# Life Journey Through Autism: A Guide to Safety





# Life Journey Through Autism: A Guide to Safety

by



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# ORGANIZATION FOR AUTISM RESEARCH Research and resources that help families today!

#### Dear Readers,

You do not need to be a parent of a son or daughter with autism to worry intensely over safety. It is part of parenthood. But as a typical child gets older, many parental concerns over safety lessen somewhat because with typical maturity comes the judgment and intuition to keep safe as well as the strategies to recognize and navigate through unsafe situations. However, an individual with autism may never have this necessary judgment thus leaving to parents and caregivers the task of manipulating the environment to insure the individual with autism is kept safe—physically, emotionally, socially and vocationally.



That task is daunting, but OAR recognizes that. This guide on safety provides detailed information on safety issues

and strategies to consider. It does so from childhood, to adolescence to adulthood. It covers safety issues in the home, the neighborhood, the school, the workplace and on the internet. It provides first-hand accounts from parents, excellent recommendations and a wide array of resources. In my view, this is OAR's most important guide to date.

OAR cannot keep the autism population safe—but it can try. OAR's efforts to do so have culminated in this much needed guide on safety. For OAR recognizes that among the numerous priorities and hopes we have to make the world better for those living with autism, safety is non-negotiable.

Sincerely,

Lori Lapin Jones Lori Lapin Jones PLLC Vice Chairwoman, Board of Directors

# ORGANIZATION FOR AUTISM RESEARCH Research and resources that help families today!

# Dear Readers,

Safety concerns for individuals with autism are on the rise and looming largely in consequence of the ongoing efforts over the last decades to move people with autism out of the shadows of institutional care and other unduly restrictive settings into situations where they are meaningfully included in the community, where they need to confront and navigate the everyday situations of life that most of us take for granted.



The tragic death of non-verbal teen Avonte Oquendo, who was allowed to wander out of his NYC public school setting in the middle of the day only to have his remains found months later in the East River, woke up an entire city to the reality that parents still need to be concerned about their children's safety even after they walk through the schoolhouse door. Obviously, all children are entitled to be safe while at school. However, students who are nonverbal or have limited communication and/or social skills are especially vulnerable, requiring greater protections. Some good has already come out of Avonte Oquendo's tragic end — in July 2014, the New York City Council passed "Avonte's Law," otherwise known as the Audible Alarms Bill. While not perfect, if another student with autism leaves his or her school building, the chances are far greater today that an alarm will sound to save a life. Another bit of good news is that Danny Oquendo, Avonte's brother, was inspired by his brother's death to go to law school and become a special education lawyer. This summer, Danny will be interning in our office, working on behalf of students with autism.

A pending case in the Connecticut courts concerns unspeakable dangers that children with autism and other disabilities sometimes face when entrusted to adults. The Connecticut court case includes allegations of sexual abuse allegedly committed by a public school classroom aide. While this kind of situation would have to be every parent's worst nightmare, fortunately, it is likely to be relatively rare. We must recognize, however, that students with autism and other developmental disabilities will be targeted for victimization *because* of their limited communication skills and the perception that any abuse has less of a chance of being detected.

Bullying finally is being recognized in our court system for the devastating scourge that it is. On this point, the data clearly shows that bullying adversely and disproportionately impacts upon the special needs population. The recent decision of the United States District Court, *T.K. v. New York City Dep't of Educ.*, recognizes bullying as a deprivation of a student's right to a free and appropriate public education. The same court decision provides a virtual "road map" to school districts as to how to respond to parental concerns about bullying.

Medical and dental procedures are yet another venue where misunderstanding and a lack of training can lead to unfortunate safety-related incidents. In a recent case now pending in the Westchester County Supreme Court, the complaint alleges that a child with autism emerging from anesthesia after a dental procedure was "slapped hard across the face" by an attending nurse who apparently was not trained to manage the child's needs as a patient. Medical and dental staff working with individuals with autism need greater training and supervision to enable them to safely provide effective services and treatments.

Finally, the ongoing case of *Commonwealth of VA v. Latson* has become an ignoble emblem of the sometimes cruel and inhuman punishment that can occur when an individual with autism is brought before the criminal justice system. The *Latson* case involves an unfortunate and apparently avoidable confrontation that left a police officer seriously injured and resulted in "Neli" Latson being sent to prison—incarceration that continues to date, most recently in solitary confinement.

The above examples certainly are not pretty and most families would prefer to think of lighter matters during the holiday season. However they loom large for our families as symbols of the reality that opportunities for the inclusion of individuals with autism into the social fabric of our communities necessarily comes with a degree of risk. Few would suggest that we go back to the unduly restrictive "dark days," but as we move forward, proper training, education, awareness, supervision and supports will continue to be needed.

We certainly cannot eliminate all risk, but as a society, we can and should do much better to sensitize and educate our community as to how to protect a vulnerable population without unduly restricting opportunities for people with autism to live meaningfully and inclusively within our social milieu. This is the elusive balance that we must strive to achieve.

Kind Regards,

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# Introduction

No parental instinct is as intense and fundamental as keeping your son or daughter safe. It starts from the moment of birth and continues even after your child has become an adult. You hear yourself saying "be careful" from the moment your child begins to explore the world until well into his adult years. In that context, safety is a parent's concern for life.

Children are vulnerable to various dangers and threats, and related safety concerns come in many forms and circumstances. Some come from nature and the environment. Others come from people, the community, and modern life. Some are foreseeable; at other times, "stuff happens," as the saying goes. When it does in the safety sense, the outcomes range from mild fright or scratches to serious injury or even death. Thus, safety becomes a parent's constant goal and one that is even more challenging and stressful to pursue when a child has autism.

Autism presents its own set of vulnerabilities—whether your child is a toddler, a tween, a teenager, or an adult. In some cases, your child's behaviors and traits may make them more susceptible to everyday safety concerns. In other cases, the characteristics of autism create the vulnerability. Either way, safety becomes a bigger issue for someone with autism because of challenges with:

- *Situational awareness and recognizing danger*. Compared to their peers, individuals with autism are less likely to grasp things intuitively. Thus, they may have problems interpreting which situations are safe and which are not. Compounding this, children with autism may be too trusting. Parents and schools teach this population to listen to authority, but in some cases those in the position of authority (whether it is a stranger or someone they know) take advantage of this.
- *Sensory issues*. Sensory processing challenges can put individuals with autism in situations that are not safe without their knowing. For example, a child who is sensitive to loud noises—in an effort to escape sensory overload—may unintentionally wander away from his family during a fireworks celebration or parade, or run into traffic, or through busy parking lots to "escape" the overload of their senses.
- *Communication*. Some individuals with autism are nonverbal; others' communication abilities develop later than those of their typical peers. As a result, they may be unable to ask for help when they need it, tell people they are lost or where they live, or speak to first responders and others who are trying to help. Finally, there are other individuals who can speak quite well but are not able to communicate their experiences or express their feelings.
- *Fixation with objects or narrow interests*. Some children with autism develop very narrow, focused interests or hobbies, which may pose little or no risk in isolation

or normal circumstances at home or at school. In other instances, they could pose safety risks. For example, a fascination with trains may mean that you need to take extra precautions when standing with your child at a station platform.

• *Generalization*. Due to their direct or literal thinking, individuals with autism often have trouble generalizing information or applying skills learned at home or school to other contexts (e.g., different environments) or novel situations. For instance, your child may understand not to answer the doorbell at home, but may respond differently while at a grandparent's house. Safety skills need to be practiced continuously in real world settings and different environments.

Both safety concerns and autism impact the whole family. Safety concerns cause stress on the entire family, which forces siblings to share the burden of their brother or sister with autism. This caregiver role can follow both the sibling and the caregiver throughout their lives.

*Life Journey Through Autism: A Guide to Safety* is intended for parents and family members who have loved ones with autism. Its purpose is to give you, your family, and the network of individuals and caregivers whom you rely on for support and services the tools, tips, and information needed to identify and address safety threats at home, school, and in the community—ideally before an emergency arises. That said, it also suggests ways to prepare in advance for that unwanted circumstance in a manner that will support more favorable outcomes. More specifically, the goals of this guide are to:

- Educate parents about the safety risks that may affect their child across the lifespan.
- Help parents teach safety habits that will build a foundation for adulthood.
- Provide guidance and resources that parents can incorporate into a family safety plan.
- Describe how to create a safety network.
- Help parents prepare for the unexpected emergency.
- Provide access to additional resources and information related to safety.

# Overview

*Life Journey Through Autism: A Guide to Safety* addresses many questions and issues that parents and individuals with autism face every day. Based on the latest research and drawing from experiences shared by families like yours, it offers practical information, tools, and tips that will help you "think safety," teach and implement safety skills and practices, and establish a safety network within and outside your home. The guide also helps you analyze the most important safety topics relevant to your situation, providing information and tools that can be used to customize safety strategies according to your child's and family's needs.

The guide begins with a description of safety basics. Next, it describes the spectrum of safety threats across the lifespan, and then transitions to a discussion of "thinking

safety" (i.e., reinforcing your natural instincts with autism-specific information and tips). The first chapter concludes by presenting the Safety Planning Cycle, a step-by-step "how to" approach you can use over and over again with the information provided in this guide to assess and address safety concerns as they arise. The ensuing chapters discuss safety in three phases of the lifespan: childhood, adolescence, and adulthood.

The childhood chapter examines safety considerations inside the home from the time a child begins to reach and crawl to later days when curiosity and mobility open the doors—figuratively and sometimes literally—to serious issues like wandering and elopement. Adolescence naturally places greater emphasis on matters outside the home and threats that arise in social settings at school, in the community, and even the cyber world. The adulthood chapter provides a look ahead to some of the challenges related to personal security and safety that adults with autism experience while living and working in the community.

The appendices at the back of the guide provide a combination of more in-depth and practical tools, tips, and resource materials.

# Using the Guide

Think of this as a user's manual for safety. With that in mind:

- *Start with the basics*. Take some extra time reading the "Safety Basics" section. Look at the threat spectrum and match it to the safety issues and concerns you have for your child. Become familiar with the Safety Planning Cycle before you proceed to the applicable lifespan section.
- *Focus on your loved one with autism.* Three sections cover safety topics through childhood, adolescence, and adulthood. Give the lifespan section that matches your child the most attention, but read ahead to prepare for what the future may bring.
- *Follow the life span.* For the most part, the guide addresses topics in the order that you and your son or daughter may encounter them, chronologically and developmentally. Thus, it starts in the home with early childhood, and then moves outside to the yard, neighborhood, schools, and community. Adolescence and adulthood further extend the discussion to the cyber world and workplace.
- *Listen to other parents.* This guide is based on the most recent research on safety and individuals with autism. Nonetheless, life has its own lessons, and no one in the autism community speaks to that more practically and emphatically than parents. Much of what you will read draws on the experiences of parents. In fact, many of them will speak to you through quotes, vignettes, examples, and advice interspersed throughout the guide.

#### Introduction

• *Read the adulthood section.* The first sections of this guide are written expressly for parents based upon where their child falls on the threat spectrum. The adulthood section is more anticipatory in its intent. The idea is that by being aware of some of the challenges adults with autism experience, you and your loved one may better prepare for them in advance.

# Language and Terminology

This guide is written for parents of children with autism. With that in mind, the use of the words *parent* or *parents* throughout the guide refers to parents who have a son or daughter on the autism spectrum.

Autism is also a spectrum disorder, characterized by a continuum of abilities and challenges. Throughout the guide, we will use the word *autism* to represent this disorder and spectrum.

Autism is almost five times more prevalent in boys than girls (CDC, 2014). To reflect this prevalence rate and for simplicity in general, the pronoun *he* will be used throughout the guide, except in specific gender-related instances or examples.

# Icons

Throughout the text, you will find images with text boxes that highlight important facts, point you toward additional information in the appendices, or provide links to online resources. Look for the following icons:

- The light bulb icon denotes an autism fact related to safety.
- The computer icon denotes a reference to an online resource.
- The speech bubble icon denotes a safety tip or quote from a parent or other community member.
- The sun icon denotes a reference to an appendix in the back of this guide.

# References

Throughout the text, you will see citations such as the following: (author, year). The full reference for that citation can be found in the back of the book starting on page <u>61</u>. It may be helpful to use this if you are interested in reading more details from the primary source.

# Appendices

The appendices that begin in the back of the book on <u>page 63</u> offer supplementary information to what is in the guide. Some simply amplify the discussion, while others include templates and tip sheets that you can reproduce and use to ensure your family's safety.

Every family's safety interests and needs are different. What works for one family may not be as important or useful for your family. Use this guide in whatever way

works best for you. You may read about one issue at a time while completing the associated appendix materials, or you may glance at what to expect in the years to come. Learn from and customize the guide's contents so that it may work for you and your family when you need it.

**Disclaimer:** This guide is intended to provide information, suggestions, and recommendations to help parents and others understand safety risks as they apply to individuals with autism. This information is meant to help parents plan accordingly and help them anticipate potentially dangerous or risky situations. Though the information provided here is based on current best practices and other sources from the autism community, it does not come with a guarantee of safety.

# **Safety Basics**

When you have a child with autism, safety can be an elusive target. Nonetheless, there are some steps and considerations that form the basis for any safety plan. By learning the basics and putting them into practice, you can lay the groundwork for an effective plan that responds to your family's current (and future) needs. The following are some fundamental items that should be included in any proactive safety plan, regardless of the severity of your child's autism diagnosis. Most (if not all) of these will apply to your typical children as well.

# 1. Create a safety binder.

Most parents find it helpful to keep their children's important documents in a binder, file cabinet, fire safe, or even in a secure location on a home computer. As a parent of a child with autism, you probably have special folders—copies of every Individualized Education Program (IEP), original diagnosis paperwork, etc. A safety plan that is specific to your family also should be part of this important collection of materials, ideally maintained in a separate and more readily accessible binder or folder.

# 2. Teach swimming and water safety.

Many children with autism have a tendency to wander away from home, and many are drawn to water. This combination often leads to tragic circumstances. Swimming is a basic skill that all children should learn from an early age, but it could be a lifesaver for children with autism. Teaching your child to swim won't just give you peace of mind when you're visiting the neighborhood pool; it decreases the likelihood of accidental drowning if your child wanders off. There are many swim classes (and instructional videos) that are tailored to children with autism and other special needs. If those options aren't available to your family, then talk to your local swim coach about how to teach and motivate your child — with patience, repetition, positive reinforcement, and breaking down the basics into more manageable pieces, etc.

#### 3. Leverage the potential of technology as safety tools.

If you have the financial means, embrace the power of available technologies that can help keep your child with autism safe. This advice applies across the lifespan. If you have a child who tends to wander, then it may mean installing a custom home alarm system. It also may mean having your child wear a tracking bracelet or other similar device. Many communities have programs that provide GPS-enabled devices free or at a reduced charge to families who have an individual who wanders. Consider a smartphone for teenagers who are navigating their communities independently. These can be used for basic threat prevention procedures, such as checking in at agreed-upon time intervals, or for more complicated tasks that arise out of necessity—a quick Internet search to clarify what something unfamiliar means or using the GPS function to get to pre-programmed destinations (home, school, etc.). You can download phone and tablet apps that explicitly teach safety skills to children and adolescents, or even record and store videos where someone models safe behavior.

#### 4. Set clear protocols for fires and other emergencies.

As you are probably aware, children with autism tend to struggle when they're forced to deviate from a routine. Nothing is more abrupt than a fire or other home emergency, and how your child responds can mean the difference between life and death. Remember that forward planning is essential to mitigate the potential consequences of any situation. For families, this not only means discussing where to go (making a list of "safe places") and what to do, but also actually practicing before something happens. The purpose isn't to scare your child with autism, but to make sure you're confident that he or she knows how to stay safe (to the greatest possible extent) if an unexpected disaster strikes.

# 5. Know who is responsible for your child at all times; implement a buddy system.

This may seem intuitive, but it can be easier said than done. While all children (especially younger ones) require a high degree of supervision, it becomes an even more important responsibility when you have a child with autism. The key is not only to remain vigilant, but also to establish guidelines as a family before going out in public spaces. For example, if you are going to an amusement park together, then coordinate who is going to be your child's "buddy" and when. The buddy system concept applies very well to school and other environments as your child becomes older. Whether it's a sibling or trusted neighborhood friend who walks your child to school, or a more formal peer buddy program, the idea is the same. Have someone with an interest in him nearby, and min-

imize the occasions when he is alone and isolated. Always have a backup or contingency plan.

There is a saying that goes "Haste makes waste." It suggests why it is so important for you to think things through deliberately. Another is "Stuff happens!" No matter how solid your family emergency plan and safety network is, unexpected things happen. Both are true. No single plan will cover all contingencies. But whether you're doing threat prevention or high-stress situational management, you can inadvertently compromise the safety of your child by making quick and reactive decisions. You can mitigate this problem and be better prepared through careful planning and vigilance. Always have a backup plan for when things do not go as you envisioned them.

A good strategy is to use the "What if?" drill. As you identify threats that will be especially relevant to your family, think about possible actions you could take, and determine the ideal way to deal with them. For example, if your child does not come home on the bus one day, or does not pick up his phone at the agreed-upon time, then what will you do? If your loved one wanders away from you during a trip to the amusement park, then what strategies or tools will you have to maximize the search? Ask yourself, in those scenarios, how effective would your responses be with and without a plan? Be prepared as best you can for days when the unexpected happens, and know how you can respond to it effectively.

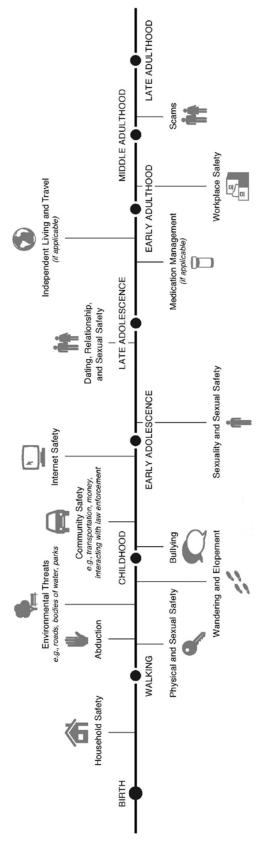
# The Threat Spectrum

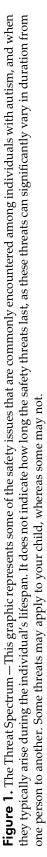
This Threat Spectrum represents some of the safety issues that you may encounter throughout your child's life. Some threats may build over time, some may fade, and others may become more complex. <u>Figure 1</u> on the following page represents when concerns typically arise, not how long they last or when they go away.

# **Thinking Safety**

One of the goals of this guide is to help you "think safety." As you think about how best to ensure the safety of your child with autism, keep these guiding principles in mind; these principles also will lay the foundation for this guide.

- Safety skills are **life skills and life-long skills**. Just like any other skill your child learns, these require time and energy to master. Start early and practice often. Depending on how your child learns best, there are different methods (e.g., visual cues, gestures, modeling, etc.) that build on his unique strengths. In general, individuals with autism are often visually attuned, so visual supports like picture stores can help them "see" situations.
- Teach, practice, test, and repeat. Safety skills must be **learned**, **taught**, **and practiced** as directly as possible. This needs to be done continuously and across multiple settings and people, so that your child can generalize the safety skill he is learning to other situations. Do not worry if a skill is not learned on the





first few tries. It may be possible that the skill needs to be broken down further, or that a different approach would be more effective. It is important to understand that this is a learning *process* for *both* of you. Stay positive and be patient. Your child will need to learn and maintain the skill over time, so be prepared to give refreshers every now and then, even after your child has shown previous mastery of the skill.

- You know your child best and will always be one of his **best advocates**. You will come to know what works best when teaching him new skills. You also will know what areas he will struggle in, what triggers he may have, and which behaviors he will show when he feels unsafe or uncomfortable. Since you and your family know his abilities and strengths best, you can use this knowledge to create the most appropriate and effective safety plans.
- Create a **safety network**. You are not alone, and you do not need to do everything alone. Having a safety network and support system for you and your child is not only helpful, but also necessary in many cases. Home, school, community, faith-based institutions, work, and the neighborhood are all environments that can be part of an ongoing safety network for you and your child. Professionals, neighbors, organizations, and law enforcement personnel are all potential partners who can support your efforts.
- It is **never too late to start** thinking safety. Wherever you are in your parenting journey and wherever your child is in his safety needs, you can start thinking safety right where you are. It's all about practicing skills and customizing approaches so that they best fit your situation.

# The Safety Planning Cycle

Staying safe requires your child to develop an important set of skills and to apply them to a variety of situations throughout his life. To be successful, he is going to need your support and encouragement. In this guide, we strive to provide general information about safety topics that can help families address their unique concerns. Thus, we created the Safety Planning Cycle as a step-by-step approach that can be used over and over again.

Throughout the guide, you will read examples from real families implementing the Safety Planning Cycle. We also provide templates to help you begin applying this approach to your own situations.

The key to the Safety Planning Cycle is that it is fluid. You will need to revisit and revise the safety topics as your child gets older and his risks change; each time, you can re-apply the Safety Planning Cycle with the knowledge and skills you've already developed.

This Safety Planning Cycle is meant to be revisited, re-used, and revised as often as necessary, as safety needs change over time.

#### Introduction

# The Safety Planning Cycle steps are:

# 1. Understand

Understanding is the first step to each safety topic. What about the safety topic is important for your child? What does he need? What makes him safe or unsafe in a particular situation? This step helps you think about, break down, and focus on the factors that impact your child's safety.

# 2. Prepare

What does your child need to practice this safety skill? Which resources, people, or skills does he need to be safe in this situation? What can be done to support him? Preparation is partly about brainstorming needs, and partly about looking for ways to meet those needs. Much of this guide is focused on providing you with ideas and ways to prepare. Actually knowing what you need and what will help can be an overwhelming task. This guide helps break down this process, providing you with resources so that you know where to get more detailed information.

# 3. Practice

Safety skills require practice. Take your ideas from the previous step and break them down into smaller, more concrete practice skills and action items. Pick one or a few skills to practice at a time, and build them into daily life. Safety can be a big topic, so you may want to focus on the most important, most salient topics for your family right now. For example, if wandering is your child's primary issue, then start there. Then, when needs change or skills are developing, you can revisit the guide, complete the Safety Planning Cycle again, revise, or practice more.

# 4. Share

Sharing takes safety from your home and your family out into the world. Safety is not just an issue for you alone; it is an issue for everyone that could potentially be part of solutions that keep your child safe. When you learn or practice things that work for your child, share them with your school (teachers, administrators, school safety officers, etc.), adult service provider or agency, and community safety personnel (police, firefighters, EMS, local safety director, etc.). Don't forget to include the family pediatrician or your child's developmental pediatrician in the discussions when it is appropriate to do so.

Safety also involves letting other people know how they can support your child and you. Maybe that means telling your neighbors that your child has autism and a tendency to wander from home. It might entail meetings at school, daycare, or work to discuss safety skills you have found helpful at home. By sharing information, you are expanding your child's support network and arming others with important knowledge. For a list of questions to guide a conversation on safety with school personnel, see Appendix A: School Safety and Crisis Planning.



# 5. Update

Work together with your child on the Safety Planning Cycle. See what works, what doesn't work, and then revise and update your plan as necessary. Safety needs will always evolve, and your plan will, too. Keep the cycle going, and it will be a useful and fluid tool to help meet your family's safety needs.



The Safety Planning Cycle

# Childhood

In the early years, your child with autism will encounter safety issues both inside and outside of the home. While many of his behaviors will create safety concerns, there are many preventative steps that you can take to make things easier. This guide defines childhood as ages 2 through 12 years of age, which encompasses a wide range of developmental stages. As a result, you can expect some safety concerns to vary over time, while others may remain constant.

# Inside the Home

# **Household Safety**

All parents have household safety concerns, usually starting when their child begins crawling around the house. Baby-proofing the home (e.g., securing cleaning products and installing safety plugs in outlets) is at the top of any parent's priority list. Children with autism tend to fixate on certain items or display sensory-seeking behaviors, which often leaves them unaware of possible dangers around them. As a result, some typical household safety concerns may become more serious based on your child's unique interests. These may include:

- Accessing medications or chemicals (e.g., cleaning supplies)
- Lamps, electrical outlets, and appliances

# A Note on Safety Skills

Individuals with autism typically have trouble generalizing skills across social situations and settings. For example, while your child may learn not to open the front door at home, he may still open the door at a friend's house. Some skills your child learns at home may not transfer well to school or other situations.

As with any skill, learning to keep yourself safe takes time and, most importantly, requires practice in a variety of different situations. The goal is not necessarily to master a particular skill but to be able to incorporate it into everyday life. You should practice these skills at home, in the neighborhood, at school, and in the community at large, so that he may hone his skills over time. However, there is no one-size-fits-all approach with children, regardless of whether or not they have autism.

Some useful strategies include behavioral training, rehearsing in mock and real environments, watching videos, modeling, and breaking skills down into smaller action steps. While this list is not all-encompassing, it does give you some idea on how to begin. Ultimately, it's about figuring out what works best for both the family and the child.

- Sharp household objects (e.g., scissors, knives)
- Starting or knowing what to do in the event of a fire (matches, lighters, stove, grill, backyard fire pit, etc.)
- Climbing on top of furniture to reach something and then falling, or having the furniture item (e.g., book case) fall on them
- Cords that operate window blinds
- Bathtubs, toilets, sinks, pools, and hot tubs
- Pet-related items (e.g., food, medicine)
- Leaving the house without someone knowing (see "Wandering and Elopement" on page 24)

# From a parent:

"Why does Colgate mouthwash look exactly like Windex? I know a kid who tried to gargle like Daddy and couldn't get the mouthwash opened. So she opened the Windex, drank the bright blue liquid, had a seizure, and passed out."

The goal is to keep everyone in your home safe and secure. As such, always remember to consider the potential dangers of household items when they are accessible to a child who may not understand their purpose or danger. Do your best to create a home environment that is not only safe, but also provides ongoing learning opportunities.

# Household Safety: Planning and Prevention

1. Use the home as a classroom.

Think of your home as your child's learning environment. The tools (e.g., picture cards, checklists, etc.) that work best when teaching your child other skills should be helpful. Everything from photos and symbols to social stories can be used to reinforce important skills in the



home (see Appendix B: Social Stories). Some ideas include the following:

- Put pictures or labels on items such as kitchen cabinets, rooms, or appliances. By having pictures or labels to identify items readily, your child can see where things go and more easily associate pictures with instructions (e.g., please do not unplug the television). It can be something as simple as using the Mr. Yuk stickers provided free by poison control centers. By placing symbols, photos, or words on everyday items that are relevant to your child's safety, it will help him learn your expectations and discourage unsafe behaviors.
- Set boundaries and limits. You might place pictures of a stop sign on any door that leads outside, to a stairwell, or on cabinets that are not meant to be opened. You also might use painter's tape to mark boundaries on the floor. These will

provide visual prompts that will reinforce other related skills, like learning not to leave house.

• Keep things organized and in their appropriate places. Knowing where things are and where to put them away creates order and structure, helping kids feel more comfortable, and less frustrated. This hopefully will make them less likely to engage in inappropriate behaviors with particular household items.

