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Challenging Behaviors: A Roadmap for Families

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Introduction

Individuals with autism spectrum disorders (ASD) are at increased risk of engaging in challenging behavior such as self-injury, aggression, and destructive behavior. These problems vary widely in terms of their severity and their responsiveness to treatment.

Despite the prevalence of challenging behaviors, the majority of families lack access to appropriate and effective treatments and services. In response to this shortage, in December 2020, the Autism Speaks Thought Leadership Summit on Challenging Behaviors brought together leaders in autism care and research across North America to characterize the landscape of services and supports for people with autism who experience challenging behaviors and act as a catalyst for innovations in programs and policies to improve systems of care for this population. Autism Speaks assembled a very comprehensive and diverse multi-disciplinary and representative group of participants, including individuals with autism and family members, to be sure all voices in the community contributed to this important discussion.

This roadmap is one product of that summit and is intended to help parents, extended family, caregivers and others supervising or in charge of care for an autistic loved one navigate challenges, help identify causes and provide guidance in managing behaviors. In this you will find:

- An overview of challenging behaviors including definitions, types and examples of challenging behaviors and levels of severity
- Supports for your loved one with autism experiencing challenging behaviors
- Action steps and links to extra resources for you and your autistic loved one

Workgroups from the summit also developed tools for providers to help navigate challenging behaviors. **The Clinician Guide: Program Development and Best Practices for Treating Severe Behaviors in Autism** is intended for clinical use by licensed professionals. Feel free to share it with your autistic loved one's providers.

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Challenging Behaviors Overview

Definition

Those with autism typically display behaviors or behavior patterns that differ from peers the same age or at the same grade level. Their behavior may also change frequently and become more complex, compared to their peers.

Some behaviors are harmless, like rocking, spinning, hand-flapping, and other repetitive self-stimulating (stimming) movements. Many non-autistic individuals also engage in this kind of behavior (for example, hair twirling, tapping a pen, or foot tapping).

For this roadmap, we consider challenging behaviors to be those that:

- Are harmful to self or others.
- Are aggressive and/or destructive.
- Prevent access to a person's learning.
- Interfere with a person's participation in all aspects of school, work and/or community life.
- Require emergency, medical and/or public safety intervention.

In some cases, a person experiencing challenging behaviors may pose a serious risk to themselves, people in their environment (such as family, caregivers, school staff and peers) and/or property.

Never ignore the signs of a crisis situation. Always take threats of suicide or harm seriously. If you are experiencing a crisis with your autistic loved one or they are exhibiting escalating risky behavior, seek help immediately.
You can start by calling your healthcare provider. Be aware that they may immediately send you to an emergency department or have you call 9-1-1.

Purpose

It is helpful to think of an individual's behavior as a response, rather than predetermined or willful behavior.

Behavior serves a function or purpose. Some behavior is biologically driven (we eat when we are hungry) or reflexive (we cover our ears when a noise is too loud). Some is in response to a social cause, such as a desire for attention, to escape a task or situation or to acquire an object or desired situation or outcome.

Behavior also serves as a form of communication. People with autism often have difficulty saying why they are upset – but their behavior can be a sign of something wrong or bothering them.

It is important then for parents and family members to become conscientious observers of their loved one's behavior, even when they are happy or in a neutral state of mind. Doing so is the first step toward understanding them better and learning how to help them in times of need. If you can develop an idea of when or why a behavior is happening, you may realize there are simple solutions to help improve a situation and even help prevent challenging behavior.

Examples

Challenging behaviors will look very different for each person with autism and may change over time. Below is a comprehensive list of examples of behaviors you may see in your child. It may very well extend beyond the concerns you have about your child. Additionally, some of these challenging behaviors may occur only rarely. However, it is helpful to be aware of possible behaviors so you are able to get the help you need when they first emerge.

Other behaviors that are common among non-autistic individuals (e.g. swearing and meltdowns) are included to remind you to monitor their severity and to seek help if they escalate.

Disruption occurs when an individual's behavior interferes with their surroundings. Examples include interrupting a classroom lesson, the operation of a work environment or a parent's ability to make a meal, yelling, crying or swearing. Challenging behaviors might include banging, kicking or throwing objects, knocking things over or tearing things.

Incontinence is the (usually) involuntary passing of feces or urine, generally not into a toilet or diaper. Sometimes there is an underlying physical concern that might need treatment or incomplete toilet training that may need additional teaching. For some individuals, it may be a sign that there is difficulty recognizing body signals before it is too late. Sometimes an individual learns to use "peeing their pants" or urinating on the floor as a means of gaining attention or escaping an undesirable task or situation.

Non-compliance is when an individual does not or refuses to follow the directions or rules of someone in authority. Non-compliance can sometimes be accompanied by whining or crying. It becomes challenging when it becomes aggressive, self-injurious or severely disruptive to everyday life.

Obsessions, compulsions, and rituals are often strong, irresistible urges that become challenging when they result in difficulty with a person's ability to cooperate, to manage change or to be flexible and adjust.

- An **obsession** is when a person's thoughts or feelings are dominated by a particular idea, image or desire, such as a person who only wants to talk about elevators.
- A **compulsion** is the drive to do something in particular or in a particular way, such as the need to straighten all the forks at the dinner table.
- A **ritual** is used to describe a repetitive behavior that a person appears to use in a systematic way in order to promote calm or prevent anxiety, such as arranging all the pillows in a certain way before being able to settle into sleep.

