

**Support: HB847 State Coordinator for Autism Strategy and
Advisory Stakeholder Group on Autism Related Needs**

February 24, 2020

Dear Madame Chair and Members of the Health and Government
Operations Committee,

As the grandmother of an Autistic young man, I have seen his struggles and the issues that he has faced. We are fortunate that he is doing well and that our family has the resources to give him the support that he needs. I realize how many children are being diagnosed with Autism and that the number of children that continue to be diagnosed is increasing at an alarming rate. Even with strong family support, our family worries about what will happen with my grandson when I and his parents are no longer around to check in with him. What will happen to the population of autistic children and adults that do not have the resources and family to support them?

I strongly support HB847.

Shirley Apple Jenkins
3 Victoria Falls Dr.
Sparks MD 21152

Testimony for Maryland HB 847: State Autism Coordinator and Advisory Stakeholder Group on Autism Needs

Name: Linda J McKibben MD, Pediatrician

Address: 98 E Wayne Ave, Silver Spring MD 20901

District 20

Date: Tuesday, February 25, 2020

- I am a community pediatrician and Mom to an adult child who is diagnosed with ASD, Autism Spectrum Disorder.
- I am also a member of the Maryland Chapter, American Academy of Pediatrics, which supports this Bill.
- My family's personal experience with Maryland's systems for vulnerable adults and with the federal and county systems that coordinate with Maryland is too complex to explain briefly; but I have had negative experiences that involve every sphere of her comprehensive set of needs, such as education, medical, vocational, mental health, and psychological.
- Overall, I can say clearly the system cannot keep up with the science and the rules involved are inflexibly and sometimes feel punitively applied.
- I believe the system is so under-resourced and probably stigmatized like the community of people with disabilities itself that some communities of people with various disabilities and their advocates are too often pitted against each other when seeking limited resources.
- Further my child is not a stereotype of autism; which historically is divided into camps of more severe cases and so-called highly functional cases.
- Most disturbingly, the system is not set up for us to plan for her long-term future in a safe inclusive environment; which is a factor that causes great anxiety for us.
- I am distressed for several of my friends with sons who have a history of physically assaulting their parents. One of those is a friend who has become depressed about the need for her son's placement in residential care. My child is not violent, not intellectually disabled, and was recognized early; yet as an adult, her creative gifts are not appreciated in typical jobs, which require time-sensitive, intensely competitive, work in teams. She has been unable to obtain a college degree despite having more than enough credits to graduate. She is unemployed and has no prospects for employment.
- Currently my child is thriving emotionally with the support of a good team and by living with me in our single-family home. But I will not live forever; and we have experienced how terribly ill she can become when she is in the wrong setting. She is loved by extended family but they do not have the wherewithal to act as guardians if something should happen to me.
- While health and human service providers need more training; we also need systems that don't punish adults who do not thrive in a typical workplace. We need systems that

do not coerce or force disabled adults into menial, stressful, poorly paying, abusive jobs or leave families as a warehouse for our community's neglected problems.

- I ask you to report favorably on HB 847 and help us move Maryland forward as leaders in the field of humane treatment of vulnerable adults.

Dear House Health and Government Operations Committee,

I am writing today express my strong support Delegate Guyton's efforts through HB 847. I want to share why this bill is so important. To do so, I will share a snapshot of my life and experiences in raising my 9-year-old son with autism. I would love to be with you today, however, a family related matter this morning is preventing me from doing so. This fact itself demonstrates the reason HB847 is so important. Families with loved ones on the spectrum are in desperate need of support so we can advance our children's developmental progress. This will allow us to take part in healthy daily life and enable our participation in community activity.

My son has moderately severe autism. He requires continuous one-to-one supervision at both home and school to ensure he does not harm himself or others. At school, he has an adult by his side across all activities. At home, due to lack of in-home support services, either my husband or I must set aside household tasks and obligations to sit within the room he is in to ensure safety. I cannot tell you the degree of compromise and hardship this creates for our family. Things such as; using the bathroom, meal preparation, helping the other children with homework or doing laundry, are not achievable if both parents are not present. Behavioral management and safety needs of my autistic son override all other needs within the home and family.

My family no longer participates together in group outings, celebrations or even attending Sunday church services as there are no community resources available to support our son's needs. In all "out of the home" tasks or events, one whole parent must separate from the family to oversee our son's every move. As a result, we have become isolated and withdrawn to avoid the overwhelming stresses an outing brings. As he is aging, my family is finding it increasingly difficult to achieve even basic provision. Either my husband or I must routinely sacrifice a fulltime work schedule as a result of the many school "half days", days off, late arriving buses for school (sometimes the bus never comes at all!). For us both to attend work one these days, or to support us on outings we must search for a trained specialist at the cost of \$20.00 (or more) an hour. It is very difficult to find this level of help and even when we do, the high hourly cost is prohibitive in nearly all cases except those that are most imperative.

