

House Health and Government Operations Committee**March 9, 2022****HB 1020: Developmental Disabilities Administration – Self-Directed Services****Position: Support with Amendments**

Disability Rights Maryland (DRM), formerly *Maryland Disability Law Center*, is Maryland’s federally-designated protection and advocacy organization charged with advancing the rights of people with disabilities for over 40 years. In our practice, DRM has seen firsthand both the value and opportunities that people with intellectual and developmental (I/DD) disabilities have when they utilize self-directed services and the difficulties they encounter due to systemic issues and barriers in the program. We understand that sponsor has made significant amendments to this bill that we support. We believe that the few additional changes outlined below help preserve the bill’s focus on ensuring the people with I/DD have access to the supports and services they indicate they need. We have spoken with the advocates who have driven this bill and understand that they are amenable to making these changes. **As such, DRM currently supports HB 1020 with the amendments outlined below, but we anticipate being fully and strongly supportive of the bill once these changes are made.**

Background:

Today, a growing number of people with developmental disabilities are choosing to direct the supports and services they receive in the community through the Developmental Disabilities Administration (DDA). This means that people with disabilities, with support from their families and others, as needed, take responsibility for managing their services, including choosing, hiring, and supervising the people who provide their direct support. In this way, self-direction allows a person to be the architect of their services—it increases a person’s self-determination by empowering them to make fundamental decisions about how and from whom they receive supports.

In 2005, the state of Maryland worked with people with developmental disabilities, families, and other advocates to create a waiver pilot program under which people self-directed the funding they received from the DDA for their needed supports. By allowing people with I/DD to make funding decisions about services and supports, it gave them more choice and control over what services they received. Individuals in the initial pilot reported remarkable improvements in quality of supports and quality of life. What started as the “New Directions” waiver pilot, became the DDA self-directed services option available through the Community Pathways, Community Supports, and the Family Supports Medicaid waivers in Maryland.

Over time; however, self-directed service definitions and the structure of the program changed significantly through waiver amendments. While some of these changes were necessary to improve oversight, many of these changes have altered and complicated the program’s successes. Some service options were eliminated; allowable expenses for services and supports were restructured; and, many of the duties that Support Brokers – people designated by the person to assist with the coordination of self-directed services – were eliminated.

In the wake of the 2021 legislative session, a work group was established to review and make recommendation on how the self-directed services system can be improved in Maryland. DRM participated in

that work group and supports its recommendations, the vast majority of which are codified in this bill. We appreciate the commitment of the Department of Health in that workgroup to reforming and bettering the self-directed services system. We recognize; however, that statutory changes are necessary to cement these changes into law.

WHY is this legislation important?

The intention of this bill is to restore and preserve the principles of self-direction envisioned in Maryland and it does so by doing the following:

- Ensuring that all people with disabilities, regardless of their physical or intellectual capacity, can self-direct their services and get the support that they need to do so from people they choose, hire, and trust.
- Codifying access to awake overnight supports, which has been a critical advocacy issue in our community for the past several years.
- Restoring some definitions that were changed in waiver amendments to their former forms, including who people with I/DD may hire as staff and many of the roles of the support broker. This will allow people who do not have access to robust family supports to receive the support they may need to self-direct their services.

What amendments do we believe are needed?

We believe the following amendments help preserve the bill intent and ensure that self-directed services are driven by people with I/DD. Again, we reiterate that we understand that the advocates who have driven this bill are amenable to these changes and as such we anticipating being fully supportive of the bill once these changes are made:

- **Amend the definition of person-centered plan in §7-101(R)(2) to “ensures that the individual is the primary contributor and may receive support from others they choose to develop the plan”.** The change in this language is critical to ensuring that the person with I/DD and no one else remains the primary contributor to the person-centered plan. While they may receive support from others of their choosing, they must remain at the center of the development of their person-centered plan.
- **Amend sections, §7-101(AA) by deleting “the individual’s family or other representative” and §7-408(B) so that it reads “to assist the recipient and others of their choosing”.** The intent of self-direction is that the person with I/DD is in control of their services. Changes are needed to ensure that while people with I/DD may need support from family and others to make informed decisions, that they remain in control of their services. It is implied that a legal representative would have authority to make decisions for a person if that person lacks the capacity to do so, but as drafted this language appears to automatically grant deference and authority to family members and representatives that may not be contemplated or authorized by the person.

While we do not seek an amendment on this issue, we recognize that the bill changes the nature of individual and family directed services to include services and supplies that are not currently available to people in traditional services. **We underscore the need to ensure parity in the Waiver system, so that there is not greater inequity between people who self-direct their services and those in provider-managed services.**

DRM strongly believes that everyone with an intellectual and/or developmental disability should have the option to self-direct their services, and have access to any support necessary to be successful in doing so. We support House Bill 1020 as it makes critical changes that will greatly improve and expand the self-directed services program. We believe the small amendments above will be incorporated into the bill shortly and will further enable more people to have the opportunity to manage and control their services.

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