The techniques you use to introduce and practice home safety skills are the same as you would use to teach any other skill. Keep steps simple and few in number. Provide positive reinforcement for skills performed correctly and in the right order, and when your child refrains from activities you've explicitly identified as being unsafe. Remember to keep steps simple, short, and few in number (chunking steps into mini-lessons helps with this). Also consider using social stories, activity schedules, visual rules, checklists, signs, or other techniques that have been successful with your child in the past. Practice is key. It also is important to apply the home safety skills your child is practicing in other environments, such as school or family member's homes.

Social stories can be used to help individuals with autism better understand interpersonal communication. In a social story, a concept or situation is broken down, often visually, and demonstrates the appropriate interactions between people and things. Social stories are a teaching strategy that were first introduced by Carol Gray in 1991.

2. Implement necessary security measures.

Home safety also involves home security. This can range from alarm systems to special locks. Some ideas for home security include:

- Install locks or sensors on any doors, windows, and cabinets as needed. Or, have locks moved higher on doors so that they are out of reach.
- Install door and/or window alarms. Of course, any alarm system will need to strike a balance between maintaining safety and being tolerable if your child has sensory issues. Many alarm options can be tailored to meet your family and child's specific needs. See more on alarm systems on page 24 in the "Wandering and Elopement" section.
- Put covers on electrical outlets and protection on any knobs (e.g., doors, oven, faucets).
- Lock the water heater so that the temperature from the water faucet cannot get too hot.
- Hide or bind appliance wires carefully.
- Keep certain rooms or areas (e.g., tool shed, unfinished basement) off limits. You can do this by marking them with a stop sign.

#### Childhood

- Secure any items that may be dangerous. Knives, matches, cleaning chemicals, or anything that could be potentially misused or inappropriately accessed can be placed somewhere locked or out of reach. If your child is a climber, then secure anything that could potentially be used as a ladder.
- Create social stories about smoke detectors, family fire safety routines, or how to behave around fire. Your family should have a fire drill so that your child knows exactly where to go in case of an emergency.
- Install video cameras if your home has multiple floors.



Many of these tips can be developed into a picture or social story. It can be helpful to create a story (such as about home alarms), and review it often with your child. An additional prevention measure is to alert first responders that a person with autism lives in the home and may not respond to their name being called during an emergency.

# Tips for Success: Household Safety

- 1) Having a well-organized home provides a foundation for the structure and predictability that help children with autism manage their behavior.
- 2) Keeping your child with autism safe requires a balance between environmental manipulation, such as installing locks on cabinets or windows, and teaching him critical skills, like how to properly answer the door. Both are very important.
- 3) Labels are your best friends. These not only help create predictability, but also can help you set physical boundaries.
- 4) Your home is not the only classroom. Make sure to help your child learn how to apply the safety skills you've taught them in multiple locations—relatives' homes, school, etc.

In the event of an emergency, your first instinct always should be to call 911 and alert the appropriate authorities. If your child has ingested (or possibly ingested) something he shouldn't have, then call poison control immediately. All emergency numbers, including people who are part of your safety network, should be written in several locations throughout your home and in your vehicles. It also may be helpful to provide your child with a laminated emergency contact card that you teach him to keep with him at all times.

# Using the Safety Planning Cycle: Household Safety Example

Jonathan's interest in seeing how things work had started to become a safety issue for him. It was one thing for him to take apart his toy cars and trucks to see what was inside, and another for him to climb up on the counter and pry apart the toaster while it was plugged in. Putting the toaster in the cabinet worked, yet his increasing interest led him to other appliances. It was hard to place everything out of reach. Beth and Samuel, Jonathan's parents, tried using the Safety Planning Cycle:

• Understand

Jonathan's parents knew that he really enjoyed taking apart appliances to see the mechanical components inside of them. However, the small pieces and threat of electric shock made this hobby an inherently dangerous one. They wanted to promote his curiosity and desire to explore, but do so in a safe and controlled way. They also wanted him to know to leave the household appliances alone; these were off limits to disassemble.

• Prepare

To learn safe boundaries with respect to household appliances, Beth and Samuel believed that Jonathan needed visual prompts to recognize that some appliances were to be left alone. They also wanted him to be sure that he was able to identify appliance names (toaster, blender, speakers, etc.) through verbal directions.

• Practice

Beth and Samuel began by labeling each appliance with its appropriate name and placed big, red "X" stickers on them. This strategy had been useful for Jonathan at school when he had been grabbing crayons and other supplies out of turn. They showed Jonathan a social story, featuring pictures of each appliance (all with red "X" stickers), and of Jonathan simply standing near the appliance without touching it. Every time they found Jonathan standing near a tempting appliance and not touching it, they would reinforce his behavior with verbal praise. Beth also went to the local thrift store and purchased some toys that were specifically for Jonathan. They created a consistent schedule; twice a week, he would have time set aside to inspect and take apart these toys.

• Share

As Beth, Samuel, and Jonathan discovered that these techniques were working to keep their regular appliances in one piece while simultaneously encouraging Jonathan's interests, they shared their idea with Jonathan's aunt because he spent several afternoons a week at her home. She also implemented these techniques with success.

• Update

Over time, Jonathan's interest in appliances began to wane, and he no longer liked to take apart the toys. He became fascinated with real life cars and how

they worked. Gradually, Beth and Samuel removed the labels and stickers from the household appliances, and looked into afterschool opportunities for Jonathan to learn more about cars.

All children, regardless of ability, are naturally curious and like to explore their surroundings, unaware of the danger in which they may find themselves. Protect your child from household dangers by teaching him through various strategies (e.g., social stories, modeling, direct instruction, positive feedback), just as Beth and Samuel did for Jonathan.

# **Physical and Sexual Safety**

You may not associate physical and sexual safety with childhood, but it is an important topic that will span the life of your child; it is covered in both the adolescence and adulthood sections of this guide. Given that children with an intellectual disability are four times more likely to be sexually abused (Sullivan & Knuston, 2000), and children



Children with an intellectual disability are four times more likely to be sexually abused (Sullivan & Knuston, 2000), and children with autism are abused at more than twice the rate of their peers (Petersilia, 2001).

with autism are abused at more than twice the rate of their peers (Petersilia, 2001), it is essential that parents keep this threat in mind. Research also shows that 90 percent of abuse victims who are children know the person who abuses them (Snyder, 2000). This is particularly relevant for autism families, who often have therapists or caregivers working in the home. In addition, children with autism may not perceive victimization or may not be able to communicate to others that they have been abused. This makes planning, practice, and prevention all the more important in keeping your child safe, not only from the immediate threat of abuse, but also from the lingering consequences.

# Physical and Sexual Safety: Planning and Prevention

1. Help your child build knowledge and skills.

Children with autism often do not pick up on "red flags" in situations that may feel threatening or inappropriate. Empower and educate your child with skills and knowledge that can keep him physically and sexually safe. Here are some suggestions:

- Practice communication skills regularly, including how to talk to you or another trusted adult about concerns; be sure your child can identify trusted adults in specific situations (e.g., school or home) upon whom they can rely.
- Help your child learn about his body and body parts, using the correct names.
- Have many discussions and practice times with your child to go over what appropriate and inappropriate behaviors are, what to do, and who to tell; specifically discuss where it's okay to be naked and where it's okay to be clothed.

- Teach your child who is allowed to see his "private parts" (i.e., "anything covered by a bathing suit") and when (e.g., parents and medical professionals in case of injury or health emergencies and health care professionals during medical examinations).
- Talk to your child often about boundaries and saying "no" assertively (with words, behaviors, or actions).
- Role-play situations, create social stories, and use pictures; offer choices and respect their decision if they do not want to do something with which they aren't comfortable. For example, forcing a child to hug or kiss an individual (even if they are family members) sends the message that he needs to reciprocate even when he's not comfortable. Respecting this hesitation can keep him safe in the long run.
- Inform your child's siblings that their interactions with him may result in his inappropriately generalizing to others, and that they should look out for and correct that.

Remember to keep your lessons and discussions fact-based, simple, and short. This will help keep the topic(s) accessible and less scary for your child. It is essential that your child knows that no matter what happens, he always should tell you if he ever feels like someone has done something inappropriate—even if that person threatens to hurt his family. Make sure he knows that abuse of any kind is never his fault and that there is always someone who can help.

2. Know the signs of abuse.

Prevention of physical and sexual abuse also includes knowing the signs.

- Physical indicators of abuse include: unexplained injuries, pain, bruising, or weight loss.
- Behavioral indicators may be more challenging to see, but they are equally telling: changes in sleeping or eating, avoiding certain people or situations, behavioral outbursts, withdrawal, regression, showing inappropriate affection, acting out inappropriate sexual behavior with others/objects, inappropriate touching of self/others, or wanting to be with the suspected abuser frequently.

Routinely ask your child questions about his time spent with various caregivers. It is important to look for signs that a potential abuser might be "grooming" your child. Grooming involves building "trust" with a child, to put the child in a position to be abused. Abusers do not want to get caught, so they often target kids who cannot or will not say "no," or try to create situations where they have alone time with a child. Grooming is really hard to notice, especially for a child with autism, since it is building a false trust (like pretending to be a friend). It may look like showing pictures of a sexual nature, testing touch boundaries (e.g., giving back rubs or tickling), or subtle intimidation.

#### Childhood

3. Be smart about selecting potential caregivers.

When looking for, hiring, or working with potential caregivers, it is always important to find out as much information as possible, and to conduct a thorough background check. Here are some tips to guide you through the hiring process:

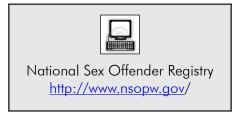
- Provide clear details when you advertise the job description and necessary skills.
- What extra duties do you need the person to do beyond the care required for someone of typical development? What things do you need help with? In what ways will the person need to interact with your child (e.g., assist toileting, tying shoes, etc.)? How many hours per day or week is the job?
- What kind of health-related certifications and skills does the caregiver need? Does the candidate need to know how to swim? Is the candidate certified in first aid//CPR?
- Consider transportation needs: Does the caregiver need their own transportation? Is the caregiver expected to travel or drive with your child?
- Consider having interested individuals contact you by e-mail first. Then, talk on the phone with candidates that remain after your initial screening.
- Develop a questionnaire for hiring that is tailored to the position. A questionnaire may include sections for: contact information, availability, experience, education, duties previously performed, and professional references (at least three).
- Consider individuals who already work in child care and have been screened by facilities or schools; that way, you can contact their current employer or seek guidance from local law enforcement before conducting background checks.
- Trust your gut instinct. It may very well be that someone who does not feel right to hire is simply not right to care for your child.

It is absolutely necessary to conduct a complete background check on all candidates under consideration. Here is some guidance from parents and professionals:



- Ask for at least three references and contact all of them. You will want at least two to be from former employers and related to work done with children in the past (even babysitting) to assess any concerns that the employer may have had with disciplinary style, vigilance/supervision, suspicious behavior, etc.
- Meet with the candidate in person, preferably outside the home in a public location; their attire, mannerisms, and body language can set off warning signals you may not get from an e-mail or phone conversation.

- Ask to see photo identification (ID). If the position requires that the individual provide transportation for your child, then verify their license, insurance, and the overall safety of their car. You might consider doing a motor vehicle records check, which can be done as part of an online background check.
- Write down and save the candidate's name, birth date, address, and phone number. Make sure to have both the individual's current and previous addresses, and run them through the National Sex Offender Registry (<u>http://www.nsopw.gov</u>/).



- If a candidate has any licenses or credentials, then check with their licensing organizations to confirm their authenticity.
- Run a criminal and driving record check; there are a number of state and federal online agencies that you could use. Check with local law enforcement for additional assistance.
- You also may want to verify if the candidate is bonded. "Bonded" means that if the individual steals from you, then you can be compensated (like having insurance). Most often, caregivers from large agencies will be bonded through their agency; it is less common for an individual to be bonded.

Be sure to have your child meet the candidate, but only after you've met or screened them first. Once a caregiver begins working with your child, show up unannounced on occasion and keep an eye out for any suspicious behavior. Ask others whom you trust, who may be in a position to observe your child's caregiver, to feel free to share their observations and, of course, any concerns.

# Tips for Success: Physical and Sexual Safety

- 1) Remember that the vast majority of children who are abused know their abuser in some capacity. To the greatest extent possible, surround him with trusted people at all times.
- 2) Teach your child from an early age about appropriate touching and conversation topics, and instruct him on whom to tell if someone has made him feel uncomfortable.
- 3) Routinely check in with your child about his interactions with adults. Be attuned to signs that he is being "groomed," or targeted for abuse.
- 4) When hiring in-home service providers or other caregivers, exercise all due diligence during the screening process, and always conduct a thorough background check.
- 5) If you see any warning signs (e.g., bruises, unexplained injuries, significant behavioral changes, etc.) or suspect that your child has been abused, then immediately contact your appropriate state/local agency or call the Childhelp National Child Abuse Hotline: 1-800-4-A-CHILD.

#### Childhood

# **Outside the Home**

# **Environmental Threats**

While your neighborhood can (and should) feel like a safe and familiar space, consider the potential threats posed by physical elements outside your home: roads, parking lots, traffic, etc. Bodies of water (e.g., pools, lakes, rivers) often are attractive to children with autism. Play spaces, parks, or other community spaces also may be causes for concern because of the lack of boundaries, potential for wandering, and the increased likelihood of encountering strangers. Crowds in any setting can cause sensory overload and can trigger unsafe behavior—even when your child has learned and practiced what to do in those uncomfortable situations.



# From a parent:

"When my son was 5, he wanted to cross the street to his friend's house by himself. I didn't want him to, but the other 5-year-olds were running all over the neighborhood, crossing back and forth all the time—and he just didn't understand why he couldn't do it like them. I'd been working with him all along about how to cross the street, and looking both ways for cars. Every time we practiced, he did it correctly. So one day, he came in from the yard and asked to cross to his friend's house. I said he could. I watched from the window and he did it perfectly. He ran to the street, looked both ways, and then proceeded to walk right into the path of an oncoming car. The car was going slow and had plenty of time to stop. We were lucky. I ran out of the house and, trying to be calm, asked him why he crossed the street when the car was coming, and all he could say was, 'I looked both ways' over and over. I knew that my child was one who takes things literally, but in my lessons, I forgot to say that after you look both ways for cars, if you see one coming at you, that you're not supposed to cross."

# Environmental Threats: Planning and Prevention

1. Practice street safety: "Stop-Look Both Ways-Walk."

You can practice street, traffic, and parking lot safety every day. Work together on crossing at designated areas, looking for traffic, and listening for loud noises from cars

and trucks. Teach "Stop-Look Both Ways-Walk." Focus on the basics: how to look both ways multiple times before crossing a street, how to respond when there is traffic, understanding what each of the colors on a traffic light mean, etc. In addition to these specific skills, it's also helpful to provide your child with context: why it is important to always pay attention and be careful near



roads and cars. Make sure to teach your child in various contexts, and ensure that he can accurately complete every step. For a sample lesson on how to safely cross the street, see Appendix E: Sample Safety Skills Lessons.

It is important to remove the training wheels gradually, so to speak, and allow your child to learn how to ride his bike by himself. For example, if your child is someone who needs to hold your hand while crossing the street, then you can support his independence by providing him safe learning opportunities to walk alone. At first, you can walk beside him without holding his hand; then, when you feel that he is ready, walk behind him so that he becomes comfortable walking in the lead. Then, you can try to walk further distances away from him while maintaining a close eye on him. Your positive reinforcement and encouragement can help him develop these basic life skills over time.

2. Enroll your child in swimming lessons and teach water safety.

Knowing what to do in and near water can be life-saving for many children with autism. If you haven't already enrolled your child in swimming lessons, then there's no better time than now—regardless of how old he is. Once your child has mastered the techniques, provide



safe, structured opportunities for him to practice. Read more information on swimming lessons and water safety in the "Wandering and Elopement" section on page 24.

3. Emphasize play space, park, and community safety.

Playgrounds, parks, and other community spaces can provide fun opportunities for children to engage with same-age peers. To keep these environments safe, consider implementing some ground rules with your child. For example, stay within the playground boundaries, don't jump off structures (kids with autism can misjudge the distance to the ground), and always have some form of ID, whether it's wearable or in a pocket. Your child might have a play buddy. In that case, it is always a good idea that they stay together. Be familiar with your community play spaces; know their boundaries and proximity to other things (e.g., rivers, ponds, and roads). Your child also may interact with animals in community spaces. While this may not be a concern for some children with autism, it may be helpful for your child to make the distinction between the family pet, others' pets, and "wild" animals, to avoid potential problems. You also may want to keep a record of what noises or triggers might cause your child to forget safety protocols. Most importantly, have a workable system in place to make sure someone (you or another trusted adult) has an eye on your child at all times.

#### Five Tips for Success: Environmental Threats

- 1) Become familiar with the places around and outside your home where your child is spending time. Once you have done that, identify any potential threats whether physical or sensory and address them.
- 2) When you teach your child community skills, try to provide context. For example, help your child understand why it's important to look both ways before crossing the street.
- 3) As mentioned earlier, it is essential for your child to learn how to swim and be safe around water. Enroll your child in lessons as soon as possible; it's never too late to learn.
- 4) Make sure that you or a trusted adult has an eye on your child at all times, especially when in crowded or open spaces.
- 5) As always, engage your safety network (including first responders) in the case of an emergency. Prepare for this in advance by writing down all of the places that your child goes and whom to call if something goes wrong. Make sure this list is part of your family's safety plan and that it is updated regularly.

#### Wandering and Elopement

"Wandering" and "elopement" are terms used to describe when someone leaves a safe place and is unsupervised. Approximately 48 percent of children diagnosed with autism have been reported to elope; of those children, only half of them had received professional guidance on the behavior (National Autism Association, 2012). Given



Approximately 48 percent of children diagnosed with autism have been reported to elope. Elopement increases the risk of death for individuals with autism at twice the rate of the general population (Anderson et al., 2012).

the serious stress and consequences that wandering and elopement can cause for families touched by autism, and given the likelihood of first responder (police, firefighters, EMS, etc.) involvement, there has been considerable publicity and research devoted to this topic. Elopement increases the risk of death for individuals with autism at twice the rate of the general population (Anderson et al., 2012). Although wandering typically peaks around the age of 5, it continues to be a major issue throughout childhood and into adolescence for some people. Because many children with autism are drawn to water, drowning is a major concern in relation to wandering behaviors (Anderson et al., 2012).

Most children who wander do so either from their home, someone else's home, stores, or school. The reasons for wandering vary for each child. Some children with autism are curious and like to explore. Others may wander to avoid something unpleasant, such as loud noises, crowds, discomfort, anxiety, or other sensory triggers. Other children may be goal-directed, trying to reach some particular thing or place that interests them. For example, a child fascinated with birds may wander in an attempt to follow a particularly colorful one.

When children wander, they put themselves at risk not only for getting lost, but also for victimization, drowning, and getting hit by a car. The search for wandering children also becomes challenging if the children have communication and response limitations. It is no surprise, then, that the risk is greatest for those who exhibit more severe symptoms (Anderson et al., 2012).

The threat of wandering and elopement strikes legitimate fear among parents; it can impact their level of anxiety, sleep, and ability to enjoy everyday activities. Many families avoid going out to public places due to concerns that their child will wander off, further isolating themselves from building and maintaining a strong social support system. While this is not a recommended course of action, there are a number of practical ways to address (and minimize the overall risk of) wandering behaviors, prevent them altogether, and give you peace of mind.

#### Wandering and Elopement: Planning and Prevention

1. Understand why your child may be wandering.

As mentioned previously, children have different reasons for wandering: to escape, out of curiosity, or directed at a goal. If the reasons are unclear right now, then you might consider keeping a "wandering log" or writing down all the details from any wandering incidents that occur. What series of



events preceded the elopement? Who was there? Were there any stimuli or triggers present? Where was your child trying to go? Once you understand the possible reason(s) why your child wanders, you then can begin to develop strategies to address the behavior. For example, if your child's goal is to escape something unpleasant, then you can teach him an alternative, improved way to cope with the unpleasant experience (e.g., plugging his ears, telling a trusted adult, etc.).

2. Practice swimming and water safety skills.

Swimming is an essential skill that can help prevent water-related injuries or death by drowning. Start swimming lessons as early as possible and continue them as needed, even when your child gets older. Many communities have programs specific to individuals with special needs, and some communities have adapted aquatics programs.

3. Implement behavior modification plans.

Work with the professionals, therapists, and teachers in your network to support and create behavior modification plans related to wandering that apply to different environments. Having a plan can help reduce panic and provide rational steps to solve problems if and when they occur. 4. Practice communicating contact information.

There are many ways your child can practice (with therapists, you, or other trusted caregivers) communicating his or her name and contact information. Have him memorize a parent's primary phone number so that he can provide contact information to police. Among the first questions police ask are "Where do you live?" and "What is your phone number?" Your child should know the answers. It also can help to have him practice giving contact information with other people (e.g., your friends, acquaintances) to test his accuracy.

- For some nonverbal children, communicating information as basic as where they live or how to reach their parent is simply not realistic. If your child struggles to do so, an alternative might be for him to have an ID card that he can show to law enforcement officials when necessary. Make sure that he practices using the above method(s) often, whether that involves showing or reciting contact information.
- In addition to verbally reciting or giving an ID card containing contact information, there are many alternative ID options for nonverbal children, such as medical ID bracelets or necklaces, clothing labels, temporary tattoos, or shoe tags. Some families really like the



temporary safety tattoos, especially if their child won't wear jewelry or carry a phone. Your child may be someone who is sensitive to irritating items on his body, so you may need to employ creative solutions that meet your child's very specific needs and preferences.

5. Explore tracking options.



There are many different methods that can be used to keep tabs on a child with autism; among them are GPS locators or other personal tracking devices. Do your homework and conduct a Web search for reviews of any GPS products listed. Some talk a big game and do not work. None is 100-percent effective. While the "Tracking Devices" section of Appendix O: Other

Safety Resources has more on tracking options that are currently on the market, some specific things to think about are:

- Will your child wear it? Like ID bracelets, a tracking device may be removed easily if your child finds it irritating.
- Different families have different tracking needs. Consider if a tracking device is removable, waterproof, connects directly to law enforcement, has a long battery

life, or connects via cell service. Also consider the type of technology used in the tracking device, like GPS versus radio frequency devices.

Options for tracking are expanding, and more funding may be available to families to help with some of the associated costs. It never hurts to ask your local law enforcement agency if they are participating in any state or federal programs that help families who have children with special needs access these devices.

6. Alarm and secure your home; inquire about alarms in your child's school.

An alarm or home security system may be something to consider if your child routinely wanders away from your home. Different types are available depending upon your specific needs and budget. Consult with a professional about the most up-to-date options and information. You can find different types of locks for doors and windows to make sure your child doesn't have an easy escape route.

7. Teach your child to stay with you when in public.

This is a program within itself. Teaching a child to discriminate between walking versus running, holding hands or walking within 6–12 inches of an adult, and compliance with the words "go, walk, stop, wait" are important for maintaining your child's safety. Use positive reinforcement, visuals, and practice when teaching these skills. While this will not help in all situations, it certainly can help when walking through a store, parking lot, etc.

### From a parent:

"We alarmed the front and back doors of our house so that the doorbell would ring every time the door was opened. It was annoying at first, but we got used to it, and every time someone came in or out, they got used to announcing themselves so that we wouldn't start 'search' procedures."

8. Get to know law enforcement.

Getting to know local law enforcement and public safety personnel in your area not only will help them become more aware of your child's wandering behavior, but also can help your child feel more comfortable around these important individuals. Seek out non-emergency opportunities to introduce your child and family to police officers and firefighters. If your child is comfortable approaching and interacting with law enforcement personnel, then it can greatly aid any search and rescue operations if the need ever arises in the future.

It also may be helpful to notify or register information about your child with law enforcement and first responders in advance of any emergency. Let them know that your child has special needs and should be addressed appropriately. You also may want

to collaborate with first responders in the local area to set up an "in-service" training module that addresses both the issues you face, and what challenges law enforcement will face when responding to a missing child call involving a child with autism.

Many communities offer the option through their 911 call centers to have special needs information already on file in the case of an emergency. You can call your local 911 call center to see if you are able to add information about your child, his needs, and his wandering behaviors prior to any incident. This way, the information is already in the system should



a wandering incident necessitate a search. Appendix G: Autism Emergency Contact Form provides helpful guidance in what information to provide.

9. Know what your child responds to (and doesn't respond to).

Knowing specific information about your child is vitally important when there is an emergency—not just for you, but for others (like law enforcement personnel) who may be involved in a search. For example, loud sounds or calling over a megaphone may scare your child, but playing a favorite song on a radio may help your child feel comfortable enough to come out of a hiding spot. Give law enforcement officials this information, no matter how trivial it may seem.

10. Practice with your child what to do if he gets lost.

Develop easy-to-remember (for you and your child) strategies for what your child can do if he becomes lost. It can be as simple as "stay where you are," or something more specific to your child or family. Regardless of the strategy, it's important to practice it over and over again. Also, if a child has a smartphone, you can use free apps like "Find My Friends" to locate your child if he has his cell phone with him.

11. Have your emergency plan located in key places.

Your Family Wandering Emergency Plan (see Appendix H) should include emergency contact information and action steps. Make sure to tell first responders how they should interact with your child (e.g., not to use loud speakers). Print out a Google map of the area complete with your 911 emergency call script. Annotate and highlight any dangerous areas (e.g., bodies of water), and points of possible interest for your child. Have multiple copies to help facilitate immediate use by first responders. Store the map and emergency plan where it can be readily located. Have copies in

several areas (e.g., house, car, work, school, etc.) and share them with key persons in your safety network. Collaborate with your child's school to ensure that they also have a crisis plan (e.g., using walkie-talkies, calling 911 right away, etc.) in place and know what to do when an emergency arises.



#### 12. Establish a safety network.

Before you begin searching for your wandering child, be sure to call 911 immediately. Do not try to search for him on your own. The more people you have who can look out for your child, the better off he will be. Once you have informed the authorities, you can look to your safety network for additional help. Make your neighbors aware of your child's needs, interests, potential challenges, and what they can do to help. You may choose to educate a neighbor about your child's wandering behaviors and share contact information before an emergency occurs. Also, help your child's school

know about the search strategies you use when he wanders, and work together with teachers and specialists to develop targeted plans that address wandering behaviors. Other individuals who work with your child, such as a therapist, also should be able to help him practice safety skills.



#### From a parent:

"We fenced in our yard and sent a letter to everyone who lives on our street, letting them know that our 4-year-old son is nonverbal and has autism. We included a picture of him as well, and asked neighbors to please gently guide our son back to our home in case he ever gets out again. Every year, we send another short note with an updated photo to our neighbors, as well as the local police department. We want them to know that he has autism, is nonverbal, and may not respond to his name."

#### Five Tips for Success: Wandering and Elopement

- 1) If your child gets lost or wanders away, then call 911. Contact law enforcement *immediately*, and implement your safety plan to augment their efforts. Do not begin a search on your own! Assign specific roles to every individual during the search. Make laminated cards with important emergency information (e.g., his diagnosis, family doctor, emergency numbers, etc.) and make them readily accessible at home, work, in cars, and at any caregiver's location.
- 2) Teach your child essential skills that can help him avoid further danger. Practice what to do in case he gets lost, and make sure he is able (in some way) to communicate his contact information.
- Do everything you can to make your home a secure environment, and keep a watchful eye on your child. Install locks and alarms, and consider purchasing a tracking device.
- 4) Make sure that people outside the family (e.g., neighbors, school staff, and first responders) know about your child's wandering tendencies *before something*

*happens,* and how to reach you if they see him in a location where he shouldn't be. This safety network is your first line of defense.

