



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

**CCD Statement on Recent Long-Term Services & Supports Financing Proposals
April 2016**

In early 2016, several bipartisan and nonpartisan organizations, including the [Bipartisan Policy Center](#) and the [Long-Term Care Financing Collaborative](#), released reports on a path forward for future financing of our nation's long-term care needs. The problem is clear: while our nation is aging and people are living longer with disabilities and chronic conditions, we lack a coherent plan on how to provide for their care and supports. Our current financing system relies almost entirely on Medicaid and unpaid family caregivers, both of which thwart family financial planning and hinder the economic opportunities of women, people of color, and people with disabilities.

The Consortium for Citizens with Disabilities (CCD) is a working coalition of 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 Long-Term Services and Supports Task Force of CCD is releasing this statement to weigh in on the recent reports on long-term care financing, express our support for Medicaid improvements, and support the emerging consensus on the need for a public insurance program.

CCD strongly supports the emerging consensus that a package of reforms must include a federal government role in insuring all Americans against the risk of significant long-term service and supports needs, often called “catastrophic” risk or needs. This emerging consensus has been discussed at each report launch, as well as by Dr. Alice Rivlin in her [testimony](#) before the Energy & Commerce Subcommittee on Health.

CCD believes that a national, actuarially sound program of LTSS coverage is not only feasible, but necessary. Such a program would relieve families struggling to find care for an older loved one, sometimes delaying or derailing their own health and careers to provide unpaid help. Such a program would support our aging population, who too often are forced to spend-down their life savings before turning to Medicaid. Such a program would support young people who acquire disabilities, often in the prime of their earning and family forming years, to stay at work and save for the future. And such a program would support people born with disabilities, who will need long-term services and supports to build and maintain their lives and employment prospects.

In order to achieve these ends, **any further policy proposals for LTSS financing solutions must include people with disabilities.** Some policy options put forward, such as those from the Urban Institute, suggest that individuals would not be eligible for benefits until age 65. Such a restriction would exclude a vast proportion of LTSS users and limit the positive economic impact and increased opportunities of a new program.

Medicaid currently funds the majority of LTSS provided in the US. While Medicaid is a crucial safety net, it is not a perfect program. **Strict income and asset limits thwart family financial planning and hinder economic growth for people with disabilities.** Medicaid's asset limits for people with disabilities are so low that earning or saving just over the limit still leaves an individual vastly below the

kind of income or asset level that would allow an individual to pay out of pocket for LTSS. Strict asset limits further prevent people with disabilities from saving for their own retirement. Medicaid also has an institutional bias that limits access to cost effective home and community-based services (HCBS). For families and individuals that rely on Medicaid LTSS, leaving Medicaid isn't an option. Some can figure out ways to structure funds to maintain LTSS access; most simply live in poverty.

Anne Tumlinson, while [testifying](#) before the House Energy & Commerce Subcommittee on Health made clear that the costs of a new LTSS program would not be new. In fact, we are currently financing LTSS through unearned wages, uncompensated labor, and (mostly) Medicaid. These costs are not evenly spread through society. Women are significantly more likely to serve as both unpaid and low-paid caregivers. Women of color disproportionately work as low-paid caregivers and disproportionately provide unpaid family caregiving. The families that “spend-down” onto Medicaid typically have low or modest incomes while only the wealthy can afford to privately pay.

In addition to a new government role in LTSS outside of Medicaid, **CCD also supports the Medicaid reforms proposed by the [Bipartisan Policy Center](#) and [Long-Term Care Financing Collaborative](#)**, including extending the Money Follows the Person demonstration, streamlining Medicaid HCBS authorities into a State Plan Option, continuing the enhanced federal match for these services, expanding the Medicaid Buy-In, and reversing the institutional bias in Medicaid to provide community-based services on an equal footing with institutional services.

Equal access to HCBS is particularly important since Medicaid nursing home coverage is mandatory, while HCBS coverage is optional. Together, these proposals could ease state paperwork burden in providing HCBS, encourage more states to provide more HCBS, and allow more people with disabilities to work, earn, and save for the future. In addition to expanding current economic opportunity, the Enhanced Medicaid Buy-In included in the Bipartisan Policy Center report, should be seen not only as a work program, but also as a retirement savings mechanism, by which people with disabilities have the freedom to save for their own retirement. Reversing the institutional bias achieves a long-term disability community objective of providing HCBS without waiting lists to all eligible people with disabilities.

All of the reports recommended changes to the private long-term care insurance market. In general, many proposals suggest an “emerging consensus” that the private long-term care insurance industry should provide front-end coverage (first 2-3 years) and a public catastrophic program should provide coverage on the back-end. These changes are outside the scope of this statement, precisely because existing private long-term care insurance is neither available nor viable for people with disabilities of any age, people who are not upper-income, and people with any pre-existing conditions. The private insurance industry currently excludes individuals with pre-existing health conditions and disabilities through underwriting, with rejection rates as high as 20% and increasingly strict underwriting practices.

While CCD supports the Bipartisan Policy Center proposal to prevent insurers from excluding individuals with pre-existing health conditions, we also see a role for a front-end public program to compete with the private market, help protect against continued substantial premium increases among private plan policyholders, and fill gaps in the market. Such a program could utilize the expertise of the many community-based organizations that have been serving persons with disabilities and older adults in most states for decades.

Finally, CCD is concerned that people with disabilities were not adequately included in the reports or the modeling that informed them. CCD expresses deep concern that policy options being put forward are based solely on modeling of individuals 65 and older. Currently, approximately half of individuals who need LTSS are under 65. None of the reports make specific recommendations for improvements in research and data collection that would allow for more complete modeling. **We call upon organizations**

building these models to put forth specific policy recommendations for improvements and for entities funding this work to ensure more holistic and complete models.

CCD looks forward to being an active participant as the discussion of long-term services and supports financing continues. We believe that all policy options and proposals should be guided by the [core set of principles developed jointly by CCD and the Leadership Council of Aging Organizations \(LCAO\)](#). Our two coalitions represent nearly all LTSS users, and we developed these principles precisely to guide policy efforts that will best serve our communities and the country.

Sincerely,

ACCSES

American Association on Health and Disability

American Network of Community Options and Resources

The Arc of the United States

Association of University Centers on Disabilities

Autism Speaks

Bazelon Center for Mental Health Law

Brain Injury Association of America

Christopher & Dana Reeve Foundation

Disability Rights Education and Defense Fund

Easter Seals

Family Voices

Lutheran Services in America Disability Network

National Academy of Elder Law Attorneys

National Association of Councils on Developmental Disabilities

National Association of Head Injury Administrators

National Association of State Directors of Developmental Disabilities Services

National Disability Institute

National Disability Rights Network

National Down Syndrome Congress

National Council on Aging

National Multiple Sclerosis Society

National Respite Coalition

Paralyzed Veterans of America

Justice in Aging

United Cerebral Palsy

United Spinal Association