Profound Autism: A PARENT'S GUIDE

HELPING FAMILIES OF PROFOUNDLY
AUTISTIC CHILDREN BUILD A FOUNDATION
FOR A LIFETIME OF LEARNING

National
AutismCenter℠
at
MayInstitute

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About May Institute and the National Autism Center

May Institute founded one of the first full time schools for autistic children in the country and currently provides a full range of services across the developmental spectrum for autistic and profoundly autistic children, adolescents, and adults. Our schools provide year-round day and residential education for hundreds of autistic children across the United States. In our early learning centers for applied behavior analysis (ABA), we teach autistic and profoundly autistic children the skills they need to learn and grow, with a focus on the unique strengths and preferences of each child. When children become adults, we provide intensive day and residential support ranging from a few hours per week to full-time, around-the-clock care.

At May Institute, we treat the people we serve, and our employees, with respect and dignity. We strive to ensure maximum autonomy and independence for everyone in our care while maintaining physical and emotional well-being and safety, and honoring choices and needs. We do this using highly skilled, inter-disciplinary teams with expertise in applied behavior analysis, education, psychology, speech therapy, occupational therapy, physical therapy, and psychiatry. Our teams are trained in the most contemporary approaches to care grounded in research, expertise, and compassion. We design interventions with input from individuals and families to ensure a focus on meaningful, culturally aligned goals and outcomes.

The National Autism Center is May Institute's center for the promotion of evidence-based practice in autism treatment, research, and the dissemination of information. It is a living repository and dissemination hub. The new Resource Library houses easily accessible materials and engaging video content, including both asynchronous on demand and synchronous webinars, as well as information about virtual and on-site training, coaching, and consultation for parents, educators, and other professionals. The National Autism Center released the National Standards Projects in 2009 and 2015 which have been used by tens of thousands of families and healthcare practitioners to identify effective, evidence-based practices and guidelines for how to make choices about interventions for children and adults with autism and profound autism.

MayInstitute
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National AutismCenter℠ at MayInstitute

Foreward

When I learned I was expecting my first child, I excitedly rushed to our local bookstore and splurged on a stack of paperbacks about pregnancy. Perhaps like me, you too poured over the chapters of What to Expect When You're Expecting (Eisenberg, Murkoff, and Hathaway, 1996).

I was determined to be prepared, and, for the most part, I was. Sleep schedules, feeding, walking, and talking all occurred pretty much on time with my daughter. This took place in the early days of the internet, so I also discovered how to interact with other first-time parents in online forums. We compared notes and secretly judged each on a regular basis.

I was a little more relaxed when my second child came along. With two kids under four and a busy household, I didn't have the time to research the latest childrearing trends and developmental goals, nor did I have the energy to spend a lot of time online. I was fortunate to have a great pediatrician, and she was the one who caught the signs of autism at my son's two-year checkup. She asked those routine developmental questions about pointing, two-word phrases, and whether my son was responding to his name. My answer again and again was no. I felt my heart sink a bit, wondering what was going on with the sweet toddler sitting on my lap sucking his thumb.

Within a few weeks, that sweet toddler was diagnosed with autism spectrum disorder. As a result, I once again rushed to the bookstore, and spent hours online seeking information about the best ways to help him. What I learned very quickly was that resources were few and far between. So were real answers. A deep sense of worry and fear settled into my bones. There was no roadmap, and the path ahead appeared steep and arduous.

Almost two decades later, many things have changed. Resources and best-practices specific to supporting people with autism have evolved and have been disseminated in meaningful ways across the United States.

That said, for those with the sort of autism that requires lifetime, round-the-clock care, there is still a great amount of work to be done. This version of parenting certainly isn't the type portrayed in all of those What to Expect books. Fortunately, the National Autism Center with its decades of clinical expertise, has created a roadmap for caregivers of people with profound autism that is practical, readable, and accessible.

With good information, progress and peace are possible. As you read through the chapters of this guide, it is my hope that you will experience validation and empowerment.

Judith Ursitti
Cofounder & President
Profound Autism Alliance

Acknowledgments

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In addition, a heartfelt thank you to the entire May team whose daily dedication to positively impacting the lives of profoundly autistic children, adolescents, and adults is the inspiration that fuels everything we do.

A huge thank you to the Doug Flutie Jr. Foundation for Autism and the Organization for Autism Research for generously funding this project and the dissemination of the guide. A warm thank you to our Board of Directors for their unwavering support of this project.

Finally, a sincere note of gratitude to the profoundly autistic individuals and families whom we have the privilege of serving. We hope that this guide will provide inspiration and a foundation for positive change.

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Introduction

When your child is diagnosed with autism, your world is changed. The life journey you expected for your child, and for your family, is suddenly diverted to a new and unfamiliar path. You may be scared, grieving, or angry. You might worry about what your child's future holds and how to help your son or daughter achieve their highest potential and live their best life. You begin to search for resources, to find the best interventions and medical treatments, and to get a glimpse into the future—all with the goal of helping your child. But what you find may not address the severity of your child's challenges or the extreme behaviors your child exhibits daily. We are here to help.

Most autism resources are written for autistic people with low to moderate support needs because most autistic people fall into these categories. But if your child is severely or profoundly autistic, these resources will likely not provide you with the information you are seeking. Your child's diagnosis is different. They are non-verbal or minimally verbal, may engage in dangerous or challenging behaviors, and struggle with many of the day-to-day tasks that seem to come naturally for other children such as sleeping, eating, toilet training, playing, and tolerating changes in their routine. Their lack of communication skills makes it difficult, or seemingly impossible, to figure out what they want or need.

Severe and profound autism are not like the autism most people know or recognize. The term "profound autism" is new but is rapidly gaining recognition in the autism community, even as the definition continues to evolve. It was first formally recognized in *The Lancet* commission on the future of care and clinical research in autism in 2022. The Centers for Disease Control and Prevention (CDC) issued its own, similar, definition the following year. Though the two definitions vary slightly, the key components are the same and are defined by the severity of autistic symptoms, and by intellectual and language disability, rather than by autistic traits. In addition, the term is generally not used with children under eight years of age. At May Institute and the National Autism Center, and in this guide, we use the following definition for profound autism:

A profoundly autistic person has a diagnosis of autism spectrum disorder (ASD), requires lifelong 24-hour care, has a significant intellectual disability, and is non-verbal or minimally verbal.

Approximately 27% of autistic people are profoundly autistic. Yet there are limited resources tailored to this population. *Profound Autism: A Parent's Guide* will help fill this gap. It was written for parents, family members, and caregivers of profoundly autistic children and is the first-of-its-kind parent guide dedicated to the unique needs of this population.

The guide provides parents with realistic and clinically proven strategies that will impact their children's lives including increasing independence and improving quality of life. It is divided into two sections to address relevant and important topics that affect profoundly autistic children and their families.

In the first section, you will find strategies to address targeted concerns. These are known as focused interventions. The areas covered include communication, sensory differences, sleep issues, mealtimes, navigating challenging behavior, toilet training, transitions and play. In section II we address topics that impact families with profoundly autistic children. This section on "family matters" includes collaboration with providers, medication, managing stress, and safety considerations. At May Institute and the National Autism Center, we are experts in the treatment of severe and profound autism and work with children and adults to develop communication strategies, acquire new and meaningful skills, and manage the dangerous and challenging behaviors that are sometimes associated with the disorder. We utilize evidenced-based interventions and strategies based on current research and our seventy-year history working with this unique population.

May Institute is a world-renowned provider of clinical, educational, and long-term support services, research, and training, for autistic people and their families and caregivers, with a specialty in providing care for profoundly autistic children and adults. We provide person-centered, compassionate, assent-based care across the lifespan. We are committed to leading the field in the conduct and dissemination of research that will enhance the lives of individuals with disabilities, and to providing comprehensive training to ensure the continuity of consistent, highly effective care within the organization and in the field.

In *Profound Autism: A Parent's Guide*, we use identity-first language when referring to a person with an autism spectrum disorder (ASD) diagnosis. Identity-first language puts the disability first, for example, "an autistic person," as compared to person-first language which emphasizes the person first. Examples of person-first language are "a person with autism" or "a person who is autistic." How a person chooses to identify, or how a parent chooses to identify for a child without the ability to choose for themself, is a matter of personal choice.

To accurately describe profound autism, its symptoms, the challenges it can create, and the life outcomes which families must consider for their child, we use words and phrases throughout this guide that some people in the autism community may find objectionable.

Controversial words and phrases that you will see throughout this guide include:

- Severe
- Profound
- Symptoms
- Challenging behaviors
- Treatment
- Disorder

We chose these words to provide specificity, and because we believe that maintaining language that clearly describes the needs of profoundly autistic people is critical to ensuring they remain a relevant part of all conversations and research about autism.

Profound autism is not a diagnosis for which any parent is prepared. But there is hope, and there is a community of organizations ready to help. Organizations like May Institute and the National Autism Center are experts in the care and treatment of children and adults with profound autism and help individuals by teaching important and essential life skills necessary for a person to remain safe and reach their full potential. Advocacy agencies including the National Council on Severe Autism and the Profound Autism Alliance are dedicated to advancing policy and regulations that support the current and future needs of profoundly autistic people. And family and community organizations abound that offer a place to come together with other families with shared experience, autism-friendly events, and information about local resources and services.

This guide will give you strategies and techniques that you can use to help your child with some of the most common challenges of profound autism. Most importantly, it will provide you with the tools to build a foundation for a lifetime of learning for your profoundly autistic child and your family.

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Goals of Focused Interventions

Focused interventions target specific needs and challenges profoundly autistic children face. They are designed to address a particular skill or range of skills, such as teaching a child to request help. We highlight focused interventions in this guide because when implemented with fidelity, you will likely see progress on the skills targeted over a two-to-nine-month period.

This section of the guide focuses on providing recommendations for specific concerns you may have for your child. These concerns can range from issues related to health and safety, learning new skills, or addressing behavioral concerns. It may be difficult to know where to start. We recommend creating a list of what is important to you as a family and prioritizing your goals for your child. For example, if your child's sleep issues are affecting your entire family, start with the chapter on sleep-related issues. For another family, eloping may be a high frequency behavior and thus the chapter on Safety Considerations would be the top priority. After addressing the top priorities for your child, you can move on to other areas. It is also useful and recommended to speak to your child's educational team and providers when developing your priority list and to share your priorities with them so that they can prioritize these issues in their settings as well.

The goals of focused interventions are very specific with the aim of improving targeted aspects of the child's functioning and quality of life. Positive outcomes are often achieved within a brief time period and can have a broad impact on the child and family's quality of life. For example, a focused intervention may concentrate solely on helping a child learn to sleep through the night or eat a broader variety of foods. Interventions can be highly individualized to address the unique strengths and challenges of a child in a specific area and family context. The intervention plan and goals are tailored to the child's profile and two children receiving the same focused intervention may have very different intervention plans.

How do I know if the intervention is working?

Setting goals is an important part of assessing whether a focused intervention is helping you and your child move towards desired outcomes. The first step is to identify the outcome you want to achieve. For example, "I want my child to sleep better," or "I want my daughter to be able to let me know what she wants and needs." These general goals can then be transformed into goals that are Measurable, Observable, Relevant, and Evaluated Frequently. We call these MORE goals and they are used throughout the manual to help guide the development of effective and meaningful goals.

Case Study: Jacob

Jacob's parents are concerned that he often leaves the bathroom without washing his hands. They are proud that he is able to use the bathroom independently for all his toileting needs but know that leaving without cleaning his hands is not hygienic. Jacob was taught to use the bathroom with a picture schedule outlining each step. Jacob's mother decided to use a similar procedure to teach him to wash his hands as part of the "going to the bathroom" routine. To do this, she added steps to the bathroom picture schedule after flushing the toilet to guide him through the handwashing task. Jacob's mother chose the MORE goal below to track his progress.

MORE Goal: Within two months, Jacob will independently use his picture schedule to wash his hands after using the bathroom.

This is a MORE goal because it can be measured (counting how many handwashing steps are completed), the focus is on observable behavior (handwashing), it is relevant (meaningful and important for good hygiene), and it can be evaluated frequently (multiple times a day).

<table>
<tr><th>Measurable</th><th>Observable</th><th>Relevant</th><th>Evaluated Frequently</th></tr>
<tr><td>There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.</td><td>To be measurable, goals must focus on observable behavior, what you see and observe.</td><td>Goals should be relevant to your child and family and result in meaningful changes.</td><td>Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.</td></tr>
<tr><td colspan="4">GOAL: Jacob will independently use his picture schedule to wash his hands after using the bathroom.</td></tr>
<tr><td>Measurable</td><td colspan="3">Record the number of handwashing steps Jacob completes.</td></tr>
<tr><td>Observable</td><td colspan="3">Handwashing is broken into steps: (1) turning on the water, (2) placing hands under water, (3) putting soap in hands, (4) rubbing hands together for 60 seconds, (5) rinsing hands, (6) turning off the water, and (7) drying hands.</td></tr>
<tr><td>Relevant</td><td colspan="3">Proper handwashing will help keep Jacob healthy.</td></tr>
<tr><td>Evaluated Frequently</td><td colspan="3">Data will initially be collected everytime Jacob uses the bathroom.</td></tr>
</table>

- See APPENDIX A for MORE Goal Worksheet

In the upcoming chapters, you'll find additional examples of MORE goals, as well as practical and useful tips to help with common concerns including communication, navigating challenging behavior, encouraging play, restricted eating, sensory differences, sleep, toilet training, and transitions. Based on our experience, we selected the most common topics that a profoundly autistic child faces. Our focus is on simple actions that you can implement quickly and easily to benefit your child and family. In this section of the guide, we will cover interventions that can be designed and delivered by a parent, although if you have professionals working with you and your child, they can assist you.

While these tips can be useful for many, we understand that not all children and families will see improvement. If you need more support, please talk to your educational team or providers. The professionals at the National Autism Center at May Institute may also be available to help.

3

Building Communication Skills

Whether connecting with a loved one, sharing a laugh with friends, or advocating for oneself, using communication is central across all areas of our lives. For young children, the development of communication is one of the most important milestones, allowing them to express their needs and wants, and engage in the social routines of early childhood and family life. As toddlers grow into children and eventually adults, language abilities may be the most significant factor in functioning across all life areas including learning, social participation, self-care, and employment (Cronin et al., 2020; Hughes et al., 2023).

When asked what spurred them to seek services for their child, parents and caregivers most often cite communication as their primary motivator. Given that 90% of autistic children present with delayed language milestones, this is no surprise. There is a great variation in language abilities among autistic children (Lord et al., 2020; Tager-Flusberg, 2016). While many autistic children develop language, about 30% do not; the majority of those who do not are profoundly autistic. One of the hallmarks of profound autism is being non-speaking or minimally speaking, and profoundly autistic children are considerably more likely to have severely limited communication throughout their lives. Given that there is increasing evidence to support the efficacy of intervening early for autistic children, finding ways to encourage and support communication as early as possible is critical.

In this chapter we offer recommendations about how you can support your profoundly autistic child in communicating wants and needs. We hope you will take away that communication is as special and diverse as every child and that you can play an important role in supporting your child on their own unique journey.

Navigating this process can be difficult, especially with all the jargon. So, let's start with some basic definitions.

Communication: The purposeful sharing of information. We all communicate in a multitude of ways including facial expressions, gestures, tone of voice, and of course, speech. This is happening all the time both verbally and non-verbally.

Language: A rule-governed, shared code consisting of arbitrary symbols (e.g., words) used to convey meaning and represent ideas. It's important to remember that language is the content rather than the medium. It does not have to be expressed to exist (as with thinking).

Receptive language is how we understand and comprehend language. For example, through reading a book or having a conversation.

Expressive language is how we convey meaning through any medium such as speech, sign language, gestures, and visual symbols (such as writing).

Speech: The acoustic representation of language (think language put to sound). This is a complex, dynamic neuromuscular process requiring the coordination of multiple body systems.

Language development in profound autism

There are many differences in language abilities across the autistic population. While most children with autism spectrum disorder (ASD) initially present with delayed language milestones, developmental trajectories can vary widely after the preschool years.

A group of individuals within the autistic population, most often referred to as minimally verbal or minimally speaking, present with limited communication throughout later childhood and adulthood. This population represents approximately one third of autistic children and as mentioned above, this is a key marker of profoundly autistic children. Minimally speaking autistic children produce a small number of single words and fixed phrases into adulthood. Pragmatically, minimally speaking children are less likely to initiate communication or engage in social language exchanges. Often, much of their communication is focused on requesting with limited language related to other communicative functions such as commenting, sharing information, or asking questions.

There is evidence that speech ability may also play a role in spoken language skills for some minimally speaking children. In the early stages of development, infants may produce limited or less diverse babble patterns. As development progresses, many, though not all, minimally speaking children demonstrate motor speech, phonological, and articulation challenges that further complicate the development of spoken language.

With all of those factors in play, language development in minimally speaking children requires significant, consistent support. Luckily, there are ways to support communication at an early age and as children grow.

KEY TAKEAWAY!

Children communicate because they have a motivating reason to do so. For example, gaining access to things they need and want. Determining what your child is motivated by will help increase communication.

Why children communicate

Children communicate when they find communicating enjoyable and there is a receptive and responsive communication partner. Usually, communicating gives them access to something they want or need. That could be something social like the response or affection of their parent, or something more tangible such as a toy or food. On the most basic level, the most important thing a parent can do to encourage communication is to provide an enjoyable and rewarding communication experience. This teaches children that communicating gets them access to what they want. While some profoundly autistic children may not readily communicate for the sake of social rewards, all children have things that motivate them. Finding that "why," giving children a way to communicate about it, and listening and responding are the fundamental steps in building communication.

How children communicate

All people communicate in multiple ways. Think about your most recent conversation. You may have raised your eyebrows, changed your tone of voice, or used your hands to express meaning. Likewise, children employ multiple means of communicating from an early age. Even though a child is not speaking, that does not mean that they are not communicating. Children may use gestures, pointing, or facial expressions to communicate their needs. In some cases, they may not yet have developed these skills and may cry or use physical behaviors (for example, pulling on someone's hand) to get their point across.

It is important to start where a child is, responding to their communication and then giving them a way to communicate more effectively. This may not be speech. Giving a child a non-speech means of communication will build the other skills necessary for communication such as initiating communication, attending to the speaker or listener, or turn-taking. These skills form the base of communication upon which to build. Practicing these listening and responding skills are key to ongoing language development. Giving a child a way to communicate allows them to practice these skills and to see the power that their communication has in controlling their environment.

What is augmentative and alternative communication (AAC) and how can it help my child?

Simply put, AAC is the replacement or support of speech with visual input. This can encompass anything from hand signs, to pictures, to tablet-based speech generating devices that use pictures, symbols, or words that a person touches to produce a message. AAC has been found to be effective for supporting both receptive and expressive language for autistic children. AAC has the potential to provide your child with a functional means of communicating, thereby creating a pathway for ongoing language development.

Forms of AAC

AAC encompasses a spectrum of approaches and systems from no-tech to low-tech to high-tech. The most common form of no-tech AAC is signs, but gestures and modified signs are also commonly used.

No-tech strategies have many benefits. They are fast and do not require any materials, and children always have access because it only requires their body. On the other hand, signs and gestures can be opaque and harder to interpret than a picture.

Low-tech strategies generally consist of picture or symbol paper-based systems such as Picture Exchange Communication Systems (PECS) or a communication book. Some benefits of low-tech systems are that they are inexpensive, easily accessible, tangible, and excellent for beginning communicators and requesting. Some downsides are that these systems can be time-consuming to make; icons are easily lost; and they offer less potential for advanced language growth.

High-tech systems typically consist of a tablet with a communication application. The vocabulary is represented as icons, pictures, or text, and words are spoken aloud by the tablet when they are selected by touch. Some benefits of these systems are that they are robust, offering a huge amount of vocabulary and language growth potential in terms of building sentences; dynamic displays make them easy to edit and change vocabulary; and they have voice output. Some drawbacks are that they are expensive; the large amount of language can be initially confusing if intervention is not planned well; editing can be difficult; and they need to be charged and cared for.

Types of high-tech AAC systems

As noted above, AAC can be used to replace or augment speech or support speech and language development. There are three general types of tablet-based, speech-generating AAC systems:

1. Grid-based systems use pictures and symbols in a grid layout with a nested vocabulary structure (i.e., pages with broad categories lead to pages with related items or actions).
2. Text-based systems in which people use text to spell words which are spoken by the device.
3. Scene displays allow one to take a picture of a “scene” (for example, a playroom or people at circle time). Hot spots are then added to the scene so that speech is generated when they are activated. For example, one could create a scene showing a picture of children lined up waiting for the slide. If you touch the slide, the device says, “Go down!”. When a person in line is touched, the device could say, “My turn.”


All these types of systems have benefits. For instance, grid-based systems allow for a large amount of vocabulary and the ability to combine words. They may be beneficial in increasing communicative functions, creating sentences, or expanding from one- to two-word messages. On the other hand, scene display systems may be easier to comprehend for some learners and offer the ability to quickly add new scenes just when they are needed. They are also generally easier for caregivers to edit and navigate.

AAC evaluation

It is very important to seek an AAC evaluation from a licensed speech pathologist with significant experience working with AAC and profoundly autistic children. There are several key elements of a quality AAC evaluation:

- **Collaborative**: The whole team (parents, therapists, teachers) should be included in the assessment process.
- **Based on assessment**: The AAC evaluator should directly assess the child's performance with several AAC tools or strategies. Frameworks such as the Student Environment, Tasks, Tools (SETT) Framework should be used to ensure all important aspects of assistive technology are assessed.
- **Evidence-based**: Trial data and ongoing data should be collected and analyzed to inform treatment decisions.
- **Comprehensive**: All AAC evaluations should include education and follow-up support for the team.

What if you don't have access to an AAC evaluation or your child is very young?

There are quick and easy ways you can support your young child's language development using AAC and give them easy ways to communicate their wants and needs. Some ideas:

- Use gestures or signs. Teach your child and model simple signs (these can be modified to accommodate fine motor needs) for important items like bathroom or food. Teach gestures like a child holding up their arms to request being picked up.
- Use items from the environment. Cut the picture from a box of cereal that your child can point to.
- Make simple communication cards or a communication book by printing pictures from your camera or from Google.

- Use pictures on your phone. With the proliferation of the smartphone, everyone has a ready repository of pictures at hand. Scroll through an album of favorite things or places and encourage your child to point to request.
- Use pictures to communicate your messages or the daily schedule. Reinforcing your communication by pointing to a picture (e.g., Saying, "Look! We are going to Nana's house!" while pointing to a picture of Nana) may make your communication easier to understand.

Multi-modal communication

Many AAC learners use a combination of speech, gestures, sign, and AAC strategies. This is great! When using an AAC device, speech and other types of communication should be encouraged as well. While the device is being introduced, other modes of communication can be used for different communication functions so that opportunities for communication are not missed. For example, a child may use the sign for bathroom, use an AAC system to request their favorite toys, and use a vocal approximation to say, "all done."

A note on AAC and speech

Parents express concern about the impact of AAC on speech development. Many worry that AAC may prevent their child from speaking. Evidence increasingly supports the idea that AAC does not inhibit speech. In fact, it may encourage speech as children repeatedly hear a voice message in concert with the message they have produced. That said, there are always situations in which children respond differently to any treatment, which is why ongoing assessment to inform treatment decisions is so important.

