

Dear Madam Secretary,

Stories of accidents related to children and adults with autism spectrum disorder (ASD) wandering from supervised environments are all too common. Every year, an unknown number of people with ASD are killed or injured as a result of these accidents that occur as a result of wandering or otherwise becoming lost.

For example, Mason Medlam was a tenacious five-year-old with boundless energy and a natural inquisitiveness about the world. Mason also had autism and no functional language skills. His family knew that he would wander if given the opportunity, and so they were hyper-vigilant about his safety, installing multiple locks on every door and monitoring his every move in the house. His mother never slept more than a foot from him because she was terrified that one night he would find his way out of their home and be lost to her forever. "I knew he had no concept of danger," she said. "I knew he was a runner, and I knew he would be attracted to the most awful dangers if we didn't always know where he was."

On July 27, 2010, Mason drowned in a retention pond about a quarter-mile from his family's home after escaping through a screen left slightly ajar for a window fan. The police had been notified that the five-year-old had gone missing but were unable to locate him in time.

Mason's story is not unique. Every year, an unknown number of people with autism spectrum disorder (ASD) die tragic deaths in incidents involving wandering. Below is a sampling of fatal incidents that occurred within the past year as a result of a child with autism wandering from a safe environment:<sup>1</sup>

- Zachary Clark, 5, drowning (August 2010)
- Kaliya Sullivan, 7, drowning (June 2010)
- Adlai Kugblenu, 8, drowning (June 2010)
- Christian Dejons, 6, drowning (April 2010)
- Aiden Johnson, 3, drowning (April 2010)
- Christian Dejons, 6, drowning (April 2010)
- Luke Selwyn, 6, drowning (March 2010)
- James Delorey, 7, prolonged exposure (December 2009)
- Bernard Latimore, 9, drowning (November 2009)
- Devine Farrier, 11, struck by vehicle (October 2009)

Many more individuals with autism wander and thankfully are found alive. But wandering remains a critical concern among families in the autism community.

Research has shown that accidents such as suffocation and drowning, along with seizures, are among the top causes of premature death among people with ASD<sup>2</sup> - a group whose mortality rate may be twice that of the general population according to one study.<sup>3</sup> The causes of wandering behavior, and potential effective supports and interventions to prevent wandering, are unknown and need additional research. Currently, there is no formal data collection on autism-specific wandering so it is unknown how frequently it occurs, in what environments it occurs, how many deaths or injuries can be attributed to wandering

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<sup>1</sup> Data obtained from the National Autism Association,  
[http://iacc.hhs.gov/events/2010/slides\\_fournier\\_mcilwain\\_102210.pdf](http://iacc.hhs.gov/events/2010/slides_fournier_mcilwain_102210.pdf)

<sup>2</sup> Shavelle RM, Strauss DJ, Pickett J (2001). Causes of death in autism. *J Autism Dev Disord.* 31(6): 569-76.

<sup>3</sup> Mouridsen SE, Brønnum-Hansen H, Rich B, Isager T (2008). Mortality and causes of death in autism spectrum disorders: an update. *Autism.* 12(4): 403-414.

incidents, why the wandering incidents may have taken place or what strategies may be most effective to prevent wandering-related injuries and fatalities.

A common misperception is that wandering is due to parental negligence and that the incident would not have happened had a parent “just been watching their child more closely.” Parents of children with ASD who wander usually take extraordinary precautions to keep their child safe. It only takes a few seconds of confusion at a family gathering or one unlocked window for a motivated child to take flight.

ASD-related wandering needs to be addressed. At a meeting of the Interagency Autism Coordinating Committee (IACC) on October 22, 2010, parents and advocates shared their experiences and urgent concerns with members of the committee, and the committee responded unanimously to form a subcommittee on safety and to take appropriate actions to address this issue. We, as members of the Interagency Autism Coordinating Committee (IACC), recommend your consideration of the following action items:

#### **Version 1:**

**Collect data on ASD-related wandering behavior.** While the autism advocacy community reports widespread and serious issues related to wandering based on anecdotes and informal data collection, it is difficult based on this information to ascertain the scale and scope of the problem. More formally and extensively gathered data will be imperative to understand how many individuals may be at risk, the settings and circumstances involved, antecedent behaviors, potential causes, effective preventative supports and interventions, and how often these incidents are reported to the authorities.