5) If your child tends to wander, then try to understand why. Keep a wandering log that recounts each incident in detail—what happened before, during, and after. While collecting data in a log, all steps should be taken to reduce your child's wandering behaviors and opportunities. Share these notes and plans with your child's care team to discuss a functional behavior analysis/behavior modification plan.

#### Using the Safety Planning Cycle: Wandering and Elopement Example

Miguel loves fire trucks, and the local fire station is just a few blocks away from his house. Ever since Miguel learned how to open the front door, he often left to see the trucks that were "sleeping" in the fire station nearby. His parents, Juan and Anna, tried different door locks, but he eventually figured them out and got outside again, walking in the direction of the fire station. Miguel's wandering tendencies had gotten so severe that Juan and Anna would often discover, in the middle of the night, that he was trying to leave the house.

• Understand

Juan and Anna knew Miguel was wandering away because of his curiosity and interest in the fire trucks. They also wanted to understand if there were particular times when Miguel would wander. They kept a wandering log for a week and noticed that often Miguel became more inclined to wander after hearing a siren outside.

• Prepare

Juan and Anna had several issues they wanted to address. First, they wanted to find an effective way to ensure Miguel did not leave the house without them knowing. They also wanted Miguel to learn that upon hearing a siren, he should not leave to find the fire trucks. Juan and Anna decided to post stop signs at each household door, and install a simple house alarm that would alert them to any outside door or window being opened. They also worked with Miguel's therapist to develop a social story about Miguel and appropriate behavior when he hears a siren.

• Practice

Juan, Anna, and Miguel's therapist began going through the social story with Miguel daily, talking about what to do when he hears a siren. They also practiced each time they heard a siren; when he stopped at the door, he would receive positive reinforcement. When he would forget and try to leave the house, they would redirect him and go through the social story again. Juan and Anna also established one scheduled trip a week to walk to the fire station with Miguel. He knew that Wednesdays were fire station days, and that he could play with his toy fire truck on the days in between.

• Share

Juan and Anna wanted their neighbors to be part of Miguel's safety network. Informally, they visited neighbors and let them know about Miguel's interest and propensity to wander toward the fire station and fire trucks when they were nearby. Juan also gave the fire fighters at the station a copy of their Autism Emergency Contact Form (<u>Appendix G</u>), and recorded Miguel's information with the local 911 call center in case of an emergency.

• Update

Over time, the simple house alarm needed to be updated to have a much louder sound – one that Miguel did not like and would deter him from trying the front door. In addition, Miguel practiced reciting his name and contact information, in the event that he did wander and/or get lost.

## Abduction



#### From a parent:

"We perpetually worry about our son's vulnerability to individuals with bad intentions. We realize that because of his autism, he's not able to discern good from bad or safe from harmful. This makes him an easy target for predators and others who seek to take advantage of him. Consequently, we never leave him alone and try our best to screen all who accompany him in public settings, including all activities of daily living, such as transit and toileting. Due to his compliant nature and the ease with which he trusts others, we remain steadfast in our vigilance and, unfortunately, constant in our fear."

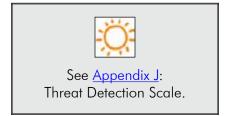
Abduction is a terrifying thought for any parent. Because children with autism tend to be naïve, lack an intuitive sense of danger, and have difficulty communicating, their risk for this threat is elevated, from strangers and familiar individuals alike. While it is less common for a child to be abducted by a stranger than it is for a child to be abused by someone they know, abduction is still a real threat. This is particularly true if your child struggles to grasp the concept of strangers, or engages in inappropriate behaviors with them (e.g., talking, following, etc.).

#### Abduction: Planning and Prevention

1. Provide relationship and social skills education.

Preventing stranger danger starts with helping your child, to the greatest extent possible, understand the social rules of relationships. Teach the difference between various types of relationships—family, friends, helpers, acquaintances, and strangers. This will help your child to distinguish among behaviors that he can associate or expect to see with different types of relationships of people (see Appendix J: Threat Detection

Scale). Then, start with the basics of engaging with strangers: what is appropriate (e.g., returning a greeting to be polite), what is inappropriate (e.g., touching beyond a handshake), and specific rules that apply with them. Then, help your child learn how to communicate any specific behaviors that don't sit right to adults he trusts.



2. Practice correct behaviors in community settings.

One useful strategy is to establish three or so "safe rides." This will help your child distinguish that grandma can pick him up from school, but not a neighbor. In addition, set up real-life "probes" (i.e., simulations) that the child would not perceive as practice to see how he responds. For example, ask someone your child does not know to approach him at the park (after you have been practicing with him on how not to engage with, or walk off with a stranger). See how your child responds to this simulation, and then offer praise and feedback as appropriate. This also will give you information on what skills your child is learning (and generalizing) with relation to strangers. Provide instructions, model proper behavior, rehearse, and give feedback; this combination has proven to be effective in teaching stranger danger skills (Gunby, Carr, & Leblanc, 2010).

#### 3. Properly identify law enforcement.

You can help your child with autism practice being able to identify law enforcement officials. Pick out visible characteristics, like uniforms, badges, or the vehicles they drive. Your child also should understand that he can approach these individuals even though they might be strangers. Many families find it helpful to plan opportunities to get to know law enforcement officials in their area (during non-emergencies) to help children feel comfortable.

#### 4. Create a child ID kit.

Using a template from the National Center for Missing and Exploited Children, parents can document important information to share



Template IDs are available at <u>http://www.missingkids.com/ChildID</u>.

with law enforcement. This includes but is not limited to: an up-to-date color photograph, identifying information, medical records, fingerprints, etc.

#### Five Tips for Success: Abduction

- 1) Remember that your child with autism may not intuitively understand the difference between someone who can be trusted and someone with bad intentions.
- 2) Teach your child about appropriate (and inappropriate) interactions with strangers. The more capably he can navigate these situations, the less vulnerable he will appear to potential predators.
- 3) With the help of your safety network, set up regular "probes" to determine if your child is able to follow safety rules and put skills into practice.
- 4) Help your child get to know and trust law enforcement. Make sure your local police and fire stations have accurate information about your child so that they can deliver a quick response in cases of an emergency.
- 5) If you suspect that your child is lost or has been abducted, then contact law enforcement immediately and implement your safety plan to augment their

efforts. Assign different roles in the search process to each individual in your safety network.

## Conclusion

As your child gets older and nears adolescence, social and relationship safety take center stage. The skills that your child has built during childhood will lay a solid foundation for the new priorities that arise during adolescence: social relationships with peers and, depending on your child's development, even dating. Their cognitive differences (e.g., challenges with abstract thinking) when compared to typical peers, however, may create or amplify safety concerns.

# Adolescence

By the time your child reaches adolescence, you and your family will have identified and addressed safety issues in the home and, to the greatest extent possible, have them under control. At the same time, new issues particular to adolescence emerge; they tend to be related to experiences outside the home—at school, in the local community, and beyond, thanks to the Internet and social media. In addition to the onset of puberty and its associated changes, the teenage experience (increased importance of social life and interpersonal relationships, the desire for independence and privacy, more adult responsibilities, etc.) comes with a unique set of challenges and concerns. As a parent, your most important role at this time is to support your adolescent, be particularly attuned to his school environment, and continue to help him develop and practice safety awareness (and other life skills) that he will take into adulthood.



From a special education coordinator:

"I know a high school student who was able to complete many highlevel academic tasks but did not know how to pick out her own clothes, do her own hair, or lock a public restroom door alone, as her parents always completed these tasks for her. I asked myself: What will she do when her parents are no longer able to do these things?"

Adolescence is a life phase that transitions between childhood and adulthood. During this phase in your adolescent's life, you will continue to protect him as much as he needs. Your adolescent can grow to become more and more independent with your support and positive encouragement. Give him opportunities to do things on his own, and teach him how to do them when he needs help.

# Community Safety

Regardless of where on the autism spectrum your adolescent falls, one of your biggest priorities should be to make sure that he participates in community life to the greatest extent possible. While the benefits of community integration for individuals with autism (and other special needs) are well-documented, it is important for you to recognize the potential dangers that come with even the most gradual increases of independence. These threats to safety exist for all teens, but are elevated for those with autism. That being said, independence is a part of growing up, and it is your constant challenge as his parent to help him safely achieve it. You can help your adolescent successfully navigate his world by helping him gradually build safety skills in the following four areas: transportation, money, interaction with law enforcement, and cell phone use.

#### Community Safety: Planning and Prevention

1. Practice transportation readiness skills.

Your adolescent and you should take every opportunity to practice getting around your community. While many teens learn how to do this through observation, your adolescent likely will require more direct (and continued) instruction.

Make sure he learns important landmarks, street names, and how to use available methods of transportation. As you are out and about in your community, help your adolescent feel comfortable, talk about good hangout areas, not-so-good hangout areas, and how to get to familiar locations. Create teaching moments every day, such as when you're running errands. While it can be quicker and more efficient to do things by yourself, the more your teen accompanies you, the more he is going to learn about the community he lives in, and how to navigate it by himself. If mass transit is available in your area, help your adolescent know how to navigate his options: modes of transportation, routes, how to purchase and use tickets, how to find seats, and other aspects of safe use. If he is less independent, then he will have difficulty with more basic life skills, such as safely crossing the street, which is possible to teach by exercising patience and positive feedback. Regardless of your child's level of abilities, try not to give wordy or vague instructions. Individuals with autism typically perform better when instructions are clear, succinct, and specific.

Some adolescents may be getting ready to drive. In fact, approximately two-thirds of the more high-functioning, independent adolescents with autism plan to or are already driving (Huang, Kao, Curry, & Durbin, 2012). However, only approximately 24 percent of adults with autism report being actual drivers. Adults with autism also report more challenges with driving than adults without autism (Daly, Nicholls, Patrick, Brinckman, & Schultheis, 2014). You can help your teen by making sure that driving goals are added to his transition plan. Teach the important driving skills in small steps, emphasize practice and repetition, and look for opportunities to simulate real-life situations in a safe and controlled environment.

For some teenagers, biking may be the safest and most efficient way of getting around. Bike safety starts with the right equipment (e.g., helmet, lights, brightly colored clothes), and includes learning standard bike safety rules: paying attention to cars and traffic patterns, signaling, and practicing proper bike maintenance. Learning to ride a bike can take time for some individuals with autism, given motor coordination challenges.

Regardless of how your adolescent gets around, make sure he adheres to these fundamental pieces of guidance:

• Always walk in known, well-lit locations with a friend. Dress appropriately, and maintain a "presence"—walk tall, be attentive, and act like you know clearly

where you are going. Looking distracted or unsure means you're more likely to be targeted by criminals.

- Know what to do if you get lost (your family should have a specific plan) and whom to ask for help; always try to limit interactions with strangers.
- Always carry ID and/or an autism information handout.
- Never leave home without a cell phone, and make sure it is charged.
- Always let family and friends know where you are and when you expect to return, especially if you are breaking from your typical routine.



2. Practice money skills.

One of the hallmarks of adolescent years is increased independence and responsibility, including learning how to maintain financial responsibility. Teach your adolescent money matters now, which can help him avoid major safety pitfalls during adulthood.

- Set up a bank account with your teen and set rules for how much money he can carry at a time (perhaps \$20). Make sure he knows never to give away money, and only to exchange it during purchases. If he does not understand the concept of money, then it may be easier to give him a prepaid card to use. That way, you do not have to worry about whether he receives exact change back. Using a prepaid card also is helpful since many card services document transactions online.
- Even something as benign as carrying a wallet or purse properly can make him less prone to being pickpocketed or targeted for more serious crimes. For example, teach him how to keep his wallet hidden out of sight, or teach her how to keep her purse secure and close to her body.
- Make sure your teen knows how to read different ATM and credit card machines for proper card orientations, and how to utilize them using the correct motor movements. Observe him negotiating financial transactions, and provide positive reinforcement and immediate corrective feedback. Then, practice more advanced ATM skills, such as only using it in the daylight, waiting your turn, and not giving the personal identification number (PIN) to anyone.
- You also may support your teen's skill development by shopping together and getting to know local stores. If your teen has realistic expectations about what items cost, then it is less likely that he will be taken advantage of. There are many apps for tablets that you can use to help your teen accurately count money or calculate sale prices.

3. Meet and interact with law enforcement.

Individuals with developmental disabilities are seven times more likely to interact with law enforcement than the general population. Thus, it is important for both your child and law enforcement to lay a foundation for such interactions. Your adolescent can get to know law enforcement officials, and those individuals can get to know him in a safe, non-emergency situation. Setting up a time to meet and share information can be a great first step to raising awareness among these important groups of individuals. Because there is potential for interactions to go wrong, it is also critical to teach him what do if approached by a police officer, regardless of the situation. This will help avoid potential misunderstandings, injuries, or even arrests.

At the same time, you and your teen also can practice appropriate ways of interacting with law enforcement officials, such as: keeping appropriate distance, providing ID or an autism information handout, and not making any sudden movements or running away—even when the "fight or flight" instinct kicks in. You might role-play to practice providing ID or having them disclose their autism diagnosis in a manner that is easiest for him. You also can practice identifying situations or locations where there may be more scrutiny by security officers, such as airports or malls.

4. Establish cell phone safety skills.

The "Safety Basics" section in the opening of this guide (see <u>page 5</u>) underscores the important role that technology plays in keeping your loved one with autism safe. In today's world of advancing technology, no piece of equipment is more important for this purpose than a cellular phone. Most teens should have a phone to make and receive calls (and text messages). Having a GPS feature for tracking purposes is an added bonus. If you cannot afford a phone for your teen, then see if there is an organization in your community that redistributes used phones to individuals and families with a variety of special needs and circumstances. You also can look into "Pay As You Go" plans that are far more affordable than standard plans.

While having a cell phone can go a long way toward mitigating threats, it is imperative that you teach your teenager with autism how to use it properly. The consequences of not doing so can be significant. Here are some tips to share with your teenager:

- Avoid talking on speaker phone.
- Speak quietly and in appropriate places, especially when providing details about your location or state of mind.
- Always keep the phone in a secure place, and always make sure it's charged before leaving home.
- Make sure your phone is loaded with important contact numbers, but also know a few select numbers (e.g., your parent's numbers) by memory, in case you lose your phone or the battery dies and you need to call from a different phone.

- Pre-program at least two "in case of emergency" numbers.
- Do not take pictures of people without their permission.

#### Five Tips for Success: Community Safety

- 1) Use every trip outside the home with your adolescent as a teaching moment. Help him learn landmarks, different ways of getting around, and where to find a trusted individual who can provide assistance when needed.
- 2) Help your adolescent avoid pitfalls associated with using money in public settings, such as disclosing how much cash he is carrying or has in a bank account, or failing to hide his PIN from potential onlookers when using an ATM.
- 3) Remind your adolescent that law enforcement officials are there for his protection and that, regardless of the situation, he should address them in a calm and respect-ful manner. This will diminish the potential for misunderstandings to occur.
- 4) Make sure your adolescent has a cell phone that serves specific purposes, in accordance with your family's safety plan. Instruct him on how to use the phone properly and facilitate opportunities for him to practice using it in a variety of emergency and non-emergency situations.
- 5) If an emergency situation occurs outside of the home, then ensure that your adolescent knows how to activate your family's safety network, regardless of where he may be. Your safety plan should include a list of places (or types of places) where your adolescent spends time and who his trusted point of contact should be. Print multiple copies and make sure your adolescent keeps one with him at all times.

## **Relationship and Sexual Safety**

In middle school and high school, your adolescent is going to be asked to navigate increasingly complex social waters—especially if he takes any classes with typical peers. Learning how to assimilate into peer groups and trying to "fit in" can be an overwhelming task, and one that has the potential to expose your adolescent's vulnerabilities, including those related to his disorder. He may not pick up on red flags in relationships, like knowing when he is being taken advantage of by someone who claims to be a "friend." Or he may unintentionally cause harm to another person because he doesn't understand the unspoken rules of relationships, which may lead to potential safety and even legal consequences. For example, Luke continued to call, text, and follow a girl at school whom he liked, despite repeated requests by the girl to be left alone. Although Luke simply wanted to enjoy her friendship, ultimately a restraining order was issued because of his inappropriate behavior.

Sexuality can be a difficult topic for teens, whose bodies are rapidly changing, and one that many parents are reluctant to discuss. The more that your adolescent knows about his body and the different types of relationships in which he may find himself, the better prepared he will be to make safe decisions.

Although adolescents with autism develop physically at the same rate as their peers, their cognitive, emotional, and social development may not be similarly aligned. Thus, they will have the same sexual urges and feelings and understand them less. Sexuality education is extremely important for this population.

Maintaining relationships and sexual safety continues with social skills and relationship training; this involves practicing the ability to communicate not only questions about sexual appropriateness, but also how to talk about when or if something has happened to threaten safety. Thus, you should always keep the lines of communication open. As a parent, you are your adolescent's most trusted authority on relationships, and have the opportunity to provide ongoing support and steer him in positive, healthy directions.

#### Sexual Safety: Planning and Prevention

1. Practice social skills.

The "hidden curriculum" of body language, facial expressions, and rules that make relationships complex can be difficult for all teens to wrap their minds around, but it can be especially hard for teens with autism to grasp. Targeted social skills instruction will help ensure that your teen knows how to interact with peers in a positive and productive manner, with fewer opportunities for misunderstandings. Help your teen learn how to say "no" to different types of inappropriate advances—with words, body language, or actions (like walking away). Always encourage him to talk to you or another trusted adult immediately if something inappropriate happens.

2. Understand the key aspects of relationships.

It is critical that your teen learns about the different levels of relationships—from stranger to romantic partner. All relationships have appropriate behaviors, conversation topics, and established (but rarely spoken about) boundaries. Explain the differences in an explicit way so that your adolescent can develop realistic expectations for the relationships in his life.

To keep your adolescent safe from abuse or being taken advantage of in a relationship, it is really important that he or she knows what abuse can look or sound like—name calling, making comments about body parts, grabbing, touching, or being shown inappropriate pictures. Sometimes, abuse comes in the form of bribes and threats—"If you do XYZ, then I'll give you an ice cream," or "If you tell anyone about ABC, then I'll hurt your parents." In this context, make sure your adolescent knows that:

- No one has the right to touch him without his permission.
- It's always okay to say "no" to something that another person suggests.
- He should never be forced to do something with which he is not comfortable.

If something does happen, then start by first reassuring the person they did nothing wrong. Then, help your adolescent learn the following steps:

- Tell the offender to stop.
- Leave the situation as soon as possible.
- Tell a trusted adult about what happened in a timely manner and in as many details as you can remember.
- After some time, re-teach the lesson on how to handle this situation so that your child may be better able to recognize and act quickly on it. Remember, too, that abuse by a caregiver or other service provider still can be a concern during this time in your child's life. Adolescents should always know that they will not be punished for telling a trusted adult if something happens to them, and that whatever happens to them is not their fault.

#### From a parent:

"While on a field trip, my son repeated some of what he heard from other students; it was sexually explicit language that he did not know the meaning of. One of the chaperones reported this to the teacher. It then went to school administration and then to social services. Social services and the police then came to my door to investigate sexual abuse in my house. Not only was I outraged, I was scared that they were going to remove my children from the home—just because of him repeating what someone else had said. I also learned that they had taken my son and other children out of the classroom and questioned them. This all stayed on my son's records at Social Services for 2 years, even though he had done nothing but be a 'parrot,' and we had done nothing wrong."

#### 3. Participate in sexual education.

Sexuality education starts at home, as you and your adolescent work together to learn about the body, puberty, public versus private behaviors, relationships, etc. Make sure this learning process incorporates the beliefs and values that are important to your family. Of course, you also can coordinate sexuality education with the school or with any of the professionals who work with your teen. Regardless of where you decide to approach the subject, make sure that intercourse is not the only item on your "sex ed" agenda; sexuality education is about more than that.

Teens with autism can get in trouble with schools and law enforcement because though they experience the same sexual feelings as their peers, they may be confused about how to act on them. For example, an infatuation with a school peer may lead to behaviors that might be perceived as stalking, even if your teen has no intention of "being creepy" or making someone feel uncomfortable. Some individuals need to be

#### Adolescence

taught not to touch other people, stare at other people, or make comments of a sexual nature to people whom they do not know. The more preparation and information your adolescent has about his own sexuality, the safer and better prepared he will be.

#### Tips for Success: Relationship and Sexual Safety

- 1) As a parent, your primary emphasis should be on helping your adolescent understand the different types of relationships (e.g., stranger, acquaintance, friend, adversary, romantic partner, etc.) and the expected behaviors associated with each.
- 2) Make sure that direct social skills instruction is part of your adolescent's daily routine at home, in school, in therapy, and in the community.
- 3) If possible, enroll your adolescent in a sexuality education program that is designed for individuals with autism, or find a suitable curriculum online.
- 4) Maintain an open dialogue with your adolescent about his changing body, friendships, sexuality, and how to appropriately act on feelings of a sexual nature. He will be less likely to put himself in unsafe situations if he knows he can come to you with concerns.
- 5) If you see any warning signs (e.g., bruises, unexplained injuries, anxiety, significant behavioral changes, etc.) or suspect that your teen has been abused, then immediately contact your appropriate state/local agency or call the Childhelp National Child Abuse Hotline: 1-800-4-A-CHILD.

#### Using the Safety Planning Cycle: Relationship and Sexual Safety Example

Fourteen-year-old Renee had just started to develop breasts. Her mom, Tasha, helped her find some bras and encouraged her to begin wearing them. Renee, however, soon learned that wearing a bra was very uncomfortable and distracting, so much so that she would often take off her shirt, remove her bra, and then put her shirt back on. Tasha told Renee that she could not remove her clothes in public places. While Renee adhered to this rule, she would simply refrain from removing her shirt, but still take off her bra through her arm sleeves. She did this when she was at school or in other community spaces. Because of this behavior, Renee began receiving unwanted attention and inappropriate comments from many of the boys in her class.

• Understand

Tasha realized that Renee was having trouble adjusting to this wardrobe change and dealing with the uncomfortable sensation of the bra on her skin. Tasha also knew that Renee needed to understand appropriate behaviors in public and private places.

• Prepare

Tasha began by purchasing many different types of bras and tank tops with support for Renee to try. She also worked with Renee and her teacher to develop a checklist of what to do when/if Renee was uncomfortable in her clothing at school. In addition, Renee, Tasha, and other support staff made a list of appropriate responses and behaviors toward inappropriate comments and attention from boys at school.

• Practice

Renee began carrying a checklist as a reference and visual reminder when she first noticed herself itching and pulling at her bra or shirt. She also began trying the different types of bras that Tasha bought, making note of which ones felt better than others. When she noticed a bra irritating her skin, she referenced her checklist, asked to be excused to the restroom, and tried putting on another bra that she had in her bag. Renee also role-played how to respond appropriately to others, first with a friend, and then toward boys commenting on her breasts at school.

• Share

Tasha shared information with Renee's teachers about her checklist and practice of appropriate behaviors in public. Each teacher was asked to direct Renee to her checklist and provide prompts as necessary if they saw her begin to fidget or remove her shirt. Teachers also were asked to take note of inappropriate behaviors or comments from other students and to address them.

• Update

Ultimately, Renee found a style of bra that was more comfortable for her. She also noticed that by the end of the day, she could no longer stand the constriction of a bra on her skin. When at home, she knew she could remove her bra in her room or the bathroom. If she had afterschool activities, then she and Tasha planned for her to bring a change of clothes, which included a skin hugging shirt to be worn under her regular shirt to provide coverage and support. Renee also is more confident about appropriately addressing comments from boys at school, and knows how and when to report the comments to trusted adults.

#### Bullying

Bullying is defined as "unwanted, aggressive behavior among school-aged children that involves a real or perceived power imbalance" (U.S. Department of Health and Human Services, 2014). Bullying peaks in the middle school years (Blake, Lund, Zhou, Kwok, & Benz, 2012) and can take many different forms: physical, verbal, psychological, and even cyber (Kloosterman, Kelley, Craig, Parker, & Javier, 2013). Given that adolescents with autism have difficulty understanding social rules and norms, they are more vulnerable to insidious ("relational") types of bullying, such as exclusion from peer groups. Even after several incidents have occurred, they still may not notice that they are being bullied.

What is important to recognize is that bullying does not just happen in plain sight. Most older people can remember their neighborhood or school bully. While that

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type of bully still exists, bullying can happen in subtle ways, and tends to be a group activity revolving around social ties (the movie *Mean Girls* demonstrates the caustic effects of social group bullying).

The keys in any case are: (1) The object of bullying is a person who isn't accepted as part of the group due to some perceived difference; and (2) the most serious acts of bullying escalate from teasing, ridiculing, and testing the rules, which often go unnoticed, or worse, brushed aside as "kids being kids." This is why a peer buddy program at school, acceptance and assimilation, and having some capacity to identify well-meaning classmates are vital components of a safety plan at school.

It is important to note that bullying is not limited to peer-to-peer relationships. Sadly, there are adults who sometimes abuse positions of trust and engage in bullying behavior out of ignorance or plain lack of acceptance. As you teach your child about relationships and friendship, be mindful of teaching what "trusted adult" means, who they are, and most importantly, what makes them trustworthy.

#### Bullying: Planning and Prevention

1. Define friendship.

Adolescence is a time when social interactions and "fitting in" matters. The relentless pursuit of peer acceptance, however, comes with inherent risks. Your teen with autism is more likely to be lured into behaving in improper or unsafe ways in the name of "friendship." It is, therefore, imperative that you teach him how to distinguish real friends from bullies. Rather than discussing the abstract traits or qualities (e.g., honest, thoughtful, etc.) of a real friend, urge your teen to consider how a classmate or group of classmates treat him. Examples can be a powerful tool: "Michael says he is your friend, but does he invite you to play basketball with everyone else after school?" Arm your teen with the strength to say no to peer pressure: "If you don't feel comfortable doing something and you know that it's wrong, then is she really your friend for demanding that you to do it?" You also can use previous incidents as teaching moments to prevent further victimization: "Would you have thrown your sandwich at the teacher if Michael didn't tell you to do it?"

#### From a teacher:

"A seventh grader with autism who is very passive had been pulling his pants down in class. We initially thought he was being naughty, but soon found out that another student had been telling him to pull his pants down. I think teachers need to be more aware of their students and consider the reasons why they might be doing something out of the ordinary, and parents should work with their teen's support professionals to create social stories about being your own person and making your own decisions." 2. Find opportunities to teach social interaction skills.

Learning the unwritten rules of social interactions, like how to read body language, can take a lot of practice for your teen to master. It helps if he can get involved with a school or other extracurricular group, where he not only can engage with peers around topics of interest, but also develop a network of real friends. Maybe these peers can help him role-play or practice some common adolescent interactions, like asking someone to get together or talking about school activities. Ask the school social worker, guidance counselor, or special education teachers if they can help facilitate those opportunities.