Physical aggression is an act of force that may cause harm to another person, and might include hitting, biting, grabbing, hair pulling, slapping, kicking, pinching, scratching, pulling, pushing, head butting, or throwing things.

Property destruction includes behavior in which belongings or property are harmed, ruined or destroyed and might include breaking, throwing, scratching, tearing, defacing, etc. belongings (their own or those belonging to others).

Self-injury is the attempt or act of causing harm to a person's own body severe enough to cause damage. Self-injury can present in a wide range of behaviors including head banging, hand-to-head banging, body slamming, hitting or punching oneself, eyeball pressing, biting oneself, wound picking, and hair pulling. Self-mutilation such as cutting one's skin, burning, or bone breaking, is less common in autism unless other psychiatric conditions co-occur.

Sexual inappropriateness can take many forms in autism and might be described as a lack of sexual inhibition or "acting out" behavior. Lack of impulse control and poor social understanding might result in acting on sexual impulses that others know to keep private, such as sexual advances (propositions), sexual touching, promiscuity, exposing one's genitals, masturbating in public, sexual talk, obscene phones calls or voyeurism (watching others in private situations). Depending on the severity and the circumstances, sexual inappropriateness may lead to, or be considered, **sexual aggression.**

Threatening behavior includes physical actions that do not involve injury or actual contact with another person (such as holding up a knife), and stated or written threats to people or property.

Tantrum or meltdown describes an emotional outburst that might involve crying, screaming, yelling and stubborn or defiant behavior. These become challenging when a person might lose control of their physical state and have difficulty calming down even if the desired outcome has been achieved.

Verbal aggression generally involves the use of threats, bullying tactics, negative language, ultimatums and other destructive forms of communication.

Wandering (often called **elopement**) refers to running away and not returning to the place where a person started. In autism, elopement is often used to describe behaviors in which a person leaves a safe place, a caretaker, or supervised situation by bolting, wandering or sneaking away.

Less common, more severe challenging behaviors include

Fecal digging occurs when an individual puts their fingers into their rectum (backside). Fecal smearing and handling of feces (poop) occurs when feces are spread on property or the individual themselves. Each of these might be rooted in medical causes such as skin or digestive tract concerns or may be learned behaviors that serve a purpose such as access to attention or escape from unpleasant situations.

Food refusal occurs when a person refuses to eat anything at all.

Pica is an eating disorder that involves eating things that are not food. Some individuals with autism eat items such as dirt, clay, chalk or paint chips. Pica can also occur when a body craves certain nutrients or minerals that are lacking in the diet or body, similar to what sometimes occurs during pregnancy.

Rumination describes the practice of (voluntarily or involuntarily) spitting up partially digested food and re-chewing it, then swallowing again, or spitting it out. Rumination often seems to be triggered by reflux or other gastrointestinal concerns.

Purposeful or self-induced vomiting is throwing up on purpose. Contributing factors such as reflux, hyper-gag reflexes and eating disorders (such as bulimia) should be considered.

It is important to repeat that while these behaviors might all be challenging, they are typically responses, sometimes learned, and serve a purpose. There could be a biological root or trigger that requires investigation or treatment to help the individual. Even if treatment is not immediately effective, sometimes just knowing of a medical or neurological cause of a behavior can change how you think about it and how you respond.

Levels of Challenging Behavior

Autism experts agree there are different levels of severity to challenging behaviors. Understanding the level of your child's behavior can help you support them and manage those behaviors. The information below is adapted from **Clinician Guide: Program Development and Best Practices for Treating Severe Behaviors in Autism**, a product of Autism Speaks Thought Leadership Summit on Challenging Behaviors.

Mild Challenging Behaviors

Some challenging behaviors are seen among non-autistic and autistics alike and carry little risk of harm to the individual, others or the environment. These behaviors may be disruptive or seem annoying to parents, caregivers or the casual observer, and/or may interfere with learning and adaptive functioning of the person or others. Some mild challenging behavior requires mild intervention. However, these behaviors are mentioned as they could become more severe without effective and early intervention. Some common examples include:

- Tantrums that include crying, screaming, and dropping on the floor,
- Mild head banging, or banging other body parts against objects, that is unlikely to cause any damage either due to low frequency or low intensity,
- Throwing small or inexpensive items, breaking toys, ripping paper,
- Hitting or kicking that is unlikely to cause any damage to the individual who is targeted,
- Hand biting or hand mouthing that does not result in swelling, redness, or signs of tissue damage.

Moderate Challenging Behaviors

Moderate challenging behaviors result in some damage or have the potential to result in moderate damage to the individual, others, or the environment (e.g., moderate property destruction), or moderate interference with learning or functioning. Some common examples include:

- Head banging that leaves a red mark but that does not cause bruising or does not require protective equipment to maintain safety, and does not occur at a frequency likely to cause cumulative damage,
- Hand-to-head self-injurious behavior, like punching, that occurs frequently and may lead to minor bruising but that is unlikely to cause any permanent damage,
- Aggressive behavior such as biting and hitting that does not cause significant tissue damage but is painful and/or may leave some redness or minor bruising,

- Elopement, or wandering off, in a store, park or other environment that does not put the individual in immediate harm,
- Pica that includes ingesting paper, or other items that are unlikely to cause harm when consumed.

