

# **AUTISM SCIENCE FOUNDATION**

# **Autism & Wandering**

Alison Singer President Autism Science Foundation

IACC January 16, 2019



# Timeline

- October 2010:
  - Wandering issue presented at IACC during public comments by President of the National Autism Assocaition
  - Safety committee formed to investigate wandering
- 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)



# Timeline

- February 2011:
  - Letter sent to Secretary Sebelius
- March 2011:
  - Response received



February 9, 2011

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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/dopement related to ASD, as exission antite that was described in detail by members of the public at the IACC meeting that took place on October 22, 2010.<sup>1</sup> This issue is the first of evereal important health and safety issues that affect people with ASD, including seclusion and restraint, bullying, abandonment, neglect, abuse, criminal justice issues and bondensenses, 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 tenacions five-year-old with boundless energy and a natural impairistiveness about the world. Mason also had aution and no functional language skills. His family have that he would wander if given the opportunity, so they were highly vigilant about his saftey, installing multiple locks or 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 be forever. If knew he had no concept of dangers' if we didn't always know where he was.<sup>2</sup>

<sup>3</sup> 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

Thoemas 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:

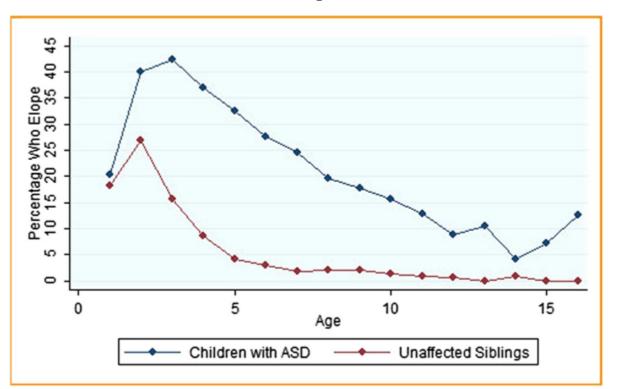
I am writing to extend my sincere appreciation to you and the Interagency Autism Coordinating Committee for your work related to autism spectrum disorder and your suggestions for changes to foderal activities the Department of Health & Human Services (HHS) may want to consider in accordance with the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

I also would like to thank you for providing background information on how the issue of autismrelated wandering/optopenent is firstering 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 Surargies Plan for Autism Spectrum Disorder Research, and also understand that the issue of medical Costing for autism cluded wandering in currently under consideration by the International Classification of Diseases Coordinating and Maintenance Committee, with final decisions expected lister the year.

Please know that HHS approximates the effort pat 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's advisory letter, and enhancing and accelerating federal and commanity efforts to improve the health and well-being of people with autism spectrum disorder.

# Initial Data Presented April, 2011

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



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Anderson, Law, et al (KKI/IAN)

# October, 2011

CDC Home



Centers for Disease Control and Prevention

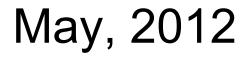
🤰 CDC 24/7: Saving Lives. Protecting People.™

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

## Classification of Diseases, Functioning, and Disability

ICD and ICF Home	NCHS Home > ICD and ICF Home
▶ICD-9	
ICD-10	ERecommend 15 Tweet Share
ICD-9-CM	International Classification of Diseases,
ICD-10-CM	
ICF	Ninth Revision (ICD-9)
Classification of Death and Injury Resulting from Terrorism	The International Classification of Diseases (ICD) is designed to promote international comparability in the collection, processing, classification, and presentation of <u>mortality statistics</u> .
North American Collaborating Center	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
Related Sites	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
Centers for Medicare and Medicaid Services 🗗	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
World Health Organization ଜ୍ୟ	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:

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# INTERNATIONAL MEETING FOR AUTISM RESEARCH

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# October, 2012



#### OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

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

**AUTHORS:** Connie Anderson, PhD,<sup>a</sup> J. Kiely Law, MD,<sup>a,b</sup> Amy Daniels, PhD,<sup>ac</sup> Catherine Rice, PhD,<sup>d</sup> David S. Mandell, ScD,<sup>e</sup> Louis Hagopian, PhD,<sup>a,b</sup> and Paul A. Law, MD, MPH<sup>a,b</sup>

<sup>a</sup>Kennedy Krieger Institute, Baltimore, Maryland; <sup>b</sup>Johns Hopkins University School of Medicine, Baltimore, Maryland; <sup>c</sup>Autism Speaks, New York, New York; <sup>d</sup>National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Atlanta, Georgia; and <sup>e</sup>University 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

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#### Nearly half of children with autism wander from safety

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



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 autismspectrum 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



#### 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

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#### **Health**Day

#### 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 nearmisses 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

"That was very scary," said "That was very scary," said Patrick's father, Brian Murphy, who has now added an alarm syspublished on Monday in the journal Pediatrics. "I knew this was a problem, but I didn't know just how signif-

A behavior that has

led to numerous

accidental deaths.

tem to the house to keep his son icant a problem it was until I realsafe. "He has broken through ly began to look into it," said Dr. brackets, windows, picked locks, Paul A. Law, senior author of the you name it. It's absolutely the study and director of the Intermost stressful part of parenting a active Autism Network, a regischild with autism." The behavior, called wandertry that is a project of the Kennedy Krieger Institute in Balti-

ing or elopement, has led to numerous deaths in autistic chil dren 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 children had tried to leave a safe place at least once, the study reported. One in four said their children had disappeared long enough to cause concern. Many morbidity for kids with autism." parents said their wandering children had narrowly escaped by autism say the findings un-

traffic accidents or had been in derscore the need to raise public danger of drowning. awareness and alter policy. While Those at greatest risk of wan-lize the public when a child is be-



their names. The research was 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

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 more. "This is probably one of to know to check streams or ponds, since many children with utism are drawn to bodies of wa-

ter, as well as highways. States received a diagnosis of autism, Asperger syndrome or a related disorder in 2008, according to the Centers for Disease Con-

trol and Prevention. While some of these children are socially the leading causes of death and awkward but high functioning, others have limited intellectual Advocates for families affected and cognitive abilities.

"For children who are prone to wander, this is a pervasive problem that affects all aspects of Those at greatest risk of wan-dering off were autistic children with severe intellectual deficits lize the public when a child is be-lize the public when a child is be-lieved to have been abducted, for instance, generally they are not they don't get any sleep at night thought," Ms. Singer said. families' lives," Dr. Law said.