My husband and I have spent countless hours on the phone seeking help. Some days, one of us can spend up to 8 hours in a day reaching out across an endless trail of "recommended" contacts trying to find programs or resources that can offer our child and family help. My child desperately needs

specialized medical care, in-home occupational and behavioral therapies and most of all, respite services so that all of us are all able to access support and establish a level of life quality. Sadly, because of the extensive waiting list for the autism waiver (at least a 10-year wait) and the cost-prohibitive limitations on accessing quality health insurance, our family has essentially no access to care. A centralized resource is desperately needed that I can utilize to guide and ensure the contact points my husband and I are making are worth our efforts and time.

I am very thankful for Delegate Guyton's listening ear, compassion and efforts. I know many families who experience similar circumstances and we all need the help HB 847 is working to foster. I thank you for your time and attention in reviewing my testimony and I ask for your support of HB 847.

Sincerely,

Nicole Landers

Support: HB847 State Coordinator for Autism Strategy and
Advisory Stakeholder Group on Autism-Related Needs

Dear Madame Chair and Members of the Health and Government Operations
Committee:

Our son Daniel is a 17-year-old young man, with Autism Spectrum Disorder (ASD), Down Syndrome (DS) and severe Celiac Disease. He is primarily nonverbal but attempts to communicate in short answers with prompts and cues, using minimal American Sign Language or intermittently using an Assistive Communication Device. He understands very well English and Spanish as his primary household language. He requires a person to dedicate, support, and provide assistance with verbal cues, prompts, visuals, for personal management skills, academics, meals, toileting, hygiene, attention and initiating of tasks, following directions and personal safety. Our goals for Daniel are for him to be as independent as possible in his personal management, self-expression and communication, engagement in the community, socialization, reading, improving handwriting, and activities of daily living (ADLs), and learn a vocation/occupation for his adult life.

We applied in 2011 for the Autism Waiver and still have been on the waiting list for the last 9 years. Daniel is in critical need of the supports that he has not been able to receive at his age of 17. He will be turning 18 years old in a few months, and has missed many educational opportunities, funds, programs, and time that would have helped improve his quality of life, especially on his social and skill sets. These are some of the challenges we have.

When Daniel comes home from school, we ask him how his day went, what did he learn, and how are his friends. Every day, he never answers. We never know what he thinks. We don't know what he's done, nor how he feels. Every conversation is like this because Daniel is non-verbal. Even though Daniel has shown frustration because of his lack in his communication skills and being understood, he still enjoys being around his family. He has a great sense of humor making the whole room laugh. He enjoys listening to music that he can dance and loves spending time outside walking.

For these reasons, I respectfully request that you support HB847, for Daniel and so many other children with their families.

Thank you all

Jose & Martha Sanchez
Timonium, Maryland 21093

FAVORABLE: HB847 State Coordinator for Autism Strategy and Advisory Stakeholder Group on Autism-Related Needs

Dear Madame Chair and Members of the Health and Government Operations Committee,

Good afternoon. My name is Jenn Lynn and I am mom of a of 17 year old with multiple diagnoses : autism, mood disorder, ADHD, Generalized Anxiety Disorder, sensory processing disorder among other learning disabilities. I am also the Executive Director of a nonprofit in Montgomery County serving roughly 500 adults with developmental and intellectual disabilities. I sit on the Youth and Family subcommittee of the Lt. Governors Commission to study Mental and Behavioral Health issues , and the Commission for people with Disabilities in Montgomery County.

As an Autism mom, I am in full support HB 847 as it is desperately needed for our growing population of individuals with Autism and co-morbid mental health challenges.

Imagine your loved one so scared and confused by the stimulating world around them, that they can do nothing but lash out physically to calm themselves.... You're exhausted from keeping them alive day to day, minute to minute, you need help.

This was our life.

Recently, Our son was rushed to the hospital after becoming so scared he jumped from my moving car in DC. When I pulled him back inside the car, injuring my own shoulder, he stabbed himself 9 times with a pen.

Due to our current system in Maryland, we had to live in the busy ER for nearly 5 days, awaiting an autism psychiatric bed to open up at the state's premiere psych hospital.

The wait was too long. He was instead sent to the adolescent male unit. In the next 10 traumatizing days, he witnessed kids getting yelled at, chemically sedated to avoid challenging behaviors, and criticized by staff. He was shown videos that have been scarred into his brain... which he relives every time he closes his eyes.

