UNDERSTANDING CHILDREN ON THE AUTISM SPECTRUM:
A Guide for First Responders

Finding and safely recovering a missing child on the autism spectrum can present unique challenges for families, caregivers, first responders, and search teams. Home Safe partner, the National Center for Missing & Exploited Children® (NCMEC), continually works to raise awareness related to children on the autism spectrum because of the rate that they go missing and are recovered deceased due to accidental deaths such as drowning in bodies of water. These recommendations for how law enforcement can best support these children are based on what NCMEC has learned about autism spectrum disorder.

DEFINITION

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, sensory, communication, and behavioral challenges. Some children with ASD may also have co-occurring intellectual disabilities. As a result of a variety of factors, these children may communicate, interact, behave, learn, or respond in ways that are different from children who are not on the autism spectrum. Their learning, thinking, and problem-solving abilities can range from needing a lot of support to needing less support in their daily lives. ASD is an umbrella term used to describe several conditions that were previously diagnosed separately as autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome.

In most instances, the phrase "children on the autism spectrum" is used because it helps responders remember the broad "spectrum" of characteristics and behaviors this population of children might exhibit. No two individuals are ever alike, and children on the autism spectrum are no exception.

CHARACTERISTICS & BEHAVIORS

While the individuality of children on the autism spectrum is important to underscore, there are some key characteristics and behaviors law enforcement should understand regarding searching for and helping to keep these children safe. For example, a child on the autism spectrum may:

- Go missing from their environment at a rate higher than other children
- Be non-speaking/non-verbal or non-responsive when their name is called by searching parties
- Exhibit a diminished sense of fear or engage in high-risk behavior, such as seeking water or active roadways
- Elude or hide from search teams
- Seek small or tightly enclosed spaces
- Be overstimulated by and avoid lights and sounds
- Have meltdowns or exhibit an intense emotional response
- Have vulnerabilities that puts them at a heightened risk for exploitation

The Centers for Disease Control and Prevention describes "wandering" as someone leaving a safe area or a responsible caregiver, and it typically includes situations where the child may be injured or harmed as a result. Other terms used to describe this behavior are elopement, bolting, fleeing, or running. When these events happen, **a child is missing**, and their life or well-being may be in danger. Studies indicate that half of children and youth on the autism spectrum go missing– a rate nearly four times higher than other children – and often seek bodies of water, such as streams, ponds, lakes, rivers, creeks, storm-water retention/detention basins, or swimming pools.[1] While not fully understood, researchers and professionals studying this issue believe children on the autism spectrum may seek the serenity bodies of water can offer to relieve their anxiety.

Research also indicates children on the autism spectrum are 160 times more likely to die from drowning than the general pediatric population.[2] Furthermore, in a 10-year analysis from 2011 to 2020, 1,516 children on the autism spectrum were reported missing to NCMEC. That report showed that 4% of reported missing children with ASD were recovered deceased, and in 70% of those cases, the manner of death was classified as accidental; 84% of which were drownings.[3]

This population of children may not speak or might have difficulty with verbal communication and in some cases may not be able to respond to their name. They may elude searchers, sometimes concealing themselves in small or tight spaces, and may display a diminished sense of fear about dangers in their surroundings. In addition to immediate threats such as water or traffic, they may travel to low-sensory areas such as the woods, abandoned vehicles, or trains, which can pose dangers.

Despite their best efforts, parents and caregivers can quickly lose control of children on the autism spectrum, even inside secure homes. It is important that parents and caregivers not be viewed as careless or reckless because their child on the autism spectrum is missing. It is recommended that law enforcement response focus on de-escalation, support, and recovery.

A WHOLE COMMUNITY APPROACH

NCMEC's recommendation for ensuring safe interactions and swift recoveries of children on the autism spectrum is that of a whole community approach. This includes training for law enforcement officers and public safety telecommunicators, support for caregivers, community partnerships, and leveraging available technology and tools. Core components of outreach and awareness that you can consider as a public safety leader are:

1. Consistently train your officers on search and response protocols for children on the autism spectrum and other populations in your community who may frequently go missing.

2. Engage community stakeholders and leverage existing relationships to build awareness, understanding, support, and trust.

3. Utilize available technological solutions so that responders immediately have key information in the event a child goes missing.

SEARCH PROTOCOLS

Because of the high mortality rate documented by NCMEC and other research entities, it is recommended that law enforcement treat incidents where children on the autism spectrum go missing as **critical** incidents requiring an elevated response. Home Safe has a free downloadable **Search Protocols & Questionnaire for First Responders** that can be referenced, and below are additional considerations for law enforcement.

The higher-than-average missing rate, coupled with attractions to water or other unsafe sites such as trains and highways, can contribute to fatal outcomes. Accordingly, it is recommended that first responders **immediately search bodies of water** – and stay there – even if it is unknown whether the child is attracted to water.

1   Centers for Disease Control and Prevention, "Disability and Safety: Information on Wandering (Elopement)," last modified September 18, 2019, https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html.
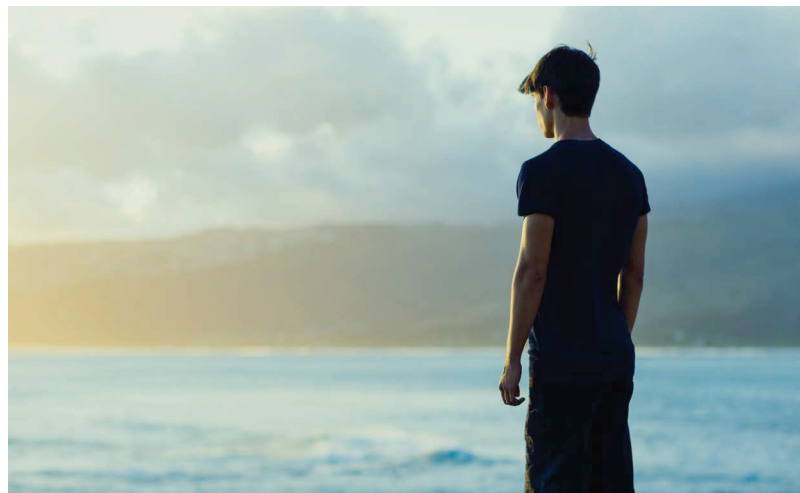
2   Joseph Guan and Guohua Li, "Injury Mortality in Individuals with Autism," American Journal of Public Health 107, no 5 (2017): 791-793, https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2017.303696.

