

[PHOTO REDACTED]

AUTISM & SAFETY

WENDY FOURNIER | NATIONAL AUTISM ASSOCIATION



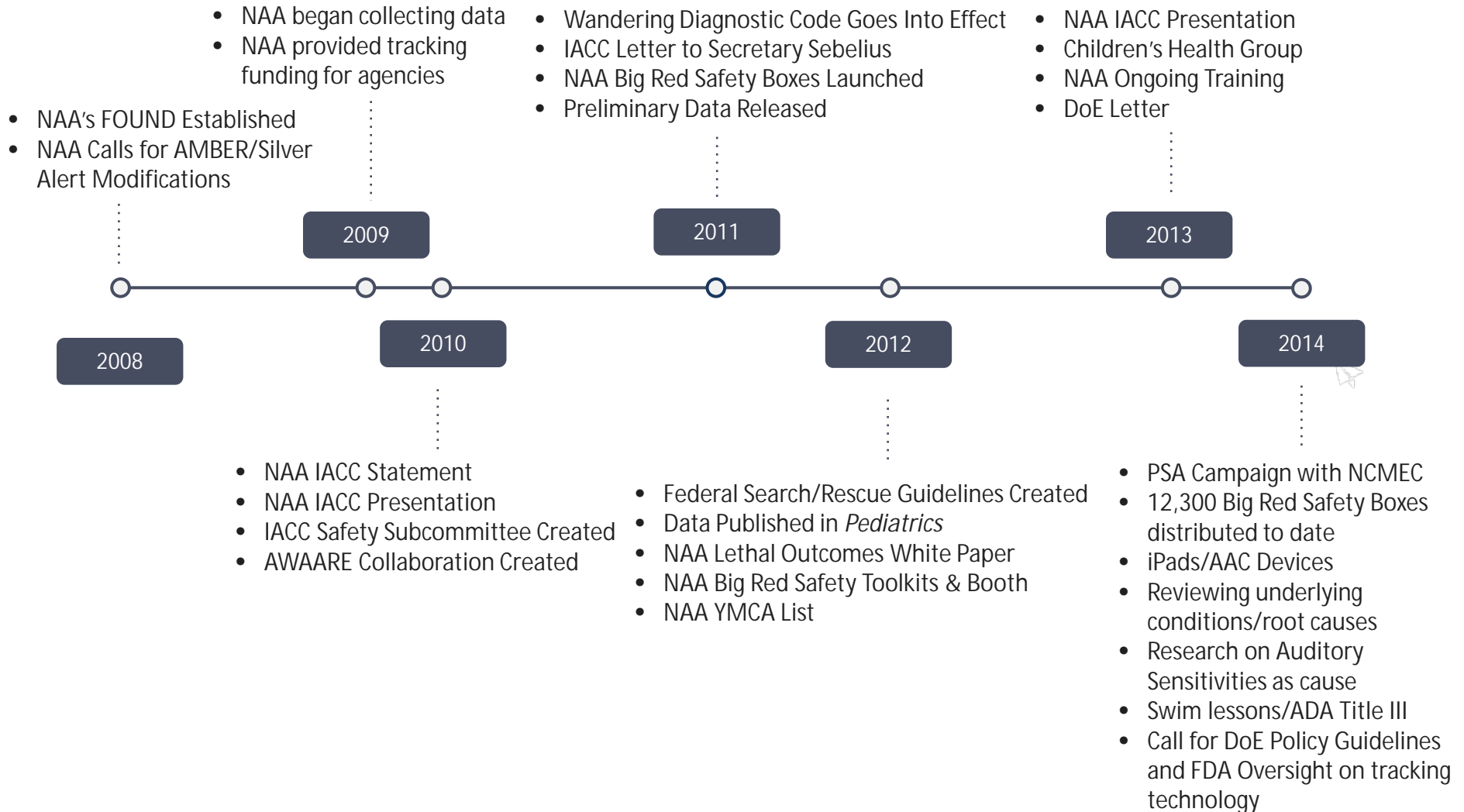
WANDERING UPDATE

[PHOTO REDACTED]

Autism-related wandering has resulted in another 27 fatalities since last year.