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 One in 88 children in the United survey was about wandering. and those coping with wandering children may have been more likely to respond, skewing the results, Dr. Law acknowledged.

autism had tried to wander from home, school or another safe place at least once after age 4; the peak age for wandering was 5. Some parents said their child wandered off several times a week or even several times a day. in public with their child because tify the scope of the problem, and it was much larger than we

Over all, 49 percent of families who participated said a child with

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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 SALAHI (@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



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son, Connor, who is autistic, will bolt from home or school if he is ever lunsupervised.

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



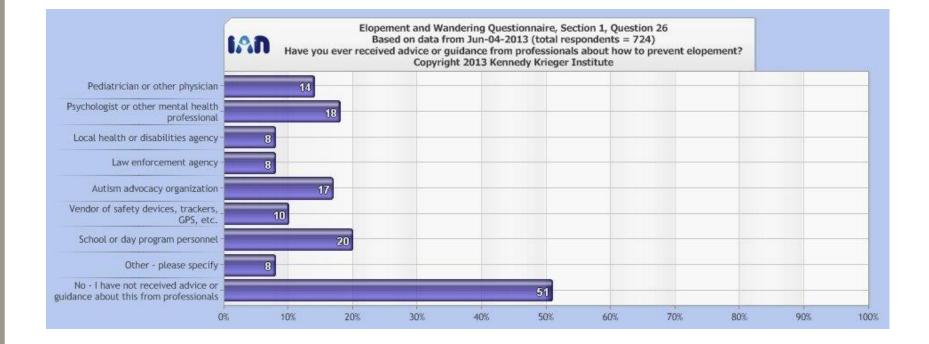
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Four years ago, Connor wandered away from a school playground and headed right toward a busy highway.

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# Anticipatory Guidance Lacking



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# American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDREN"

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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?

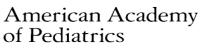
Parents of children with ASDs report the following top 5 reasons for wandering:

- 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)
- Terrina to accord uncomfortable concorrectional: /liles load

t <u>http://awaare.org/docs/wanderingbrochure.pdf</u>, and IAN Research Report: Elopement and Institute, Baltimore, Maryland. This information appeared originally at: <u>www.iancommunity.org/cs/</u>



e course of treatment or individual circumstances, Caring for Children With dition. Copyright © 2013 1 Academy of Pediatrics 1t and in no event shall





DEDICATED TO THE HEALTH OF ALL CHILDREN

# Other AAP initiatives

- Presentation by Dr. Susan Hyman and Dr. Susan Levy at 2017 AAP meeting.
- Article in AAP magazine in 2017; another one planned in 2019

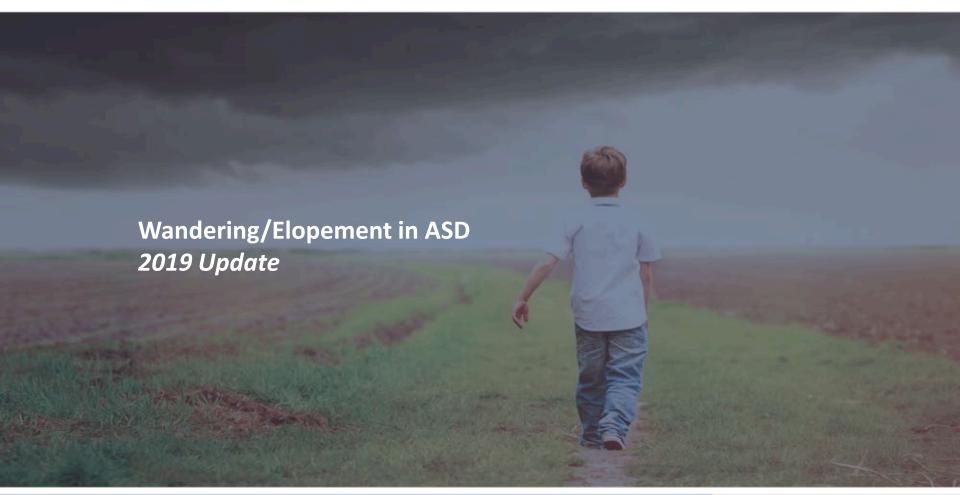


# March, 2018: Kevin and Avonte's Law

- Still no Appropriation for Kevin and Avonte's Law
  - Autism "alert"
  - GPS tracking devices
  - First Responder training







Lori McIlwain National Autism Association IACC January 2019



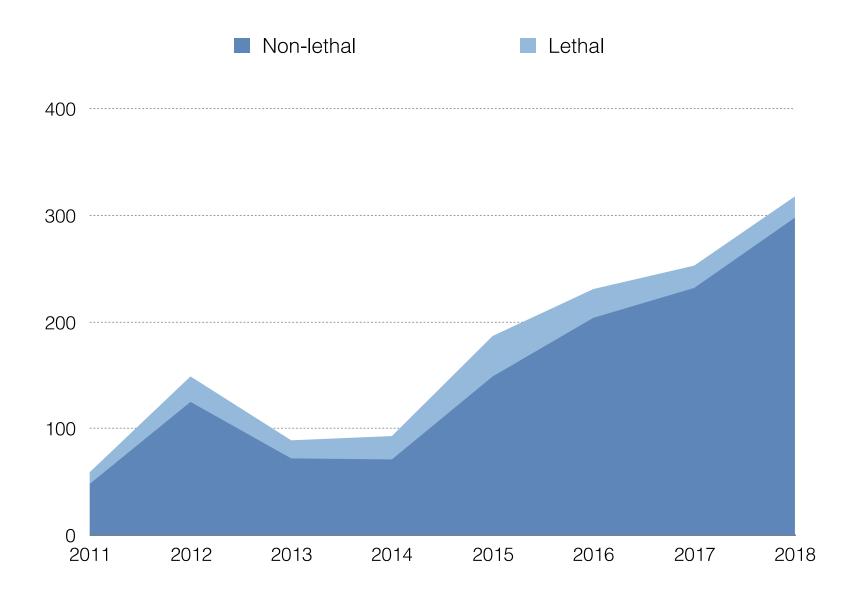
1338 ASD missing and "found missing" person cases in the U.S. since 2011, 180 reported fatalities.