KEY TAKEAWAY!

Communication is not just talking; people communicate in a variety of ways. Not all children will use their voice to communicate. It's important to determine your child's preferred communication modality, so you can work on building communication skills.

How can I help my child communicate their basic needs?

Listen/observe

For many young children, the best thing to do to encourage communication is to wait and listen or observe. It can be very difficult to not "fill the space" with questions or encouragement when we want our children to communicate. By pausing and listening, you may be able to identify the communication that your child is providing and give them the time they need to communicate it. This communication may be as simple as a child looking at an item they want, looking at you, or reaching for an item on a table. For young children, you may need to get down to their eye-level to see the world from their point of view. You may have to do some guesswork for interpreting, and you will not always be right, but that is OK!

Respond

As we mentioned earlier, children communicate because they get something enjoyable form the interaction. Responding immediately to communication is key to developing ongoing language growth. If your child points to an object to request, reinforcing that behavior by quickly providing access to the item is the best way to encourage continued requesting. If your child is trying to get your attention, respond immediately. Using a happy and enthusiastic tone of voice and praising your child helps to make communication enjoyable. What if you are not sure what they want? Respond anyway! It is OK to make mistakes. Even if you do not know exactly what they are asking, responding will teach them that their communication gets a response—a valuable lesson.

Create opportunities for communication

Many profoundly autistic children may not readily initiate communication. In that case, creating opportunities for interaction may be necessary. Here are some ways you can encourage communication:

Engineer the environment. Put your child's favorite toy in a place where they will need assistance to get it. This may prompt them to seek you out. It may also prompt them to climb or exhibit another behavior to gain access. That's OK! It gives you an opportunity to observe their behavior and model or prompt a desired form of communication.

Introduce toys that are very exciting for them but that require your help. This provides many opportunities for communication at any level, whether pointing, signing "more," or saying help.

Wait for requests. Hold something that you know your child wants. Wait for them to initiate with you to get it. Give the item to your child when he/she communicates their want or need.

Remember, we are aiming to achieve enjoyable interaction. It is important that your child has a quick way to initiate communication. Identify discrete opportunities or periods of time to implement this approach. You will need to closely observe your child's affect and be aware of signs of frustration. Too much delay in reinforcement or making a child work too hard to communicate may backfire and make communication aversive.

KEY TAKEAWAY!

Parents, caregivers, and family members are the most important communication partners in every child's life. If your child isn't initiating communication independently, you can help them by setting up the environment and creating situations that will encourage communication.

Give your child a way to communicate

Your child will need a reliable way to communicate in order to respond or initiate. You can help your child by prompting fundamental communication behaviors such as looking, pointing, gestures, and using an AAC device.

Looking

This is the primary behavior many children initially use to express interest in something. Following a child's gaze and responding may be an excellent entryway into expanded communication.

Pointing

Help your child point to items that they want. In the beginning, they may use their whole hand, and that is OK.

Gestures

Prompt gestures such as waving toward oneself for "come here" or head-shaking for "no."

AAC

Use pictures or signs to enable quick initiations. See the AAC section above for other ideas.

Functional communication

When children cannot use speech or conventional methods to communicate, as is the case for many profoundly autistic children, they may use other, less ideal behaviors to communicate. For instance, a child who wants to communicate that they are done with a plate of food may knock the plate on the floor. In other cases, a child may bite or scream to express displeasure or gain access to something they want. Functional communication is the replacement of unwanted behaviors used to communicate with a desired conventional form of communication. This approach uses the principles of reinforcement to shape a desired communication behavior. That is, reinforcing the wanted communication behavior while not reinforcing the unwanted behavior. Ideally, you will plan these functional communication interventions with your clinical team, but you may find situations where you can easily implement them on your own.

For example, your child hits the TV because they want you to turn it on for them. You might present them with a picture of the TV, prompt them to point to it as a replacement behavior, and immediately reinforce the request by turning on the TV.

1. The first step is to identify the behavior you want to replace with the target communication behavior (i.e., hitting the TV)
2. Identifying the replacement communication behavior (i.e., pointing to a picture card)
3. Teaching the child the new communication skill (using prompting)
4. Immediately reinforcing the child's behavior when they use the desired skill (turn on the TV)
5. Not reinforcing the unwanted behavior (the child does not get the TV when they hit the TV)
6. Consistently prompting your child to use the new communication behavior

How can I encourage language growth?

Follow the joy. I can't stress this enough. People are much more likely to talk about the things that interest them. It can be tempting to choose topics that we think are important, but these may not be important for your child. For instance, you may want to introduce a new book to your child because it has great vocabulary in it, but reading a book that they really love is more likely to provide the motivating experience they need to communicate. Using the strategies below for preferred activities or topics will provide an excellent context for language growth.

Use AAC

Activities like circle time at school or a shared book-reading activity for a parent are excellent learning opportunities. In the early years, these are primary ways in which children build joint attention and engagement. This act of listening and responding also builds basic pragmatic and social skills. At the same time, having a mode to engage in responding allows the development of expressive language skills. For minimally speaking children, these experiences may present with many missed opportunities for language growth.

Using AAC to support joint engagement, listening and responding, and expressive communication is an excellent way to address this challenge. Scene display AAC systems may be ideal for younger minimally speaking learners who may or may not go on to develop speech but need a way to practice responding in order to build up their underlying expressive language skills. Scene displays allow one to quickly take a picture and add a speech output "hot spot" providing timely vocabulary access. This may also enable important social interactions with peers or adults. For example, imagine your child is at morning meeting in their preschool. Children are working on greeting each other, saying their name, and responding to questions. A caretaker could quickly take a picture of the group and add the names of children or add social expressions.

As your child ages, it may be appropriate that another type of AAC system such as a grid or text-based system be implemented. These types of systems may better allow for development of vocabulary, sentence length, and grammar. Ongoing assessment is a key consideration in the use of AAC.

Model

Modeling is one of the most powerful tools that we can use to build language. Modeling is the act of demonstrating the behavior you want your child to demonstrate. This could be an expanded speech message or a communication behavior such as pointing. The key to language modeling is to model a desired message that is reasonably attainable for your child. For instance, if your child is using one word to communicate, such as saying "down" on the slide, you might model "Go down!" to encourage two-word productions. Modeling can be done with an AAC system as well. For instance, if you want your child to begin to ask questions, you may model them by using their device (in a position where they can see it) to navigate to the appropriate page and select "who?" or "where?" Modeling can be done very easily throughout the day and in all activities. One benefit is that it is unobtrusive—it does not require an immediate response. On the other hand, modeling does not work for all children. In those cases, some of the other techniques discussed in this chapter are recommended.

Reinforce progression

As your child starts to communicate more frequently, you can help them improve their communication by prompting and reinforcing desired communication behaviors. Imagine a situation in which you are accepting pointing as a primary mode of requesting while modeling sounds to encourage speech. Once you have established that your child can say the sound "buh" to represent the word, "bubble," you may begin to expectantly wait for them to say the sound rather than accepting a point to request a bubble. You would immediately reinforce this by blowing a bubble and saying "bubble!" As their speech progresses, "buh" may be shaped into "buhbuh." At that point, you would start accepting "buhbuh" as the request for bubble. This principle can be applied across all communication modes. For instance, accepting looking as a request while prompting your child to progress to pointing, or accepting pointing while prompting using a picture system to request.

Expand communicative functions

People communicate for many reasons; these are called communicative functions. Common communicative functions are:

- Requesting: asking for something
- Commenting: talking about something (e.g., "Look! Plane!")
- Gaining Attention
- Refusing/Rejecting: talking about what we DON'T want (e.g., "All done!")
- Asking questions
- Social: interacting with the goal of social communication in mind ("Hello!")

When working with children with profound autism, we can often get stuck focusing only on requesting. There are many ways you can encourage the expansion of language functions, such as incorporating language into routines and play.

Build language functions into common routines and play

Routines offer the best time to infuse language into a child's day. Because they are predictable, routines like dinner time, getting ready for school, or feeding the dog are replete with opportunities for communication.

Take bath time, for example. This is a time when you will be face to face with your child and interacting. There are a number of strategies to target language expansion.

- Model various communicative functions (e.g., Exclamations, "Splash, splash!" Commenting, "Under!" Termination, "All done." Requests "Out.").
- To encourage initiation, change the routine and wait for a reaction.
- Make up songs or sayings ("Here comes the water!") and pause them ("Here comes the…"), waiting and looking expectantly for your child to fill in the blank.
- "People games" or games that require no outside prop, like peek-a-boo, tickles, or airplane are excellent ways to build language and communication. They are also excellent for building connections because you are the reinforcer!
- Build language into the game. Model descriptive, exaggerated language such as, "Going up, up, up!" or "Oh no, a big crash!" Try to keep the language as consistent as possible.
- Pause for a fill-in. Using repetitive, routine scripts that can be paused to elicit communication will provide a scaffold for your child ("Ready, set, go!!").
- Pause the game at the most exciting part (e.g., right before the peek-a-boo) and look expectantly for initiation. For young children or those who do not have a way to communicate, assign an action such as pulling on your hand or holding up their arms as the initiation.

  Focus on turn-taking: even if your child is using non-speech methods to communicate, you can still encourage turn-taking. In a game of peek-a-boo, pausing and allowing for multiple initiations and responses will build this skill even if your child is using simple gestures or eye gaze. This back and forth will translate into an excellent foundation for future language growth.

Develop a MORE goal

Now that we've reviewed different ways to encourage communication with your child, let's utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently for the following case study.

Case Study: Anthony

Anthony is a 10-year-old profoundly autistic boy who is able to communicate effectively with his AAC device. But when he meets new people, he has several "rote" questions that he always asks (e.g., What is your name? Do you have any pets?). He doesn't often listen to the answer before he goes on to another question. Nor does he respond when the speaker asks him a question in return. His parents would like Anthony to pause after a question has been answered and either wait to ask another question or answer any questions that have been put to him using his device. Anthony is motivated to connect with others and enjoys talking to peers, but his "rote" question approach often creates barriers to ongoing communication. His parents want to support his desire for social connection. Thus, they would like to set a goal to help Anthony improve this communication skill.

Measurable	**Observable**	**Relevant**	**Evaluated Frequently**
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Anthony will wait for the listener to respond before asking a new question using his AAC device.

Measurable	Number of times Anthony responds to an answer to one of his questions. This can be either making a comment about the response (e.g., "That's a nice name") or providing an answer to a question (e.g., "My name is Anthony").
Observable	Anthony responds to questions or pauses after a comment or when he meets someone.
Relevant	Waiting for listeners to respond and answering questions will help Anthony strengthen his conversation skills, which will lead to more positive social interactions.
Evaluated Frequently	Track the number of times each week that Anthony engages in a back and forth conversation.

- See APPENDIX A for MORE Goal Worksheet

Communicating needs and wants may be one of the most important skills that your child will develop. We hope that this chapter provides clarity regarding this process and offers some practical strategies that you can begin to implement immediately. Remember that communication development is ongoing and may require reassessment and regular consultation with your clinical team. Helping your child find his or her unique path to communication may present challenges but will certainly be rewarding.

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4

Encouraging Play

All children benefit from social interaction. Beginning in the early years this is accomplished through play. Although play is a central area of child development, not all children can engage in play without support. As a parent of a profoundly autistic child, you may find that your child has difficulty in this skill area. If this is the case, you are not alone.

It is important to remember that just because your child may not currently be engaging in play does not mean they don't want to play or that they don't want friends. The reason they are not engaging in play could be because they need more support in developing play skills and/or their play and social interactions look different than other children. It is important for you to know that you are a critical force in developing your child's exposure to play. As a parent you are a role model for your child, and they will benefit from watching you engage in play with them.

Remember, play takes many forms and all children, regardless of their level of current play skills, should be encouraged to engage in it. Therefore, in this chapter we will focus on how you as parents can encourage play with your child. We will do this by tackling frequent questions that have been posed by parents to help you create a strong home environment to encourage play in any of its various forms.

What is considered play for a profoundly autistic child?

There is not one single definition of what play looks like. Play can take many different forms and there are benefits to encouraging different types of play. On the following page, you will find a few visual guides to the different types of play. These are broken down in terms of how toys are utilized in play (infographic 1: Lifter et al., 2011) and the involvement of other individuals in play (infographic 2: Parten, 1932).

PLAY DEVELOPMENT: HOW TOYS ARE UTILIZED (LIFTER ET AL., 2011)

1

Exploratory Play

- Involves exploring the environment and picking up toys and examining how they work and manipulating them.

  Example: pushing a key on a play piano and hearing it make a sound; pushing a toy car and watching it move.

2

Functional Play

- Expands upon exploratory play and involves intentionally using toys as they were designed to be used.

  Example: kicking a ball; racing a car; making a tower out of blocks.

3

Pretend Play

- The main idea behind pretend play is that the child is pretending a toy is something that it is not (a wooden spoon is a microphone) OR that they are something they are not (pretending to be a chef in a kitchen). It could also involve a key item missing from play that they are pretending is there (eating imaginary food off of plates).

  Example: using a block to brush hair; pretending to be firefighters putting out a fire; using an imaginary jump rope.

PLAY DEVELOPMENT: SOCIALIZATION COMPONENT (PARTIN, 1993)


1

Unoccupied Play

- Involves learning about one’s own body and how body movements impact the things around them. This type of play should look very similar to exploratory play. It can at times look like functional play, but the difference is there may not have been an intent behind the action.

  Example: child kicks out leg and because of where the ball is placed on the ground, the child kicks the ball.


2

Solitary Play

- Involves the child playing by themselves. Here the child is intentionally playing with a toy but is not interacting with anyone else.

  Example: child is lining up his toy cars.


3

Onlooker Play

- The child, while playing, is now periodically looking at another individual who is also playing but is not interacting with them. The key here is that the child is aware that the other child is playing and is watching them but does not try to engage with the child.

  Example: while lining up the cars, the child looks at the other child who is also playing with cars.


4

Parallel Play

- In this type of play the child is still not interacting with the other child, but the child has moved closer and may be looking at the other child more often than they were in onlooker play.

  Example: the child has now moved their body and cars closer to the other child and is spending longer amounts of time watching the other child play while also playing with their own cars.


5

Associative Play

- The interest in other children’s play increases in this stage and now the two children may be sharing toys, but they are still not engaged in play together.

  Example: child looks at one of the other child’s cars and points. The other child hands them the car they are pointing at and the children continue to engage in their own play while looking at each other frequently. The child may also start to imitate some of the other child’s actions, like moving the cars back and forth.


6

Cooperative Play

- The children are starting to work together in play toward a common goal. This is the first type of play that falls within the early stages of pretend play.

  Example: children are now lining up the cars together and racing them against each other.

- Socio-dramatic play and group play are other types of pretend play that can expand from cooperative play. These types of play may involve:
  - Pretending to be people they are not.

    Example: the children are pretending to be the mechanics fixing the race cars.
  - Mutually agreeing to use an item to represent something else.

    Example: the blocks are now being used as screwdrivers to fix the cars.
  - Adding rules to their game that all the children in the game are expected to follow.

    Example: the red car only races the blue car, and the green cars always race each other.

A profoundly autistic child may benefit from opportunities to engage in exploratory play (e.g., having the opportunity to hold, examine, and manipulate a variety of toys) or functional play with objects (e.g., playing the keys on a toy piano or playing catch with a ball). In terms of the social aspects of play, they may also benefit from opportunities to play near other individuals even if they are not engaged with others or playing with the same toy (e.g., your child is playing with a car and their sibling is sitting next to them playing with action figures). It may also be helpful to expose your child to group games with simple rules (e.g., Jenga or duck-duck-goose).

Profoundly autistic children may have more difficulty engaging in some of the higher levels of pretend play such as sociodramatic play (e.g., pretending to be superheroes saving the world) or symbolic play (e.g., using a block as a phone and pretending to make a phone call). It is important to remember that pretend play has many different forms and even if your child does not have the skill set to engage in sociodramatic play, it does not mean that they can't engage in other types of pretend play such as cooperative play (e.g., building a tower of Legos together with another individual) or group games with simple rules (e.g., playing kick ball, or simple turn taking games).

KEY TAKEAWAY!

Remember play in any form can be beneficial for your child. Don't overly concern yourself with the fear that your child's play is not identical to other children's and instead try to model and encourage play in any of its forms.

There are so many skills my child is working on, why should I spend time encouraging play?

Children's play has been shown to have a positive impact on a variety of skills they may be working on in other settings. For example, several academic skills are addressed in the play environment. Here are just a few of the many skills that can be positively impacted by play: problem solving, language development, mathematics, sharing, working with others towards a common goal, fine and gross motor skills, understanding other peoples' emotions, and developing coping skills when something does not go your way (Kasari et al., 2012; Lai et al., 2018; Siegler et al., 2006). Play, therefore, may also help your child develop other skills.

KEY TAKEAWAY!

Engaging in play can help your child to develop a wide range of important skills that will benefit them throughout the lifespan.

How do I interact and encourage play with my child?

1. **Observe what they like and dislike:** You can learn so much about your child's interests just by watching them interact with the toys in their environment. Put multiple choices of toys nearby and see what toys they reach for. It may help to select three items to start with so there are not too many choices at once, and then switch out items that they are not showing an interest in.
2. **Take advantage of natural opportunities to interact with your child:** If your child holds up an item to show you, this is a great time to comment on it. You can also show your child how certain toys work.
    - For example, if your child is looking at the piano, you could try pushing down the piano keys, so it plays sounds. In this situation your child might not be playing with the toy because they are unsure how to use it. Through your modeling, you can help encourage play.

    A toy may also not be interesting enough just sitting there. You may be able to increase interest by actively playing with the toy yourself.

    - For example, if your child looks at a race car, you could grab the race car and start moving it across the floor while saying "vroom, vroom". While doing this, make sure to keep an eye on your child for any reaction that they have that may indicate interest or disinterest.
3. **Follow your child's lead:** One of the most important aspects of encouraging play involves following your child's lead. Your child should be in the driver's seat. This means when they decide to switch from one toy to the next, you should follow their example and move with them to the new toy.
    - If they decide that the blocks should be stacked as high as they can go and then knocked immediately down, you should imitate this behavior by making a tall tower of blocks next to theirs and then knocking them down as well. Taking the time to imitate their play style may make them more likely to want to engage in play with you in the future. Play is a time for children to explore their environments and discover their interests both in terms of toys and play partners.
4. **Talk and listen:** Play is a wonderful time to encourage both verbal and non-verbal communication (Kasari et al., 2012). Even if your child is not communicating verbally this does not mean that you should not be speaking as well.
    - For example, if your child is moving a toy car along the ground, you could say "Look at how fast that car is going! Watch out for the couch! Honk Honk. You are such a good driver. I love how you drove right around the couch. Wow, it looks like you are going even faster now! Vroom vroom."

   - Or, if they are stacking blocks "I love the tower you are making. Which color block are you going to choose next? The red one, good choice. I love red, it is my favorite color."

   It is also important that if your child does communicate something either verbally (points at item and says the name of it) or non-verbally (looks at item and points at it) that you acknowledge the communication and provide praise. You can also expand on their communication.

   - For example, if your child is pointing at a Slinky, you could say, "Slinky! Yes, that is a Slinky. Great job letting me know that it's a Slinky. I love how colorful it is!"

   Or, if your child is looking at a ball and pointing at it, you could say, "Ball. You want the ball? Thank you so much for letting me know you want the ball. Should we play catch?"

5. **Provide different forms of attention:** One way to encourage play is through your body language and by providing non-verbal attention.
   - For example, your child may enjoy high fives, fist bumps, a thumbs up, or another forms of encouragement.

KEY TAKEAWAY!

The best way to encourage play is through observing your child to see what they like and dislike and then engaging with them by: following their lead, modeling how to use toys, copying the play actions they are doing, talking and responding to both verbal and non-verbal attempts at communication, and praising them using words and your body language.

What toys should I buy for my child? I see a number of "autism friendly" toys at stores, should I buy those?

The best way to encourage play is to buy toys that your child is interested in regardless of the design of the toy. This means that both "autism friendly" toys and general toys seen are both okay, as long as your child is showing interest in the item. It is important to keep in mind that buying toys they are likely to see in other settings, such as the soccer ball that is identical to one they might see at the park or at school, can be helpful for encouraging play across play environments (Charlop et al., 2018; Stokes & Baer, 1977). For example, the soccer ball is identical to one they might see at the park or at school, but its larger size can help build motor skills.

KEY TAKEAWAY!

Buy the toys your child is most engaged with. Toys similar in design to the ones your child will see in other play settings (the park, a friend's house, at school) may help promote play across multiple environments.

My child prefers to play alone, so why should I try to play with him or her?

Your child may like playing alone, but this does not mean they would not enjoy playing with you also. The key here is how you are playing with your child. If your child is playing with one toy and you are working on trying to engage them in a different toy, then in this instance they may not want to engage in play with you. If you are following the "How to encourage play" steps highlighted in the prior section, your child's interest in playing with you may change. The key here is to watch your child's body language for signs that they might be interested in engaging in play (e.g., looking at you or the toy you are playing with, moving towards you, holding up a toy, accepting high fives or fist bumps, responding to any of your verbalizations, smiling).

The best way to encourage play in the early stages, especially if you are concerned that your child does not like to play with others, is to avoid placing any demands on your child during play. What this means is that play is a time for your child to be in charge and to play in the format they choose. Therefore, if you are working on trying to join their play world, the best way to do this is by playing the way they like to play (e.g., if they are stacking blocks, you are stacking blocks too). You can always expand the play as well (e.g., showing them that you can make a house out of the blocks) but make sure, especially in the early stages, that you are not taking over and directing the play activities.

KEY TAKEAWAY!

Even if your child tends to play alone, it does not mean they are also not interested in playing with you.

What if my child is not playing but rather just grabbing and holding items?

This may be a great time to model how to play with the toys your child is grabbing. They may not be playing with these toys purely because they don't know how to. Teaching your child how to play with the toys in the way they were intended to be played with (e.g., holding a toy phone to your ear, playing a piano, rolling a ball) is called teaching functional toy play (Williams et al., 2001). One way to teach functional toy play is by encouraging imitation of your play actions. This process of teaching functional toy play involves gaining your child's attention so that they are focused on both you and the toy and then using labeling, modeling (and higher levels of prompting as needed), and imitation to encourage toy play. Using these techniques has also been found to encourage communication and expand vocabulary (Kasari et al., 2012; Toth et al., 2006). You can encourage functional toy play by following this guide:

TEACHING FUNCTIONAL TOY PLAY

STEP 1

- Pick up the toy that your child is showing interest in (the toy your child is pointing to or looking at).

STEP 2

- Hold up the toy to make sure you still have your child's attention (make sure they are still looking at the toy; if not, identify where they are looking and pick up that toy instead).

STEP 3

- Label the toy and play action for your child by saying "play the drum" while hitting the drum with your hands (here you are using both a verbal prompt and modeling).

STEP 4

- Then say "your turn" and hand the toy to your child and give them a chance to do the action.

  If your child doesn't engage with the toy independently, this may mean that they need another model or a higher level of prompting (e.g., hand-over-hand assistance). The key is fading out your assistance as soon as your child is starting to independently play with the item.

