



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

November 29, 2005

Dear Conferee:

The Consortium for Citizens with Disabilities is a coalition of over 100 national disability organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. The Medicaid program plays a critical role in these efforts. We are writing to urge you not to make unnecessary and harmful changes to Medicaid as part of the reconciliation process.

Important beneficiary protections that ensure that people with disabilities can access the range of disability services they need have been built into the law over Medicaid's 40 year history. These essential protections are an extremely valuable resource for individuals with disabilities and must not be weakened or removed to meet arbitrary budget targets or under the guise of state flexibility. We continue to believe that Medicaid is an under-funded critical national resource—and any Medicaid program savings should be reinvested in Medicaid.

The House Medicaid savings package is pointlessly harmful to people with disabilities. The result of a Senate-House conference must not be a split-the-difference approach. Such action would produce "savings" not by making Medicaid better, more efficient, or more sustainable. But rather by limiting access to necessary services to people with disabilities of all ages, as well as low-income seniors, children, and families. The majority of the House Medicaid savings would be due to provisions that harm beneficiaries. This is completely unacceptable.

We cannot endorse efforts to cut Medicaid funding, however the differences between the House and Senate approaches to seeking Medicaid program savings are so stark that CCD must commend Chairman Grassley and his colleagues for developing a Medicaid savings package that would achieve program savings without harming beneficiaries. Overall, CCD continues to oppose reconciliation savings that fall on the backs of people with disabilities and the poor – cutting critical life-saving programs in order to apply so-called savings to tax cuts.

The Senate package also includes the Family Opportunity Act and the Money Follows the Person Demonstration, legislative proposals that have been a high priority of the disability community for many years and which have engendered broad bipartisan support in both the House and Senate. This is one more reason the CCD supports the Senate Medicaid savings package over the House Medicaid package.

From the perspective of Medicaid beneficiaries with disabilities, the following are the most pressing issues that must be resolved in conference:

- ➡ **Reject policy changes that undermine Medicaid’s coverage of medically necessary disability services.** A Budget Reconciliation Conference Report must not include additional flexibility for states to offer alternative benefits packages. People with disabilities often end up in the Medicaid program because it is the only place where they can get the range of acute and long-term services and supports they need. Coverage for essential disability services (often called Medicaid optional services) is generally non-existent or insufficient in the private market or Medicare.

CCD believes that benefit flexibility provisions in the House Medicaid savings package would harm people with disabilities by creating the potential that Medicaid—their last and best chance of getting their health needs met—would provide them with an insufficient range and level of services.

The CBO estimated that benefits flexibility would lead states to offer some adults with disabilities benefits packages modeled after state employee programs or private sector plans—coverage that is known to be inadequate (as well as unaffordable) for many Medicaid beneficiaries with disabilities. Moreover, CBO estimated that alternative benefits packages would reduce per capita spending by 15-35% for the affected populations and that most of the reductions would be for services such as dental, vision, mental health and certain therapies—all critically essential disability-related services—as well as restrictions on the amount, duration, and scope of covered services.

In addition, the House bill would permit states to eliminate coverage for services such as hearing aids, speech therapy, occupational therapy, physical therapy, eyeglasses, mobility and assistive technology products, and dental care for children. This would have a devastating effect on the health, mobility, function, and independence of children with disabilities who rely heavily on the services provided through the Early and Periodic Screening, Diagnosis and Treatment program.

- ➡ **Reject policy changes that achieve Medicaid savings by making Medicaid services unaffordable to low-income beneficiaries.** CCD is categorically opposed to the cost-sharing changes in the House bill. We urge conferees to recede to the Senate package, which does not make harmful changes to Medicaid cost-sharing policies.

Under current law, when Medicaid imposes cost-sharing, people with disabilities and chronic conditions — people who access the most services — tend to bear the highest burden.¹ Much of the policy debate over the acceptable level of cost-sharing for Medicaid beneficiaries has been based on presumptions that are applicable to middle class Americans, but that do not reflect the financial circumstances of most Medicaid beneficiaries. Many policy makers have spoken of the need to make beneficiaries price sensitive to the cost of their care as a strategy to eliminate unnecessary use of services. This ignores the reality that Medicaid does not cover all of the health and long-term services needs of people with disabilities who must often spend extensive personal resources on out-of-pocket medical costs, transportation to multiple doctors’ offices and to visit other service providers. A recent analysis found that, on average, Medicaid beneficiaries with disabilities

¹ Stuart, B. and Zacker, C., “Who Bears the Burden of Medicaid Drug Copayment Policies?”, *Health Affairs*, 18(2):201-12, 1999.

receiving SSI income (74% of the poverty level) paid \$441 in out-of-pocket medical expenses in 2002 (6.7% of income if SSI is the only source of income).²

People with disabilities already bear responsibility for a significant share of their health care costs in relation to their income.

The House-passed reconciliation bill — even as modified by the Rules Committee prior to passage -- is unaffordable to beneficiaries and would permit states to deny essential services for failure to pay cost-sharing. It imposes non-nominal cost-sharing to individuals above poverty and children above 133% of poverty, and imposes a greater cost-sharing burden over time. The House bill would impose co-pays of \$30 or more monthly for prescription drugs and other essential medical services for many people with disabilities who rely on multiple prescriptions and multiple services — an amount that may appear modest to middle-income individuals, but which could present an insurmountable hardship for SSI recipients receiving only \$579 per month (2005 SSI payment level), a level of income support that is already inadequate to meet rent, food, and other non-health-related essentials for life.