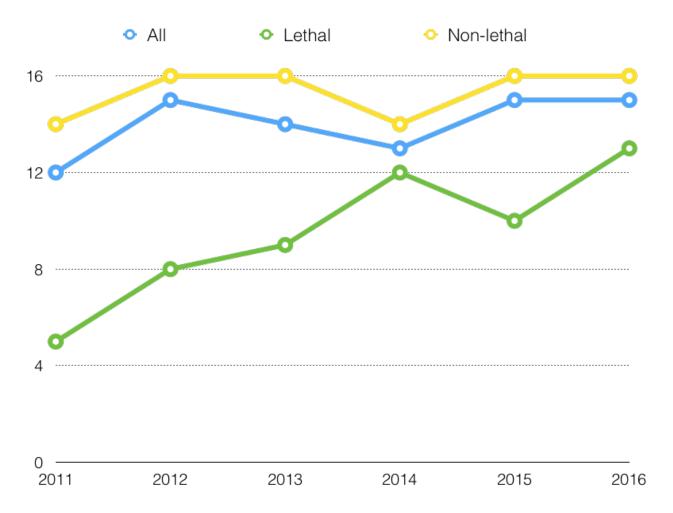


On average: 20 cases, 2 to 3 deaths per month. Drowning remains leading cause of death.





## Average Age by Year, 2011 to 2016



\*Current average age for lethality, 15



## What **Increased** Lethal/Injury Risk

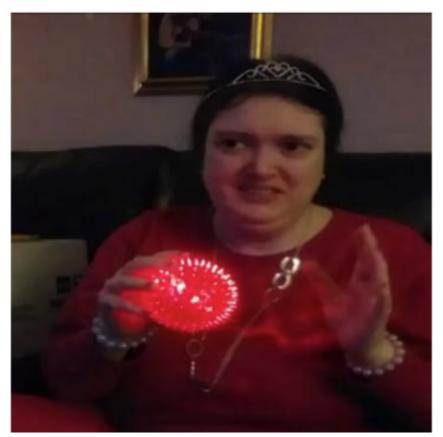
- Residential settings, esp. those unfamiliar, near water
- Times of transition, disruption
- Heightened response to stress
- Caregiver/staff distracted
- Commotion, esp. during holidays/family gatherings
- Longer Search Time
- Police unaware, unprepared





01/12/2019, 04:14am

## Autistic woman, reported missing, dies after being found in creek



Last Week

Wendy M. Lippard | Kendall County sheriff's office

By Sun-Times Wire email



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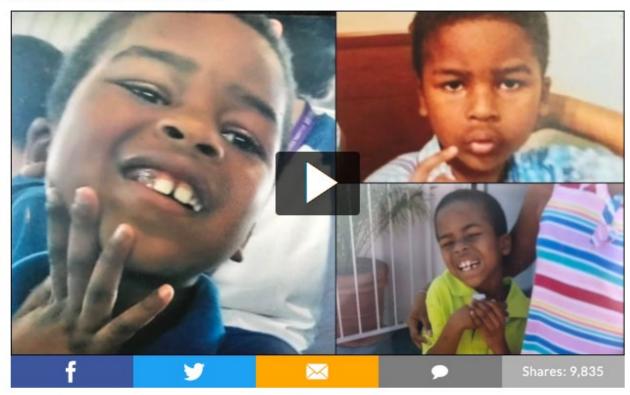
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A woman with autism died Thursday following a five-hour police search that led to her rescue from a creek in west suburban Bristol.

# Body found in pond confirmed as missing Texas City child with autism, officials say

By Andy Cerota - Anchor/Reporter, Jacob Rascon - Anchor-Reporter, Brittany Taylor - Digital News Editor, Daniela Sternitzky-Di Napoli - Digital News Producer, Sofia Ojeda - Anchor/Reporter

Posted: 4:53 PM, January 06, 2019 Updated: 11:34 AM, January 09, 2019



Two weeks ago

**TEXAS CITY, Texas** - A body found in a pond has been identified as a boy with autism who recently went missing in Texas City, officials said Tuesday.



# Maddox Ritch, who disappeared from park, died from accidental drowning

The Gastonia Police Department in North Carolina said no criminal charges will be filed.



## **Notable Recent Cases**



—— The FBI has joined in on the search for 6 year old Maddox Ritch. Gastonia Police Dept.

# Missing 9-year-old safe with parents on the way to hospital; asked for pizza

by Taylor Johnson |

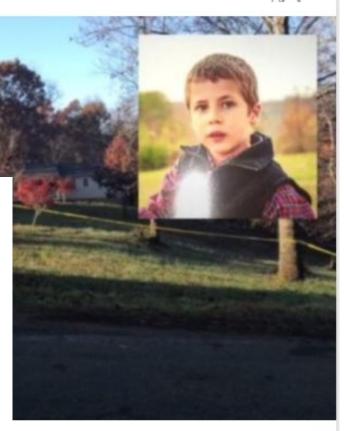
Wednesday, November 7th 2018

UPDATE: 12:40 p.m.

The Pittsylvania County Sheriff's Office said Andrew Yarboro was located Wednesday morning in the 6000 block of Strawberry Road in Chatham, about 1.4 miles away from his home.

They said he had scratches on his back and was very tired, but appeared to be okay.

He was being treated by EMS, helping with the search, when searchers and the boy's father said he got away from them again.



## Body pulled from Genesee River identified as Trevyan Rowe

By Spectrum News Staff | Rochester PUBLISHED March 12, 2018 @4:16 PM



ROCHESTER N.Y. — Rochester Police say the body recovered from the Genesee River Sunday has been identified as 14-year-old Trevyan Rowe.

Police say they found the body near the Frederick Douglass-Susan B. Anthony Memorial Bridge. They say tips made to the department focused their search efforts along the river in that section.

"State police responded because they have a responsibility for the express way, were unable to find anything," Ciminelli said. "In tracking this back, our investigators located one of the individuals who called and they pointed out the location where they had seen the person standing and in fact I think this individual met with our scuba squad to try to pinpoint the location."