3. Build awareness and self-advocacy skills.

Teens with autism often need help knowing what bullying looks like. Use real-life examples so that the information resonates more, and work together to practice identifying the signs of bullying. Remind him that while bullying can hurt (physically and emotionally), it is not his fault, and he should always tell you or another trusted adult if he feels like he isn't being treated properly. In addition to knowing whom to tell about bullying, adolescents need to learn how to deal with bullies in an effective way. This may mean walking away from a situation or seeking assistance from someone. You can help him develop this important skill by creating a social story or role-playing.



#### From a parent:

"Teach your adolescent how to distinguish when someone is taking advantage of you—borrowing money and not paying it back, asking for favors but not reciprocating, baiting you so others laugh at your naiveté, or asking you to do inappropriate and illegal things in exchange for friendship. Teach your child about 'friendship."

#### 4. Address peer awareness and peer education.

You and your teen cannot address this issue in a vacuum. Make sure his school promotes inclusion to the fullest extent and has strong policies against bullying. Information and awareness training about autism for peers, teachers, and other staff members also can make a difference. It may help students who assist bullies or reinforce their behavior to reconsider their role in the process, and convince students who would otherwise be bystanders to take supportive action. Even a small group of school peers (e.g., neighbors, club members, student government leaders) who are "tuned in" to your teen can provide a secure layer of protection.

5. Ensure school awareness and education.

In many cases, it falls to you as a parent to make sure the school is taking the appropriate steps to prevent or address bullying. Talk to the teachers and administrators about autism and what it means for your teen in particular—behaviors, anxiety, triggers, and potential vulnerabilities. Try to identify specific incidents that already may have impacted your teen so school staff can prevent it in the future. The federal government has anti-bullying guidelines that relate specifically to students with spe-



cial needs. In fact, the Office of Special Education and Rehabilitative Services (OSERS) issued a letter with guidance on bullying and students with Individualized Education Programs (IEPs). In brief, it directs that if students with IEPs are bullied or are bullies of others, then the IEP team is required to hold a meeting to discuss and determine if services and supports are required

to address the bullying. Similarly, your state or school district might have its own guiding documents as well. Make sure to be aware of these.

Five Tips for Success: Bullying

- Remember that bullying doesn't just happen. It is preceded by teasing, ridiculing, and testing of rules that often gets brushed aside. If you find that your adolescent is being picked on or left out, then address it with school staff immediately before it escalates into something more significant.
- Help your child understand what a "real friend" is. Use specific, real-world examples and create social stories so he knows how to respond when someone doesn't treat him appropriately.
- See <u>Appendix M</u>: Five Steps Parents Can Take to Prevent Bullying.
- It's never too early to build self-advocacy skills. Do everything you can to make sure that your adolescent can confidently stand up to his bullies and express concerns to a trusted
  - to his bullies and express concerns to a trusted adult, regardless of where he is.
- 4) Typical peers are less likely to bully if they understand that your adolescent has autism and isn't just "weird." Encourage his school to educate peers and staff members about autism; seek out opportunities (e.g., clubs and buddy programs) for him to make friends.
- 5) Be attuned to the signs of bullying: avoiding preferred activities, increased sensitivity or anxiety, changes in daily eating or sleeping patterns, declining grades, cuts or bruises, and suicidal ideation.\*

<sup>\*</sup>If bullying does occur, then make sure to notify the appropriate parties at the school, and work with administrators to ensure not only that your adolescent has a safe way to report these types of incidents, but also that they swiftly implement a plan to address the problem. This will help the offenders (and those less directly responsible but who may have assisted/reinforced) realize that these behaviors are

6) Broach this subject with school administration before the start of the school year to facilitate discussions and awareness, should you have any concerns in this area.

# **Internet Safety**

Individuals with autism are generally comfortable using computers, the Internet, and overall technology. Some may even prefer socializing over the Internet rather than face-to-face because it is more comfortable that way. However, it can be challenging for many teens in general to identify inappropriate situations and interactions that happen online. For adolescents with autism, they may be even more vulnerable to cyber threats.

The Internet connects people, and while it provides many benefits, it also can be potentially dangerous when adolescents connect online with people they do not know. There are other potential pitfalls as well: giving away personal information; accessing inappropriate content; becoming vulnerable to identity theft when making unsecured online transactions; undesired exposure to social media; and even becoming victim to cyberbullying. As a result, it is extremely important to be technologically educated and prepare for such vulnerabilities.

Have a discussion with your teen's school to see if they explicitly teach about Internet safety. If your teen often uses computers and other Internet devices at school, then be sure to inquire about the strength of the school's safety filters. Let the teachers



know that Internet safety is a priority for you, and explain to them the protections you use at home. If you feel unprepared to instruct your teen about the vulnerabilities of Internet usage, then use the *Netsmartz Workshop* for resources to develop your family safety plan further.

#### Internet Safety: Planning and Prevention

Much like the rules you established when your child was younger, you and your teen can work together to create some basic Internet safety rules that apply to all situations, such as:

- Do not share full name, Social Security number, phone number, or address online.
- If you feel uncomfortable online, for any reason, then exit the Web site and tell a trusted adult.

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not taken lightly, and help your teen realize that he has a network of support and protection. You also may use your school's complaint process or other reporting process. If bullying is taking place outside of school, then consult the police. In all cases, seek counseling for your adolescent if he is experiencing significant distress due to bullying.

- Never send pictures to people you do not know.
- Never meet anyone you don't know from the Internet in person, unless accompanied by a parent or trusted adult.
- Keep your passwords safe, protected, and hidden; do not share them with others (except parents).
- Use all privacy settings when accessing social networks.



#### From a parent:

"My son has autism. Since he is high-functioning, it can be easy to forget that he is a visual learner. As such, I know I have to be very careful about how and when he accesses the Internet. I only allow him to access the Internet when he is with me on one device, so he knows at any time I can come over and see what he is looking at or check his history. If he wants to surf on his own, I ensure that he is using the K9\* browser. I do not allow him to use social media at this time. To all parents out there, I can't stress enough the dangers of what is on YouTube for any child, let alone one with autism."

Here are some Internet safety tips that many parents have found helpful:

- Have a desktop as your home computer and put it in a visible location; consider downloading monitoring and use tracking software.
- Have a curfew for using handheld electronics with Internet access so that your teen turns them in at a certain hour.
- Encourage your adolescent to practice online the same behaviors and conversations that are appropriate in public and private in person.
- Be familiar with your adolescent's favorite Web sites and use technology together—see what your adolescent likes and work together to support appropriate online behaviors.
- Communicate with your child about online bullying and his online activities.
- Use technology together.
- Enable safe searching settings on your browser or age-appropriate filters.
- Show your child how to keep their social media setting "private."
- Limit computer and Internet time using visual schedules, timers, etc.
- Model appropriate online behavior in your own use of technology.

<sup>\*</sup>Note: K9 Web Protection is a free Internet filter that gives parents control over the content viewable by their children. For more information, see the "Internet Safety" section of <u>Appendix O</u>: Other Safety Resources.

- Monitor your credit card for any unauthorized purchases.
- Install safety software onto your computers. Your Internet service provider or computer retailer can assist with this.

#### Pornography

Parents and clinical professionals have started to see a significant increase in porn addiction among older clients with autism. It is easy to access pornographic material online, and addiction can occur after only one or two exposures on a computer or smartphone. Child pornography also can be an issue. Teens and young adults diagnosed with autism, who often feel connected to developmentally younger individuals, may seek out material that is illegal without even knowing. Since it is very hard to find qualified providers to help them on the subject, prevention is critical.

Prevention starts by blocking pornographic sites and advertisements that may be inappropriate for teens; there are many types of software programs that offer this capability. Monitor and be familiar with your adolescent's Internet use on any of his devices, not just the main computer. Continue to check in with him regarding the sites he likes, individuals he talks to online, and his general online behavior.

Parents should be vigilant about what their child accesses on electronic devices, and even what is shown to them by others. It can take only one exposure for this automatically reinforcing behavior (or just plain curiosity) to take root and can be very hard to treat.

#### Cyberbullying

Cyberbullying is when a child or teen is harassed, teased, threatened, or otherwise negatively focused on by another child or teen in an Internet, digital, or mobile setting. When adults are harassed online or via mobile technology, it is called cyber-harassment or cyber-stalking.

The unfortunate reality is that cyberbullying and online exposure to inappropriate or negative content is not uncommon. If your adolescent experiences these problems related to Internet safety, then make sure he knows to:

- Always tell a trusted adult about the experience or situation.
- Not respond to the bullying message or inappropriate content, and not forward it to others.
- Document, print, and save the message.

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- Block the bully from accessing your adolescent (different programs have privacy settings that can be enabled).
- Report it to the online service provider or social media site if the problem persists.

#### Five Tips for Success: Internet Safety

- Remember that while the Internet may seem like a "safe haven" for your adolescent with autism to interact with others, the pitfalls of misuse can pose significant safety threats. Staying vigilant can help protect your adolescent from giving away important personal or financial information, being targeted by cyberbullies, or accessing inappropriate or illegal content.
- 2) Establish clear guidelines for Internet use, and make sure your adolescent understands that the rules do not apply just on home computers, but on every computer and Internet-accessible device (e.g., phone, tablet, etc.).
- 3) For additional protection and peace of mind, set up Internet monitoring so you can regularly check your adolescent's browsing history. Safe search filters and anti-spam software also can make a difference.
- 4) If your adolescent uses social media (e.g., Facebook, Twitter, Instagram), then pay especially close attention to his accounts. This is where he is most likely to interact with strangers or fall victim to cyberbullying.
- 5) If something goes wrong, then take swift action to avoid further problems. If your adolescent inadvertently gives away bank account or other financial information online, then contact your bank immediately. Report any instances of inappropriate



National Center for Missing and Exploited Children: <u>http://report.cybertip.org</u>

Internet use targeting your adolescent to the National Center for Missing and Exploited Children; log on to <u>http://report.cybertip.org</u>.

# Conclusion

Adolescence brings with it several significant safety concerns for individuals with autism. Some are extensions of threats that appear during childhood, and others are new threats that go hand-in-hand with this period of development. With proper planning and action, however, you and your teen can learn and practice the safety skills needed to enjoy this exciting time and be prepared for adulthood. As a parent, be sure to read through the adulthood section of this guide to help you gain a better perspective on where your adolescent is heading.

# Adulthood

# Introduction

Like all other children, individuals with autism grow up to become adults who live in and contribute back to their communities. While some safety threats become less of a concern as your loved one gets older, new safety threats appear and take on a different form. Even adults on the spectrum who live, work, and socialize



The skills you have helped them master during childhood and adolescence ultimately serve as the foundation for safety and personal fulfillment in adulthood.

independently are still vulnerable to certain "blind spots," particularly in unfamiliar situations. The skills you have helped them master during childhood and adolescence, however, ultimately serve as the foundation for safety and personal fulfillment in adulthood. This underscores the importance of starting early and practicing often.

As mentioned earlier in this guide, safety skills last a lifetime and are essential to survival. They build on each other and allow your loved one to navigate more complex and nuanced threats successfully with age. These types of threats cut across environments (e.g., home, workplace, community, etc.) and are the hallmark of adulthood. The "hidden curriculum" still is very much a reality, and the consequences of violating it become more severe. A simple misunderstanding can spiral out of control quickly, with significant health, legal, and financial implications. This can seem overwhelming and even scary, but being aware of what to expect can help you and your loved one plan ahead.

As you read this chapter, remember that nobody becomes a perfect adult. Your loved one is going to make mistakes along the way, especially during the transition years when he will likely be trying to balance the need for independence with the need for support. As a parent or caregiver, you can always help your loved one "think safety." Encourage him to always have a plan in place, build a safety network (e.g., relatives, friends, mentors), and become a capable self-advocate. It is never too late to make a difference!

### From a parent:

"Our daughter is very independent and motivated, but is not aware of dangers. Throughout her life, many strangers have helped her and thankfully none have hurt her in any way. However, she needs to understand options, such as saying 'No, thank you' or phoning a parent or trusted individual."

#### Note to Reader

This section is designed to help parents and caregivers begin to prepare for adulthood. Some of the safety issues and threats identified may not apply to individuals who are more severely impacted by autism or dependent on caregivers to meet everyday needs. For this population, the content from the previous sections will remain useful.

# **Community Safety**

Adults with autism may know how to navigate certain locations, like their neighborhood, successfully because they have practiced and are familiar with people and places in their daily lives. When an individual on the spectrum is required to function in unfamiliar locations or travel for any number of reasons, maintaining personal safety can be more challenging, especially if the individual has not had opportunities to generalize the skills he has learned. Adults with autism need to be prepared to get around safely, understand travel basics and transportation options, and apply safety skills in new settings.

Here are some helpful threat prevention tips:

- Teach travel safety basics during childhood and adolescence. Make family vacations a learning opportunity, so your loved one becomes comfortable with the process of traveling—whether by car, train, airplane, or other means—and knows how to seek out information from trusted sources (e.g., hotel concierge) regardless of the destination.
- Encourage your adult with autism to research any known travel destinations thoroughly beforehand, even if it is just an unfamiliar location in his hometown. It will help him feel more comfortable and confident. This is especially important because appearing lost or confused can increase the likelihood of being targeted or taken advantage of.

Money also is important for community safety. Your loved one may be very capable and comfortable with using money, understanding its value, and saving it. With greater independence comes greater exposure to all the common pitfalls. Financial safety issues in adulthood often revolve around naiveté or too much trust. This is no less true for adults with autism. Your loved one with autism must know what specific personal information needs to be protected, such as Social Security number, bank account information, or Internet passwords. He should understand the risk posed by identity theft and be taught to identify schemes and scams that could come in the form of e-mails from strangers asking for financial information (this type of attack is called "phishing"), phone calls from people he does not know asking for personal information, or more recently, unannounced cold calls from unknown persons to someone's home or apartment. Sometimes the caller says a bill is unpaid, a relative is stranded and needs money, or that they have just won the lottery, all intended to get the person to provide his credit card or bank account number.

As mentioned earlier, individuals with autism are more likely to interact with law enforcement than their typical peers. That happens for any number of reasons. On one hand, maybe a behavior is misperceived (e.g., lack of eye contact or not being able to communicate verbally), they have been victimized, or they need some other type of public safety support (e.g., from wandering away). On the other, the person with autism may have inadvertently misread a situation in a public setting. Either way, it is important for the person with autism to understand that police officers and first responders may not know anything about autism, and certainly have no way of spotting a person with autism by simple observation.

With that in mind, there are many ways to make such interactions go smoothly. While more and more law enforcement agencies are providing their personnel with some autism awareness training, it is also good practice for adults on the spectrum to understand the role of law enforcement and first responders, and know how to appropriately interact with them.

Here are some helpful tips to avoid major misunderstandings:

• *Get to know local law enforcement personnel.* Practice interacting with them early and often. This might involve visiting the station, and introducing oneself. Ideally, the foundation for this will have been laid down during similar meetings in adolescence, and by role-playing appropriate behaviors and specific

types of situations in which your loved one might need to be in contact with an official.

• *Know when to disclose.* Make sure your loved one has an autism diagnosis disclosure plan in place, and that he understands



how important it is in emergency situations or encounters with law enforcement personnel. In addition to having a clear and rehearsed disclosure statement, it might be useful also to have an ID card or perhaps an information card about autism to help explain.



#### From a community member:

"There is a young man with autism who lives in the same urban area as my 80-year-old mother. He has a scheduled walking routine throughout the day; he walks very fast, occasionally stims with his hands, avoids eye contact and social greetings, and wears headphones. While driving home one day, my mother happened upon three police cars surrounding this young man several blocks from his house. The officers were yelling at him to stop and show his hands. The young man appeared confused, agitated, and upset. My mother stopped her car and approached the officers, informing them that she believed he has autism; she has never seen him involved in any trouble and told them where he lived with his parents. Apparently, there was a robbery of a 7-Eleven store close by and they suspected he was involved. My mother explained that this was the time that he routinely walks and she was sure he was not involved in the robbery. This situation could have ended badly in many ways: aggression by police, arrest, or even shooting. My advice to parents is to make sure that your adult carries backup communication supports everywhere."

# **Relationship and Sexual Safety**

Every relationship has a natural progression and different sets of appropriate interactions. Although an individual with autism's cognitive and social development may not be aligned with their physical development, they will have the same sexual urges and feelings that their peers are having. Hence, sex education is just as important for this population. Your loved one with autism most likely has been practicing relationship safety skills and social skills training throughout his life. While adolescents may have trouble understanding the difference between an acquaintance and a friend, adults may have trouble navigating more nuanced relationships with co-workers, colleagues, or romantic partners.

Adults with autism are more susceptible to misunderstandings and misinterpretations, which can sometimes lead to negative consequences. For example, a young man on the spectrum may show interest in a young woman at a social event, but she does not reciprocate this interest. The young man may not pick up on her body language or verbal cues. Thus, she may perceive his behavior as harassment or even stalking. It also can be hard for adults with autism to know what information is appropriate to share or do publicly as opposed to privately.



#### From a parent:

"Carefully teach the ins and outs of dating and sexuality, including the legal aspects (e.g., respecting when a partner says 'no' and expecting the same respect from them, not dating someone too young even though they may be a good fit socially or intellectually, the difference between stalking and flirting, etc.), which can have terrible consequences. For adults contemplating marriage, help them understand what is expected of a marriage partner and how that relationship is unlike any other."

Relationship safety is built on direct instruction, practice, and experience in relationships. Understanding different relationship types, how relationships progress, and appropriate expectations for relationships often starts in adolescence. While your adult with autism may require ongoing support (e.g., practicing appropriate behaviors and conversations for different types of relationships, reinforcing the distinction between what information is public and what should be kept private, etc.), investing that time and energy will go a long way toward keeping him safe later in life.

While the discussion of sexuality during adolescence largely revolves around the changing body and understanding/controlling urges, the discussion of sexuality in adulthood encompasses more complex, interpersonal variables, such as: fulfilling desires, partnership, and love. These can create trouble spots for adults with autism, even though they may have a fairly developed understanding of what sex entails from an anatomical perspective. Most notably, they are at a higher risk for being taken advantage of. Recent research indicates that adults with autism, when asked about their involvement in unwanted sexual experiences, report at least one instance of victimization than adults without autism (78% compared to 47.4% of adults without autism) (Brown-Lavoie, Viecili, & Weiss, 2014).

Though it may be an extremely uncomfortable topic, it is important to make sure that your loved one is able to determine if and when he is being victimized. Your earlier conversations with him about defining what it means to be a friend will certainly apply here—trust your instincts if you feel like someone isn't treating you correctly—but the circumstances and vocabulary are completely different when sex is involved. Be direct about what harassment (or even rape) entails, and give him strategies for how to get out of an unwelcome or potentially dangerous situation.



### From a parent:

DVDs for teaching safety in the workplace, dating, and preventing sexual abuse can be found at http://www.stanfield.com/.

# **Workplace Safety**

Individuals with autism are capable and valued employees in many businesses and organizations. However, challenges with behaviors and social skills can make some workplace situations difficult to navigate. Adults with autism can be vulnerable to bullying, isolation, and harassment in the workplace. It takes employer support and partnership to create positive, effective, and safe work environments. The most important thing for parents to remember is that the business community is going to treat your loved one like everyone else; your loved one's supervisor or human resources manager is not going to have the same insight as you. Therefore, the goal should always be to establish (and maintain) clear expectations.

Disclosure, or telling others about your diagnosis, can be a significant first step. It is, however, a very personal decision. Some individuals find that full (i.e., mentioning autism explicitly) or partial (i.e., referencing only certain behaviors or aspects of the disorder) disclosure can lead to more positive and productive work experiences. Sharing this information also can support autism awareness in the workplace, as well as increase opportunities to communicate any needs for accommodations. Disclosure often starts with the employer's human resources department (in some companies) or with a direct supervisor. Talk about this process with your loved one and make sure he is prepared for the initial and subsequent conversations. Also note that disclosure is the basis for certain workplace anti-harassment protections, which may be critical down the road.

While adults with autism likely will take workplace rules and regulations more seriously than their typical counterparts, the potential for things to go wrong increases when the rules are either unwritten or simply do not exist. For example, your loved one may not intuitively grasp that



it is widely regarded as inappropriate to bring up religious or political beliefs with co-workers. If your loved one requires guidance regarding the social aspects of the workplace, then suggest that he find a mentor (e.g., supervisor, co-worker, etc.) who can provide coaching or answer questions as needed. For additional guidance from an adult self-advocate, see Appendix N.

There also are situations in which an individual with autism—because of a curiosity or fascination—might actually put themselves, their co-workers, or their employer at risk. Here's a real-life example provided by a job coach:

"One troubling situation happened with an extremely high-functioning and efficient worker who was cleaning an office. The office was connected to a warehouse and there were no barriers to prevent him from entering one section or another. He demonstrated that he could work independently and job coaching had faded over time. One day, he became fixated on something and began to wander, leading him to the warehouse area and — more specifically — a circuit breaker box. He was fascinated by the workings of the box and flipped a couple switches. While he was in no immediate danger, this was obviously a serious offense and could have put himself in danger. He was terminated shortly thereafter. Employers will have some flexibility, but when it comes to issues of safety and disregard for protocols, no second chances are guaranteed."

Regardless of how understanding a supervisor might be, these types of offenses can get your loved one fired. In situations where rules have not been established, always encourage your loved one to ask for permission instead of forgiveness.



Much like disclosure, employer and staff education about autism can be a powerful tool. While your loved one still needs to be his own advocate at work, increased awareness ensures that colleagues will be more attuned to his needs.

# Conclusion

A safe and successful adulthood builds on many of the skills that individuals practice throughout life. Adulthood is about independence, community, and contribution. With the proper preparation and support, individuals with autism certainly can enjoy and impact their world (though this will look different for each person) in a safe and responsible manner.

# **Summing Up Safety**

If you have read through this guide and examined the threats across the lifespan, then you understand that safety is not only a function of many variables, but also is shaped by two overarching questions:

- How attuned is my child to the safety threats he may encounter?
- How prepared is he to navigate his environment (i.e., home, school, community, etc.) with success?

When your child took his first wobbly steps, you no doubt held his hands and supplied a little extra strength and balance. Soon thereafter, he was moving about without assistance, and not long after that you were running to catch him. Each phase brought excitement and the anxiety that comes with letting go of his hand. So, you child-proof your home and provide as much protection from harm as possible as you teach him what to do, what not to do, and how to be safe. Physical safety takes precedence over anything else.

This scenario repeats itself, in one way or another, during every phase of your child's life. What changes most are the scope and complexity of his environment, the variety and nature of new challenges, and the degree to which you can provide protection. As your child enters adolescence, he takes a more active role in ensuring his own safety. You must rely on others outside the home—teachers, classmates, neighbors and others—to shape the safety environment. While physical safety remains a concern, the implications and threats that emerge from the socialization process, particularly for individuals with autism, cause greater concern.

When your child has completed high school and begun to live and work as independently as possible, he assumes complete (or nearly complete) responsibility for his safety. The threats he will experience are likely to be more subtle and nuanced, predicated more on vulnerabilities due to naiveté (think "hidden curriculum" for adults) than risks to physical safety. The workplace, social relationships, and dating create circumstances that present emotional and possibly legal risks. Because of the number of interactions that now occur online, the Internet also can pose significant threats (e.g., identity theft) to your adult child's well-being. Keep these in mind as you and your child with autism plan for their transition to the adult world.

As this guide has stressed from cover to cover, thorough preparation—at every stage is the key to success. While you as a parent will not always be able to manipulate the environment to ensure the safety of your child with autism, the skills that you help him build from his earliest days will last a lifetime. Anticipate what threats your child may encounter, create a reliable network of support, and always, always have a plan—and a backup plan.

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## Appendix A School Safety and Crisis Planning

For children with autism, making transitions (between activities, routines, etc.) can be difficult, especially if they are done abruptly or without prior notice. When an unforeseen event occurs, such as sudden and violent weather, it can become even more challenging for both the caregiver and the child to cope with the situation.

For cases of home emergencies, your family should have an up-to-date plan in place — one that should be discussed, reviewed, and practiced regularly. It also is helpful to have an emergency plan specifically designed for when your child is at school, where other people are involved. The adults in school emergencies (e.g., teachers, administrators, and other staff) need to be informed about how best to help your child stay safe while under their supervision. The purpose of this appendix is to help you advocate for your child before a crisis occurs at school.

#### Consider the questions below before meeting with school personnel:

- How have we handled (or plan to handle) crisis situations at home? What works? Are there effective strategies that we can share with school staff in order to maintain some consistencies?
- Does my child have any "triggers" (i.e., words, images, sounds, etc.) that make him feel unsafe? What cues should a teacher or other staff member look for that indicate my child is upset?

# The questions below should be asked in the context of a meeting (IEP review or otherwise) between you and the school staff before the academic year begins:

- Has the school staff—not just special educators—been trained on how to provide support to students with autism? What does the training entail?
- Does the school's emergency plan include contingencies and accommodations for students with special needs, including autism? Do the contingencies extend to activities beyond the classroom (e.g., locating a child who gets on the wrong school bus after school)?
- Will my child be allowed to observe, take part in, routinely practice, and debrief fire drills, or any other emergency (e.g., earthquake, building lockdown, etc.) drills with all the students?
- Are drills for my child practiced in different settings (e.g., classroom, cafeteria, gym, assembly hall)?

Remember that schools might be unable to share the specifics of their crisis plan, but you can always ask for information about their preparations as they pertain to your child and others with special needs.

# The following questions can help you coordinate with school staff in the aftermath of a crisis, so as to be better prepared should something happen again:

- What plans and procedures are in place to ensure that my child receives proper support in the aftermath (e.g., processing emotions, understanding what happened, etc.) of a crisis situation?
- Does the school have a plan in place for documenting specific information about my child's reaction to the event and the supports that were provided?

#### **Based on information from:**

- Fowler, S. (2014, May 12). *ASD crisis management and the public schools: Thoughts, recommendations, and practices*. Retrieved from: <u>https://medium.com/@ScottFo53814984/</u> <u>asd-crisis-management-and-the-public-schools-1d84e8dcadee</u>
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# Appendix B Social Stories

Social stories are a teaching strategy that were first introduced by Carol Gray in 1991. In this appendix, Scott Fowler, a parent and autism advocate, explains the construction and implementation of social stories, and provides an example that he used with his son with autism.

To maximize the effectiveness of your social stories, be sure to include pictures that are significant to your child; try to avoid using generic images found online. The more relevant the images are to your child, the stronger the comprehension becomes.

More importantly, you want to rehearse the social stories several times over an extended period of time (e.g., 2 weeks). The more realistic the practice, the stronger the comprehension becomes.

For more detailed information on the purpose and procedure of delivering social stories, see Carol Gray's *The New Social Story Book* (1994).

### How to Construct and Implement Social Stories

Prior to building a social story, it is necessary to take stock of the event you want to practice, and to make a list of potential issues so that they are addressed in advance. This can be completed in a simple outline form and will serve as a reference for you as you "build out" the social story.

