

Elizabeth Benevides Associate Director, Hussman Foundation Hussman Institute for Autism

House Bill No. 1176 Public Safety – Voluntary 9-1-1 Registry March 29, 2023

Position: SUPPORT

More than 10 years ago, I requested the support of the Howard County Police Department (HCPD) in developing a Voluntary 9-1-1 Registry for residents with disabilities. HCPD responded to that request and since then, several hundred Howard County individuals have enrolled in the registry.

My son is autistic, limited in speaking, slow in processing, prone to anxiety, and at times may use negative behavior to communicate. In an emergency, he has no way to tell a first responder any of this. He also has no way to tell a first responder that he is unaware of danger, or that he does not understand why he must stay outside of a burning house or why he should not climb out his window. He has no way to describe the pain he feels when he is having a migraine; or why he is incredibly frightened by sirens or that flashing lights may cause a seizure.

The Voluntary 9-1-1 Registry for people with disabilities provides me with the peace of mind that a first responder will know all of this before arriving at my home, or at an emergency scene involving my son.

The registry is not only connected to a name, but to an address. It leads to an "address flag" so that not only is my son's name pulled up, but should there be an emergency in the area, first responders will know my son is nearby. If my neighbor's home is on fire, first responders will know that next door, there is a person who may need their protection as well. Similarly, if a tornado or storm blows through and takes down trees, it is important to know that there is a person with oxygen in a particular home or a person who relies on electricity to breathe. If there is a car accident, it is important to know that a child in the car has seizures and that may be more important to watch for, then exchanging insurance information.

For any one of us, the more we know, the better prepared we are to help. For people with disabilities, a first responder "in the know" can make all the difference.

The Voluntary 9-1-1 Registry does not benefit just one particular group of people. It is there for people with autism, such as my son, and also for people who are affected by dementia, a mental health issue, a physical disability, or any other condition that may heighten an emergency situation.

It is there for a blind person who wants a firefighter to know that they may require additional assistance to exit a building, or that they cannot be separated from their service animal. It is there for people with dementia who may go wandering and who may not be able to remember how to get back home. It is there for a child who runs to a nearby pond each time they elope from a guardian's home.

The registry saves first responders critical time. They know where to go, they know where to look first.

We know of situations in which first responders are aware of a person's favorite topic. In an emergency situation, talking about the Ravens, Jeopardy, Clifford the Big Red Dog, or the weather – whatever matters most to that individual person – can de-escalate a situation, bring calm when everything else is in disarray.

We also know of situations in which first responders are told to speak slowly, allow more time for processing, to be aware of an OCD or particular behavior. Training is critical, but personal information that may not be able to be relayed in the middle of an emergency is crucial.

The registry allows us to put individual, person-specific information in the 911 system so it is there the minute a name or an address is given.

When my son experienced a migraine and the caregiver could not get through to me, she called 911. She did not understand why my son was kicking so hard he put his foot through the wall, why he was screaming in despair, or throwing things all to be "heard." When the dispatcher typed in his name and our address, *my voice* could be heard through my written words: "experiences migraines, needs Motrin; give him space, approach calmly, turn off sirens, no flashing lights. No demands. Usually lasts no more than 20 minutes."

When my friend's son had an emotional crisis at the community center swimming pool and the lifeguard called 911 for help, the officers knew in advance that this child's favorite topic was his family's boat. If they could redirect his attention, they could buy some time to calm him down, and guide him to a safe space to fully deescalate.

When a child wandered away from home and was found walking along a city street, she could be quickly identified by her picture in the 911 registry.

This bill protects people with disabilities. It is voluntary. A person's name and information cannot be entered without the person's permission or, for minors or adults with guardianship, without the parent or guardian's permission. We—as individuals and parents--decide what goes in the registry—how much or how little, and for how long. We can update or withdraw information at any time.

We know this program has worked in Howard County and has the potential to save lives. We know it has given families in Howard County peace of mind that first responders are more informed about their loved one. All individuals and families in every county and district in Maryland should be given this same peace of mind.

We know police officers and first responders benefit from this advance information. They feel better equipped to help. The costs are minimal. The data system is already in place in every

police jurisdiction. It is a matter of choosing a point person in the emergency dispatch system to enter the information, update the information, and send a notice to registrants once a year.

Many other states have these programs. Very few counties in Maryland have them. Maryland is a leader in first responder training on intellectual and developmental disabilities. Adding this registry will enhance its effectiveness and responsiveness to people with disabilities.

Respectfully submitted,

Elizabeth Benevides