Severe Challenging Behaviors

Severe challenging behavior results in or has the potential to result in significant injury or harm to the individual exhibiting the behavior, others, or the environment (e.g., severe property destruction), or significant interference with learning or functioning. Some common examples include:

- Head-directed self-injurious behavior (e.g., headbanging, hand to head, knee to head, any object to the head) that results in severe injury including tissue damage, bleeding or skin lacerations and/or broken bones,
- Hitting or kicking others that causes significant tissue damage, bleeding or skin lacerations, broken bones or concussion,
- Aggression or self-injurious behavior that does not cause damage in a single instance but that over time can cause significant injury. For example, ear hitting that causes mild redness when it occurs and, over time, results in deformation of the ears,
- Elopement towards busy streets, bodies of water or other acutely unsafe environments,
- Pica that includes ingesting safety pins, screws, batteries, coins, cleaning liquids or other potentially lethal objects.

Questions to ask yourself

There are many things to consider when trying to understand what might be contributing to challenging behaviors in your autistic loved one at a certain point in time. You can start by asking yourself the following questions a few times when you observe your loved one exhibiting a challenging behavior. Document your answers each time and see if you see any patterns or if your answers change.

- Did this behavior start suddenly? If so, might my child be sick or is there another change that might have caused this?
- Is there some underlying medical concern or condition that is making them reactive? Are they tired? Are they under stress?
- What is my child attempting to gain from this behavior? Are they trying to escape something?
- What could they be trying to tell me?
- Does this behavior happen in certain places, with specific people or in similar-type situations? For instance, do they only behave this way when they are hungry? Or is there a certain environment or certain surrounding when this occurs? Are there any easy fixes that could help improve their behavior (eg. Having a favorite snack on hand at all times; Always carrying an umbrella or hooded jacket in case of rain, even if the forecast is for sun)?
- What happens before the behavior? Is there something that makes it more likely to occur?
- What happens after the behavior occurs? Is there anything that happens that causes the behavior to persist?
- What do I or another caretaker typically do to get my child to stop engaging in the behavior? Am I or are they giving my child more attention, or doing something that might make my child think the behavior works to get them what they want?

Co-occurring conditions and environmental influences

You should share your documented answers from above with your provider and/or child's care team. They will probably want to explore possible co-occurring conditions to see if they are at the root of some behavior. If they do not, suggest exploring them. At the very least, their process could help in identifying what might trigger or maintain certain behaviors.

The following chart lists areas of potential consideration. It is by no means exhaustive, but covers the more common causes of many challenging behaviors. If this list suggests an area that a provider is not investigating, be sure to question why. Also, consider second opinions. Consultations with other professionals is standard of care and ensures you are getting your child the attention they deserve.

Things to consider: adapted from Psychopharmacology of Autism Spectrum Disorders: Evidence and Practice (Siegel, 2012).

Possible cause	Potential area or focus	Questions to ask
Medical	Pain (e.g. ear infection, toothache)	Could this person be in pain?
	Seizure	Could this be seizure-related?
	Sedation/polypharmacy (multiple medications)	Is this individual sedated? Are they on too many medications? Are they on the wrong medication(s) or dose of medication(s)?
	Insomnia/inadequate sleep	Does the person get enough sleep?
	Allergies	Are there seasonal, food, or environmental allergies involved?
	GI issues/nutrition	Is the behavior related to meal times or food? Has there been a change or concern about bowel habits?
	Dental concerns	When was the person's last dental exam? Is there tooth pain?
	Vision/hearing	Is there a change in or problem with perception?

Possible cause	Potential area or focus	Questions to ask
Genetic	Fragile X, Down syndrome, etc.	Could this behavior be related to an undiagnosed genetic syndrome?
Mental health	Co-occurring mental illness	Could the person be experiencing anxiety, depression, ADHD, or OCD?
Cognitive	Intellectual ability/ processing abilities	Are the demands on the individual too high or too low for their cognitive level?
Communication	Adequacy of communication system	Does this person have a functional communication system? Do they use it spontaneously (i.e. without prompting)?
Sensory dysregulation	Unmet or overwhelming sensory factors	Is the behavior supplying sensory input or attempting to meet sensory needs?
	Sensory defensiveness	Is the behavior in response to sensory overload? Are there big responses to things in the environment (e.g. loud noises)?
Environmental factors	Location, time of day, setting, activity	Is the person too exhausted at the end of the day to handle this demand? Why are they okay at other doctors' offices, but not here? Is this task beyond their motor ability?

Possible cause	Potential area or focus	Questions to ask
Environmental reinforcement of behavior	Family, staff, educator, and/or caregiver responses to behavior	Is the behavior responded to with attention, removal of a request, or something else?
Family/staff dynamics	Changes in family environment	Have you experienced losses or changes in the family?
	Changes in staffing	Has a favored staff member left? Are new staff members adequately trained? Has there been a shift in schedules or routines?

Treatment for Challenging Behavior: Evidence-Based Interventions

It is important to keep in mind that there is help for your child's challenging behaviors. Work with your child's pediatrician and developmental psychologist or psychiatrist to find the right therapists or providers to meet your child's unique needs.

Experts from the Autism Speaks Thought Leadership Summit on Challenging Behaviors put together a guide, **Evidence-Based Practices in the Treatment of Challenging Behavior**, that outlines treatments backed by research that have proven effective in addressing challenging behavior in people with autism. Below is a brief overview of those treatments. Your child's medical team and therapists can help determine which might be right for your child.

Reinforcement

Reinforcement includes the contingent presentation of a stimulus following the occurrence of a behavior that results in an increased likelihood of that behavior. This behavioral mechanism is used to build up or support appropriate behavior in an attempt to replace challenging behavior. Reinforcement as a procedure appears across several evidence-based practices.

