

Senate Budget and Taxation Committee

SB 636

March 2nd, 2022

Position: Support

Imagine being the parent of a toddler newly diagnosed with autism. You're fatigued by months of worry about your child's development, and haunted by what this diagnosis may mean for your child. You are scared, unsure, and anxious about your child's future, but you push past the overwhelm, determined to find help.

You are told by multiple providers that your child needs 40+ hours per week of therapy and intervention. You are advised to start sooner rather than later because research tells us that early intervention is critical for patient outcomes. You are given the "First 100 Days of Autism Tool Kit", filled to the brim with calls to make and lists to join. The overwhelm creeps back in, but you push forward.

You call your insurance company to inquire about your coverage for things like speech therapy, physical therapy, occupational therapy, and Applied Behavioral Analysis (ABA). All therapies demonstrated as effective in addressing the key symptoms of autism. After several transfers and many minutes on the phone, a customer service rep tells you that unfortunately, your employer's plan does not cover ABA, and places visit limits on therapies like speech therapy, physical therapy, and occupational therapy. The 40 hours per week you were shooting for is now 1-2 hours per month if you are lucky.

You apply for medical assistance only to be told that your income doesn't meet the guidelines. You make too much money to qualify for assistance by not enough to pay the thousands of dollars needed to cover the amount of therapy required. You apply for DDA services and receive a rejection there too. You then call the Autism Waiver Registry number. They praise you for adding your child at a young age because it will be 8-10 years before your child will be called. They explain that the wait could be less or more depending on the need, and of course funding. Let me repeat that, 8-10 years before Maryland can provide assistance including health coverage to cover the therapies needed when a child is young. **Early intervention will happen a decade later than it should.**

You turn to the public school system and you are told that your child will receive speech therapy, occupational therapy and physical therapy twice per month for 30 minutes each, along with once per month special instruction. They use a parent training model when your child is preschool age which means that they teach parents how to provide intervention and then carry it through at home. This is nearly impossible for you because you work during the day and the visits occur while you are at your job. Your child enters school and the services continue during the school day but are a drop in the bucket compared to the level of intervention they actually need. Remember the 40 hours per week desired by your child's doctor?

In addition to the missing health coverage, you miss out on respite, in-home support, home modifications, and prescription drug coverage, to name a few of the supports accessible when on the waiver. You will need to wait 10 years for the coverage that a child could get on day one if they moved to Pennsylvania.

In 2015 my son was diagnosed with autism, and the number one piece of advice we were given was to move, and you can see why. We chose not to, and each year I make a phone call to the registry to see what year they are serving. I called last month, and they are serving those who were added to the list in

2013 and 2014. So I've got perhaps another year or two to go until my son can get the assistance he's been waiting for since he was two years old.

This is unacceptable and a failure for children across the state who need access to services and support. A failure to families who are burnt out and need a break. And a failure for all of those parents and caregivers who have continued to push past their overwhelm, make sacrifices, and rearrange their lives in order to provide the best possible care for their children. We need to support our families and cutting the wait will accomplish this.

Maryland can and should do better.

For more information, please contact Angie Auldridge, mother of a child with autism at AngieAuldridge@gmail.com 301-964-0612

Respectfully submitted.

Angie Auldridge