Based on our data, there have been at least 67 U.S. deaths since we first brought this issue to IACC in 2010.

TIMELINE



TRENDS

WANDERING UPDATE

[PHOTO REDACTED]

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TRENDS

[Photo Redacted]

[Photo Redacted]

[Photo Redacted]

MORE TEENS AND ADULTS AT RISK

[PII redacted]

Missing since June 27th

Minimally verbal

Functions at 10-year-old level

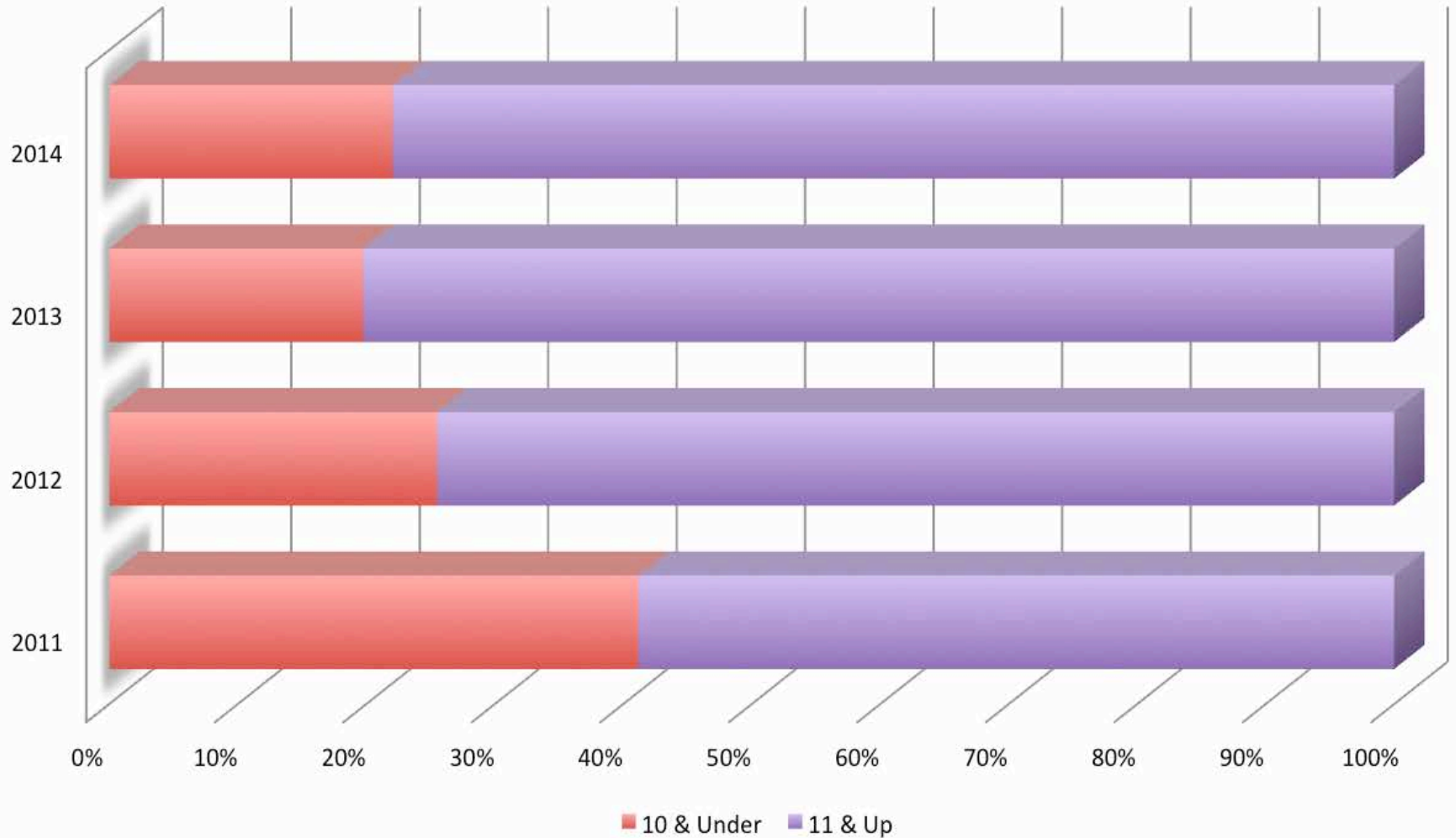
[PII redacted]

