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House Health and Governmental Operations Committee March 15, 2022

HB1403: Maryland Department of Health - Waiver Programs - Waitlist Reduction Act (End the Wait Act)

Position: Support

The Arc Maryland is the largest statewide advocacy organization dedicated to protecting and advancing the rights and quality of life of people with intellectual and developmental disabilities. The Arc Maryland supports HB1403, which requires the Department of Health to develop plans to reduce the waitlists for waiver programs by 50%, and beginning in FY 2024, requires the Governor to include sufficient funds to carry out the plans in the annual budget.

Background on waiver services: People with intellectual and developmental disabilities often need some degree of home and community based services (HCBS) which provides them with assistance to eat, to dress, for personal hygiene, and for managing health care or finances. For people with limited incomes, these services can only be obtained through Medicaid. Unfortunately, in Maryland the Medicaid HCBS programs currently have long waiting lists.

Medicaid is technically an institutional insurance. It is used for nursing homes and other long-term care services. The Medicaid waiver services in Maryland (meaning that the requirement that these services must be provided in an institutional setting has been "waived") support people to receive these services in the community (HCBS). While the institutionally-based services are provided as they are needed by a person--there are no waiting lists--there ARE waiting lists for the HCBS services. That is because in Medicaid, HCBS services are considered "optional." This is what we term the "institutional bias" of Medicaid that The Arc and others have advocated for seven decades to change.

This institutional bias persists even though it is shown in study after study that HCBS services are more cost effective than institutionally-based services, and promote the best quality of life.

The majority of The Arc members are people with developmental disabilities, parents or family members of people with developmental disabilities, and providers of The Arc across the state who collectively support more than 30% of people with IDD who receive services funded by through the Autism Waiver and the Maryland Developmental Disabilities Administration. Thousands more Marylanders access The Arc's education, training, and information and referral services. These individuals and/or their families want and need services and supports to live, learn, work, and play alongside Marylanders without disabilities, but are waiting in long lines for these services. The wait and lack of services and supports impacts the ability of people with disabilities and their families tremendously.

Close to 4,000 people are on the Developmental Disabilities Community Pathways Waiting List with some waiting for decades to access needed services. Over 6,000 children and their families are waiting on the Autism Waiver Registry, some for as many as 10 years.



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When the Autism Waiver Program was created in 2001 it was intended to be a program of Early Intervention, designed to provide children and families to access services early, thus preventing lifetime reliance on more extensive, and expensive state services and supports. Unfortunately, the funding for this waiver has not kept pace with the need and many who enter the waiver registry as a child wait so long for services they age out of eligibility before their "number" even comes up.

It is clear that Maryland needs to do more to prioritize the availability of services and supports for children and adults with disabilities and their families. We believe HB1403 will accomplish that.

The clarifying amendments presented for this bill are important to ensure the plans created by the department examine existing and needed capacity of providers in Maryland, and rates for services to ensure they are sufficient to provide quality services and supports. The COVID-19 pandemic has exacerbated the professional caregiver (Direct Support Professional) workforce crisis. Direct support professionals play a critical role in people's lives and plans for expansion of services must include measures to build the capacity of providers, measures to recruit and retain providers and direct support professionals, and changes to reimbursement rates.

The Arc Maryland supports HB1403 and urges the Committee to return a favorable report.

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