



HB352: Budget Reconciliation and Financing Act of 2024

February 28, 2024

Position: Favorable with Amendment

The Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of the five Down syndrome organizations in Maryland and individuals with Down syndrome and their families who come together to advocate for improved quality of life for all individuals with Down syndrome in Maryland. MDAC works in coalition with other disability and advocacy organizations across the state and supports many legislative and policy efforts.

Most adults with Down syndrome rely on services provided under a Medicaid waiver through the Developmental Disabilities Administration (DDA) to live the lives they choose in the community. Some individuals choose to receive these services through a traditional provider model, while others choose to self-direct their services. In 2022 the Maryland General Assembly passed the Self-Direction Act which guaranteed key flexibilities in self-directed services. We are concerned by the section in HB352 (p. 20, lines 8–21) that would remove an important provision of the Self-Direction Act disallowing DDA from establishing a limit on “the dollar amount of individual-directed and family-directed goods and services provided to a recipient.” The imposition of such a limit would be antithetical to the rate parity that underlies Maryland’s waiver programs. Regardless of the service model that an individual chooses, the dollar amount per hour for personal support services is equal in both traditional and self-direction. The limit for every individual is their budget, which is based on a Person-Centered Plan, approved by DDA, and may include only expenses authorized by the Centers for Medicare and Medicaid Services (CMS).

IFDGS are “services, equipment, activities, or supplies” that “relate to a need or goal in the person-centered plan, maintain or increase independence, promote opportunities for community living and inclusion, and are not available under another waiver service” and are authorized by CMS. IFDGS allow a person to exercise control over the design of their own life and build meaningful activities into their lives as defined by their Person-Centered Plan. For example, this category of expenditure could include therapeutic riding or a membership at the Y. These activities and programs are similar to those that might be offered as part of a day program in a traditional services model.

MDAC’s guiding principles include that people with Down syndrome and other intellectual disabilities are able to make informed choices about all aspects of their lives, have the freedom to choose their daily routines and other activities, and should have readily available, easily accessible, fully funded, and flexible home and community-based services (HCBS) and long-term services and supports. In our view, it is critical that all people, including those with intellectual and developmental disabilities, are able to exercise maximal choice and control over their lives. Individuals who self-direct their services under a Medicaid waiver should, as guaranteed by the Self-Direction Act of 2022, have full rate parity with those who utilize other models of service provision, have access to their full budget, and be able to exercise full choice and control over their budget.

We request the referenced section (p. 20, lines 8–21) be stricken, upholding the original intent of the Self-Direction Act of 2022.

Respectfully submitted,
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