



Center for Disability Rights, Inc.

Testimony before the Joint Senate and Assembly
Hearing on the New York Health Act
October 10, 2019

Access to adequate healthcare is a key concern for people w with disabilities. Even in a society that tends to see disability through a medical model – the idea that disability is a medical issues needing to be fixed, and not discrimination or a social barrier needing to be removed- disabled people ironically face tremendous barriers to access the healthcare we need to simply live our lives.

The New York Health Act AB5248/SB3577 and the New York Health Plan it would create would improve the quality of life for disabled people. I will address several aspects of the bill in turn.

1. Providing Universal Coverage also Provides Dignity

The New York Health Act would provide universal coverage to all New Yorkers. Universal coverage means everyone gets access to quality care without being exposed to financial hardship and recognizes the dignity and worth of the individual. The movement to recognize this dignity is being experienced all over the world. The United Nations recently held a High-level Meeting on Universal Health Coverage. The delegates to that meeting released a Political Declaration on September 23rd. The Declaration called upon governments to:

14. [r]ecognize the fundamental importance of equity, social justice, and social protection mechanisms as well as the elimination of the root causes of discrimination and stigma in health-care settings to ensure universal and equitable access to quality health services without financial hardship for all people, particularly those who are vulnerable or in vulnerable situations;

and to

70. [e]nsure no one is left behind, with an endeavour to reach the furthest behind first, founded on the dignity of the human person and reflecting the principles of equality and non-discrimination, as well as to empower those who are vulnerable or in vulnerable

situations¹ and address their physical and mental health needs....including... persons with disabilities...²

Without question, disabled people require a solution - because of the discrimination based on our disabilities, the disproportionate poverty and financial hardship we experience, and the stigma attached to anyone with a multiply marginalized identity, are in need of a solution that preserves our dignity by creating access to quality care.

Regarding the principle of equity and empowering marginalized people including persons with disabilities, it is important to note the composition of the New York Health Board of Trustees. The New York Health Act would require that six members of the Board be

...be representatives of health care consumer advocacy organizations which have a statewide or regional constituency, who have been involved in issues of interest to low- and moderate-income individuals, older adults, and people with disabilities; at least three of whom shall represent organizations led by consumers in those groups;³ [underline added]

Having representatives of *consumer-led* advocacy organizations is an important component of ensuring equity and empowerment of disabled people. There is a saying in the Disability Community, “Nothing about us without us.” That is, it is not acceptable to listen to nondisabled people speaking on behalf of disabled people – it is necessary to listen to disability-led organizations.

2. Replacing traditional healthcare coverage creates employment mobility.

The New York Health Act would replace traditional healthcare coverage with a State-administered public plan. This offers some benefits to people with disabilities. Disabled people experience discrimination in seeking and obtaining employment. Part of the discrimination is based on the belief that we will be costly, and that hiring disabled people will cause health insurance premiums to rise. Additionally, disabled people who are employed⁴ can be limited in our mobility within the job market. If we are fortunate to get quality insurance through our current job which we rely on, we are deterred from seeking other work that might allow us to make more money, be happier, or have a higher quality of life. By switching jobs, we all run the risk of not getting the same level of coverage and losing our providers, but that would not be the case with New York Health with its continuity of care and absence of networks. Doing away with traditional coverage, including employer-linked coverage, we can hope improve the employment rate and workforce mobility of disabled people.

3. Long term supports and services (LTSS) coverage will prevent financial hardship.

¹ While the Center for Disability Rights does not agree with the classification of disabled people as inherently vulnerable, it does agree that existing structure and discrimination place disabled people are put into “vulnerable situations.”

² The Declaration is available at <https://www.un.org/pga/73/wp-content/uploads/sites/53/2019/09/UHC-HLM-silence-procedure.pdf>.

³ AB5248/SB3577 Sec. 5102 (2)(b)(1)

⁴ Only 19.1% of disabled people were employed in 2018 according to the Bureau of Labor Statistics <https://www.dol.gov/general/topic/disability/statistics>.