Rowe was last seen leaving School No. 12 Thursday morning. His family says they did not know he was missing until he did not get off the bus with his sister later that afternoon. They say Rowe is autistic and may have been upset when he walked away after getting off the bus Thursday morning.



# 'He said he was going to kill himself': Trevyan Rowe's history of red flags needed support

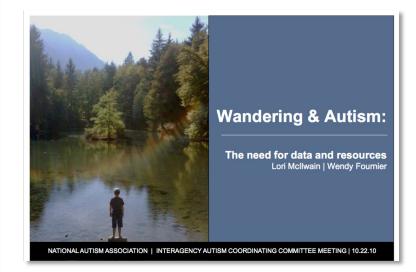
IF THE 14-YEAR-OLD HAD A HISTORY OF SUICIDAL THREATS AND MENTAL HEALTH ARREST, IT'S FAIR TO ASK IF HE GOT THE INSTITUTIONAL AND FAMILIAL HELP HE NEEDED.

Justin Murphy and

Steve Orr, Democrat and Chronicle

Published 12:44 p.m. ET March 18, 2018 | Updated 9:38 a.m. ET March 19, 2018

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## IACC Impact:

- April 2010: NAA statement on wandering
- October 2010: NAA IACC presentation on wandering
- April 2011: IAN data

Data created incredible amount of awareness, opened door for resources.





## NAA Program Impact:

- Nearly 50,000 NAA Big Red Safety Boxes shipped across the U.S.
- Over \$100,000 provided to agencies for tracking technology by NAA
- Ongoing training for agencies, families and service professionals
- No current funding for agency resources, tracking and training



## **Prevention is Essential.**

	Not Helpful	Helpful	Very Helpful
Door/Window Alarms	2%	19%	78%
Adhesive Stop Signs	12%	38%	50%
Safety Alert Wristband	15%	36%	49%
Safety Alert Window Clings	6%	33%	61%
Personalized ID Tags	8%	28%	64%
BeREDy Booklet	2%	35%	62%
Child ID Kit from the National Center for Missing & Exploited Children	3%	35%	63%



# Missing Saratoga boy located with Project Lifesaver

9-year-old with autism was wearing bracelet transmitter

By Rachel Silberstein Updated 6:00 pm EDT, Saturday, September 29, 2018

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## Gaston County Sheriff's Office sees spike in Project Lifesaver requests after search for Maddox Ritch



Device capable of tracking missing people



GASTONIA, NC (WBTV) - In the wake of a community-wide tragedy, more and more people are requesting to be a part of a potentially life-saving program used to find missing persons.

## Too many counties still carry age exclusions. Funding for autism and other disabilities needed.

## How to obtain a Bracelet:

**Eligibility** See 60 or older See Saginaw County resident Suffering from a dementia related illness

**Contact** Saginaw County Commission on Aging at (989) 797-6880 or Strep 1-866-763-6336

**Process** Initial Assessment from a Commission on Aging caseworker to determine eligibility. Determine approved, client will be set up with the Lifesaver Bracelet. Staff will make monthly in-home visits to ensure equipment is working properly.



### ALZHEIMER'S INITIATIVES



With more than 5 million Americans currently living with Alzheimer's disease and approximately 500,000 new cases of this disease emerging each year, projections pronounce that there could be as many as 16 million Americans that will have Alzheimer's by 2050. To help law enforcement protect this special population, IACP's Alzheimer's Initiatives program is committed to helping first responders improve their knowledge and skills to safeguard this special population.

### A STATE-BY-STATE GUIDE TO:

#### Missing Senior/Adult Public Alert Systems



DOWNLOADS	HELPFUL LIN	KS		
Pocket Card: 10 Signs & Steps				
Guide to Voluntary Registry Systems				
Identifying and Helping Drivers				
MedicAlert Access		>		
Program Overview Brochure				
ID & Evaluate the At-Risk Older Adult				
Evaluative Questions to Ask Caregivers				
IACP Model Policy				
Concepts and Issues Paper				
Training Key				
Locative Technologies 101				
Podcast: Alzheimer's Initiatives				
Post Card: Alzheimer's - Do's and Don'ts				
Post Card: Alzheimer's - Senior Drivers				

# DID YOU KNOW?

5.4 million Americans of all ages currently have Alzheimer's disease. That could be as many as 16 million by 2050.\*

It's not a question of *if* law enforcement will be dealing with persons with Alzheimer's disease, but rather *when* and how we'll respond.

lzheimer's

**IACP's** 

## First responders need to become skilled at effective interactions with people with Alzheimer's disease:

#### "Do's"

- Introduce yourself and explain you are there to help
- Remain calm, smile, and use a friendly voice
- Speak slowly and ask simple questions
- Check for a tracking device or MedicAlert IDChange the topic to something pleasant
- if the person becomes agitated Provide security and comfort (i.e. blanket, water, or someplace to sit)

#### "Don'ts"

- Don't take comments personally
- Don't correct the person
- Don't approach from behind without warning
- Don't argue
- Don't touch without asking/explaining
- Don't repeat a question too many times as it may provoke agitation

To help law enforcement protect this special population, IACP's Alzheimer's Initiatives program is committed to helping first responders improve their knowledge and skills, and interact appropriately with persons with Alzheimer's disease and their families and caregivers.

For more information, please visit: www.theiacp.org/alzheimers. To request additional postcards for your department, please email alzheimers@theiacp.org.

#### to request additional postcards for your department, please email alguements

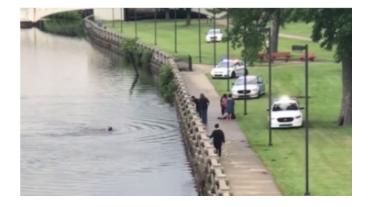
Unsummore conversely on preferences Proceedings of a pair or space service on an analysis of the preference service of the preference service of the preference service of the Office of Justice Programs, which also includes the Survey of Justice Statistics, the National Institute of Justice, the Office of Justice Assistance of Lance Assistances in a component of the Office of Justice Programs, which also includes the Survey of Justice Statistics, the National Institute of Justice, the Office of Justice Assistance of Justice Assistances in a Component of the Office of Justice Programs, which also includes the Survey of Justice Statistics, the National Institute of Justice, the Office of Justice Programs, which also includes document are those of the authora and on the present the official position or policies of the United State Department of Justice.



