Chapter 3
Inclusion is a Matter of Life and Death: More Than We Realize

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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 the noise of the fire alarm. The chaotic events of a fire may cause a child to run back into the home, seeking a comfortable space. Some may run from firefighters trying to save them or refuse to leave the home because their senses are overloaded. It is notable that currently in certain parts of the country (and the world), fires are becoming an unfortunate seasonal occurrence associated with global warming. It seems we can now expect a certain number of fires with increasing frequency in parts of Southern CA and the Pacific Northwest. Fires also seem to occur with regularity in certain parts of Australia. The increasing concern over fires, combined with the increased rates of children being diagnosed with an autism spectrum diagnosis leads us to urge those providing support to these children and their families to discuss, prepare and practice the steps needed for fire safety and prevention.

APPLIED BEHAVIOR ANALYSIS

Applied Behavior Analysis, ABA, is a science devoted to the understanding and improving of human behavior. Applied behavior analysts focus on objectively defined behaviors of social significance; they intervene to improve the behaviors under study while demonstrating a reliable relationship between the interventions and their interventions and the behavioral improvements. Behavior analysts use the methods of scientific inquiry-objective description, quantification, and controlled experimentation (Cooper, et. al, 2007). ABA is based on many principles, particularly a principle called Operant Behavior. Operant Behavior is defined as any behavior whose future frequency is determined primarily by its history of consequences. Operant behavior is selected, shaped, and maintained by the consequences that have followed it in the past (Cooper, et. al. 2007). From this perspective, a functional consequence is a stimulus change that follows a given behavior. When operant conditioning consists of an increase in response frequency, we say that reinforcement has taken place, or the response was reinforced. Reinforcement is the most important principle of behavior and a key element of most behavior change programs designed by behavior analysts (Flora 2004; Northrup Vollmer & Serrett, 1993).

According to Cooper, et. al, one of the first studies to report the human application of principles of operant behavior was conducted by Fuller (1949). The subject was an 18-year-old boy with profound developmental disabilities who was described in the language of the time as a "vegetative idiot." He lay on his back and was unable to roll over. Fuller filled a syringe with a warm sugar-milk solution and injected a small amount of the fluid into the young man's arm every time he moved his right arm (that arm was chosen because he moved it infrequently). Within four sessions the boy was moving his arm to a vertical position at a rate of three times per minute.

Baer, Wolf, and Risley (1968) recommended that applied behavior analysis should be applied, behavioral, analytic, technological, conceptually systematic, effective, and capable of appropriately generalized outcomes. The term applied refers to the commitment to affecting improvements in behaviors that enhance and improve people's lives; they have meaning and social significance. The term behavior refers specifically to the behavior or response, that needs improvement; the skill to learn. Analytic refers to the study of, and determination of a functional relationship between the manipulated events and the reliable change measured. Technological refers to the behavior change process as being identified and described in a manner that others using the techniques would likely have the same desired outcome; they are conceptually systematic in nature. We say that there is an effective application of behavioral techniques when the behavior is improved. Finally, we plan for behavior change generality if the behavior

change lasts over time, appears in other environments than initially implemented and effects may spread to other behaviors not directly treated by the intervention.

Applied Behavior Analysis and Autism

The history of using ABA as a methodology to teach can best be traced back to a group of faculty and researchers at the University of Washington, including Donald Baer, Sidney W. Bijou, Bill Hopkins, Jay Birnbrauer, Todd Risley, Montrose Wolf, who began using the principles of behavior analysis to instruct developmentally disabled children and were able to manage the behavior of children and adolescents in juvenile detention centers. In 1968, Baer, Bijou, Risley, Birnbrauer, Wolf, and James Sherman joined the Department of Human Development and Family Life at the University of Kansas, where they founded the Journal of Applied Behavior Analysis.

