

Safety Issues and Individuals with Autism Spectrum Disorder

Submitted by the Autism Society of America to the Interagency Autism Coordinating
Committee

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The safety of individuals with autism spectrum disorder (ASD) is a serious problem which has gone largely unrecognized. ASD is a complex lifelong developmental disability typically appearing during childhood, affecting a person's ability to communicate and interact with others. Many of the characteristics of ASD contribute to leaving these individuals vulnerable to unintentional injury and in some cases, death.

The Autism Society of America (ASA) is the nation's leading grass roots organization working to increase public awareness about the day to day issues of people across the spectrum, advocating for appropriate services for individuals of every age and providing the latest information regarding treatment, education, advocacy and research. The ASA has developed and implemented safety programs that have been delivered in over half of the United States and trained over 20,000 police, firefighters, and first responders collectively. The ASA is aware of the magnitude of issues surrounding ASD and safety, yet we do not see a national agenda to appropriately document the problem and deliver consistent training for families, individuals with ASD, educators and all first responders.

Under-documentation of unintentional injury and mortality is a major gap preventing researchers from getting to the level of precision needed to serve as the basis for public policy decisions.

Data, though sparse, in the form of mortality studies, illuminate the scope of the problem. Researchers reported on deaths of individuals with ASD in California finding far higher death rates than might be expected (Shavelle, Strauss, and Prickett (2001). They reported a 16.8 Standardized Mortality Ratio (SMR) for females ages 5-10 years and an overall SMR for person with ASD of all ages of 2.4. Guan and Lee (2017) looked at data on autism deaths in the United States from 1990 to 2014 from the National Vital Statistics System and found that the mean age of death for individuals with ASD was 36.2 years compared to 72.0 years for the general population. They also examined the nature of drowning deaths in the US based on newspaper accounts. It is important to note here that, in spite of nationwide mortality reporting systems, these researchers found it necessary to rely on newspaper accounts for this research because there is no coordinated, standardized effort to maintain data. They found 23 fatal drownings between 2000 - 2017 with an average age of 7.7 years. Wandering accounted for 73.9% of the incidents.

Wandering was also found to be common among children with ASD compared to their siblings without ASD (Anderson et.al, 2012). In a parent-reported survey on elopement occurrence, nearly half of the 1218 participants with ASD were reported to have attempted to elope with 26% reported to be missing long enough to be of concern. Rice et al, 2016, writing the *The Journal of Pediatrics*, found that 37.7% of children with ASD and intellectual disability wandered in the previous year and that even those with ASD without intellectual disability wandered at a very high rate. Also referred to as

elopement, wandering was assigned its own International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) code in 2011 (Centers for Disease Control and Prevention, 2014b).¹

The Autism Society advocated for the successful passage of Kevin and Avonte’s Law signed by President Trump March 23, 2018 (S. 2070 included in P.L. 115-141). Kevin and Avonte’s Law is named in honor of two boys with autism who perished after wandering. Nine-year-old Kevin Curtis Wills wandered from home and drowned in Iowa’s Raccoon River in 2008. Fourteen year-old Avonte Oquendo left his school and drowned in New York City’s East River in 2014. The law authorizes the Department of Justice to provide grants to health care agencies, law enforcement agencies, and non-profit organizations that provide training and prevention and response information. Grants will also be used to develop or enhance a notification or communications system for alerts and assist agencies in designing and operating locative tracking technology programs. It is imperative that this law receive sufficient funding to help states and local communities develop infrastructures to prevent wandering and other avoidable dangers to individuals at risk. The Autism Society is working with congressional appropriators to include funding in the Labor, Health and Human Services funding bill.

The finding of much higher death rates for individuals with ASD is not unique to the United States. Mouridsen et. al (2008) examined ASD deaths in Denmark. They found a death rate nearly twice as high for ASD than that of the general population. These issues are worldwide and persistent and most certainly underreported and under-documented.

Attachment A contains additional information on ASD and unintentional injury.

¹ ICD-9-CM is the official system of assigning codes to diagnoses and procedures associated with hospital utilization in the United States.