INTERNATIONAL ASSOCIATION OF CHIEFS OF POLICE 515 North Washington Street Alexandria, VA 22314

## **Summary**

- Wandering/elopement is still an urgent issue in need of federal support
- Less notifications to NCMEC due to age, but more cases overall
- Major differences in Alzheimer's versus autism, but similar resources needed
- Increase in average age of lethal cases
- More agencies requesting training, especially centered on interaction
- Mental health and other conditions adding complexity to the issue, more discussion needed









### LORI McILWAIN National Autism Association P: 877.622.2884 Iori@nationalautism.org

Wandering/Elopement in ASD: 2019 Update



BUREAU OF JUSTICE ASSISTANCE

# The Justice and Mental Health Portfolio

Maria Fryer Policy Analyst for Mental Health and Substance Addiction

**Programs, Policy Initiatives and Improved Responses** 





## IMPROVING RESPONSES TO PEOPLE WITH AUTISM/IDD AND ALZHEIMER'S DISEASE

THE JUSTICE AND MENTAL HEALTH COLLABORATION PROGRAM

OTHER LAW ENFORCEMENT INITIATIVES THAT BUILD COLLABORATION AND IMPROVE RESPONSE





BJA's role is to assist law enforcement at the state, tribal and local levels:Programs and Initiatives that provide the foundation to operationalize Kevin and Avonte's Law. What have we learned? And, How can we build this together?



# National Center on Criminal Justice & Disability (NCCJD) and Serving Safely

- NCCJD: In 2013, BJA recognized the need to take a closer look at the prevalence of people with IDD in the Justice System and through the National Arc, the Pathways to Justice Program was established.
- Serving Safely: In 2017, BJA recognized the need to increase products and services to support law enforcement in their response to people with MHD and IDD and the first National Center, focusing on the delivery of expert TTA in both areas, was established.



# National Center on Criminal Justice & Disability (NCCJD)

- Created in 2013 with funding from Bureau of Justice Assistance
- Advocates at the intersection of criminal justice reform and the advancement of disability rights
  - Serve as a bridge connecting the criminal justice and disability worlds
  - Build capacity to respond to gaps in existing services



# Why Pathways to Justice?

## Victims/Witnesses

- Not considered credible witnesses
- ✓ Targeted for victimization
- ✓ Difficulties reporting
- ✓ Confuse actions for friendship
- ✓ Lack of inclusive services

## Suspects/Defendants

- ✓ Account for mental state (competency)
- ✓ "Cloak of competence"
- ✓ Eager to please
- $\checkmark$  High risk for false confessions
- ✓ Confused about who is responsible

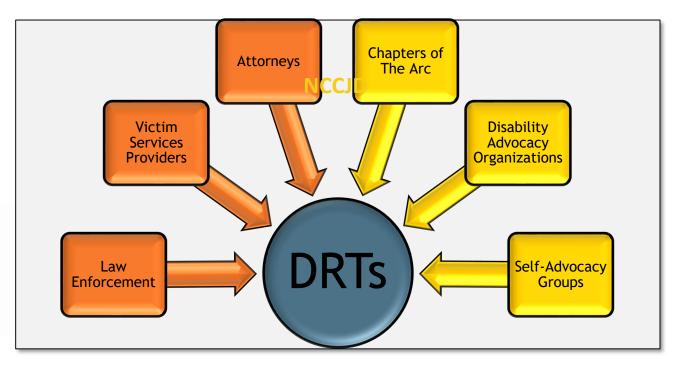
Achieve with us.





## **Disability Response Teams**

## Multidisciplinary Teams of Community Stakeholders









Objectives	Facilitate greater access to mental illnesses (MI) and intellectual developmental disabilities (IDD) training, technical assistance, resources, research, and subject-matter experts to enhance practice
	Equip police and their service partners with tangible tools and knowledge to safely respond to and resolve incidents involving persons with MI/IDD
	Build and support a national community of practice
	Promote a no-wrong-door approach to MI/IDD training and technical assistance



Expose police agencies to a wide range of response models
Streamline access to other BJA- and federally-funded MI/IDD training and resources
Identify gaps and recommend an agenda to inform future police-oriented MI/IDD research



the use of data and technology



# **Serving Safely**

<sup>a</sup>Local law enforcement is most effective when it has the necessary guidance and tools to ensure the safety of all residents, particularly those who come into contact with the system at higher rates," said Ron Serpas, Retired Police Chief and Professor of Practice at Loyola University, New Orleans.

"Smart initiatives like Serving Safely will be an invaluable source to any department committing to building and maintaining trust between law enforcement and the communities they serve."

To Request Technical Assistance:

www.vera.org/projects/serving-safely/training-and-technical-assistance



The Justice and Mental Health Collaboration Program (JMHCP) supports innovative crosssystem collaboration to improve responses and outcomes for individuals with mental illnesses or co-occurring mental health and substance abuse who come into contact with the justice system.

## The JMHCP Program

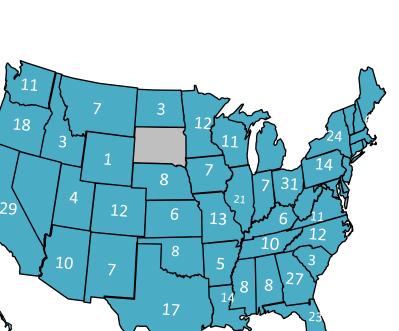
# Grantees in Category 1, 2 and 3

Nearly 122 million dollars in grants to

482 Awardees from across the nation

Representing 49 states and two U.S. territories, American Samoa and Guam

JMHCP also provides resources for unfunded communities with Training and Technical Assistance.







- Category 1: Collaborative County Approaches
  - ID and train stakeholders, SIM mapping, service gap analysis, data collection, process evaluation, validated screening and assessment, connections to treatment.
- Category 2: Law Enforcement Strategies
  - Law enforcement response model, review of policies and procedures, MOUs with behavioral health, baseline data, peer to peer learning.

## Category 3: Implementation and Expansion

 Enhancing Law Enforcement, Courts, Pretrial, Corrections, direct services, wrap around services.



## **The Law Enforcement-Mental Health Learning Sites**

The sites serve as national learning sites to expand knowledge, by providing peer-to-peer learning for law enforcement agencies; and respond to technical assistance requests from the field.

