

Dear Madam Secretary,

Stories of children and adults with autism spectrum disorder (ASD) fatally wandering from a supervised environment are all too common. Every year, an unknown number of people with ASD are killed as a result of their wandering. These deaths are preventable and immediate steps must be taken to ensure that no more lives are senselessly lost.

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, like so many other children with autism, 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 and preventable deaths as a result of wandering. Below is a sampling of fatal incidents in the past year:

- Zachary Clark, 5, drowning (August 2010)
- Kaliya Sullivan, 7, drowning (June 2010)
- Adlai Kugblenu, 8, drowning (June 2010)
- Christian Dejons, 6, drowning (April 2010)
- Erik Lippmann, 30, 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 wander and thankfully are found alive. But wandering remains a critical issue in the autism community, with 92 percent of parents reporting that their child has wandered from a safe environment one or more times.¹

Research has shown that accidents such as suffocation and drowning are among the top causes of death among people with ASD² - a group whose mortality rate is twice that of the general population.³ The causes of wandering are unknown and need additional research. Anecdotally, many parents report that their child with ASD naturally gravitates toward water. Currently, there is no formal data collection on

¹ National Autism Association (2007). Survey on ASD and wandering.

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

³ 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.

autism-specific wandering so it is unknown how frequently it occurs, how many deaths can be attributed to wandering, or why the wandering may have taken place.

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.

Immediate action must be taken to address the urgency of ASD-related wandering. We, as members of the Interagency Autism Coordinating Committee (IACC), recommend the following:

Collect data on ASD-related wandering. To combat the phenomenon more must be known about it. It is imperative to understand how many individuals are at risk, the settings and circumstances of the incident, what may have prompted the wandering, and how often these incidents are reported to the authorities. Data should be collected to compare the cost of search efforts to the cost of protecting a person with a tracking device.

Create medical subclassification coding or general medical coding for ASD wandering and similar neurological disorders. Such a medical coding could help validate insurance coverage for tracking devices and related expenses. It could also be used to collect data on ASD-related wandering.

Increase awareness by disseminating materials about ASD-related wandering. Parents report receiving little guidance from their physicians about wandering. Informational toolkits for parents on prevention strategies should be created and information on ASD-related wandering should be disseminated through the American Academy of Pediatrics (AAP) Autism Family Handouts and the Centers for Disease Control and Prevention (CDC) “Learn the Signs. Act Early.” campaign. Wandering awareness materials should be developed and disseminated to school personnel, first responders, and physicians. Also, a central distribution center for wandering-related materials should be created.

Coordinate with the Department of Justice and other relevant Federal agencies to support efforts to:

Establish a registry of at-risk individuals that can provide quick access to information for first responders. Such a registry could include a picture and description of the individual, whether he is verbal or nonverbal, information about his particular fascinations (e.g., attracted to water, highway signs), and local hazards. Quick access to this information could greatly aid search efforts. The registry could be part of the central distribution center for related resource materials.

Develop training for first responders on specific challenges faced when searching for an individual with autism. With greater knowledge about ASD-related wanderings, first responders can search more effectively for a missing individual.

Develop an alert system similar to AMBER Alert for child abductions when an individual with ASD goes missing. An AMBER alert can only be issued if a confirmed abduction of a child has taken place. A similar alert for seniors who wander, called a “Silver Alert,” has also been established. Children

with ASD who wander have no such alert and an AMBER alert does not apply. Currently, there is no federal funding to combat autism-specific wandering. By comparison, the Department of Justice contributes \$5,000,000 annually for first responder training on Alzheimer's-related wandering and tracking technology.

Promote federal laws that mandate parental notification of any wandering or fleeing incidents in schools. Currently, schools are not required to notify parents if a child with ASD wanders during the school day. Schools should also be required to develop emergency response protocols specific to wandering.

Autism and wandering is an urgent issue that demands immediate action. Please help to ensure that no more preventable deaths occur. We greatly appreciate your swift attention to this matter.

Sincerely,

IACC Subcommittee on Safety Issues
and Autism Spectrum Disorder