

IACC Activities to Address Wandering

Alison Singer
Autism Science Foundation
IACC Public Member

IACC Meeting
July 9, 2013

Timeline

- October 2010:
 - Wandering issue presented at IACC during public comments
 - Safety committee formed to investigate wandering
 - Advisory Letter sent to HHS Secretary Kathleen Sebelius

Feb-March, 2011



February 9, 2011

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 Madam Secretary,

The Interagency Autism Coordinating Committee (IACC) would like to bring to your attention the issue of wandering/elopement related to ASD, a serious matter that was described in detail by members of the public at the IACC meeting that took place on October 22, 2010.¹ This issue is the first of several important health and safety issues that affect people with ASD, including seclusion and restraint, bullying, abandonment, neglect, abuse, criminal justice issues and homelessness, that the committee would like to update you on in the coming months.

Stories of accidents related to children and adults with autism spectrum disorder (ASD) wandering/eloping 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/eloping 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, so they were highly 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."

¹ IACC meeting of October 22, 2010 - Agenda, minutes, slides and archived webcast available at:
<http://iacc.hhs.gov/events/>



THE SECRETARY OF HEALTH AND HUMAN SERVICES
WASHINGTON, D.C. 20201

March 23, 2011

Thomas R. Insel, M.D.
Chair, Interagency Autism Coordinating Committee
Director, National Institute of Mental Health
National Institutes of Health
Building 15K, Room 107
North Drive
Bethesda, MD 20892

Dear Dr. Insel:

I am writing to extend my sincere appreciation to you and the Interagency Autism Coordinating Committee for your work related to autism spectrum disorder and your suggestions for changes to federal activities the Department of Health & Human Services (HHS) may want to consider in accordance with the Combating Autism Act of 2006.

I also would like to thank you for providing background information on how the issue of autism-related wandering/elopement is affecting the autism community and for your recommendations on this issue. I understand the Committee has already taken action to encourage research on wandering behavior by including this issue in the research objectives in the *2011 IACC Strategic Plan for Autism Spectrum Disorder Research*, and also understand that the issue of medical coding for autism-related wandering is currently under consideration by the International Classification of Diseases Coordinating and Maintenance Committee, with final decisions expected later this year.

Please know that HHS appreciates the effort put forth by this Committee and will give serious consideration to the recommendations communicated in the Committee's advisory letter. On behalf of the Department, I thank you and the Committee for your dedication and commitment to enhancing and accelerating federal and community efforts to improve the health and well-being of people with autism spectrum disorder.

