

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

TO: Delegate Guyton

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

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DATE: March 19, 2021

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 and her needs cross county, state and federal policies and bureaucracies. While good things have been happening for my daughter this past year, including her residency in the unique, inclusive community, The MainStreet Apartments in Rockville. Yet, we continue to struggle to work effectively across multiple systems that fall short of supporting her to live fully independently and with an optimal quality of life, all of which is exacerbated by the COVID pandemic.

For example, recently 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, mental confusion or fog! I know her perception was not a figment of her imagination because I have witnessed similar attitudes from numerous care providers.

Please allow me to briefly paint the picture at the systems level. In Maryland, the state agency for developmental disabilities decided that my daughter does not qualify for services as a person with developmental disabilities; the county mental health agency that asserts we cannot list her ASD as a primary diagnosis because insurers will not cover their mental health and social services; the federal social security system defines "disability" as not capable of holding **any** work and refuses to recognize her ASD as a developmental disability; and our state agency for rehabilitation and work support system has been ineffective in her case. In the past, local mental health units in hospitals refuse or simply cannot find appropriate settings to quickly discharge complex, mentally ill patients and profess to lack "neurodevelopmental" expertise for patients with autism. A hospital social worker told me that I must "make" the system work by complaining about the services that we depend upon for help. A hospital social worker once told me that I must "make" the system work by complaining about the services that we depend upon for help. At that time, the housing system for adults with disabilities was dysfunctional. Lastly, we have multiple challenges to schedule a COVID vaccine for her.

Because of this last critical issue, I want to add that I have great confidence that Delegate Guyton will help select a highly qualified person to direct the new Office of the Coordinator to address the needs of

persons with Autism. As I have discussed with her, we need someone who is lead by sound science to help make good policy. She knows we need a leader who can work across bureaucracies such as mental health, medical and social services; and we need a champion for vaccines and evidence-based therapies and innovative research. In these times, we particularly need a health equity leader to respond to disparities impacting women and persons of color.

Please help to assure that Delegate Guyton's Bill 718 is enacted this year with adequate funding. We must begin to identify and solve systemic problems to assure equity for children and adults with ASD and their families.

Thank you!

Sincerely,

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

Linda J McKibben MD DrPH