entire family, Medicaid will pay associated premiums for full family coverage if doing so is cost-effective. However, Medicaid will not pay deductibles, co-insurance or other cost-sharing for family members ineligible for Medicaid. Third, party liability rules apply to coverage in a group

health plan. That is, such plans, not Medicaid, must pay for all covered services under the plan.

Under current law, cost-effectiveness means that the reduction in Medicaid expenditures for Medicaid beneficiaries enrolled in a group health plan is likely to be greater than the additional costs for premiums and cost-sharing required under the group health plan. Group health plan means a plan of (or contributed to by) an employer or employee organization to provide health care (directly or otherwise) for employees and their families.

In sum, when it is cost-effective, Medicaid pays the premiums and other cost-sharing under certain group health plans for Medicaid eligibles, as well as for Medicaid services not covered under the group health plan. This includes payment of any premium and cost-sharing amounts that exceed limits placed on such payments in Medicaid law.

(c) State Option To Impose Income-Related Premiums.—Generally, for certain eligibility categories, States may not impose enrollment fees, premiums or similar charges. Further, States are specifically prohibited from requiring payment of deductions, cost-sharing or similar charges for services furnished to persons under 18 years of age (up to age 21, or any reasonable subcategory of such persons between 18 and 21 years of age, at State option).

In certain circumstances, States may impose monthly premiums for enrollment in Medicaid. For example, States may require certain qualified severely impaired persons ages 16 and above who but for earnings would be eligible for SSI to pay premiums and other cost-sharing charges set on a sliding scale based on income. Further, States may require such persons with income between 250 to 450 percent of FPL to pay the full premium. However, the sum of such payments may not exceed 7.5 percent of income.

For other groups, States may not require prepayment of premiums and may not terminate eligibility due to failure to pay premiums, unless such failure continues for at least 60 days. States can also waive premiums when such payments would cause undue hardship.

#### EXPLANATION OF PROVISION

(a) Effective October 1, 2005, the Committee mark would add a new optional eligibility group for disabled children to Medicaid. The new group includes children under 18 years of age who meet the disability definition for children under the Supplemental Security Income (SSI) program and whose family income is above the financial standards for SSI but not more than 250 percent of FPL. States may exceed 250 percent of FPL, but Federal financial participation is not available for coverage of disabled children in families with income above that level.

(b) As part of the optional Medicaid “buy-in,” the Committee mark would allow States to require parents of disabled children who are eligible for the newly defined coverage group to enroll in employer-sponsored family coverage under certain circumstances. Specifically, when the employer of a parent of a disabled child offers family coverage under a group health plan, the parent is eligible for such coverage, and the employer contributes at least 50 percent of the annual premium costs, States shall require participation in such employer-sponsored family coverage plan as a condi-

tion of continuing Medicaid eligibility for the targeted child under the proposed optional eligibility category. In addition, if such coverage is obtained, States may elect to have families pay an amount that reasonably reflects the premium contribution made by the parent for this coverage on behalf of the disabled child. States may pay any portion of a required premium for family coverage under an employer-sponsored plan; for families with income that does not exceed 250 percent of FPL, the Federal Government will share in the cost of these payments.

In addition, States that use employer-sponsored family coverage for the new optional eligibility group must insure that these plans, not Medicaid, pay for all covered services under the plan, as is the case with all other third party liability situations.

(c) The Committee mark also adds a new section to Medicaid law governing premiums applicable to the new optional eligibility group. It would allow States to require families with disabled children eligible for Medicaid under the new optional eligibility group to pay monthly premiums for enrollment in Medicaid on a sliding scale based on family income. Aggregate payments for premiums paid by families for employer-sponsored family coverage may not exceed 5 percent of income.

Consistent with current law, States may not require prepayment of premiums, nor are States allowed to terminate eligibility of a targeted child for failure to pay premiums unless lack of payment continues for a minimum of 60 days beyond the payment due date. States may waive payment of premiums when such payment would cause undue hardship.

The mark does not change current law with respect to other cost-sharing by beneficiaries (e.g., deductibles, co-insurance, co-payments), which is not permitted for children under 18 years of age. Thus, Medicaid would pay such cost sharing obligations rather than the families of qualifying children under the new optional group.

#### REASONS FOR CHANGE

The provisions in Section 2 of the Committee mark provide similar work incentives as those included in the successful Ticket to Work and Work Incentives Improvement Act (TWWIIA; P.L. 106–170), which encouraged disabled adults to enter the workforce without risk of losing their Medicare (Part A only) and Medicaid benefits.

Before P.L. 106–170 took effect, adults who made more than \$500 a month lost SSI eligibility and therefore became ineligible for Medicaid. As a result, many adults with disabilities were reluctant to enter into the workforce and purposely kept their incomes under the cap to remain eligible for Medicaid via the SSI pathway. TWWIIA reversed the disincentive to work by allowing these adults to enter the workforce without the threat of losing the health care they needed.

Parents of children with disabilities should have the same opportunities as was granted to adults with disabilities TWWIIA. The provisions in Section 2 of the Committee mark provide a similar incentive to work for parents of a disabled child. Currently, low-income parents of severely disabled children who work are at risk of jeopardizing Medicaid eligibility for their disabled children if they

have income and resources above the poverty level. The Committee mark allows parents to go to work and earn above-poverty wages while maintaining health care for their disabled children by purchasing Medicaid. Right now, in too many cases, parents are forced to stay poor so that they can maintain Medicaid eligibility for a disabled child. Specifically, by providing States an option to allow families with disabled children to “buy into” Medicaid if the family income falls between 100 and 250 percent of the Federal poverty level (\$37,550 for a family of three and \$45,250 for a family of four), parents can go back to work and increase wages without worrying about losing access to critical health care services for their disabled child. In short, parents won’t have to choose between work and health care for their child.

Medicaid services are important to children with disabilities because Medicaid offers access to medically necessary services such as physical therapy, mental health services, and customized durable medical equipment, to list a few. Many children with severe disabilities need these services in order to have a chance to grow and develop into contributing members of their community.

Children with significant disabilities who come from families that have an annual income above the eligibility level for Medicaid are at risk of not receiving these medically necessary services unless their parents choose to remain in poverty or to move into poverty in order to keep Medicaid.