STEP 5

- When your child does the action you were modeling (e.g., hitting the drum) immediately praise them by saying "Great job playing with the drum"; this can be paired with a high five or fist bump. They should then be given access to the toy and an opportunity to play with the toy for a little longer. This additional opportunity for more play time with the toy is called natural reinforcement and is likely to help encourage your child to imitate play behavior in the future. Remember to make sure to always provide praise and additional play time with the item even if they needed full physical prompting to complete the action.

One question you might have is how do you fade your prompting to encourage play with a toy independently? For example, you may have had to use the highest level of prompting, hand over hand prompting, to encourage your child to play with the toy functionally. We will break down how to fade prompting below using playing with the drum as our example. Keep in mind that prompting and prompt fading techniques are not only used for teaching play, they can be utilized to teach a variety of skills both through play and outside the play environment.

PROMPT FADING TECHNIQUES

LEAST PROMPTING

Verbal prompt

- Involves saying what you would like your child to do.

  Example: "Play the drum."

Gestural prompt

- Involves using a gesture such as pointing to encourage the action.

  Example: You point to the drum.

Modeling prompt

- Involves demonstrating how to do the action for your child to imitate.

  Example: You hit the drum with your own hands.

Partial physical prompt

- Involves putting your hand on your child's arm or elbow as a guide.

  Example: You put your hand behind your child's elbow and help guide them through the same up and down motion of playing the drum.

Full physical prompt/hand over hand prompting

- Involves hand over hand guidance.

  Example: You put both your hands over your child's hands and move them up and down to demonstrate how to play the drum.

MOST PROMPTING

Some quick tips:

- When moving from one level of prompting to another, make sure to give an opportunity to assess for independence (e.g., give the child a chance to hit the drum on their own before providing prompting). The reason for this is your child may not need all the levels of prompting - your child may be able to hit the drum after only seeing you model it or may be able to reach independence after one hand-over-hand prompt and may not need the lower levels of prompting as well.
- Please note that although verbal prompting can be used, it is sometimes the hardest form of prompting to fade. If you are able to get your child to be independent without using this form of prompting, then fading will be easier.
- It is also important to remember that it is good practice to ask your child if it is okay for you to touch them prior to using some of the higher levels of physical prompting. Doing this extra step can help remind your child that they have a right to decide whether or not they are okay with physical touch. They don't have to answer the question verbally, but they could instead indicate whether or not they are okay with physical touch by using their body language (such as a head nod or moving away). If they are not okay with physical touch, use a different form of prompting.

KEY TAKEAWAY!

Your child may not be playing with toys currently because they don't know how. The good news is that you can teach your child how to play with those toys by encouraging them to imitate how you play with the same toys. This can be done through capturing their attention and then using a variety of prompting techniques and praise.

What if my child is not able to vocally communicate, how will that impact play?

It is important to recognize that because your child is not communicating vocally, it does not mean they are not communicating during play in other ways. Your child is communicating every time they look at a toy, look at you, smile at something, point at an item, grab a toy, push a toy away, accept a high five or fist bump, wander away from the toys, or hand you the toys. Even a meltdown during play is a form of communication that something is wrong. So, if your child is not communicating vocally during play, they are still communicating in other ways.

If your child is not a vocal speaker, you can encourage alternative communication during play. This can be accomplished by having your child bring their picture book or speech generating device to the play area and having it pre-programed with the toys that are currently available. Once your child has a way to communicate, you can encourage them to request items by putting toys slightly out of your child's reach, so they need to communicate to you what they want. Once they indicate wanting the item, you would then follow the "requesting procedures" outlined in the chapter on Building Communication Skills.

Another way to increase your child's exposure to communication during play is to narrate what your child is doing. For example, if your child is coloring a picture you could say "I love how you are drawing so nicely. That is such a pretty picture of a cat. I wonder what color you are going to choose. You picked blue, such a good choice. Blue is my favorite color..."

KEY TAKEAWAY!

Just because your child is not communicating vocally through play does not mean that they are not communicating in other ways. In addition, all forms of communication can be encouraged by narrating the play environment, encouraging communication devices be brought to the play areas, and putting toys in places that require your child to communicate for your help to access them.

How do I continue to play, when interfering behaviors occur?

One common concern is what to do during play if your child becomes upset or even engages in a meltdown during play. This could occur if a toy is missing a part, a toy breaks, another child is not playing with the toy the way your child wants them to, they lose a game, they don't understand the rules to the game, play time is over and they need to transition to another activity, etc.

Play is a wonderful environment to practice coping skills that can benefit your child throughout their life. If something upsets your child during play, this is a perfect time to figure out the cause and then teach skills they can use in the future when they get upset.

To start, you should collect some "ABC" data. You do not need any special materials for this. All you need is a piece of paper and a pen. When you see your child have a meltdown during play, write down what occurred immediately before they became upset; this is called the *Antecedent*. Then write exactly what they did when they were upset; this is called the *Behavior*. Lastly you can record what happened immediately after the behavior; this is called the *Consequence*.

Once you have this information collected you may have a better idea of what your child was trying to communicate with their behavior.

COLLECTING ABC DATA

EXAMPLE: You are coloring with Brian and you notice that he starts to scream any time you try to draw on the same page as him, so you stop drawing with him.

What you observed	The information that you learned from this	What skills can you teach your child?	How will you interact with your child in the future
Antecedent: Brian was drawing in his coloring book and I started to draw on the same page as him. **Behavior**: Brian started to scream. **Consequence**: I stopped drawing with Brian.	Brian might not like it when you color on the same page as him.	The next time Brian is drawing tell him "If you don't want me drawing on your page you can tell me "no thank you" (he can do this verbally, with his device, or through sign language). Immediately praise him when he does this and say "thank you for telling me, I won't draw on your paper". You can also remind him if he gets upset, to take some deep breaths, and then practice this skill with him.	Just because he doesn't want you to draw with him doesn't mean you can't continue to engage with him while he is drawing. Maybe he likes it when you narrate what he is drawing. Or you can bring another coloring book to the play area for yourself, and he can help you pick out which picture you should color. Keep an eye how Brian responds to the new strategies you do to see if he likes or dislikes them.

- See APPENDIX B for ABC Data Sheet

Please refer to the Navigating Challenging Behavior chapter for additional strategies to respond to interfering behaviors.

KEY TAKEAWAY!

It is important to find out why the meltdown is occurring so that skills can be taught to your child for them to use in the future when they are in similar situations. Remember the meltdown is likely a form of communication and it is therefore important to figure out what your child is trying to communicate so you can encourage them to communicate their desires in more appropriate ways.

How can I encourage my child to play with other children and across settings?

Let's start first with how to encourage play with other children. Just by taking the time to engage in high quality play with your child, you are already helping to encourage play with other play partners. The first steps to encouraging play with other children is teaching your child how to play and to experience the positive aspects of interacting with a play partner. By using these techniques you are laying the groundwork for their growing interest in playing with other children. The next step is to take very preferred toys you have identified through play with your child and start to associate those toys with other children (this can also help with transferring play across settings). For example, if your child is very interested in bubbles, give the bubbles to another child and have them hand the bubbles to your child or blow bubbles with your child. Doing this can help your child see the other child as a fun play partner. Siblings can also help in the process. Siblings, or similar aged relatives, can learn the techniques in this chapter and can engage in play opportunities at home to encourage play with other children.

The best way to transfer play across settings is to create opportunities for play with your child in multiple environments. Play time does not need to occur in the house every time. You could try doing some play sessions in your backyard, at a park, at a relative's house, etc. Changing the environment while learning play skills can help transfer the play skills to multiple settings (friends, house, school, park). The more you can practice in settings in which play is likely to occur in the future, the better. You can also bring your child's favorite toys into other settings to encourage play. As mentioned previously it is helpful to purchase toys your child is likely to see in other settings so they become familiar with these toys and recognize them when they see them elsewhere (e.g., the same soccer ball that is at school, or the puzzle that is also at your mother's house).

KEY TAKEAWAY!

The best way to encourage play with other children is to use the toys your child has already shown an interest in and bring them to interactions with other children so that your child associates the fun toys with play partners. Having your child play with siblings or relatives of similar age during the early stages of skill development may also help. To encourage play across play environments, try playing with your child in multiple settings and use common toys they are likely to see across environments (e.g., basketball that is identical to the one at school).

How much time a day do I need to dedicate to play and how do I tell if my child's play skills are improving?

There is no specific amount of time that should be dedicated to play each day. It is more important that your child is exposed to play frequently and that the exposure is high quality (Ginsburg, 2007). This means that during play time you are using all of the strategies mentioned in this chapter and are utilizing the interventions and tips on promoting functional toy play, encouraging play with a variety of toys and in multiple settings, fading prompting to allow for independence in play, and transferring the play skills to other play partners such as siblings or other children. By utilizing these strategies, you are making playtime a valuable and enjoyable experience.

Develop a MORE goal

While you are engaging in high-quality play, you may be wondering how you track your child's progress on play and social skills. Let's utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently for the following case study.

Case Study: Elise

Elise is a 6-year-old potentially autistic girl who rarely engages with toys in the way they are intended. For example, rather than building with blocks, she will often shove them into her pockets. Her mother would like to work on teaching her to play with a variety of toys functionally. Below is an example of how the MORE framework will help her mother track her progress.

Measurable	**O**bservable	**R**elevant	**E**valuated Frequently
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: In three months, Elsie will functionally play (i.e., play in the manner the toy was designed for) with 10 different toys.

Measurable	Count the number of toys Elise played with functionally.
Observable	Elise plays functionally with a toy for at least 2 minutes.
Relevant	Teaching Elise to play with a variety of toys will ensure she does not get bored and that she has options when her favorite toys are not available. It will also promote play with other children.
Evaluated Frequently	Collect data every time Elise plays with a toy.

- See APPENDIX A for MORE Goal Worksheet

KEY TAKEAWAY!

High quality and frequent opportunities for play with your child is more important than the length of any single play session. If you want to track how your child is progressing in developing play skills, use the "Measurable, Observable, Relevant and Evaluated frequently" framework.

Conclusion

You have reached the end of the chapter! Congratulations! The fact that you took the time to read this chapter shows that you understand the importance of play and are ready to help your child grow their play skills. This is such an important step, and you are such a key component in encouraging play and developing your child's skills. So, what should you do now? A great first step is to determine what toys your child might be interested in. Take some time to observe your child's play and get a sense of what they like or dislike and the types of toys they gravitate towards. Then begin using the strategies discussed in this chapter to create a fun play environment and allow your child to be in the driver's seat for play time and limit demands.

Once you have taken the time to show your child how much fun playing with you can be, then you can start to use the approaches discussed in this chapter to encourage functional toy play and expand their play repertoire. Also remember that playing in different settings and bringing other people into the play environment will help transfer the skills to other play environments and play partners. Lastly, if your child's play does not look like other children's play, do not get discouraged. Play can take various forms and just like with any other skill, continued practice and exposure will be instrumental in fostering growth.

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5

Understanding Sensory Differences

Sensory differences are common among profoundly autistic children (Leekam et al., 2007). More than 96% of autistic children report experiencing either hypo-or-hypersensitivity to sensory stimulation (Marco et al., 2011). Children who are hyposensitive to sensory stimulation experience little to no sensory feedback, while children who are hypersensitive to sensory stimulation may experience extreme levels of sensory feedback. For example, if your child is hyposensitive to sound, you may notice them seeking loud noises and high volume. Alternatively, if your child is hypersensitive to sound, they may become easily overwhelmed by auditory feedback and try to diminish or avoid it. Most autistic children have a mixture of hyposensitivity and hypersensitivity to sensory stimulation (Balasco et al., 2020). Understanding how your child is experiencing the world through their senses will help you provide better support to them.

How many sensory systems are there?

Remember the five senses you grew up learning about: touch, sight, hearing, smell, and taste? Those original five senses help us gather information from the outside world. For this discussion, we are going to include three additional sensory systems: proprioception, vestibular, and interoceptive. These additional three senses help us gather information from *inside* our bodies.

- The **visual sensory system** is the sense of sight. It allows us to process information we take in through our eyes.
- The **auditory system** is the sense of sound. It allows us to process information we receive through our ears and to filter out sounds we do not need.
- The **olfactory system** is the sense of smell. It allows us to process information we receive through our noses. The olfactory system is closely connected to sense of taste.
- The **gustatory system** is the sense of taste. It is responsible for our perception of taste. This system allows us to determine whether something is sweet, bitter, salty, sour, or umami.
- The **tactile sensory system** is the sense of touch. It allows us to process information through receptors in our skin to determine whether we touched something and what we touched.
- The **proprioception sensory system** is the sense of muscle and joint movement. It allows us to process information about where body parts are and what they are doing. This sensory system is also known as body awareness. The proprioception system is triggered when we exert force (e.g., running, jumping, pushing).

- The **vestibular sensory system** is located in the inner ear and is the sense of balance and spatial awareness.
- **Interoception** is the internal body sensory system. It allows us to process sensations from internal organs such as when we feel hungry or have the urge to use the bathroom.

How can I tell if my child is seeking sensory stimulation?

Does your child insist on the television being louder? Do they endlessly spin in circles until they fall down with dizziness? Do they put anything and everything into their mouth? If so, your child may be seeking additional sensory stimulation. Below are some signs of sensory-seeking behavior.

SIGNS OF SENSORY-SEEKING BEHAVIOR

Sensory System	Behaviors	Sensory System	Behaviors
Visual	■ Stares at moving objects ■ Excessive blinking ■ Repeatedly moves objects in a specific way	Tactile	■ Touches everything ■ Seeks messy play ■ Fidgets with items
Auditory	■ Puts their ear close to things that make noise ■ Requests music and TV to be louder	Vestibular	■ Is always "on the go" ■ Doesn't seem to get dizzy ■ Seeks out movement (e.g., swings, spinning, jumping)
Olfactory	■ Smells everything and/or everyone ■ Seeks strong scents	Proprioception	■ Seeks out rough-and-tumble play ■ May use too much force when playing ■ May chew or mouth non-edibles
Gustatory	■ Mouths non-edible items ■ Seeks crunchy and chewy foods ■ Seeks strong flavors	Interoception	■ Eats until overly full ■ May not hold bowel movements

KEY TAKEAWAY!

Some autistic children are under-sensitive to sensory feedback and may seek out additional sensory stimulation.

What are some activities I can do with my child if they are seeking sensory stimulation?

If your child is seeking additional sensory stimulation, you will want to integrate appropriate ways to meet that need. Below are suggestions for helping your child gain access to the sensory input they crave.

WAYS TO PROVIDE SENSORY INPUT

Sensory System	Input
Visual	■ Reduce visual clutter in learning environment ■ Have visual stimulation available (e.g., lava lamp)
Auditory	■ Use visual supports ■ Be sure to gain your child's attention before speaking
Olfactory	■ Provide scented items such as markers, Play-Doh, or stickers during play
Gustatory	■ Incorporate a variety of foods into your child's diet ■ Keep crunchy or chewy snacks on hand ■ Have a chew toy readily available
Tactile	■ Provide messy play opportunities ■ Have a fidget toy readily available ■ Provide pressure (e.g., weighted blanket)
Vestibular	■ Allow your child to rock, swing, or sway to self-soothe ■ Engage in bouncing activities (e.g., small trampoline)
Proprioception	■ Consider offering a weighted blanket ■ Encourage safe jumping and climbing activities
Interoception	■ Encourage activities that increase interoception awareness (e.g., simple yoga poses) ■ Develop accommodations to support your child (e.g., set alarm for when to use the bathroom)

How can I tell if my child is avoiding sensory stimulation?

Does your child cover their ears when you have the radio on? Do they avoid washing their hands? Do they insist on wearing a specific shirt because the tag isn't itchy? If so, your child may find some sensory input overstimulating and try to avoid it.

SIGNS THAT A CHILD IS TRYING TO AVOID SENSORY STIMULATION

Sensory System	Signs
Visual	■ Shows sensitivity to bright lights ■ Becomes nauseous or gets headaches from continuous visual stimulation
Auditory	■ Puts hands over ears ■ Is easily distracted by sounds
Olfactory	■ Has a strong reaction to smells (even when others don't notice them) ■ Refuses certain foods due to smell
Gustatory	■ Has a limited food repertoire ■ Has difficulty with mixing textures
Tactile	■ Has a strong aversion to being touched, clothing tags, certain fabrics ■ May act out aggressively in response to touch ■ Is sensitive to temperatures
Vestibular	■ Experiences car sickness ■ Expresses anxiety on swings or walking down stairs ■ Struggles with coordination
Proprioception	■ Avoids physical contact ■ Avoids physical play ■ Anxious in crowded spaces
Interoception	■ Heightened awareness of pain, hunger, and/or thirst ■ Feels emotions more intensely

KEY TAKEAWAY!

Some profoundly autistic children are extra sensitive to sensory stimulation and try to avoid it.

How can I help my child be less overwhelmed by sensory stimulation?

Once you understand what type of sensory stimulation your child finds overwhelming, you can introduce some strategies to avoid overstimulation. Additionally, you will want to teach your child to advocate for themselves when they begin to feel overstimulated. For example, if your child becomes overwhelmed by loud noises, you may want to teach them to wear noise-reducing headphones in noisy environments. Because you may not always be with your child, it is helpful to keep headphones easily accessible or to teach your child to request headphones when they need them using the communication modality that is easiest. For example, if your child is non-vocal, you could teach them to ask for their headphones by using their AAC device, pointing to a picture card or a simple hand sign.

SUGGESTIONS TO REDUCE SENSORY OVERSTIMULATION

Sensory System	Signs
Visual	■ Use dim and natural light when possible ■ Use sunglasses in bright environments
Auditory	■ Use noise-reducing headphones ■ Watch TV with minimal volume or sound off
Olfactory	■ Use preferred scents to mask unpleasant odors ■ Use a face mask to block scents ■ Use fragrance-free soap and cleaning products
Gustatory	■ Introduce new foods outside of mealtime ■ Keep “safe” foods on hand ■ Keep eating environment calm
Tactile	■ Provide sensory-friendly clothing; cut out tags, look for fabrics and materials your child likes ■ Communicate with others about your child’s boundaries in reference to being touched
Vestibular	■ Allow your child to engage in new movement activities at their own pace ■ Avoid spinning or activities intended to cause dizziness
Proprioception	■ Talk your child through physical movement and tell them what to expect ■ Advocate for healthy physical boundaries – It’s okay to communicate “no thank you” to a hug request!
Interoception	■ Encourage activities that increase body awareness (e.g., simple yoga poses) ■ Engage the vestibular and proprioceptive systems (e.g., swinging, rocking, lifting heavy items)

Develop a MORE goal

Now that we've reviewed the sensory systems and suggestions for how to address sensory seeking and sensory avoidance behavior, let's utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently for the following case study.

Case Study: Jack

Jack is an 8-year-old profoundly autistic boy with minimal language abilities who finds the loud noise of a lawn motor overstimulating. Jack covers his ears and attempts to hide from the noise. Most recently, he has attempted to elope from his home when neighbors use their lawn mowers. Jack's parents installed deadbolts and an alarm system as a safety measure at home but are concerned that he may try to elope from other environments when he hears a similar sound.

Jack's parents determined that blocking out the noise using headphones is helpful and can potentially mitigate the risk of elopement. They began by teaching Jack to put on his headphones using hand-over-hand guidance. Jack's parents followed these steps to implement hand-over-hand guidance as described below.

1. **Informed Jack of what they were going to do, "Jack, I'm going to help you put your headphones on."**
2. **Next, they placed their hands over Jack's hands to assist him in putting the headphones over his head and onto his ears himself.**
3. **After several repetitions, Jack acquired this skill, and his parents began to fade their assistance. Jack's parents would hand him the headphones; he would put the headphones on his head, and only needed assistance with adjusting them over his ears. Eventually he was able to complete both steps independently. Once Jack knew how to put his headphones on without their assistance, his parents started to prompt him to put them on independently by handing them to him when there was a loud noise and saying, "headphones on." When he mastered this step, they stopped handing him the headphones and simply stated "headphones on" when there was a loud noise. Jack's parents began to notice that he would occasionally put his headphones on when he heard a noise without any prompts.**

Measurable	**O**bservable	**R**elevant	**E**valuated Frequently
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Jack will independently put on noise-reducing headphones when he hears a lawn mower.

Measurable	Record when he puts his headphones on independently as well as when he is prompted to use them.
Observable	Placing the headphones over his ears.
Relevant	Reducing the level of auditory stimulation will decrease attempts to elope.
Evaluated Frequently	Data will be recorded when neighbors mow their lawns.

- See APPENDIX A for MORE Goal Worksheet

Once Jack masters putting on his headphones when he hears a lawn mower, his parents will work with him to generalize this skill to other loud noises. Their plan is to prompt him to utilize the headphones when he hears other noises that bother him. For example, they will start by cueing him to put the headphones on when he hears thunder. The goal will be for Jack to independently use the headphones when he hears a loud, disturbing noise.

What resources are available to help address sensory differences?

If you feel as though your child's sensory differences are impeding their learning or interfering with day-to-day activities, you may want to consider different treatment options and determine what is best for your child.

- **Occupational Therapy**: An occupational therapist is trained to conduct sensory assessments and develop individualized interventions aimed at helping children regulate their sensory responses.
- **Applied Behavior Analysis**: A behavior analyst can work with you to develop coping strategies to help your child manage overwhelming sensory stimulation and to identify precursors to feeling overwhelmed.
- **Feeding Therapy**: Feeding therapy is typically provided by a speech therapist and focuses on helping children who engage in food refusal, frequent gagging, and spitting out food due to sensory sensitivities.
- **Speech Therapy**: A speech therapist can help your child communicate their preferences around sensory stimulation either verbally or via an augmentative and alternative communication (AAC) device.

KEY TAKEAWAY!

If you feel that your child's sensory sensitivities are affecting their education, development, or health, be sure to seek out assistance from professionals.

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6

Navigating Challenging Behavior

For profoundly autistic young children, challenging behavior can be exhibited as tantrums, meltdowns, outbursts, crying, and whining. As your child gets older and physically larger, more intense behavior can emerge including throwing and breaking things, and aggression towards you, members of your family, or other children. This can be very worrisome as it can affect your entire family and make it unsafe to bring your child into the community. Self-injurious behaviors (or SIBs) may also emerge. These may involve hand biting, head hitting, head banging, and other behavior directed at oneself. These behaviors often occur when your child has had a meltdown and is extremely frustrated with a person or situation. It is heartbreaking to observe your child hurting themselves and unfortunately, when you try to block or stop the behavior, your child may turn towards hurting you. For some children, SIB can appear compulsive, as if they can't stop themselves.

In this chapter, we will discuss what you can do to address all forms of challenging behavior—not just meltdowns and tantrums, but aggressive and self-injurious behavior as well, as they often occur together. The circumstances surrounding challenging behavior are unique to each person. The origins may be tied to behavior patterns learned over time, part of an emotional reaction or, most likely, a little of both. Challenging behavior is often distressing for the profoundly autistic people experiencing it and for parents and caregivers who want to help.

Why is challenging behavior happening?