Antecedent-based Interventions

The **antecedent** is the situation, events and conditions that occur before a challenging behavior begins. Antecedent interventions are strategies that manipulate the environment prior to the behavior in order to prevent it from happening.

Extinction

When **extinction** is used, the relationship between the behavior and the consequence that reinforces it is removed. For example, if a person's hitting others is occurring frequently because it results in frequent delivery of attention, extinction would involve ensuring that attention no longer followed incidences of aggression. In other words, extinction works when the result is that the behavior no longer "pays off" for the person.

Response Interruption and Redirection

Response interruption and redirection (RIRD) is used to reduce behaviors that are repetitive and stereotypical and that interfere with a person's daily life. In response interruption, an effort is taken to prevent the behavior from occurring. For example, a teacher might block a person's attempt to scrape their skin. Redirection follows blocking and involves prompting the person to engage in an alternative behavior.

Differential Reinforcement of Alternative, Incompatible, or Other Behavior (DRA/I/O)

This practice includes providing reinforcement for a particular alternative behavior or following predetermined time intervals during which the behavior does not occur, and withholding reinforcement when the behavior occurs (i.e., extinction).

Functional Communication Training (FCT)

One generally effective strategy to reduce challenging behavior is through the establishment of appropriate, communicative behavior from the individual. **Functional communication training** includes identifying the reinforcer(s) that maintain the problem behavior and then delivering the identified reinforcer(s) following appropriate communicative responses.

Parent-Implemented Instruction & Intervention

In **parent training (PT)**, caregivers are taught to implement specific procedures designed to improve parent-child interactions, decrease behavioral problems, and increase positive behaviors. Teaching caregivers to be the therapist for their child allows for delivery of treatment anywhere and anytime. With guidance from a therapist, caregivers are taught to address disruptive behavior by:

- attending to the child's positive behaviors
- ignoring inappropriate behaviors
- decreasing the use of punitive discipline strategies
- increasing the use of effective, appropriate child management strategies

Prompting (including Time Delay)

Prompting includes anything that helps an individual correctly complete a task or follow an instruction or rule. There are many different prompting strategies that include visual prompts, verbal prompts, gestural prompts, modeling prompts, partial physical prompts, full physical prompts and textual prompts.

Picture Exchange Communication System (PECS)

PECS is a pictorial system that teaches autistic individuals with social-communication deficits how to communicate using pictures (black-and-white or color drawings). PECS is specifically designed to support nonverbal or minimally verbal individuals and has been successfully implemented across a wide range of challenging behavior severities.

Visual Supports

Visual supports (VS) are objects or pictures/symbols that can be seen and/or held, which are used to provide information visually to enhance an individual's understanding of the physical environment, people and the social environment, or more abstract concepts, such as the passage time, a sequence of events or socially abstract concepts such as emotions or reasons to do something in a particular way. They also can support expressive communication, offering an alternative or supplement to speech, signs, gestures or actions (see PECS). They are either "low-tech" – objects, photos, pictures, symbols, or written words – or "high tech" – on electronic devices. VS have the potential to increase an individual's understanding of expectations, reduce anxiety, facilitate participation, support communication and increase independence, thereby reducing the risk of challenging behavior and supporting inclusion.

Exercise

There is some evidence to support that **exercise** in various forms may reduce problem behaviors such as wandering, self-injury, disruptiveness, and aggression in autistic individuals. Benefits appear to be short-term, impacting behavior during as well as up to several hours after exercise.

Self-Management

Self-management involves an individual monitoring, recording, and reinforcing their own behavior. Based on the self-directed nature of the program, it is likely most appropriate for mild to moderate challenging behavior.

Getting Help

Once you recognize your child's challenging behaviors, it is time to find them the help they need to improve their well-being and yours. Identifying and treating various kinds of challenging behavior is ideally managed with a team approach. Where possible, an autistic person will play an active part in this process too, and your role will include crucial advocacy for the best outcomes.

Building a Team

It is a good idea to start your team with your pediatrician, or more specifically a developmental pediatrician, and a behavioral psychologist or psychiatrist with a background in autism. Based on your child's behavior, you may want to also seek out other medical professionals to see if certain medical issues may be causing the behavior. These may include specialists in hearing, vision, gastrointestinal issues, diet and nutrition, allergies, or immune system function. You may also want to include a behavioral health provider or behavior analyst, who are trained to work with and understand a person's behavior and will work with your child and the team to develop supports and strategies.

To aid your search, you may want to consider the following avenues:

- Ask for referrals and recommendations from existing providers who know you and your family member with autism. Your pediatrician should be able to make referrals.
- For school age children, many of these providers will be available through your school. Your child's Individualized Education Program (IEP) or 504 case manager, your school's special education office or your child's teacher should make referrals or recommendations for review.
- Search for any research centers in your state that are part of the **University Centers for Excellence on Developmental Disabilities (UCEDD)** and reach out to the Family Faculty for guidance on providers.
- Talk with members of local autism family groups. Often, they are seasoned parents who can offer suggestions for local providers.
- Ask your state, county, or local area agency health department or similar office that handles autism for information on current providers.

Finding the Right Providers

If you are meeting a provider for the first time, it is important to consider the following:

- Can they speak about their experience working with other patients with autism on issues of behavior?
- How do they suggest you communicate as a team?

- What information can this provider give you to share with other team members?
- Observe: Do they try to understand your loved one, your family dynamics, priorities, strengths, confounding factors?
- Ultimately, you should discuss a diagnosis and treatment plan.

