

Chapter 3

Inclusion is a Matter of Life and Death: More Than We Realize

Kelly Bermingham

Social Skills Learning Collaborative, USA

Veronica Glickman

Autism Behavioral and Educational Services, Inc., USA

ABSTRACT

Inclusion is considered a universal human right. It is about giving and ensuring equal access and opportunity and the removal of barriers to inclusion. When it comes to safety, this is an area that many on the autism spectrum have been denied true inclusion. Being able to evacuate in the event of a fire or disaster is inclusion. Not dying in a fire is inclusion. Safety protocols and training is necessary and needed for all families, children, and adults living with autism, as well as other developmental disabilities. Inclusion for safety starts here. Ways to ensure inclusion as it relates to safety, life, and death will be discussed in this chapter through the lens of applied behavior analysis.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social communication and behavioral challenges. Patterns of impairment in social interactions and communication and restricted, repetitive, and stereotyped behaviors may emerge in early childhood, usually between age 2 and 3 years, and last throughout adulthood. Examples of such maladaptive behaviors include self-harm and forms of aggression with various degrees of severity. Prevalence and rates of autism have continued to increase. In 2016, according to the Center for Disease Control and Prevention, CDC, nearly 1 in 44 children has been identified with autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network.

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Individuals with Autism are at an elevated risk for injury or death when they are confronted with emergencies. According to the 2021 National Autism Indicators Report: Family Perspectives on Services and Supports. (Roux et al., 2021) families reported inadequate planning for emergencies. Of those reporting, nearly 4 in 10 families, 40%, reported they did not discuss a plan for handling crises and emergencies at their last person-centered planning meeting. The National Autism Association notes that half of the families that have children or adults with ASD or other Neurodevelopmental disorders report they have never received advice or guidance about elopement from a professional. Many report not discussing it with their in-home Applied Behavior Analysis (ABA) provider. Being prepared for such emergencies and disasters is arguably the ultimate form of inclusion that is not currently met.

According to one study, (Anderson, et al., 2012), 49% of survey respondents reported their child with an ASD had attempted to elope at least once after the age of 4; 26% were missing long enough to cause concern. Of those who went missing, 24% were in danger of drowning and 65% were in danger of traffic injury, a rate nearly four times higher than their unaffected siblings. In 2009, 2010, and 2011, accidental drowning accounted for 91% of total U.S. deaths reported in children with ASD ages 14 and younger after wandering/elopement. This is a concerning number. Most children and adults with autism lack safety awareness or the capacity to follow basic safety rules. While each child diagnosed on the autism spectrum will present a unique, it is important to consider their responses when faced with an emergency such as fire and to ensure preparation and planning is in place.

BACKGROUND

The National Institute on Mental Health (NIMH) describes Autism Spectrum Disorder (ASD) as a “neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave.”. Although autism can be diagnosed at any age, it is described as a “developmental disorder” because symptoms generally appear in the first two years of life.

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder that affects how people socially interact, communicate, learn, and behave. Some people with ASD may engage in repetitive patterns of behavior and have very narrow interests. These behaviors and interests impact their daily functioning and are usually present from early childhood.

Autism presents its own set of vulnerabilities. Safety becomes a big issue for someone with autism because of challenges with sensory issues, communication, and challenges with situational awareness, and recognizing danger. Sensory processing challenges can put children with autism in situations that are not safe, without realizing it. For example, a child who is sensitive to loud noises that others may not notice as loud may run from sounds into a dangerous situation such as a busy street. A child with autism who is nonverbal may not be able to communicate if they are lost or identify themselves to a first responder. A child with autism may have difficulties identifying if someone is a safe adult or a dangerous stranger.

Safety is not a skill that comes naturally to individuals with ASD. Children with disabilities are at a greater risk than neurotypically developing children. They may engage in wandering or elopement behavior due to their lack of safety awareness. They may want to play in the water, but they do not know how to swim. Their lack of swimming skills will not stop them from entering the water, which may lead to drowning.

If you google autism death and fire, you will see pages of stories of children and family members that have had a child with autism perish in home fires. Individuals with autism face unique challenges in a fire emergency. Some individuals with autism may retreat deeper into their burning home to avoid

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