The provisions in Section 2 regarding employer-sponsored insurance are intended to promote the take-up and utilization of private market insurance. For instance, a participating family could have private insurance through an employer and still need to purchase certain Medicaid services that aren’t offered through the private plan. In this case, Medicaid serves as a “wrap around” only—meaning that if a parent has access to employer-sponsored insurance (ESI), the ESI coverage would pay first and Medicaid would cover only the cost of the benefits not available through the employer’s plan.

The Committee mark only provides access to Medicaid for children with a severe disability. The child must meet the level of disability required for SSI. The legislation does not make SSI available to additional children; the legislation references SSI for purposes of disability criteria.

To be disabled under SSI, a child under age 18 must have a “medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.” Depending on the determination process, an example of a child who qualifies could be a child with one of the following disabilities or chronic conditions: cerebral palsy, blindness, neurologic impairments (spina bifida), musculoskeletal (juvenile rheumatoid arthritis or muscular dystrophy) incapacity, Downs Syndrome, Autism, or pervasive developmental disorder.

*Section 3. Treatment of inpatient psychiatric hospital services for individuals under 21 in home or community-based services waivers*

(a) Medicaid.—

## PRESENT LAW

Medicaid home and community-based service (HCBS) waivers authorized by Section 1915(c) of Title XIX of the Social Security Act give States the flexibility to develop and implement alternatives to placing Medicaid beneficiaries in hospitals, nursing facilities, or intermediate care facilities for the mentally retarded (ICF-MRs). These waivers allow such individuals to be cared for in their homes and communities as long as the cost is no higher than that of institutional care.

Federal regulations permit HCBS programs to serve the elderly, persons with physical disabilities, developmental disabilities, mental retardation or mental illness. States may also target waiver programs to persons with specific illnesses or conditions, such as technology-dependent children or individuals with AIDS.

Services that may be provided under HCBS waiver programs include: case management, homemaker/home health aide services, personal care services, adult day health, habilitation, and respite care. Other services needed by waiver participants to avoid institutionalization, such as non-medical transportation, in-home support services, special communication services, minor home modifications, and adult day care may also be provided, subject to approval by Centers for Medicare and Medicaid Services (CMS). The law further permits day treatment or other partial hospitalization services, psychosocial rehabilitation, and clinic services for persons with chronic mental illness. Room and board are excluded from coverage except under limited circumstances.

Under HCBS waiver programs, States may select the mix of services that best meets the needs of the targeted population to be served. Programs may be Statewide or limited to a specific geographic area.

## EXPLANATION OF PROVISION

The Committee mark adds to the list of persons eligible for HCBS waiver programs individuals under 21 years of age requiring inpatient psychiatric hospital services, effective for medical assistance provided on or after October 1, 2004.

## REASON FOR CHANGE

Home and community services are an attractive option to disabled and elderly individuals who prefer to receive services in the home or community as an alternative to institutional care. Additionally, many States design HCBS services as a cost-effective approach to providing long term care health services. It is often less costly to provide targeted home and community services than it is to cover institutional care. At the present time, States are operating nearly 264 home and community based waivers.

The provisions in Section 3(a) of the Committee mark aim to improve mental health parity for children with mental health illnesses. Under current law, States can offer home and community based services as an alternative to one of three institutional settings, including (1) hospitals, (2) nursing facilities, or (3) intermediate care facilities for the mentally retarded (ICFMRs). Current law does not allow States to offer home and community based services as an alternative to inpatient psychiatric hospitals.

This provision corrects this omission by including inpatient psychiatric hospitals to the list of institutions for which alternative care through home and community based waivers may be available.

Unfortunately, some parents have been faced with the impossible decision of relinquishing custody of a child to a State institution so that the child can get necessary, life-saving services. This problem presents itself most often when the child suffers from a mental health illness. Medical and health care experts report on the benefits and effectiveness of community based care for children with serious mental health disorders. Residential treatments centers offer an important alternative to psychiatric hospitals. Improving access to community-based mental health services for children with serious mental health needs should lead to improved health outcomes in mental health.

*Section 4. Development and support of family-to-family health information centers*

(a) Maternal and Child Services Block Grant.—

PRESENT LAW

Title V of the Social Security Act authorizes the Maternal and Child Services Block Grant program, which provides grants to States for improving the health of mothers and children. The program has three components: (1) Formula block grants to 59 States and territories; (2) Special Projects of Regional and National Significance (SPRANS); and (3) Community Integrated Service Systems (CISS) grants.

Activities supported under SPRANS include Maternal and Child Health (MCH) research, training, genetic services, hemophilia diagnostic and treatment centers and maternal and child health improvement projects that support a broad range of innovative strategies.

By law, 15 percent of the amount appropriated for the Maternal and Child Health Block Grant Program up to \$600 million, is awarded to public and private not-for-profit organizations for SPRANS. SPRANS also receive 15 percent of funds remaining above \$600 million after CISS funds are set aside. The CISS programs are initiated when the MCH appropriation exceeds \$600 million. Of any amount appropriated over \$600 million, 12.75 percent must be for CISS. The remaining amounts are allocated to the block grant program and to SPRANS.

EXPLANATION OF PROVISION

The Committee mark would increase funding for SPRANS for the development and support of new family-to-family health information centers. The mark would appropriate to the Secretary out of any money in the Treasury not otherwise appropriated, for this new purpose an additional \$3 million for FY2005; \$4 million for FY2006; and \$5 million for FY2007. For each of fiscal years 2008 and 2009, the bill authorizes to be appropriated to the Secretary \$5 million for this purpose. Funds would remain available until expended.

The family-to-family health information centers would: (1) Assist families of children with disabilities or special health care needs to

make informed choices about health care so as to promote good treatment decisions, cost-effectiveness, and improved health outcomes for such children; (2) provide information regarding the health care needs of, and resources available for children with disabilities or special health care needs; (3) identify successful health delivery models; (4) develop a model for collaboration between such children and health professionals; (5) provide training and guidance with regard to the care of such children; and (6) conduct outreach activities to the families of such children, health professionals, schools, and other appropriate entities and individuals. The family-to-family health information centers would be staffed by families of children with disabilities or special health care needs who have expertise in Federal and State public and private health care systems, and health professionals.

The Committee mark would require the Secretary to develop such centers in: (1) Not less than 25 States in FY2005; (2) not less than 40 States in FY2006; and (3) all States in FY2007. States would be defined as the 50 States and the District of Columbia.