- 1. Take pictures of the child that the story is about, along with familiar pieces of the story, and save them to a file to copy and paste for later.
- 2. Open a word processor and give the story a short title, placing it in bold print and making the font size larger than the rest of the document.
- 3. Add numerical steps and begin the copying and pasting of the pictures in sequential order.
- 4. Add very short narratives, as children with autism are more visually attuned to their environment.
- 5. Keep the story brief and **let the pictures tell the action and direction** of the story.
- 6. Prepare to rehearse the story for **at least 2 weeks** (this is true for a new skill, such as learning to use the restroom, or for more complex actions that the child will need to learn) prior to actual implementation of the lesson you wish your child to learn. For activities and actions that your child is already familiar and has some experience with, 1 week will suffice.
- 7. Read the social story together with your child. Do so in a comfortable environment that is free of any distracting stimuli.

- 8. Continue to read the social story several times each day prior to the event, **until your child has internalized the requirements of the story and can relate them back to you**. For nonverbal/partially verbal children with autism, it can be helpful to make a second copy of the social story, cut out the pictures and narrative to make flash cards, and then mix them up. Have your child re-order them (include the numerical order on the cards).
- 9. Once the action/behavior from the social story is internalized, begin practicing with them—without actually implementing them—and guiding them appropriately. This will take 1–2 weeks, depending on the complexity of the social story and its action steps.
- 10. On the day of the task—approximately an hour prior to the actual event—do a "walk through" with your child, giving him the chance to practice once again. Be sure to include environmental "props" as you do so (e.g., for a social story on getting his hair cut, set up a "salon" in your home, complete with sign in, wait time, a chair to sit in, something to simulate a cape to keep hair off him, using plastic play scissors to simulate cutting, etc.)
- 11. Implement the story and remediate as needed.

The example on the following page was an actual story used in preparation for Halloween and trick-or-treating. To better guide your understanding, it includes a narrative for each step.

### It's Time to Trick-or-Treat!

#### 1. Put on my costume!



We have reviewed this social story for 2 weeks, three times a day with our son. At the start of the second week, we introduced the costume and began letting him try it on. As we built interest, we also were desensitizing him to the feel, smell, and constraints of the costume, gradually increasing the time he was in it to the approximate time he would go to trick-or-treat, which was approximately an hour.

#### 2. Get my pumpkin!



The candy holders were laid out in exactly the same way each practice session, and we made sure to articulate which pumpkin was his and which one was his brother's. Again, we let him carry it around after dressing in his costume and placed practice candy in his pumpkin each time—we also practiced the "Trick or Treat" narrative prior to giving them candy. For the nonverbal child with autism, a simple cue card can be used as an alternative.

3. Walk and hold hands!



For safety, we reiterated that holding hands was required. We practiced this as well, again building up the time to the full hour mentioned above.

**Appendix B** 

#### 4. Don't go in the house!



Again, for safety and to practice social norms, we reiterated that when we trick-or-treat, we do not ever enter the house we are going to.

#### 5. After <u>10</u> houses, go home and hand out candy!



We contacted our neighbors to ask if they would be participating in trick-or-treat and set up a prescribed number of houses in an order that we would visit. This is necessary to reduce anxiety and provide reassurance. Remember that there will be a lot of external stimuli going on, and by limiting the number of houses to 10, we were able to coach our son through the process and keep him focused. Furthermore, by adding an "ending" by going home and handing out candy to others, we gave clear direction and time to allow for decompression for our son.

**Notes about the example:** In this case, our older son (6 years old at the time) would be trick-or-treating with our younger son (4 years old, neurotypical), so we included both boys in the social story to participate in the practice sessions. These included social visual cues and reinforced conformity for both boys. Additionally, we also would set the analog wall clock each time for the exact time we would dress and begin trick-or-treating, always verbally cueing for the time we would dress and leave the house.

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# Appendix C Basic Fire Safety—Teaching Tips for Parents

An essential part of a family emergency plan is to make sure that your child with autism knows how to react in dangerous situations, including fire emergencies. Fortunately, house fires may not happen all that often, but when they do, and when there is a child with special needs involved, it presents a very dangerous situation. This appendix suggests some basic fire safety tips for teaching your child about fires, fire emergency procedures, firefighters, and smoke alarms.

#### What is an emergency?

Explain that *an emergency is a time when something serious happens and immediate help is needed.* Tell your child that it is normal to feel scared when an emergency arises, and that being prepared can help him be safer and feel better. To help him understand this concept:

- Give examples of various situations, and ask your child to identify whether they are considered emergencies (e.g., a home fire versus a sibling taking away a preferred toy; falling off a bicycle versus getting a flat tire, etc.). Discuss his answers to ensure comprehension, and repeat from time to time.
- Create a word web on chart paper. Include terms that relate to the word emergency, such as: "danger," "important," "risk," or "scary." Have him write out or draw pictures of examples, whichever is easier or more effective.
- Teach that the most important thing to do in an emergency is to "listen and stay calm." Staying safe means finding a trusted adult (e.g., a designated sibling, teacher, police officer, firefighter, paramedic, etc.) during an emergency, and following their directions. Explain why it may be dangerous to hide during some situations. Build your child's repertoire of coping mechanisms to better handle emergencies.

#### Good fire versus bad fire

Teach your child about fire. Help him learn that fire has many safe and good uses. Then, explain that it also can be dangerous in certain circumstances, for which there are serious consequences. To help your child understand this:

• Show pictures of "good" fires (e.g., fire in a fireplace or a campfire) and "bad" fires (e.g., house or forest fire), identify them as such, and have him say or write reasons why that specific fire might be "good" or "bad."

- Teach him about combustible and flammable materials. Have him sort everyday items into a "will burn" or "won't burn" pile. Some good ones to use for starters are: a pinecone, a piece of wood, a small glass bottle, a rock, cardboard, a T-shirt, paper, a leaf, a wrench, and a coin.
- Teach basic fire safety from an early age. "Don't play with matches or lighters," and always say "no" if anyone wants to play with fire. Finally, make him aware that even good fires can become bad fires if they are not watched properly and get out of control.

### Stop, drop, and roll

Explain to your child that he should be careful and aware of the possibility that his clothing could catch fire when using matches, lighters, fireplaces, heaters, grills, or gasoline. This simple but important technique should be taught to your child as the response to use if his clothing ever catches fire. It involves the following three steps:

- 1) *Stop* where you are.
- 2) *Drop* to the ground (lay flat with your legs out straight, cover eyes and mouth).
- 3) Roll over and over, back and forth (until the flames are out).

Stress the importance of doing the technique only when clothing catches fire. Children who do not have a good understanding of when to adopt this technique might get confused about when to stop, drop, and roll. If a child accidentally burns his finger or hears a smoke alarm and mistakenly reacts by using the stop, drop, and roll technique, then he can cause more danger to himself and others. Again, give various scenarios and discuss whether he should use the technique in those specific situations.

Be aware that teaching your child to physically stop, drop, and roll may be initially challenging if he is sensitive to sensory feedback. Once your child can demonstrate that he knows the three steps, explain what other people around him might do. For example, others may use blankets to try and smother the flames. The more your child is prepared for what to expect in a real situation, the safer he will feel.

#### **Firefighters are your friends**

Children have sometimes died because they hid from a firefighter. A fire is a scary ordeal as it is, and it can become even more so when they see someone dressed in what looks like a big space suit, breathing like Darth Vader, and carrying an axe. To help prepare your child not be scared in the event of a fire:

• Teach him that firefighters are friends and that even though they may look scary in their firefighters' suits, they are there to protect people. Further, instruct him that in any emergency involving fire and firefighters, crawl to them as fast as possible, unless the firefighter tells him not to move until he reaches him.

- Take your child to the fire station. Let him see a firefighter in full uniform and talk to him. Explain that a firefighter is a normal person who wears a lot of equipment for safety purposes.
- Ask the firefighter to talk about his firefighter's equipment and how he uses each piece. The axe helps break down walls during a fire, and is used as a safer and easier to reach people who need help. The suit protects the firefighters from the flames, and the helmet and oxygen tank keeps them from breathing in all the smoke.

### Create a fire escape plan

Every family should have a fire escape plan and practice it regularly. Firefighters recommend that families conduct a drill at least once every 6 months, but you may need to practice parts with your child more often, especially when he is just learning the drills. The goal is to make sure he is familiar with what to do in an actual fire. When you create a plan, make sure to designate a safe place to meet outside the house where everyone should plan to meet in the event of a fire emergency. When teaching and practicing, be sure to cover these important fire safety basics:

- Leave everything! Do NOT stop to take your favorite toys or other belongings with you.
- Get low to get under the smoke to the nearest way out
- Feel your way out of the house in the dark or with your eyes closed. Do not open any doors before checking to make sure they are not hot.
- Get out of the house, and stay out. Do not go back, no matter what.
- Meet the family at the designated meeting place.

### Smoke alarms

Smoke alarm noises can be scary and disorienting for individuals with autism. It is a good idea to test any smoke alarms with your child present to see how he reacts. Familiarize him with the alarm sound so that he won't be frightened by it during a real emergency. Be sure to stress that when he hears the sound, he should listen to a trusted adult, stay calm, and follow the family emergency plan. If there is no trusted adult nearby, then he needs to understand alternatively how to get outside immediately and go to the designated meeting place.

*This appendix was written based on a fire safety lesson plan provided by Dwight Good, Fire Marshal, Morgan Hill (Ca.) Fire Department* 

## Appendix D Background Check Template

This is a basic form for a background check to use when hiring a potential caregiver for your child with autism. This is not an actual background check form; it is simply meant to give you an idea of the type of questions you want to ask. Employment laws may vary according to your state, county, or municipality, so you are responsible for making sure that you are in compliance when hiring a caregiver.

#### **Basic Information**

Full name:	
Current address:	
City:	State: ZIP:
Phone number:	E-mail address:
Date of birth:// Place	e of birth:
Social Security number:	
Driver's license number:	State:
Previous address #1:	
City:	State: ZIP:
Previous address #2:	
City:	State: ZIP:
Employment History	
Previous employer #1:	Dates of employment:// to//
Address:	
	State: ZIP:
Phone number:	Reason for leaving:
Permission to contact?  □ Yes □ I	No
Major tasks:	

Previous employer #2:	_ Dates of employment: _	_// to//
Address:		
City:	State:	ZIP:
Phone number:	Reason for leaving:	
Permission to contact? $\Box$ Yes $\Box$ No		
Major tasks:		
Previous employer #3:	_ Dates of employment: _	_// to//
Address:		
City:		
Phone number:	Reason for leaving:	
Permission to contact? $\Box$ Yes $\Box$ No		
Major tasks:		
Have you ever been fired from a job for	misconduct? 🗆 Yes 🗆 N	Io
If yes, please specify:		

## **Education History**

Appendix D	73
Major / minor:	
Did you graduate? □ Yes □ No	Degree earned:
Graduate:	Dates of attendance:// to//
Major / minor:	
Did you graduate? $\square$ Yes $\square$ No	Degree earned:
College:	Dates of attendance:// to//
Did you graduate? □ Yes □ No	
High school:	Dates of attendance:// to//

Have you received any formal training on autism? □ Yes □ No If yes, please specify:

Are you a member of any professional societies? □ Yes □ No If yes, please specify:

Do you have any of the following American Red Cross or equivalent credentials?

First Aid Certificate	$\Box$ Yes $\Box$ No	Expiration://
CPR Certificate	$\Box$ Yes $\Box$ No	Expiration://
Water Safety Instructor	$\Box$ Yes $\Box$ No	Expiration://
Advanced Lifesaving	$\Box$ Yes $\Box$ No	Expiration://
we you over had a traffic vi	alation before?	Voc. 🗆 No

Have you ever had a traffic violation before?  $\Box$  Yes  $\Box$  No

If yes, please specify:

#### **Criminal History**

Have you ever been convicted or pled guilty before a court for any federal, state, or municipal criminal offense (excluding minor traffic violations)? □ Yes □ No

If yes, please specify:

#### **Professional References**

Reference #1:	Relationship:	
Employer::	City:	State:
Phone number:	E-mail address:	
Reference #2:	Relationship:	
Employer::	City:	State:
Phone number:	E-mail address:	
Reference #3:	Relationship:	
Employer::	City:	State:
Phone number:	E-mail address:	

#### **Certification and Authorization**

I hereby certify that all the information that is provided in this form is true, correct, and complete. All offers of employment are contingent upon the applicant's successful completion, as determined by the employer's sole discretion, of this criminal history/ background check.

Signature: I	Date:/	//	/
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I hereby authorize \_\_\_\_\_\_ to investigate my background. I also understand that I may withhold my permission and that in such a case, no investigation will be done, and my application for employment will not be processed further.

Signature:	Date://
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## Appendix E Sample Safety Skills Lessons

#### **Introduction to Teaching Safety Skills**

Children with autism may not learn important safety skills as readily as their typical peers. In most cases, you will need to give your child explicit instructions on how to react appropriately in potentially dangerous situations to help keep him safe. Research shows that certain instructional plans have been effective in teaching safety skills to children on the autism spectrum (Summers et al., 2011). By teaching him in a systematic way, he will be better prepared to handle emergency situations or prevent them from occurring. This appendix offers example evidence-based instructional plans designed for a child with the ability to follow simple instructions and a need to develop basic safety and life skills. Remember that when you work with a professional to design or support these types of lessons, the lessons will be modified to your child's specific needs and abilities.

#### **Five Helpful Teaching Tips**

While teaching your child at home, remember to:

- **Model the behavior**. Show your child how to physically perform the skill. Do not forget to include directions about body positions and movements, particularly if your child has motor delays.
- **Give directions that are specific, clear, and concise.** Children with autism do not perform well with vague directions. Take the lesson one step at a time. If your child does not perform the task immediately, do not worry. You may need to adjust the approach, break down the step further, or give your child a small break.
- Use positive reinforcement. Let your child know when he is doing well. Correct him immediately when he does something wrong, and show him the correct way of performing the task.
- **Be patient.** This may be a learning process for both you and your child. If you stay positive and have high (albeit realistic expectations) for your child, then you can expect to see results over time.
- **Coordinate with your child's teachers and caregivers.** The best way for your child to master and generalize a safety lesson is to practice it in as many settings and with as many different people as possible. Collaborate with his teachers to see how he performs at school, and encourage his caregivers to reinforce the safety skill by teaching him as well.

#### Sample Lesson Plans

- 1. What to Do When the Doorbell Rings
- 2. How to Respond to the Presence of Household Cleaning Supplies
- 3. What to Do if You Get Lost in a Public Space
- 4. How to Pay for a Train Ride
- 5. How to Cross the Street

### **Model Lesson Plan**

#### The plan consists of three components:

- 1) **Rules**: Deliver clear instructions for what to do in certain situations (e.g., "When the doorbell rings, do not open the door. You need to go tell Mom.").
- 2) **Prompting**: If the child does not follow the rule, then an instructor (prompter) should give the child a verbal cue/reminder of the rule they are supposed to be following (e.g., "Go tell Mom the doorbell rang"). If the child does not respond to the verbal prompt, then the prompter should guide the child with an indirect physical prompt (e.g., pointing in the direction of the room where the child's mother is located). If the child does not respond to the partial physical prompt, then a more direct prompt may be used (e.g., gently directing the child physically to the room where his mother is located). If the child requires a significant amount of physical guidance on the first few trials, then gradually reduce the amount of physical guidance on each trial to ensure the child can perform the skill without the assistance of a prompter in the future. The child has demonstrated mastery of the independent life skills when he can properly execute the rules without any prompting over a sustained period of time.
- 3) **Feedback**: Immediate and enthusiastic praise should be given to the child when he exhibits the appropriate skill correctly. The child will never fail the task because the prompter will guide the child as needed until the skill is performed, which is always followed immediately by positive feedback.

Now, we will go through step-by-step instruction on how to apply this three-part teaching plan to an actual lesson, using five examples from different settings.

#### Lesson Example 1: What to Do When the Doorbell Rings

**Set-up:** The lesson should involve at least one primary caregiver and one other adult (the prompter) to prompt the child throughout the lesson. The primary caregiver should not do any prompting, since the child is being taught to find the caregiver after the doorbell rings. In this situation, the caregiver role should not be confused with that of the prompter. Finally, you will need someone to ring the doorbell. The caregiver should go to a nearby room before the doorbell sounds.

**Rules:** The child should be provided with a clear rule. For example, "When the doorbell rings, do not open the door. You need to go tell Mom."

**Prompting:** Someone rings the doorbell. If the child does not correctly respond in 5 seconds (refrain from opening the door and acquiring the attention of the parent), then the prompter gives the child a verbal prompt. An example of a verbal prompt would be, "Go tell Mom the doorbell rang." If the child still does not respond correctly within 5 seconds of the verbal prompt, then the prompter should give an indirect physical prompt. An indirect physical prompt would be to point in the direction of the room where the mother is located. If the child does not respond to the indirect physical prompt within 5 seconds, then the prompter should give a more direct physical prompt. An example of this would be to guide the child gently in the direction of the room the mother is located.

**Feedback**: Immediate and enthusiastic praise should be given to the child responding correctly, whether the child responds correctly immediately, after the verbal prompt, or after the physical prompt.

For best results, the child should practice the lesson as often as possible until he or she responds correctly without prompting 10 times in a row. Once the skill is developed and the child shows that he or she can respond correctly on a consistent basis, it is important to practice the skill occasionally to sustain the desired behavior. Be sure to practice with other caregivers so that the child can generalize the behavior across settings and with different people.

### Lesson Example 2: How to Respond to the Presence of Household Cleaning Chemicals

**Set up:** For this lesson, you will need to empty a container of cleaning chemicals. Once the container is safe and chemical-free, it should be filled with water. This way, the child cannot be harmed throughout the lesson, but is unaware that the container is different than those with cleaning chemicals he or she should avoid. The lesson also requires the participation of a primary caregiver and a prompter.

**Rules:** The child should be provided with clear rules such as "Never touch any cleaning chemicals," "Leave the room if you see cleaning chemicals," and "Tell Mom if there are any chemicals out." If three rules are too many to begin with, then start with fewer rules and work your way up. You know your child best and should plan the lesson based on his capabilities.

**Prompting:** The primary caregiver pretends to be cleaning using the chemical container (which is now safely filled with water). The caregiver then leaves the room without putting the chemicals away. If the child does not respond to the situation correctly in 5 seconds (not touching the chemicals, leaving the room, and informing the caregiver of the chemicals), then the prompter should give the child a verbal prompt. An example of this would be, "Go tell Mom about the chemicals." If the child does not respond correctly within 5 seconds of the verbal prompt, then the prompter should give the child a partial physical prompt. An example of this would be to point in the direction of the room where the parent is located. If the child does not respond correctly to the partial physical prompt within 5 seconds, then a more direct physical prompt should be used. An example of this would be to physically guide the child gently with your hand in the direction of the room where the parent is located.

**Feedback**: Immediate and enthusiastic praise should be given to the child upon correctly responding, whether the child responds correctly immediately, after the verbal prompt, or after the physical prompt.

#### Lesson Example 3: What to Do if You Get Lost in a Public Space

**Set up:** Pick a public space in your community to perform the lesson. This could be a local mall, food court, park, neighborhood pool, or any number of commonly visited areas. For this example, we will use the mall as the setting. The lesson will require a caregiver and a prompter. You may want to inform a store employee about your lesson because the skill will include his or her participation as well.

**Rules:** Provide the child with a clear set of rules (e.g., if you get lost, you should find Mom or Dad. If that doesn't work, then go find a worker and tell him or her that you are lost.).

**Prompting:** After reviewing the rule, the child's caregiver should walk away quietly while the child is looking at an item. Once alone, if the child does not realize his or her situation, then the prompter should make it clear that the child is now "lost." The prompter could say, "Oh no, where's Mom? Uh oh, we're lost." If the child does not begin to react correctly within 5 seconds (e.g., search for caregiver or begin to locate a worker), then the child should be given a verbal prompt, such as "What are you supposed to when you are lost?" If the child does not respond correctly to the verbal prompt within 5 seconds, then the prompter should give a more direct verbal prompt, such as "Go find Mom" or "Go find a worker." If the child does not respond correctly to this within 5 seconds, then provide the child with an indirect physical prompt, such as pointing at the child's mother. If this still is not effective, then provide the child with a direct physical prompt, such as gently guiding him to his parents or to the worker.

**Feedback:** Immediate and enthusiastic praise should be given to the child upon correctly responding, whether the child responds correctly immediately, after the verbal prompt, or after the physical prompt.

#### Lesson Example 4: How to Pay for a Train Ride

**Set up:** This lesson takes place at a train station and requires a prompter and child. It includes an example task analysis (i.e., a step-by-step breakdown of a task) on how to pay for a train ride, and a completed rubric that was used to track a child's performance over multiple trials.

**Rules:** The child should be provided with clear rules such as "use only one coin in the machine."

**Prompting:** Use the following instructions to explicitly teach the student how to pay for a train ride. If after 5 seconds the child does not perform the next task, then provide a verbal prompt (e.g., "Find the entrance"). If after 5 seconds the child does not respond to the verbal prompt, then the prompter should guide the child with an indirect physical prompt, then a direct physical prompt if necessary.

#### Instructions

- 1. Locate the train station and enter.
- 2. Locate and walk up to the booth.
- 3. Take the travel pass out of your pocket using your index finger and thumb.
- 4. Locate the card slot at the top of the coin machine.
- 5. Orient the travel pass into the card slot and slide it through. You should hear a beep.
- 6. Push the turnstile using your hand and walk through.

**Feedback:** Immediate and enthusiastic praise should be given to the child upon correctly responding, whether the child responds correctly immediately, after the verbal prompt, or after the physical prompt.

Da	nte:	October 9, 202	14			
Cł	nild's Name:	John Smith	John Smith			
		Trial 1	Trial 2	Trial 3	Trial 4	
1.	Locate the train station and enter.	3 3	3	2	1	
2.	Locate and walk up to the booth.	3	2	2	1	
3.	Take the travel pass out using index finger and thumb.	4	3	2 2	2	
4.	Locate the card slot at the top of the coin machine.	3	2	1	1	
5.	Orient the travel pass into the card slot and slide it through.	4	3	2	1	
6.	Push the turnstile using your hand and walk through.	4 3	4	2 2	2	

### Lesson Example 4 Rubric: How to Pay for a Train Ride

Indicate the **type** of prompt used for each step.

- **1** = Independent (*performed step without any verbal or physical prompts*)
- **2** = Verbal prompt (e.g., "Stop here," or "Now what do we do?")
- **3** = Indirect physical prompt (e.g., pointing)
- **4** = Direct physical prompt (e.g., hand-over-hand assistance)

### Lesson Example 5: How to Cross the Street

**Set up:** Before practicing how to cross a street at a real intersection, start with covering the basics. Use toy cars, pictures of traffic lights, and videos of pedestrians walking at intersections, to make sure that the child knows the fundamentals (e.g., traffic light colors, crosswalk area, etc.). Once the child has demonstrated an understanding of the basics, practice crossing the street in a controlled environment (e.g., an intersection with limited traffic). In the beginning trials, start by holding the child's hand. After multiple successful trials, use your discretion to begin letting the child walk further distances away without holding his hand. Remember to observe how consistently he performs in multiple crossings and at different times of the day.

**Rules**: Deliver clear instructions for what to do in certain situations (e.g., "Stop at the intersection").

**Prompting**: At a real intersection, the prompter should be within arm's reach of the child to give immediate feedback and to ensure the child's safety. Use the following instructions as a guide to delivering clear prompts. For example, the prompter can say on step 3 (see below), "The light is green. You can cross the street when the light is green." Use indirect and direct physical prompts if necessary.

Instructions		Example Visual*
1.	Walk to intersection.	Picture of boy walking up to street intersection
2.	Stop at intersection. Do not cross yet.	Picture of boy standing at street intersection
3.	Identify traffic light color and make decision.	<i>Pictures of traffic lights (red, yellow, green, pedes-</i> <i>trian variants, etc.)</i>
	"What color is the light?"	
	"Can we walk on?"	
4.	Look both ways to see if it is	Video 1: Cars moving
	safe to cross the street.	Video 2: Cars not moving
	"Is it safe to cross the street?"	
5.	Use only the crosswalk area	Yes: Picture of someone using crosswalk
	between the white lines of the street.	No: Picture of someone not using crosswalk
6.	Cross the street quickly.	Model behavior

\*Use pictures of familiar places and people whenever possible.

**Feedback:** Immediate and enthusiastic praise should be given to the child when he exhibits the appropriate skill correctly (e.g., when he correctly identifies the traffic light as red and waits for it to turn green before walking). The child can never fail the task because the prompter will guide the child as needed until the skill is performed, which is always followed immediately by positive feedback.

Lesson Example 5 Rubrid	: How to Cross the Street
-------------------------	---------------------------

Date:				
Student Name:				
	Trial 1	Trial 2	Trial 3	Trial 4
1. Walk to intersection.				
2. Stop at intersection.				
3a. Identify traffic light color				
(if not applicable, then write N/A).				
3b. Make correct walking deci- sion (Y = Yes, N = No)				
4a. Look both ways.				
Moving car or red light = Don't walk				
No moving car + green light = Walk				
4b. Is it safe to cross the street?				
Moving car or red light = Don't walk				
No moving car + green light = Walk				
5. Use crosswalk.				
6. Crossing pace.				
(R = Run, W = Walk, S = Slow)				

### **Rubric Codes:**

Y = Yes; N = No

Checkmark = correct response; X = incorrect response

### **Conclusion and Tips**

You can easily apply these examples to create your own modified lessons for a variety of other safety skills. Some important skills to teach are what to do if you get lost, what to do if you are approached by a stranger, and what to do in a fire/fire drill. All of these skills and many more can be taught with rules, prompting, and feedback if you organize your lesson well and practice often!

It is important to keep the rules given to the children at the beginning of the lesson simple and clear. If a child is given a list of eight rules involved in the skill, then it is going to be extremely difficult to remember what to do. Remember to keep the number of rules, the complexity of the rules, and the difficulty of the task in mind when creating your lesson. If the safety skill is complex by nature, such as knowing how to cross a street independently, then chunk the task into smaller lessons. For example, you can take lesson five and break it down into "how to look both ways before crossing the street" and "how to cross the street based on traffic colors."

During the lesson, it is helpful to prompt the child less and less after each trial. You can prevent the child from becoming dependent on the prompter's cues by gradually decreasing the amount of prompting. It may be necessary to use physical prompting during the lesson at first, but after some practice, the amount of prompting should be reduced gradually until the child can perform the skill without any prompting at all.

Remember that every child is different and, as a caregiver, you know your child best. The type of feedback that will be most successful in teaching safety skills will differ amongst children. Feedback can range from giving the child verbal praise to awarding the child with a reinforcing token reward whenever the correct skill is demonstrated. It can even be game time on a tablet after successful completion of the entire task. Whatever type of feedback works best for your child is the type that you should incorporate into your lesson.

Finally, whatever skill you apply to this lesson plan, remember to practice, practice, practice? Practice as much as you can until the child can confidently respond to the situation safely and without prompting on a consistent basis. Once the child masters the skill, practice it occasionally to keep the lesson fresh.

#### Design Your Own Lesson Plan

#### Safety Skill: What to Do When You Are Lost in a Public Space

#### Set Up:

Setting: Mall

People: Caretaker, Prompter, Store Employee

**Other:** After explaining the rules, the caregiver should quietly walk away from the child while the child is looking at an item.

#### **Rules:**

If you get lost, then you should yell out "Mom!" or "Dad!"

If that doesn't work, then go find a worker and tell him or her that you are lost.