In 1962, Psychologist Ivar Lovaas established the UCLA Young Autism Project while teaching at the University of California, Los Angeles where he began his research and authored training manuals, of himself and his graduate students implementing strategies based on operant conditioning and what was then referred to as behavior modification, to instruct autistic children. He later coined the term "discrete trial training" to describe the procedure, which was used to teach listener responding, eye contact, fine and gross motor imitation, receptive and expressive language, and a variety of other skills. In an error-less discrete trial, the child was to sit at a table across from the therapist who provides an instruction (i.e., "do this", "look at me", "point to", etc.), followed by a prompt, then the child's response, and a stimulus reinforcer. The prompts are later discontinued once the child demonstrates proficiency. During this time, Lovaas and colleagues also employed physical aversive stimuli (punishment), such as electric shocks and slaps, to decrease aggressive and self-injurious behavior, as well as verbal reprimands if the child answered incorrectly or engaged in self-stimulatory behavior.

In 1987, Lovaas published a study that demonstrated that, following forty hours a week of treatment, 9 of the 19 autistic children developed typical spoken language, increased IQs by 30 points on average, and were placed in regular classrooms. A 1993 follow-up study found that 8 maintained their gains and were "indistinguishable from their typically developing peers", scoring in the normal range of social and emotional functioning. His studies were limited because Lovaas did not randomize the participants or treatment groups. This produced a quasi-experiment in which he was able to control the assignment of children to treatment groups. His manipulation of the study in this way may have been responsible for the observed effects. The true efficacy of his method cannot be determined since his studies cannot be repeated for ethical reasons. A 1998 study subsequently recommended that Early Intensive Behavioral Intervention programs, EIBI, be regarded with skepticism. In 1999, the United States Surgeon General said, "Thirty years of research has demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior", and he also endorsed the 1987 study.

ABA as a treatment for autism spectrum disorder continued to gain momentum. In 1998, The BACB, Behavior Analyst Certification Board was established in an effort to meet the credentialing needs of those who were practicing, using the science and techniques of applied behavior analysis. Credentialing became vital to behavior analysis because of the particularly vulnerable populations that a majority of behavior–analytic practitioners serve. This certification requires a master's degree and related coursework in psychology and behavior analysis, and 2,000 hours of supervised fieldwork. In 1998 there were 28

certified. 10 years later, in 2008 there were 4,747 Master's level certified behavior analysts. To date, in the year 2022, there are 56,628 Master's level behavior analysts certified.

Since 1998, hundreds of peer-reviewed studies published over the last 50 years have made ABA the standard of care for the treatment of ASD. All 50 states now have insurance mandates that ensure ABA treatment is a covered insurance benefit for a child or adult on the autism spectrum. At the core of ABA is a comprehensive assessment that describes specific levels of skills a person on the autism spectrum has at baseline that informs the establishment of treatment goals. Behavior analysis, following the approaches originally identified by Baer, Wolf, and Risley (1968) helps teach new skills to these individuals and helps identify any challenging or interfering behavior in the learning process. The assessment is designed to have an emphasis on goals that have social validity and are individualized to the family and the person receiving ABA services. Social validity in these instances means what are the skills needed for the person on the autism spectrum to have a quality of life. What skills do they need to be happy, safe, healthy, and as independent as possible?

Behavior Skills Training

Applied Behavior Analysis can be utilized as a tool for teaching safety skills to all learners on the spectrum. It can be taught by starting with the simplest step such as receptively identifying dangerous situations, then expressively teaching them whether the learner is vocal or has an augmentative communication device. Once this skill is mastered, solutions to these situations can be taught, again in a receptive manner and then expressive. The learner can then learn to match the dangerous situation with the correct solution. In addition, community helpers can be taught how to access them. Generalizing the skills of identifying community helpers in the community and even having them interact with them to promote comfort. A specific type of ABA teaching is Behavior Skills Training or BST. Individuals with developmental disabilities can sometimes tell you what to do in a given situation, but when that situation arises, they do not behave correspondingly. It is often assumed that saying equals knowing which equals doing but Say-Do correspondence is often lacking. When working with individuals with ASD, teaching should be focused on what to do rather than what to say. This can be done through the utilization of Behavioral Skills Training (BST). This teaching methodology can be used for safety skills such as fire, gun, and abduction prevention, communication skills like assertiveness, greetings, shifting conversation topics, and interrupting appropriately. Other areas BST can be utilized are when taught coping skills and play skills.