It is apparent that there are major gaps in the documentation of statistics related to unintentional injury and deaths among individuals with ASD. There is a great need for an evaluation of serious injury and mortality data systems to see how ASD and disability can be accurately recorded. While the Centers for Disease Control and Prevention are actively engaged in child injury risk reduction (An Agenda to Prevent Injury and Promote the Safety of Children and Adolescents in the United States, 2010) they have not addressed ASD or disability specific safety issues. In the past, communicable diseases had been the big killer of children. Now, in the US, unintentional injury, what the public would refer to as *accidents*, are the big killer of children with ASD and for typically developing children as well. Much more needs to be done to address the gaps in reporting these injuries and deaths for all children, and in light of their higher risk for death and serious injury, children with ASD.

Based on the above information are requests that will keep both children and adults with ASD safe:

1. STANDARDIZED REPORTING SYSTEMS must be put into place across the nation.
 - a. In most states, calls (EMS, police, fire department) are not tracked. Outcomes are not tracked. Data are coming from narratives in police reports and through news media.

2. LAW ENFORCEMENT ISSUES (First Responders)
 - a. First responder training has increased in many states over the years but is not a national effort. Every state should have mandatory autism training

included as a part of training for law enforcement, firefighters and other first responders. Examples of training curriculum include The Autism Society of America -*the Safe and Sound Program*, The Organization for Autism Research – *Think Safety*, National Autism Association – *Autism Safety Initiative*, Autism Speaks, *Autism Safety Project* – Emily Iland – *Be Safe* and *Experience Autism*. It is clear that there are a core set of skills relating to ASD that are needed by first responders and available from several sources. These need to be incorporated in both initial and ongoing training requirements.

- b. Tracking devices should be funded for all who have the need in the nation. Expand availability of Project Lifesaver and investigate the utility of other emerging technologies for tracking vulnerable persons with ASD who are missing. We recognize that valid concerns have been raised about tracking for more capable persons with ASD, but allowing parents to provide for voluntary tracking of their vulnerable child or adult child with ASD is a life-saving safety measure. It represents a natural and essential, and voluntary partnership between law enforcement and parents of persons with ASD.
- c. In conjunction with the more widespread use of electronic tracking facilitated by Kevin and Avontes Law, the National Institutes of Health should authorize funding for investigations of the effectiveness of such electronic

technologies and how they can be best used in urban, suburban and especially rural settings.

- d. 911 systems nationwide should be expected to allow parents to register a child with ASD or other vulnerabilities to the 911 database. We recognize that many 911 systems are outdated and face challenges. But as they are revamped, the ability to register persons with ASD must be required. *Take Me Home*, a free ASD registration program for law enforcement agencies to use with parents on a voluntary basis demonstrates the value of such an approach. This would allow law enforcement to have, on file and ready for immediate use, information about the child such as places their might elope to and special interests, a digital photo of the child and other critical and time saving information. Now, parents face a challenge in most jurisdictions when they attempt to have this type of information posted to 911.

3. SCHOOL ISSUES

- a. Schools should be mandated to have elopement policies and plans
 - i. Schools should incorporate strategies for managing children who tend to wander into several plans, such as the emergency operations plans, positive behavior plans, and school safety plans, as appropriate. These plans should be reevaluated on an annual basis, at a minimum.
 - ii. Reference to elopement or other safety issues should be included in the next reauthorization of the Individuals with Disabilities Educa-

tion Act IDEA along with language that makes it clear that school-based prevention and behavioral treatment for elopement are potentially suitable goals for the IEP.