Bring your notes, all medical documents, any observations via video and any other documentation to help you clearly voice your concerns. In the appointment, focus on what the provider and you can do to build a day-to-day plan to anticipate and manage situations that trigger your child's challenging behavior. This plan will be built by your team, based on emerging diagnosis and while further tests or appointments continue. Talk to your team about when the treatment plan can be ready to implement.

When considering any strategy, make sure you feel the provider has fully answered for you these questions:

- What is the target behavior of this intervention?
- How will we know if it is working?
- What are we tracking?
- What are the side effects?
- What is our role in the intervention?

Accessing Services

To access many of the supports your child needs, you may need to attend programs, create individual plans and adapt to new routines. You may also need help from state and local agencies that provide or facilitate some of the necessary services. Starting to access all of these coordinated services may feel more like a winding pathway than a straight line.

Even for mild behaviors, essential supports may include:

- School plans (e.g. IEP, 504, Individualized Healthcare Plan)
- Behavior intervention plans
- Home supports (e.g. respite services, in-home applied behavioral services, etc.)
- Medical and psychological or psychiatric supports
- Clinical or applied behavior analysis (ABA) supports (e.g. in-clinic supports, consultation with a board-certified behavior analyst (BCBA), etc.)
- Other tailored approaches

Each of these approaches may be used in a coordinated way to manage aspects of the behavior. Stay open-minded and concentrate on energizing yourself and your care team to explore promising avenues for good outcomes.

As your loved one ages, or as unexpected events, like a pandemic, occur, it might be necessary to update services and the plan. Similarly, when progress is made, changes and updates might be necessary to build off the momentum.

Parents and other family members and caregivers who live together will be instrumental in helping an autistic loved one manage their challenging behavior. Given an autistic child's unique needs, collaboration with a treatment provider with training in behavior management and developmental disabilities who can individualize, monitor, and adapt strategies for each child and family is encouraged. They may recommend some of the following strategies.

Adapt the Environment

With careful monitoring, you will likely observe your child's behavior occurring at specific times, with certain people or in particular environments. Once you do it is important that you start tuning in for signs of increasing tension, anxiety or frustration that eventually lead to their behavior. You may notice there is a ramping up, or escalation period. Some signs may be very subtle–like red ears, a tapping foot, heavier breathing, or a higher pitched tone of voice. But learning to recognize these, and early, and using many of the approaches here are a good start in managing and even preventing challenging behavior.

The best way to set up your autistic loved one for success is to engage in positive situations, relationships, and places as often as possible. If possible, avoid situations that are triggers for challenging behavior. But when you cannot, preparing for and adapting the environment can often reduce frustration and anxiety and increase mutual understanding. Below are some things to consider:

- **Organize and provide structure:** Provide clear and consistent visual schedules, calendars, consistent routines, etc. so that your loved one always knows what is coming next.
- **Inform transitions and changes:** Recognize that changes can be extremely unsettling, especially when they are unexpected. Refer to a schedule, use countdown timers, give warnings about upcoming changes, etc.
- **Use visual supports:** Pictures, text, video modeling and other visuals are best because they provide information that stays. The Visual Supports Tool Kit provides a step-by-step, easy-to-understand introduction to visual supports.
- **Provide a safe place and encourage using it:** A calming room or corner and/or objects or activities that help to calm (e.g. bean bag) provide opportunities to regroup and can be helpful in teaching self-regulation and relaxation.
- **Remove or dampen distracting or disturbing stimuli:** Replace flickering fluorescent lights, use headphones to help block noise, avoid high traffic times, etc.
- **Pair companions appropriately for challenging activities or times:** Some people are more soothing and calmer than others in certain situations. If going shoe shopping when a grandparent comes along, then try to coordinate those trips with the grandparent.

- **Consider structural changes to your home or yard:** These changes might address some of the specifics of your situation to increase independence or reduce the risks when outbursts occur. The federal government's **Interagency Autism Coordinating Committee's (IACC) Making Homes that Work** tool includes a range of potential changes that can be made to reduce property damage, improve safety and increase choice and independence.

Teach Replacement Behaviors

Since behavior often represents communication, it only stands to reason that behavior can be then improved by building more adaptive communication skills. Of course, it is important to remember that a hallmark of autism is issues with communication, so patience is necessary here. Be prepared to use simple instruction steps and motivation to build new abilities. You and your team should specifically work on skills that will address the behavior's function, and thereby help to replace the target behavior. Skill building can take some time, so be persistent and celebrate the small steps along the way.

Some important skills to focus on include:

- communication and functional skills to promote greater independence
- social skills to promote greater understanding and reduce apprehension
- self-regulation skills

It is essential to teach skills in the context of a positive learning situation, not while a behavior is occurring. These skills need to be part of a comprehensive educational plan. Just like math facts, they may need to be practiced many times during the day when your autistic loved one is calm and attentive. Label "calm" and "ready to learn" states for your child so they learn what they feel like.

Reflection point: When you adjust your own behavior to meet your child's needs or help your child develop a new skill, celebrate yourself as much as you celebrate their growth. Reward a sibling for being extra patient or modeling a skill you are teaching. Use your successes, no matter how small, to help you stay focused and dedicated. Take time to reflect on the good things in your child and your family.

Respond Effectively to the Behavior

Punishment strategies by themselves are not effective, because they do not teach your child what they should do or have done instead. However, it is very important that parents, teachers, and therapists know how to respond after a child exhibits challenging behavior.

