

United States Senate

For Immediate Release

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Grassley, Kennedy Re-introduce Bill to Help Disabled Children

WASHINGTON -- Sen. Chuck Grassley, chairman of the Committee on Finance, and Sen. Edward Kennedy, ranking member of the Committee on Health, Education, Labor and Pensions, today re-introduced their bipartisan legislation to help children with disabilities and their families. The senators won Senate approval of this long-time priority measure last May, but negotiations with the House to find a budgetary offset broke down, and the bill never received final approval.

“Medicaid works well for a lot of people,” Grassley said. “The problem is some families fall through the cracks. Many parents of disabled children have to drop out of the workforce or keep themselves in a low-paying job just to remain eligible for Medicaid. In effect, the government is forcing parents to choose between near-poverty and their children’s health care. We need to fix that. We came close last year, but time ran out. I hope we’ll succeed in this Congress.”

Kennedy said, “The *Family Opportunity Act* may be the most important legislation we pass this Congress. It will close the health care gap for the nation’s most vulnerable children, and enable families of disabled children to be equal partners in the American dream.”

The *Family Opportunity Act* allows states to create options for families with disabled children to buy into Medicaid while continuing to work. Parents would pay for Medicaid coverage on a sliding scale. Medicaid is critical to the well-being of children with multiple medical needs because it covers many services that these children need, including physical therapy and medical equipment, the senators said. Private health plans often are much more limited in what they cover. And many parents can’t afford needed services or multiple co-payments out-of-pocket.

Grassley and Kennedy said the *Family Opportunity Act* is pro-work because it lets parents work without losing their children’s health coverage, pro-family because it encourages parents to work and build a better life for their children, and it’s pro-taxpayer because it means more parents continue to earn money, pay taxes and pay their own way for Medicaid coverage for their children.

“Parents want to provide the best they can for their children,” Grassley said. “Congress should give states the flexibility to give families options without the federal government getting in the way.”

Kennedy said, “These families deserve better --- continuing to force families into poverty or having families give up their disabled children to secure health care is a tragedy we have an obligation to prevent. ”

Medicaid is a medical assistance program jointly financed by the federal government and state governments for eligible low-income individuals. It also covers health care expenses for the needy elderly, the blind and the disabled receiving cash assistance under the Supplemental Security Income Program.

The *Family Opportunity Act* has attracted widespread bipartisan support in each Congress since Grassley and Kennedy authored it in 1999, with co-sponsors numbering 70 or more. A House version of the measure sponsored by Reps. Pete Sessions and Henry Waxman also enjoyed strong support with more than 235 cosponsors. The Senate Finance Committee first approved the measure in 2002, on a voice vote, without controversy. The full Senate first passed the *Family Opportunity Act* in May 2004.

A summary of the *Family Opportunity Act* follows.

**SUMMARY OF THE MAJOR PROVISIONS OF
THE FAMILY OPPORTUNITY ACT OF 2005
(also known as the “Dylan Lee James Act”)**

PROBLEM

The National Health Interview Survey (NHIS) and current census data shows that 8% of children in this country have significant disabilities, many of whom do not have access to critical health care services they need. In order for these families to get needed health services for their children, 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. Many employer health plans and a number of CHIP/SCHIP programs do not cover essential services that these children need to maintain and prevent deterioration of their health status. Medicaid can provide these comprehensive services.

In a recent survey of 20 states, families with special needs children report they are **turning down jobs, turning down raises, turning down overtime, and are unable to save money for the future of their children and family** ---- so that they can stay in the income bracket that qualifies their child for SSI and/or Medicaid.

Currently, less than 4% of the 850,000 children receiving social security benefits leave the Social Security rolls due to increased family income, however many would if access to needed health services was available. More than half the States in this country are reporting increasing rates of families giving up custody of their children in order to secure needed health care services and supports.

The Family Opportunity Act of 2005 is intended to address the two greatest barriers preventing families from staying together and staying employed — (1) lack of access to appropriate services, and (2) lack of access to the advocacy and assistance services they need to help cut the “red

tape” to meeting their children’s health care needs.

THE FAMILY OPPORTUNITY ACT OF 2005

Access to Health Care Coverage

Expanding Medicaid Coverage Options. A new optional eligibility category will allow states to expand Medicaid coverage to children with disabilities up to age 18, who would be eligible for SSI disability benefits but for their income or resources. This option builds on previous reforms including the provision enacted in the Balanced Budget Act of 1997 (BBA) and the Ticket to Work and Work Incentives Improvement Act of 1999.

These provisions permit states to offer a Medicaid buy-in for disabled children who would be eligible for SSI disability benefits but for their income, who are in families earning up to 300% of poverty.

- In order for a family to participate in the medicaid buy-in for their disabled child or children, a state must require a parent to take employer-offered insurance within the following guidelines: (1) the employer offers family coverage under a group health plan, and (2) the employer contributes at least 50% of the total cost of the annual premium for the coverage.
- If such coverage is attained by the family, the state is required to reduce the premium charged for the buy-in, in an amount that reasonably reflects the parent’s premium contribution for private coverage for their child with a disability.
- Participating states may charge premiums up to the full cost of the premium as long as that premium does not exceed 5% of family incomes up to 200% of the poverty level and 7 1/2% of family incomes between 200-300% of the poverty.
- The state may waive payment of a premium in any case where the state determines that requiring a payment would create an undue hardship.

Alternatives to Psychiatric Residential Treatment Facilities for Children

- The bill provides funds for demonstration projects in ten States to examine the effectiveness of home- and community-based alternatives to psychiatric residential treatment facilities for medicaid enrolled children.

Restoration of Medicaid Eligibility

- Restores **only the medicaid** eligibility for children meeting the “presumptive eligibility” requirements under SSI without having to wait until the “first day of the month following” the establishment of eligibility.

Access to Health Information and Resources

Establishing Family to Family Health Information Centers. The bill provides funds for establishing health information centers to assist and support families of children with disabilities and special health care needs. These centers, staffed by both parents of children with special needs and professionals, would provide technical assistance and accurate information to other families on various health care programs and services available and appropriate for children with special needs, including identifying successful health delivery models. In addition, these centers would act as a resource to healthcare insurers, providers, and purchasers in developing ombudsman models for collaboration between families of children with special needs and health care professionals.