Behavioral Skills Training is a training technique that incorporates four key ingredients: instructions, modeling, practice, and feedback (Dixon, et al., 2010; Wright and Wolery 2011). Instructions consist of describing the appropriate behavior to the learner and presenting the description at the learner's level (vocal, written, or via pictures). Instructions should be delivered by someone credible, paired with modeling, provided when the learner is paying attention, and repeated by the learner (when possible).

Modeling is the correct behavior demonstrated by the model as the learner observes. Modeling may be conducted in a live manner when a person demonstrates appropriate behavior in appropriate situations while the learner observes, or it can be done symbolically when the behavior is demonstrated in a recording, cartoon, or movie. The model should resemble the learner or be someone that the learner likes and respects. The model should exhibit correct behavior and receive a reinforcer for engaging in the appropriate behavior. The complexity should be matched to the learner's level. The learner should be paying attention and modeling should occur in the popper contacts with all relevant materials.

Practice scenarios should address various environments, including different people, and use different scripts for the learner and the other participant so that generalization may take place. The practice may need to include prompting and/or shaping so that errors do not occur. Parents should be involved in teaching safety skills to individuals with ASD as then generalization can take place quicker (Wright & Wolery, 2011). Research has shown that when the family is involved in the individual's treatment, the effects of that treatment are much greater, but family participation and training have always been very minimal (Crockett et al., 2007).

The final ingredient in BST is feedback. Feedback should be provided immediately. For some learners that may mean after each step and for others it may be at the end of the entire practice. It should always be specific and may include tangibles.

Research indicates that training does increase the safety skills of individuals with who ASD receive training during post-intervention (Harriage et al., 2016). Safety should be the first skill taught to individuals with Autism and their families through the utilization of ABA and external stimuli such as proper locks on doors, QR codes with the individual's information, and more.

FIRE SAFETY

Individuals with autism face unique factors when faced with a fire emergency. In 2006, the Autism Society of Maine (ASM, 2006) reported research that children with autism have died in fires when they retreated to a favorite hiding space; others have died when running and hiding from approaching firefighters. Continue searching and stories emerge of children not responding to fire alarms or pleads from family members to leave.

On September 26th, 2022, Feda Alamalti, a mother of three and tireless advocate for people with autism and their families, who helped shift the healthcare landscape in California by ensuring autism was a covered benefit by insurance in California, died, alongside her son Mu, who was on the autism spectrum. According to the family and fire reports, Mu was overwhelmed by the fire and would not leave his bedroom to go down the stairs and exit the home. Feda who initially escaped, ran back into their home to get Mu, but due to his fear and lack of abilities of what to do in case of a fire, were both found dead in the home, with Feda wrapped around her son Mu.

As a fierce advocate, Feda had secured services for her son. He was gaining skills and making progress. Like many of the families in the 2021 National Autism Indicators Report: Family Perspectives on Services and Supports. (Roux et al., 2021), Feda was one of the families that had inadequate planning for emergencies. The home did not have working fire alarms and did not have a plan or rehearse of what to do in the event of a fire emergency (CBS Interactive, 2020). After her and Mu's death, The September 26th project was created to honor her legacy, and to provide safety and prevention planning and resources for families in three core areas of safety: fire safety, wandering and elopement planning and prevention, and planning in the event of a natural disaster. The website walks the user through key components of prevention.