## 1. Arlington (MA) Police Department\*

- 2. Houston (TX) Police Department
- 3. Jackson County (OH) Sheriff's Office\*
- 4. Los Angeles (CA) Police Department
- 5. Madison (WI) Police Department

## 6. Madison County (TN) Sheriff's Office\*

- 7. Portland (ME) Police Department
- 8. Salt Lake City (UT) Police Department

## 9. Tucson (AZ) Police Department\*

10. University of Florida Police

Department





A comprehensive online reference that provides resources for law enforcement agencies to partner with mental health providers to effectively respond to calls for service, improve outcomes for people with mental illnesses, and advance the safety of all.

## www.bja.gov/pmhc



- Draws upon the experience of most advanced PMHCs in the nation
- Articulates the core components of a comprehensive and robust PMHC that can produce improvements in communitywide outcomes
- Shifts the focus away from standalone training or small-scale programs/teams toward agencywide collaborative responses and metrics-driven performance management





# STEPPINGUP

Launched in May 2015

Vision: There will be fewer people with mental illnesses in jails than there are today



## The Stepping Up Initiative



# Almost 461 counties across 43 states have committed to reduce the number of people with mental illnesses in jails.



2

3

5

6

# **The Six Questions Guide**

JANUARY 2017

## Reducing the Number of People with Mental Illnesses in Jail

#### Six Questions County Leaders Need to Ask

Risë Haneberg, Dr. Tony Fabelo, Dr. Fred Osher, and Michael Thompson

#### Introduction

N of long ago the observation that the Los Angeles County Jall serves more people with mental illnesses than any single mental health facility in the United States elicited gaps among elected officials. Today, most county leaders are quick to point out that the large number of poople with mental illnesses in their jails is nothing short of a public health crisis, and doing something about it is a top oriority.

Over the part decade, police, judges, corrections administratore, public definides, prosectores, community-based service providers, and advocates have mobilized to better respond to people with mental illnesses. Most large urban counties, and many smaller counties, have canted specialized police response programs, established programs to divert people with mental illnesses, and method with low-lovel crimes from the justice system, launched specialized courts to meet the unique needs of defendance with mental illnesses, and embedded mental health professionals in the juli to improve the likelihood that people with mental illnesses in concered to community-based services.

Despite these tremendous efforts, the problem persists. By some measures, it is more acute today than it was ten years ago, as counties report a greater number of people with mental illnesses in local jails than ever before.<sup>1</sup> Why?

After revesting a growing body of research about the characteristics of people with mental illnesses who are in contact with local criminal justice systems; analyzing millions of individual arrest, juli, and behavioral health records in a cross-section of counties across the thind States; examining initiatives designed to improve outcomes for this population; and meeting with oundies people who work in local justice and behavioral health systems; as well as poople with mental illnesses and there families, the authors of this heid offer four reasons with efforts to due have not that the impact counties are desperate to see:

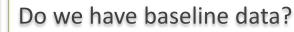
There are insufficient data to identify the target population and to inform efforts to develop a system-wide response. New initiatives are frequently disigned and included after considerable discussion but which stifficture local data. Data that statisfields a basiline in a jurisdiction—such as the number of people with mental illnesses currently booled into juil and their length of stay once incarcerated, their connection to treatment, and their rate of rearrest—inform a plan's design and maximize its impact. Purchermore, eligibility criteria are frequently established for diversion programs without the data that would show how many people actually meet these enteria. As a result, county leader subsequently find themselves disapointed by the impact of their initiative. Countries that recognize the importance of using this data to plan their diversion field the data they need to not exist. Is is rare to find a county that effectively and systematically collects information about the mental health and substance use treatment needs of each person booled into the ling. and records that information are a speared weat a system levil.

Program design and implementation is not evidence based. Research that is emerging on the subject of people with mental illnesses in the justice system demonstrates that it is not just a person's utreated mental illness but also co-occurring substance use disconters and criminopuler risk factors that not robust to bits or her involvement in the justice system. Programs that treat only a person's mental illness and/or substance use disorder but do not address other factors that contribute to the illiallhood of a person refielding are unlikely to have much of an impart. Further, intensive supervision and limited treatment resources are often not targeted to the people who will henefit most from them, and community-based behavioral health care providers are rarely familiar with (or skilled in delivering) the approaches that need to be integrated into their treatment models to reduce the likelihood is sumeone redifieding.



Is our leadership committed?

Do we conduct timely screening and assessments?



Have we conducted a comprehensive process analysis & inventory of services?

Have we prioritized policy, practice, and funding improvements?

Do we track progress?



#### Project Coordinator's Handbook

#### Reducing the Number of People with Mental Illnesses in Jail: Six Questions County Leaders Need to Ask

The Project Coordinator's Handbook

#### Choosing a Stepping Up Project Coordinator

Determining who will serve as the project coordinator is the first step for a juriadiction in the Stepping Up planning process. A criminal justice coordinator can fil this role, if that pusition already exists. If not, the country can contract for these services, or the count planning tarm can designate summore to serve in this role—auch as a stiff member from the julbehavioral health care provider, or community supervision agreey—in addition to that person's regular duties. The person selected shuld have traveledge of the local orientical justice and behavioral health systems, how excellent facilitation and organizational skills, and denorative the addition to that person's process to ensure progress.

This handbook is designed to complement the <u>Buductory</u> the <u>Number of People with Menial Binasses in José-Six</u> <u>Quastions County Loader Need to Adt</u> Gir Queethons) framework as a size-J9-asip facilitation guide for project coordinations. For each of the framework's six quastions, this handbook provides:

- A summary of the question and its related objectives for the planning team;
- · Facilitation tips to assist the project coordinator in managing the planning process; and
- Facilitation exercises designed to achieve objectives and establish an efficient process for capturing the work of the planning learn.

#### The Role of the Project Coordinator

Your role as the project coordinator is critical to the success of your country's Stepping Up efforts. It is the project coordinator who ensures that key leades are engaped, manages meeting agends and minutes, coordinates subcommittee work, provides research and data to guide the decision-making process, and continuously motivates the planning team.

