

Testimony for Maryland HB 847: State Autism Coordinator and Advisory Stakeholder Group on Autism Needs

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- I am a community pediatrician and Mom to an adult child who is diagnosed with ASD, Autism Spectrum Disorder.
- I am also a member of the Maryland Chapter, American Academy of Pediatrics, which supports this Bill.
- My family's personal experience with Maryland's systems for vulnerable adults and with the federal and county systems that coordinate with Maryland is too complex to explain briefly; but I have had negative experiences that involve every sphere of her comprehensive set of needs, such as education, medical, vocational, mental health, and psychological.
- Overall, I can say clearly the system cannot keep up with the science and the rules involved are inflexibly and sometimes feel punitively applied.
- I believe the system is so under-resourced and probably stigmatized like the community of people with disabilities itself that some communities of people with various disabilities and their advocates are too often pitted against each other when seeking limited resources.
- Further my child is not a stereotype of autism; which historically is divided into camps of more severe cases and so-called highly functional cases.
- Most disturbingly, the system is not set up for us to plan for her long-term future in a safe inclusive environment; which is a factor that causes great anxiety for us.
- I am distressed for several of my friends with sons who have a history of physically assaulting their parents. One of those is a friend who has become depressed about the need for her son's placement in residential care. My child is not violent, not intellectually disabled, and was recognized early; yet as an adult, her creative gifts are not appreciated in typical jobs, which require time-sensitive, intensely competitive, work in teams. She has been unable to obtain a college degree despite having more than enough credits to graduate. She is unemployed and has no prospects for employment.
- Currently my child is thriving emotionally with the support of a good team and by living with me in our single-family home. But I will not live forever; and we have experienced how terribly ill she can become when she is in the wrong setting. She is loved by extended family but they do not have the wherewithal to act as guardians if something should happen to me.
- While health and human service providers need more training; we also need systems that don't punish adults who do not thrive in a typical workplace. We need systems that

do not coerce or force disabled adults into menial, stressful, poorly paying, abusive jobs or leave families as a warehouse for our community's neglected problems.

- I ask you to report favorably on HB 847 and help us move Maryland forward as leaders in the field of humane treatment of vulnerable adults.