Became separated from caregiver while shopping. Her half-naked body was found the next morning 5 miles away.

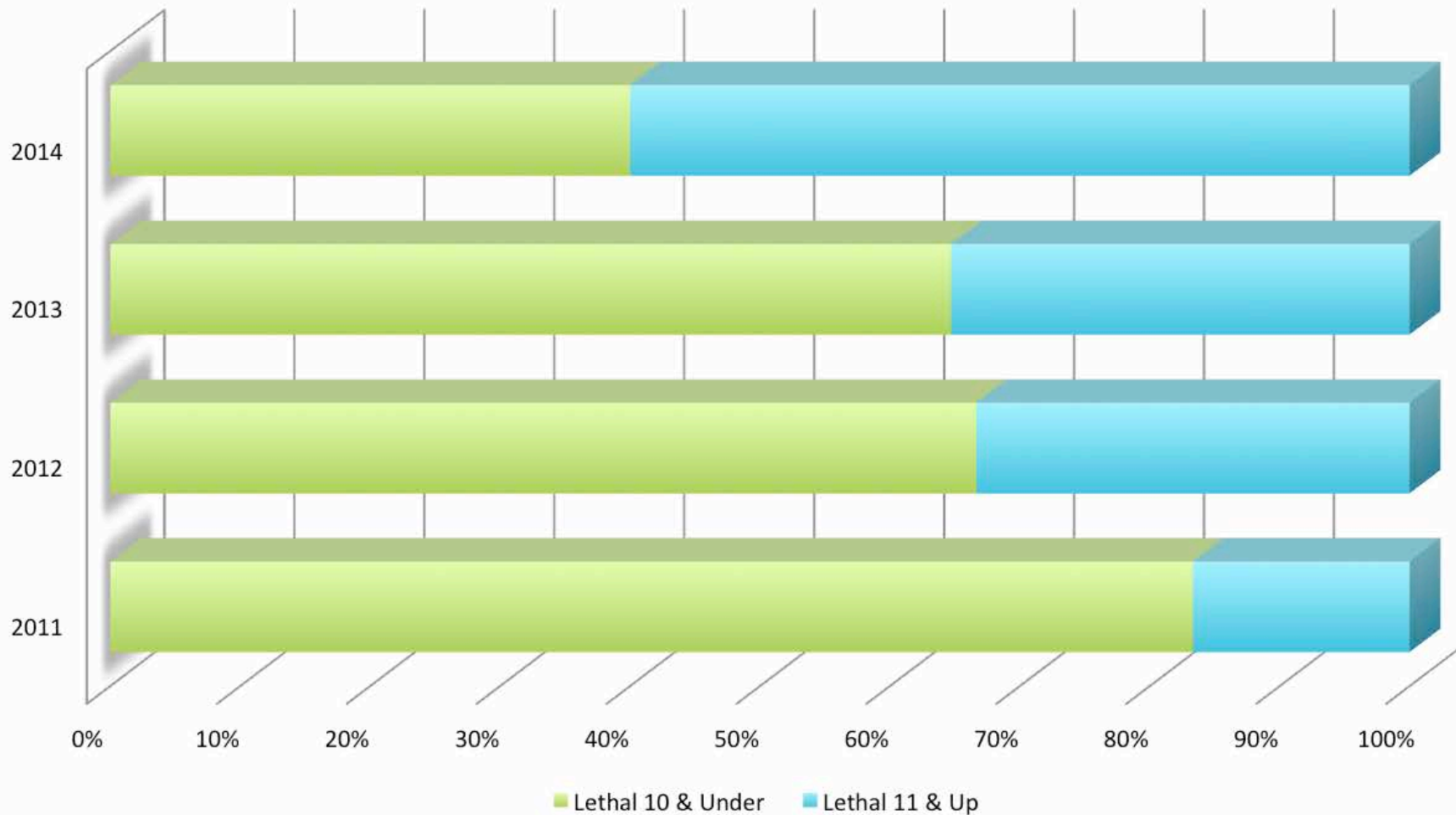
[PII redacted]