As seen in table 1, ABA therapists and other service providers can work with local fire departments to ensure that a house is adequately set up. Firemen can come into a home to check the alarm system to ensure that they are working properly, check that there are enough fire alarms in the h, use and can also note in their system where an individual with Autism would be located (i.e., bedroom) if a fire were to erupt so that they can focus their efforts in getting the individual out.

Table 1. Fire safety assessment checklist

Fire Safety Assessment Checklist	Reminder	Completed?	Goal needed for ABA?	Resources
Smoke alarm on every floor	Test or change battery			Red Cross Fire Safety: https://www.redcross.org/get-help/how-to-prepare-for-emergencies/types-of-emergencies/fire/fire-safety-equipment.html Red Cross Fire Plan: https://www.redcross.org/content/dam/redcross/get-help/fire-safety/Home-Fire-Escape-Plan-English-Spanish.pdf Glass House Evacuation Plan: https://bkglasshouse.com/importance-of-a-home-fire-evacuation-plan.html Autism Society Safety Guide: https://www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound/
Carbon monoxide detectors on every floor	Test or change battery			Red Cross Fire Safety: https://www.redcross.org/get-help/how-to-prepare-for-emergencies/types-of-emergencies/fire/fire-safety-equipment.html Autism Society Safety Guide: https://www.autism-society.org/living-with-autism/how-the-autism-society-can-help/safe-and-sound/
Two exits out of the home planned	Child sleeping on ground floor is preferable. Update, plan and practice			Red Cross emergency preparation: https://www.redcross.org/get-help/how-to-prepare-for-emergencies/types-of-emergencies/fire/prevent-home-fire.html
Familiarity with the "close the door" fire prevention initiative	Update, plan and practice			Close the Door Initiative: https://closeyourdoor.org

Additional skills that can be targeted by ABA providers are how to utilize stairs that get hooked up to window ledges and thrown outside so that the individual learns how to utilize them in a fire emergency. Desensitize individuals with ASD to sounds such as the fire alarm going off and smells from a fire.

Behavior skills training can be used to teach and support the child or adult to recognize the fire alarm sound, to leave the home when told, "It's an emergency, go to the meeting spot" and to wait at the meeting spot safely. Through the concept of instruction, modeling, rehearsal, and feedback, the family and the child will have a plan and practice scenarios.

WANDERING, ELOPEMENT & DROWNING

Wandering and elopement are terms used to describe when someone leaves a safe place. According to the National Autism Association, (National Autism Association 2012), drowning is among the leading causes of death for individuals with autism. According to this group, roughly half, or 48% of children with ASD attempt to elope, or leave a safe environment, at a rate considered nearly four times higher than those not affected with ASD. Wandering was ranked among the most stressful ASD behaviors by 58% of parents of elopers and 62% of families of children who elope were prevented from attending/

enjoying activities outside of the home due to fear of wandering. Elopement increases the risk of death for individuals with autism at twice the rate of the general population (Anderson, et al., 2012).

Other potential environmental safety threats and concerns include roads, traffic, parking lots, street crossings, and water bodies. In 2009, 2010 and 2011 accidental drowning accounted for 91% of U. S deaths in children with ASD ages 14 and younger.

Certified behavior analysts need to assess the concerns associated with wandering and elopement, develop treatment goals and strategies for safety and prevention, and support families in creating proactive and reactive intervention plans. If an individual is looking to leave their safe environment, service providers should work on teaching the individual with autism how to ask to leave their environment, accepting "no" as an answer, and teaching replacement skills while proactively working with families on utilizing safety products that can be found later in this chapter.

Using behavior skills training to identify, prevent, and address wandering and elopement is a necessary part of an ABA assessment and treatment plan. Teach children how to remain safe in their homes, or to tolerate a tracking device. Teach children to ask for what they want instead of leaving the home to go to it. Teach children to carry an Augmentative and Alternative Communication device, AAC, out in the community so their voice is not taken away.