While it is sometimes difficult to predict behavior, it is important to look for clues and triggers that may help you understand why the behavior is occurring. One of the best ways parents can help is to think about the times and places that challenging behavior usually occurs and use that information to try to prevent the behavior in the future. The most common reasons for challenging behavior are frustration over wanting something that isn't available, wanting to avoid something difficult or scary, or reactions to unpleasant or overwhelming sensory experiences. To predict behavior, you must make careful and objective observation of the events that lead to the behavior.

Behavior: As Predictable as the Weather

In the early 20th century scientists were laughed at when they proposed we might be able to predict the weather. Since then, scientists have figured out how to predict weather with increasing accuracy. Even when they get it wrong, we know that there is solid science backing the effort. Similarly, our understanding of human behavior is allowing us to predict meltdowns with increasing accuracy.

In this section, we will review some of the most common reasons that challenging behavior may occur to help us predict, and then try to prevent it from happening. In any situation where challenging behavior occurs, it is critical to try to address the signs and symptoms early when you notice your child is becoming upset so that milder forms of challenging behavior (for example, whining, crying, yelling) don't escalate to more serious or dangerous forms of challenging behavior such as aggression and SIB.

Sensory overload

If the most common events before challenging behavior tend to be related to the presentation of some sort of sensory stimulation that was too loud, bright, repetitive, or otherwise overwhelming, then challenging behavior might be happening because of sensory overload. If this is the case, you should focus your efforts on preventing triggers and refraining from presenting tasks that may include aversive sensory stimulation. Unfortunately, sometimes it is essential tasks or activities that may cause sensory overload (e.g., brushing teeth or washing hands). In these cases, you'll need to get creative in finding ways to modify the task or activity to eliminate the uncomfortable sensory aspect. For example, if tooth brushing is aversive to your child due to sensory aspects of the process, try different flavored or types of toothpastes, you may try rinses that can be used instead of brushing, or you can look at alternative toothbrushes such as electric or soft brushes. It is important to teach your child how to ask to get away from, or limit, certain kinds of sensory stimulation, such as "taking space" from other people or taking a break from the current environment if they find it overwhelming or over stimulating.

Wanting something that isn't available

Another common trigger for profoundly autistic children is being told no, they can't have something, trying to find something that's missing, trying to get a favorite toy to work, or wanting attention when caregivers are busy. These are scenarios that all involve the child not being able to access what they want or need. This can be especially frustrating when a child doesn't have an effective way to ask for these things. In these cases, great emphasis should be placed on teaching communication surrounding the things the child likes most, so that they can ask for what they want in an effective way. If it is difficult to communicate what they want, they will resort to something that is easier—engaging in challenging behavior. As long as that "works" for them, it will become the most likely response when they can't get something they want or things are not going their way.

Of course, the problem with this is even if the child can effectively communicate that they want something, they can't always have it. For example, a child may want to go visit their grandmother, but if she isn't home, then you'll have to say "no". Let's take an even more extreme example, what if your child wants a dog or to go to Disney World? These examples describe situations that are not always available, possible or feasible. So, what do you do? How about calling grandma on the phone or using FaceTime to say hello to her. How about watching videos of dogs playing? Or watching a video of a guided tour of Disney World? You'd be surprised at how many videos and activities you can find on the internet that, even though they are not quite what your child wants, they may be a good substitute.

Another consideration when your child asks for something they cannot have is to use a phrase that is a little different than simply saying "no, you can't have it". Perhaps "not right now", "maybe later" or simply redirecting the child to something else may be a more effective way to defuse a situation that could lead to a meltdown or other challenging behavior.

What if your child asks for something you could give them, but don't want to. Maybe your child asks for a snack right before dinner. Consider whether this is a time to put your foot down and say "no" or if you can compromise with something small. If you decide to say "no" and difficult behavior occurs, will it be safe or therapeutic to continue to hold out? If the answer is no, you may end up giving them the snack to stop the difficult behavior, thus, it may be more effective to honor the communication and give the snack before the behavior occurs. Giving the snack at the height of the meltdown might be necessary for safety, but risks teaching the child that asking will not get them what they want but challenging behavior will.

Similarly, it may be the case that an item was inadvertently denied. For example, maybe you thought the child was pointing to the cookies in cupboard, but they were really pointing to the door of the cupboard to ask you to shut it and you realized this too late. It is much better to shut the cupboard door as soon as you realize that is what the child wanted. You can then work on refining the communication for next time, rather than trying to hold out and eventually closing the cupboard when the challenging behavior has escalated to more intense and dangerous behavior.

Wanting to escape or avoid something

Another trigger for challenging behavior is your child's desire to escape or avoid demands an adult has placed on them, or a task that is difficult or challenging. This might be an academic task, self-care task, or a household chore.

First, identify why the task is aversive or hard for the child in the first place. If it is due to a sensory aversion triggered by the task, then refer to the previous section regarding sensory overload. Alternatively, tasks are often hard when children don't know how to complete them, because they take a long time, or because the task requires a lot of physical or mental effort. It might be that the child does not have the necessary prerequisites to complete the task or that the task feels unnecessary or pointless to the child and takes time away from a preferable activity.

In this situation, your efforts should focus on modifying the task so that the child can complete it successfully. There are several ways to go about this. As always, prioritize tasks that have meaning to your child and give them choices. This can look like asking if they want to help empty the dishwasher or put the toys in the toy bin. Provide extra help throughout the task and only fade your support when you see that the child is getting the hang of it and starting to complete parts of the task independently. Don't require your child to complete the entire task at first. Increase your expectations as you see success.

Make sure that your child can ask for a break or stop when the task becomes overwhelming. Use communication teaching strategies to teach requests like "stop" or "all done." Be sure to honor these requests.

Finally, be sure that your child can confidently engage in all the fundamental steps necessary to complete the task. For example, a child cannot easily be successful at writing letters if they cannot hold a pencil with a pincer grasp. It is hard to put away the silverware without being able to match and sort objects. Working on skills out of sequence can result in frustration and can create an aversion to the learning environment. You can imagine that if your piano teacher insisted you practice Mozart when you haven't mastered a basic scale, it might diminish your love for the instrument.

KEY TAKEAWAY!

There is a reason why the challenging behavior is happening, and it requires taking a moment and being a calm detective to figure it out.

Learning from behavioral challenges

Careful observation of the circumstances surrounding challenging behaviors can help prevent them in the future. Remember to jot down what happened just before the challenging behavior, as well as what milder behaviors occur first and how and when it escalates to more severe behavior. Do this as soon as possible after the challenging behavior occurred. This data can give you important information towards preventing the next incident. Once you identify the circumstances that lead to challenging behavior, you can focus your efforts on changing those circumstances in the future. Here are some examples of things you might notice.

- Were there any unpleasant sounds or sensations?
- Was your child looking for something they couldn't find?
- Was your child asking for or trying to get something they couldn't have?
- Was a routine interrupted?
- Were they alone?

- Did someone approach them?
- Did you ask them to do something?
- Did you tell them to stop doing something?
- Did you take something away from them?
- Did something they like break or stop working?

All these observations will lead you to understand why challenging behavior is happening. It's not easy to accurately remember what happened in a situation long after it occurs. In fact, it is human nature to fill in the gaps by perceiving patterns whether those patterns actually exist (Boudry et al., 2015). To be sure that you are gaining an accurate understanding of why challenging behavior is happening, write down what happened before and after the challenging behavior and how long it lasted as soon as you can once the challenging behavior is over. Try posting a data collection sheet on the fridge or somewhere that is clearly visible so you can complete it right away.

You can then use this information to track your child's progress. The data will tell you if challenging behaviors are increasing or decreasing in frequency and duration. If your child has an episode of challenging behavior every day but it used to last an hour and now the episodes are only 5 minutes long, this is important information that you are on the right track and should stick with what you are doing. Or if the behavior had been escalating to aggression and SIB and now you are just observing milder forms of behavior, this can be meaningful as well.

Develop a MORE goal

Now that we've reviewed challenging behavior and suggestions for what to do when your child is experiencing one, let's utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently for the following case study.

Case Study: Jonathon

Jonathon is a 9-year-old profoundly autistic boy who engages in 3–5 meltdowns daily. Jonathon's parents have noticed that he engages in meltdowns most often when they ask him to complete a task, such as putting his toys away. When Jonathon engages in a meltdown, he often yells, cries, hits, and kicks others. Jonathon's parents would like to help him engage in fewer meltdowns.

Measurable	**O**bservable	**R**elevant	**E**valuated Frequently
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Jonathon will engage in fewer than 3 meltdowns daily.

Measurable	Number of times a meltdown occurs in a day and how many minutes (approximately) each meltdown lasts.
Observable	A meltdown includes crying, yelling, hitting, and kicking.
Relevant	The goal of one less meltdown per day would make a difference by reducing stress for our family.
Evaluated Frequently	Review the numbers of meltdowns each day and see how often and for how long they occur each week.

- See APPENDIX A for MORE Goal Worksheet

The following is an example of a simple data sheet you can use to track progress. To help keep track, there are several apps available for your phone and links to them as well as free data sheets can be easily found at the National Autism Center website: https://nationalautismcenter.org/

BEHAVIOR FREQUENCY

WEEK OF:	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Ex: Kicking	𝍸 𝍸 |||	𝍸 ||	||||	𝍸	||||	|||	||
Notes:							

- See APPENDIX C for Behavior Frequency Data Sheet

The first step is to start collecting information using a system that works for you. The next step is to start figuring out how to stop the challenging behavior from happening in the first place.

KEY TAKEAWAY!

Data is your friend and the best way to know whether you are making progress or not.

How can I prevent challenging behaviors?

Some of the simple and most effective things you can do to prevent challenging behaviors at home are:

- Help your child communicate their wants and needs.
- Teach a replacement behavior.
- Create areas for your child where they can easily access calming items and activities.
- Remove triggers from sight.
- Set priorities for you and your family.
- Make requests more predictable.

The next sections will further describe each of these strategies. If this information seems overwhelming, pick one area that seems most relevant to your family and focus your efforts there.

Communication

Effective communication is important in every interaction. Communication goes both ways and parents must be sure that they are communicating information to their profoundly autistic child in a way that can be easily understood. This is especially important during times when a child is becoming frustrated, or when we are teaching something new. Sometimes *too* much language can be overwhelming. Be sure to use concise and simple language when working on essential skills or after signs of distress. Watch your child and figure out how they like to be spoken to and what words help them respond best.

Teaching children to ask for what they want or need, and to ask to remove or avoid things that are overwhelming or unpleasant (Carr et al., 1985), is essential. Every child can benefit from this skill (Ala'i-Rosales et al., 2019). Wants and needs can generally be categorized into one of four major categories. These categories are different forms of attention; toys, food and other items; escape or avoidance of something; and sensory needs. Use the worksheet to identify your child's specific wants and needs from each of these categories. The escape category refers to things that your child wants to stop or avoid. If your child does not already have a way to ask for each of these things, this is a great place to focus your efforts.

	EXAMPLES OF WANTS AND NEEDS
Attention	■ Conversation ■ Hugs
Items	■ iPad ■ Snacks
Escape	■ Loud Noices ■ Hard Work
Sensory	■ Rocking ■ Twisting Hair

	FILL IN YOUR CHILD'S WANTS AND NEEDS
Attention	■ ________________ ■ ________________
Items	■ ________________ ■ ________________
Escape	■ ________________ ■ ________________
Sensory	■ ________________ ■ ________________

Now that you have a list of requests to teach, develop a plan for teaching your child how to ask for them (note: these requests are sometimes referred to as “mands”). It’s usually not enough to rely on this to occur without direct teaching, particularly if your child is profoundly autistic. If the “wait and see” approach was going to work, it probably would have already. Here are the basic steps to teach *effective* communication.

1. Look for signs your child wants something (for example, pointing, gesturing, or looking intensely at something).
2. Quickly, without delay, show them how to ask.
3. Give them what they asked for, even if you had to help and even if it wasn’t perfect.

Example:

- Your child is looking intensely at what his sister is eating.
- You prompt “do you want a cookie too?” Say “cookie.”
- If they nod, or even try to say “cookie” immediately give them the cookie and provide them with praise or other interactions you know your child likes (e.g., hug, high five).

Your child might need lots of help with this at first. It’s okay to do it for them, as long as you are committed to eventually fading your support and letting your child start to do it on their own. Err on the side of giving a lot of help very quickly at first so they don’t get frustrated. Do this as frequently and ask others to do the same. The goal is to teach your child how to ask for what they want or need so that they don’t feel that they have to resort to unsafe behavior to get these needs met.

If your child is tolerating this well, try occasionally waiting before helping to see if they are ready to ask or “mand” for the item independently. The less help you need to give and the more independently they ask, the more good things they should get! For example, if your child usually asks for hugs after you model the word “hug,” but this time, you only needed to say “hu_” this deserves the biggest, best hugs ever!

Teaching a replacement or coping strategy

Even when you've done a great job of removing triggers, things can happen that can cause challenging behavior. When triggers happen and you see signs of an impending outburst, help your child figure out something to do instead of resorting to challenging behaviors (Bacotti et al., 2022). This should be something calming that isn't easy to do at the same time as kicking, throwing, or hitting, etc. Some examples are squeezing a pillow or taking a deep breath. Pick one or two things your child can do quickly and easily and practice them many times a day when your child is calm. If you practice these simple skills a lot during calm times, it is more likely that your child will be able to do them when it matters, like during an episode of challenging behavior or when they are becoming agitated.

Finally, remember not to skimp on the paycheck for your child's hard work in practice! Make sure that you give tons of praise and access to good things to make practice worth it. Just like most people wouldn't go to work every day without getting paid, we can't expect kids to work hard for free.

Creating a positive environment

Even if you don't yet know the specific reasons why your child has challenging behaviors, you can identify the times when they are least likely to have a challenging behavior and build on those contexts. Identify specifics of the environment where your child is happiest using the questions below.

- Activities: What is the child doing?
- Location: Where is the child?
- Items: What items does the child have?
- Sensory: What does the child see/hear/smell/feel?
- People: Who is with the child and what are they doing?

EXAMPLES OF WHAT SOMEONE MIGHT OBSERVE WHEN THEIR CHILD IS AT THEIR HAPPIEST

Activities?	**Location?**	**Items?**	**Sensory?**	**People?**
humming	bedroom	fidget	dark	alone
rocking			quiet	

USE THIS SECTION BELOW TO IDENTIFY WHAT LEADS TO YOUR CHILD'S HAPPIEST MOMENTS

Activities?	Location?	Items?	Sensory?	People?

It might sound obvious, but when profoundly autistic children have access to the things that make them happy, they are less likely to become upset or have challenging behaviors. Of course, parents can't and shouldn't, give kids whatever they want all the time. However, a good attempt at creating an area where the child can access their preferred items can be a great starting point in preventing challenging behaviors (Bacotti et al., 2022). Using the answers to the questions above, try to recreate this scenario and create a happy space for your child. Make toys and leisure items as accessible as possible by using containers that the child can access on their own on shelves that are low enough for them to reach. This space can be used for play time throughout the day or as a space to go when you see signs that a challenging behavior might be coming or when they need to take a break. To keep your child interested in using the space, it may be important to rotate the items that are available so that you are frequently offering new and exciting options.

It is important to remember that the spaces you create for your child are not meant to be places that your child goes to play alone (unless that is their preference). You can and should enjoy the space with your child. Remember that this is a safe place where visitors should follow the child's lead and play the way the child wants to play. It's okay to encourage your child to try something new and engage with you or with items in a new way, but this should not be forced on them. If your child doesn't seem to like an interaction or activity, move on to something else. Encourage a robust repertoire of interests. The more leisure skills that your child can engage in, the more likely they will be able to find something fun to do even if their favorite toy is broken. See the chapter on Encouraging Play for more ideas.

Minimizing triggers

Another way to prevent challenging behaviors is to minimize the presence of triggering events or items. Put away anything that your child might want but isn't available to use at the present time (for example, when you need to re-charge their iPad or tablet).

Get in the habit of checking your home regularly. Recruit help from others in your household to make and maintain these spaces so that they are safe and minimize things that may "set off" your child. Provide yourself with the same supports you would provide your child. Hang a checklist in a common area or use technology to remind yourself and family members to ensure all areas of the home are welcoming and safe for your child. To help ensure safety in the event your child has an outburst, remove or secure any items that could be unsafe or dangerous.

It is important to note that sometimes profoundly autistic children want (perhaps demand) that things are kept in a certain way. This is a common characteristic of autism. In an effort to minimize triggers, you may find yourself and your family making excessive compromises to keep your child happy. It is important to prioritize what you want and need to keep everyone (not just your child with profound autism) happy. While it may be no big deal for your family to keep your cabinet doors in the kitchen closed all the time, it may be a problem that your autistic child has complete control of the TV all the time and won't let others watch what they want. Similarly, stopping at McDonald's occasionally for a treat is fine, but stopping every day for a specific treat might be more than you want to do. If you find that you are bending over backwards to keep your profoundly autistic child happy, think about what you can do over time to change the child's expectations and help them manage disappointment.

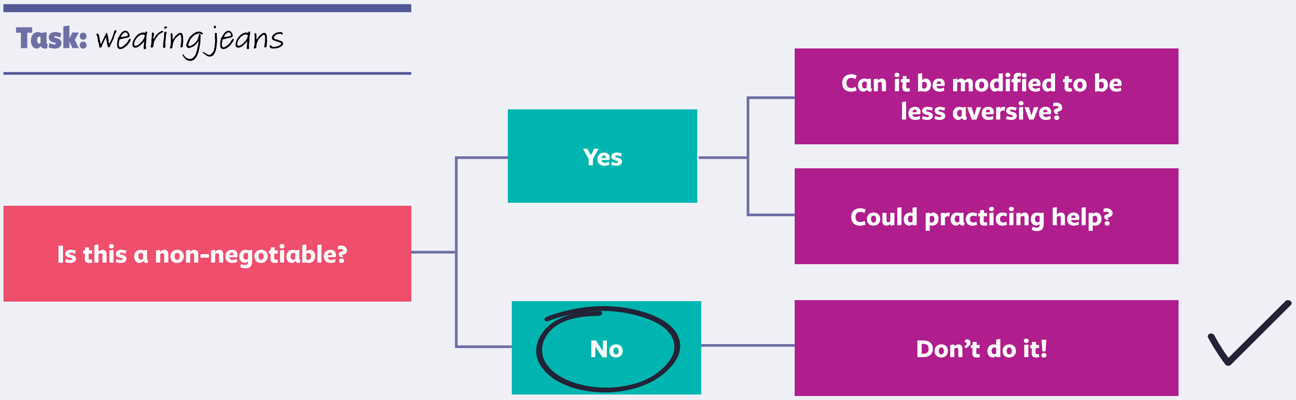
Setting priorities and modifying expectations

As noted above, it is important to do some self-evaluation of what you hope to achieve for you and your family. You might find that some challenging behaviors can be avoided simply by re-evaluating your expectations and focusing on your top priorities (Byrne et al., 2021).

First, evaluate your family's priorities in the broadest terms then hone in on what is truly important. An example of a priority in its broadest terms is to ensure your child and family members are happy. How would that be defined for your profoundly autistic child? Remember it is your child's definition of happy that you are assessing, not yours. What makes you happy might be different from what makes your child happy. No matter how you envision the priorities for your family, keep them in mind as you begin to take steps towards meeting them. Undoubtedly, minimizing challenging behaviors will be part of the solution.

You will need to learn when to let go of an expectation that isn't worth the battle, particularly if it doesn't impact health or safety. Notice early signs that a challenging behavior is likely and try to remove triggers and offer help before you are past the point of no return. This may mean you must compromise in the moment and respect that your child is telling you they are not ready, able, or willing, to do the task.

For example, it might seem important that your child wear jeans or pants rather than sweatpants in public. However, in the grand scheme of things, it might not be worth the challenging behavior. When considering your child's sensory sensitivities and personal preferences, think about what expectations you can let go of.



There are some tasks that we must do in life that are essential to health and well-being, not all of which are pleasant. Here are some examples.

- Eating
- Bathing
- Dressing
- Using the toilet
- Sleeping
- Tolerating medical treatment
- Responding safely to emergencies

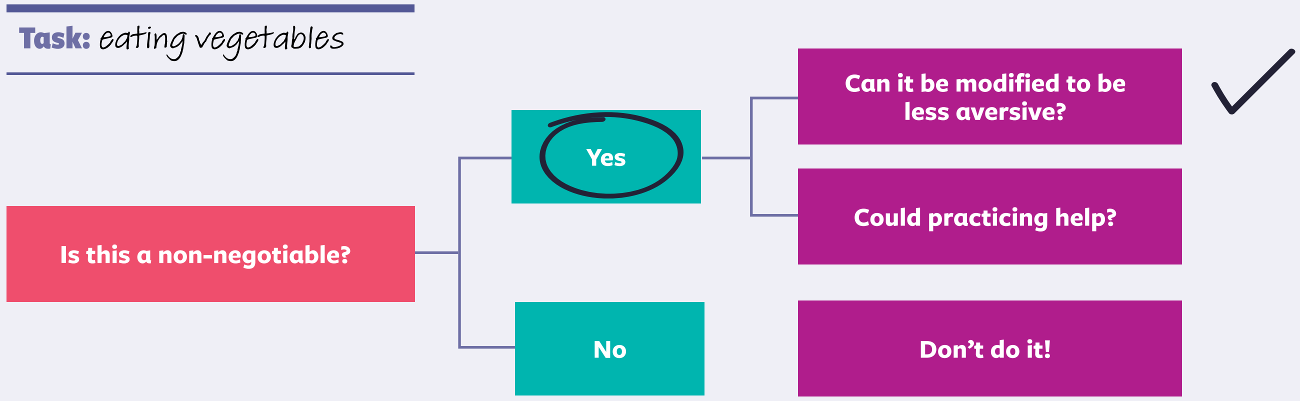
Unfortunately, endeavoring to complete these is sometimes at odds with the greater goals you hope to help your child achieve. There can be tradeoffs between short-term avoidance of challenging behaviors and long-term effects on health and well-being. For example, while your child needs to eat a balanced diet to be healthy and avoid future pain from poor health, some children may engage in challenging behavior when pressed to eat vegetables. While eating vegetables helps to accomplish the long-term goal of health, the immediate result is unlikely to make anyone involved happy.

If any of the essential tasks listed above are challenging for your child, it is worth considering the answers to the following questions.

- Is this task a non-negotiable priority that is essential to your child and family’s well-being?
- Can this task be modified to make it easier or less difficult?
- Would practicing manageable aspects of this task in small doses be helpful or harmful?

For example, if the pediatrician has determined that your child has low levels of healthy vitamins and minerals because she doesn’t like to eat vegetables, the doctor may say it’s important to find a way for her to get the needed nutrients for her health. However, the parents report that the child cannot tolerate the texture of any veggies and that any presentation of veggies causes challenging behaviors.

The family can work with the doctor to determine whether the vegetables would provide the same benefit if blended. They might try blending vegetables into fruit smoothies or pasta sauces to provide the needed nutrients without resulting in challenging behaviors.



Many of the tasks that we deem to be essential to our greater goals can be modified in a way that makes them more tolerable. They may be done less frequently (bathing once a week instead of daily) or with different materials (instead of nail clippers, use a file).