Seen walking on a San Antonio freeway in the early morning hours. Fatally struck by several cars.

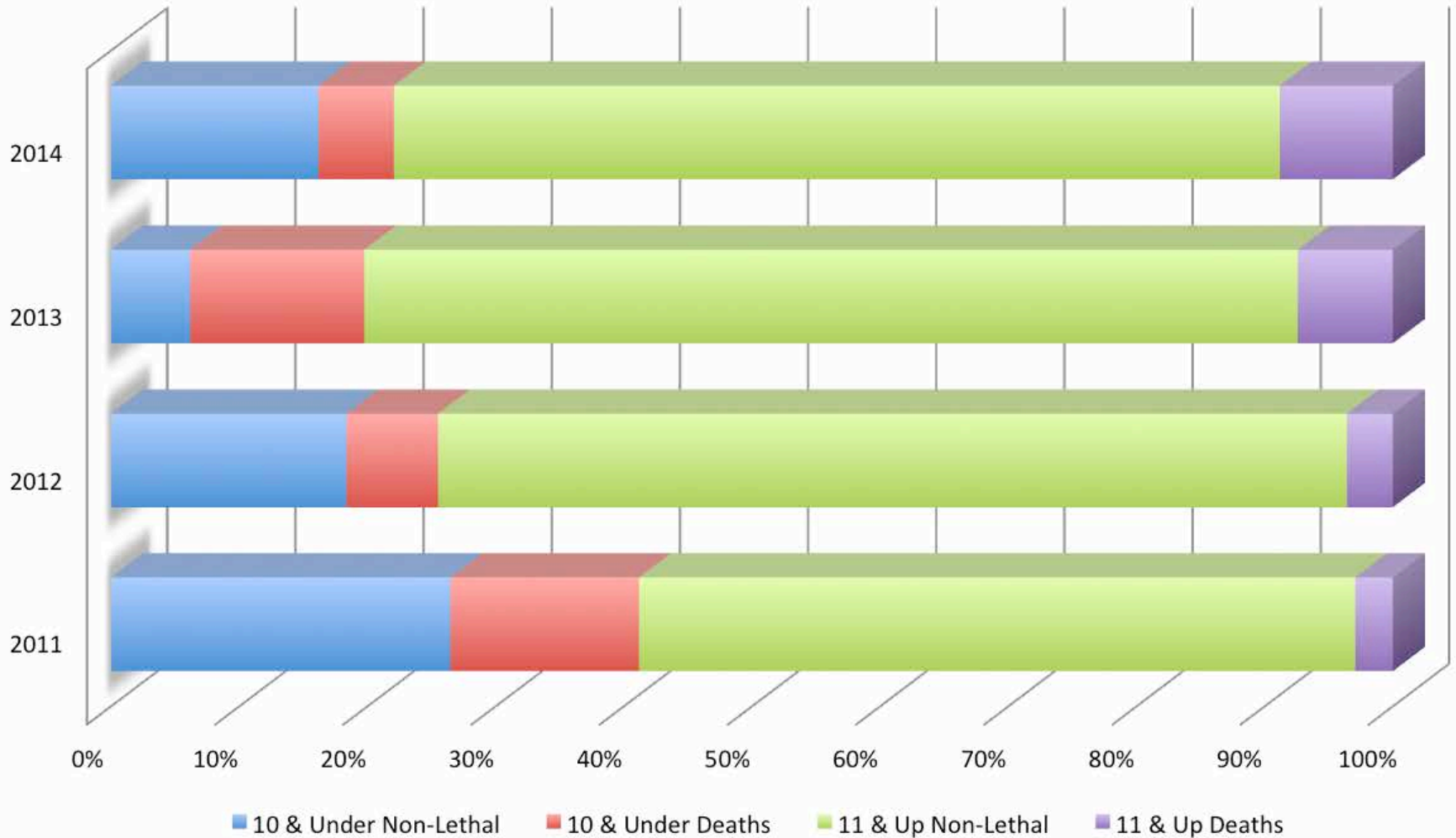
All Cases



Lethal Outcomes



All Cases



CAUSES

CAUSES

2012 IAN STUDY DATA

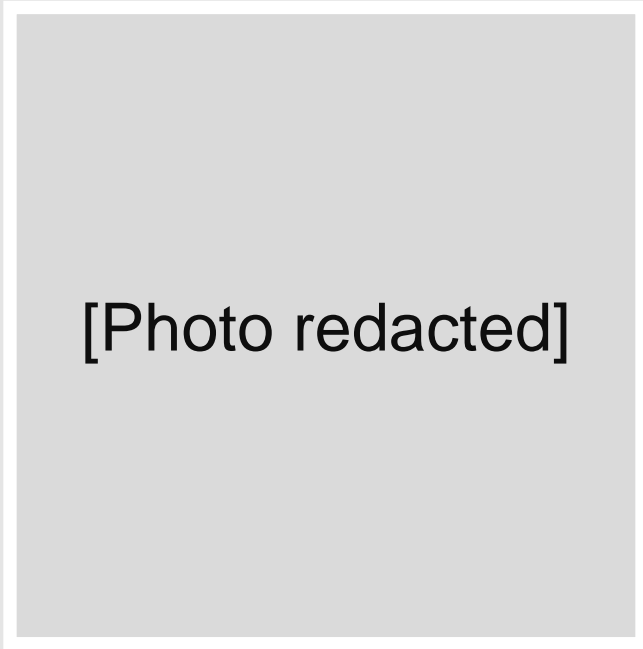
Parents reported their child:

“tries to reach a place he or she enjoys”
(36%)

“tries to escape an anxious situation”
(34%)

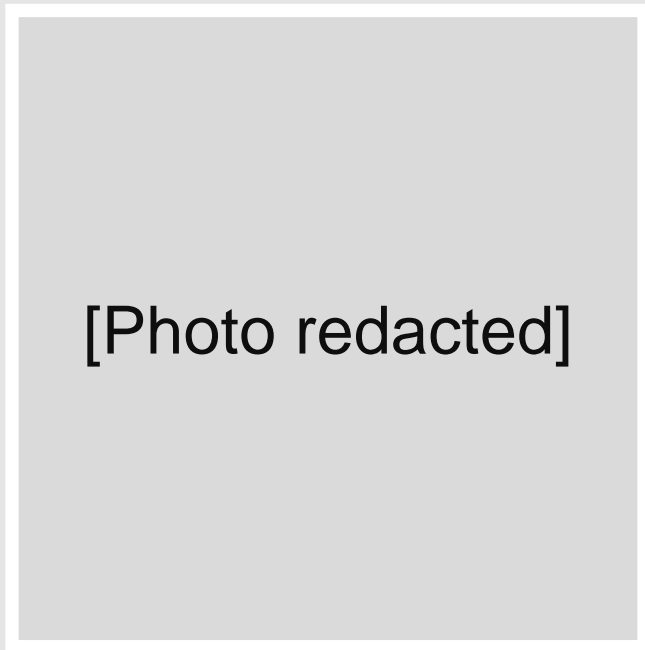
“tries to escape uncomfortable sensory
stimuli” (30%)

“pursues his or her special topic” (30%)



Ref: Connie Anderson, J. Kiely Law, Amy Daniels, Catherine Rice, David S. Mandell, Louis Hagopian, and Paul A. Law. Occurrence and Family Impact of Elopement in Children With Autism Spectrum Disorders. *Pediatrics*, October 8, 2012 DOI: 10.1542/peds.2012-0762

CAUSES



COMMUNICATION DISORDERS

According to CDC, approximately 40% of people with an ASD are non-verbal.

