

## Written & Oral Testimony to the Senate Finance Committee

**Submitted by:** [Serena Lowe](#) Former Consultant, Self-Direction Advocacy Network  
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**Regarding:** HB 1020 – Developmental Disabilities Administration –  
Self-Directed Services (Self-Direction Act of 2022)

**Position:** Favorable

**Date:** March 7, 2022

My name is [Serena Lowe](#)<sup>1</sup>, and I would like to offer my strong support in favor of the [Self-Direction Act of 2022](#) (HB 1020). From 2015-2019 I served as a Senior Policy Adviser to the [Administration for Community Living](#)<sup>2</sup> within the [U.S. Department of Health and Human Services](#). In this role, I was ACL’s primary liaison to the Home & Community Based Services (HCBS) Implementation Team of the Disabled and Elderly Health Programs Group within the Centers for Medicaid and CHIP Services at the Centers for Medicare and Medicaid Services. In this capacity, I provided technical assistance to all fifty states and the District of Columbia in the implementation of the federal regulation governing the provision of Medicaid-funded home and community based services.

Published in January of 2014, the federal [Home and Community-Based Setting Requirements for Community First Choice and Home and Community-Based Services \(HCBS\) Waivers](#)<sup>3</sup> established for the first time a set of criteria to assure that qualifying individuals with disabilities, mental illness, and older adults have access to an array of services in settings that are integrated in and supports access to the greater community; provides opportunities to work in competitive, integrated employment, engage in community life and control personal resources; optimizes individual initiative, autonomy, independent in making life choice; ensures individuals receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS; ensures rights of privacy, respect, and freedom from coercion and restraint; and facilitates individual choice regarding services and supports and who provides them.

Later in that same year, in October 2014, CMS issued [guidance](#)<sup>4</sup> on the Implementation of Section 2402(a) of the [Affordable Care Act](#)<sup>5</sup>, which outlined standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services Programs. This section of the Affordable Care Act requires the Secretary of the U.S. Department of Health and Human Services to ensure that all states receiving federal funds develop service systems that are responsive to the needs and choices of beneficiaries receiving home and community-based long-term services (HCBS), maximize independence and self-direction, provide support coordination to assist with a community- supported life, and achieve a more consistent and coordinated

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<sup>2</sup> <https://acl.gov/>

<sup>3</sup> <https://www.federalregister.gov/documents/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider>

<sup>4</sup> <https://acl.gov/sites/default/files/news%202016-10/2402-a-Guidance.pdf>

<sup>5</sup> <https://www.hhs.gov/sites/default/files/ppacacon.pdf>

approach to the administration of policies and procedures across public programs providing HCBS.

The subsequent guidance on Section 2402(a) issued by CMS requires that self-direction programs be aligned with the HCBS Final Rule requirements and based on a person-centered plan. SD, when offered within programs, must also be made available to all eligible individuals regardless of age, disability, diagnosis, functional limitations, cognitive status, sex, sexual orientation, race, ethnicity, physical characteristics, national origin, religion, and other such factors. Individuals thus must have access to information and counseling and information on self-direction through a variety of sources as needed or desired, so they can make an informed decision when choosing a SD service delivery model. Additionally, when representatives are required, they must be freely chosen when circumstances permit.

Given the strong synergy between self-direction and the provision of Medicaid-funded HCBS, I and my colleagues at ACL and CMS also spent a great deal of time supporting states to use their various statutory authorities to expand and improve self-direction programs as a pathway to assuring strong implementation of the federal HCBS regulation. Individuals and their families should have access to the technical supports and flexibility needed to successfully engage in self-directing their Medicaid HCBS resources to assure they get what they need to live, work, and thrive in the greater community. Self-direction is not only a tool for assuring that people have the opportunity to receive services in the most integrated setting (a primary aim outlined in Title II of the [Americans with Disabilities Act](#)<sup>6</sup> and subsequently the landmark U.S. Supreme Court decision *Olmstead v. L.C.*<sup>7</sup>), but also to addressing critical labor shortages among the direct care workforce as we have witnessed during the global COVID-19 pandemic by allowing individuals through self-direction to hire family members as a way of assuring they continued to receive services necessary for avoiding institutionalization.

In 2021, I served as a technical consultant to the [Self-Direction Advocacy Network of Maryland](#)<sup>8</sup>, and during this time was a member of the Maryland General Assembly's Workgroup to Review and Recommend Policies for the Maryland Self-Direction Program.