Attempting to teach in the moment when a child is upset and exhibiting challenging behavior will likely be ineffective, too. It may even make the behavior worse in the long run. Giving a problem behavior attention (even if adults are providing correction) tends to make it increase in frequency and intensity over time. Instead, when your child exhibits a challenging behavior, it is important not to reinforce it. **The bottom line: do not let your child's problem behavior be effective in obtaining desired objects or activities.**

For example, if your child is having a tantrum to escape a task or gain access to an object or activity, do not let the problem behavior become a tool they use to get out of things they have been told to do or get things they want. It is worth mentioning that this is very hard to do, especially if your child has difficulty communicating what they want, you know what they want, and/or giving in to them will end their distress. But if your child learns that problem behavior is the best way to meet their needs, this may interfere with their ability to learn more appropriate communication.

Redirection, a technique that involves interrupting a child's focus from an undesirable behavior and refocusing to a more positive one, can be used very early in a child's behavior, not after problem behavior. If the child is "redirected" to an activity or object they enjoy, it could unintentionally reinforce problem behavior. They may learn the problem behavior leads to things they want.

Other Strategies

Your team's recommendation may include teaching accountability (if your child spilled the milk, your child is the one to clean it up), or using positive practice, sometimes known as do-overs. For example, if your child let the door slam in someone's face, your child would practice how to enter your house at the doorway and hold the door five or ten times. Feedback during this exercise could sound like, "Almost. Let's practice doing that the right way." When doing this, eliminate a sense of punishment. Reinforcement with positivity and praise should help build the desired behavior over time. That could sound like, "I love that you noticed I am right behind you and you held the door open!"
When behavior does occur, be careful not to:

- Feed into the behavior, give in or provide what your child wanted to get from the behavior
- Show disappointment or anger
- Lecture or threaten
- Physically intervene (unless necessary for safety, such as keeping a child from running into the street)

If your child's behavior is intense, destructive, and/or harmful, it is highly recommended you work with a therapist to address problem behavior **immediately.**

Generally, when a child is engaged in the active, disruptive stage of a behavior, such as a tantrum or aggression, the essential focus has to be on the safety of the individual, those around them, and the protection of property. It is important to keep in mind that when they are in full meltdown mode, they are not capable of reasoning, being redirected, or learning replacement skills. However, this level of agitation does not usually come out of thin air. You can learn skills to help anticipate and turn around an escalating situation that seems to be headed in this direction.

Have a Crisis Plan

Preparation and strategies for coping and staying safe in these situations is essential, and it is important for you and your team to develop a Crisis Plan together. A sample plan is provided on the next page. Feel free to print it, fill it out and hand to anyone involved in the care of your loved one. A well-designed plan will include:

- Defined setting events, triggers or signs that a crisis situation might develop,
- Tools and strategies for keeping the individual and those around them safe in any setting (school, home, community),
- Intervention steps and procedures promoting de-escalation that are paired at each level with increasing levels of agitation,
- Lists of things to do and not to do specific to the history, fears and needs of the individual
- Hands-on training and practice for caregivers and staff,
- Data collection and monitoring for continued re-evaluation of the effectiveness of the plan,
- Knowledge of the best prepared facility if hospitalization or an emergency room visit might be necessary,
- Secured guardianship if your child is above age 18 and you need to continue to make decisions for them. (See our **Transition Tool Kit** for more information.)

Sample Crisis Management Plan: This plan is adapted from the Pacer Center's Crisis Management Plan: Support for Children and Youth with

Name of your autistic family member:	**Your name:**
Date:	
1. What behavior shows that your family member is feeling **well?**	
2. What words, gestures, or situations **trigger or increase** unwanted behaviors?	
Words	Situations
Gestures	Other
3. How does your family member show that they are **upset**? Describe their behaviors, actions, and words, and when and where it usually happens.	
4. List specific actions **you** can take in a crisis situation that have previously helped when challenging behaviors are becoming more intense.	
5. List the specific strategies that help. Identify a plan to **use** these strategies.	
Strategies	Plan
6. What can **others** do to help?	
Who might be able to help?	How can they help?

Be Prepared to Calm an Escalating Situation

- Be on alert for triggers and warning signs.
- Try to reduce stressors by removing distracting elements, going to a less stressful place or providing a calming activity or object.
- Remain calm, as their behavior is likely to trigger emotions in you.
- Be gentle and patient.
- Give them space.
- Provide clear directions and use simple language.
- Focus on returning to a calm, ready state by allowing time in a quiet, relaxation-promoting activity.
- Praise attempts to self-regulate and the use of strategies such as deep breathing.
- Discuss the situation or teach alternate and more appropriate responses once calm has been achieved.
- Debrief with the individual, as well as the team, to prepare for increased awareness of triggers and strategies for self-regulation in future experiences.

What to do in a Crisis Situation

- Remain as calm as possible.
- Assess the severity of the situation.
- Follow your Crisis Plan and focus on safety.
- Determine who to contact:
    - Dial 211 for free, confidential crisis counseling
    - Dial 911 for an emergency: fire, life-threatening situation, crime in process, serious medical problem that requires mental health and basic life support ambulance services
    - Call local police for non-emergencies

Severe and Dangerous Behavior

When severe and dangerous behaviors pose a risk of physical harm to the individual or to others in the vicinity, physical restraints or seclusion as a brief intervention are sometimes necessary to maintain safety.

