

February 9, 2021

Health and Government Operations Committee Maryland House of Delegates

## **RE: Support of HB598**

Dear Chair Pendergrass and Members of the Committee:

Thank you for the opportunity to provide written testimony in strong support of HB598 by Delegate Ariana Kelly. <u>This</u> <u>important bill will pave the way for more meaningful and</u> <u>equitable access to critical autism-related therapies for</u> <u>children who need them.</u> It will do so by removing a burdensome and unnecessary requirement within current Maryland Medicaid reimbursement practice, which often has the impact of forcing a parent to choose between paid work or other household duties and ensuring their autistic child receives medically necessary services.

Applied behavior analysis (ABA) is a common and often life-changing behavioral health therapy for individuals with autism and their families. Together with other prescribed services for some autistic children and adults, such as occupational therapy and/or speech therapy, <u>ABA helps</u> <u>people with autism reach their full potential in areas</u> including education, employment, independent living, and life satisfaction.

In 2014, the Maryland Legislature passed a law requiring state-regulated private insurance plans to provide coverage of autism-related services including ABA. <u>Under</u> <u>this law, there is NO mandate that a parent or caregiver</u> <u>of children receiving ABA services must be present and</u> <u>available at all times in the setting of that service provision.</u>



"The new year signified a fresh start and a reason to celebrate for our family: our 7-year-old son, Owen, who was diagnosed with autism at 19 months, returned from winter break to his first FULL DAY in a mainstream, general education classroom. In his words, "It was awesome!"

Now, it may be difficult for families without children on the spectrum to understand why this was such an important day for us but trust me – this was huge! This is a moment that he's worked for since he was diagnosed. Nearly six years of 20+ hours of [ABA] therapy a week....working through more challenges than we even knew existed: being non-verbal, echolalia, scripting, teeth grinding, transitions, *meltdowns, stimming, splinter* skills and difficulty with gross and fine motor skills.

And finally, in 2021, it happened! Owen's first full day in a general education classroom was a success! We share O's story because early intervention/diagnosis was so instrumental in bringing him to this awesome day."



"As a mom, I felt a lack of understanding and connection with my son, Kenden, better known as Mr. K. I knew something was missing from our relationship. He was nonverbal with screaming and crying as his only form of communicating.

His behaviors were very impulsive and uncontrollable. He would hit, kick, bite, throw himself into doors, walls, or fall on the floor. I had no clue how to handle or help him. Kenden's autism journey began at the age of 2.

His diagnosis provided a relief. It gave me permission to stop holding my breath and to breathe. I knew this would be work but I was definitely up for the challenge and welcomed it.

Now, Kenden is a thriving 8year-old little boy. His smile is contagious, and his selfconfidence will give you strength. He defines the saying 'if there is a will, there is a way!" Two years later in 2016, the Maryland Department of Health filed a Medicaid State Plan Amendment (SPA) to add ABA therapy coverage for children with an Autism Spectrum Disorder diagnosis, as is a federal Medicaid requirement. This SPA was approved by the Centers for Medicare and Medicaid Services (CMS) and it took effect on January 1, 2017.

That 2016 SPA contained NO mandate that a parent or caregiver of children receiving ABA services must be present and available in the setting of that service provision, and such mandates are not common in other state Medicaid programs.

While a component of ABA therapy for an individual with autism is training of the family to support that individual at home, the majority of hours spent are between just the Registered Behavior Technician and/or the Board-Certified Behavior Analyst working with the autistic person. Some children require very intensive ABA therapy, up to 40 hours per week.

For most families to function – typically with one or more parent(s) working, a household to run, and sometimes with the needs of other children to be met – <u>a parent or</u> <u>caregiver does not have the ability to spend up to 40</u> <u>hours a week at the site of the child's ABA therapy, as is</u> <u>currently required under Medicaid.</u> Often in only the most privileged families can a parent or caregiver devote this much of their time to being present during all of their child's autism-related care.

I urge your support of HB598 to help solve this problem and create greater access and equity for the growing number of children with autism. Thank you.

Respectfully submitted,

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