The answers to these questions are unique to each family and individual. They should involve the child whenever possible as well as any relevant family members, doctors, and other professionals on your team. The answer for your child and family will not be the same as the answer for another. For example, in the scenario above with a child who has an aversion to veggies, one family may find blending the veggies is too messy and time consuming but providing vitamins is quick and easy for them. Another family may find that their child does not tolerate vitamins well, so blending in the veggies is a better solution. Check out the chapter on Navigating Mealtime Challenges for more ideas.

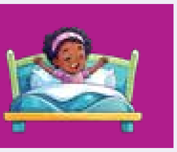
Predictability and routines

Creating predictable routines for profoundly autistic children can help alleviate anxieties or aversions to unexpected events. For some children, too much down time is not a good thing. If your child seems to be less likely to have challenging behaviors when they have structured activities to keep them busy, consider providing additional structure to their day. While it can be effortful for parents to schedule their child's day, sticking to a routine can be a powerful tool in preventing challenging behaviors.

Consider using pictures for both your child and you to help make what will happen next predictable. Examples include written or picture representations of what is to come. This may be in the form of a visual schedule of the events that will occur during the day or an activity schedule that shows the steps to completing a specific activity. Giving rules ahead of time or showing videos and pictures might help and can be enhanced by active practice if your child is ready and willing to do so.

MY NIGHT ROUTINE

1. Get Up From Nap ☐



2. Get a Snack ☐

3. Play Games ☐

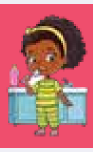
4. Go Outside ☐

5. Sensory Play ☐

6. Do a Chore ☐

7. Dinner ☐

8. Brush Teeth ☐



9. Bedtime ☐

KEY TAKEAWAY!

There are lots of ways that you can prevent challenging behavior from happening, look at each of the ideas above and see what fits best for you and your family.

How do I keep everyone safe?

Challenging behavior can be scary and emotional for all involved, particularly when it escalates to dangerous behavior such as property destruction, aggression, and self-injury. The first and most important parental response to a challenging behavior is to ensure safety. Safety measures will depend on each child's unique needs. It might be necessary to move to a safe and quiet place in your home. Somewhere without many hard surfaces or objects is ideal, such as a bedroom, particularly if they engage in SIB that is directed at hard objects. If a safe space isn't available and your child has a history of throwing objects, remove anything that might be dangerous if thrown.

If possible, create a calm environment by removing anything that you suspect might add to your child's distress. For example, remove anything that makes loud noises and dim or turn off bright lights. Put away items the child may see and want if you are not going to be able to give it to them. Having to say "no" to something at this moment will only add fuel to the fire.

Ask siblings or other vulnerable members of the household to go to an area where they are safe, particularly if your child is prone to aggression when they are upset. If there are other young children in the household, you may consider having a bin of fun items or activities at the ready to be given quickly during these critical moments. This will allow the other children to be safely occupied so you can be there for the child who is upset or agitated.

Managing your own emotions in these times is critical but can be challenging, particularly if your child is being aggressive towards you. Having a well thought out plan beforehand can make your experience during an episode feel less chaotic. What are things you do during stressful moments that help you keep your cool? Try writing down the steps you will take or talk them through with a friend, colleague, or family member. You might be tempted to yell or threaten to take something away to make your child stop. Doing anything punitive during an outburst will only make things worse and should be avoided, but that is hard to do when your house is being destroyed or you or other children are in danger.

Once everyone is safe, be available for help and comfort. Any communication from your child should be validated and praised. Communication from your child during an episode is a step in the right direction and can be a sign your child is calming. Waiting during the dangerous parts of the outburst but praising communication and other signs of calming, you can begin shifting the challenging behavior towards a safer situation.

EXAMPLE OF STEPS FOR SAFETY DURING EPISODES OF CHALLENGING BEHAVIOR

My Safety Plan

1. Bring Amy to her bedroom
2. Put the dog in her crate
3. Lock the closet door with art supplies
4. Take deep breaths instead of yelling
5.
6.

FILL IN THE STEPS YOU WILL TAKE FOR SAFETY DURING YOUR CHILD'S CHALLENGING BEHAVIOR EPISODE.

My Safety Plan

1.
2.
3.
4.
5.
6.

- See APPENDIX D for Challenging Behavior Safety Plan

KEY TAKEAWAY!

Develop a plan in advance to keep your child safe and yourself calm during episodes of challenging behavior.

Severe challenging behavior

For some children with profound autism, what may start as a tantrum or meltdown when the child is younger can escalate to more severe problem behavior such as aggression, self-injury, property destruction, elopement, and/or smearing feces as the child gets older. All of the recommendations above can help you address all types of challenging behavior. If you find that more and more often you are using your safety plan and fear for the safety of your child, yourself, or others in the environment, it may be time to seek help. Additional considerations for pica and elopement are addressed in the chapter on Safety Considerations.

Your first step is to talk to your child's physician and make sure there isn't a medical reason for the behavior. For example, toothaches and headaches are often associated with SIB such as head banging or hitting because the individual is trying to alleviate the pain. Allergies are associated with severe scratching that may lead to lesions and scabs associated with skin picking, another form of SIB. If your child is ill or uncomfortable they may also be more likely to engage in challenging behavior like aggression or property destruction because they are so unhappy and are not able to tolerate challenges. A request that is usually something that a child willingly does may become insurmountable for them when they are feeling sick. It is particularly important that your profoundly autistic child is thoroughly evaluated for any medical cause of discomfort and is treated as quickly as possible. Teaching your child to communicate in some way when they are unwell or in pain can help you identify when those conditions are occurring so that you can alleviate them and help them through the situation.

The second step is to talk to others in your child's environment to see if they are seeing the same degree of challenging behavior you are. Ask day care providers, other family members, and school personnel if they see the same or similar episodes of challenging behavior and whether they escalate to a severe form of behavior. You are likely to have heard about it if it is occurring, but it is possible that your child's challenging behavior is specific to situations at home or in the way you are interacting with him or her. If there are differences in the frequency or intensity of challenging behavior with others in the child's life, find out if there are certain things that others are doing to that may give you insight into alternative interventions for you to try. It is important to be open to listening to others and take their comments not as criticism but as tactics that may be helpful for everyone to use.

Finally, if your profoundly autistic child's behavior is so severe or even life threatening, seek out clinical expertise to help you treat your child's behavior. There are many outpatient and inpatient programs across the country that can provide you with clinical support and intervention. Most of these programs use applied behavior analysis (ABA) and other evidence-based interventions provided by Board Certified Behavior Analysts, licensed psychologists, speech and language pathologists, and other professionals. The model used is to first assess and then develop interventions based on identifying the triggers and common consequences or reinforcers for your child's challenging behavior as we described. Most of these programs are covered by insurance or can be provided by your child's school district. Families of profoundly autistic children often need help beyond what their pediatrician and they can provide, so don't hesitate to ask for help and referrals to programs as soon as possible. There are several resources available to you on the National Autism Center's website that will direct you to the help that you need: https://nationalautismcenter.org/

What if I can't do it all?

This chapter proposed a lot of ideas, and it would take superpowers to do it all. Don't let this overwhelm you. Prioritize the strategies that seem most relevant and most doable for your family. Remind yourself of all the things you are already doing and when you feel stuck, review the chapter for other ideas and get help from others. Remember to celebrate what you have accomplished. Use your data to guide the decisions you make. Have you been working hard on preventing triggers, but challenging behavior is continuing to happen with increasing frequency? That is a sign that you need to make a change or try a new strategy. Be sure that you give one strategy a try for at least a couple of weeks before moving on. Behavioral interventions are like diet and exercise. It takes time and consistency to see change.

The goal of this chapter is to provide helpful tips and tools for parents and profoundly autistic children to have better days. While challenging behaviors are tough for families, there are concrete steps you can take to make them more manageable. Like predicting the weather, we can now use science to help predict when behaviors will occur. We can prepare for these behaviors and even prevent them. Even more impressive is our ability to change the likelihood that these behaviors will happen again in the future. In the end, this science is most effective when focused on nurturing desirable behaviors rather than focusing on reducing the undesirable. As you take small, daily steps towards managing challenging behaviors, don't forget about all the things your child does that you love. You may find that if you spend extra time nourishing the cuddles, smiles, play, and positive interactions you will spend less time managing challenging behaviors.

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7

A Seat at the Table: Making Mealtimes Work

Good nutrition and a balanced diet contribute to our physical and mental wellbeing. Eating requires fine motor skills that grow progressively more complex from an infant holding their bottle, to a toddler finger feeding to a young child using utensils. Additionally, eating is a social experience; we eat with our families, with our classmates in school, and with friends. Eating outside of the home can broaden your world. These are all important experiences for all children, especially for autistic and profoundly autistic children. Unfortunately, if your child engages in challenging mealtime behavior, rituals, or has significant food restrictions, mealtime can become challenging. This chapter will discuss some strategies for addressing mealtime difficulties and offer suggestions for reducing mealtime stress.

Addressing medical concerns and challenging behavior

Prior to addressing food-related challenges behaviorally, you'll want to be sure your child isn't experiencing any medical conditions or food allergies that may be contributing to poor eating. Some common medical conditions that may impede eating include reflux, constipation, oral motor difficulties or delays, difficulty swallowing, vomiting, and rumination. Rumination is the deliberate regurgitation, chewing, and swallowing of stomach contents. We do not know the prevalence of rumination in profoundly autistic children, but approximately 6% of individuals with an intellectual disability engage in rumination (Lang et al., 2011). If your child is exhibiting symptoms of any of these conditions, you'll want to discuss treatment options with your pediatrician or gastrointestinal specialist. Additionally, if your child exhibits challenging behavior outside of mealtimes, such as aggression, tantrums, or self-injury, you may want to address the challenging behavior first, as this alone may carry over and improve mealtime behavior.

KEY TAKEAWAY!

Discuss any medical concerns with your child's physician prior to initiating a mealtime intervention.

My child struggles with mealtime. Is this typical?

If your child struggles with food-related issues, you are not alone. Research indicates that approximately 70% of autistic children engage in atypical eating behavior, most often associated with limited food preferences (Mayes & Zickgraf, 2019). Limited food preference may be a result of sensory sensitivities which leads to food aversions (Nadon et al., 2010). Some children may also experience physical issues related to oral development (e.g., chewing, swallowing) or find the social aspects of mealtime challenging (Smolko et al., 2023). Navigating food-related challenges can be stressful and frustrating. However, there are steps you can take to help make mealtime more successful.

When do mealtime challenges become a problem?

Mealtime challenges are often not addressed until a child is under or overweight, at risk for a feeding tube, engaging in food refusal, or exhibiting symptoms of failure to thrive or nutritional deficiencies. It is, however, best to address meal and food-related challenges prior to the development of medical issues. Address mealtime challenges if you‘ve noticed that your child‘s food preferences are becoming more limited, there‘s a lack of mealtime enjoyment (by your child or you), you‘ve started to cook separate meals for your child, you find that you no longer want to take your child to restaurants, and/or if there‘s a lot of stress around mealtimes.

KEY TAKEAWAY!

Be proactive and intervene as soon as you notice challenging behavior associated with mealtimes.

How do I start to address mealtime difficulties?

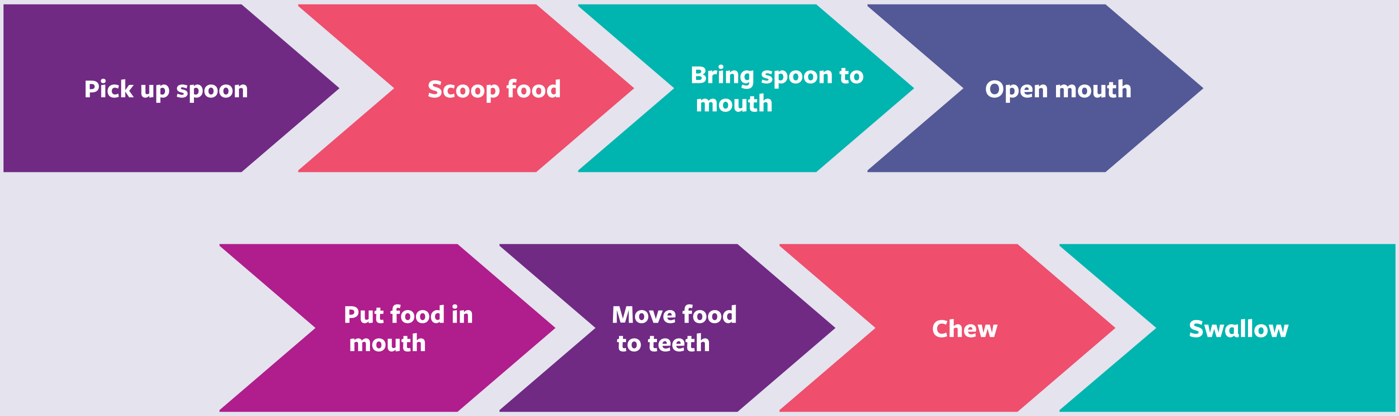
Understanding the challenging behavior

Broadly speaking, there are two categories of mealtime challenges. One is that a child does not consume an age-appropriate variety or type of foods, and/or engages in significant challenging behavior during meals. A second challenge is related to a skill deficit—the child may not know how to feed herself at all, how to use a spoon, fork or knife, drink from a cup, etc. You can think of these as “won’t do” and “can’t do” challenges.

Understanding why the behavior is occurring

Once you understand the challenging behavior, you will want to understand *why* it is occurring. First, think about the behavior—what is happening at mealtimes and what you would like to happen. Behavior is what we say and do—walking, talking, smiling, thinking, hitting, etc. Basically, if you take a word and you can put “ing” on it—think, run, cry, and yes, sleep—then it is behavior. So, eating is a behavior, but it is made up of lots of smaller behaviors, and sometimes it is helpful to think about it that way.

EATING



If you are trying to increase eating, begin by identifying the behaviors that are occurring instead of eating. Things like sealing the lips, screaming, throwing food, tantrums, continuously leaving the table, etc. These are interfering behaviors. To begin to address these problems we need to understand *why* they are occurring. Even if an illness or a medical event initiated the eating problem, it doesn't mean it is maintaining the problem. If the issue is persisting even after an illness or medical event has been resolved, then there are other things happening around mealtimes that are likely sustaining the behavior. Once you determine why the interfering behavior is occurring, you can better address it.

Develop a MORE goal

Now that we've reviewed some common mealtime challenges, let's utilize the MORE framework to address why a mealtime behavior is occuring and to develop a goal that is measurable, observable, relevant, and evaluated frequently.

Case Study: Josephine

Josephine is a 7-year-old profoundly autistic girl. She engages in a lot of disruptive behavior during mealtimes. For example, she will push her plate away, scream, and sometimes throw her fork or food. She often tries to get up from the table and will run off. Her parents reported that she didn't have many mealtime problems until age one and a half years old, when she got very sick and had to be hospitalized. She lost a substantial amount of weight, and, at the advice of her pediatrician, was put on a high calorie diet. She developed a special affection for strawberry ice cream, which her parents started offering at every meal. Over time Josephine started to only want strawberry ice cream during meals. Now when her parents try to get her to eat anything else she refuses until they give her strawberry ice cream.

For Josephine, the behaviors of concern are food refusal, screaming, throwing food, and leaving the table. Addressing all of these behaviors at once would be overwhelming. It's best to begin with the most important behavior, food refusal, since this could have a significant health impact. The family's long-term goal is to expand Josephine's food repertoire so that she consumes a healthy, well-balanced diet. Similar to other interventions, however, you should start with a small goal. Because Josephine's food repertoire is so limited (only strawberry ice cream), start by Josephine simply putting a new food to her lips, and not actually consuming it. Because we know Josephine likes strawberry ice cream, work with that and begin with a strawberry.

Measurable	**Observable**	**Relevant**	**Evaluated Frequently**
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Josephine will bring a strawberry to her lips and hold it there for 3 seconds a total of 5 times during snack time.

Measurable	Record the number of times Josephine brings the strawberry to her lips and if she holds it there for 3 seconds.
Observable	Bringing the strawberry to the lips and holding it there for 3 seconds
Relevant	This goal will expand Josephine's food repertoire.
Evaluated Frequently	Data will be collected every day during snack time.

◻ See APPENDIX A for MORE Goal Worksheet

Once Josephine has mastered this goal, we can move on to tasting the strawberry. Below is an example of how we can use the MORE framework to develop a goal for tasting.

Measurable	**Observable**	**Relevant**	**Evaluated Frequently**
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Josephine will taste a strawberry by placing the strawberry on her tongue for 3 seconds for a total of 5 times during snack time.

Measurable	Record the number of times Josephine places the strawberry on her tongue and if she holds it there for 3 seconds.
Observable	Bringing the strawberry to her mouth and placing it on her tongue for 3 seconds.
Relevant	This goal will help expand Josephine's food repertoire.
Evaluated Frequently	Data will be collected every day during snack time.

- See APPENDIX A for MORE Goal Worksheet

Once Josephine has mastered tasting the strawberry, begin working on chewing, and eventually eating, the strawberry. As you see progress with the initial goal of decreasing food refusal, you can address the other challenging behaviors Josephine is engaging in. For example, teaching Josephine to sign "all done" or to ask to leave the table and honoring that request (when appropriate) will likely lead to a decrease in elopement from the table, throwing food, and screaming. Please refer to the chapter on Challenging Behavior for suggestions on how to address such behavior.

KEY TAKEAWAY!

Start with small, manageable goals and then build on those successes until the long-term goal is accomplished!

What are some intervention strategies I can try at home?

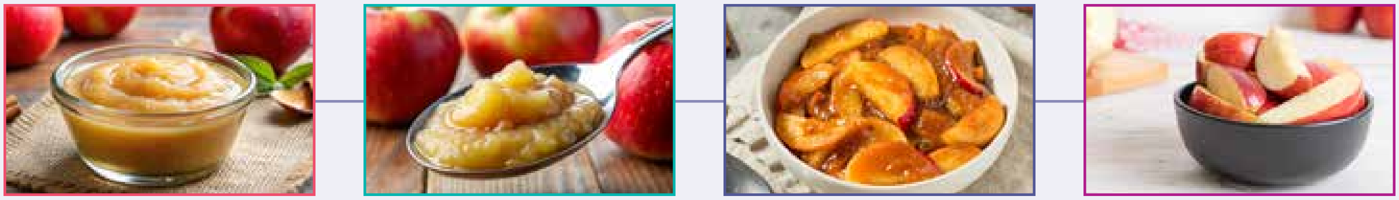
Repeated exposure

It's important to continue to expose children to the same foods, even if they have refused to consume it in the past. But don't force your child to eat something, just expose them to it. Research has shown that repeated exposure leads to increased food acceptance (Maier et al., 2007). For example, a study conducted by Maier et al., found that when an unliked vegetable was presented to a child participant daily, they began to consume more and more of the vegetable each day. These findings are important because sometimes it can feel like we are presenting food repeatedly without any notable change, over weeks or months. The challenge is to present the disliked food consistently.

Fading: texture continuum

Some children have difficulties with textures and prefer smooth or pureed foods. If this is an issue for your child, you will want to start with a small goal in mind and with something familiar. For example, if you're child eats applesauce and your goal is for your child to eat apple slices, start by introducing chunkier applesauce, then baked apples, and finally move to apple slices. Slowly fading the texture continuum allows your child to gradually get used to new food textures over time.

TEXTURE CONTINUUM



Modeling

Another strategy is to model the mealtime behavior you want to see. Encourage family-style meals and trying new foods. Use hunger and satiety words so that your child becomes familiar with them. For example, model saying "no, thank you, I'm full" when offered an additional serving during dinner.

Providing choices

Whenever possible, provide opportunities for choices. Allowing your child to make choices will give them a sense of autonomy and make them feel involved in the process. You can provide choices about what they eat, where they eat, and even how they interact with the food. For example, "Do you want to sit at the counter or at the table to eat?" "Do you want apples or grapes for snack?" "Do you want to try a lick or a mouse bite of the green beans?" It's best to offer two choices at a time so that you do not overwhelm your child. Additionally, teach your child how to advocate for themselves to say or sign "no, thank you" when appropriate.

Shaping

Shaping is the reinforcement of small steps to increase a behavior. When using shaping procedures with food programs, the child will first touch the food to their lips. After that step is mastered, they will lick the food, then place the food item into their mouth, and eventually chew and swallow the food. Reinforcement is provided at each step to shape the behavior of eating new food and reaching their goal.

Involve your child in the mealtime process

Another strategy is to involve your child in the mealtime process. For some children this might mean simply going grocery shopping with you and assisting with meal prep. For others, it might mean being in the kitchen while you prepare the meal. Try to meet your child where they are and include them as much as possible. Encourage your child to participate in mealtime with the family, so everyone is sitting down and eating together.

Incorporate play

And last, but not least, incorporate play! Get creative and pair food with fun! You can make tasting new foods into a game, allow your child to feed a doll, or finger paint with pudding. Allowing your child to play with food will help expose them to new foods in a fun and exciting way and may help reduce stress!

Collaborate with professionals

In addition to implementing these strategies, it can be helpful to collaborate with professionals, such as occupational therapists, speech therapists, and nutritionists, who specialize in working with profoundly autistic children. These professionals can provide personalized guidance based on your child's specific needs and challenges.

- **Occupational Therapy**: Seek the guidance of an occupational therapist to address issues related to physical or oral motor development that may be impeding eating. Occupational therapists can suggest specific exercises and activities to improve the child's comfort and coordination during mealtimes.
- **Speech Therapy**: Work with a speech therapist to address communication challenges, including difficulties with verbal expression and understanding. Speech therapists can provide strategies to enhance communication and interaction during meals. Additionally, speech therapists provide guidance and treatment for issues related to oral development and swallowing.
- **Nutritional Support**: Consult with a nutritionist to ensure your child is eating a balanced and nutritious diet. Nutritionists can help identify potential nutritional deficiencies and recommend supplements.

Food for thought

There are so many valuable lessons children learn during mealtimes. Mealtimes offer children the opportunity to try new foods and learn how to politely refuse something they do not want. Additionally, when children have the opportunity to eat with others, they learn that some people may eat things they do not eat. They also learn that it's enjoyable to be at the table, or in the same room as others during meals. The goal of mealtimes should be for your child to learn that participating in mealtime makes them feel good socially, emotionally, and physically.

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8

Striving for Independence: Toilet Training

Many parents of profoundly autistic children wonder if their child is too old to toilet train. Regardless of your child's age, they are not too old to begin the toilet training process. Research shows that many children with profound autism can successfully learn to use the toilet (Kroeger & Sorensen-Burnsworth, 2009). However, profoundly autistic children typically do so at a later age than their non-autistic peers (Faulkner, 2017). The techniques in this chapter can be applied at any age, although they may not work for everyone. Many profoundly autistic children experience incontinence into their teens and adulthood (Gubbiotti et al, 2024). For these individuals, the use of diapers is a reality and a tool to manage toileting. Even if toilet training was unsuccessful at an earlier age, it is always okay to try again.

Is my child ready for toilet training?

If your child indicates they have a wet or soiled diaper, can stay dry for 1–2 hours while awake, has predictable bowel movements, and can follow simple instructions, they may be ready for toilet training! However, if your child isn't exhibiting these indicators, have no fear. Here are some suggestions for helping your child get there.