The House bill's cost-sharing provisions would also impose a progressively worsening burden on beneficiaries, as cost-sharing requirements would rise more rapidly than SSI payments. This means that over time, the cost-sharing burden on low-income individuals with disabilities would increase significantly, even though current cost-sharing already is unaffordable for some beneficiaries. The result would be that children and adults with disabilities would not get the services and supports they need and — in the long run — this lack of access would exacerbate disabilities and lead to a loss of independence. All in all, this would cost more in terms of individuals' lives, as well as in increased health and long-term care costs.

- ➔ **Reject or refine all provisions related to Targeted Case Management and Third Party Liability in both the House and Senate bills.** Targeted Case Management is a benefit of extreme importance to many children and adults with disabilities, including thousands of people with mental illness, children in foster care, individuals with physical disabilities attempting to transition from nursing facilities to community settings, and persons with HIV/AIDS. Third-party liability requirements control when states can receive federal matching payments for TCM and other Medicaid services.

For many years, there has been serious confusion about the requirements of the Medicaid statute regarding third-party liability. In brief, the statute says that if another party is liable to pay for services that Medicaid would otherwise pay for, then that party must pay for them and Medicaid cannot. This makes Medicaid genuinely the payer of last resort. On a number of occasions, states have, however, been advised by the Federal government that if another party might be able to pay for services, then Medicaid cannot. This is not the law, and it can make Medicaid an unreliable payer.

It is critical to be clear that the prohibition on Medicaid funding includes only true liability, i.e., insurance for which an insurer is legally responsible for payment, and not all sources of funding that might be potentially available.

² Ku, L. and Broaddus, M., *Out-of-Pocket Medicaid Expenses for Medicaid Beneficiaries are Substantial and Growing*, Center on Budget and Policy Priorities, May 2005.

In addition to these issues affecting all Medicaid beneficiaries, the contrast between the Senate and House Medicaid savings packages (and a disability-focused Medicare policy issue) offers a harsh contrast between doing more or doing less to meet the needs of individuals with disabilities and their families. CCD also urges conferees to:

- ➡ **Include the Senate-adopted Family Opportunity Act in the final Conference Report.** This is a family-friendly program with strong bipartisan support designed to help families gain access to the health care services and supports their children need and to keep their children with disabilities out of institutions and at home where they belong.
- ➡ **Include the Senate-adopted Money Follows the Person Demonstration in the final Conference Report.** To protect the civil rights of people with disabilities, more progress must be made to provide people who need long-term services and supports the opportunity to live in their own communities instead of being forced to reside in nursing and other facilities in order to receive needed assistance. The Money Follows the Person Demonstration is a modest step forward that would create incentives and resources for demonstration states to transition people out of institutions into the community.
- ➡ **Reject the long-term care provisions in Section 3131 of the House bill.** The provisions in Section 3131 of the House Medicaid savings package would permit states to provide home-and community-based services as a state option without requiring a waiver. While increasing access to community-based services is a primary goal of the disability community, CCD does not support Section 3131 and strongly urges conferees to remove this provision from the final bill. Section 3131 would extend the worst aspects of waiver policies — enrollment caps and waiting lists — to a new Medicaid option.
- ➡ **While not included in the Senate Medicaid savings package, again, the Senate provides a positive alternative. The Improving Long-Term Care Choices Act of 2005 (S. 1602) introduced by Senator Grassley would provide states with a new Medicaid option to offer home and community-based services without the approval of a federal waiver, but this approach does not permit enrollment caps or waiting lists.**

Finally, CCD has a recommendation specific to the Medicare program. We urge conferees to:

- ➡ **Accept Senate-adopted language that would protect access to inpatient rehabilitation hospitals by freezing the implementation of Medicare’s “75% Rule” for inpatient rehabilitation hospitals pending further study.**

Inpatient rehabilitation hospitals provide essential, specialized medical rehabilitation for persons who have had a significant injury, condition, disability and/or are recovering from surgery or medical treatment. Medicare’s 75% Rule, as it currently stands, requires rehabilitation hospitals to confine their admissions to an arbitrary percentage of patients that fall in one of 13 diagnostic categories, rather than basing admission decisions on true need of inpatient rehabilitation. More often than not, patients not admitted to intensive rehabilitation in the hospital setting are diverted to nursing homes. Unless the Senate language becomes law, further implementation of the rule will continue to severely threaten access to inpatient rehabilitation for all people with disabilities.

Other provisions in the reconciliation legislation -- outside of Medicaid and Medicare -- will have an impact on individuals represented by CCD organizations and the broader disability community. In separate communications, CCD will share its perspective on critical issues, such as Food Stamps and other nutrition programs, child support enforcement, child care funding, children in foster care, and harmful changes related to back payments of SSI to people with disabilities.

At this crossroads in federal policy, CCD urges the Congress not to back away from supporting people with disabilities and other Medicaid beneficiaries. We urge you to accept the reasonable and moderate policy changes offered by the Senate and reject the radical cost-shifts that the House Medicaid savings package would impose on Medicaid beneficiaries with disabilities, seniors, and children and families. Legislation that cuts programs that are designed to improve the lives of children and adults with disabilities and others in order to pay for tax cut extensions does not reflect well on our nation.

Once again, we urge you to reject the damaging provisions in the House bill.

Sincerely,

Co-chairs of the CCD Health and Long-Term Services and Supports Task Forces

Kirsten Beronio
National Mental Health Association

Kathy McGinley
National Disability Rights Network

Liz Savage
The Arc/UCP Public Policy Collaborative

Peter Thomas
American Academy of Physical
Medicine and Rehabilitation

Marty Ford
The Arc/UCP Public Policy Collaborative

Suellen Galbraith
American Network of Community
Options and Resources

Kim Musheno
Association of University Centers on
Disability

Lee Page
Paralyzed Veterans of America