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

Responders should **quickly identify the unique interests** of the child and create a list of their favorite people or places. Talk to the parents, siblings, relatives, caregivers, and others who know the child well to ask for information about interests, fascinations, stimulations, or obsessions when developing search plans and determining where the child may go. This information could be the key to a successful recovery.

NCMEC also recommends that searches should be extended over a period of time if needed as they have assisted in cases where a child on the autism spectrum was recovered alive after several days of being missing and exposed to the elements outdoors.

As with all critically missing children, time is a vitally important factor in a safe recovery. Law enforcement agencies are encouraged to **contact the National Center for Missing & Exploited Children®️ at 1-800-THE-LOST®️ (1-800-843-5678)** for free technical assistance and resources, including search and rescue experts who may be able to immediately deploy to help find the child.

> **For more information on recommended search protocols check out NCMEC's free one hour webinar:** How to Search for and Protect Children on the Autism Spectrum as well as Search Protocols & Questionnaire for First Responders.

BUILDING AWARENESS THROUGH COMMUNITY PARTNERSHIPS

One approach to providing long-term and comprehensive support to children on the autism spectrum and their caregivers is to have robust outreach and awareness programs. NCMEC and nationally recognized law enforcement experts recommend collaborating with existing organizations such as local non-profit organizations, schools, fire and rescue, and government agencies that provide adult and child protective services. This is important because it leverages existing community partners and stakeholders to build community understanding, increase lines of communication, and provide innovative solutions when resources are scarce.

> **For more information on simple ways to build awareness in your community check out NCMEC's free one hour webinar:** How Local Law Enforcement Organizations Can Build an Autism Awareness & Outreach Program.

UTILIZING TECHNOLOGICAL SOLUTIONS

Another proactive measure that law enforcement agencies can take is setting up safe and secure electronic information systems identifying the populations in their community that may have a higher rate of going missing. These voluntary programs allow members of the community to sign up a dependent or loved one with local law enforcement agencies so officers can access data with identifying and descriptive information about the child during critical times. The goals of these registry programs are to promote communication and give field personnel immediate access to relevant information about the enrolled individual, saving time and promoting the safety of the individual during the contact. When making resource decisions, keep in mind that these programs can support not only families with children with intellectual or developmental disabilities such as ASD, but also other populations that may go missing such as individuals with Alzheimer's or dementia.

> **For more information on how safe and secure registries work check out NCMEC's free one hour webinar:** Resources for Family and Caregivers of Children on the Autism Spectrum.

Locative technology is another resource that can be considered. This technology allows for the tracking of the location of the child who is wearing the device. Concerns over lack of service, battery and charging failures, removal of the devices, and not working in water are among some of the issues that caregivers and law enforcement should consider with regard to the use of locative technology. Locative technology should be viewed as one tool in the toolbox for caregivers and law enforcement, and by no means the only one, particularly due to not only the technical vulnerabilities, but also the lack of access that caregivers may have to these devices. Home Safe does not endorse any specific type of locative technology but encourages caregivers to make informed decisions about whether these devices may be helpful for their children. Home Safe has a resource focused on considerations related to locative technology, ***Considering Locative Technology in the Disability Community: Balancing Autonomy and Safety***. *This resource outlines the advantages and disadvantages of using locative technology, highlights considerations for caregivers in balancing an individual's autonomy with their safety, and discusses alternatives that can be used in place of or in addition to locative technology.*

For more information about IACP's resources and support available on this topic visit:
https://www.theiacp.org/projects/home-safe

ADDITIONAL RESOURCES

National Center for Missing & Exploited Children: https://www.missingkids.org/theissues/autism

National Autism Association: https://nationalautismassociation.org/ and https://nationalautismassociation.org/resources/autism-safety-facts/

Autism Society of America: https://autismsociety.org/

National Institute on Deafness and Other Communication Disorders Fact Sheet (Updated April 2020): https://www.nidcd.nih.gov/health/autism-spectrum-disorder-communication-problems-children

Occurrence and Family Impact of Elopement in Children with Autism Spectrum Disorders (November 2012): https://pediatrics.aappublications.org/content/130/5/870

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

The Kevin and Avonte Program: Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities

Through the *Kevin and Avonte Program: Reducing Injury and Death of Missing Individuals with Dementia and Developmental Disabilities*, the International Association of Chiefs of Police (IACP), in partnership with NCMEC, The Arc, and the Bureau of Justice Assistance, Office of Justice Programs at the U.S. Department of Justice, supports local jurisdictions' efforts to reduce the number of deaths and injuries of individuals with forms of dementia such as Alzheimer's disease or developmental disabilities such as autism who, due to their condition, wander from safe environments.

CONTACT US: homesafe@theiacp.org

Visit us:
theiacp.org/projects/home-safe

Visit The Arc s webpage:
thearc.org/our-initiatives/criminal-justice/pathway-justice/

Visit NCMEC's autism webpage:
missingkids.org/theissues/autism