- Provide lots of praise when your child displays interest in toileting, as well as any attempts. Even if your child simply sits and nothing happens, we want to celebrate this!
- Model toilet use—this can spark your child's interest.
- When changing your child's diaper, direct attention to the fact that they have wet or soiled and describe what you are doing through diaper changes so that your child begins to associate those actions with toileting. For example, "Your diaper is wet, I'm going to take it off, now let's clean you up with a wipe, now that you are clean, let's put a new diaper on."
- Have your child help with the diaper changing process; have them undo the tabs, hand you the wipes, and throw away the diaper.
- Make the process fun! Sing songs, read stories about using the potty, and engage in pretend play by demonstrating potty use with a doll or stuffed animal. Making the toileting process as fun as possible may help reduce stress and anxiety.
- Make sure your child is as comfortable as possible in the bathroom. Have an age-appropriate toilet seat and stepstool readily available.

Am *I* ready for toilet training?

Now for the real question, are *you* ready for toilet training? Toilet training can be stressful (Shepard et al., 2018) and time-consuming, so you will want to be prepared! You will need at least 1-2 hours per day. However, toilet training is most effective when caregivers can devote several consecutive full days. So, you may want to start over a school break or on a Friday so you can work on toileting throughout the weekend.

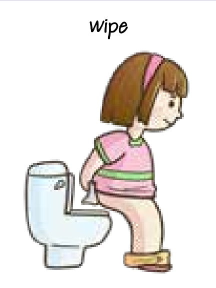
KEY TAKEAWAY!

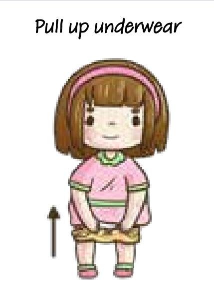
Prior to starting toilet training, you want to ensure you and your child are both ready and that you have time built into your schedule.

What are some common challenges I might encounter?

There are many reasons profoundly autistic children may struggle with toilet training. Understanding some of the obstacles you may encounter will help you better prepare for how to address them. Because of some of the unique characteristics related to autism, some children may need extra support and strategies to assist with the toilet-training process.

- **Physical**: There may be a physical or medical reason for toileting difficulties. If you suspect any medical issues, you'll want to meet with your child's physician prior to proceeding.
- **Language**: Receptive and expressive language delays can make it difficult for autistic children to understand directions related to toilet training, as well as express their need to use the bathroom. This is where visual supports can be especially useful. Visuals can help the child understand what you are asking them to do and can help organize the sequence of steps.





If your child is not yet speaking, is non-verbal, or minimally verbal, it is important to “pair” the picture of the bathroom with your words when you tell your child that it’s time to go to the bathroom. By doing this, and having that picture readily available, your child may start to use the picture to communicate the need to use the toilet.

- **Dressing**: To make the potty-training process as smooth as possible, you’ll want to dress your child in clothing that is easy to pull down and up. Consider elastic waistbands and try to avoid buttons and zippers.
- **Fears**: Some children are afraid of sitting on toilet seats or hearing toilets flush. Getting used to the toilet by using a visual schedule and making it part of the routine can make it less scary. Have your child practice sitting, flushing, and handwashing when the schedule indicates, even if they don’t need to void. This will help them get used to being in the bathroom and may reduce associated fears faster.
- **Recognizing body cues**: Some children may not be aware that they need to use the bathroom or that their clothes are wet or soiled. You can help your child become more aware of these cues by verbally labeling when clothes are wet and soiled and talking through your actions as your child is cleaned and changed.
- **A need for sameness**: This is a big one for profoundly autistic children. Some children learn a toileting routine at home or school but have a hard time generalizing and using the bathroom in restaurants or other places such as public restrooms. Remember that practice, encouragement, and patience will get you and your child to the goal! Once your child has their toileting routine down in one setting, you’ll want to ensure those skills are being generalized to other environments. Be sure to speak with your child’s school providers so they can consistently implement the same routine. Additionally, you’ll want to encourage your child to use the toilet in other public settings to ensure generalization. If your child is reluctant to use a new toilet, you may want to introduce an incentive (discussed below).

KEY TAKEAWAY!

Remember: practice, encouragement, and patience will get you and your child to the goal!

Where should I start?

The first thing you’ll want to do is choose a highly preferred item to be an incentive. This should only be used for toilet training and only provided when your child voids in the toilet. Some examples include special foods, toys, stickers, or activities. Again, be sure to select something that your child will be excited about, but that you are willing to restrict access to.

FREQUENT SIT METHOD

Set timer for 30 minutes

Prompt your child point to sit on the toilet for 5 minutes

Provide praise and incentive when your child voids on the toilet!

Document if whether or not your child voided and reset the timer

Frequent sit method

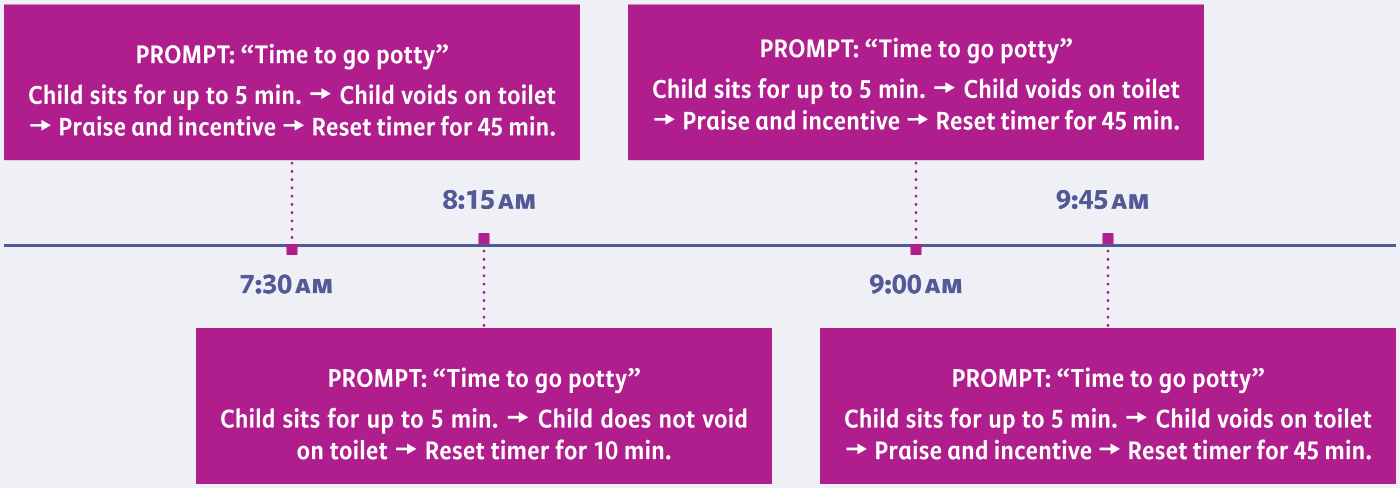
The simplest place to start is with what I like to call the "Frequent Sit" method. The frequent sit method is as straightforward as it sounds. You start by having your child sit on the toilet every 30 minutes for up to 5 minutes to see if they void in the toilet. You may be wondering how to get your child to sit on the toilet for this long, and this is where you're going to get creative! You can read stories, sing songs, blow bubbles, or allow them to play with a special toy while they sit. If your child successfully voids on the toilet, provide that highly preferred incentive right away, along with lots of praise! If your child has not voided on the toilet after 5 minutes, that's okay! No matter what, reset the timer for 30 minutes and try again once the timer elapses. If you notice that your child is having accidents between scheduled sits, go ahead and decrease the time between toilet sits. If your child is staying dry, but doesn't void every 30 minutes, you can go ahead and slowly increase the time between sits on day two.

Scheduled sit method

If you have tried the frequent sit method and aren't noticing progress, it may be time to move on to the more structured "Scheduled Sit" method. Start by collecting information about your child's voiding habits for a couple of days; we'll call this "baseline." Collecting baseline data will help inform you of how often your child needs to sit on the toilet. Be sure to choose a typical day at home so that the baseline data will be as accurate as possible.

During baseline, you can either have your child wear diapers or underwear. If your child wears diapers, you will check to see if they are dry every 10 minutes. Document whether they are wet or dry on your data sheet. If your child wears underwear, you will simply document the time of each accident. Once you have collected baseline data for a few days, you will identify the average time between accidents and then subtract 15 minutes. This will give you an appropriate sit schedule for your child. For example, if your child's average time between

45-MINUTE SIT SCHEDULE



7:30 AM

PROMPT: “Time to go potty”
Child sits for up to 5 min. → Child voids on toilet → Praise and incentive → Reset timer for 45 min.

8:15 AM

PROMPT: “Time to go potty”
Child sits for up to 5 min. → Child does not void on toilet → Reset timer for 10 min.

9:00 AM

PROMPT: “Time to go potty”
Child sits for up to 5 min. → Child voids on toilet → Praise and incentive → Reset timer for 45 min.

9:45 AM

PROMPT: “Time to go potty”
Child sits for up to 5 min. → Child voids on toilet → Praise and incentive → Reset timer for 45 min.

accidents is 60 minutes, you will prompt them to sit on the toilet every 45 minutes. If your child sits on the toilet but does not void, reset the timer for 10 minutes. Once they successfully void in the toilet, resume 45-minute sit schedule.

Increasing the schedule

After three consecutive successful voids on the toilet, you can begin increasing the schedule by 5 minutes. However, if your child has frequent accidents, you will want to decrease the schedule by 5 minutes. The goal is to gradually increase the sit schedule to 120 minutes, but this needs to be done gradually.

Develop a MORE goal

Now that we’ve reviewed some common toileting challenges let’s utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently for the following case study.

Case Study: Max

Max is an 8-year-old profoundly autistic boy. Max has been working on toileting at home, and although he has made progress, he still has several accidents daily. Max’s parents would like to be able to take him into the community without having accidents and have developed the following MORE goal to track his progress.

Measurable	**Observable**	**Relevant**	**Evaluated Frequently**
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Within 2 months, Max will have two or fewer accidents per day.

Measurable	Record the number of times Max uses the toilet and the number of times he has accidents.
Observable	Voiding while using the toilet.
Relevant	Reducing the number of accidents will allow Max to do more within the community.
Evaluated Frequently	Record the number of successful voids as well as accidents daily.

- See APPENDIX A for MORE Goal Worksheet

When can I stop following the sit schedule?

It is recommended to stop following the schedule when the following is achieved:

- The sit schedule increased to 120 minutes and your child is consistently accident-free
- Your child is asking to use the toilet and is voiding
- Your child is independently using the toilet without any prompts

KEY TAKEAWAY!

Consistency is key here! Be sure to stick to the sit schedule until your child is independently using the toilet.

How should I navigate accidents?

Interrupt your child at the first sign of an accident by saying something like, “Uh oh, let’s go to the toilet” in a neutral voice. This should not be a reprimand. Then quickly guide your child to the bathroom and have them sit on the toilet. If your child happens to void while sitting (even the smallest amount), provide lots of praise! If your child does not void after 5 minutes, assist them with getting dressed and resume the schedule. Toilet training can be very challenging, so remember not to reprimand or punish your child if they have an accident.

KEY TAKEAWAY!

Accidents are going to happen and are a part of the process. Remember to redirect your child to the toilet right away and remain calm.

How do I teach my child to wipe themselves?

When you begin the toilet training process, you may need to assist your child with wiping. However, once your child is ready to independently clean themselves, you can begin by teaching them how much toilet paper to use and prompting the wiping motion with hand-over-hand guidance. Using a visual to remind your child of each step may be helpful and encourage independence. If your child finds wiping aversive, you could try flushable wet wipes, or a bidet attachment.

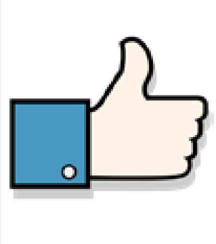
Get toilet paper

Wipe

Put soiled paper in toilet

Flush the toilet

Great job!



How and when should I navigate bedtime training?

It’s not uncommon for overnight toilet training to take longer than daytime toilet training. This is especially true for autistic children who may have limited communication skills and sensory sensitivities. Even so, there are some strategies you can implement to help with the process.

- Establishing a consistent bedtime routine will help your child prepare for sleep. This routine can include bathing, putting on pajamas, brushing teeth and should end with using the toilet. This will help set your child up for success.
- Limiting fluid intake prior to bedtime can help reduce the likelihood of accidents. You may want to avoid drinks for 60 minutes before you begin the bedtime routine.

- Using a visual aid, such as a visual schedule of the bedtime routine, can be extremely useful. It can help your child understand what comes next during the bedtime routine and assist with reminding them to use the toilet right before bed. Additionally, reading social stories about bedtime toilet training may help your child understand what to do if they wake up and need to use the toilet during the night.
- To assist with bedtime training, you could set an alarm and wake your child every 1-2 hours to take them to the bathroom. Once you have an idea of when they need to void throughout the night, you could then reduce the number of wake-ups and eventually move the alarm to your child's room. However, if your child is a heavy sleeper, and tends to sleep through bedtime accidents, you could try using a bedwetting alarm. These alarms make a noise as soon as they sense moisture, encouraging the child to wake up and finish voiding in the toilet. If you notice that these interventions aren't improving bedtime accidents, you may want to speak to your physician. Additionally, as previously mentioned, it is common for bedtime training to come later than daytime training. If you notice that you and your child are exhausted, it's okay to take a break and try again later!

KEY TAKEAWAY!

It is common for bedtime training to come later than daytime training. If you notice that you and your child are exhausted, it's okay to take a break and try again later!

What if my child is afraid to have a bowel movement?

For some children, bowel movement training accompanies urination training. But for others, having a bowel movement can be frightening. In fact, it is common for autistic children to hold in bowel movements during toilet training (Holingue et al., 2023). If your child is doing this, you may want to consider allowing them to continue pooping in a diaper, but while they are in the bathroom. Next, you will want to transition having them poop into the diaper while sitting on the toilet, and eventually they should feel more comfortable sitting on the toilet with the diaper off. Also, if you suspect your child is experiencing stomach-related issues, such as constipation, consult your child's physician.

What if my child is afraid of the toilet, or the sound of it flushing?

One of the barriers to toilet training an autistic child is the sensory differences they may experience. Two of the most common sensory differences are the sound of the toilet flushing and fear of sitting on the toilet. For children with sound sensitivities, it can be extremely helpful to provide them with noise-blocking headphones to wear while in the bathroom. Additionally, you can help reduce anxiety by waiting until the child has left the bathroom to flush the toilet. Flushing the toilet is a skill that can be worked on later. Remember, we want the toilet training experience to be as stress-free as possible!

As far as sitting on the toilet goes, it can be helpful to place a child-size seat on top of the adult toilet seat to avoid the feeling of “falling in.” It can also be beneficial to allow your child to hold a favorite toy or read a book while they are learning to sit on the toilet. This may help distract them and make the process more positive. It can also be beneficial to allow your child to hold a favorite toy or book during the time they are learning to sit on the toilet. Finally, it can be helpful to have a stool for your child to put their feet on, so they do not feel as though they are dangling.

KEY TAKEAWAY!

Be sure to address any sensory sensitivities or bathroom-related fears your child has so that they will be as comfortable as possible throughout the toilet training process.

Tips for Success!

- **Be patient with your child (and yourself)—Toilet training takes time!**
- **Set achievable goals.**
- **Start when you both are ready.**
- **Get everyone on board—If your child attends childcare, be sure to discuss toilet training with their caregivers so that you are all consistent.**
- **Have the necessary toileting aides (seat, step stool) and reinforcers available.**
- **Develop a toilet training plan and stick to it!**

Although toilet training can be time-consuming and frustrating at times, there are so many benefits! Once your child is toilet trained, they will be more independent, exposed to more social opportunities, will have improved personal hygiene and experience overall wellbeing (Van Herzeele et al., 2015). Toilet training is a pivotal skill for all children because mastering it opens doors of increased independence in the home and community.

- ◻ See APPENDIX E for Toilet Training Data Sheet

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9

Addressing Sleep Related Issues

When a child struggles with sleep, parents often do not get a good night's sleep either. Thus, the negative repercussions of sleep problems can extend beyond the child to the entire family. Unfortunately, sleep problems are common for autistic children, experienced by 50% to close to 90% of autistic children (Krakowiak et al., 2008; Malow et al., 2016; Souders et al., 2009). The most common difficulty reported by parents of autistic children is trouble falling asleep, but other problems include waking up during the night, frequent nightmares, and difficulty falling asleep alone. Sleep problems are more commonly experienced by younger children. By the time adolescence is reached, many autistic children have less difficulty falling asleep and staying asleep (Goldman et al., 2012).

What are common sleep problems experienced by profoundly autistic children?

Sleep problems are more commonly experienced by autistic children than neurotypical children and we don't know exactly why. Sleep studies with both children and adults have provided some insight, revealing that brain activity of autistic people when sleeping is different from brain activity of neurotypical people when asleep. For example, many autistic people spend less time in the phase of REM sleep than neurotypical people (Buckley et al., 2010). There is also some evidence that autistic people have altered circadian rhythms that may disrupt their sleep cycle. But it is unclear if this has a physiological basis or is due to the possibility that autistic people ignore environmental and social cues that it's time to go to sleep and thus stay awake even after they have become sleepy (Amos, 2013). Finally, there is some evidence that autistic people have disrupted melatonin production which is needed for sleep, although there are inconsistent findings in this area of research (Delienes et al., 2015).

No parent needs to be told the importance of a good night's sleep. Children who struggle with sleep are often tired during the day and may miss out on important learning and socialization opportunities. Autistic children who experience sleep problems are also more likely to have behavioral challenges such as tantrums or aggressive behavior (Mughal & Dimitriou, 2017; Richdale et al., 2000), and this is particularly true for profoundly autistic children (Didden et al., 2002). In addition, autistic children who have sleep difficulties are more likely to experience ADHD, depression, and obsessive-compulsive disorder (Veatch et al., 2017).

In this chapter we provide proven strategies to help with common sleep concerns. Sleep is a complex behavior and many sleep difficulties can be difficult to treat. Although the suggestions provided here will help many families, some children may require more intensive supports. Reach out to your child's pediatrician if your child's sleep habits do not improve after trying these strategies.

What does “good sleep” behavior look like?

All of us know what a good night’s sleep feels like, and we generally have an idea of how we wish our children would sleep. For example, a good night’s sleep means falling asleep quickly, usually within 20 minutes or less, remaining asleep throughout the night, and then waking feeling refreshed in the morning. The amount of sleep a child needs varies by age and by individual, so different people require different amounts of sleep. In addition, waking during the night is more common and even normal at different ages, as are naps during the day. Here are some guidelines from the American Academy of Sleep Medicine (AASM) for what good sleep looks like at different ages. Again, these are just guidelines, and every child is different.

AMERICAN ACADEMY OF SLEEP MEDICINE GUIDELINES

Age	Recommended Hours of Sleep
Newborns and infants	14-17 hours, including naps
Toddlers (1-2 years)	11-14 hours, including naps
Preschool age children (3-5 years)	10-13 hours, including naps
School age children (6-13 years)	9-12 hours
Teenagers (13-18 years)	8-10 hours
Adults	7-9 hours (can sometimes decline with age)

You can use these guidelines to determine whether your child is getting enough sleep and to ensure that sleep is happening more during the nighttime and less during the day as your child gets older. These guidelines can also be used to set your child’s bedtime and wake-up time. For example, if your child starts school at 8:00 a.m. and needs an hour to get up, get dressed, eat breakfast, and get to school, then the wake time should be 7:00 in the morning. Knowing how much sleep your child needs will help you work backwards to establish a bedtime.

KEY TAKEAWAY!

Although the exact number of hours may vary, there are specific developmental stages of sleep that can help you identify how much sleep your child needs using the table above.

How do I help my child develop better sleep habits?

It's challenging for anyone, including children, to make themselves fall asleep. Just as you can't force sleep, your child can't either, no matter how much you both wish for it. Instead of focusing on making your child fall asleep, concentrate on what you can do to enhance your child's bedtime habits and behaviors. This involves (a) establishing *and sticking* to a regular calming bedtime routine, (b) getting into bed when it's time to sleep, and (c) engaging in relaxing behaviors once in bed.

To help your child develop good sleep habits, creating a consistent bedtime routine is crucial. If your family travels, try to design routines that can be easily done when away from home. Bedtime routines vary for each child and family, and there's no one-size-fits-all routine. Think about what your child needs to do before bedtime, including activities they enjoy that are relaxing and calming. Common bedtime activities include washing up, brushing teeth, putting on pajamas, listening to music, and reading stories.

While these are routine activities for many people, profoundly autistic children may find activities like brushing teeth challenging due to sensory sensitivities. If an activity upsets your child, try doing it at another time (e.g., immediately after dinner) to keep the bedtime routine positive and relaxing. Many autistic children engage in repetitive behavior that may be soothing or relaxing for them. If this is the case for your child, the bedtime routine may include time for this behavior to occur. Although a general recommendation is to avoid screen time before bedtime, for some autistic children, this is one of the few activities that seems to instill calmness and stillness. If this is the case for your child, you might try allowing screen time before bed if it helps your child fall asleep. A good option is to watch TV on a larger screen rather than on a tablet or iPad so that it can be controlled by the parent. Warning your child

that screen time will soon be over may or may not be helpful, depending on your child. Warnings can sometimes cause anxiety in autistic children and therefore would not be effective and should be avoided. If stopping a preferred activity such as screen time leads to meltdowns or other challenging behavior, it might be wise to avoid them at least an hour before bedtime (See the Transitions chapter for other ideas on how to transition from a preferred activity).

After creating a bedtime routine, pay attention to how long the routine takes; generally, bedtime routines last between 15 minutes to half an hour, but the appropriate duration varies by individual. Since the goal is to set the stage for sleep, adjust the routine's duration as needed to promote relaxation. Some children may require longer routines to wind down, while extended routines may have the opposite effect for others. Once you have a routine that works, stick with it so it becomes predictable for your child. You want the bedtime routine to become a habit. Try to keep the start time of the routine and the duration of the routine consistent every night, as this will help regulate your child's internal clock. Although it's difficult, try to put other activities or responsibilities off until you get your child in bed. For example, don't run downstairs to put laundry in the dryer in the middle of the nighttime routine.

KEY TAKEAWAY!

Although it may be difficult to stick to a bedtime routine when traveling or when family activities interfere, the more closely you can stick to a sleep routine, the greater the likelihood of sleep for your child.

How can I help my child fall asleep?

There are a number of things you can do to make it easier for your child to fall asleep and stay asleep at night. In addition to establishing a bedtime routine, consider these steps to help your child sleep at night:

1. Make sure the bedroom is conducive to sleep. If your child feels safe and calm in a dark room, then do what you can to block sources of light. The absence of light signals to the body that it's time to produce melatonin, a hormone that regulates sleep-wake cycles. Exposure to light, especially blue light from electronic devices, can suppress melatonin production, making it more difficult to fall asleep. If your child is afraid of the dark or uncomfortable in dark rooms, use a night light in your child's room to provide gentle, low-level illumination. This can create a sense of security without disrupting their ability to sleep. There are also some toys that provide ambient light that may help your child feel more comfortable and ready to fall asleep.
2. Try to keep your child's room at a comfortable temperature. For most people, sleep is facilitated by cooler temperatures; but again, everyone is different. Think back to situations when your child has slept well. Does your child seem to sleep better in cool rooms or when the room is warmer? You might need to try different room temperatures to determine what works best for your child.