They are *unable to communicate their wants and needs – which could be triggers for wandering/elopement.*

“It’s too loud, I need to leave.”

“I’m scared.”

“I want to go to the swings at the park.”

“I want to go home.”

“I want to go swimming.”



National Institute on Deafness and Other Communication Disorders (NIDCD)

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Why NIDCD Supports Voice, Speech, and Language Research

Communication allows us to participate in society and is a defining characteristic of what it is to be human. Other organisms clearly communicate; however, in no other species does it appear that communication—specifically the use of language in communication—is as highly developed as in humans, nor as central to an organism's function and identity. Communication impairments that involve voice, speech, or language often limit a person's ability to participate in society, whether the activity is educational, occupational, or social. In addition, because effective communication is needed to get aid in life-threatening situations, loss of communication can put people at risk for compromised physical safety and survival.

CAUSES

EVERYONE DESERVES TO HAVE A VOICE

[Photo redacted]

With an iPad, [PII redacted] has learned how to ask for help when needed without having tantrums.

CAUSES

[PII redacted]

AUDITORY SENSITIVITIES

**Anxiety. Stress. Pain.
Quality of Life?**

“tries to escape uncomfortable sensory stimuli” (30%) – IAN study

IAN/NAA Follow-up study currently in development on auditory sensitivities as a safety risk.

[PHOTOS REDACTED]

It is well known that the use of directional acoustic sensing in hearing aids can be a very effective means of reducing the influence of unwanted background acoustic noise and as a result can significantly improve the understanding of speech in noisy environments.

(Amlani et al., 2006; Blamey et al., 2006; Hornsby and Ricketts, 2007; Ricketts et al., 2003; Walden et al., 2004)

In hearing aids, it is highly desirable that the distance between the points at which the pressure is sensed be kept to a bare minimum, on the order of a few millimeters in order for the size of the device to be cosmetically acceptable.

[Photos redacted]

Effective? Safe?
Cosmetically acceptable?

CAUSES

AUDITORY AND COMMUNICATION DISORDERS

Just part of autism? No!

How we categorize disorders influences how we treat them. These are significant medical issues that affect both quality of life and personal safety. They should never be overlooked or dismissed because of a co-occurring Autism diagnosis.

A medical model needs to be established through the NIDCD under the advisement of HHS through the direction of IACC. Our loved ones deserve access to effective technology and treatment for auditory and communication disorders.

WHAT WE NEED

WHAT WE NEED

RESEARCH

To discover underlying causes of elopement. To establish a medical model addressing auditory and communication disorders, focusing especially on how they relate to safety issues.

AAC DEVICES

Communication challenges create serious safety risks. AAC devices should be considered medically-necessary and covered by insurance providers.

DATA

Coordination between agencies to collect data on wandering incidents, triggers and possible root causes that could be further researched leading to prevention of elopement incidents.

RESOURCES

Families need support from physicians, schools, law enforcement and social workers. They need access to swimming lessons and an Emergency Alert System that applies to all who have a disability regardless of age.

TECHNOLOGY

To assist in preventing wandering incidents, based on unique medical needs of individuals with autism including auditory sensitivities and communication disorders. FDA oversight of GPS devices.

EDUCATION

Training for caregivers, school administrators, clinicians, law enforcement officers, first responders, CPS workers and the public. Policy Guidance from Dept. of Education for wandering prevention in all schools.

THANK YOU.

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