

The Honorable Patty Murray U.S. Senate 154 Russell Senate Office Building Washington, D.C. 20510

Commemorating 40 Years Of Disability Advocacy 1973-2013

The Honorable Paul Ryan U.S. House of Representatives 1233 Longworth House Office Building Washington, D.C. 20515

November 5, 2013

Re: Protection of Medicaid for People with Disabilities

Dear Senator Murray and Representative Ryan:

The Health Task Force and the Long-Term Services and Supports Task Force of the Consortium for Citizens with Disabilities (CCD), a coalition of over 100 national disability organizations, are writing to express our strong support for Medicaid, a vital public health program that serves millions of children, seniors, people with disabilities and their families. In the Budget Control Act of 2011, because it serves such a vulnerable population, Congress elected to exempt Medicaid from sequestration. As budget discussions are re-opened pursuant to the Continuing Appropriations Act (P.L. 113-46), CCD urges Congress to continue exempting Medicaid and protecting it as an entitlement program for vulnerable Americans.

Medicaid is a lifeline for millions of Americans with disabilities. Nearly 25% of all Medicaid beneficiaries are seniors and individuals with disabilities. Medicaid provides critical health coverage to 8 million individuals with disabilities and 10 million low-income Medicare beneficiaries who rely on Medicaid to fill Medicare's gaps. CCD strongly supports Medicaid precisely because of the program's track record for providing services that allow individuals with disabilities to remain independent, access employment opportunities and access cost-effective healthcare services. Medicaid provides a comprehensive set of benefits designed to meet the complex needs of people with disabilities and its costs per beneficiary are actually rising less rapidly then private insurance premiums.

The following are a few examples of the critical features of Medicaid that allow it to work effectively for children and adults with disabilities:

- For children with disabilities, access to the cost-effective Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, can often make a major difference in their lives, enabling them to lead healthy and more active lives and participate actively in the community in which they live.
- Medicaid is the primary public source of funding for long-term services and supports (LTSS) for people with disabilities of all ages. It is the largest funder of state and local spending on mental health 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 long-term diseases or conditions like multiple sclerosis who eventually become disabled enough that they lose access to and/or cannot afford private coverage and have spent most of their earnings and savings on management of the disease, Medicaid becomes the only affordable, comprehensive health coverage option—particularly for LTSS.

- For people with a variety of physical disabilities, such as spinal cord injuries and limb loss, Medicaid usually is the only way they have access to durable medical equipment like wheelchairs, prosthetic limbs and orthotic braces, as well as assistive technology.
- For many people with intellectual, cognitive and other disabilities, Medicaid is the main source of funds for them to live and work in the community, avoiding costly, segregated nursing homes or institutions.

CCD strongly opposes any proposal that would remove the individual entitlement to Medicaid and have a detrimental impact on services needed by persons living with disabilities. Although placing fixed limits on Medicaid expenditures through capping or block-granting Medicaid could at first glance seem like a cost-saver, in actuality those approaches would simply shift costs to states and providers and to individuals least able to afford them, jeopardizing access to needed services for millions of seniors and people with disabilities. Some of our specific concerns with per person block grants or any other form of capping Medicaid are below:

- Shifting the Balance of Power Block granting or capping would remove the entitlement to Medicaid for children and adults with disabilities and their families and cap funding, leaving states unlimited discretion to limit access to health and long-term services and supports that these individuals need. For many individuals with disabilities, 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.
- *Increased Cost Sharing* Medicaid also ensures that coverage is affordable by generally not charging premiums and requiring only modest co-payments; research has found that premiums and cost-sharing tend to disproportionately lead poor households to forgo needed care or remain uninsured. Under a block grant, states could begin charging premiums beyond levels not permitted under current law that discourage enrollment (and leave people uninsured) and require burdensome deductibles and co-payments that reduce access to needed health care.
- *Target Populations For Cuts* Seniors and people with disabilities would be at particular risk since they constitute one-quarter of Medicaid beneficiaries but account for two-thirds of all Medicaid spending as Medicaid is the primary funder of long-term care services, particularly nursing home care. Block granting or capping federal Medicaid funding would place significant financial pressure on states to scale back coverage on funding for services to low-income seniors and people with disabilities in spite of their greater health needs.
- *Strain on Medicaid Providers* States facing inadequate block grant or capped funding would also likely have to further scale back provider rates, which would result in decreased access to services and providers withdrawing from Medicaid, undermining the comprehensive service structure for delivering specific health and long-term services. Rural areas would be especially vulnerable to a health and long term services delivery system that is even more limited in providing access to vital services.
- *Failure to Recognize Heterogeneous Nature of People with Disabilities* People with disabilities are a very heterogeneous group and to categorize all together to receive the same financial cap fails to recognize their unique situations and needs and threatens the ability to ensure that people will receive services unique to their needs. A child with autism for instance has very different needs from an adult with mental illness. Even within the same condition or disease group, there are vast discrepancies in needs and associated costs. For instance, an adult with relapsing-remitting multiple sclerosis (MS) currently not experiencing any exacerbations has very different

needs from an adult with primary-progressive MS who may very well have LTSS needs for many years. Similarly, people with traumatic brain injury have widely different needs, depending on the severity of injury.

While the economic situation demands leadership and thoughtful action, shifting Medicaid to a block grant or per capita cap structure will negatively impact people with disabilities and seriously threatens the services that they need. We urge that Medicaid be protected as an entitlement program so that it can rightly serve our nation's most vulnerable and their unique needs.

Co-Chairs of the Health and Long Term Services and Supports Task Forces:

Mary Andrus	Lisa Ekman	Theresa Morgan
Easter Seals	Health & Disability Advocates	ACCSES
Julie Ward The Arc	Peter Thomas Brain Injury Association of America	Dan Berland National Association of State Directors of DD Services
Maureen Fitzgerald	Lee Page	Laura Weidner
The Arc	Paralyzed Veterans of America	National MS Society

CC: Rep. Diane Black (TN-6) Rep. James Clyburn (SC-6) Rep. Tom Cole (OK-4) Rep. Nita Lowey (NY-17) Rep. Tom Price (GA-6) Rep. Chris Van Hollen (MD-8)

> Sen. Kelly Ayotte (NH) Sen. Tammy Baldwin (WI) Sen. Chris Coons (DE) Sen. Mike Crapo (ID) Sen. Mike Enzi (WY) Sen. Lindsey Graham (SC) Sen. Charles Grassley (IA) Sen. Ron Johnson (WI) Sen. Tim Kaine (VA) Sen. Angus King (ME) Sen. Jeff Merkley (OR) Sen. Bill Nelson (FL) Sen. Rob Portman (OH) Sen. Jeff Sessions (AL) Sen. Bernie Sanders (VT) Sen. Debbie Stabenow (MI) Sen. Pat Toomey (PA) Sen. Mark Warner (VA) Sen. Sheldon Whitehouse (RI) Sen. Roger Wicker (MS) Sen. Ron Wyden (OR)