#### REASON FOR CHANGE

The family-to-family health information centers authorized by this provision are modeled after successful demonstration programs that provide important information and outreach centers for parents with disabled children. The complexity of the health care system poses challenges to even the most informed parent. Health information centers can guide and assist a parent through the maze and promote efficiency. Families report that they spend extraordinary amounts of time and energy investigating resources and coordinating their child's care.

Family to family health information centers would be run by trained parents and professionals and would provide technical assistance and accurate information to other families about local health care programs and services. For instance, a mother of a newborn infant with serious medical problems could turn to one of these centers for guidance, such as information about local doctors who specialize in certain disease management, information about parent training courses, information about day care centers in the area that care for disabled infants, etc.

The family-to-family health information centers will not only assist parents, but they will also provide information to health care insurers, providers, and purchasers. The successful demonstrations of these centers are proof that the medical and provider community rely on family members for their expertise in certain decision-making.

#### *Section 5. Restoration of Medicaid eligibility for certain SSI beneficiaries*

##### (a) Medicaid.—

#### PRESENT LAW

Except in the case of "209(b)" States, States are required to provide Medicaid benefits to all individuals who are receiving Supplemental Security Income (SSI). Persons eligible for SSI are low-income aged, blind, and disabled individuals. (Under the 209(b) provision, States may apply more restrictive income and resources

standards and/or methodologies for determining Medicaid eligibility than the standards under SSI.) For disability purposes, two groups of disabled children exist: Those under the age of 18 and those age 18 through 21 (if a full time student). Eligibility for SSI is effective on the later of: (1) The first day of the month following the date the application was filed, or (2) the first day of the month following the date that the individual became eligible.

#### EXPLANATION OF PROVISION

The Committee mark confers Medicaid eligibility to persons who are under age 21 and who are eligible for SSI, effective on the later of: (1) The date the application was filed, or (2) the date the individual became eligible for SSI.

The Committee's provision would apply to medical assistance for items and services furnished on October 1, 2004.

#### REASON FOR CHANGE

This provision addresses a technical matter that resulted inadvertently in previous legislation. It addresses the interaction between Medicaid and SSI. Most States are required to make Medicaid available to persons receiving SSI. Persons eligible for SSI are low-income, AND aged, blind, or disabled.

Eligibility for SSI is effective on the first day of the month following the date the individual was determined eligible. Medicaid for SSI eligible individuals would therefore also become available on the first day of the month following the date the individual was determined eligible for SSI.

An example can help to clarify: A woman has a child on December 3; the child is born with a disabling condition and is placed in a neonatal intensive care unit for 6 weeks. On December 4, the child's mother applies for SSI with the help of a hospital aide. SSI is established for the child based on the disability that exists on December 4. Due to the administration of the program, SSI would not begin until January 1, and therefore Medicaid would begin on Jan. 1. Under this example, 28 days of hospital bills will likely go unpaid by the family. The hospital would assume the costs.

This provision removes the arbitrary "first date of the following month" rule as it applies to Medicaid without changing SSI in any way. This provision allows Medicaid coverage to apply upon the date that SSI disability determination is made—which is December 4 in example above.

This provision will assist low-income families as well as hospitals.

States who are considered to be 209(b) States have more restrictive policies and therefore this provision does not apply to those States.

### III. REGULATORY IMPACT STATEMENT AND RELATED MATTERS

#### A. REGULATORY IMPACT

In accordance with paragraph 11(b) of rule XXVI of the Standing Rules of the Senate, the Committee makes the following statement

concerning the regulatory impact of the Family Opportunity Act of 2002.

#### IMPACT ON INDIVIDUALS AND BUSINESSES

The bill as reported would expand eligibility and benefits for children with disabilities under the Medicaid program. The mark would give States the option of providing coverage to certain children who meet the disability standard used in the Supplemental Security Income program but are ineligible for SSI because they do not meet that program's income or asset requirements. The bill would also allow States to provide home and community-based services to individuals under age 21 who need inpatient psychiatric hospital services, and would extend eligibility to SSI recipients under age 21 during the month that they apply for SSI benefits.

Specifically, Section 2(a) creates a State option to allow families of disabled children to purchase Medicaid coverage. Section 3(a) expands authority under Medicaid for the development of 1915(c) waivers, also known as home and community-based waivers. Section 4(a) provides increased funding under Title V of the Social Security Act for the development of new family-to-family health information centers. None of the aforementioned provisions poses a mandate on States; each provision provides new options for States to consider. If a State takes up an option, the program would be utilized on a voluntary basis by disabled children and their families. Therefore, no provision imposes any additional paperwork or regulatory burdens on State governments or individuals.

Section 2(b) includes a provision that requires States to require participating parents to take up employer-sponsored coverage if the parent of a disabled child is offered family coverage under a group health plan and the employer contributes at least 50 percent of the annual premium costs. This requirement is a condition of eligibility for the participating parent; however, since the requirement only applies to parents who are offered employer-sponsored coverage, it is implicit that the employer is already offering employer-sponsored coverage to employees. Therefore, this provision does not impose any additional paperwork or regulatory burden on businesses.

Section 2(c) establishes a new section to Medicaid law governing premiums applicable to the new optional eligibility group. It would allow States to require families with disabled children eligible for Medicaid under the new optional eligibility group to pay monthly premiums for enrollment in Medicaid on a sliding scale based on family income. Aggregate payments for premiums paid by families for employer-sponsored family coverage may not exceed 5 percent of income. Because participation in the program is voluntary, no individual is subject to this provision unless one opts to participate.

Section 5(a) addresses a technical correction in Medicaid by conferring Medicaid and SSI eligibility to persons under age 21 and who are eligible for SSI. This provision does not impose additional paperwork or regulatory burdens on businesses or individuals.

#### IMPACT ON PERSONAL PRIVACY

The Committee mark permits States to provide new pathways for Medicaid eligibility to children with disabilities who are not presently eligible. To establish eligibility for coverage in States that take up a new option, parents of children with disabilities may be

required to provide information regarding their income, their assets, and their medical condition, but they would not be required to provide any more information than presently eligible parents must provide.

#### B. UNFUNDED MANDATES STATEMENT

According to the Congressional Budget Office, the bill as reported contains no intergovernmental or private sector mandates as defined by the Unfunded Mandates Reform Act (UMRA).