Sincerely,

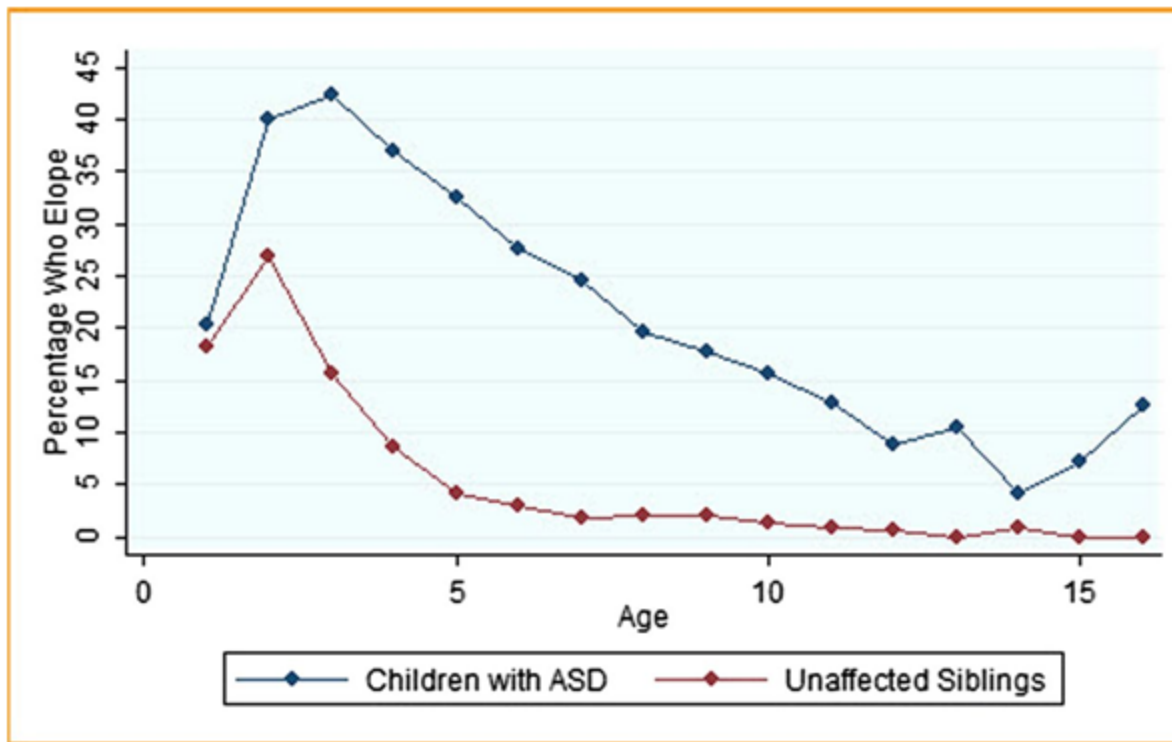
Kathleen Sebelius

Timeline

- October 2010:
 - Wandering issue presented at IACC during public comments
 - Safety committee formed to investigate wandering
 - Advisory Letter sent to HHS Secretary Kathleen Sebelius
- November 2010:
 - Consortium Formed to Study Wandering
 - Jan-Feb 2011: Survey designed
 - March 2011: Survey released to community
 - (Parents of 1218 kids with ASD, 1076 sibs)

Initial Data Presented April, 2011

Reported rates of elopement at specific ages: a comparison of children with ASD and unaffected siblings.



October, 2011

CDC Home



Centers for Disease Control and Prevention

CDC 24/7: Saving Lives. Protecting People.™

A-Z Index [A](#) [B](#) [C](#) [D](#) [E](#) [F](#) [G](#) [H](#) [I](#) [J](#) [K](#) [L](#) [M](#) [N](#) [O](#) [P](#) [Q](#) [R](#) [S](#) [T](#) [U](#) [V](#) [W](#) [X](#) [Y](#) [Z](#) <#>

Classification of Diseases, Functioning, and Disability

ICD and ICF Home

► ICD-9

ICD-10

ICD-9-CM

ICD-10-CM

ICF

Classification of Death and Injury Resulting from Terrorism

North American Collaborating Center

[NCHS Home](#) > [ICD and ICF Home](#)



15



Share

International Classification of Diseases, Ninth Revision (ICD-9)

The International Classification of Diseases (ICD) is designed to promote international comparability in the collection, processing, classification, and presentation of [mortality statistics](#).

This includes providing a format for reporting causes of death on the death certificate. The reported conditions are then translated into medical codes through use of the classification structure and the selection and modification rules contained in the applicable revision of the ICD, published by the World Health Organization. These coding rules improve the usefulness of mortality statistics by giving preference to certain categories, by consolidating conditions, and by systematically selecting a single cause of death from a reported sequence of conditions. The single selected cause for tabulation is called the underlying cause of death, and the other reported causes are the nonunderlying causes of death. The combination of underlying and nonunderlying causes is the multiple causes of death.