As seen in table 2, language programs to teach wants and needs, or breaks and items can be a very effective way to reduce the need for wandering and elopement behaviors

NATURAL DISASTERS

Natural disasters prove challenging for children on the autism spectrum disorder for many of the same reasons a fire does. As previously described, 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. Prevention and planning are particularly important for children and adults with ASD. In the case of a tornado, flood or earthquake, a family may be displaced. Personal items might be lost. An estimated 46–89% of children with autism spectrum disorder (ASD) have feeding problems (Ledford and Gast 2006). This often means some children will only eat very specific food items and only those items including a specific brand. Not having these food items may be very disruptive to a child with ASD.

The co-occurrence of two or more diagnosed conditions in the same person is called comorbidity. An estimated 75% of children and young adults on the spectrum are diagnosed with at least one comorbid condition in their lifetime. Comorbid conditions may include health issues, epilepsy, anxiety, depression, and attentional issues. These conditions often include the need for specific medical treatment and medications. Not having these medications could in some cases be life-threatening. Preparation and planning again become lifesaving for families.

The following table describes areas to address.

CONCERNS, SOLUTIONS AND RECOMMENDATIONS

Families living with a child with ASD, or a Developmental Disability can experience more stress overall stress than families raising neurotypical children. They may feel stressed because they are coming to terms

Table 2. Wandering and elopement assessment

Wandering and Elopement Assessment	Reminder	Completed?	Goal needed for ABA?	Resources
Is your home safely secured?	Should you consider a locating or tracking device?			Autism Speaks Wandering Prevention: https://www.autismspeaks.org/worksheet/safety-wandering-prevention-checklist Autism Speaks Locating Devices: https://www.autismspeaks.org/family-services/resource-library/locating-devices
Do you have an identification device or label?	Disclosure ability can be vital in times of wandering. Id items in pockets can be misinterpreted. Items readily observable are best and teaching your child to show them is key.			There are many ways to consider disclosure. Here are a few ideas: Wearing a medical ID bracelet that discloses your medical information; Have a picture of your medical diagnosis on a phone or tablet; Have diagnostic information sewn into your sleeve; Practice a vocal disclosure
Is there a neighborhood alerting and communication plan?	Neighbors and your community can help watch and look for your child in eloping or wandering incidents.			Alert your neighbors when wandering incidents may occur
Does your child know how to swim?	Identify all bodies of water that could pose a risk			National Autism Association Wandering: https://nationalautismassociation.org/resources/awaare-wandering/ Parents Benefit of Swimming for kids with Autism: https://www.parents.com/health/autism/resources/tips-for-teaching-kids-with-autism-to-swim-and-how-to-find-lessons-near-you/
Do you have a log for wandering attempts?	Watch for patterns to better anticipate or understand the behavior			Children wander for many reasons, most commonly related to wanting to see something they couldn't tell you they wanted to see, to go to a favorite place, or to just go out. Tracking the behavior can give important insights to caregivers.
Does your child have a way to ask for what they want and need?	Explore AAC devices or other methods if nonspeaking or nonverbal			Language programs to teach wants and needs, or breaks and items can be a very effective way to reduce the need for wandering and elopement behaviors

with the diagnosis and what it means. There are financial stressors that come with paying for therapies or co-pays for therapy. The daily challenges of caring for the child are endless and affect all aspects of the child's care as well as the parent's mental health and ability to manage the needs of the child and family. As a result of these stressors, considering safety planning and prevention are often not thought about or discussed with the providers in their life. However, the nature of the responses children with ASD might demonstrate in the event of an emergency such as a house fire as been discussed, creates an even greater sense of need and urgency. Essentially, for those living with a child with ASD and other neurodevelopmental challenges, emergency preparedness is vital to their survival in ways that are more profound than for those that are neurotypical.