#### IV. BUDGET EFFECTS

In total, the Congressional Budget Office estimates that enacting the bill as reported would increase mandatory spending (primarily for expanded Medicaid assistance) by \$0 in 2004 and by \$7.03 billion over the 2004–2013 period. CBO also estimates that appropriation of the authorized amounts for the health information centers would cost \$10 million over the 2005–2010 period. CBO estimates that total State spending for Medicaid would increase by \$5.5 billion over the 2004–2013 period and that State spending for the State Children’s Health Insurance Program (SCHIP) would decrease by \$110 million over the same period.

Following is the Congressional Budget Office’s full statement on this bill:

##### *S. 622—Family Opportunity Act of 2003*

Summary: S. 622 would expand eligibility and benefits for disabled children under the Medicaid program. The bill would give states the option of providing coverage to certain children who meet the disability standard used in the Supplemental Security Income (SSI) program but are ineligible for SSI because they do not meet that program’s income or asset requirements. The bill also would allow states to provide home and community-based services to individuals under age 21 who need inpatient psychiatric hospital services, and would extend eligibility to SSI recipients under age 21 during the month that they apply for SSI benefits.

In addition, the bill would appropriate \$12 million in funding over the 2005–2007 period for health information centers for families with disabled children, and would authorize the appropriation of an additional \$10 million for those centers for fiscal years 2008 and 2009.

In total, CBO estimates that enacting S. 622 would increase mandatory spending (primarily for expanded Medicaid assistance) by \$52 million in 2005 and by \$7 billion over the 2004–2013 period. The bill would not affect spending in 2004. CBO also estimates that appropriation of the authorized amounts for the health information centers would cost \$10 million over the 2008–2012 period.

The bill contains no intergovernmental or private-sector mandates as defined in the Unfunded Mandates Reform Act (UMRA). CBO estimates that total state spending for Medicaid would increase by \$5.5 billion over the 2004–2013 period, and that state spending for the State Children’s Health Insurance Program (SCHIP) would decrease by \$110 million over the same period.

Estimated cost to the Federal Government: The estimated budgetary impact of S. 622 is shown in the following table. The costs of this legislation fall within budget function 550 (health).

	By fiscal year, in millions of dollars—										
	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2004–13
CHANGES IN DIRECT SPENDING											
Medicaid coverage for disabled children:											
Medicaid:											
Estimated budget authority .....	0	0	90	260	490	670	790	840	900	970	5,010
Estimated outlays .....	0	0	90	260	490	670	790	840	900	970	5,010
State Children's Health Insurance Program:											
Budget authority .....	0	0	0	0	0	0	0	0	0	0	0
Estimated outlays .....	0	0	-10	-25	-45	-35	-60	-60	-60	45	-250
Medicaid interaction with SCHIP:											
Estimated budget authority .....	0	0	0	-10	-20	-45	-40	-50	-50	-25	-240
Estimated outlays .....	0	0	0	-10	-20	-45	-40	-50	-50	-25	-240
Medicaid home and community-based services:											
Estimated budget authority .....	0	25	90	170	230	260	295	335	375	425	2,205
Estimated outlays .....	0	25	90	170	230	260	295	335	375	425	2,205
Medicaid eligibility for certain SSI recipients:											
Estimated budget authority .....	0	25	25	25	30	30	35	40	40	45	295
Estimated outlays .....	0	25	25	25	30	30	35	40	40	45	295
Health information centers:											
Budget authority .....	0	3	4	5	0	0	0	0	0	0	12
Estimated outlays .....	0	2	3	4	2	*	*	0	0	0	12
Total changes in direct spending:											
Estimated budget authority .....	0	53	209	450	730	915	1,080	1,165	1,265	1,415	7,282
Estimated outlays .....	0	52	198	424	687	880	1,020	1,105	1,205	1,460	7,032
CHANGES IN SPENDING SUBJECT TO APPROPRIATION											
Health information centers:											
Authorization level .....	0	0	0	0	5	5	0	0	0	0	10
Estimated outlays .....	0	0	0	0	3	5	2	1	*	0	10

Note.—Components may not sum to totals because of rounding. \* = less than \$500,000.

Basis of estimate: Enacting S. 622 would have significant effects on direct spending over the next 10 years, as well as a small effect on discretionary spending beginning in 2008.

### *Direct spending*

CBO estimates that S. 622 would increase direct spending by a total of \$7 billion over the 2004–2013 period. Those costs would be due primarily to expanded Medicaid coverage of disabled children and the increased use of Medicaid home and community-based services.

Medicaid Coverage for Certain Disabled Children. Section 2 of the bill would allow state Medicaid programs to cover individuals under age 18 who meet the disability standard used for children in the SSI program but do not meet the program's income or asset restrictions. Eligibility would be limited to children with family income below a specified amount, set by each state, that could not exceed 250 percent of the federal poverty level. The parents of those children would be required to purchase private health insurance through their employer if the employer offers family coverage and subsidizes at least 50 percent of the cost of premiums. States also would be able to impose premiums on a sliding scale for the Medicaid coverage. This provision would take effect on October 1, 2005.

CBO estimates that this provision would lead to a net increase in direct spending of \$4.5 billion over the 2006–2013 period. Additional Medicaid spending for disabled children would cost \$5.0 billion over that period, but those costs would be offset by savings of \$0.3 billion in SCHIP and \$0.2 billion in Medicaid because of interactions between Medicaid and SCHIP. The provision’s effects are discussed in greater detail below.

*Number of Disabled Children.* CBO relied on data from the National Health Interview Survey (NHIS) on the number of people with disabilities in 1994 and population projections from the Social Security Administration to estimate the number of children that have a disability that meets the SSI standard. We made several adjustments to the number of children that the NHIS estimated had a “specific, chronic, and life-limiting” disability—the most severe definition used in the survey. We accounted for underreporting (the NHIS did not assess all forms of disability) and excluded 18-year-olds, who would not be eligible under the bill.

The SSI disability standard for children is quite stringent, requiring a child to have a medically determinable condition that results in “marked and severe functional limitations” and will either last at least 12 months or result in death. For this reason, CBO assumed that only 90 percent of those children would qualify as disabled under the bill. After those adjustments, CBO estimated that 2.6 million children—about 3.4 percent of U.S. children—would meet the SSI disability standard in fiscal year 2006, the year the provision would take effect.