This handbook is designed to help you manage your county's planning process. It will guide and systemative the flow of your work as you develop meeting agendas and decide how best to utilize members of the planning team. Other members of the planning team may benefit from having access to this handbook, especially those who are providing facilitation support, such as leading subcommittee work. You are not required to fill out or submit this handbook to the Shapping Uppartners.

Additional complementary training materials are available through the <u>Stepping Up Toolkit</u>, including webinars, briefs that provide information and guidance for applying the *Six Questions*, and other <u>resources</u>.

### Online County Self-Assessment

The Stepping Up County Self-Assessment is designed to assist counties participating in the Stepping Up initiative or other counties

intertested in evaluating the status of their current efforts to reduce

the prevalence of people with mental illnesses in jails and in

determining their needs for training and technical assistance to

#### **STEPPING**<sup>U</sup>P

#### Welcome

advance their work.

Create Your Account

Sign In	
E-Mail Address	
Password	Forgot Your Password
Login	

#### TAKE ASSESSMENT m @ Resu Outstion 1 Question 4 Here are Your Results See where othe in implementa Total Stips: 60 1. Is our h 3. Do uno a You: 100% Others: 50% 3. Do we have be You: 48% New APR lotal Steps: 22 Total Steps: 4 5. Have we price ized policy, practice, and funding 6. Do we track progress Total Steps: 7 Ental Olana - 0

### Series of Briefs

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### <u>ŠTĘPPING</u><sup>u</sup>P

#### IN FOCUS IMPLEMENTING MEN HEALTH SCREENING AND ASSE

This brief focuses on implementing a mental health screening and assessment process, specifically to identify the number of people booked into jails who have serious mental illnesses (SMI). While implementing this process may also identify people who have less serious mental illnesses and other behavioral health needs who may require treatment while in jail, this brief is focused on identifying the people who have SMI because this population tends to represent the greatest dreaw on scarce behavioral health needs who ave SMI in jails will allow counties to develop or refine a strategic plan that will have the greatest impact on addressing this population's needs.

#### WHY IT'S IMPORTANT

To reduce the number of people who have SMI in jails, counties need to have a clear and accurate understanding of the size of the population that has SMI. Frito to being booled in bajal, some people who have SMI may never have been diagnosed and may be unaware of their mental illness, while others may have been diagnosed with a mental illness and received but discontinued treatment. Screening and assessment are essential to identifying who should be connected or necesses and treatment to address their behavioral health needs, which may also decrease the likelihood that they return to jail. Having this information will make counties better able to determine the treatment resources required to address this population's behavioral health needs. Moreover, having the ability to accurately and consistently identify the number of people who have SMI will help counties to track moreores toward their onals.

#### WHY IT'S CHALLENGING

Implementing a screening and assessment process can be difficult, especially for counties the staff, tools, and procedures in place to systematically conduct these activities. Jails are with many people being released in less than 48 hours, there is little time to complete scree to complete screening and the state of the stat

 This brief does not include detailed information about additional screenings and assessments for suicide, substance which are also beneficial to complete at the time of booking into juit to best match populo with other services they on langeting resources based on behavioral health needs and criminopric risk factors, refer to Adults with Behavio Controlland Spreaking Assessment for Maching Maching Maching and Humaning Recovery



## Going Forward:

- Exploring what has been done: what works, what doesn't work
- What do we know/ don't know?
- Gaps in knowledge
- Gaps in service
- How can we leverage what we have and help each other?



# **Additional Resources:**

- Justice and Mental Health Resources list
- Law Enforcement-Mental Health Resources
- Justice and Mental Health Program Brief
- Serving Safely one-pager
- PMHC/Effective Community Responses P-C
- Pathways to Justice Handout and Information



# **Contact Information:**

# Maria C. Fryer.....Maria.Fryer@usdoj.gov Thank you!

## NATIONAL CENTER FOR MISSING & EXPLOITED CHILDREN

## NCMEC's Response to Children Missing with Autism

IACC Meeting 2019



## National Center for Missing & Exploited Children

- Founded in 1984
- Nonprofit, non-governmental organization
- National resource center for families, law enforcement and other professionals
- Assistance to more than 18,000 law enforcement agencies
- Headquartered in Virginia, with regional offices in California, Florida, New York and Texas

Learn more at missingkids.org





Data reported to NCMEC: January 1, 2007 and December 31, 2016

- 952 children with autism reported missing to NCMEC
- A majority of missing children with autism were male (74%)
- Endangered Runaways made up 61% of intaked cases of children with autism
- The second most common case type was the Lost, Injured or Otherwise Missing (20%).





Recovery time:

- 48% of children with autism reported missing to NCMEC were recovered within one day of going missing
- 74% were recovered within one week

Deceased children:

- 43 missing children with autism were recovered deceased (4% of the total 952).
- 72% of the time, manner of death was described as accidental
- For 65% of deceased missing children with autism, drowning was listed as the official cause of death.

Data reported to NCMEC: January 1, 2007 and December 31, 2016



## Texas City, TX - 2019





NCMEC's Response



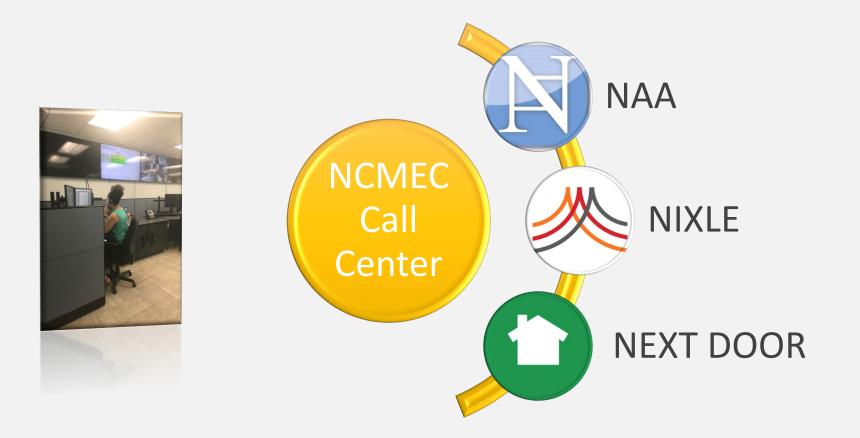
## **Building Awareness**

- Law Enforcement Checklist, Questionnaire, Search Considerations
- Call Center Protocol
- "Train the Trainer"
- Awareness materials and publications
- Focus Group
- Sensory Friendly First Responder Event
- Partnerships and Trainings





