

MOTHER OF NECESSITY

Public safety telecommunicator's autistic children inspire work for emergency response on behalf of people with disabilities.

By Kelly Conley

It's no secret that working as a public safety telecommunicator can be a tough job. For Spokane Regional Emergency Communications (SREC) telecommunicator Raegan Hays, that job can be even tougher as the single parent of two children on the autism spectrum. That's why working to support other parents of children on the spectrum, as well as first responders in Spokane County, is so important to her. Hays has been with SREC for nearly 10 years, and in that time she has turned her passion for her kids into a true benefit for the community — and for her communications center.

In addition to being a parent and a telecommunicator, Hays is also a communications training officer (CTO) for SREC. In that role she educates new employees on how to manage emergency calls for those with intellectual or developmental disabilities such as autism spectrum disorder. Autism disabilities can present very differently from person to person with three levels of recognized impact. Hays' children are no exception. While her older son has Level 2 — or moderate autism — her younger daughter has Level 3 autism and is severely impaired. For her son, this means some intellectual disabilities, but his primary struggle is with communicating and socialization. He knows he has autism and is aware of his differences. Like many on

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Resources from NCMEC for Supporting Children on the Autism Spectrum

This briefing summarizes information from the National Center for Missing & Exploited Children (NCMEC), established in 1984 with a mission to help find missing children, reduce child sexual exploitation and prevent child victimization. NCMEC has free resources and training to support caregivers, first responders and search teams and to mitigate missing incidents for children on the autism spectrum.

Autism Facts:

- In 2018, 1 in 44 children aged 8 were estimated by the CDC to have autism spectrum disorder (ASD).
- In 2021, 286 children on the autism spectrum were reported missing to NCMEC
- Half of children with ASD wander/elope
- Wandering occurs across all settings, by people with ASD of all ages, under every type of adult supervision
- More than one-third of children with ASD cannot communicate their name, address or phone number
- Risks increase with autism severity: drowning, exposure, dehydration, hypothermia, traffic injuries, falls, physical restraint, encounters with strangers, encounters with law enforcement
- Individuals on the autism spectrum may have a co-occurring disability such as epilepsy, ADHD, sleep disorders, depression, anxiety disorders and schizophrenia

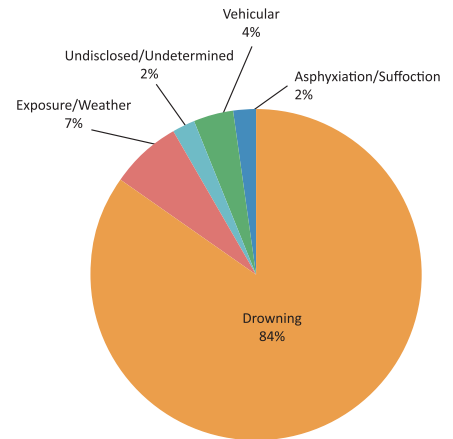
NCMEC DATA (2011-2020)

The National Center for Missing & Exploited Children's 10-year analysis of children on the autism spectrum reported missing to the Center showed that of accidental deaths, 84% were drownings.

A child on the autism spectrum may:

- Have a diminished sense of fear or engage in high-risk behavior, such as seeking water or active roadways
- Seek small or tightly enclosed spaces concealing themselves from search teams
- Be unable to respond to law enforcement because of their communication style
- Be at a higher risk for exploitation because of their disability

Communication and sensory processing may be characterized by:



SOURCE: NCMEC

- Verbal, non-verbal/non-speaking, minimally verbal
- May use alternative modes of communication
- May only cite scripts or use echolalia
- May only understand direct language
- May require additional processing time
- Sensory overload (causes bolting)
- Hypo- or hyper-sensitivity to sound, light, touch