The purpose of the Workgroup, which met monthly over the course of seven months (from June-December of 2021), was to determine whether changes in the state's self-direction program for Medicaid HCBS since its inception in 2005 had become too administratively burdensome and had impeded the ability of individuals and families from accessing the supports and services they needed to obtain optimal independence and community integration. The Workgroup was charged with reviewing and understanding the self-direction model for participant-led healthcare; determining if program accessibility and flexibility has decreased; identifying and collating the needs and gaps for individuals practicing self-direction; and investigating financial concerns by reviewing existing CMS waivers for participants.

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<sup>6</sup> <https://www.eeoc.gov/americans-disabilities-act-1990-original-text>

<sup>7</sup> <https://www.law.cornell.edu/supct/html/98-536.ZS.html>

<sup>8</sup> <https://marylandsds.org/>

In its deliberations, the Workgroup determined that the introduction of various policy changes over the years had the effect of creating unnecessary administrative burdens on individuals and families, as did restrictions on the use of self-direction resources that inhibit an individual's ability to get the level of supports required to live in one's own home or with family. For example, new rules were implemented that prevented individuals from receiving overnight supports for personal care or habilitative reasons unless they agreed to forgo hiring their own staff and agreed to go through a provider agency. Requiring participants to relinquish their ability to choose the individuals they would like to have provide the overnight supports in their home is the antithesis of self-direction. In another example, the state's diluted support broker services greatly limited self-direction as a feasible option for individuals who lack the natural supports or technical expertise to manage the various administrative complexities involved with self-direction. By limiting access to support brokers, whose sole purpose is to advocate for the individual participant, significant inequities persist in who truly can access and successfully participate in the state's self-direction HCBS option.

The Workgroup issued nine recommendations to provide greater access and flexibility to self-direction participants, which have been incorporated into the Self Direction Act of 2022 ([House Bill 1020](#))<sup>9</sup>:

- Require DDA to reinstate full employer authority for all personal supports to self-directed participants, to include individuals who have an established need for overnight supports and/or those living independently or in their family homes.
- Restore support brokers' responsibilities to match guidelines; allow for individuals to receive up to 40 hours of support broker services a month; and require a third-party support broker to be hired in any self-direction case where the individual hires a family member or guardian as paid staff in order to address any conflicts of interest and assure the fiscal integrity of the program.
- Invest in increased training for the Coordinator of Community Services to include proper policies, resources, and roles and strategies for working with transitioning youth, individuals without strong family supports, and historically disadvantaged communities.
- Expand coverage of transportation services to allow for mileage coverage to owners of vehicles who are not paid staff but are supporting participants under self-direction.
- Expand coverage of transportation services to allow for mileage reimbursement to nonemployee owners of vehicles used by the participant for plan goals and activities; create more flexibility with Individual and Family Directed Goods and Services; remove the five-thousand-dollar cap on IFDGS and instead base the determination on individual needs.
- Eliminate competency assessment in any form from all DDA policies and proposals.
- Ensure self-direction plans and budgets are easily accessible to individuals and their support teams by allow access to the Long-Term Services and Supports Computer System (LTSS).

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<sup>9</sup> <https://mgaleg.maryland.gov/mgaweb/legislation/details/HB1020>

- Enshrine in regulation the parity in budgets and compensation for individuals participating in the self-direction program, so they align with the budgets and compensation for individuals utilizing a provider-managed program.
- Require the [Developmental Disability Administration \(DDA\)](#)<sup>10</sup> to provide an annual update for three years to the Maryland General Assembly outlining its implementation and relevant outcomes of the Workgroup's recommendations.

Passage of the Self-Direction Act of 2022 would help streamline administrative burdens, assure parity between services that are provider-managed and those that are self-directed, and assure a balance between optimal participant flexibility and fiscal integrity. The implementation of the Workgroup's recommendations that are embedded in the Self-Direction Act will increase access and result in the successful use of self-direction as a viable option for individuals eligible for Medicaid-funded HCBS. Additionally, the provisions of House Bill 1020 are consistent with federal policy and would assure stronger alignment of the state's HCBS self-direction option with the federal HCBS regulation and subsequent guidance related to Section 2402(a) of the Affordable Care Act.

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<sup>10</sup> <https://health.maryland.gov/dda/Pages/home.aspx>