CBO anticipates that about 1.7 million of those children would be receiving Medicaid under current law, either as SSI recipients (who are automatically eligible for Medicaid in most states) or under other eligibility categories. The remaining 900,000 children, who have a disability that meets the SSI standard but are not enrolled in Medicaid, form the starting point in estimating the number of new Medicaid recipients under the bill. We estimate that the number of children in this category would gradually decline to about 800,000 by 2013, mainly because of continued growth in the number of SSI recipients.

*Number of New Enrollees.* CBO classified the disabled children not enrolled in Medicaid by family income and health insurance status using research from the NHIS, the General Accounting Office, the Economic and Social Research Institute, and other sources. (We estimate that about half of those children have family incomes below 250 percent of the poverty level and a majority of them have private health insurance.) We then estimated the additional Medicaid enrollment under the bill by making assumptions about the eligibility limits that participating states would set and the premium amounts that they would charge.

CBO anticipates that most of the states that expand Medicaid coverage under the bill would set their eligibility limits around 200 percent of the poverty level and that only a minority of participating states would set their limits above that level. We also expect that states would require the new enrollees to pay premiums on a sliding scale, as allowed under the bill. We assume that the premiums charged would range from zero for families with incomes below the poverty level to 2.5 percent of income for families with income equal to 250 percent of the poverty level.

CBO estimated the number of children that would enroll under the bill based on research from several sources on participation rates in SCHIP, where premiums are commonly charged. (Medicaid generally does not allow states to charge premiums.) We assumed that the participation rate under the bill would be on the high end of rates found in the studies. Families with disabled children are less likely than SCHIP families to view premiums as a deterrent because disabled children frequently have high medical expenses.

Overall, CBO estimates that Medicaid enrollment in 2006 would increase by about 90,000 children on a full-year equivalent basis, if all states decide to provide coverage under the bill. (Projected state participation is discussed below.) After 2009, the additional enrollment would range between 140,000 and 150,000 annually.

Based on research on health insurance coverage, we estimate that most of the additional enrollees—about 65 percent—also would have private health insurance from an employer that pays at least 50 percent of the cost of premiums. Another 15 percent otherwise would have private health insurance from an employer that pays less than 50 percent of the cost of premiums; CBO assumes that this group would substitute coverage under the bill for family coverage. The remaining 20 percent would be uninsured.

*Effect on the Medically Needy.* In addition to new enrollees, the bill also would affect some children who receive Medicaid under current law through what is known as a “medically needy” program. About 35 states currently have medically needy programs that allow individuals to receive Medicaid after first spending a specified portion of their income on medical expenses. CBO anticipates that some of those states also would cover disabled children under the bill. In those states, some children who now receive Medicaid through a medically needy program would be able to qualify under the new eligibility category for disabled children. Medicaid spending for those children would increase because the program would now provide benefits without first requiring the children’s families to pay some costs themselves.

CBO estimates that about 2,000 medically needy children in 2006 would qualify under the new eligibility category for disabled children. This figure would rise to about 10,000 in later years. Those estimates are based on enrollment data from the Centers for Medicare & Medicaid Services (CMS) and reflect CBO’s assumptions about the number of states that would provide Medicaid coverage under the bill.

*Per Capita Costs.* CBO used two sets of per capita costs for newly enrolled disabled children—one for children with Medicaid only and another for those with both Medicaid and private health insurance. We estimate that the federal costs per full-year equivalent for children with Medicaid only would be about \$7,300 in 2006, rising to \$12,700 in 2013. For children with private health insurance, the Medicaid costs would be about \$4,000 in 2006 and increase to \$7,200 in 2013. Costs for children with private health coverage would be lower than for children with Medicaid only because private insurance would cover some costs that Medicaid would otherwise pay. Those estimates are based on Medicaid spending data from CMS and research on the value of private health insurance under the Federal Employees Health Benefits Program.

As noted above, the bill also would increase Medicaid spending for some children who currently qualify through medically needy programs. CBO estimates that the additional federal spending for those children would be about \$1,200 in 2006 and rise to \$1,900 by 2013.

*State Participation.* CBO anticipates that under the bill states with about 10 percent of potential Medicaid costs would choose to cover disabled children in 2006. We expect that proportion to reach two-thirds by 2009 and remain at that level in subsequent years.

CBO believes that state participation eventually would be relatively high because the bill would give states another way to pay for services for children who are covered by the Individuals with Disabilities Education Act (IDEA), which requires states to provide special education services to all eligible students. States pay most of the costs of IDEA; federal funding for the program is subject to appropriation and represents less than 20 percent of the program's total cost. Because the bill expands Medicaid to more disabled children, states would be able to use Medicaid to pay for some of the services, such as transportation and physical therapy, that states currently provide to IDEA-eligible students. Medicaid would be an attractive funding source because the federal government pays at least 50 percent of the program's total cost and funding for the program is open-ended (i.e., it is not limited by appropriation or any other programmatic cap).

*Premiums.* The bill would allow states to charge premiums set on a sliding scale for Medicaid coverage for the newly eligible disabled children. Those premiums could not exceed 5 percent of family income and would be reduced to account for any premiums that families would be required to pay for private health insurance. CBO assumes that states would impose premiums only on families with incomes above the federal poverty level, and that the maximum premium would be 2.5 percent of income for families with income equal to 250 percent of the federal poverty level. (Using current poverty guidelines, the maximum premium would be about \$100 per month for a family of four.)

CBO estimates that the federal share of premium receipts would be about \$2 million in 2006 and would rise to \$20 million by 2013. Those receipts would offset only a small portion of the bill's costs because premiums would be based on family income rather than actual costs, which would be high for the children covered under the bill. The share of costs offset by the premiums also would decline over time because family income is expected to grow more slowly than the costs of medical care.

*Additional Administrative Costs.* CBO estimates that the bill would increase spending on Medicaid administrative costs by about \$40 million in 2006, rising to \$100 million by 2013. We anticipate that about 25 percent of those costs would be for eligibility determinations, claims processing, and collection of premiums. We assume that costs for eligibility determinations would be similar to those for disabled SSI applicants. The remainder would be administrative costs for disabled children that are currently paid by local school systems.

*Effect on SCHIP.* CBO anticipates that some of the disabled children who would receive Medicaid under the bill would be enrolled in SCHIP under current law. Because children who are eligible for

Medicaid cannot receive SCHIP, the bill would lead to savings in SCHIP.