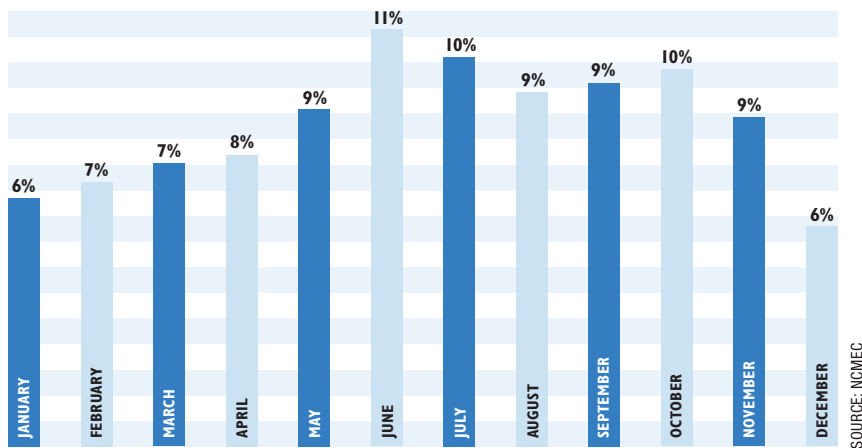
BEHAVIORAL EFFECTS

Self-stimulatory behavior, also known as “stimming” and self-stimulation, is the repetition of physical movements, sounds or repetitive movement of objects common in individuals with developmental disabilities but most prevalent in people with autistic spectrum disorder. Such behavior can result in:

- Obsessive tendencies or interests, or rigidity
- Impulsive actions
- Repetitive behaviors that provide sensory stimulation (stimming)
- Anxiety can increase stimming
- Challenging behavior could be caused by inability to communicate, pain, anxiety, defense mechanism

NCMEC offers a variety of free resources for both first responders and caregivers. These include “Tips for Caregivers” (www.missingkids.org/content/dam/missingkids/pdfs/supporting-children-on-the-autism-spectrum-tips-caregivers.pdf), such as a 9-1-1 script, which provides guidance for families and caregivers on how to effectively communicate with emergency professionals in

MISSING MONTH ACROSS ALL YEARS



SOURCE: NCMEC

MOST COMMON CHARACTERISTICS OF MISSING CHILDREN ON THE AUTISM SPECTRUM

SEX: MALE (75%)	AGE: 16 or 17 (19%)	RACE: WHITE (60%)	CASE TYPE: ERU (67%)	CASE STATUS: RECOVERED (98%)
MISSING MONTH: JUNE (11%)	MISSING LOCATION: HOME (45%)	RECOVERY LOCATION: HOME OR OUTDOOR AREA (2.6%)	RECOVERY METHOD: POLICE INVESTIGATION (46%)	RECOVERED IN THE SAME STATE FROM WHERE THEY WENT MISSING: (87%)

SOURCE: NCMEC

the event of an emergency involving their child. This is a proactive measure to help be prepared in the event a child goes missing. NCMEC also has published “Search Protocols and Checklists for First Responders” (www.missingkids.org/content/dam/missingkids/pdfs/children-on-the-autism-spectrum-search-protocols-questionnaire-first-responders.pdf) and “Understanding Children on the Autism Spectrum: A Guide for First Responders” (www.missingkids.org/content/dam/missingkids/pdfs/understanding-children-on-the-autism-spectrum-guide-first-responders.pdf).

In addition, NCMEC provides virtual and in-person training on how to search for and protect children on the autism spectrum. Because of the high drowning rates documented with this population of children, teaching them to swim and immediately searching water are strong recommendations. 9-1-1 professionals are the first line of defense for ensuring swift and safe recoveries of missing children on the autism spectrum. They can provide first responders with critical information based on a few simple questions that can save lives.

SUGGESTED DATA SOURCES AND ADDITIONAL RESOURCES

Centers for Disease Control and Prevention, Disability and Safety: Information on Wandering (Elopement) (September 18, 2019): <https://www.cdc.gov/ncbddd/disability-and-safety/wandering.html#ref>.

Joseph Guan, Guohua Li, “Injury Mortality in Individuals With Autism,” American Journal of Public Health 107, No. 5 (May 1, 2017): <https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2017.303696>.

Summary of findings available at “Individuals with Autism at Substantially Heightened Risk for Injury Death”: www.publichealth.columbia.edu/public-health-now/news/individuals-autism-substantially-heightened-risk-injury-death.

National Center for Missing & Exploited Children, Missing Children on the Autism Spectrum: A summary of Data Intaked between 2011-2020: www.missingkids.org/content/dam/missingkids/pdfs/ncmec-analysis/missing-children-on-autism-spectrum-2021.pdf.

U.S. Department of Health and Human Services Interagency Autism Coordinating Committee <https://iacc.hhs.gov>.

For additional resources, please visit www.missingkids.org/theissues/autism and connect.missingkids.org.