Table 3. Emergency and natural disaster preparedness assessment

Emergency and Natural Disaster Preparedness Assessment	Reminder	Completed?	Goal needed for ABA?	Resources
Is your home safely secured?	Should you consider a locating or tracking device?			Autism Speaks Wandering Prevention: https://www.autismspeaks.org/worksheet/safety-wandering-prevention-checklist Autism Speaks Locating Devices: https://www.autismspeaks.org/family-services/resource-library/locating-devices
Do you have an identification device or label?	Disclosure ability can be vital in times of wandering. Id items in pockets can be misinterpreted. Items readily observable are best and teaching your child to show them is key.			There are many ways to consider disclosure. Here are a few ideas: Wearing a medical ID bracelet that discloses your medical information; Have a picture of your medical diagnosis on a phone or tablet; Have diagnostic information sewn into your sleeve; Practice a vocal disclosure

Issues and Problems

- Parents' needs may be different, and parents lack awareness that certain issues they have grown accustomed to are safety issues that must be addressed.
- Insurance companies limiting the ability to teach safety skills (generalizing crossing the street in the community. Some do not allow ABA providers to work in the community with the client. Other insurances will not allow ABA care to be provided in the home
- Resources for the items needed to be prepared or safe may be hard to get.

Many individuals living with autism still live with their parents which decreases their abilities to attain residential independence (Farley et al., 2009). Previous studies have shown that this number is significantly lower for individuals with ASD than those with Down syndrome (Esbenson et al., 2010) and other youth with developmental disabilities, traumatic brain injuries, speech, and language impairments, learning disabilities, and emotional disturbances (Newman et al., 2011). Could there be a correlation between individuals with ASD having a place to live after they complete their K-12 education? Is there little to no motivation to expand on these skills so that they can have residential independence? What do parents and families have to do with this?

In a study conducted by Liptak et al (2011) parents, education, and household income were key components of the individual's ability to have positive outcomes in life. Chiang et al., (2013) also found that parent expectations were correlated with an individual with ASD's ability to gain successful employment, residential stability, and social relationships.

Do parents have unrealistic expectations? Have the providers whether it is through the school, ABA or other community resources providers set unrealistic expectations for the parents of children with ASD? The Expectancy-Value Theory of Achievement Motivation (Eccles and Wigfield, 2002) which focuses on an individual's expectations can be utilized to help families make decisions about their child's future and outcomes. The September 26 Project has checklists to ensure that families and their children with

ASD are prepared for fires, and natural disasters, and wandering prevention can also be a simple start to begin these conversations with families.

Are there discussions that take place about children's futures that should force the conversation of safety and safety behaviors? Though these conversations may be unpleasant at times, parents of individuals with Autism have no idea what to expect, or what their child is capable of and at times settle with the unsafe behaviors their children with ASD engage in. This must change!

Another solution to teaching safety skills is having insurance companies fund ABA services to allow ABA providers to generalize safety skills such as crossing the street within their community and outside of their immediate community. Allowing the providers to teach skills of what to do when the individual is lost and allowing the providers to practice outside of a controlled environment such as the home or a clinic. As an ABA provider, insurance companies create many limitations in teaching critical survival skills and generalizing them across various settings and individuals.

Since Autism is a spectrum, abilities vary from person to person. For a piece of mind, families can purchase appropriate safety products listed below to address behaviors of elopement, fixating with water which may lead to drowning, and possible abduction to address these behaviors proactively until their child can learn these skills.

The September 26th Project is a call to action, with September 26th being the day that all families are to be reminded that they must be prepared and ready. The September 26th Project provides information to gather the resources needed to be prepared and walks families and ABA providers through all the steps needed to be prepared. Additionally, please check our Appendix for more safety resources.

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KEY TERMS AND DEFINITIONS

AAC Device: An augmentative and alternative communication (AAC) device. The term AAC device is often used interchangeably with terms like speech-generating device (SDG) or assistive communication device or simply communication device. AAC devices help users to communicate through a combination of words, sentences, and images that the device then "says out loud." Additionally, users can also communicate by typing or drawing, sharing pictures and videos, or even repeating words they hear out loud.