Upon discharge, after the 10 days allotted by insurance, we had no one to help us and no where to go. We were told to put our child into foster care and relinquish our parental rights so he will be helped.

Helpless and nearly hopeless, We risked all of our lives and brought him home.

Marylanders deserve organized and efficient care, Not waitlists and Voicemail's. We need one office familiar with all the services, public and private, to guide families through crises. A services manager supported by stakeholders statewide.

As for Jake, the nationally decorated Chief Autism Ambassador for MC-PD, he is living 100 miles from home. His heartbreaking relocation to find appropriate services, has brought his valuable law enforcement trainings about de-escalation and autism, to a screeching halt.

More indecision on this issue will cost valuable lives.

Thank you.

Peace and Gratitude,

Jenn Lynn

TheWorldAccordingtoJake.com

<https://matteroffact.tv/a-teen-with-autism-helping-police-learn-to-help-those-in-a-mental-health-crisis/>

TESTIMONY IN SUPPORT OF HB 847

Testimony submitted by:

Leslie Weber, Baltimore County Education Advocate

3829 Bay Dr.

Middle River, MD 21220

Thank you so much for sponsoring House Bill 847 to establish the State Coordinator for Autism Strategy in the Department of Disabilities to develop an autism-related strategic plan in consultation with the Advisory Stakeholder Group on Autism-Related Needs. As a long-time education advocate in Baltimore County Public Schools and the aunt of a nephew with Asperger's Syndrome, I'm aware of the dramatic increase in autism and the need to support children and adults with autism. My sister and her family are finding it much more difficult to access resources and receive support now that my nephew is no longer in the public school system. I believe they would be helped greatly by this strategic plan.

Thank you,

Leslie Weber

Support: House Bill 847

State Coordinator for Autism and Advisory Stakeholder Group on Autism-Related Needs

Dear Madame Chair and Members of the Health and Government Operations Committee,

As a volunteer fire fighter and an uncle to a child with autism, I support this bill because there is a desperate need to provide additional training for first responders specifically on how to communicate and understand the special needs of people with autism.

Please close your eyes and imagine that you wake up to the sound of your smoke alarm going off, your house is on fire and filling up with smoke. Your heart is probably racing just thinking about it, now take that fear and panic and multiple it by 100... because that is what it would be like for someone with Autism. Now imagine that in all that confusion, a large body approaches you with a helmet and SCBA (face mask) talking to you in a strange voice because of the face mask.

There are many different outcomes for this scenario but the danger to the first responders and the potential victims is real and this bill will provide the resources to help address this situation. I ask you to support this bill for the protection of the first responders and the autism community.

Peter Martin

Testimony of Lisa Wiederlight, M.P.P.
February 26, 2020
Maryland House of Delegates
Committee on Health and Government Operations

Good afternoon. My name is Lisa Wiederlight. I am a mother of young adult with autism, ADHD, epilepsy, developmental coordination disorder, colitis, and dyspraxia. Until last month, I served five years as executive director of a national autism organization, and now I am responsible for evaluating and reporting on the performance of multi-agency drug policy initiatives. I have also served a U.S. Senator on Capitol Hill, and in the White House Office of National Drug Control Policy.

I support HB 847 because it is good public policy. It provides an accountable, inclusive, and effective means to improve the safety, health, and independence of people with autism and their caregivers. It provides a point person on autism, a forum for regular feedback and input from stakeholders, and a strategy that can be evaluated with performance measures.

Autism is the fastest-growing developmental disability. From personal experience I know that our families are suffering because state agencies and many service

organizations are failing us. I am waiting almost three weeks now for the Department of Health to approve a service provider change on my son's service plan for the Community First Choice waiver. All the Department of Health needs to do is check a box. But I am waiting three weeks. Why? The system, which is broken, must be fixed by someone appointed to find what's broken and fix it.

You may have noticed I listed multiple disabilities in addition to autism for my son. He is not alone. A 2018 study published in the *Journal of Autism and Developmental Disorders* found of nearly 800 four-year olds with autism, and over 1,000 eight-year olds with autism that over 95 percent have at least one co-occurring condition with their autism, including ADHD, gastrointestinal disease, and epilepsy, among at least 15 others. The study also found that about 70 percent of the eight-year olds and half of the four-year olds have four or more co-occurring conditions. Help the autism community, help others with disabilities. A rising tide lifts all boats.

Thank you for your time. I hope you will also support this cost-effective bill that increase the accountability, responsiveness, and effectiveness of Maryland's services to those Marylanders with autism and those who love them.