3. Be mindful of sensory sensitivities that may affect your child's ability to relax. Your child may benefit from specific sleepwear that is comfortable for them. Some children find loose, soft clothing more comfortable whereas others prefer tight-fitting garments. This again may be trial and error to figure out what works for your child. Also think about the bedding—some children sleep better with soft sheets, such as flannel sheets whereas others prefer slippery material such as satin or satin-like sheets. If your child has a favorite blanket, stuffed toy, or other object, it may be helpful to allow your child to have those items in bed, even if they don't seem like "sleep" items. For example, 9-year-old Malcolm enjoys playing with Legos, and just holding the small blocks and manipulating them in his hands seems to help him relax and be calm. At night he likes to hold several Legos in his hands and plays with them until he falls asleep.
4. Although meals often occur hours before bedtime, what a child eats and drinks may affect their ability to sleep. It's a good idea to limit caffeine and sugar intake in the evening. If your child is dehydrated, they may have trouble sleeping at night. Do what you can to encourage your child to drink and stay hydrated during the day but limit drinks close to bedtime (within about 40 minutes of bedtime) to minimize disruptions from bathroom visits.
5. Many autistic people are visual learners and find visual supports helpful in understanding what will happen and when. This is a good way to increase your child's independence as well. Visual schedules illustrating different steps of the bedtime routine may help your child predict what is going to happen next as well as participate in the bedtime routine independently.

How can I help my child fall asleep in their own bed on their own?

Although you can't make your child fall asleep, you can help your child learn to stay in their bed or their room and engage in relaxing behaviors. If your child engages in dangerous or potentially dangerous behaviors, then they will need to be supervised whenever they are awake unless there are ways you can ensure they can stay safe in their room.

If your child falls asleep in your bed, and you'd like them to sleep in their own bed, work on this in a series of steps; know that it may take several weeks or even months for your child to learn to feel safe and secure in their own bed. Below are steps you and your child can move through to help them learn to sleep in their own bed. Adjust the steps for your child and your child's routines. You may be able to skip some steps or may need to add additional steps, so it works for you. Don't move from one step to the next until your child is comfortable and relaxed at each stage. Remember that being scared or upset is not conducive to sleeping. You may need to move very slowly, allowing your child time to get comfortable at each step before moving to the next.

1. Have your child get comfortable in their own bed. This may need to occur during the day and you may want to give your child access to preferred activities and objects so that their bed becomes at least a neutral place, if not a preferred place.
2. At bedtime or naptime, complete bedtime routines in the child's bedroom, transitioning to your room only when the routine is done and it is time for sleeping.
3. Get into your child's bed and stay with them until they fall asleep (or all night if needed).
4. Sit up in bed next to your child until they fall asleep.

5. Sit in a chair next to your child's bed.
6. Gradually move the chair further from your bed, initially moving the chair no more than a few inches at a time.
7. Sit outside the child's bedroom with the door open and in view of your child.
8. Sit outside the bedroom but out of view of your child (you may need to talk to them a bit or answer their calls).

As you move through these steps, some may take longer than others. You might also need to back up at times. For example, you might have gotten all the way to the door, and then your child starts to have difficulties. If this occurs, don't be discouraged, just back up until your child is once again comfortable and start from there. It may be a long process, but you will get there.

How can I help my child go to bed at a good time?

Some autistic children have difficulty going to sleep at a time that seems developmentally appropriate. For example, Carem's parents know he probably needs about 9 to 10 hours of sleep a night. He has to get up each morning by 7:00 to get ready for school. Unfortunately, Carem does not usually settle down until midnight or later. He is still sound asleep at 7:00 a.m. and, once roused, he is tired and grumpy and difficult to keep awake. When he gets home, he often takes a nap for an hour or more, or sometimes even falls asleep at school. For a child like Carem, who stays up later than he should and then is sleepy during the day, a solution is to slowly help your child adjust to an earlier bedtime. Some steps you can take to do that are outlined below. Keep in mind that you can adjust these steps so they work for you and your child.

1. Begin by figuring out how much sleep your child needs. This can be based on the developmental guidelines previously listed or you can collect data over a period of time to see how much they typically sleep. It would be particularly helpful to see how long your child sleeps when allowed to sleep in on a weekend or holiday.
2. Based on the number of hours you think your child needs, start moving up bedtime by 10-15 minutes each night so that if your child takes 30 minutes to fall asleep, and sleeps the amount he/she wants to sleep (if allowed), your child can get up at 7:00. It may take some time to fade your child's bedtime, so stick with it for a week or two.
3. Remember to use the nighttime routine described and make the bedroom as conducive to sleep as possible.
4. Although nobody likes to wake up a sleeping child on the weekends, wake your child up at 7:00 a.m. *every day* regardless of whether it's a school day or not. We all know what happens when we sleep in on a holiday and how hard it is to get back to our routine when we need to go back to work. If possible, ask family members to take turns getting your child up at 7:00 *every morning*, so you can get at least a day to sleep in periodically.
5. Finally, minimize the opportunity to take naps so that your child doesn't get into the habit of making up the missing sleep hours by napping during the day. This makes it even harder to fall asleep at night.

KEY TAKEAWAY!

We have described several strategies to help your child go to bed, stay in bed, and not get up early. There are several consistent themes, but the biggest ones are to make a plan, be consistent, and take patient steps towards your final goal.

What if it my child simply needs less sleep than everyone else?

Many parents of autistic children feel like their child simply needs less sleep than other children their age. For example, 6-year-old Jill does not seem to need very much sleep at all. She stays up each night until well after 10:00 p.m. and then she is usually up and ready to go at 5:30 or 6:00 each morning. She does not nap during the day at all.

While it is possible that some children need less sleep, it may be the case that they are simply more sensitive to environmental cues indicating that it's time to get up. For example, they may be very sensitive to sound, light, or temperature and changes in these events in the environment can cause them to wake up. Keeping all the possible cues in place for sleep, including a blackout shade in the summer or air conditioning at a cool setting can help your child stay asleep. White noise machines and other soothing sounds can block out sounds outside. Children sometimes get up early because they want something (e.g., to play with a toy or iPad). It is best to minimize the options for active play in the child's sleep area to allow them to fall back asleep more easily.

How can I help my child stay in their room until it is time to get up?

Like the example with Jill above, many children wake up before their parents. You can help your child learn to stay in their room until a certain time, as long as your child is able to stay there safely. The examples described for Jill above will help your child return to sleep. The other option is to use visual signals so your child knows when to get up to begin the day. For example, there are "clocks" that change colors to indicate when a child should be in bed and when they should be awake by changing colors. To make this work for your child, you will need to show them the clock (or other signal you are using) and explain it to them. Some clocks can verbally announce when it is time to wake up. If you do not want to purchase a clock, you could make your own signal. If you have a smart home device, you could have a speaker in your child's room that plays a certain song as a signal. Or, if your child keeps their door open, you could turn the light on in the hallway when it is time to get up. Another option might be to open their door when it is time to get up.

Because many autistic children learn from visual stories, you might make a picture book for your child explaining how the clock works and what it means. If your child gets up and comes out of their room before it is time to get up, walk them back to their room and remind them that it is not yet time to get up. If your child struggles to learn this, you might help them with the following strategies:

- Begin with the "okay to get up" time closer to when your child often gets up, rather than when you wish they would get up. For example, if you want your child to stay in their room until 7:00 a.m. but they currently are getting up at 5:30, start with the "okay time" at 5:45, or maybe even 5:35, then gradually work towards your goal. If you use this approach, be sure to only shift the "okay" time after your child has been successful for several days.
- Consider using incentives when your child stays in their room until it is time to get up. For example, if your child loves screen time, perhaps they could have screen time in the mornings on days they stay in bed until it is time to get up.

Develop a MORE goal

Now that we've reviewed some suggestions for how to address sleep-related concerns let's utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently for the following case study.

Case Study: Tyree

Tyree is a 9-year-old profoundly autistic boy who has a difficult time falling asleep and remaining in his room throughout the night. After being tucked in, Tyree will often call out to his parents several times and if they do not respond he will come find them. Additionally, if he wakes up during the night, he will either call out to them or leave his bedroom to find them. Tyree's parents are teaching him to remain in his room throughout the night with the use of an alarm clock. They placed a large number 7 on wall and told him that when the alarm clock says 7:00 a.m. and plays his favorite song he may get out up for the day. They have developed the following MORE goal to track his progress.

Measurable	**O**bservable	**R**elevant	**E**valuated Frequently
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Tyree will sleep through the night without leaving his bed.

Measurable	Number of times Tyree gets out of bed each night.
Observable	Tyree stays in bed all night without any challenging behavior.
Relevant	Tyree has a good night's sleep, is well-rested, and is able to use a wake-up clock independently.
Evaluated Frequently	Record the time Tyree goes to bed, the time he falls asleep, the number of times he gets up each night, and the time he wakes up for the day. Keep track of whether you slept in the room with him or not. f he will tolerate it, there are several wearable monitors that can be used to track these data as well (e.g., a Fitbit, Google watch).

- See APPENDIX A for MORE Goal Worksheet

Nothing has worked. Help!

If your child continues to struggle with sleep, talk to your pediatrician about other interventions or possibly medication that might help. A sleep study may be helpful to determine if there is a medical or other biological basis for a sleep disorder or insomnia (e.g., sleep apnea). Medications, such as clonidine, have been shown to help reduce time to fall asleep and to reduce night waking in a small clinical trial with autistic children (Myers & Johnson, 2005). Some families have found that over-the-counter medications such as Benadryl and melatonin may help, but there are currently no consensus guidelines on the use of medication to treat insomnia in autistic children (Mammarella, et al., 2023).

Most parents will identify sleep disturbances as one of the most difficult behaviors to address because they not only affect the child and how they feel the next day, but also affect the parent and the entire family. It might *seem* easier to let your child sleep in your bed or keep their iPad to get through the night, but it will cause even greater problems when you try to establish new routines. As we shared, getting your child to go to bed and stay in bed on their own is the greatest gift you can give them. Not to mention a beautiful gift to yourself and your family.

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10

Transitions Without Tears

An unexpected change in routine is often frustrating. A detour on your regular route to work, for example, or losing power during your favorite show, are common occurrences people find irritating. Anyone who has tried to get a child to leave a birthday party, or pause a favorite activity, can attest to how transitions, interruptions, and changes in routine are even more frustrating for children!

Transitions, interrupting preferred activities, and unexpected change

Children have not had as much opportunity to practice being successful with transitions and changes as adults. The motivation to stay on the playground, or to continue to eat cake with friends is so strong that it can cause challenging behavior to delay or prevent a transition. Keep in mind that the term ‘challenging behavior’ often means challenging for others, not for the child. If this behavior has a history of successfully delaying or preventing the transition, challenging behavior is how the child has learned to advocate for their desire to remain on the playground or at the birthday party. For profoundly autistic children, these transitions can be even more difficult because they may not have yet learned the skills to understand what is being asked of them or that moving from one activity to another doesn’t necessarily mean that the first activity is terminated for good.

Fortunately, there are pragmatic strategies that can help teach children how to tolerate and cooperate with interruptions, transitions, and changes to routine. In this chapter we will define *transition* as any time the child is asked to move from one place to another. This could be as simple as transitioning from one chair to another that is close by or moving from the living room to the kitchen. *Interruption* will be defined as any time the child is asked to cease one activity and move to another. Some examples could be pausing a show to help set the table, stopping schoolwork to go to recess, or putting down a book to play videogames with a sibling. Finally, a *change in routine* will involve any time the child is asked to do something that is different while engaging in a sequence of actions they typically do in a specific order. Some examples are putting on water shoes without socks, even though the child’s dress routine typically includes putting socks on before their shoes, having to leave school early for a medical appointment, or needing to participate in indoor recess because of weather conditions.

Notice that each of these definitions can include elements of each other. A change in routine might or might not include an interruption and transition to a new environment. The change in routine could be tolerating a new kind of toothbrush during a hygiene routine. A transition might include interrupting an activity, but it might not. For example, a child might not be engaged in any particular activity and be asked to go to the playroom. Interrupting an activity might require a transition, but a new activity might be introduced to your child with no transition from one spot to another necessary. The reason for these definitions is to help you identify which specific skill or skills need to be taught, and then to form a sequence of skills to teach to make success more likely by moving from easiest to hardest skills.

What are the first steps I need to take?

Preparing to teach a new skill is a critical step. It allows you to plan what will be taught, how to teach the skill, what to do if something goes wrong, and how to determine if the skill has been truly mastered. With interruptions, transitions, and changes to routine, these issues can be especially complex. Let's start with an example common to many parents and school staff who work with younger learners.

Example:

Isabelle often throws a tantrum when asked to come inside after recess is over. Isabelle's parents report that she does the same thing when asked to leave their neighborhood playground. In preparing to teach Isabelle to leave the playground without engaging in a tantrum, we should ask ourselves several questions.

- **What steps can we take to prevent the tantrum?**
- **What should we do if a tantrum occurs?**
- **How often is Isabelle able to leave the playground without tantrums occurring?**
- **How will we teach the skill in a way that makes successfully managing interruptions and transitions more likely?**
- **How often can we practice the skill?**

This final question is a critical consideration that is often overlooked. Many grade schools have only one recess period a day. If that schedule is maintained, Isabelle only has one opportunity a day to leave the playground successfully at school. There is probably even less opportunity at home, as many parents do not have the time to take their child to the playground daily, let alone practice multiple transitions off the playground!

It will be necessary to plan and schedule as much practice as possible if the tantrum behaviors are of significant concern. This might include scheduling more frequent trips to the playground, and transitions from the playground, that are gradually decreased over time. This could involve having Isabelle practice responding to "time to go" or "come here." Then, if no tantrum occurs, allow Isabelle to go back to the playground immediately after she gets ready to leave or approaches the adult who asked her to come here. Increased opportunities to practice with one of the skills necessary to exit the playground will help Isabelle learn to respond quickly and calmly. This will, in turn, allow her parents and school staff to reward her appropriate behavior. For example, Isabelle's parents might present a preferred snack or toy, ask her to "come here" and then provide the preferred item and allow her to go back to the playground if she responds appropriately. This will teach Isabelle that when she responds appropriately when her parents call her from the playground, it results in something positive and increases the likelihood she will respond appropriately in the future. Additionally, this will give Isabelle the opportunity to practice the skill of tolerating an interruption to playing and teach her that interruptions aren't always a bad thing. Sometimes you get your favorite snack, *and* you get to go back to play! This type of teaching allows Isabelle to practice the first behavior necessary to leave the playground many times during one recess or trip to the playground.

The next step might be to present a favorite item and say, "Let's play with our toy in the car" while gesturing Isabelle toward the car. If she makes it to the car without a tantrum, immediately deliver the toy. Over time, the use of the promised preferred item/activity will need to be decreased and eventually eliminated as Isabelle is successful with each step in leaving the playground. This can be done by occasionally not presenting the preferred item so it becomes unpredictable whether the interruption and approach will result in getting a toy or snack.

Another option is to teach Isabelle to request more time at the playground by telling her it is time to leave earlier in the recess/playground time, prompting her to ask for more time at the playground when you see she is likely to tantrum (but before the tantrum begins), and then honoring the request. This might help to teach a skill (asking) that replaces challenging behavior because it teaches Isabelle to communicate that she wants more time, rather than tantrum to delay the transition. Consideration for how to eventually teach Isabelle to accept being told 'no' will have to be a part of teaching this skill because some transitions must occur immediately and a request for more time on the playground cannot be honored (e.g., the playground is closing, change in weather).

In preparing to teach the skill of interrupting play and transitioning off the playground, we have identified items that need to be considered. We need to consider how often the skill can reasonably be practiced, and how we can schedule greater amounts of practice. Another important issue is how we teach procedures to prevent tantrums. This can include teaching an appropriate request, using preferred items/activities, and subsequently reducing the use of these items/activities with increased success. However, we still need to identify two significant issues—what do we do if a tantrum occurs and how do we know the transitioning skill has been successfully taught?

You could say a skill has been learned or mastered, when someone can do it accurately, in a reasonable timeframe, and across environments, people, and places. If Isabelle learns to transition off her neighborhood playground, but still has tantrums on the school playground, that skill has not been mastered yet. The same would be true if we taught Isabelle to request more time on the playground, but she only asks for more time when she is at the playground with her mom. Additionally, if Isabelle no longer engages in tantrums, but instead takes 40 minutes to complete the transition to her parent's car by dragging her feet, wandering away, or just not responding to requests to leave, we would also not say the skill is mastered. The skill will be truly mastered when Isabelle transitions off any playground, in a reasonable amount of time, when she is asked to do so. Additionally, if Isabelle still requires the use of a preferred item/activity to transition, we need to fade the use of those items so that she can transition independently.

Finally, what should we do if Isabelle has a tantrum even though we used a highly valued item or prompted her to ask for more time? Addressing challenging behavior can be an emotionally and physically exhausting process. Care and consideration for Isabelle, her parents, and any school staff should be a part of teaching a skill like interruption of preferred activities and transitioning away from those activities. Safety is always the priority if challenging behavior is dangerous or has the potential to become dangerous. Ideally, if challenging behavior occurs, Isabelle would be prevented from continuing to access the playground equipment. Access to any preferred activities would also be blocked or otherwise made unavailable until the challenging behavior has ended, and Isabelle has transitioned off the playground. However, we often find ourselves in less-than-ideal situations and sometimes we must respond with less-than-ideal methods.

Planning to address challenging behavior is critical because challenging behavior is often an attempt by the child to communicate something they have not yet learned how to communicate in more appropriate ways. A good rule of thumb is to maintain safety, prevent or minimize access to preferred items and activities during and immediately after challenging behavior, and have a plan of what to do if you can no longer safely limit access to the playground (Ferlick, 2022).

How can I help my child learn to transition?

The previous example illustrates a potential way to help a child learn to tolerate both an interruption of a preferred activity (playing on the playground) and a transition (going to their parent's car). However, some children have difficulty transitioning from one area to another without having any difficulty tolerating an interruption of an activity. For these children, it is beneficial to practice easy transitions, under conditions where the successful transition results in improving conditions for the child. This way, they learn that transitions are not something to be avoided, but rather something that results in accessing their favorite toys, snacks, activities, interactions, etc. (Carbone, Morgenstern, Zecchin-Tirri, & Kolberg, 2007).

We should first identify what transitions are easy for the child. For some children, easy transitions might start with moving from one chair to another chair that are very close together. For other children the distance for an "easy" transition might be much further. And for some children all transitions might be easy, but transitioning to a specific place is difficult. We will start by discussing what to do to teach the act of moving from one area to another and then discuss what we can do if the transition to a specific place is the issue.

For a child who has not yet learned to transition from one area to another, we want to identify some preferred items/activities we can use as promised rewards for successful transitions. We will then present these items before asking the child to make the transition. This might look like someone showing the preferred item to the child and saying, "Sit here for *item*" while gesturing to a chair right next to them, and then immediately providing access to the item when they sit down. Once the child can transition to the chair (or table, desk, area, etc.) successfully, we can increase the distance to transition in small amounts (e.g., two feet away to three feet away). However, we still want to practice those previously mastered "easy" steps frequently so that the request to transition does not always occur at the most difficult step. As with the playground example, we will also need to fade the use of the promised reward so the child can transition without the promise of preferred items/activities. It will be best to start fading the promised reinforcement with those easier transitions. For example, only occasionally offer a promised reward when asking them to transition a shorter distance.

KEY TAKEAWAY!

Transitions for autistic children can be difficult and it is important that you don't avoid them. By creating an end goal and identifying small steps to get there, you can help your child learn to be more successful with difficult transitions.

What can I do to make interrupting a preferred activity easy?

No one likes to have a preferred activity interrupted. Movie theaters ask patrons to turn off the sound on their cellphone to avoid interrupting the movie-watching experience of others. If you are lounging and reading your book and your spouse asks you to repair the toilet, you might find yourself less than thrilled with the interruption. Fortunately, tolerating interruption of preferred activities, like all the skills we discuss in this chapter, is something that can be taught.

Often, the ability to tolerate interruption of preferred activities can be assessed by identifying what is easier for the child to tolerate (e.g., interrupting schoolwork) and what the child never tolerates (e.g., interrupting a favorite TV show). As an example, a child might tolerate having an art activity interrupted and only engages in challenging behavior occasionally when asked to do so. But if they are watching their favorite cartoon or playing on an iPad, the interruption is far less likely to be tolerated and will most likely result in challenging behavior.

An assessment of activities that are more and less difficult to tolerate for the child is extremely important because we do not want to start out teaching with the most difficult activity to interrupt. When teaching any skill, it is always a good rule of thumb to move from easiest to hardest so that successful practice occurs more often. In this case, we might start by offering a highly preferred item (ideally more highly preferred than the craft) to interrupt the craft activity, and then offer the child the option to immediately return to the craft after they have engaged with the item. Part of what you are teaching is that ceasing a preferred activity can lead to something better and a return to the activity. Essentially, interruption does not always lead to the end of the activity.

KEY TAKEAWAY!

We all dislike being interrupted, particularly if we are doing something fun. But it is important that we don't avoid interrupting our children when it is time to do something or a change in activity is needed. Small daily steps with activities that are easy to interrupt will lead to less challenging behavior.

How can I help with unexpected changes in routine?

An unexpected change in routine can be difficult for children for many reasons. The child may not understand that a change in routine does not mean the routine is being terminated. Or they may be confused about what they are supposed to do if the change in routine involves a skill with which they are not proficient. These are just two possible reasons changes can lead to challenging behavior. Think about your own experience with changes in routine. Have you ever decided you will get up thirty minutes earlier to exercise, only to find that you hit snooze on the alarm, or have a second cup of coffee, or scroll on your phone instead of exercising? The change in routine is difficult because it involves increased response effort (getting up earlier and exercising) as well as delaying other activities that might be preferred (sleeping in and enjoying a cup of coffee).

All children benefit from being taught routines. Preparing for bedtime, completing hygiene routines, doing chores to help around the house, and having specific times dedicated to completing schoolwork are all common routines that many parents attempt to teach their children. In teaching a routine, parents will often set expectations, provide rewards and praise for completing the routines, and give guidance on how to complete the routine more effectively. However, many children have difficulty when a routine is changed or interrupted. Profoundly autistic children can find a sudden change in routine to be extremely difficult, because after going through the extensive effort to learn to complete a routine, a change can be frustrating.

Develop a MORE goal

Now that we've reviewed how you can help your child with unexpected changes in routine, let's utilize the MORE framework to develop a goal that is measurable, observable, relevant, and evaluated frequently.

Case Study: Rosie

Rosie's father drives her to school every day along Franklin Road. One day, because of construction on the road, he had to take an alternate route. The first time it happened, Rosie cried and complained that he was going the wrong way. She attempted to take off her seat belt and banged on the windows. Now, every time her father must drive a route different than expected Rosie cries and screams the whole time. It has gotten to the point that her father avoids taking Rosie anywhere in the car unless absolutely necessary.

Measurable	**Observable**	**Relevant**	**Evaluated Frequently**
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL: Rosie will tolerate a different route without engaging in challenging behavior.