Applied Behavior Analysis: A science devoted to the understanding and improvement of human behavior.

Autism Spectrum Disorder: A neurodevelopmental disorder that affects how people socially interact, communicate, learn, and behave.

Behavior Skills Training: A training technique that incorporates four key ingredients: instructions, modeling, practice, and feedback.

Discrete Trial Training: A highly structured teaching technique based on the principles of applied behavior analysis. The teaching involves breaking skills down into smaller components and teaching those skills individually. Repeated practice of skills is conducted. Prompting and reinforcement procedures are utilized to facilitate the learning process.

Generalization: Generalization is the ability of a student to perform a skill under different conditions (stimulus generalization), the ability to apply a skill differently (response generalization), and also to continue to exhibit that skill over time (maintenance).

Operant Behavior: Any behavior whose future frequency is determined primarily by its history of consequences.

Person-Centered Planning: Person-centered planning (PCP) is a process for selecting and organizing the services and supports that an older adult or person with a disability may need to live in the community. Most important, it is a process that is directed by the person who receives the support.

Prompting: Prompts are instructions, gestures, demonstrations, touches, or other things that we arrange or do to increase the likelihood that children will make correct responses. In other words, it is a specific form of assistance given by an adult before or as the learner attempts to use a skill.

Self-Injurious Behaviors: Self-injurious behavior (SIB) involves the occurrence of behavior that could result in physical injury to one's own body. Common forms of SIB include, but are not limited to, head-hitting, head-banging, and self-biting.

Self-Stimulating Behaviors: Stereotypy or self-stimulatory behavior refers to repetitive body movements or repetitive movements of objects. These movements are used solely to stimulate one's senses. This behavior is common in many individuals with developmental disabilities; it appears to be most common in children and adults with autism.

September 26th Project: The September 26th project is a website in honor of Feda Almaliti to provide a checklist to assess and prepare safety preparedness for families living with autism.

Stimulus Reinforcer: A stimulus that strengthens or weakens the behavior that produced it. If a stimulus increases the frequency of a behavior it follows, then the stimulus is a reinforcer, by definition.

APPENDIX

Safety Products

Identification products, like wristbands, personalized tags, and ID cards provide a simple way to reach an emergency contact. This emergency contact information can be customized to create your child's unique label. These products can be worn or attached to an item of clothing your child wears daily. This list provides examples of the most common types of safety products. It's not a complete list, and the items here should not be seen as our recommendations. Parents may use this guide as a starting point for determining the products that suit their needs. No safety device should be seen as providing 100% security or as a replacement for adult supervision. Consider some of the professionally-recommended products below, and visit the September 26th Project for more information and resources.

Locks

These devices are intended to prevent your child from exiting your home or entering a room with danger. These locks can also be used when staying in hotels. Locks are useful tools; however, you should be sure to consult with your local fire department regarding the safety of any lock system you are considering. Seat belt locks provide an extra level of safety when driving with your child. Before installation, you should consult with your local responders to learn if using such a lock is advised. For doors and windows these locking devices can be utilized to prevent doors from opening which can be a hazard to your child. All the items listed below can be purchased on amazon.com.

- Kidco Mesh Window Guard
- Prime-Line Products U 9888 Flip Action Steel Door Lock, White Finish
- Cardinal Gates Door Guardian, White
- Complete Deluxe Bi-Fold Door Lock, 2 Pack
- Keyless Child Safety Locks for Patio, Closet, Shower Sliding Doors, Shutters, and More | No Tools Install (4 Pack, White)
- Door Lever Lock

Alarms

These are examples of devices that can be attached to an individual that alerts them of their child's location and can be purchased at amazon.com unless noted.

