



WRITTEN TESTIMONY IN SUPPORT OF HB 847 with AMENDMENTS

My name is Carrie Hubbard Pineau and I am the Associate Director of Itineris, Inc. Itineris is a Baltimore City based provider that exclusively supports adults on the autism spectrum. We are here today in support of HB847 with amendments and thank Delegate Guyton for tackling this huge challenge. Today I am wearing 2 hats. My first, being my role as Associate Director of the only adult autism provider in Baltimore. The issues we face are tremendous. Some autism statistics for you to think about.

- The CDC estimates that 1 in 50 babies born in Maryland will receive an autism diagnosis. Maryland has the second highest incidence in the Country.
- The latest National Longitudinal Study 2 reports that between 19.2% and 25% of autistic adults are currently employed. That means between 75 and 80% are unemployed or underemployed.
- 500,000 students will exit the school system over the next decade flooding the workforce with more people who will be looking for work.
- Only 1% of autism research funding goes towards adult and lifespan challenges. Most money is spent on early identification and intervention.
- Very few adult programs have the capacity for supporting the complex needs of adults on the spectrum, leaving many adults without much needed long-term services and supports.
- The fact that Itineris is still the only autism exclusive provider after 10 years in Baltimore indicates a huge barrier for the tsunami of exiting students with autism.
- It has been reported that 80% of individuals with ASD also receive a comorbid diagnosis, such as anxiety, depression, OCD, Bipolar disorder, etc.
- There is a huge gap in services for 18-21 year olds that need to be addressed.
- There is much research to be done on aging adults on the spectrum and their needs. We have tremendous experience with youth to early 40's but what will the needs for aging or chronically ill to end of life care for these adults.

Our other hat is that of a Developmental Disabilities Provider. The challenges and barriers here are many as well:

- Adult funding is completely insufficient as the young transitioning adults receive less funding than they received during their school years in spite of the fact that providers are supporting the adult for 66% of their lives.
- Employment challenges are global barriers for the entire DD population.

- Affordable housing is unavailable to most or located in areas that are unsafe for an already vulnerable population.
- Transportation challenges are at the forefront as many DD clients rely on the most unreliable network of mobility, taxi access or public transportation.
- Staff turnover is an enormous expense and challenge as the budget presumes that Direct Support Professionals are similar to home health care aids, rather than professionals who are required to work with highly complex clients with high levels of clinical need. The turnover rate is approximately 33% within 6 months. Over 50% don't stay one year. This costs agencies thousands and thousands of dollars in training, retraining, continuous hiring as well as huge disruptions to those we are supporting. This needs to be professionalized with certifications required.

It is our hope that the State Coordinator for Autism Strategy will develop a strategic plan for addressing autism-related needs in the State in the areas of employment and neurodiversity training, housing, health care, training , as well as a review of services licensed and funded by the Developmental Disabilities Administration, and how those programs and services can best meet the needs of transitioning youth and adults with autism, including identification of the availability of services and supports, and the need for resources, training, and policy changes within existing programs and services. As we operate in the larger DD system, we are asking for your support of the attached amendment to our testimony to ensure that the work carried out in this bill will consider the broader Developmental disability system.

HB 847 Amendment #1:

On page 2, line 30:

(2) ON OR BEFORE JULY 1, 2021, DEVELOP A STRATEGIC PLAN FOR ADDRESSING AUTISM-RELATED NEEDS IN THE STATE, INCLUDING, AT A MINIMUM:

(a) NEEDS IN THE AREAS OF EMPLOYMENT, HOUSING, HEALTH CARE, TRAINING FOR FIRST RESPONDERS AND CRIMINAL JUSTICE PROFESSIONALS, AND IDENTIFICATION AND INTERVENTION; and

(b) a review of services licensed and funded by the Developmental Disabilities Administration, and how those programs and services can best meet the needs of transitioning youth and adults with autism, including identification of the availability of services and supports, and the need for resources, training, and policy changes within existing programs and services.

Amendment #2:

Insert a sunset provision for June 30, 2023.