CBO estimates that about 2,000 children would lose their SCHIP eligibility in 2006 under the bill. That figure would rise to about 21,000 children by 2010, before declining slightly in later years. Those figures are based on the NHIS disability survey and account for state participation. The number of affected children would decline in later years because CBO's baseline projections assume that annual SCHIP funding will remain constant after 2007. (Unlike Medicaid, which is an open-ended entitlement program, annual funding levels for SCHIP are set at specific amounts.) Since we expect the cost of medical care to continue growing in those years, we assume that one of the ways that states will respond will be to trim enrollment.

CBO varied the per capita savings for those children by type of SCHIP program. (A state can administer its SCHIP program either as an expansion of its Medicaid program or as a completely separate program.) Federal savings per capita in states with Medicaid expansions, which provide the comprehensive Medicaid package of benefits, would rise from \$8,900 in 2006 to \$15,600 in 2013. For states with separate programs, which provide less generous benefits, the corresponding savings would be \$4,000 in 2006 and \$6,800 in 2013. CBO assumes that about 80 percent of affected children would come from states that administer their SCHIP programs separately from Medicaid.

Based on those assumptions, CBO estimates that moving SCHIP disabled children to Medicaid would reduce SCHIP spending by \$900 million over the 2004–2013 period. However, states would use some of those savings to cover other children under SCHIP, particularly in later years as constraints on spending grow tighter. On net, estimated savings would be \$250 million over the 10-year period.

*Medicaid Interaction with SCHIP.* Under current law, CBO expects that states will adopt a variety of measures to respond to the limited availability of SCHIP funds. One response—trimming enrollment—has already been discussed. We also anticipate that states will react by expanding Medicaid eligibility and shifting some children from SCHIP to Medicaid. That approach would enable states to continue receiving federal matching funds (albeit at a less-favorable match rate) and avoid cutting enrollment.

Since S. 622 would free up SCHIP funds to cover more non-disabled children states would not need to rely on Medicaid to cover those children. As a result, CBO estimates that this effect would lead to savings in Medicaid totaling \$240 million over the 2004–2013 period.

*Medicaid Home and Community-Based Services.* Under Medicaid, states can establish programs—known as 1915(c) waiver programs after the section of the Social Security Act that authorizes them—that provide coverage for home and community-based services for individuals who otherwise would need services in an institution. Current law limits eligibility for 1915(c) waiver programs to individuals who otherwise would need services in a hospital, nursing home, or intermediate care facility for the mentally retarded. Section 3 of the bill would allow 1915(c) waiver programs to cover individuals under age 21 who would otherwise need services in an

inpatient psychiatric hospital. This provision would take effect on October 1, 2004.

CBO estimates that this provision would increase net federal spending on Medicaid by \$25 million in 2005 and by \$2.2 billion over the 2004–2013 period. Spending on home and community-based services would increase by about \$3.3 billion over that period, and be offset by \$1.1 billion in savings on spending for institutional services.

*Spending on Home and Community-Based Services.* CBO assumes that this provision would affect the same population as section 2 of the bill—children who have a disability that meets the SSI standard but are not enrolled in Medicaid. Based on research by the General Accounting Office, CBO assumes that about 25 percent of those children have a mental disorder. We increased the number of disabled children with mental disorders to account for those between the ages of 18 and 20, who are ineligible under section 2. After those adjustments, CBO anticipates that the number of children potentially affected by the bill would be about 295,000 in 2005 and would decline to about 250,000 by 2013.

CBO anticipates that this provision would increase enrollment in 1915(c) waiver programs by about 2,400 children in 2005, rising to 17,300 by 2013. About 80 percent of those children would be new Medicaid enrollees; the remainder would be existing enrollees that now receive institutional services. The new enrollees would ultimately be about 5 percent of the eligible population. Based on CMS data for current enrollees in 1915(c) waivers, CBO estimates that the per capita costs for those children would be about \$17,900 in 2005 and would rise to \$35,700 by 2013.

The additional spending for those children would represent only a modest increase in spending on 1915(c) waiver programs. The waivers are commonly used in Medicaid, partly because states can limit total enrollment in the programs. Based on data from CMS, we estimate that the number of people enrolled in 1915(c) waiver programs under current law will increase from about 680,000 in 2005 to about 820,000 by 2013. During the same period, federal spending on those waivers will jump from \$12.8 billion to \$30.8 billion. S. 622 would thus raise both the number of enrollees and spending in 1915(c) waiver programs by about 2 percent.

*Spending on Institutional Services.* Using data from CMS, CBO estimates that under current law Medicaid covers about 50,000 children annually in inpatient psychiatric hospitals. Under the bill, some of those children would be able to receive services in the community instead of in an institution. Services in an institution are extremely expensive, so the shift to home and community-based services for those children would reduce Medicaid spending.

As noted earlier, CBO estimates that about 20 percent of the new enrollees in 1915(c) waivers under the bill would be children that previously received institutional services. Drawing on CMS data, we estimate that per capita savings for those children would rise from about \$69,000 in 2005 to \$110,000 in 2013. However, we anticipate that only 50 percent of those savings would be realized because some of the newly available capacity in psychiatric institutions would be used to serve additional Medicaid enrollees.

*Medicaid Eligibility for Certain SSI Recipients.* Before the enactment of welfare reform in 1996, applications for SSI benefits were

considered effective on the day that they were submitted. The welfare reform law changed the effective date of SSI applications to the first day of the following month and delayed when applicants become eligible for SSI. Since most SSI recipients are automatically eligible for Medicaid, the provision also delayed the effective date of Medicaid eligibility for new SSI recipients.

Section 5 of S. 622 would restore Medicaid eligibility for SSI recipients under age 21 between the day they apply for benefits and the first day of the following month. This provision would take effect on October 1, 2004. CBO estimates that this provision would increase federal Medicaid spending by \$25 million in 2005 and \$295 million over the 2004–2013 period.

We estimate that about 210,000 people under age 21 would become eligible for SSI in 2005, rising to about 220,000 by 2013. However, we anticipate that only about a third of those individuals would be affected by the bill. The remainder would be able under current law to offset the effects of the welfare reform law by using other eligibility categories to receive Medicaid between the day they apply for SSI benefits and the first day of the following month.

CBO assumes that the individuals affected by this provision would receive an additional two weeks of Medicaid benefits, on average. Based on Medicaid spending for disabled recipients, we estimate that the federal cost per capita of those additional benefits would be about \$320 in 2005 and increase to about \$610 in 2013.