- Door Alarm
- Window Alarm
- All-in-One Motion Sensor and Alarm
- Wireless Motion Sensor Alarm
- Motion Sensor and Pager
- Wireless Motion Sensor with Push Notifications (Home depot)

Pool

The pool Alarm that is listed below can be purchased on amazon.com.

- In-Ground Pool Alarm

Locators

These devices alert parents to a safe zone breach and provide GPS location ability.

- The PAL is a lockable wristwatch, smartphone, and a sized-Base unit for parents. They alert sounds when the wristwatch is separated from the base unit within 150 ft or less. It also includes a panic button and has text and email alert capabilities. Both PAL and F4K are identical, except that the F4K comes in different colors and its panic button can be disabled. These devices also report addresses in areas with no GPS. This device cost $299.00 for the Device and $29.99 Monthly. Project Lifesaver: Personal Locator System can be purchased on projectlifesaver.org
- Amber Alert GPS: This device is a pager GPS device that can be put in a holder for wrist, belt, or lanyard use. Texts and emails are created when entering or leaving safe zones exceeding 1,100 Ft. It comes equipped with two-way communication. The device also sends alerts on registered sex offenders and speed zones. The breadcrumb feature automatically advises about location and the GPS updates every 5 minutes. There is an app available for monitoring the device. The costs are $125.00 for the device and the activation is $18.00 monthly. This item can be purchased at amberalertgps.com.
- Child “Locator” (Video and Website): These devices do not produce an alarm sound but do provide live GPS location capabilities for quickly locating a wandering child. The watch features a camera equipped for video calling. GPS Kids Tracker can be purchased at pamagoods.com.
- GPS Locator Watch can be purchased at Walmart.com
- Child Locator Teddy Bear can be found on amazon.com
- Apple Air Tag - this item can be attached to any piece of clothing or your child’s backpack which allows the parent to track them via findmyapp.com to find the airbag. Can be purchased at apple.com

Identification device and labels

Wristbands are removable bracelets or bands worn by a child. They can be worn daily or used when traveling or on outings. Some are designed to be removed by an adult, intending that the child cannot remove it themselves. Some are single-use, and others are reusable.

- Alert Me in + Case + of Emergency, removable and reusable and can be purchased on alertmebands.com
- Reusable Child Safety ID Bracelets, waterproof adjustable travel ID wristbands for kids, One Size Fits All, Blue, Pack of 3 can be purchased on amazon.com

- Clear Wrist Identification Band, Briggs Wristbands, removable and reusable, can be purchased on amazon.com
- Temporary Child Safety ID Bracelets, and Tyvek Wristbands, single-use and pre-printed with your details can be also purchased on amazon.com
- Shoe Tags can be secured to your child's laces for daily wear so that if they were to elope if they were to be found, they could use the identifying information to inform the child's family. Both the Shoe ID tags and the SmartKidsID shoe tags can be purchased on amazon.com
- Tattoos/Adhesive ID products can be applied to your child or any item your child will have on their person. Some of these materials are waterproof. SafetyTat Child ID Tattoos (Multi-Design 6pk) can be purchased on amazon.com and the Safety Tattoo with a QR code can be purchased at https://www.ohmytat.com/products/fake-qr-code-temporary-tattoo-sticker.
- ID Cards products are printable photo identification your child can place in a lunch box, backpack, or pant pocket. These ID cards can be purchased on amazon.com. Laser/Ink Jet Child Protection Information, Child Safety Photo ID Kit
- QR Code Clothing Patches can be put on your child's clothing. They are scannable by any mobile device. Once scanned, they provide information for others on how to reach you in case of an emergency. These patches can be purchased on ifineedhelp.org.

Seat Belts

- Seat Belt Buckle Guard can be bought at amazon.com
- Buckle Boss Seat Belt Guard can be purchased at autismproducts.com
- Seat Belt Lock can be found at walmart.com
- A Seat Belt Cover with Medical Information can be bought at safetyawarenessproducts.com