#### Prompting:

- 1) If the child does not realize he or she is lost, then give the verbal prompt, "Oh no, where's Mom? Uh oh, were lost."
- 2) If the child does not begin to act correctly (yelling out "Mom!" or "Dad!," or notifying an employee) within 5 seconds the first prompt, then give the slightly more direct prompt, "What are you supposed to do when you are lost?"
- 3) If the child does not begin to act correctly within 5 seconds of the second prompt, then give the direct verbal prompt, "Go find Mom" or "Go find a worker."
- 4) If the child does not begin to act correctly within 5 seconds of the third prompt, then give the partial physical prompt of pointing in the direction that caretaker is in.
- 5) If the child does not begin to act correctly within 5 seconds of the partial physical prompt, then give the child a direct physical prompt by gently guiding him to his caretaker.

This child never fails the task because the amount of prompting may be adjusted to ensure the child performs the skill correctly. Gradually reduce the amount of prompting as the child improves so that the child does not become prompt dependent.

#### Feedback:

Immediate and enthusiastic praise should be given to the child upon correctly responding, whether the child responds correctly immediately, after the verbal prompt, or after the physical prompt.

For the best results, the child should practice the lesson as often as possible until the child responds correctly without prompting 10 times in a row. Once the skill is developed and the child shows that he or she can respond correctly on a consistent basis, it is important to practice the skill occasionally to sustain the desired behavior. It will be helpful to practice the skill in a variety of locations, such as other public malls, a public pool, a park, or a food court, so that the skill may be generalized to getting lost in any public area.

### Design Your Own Lesson Plan

Safety Skill: \_\_\_\_\_

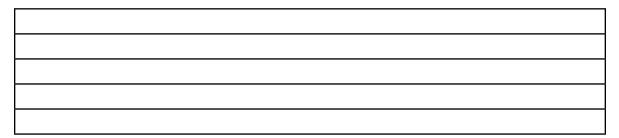
Set Up:

Setting:	
People:	
Other:	

**Rules:** 

### **Prompting:**

### Feedback:



# Appendix F Wandering Log

The following page includes a wandering log template. You can use this template to track your child's wandering events and data summary.

Guardian's Name:	Guardian's Name:		Date:	
Date / time	where/whom?	Behaviors displayed before wandering	Was found at	Possible reason(s) for wandering:
SUMMARY				
My child:			_has wandered/elc	has wandered/eloped in the past to (fill in as they apply):
□ Avoid		. I wi	ill help my child b	I will help my child by (teaching alternative behavior, etc.):
Find out / 1 scheduled ti	Find out / follow / obtain	. I will h	a controlled and sa	
		Be specific!	ici	

# Appendix G



## Autism Emergency Contact Form

Place

Photo

Name of Child/Adult with Autism			Nickname (if any)	неге	
Date of Birth	Height	Weight	Eye Color	Hair Color	
Medical Conditions Scars or Identifying Marks					
Address City, State, Zip Home Phone Other Phone					
Method of Communic	ation, if non-verbal: si	gn language, picture b	oards, written word, etc		
Identification Worn: (e	ex. Jewelry/Medic Aler	t®, clothing tags, ID ca	ard, tracking monitor, et	c.)	
Current Prescriptions	(include dosage):				

	r
Sensory/Medical/Dietary issues and requirements, if any:	Medical Care Providers
	Name/Phone:
Inclination for wandering behaviors or characteristics that may attract attention:	Name/Phone:
	Parent/Caregiver Info
	Name:
Favorite attractions or locations where person may be found, if missing:	Address:
	Home/Other Phone:
Likes/Dislikes (Include approach and de-escalation tech-	Other Contact Info:
niques:	Emergency Contact Info
	Name:
Please attach any additional information.	Address:
Use extra paper if necessary.	Home/Other Phone:

For additional information & tips, please go to www.AutismRiskManagement.com

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# Appendix H Family Wandering Emergency Plan

### For Searchers: Map of Local Area

**Tips for parents:** Have a printed Google map of an area that is frequented often by your child (e.g., around home, school, or points of child interest). Prepare it before a wandering event happens. Highlight dangerous areas (e.g., bodies of water) and points of known or possible interest to your child.

MAP: (location)		

#### Map Key

- ] Dangerous Area
- ] Point of Interest

WHEN YOU APPROACH MY CHILD:

• DO: \_\_\_\_\_

PLEASE DO NOT: \_\_\_\_\_\_

CALL THIS NUMBER AS SOON AS POSSIBLE:

# family wandering emergency plan awaare.org

Make sure your family has a plan in case of a wandering emergency. Before an emergency happens, sit down together and decide how you will get in contact with each other, where you will go and what you will do in an emergency. Keep a copy of this plan in your emergency supply kit or another safe place where you can access it in the event your child is missing.



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#### critical information to remember

#### MY CHILD'S TRANSMITTER TRACKING NUMBER (if applicable)

#### MY CHILD'S OFFICIAL DIAGNOSIS\_

MY CHILD'S IDENTIFYING MARKS, BEHAVIORS, MEDICATIONS & MEDICAL NEEDS\_

#### emergency steps:

# ☑ ALWAYS CALL 911 IMMEDIATELY IF YOUR LOVED ONE IS MISSING FROM YOUR HOME. ☑ IF YOUR CHILD IS ATTRACTED TO WATER, SEARCH NEARBY WATER SOURCES FIRST.

Clearly state your child's name for the 911 operator.

State that they have a cognitive impairment, provide the diagnosis, state they are endangered and have no sense of danger.

- Provide your child's radio frequency tracking number (if applicable).
- V Provide your child's date of birth, height, weight, and other unique identifiers (eyeglasses, braces, hand-flapping, etc.)
- V If your child is attracted to water; tell them to immediately dispatch personnel to nearby water sources (lakes, ponds, pools)
- I Tell them when you noticed that your child was missing and what clothing he or she was wearing.
- Request an AMBER Alert be issued, or Endangered Missing Advisory.
- ✓ Request that your child's name and identifying information be immediately entered into the National Crime Information Center (NCIC) Missing Person File.

Search known areas your child would likely be or attracted to. If you have an emergency point person assigned to contact neighbors, pick up your other children from school, watch your children, etc., alert them while searching known areas your child would likely be. **If you have other small children, never leave them unattended**.

## TIP: create an emergency point person who can contact neighbors, fax your alert form to local law enforcement, and assist in making arrangements for your other children.

Should your child go missing, make sure this contact has a cell phone, knows what your child is wearing, any identifying features, where you child was last seen, how long your child may have been gone, any medical needs or allergies your child may have, your child's likes and dislikes and main attractions. Ideally, the emergency contact will be a relative or close friend. Provide your emergency contact with a copy of this plan and ask them to keep it in a safe, accessible place.

#### EMERGENCY CONTACT NAME: \_\_\_\_\_ EMERGENCY CONTACT NUMBER: \_

**TIP: list the main places your child may likely go within the neighborhood, as well as the most dangerous areas nearby, such as ponds, lakes, pools, etc.** Search these areas **first**. If you have assigned "search angels" ahead of time, make sure they know which location is assigned to them. Draw maps of these locations, or physically show the volunteers the location to which they are assigned **before** an emergency happens.

LOCATION NAME	LOCATION DESCRIPTION
1.	
2.	
3.	
4.	
5.	

**TIP:** Before an emergency happens, assign at least five (5) willing "search angels" who will commit to searching for your child in the event of an emergency. Make sure they would be immediately available (are typically home), willing, and understand which search location is assigned to them.

NAME	NUMBER	NUMBER	ASSIGNED LOCATION

#### **OTHER NUMBERS:**

**LAW ENFORCEMENT FAX NUMBERS:** (in case local law enforcement does not have your child's information on file, have your assigned emergency point person fax it.)

National Center for Missing & Exploited Children (NCMEC): 1-800-THE-LOST (1-800-843-5678) LOCAL MEDIA CONTACT NUMBERS:

\_ \_

**OTHER NOTES:** (make any notes you feel may be important in case of a wandering emergency.)

**TIPS:** JOIN "NAA AUTISM & SAFETY: WANDERING PREVENTION" ON FACEBOOK so that social media tools are readily available. Keep this document with you at all times. Keep a copy in a safe, accessible place within the home. Keep this with your child's first responder alert form, documentation of diagnosis, medical papers and any other important information.

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#### Appendix H



#### AUTISM ELOPEMENT ALERT FORM

Date Submitted:\_

PERSON-SPECIFIC INFORMATION for FIRST RESPONDERS

TOOLKII				   !
Individual's Name				_
(First)	(M	l.l.) (Last)		Attach current
Address:(Street)		(City)	(State) (Zip)	_ photo here
Date of Birth	Age	Preferred Name		
Does the Individual live a	alone?			<u></u>
Individual's Physical Des	cription:			
MaleFemale	Height: W	eight: Eye	color:	Hair color:
Scars or other identifying	g marks:			
Other Relevant Medical	Conditions in addition to	o Autism (check all that apply	:	
No Sense of Danger	BlindDeaf	Non-Verbal	Mental Retarda	ation
Attracted to Water	Prone to Seizures	Cognitive Impairmer	ntOther	
If Other, Please explain:				
Prescription Medications	needed:			
	:f			
Sensory or dietary issues	s, if any:			
Calming methods, and ar	ny additional informatio	on First Resonders may	need:	
EMERGENCY CONTACT I				
		c Hood of Household /D	asidanca ar Car	Drovidors)
Name of Emergency Con	tact (Parents/Guardians	s, nead of household/R	esidence, or Care	e Providers):
Emorgoney Contact's Adv				
Emergency Contact's Add	(Street)		(City)	(State) (Zip)
Emergency Contact's Pho	one Numbers:			
Home:	Work:	Cell P	hone:	
Name of Alternative Eme	ergency Contact:			
Home:				

Information Specific to the Individual continued on next page.

INFORMATION SPECIFIC TO THE INDIVIDUAL

Nearby water sources & favorite attractions or locations where the individual may be found:

Atypical behaviors or characteristics of the Individual that may attract the attention of Responders:

Individual's favorite toys, objects, music, discussion topics, likes, or dislikes:

Method of Preferred Communication. (If nonverbal: Sign language, picture boards, written words, etc.):

Method of Preferred Communication II. (If verbal: preferred words, sounds, songs, phrases they may respond to):

Identification Information. (i.e. Does the individual carry or wear jewelry, tags, ID card, medical alert bracelets, etc.?):

Tracking Information. (Does the individual have a Project Lifesaver or LoJack SafetyNet Transmitter Number?):

- MANY CHILDREN WITH AUTISM ARE DRAWN TO WATER. SEARCH & SECURE NEARBY WATER SOURCES FIRST.

- REVERSE 911 IS AN EFFECTIVE TOOL FOR FINDING A MISSING CHILD AND FREE TO AGENCIES. VISIT achildismissing.org.

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#### Appendix H

# Appendix I How to Talk to a Neighbor About Wandering

This appendix is designed to provide useful tips on how to explain autism and your child's tendency to wander to your neighbors. Engaging your neighbors and making them part of your extended safety network can help you and your family prevent a possible emergency situation, and help manage one if it arises.

When explaining autism and wandering to neighbors, it is always a good idea to:

- Let them meet your child. Introduce him to your neighbors so that they're as familiar with each other as possible. Describe his tendencies, preferences, and what rules you have in place about being outdoors unsupervised.
- Leave your contact information and a flyer with a picture of your loved one.

Ask your neighbors to call the number on the flyer immediately if they see your loved one wandering unaccompanied, and to notify the authorities if they cannot reach you or anyone at your home. To better prepare them for interacting with your child, tell them a little about autism and let them know that people with autism:

Fixate on things that others might not, such as water or trains.

- Are sensitive to loud noises and bright light.
- Might not make eye contact, respond to commands, or come when their name is called.

Advise neighbors that when approaching your child, it's best to:

- Speak calmly and softly.
- Avoid using figurative language (e.g., slang).
- Allow for a delayed response from your loved one.
- Be prepared to repeat themselves.

Here are some additional points you may want to cover:

- Explain that you are not a negligent caregiver; people with autism are known to wander.
- If your neighbor has a pool or an outdoor pond, then explain that people with autism tend to be attracted to water, and ask permission to search that area first.
- Ask if there are locks that prevent someone from accessing water sources; if not, then ask about potentially installing them.
- If your neighbor is amenable to the idea, then suggest putting up stop signs on the doors leading to the pool or pond.

## **Additional Resources**

The following are some materials created by well-known autism safety expert Dennis Debbaudt. These materials can be helpful when explaining to neighbors how to interact with your loved one when he has wandered. Though designed for law enforcement, the materials provide useful guidance for interacting with individuals on the spectrum during an emergency situation.

Avoiding Unfortunate Situations: Autism and Law Enforcement http://www.poac-nova.org/pdfs/Debbaudt%20AUS%20Handout.pdf

Autism and Law Enforcement: 25 Field Response Tips http://autismriskmanagement.com/documents/Law\_Enforcement.pdf

The following are links to toolkits created as part of the National Autism Association's *Autism Wandering Alert Awareness Education* (AWAARE) collaboration:

For caregivers:

http://nationalautismassociation.org/docs/BigRedSafetyToolkit.pdf

For first responders:

http://nationalautismassociation.org/docs/BigRedSafetyToolkit-FR.pdf

# Appendix J Threat Detection Scale

The purpose of this scale is to help your child recognize when a situation might be unsafe, and to be better prepared to take action if necessary. The example below is written for a school-aged child who is putting himself in danger by responding to adult strangers outside the home. Once you have read it, fill in the template at the bottom of the page with your child, focusing on a relevant safety concern specific to your child. Complete one for each major safety topic you are teaching.

Rating	Looks like	Feels like	What should I do?
5	Someone I don't know wants me to go somewhere with them	Scared, shaky, afraid	Walk away quickly or yell for Mom or Dad to come help
4	Someone I don't know is trying to talk to me	Nervous, anxious	Walk away fast, find Mom or Dad, and tell them what happened
3	Someone I think I know but am not quite sure	Confused, curious	Go ask Mom or Dad to come talk to the person with you
2	Teacher, therapist, coach, or someone else I know well	Excited, happy	Make sure Mom or Dad knows who I'm with and ask before going anywhere
1	Parent, grandparent, or another relative	Calm, comfort- able, like I feel at home	Stay nearby and ask before going somewhere else

Rating	Looks like	Feels like	What should I do?
5			
4			
3			
2			
1			

#### Adapted from:

Buron, K., & Curtis, M. (2003). *The incredible 5-point scale: Assisting students with Autism Spectrum Disorders in understanding social interactions and controlling their emotional responses*. Shawnee Mission, KS: Autism Asperger Publishing Company.

To download and print blank worksheets, go to:

https://www.aapcpublishing.net/9936

# **Appendix K** Sample Identification Documents

## For Children and Adolescents

This is a sample identification card meant to help community members (e.g., neighbors, first responders, etc.) identify a child with special needs after they have wandered off, or in the event of an emergency. It is written for an unspecified child with autism, but should serve as a guide for how you would want a similar document to look like for your child. Regardless of what information you choose to include, it is your responsibility to teach your child how to use the card properly.

## DISABLED CHILD—PLEASE HELP ME

My name is:

I have AUTISM. This is a developmental disorder. I do not speak or understand danger. I become lost very easily and may not know that I am lost.

I may have outbursts, pinch, scream, shake my arms and hands, or act in other unusual ways, particularly when I am under stress.

HOWEVER, I AM NOT DANGEROUS. I DO NOT HAVE OR USE ANY KIND OF WEAPON. I NEVER INTEND TO HARM ANYONE.

My mother's name is:	Phone number:
My father's name is:	Phone number:
My doctor's name is:	Phone number:

If you have found me in a store or a building with a public address system, then please ask someone to page my mother and father. Do not leave me alone or let me wander off. If you cannot locate my parents, then please call the police or an ambulance.

I am on the following medications:

## **REWARD FOR MY RETURN**

## Adapted from:

Hasselbrink, G. (2014). *Autism safety*. Retrieved from <u>http://hasselbrink.com/autsafety</u>. <u>html</u>.

## For Adult Self-Advocates

This is a sample identification card meant to help an adult with autism communicate with community members, particularly first responders, during an emergency situation. It has been written for an unspecified individual with autism, but should serve as a guide to help you tailor a similar document to your own specific needs.

I HAVE AUTISM				
My name is:				
City:	State:	ZIP:		
Date of Birth:		Home Phone:		
In cases of emergency, or to help both you and me better communicate to resolve this situation, please contact one of the following people:				
Name:		Name:		
Relationship:		Relationship:		
Phone number:		Phone number:		

I have autism, a condition that impairs my ability to communicate with others. Because of my autism, I may:

- □ Panic if yelled at, and lash out if touched or physically restrained.
- □ Misinterpret things you tell me or ask me to do.
- □ Not be able to answer your questions.
- □ Appear not to be listening or paying attention.
- □ Tend to interpret statements literally.
- □ Have difficulty making eye contact.
- Speak too loudly, too softly, or with unusual intonation.
- Appear rude or say things that sound tactless, especially when anxious or confused.

I would like to cooperate. To help me do so, please:

- Clearly identify yourself.
- □ Call one of my emergency contacts (see reverse side of this card).
- Do not assume that my traits constitute suspicious behavior.
- Avoid touching or restraining me.
- **G** Speak to me in normal, calm, non-confrontational tones.
- Tell me exactly what I need to do, politely, clearly, simply, literally, and in a stepby-step manner.

#### Adapted from:

Asperger's Association of New England. (2006). *Wallet card for disclosure to first responders and law enforcers*. Retrieved from <u>http://www.aane.org/docs/resources\_aane\_</u> <u>wallet\_card.pdf</u>.

Appendix K

## Appendix L Bullying Letter from the Office of Special Education and Rehabilitative Services

Starting on the following page, this appendix includes a letter and enclosed memo on the subject of bullying. It was released in 2013 by the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS), and covers the following topics:

- The nature of school bullying
- Bullying of students with disabilities
- Overview of school district and IEP team responsibilities to address and report bullying
- Rights to a Free and Public Education in relation to school bullying
- Effective evidence-based practices for preventing and addressing bullying
- Resources on preventing and addressing bullying



UNITED STATES DEPARTMENT OF EDUCATION OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES

AUG 2 0 2013

Dear Colleague:

The U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS) is committed to working with States to ensure that school districts provide all children with positive, safe, and nurturing school environments in which they can learn, develop, and participate. OSERS is issuing this letter to provide an overview of a school district's responsibilities under the Individuals with Disabilities Education Act (IDEA) to address bullying of students with disabilities.<sup>1</sup>

As discussed in this letter, and consistent with prior Dear Colleague Letters the Department has published, bullying of a student with a disability that results in the student not receiving meaningful educational benefit constitutes a denial of a free appropriate public education (FAPE) under the IDEA that must be remedied.<sup>2</sup> However, even when situations do not rise to a level that constitutes a denial of FAPE, bullying can undermine a student's ability to achieve his or her full academic potential. Attached to this letter are specific strategies that school districts and schools<sup>3</sup> can implement to effectively prevent and respond to bullying, and resources for obtaining additional information.

Bullying of any student by another student, for any reason, cannot be tolerated in our schools.<sup>4</sup> Bullying is no longer dismissed as an ordinary part of growing up, and every effort should be made to structure environments and provide supports to students and staff so that bullying does not occur. Teachers and adults should respond quickly and consistently to bullying behavior and

<sup>3</sup> In the context of this letter "school" includes public preschools; elementary, middle, and high schools; and public agencies, including the State Educational Agency (SEA), Educational Service Agencies (ESA), Local Educational Agencies (LEA), nonprofit public charter schools that are not otherwise included as LEAs or ESAs and are not a school of an LEA or ESA, and any other political subdivisions of the State that are responsible for providing education to children with disabilities. See 34 C.F.R. §300.33.

<sup>4</sup> Although the focus of this letter is peer-to-peer bullying, it is important to acknowledge that it is also intolerable for teachers and school staff to be party to school bullying and disability harassment (*i.e.*, being active participants in bullying), or observers to school bullying without taking action to address the behavior. While teacher-student disability harassment also may constitute a denial of FAPE, those issues are beyond the scope of this letter. We recommend that States and school districts consult with legal counsel regarding their responsibilities and duties in cases of bullying that involve school personnel, including taking the matter seriously, and promptly addressing any problematic behaviors.

400 MARYLAND AVE. S.W., WASHINGTON, DC 20202-2600

www.ed.gov

The Department of Education's mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access.

<sup>&</sup>lt;sup>1</sup> This letter is intended to supplement the July 25, 2000, joint Dear Colleague Letter from OSERS and the Department's Office for Civil Rights (OCR), which addressed disability harassment under Section 504 of the Rehabilitation Act of 1973 (Section 504), Title II of the Americans with Disabilities Act of 1990 (Title II of the ADA), and the IDEA (available at: <a href="http://www.ed.gov/ocr/docs/disabharassltr.html">http://www.ed.gov/ocr/docs/disabharassltr.html</a>).

<sup>&</sup>lt;sup>2</sup> Some bullying of students with disabilities may also constitute discriminatory harassment and trigger additional responsibilities under the civil rights laws that OCR enforces, including Section 504, Title II of the ADA, Title VI of the Civil Rights Act of 1964, and Title IX of the Education Amendments of 1972. See OCR's October 26, 2010, Dear Colleague Letter on Harassment and Bullying (available at: <u>http://www.ed.gov/ocr/letters/colleague-201010.html</u>).

#### Page 2 - Dear Colleague: Bullying of Students with Disabilities

send a message that bullying is not acceptable. Intervening immediately to stop bullying on the spot can help ensure a safer school environment.

Bullying is characterized by aggression used within a relationship where the aggressor(s) has more real or perceived power than the target, and the aggression is repeated, or has the potential to be repeated, over time. Bullying can involve overt physical behavior or verbal, emotional, or social behaviors (*e.g.*, excluding someone from social activities, making threats, withdrawing attention, destroying someone's reputation) and can range from blatant aggression to far more subtle and covert behaviors. Cyberbullying, or bullying through electronic technology (*e.g.*, cell phones, computers, online/social media), can include offensive text messages or e-mails, rumors or embarrassing photos posted on social networking sites, or fake online profiles.

Addressing and reporting bullying is critical. Students who are targets of bullying behavior are more likely to experience lower academic achievement and aspirations, higher truancy rates, feelings of alienation from school, poor relationships with peers, loneliness, or depression.<sup>5</sup> Bystanders, or those who only see or hear about bullying, also may be negatively affected as bullying tends to have harmful effects on overall school climate. Bullying can foster fear and disrespect and negatively affect the school experience, norms, and relationships of all students, families, and school personnel.<sup>6</sup> The consequences may result in students changing their patterns of school participation or schools eliminating school activities (*e.g.*, dances, sporting events) where bullying has occurred. Teachers, school personnel, parents, and students should report bullying when they become aware of it.

Students with disabilities are disproportionately affected by bullying.<sup>7</sup> For example, students with learning disabilities, attention deficit or hyperactivity disorder, and autism are more likely to be bullied than their peers.<sup>8</sup> Any number of factors -- physical characteristics, processing and social skills, or intolerant environments -- may increase the risk that students with disabilities will be bullied. Due to the characteristics of their disabilities, students with intellectual, communication, processing, or emotional disabilities may not understand the extent to which bullying behaviors are harmful, or may be unable to make the situation known to an adult who can help. In circumstances involving a student who has not previously been identified as a child with a disability under the IDEA, bullying may also trigger a school's child find obligations under the IDEA. 34 C.F.R. §§300.111, 300.201.

Whether or not the bullying is related to the student's disability, any bullying of a student with a disability that results in the student not receiving meaningful educational benefit constitutes a

<sup>&</sup>lt;sup>5</sup> Gini G., & Pozzoli T. (2009). Association between bullying and psychosomatic problems: A meta-analysis. *Pediatrics*, 123(3):1059-1065.

<sup>&</sup>lt;sup>6</sup> O'Brennan, L. M., Bradshaw, C. P., & Sawyer, A. L. (2009). Examining developmental differences in the socialemotional problems among frequent bullies, victim, and bully/victims. Psychology in the Schools, 46(2), 100-115.

<sup>&</sup>lt;sup>7</sup> Swearer, S. M., Wang, C., Maag, J. M., Siebecker, A., B., & Frerichs, L. J. (2012). Understanding the bullying dynamic among students in special and general education. *Journal of School Psychology*, 50, 503-520.

<sup>&</sup>lt;sup>8</sup> Twyman, K. A., Saylor, C. F., Saia, D., Macias, M. M., Taylor, L. A., & Spratt, E. (2010). Bullying and ostracism experiences in children with special health care needs. *Journal of Developmental Behavioral Pediatrics*, 31, 1-8.

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denial of FAPE under the IDEA that must be remedied.<sup>9</sup> States and school districts have a responsibility under the IDEA, 20 U.S.C. § 1400, *et seq.*, to ensure that FAPE in the least restrictive environment (LRE) is made available to eligible students with disabilities. In order for a student to receive FAPE, the student's individualized education program (IEP) must be reasonably calculated to provide meaningful educational benefit.<sup>10</sup>

Schools have an obligation to ensure that a student with a disability who is the target of bullying behavior continues to receive FAPE in accordance with his or her IEP. The school should, as part of its appropriate response to the bullying, convene the IEP Team to determine whether, as a result of the effects of the bullying, the student's needs have changed such that the IEP is no longer designed to provide meaningful educational benefit. If the IEP is no longer designed to provide a meaningful educational benefit to the student, the IEP Team must then determine to what extent additional or different special education or related services are needed to address the student's individual needs; and revise the IEP accordingly. Additionally, parents have the right to request an IEP Team meeting at any time, and public agencies generally must grant a parental request for an IEP Team meeting where a student's needs may have changed as a result of bullying. The IDEA placement team (usually the same as the IEP Team) should exercise caution when considering a change in the placement or the location of services provided to the student with a disability who was the target of the bullying behavior and should keep the student in the original placement unless the student can no longer receive FAPE in the current LRE placement. While it may be appropriate to consider whether to change the placement of the child who was the target of the bullying behavior, placement teams should be aware that certain changes to the education program of a student with a disability (e.g., placement in a more restrictive "protected" setting to avoid bullying behavior) may constitute a denial of the IDEA's requirement that the school provide FAPE in the LRE. Moreover, schools may not attempt to resolve the bullying situation by unilaterally changing the frequency, duration, intensity, placement, or location of the student's special education and related services. These decisions must be made by the IEP Team and consistent with the IDEA provisions that address parental participation.

If the student who engaged in the bullying behavior is a student with a disability, the IEP Team should review the student's IEP to determine if additional supports and services are needed to address the inappropriate behavior. In addition, the IEP Team and other school personnel should consider examining the environment in which the bullying occurred to determine if changes to the environment are warranted.

As discussed above, any bullying of a student with a disability that results in the student not receiving meaningful educational benefit from the special education and related services provided by the school is a denial of FAPE. A student must feel safe in school in order to fulfill his or her full academic potential. We encourage States and school districts to alert Boards of Education, school administrators, teachers, and staff that bullying can result in a denial of FAPE.

http://www.ed.gov/ocr/docs/disaonarassitr.html); and OCK's October 26, 2010, Dear Colleague Letter on Harassment and Bullying (available at: <u>http://www.ed.gov/ocr/letters/colleague-201010.html</u>).