Source: National Center for Missing and Exploited Children

the spectrum, he also has sensory issues. For him, this presents as sensory avoidant when it comes to loud noise, strong smells, textures or physical touch, which can be uncomfortable for him. Her daughter, on the other hand, is non-verbal/non-speaking and has severe cognitive delays. At 11 years old, she functions at the 3-5-year-old level and is largely unable to express herself. Unlike her brother, she is a sensory seeker. She loves all kinds of textures, strong tasting foods and often needs physical sensory input from hugs, squeezing her arms and legs, foot massages and compression. She also loves roller coasters, swings and spinning.

Hays is keenly aware of the risks inherent to her children, especially in an emergency. When her daughter was three, the babysitter lost her in a public park while Hays was on duty. Anytime a child goes missing, parents are desperate to find them, but with a child that is non-verbal/non-speaking, functioning significantly below age level, and not afraid of cars, animals or people, the situation is even more dire. The babysitter didn’t call 9-1-1 until 40 minutes had passed, but luckily, Hays’ daughter was found by police officers in a vacant lot. She had crawled through a hole in a fence and had cuts all over her body from playing with a prickly bush. She wasn’t even aware she was lost.

This experience and her day-to-day job motivated Hays to do more. She first discovered the Isaac Foundation, which provides services to families of children with autism, about seven years ago. Since then, she has been active with the local organization and now serves as SREC’s Isaac Alert coordinator, funneling parent alert requests into the regional communication system so responders have information that can enhance their response. The Isaac Foundation provides a variety of services, including community outreach, education to families with children on the autism spectrum or with other developmental delays, and training to the first responder community. She also connects with other parents online, volunteers at events and shares her expertise in the public safety communications field. Along with other first responders Hays has been a guest on the “Issac’s Autism in the Wild” podcast. Additionally, she’s consulted with the Isaac Foundation to put together telecommunicator training.

When asked what she wants other parents or caregivers of individuals affected by autism or other developmental disabilities to know, Hays says, “It’s so important to

know there are resources to help you, and that when you're having an emergency, the voice on the other end of the phone understands and is working to get you help." Hays advises parents in Spokane County to complete a form on the Isaac Foundation website (theisaacfoundation.configio.com) so that temporary caution notes can be placed on their address. Notes that can help create positive interactions between first responder and the lost person include whether the subject is afraid of responders, sirens or lights, and whether the subject will respond to their own name. It's also helpful for responders to know if the person will be combative or cooperative, or how they respond to physical contact with strangers (for example they like

or do not like hugs). As someone who's been on the side of first responders and the side of the family during the search for a missing child, Hays feels fortunate that the passions and experience of her personal life can benefit her professional life.

The Isaac Foundation is based and operates in the Spokane County area but does networking and advising across the country. Agencies or counties can contact The Isaac Foundation for advice or support on setting up a similar program in their area.

Information about people on the autism spectrum or with developmental disabilities is critical for telecommunicators and responders. Key information from autismspeaks.org includes:

- Nearly half of those with autism wander or bolt from their environment.
- Nearly 28% of 8 year olds with ASD have self-injurious behaviors.
- Drowning remains a leading cause of death for children with autism and account for approximately 90% of deaths associated with wandering or bolting by those age 14 and younger.
- Comorbidity is often seen in people impacted with autism spectrum disorder including epilepsy, ADHD, sleep disorders, depression, anxiety disorders and schizophrenia. ●

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CDE EXAM #65175

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|--|---|--|
| 1. Many people on the autism spectrum experience sensory issues?
a. True
b. False | 5. What percentage of children with autism spectrum disorder wander?
a. 15%
b. 25%
c. 75%
d. 50% | 8. A child on the autism spectrum may have a diminished sense of fear.
a. True
b. False |
| 2. For those on the autism spectrum, how many recognized levels of impact are there?
a. 2
b. 3
c. 4
d. 5 | 6. More than one-third of children with autism spectrum disorder cannot communicate their name, address or phone number.
a. True
b. False | 9. What foundation did Hays find useful for providing services to families with children on the autism spectrum?
a. Missing Children Foundation
b. Evan's Foundation
c. Spokane Foundation
d. Isaac Foundation |
| 3. Was Hays' daughter aware that she was lost when the police found her in the vacant lot?
a. Yes
b. No | 7. What month has the highest reports of missing children on the autism spectrum?
a. May
b. June
c. September
d. October | 10. What does "stimming" mean?
a. Sensory stimulation
b. Seeking small spaces
c. An anxiety disorder
d. An allergy |
| 4. What is the leading cause of death for children with autism spectrum disorder?
a. Self-injury
b. Seizures
c. Drowning
d. Traffic injuries | | |

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