

**Testimony in Support of HB 718: State Coordinator for Autism Strategy and Advisory
Stakeholder Group on Autism–Related Needs – Mandated Appropriation**

TO: Delegate Guyton

FROM: Linda J McKibben MD DrPH FAAP FACPM, CEO, The McKibben Group LLC

98 E Wayne Ave/Silver Spring MD 20901

Phone: 301-557-0059

DATE: February 15, 2021

As a Maryland citizen since 2009, a licensed pediatrician and a preventive-medicine physician, a member of the Maryland Chapter of the American Academy of Pediatrics, and proud mother to my adult daughter with autism spectrum disorder (ASD) and other mental and physical conditions, I am pleased to support Delegate Guyton's Bill that mandates annual funding of the program described within the Bill as the *State Coordinator for Autism Strategy and Advisory Stakeholder Group on Autism*. I am very disappointed, however, that this step is needed because the minimal costs for this much needed Program were not covered in the Governor's budget last year. Maryland's struggle to bring resources to persons with ASD and other disabilities is emblematic of my experience as a parent.

During the last General Assembly session, I provided oral and written testimony in support of the Bill that became Maryland law to create this new Program. I gave several examples of my experiences as a single mother seeking social, mental healthcare, physical healthcare, and other support resources and services to enhance the quality of my daughter's life. I explained how my daughter suffered because she cannot fit in with the career and life expectations met by her friends or peers without autism. While good things have been happening for my daughter this past year, we continue to struggle to work across multiple systems that fall short of supporting her to live fully independently and with a good quality of life.

For example, this week my daughter wept because her mental health provider seemed to blame her for not explaining her needs clearly; she also felt shamed for needing a parent to be present to help her explain the problem. I know this was not a figment of her imagination because I have seen the same attitude from multiple mental healthcare, medical and educational professionals.

To help you understand why I support this Bill, I must paint the picture at the systems level. In Maryland, we have a state agency that says my daughter does not qualify for services as a person with developmental disabilities; we have a mental health system that says we cannot list her ASD as a primary diagnosis because insurers will not cover their mental health and social services; we have a federal social security system that defines "disability" as not capable of holding **any** work and refuses to recognize her ASD as a developmental disability; and we have a dysfunctional rehabilitation and work support system that is simply ineffective in her case and for many others. We have hospitals that refuse to or simply cannot find appropriate settings to discharge complex, mentally ill patients and that also blame not having "neurodevelopmental" expertise for patients with autism. We have a dysfunctional

housing system for adults with disabilities, period. Need I mention the challenges we are having finding a COVID vaccine for these individuals?

The “last” straw occurred years ago. A hospital social worker told me that I must “make” the system work by complaining about the services that we depend upon for help. I have had to fire and change providers a number of times, but that is always painful and stressful for me; and more so for my daughter who does not do well with transitions. Firing individual professionals also does nothing to help other families like ours. No individual can fix the system that helping professionals and their agencies are currently invested in maintaining. We need Delegate Guyton’s Bill 718 to be enacted this year so we can begin to identify and solve systemic problems by better coordinating resources and services for children and adults with ASD and their families.

Thank you!

Sincerely,

A handwritten signature in black ink that reads "Linda Joan McKibben MD DrPH". The signature is written in a cursive, flowing style.

Linda J McKibben MD DrPH