



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

Senate Budget and Taxation Committee

Testimony Provided by Stuart Spielman, Senior Vice President for Advocacy, Autism Speaks

March 2, 2022

Chair Guzzone, Vice-Chair Rosapepe, sponsor Zucker, 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. I am Senior Vice President for Advocacy at Autism Speaks, which is dedicated to promoting solutions, across the spectrum and throughout the life span, for the needs of individuals with autism and their families. We do 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 PREVALENCE



Autism, or autism spectrum disorder (ASD), 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, 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 approximately 1350 children.

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.

*6196 children in Maryland
are waiting on the
statewide registry. **

**As of February 1st*

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 February 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 Montgomery County and Baltimore City,

Washington County and Talbot County, and places throughout our state. As of February 1st, 6196 children were on the statewide registry.

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.