<sup>&</sup>lt;sup>9</sup> OCR also has authority to investigate complaints alleging denial of FAPE under Section 504 and Title II. See the July 25, 2000, joint Dear Colleague Letter on Disability Harassment; (available at: <u>http://www.ed.gov/ocr/docs/disabharassltr.html</u>); and OCR's October 26, 2010, Dear Colleague Letter on

<sup>10</sup> See Hendrick Hudson Central Sch. Dist. Bd. of Educ. v. Rowley, 458 U.S. 176, 201 (1982).

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for students with disabilities. We also encourage States and school districts to reevaluate their policies and practices addressing problematic behaviors, including bullying, in light of the information provided in this letter, as well as in OSERS' July 25, 2000, joint Dear Colleague Letter and OCR's October 26, 2010, Dear Colleague Letter. The enclosure to this letter, "Effective Evidence-based Practices for Preventing and Addressing Bullying," includes practices for use as part of any bullying prevention and intervention program to help ensure that school and classroom settings are positive, safe, and nurturing environments for all children and adults.

We look forward to continuing to work with you to ensure that students with disabilities have access to high-quality services in positive, safe, and respectful school environments.

Sincerely,

Melody Musgrove, Ed. D.

Director Office of Special Education Programs

Michael K. Yudin Acting Assistant Secretary

Enclosure:

Effective Evidence-based Practices for Preventing and Addressing Bullying

#### Enclosure

#### Effective Evidence-based Practices for Preventing and Addressing Bullying

There is no one-size-fits-all or simple solution for addressing bullying behavior. Rather, efforts to prevent and address bullying behavior should be embedded within a comprehensive, multitiered behavioral framework used to establish a positive school environment, set high academic and behavioral expectations for all students, and guide delivery of evidence-based instruction and interventions that address the needs of students, including students with disabilities. In such a framework, policies and practices would be aligned and consistently implemented school wide; that is, across general and special education, each grade level, and in all school settings and activities. Data-based decision making would be used to identify needs, analyze problem situations, outline clear evidence-based practices to be used in delivery of instruction and implementation of interventions, and monitor progress toward clear, positive academic and behavioral outcomes as part of an ongoing, continuous improvement model.

When deciding which strategy or strategies to use to address bullying behavior, each school needs to consider the relevant factors given its school environment, students' social and cognitive development, and the evidence on programmatic prevention and intervention. Teachers, administrators, and staff understand that students' social behavior affects their academic learning. In many high-performing schools, academic instruction is combined with effective behavioral supports to maximize academic engagement and in turn, student achievement. That is, successful schools focus on decreasing academic failure and problem behaviors, including bullying, and increasing opportunities for all students to fully participate in learning. There is a growing body of research on promising school bullying interventions that can inform practice. For example, a metaanalysis of research across a 25-year period found that school bullying prevention programs led to changes in knowledge, attitudes, and self-perceptions of those targeted by bullying, engaging in bullving, and bystanders.<sup>1</sup> Another meta-analysis of school-based programs implemented in the United States and internationally to reduce bullying concluded that overall school-based antibullying programs were often effective in reducing bullying, and identified program elements (*i.e.*, critical practices or strategies) associated with effective programs; but results varied based on context.<sup>2</sup> Experimental research has also demonstrated lower rates of bullying and peer rejection when critical practices or strategies were used within a multitiered behavioral framework.

The following effective evidence-based practices are found in many multitiered behavioral frameworks. We encourage you to carefully consider each of these practices as part of any bullying prevention and intervention program you undertake to help ensure that your school and classroom settings are positive, safe, and nurturing environments for all children and adults.

<sup>&</sup>lt;sup>1</sup> Merrell, K. W., Gueldner, B. A., Ross, S. W., & Isava, D. M. (2008). How effective are school bullying intervention programs? Meta-analysis of intervention research. *School Psychology Quarterly*, *23*, 26-42.

<sup>&</sup>lt;sup>2</sup> Farrington, D. P., & Ttofi, M. M. (2009). School-based programs to reduce bullying and victimization. *Campbell Systemic Reviews*, 2009:6.

<sup>&</sup>lt;sup>3</sup> Bradshaw, C. P., Mitchell, M. M., & Leaf, P. J. (2010). Examining the effects of school-wide Positive Behavioral Interventions and Supports on student outcomes: Results from a randomized controlled effectiveness trial in elementary schools. *Journal of Positive Behavior Interventions*, *12*, 133-148.

#### Use a comprehensive multitiered behavioral framework

Just as important as determining which strategies will be used is knowing how, when, and by whom those strategies will be implemented. Evidence-based instructional and intervention strategies for preventing and addressing bullying of students, including students with disabilities, are most effective when used as part of a comprehensive multitiered behavioral framework that engages the whole school community, and establishes and maintains positive, safe, and nurturing school environments conducive to learning for all students. Providing clear and formal instruction for all students, and staff on how to behave in respectful and responsible ways across all school settings and activities is a vital component of this approach.

Issues related to the bullying of students with disabilities should be included in the topics addressed by the school's comprehensive multitiered behavioral framework, and also as a specific area of focus in policies and practices addressing behavioral expectations. In addition to implementing certain steps for the whole school (*e.g.*, consistent rules and rewards for good behavior), a comprehensive multitiered behavioral framework of instruction and interventions also includes using strategies that address bullying and other problematic behaviors, such as steps for groups of students exhibiting at-risk behavior and individual services for students who continue to exhibit troubling behavior.

Using a comprehensive multitiered behavioral framework for making decisions on identifying, implementing, and evaluating effective evidence-based practices helps schools to: (a) organize evidence-based practices, including those that will be used to address bullying of students with disabilities; (b) support the use of evidence-based practices according to the practice guidelines; and (c) monitor the outcomes for students to determine the effectiveness of the evidence-based practices and need for any additional instruction and intervention. Preventing and addressing bullying of students with disabilities needs to be aligned with, and embedded as part of each school's comprehensive multitiered behavioral planning, and given explicit consideration to ensure that the individual needs of each student with a disability are addressed fully in the school-wide plans for creating and sustaining a positive, safe, and nurturing school environment.

One example of a multitiered behavior framework that school personnel can use to plan, implement, and evaluate evidence-based instruction and intervention practices is Positive Behavioral Interventions and Supports (PBIS). The PBIS framework can help to create an appropriate social culture, learning and teaching environment, achieve academic and social success, and minimize problem behavior, including reducing the risks and decreasing the occurrence of bullying. Using this multitiered framework, school personnel establish a continuum of evidence-based behavioral practices that include school-wide strategies, more intense strategies for groups of students exhibiting at-risk behaviors, and individual services for students who continue to exhibit problematic behavior and need additional support.<sup>4</sup> Rather than offering a packaged curriculum, a manualized strategy, or a prescripted intervention, PBIS provides school personnel with a decision-making structure that they can use to identify, implement, and evaluate effective evidence-based instruction and intervention strategies within a comprehensive multitiered framework to prevent and respond to bullying in their school setting.<sup>5</sup> By outlining a comprehensive school-wide approach

<sup>&</sup>lt;sup>4</sup> Bradshaw et al. (2010).

<sup>&</sup>lt;sup>5</sup> Sugai, G., Horner, R.H., Algozzine, R., Barrett, S., Lewis, T., Anderson, C., Bradley, R., Choi, J. H., Dunlap, G., Eber,

L., George, H., Kincaid, D., McCart, A., Nelson, M., Newcomer, L., Putnam, R., Riffel, L., Rovins, M., Sailor, W., &

with multitiered instruction and intervention, schools work to create school cultures that prevent the development and reduce the occurrence of bullying. In addition, schools are prepared to respond to problematic behavior using a team-based, data-driven problem-solving process when needed.

The following are practices found in many effective, evidence-based behavioral prevention and intervention school-wide frameworks.

#### Teach appropriate behaviors and how to respond

Preventing bullying begins by actively and formally teaching all students and all school personnel: (1) what behaviors are expected at school and during school activities; (2) what bullying looks like; and (3) how to appropriately respond to any bullying that does occur. Specifically, clear behavioral expectations are taught to students and adults in the same manner as any core curriculum subject.<sup>6</sup> Consistency in behavioral expectations from class to class, adult to adult, and across settings is very important in establishing shared and predictable expectations that both students and school personnel understand and follow.

#### Provide active adult supervision

Adults play an important role in actively supervising and intervening early to correct behavior problems, especially in common areas (*e.g.*, hallways, cafeteria, playgrounds, and extracurricular events). By moving continuously throughout an area and having positive interactions with students, adults are able to teach and model expected behavior and routines, notice and reward appropriate behavior, and intervene early so that minor rule violations are handled effectively before problematic behaviors escalate.

#### Train and provide ongoing support for staff and students

Training, ongoing professional development, and support, including coaching, to all personnel on the use of effective evidence-based strategies for responding to inappropriate behavior, including bullying, as well as evidence-based instruction and classroom management practices, are important tools to ensure that school staff are equipped to effectively address bullying. In addition, clear guidance on legal requirements, policy, and practice implications for students with disabilities needs to be explicitly provided in training.

School personnel need to be aware that students with disabilities are significantly more likely than their peers without disabilities to be the targets of bullying.<sup>7</sup> Any number of factors may explain their increased risk of being bullied, including but not limited to the student's physical

Simonsen, B. (2010). School-Wide Positive Behavior Support: Implementers' Blueprint and Self-Assessment. Eugene, OR: University of Oregon.

<sup>&</sup>lt;sup>6</sup> Sugai et al. (2010).

<sup>&</sup>lt;sup>7</sup> Young, J., Ne'eman, A., & Gelser, S. (2011). *Bullying and Students with Disabilities. A Briefing Paper from the National Council on Disability.* Washington, DC: National Council on Disability (available at: <a href="http://www.ncd.gov/publications/2011/March92011">http://www.ncd.gov/publications/2011/March92011</a>).

characteristics, processing and social skills, or simply being in environments with others who are intolerant.<sup>8</sup>

Training is essential in helping school personnel recognize the different forms of bullying that may be directed at students with disabilities, and the unique vulnerabilities these students may have to social isolation, manipulation, conditional friendships, and exploitive behaviors. Students, with and without disabilities, do not always recognize problem behaviors as bullying, or may be reluctant to stand up for themselves or others, seek help, or report bullying due to fear of retaliation, particularly if adults are involved. Due to the complexities of their disabilities, students with intellectual, communication, processing, or emotional disabilities may not understand manipulation or exploitive behavior as harmful, or have the knowledge and skills to explain the situation to an adult who can help.

All students should receive clear, explicit instruction on how to respond to and report bullying. For students with disabilities, instruction on how to respond to and report bullying needs to be provided in a manner consistent with their IEPs and any accommodations that are provided to support learning. In addition, school staff should monitor for bullying and its possible effects on FAPE for students with disabilities, as it is not sufficient for school personnel to rely only on students to report bullying or identify how the bullying is interfering with FAPE.

#### Develop and implement clear policies to address bullying

We encourage schools to develop clear policies and procedures, consistent with Federal, State, and local laws, to prevent and appropriately address bullying of students, including students with disabilities.<sup>9</sup> In these antibullying policies, schools may want to include a reminder that harassment against a student on the basis of disability and retaliation against any student or other person are also prohibited under Section 504, Title II, and other Federal civil rights laws enforced by the U.S. Department of Education's Office for Civil Rights.<sup>10</sup>

Schools should widely disseminate their antibullying policies and procedures to staff, parents, and students, and post the policies in the school and on the school's website. Any published policies and procedures must be accessible to students with visual or other disabilities. Schools should provide ongoing training to staff, parents, and students on their antibullying policies and procedures so that everyone in the school community is aware that bullying behavior will not be tolerated.

<sup>&</sup>lt;sup>8</sup> Young et al. (2011).

<sup>&</sup>lt;sup>9</sup> Under Title II and Section 504, school districts must notify students, parents, and school personnel (including persons with impaired vision or hearing) that the district does not discriminate on the basis of disability; must adopt grievance procedures providing for the prompt and equitable resolution of complaints alleging disability discrimination (including harassment); and must designate at least one person to coordinate compliance with those laws. See 28 C.F.R. § 35.106; 28 C.F.R. § 35.107; 34 C.F.R. § 104.7; 34 C.F.R. § 104.8.

<sup>&</sup>lt;sup>10</sup> It is unlawful to retaliate against an individual for the purpose of interfering with any right or privilege secured by Section 504, Title II, Title VI of the Civil Rights Act of 1964 (Title VI), Title IX of the Education Amendments of 1972 (Title IX), the Age Discrimination Act of 1975 (Age Act), or the Boy Scouts of America Equal Access Act (BSA Act). See 34 C.F.R. § 100.7(e) (Title VI); 34 C.F.R. § 104.61 (Section 504) (incorporating 34 C.F.R. § 100.7(e) by reference); 28 C.F.R. § 35.134 (Title II); 34 C.F.R. § 106.71 (Title IX) (incorporating 34 C.F.R. § 100.7(e) by reference); 34 C.F.R. § 110.34 (Age Act); and 34 C.F.R. § 108.9 (BSA Act) (incorporating 34 C.F.R. § 100.7(e) by reference).

When bullying occurs, school personnel need to respond quickly, to act in accordance with school policies and procedures, and to address the issue in a professional manner. School personnel should be sure to document the response to a bullying incident in writing.

#### Monitor and track bullying behaviors

Collecting and analyzing data on bullying behaviors can provide a clearer picture of what is happening in school and school activities, guide planning of prevention, instruction, and intervention efforts, and inform decision making on the effectiveness of current policies and practices over time. Adults tend to underestimate the rates of bullying because students rarely report it, and it often happens when adults are not around.<sup>11</sup> Thus, data collected from multiple sources, including surveys of students, will help establish a more accurate understanding of bullying behaviors occurring in school and school activities. Data collection should be linked to existing data systems (e.g., attendance, discipline) when possible, and include information such as the frequency, types, and location of bullying behavior, other contextual factors, adult and peer responses, and also perceptions of safety and school climate.

#### Notify parents when bullying occurs

Parents or guardians should be promptly notified of any report of bullying that directly relates to their child in accordance with Federal, State, and local law, policies, and procedures. Clear and accurate communication is needed to inform the parents or guardians of both the student who was the target of bullying behavior and the student who engaged in the bullying behavior.<sup>12</sup> Parents and guardians should also be encouraged to work with their child's teachers and other school personnel to determine the steps that need to be taken to address the bullying and prevent its recurrence.

#### Address ongoing concerns

Expected school behaviors and routines should be taught to and known by all students and staff. Students whose school behavior is not safe, responsible, and respectable, and consistent with the established school expectations may need: (a) more focused social skills instruction; (b) frequent, specific feedback on their behavior, or (c) increased adult engagement.<sup>13</sup> School personnel should use data measuring an individual student's responsiveness to antibullying instruction and intervention to determine the need for continued, more intensive, and specialized assistance for each student.

Additionally, if a school suspects that bullying is becoming a problem school-wide, a team-based and data-driven problem-solving process should be initiated. Such an approach should examine discipline and performance data to determine: (1) the current status of bullying, including how

<sup>&</sup>lt;sup>11</sup> Cohen et al. (2009).

<sup>&</sup>lt;sup>12</sup> The Family Educational Rights and Privacy Act (FERPA), 20 U.S.C. § 1232g, restricts the nonconsensual disclosure of personally identifiable information from a student's education record, including information on disciplinary actions taken against a student. State and local officials are encouraged to seek guidance to be sure that all policies are implemented consistent with these provisions.

<sup>&</sup>lt;sup>13</sup> Sugai et al. (2010).

often, when, and where specific bullying incidents occur, how many and which students are involved, including whether any are students with disabilities, and which adults, if any, are involved; (2) the extent to which positive school-wide behavioral expectations have been explicitly taught, as well as the extent to which students easily and naturally meet those expectations by routinely behaving in a manner consistent with the expectations at school and school activities; and (3) whether all students are actively academically engaged, successful, and appropriately challenged. Based on the data, a common strategy should be outlined to address the settings (*e.g.*, hallways, cafeterias, and buses) and situations (*e.g.*, unstructured class time, transitions, field trips, and during assemblies) in which bullying frequently occurs. The strategy should include certain steps that will be taken for the whole school (e.g., consistent rules and rewards for good behavior), more intense steps that will be taken for groups of students exhibiting at-risk behavior, and individual services that will be provided for students who continue to exhibit problematic behavior.

#### Sustain bullying prevention efforts over time

Prevention of bullying should be ongoing, and accepted as an integral component of the school's overall behavioral framework that delineates a school's environment and routine operation. We must remain mindful of the importance of providing positive, safe, and nurturing environments in which all children can learn, develop, and participate. Just as each year schools work to maximize academic engagement and learning outcomes for all students, including students with disabilities, we also must take steps to prevent and address bullying behavior. Effective, evidence-based practices created and sustained within a comprehensive multitiered framework will prevent the occurrence and reduce the impact of bullying in our schools, and also enhance learning and developmental outcomes for all students.

#### **Resources on Preventing and Addressing Bullying**

Additional information about preventing and addressing bullying behavior is available from the resources listed below.

- **StopBullying.gov** This U.S. government website is hosted by the U.S. Department of Health and Human Services in partnership with the U.S. Department of Education. It provides information on how kids, teens, young adults, parents, educators, and others in the community can address bullying behaviors. Information about cyberbullying also is available. <u>http://www.stopbullying.gov</u>
- PACER.org/bullying/ This National Parent Center funded by the Office of Special Education Programs (OSEP) supports families with children with disabilities by providing assistance to individual families, conducting workshops, and providing information through materials and websites. PACER's National Bullying Prevention Center educates communities nationwide to address bullying through creative, relevant, and interactive resources. PACER's bullying prevention resources are designed to benefit all students, including students with disabilities. PACER also hosts TeensAgainstBullying.org, created by and for teens to address bullying. In addition, PACER hosts KidsAgainstBullying.org, designed by and for elementary school students to learn about bullying prevention. <u>http://www.pacer.org/bullying/</u>

- PBIS.org The Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS), funded by OSEP, gives schools capacity-building information and technical assistance for identifying, adapting, and sustaining effective school-wide disciplinary practices. It also: (a) provides technical assistance to encourage large-scale implementation of PBIS; (b) provides the organizational models, demonstrations, dissemination, and evaluation tools needed to implement PBIS with greater depth and fidelity across an extended array of contexts; and (c) extends the lessons learned from PBIS implementation to the broader agenda of educational reform. http://www.pbis.org
- NICHCY.org This national dissemination center funded by OSEP provides a wealth of information on disabilities in children and youth; programs and services available for infants, toddlers, children, and youth with disabilities under IDEA; and research-based information on effective practices for children with disabilities (birth through 21 years of age). Information and links to resources that address bullying relative to children with disabilities are also provided. http://nichcy.org/schoolage/behavior/bullying/
- FindYouthInfo.gov This U.S. government website was developed by 12 Federal agencies, including the Department of Education, in partnership with the White House, to disseminate information and to leverage resources to support programs and services focusing on positive, healthy outcomes for youth. The website provides facts and information on a wide range of topics including bullying, cyberbullying, and positive youth development. It also contains information on assessing community assets, generating maps of local and Federal resources, searching for evidence-based youth programs, and keeping up-to-date on the latest, youthrelated news. Information is provided on funding opportunities available to those interested in addressing bullying and related topics, as well as on Federal funds awarded to states and communities for use in locating potential resources or partners already available. http://www.FindYouthInfo.gov/
- Safesupportiveschools.ed.gov The National Center on Safe Supportive Learning Environments is funded by the U.S. Department of Education's Office of Safe and Healthy Students, and the U.S. Department of Health and Human Services' Substance Abuse and Mental Health Services Administration (SAMHSA) to help schools and communities contend with many factors that impact the conditions for learning, such as bullying, harassment, violence, and substance abuse. The Center provides resources, training, and technical assistance for State and local educational agency administrators, teachers, and staff; institutions of higher education; communities, families, and students seeking to improve schools' conditions for learning through measurement and program implementation, so that all students have the opportunity to realize academic success in safe and supportive environments.

http://safesupportiveschools.ed.gov/index.php?id=01

# **Appendix M** Five Steps Parents Can Take to Prevent Bullying

These helpful tips come from Deborah Hammer, an autism specialist from Arlington (Va.) Public Schools who has worked professionally for more than 20 years on behalf of individuals with special needs and their families. Beginning as a teacher for students with autism and other developmental disabilities, she also has served as an advocate, administrator, trainer, adjunct professor, and consultant in the field of special education.

**Step 1:** Ask your child's school to teach typical peers about Autism Spectrum Disorders (ASDs), and to start that education in the early grades.

• Children often are prejudiced against what they don't understand. If they are confused about why a classmate is unable to speak, repeats words, or talks constantly about certain topics, then they may tease that classmate. It is important for them to understand the challenges and difficulties that a classmate with autism may deal with, but also to understand that student's strengths, interests, and talents. Peers can be taught to be tolerant and respectful of others as well as strategies for communicating and including classmates who have ASD.

**Step 2:** Meet with the people at your child's school who have the most power to prevent bullying: teachers and the principal.

• The school should have an expectation that all students are to be treated with respect. Strategies should be put into place to teach and reward behaviors that are positive and polite. It also is helpful to talk to teachers and the principal about what strategies they have in place to prevent cyber-bullying, such as limits on certain Web sites, and supervision when students are online and using social media in conjunction with their schoolwork.

**Step 3:** Reach out in a friendly way to support staff, such as cafeteria workers, hall monitors, security guards, secretaries, and bus drivers.

• According to the National Education Association, bullying often takes place in cafeterias and other places where teachers and principals may not be the ones supervising students. Make sure that school staff on the front lines know who your child is and what types of social supports and accommodations he requires in non-classroom school environments. If these critical staff members are watching out for the best interests of your child, then bullying is less likely to occur.

Step 4: Ask your child's school to set up a peer buddy club.

• This strategy involves a select group of typical students and one or more students with special needs. The students are all there by choice and are facilitated by a trained faculty member—usually a special education teacher, counselor, or therapist. The typical students learn how to befriend their classmate with special needs and include her or him in a variety of settings, such as the cafeteria or football games. The support and friendship of typical peers can increase the self-esteem of students with ASD and decrease their chances of being targeted by bullies.

Step 5: Make sure your child receives social skills instruction.

• Students with ASD usually require direct instruction to master many of the social and communication skills that their peers are able to just "pick up" from other children. The range of skills varies greatly, depending on age, grade, gender, and location, so even if a child mastered all of the social skills goals for third grade, he probably will have an entire new set of skills to learn in the fourth grade. In other words, learning the skills necessary for fitting in with peers is usually a life-long process.

# Appendix N Safety for Adult Self-Advocates

This appendix provides guidance to adults with autism spectrum diagnoses, discussing some of the safety-related "blind spots" that may become relevant in everyday interactions. It was written by Colin Weiss, self-advocate and OAR Special Projects Intern, Summer 2014.

#### Introduction

#### What is self-advocacy?

Self-advocacy is based on the idea that the only person who can truly understand what your best interests and needs are is you, and that you should be able to make the decisions that matter most in your life without the unwanted interference of others. Not only does this grant you greater control over your life, it also serves to reinforce other skills required to live independently as a functioning member of society, and helps you have more confidence in yourself. However, this is not to say that you must cut out all forms of support in the process or do everything entirely on your own—it is these supports that will prove to be your most valuable resource as a self-advocate. No neurotypical is ever expected to handle all of his problems alone, and neither should you. That's why you have the right to request accommodations from others or ask for help when you need it. Ultimately, your goal should not be independence so much as *interdependence*. You might not be able to live entirely on your own, but you can always work toward a greater degree of control over your life.

#### Self-advocacy and safety

The purpose of this appendix is to teach you to take your safety into your own hands. This will help ease the burden on your loved ones and aid you in becoming more able to support yourself. While you may currently be living with a parent, guardian, or another caregiver, there's no guarantee that you will always have somebody looking after you. It is, therefore, vital to learn how to identify and deal with threats to your safety as needed. This appendix will review some of the most common threats that you are likely to encounter, suggestions for how to plan for and overcome them, and helpful resources that can support your efforts.

#### Personal and Community Safety

This section focuses primarily on the safety threats you might encounter during your everyday life, regardless of where you are at the time. Many of these threats are not limited to a specific context or place, and it is likely you may run into them more than once during your lifetime. Due to the variety inherent in these threats, this section is split into two parts: The first part covers everyday issues and the second part covers more specific ones.

#### Remember the basics

While it may seem condescending, unnecessary, or ridiculous to be reminded of safety tips as elementary as "look both ways before crossing the street" or "fasten your seat belt when you're in a car," the fact is that it only takes one mistake on your part to be seriously injured or killed in an accident that might have been easily prevented with the proper precautions. If you find yourself forgetting to practice basic safety tips such as these, then repeat them to yourself and exercise them as much as you can—over time, they will come to you naturally.

#### **Everyday threats**

#### Travel safety

While you might be capable of finding your way around your neighborhood or other areas you are familiar with, it can be very easy to get lost if you are travelling somewhere new. When travelling to an unfamiliar place, be certain to have a map as well as a way to contact someone you trust if you end up getting lost. Most smartphones on the market come with GPS capability as well as a route planner, which will help you find the fastest or most efficient route to wherever you need to be (and obviously can be used to call someone in case of an emergency). While travelling, you should take the time to get familiar with your surroundings and find some helpful points of reference if you need to use that particular route more than once (e.g., a commute to work).

If you are unable to drive or otherwise are not willing to do so, then you should be aware of alternative methods of travel. Public transport via buses, trains, and subways is often the most efficient, but there are some places (such as rural areas that do not support the infrastructure for public transportation) that may not have them available. In this case, you should try to contact someone you can trust to act as a driver for you. More recently, ride-sharing services have become prominent as an alternative method of travel, so it may be helpful to sign up for one of these.

When traveling by airplane, remember that security officers at airport security checkpoints are not trained on how to interact with individuals with autism. Due to the fear of terrorist attacks, airport security officers also may view some of your behaviors as being suspicious or indicative of criminal intent. In some cases, you may even be held for questioning if you are deemed a possible security threat. While you might be angry at the false accusation, stay calm and cooperate with them. Many of the same tips for interacting with the police (which are discussed later in this appendix) are relevant to this situation as well, so be sure to use handouts or a card to explain your condition and prevent any unfortunate misunderstandings.

You also should be aware of your rights as a disabled individual under the Department of Transportation's Air Carrier Access Act. The full list of rights you are entitled to under it can be found at <u>http://airconsumer.dot.gov/publications/disabled.htm</u>. The

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most important ones to remember are that an airline may not refuse service to you on account of your autism, nor can it force you to travel with someone or sit in a specific seat without your consent. This law applies both to U.S. airlines and flights that travel to and from the United States by foreign airlines.

## CHECKLIST

Before you travel, be sure to:

- ✓ Have a map or a smartphone with a GPS available to you.
- ✓ Be in possession of a cell phone or smartphone to contact someone you trust in an emergency.
- ✓ Inform others of where you are planning to go before leaving and when you expect to arrive.
- ✓ Bring along anything that you may need (e.g., medications, spare clothing, identification).
- ✓ Know what forms of transportation will be available to you.
- ✓ Research your destination so you know what to expect there.

