



## **TESTIMONY IN SUPPORT OF SENATE BILL 636, “END THE WAIT ACT”**

### **House Health and Government Operations Committee**

**Testimony Provided by Stuart Spielman, Senior Vice President for Advocacy, Autism Speaks  
March 29, 2022**

Chair Pendergrass, Vice-Chair Pena-Melnyk, members of the committee, thank you for affording me the opportunity to testify in support of Senate Bill 636, the “End the Wait Act,” on behalf of Autism Speaks and myself personally, as a resident of Montgomery County. My name is Stuart Spielman. I am Senior Vice President for Advocacy at Autism Speaks, a national organization dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. Autism Speaks does this through advocacy and support; increasing understanding and acceptance of people with autism; and advancing research into causes and better interventions for autism spectrum disorder and related conditions.

As you know, the End the Wait Act would require the Maryland Department of Health to develop a plan to reduce the waitlist for eight Maryland Medicaid home and community-based services waiver programs. I will limit my remarks to one of those waivers, the Waiver for Children with Autism Spectrum Disorder (Autism Waiver).

Autism, or autism spectrum disorder, refers to a broad range of conditions characterized by challenges with social skills, repetitive behaviors, speech, and nonverbal communication. According to the Centers for Disease Control and Prevention, autism affects an estimated 1 in 49 children in Maryland and 1 in 44 children nationwide.

The principal goal of the Autism Waiver is to keep children safe at home and in the community. The waiver furthers this goal by providing intensive individual support, respite care, and other services to 1378 children as of March 15th.

My older son, Zak, who is now 27 years old, was one of the first children in Montgomery County on the waiver. He was a young child back in 2001, when the waiver first became effective. He remained on the waiver until he turned 21, receiving services that enabled him to enjoy a fuller family and community life.

Zak was fortunate to receive services at an early age. The Autism Waiver was a first-in-the-nation Medicaid program, an effort to support children who met an institutional level of care and the families who looked after them. It was the vision of Delegate John Adams Hurson, who introduced the legislation that led to the development of the waiver, as well as Marjorie Shulbank, June Cohen, Boyd Pusey, and other creative thinkers at the Maryland State Department of Education, to intervene early in the lives of children with autism so that they would have the best chance to reach their potential.



Sadly, the dream of the visionaries is no longer being fulfilled. Newly enrolled Autism Waiver participants on average are in their teenage years. Children who today are first being served by the Autism Waiver have been waiting since 2014. The number of affected Maryland children has exceeded the capacity of the waiver to serve them. And so, children wait, and continue to wait, in Howard County, Prince George's County, Anne Arundel County, and places throughout our state. As of March 15<sup>th</sup>, 6291 children were on the statewide registry. When I submitted written testimony to the Senate Budget and Taxation Committee on March 2<sup>nd</sup>, the number on the registry, current as of February 1st, was 6196 children.

The End the Wait Act would reduce the appalling number of children who today are unserved by the Autism Waiver. We commend Senator Zucker for sponsoring the End the Wait Act and ask this committee to issue a favorable report on the legislation.