- **Physical restraints** are physical restrictions immobilizing or reducing the ability of an individual to move their arms, legs, body, or head freely.

- **Seclusion**, or putting the individual briefly in a room by themself, is often employed in schools and other group environments. Seclusion can provide a quick halt to an immediate threat, but in the long run, seclusion is not a solution to the behavior itself, especially if the function of the behavior is to escape or avoid something. School programs should be focused on developing functionally based, positive behavior intervention plans to eliminate the need for seclusion practices all together.

It is important to note that while restraints and seclusion can serve to maintain safety, it is an intervention of last resort and should only be used when less restrictive and alternative interventions are not effective, feasible, or safe.

Improper use of these techniques can have serious consequences physically and emotionally. Parents and caregivers should seek out and receive professional guidance and training on positive behavior interventions and supports, crisis prevention, and the safe implementation of restraints and seclusion techniques when necessary.

Emergency Room Visits

Whether it is for behavioral concerns or just necessary medical care, the emergency room can be a difficult place for people with autism. It is important to be prepared to advocate for yourself and your child. You may need to make suggestions for medical staff regarding how they might be more accommodating.

It is important to bring documentation of:

- Behaviors that are causing concern
- Information about psychiatric history and any previous psychiatric evaluations
- Recent functional behavioral assessment (FBA) and/or behavior intervention plan (BIP), if applicable
- A list of current and past medications
- Names and contact information for doctors, behavioral provider(s) or other important care team members

Having all this information formally, in one place, will help you be prepared in the event of a crisis. It might be helpful to prepare this information in advance and pack it in your emergency prep kit so you can pass it along to ER staff upon your arrival.

Psychiatric Evaluation

If your autistic loved one is involved in extreme self-harm including suicidal ideation, desire to harm others, uncontrolled mania that involves harm to self, others or property, you should consider taking them to the ER and asking for a psychiatric evaluation. Alternatively, if you call 9-1-1 about such behavior from your autistic loved one, you might trigger police or first responders' concern for your loved one, and they might issue orders to have them transferred to the ER, even if that is not your wish. A police officer who responds to a distressed individual by sending them to the ER and hospital staff have the authority to place your loved one on a Mental Health Hold. When this happens, they can usually be held for up to 72 hours for a psychiatric evaluation. This does not necessarily mean that they will be held for the entire time. The evaluation often takes place within 24 hours.

Before a psychiatric evaluation can occur, the ER staff must evaluate and medically clear the individual. In many cases, they are likely to do a drug screen and toxicology report. The process to get medical clearance may take several hours, and maybe longer based on the staffing and volume at the ER and the complexity of the medical situation. Then, a psychiatric evaluation will be performed, and will include interviews, a record review and an examination.

Arriving at an ER does not necessarily translate into an admission to the hospital. Many trips to the emergency room may involve calming the individual, often with medication, before releasing them. Sometimes, the ER visit will turn into a longer stay of 1-2 weeks, with the length of stay sometimes a reflection of insurance issues.

If the hospital staff decides that the individual is at particular risk of harm to themselves or others, they may recommend commitment to a mental hospital or psychiatric ward. It is important to know that if you or an adult patient does not approve, the law provides for a process known as Involuntary Commitment or Civil Commitment. This allows for court-ordered commitment of a person to a hospital or outpatient program against their will or protests.

Psychiatric Inpatient Hospitalization

Often individuals are brought to the nearest hospital or the closest one that has an open bed. While this may be the fastest response in a crisis, it is best to be at a facility that can best respond to the needs of your child. If possible, discuss with your providers ahead of time if there is a preferred treatment setting for individuals with autism in the event of a crisis.

Some hospitals have a psychiatric emergency room. In a few states, there are specialized hospital programs specifically designed for individuals with autism and other developmental disorders. These Crisis Intervention Centers can often provide more targeted treatment options and assessment expertise. Pre-planned stays in bio-behavioral units may be hard to arrange since so few of these facilities exist, but the length of stay is generally a 3-to-6-month period.

Checking In

Just as you might do when planning a trip, it is important to remember to bring your loved one's necessary supports, including communication devices, visual supports, preferred toys and sensory items, as well as a familiar blanket or pillow. Entering a hospital can be quite stressful, so anything you can do to reduce anxiety and increase predictability should be considered.

If your loved one is placed in a psychiatric facility or ward, it will be important for you to help the staff understand their particular skills and challenges. You should be prepared for the fact that unlike many medical situations you may have experienced, a psychiatric ward is likely to have locked doors and may have stricter limits on visitation. Though most hospitals are family-friendly and have extended visiting hours for children, you may not be able to be present during your child's entire stay or there to be their "interpreter" of behaviors, food aversions, fears and anxieties as you might otherwise do.

Separating from your child can be difficult and leave you with feelings of guilt, but it is essential to remember that this is in the child's best interest. They need specific help, and you need an opportunity to recover from a challenging situation.

You may need to advocate for a role in helping the hospital to understand your child. It might also be important to advocate against the use of restraints for your loved one, as this may increase anxiety and the intensity of negative behavioral responses. There are established policies on the use of restraints and seclusion in healthcare that you can read **from the American Psychiatric Association**. You can also request that a medical provider who knows your child be involved with the hospital staff.

Note that these facilities are not obliged to provide behaviorally based treatments and interventions, though some do.

Patient Rights

Patients receiving services in a hospital have the same human, civil and legal rights accorded to all minor citizens (those under the age of 18) or adults. Patients have the right to a humane psychological and physical environment. They are entitled to respect for their individuality and to recognition that their personalities, abilities, needs and aspirations are not determined on the basis of a psychiatric label. Patients are entitled to receive individualized treatment and to have access to activities necessary to achieve their individualized treatment goals.