The ICD has been revised periodically to incorporate changes in the medical field. To date, there have been 10 revisions of the ICD. The years for which causes of death in the United States have been classified by each revision are as follows:

Related Sites

[Centers for Medicare and Medicaid Services](#)

[World Health Organization](#)

 **AUTISM SCIENCE FOUNDATION**

May, 2012



October, 2012

PEDIATRICS®



OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders

AUTHORS: Connie Anderson, PhD,^a J. Kiely Law, MD,^{a,b} Amy Daniels, PhD,^{a,c} Catherine Rice, PhD,^d David S. Mandell, ScD,^e Louis Hagopian, PhD,^{a,b} and Paul A. Law, MD, MPH^{a,b}

^aKennedy Krieger Institute, Baltimore, Maryland; ^bJohns Hopkins University School of Medicine, Baltimore, Maryland; ^cAutism Speaks, New York, New York; ^dNational Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia; and ^eUniversity of Pennsylvania Perelman School of Medicine, Center for Mental Health Policy and Services Research, Philadelphia, Pennsylvania.

KEY WORDS

autism spectrum disorders, elopement, wandering



WHAT'S KNOWN ON THIS SUBJECT: Anecdotal accounts suggest elopement behavior occurs in children with autism spectrum disorders (ASDs), that injuries and fatalities can result, and that associated family burden and stress are substantial. However, there has been little research characterizing the phenomenon or its frequency.



WHAT THIS STUDY ADDS: Nearly half of children with an ASD elope, and more than half of these “go missing.” Elopement is associated with autism severity, and is often goal-directed. Addressing elopement behavior is an important aspect of

AUTISM SCIENCE FOUNDATION

Nearly half of children with autism wander from safety

12:12 a.m. EDT October 8, 2012



(Photo: Ron Chapple, jupiterimages)

STORY HIGHLIGHTS

The fear that overtakes a parent when a child wanders away from home or other safe place is easily compounded when that child has an autism-spectrum disorder. A new study shows that such behavior occurs more often than in other kids, and that the hazards can be significant.

In a sample of 1,200 children with autism, 49% had wandered, bolted or "eloped" at least once after age 4; 26% went missing long enough to cause their family concern. By comparison, only 13% of 1,076 siblings without autism had ever wandered off at or after age 4, developmentally the age when such behavior becomes less common, finds the study

U.S. & WORLD REPORT News

Nearly Half of Children With Autism Wander From Safety: Survey

Advocates say a system such as Amber Alerts is needed for these kids

October 8, 2012 | RSS Feed | Print

HealthDay

By Maureen Salamon
HealthDay Reporter

MONDAY, Oct. 8 (HealthDay News) -- Nearly half of children with autism wander or "elope" from safety -- often to pursue a special interest or goal -- with more than half of those kids disappearing long enough to cause great concern about their well-being, new research suggests.

Researchers from the Interactive Autism Network, a project of the Kennedy Krieger Institute in Baltimore, found that close calls with traffic injuries were reported for 65 percent of the missing children and near-misses with drowning were reported in nearly a quarter of all cases.

Study Shows Children With Autism Tend to Stray

By RONI CARYN RABIN

When Patrick Murphy was 6, he became obsessed with vacuum cleaners. The boy, who has autism, used to slip out of his house near Buffalo without telling his parents, running to a nearby appliance store or into strangers' homes to marvel at vacuum cleaners.

Patrick is now 14, and his parents have double bolts on the doors in their home and brackets on their windows. Still, Patrick — who is now focused on dogs — manages to sneak out. Two weeks ago, he crept from the house after his mother went to bed. When his father came home, he alerted the police. They found Patrick running barefoot in his pajamas at 2 a.m., three miles from his home.

"That was very scary," said Patrick's father, Brian Murphy, who has now added an alarm system to the house to keep his son safe. "He has broken through brackets, windows, picked locks, you name it. It's absolutely the most stressful part of parenting a child with autism."

The behavior, called wandering or elopement, has led to numerous deaths in autistic children by drowning and in traffic accidents. Now a new study of more than 1,200 families with autistic children suggests wandering is alarmingly common. Nearly half of parents with an autistic child age 4 or older said their child had tried to leave a safe place at least once, the study reported. One in four said their child had disappeared long enough to cause concern. Many parents said their wandering children had narrowly escaped traffic accidents or had been in danger of drowning.