#### Medication management

Many individuals with autism use medications to manage and control anxiety, depression, and other unrelated disorders they might have been diagnosed with. Although these medications can be invaluable for managing these disorders, they can pose a danger to your health if used incorrectly. Using a transparent pillbox marked with the individual days of the week is a good way of preventing both the possibility of skipping a dose of your medication by mistake and the threat of taking it twice in one day (and subsequently overdosing). It is not foolproof, though, and it is possible that you might still forget to take your medication. If you suspect that you have missed a dose or cannot remember if you have taken it, then skip it and take a normal dose the next time you are supposed to. As a general rule, failing to take medication is usually less life-threatening than an overdose.

If for whatever reason you believe you may have overdosed, then call your local poison control center (1-800-222-1222) and inform them immediately. They will advise you on what to do and send medical assistance. Remember to do this quickly; the sooner you report it, the more likely you are to survive the overdose.

#### Safety on the Internet

Many individuals with autism prefer socializing online over talking with people face-to-face, since it removes most of the nonverbal cues that they might have trouble understanding and allows them a degree of anonymity that blunts the impact of

possible rejection. However, this same anonymity also removes what could be called the "human element of socialization": By reducing the person you are speaking with down to lines of text on a screen, it is easy to disregard the feelings of others without even realizing it (especially since there are also fewer consequences for doing so than in face-to-face interactions). Far more threatening is the possibility that the person with whom you are communicating online is not who they claim to be and may wish to take advantage of you. If you absolutely must make contact in the "real world" with someone you met online whom you do not already know, be sure to meet in a public place in the daytime, with a friend or other trusted individual accompanying you in case the meeting goes poorly.

## CHECKLIST

Before meeting with someone you know from the Internet, be sure to:

- ✓ Arrange to meet in a public, well-lit area during daytime.
- ✓ Have someone you trust accompany you.
- ✓ Inform others where you will be.
- ✓ Have a phone or some other way to contact someone you trust in case of emergency.

Additionally, never give away important information when communicating with someone online (via email, a forum, instant messaging, etc.). This includes never providing your real name, address, or Social Security number. There's no telling where it might end up after you give it away. For example, you could easily become a victim of identity theft if someone uses information you provided to gain access to your bank account. Even on social networking sites like Facebook or Twitter, you should try not to post any photographs that might reveal where you live or work. Consider only being "friends" with people you know in real life, and making your page visible only to people on your "friends" list. This can minimize the risk of someone using your page to determine where you live or other important information about you.

## CHECKLIST

Before sharing personal information online, be sure to:

- ✓ Check to see if the site you will be sending information to is legitimate.
- ✓ Ensure that it will not be posted elsewhere without your knowledge.
- ✓ Withhold any data that might be used for identity theft if the site is not secure.

The Internet is also home to numerous scams and frauds. Just like in real life, the best way to steer clear of them is to remember that if an offer sounds too good to be true,

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then it probably is. A particularly dangerous scam to look out for is "phishing," which takes the form of a seemingly legitimate email (usually from a bank or other financial institution) explaining that for one reason or another, it requires you to confirm important information (such as a password or PIN) and directs you to a link that supposedly comes from the trusted source. Look carefully at the link by placing the mouse cursor over it, and it will reveal that the "official" site is in fact a carefully constructed fake. Any information you enter into it will be used to commit fraud in your name. Delete the email at once and call your financial institution to ensure that there are no issues with your account. On that note, you should also avoid downloading attachments from an email whose sender you do not recognize, as many of them contain viruses that can damage your computer or spyware that can track the Web sites you visit and access information stored on the computer. There are numerous anti-virus products available, and installing one is a good way to keep your computer safe.

#### Situational threats

#### Dealing with street crime

To avoid detection and arrest, street criminals are skilled at picking out people who appear to be easy victims, and some of your behaviors are likely to draw their attention. Just about any public area or place with pedestrian traffic will give them a chance to look for a potential "mark." Minimizing the risk of becoming a crime victim is dependent on your ability to blend into the crowd, so to speak. An isolated individual is an easy victim; staying in a crowd will keep you safe as long as you can remain inconspicuous. Consequently, you should dress appropriately for the area you are in, avoid carrying large amounts of cash, and do not appear to be rushed or dawdling—if it can draw attention to you, it will. If you are attacked by someone and threatened to give up money or valuables, then do so without resistance; they will be likely to resort to violence if you refuse, and losing your belongings is a better outcome than risking your life. After you are in a safe place, call the police immediately afterwards to report the crime, preferably with the aid of a trusted individual who can help you with the interview.

#### Interacting with police and other first responders

Most law enforcement agencies are still in the initial stages of training their officers how to interact with people on the autism spectrum, let alone recognize them. Combined with the fact that many behaviors that are normal for individuals with autism (e.g., avoiding eye contact, failing to answer questions when asked) often appear to be signs of noncompliance or guilt from an officer's perspective, this can lead to stressful and possibly dangerous misunderstandings. To avoid undue suspicion if unexpectedly confronted by a police officer, consider carrying a set of handouts or a card explaining your condition and how it affects you, along with some form of identification and a way for him/her to contact someone you trust. An example of such a card can be found at <a href="http://www.aane.org/docs/resources\_aane\_wallet\_card.pdf">http://www.aane.org/docs/resources\_aane\_wallet\_card.pdf</a>, and a template that can be used to make your own can be found in <u>Appendix K</u>.

If you lose the ability to speak while under stress, then you also should wear a medical alert bracelet that alerts them to the fact that you have autism, and that you can provide an information card to them. Under no circumstances should you simply try to pull out the card without requesting permission (ideally verbally, but if you are unable to speak, a sign language card or other communication tool will suffice), especially if it is in a coat pocket, pants pocket, or glove compartment box. Police are trained to assume that sudden movements are an indication that you are reaching for a weapon and may respond with lethal force. It is just as important to resist the urge to flee from an unexpected encounter; most officers will assume that if you are trying to get away from them, then you must have done something wrong. Instead, remain calm and present the card or handouts as described above.

## **Helpful Resources**

#### FBI-Be Crime Smart

This set of resources collected by the Federal Bureau of Investigation discusses multiple ways to avoid becoming a crime victim, general safety information applicable to a variety of situations, and some of the more common forms of fraud of which you need to be aware. <u>http://www.fbi.gov/scams-safety/be\_crime\_smart</u>

#### Preparing for Disaster for People with Disabilities and other Special Needs:

This pamphlet was designed by the Federal Emergency Management Agency; although it is not specifically geared toward individuals with autism, the principles and guidelines it provides are nonetheless invaluable in the unlikely event that you have to deal with a natural <u>disaster.http://www.fema.gov/media-library-data/20130726-1445-20490-6732/fema\_476.pdf</u>

## Dating, Relationship, and Sexual Safety

This section contains information on threats you are most likely to encounter when attempting to enter into or remain in an intimate relationship, as well as situations where sexual activity is likely to occur. While physical risk is rather low in these situations (with the exception of sexually transmitted infections), there are many more subtle risks to your psychological and emotional well-being of which you need to be aware.

#### Remember the basics

No two relationships will ever develop in the same way; sometimes they may take years to fully form, while others can develop over a course of several weeks or fewer. However, there are a few issues of note that are likely to show up in all relationships of which you should be aware. The first of these is the most obvious one: When someone says they are not interested in dating you, they mean it. Asking again will not change their response, and is likely to result in that person charging you for stalking or sexual harassment (especially if you also attempt to touch them without their consent). To put simply, *no means no.* 

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Direct sexual advances are generally frowned upon, but this may be a problem if you are unsure of whether or not your partner is willing to engage in sexual activity—or even romantic activity, such as kissing. While you should always ask for permission before "making a move," try considering a somewhat more subtle approach rather than outright asking if they want to engage in a specific activity. If you are still not sure what they want, then ask them directly, but make sure you do so in the most polite way possible. The most important things to remember are that you should not force your partner to do anything that he/she is not comfortable doing, nor should you allow yourself to be forced into anything that you have not consented to doing. Again, *no means no*.

While this guide attempts to give reasonable advice regarding dating and sexual relationships, it cannot take into account your own family and personal values. If your own values are irreconcilable with the information in this guide, then do not feel compelled to compromise them to have a safe and successful relationship.

#### Disclosure and privacy

The choice to disclose your condition to your partner can be a difficult one. While it may aid them in understanding the reasons why you act the way you do, there is no way to be sure that they will accept you for who you are after learning you are on the autism spectrum; many people still believe that individuals with autism are simply incapable of engaging in relationships or are unable to achieve the intimacy required for a relationship to succeed. It may be helpful to "test the waters" before making the decision by bringing up topics relating to autism and watching how they react to it. In theory, it might be possible to keep your diagnosis a secret, but the act of keeping a secret that important is itself inherently damaging to a relationship, as your partner might believe you do not trust them or are hiding something more serious from them (e.g., an affair).

Your body is only as public as you want it to be—if you don't want to share something about your body with other people, then that decision is yours to make. Just remember that you do have an obligation to inform others if it might pose a safety threat to them. In other words, choosing not to reveal that you think part of your body is unattractive is fine, but choosing not to reveal that you have herpes is not acceptable, and will likely cause problems in the long run if your partner is infected and realizes he or she got it from you.

#### The role of sex in relationships

Sex does not necessarily lead to love, nor does love automatically lead to sex. This is particularly important for women with autism to remember, as they can easily be taken advantage of by unscrupulous men who might claim to be in love with them as a way of making them agree to sex, only to break off the "relationship" after they get what they want. It is an unfortunate fact that many men still view women as sex objects. As women with autism may lack the social skills needed to determine if a man is genuinely interested in forming a relationship with them (as opposed to simply

wishing to have sexual relations with them) and may be naïve about relationships in general, they are at greater risk at being victimized in this manner. Never act under the assumption that you are obliged to engage in sexual activity simply because you are in a relationship or someone has expressed interest in you. If someone really loves and cares about you, then they will respect your wishes enough not to pressure you into doing something you don't want to do.

Men with autism also should keep this principle in mind, albeit for somewhat different reasons. If a woman says she is not interested in sexual activity, she is not being a tease or "playing hard to get," but really means it. Going ahead and doing it anyway without consent not only is dehumanizing and hurtful to your partner, but also is considered rape; this is a very serious crime that can lead to harsh fines or even imprisonment. No means no. That said, it is equally possible that you may find yourself in a position in which a woman appears to be coming on too strongly. In this case, you should keep in mind that she is not obliged to do anything without your consent, regardless of your gender.

#### Abusive relationships

Some people will try to exploit their relationship with you as a way of benefitting from it at your expense. While it can occur in a variety of forms, some of the more common behaviors shown by abusive partners as described by the Center for Relationship Abuse Awareness are listed in the following table. Generally, if you have reason to believe that you are in an abusive relationship, you should inform the authorities at once and/or contact the National Dating Abuse Helpline at 1–866–331–9474.

Willingness to publicly embarrass and humiliate you, including via online attacks	Threatens you or himself/herself if you try to leave the relationship
General disregard for your feelings	Physical abuse (beating, restraint, etc.)
Controlling behavior (demands to know where you are at all times, forces you to cease contact with family and friends, restricts access to money, etc.)	Makes excuses for his/her behavior (e.g., "I wouldn't hurt you if you didn't do those things" or "I was stressed") and attempts to avoid responsibility for abuse
Criticism of behaviors resulting from your autism	Withholds affection and approval as punishment
Makes statements that suggest they are the only person willing to engage in a relation- ship with you as a result of your supposed personality flaws	Excessive criticism of not understanding social customs or failure to make eye con- tact when they know why it is difficult for you
An "uneven" treatment of the relationship that places you in a lower status than the abuser	Irrational jealousy and a fixation on affairs (real or perceived) you might be having
Claims that they might stop the abuse if you just changed to suit their needs	Apologizes and promises to stop the abuse, but never actually follows through

#### Contraceptive measures

Numerous types of contraception (also known as birth control) exist and are capable of preventing pregnancy, but only the "barrier methods" (e.g., condoms and other forms of birth control that involve a physical barrier to keep sperm out of the uterus) have been confirmed to be effective at preventing both pregnancy and the spread of sexually transmitted infections. While most women take birth control pills as their preferred form of contraception, the use of a condom is still advised as a secondary contraceptive measure, especially if you and/or your partner have not been recently tested for sexually transmitted infections. If you are sexually active and have not been tested, then do so and recommend that your partner do the same; there are no drawbacks to it, and it can keep you from contracting or spreading any infections further without your knowledge.

While this may sound obvious, the only form of contraception guaranteed to work is abstinence—after all, pregnancy isn't a risk when you never actually engage in sex.

## Sexually transmitted infections

Sexually transmitted infections (also known as STIs, sexually transmitted diseases, or venereal diseases) are diseases that can be passed on through sexual activity. While their symptoms may not always be apparent, many of them can lead to infertility, chronic pain, or death if not detected and treated early. The simplest way to cope with them is to use a condom during sexual activity. It can prevent infected fluid from escaping, minimizing the chances of transmitting the pathogens responsible for the infections. That said, they are not guaranteed to prevent STI transmission, so ensure that before engaging in sexual activity, your partner and you get tested for STIs, especially if either of you has engaged in sexual relations with other people in the past.

You can find more information about STIs on the Centers for Disease Control and Prevention Web site: <u>http://www.cdc.gov/STD</u>/.

## CHECKLIST

Before engaging in intimate activity, be sure to:

- ✓ Get tested for STIs and inform your partner if you are diagnosed with one.
- ✓ Have at least one form of contraception available to you.
- ✓ Obtain consent from your partner.

## **Helpful Resources**

#### National Dating Abuse Helpline

This 24-hour resource is designed specifically for teens and young adults, and can offer real-time one-on-one support from peer advocates to individuals involved in

abusive relationships. In addition to its Web site, it can be accessed via phone at 1-866-331-9474. <u>http://www.loveisrespect.org</u>/

## Dating and Socialization on the Spectrum

While somewhat outdated, the general advice provided on this site is still relevant, and it has some important points to make on the nature of relationships in general. <u>http://www.scn.org/autistics/relationships.html</u>

## Workplace Safety

This section covers threats that you may encounter at your workplace. Although this guide cannot comprehensively cover every possible risk given the wide variety of workplaces available, there are a handful of common risks of which you should be aware and be able to respond to regardless of what your job might be.

#### Remember the basics

While most jobs today are unlikely to carry any specific safety threats, some workplaces (especially those that require working with heavy machinery or in potentially dangerous conditions) are inherently risky and may require you to be exposed to unsafe conditions. Be sure to learn of any threats associated with your job as well as the safety precautions that have been implemented to protect you from them.

For more information about workplace-specific safety risks, it may be useful to enroll in one of the Occupational Safety and Health Administration (OSHA) outreach training programs. These cover information on how to identify and avoid most job-related hazards while also explaining your employer's responsibilities and your rights as a worker. More information can be found at <u>https://www.osha.gov/dte/outreach/index.</u> <u>html</u>, along with information on how to find nearby outreach training programs. In many cases, your job also will provide some degree of safety training.

## Disclosure

Although the decision to disclose your condition to your co-workers should be a personal one and may not always be necessary, there are several reasons it may be worthwhile to share your diagnosis with your employer and/or supervisor. Not only will they be better able to respond to your needs and accommodations, it can also help prevent misunderstandings that arise from your behavior. More importantly, you cannot apply for workplace anti-discrimination protection unless you have already disclosed your condition. Without this protection, your employer is under no legal obligation to stop any harassment directed at you on account of your disability.

However, it may not always be wise to disclose at the earliest possible time. Revealing your condition during the job application process may cause your application to be turned down, and choosing to disclose upon criticism of your job performance can give the impression that you are using the diagnosis to avoid responsibility or are simply

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making excuses. Ideally, you should disclose on your own initiative during a time when work is going well for you; when doing so, be sure to present it in a positive light while asking for specific accommodations that will maximize your job performance.

In some cases, it may even be possible to request accommodations without specifically disclosing that you are on the autism spectrum (e.g., explaining that you have trouble working under fluorescent lights without actually saying that your autism makes it difficult for you to cope with them); if you have reason to believe that disclosure may do more harm than good, then it may be beneficial to ask for accommodations in this more roundabout manner rather than being explicit about why they are needed.

Ultimately, the decision on whether to disclose sooner or later (if at all) is just as dependent on your employer and job as it is on you. If you think that disclosing your condition may do more harm than good for any reason, then consider not disclosing. This should only be done if you have no better alternatives. In this case, however, your best bet may be to find a new job that would be more accepting of your condition.

## Bullying

Some people might claim that bullies pick on others because they lack self-esteem, but this is far from the truth—they do it because they have learned that they can get away with using force to control other people and gain satisfaction from exerting that power over those who lack the ability to retaliate against them. As an individual with autism, you are a preferred target for bullying, and the same traits that lead individuals with autism to become frequent bullying victims can in some cases encourage observers to blame the victim instead of the bully. For example, situations in which your behavior already distinguishes you in a negative manner can lead onlookers to perceive that you "had it coming." While it may not always be possible to suppress these behaviors completely, it may be helpful to learn how to control them just enough to avoid drawing unnecessary attention to you.

The stereotypical image of a bully is a brutish individual demanding that you give him your lunch money, but in practice there are also more subtle methods of bullying that do not rely solely on threats and physical violence. Bullying also can take the form of teasing and verbal abuse, as well as spreading rumors, exclusion from social activities, and online harassment (commonly referred to as "cyberbullying"). More malicious are the bullies who may feign friendship with you just long enough for you to trust them, only to betray that trust when doing so would be most damaging (personally or professionally) for you. This can be especially devastating since it can make it difficult to trust people enough to form friendships in the future.

Regardless of what form the bullying takes, your best option is to inform a trusted authority figure (such as a supervisor or an HR representative) with all due haste. Ignoring bullying will not stop it from happening, and trying to fight back might escalate the bullying, and that is more likely to get you in trouble than anything else. If the authority figure in question fails to acknowledge or stop the bullying, then seek help from a higher-ranked authority figure as needed. If the bullying is so severe as to affect your job performance or is being carried out by one of your superiors, then you should contact the Equal Employment Opportunity Commission. They will determine if your employers have violated anti-discrimination laws, provide mediation services and the possibility for an out-of-court settlement, and grant you permission to sue your employer (or do so themselves if they find that your employer has violated the laws) if mediation fails. Information on how to file a complaint to them can be found here: <u>http://www.eeoc.gov/employees/charge.cfm</u>

## **Helpful Resources**

## Understanding Autism: An Employer's Guide

This guide from the Organization for Autism Research (OAR) should be presented to your employer at your earliest convenience to help them understand your needs and adapt to them. <u>http://www.researchautism.org/resources/reading/documents/</u><u>UnderstandingAutismAnEmployersGuide.pdf</u>

#### Workplace Bullying Institute

This site hosts information on how to identify and stop workplace bullying, as well as provides access to educational material for employers and psychotherapists to help them combat workplace bullying. <u>http://www.workplacebullying.org/</u>

## Occupational Safety and Health Administration (OSHA)

OSHA's role is to ensure safe working conditions and provide information on a variety of health hazards that may be encountered in the workplace. If you believe that your workplace's safety regulations are insufficient, the Web site also has information on how to request an inspection from OSHA to ensure that those regulations meet OSHA standards. <u>https://www.osha.gov/index.html</u>

#### Additional Resources for Self-Advocates

#### Autistic Self-Advocacy Network (ASAN)

ASAN is one of the most prominent members of the self-advocacy movement; in addition to their work in the disability rights movement, they also have various resources that self-advocates can use to take control of their lives. <u>http://autisticadvocacy.org/</u>

#### The National Autism Resource and Information Center

This Web site contains numerous articles on nearly every aspect of autistic life, from how to prepare for college to the different varieties of public transportation that are available to you. <u>http://autismnow.org/</u>

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# Appendix O Other Safety Resources

There are many organizations that provide useful resources related to your child's safety. This appendix lists safety-related resources that complement what you have read in this guide. The information is organized by topic.

#### General

- A 5 Is Against the Law! Social Boundaries: Straight Up! An honest guide for teens and young adults is a book that helps teens and young adults with autism avoid putting themselves and/or others in compromising situations: <u>http://www.aapcpublishing.net/affiliate-link/79</u>
- *Autism Risk Management* is a Web site created and managed by Dennis Debbaudt, a well-known expert on autism and safety. The site includes some excellent resources for both families and law enforcement officials: <u>http://www.autismriskmanagement.com/index.cfm</u>
- *Autism Safety Project* is an Autism Speaks initiative that includes a portal with information for families about maintaining safety in several different environments: <u>http://www.autismspeaks.org/family-services/autism-safety-project</u>
- *Dangerous Encounters—Avoiding Perilous Situations with Autism* is a useful book for law enforcement, firefighters, and EMTs: <u>http://www.jkp.com/catalogue/book/1-84310-732-5/</u>
- *Safe and Sound* is an initiative of the Autism Society of America Web site that creates safety resources for families of individuals on the spectrum and first responders: <u>http://www.autism-society.org/living-with-autism/how-the-autism-society-canhelp/safe-and-sound/</u>
- *Speak Unlimited* is a nonprofit organization dedicated to promoting safety for individuals with special needs: <u>http://papremisealert.com/us</u>/

#### Water Safety

- *List of YMCA locations that offer special needs swimming instructions* within the National Autism Association's Web site: <u>http://nationalautismassociation.org/resources/</u><u>autism-safety-facts/swimming-instructions/</u>
- "Water Safety: The Ultimate Life Skill" is an article by James Ball that was published in *Autism Digest*: <u>http://autismdigest.com/water-safety- the-ultimate-life-skill/</u>

#### **Tracking Devices**

There are many companies that sell tracking devices with varying capabilities and associated costs. Many local law enforcement agencies, however, partner with Project

Lifesaver (<u>http://www.projectlifesaver.org</u>/), a nonprofit organization, to provide tracking devices for individuals with autism at little to no cost to families. Ask your local law enforcement agency if they are part of the Project Lifesaver network.

## **Training Materials for Firefighters and Emergency Medical Personnel**

Autism Information for Paramedics and Emergency Room Staff is a handout from the Autism Society of America: <u>http://www.autism-society.org/files/2014/04/</u> <u>Paramedics\_and\_Emergency\_Room\_Staff.pdf</u>

## **Emergency Preparedness**

Preparing for Disaster for People with Disabilities and Other Special Needs is an informational booklet that was created by the Federal Emergency Management Agency and the American Red Cross: <u>http://www.redcross.org/images/MEDIA\_</u> <u>CustomProductCatalog/m4240199\_A4497.pdf</u>

## Wandering and Elopement

- *Big Red Safety Toolkit: A Digital Resource for Caregivers* is a booklet from the National Autism Association: <u>http://nationalautismassociation.org/docs/BigRedSafety</u> <u>Toolkit.pdf</u>
- *Big Red Safety Toolkit: A Digital Resource for First Responders* is another booklet from the National Autism Association: <u>http://nationalautismassociation.org/docs/</u><u>BigRedSafetyToolkit- FR.pdf</u>
- *Missing Children with Autism* is a page within the National Center for Missing and Exploited Children's Web site: <u>http://www.missingkids.com/autism</u>
- *Report an incident at* <u>http://report.cybertip.org</u> with the *National Center for Missing & Exploited Children*

## **Training Materials for Law Enforcement**

Resources from Dennis Debbaudt, a well-known expert in autism and safety:

- Autism, Advocates, and Law Enforcement Professionals: Recognizing and Reducing Risk Situations for People with Autism Spectrum Disorder (book): <u>http://www.jkp.com/</u> <u>catalogue/book/9781853029806</u>
- *Autism, Fire Rescue Emergency, & Medical Service* (video, in collaboration with Dave Legacy): <u>http://www.debbaudtlegacy.com/autism\_fire\_rescue\_emergency\_medical\_service.cfm</u>
- Autism Information for Law Enforcement and Other First Responders is a handout from the Autism Society of America: <u>http://www.autism-society.org/files/2014/04/Law\_Enforcement\_and\_Other\_First\_Responders.pdf</u>
- *Autism & Law Enforcement Roll Call Briefing* (video, in collaboration with Dave Legacy): <u>http://www.debbaudtlegacy.com/autism\_law\_enforcement\_roll\_call\_briefing.cfm</u>

- *Autism Spectrum Disorders: A Special Needs Subject Guide for Police Officers* is a booklet created by the Children's Hospital of Wisconsin: <u>http://ddq74coujkv1i.cloudfront.net/autismguideforCO.pdf</u>
- Avoiding Unfortunate Situations: Autism and Law Enforcement (handout): <u>http://www.poac-nova.org/pdfs/Debbaudt%20AUS%20Handout.pdf</u>
- *Recognizing/Responding to Autism and Other Developmental Disorders: A Guide for First Responders* is a presentation created by Matt Brown of the Maine Criminal Justice Academy: <u>http://video.mpbn.net/video/2164509009</u>/

## Bullying

Perfect Targets: Asperger Syndrome and Bullying—Practical Solutions for Surviving the Social World is a book by Rebekah Heinrichs: <u>http://www.aapcpublishing.net/</u> Product Description/tabid/144/ProductID/135/Default.aspx

## **Internet Safety**

- *K9 Web Protection* is a free Internet filter that gives parents control over the content viewable by their children: <u>http://www1.k9webprotection.com/</u>
- *Netsmartz Workshop* is a comprehensive, user-friendly Web site designed by the National Center for Missing & Exploited Children. It educates kids, tweens, and teens on Internet safety, and offers resources for parents, educators, and law enforcement: <u>http://www.netsmartz.org/Parents</u>

## Air Travel

Airport Awareness: Travel Advice for Parents and Careers of Children on the Autism Spectrum is a booklet created by the Manchester (UK) Airport: <u>http://www.manchesterairport.co.uk/manweb.nsf</u> /content/airportawareness

*The Transportation Safety Administration provides air travel information for individuals with disabilities:* 

- http://www.tsa.gov/traveler-information/autism-or-intellectual-disabilities
- http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions
- http://quest.mda.org/sites/default/files/Notification%20Cards%20II.pdf

## **Relationship and Sexual Safety**

DVDs for teaching safety in the workplace, dating, and preventing sexual abuse can be found through James Stanfield: <u>http://www.stanfield.com</u>/



Safety is an everyday concern for all parents. That concern becomes magnified and more complicated when your child has autism. In some instances, your child's behaviors and traits may make them more susceptible to common safety risks. In other cases, the characteristics of autism may actually create the vulnerability. *Life Journey Through Autism: A Guide to Safety* is intended for parents and family members who have loved ones with autism. It examines safety across the lifespan; identifies safety threats at home, school, and in the community; and offers tools, tips, and information you need to prepare in advance for that unwanted circumstance – ideally before an emergency arises.

More specifically, the goals of this Guide are to:

- Educate parents about the safety risks that may affect their child across the lifespan
- Help parents teach safety habits that will build a foundation for adulthood
- Provide guidance and resources that parents can effectively incorporate into a family safety plan
- Describe how to create a safety network
- Help you prepare for the unexpected emergency
- Provide access to additional resources and information related to safety

The Organization for Autism Research (OAR) is a national non-profit organization dedicated to promoting research that can be applied to help families, educators, related professionals, and individuals with autism spectrum disorders find the much-needed answers to their urgent questions. Committed to excellence in service to the autism community, OAR funds applied research that will make a difference in the lives of individuals; provides accurate and useful information; and offers opportunities for the autism community to collaborate and make advances together.

#### www.researchautism.org