**Investigate the use of a medical subclassification coding or general medical coding for ASD wandering, similar to the existing coding for dementia-related wandering that would be specific for children with ASD.** Such a medical coding could be used to collect data on ASD-related wandering, establish the need for support and assistance for families affected, and help validate insurance coverage for personal locating devices and related expenses for families who are currently unable to afford them. The Centers for Disease Control and Prevention (CDC) has already submitted a proposal for an ICD-9-CM secondary diagnostic code for “wandering in conditions classified elsewhere” (e.g., autism, mental retardation/intellectual disability, certain genetic disorders). The proposal will be considered by the ICD-9-CM Coordination and Maintenance Committee at its meeting in early March, 2011.

#### **Version 2**

**Collect data on ASD-related wandering behavior.** While the autism advocacy community reports widespread and serious issues related to wandering based on anecdotes and informal data collection, it is difficult based on this information to ascertain the scale and scope of the problem. More formally and extensively gathered data will be imperative to understand how many individuals may be at risk, the settings and circumstances involved, antecedent behaviors, potential causes, effective preventative supports and interventions, and how often these incidents are reported to the authorities. Several efforts to improve data collection are underway, including questions on the National Survey of Children with Special Healthcare Needs (NS-CSHCN) sponsored by the Health Resources and Services Administration (HRSA), a proposal from the Centers for Disease Control and Prevention (CDC) to include a secondary diagnostic code for wandering associated with autism spectrum disorders and other developmental disabilities in the ICD-10 update (which will be open to public comment in March) to facilitate data collection, and a survey being developed by the Interactive Autism Network (IAN).

**Explore options in the human service, medical, and education systems to collect information on, research and evaluate appropriate responses to wandering by individuals with ASD and other developmental disabilities.** Safety challenges posed by wandering and elopement require appropriate responses that take into account the serious safety risks involved, environmental factors, behavioral and medical implications, and ethical concerns related to self-direction. HHS and the Department of Education should explore a variety of options to research the extent and cause of this problem and to make available appropriate and effective responses across settings.

**Explore and research the potential need for and utility of an alert system similar to the AMBER alert or Silver alert, but tailored to the specific needs and characteristics of children under the age of 18 with autism who wander, to help families and communities rapidly locate children with autism who have wandered.** The AMBER alert system, a voluntary partnership in states between law-enforcement agencies, broadcasters, transportation agencies, and the wireless industry to issue urgent bulletins, can only be activated if a confirmed abduction of a child has taken place. The Department of Justice has a federal AMBER alert coordinator who assists state and local officials with development of AMBER plans. A similar alert system, called the “Silver Alert,” is in place in many states to broadcast information to help locate seniors with dementia who have wandered. Currently, children with ASD who wander are not covered by either of these two alert mechanisms, but availability of such a system to families and communities could potentially play a critical role in preventing adverse outcomes when ASD-related wandering incidents occur.

**Develop and test programs to prevent wandering incidents.** HHS and the Department of Education should work closely with national medical, education and disability organizations to develop preventative information about autism-related wandering to be communicated to parents at the time of autism diagnosis. Preventative programs could include parent training, training for children with autism, teacher training, and first responder training. Currently, there is no federal funding to provide training or support to prevent autism-specific wandering. By comparison, the Department of Justice contributes over \$1M annually for first responder training on Alzheimer’s-related wandering and tracking technology.

**Work with the Department of Education to research and develop best practice models related to parental notification of any wandering or fleeing incidents in schools.** In order for parents to be aware of their children’s potential risk and to be able to effectively find strategies to prevent wandering, incidents involving wandering and missing students should be a component of school safety planning, including parental notification protocol. HHS and the Department of Education should coordinate to develop best practice models and guidance in this area.

Autism-related wandering is an urgent issue that demands federal attention. We greatly appreciate your consideration of this issue.

Sincerely,

The Interagency Autism Coordinating Committee (IACC)