Those at greatest risk of wandering off were autistic children with severe intellectual deficits

and those who do not respond to their names. The research was published on Monday in the journal *Pediatrics*.

"I knew this was a problem, but I didn't know just how significant a problem it was until I really began to look into it," said Dr. Paul A. Law, senior author of the study and director of the active Autism Network, a registry that is a project of the Kennedy Krieger Institute in Baltimore. "This is probably one of

A behavior that has led to numerous accidental deaths.

the leading causes of death and morbidity for kids with autism." Advocates for families affected by autism say the findings underscore the need to raise public awareness and alter policy. While the public when a child is believed to have been abducted, for instance, generally they are not

used when a disabled child goes missing, said Alison Singer, president and a founder of the Autism Science Foundation, one of the organizations that supported the study.

Emergency responders should receive special training on how to search for autistic children who are nonverbal and often scared by lights and sirens, she said. Emergency personnel also need to know to check streams or ponds, since many children with autism are drawn to bodies of water, as well as highways.

One in 88 children in the United States received a diagnosis of autism, Asperger syndrome or a related disorder in 2008, according to the Centers for Disease Control and Prevention. While some of these children are socially awkward but high functioning, others have limited intellectual and cognitive abilities.

"For children who are prone to wander, this is a pervasive problem that affects all aspects of families' lives," Dr. Law said. "Many parents just don't go out in public with their child because they don't feel safe with them, or they don't get any sleep at night

because the child once escaped through the upstairs window."

The idea for the new study came from a family coping with autism, and it was financed by several advocacy organizations. Researchers surveyed families who had a child with autism or a related disorder between the ages of 4 and 17.

Most of the respondents came from 1,098 of Interactive Autism Network's most active participants, 60 percent of whom completed the survey. Families who chose to participate knew the survey was about wandering, and those coping with wandering children may have been more likely to respond, skewing the results, Dr. Law acknowledged.

Over all, 49 percent of families who participated said a child with autism had tried to wander from home, school or another safe place at least once after age 4; 5. Some parents said their child wandered off several times a day. "This is the first study to quantify the scope of the problem, and it was much larger than we thought," Ms. Singer said.



Patrick Murphy, 14, will sometimes sneak out of the house to pursue his latest interest.



WATCH LIVE: GEORGE ZIMMERMAN ON TRIAL FOR TRAYVON M



HOME > HEALTH > ABC NEWS ONCALL+ AUTISM CENTER

Wandering More Common in Autistic Children Than Once Thought



Twelve-year-old Connor McIlwain is one of many children with autism who have repeatedly wandered away from home. (Courtesy Lori McIlwain)



By LARA SALAH (@BostonLara)
October 5, 2012

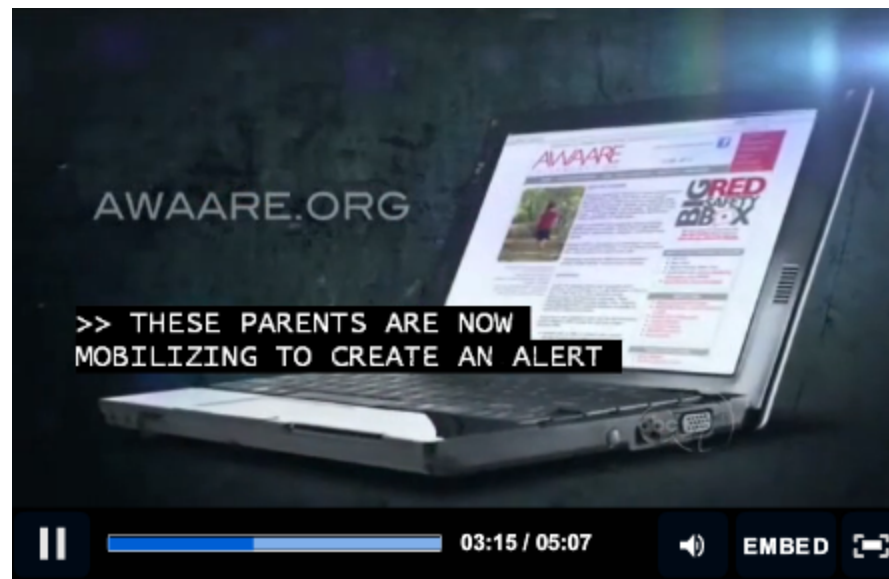
Lori McIlwain, 39 of Cary, N.C., lives in constant fear that her 12-year-old son, Connor, who is autistic, will bolt from home or school if he is ever left unsupervised.