Some disabled people require LTSS to live our daily lives. LTSS include a range of range of assistance with tasks of daily living, including eating, bathing, toileting, dressing, and cueing and supervision of tasks. Without LTSS, disabled people are stuck in bed or at home, unable to accomplish basic tasks necessary to live let alone fully participate in our communities.

Medicaid is the nation's primary payer of LTSS. In order to get the LTSS we need, disabled people must qualify for Medicaid by complying with its income and asset limits. In other words, disabled people need the LTSS that Medicaid covers and must impoverish ourselves to qualify. Even people participating in Medicaid buy-in are constrained by the asset limit and income cap.

The New York Health Plan proposes to ensure payments of federal funds for health coverage are deposited into the New York Health trust fund, essentially merging federal programs like Medicaid into the New York Health Plan to create a truly single payer system.⁵ Being Medicaid beneficiaries under the Plan would remove the onerous financial hardships imposed on disabled people in exchange for receiving coverage of LTSS. It is overwhelming to think of the possibilities available to individuals who are not subject to enforced poverty.

4. LTSS coverage is necessary to ensure access to quality care and creates equity.

We need to account for the current and future unmet need for LTSS. Despite having access in theory to adequate quality LTSS through Medicaid, disabled people do not experience this. We struggle to get authorized for services, find providers, and wait unacceptably long to get services. Access deteriorates overnight whenever the State cuts funding or limits a benefit. Furthermore, we know that Medicare beneficiaries are not getting access to the very limited LTSS benefits available through Medicare.⁶ The population is aging, resulting in more people who are acquiring age-related disabilities and need LTSS. The New York Health Act would simply cover LTSS for everyone, and would remove the need for individuals to be in the "right" plan for the services you need.

Taking care of disabled family members is often unpaid working falling on women, who may have to give up jobs and career opportunities.

5. Prioritization of community-based services supports disabled people's right to integration.

State Medicaid programs are required to cover LTSS provided in institutions, such as nursing homes, but coverage of the same services in the community are option. Optional home- and community-based services (HCBS) create an incentive for States to deliver LTSS in institutional settings. Furthermore, State action can influence the availability of HCBS. One example is the nursing home carve-out from managed care that was included in the FY2018-2018 State budget and is waiting a decision by CMS. If nursing facilities were carved out of managed care, it would create an incentive for managed care companies to facilitate placement of individuals in institutions long enough to be moved to fee-for-service (FFS) Medicaid, thus creating a "savings" for the managed care company.

⁵ See AB5248/SB3577 legislative intent.

⁶ Carter, Julie. Many Older Adults with Medicare Not Getting the Long-Term Help They Need. *Medicare Watch*. Medicare Rights Center. Feb. 21, 2019. Available at https://blog.medicarerights.org/many-older-adults-medicare-not-getting-long-term-help-need/?utm_source=Medicare+Rights+Center&utm_campaign=a25c52e174-Medicare_Watch_02_21_2019&utm_medium=email&utm_term=0_1c591fe07f-a25c52e174-85115317&mc_cid=a25c52e174&mc_eid=fda68ab68c.

Meanwhile, States have an obligation under the Supreme Court's 1999 decision in *Olmstead v. L.C.*⁷ The Court in *Olmstead* held that disabled people have a right to be served in the most integrated setting. Community integration depends on access to HCBS. For disabled people, HCBS represent being able to have a good quality of life, free to live in our own home, build families if we choose, see out work, participate in the community – freedom from the prison of an institution where none of these things is possible.

This is why the prioritization of community-based services in the New York Health Act is important to the Disability Community. Among the requirements of the program created by the New York Health Act would be:

especially in relation to long-term supports and services, the maximization and prioritization of the most integrated community-based supports and services.⁸

Disabled people support this proposal to move us from a healthcare system in which disabled people must impoverish themselves to qualify for LTSS, struggle to achieve access to services, and are only provided HCBS as an option to one in which LTSS is covered for everyone without requiring financial hardship and prioritizes services and supports that allow us to live in freedom with dignity in the community.

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⁷ *Olmstead v. L.C.*, 527 U.S. 581 (1999)

⁸ AB5248/SB3577 Sec. 5107(2)(f)