



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

October 8, 2003

**Medicaid Works for Children and Adults with Disabilities and Their
Families:
It Must Not Be Block-granted**

The Consortium for Citizens with Disabilities is a Washington-based coalition of over 100 national disability organizations. The CCD is strongly supportive of Medicaid because often it is the only source of comprehensive and appropriate coverage that addresses the health care and long-term services needs of people with disabilities. Indeed, more than 10.5 million children, adults, and seniors with disabilities count on Medicaid. Medicaid is recognized as the driving force behind the individual supports and services people with disabilities need to lead fuller, healthier, and more productive lives in their communities. The Medicaid entitlement, the strong federal commitment demonstrated by open-ended financing, and the existing extensive state flexibility has helped Medicaid adapt and be innovative in meeting the individual needs of children and adults with disabilities.

While CCD is on record in support of the critical role that Medicaid plays in the lives of people with disabilities, we appreciate the important role it plays in the lives of many other Americans. The Medicaid program is crucial to the viability of the nation's health care infrastructure. According to a recent report by the Census Bureau, the ranks of those individuals without health insurance grew from 41.2 million in 2001 to 43.6 million in 2002. The primary cause for this dangerous drop in coverage was the erosion of private health insurance coverage. This, in turn, was driven by the weak economy, growing unemployment, and ever increasing health care and health insurance costs. However, at the same time enrollment in both Medicaid and the SCHIP program rose in response to this loss of coverage and the ever-growing number of families with low incomes. Medicaid enrollment grew by 3.2 million in 2002 and if it was not there, the number of Americans without health insurance would have been much higher. Individuals with disabilities and families with children with disabilities are the most likely people to face disaster as the economy weakens and as private health insurance plans become even more limited and even more expensive.

Medicaid Works

The following are critical features of Medicaid that allow it to work effectively for children and adults with disabilities.

- For children with all types of disabilities, access to the cost-effective Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, with its screenings, services and therapies, can often make a major difference in their lives. Access to these important services is what enables them to lead healthy and more active lives; avoid additional disabilities; continue to live at home with their families; make it through school; get and keep a job; and participate actively in the community in which they live.
- Medicaid is the primary public source of funding for long-term services and supports for people with disabilities of all ages. It is the largest funder of state and local spending on mental health, mental retardation, and developmental disabilities services in the country.
- For people with epilepsy, mental illness, HIV, and a variety of other conditions, Medicaid is very often the only source of access to essential prescription drug coverage.
- For people with a variety of physical disabilities, such as spinal cord injuries, traumatic brain injuries, cerebral palsy, or amputations, Medicaid usually is the only way they can get access to durable medical equipment like wheelchairs or prosthetic devices, as well as assistive technology.
- For many people with cognitive and other types of disabilities, Medicaid generally is the only source of funds for them to live and work in the community with friends and families and avoid more costly and segregated nursing homes or institutions.

Current Threats to the Medicaid Program

The CCD is extremely worried by inaccurate statements made about Medicaid by its critics – many of whom portray it as broken in their zeal to “restructure” Medicaid. We are strongly opposed to any proposal that would remove the individual entitlement to Medicaid and that would move Medicaid away from an open-ended financing system to one that provides for fixed allotments. We also oppose any federal legislative or administrative actions that would limit the federal resources that are currently available for providing the broad range of services needed by people with disabilities in Medicaid.

The Administration and some in Congress are proposing reforms that give only one stakeholder in the Medicaid program — the states — virtually unchecked flexibility at the expense of beneficiaries and providers. Removing the entitlement to Medicaid for children and adults with disabilities and their families— and capping funding -- will give states unlimited discretion to limit access to health and long-term services and supports that these individuals need. For many individuals with disabilities in Medicaid, including so-called “optional” beneficiaries, access to Medicaid has life-altering implications. Undermining well-reasoned and time-tested beneficiary protections as though they were responsible for current challenges in financing Medicaid is dangerous for children and adults with disabilities. Federal oversight of state programs is often the only way to ensure fairness and non-discrimination. It is often the only way to protect the most vulnerable individuals from abuse, as well as demand accountability for this taxpayer-supported program.

Moving Medicaid Into the Future the Right Way

The CCD supports numerous positive approaches that would strengthen rather than weaken Medicaid. These include:

- Ensuring that states effectively implement the Early and Periodic, Screening, Diagnosis and Treatment (EPSDT) benefit. EPSDT is a critical tool to prevent and minimize disability and to ensure that children get the best possible start in this world so they can grow up to be contributing members of society.
- Enacting the bipartisan Family Opportunity Act, which would let moderate-income families with children with disabilities buy into Medicaid for the essential services they need and which are not covered by private insurance. This would allow families to stay together instead of forcing parents to put their children in inappropriate and unwarranted institutional settings because they cannot get the supports they need in the community.
- Establishing mandatory coverage for home and community-based long-term services that provide a viable alternative to institutional living for people with disabilities and the elderly.
- Increasing the federal responsibility for the cost of providing services to Medicare beneficiaries. This includes increased federal support for prescription drug coverage, durable medical equipment, and long-term care services for low-income persons eligible for both Medicaid and Medicare.

Any changes to Medicaid must recognize the unique populations enrolled in Medicaid, including seven million people with severe disabilities – both children and adults. SCHIP and private market benefits packages are not only inadequate for these individuals, but they often are completely unavailable. What the Medicaid program calls “optional” benefits are, in reality, mandatory disability services for the children and adults who need them. These services often are not only life-saving, but the key to a positive quality of life – something everyone in our nation deserves.

As reported above, currently Medicaid is one critical solution to the nation’s problem of the uninsured. Until there are not millions of uninsured or underinsured children and adults, Medicaid will continue to play a critical role in mitigating the health care crisis we face as a nation. Very often it is families with children, the elderly, and people with disabilities — some of the most vulnerable and poorest individuals in the country -- who are in the worst circumstances and who would be completely without any coverage without Medicaid.

The CCD wants to work with the Congress to ensure that any modifications to the program are in the best interests of children and adults served by Medicaid -- which in the long run would be in the best interests of our nation.

ON BEHALF OF:

Adapted Physical Activity Council
 Advancing Independence: Modernizing Medicare and Medicaid
 American Academy of Child and Adolescent Psychiatry
 American Association on Mental Retardation
 American Association of People with Disabilities
 American Congress of Community Supports and Employment Services
 American Council of the Blind
 American Foundation for the Blind
 American Medical Rehabilitation Providers Association
 American Music Therapy Association
 American Network of Community Options and Resources
 American Occupational Therapy Association

American Psychological Association
American Therapeutic Recreation Association
Association for Educators of Community-Based Rehabilitation Programs
Association of Maternal & Child Health Programs
Association of Tech Act Projects
Association of University Centers on Disabilities
Bazelon Center for Mental Health Law
Brain Injury Association of America
Center on Disability and Health
Center on Disability Issues & the Health Professions
Council of Parent Attorneys and Advocates
Council for Learning Disabilities
Disability Service Providers of America
Easter Seals
Epilepsy Foundation
Federation of Families for Children's Mental Health
Family Voices
Inclusion Research Institute
Inter/National Association of Business, Industry and Rehabilitation
Lutheran Services in America – Disability Network
National Association for the Advancement of Orthotics and Prosthetics
National Association of Developmental Disabilities Councils
National Association of Orthopaedic Nurses
National Association of Protection and Advocacy Systems
National Association of Rehabilitation Research and Training Centers
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