"You live in constant prevention mode," said McIlwain. "You're always on high alert."

Four years ago, Connor wandered away from a school playground and headed right toward a busy highway.



AUTISM SCIENCE FOUNDATION



Related Video

ALL LIVE VIDEO : ALL VIDEO ▾



Protect Our Children: Segment 2

TAGS: [seasonal](#)

[Comment Now](#) [Email](#) [Print](#) [Report a typo](#) [RSS](#) [Facebook](#) [Twitter](#) [Google+](#) [LinkedIn](#) [StumbleUpon](#)

NEW YORK -- On Saturday, April 6th, WABC-TV aired a special entitled, "Protect Our Children: Anxious & Stressed" at 7 PM, EDT. (Also to be re-run Sun. 4/7 at 5:30am).

AUTISM SCIENCE FOUNDATION

The program is hosted by Eyewitness News Anchor, Diana Williams, and reports on the mental health of our children, an issue that has come into greater focus since the tragedy of Newtown, Connecticut. Our children are exposed to more

2013



CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS: A RESOURCE TOOLKIT FOR CLINICIANS, 2ND EDITION

FAMILY HANDOUTS

Wandering Off (Elopement)

What is wandering off (elopement)?

This is 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. This might include running off from adults at school or in the community, leaving the classroom without permission, or leaving the house when the family is not looking. This behavior is considered common and short-lived in toddlers, but it may persist in children and adults with autism spectrum disorders (ASDs). Children with ASDs have challenges with social and communication skills and safety awareness.

This makes wandering a potentially dangerous behavior.

Why do children with ASDs wander off?

Parents of children with ASDs report the following top 5 reasons for wandering:

- Simple enjoyment of running or exploring
- Desire to reach a place he enjoys (such as the park)
- Trying to escape an anxious situation (like demands at school)
- Pursuit of a special interest (as when a child fascinated by trains heads for train tracks)

• Trying to escape uncomfortable sensations (like loud

Adapted from AWAARE *Autism & Wandering*, available at <http://awaare.org/docs/wanderingbrochure.pdf>, and IAN Research Report: Elopement and Wandering, reprinted with permission of Kennedy Krieger Institute, Baltimore, Maryland. This information appeared originally at: www.iancommunity.org/cs/ian_research_reports/ian_research_report_elopement.

The recommendations in this publication do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate. Original document included as part of *Autism: Caring for Children With Autism Spectrum Disorders: A Resource Toolkit for Clinicians*, 2nd Edition. Copyright © 2013 American Academy of Pediatrics. All Rights Reserved. The American Academy of Pediatrics does not review or endorse any modifications made to this document and in no event shall the AAP be liable for any such changes.

American Academy
of Pediatrics



DEDICATED TO THE HEALTH OF ALL CHILDREN™

Today: “Autism Alert”

Explore and research the 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 age 18 with ASD who wander or elope to help families and communities rapidly locate children with autism who have wandered or eloped.

IACC Letter to Sec. Sebelius, Feb 2011

