

# Center for Disability Rights, Inc.

Testimony of the Center for Disability Rights  
before the Joint Hearing of the Senate and Assembly Committees on Health  
on the New York Health Act  
May 28, 2019

## Introduction

Thank you, Chairmen Gottfried and Rivera, for allowing the Center for Disability Rights to provide testimony on this important topic, and thank to all Committee members for your attention and your questions.

In your invitation to testify today, you specifically asked for the perspectives of different stakeholders. The Center for Disability Rights can provide the perspective of New Yorkers with disabilities. The Center for Disability Rights is a disability-led, not-for-profit organization headquartered in Rochester, with satellite offices in Geneva, Corning, Albany, and Canandaigua. CDR advocates for the full integration, independence, and civil rights of people with disabilities. CDR provides services to people with disabilities and seniors within the framework of an Independent Living Model, which promotes independence of people with all types of disabilities, enabling choice in living setting, full access to the community, and control of their life. CDR works for national, state, and local systemic change to advance the rights of people with disabilities by supporting direct action, coalition building, community organizing, policy analysis, litigation, training for advocates, and community education.

Not only do we provide independent living services as a center for independent living, we also connect disabled people who need long term healthcare services and supports with the ability to direct own own attendant services through the Consumer Directed Personal Assistance Program, and to traditional agency-model attendant services. We understand the importance of healthcare and long term healthcare services in particular to disabled people. Having access to adequate and appropriate healthcare is critical to disabled people being able to live our lives independently and participate fully in the community. To this point, there are a few features of the New York Health Act I want to highlight that would improve the lives of disabled people in New York.

## Long Term Services and Supports

Across the nation, Medicaid is the primary payer for long term care services and supports, or LTSS. It is generally the only way disabled people can access the personal care and assistance with activities of daily living that we require to live our lives.

The legislative findings of the bill we are discussing correctly describe the reality that disabled people face:

*Older adults and people with disabilities often cannot receive the services necessary to stay in the community or other LTSS. Even when older adults and people with disabilities receive LTSS, especially services in the community, it is*

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*often at the cost of unreasonable demands on unpaid family caregivers, depleting their own or family resources, or impoverishing themselves to qualify for public coverage.*

This reality is unsustainable; that is why the Disability Community is supportive of the inclusion of LTSS in the coverage that would be provided by a New York health plan under the New York Health Act.

LTSS is a necessity for some people with disabilities and older adults, and this is something the Act would address upfront. Just last year, the Centers for Disease Control (CDC) reported that 1 in 4 U.S. adults live with a disability.<sup>1</sup> The demand for LTSS will increase dramatically due to factors including the aging of the baby boom population and the increased chances of developing a disability or chronic condition as one ages, the prevalence of dementia related to Alzheimer's disease, and the increasing life expectancy of people with developmental disabilities.<sup>2</sup> Data shows that nearly half a million people were receiving Medicaid LTSS in New York in 2013; this number does not include the people who were unable to qualify for LTSS through Medicaid, or were relying on informal support for their personal assistance.

LTSS helps disabled people participate in the community by going to doctor appointments, visiting friends and family, going shopping, going to school, and working. To remind everyone of how important LTSS is to the Disability Community, I would like to refer to the protests by disabled people against the proposed repeal of the Affordable Care Act by the Graham-Cassidy bill that would have turned federal Medicaid into block grants, severely cut overall healthcare spending and would have eliminated Medicaid expansion. Disabled people were dragged out of their wheelchairs, and out of Congress, while protesting a bill that would have literally contributed to their deaths.<sup>3</sup> For us, access to LTSS is a matter of life or death. I am proud to remind everyone here that the New York Chapter of the disability rights organization ADAPT had a role in coordinating efforts across the country in opposition to proposals to cut Medicaid.

That was less than two years ago, and today, we are still concerned that the federal government will try to shrink access to Medicaid, such as by turning it into block grants to States which would significantly reduce overall spending and guarantee a reduction in access. This underscores why we need a State plan that ensures access to the healthcare we need.

Thank you for including LTSS in the New York Health Act.

### **Home- and Community-Based Services**

Another feature of the New York Health Act that would positively impact the Disability Community is the prioritization of community integration. Under Program Standards, the bill reads:

<sup>1</sup> Centers for Disease Control and Prevention. "CDC: 1 in 5 US adults live with a disability." <https://www.cdc.gov/media/releases/2018/p0816-disability.html>.

<sup>2</sup> U.S. Department of Health and Human Services. "An Overview of Long-Term Services and Supports and Medicaid: Final Report." (May 2018) <https://aspe.hhs.gov/system/files/pdf/259521/LTSSMedicaid.pdf> p. iv, p.1; University of Minnesota. Institute on Community integration. *Impact*. "People with Intellectual and Developmental Disabilities Growing Old: An Overview." <https://ici.umn.edu/products/impact/231/2.html>.

<sup>3</sup> Business Insider. "Chaos erupted at a Senate hearing on the GOP healthcare bill as protesters were dragged out and arrested." (Sept. 25, 2017) <https://www.businessinsider.com/senate-healthcare-hearing-protesters-arrested-2017-9>.

*(f) especially in relation to long-term supports and services, the maximization and prioritization of the most integrated community-based supports and services.*

The importance of this provision cannot be overstated. The core belief of the independent living movement is that every disabled person has the right to community integration. Not only is this a belief closely held by the network of independent living centers and the Disability Community, but it is required by the U.S. Supreme Court's *Olmstead* decision. *Olmstead* found that the Americans with Disabilities Act has an "integration mandate," requiring that disabled people receive services in the most integrated setting.<sup>4</sup> Without HCBS, disabled people are forced to accept services in institutions – nursing homes – that provide lesser quality care, endanger our lives, and keep us segregated from society. The Disability Community is supportive of a New York Health Plan that acknowledges our right to live independently in the community.

We agree with the legislative findings in the Act that the federal Affordable Care Act has provided tremendous benefits, but falls short of providing adequate healthcare coverage. Part of this failure is evident in the delayed rollout of Community First Choice Option (CFCO). CFCO was enacted as part of the Affordable Care Act and allows States to provide home- and community-based-attendant-services and supports to eligible Medicaid enrollees under their State plan.<sup>5</sup> New York's State Plan Amendment for CFCO was approved back in 2015; since then the State has delayed the full implementation of CFCO numerous times so that we are now looking at a January 2020 implementation date.

From the point of view of disabled people who want and have a right to community-based services, the delay is unacceptable. Therefore, the Disability Community celebrates a universal single-payer health care plan that explicitly prioritizes access to home- and community-based services.

## **Conclusion**

The inclusion of long-term services and supports, and the emphasis on providing home- and community-based services, especially in relation to long term care, demonstrate that NY Health would be a plan for all New Yorkers, including those of us with disabilities. For these reasons, the Center for Disability Rights is supportive of the New York Health Act. Thank you for your time and attention.

<sup>4</sup> U.S. Department of Health and Human Services. "Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead." <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html>.

<sup>5</sup> Medicaid.gov. "Community First Choice (CFC) 1915 (k). <https://www.medicaid.gov/medicaid/hcbs/authorities/1915-k/index.html>.