



## Maryland Developmental Disabilities Council

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House Health and Government Operations Committee

March 9, 2022

**HB 1020: Developmental Disabilities Administration – Self-Directed Services**

Position: Support IF Amended

The Maryland Developmental Disabilities Council (DD Council) is a statewide public policy organization that creates change to make it possible for people with developmental disabilities to live the lives they want with the support they need. The DD Council is led by people with developmental disabilities and their families. From that perspective, the DD Council supports HB 1020, but only if amended.

**We understand the Sponsor has significant amendments, most of which the DD Council supports. In addition to some of those amendments, we can support if the following recommendations are addressed:**

- 1. Strengthen language about the person by deleting “and family or representative” from the proposed amendment to §7-408(B) and by deleting “the individual’s family or other representative” §7-101(AA).** The goal of self-directed services is to provide people a greater degree of choice and control in how services are delivered. **The person with a developmental disability is at the core of the choice and control.** While people with disabilities sometimes need support from family and others to make informed decisions, we believe it is a problem to codify “and family or representative” in any part of a law created to ensure the person has choice and control.
- 2. 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 ensure the person with developmental disabilities 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.
- 3. Remove the proposed amendment to §7-409(A)(6) in its entirety.** The proposed amendment would give people the ability to use funds to hire someone to help manage the person’s “home, staff, and other administrative duties.” **This is already within the allowable functions of a support broker, and is therefore too broad and unnecessary.** In addition, the proposed amendment adds the ability to use funds to “pay administrative expenses needed to operate the recipient’s plan of service including internet services and office equipment. **This is not an allowable expense through any Medicaid waiver.**
- 4. Remove the proposed amendment to §7-409(C)(I).** People who self-direct their services receive up to \$5,500 for individual and family direct services. According to the approved waiver application, this is for “services, equipment, or supplies that enable the participant to maintain or increase independence and promote opportunities for the participant to live in and be included in the community, relate to a participant’s need or goal identified in the participant’s Person-Centered Plan, and are not available under the Waiver program or Maryland Medicaid Program.” **Similar funds are NOT available to people in traditional services, therefore, removing the cap of \$5,500 to individual and family directed services creates greater inequity between people who self-direct their services and people supported by a provider.**

**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 IDD 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.

#### **WHY is this legislation important?**

The intent of this bill is to restore and preserve the principles of self-direction in Maryland and it to some extent it does that by:

- 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.
- Restoring some definitions that were changed in waiver amendments to their former forms, including who people 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.**

After the 2021 legislative session, a work group was established to study and review self-directed services in Maryland. A number of policy recommendations were made by members of the work group. **While this legislation, with the drafted amendments, addresses some of them, the Council wants to ensure people with developmental disabilities remain the focus of self-directed services. We remain concerned about the resulting inequities for people with developmental disabilities who do not self-direct their services.**

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