- iii. Schools must educate families that they can ask for safety goals to be included in a personal safety plan and be noted in their Individual Education Program (IEP)
 - iv. The U.S. Department of Education should release the School Safety Panel Report to schools and families regarding how to keep students with autism spectrum disorder and other disabilities safe, including safety and wandering. It is our understanding that these draft technical assistance documents are already in existence and should be published and distributed as soon as possible.
- b. Every child with ASD safety issues should have a safety plan attached to the IEP
 - c. Fire drill and active shooter protocols must be individualized for each child with ASD/ID and added to the child's safety plan and noted in the IEP. While active shooter drills can be traumatic for all children, they can be especially traumatic for students with ASD. The protocol for these students should receive particular attention.
 - d. Schools are currently required to conduct a Functional Behavioral Assessment (FBA) *after* the student with a disability is removed from her classroom. All students with behavioral disabilities should have an FBA followed by a Positive Behavioral Intervention Services (PBIS) plan. This

plan should include understanding and preventing possible triggers or antecedents that lead to wandering. And, students with ASD who do wander from school should, additionally, have an FBA that examines the likely behavioral functions of their elopements, providing a pathway for successful prevention and treatment.

4. FAMILY ISSUES

- a. Families must be educated about wandering prevention strategies, prevention of poisoning strategies and availability of safety devices (see also medical section).

5. FEDERAL ISSUES

- a. CDC should develop a new and expanded agenda that targets ASD and safety. This would, we suggest bring together the researchers from the CDC National Center of Birth Defects and Developmental Disabilities with those from the National Center for Injury Prevention and Control in a new ASD focused safety initiative.
 - i. Incidence of mortality due to safety issues
 - ii. Funding targeted for poorer, rural families who are less likely to have safety technologies and prevention education and strategies
- b. Training curriculum for rangers and officers with the National Parks, National Wildlife System and all federal officers serving in any geographic area in which the elopement of a person with ASD could pose substantial risk.
- c. Training for FBI personnel and TSA personnel

- d. Training for Judicial system
- e. The National Institutes of Health could take a leadership role in recognizing ASD safety as a critical health issue with both internal investigations of the nature of these risks and awarding grants to examine the extent of ASD risk and effective prevention and treatment strategies.

6. MEDICAL PROFESSIONALS

- a. Must be trained on discussing elopement, child proofing home, and other aspects of keeping children with ASD safe.

SUMMARY OF INITIAL ASKS

With increasing incidents of wandering and other safety issues (many leading to death) we need to address safety for individuals with ASD at a national level.

1. **DATA:** Develop a nationwide tracking system for first responders. Without the data, outcomes of prevention strategies put in place cannot be ascertained.

2. STRATEGIES

- a. Legislation for safety and ASD training to be mandatory for all first responders nationwide.
- b. Kevin and Avonte's Law must be fully funded (grants are currently authorized at \$2 million). This law should be expanded to include funding for every state.
- c. Modify the safety and ASD curriculum for families, school personnel, judicial system, parks and recreation, medical professionals and the community.

- d. Include in IDEA – children with ASD and safety issues must have a safety plan attached to and noted in the IEP. Families must be informed that safety plans may be attached to and noted in the IEP, including the need for individualized plans for active shooter and fire drills for those with ASD that may need them. All schools must have an elopement plan in place.
- e. CDC should be funded to target safety and ASD issues, particularly in poorer areas of the country and we should see greater collaboration within CDC between researchers working in the developmental disability and injury prevention centers.

- d. The National Institutes of Health should formulate plans to address ASD safety as a national health issue and increase both internal efforts in this initiative and increase external grant funding.
- e. Federal compliance with all existing laws that protect the safety of students with ASD should be 100% enforced.

3. Initial Expected Outcomes

A unified national tracking system would allow researchers, public health officials and the ASD community to see the true scope of the crisis. The true picture, as it emerges, will provide impetus for a national agenda to address the risk for unintentional injury to individuals with ASD. With this in place and with a national autism safety training curriculum in place we would expect:

- a. Incidents of elopement/wandering and death will decrease.

- b. Incidents of accidents (poisoning, abduction, etc.) will decrease.
- c. Families will be more informed on issues related to their children's safety leading to reductions in stress.

It is the hope of the Autism Society of America on behalf of the many families and individuals with ASD across the country that safety outcomes will improve for children and adults with ASD and that fewer will be injured and die. We further hope that with continued efforts by the Autism Society and other autism organizations, parents, professionals and advocates and the federal government with the facilitation of this Committee, that greater safety awareness will be achieved and that safety for all persons with autism spectrum disorder becomes a *shared value* for all members of the autism community.