

February 8, 2021

Senator Susan Deschambault, Chair
Representative Charlotte Warren, Chair
Joint Committee On Criminal Justice and Public Safety
State House, Room 43
Augusta, ME 04333

Re: Testimony in Support of LD 28, An Act to Create an Alert System to Notify the Public When a Person with an Intellectual or Developmental Disability is Missing

Dear Senator Deschambault, Representative Warren, and Members of the Joint Standing Committee on Criminal Justice and Public Safety,

My name is Maeghan Swanson. I am a resident of Presque Isle. I currently work at Zippel Elementary in special education, I am the co-founder of the Aroostook Autism Support Group, spouse of a law enforcement officer, and most importantly mother to my children, Kaeleigh and Garrett. It is in this role today that I am before you, advocating for my autistic son and all special needs individuals in our state. While I cannot possibly share all the personal accounts others have told me over the years, I can share mine and why I urge you to consider lending your support to LD 28.

For those of you not familiar with autism, we - the parents of autistic children, face numerous challenges. These challenges include, but are not limited to: communication barriers and struggles, self-injurious and/or aggressive behaviors, sensory overload, anxiety and fear based on sensory processing disorder, and desire to escape social situations that are overwhelming, as well as fear inducing. We stand by feeling helpless as we watch our children experience their daily struggles and try to help them whenever we can. One of the biggest fears of all parents of autistic individuals, is our children's propensity to wander. Wandering, also referred to as elopement, is defined as the tendency for an individual to try to leave the safety of a responsible person's care or a safe area, which can result in potential harm or injury.

My son Garrett was diagnosed as autistic in 2012, shortly before his third birthday. At that time, Garrett was considered nonverbal, was self-injurious, easily over stimulated, and often bolted from situations with no warning. In the fall of that year, on one occasion, I went to use our bathroom while Garrett was in our living room, happily playing with his toys. Within moments of entering the bathroom I felt a cool breeze come thru the hallway. I ran out of the bathroom to find the front door of our house open, and my son had eloped. He ran down our driveway and out into the heavily traveled main road. I am so thankful that I had left the bathroom door open that day, and when I felt that breeze I immediately knew there was a problem. Had I not been so quick to react, Garrett could have wandered further, could have been struck and killed by a car, and I would potentially be telling a much different story before you today. Garrett was lucky, as was I. Unfortunately, the same cannot be said for so many others that wander.

Our family, like so many others, lives in a world where aside from teaching safety and behavioral skills daily, extreme measures need to be taken such as extra door locks, window reinforcements, and door alarms in an effort to protect our son from wandering. Over these years I learned to sleep very lightly, often stirring at the slightest sound, and then checking his room to make sure he is safe. Each day I write down what he is wearing in case I need to call for help. The small details are crucial if a search is needed. To this day, I live with the reality that my son does not understand simple concepts like fire is hot and will burn you, knives are sharp and can cut you, and traffic will not always stop and can hit you.

If autism has taught me anything over the past decade, it is everything can change in an instant. Many nights I lay awake knowing that at any point, my son could wander and we will have to place that call for help. Having a state wide system in place to immediately alert first responders, various agencies, and the general public to the situation, might just be the difference it takes to bring him home safely.

A 2016 study conducted by the CDC(Centers for Disease Control and Prevention) found that “among children with confirmed ASD in this study, more than half, or about 60% were reported to wander”. It also went on to state that “among children with other developmental disabilities, about 22% were reported to wander”. (<https://www.cdc.gov/ncbddd/autism/features/Key-Findings-Children-with-Autism-Spectrum-Disorder.html>) As of today, there are seventeen

states(Alabama, Arizona, California, Colorado, Delaware, Georgia, Indiana, Louisiana, Mississippi, New Jersey, New York, North Carolina, North Dakota, Oklahoma, South Carolina, Texas, and Virginia) that have adopted alerts systems for developmentally and intellectually disabled individuals, with the majority of the states providing this for both children and adults. As the number of children diagnosed each year with developmental and intellectual disabilities continue to rise, the likelihood that we will see more searches for these children does as well. Without an alert system in place, searchers will undoubtedly lose valuable time and possible help from the general public. In these situations, time is of the essence and not only minutes, but seconds can affect the outcomes.

The current language of this legislation is written to include both children and adults. A feasible amendment to the current language could be to change the age range up to the age of eighteen years, as there is much gray area when discussing rights of individuals who may or may not have guardianship needs as adults. Ultimately, we will need to recognize our duty to help those with special needs because my son, like so many others, will not outgrow his autism. He and so many others with similar challenges do not always know when or how to ask for help. This is compounded in situations such as elopement, where an individual may feel lost and scared. Like our son, the challenges they face will more than likely continue into their adult years.

I am aware of opposition to this legislation based on the perception that it will label and stigmatize individuals with developmental and intellectual disabilities. So often we engage in working against labels, but for those in the special needs community that label is necessary to attain the help and support needed. If we allow ourselves to focus on that perception, rather than protecting our most vulnerable population, I fear we will expose them to possible accidents, injuries, and even death due to insufficient support. We are asking to help to them, not restrict their freedoms. By taking this step to establish an alert system which would immediately identify to all law enforcement and public safety agencies, as well as the general public, missing individuals with developmental and/or intellectual disabilities, we will provide support for our special needs community in times of crisis, and save lives as well. This is the direction we all need to move in. Thank you for your time and consideration of this piece of legislation.

Sincerely,

Maeghan Swanson