

The Honorable Kathleen Sebelius
Secretary, U.S. Dept. of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Sebelius:

The Interagency Autism Coordinating Committee (IACC) remains committed to advancing areas of research, intervention, and services to enhance the health and wellbeing of all individuals affected by an Autism Spectrum Disorder (ASD). As such, we respectfully request your consideration regarding growing concerns surrounding the safety of children and adults within the autism community.

Autism Elopement is a very serious issue that is responsible for an increased number of deaths among those diagnosed with an autism spectrum disorder. The vast majority of fatalities following autism elopement are attributed to drowning, yet federal safety guidelines, resources and formal preventative measures remain absent.

After careful review of the dangers associated with Autism Elopement, members of the IACC have unanimously favored the formation of a subcommittee dedicated to safety issues and the prevention of external causes of death. It is hereby our recommendation that the following measures be taken to reduce the threat of bodily harm and death associated with Autism Elopement:

- **Establish a medical diagnostic code for at-risk individuals with ASD who are prone to wandering**

A diagnostic code for Autism Elopement may serve to assist caregivers in obtaining insurance coverage for tracking technology, as well as prompt important safety discussions between physicians and caregivers, and caregivers and school administrators. It may help first responders, school administrators and residential facility administrators to better recognize and understand the condition so that proper emergency protocols and response may be implemented.

- **Create policy recommendations for an emergency broadcast alert system**

AMBER Alert's federal guidelines recommend that alerts only be issued for minors that have been abducted. In the case of Benjy Heil, a seven-year-old boy with autism who was found dead in a nearby creek in 2007, an AMBER Alert could not be issued because Benjy's case did not meet AMBER Alert criteria. A neighbor did spot Benjy, but did not realize he was missing. The Silver Alert Emergency Broadcast System is designed for at-risk adults who may suffer from dementia or other cognitive disorders. Many States that allow both AMBER and Silver Alerts cover minors that are abducted, and adults that have cognitive impairments, but minors with cognitive impairment are excluded from the inclusion criteria. Because members of the public act as a valuable tool in bringing

missing children home safely, the Committee feels that the risk of death can only decrease if strong alert and response measures are in place.

- **Create policy recommendations for federal programs related to first-responder training, tracking technology access and oversight, and swimming lessons**

The Department of Justice currently facilitates a federally funded program designed to combat dementia-related wandering occurrences and deaths. The program allocates funding each year towards tracking technology for those with an Alzheimer's or dementia diagnosis, and first-responder training related to wandering emergencies involving an individual with Alzheimer's or dementia. However, individuals diagnosed with an ASD do not qualify for this program. The Committee feels that similar resources and safeguards should be made available to those that carry an ASD diagnosis and are prone to wandering.

- **Establish formal safety information and materials for caregivers, first responders, physicians, school administrators, and residential facility administrators, and establish recommendations and support for material distribution and outreach**

There is currently no federal oversight or distribution of safety and informational materials that address autism and wandering. The Committee feels that parents, caregivers, physicians, first responders and school and residential administrators should have ample access to this safety information and that all materials contain appropriate, federally backed recommendations related to safety.

- **Recommend data collection through Centers for Disease Control**

Currently no formal data exists in relation to autism and wandering. Tracking fatalities associated with autism elopement is an important step to understanding how frequently it is occurring. Data will also provide valuable clues for prevention and response.

In addition to addressing wandering prevention and response, our newly-appointed safety subcommittee will also work to enhance safety standards and preventative measures pertaining to, but not limited to, dangerous restraint and seclusion practices in public and private schools, bullying, victimization and domestic crises.

It is with great determination and hope that we submit these recommendations for your review and response. We thank your for your consideration and continued support.

Sincerely,