

HB1423 Maryland Department of Health - Workgroup on Home- and Community-Based Services Position: Favorable with Amendments

To Health Committee Chair Delegate Heather Bagnall and Vice Chair Delegate Bonnie Cullison:

I am submitting this testimony in favor of revising this bill to include members of the work group to consist of people with disabilities and those who receive or who have received services from an agency providing Home and Community Based Waiver services.

I am an Autistic and transgender woman and I was diagnosed with Asperger's while I was in middle school and ADHD in elementary school while attending a school for students with learning disabilities. I earned my Bachelor's degree in Psychology and began working as a residential direct support professional; I helped provide various levels of personal care to adults with developmental disabilities. I currently work as a service coordinator in the Medicaid HCBS Waiver field for people with developmental disabilities. In my time outside of my day job, I serve on The Arc of the United States National Council of Self Advocates, the Institute for Exceptional Care IDD Advocate Corp, community advisory boards for Drexel University AJ Drexel Autism Institute and Temple University Institute on Disabilities.

In the bill, "representative" is not defined. Is the bill saying employees can only be the representative? If you are going to define "representative" please make sure the definition can include clients or consumers of the HCBS service provider agency. In the self-advocate community we have a slogan "Nothing about us without us." One thing I have noticed during my 10+ years working in the developmental disability field is that many organizations serving this population do not often have people with disabilities on their staff, leadership, and advisory boards. However, I notice with civil rights organizations such as the NAACP, there is a good number of non-white staff and leadership and at LGBTQ organizations several openly-LGBTQ people are on staff and leadership. I have noticed that my own lived experience with Autism has been an asset for me working in the developmental disability field; I work to educate the families of the children on my caseload both what accommodations they can put in place for their loved ones with a disability as well as helping their child gain independent living skills. I take a primary emphasis approach on the social model of disability (<https://neurodivergentinsights.com/medical-vs-social-model/>) Also, some of the best teachers I had in school also had learning disabilities; for example my junior high reading teacher told us she was dyslexic. I was diagnosed with a reading comprehension disability in elementary school and if someone with a reading-based disability could enjoy reading, I realized I could too and I began again reading for pleasure outside of school-required reading.

Without having people with disabilities who receive or have received these support services on these advisory groups, I believe the work group will create the impression that they

are working to ensure the needs of the non-disabled community are met more than those with disabilities they are serving.

I ask that you please revise this bill to ensure that people who are receiving or who have received Home and Community Based support services are represented in the workgroup.

Ms. Elizabeth K. Graham
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never being understood or empathized with.

Researchers Zablotsky, Bramlett, and Blumberg set out to understand how parents perceive the “severity” of their Autistic kids’ symptoms.⁹ They surveyed nearly a thousand families raising Autistic kids, and also measured the Autism symptom severity of the children themselves. What the researchers found was that parents did not accurately perceive the level of their kids’ suffering. Instead, parents based their ratings of Autism “severity” on how much their kids’ behavior bothered them and required a lot of their time and attention. Many children described by parents as “high functioning” were quietly coping with debilitating sensory pain, or were falling behind academically or socially in significant ways. This carries over to how Autistic adults are perceived, and the expectations that neurotypical institutions place on us to appear “normal.”