

Commemorating 40 Years Of Disability Advocacy 1973-2013

The Honorable Bill Cassidy (LA-6) U.S. House of Representatives Longworth House Office Building Washington, D.C. 20515

June 17, 2013

Re: Medicaid Accountability and Care Act (H.R. 1853)

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 concerns with the Medicaid Accountability and Care Act (H.R. 1853).

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, Medicaid usually is the only way
 they have access to durable medical equipment like wheelchairs or prosthetic devices, 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.
- Medicaid also funds services for students with disabilities so that they can attend school and keep up with their
 peers in the general curriculum. Without this support, school districts and states would have to
 pay addition funds to cover the cost of educating students with disabilities because these services must be
 provided in order to ensure that students with disabilities receive a free, appropriate public education as required
 by law.

CCD is strongly opposed to any proposal that would remove the individual entitlement to Medicaid and have a detrimental impact on services needed by persons living with disabilities. We are very concerned with proposals like the one contained in the Medicaid Accountability and Care Act that would create global or per person caps for the following reasons:

- Caps in the Medicaid program simply shift costs to states. By significantly limiting the federal funding available by beneficiary category, states that continue to experience economic challenges would be forced to cut services and/or populations. Many Medicaid services on which people with disabilities rely such as LTSS and rehabilitative services are optional Medicaid services and would likely be the first ones cut. 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. While we appreciate the bill's efforts to provide protections such as a state's right to appeal the base rate per beneficiary and opportunity for chronic care bonus payments, with the removal of entitlement, there is no overarching guarantee that people with disabilities with complex needs will continue to receive the comprehensive services they so desperately need.
- 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. The bill does provide the state opportunities to appeal, but the appeals are by category (again not recognizing the unique needs within a particular category). Chronic care bonus payments would not necessarily recognize the diverse needs even within a particular condition.
- Caps would not accurately reflect increased health care costs, innovations, or catastrophes. In order to reduce costs, caps would grow more slowly than health care costs. They would not reflect the costs associated with new treatments or drugs, disasters or epidemics. In addition, in times of fiscal challenge, the cap could be scaled down, placing more financial burden on the states.

While the economic situation demands leadership and thoughtful action, shifting to a 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:

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CC: The Honorable Fred Upton (MI-6) The Honorable Orrin Hatch (UT)