

## Health and Government Operations Committee HB 1171: Public Health- Demonstration Program Developmental Disabilities March 4, 2020

**Position: Support with Amendments** 

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7000 Tudsbury Road Windsor Mill, MD 21244 The Maryland Developmental Disabilities Coalition (DD Coalition) is comprised of five statewide organizations that are committed to improving the opportunities and outcomes for Marylanders with intellectual and developmental disabilities (IDD). As such, the DD Coalition supports HB 1171 with amendments.

Background: A growing number of people with IDD and their families are choosing to actively direct the supports and services they receive. This means that people with disabilities, with support from their families and others if needed, take responsibility for managing their services, including hiring and supervising the people who provide their direct support.

In 2005, the state of Maryland worked with people with IDD, families, and other advocates to create a waiver pilot program under which individuals with intellectual and developmental disabilities self-directed the funding they received from the Developmental Disabilities Administration (DDA) for their needed supports. The program allowed people to hire their own staff and make decisions regarding where and how their funding would be used to access service options they needed. By allowing people with IDD to make funding decisions about services and supports, it would give them more choice and control over what services they received. The belief was that as a result, funds would be spent more effectively and efficiently. 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, self-directed service definitions and the structure of the program changed significantly through waiver amendments. While some of the changes were necessary to improve oversight, many of the changes have fundamentally altered the successful program. This included the elimination of some service options; the restructure of allowable expenses for services and supports; and, the elimination of many of the duties that Support Brokers — people designated by the person with IDD to assist with the coordination of self-directed services - used to be allowed to handle with and for people.

## WHY is this legislation important?

The intention of this bill is to restore and preserve the principles of self-direction envisioned in Maryland.

- People with disabilities should be empowered and supported to self-direct their services and to receive assistance to do so from people they choose, hire, and trust.
- Self-Directed service options should be designed with cost-neutrality in mind compared to traditional service costs and should be flexible to meet the needs of the individual to meaningfully live, learn, work, play, and worship as the person chooses.

## WHAT does this legislation do?

- > The bill, as significantly amended, establishes a State Advisory Council on Self-Directed Services. Stakeholder members would include individuals who self-direct their services, parents, Department personnel, and others integral to the development and maintenance of a responsive system of self-directed supports.
- The purpose of the Advisory Council is to restore and preserve the principles of self-direction in DDA services and supports.
- The bill also restores some definitions that were changed in waiver amendments to their former forms, including the duties of support brokers to aid individuals to selfdirect their services, who individuals may hire as staff, and who may self-direct their services. The DD Coalition strongly believes that everyone with an intellectual and/or developmental disability should have the option to self-direct their services, and supports to be successful in doing so.

The DD Coalition supports the creation of a statewide advisory council to address these issues and to support more people to take responsibility for managing their services and supports; however we are not taking a position on the section of the bill that addresses the employed individuals with disabilities pilot program.

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