**Health Information Centers.** Section 4 would require the Secretary of Health and Human Services to establish health information centers that provide various types of assistance to families with disabled children. Those services would include providing information on available health care resources and identifying successful ways to provide health care to disabled children. The centers would be part of the Maternal and Child Health grant program administered by the Health Resources and Services Administration.

The bill would fund the health information centers by appropriating \$3 million in 2005, \$4 million in 2006, and \$5 million in 2007. CBO estimates that outlays from that funding would be \$2 million in 2005 and a total of \$12 million over the 2005–2010 period. Our estimate is based on historical spending patterns in the Maternal and Child Health grant program.

*Spending subject to appropriation*

The bill would make funding for the health information centers subject to appropriation in 2008 and 2009, and would authorize the appropriation of \$5 million in each of those years. Assuming appropriation of the authorized amounts, CBO estimates that this provision would cost \$10 million over the 2008–2012 period.

**Intergovernmental and private-sector impact:** The bill contains no intergovernmental or private-sector mandates as defined in UMRA. CBO estimates that, assuming states take advantage of the options provided in the bill, total state spending for Medicaid would increase by \$5.5 billion over the 2004–2013 period, and that state spending for SCHIP would decrease by \$110 million over the same period.

Estimate prepared by: Federal Costs: Eric Rollins and Jeanne De Sa. Impact on State, Local, and Tribal Governments: Leo Lex. Impact on the Private Sector: Stuart Hagen.

Estimate approved by: Peter H. Fontaine, Deputy Assistant Director for Budget Analysis.

**V. VOTES OF THE COMMITTEE**

On September 10, 2003, a substitute for S. 622, entitled “The Family Opportunity Act of 2002,” was ordered favorably reported by a voice vote. A quorum was present.

No amendments were offered.

**VI. CHANGES IN EXISTING LAW**

In compliance with paragraph 12 of the Rule XXVI of the Standing Rules of the Senate, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, exiting law in which no change is proposed is shown in roman):

**SOCIAL SECURITY ACT**

\* \* \* \* \*

**TITLE V—MATERNAL AND CHILD HEALTH SERVICES BLOCK GRANT**

\* \* \* \* \*

**AUTHORIZATION OF APPROPRIATIONS**

SEC. 501. \* \* \*

\* \* \* \* \*

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

*(i) there is appropriated to the Secretary, out of any money in the Treasury not otherwise appropriated—*

- (I) \$3,000,000 for fiscal year 2005;*
- (II) \$4,000,000 for fiscal year 2006; and*
- (III) 5,000,000 for fiscal year 2007; and*

*(ii) there is authorized to be appropriated to the Secretary, \$5,000,000 for each of fiscal years 2008 and 2009.*

*(B) Funds appropriated or authorized to be appropriated under subparagraph (a) shall—*

- (i) be in addition to amounts appropriated under subsection (a) and retained under section 502(a)(1) for the purpose of carrying out activities described in subsection (a)(2); and*
- (ii) remain available until expended.*

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

*(A) assist families of children with disabilities or special health care needs to make informed choices about health care*

*in order to promote good treatment decisions, cost-effectiveness, and improved health outcomes for such children;*

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

*(C) identify successful health delivery models for such children;*

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

*(E) provide training and guidance regarding caring for such children;*

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

*(G) are staffed by families of children with disabilities or special health care needs who have expertise in Federal and State public and private health care systems and health professionals.*

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

*(A) With respect to fiscal year 2004, such centers shall be developed in not less than 25 States.*

*(B) With respect to fiscal year 2005, such centers shall be developed in not less than 40 States.*

*(C) With respect to fiscal year 2006, such centers shall be developed in all States.*

*(4) The provisions of this title that are applicable to the funds made available to the Secretary under section 502(a)(1) apply in the same manner to funds made available to the Secretary under paragraph (1)(A).*

*(5) For purposes of this subsection, the term "State" means each of the 50 States and the District of Columbia.*

**TITLE XIX—GRANTS TO STATES FOR MEDICAL ASSISTANCE PROGRAMS <sup>1</sup>**

\* \* \* \* \*

STATE PLANS FOR MEDICAL ASSISTANCE

SEC. 1902. (a) A State plan for medical assistance must—

\* \* \* \* \*

(10) provide—

(A) for making medical assistance available, including at least the care and services listed in paragraphs (1) through (5), (17) and (21) of section 1905(a), to—

(i) all individuals—

(I) who are receiving aid or assistance under any plan of the State approved under title I, X, XIV, or XVI, or part A or part E of title IV (including individuals eligible under this title by reason of section 402(a)(37), 406(h), or 473(b), or consid-

ered by the State to be receiving such aid as authorized under section 482(e)(6)),

(II) *(aa)* with respect to whom supplemental security income benefits are being paid under title XVI (or were being paid as of the date of the enactment of section 211(a) of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104—193) **and** *and* would continue to be paid but for the enactment of that **section or who are** *section*), *(bb)* who are qualified severely impaired individuals (as defined in section 1905(q)), or *(cc)* who are under 21 years of age and with respect to whom supplemental security income benefits would be paid under title XVI if subparagraphs (A) and (B) of section 1611(c)(7) were applied without regard to the phrase “the first day of the month following”.

\* \* \* \* \*  
 (ii) \* \* \*

\* \* \* \* \*

(XVII) who are independent foster care adolescents (as defined in section 1905(w)(1)), or who are within any reasonable categories of such adolescents specified by the State; **or**

(XVIII) who are described in subsection (aa) (relating to certain breast or cervical cancer patients); or

(XIX) who are disabled children described in subsection (cc)(1);

\* \* \* \* \*

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

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

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

*(C) whose family income does not exceed such income level as the State establishes and does not exceed—*

*(i) 250 percent of the income official poverty line (as defined by the Office of Management and Budget, and revised annually in accordance with section 673(2) of the Omnibus Budget Reconciliation Act of 1981) applicable to a family of the size involved; or*

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

*(I) any medical assistance provided to an individual whose family income exceeds 250 percent of such poverty line may only be provided with State funds; and*

*(II) no Federal financial participation shall be provided under section 1903(a) for any medical assistance provided to such an individual.*

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

(i) require such parent to apply for, enroll in, and pay premiums for, such coverage as a condition of such parent's child being or remaining eligible for medical assistance under subsection (a)(10)(A)(ii)(XIX) if the parent is determined eligible for such coverage and the employer contributes at least 50 percent of the total cost of annual premiums for such coverage; and

(ii) if such coverage is obtained—

(I) subject to paragraph (2) of section 1916(h), reduce the premium imposed by the State under that section in an amount that reasonably reflects the premium contribution made by the parent for private coverage on behalf of a child with a disability; and

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

(B) In the case of a parent to which subparagraph (A) applies, a State, subject to paragraph (1)(C)(ii), may provide for payment of any portion of the annual premium for such family coverage that the parent is required to pay. Any payments made by the State under this subparagraph shall be considered, for purposes of section 1903(a), to be payments for medical assistance.

