

HOUSE BILL 0847: State Coordinator for Autism Strategy and Advisory Stakeholder Group on Autism-Related Needs Health and Government Operations POSITION: SUPPORT

Pathfinders for Autism (PFA), a 501c3 nonprofit, is Maryland's largest autism organization dedicated to helping individuals, parents, and professionals find resources, support, and training while working to increase the awareness of autism spectrum disorders. We accomplish this through a variety of programs and services, all of which are offered FREE of charge. Last year our programs directly served 16,500 Maryland residents.

The Centers for Disease Control and Preventions (CDC) estimates that Autism Spectrum Disorder (ASD) affects 1 in 59 US children, 1 in 50 children in Maryland. There are over 12,400 children in Maryland public schools diagnosed with Autism (2018 MSDE census data). In addition, there are 34,000 adults with Intellectual and Development Disabilities (IDD), including Autism, receiving services through the Developmental Disabilities Administration (DDA).

Individuals with autism and their families face numerous barriers in accessing state services and supports, to include:

- A nearly ten year wait list for autism waiver services through MSDE
- Limited crisis funding through DDA
- Decade long wait lists for housing and other support services through DDA
- An inadequate provider network for the Autism Waiver services and Medical Assistance in large part to the low reimbursement rates
- Longer wait times to access mental health services (routinely turned away from inpatient units because of their autism diagnosis)
- The lowest employment rate among their peers with disabilities (Drexel University AJ Drexel Autism Institute)

Individuals with autism have shorter lifespans not because autism itself is fatal, but because people with autism are often vulnerable. Nearly 50% of people with autism have tendencies to wander away from safe places and are at risk of death from drowning, accidents and exposure. Many are victims of medical neglect from untrained professionals that mistake symptoms of a medical crisis for bad behaviors. Rates of suicide among individuals with autism are 10x greater than the general population.

Maryland needs to do more to serve individuals currently in need of supports and services. The prevalence rate is not going down. In fact, Johns Hopkins Bloomberg School of Public Health, which is a site for the CDC's national study, estimates the rate in MD will be 1 in 29 by the year 2030. We cannot continue to ignore the challenge that is in front of us. We need to find ways to more efficiently use the resources and systems we have in place now and identify ways to fill the gaps.

A statewide coordinator would help to facilitate interagency collaboration in order to identify effective solutions that will benefit all individuals with IDD. A statewide coordinator would work with the existing advisory committees, work groups, commissions, task forces, agencies and organizations already focused on many of the issues outlined in the legislation. The coordinator, with input from the stakeholder advisory group, would help to identify overlapping resources, areas in need of attention, and potential barriers in an effort to develop recommendations for a coordinated strategy to address these challenges.

We respectfully ask that you vote in favor of HB847. For more information, please contact Rebecca Rienzi, Executive Director, Pathfinders for Autism at <u>443-330-5370</u> or <u>rrienzi@pfamd.org</u>.