Note on commitment: As mentioned above, a psychiatric evaluation will be performed to determine if your loved one is a danger to themself or others. If they are considered a danger, they can be committed against their (or your) will with a court order.

Parent Rights

Parents (or guardians) retain their legal rights for decision-making regarding the health and welfare of their child under the age of 18. Parents have the right to informed consent to treatment, including notification of the possible risks and benefits of any treatment that is proposed. Parents have the right to be involved in the treatment that is provided to their child, which includes visiting their child during the course of their treatment, ongoing communication from the providers about the child's progress, and copies of medical, behavioral and educational records.

If you feel your child would be better served in a different setting, you should engage the attending physician and other members of the hospital clinical team in a discussion of the risks and benefits of changing treatment programs. While you know your child best, it is important to evaluate the implications for safety and treatment in any setting being considered.

Age of Majority and Guardianship: For many years, you have been making decisions on behalf of your loved one with autism. But at the age of 18, the law says they get to decide for themselves and can give the required "informed consent."

They can refuse treatment or be declared unfit to decide. Either way, unless you apply for and are granted guardianship, the decisions are now out of your hands.

If you think your loved one will need your assistance in making medical, safety and/or financial decisions, it will be important for you to learn about and consider your state's laws and procedures for obtaining guardianship status. This may take some time and the process involves a series of procedures, so it is important to consider this in advance of their 18th birthday, if possible. Sometimes there are allowances for temporary guardianship status while guardianship proceedings are in process. Guardianship is different from conservatorship, which allows for financial responsibility of another person. You can learn more in the **Transition Tool Kit** section on Legal Matters to Consider.

Discharge Plan

When the hospital stay is complete, your child or loved one should leave with a Discharge Plan created by the hospital, ideally with the input of other team members. It is not necessary for you to agree to the terms or components of the plan, but the hospital is required to counsel you, your loved one and other relevant team members about the components of the plan. The hospital is also supposed to begin implementation of the plan and assist in the coordination and connection to local social services organizations, making referrals or transfers and forwarding information and records. Such a plan is not likely to occur after a brief ER stay but should be developed for your child over the course of an extended inpatient hospitalization.

A discharge plan should include:

- A statement of your child's need, if any, for supervision, medication (what, when, how much), aftercare services and supports, assistance in finding employment,
- Recommendation of the type of residence in which your child is to live and a listing of the services available to your child in such residence,
- Lists of the organizations, facilities, and individuals who are available to provide services in accordance with each of your child's identified needs,
- Notice to the appropriate school district, if relevant, regarding the proposed discharge or release of your child,
- An evaluation of your child's need and potential eligibility for public benefits following discharge, including public assistance, Medicaid, and Supplemental Security Income,
- Follow-up evaluation plans.

For anyone who has been hospitalized for any reason, recovery is best when there is a solid support network. This network can be family, friends or team members, often working together. Involving others in the discharge process will help your loved one and support you in moving forward.

Taking Care of You

It is normal to feel encouraged and hopeful at times, and tired or confused at others. Recognize these feelings and discuss them with trusted people on your team. Days can be long, especially when your child's challenging behaviors can interrupt their usual participation in regular activities. Avoid putting pressure on yourself to find instant solutions.

Your well-being is important. Wherever possible, and especially in conversations with members of your team, raise how you are feeling, including ways in which the new realities impact your routine. Then make a point of discussing any steps you have all taken forward. Notice progress, however small.

If you feel burned out, you may find it useful to seek a therapist or other supports. Many family members connect with online support groups for families dealing with autism. Additionally, you can practice self-care with the following:

- **Motivate:** Tell your child what they do well and what you like. A sense of competence often fosters interest and motivation. Strive to give positive feedback much more frequently than any correction or negative feedback.
- **Monitor your response to challenging behavior:** Do your best to keep the challenging behavior from serving as your child's primary way of communicating. For example, do not allow their screams to get them out of brushing their teeth, or their biting to get them the lollipop that they want. Behaviors may get worse before you start to see them get better. Be empathetic of your child's needs but stay strong. Make sure all family and team members are consistent in this approach.
- **Validate their concerns and emotions:** Do not brush aside your child's fears or tell them not to worry. Their emotions are real and valid. Help to give language to what they are feeling. "I know you do not like spiders. I can see that you are very afraid right now." "I can see that you are angry that our plans have changed."
- **Set up reinforcement systems:** Use simple, predictable processes that reward your child for desired behavior. Notice them being good and reward that, verbally and/or with favored activities, objects or small treats. "I love that you stayed with me during our shopping trip. You earned a ride on the airplane toy!"
- **Set your child up for success:** Provide accommodations. Accept a one-word answer instead of demanding a whole sentence. Use a larger plate and offer a spoon to allow them to be neater at the dinner table. Use slip-on shoes, velcro shoes or self-tying laces if tying is too frustrating.
- **Strive for balance:** Focus on the behaviors and skills that are most essential. Be sure to include positive feedback and intersperse opportunities for success and enjoyment for you, your family, and your loved one with autism. Be resilient. Celebrate the fun and the good things.
- **Manage your expectations:** Have patience. There are no quick fixes. Meaningful change takes progress; it does not happen overnight. Also, do not expect your autistic loved one, especially minors, to understand and manage behavioral change like you or an adult.