## Notifications





## Lafayette, LA - 2018





## Team Adam Consultants

Team Adam will deploy on cases of missing children with special needs

Specialized Team Adam search personnel may also deploy

Quickly provide law enforcement with the following recommendations:

- ➤Investigative measures
  - Sex Offenders/Attempted Abductions
- ➤Search and rescue measures
- Recovery and reunification measures
- ➢Other supporting resources
  - Families: Victim Services Support referrals





## Team Adam & CART Initiative





## Sensory Friendly First Responder Events



#### How to Host a Sensory Friendly First Responder Event for Children with Autism

According to survey data published in the journal Pediatrics, nearly half of families reported their children with autism madered or eloped from side environments. And more than a third of the children who wandered were unable to communicate their name and/ or address. Finding and safely recovering a missing child with autism presents unique and difficult challenges for families, law enforcement, first responders and search teams. This running away or wandering behavior puts these children at risk of accidental drowning. raffic lingvi and other dangers. As police, fire and EMS pessional are deten the risk to respond in these situations, it is important that autistic children are comfortable with the various types of first responders, and not fearful or overwhelmed by their presence.

The goal of hosting a sensory friendly event is to familiarize children with autism to the sights and sounds associated with different types of law enforcement, fire and rescue units. This includes introducing them to police officers, firefighters and EMS personnel, demonstrating how different equipment looks, functions and sounds, and other things they may see in the case of a wandering incident, like special K-9 teams. Making these resources more familiar may help alleviate some of the fears children may associate with rescuers and rescue situations.

- Sind the right partners: If you have a school for children with autism in your community, approach them to see the school share of the school school share of the school school school share of the school sc
- 2. Semble a planning committee- Determine a date, time and agenda for the event. Find out from the school/ community group personnel if they want lights and sirens, or if they wish to keep it more low key for the kids. Arrange to have Child IDs provided that include maps of existing hazards, including water. Distribute NCMEC Autism Wandering Tips to participating students and families.
- Keep it simple-Sometimes less is more, especially with a population that can be overwhelmed with too much stimulation. Make sure the assets are positioned in a way it's easy for kids to access and not too much for the experience.
- 4. Opticize the event-Let local media know, and follow-up, so the event gets good coverage. Make sure the host school/community group has obtained signed permission slips from students' parents or guardians before position any photographs or videos of students.
- 5. Bobilize social media- Letting your followers know what's happening is a great way to spread the word. And remember, a picture is worth a thousand words.
- 6. Observe what works- The kids will let you know their favorite parts. At one event, a custom police microphone might boy in the custom over stimulate children as nother event. Children with autism actively engage all five of their senses in order to process the scene. Ensure that if they reach out to touch something, it's not too hot, sharp, or toxic if they then taste it.
- 7. O Make the event a learning experience for first responders- Remember, they may not have a lot of experience dealing with children with special needs, so it may be new to many of them. Gather the first responders on the day of the event and ask an administrator from the school/community group to share some of the coping behaviors that may be observed while interacting with the kids.
- 8. Get feedback- Once the event is over, talk to parents and teachers to find out how the kids reacted. You'll want to gather as much feedback as possible to make the next event an even bigger success!
- 9. Be ready for different responses from the kids- Having adequate support from teachers and aides help manage the kids and keep the event on track.
- 10. Thank everyone who participated- It takes cooperation and commitment to pull off an event like this. With the right partners, you can have a great and memorable event for the kids.
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#### How to Host a Sensory Friendly First Responder Event for Children with Autism

WHAT SYMBOL-SUPPORTED RESOURCES ARE AVAILABLE TO PREPARE FOR THE EVENT?

Vocabulary Strips, Helper Bingo, Sensory Communication Board, Vocabulary Communication Board, Word Definitions, and the First Responders social marative - Consider providing symbol-supported materials to teachers and event facilitators 30 days before the event for planning, review, completion, and instruction.



#### WHAT SYMBOL-SUPPORTED RESOURCES ARE AVAILABLE TO USE DURING THE EVENT?

Communication and Sensory Boards - Consider providing communication and sensory ymbol-upports throughout the event. Have laminated familiar supports available for attendees to use for reciprocal understanding and learning, Any of the symbol-supported materials teachers and facilitators have used for planning could be helpful, but pecifically the Sensory Scales and communication boards may need to be readily available on the day of the event.



WHAT SYMBOL-SUPPORTED RESOURCES ARE AVAILABLE TO PROCESS AND DISCUSS AFTER THE EVENT?

Participant Survey - Encourage all attendees to complete the 2-page Participant Survey with trusted adults and return to a central location or contact person for compiling. Make a plan to share the results of the survey and your observation of what worked with the original planning team for future events.

Paragraph Completion - This symbol-supported Paragraph Completion activity assists attendees with processing and internalizing the lessons taught that day.

The Class Newspaper Activity - This small or large group discussion activity template is designed to help event attendees learn from each other and have dialogue about their experiences. Consider copying, binding, and classroom publishing a completed work that remains a constant in a classroom library or home reading collection.

The Personal Story Activity - This activity helps event attendees define, articulate, and process their personal thoughts and experiences from the day's events. If laminated and bound as a book, this can be a self-published work by an individual student that is kept, tre-read, and shared with home care providers.

All Symbol-supported Materials - Disseminate any printed materials or digital PDFs to first responders, parent, caregivers, media, and attendees with the goal of communicating effectively to children with autism during a safety event.



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## **OTHER RISKS**



## **Case Illustrations**











- Fifteen percent of reported children with autism were missing from foster care. They were more likely to be Endangered Runaways (79%) and older teens (a mean age of 15)
- A little over half (54%) of children with autism who were missing from group or foster care were recovered within a week after they went missing.

Data reported to NCMEC: January 1, 2007 and December 31, 2016



## Results: "Train the Trainer" State Trooper Participant





Thank you! Questions?

Leemie Kahng-Sofer Missing Children Division 1-877-446-2632 ext. 2161 Lkahng-sofer@ncmec.org





www.missingkids.org

1-800-THE-LOST®

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For more resources please visit MissingKids.org



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