\* \* \* \* \*

PAYMENT TO STATES

SECT. 1903. \* \* \*

\* \* \* \* \*

(f)(1)(A) \* \* \*

\* \* \* \* \*

(4) The limitations on payment imposed by the preceding provisions of this subsection shall not apply with respect to any amount expended by a State as medical assistance for any individual described in section 1902(a)(10)(A)(i)(III), 1902(a)(10)(A)(i)(IV), 1902(a)(10)(A)(i)(V), 1902(a)(10)(A)(i)(VI), 1902(a)(10)(A)(i)(VII), 1902(a)(10)(A)(ii)(IX), 1902(a)(10)(A)(ii)(X), 1902(a)(10)(A)(ii)(XIII), 1902(a)(10)(A)(ii)(XIV), 1902(a)(10)(A)(ii)(XV), 1902(a)(10)(A)(ii)(XVI), 1902(a)(10)(A)(ii)(XVII), 1902(a)(10)(A)(ii)(XVIII), 1902(a)(10)(A)(ii)(XIX), or 1905(p)(1) or for any individual—

\* \* \* \* \*

PROVISIONS RESPECTING INAPPLICABILITY AND WAIVER OF CERTAIN REQUIREMENTS OF THIS TITLE

SEC. 1915. \* \* \*

\* \* \* \* \*

(c)(1) The Secretary may by waiver provide that a State plan approved under this title may include as “medical assistance” under such plan payment for part or all of the cost of home or community-based services (other than room and board) approved by the Secretary which are provided pursuant to a written plan of care to

individuals with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in a hospital or a nursing facility or intermediate care facility for the mentally retarded, *or would require inpatient psychiatric hospital services for individuals under age 21*, the cost of which could be reimbursed under the State plan. For purposes of this subsection, the term “room and board” shall not include an amount established under a method determined by the State to reflect the portion of costs of rent and food attributable to an unrelated personal caregiver who is residing in the same household with an individual who, but for the assistance of such caregiver, would require admission to a hospital, nursing facility, or intermediate care facility for the mentally retarded *or would require inpatient psychiatric hospital services for individuals under age 21*.

(2) A waiver shall not be granted under this subsection unless the State provides assurances satisfactory to the Secretary that—

(A) necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended with respect to such services;

(B) the State will provide, with respect to individuals who—

(i) are entitled to medical assistance for inpatient hospital services, nursing facility services, **[or services in an intermediate care facility for the mentally retarded]** *services in an intermediate care facility for the mentally retarded, or inpatient psychiatric hospital services for individuals under age 21* under the State plan,

(ii) may require such services, and

(iii) may be eligible for such home or community-based care under such waiver,

for an evaluation of the need for inpatient hospital services, nursing facility services, **[or services in an intermediate care facility for the mentally retarded]** *services in an intermediate care facility for the mentally retarded, or inpatient psychiatric hospital services for individuals under age 21*;

(C) such individuals who are determined to be likely to require the level of care provided in a hospital, nursing facility, or intermediate care facility for the mentally retarded, *or who are determined to be likely to require inpatient psychiatric hospital services for individuals under age 21*, are informed of the feasible alternatives, if available under the waiver, at the choice of such individuals, to the provision of inpatient hospital services, nursing facility services, **[or services in an intermediate care facility for the mentally retarded]** *services in an intermediate care facility for the mentally retarded, or inpatient psychiatric hospital services for individuals under age 21*;

\* \* \* \* \*

(7)(A) In making estimates under paragraph (2)(D) in the case of a waiver that applies only to individuals with a particular illness or condition who are inpatients in, or who would require the level of care provided in, hospitals, nursing facilities, or intermediate care facilities for the mentally retarded, *“or would require inpatient psychiatric hospital services for individuals under age 21*, the State

may determine the average per capita expenditure that would have been made in a fiscal year for those individuals under the State plan separately from the expenditures for other individuals who are inpatients in, or who would require the level of care provided in, those respective facilities *or who would require inpatient psychiatric hospital services for individuals under age 21.*

\* \* \* \* \*

USE OF ENROLLMENT FEES, PREMIUMS, DEDUCTIONS, COST SHARING, AND SIMILAR CHARGES

SEC. 1916. (a) Subject to [subsection (g) *subsections (g) and (h)*], the State plan shall provide that in the case of individuals described in subparagraph (A) or (E)(i) of section 1902(a)(10) who are eligible under the plan—

\* \* \* \* \*

\* \* \* come for a year that exceeds 250 percent of the income official poverty line (referred to in subsection (c)(1)) applicable to a family of the size involved, except that in the case of such an individual who has income for a year that does not exceed 450 percent of such poverty line, such requirement may only apply to the extent such premiums do not exceed 7.5 percent of such income; and

(2) such State shall require payment of 100 percent of such premiums for a year by such an individual whose adjusted gross income (as defined in section 62 of the Internal Revenue Code of 1986) for such year exceeds \$75,000, except that a State may choose to subsidize such premiums by using State funds which may not be federally matched under this title.

In the case of any calendar year beginning after 2000, the dollar amount specified in paragraph (2) shall be increased in accordance with the provisions of section 215(i)(2)(A)(ii).

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

*(2) A premium requirement imposed under paragraph (1) may only apply to the extent that—*

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

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

*(3) A State shall not require prepayment of a premium imposed pursuant to paragraph (1) and shall not terminate eligibility of a child under section 1902(a)(10)(A)(ii)(XIX) for medical assistance under this title on the basis of failure to pay any such premium until such failure continues for a period of not less than 60 days from the date on which the premium became past due. The State may waive payment of any such premium in any case where the*

*State determines that requiring such payment would create an undue hardship.*