Measurable	Rosie will tolerate different routes to and from school.
Observable	Rosie will not engage in challenging behavior during the ride to school which means no screaming, crying, and banging on the seat or windows.
Relevant	Being calm in the car will help keep Rosie and others safe and allow her father to drive without becoming distracted.
Evaluated Frequently	Rosie's father will track how many times each week she has challenging behavior on her trips to and from school. This will be extended to all car trips once school transportation is mastered.

- See APPENDIX A for MORE Goal Worksheet

KEY TAKEAWAY!

Profoundly autistic children like routines because it helps them know what is to be expected. Helping them cope with those changes using the strategies described above can lead to long-term benefits when unavoidable changes need to occur.

Should I give my child a warning about an upcoming change?

One step many people will attempt is to provide a "warning" about a change in routine. Prior warning is something that many parents, caregivers, teachers, and others attempt to use to reduce a child's anxiety or frustration about a change by telling them in advance that something different is going to happen. While this sometimes works with autistic children, there are just as many examples of it not working. Because of this lack of agreement about whether giving a warning works or not, Brewer, Strickland-Cohen, Dotson, and Williams (2014) created some practice guidelines to address challenging behavior that occurs during transitions.

They found that if the caregiver felt that the challenging behavior was *due to uncertainty* about the transition, a prior warning may be effective. If the individual's challenging behavior is due to wanting to have continued access to the activity, or if they were moving to something that was less preferred, a prior warning is not likely to be effective. Often adults feel that giving a warning helps to prepare the child for a change or provides them with information. For an autistic child, a warning may result in challenging behavior because it serves as a reminder that they must stop doing something fun or do something they don't want to do which can lead to anxiety.

Much like the previous recommendations for teaching a child to transition or tolerate interruptions, we should start with making the change as easy to tolerate as possible. One way to make changes more tolerable is to make changes gradually. This strategy works especially well in situations that occur annually or with advanced notice. For example, if winter is approaching and you know your child has a difficult time tolerating wearing snow boots, you can take steps to make the transition to boots smoother. If your child insists on wearing flip flops, you'll want to start by introducing a soft shoe, such as a slip-on sneaker. Once your child tolerates the slip-on sneaker, you'll introduce socks and shoes, and once those are tolerated, you can move to boots. As your child transitions from one type of shoe to the next, you will want to provide reinforcements that your child considers valuable. Watching a favorite cartoon or engaging in some preferred activity can be rewards for putting on weather-appropriate footwear. Caregivers should remember to focus on incremental success so that tolerating snow boots is taught at a level that is not too difficult for the child.

What about changes that are sudden and cannot be predicted?

Sometimes, changes to routine occur without any opportunity for practice or teaching. A fire alarm goes off, a restaurant that you frequent is unexpectedly closed, or a scheduled activity is cancelled due to weather. It is unlikely that anyone can anticipate, practice, and teach tolerating every possible change in routine. To address this issue, we must look at how we can teach a class of behaviors (tolerating a sudden change in routine) rather than a specific behavior (using mouthwash as a new step in a routine).

The most essential step in teaching a class of behaviors such as tolerating a sudden change in routine is to strike when the iron is cold. Don't wait for the sudden change to happen and the potential challenging behavior to occur. Once challenging behavior is occurring, there is very little opportunity for teaching because you are already managing a crisis. Instead, start small. What are some routines that are not reliably evocative of challenging behavior? Begin with providing a dense amount of preferred items/activities, attention, praise, preferred snacks, etc., when the child tolerates sudden changes to these activities. You can also begin systematically planning to disrupt routines, immediately reward the child's toleration of the disruption, and return to the routine (Hanley, Jin, Vanselow, & Hanratty, 2014).

In a school setting, there should be a schedule that guides staff and student behavior. An instructor who wishes to teach toleration of changes to routine can program in such changes and provide rewards for tolerating the changes. Parents can identify routines and plan to briefly alter them to practice toleration in much the same way. Practicing a change in routine can also include changes that are preferable to the routine so that tolerating the change leads to preferred activities. A bedtime routine that is interrupted with a preferred activity such as playing with a favorite toy can be a first step to teaching a child to practice tolerating changes that occur in day-to-day life.

When planning such disruptions, it might be helpful to offer a promised reward to reduce motivation to engage in challenging behavior. In an example earlier in this chapter, a child who must tolerate a sudden change in their dressing routine, putting on water shoes without putting on socks, might practice this change by showing the child a preferred snack and saying, “Put on your shoes and you can have popcorn!” and immediately providing popcorn when the child has put on their shoes without socks.

Conclusion

Hopefully, this chapter has provided some ideas for teaching critical skills related to interruption of preferred activities, transitioning from one place to another, and tolerating sudden changes in routine. With practice these are skills that can be taught, and mastered. In addition to frequent practice, children’s appropriate behavior should result immediately in preferred activities, effusive praise, favorite snacks, fun interactions, etc. One step that parents, caregivers, and school staff can take to encourage smooth transitions is to make sure to have preferred items with them because teaching these skills requires a lot of practice.

Trying to teach when challenging behavior is occurring is difficult because the focus needs to be on keeping everyone safe and/or addressing the challenging behavior. It is far more effective to work toward identifying small steps that can be taught to proficiency and then building upon those newly mastered skills to teach another more complex skill.

Teaching children to tolerate transitions, changes in routine, and interruptions of preferred activities is no different than teaching other skills in the sense that you should build upon previously mastered skills that are easier for your child and move incrementally toward more complex skills.

References & Resources

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Parent Sessions from the National Autism Conference (*Available for free*) Behavior Management Survival Guide: https://sched.co/150s9

"I want to go to the doctor!" Setting Individuals with ASD up for Successful Interactions with Healthcare Providers and Teaching Them to Toleration Necessary Healthcare Exams and Procedures: https://sched.co/150s9

Programming in the Home: Structuring Effective Interventions for Parents, Caregivers, Schools, and Providers: https://sched.co/1OGMo

11

Introduction to Family Matters

In this section of the guide, we address issues related to many of the challenges families face providing support to their profoundly autistic child. We selected each of these topics based on the most common concerns we have heard from families over the past several years. We know how stressful it is to care for a profoundly autistic child while balancing work, friends, self-care, and other family members. The constant vigilance and support required can be exhausting and the small steps of progress frustrating. Of the numerous topics to cover, we decided to focus on managing stress, creating safe environments, how to choose providers with expertise in profound autism, and making decisions about medications prescribed for profoundly autistic children. These topics are key to supporting your profoundly autistic child.

Managing stress is critical because we know that if you don't keep yourself healthy, it will be even more challenging to provide effective care to others. In our chapter on Managing Caregiver Stress, this point is exemplified by the directions we received on planes to "always put our mask on first before helping others". This exemplifies the fact that if we don't take care of ourselves, we will not be able to effectively care for others. We hope that this chapter will provide you with strategies to reduce stress in your day-to-day life.

A significant source of anxiety for many families is ensuring your profoundly autistic child stays safe. In the Safety Considerations chapter, we address what you can do at home to avert dangerous situations, such as preventing elopement or keeping items that a child might ingest in safe places. In addition, the chapter describes how important it is to work collaboratively with local law enforcement and other first responders to keep your child safe when they are in the community or if there is an emergency.

Collaborating with medical and other providers is the focus of the next chapter because most families with profoundly autistic children have a variety of needs that require expertise from a range of professionals. In this chapter we provide information on how to identify a qualified provider and what you can do to make the therapeutic relationship successful. In the final section of the chapter, we discuss ways to avoid the hazards associated with interventions that are not proven or regulated (e.g., not FDA-approved), and for which there can be misinformation about their effectiveness. For many people with profoundly autistic children, it is hard not to look at new interventions with the hope that the scientific support will follow. But it is critical to seek information and advice from your trusted providers before you implement a new and unproven intervention.

Finally, in conjunction with other forms of therapy and treatment, many profoundly autistic children are prescribed psychotropic medication to address medical and behavioral concerns. In the final chapter of this guide, we describe the most commonly used medications and the conditions for which they are prescribed. The chapter also provides several important indicators that a parent can use to track whether the medication is working and whether there are significant side effects. These indicators are important to evaluate so you can determine the risks and benefits of using a particular medication or dose. The more informed you are about a medication being prescribed, the behavior targeted for change, and the side effects that may emerge, the easier it will be to decide about medication and the impact on your child.

We know that having a profoundly autistic child is difficult and can be taxing mentally, physically and emotionally. We hope that this last section of the parent's guide will give you techniques and supports to reduce your stress and anxiety. You will experience many moments of joy and fulfillment with your autistic child. This guide will help you develop the tools you'll need to feel informed and empowered to enjoy more of those wonderful moments.

12

Managing Caregiver Stress

Stress is an experience shared across all people, presenting in varying ways throughout all stages of life. Stress may present internally as anxious thoughts, negative feelings, difficulty concentrating, or reduced or increased appetite. It can physically manifest as sweating, muscle soreness, headaches, or a racing heart. While there are common stressors many people face such as stressors related to health, safety, security, or finances, stress can also appear in situations that are unique to the individual person or to a group of people. In this chapter, we will focus on stress and stress management related to caregiving for profoundly autistic children.

Caregiving as a parent, guardian, family member, or friend can come with unique responsibilities in ensuring the child you are caring for not only has their needs met, but is also happily thriving in the environment in which they are receiving care. Caregiving for profoundly autistic children comes with additional responsibilities as compared to caring for neurotypical children. Caregivers of profoundly autistic children strive to teach and encourage communication and daily living skills to support the autistic child in gaining their highest level of independence.

In addition to incorporating learning opportunities into the child's daily routine, caregivers also manage behaviors that may interfere with the child's learning or ability to safely navigate their world. Research indicates that caregivers of autistic children may experience up to four times more stress than caregivers of neurotypical children (Silva & Schalock, 2011). Externalizing behaviors such as meltdowns, aggression, and self-injury, and deficits in communication and social skills can contribute to higher levels of caregiver stress (Olsen et al., 2021). While caregivers of profoundly autistic children may experience even higher levels of stress than caregivers of both autistic and neurotypical individuals, there are many strategies and supports available.

Throughout this chapter, you will find a variety of reflections and activities to complete to help you reflect on how the material discussed relates to you personally and to practice the strategies. Please take the time to complete each reflection and activity before you continue reading to help you better engage with and absorb the information presented.

REFLECTION #1

How does the stress you experience impact you both mentally and physically?

How do I take time to focus on managing my stress when I have no time for myself?

Time is a limited and highly valuable resource, especially as a caregiver and even more so as a caregiver of a profoundly autistic child. As the caregiver of a profoundly autistic child, you are in charge of the typical responsibilities of caregiving. In addition, you are responsible for coordinating necessary therapies, participating in therapy to foster generalization, monitoring your autistic child's behaviors and affect to ensure they are healthy, especially if they are unable to communicate pain or symptoms of illness, and ensuring the environments are safe and accessible. On top of these responsibilities, you must advocate for your child who will likely be unable to self-advocate. Your profoundly autistic child may require around-the-clock care, making it feel impossible to take any time to make changes in your life and routines to manage stress.

Before you consider strategies to support time management to create time and space to manage stress and focus on personal wellbeing, take a moment to reflect on a principle shared by hundreds of flight attendants across the world each day.

REFLECTION #2

Always put your mask on before helping others.

This notion is applied when traveling on an airplane in an emergency scenario when oxygen in the cabin of the plane is depleted. The idea behind this principle is that if we do not have oxygen to continue breathing, we will quickly lose our ability to help others get their masks on to support their breathing. While we should not wait for an emergency to "put our masks on," this can serve as a good reminder that to provide the best support we can as caregivers, we must take care of our own mental and physical health so we can be our best selves for the people we support and care for.

There are several strategies that can be utilized by caregivers seeking support in stress management. Identifying the people in your support system is an important step in managing stress. As many caregivers say, it takes a village to raise a child. Caregivers can join a local parent support group for in-person or virtual support. Parent support groups create the opportunity to meet other parents experiencing similar stressors. Caregivers of profoundly autistic children can share ideas and information to help each other learn more about resources available to support their child's and family's needs.

Identifying an alternative caregiver can also help support caregivers in managing their stress. Family members or friends can be trained to help care for your child for short periods of time to provide you with an opportunity to dedicate some time to yourself. Having even an hour to dedicate to personal wellbeing can go a long way for a caregiver. If there is not a support person who can safely provide care, respite care options may be available through state agencies or insurance. For those who are unable to identify a support person who can safely assume the responsibility of caregiving, setting aside personal time may be more difficult, but can still be achievable. Schedule self-care when your child is napping or sleeping. You can coordinate your schedule with your child's care team so you can run errands or do something for yourself such as getting a haircut, going to the market, or spending some quality time with another child.

KEY TAKEAWAY!

Ensure you care for yourself to maximize your ability to care for the child you support. Consider joining a parent support group, identifying a secondary caregiver, or accessing respite care to dedicate time to yourself.

REFLECTION #3

> *"It's not the load that breaks you, it's the way you carry it."*
>
> – Unknown Author

I have a small bit of time set aside to focus on myself but I'm still struggling to control my stress. Now what?

From a young age, people are told to control their negative feelings. You may have been told or have heard others being told, "*Control your anger*," "*Just stop being sad*," "*Calm down*," "*Don't worry about it*," etc. These statements all imply that you have control over the thoughts and feelings you experience. If you can control your thoughts and feelings, why is it so difficult to stop thinking and feeling undesired thoughts and emotions? If you can learn to control your thoughts and feelings, you can learn to stop them before they consume you or just avoid them completely, right?

Dr. Russ Harris discusses the notion of controlling our negative thoughts and feelings in his book *ACT Made Simple* where he includes an exercise that tests this concept (Harris, 2019). Let's practice a similar exercise below.

ACTIVITY #1

Don't think about apples. Don't think about all the colors of apples you have tried before such as red apples, green apples, and yellow apples. Don't think about the different types of apples. Don't think about Mcintosh apples, red delicious apples, granny smith apples, or gala apples. Don't think about how apples taste or how crunchy they are. Don't think about activities you have done with apples such as apple picking or apple bobbing. Don't think about apples.

How did you do? Were you able to stop yourself from thinking about apples? Most likely not. How can you stop yourself from thinking about apples when you are constantly hearing about apples or seeing apples? The same goes for the daily stressors you are faced with and the stress you experience as a result. You are naturally going to think about the things you are hearing, seeing, and experiencing. You cannot control your thoughts and feelings, but you can control the way you respond to them and what you do when you face those stressors.

You can not only control the way you respond to stress, but also the way you think about stress. Kelly McGonigal (2013) shares in a TED Talk that research on stress suggests that the way we think of stress may impact our physical health. We typically perceive the characteristics of stress (e.g., racing heart, quick breathing, and sweating) as negative. However, McGonigal discusses a study that suggests that viewing these stress responses as our body preparing us to protect ourselves may lead to positive health outcomes. In addition, she discusses how stress impacts us socially. When we experience stress, our bodies release oxytocin, a hormone often referred to as the "love hormone." The release of oxytocin in stressful situations can increase our empathy and drive us to seek support from friends and family or promote providing support to others. When we give or seek support, our body releases more oxytocin (McGonigal, 2013). While you cannot control your stress, you can change the way you view stress to help support changes in the way you respond to stress.

ACTIVITY #2

Search "How to Make Stress Your Friend," a TED Talk delivered by Kelly McGonigal to watch the TED Talk discussed above to learn more about how our perception of stress can impact us.

KEY TAKEAWAY!

One of the first steps in managing your stress is recognizing that you cannot control your stress and the feelings that come along with it, but you can control the way you think about and respond to it.

If I can't control my stress, how do I start to manage it?

Now that you know you can't control the stress you experience, you can focus on changing the way you think about and respond to stress. Just as stress impacts us all differently, the way each person perceives stress and the strategies that are effective for them will differ as well. There is no "one size fits all" approach to managing stress, but there are frameworks that can be individualized to help manage stress. Identifying your values can help you identify stress management strategies that will work for you. Your values reflect what is most important to you; they serve as your guiding principles in life. By identifying your values, you can gain a better understanding of what is personally important to you in the way that you respond to high stress situations.

ACTIVITY #3

Read through the list of values below and circle your top three values.

Accomplishment
Accountability
Achievement
Adventure
Authenticity
Balance
Beauty
Bravery
Brilliance
Capable
Caring
Challenge
Charity
Cleanliness
Comfort
Commitment
Community
Compassion
Confidence
Creativity
Dependability
Equality
Faith
Family
Freedom
Friendship
Happiness
Honesty
Humor
Independence
Kindness
Love
Optimism
Passion
Patience
Power
Purpose
Respect
Responsibility
Selfless
Service
Sharing
Simplicity
Strength
Sustainability
Teamwork
Thoughtful
Timeliness
Tolerance
Transparency
Trustworthy
Unity
Wisdom

As stated earlier, your values reflect what is most important to you. When you experience a high-stress situation, take a moment to pause and think about how you can respond in a way that embodies your values. For example, envision that your values are communication, family, and respect. After a long day at work, you pick up the groceries you ordered and then pick up your child from school. As you put the groceries away, you notice your child's favorite snack is missing from the order and see it was listed as out-of-stock in the order summary received with your groceries. Your child starts searching the usual spot in the pantry for their snack, and also notices it is missing. This leads to your child having a meltdown.

There are many ways you could react in a moment like this where one small issue leads to a difficult situation for both you and your child and no immediate solutions are available. Instead of reacting, pause to briefly recall your values of communication, family, and respect. In that moment, choose to respond in a way that aligns with your values such as empathizing with your child's frustration at the unexpected change, offering comparable alternatives, and making a mental note to contact the grocery service to ask if they can provide an accommodation for your family by texting or emailing the order summary before you pick up your groceries. By identifying your values, you can better identify responses to stressful situations that align with what is personally important.

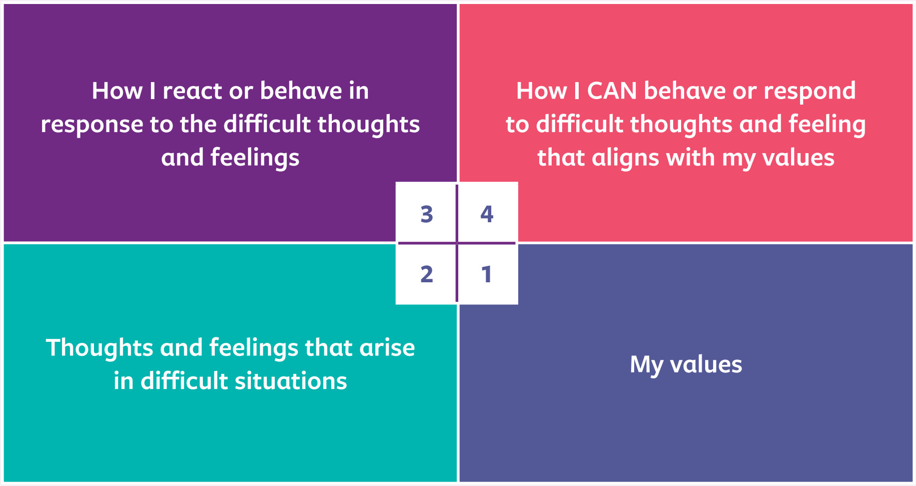
KEY TAKEAWAY!

Identify your values and use your values to guide you as you think about how you want to manage your stress and response to stressful situations.

I know how I want to respond to stressful situations based on my values, but I'm still reacting to my feelings rather than responding to the situation. How do I practice responding to my stress in a way that aligns with my values?

Changing the way you respond to stressful situations is not a skill that you can develop or master overnight. This skill requires lots of practice. Even with practice, you may not always respond in a way that perfectly aligns with your values. As you work on changing the way you respond to stress, remember to give yourself grace and remember that each small step you make towards changing your response to stress is bringing you closer to your larger goal. It takes time to relearn how to respond to difficult thoughts and feelings. Before you begin practicing this skill in real-life scenarios, practice thinking about how you currently respond to your most common stressors and how you would like to respond in the future.

Below is a grid that is referred to as the ACT matrix. This tool is derived from Acceptance and Commitment Therapy (ACT), a type of therapy that focuses on accepting the negative thoughts and feelings we naturally experience as human beings and committing to responding to difficult thoughts and feelings in a way that aligns with our personal values.



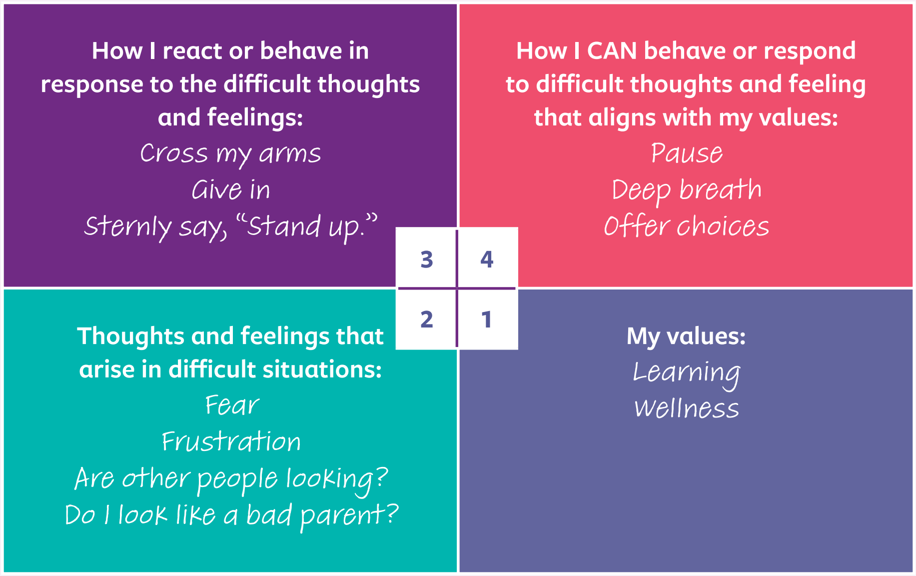
3 How I react or behave in response to the difficult thoughts and feelings	4 How I CAN behave or respond to difficult thoughts and feeling that aligns with my values
2 Thoughts and feelings that arise in difficult situations	1 My values

In the first box in the lower righthand corner, write down your top 2–3 values. In the second box in the lower lefthand corner, write the thoughts and feelings that arise when you encounter difficult situations that evoke stress. Consider what is going on internally when you experience stressful situations; these are the thoughts and feelings that others cannot see. In the third box in the upper lefthand corner, write down how you react or behave in response to the difficult thoughts and feelings that arise in stressful situations. These are the things you are saying and what you are doing that other people can see. In the fourth box in the upper righthand corner, write down what you can do in response to the thoughts and feelings that arise in difficult situations that align with your values. Note that the way you respond to stress may vary situation by situation. The way you respond to a stressful situation at work will most likely differ from how you respond to a stressful situation at home. The ACT matrix allows you to reflect on how you currently respond to the thoughts and feelings that emerge when you are in stressful situations and allows you to consider how you can respond differently in a way that reflects your values.

Example:

Chris' values are learning and wellness. Chris' profoundly autistic son has a meltdown at the grocery store when she tells him he can't have the stuffed animal on display. When this happens, Chris feels scared and embarrassed. Her heart begins to beat faster. She wonders if other people are looking at her and her son. She wonders if they think she is a bad parent for not buying him the stuffed animal he wants. She also feels frustrated because she is in a rush. In response to those thoughts and feelings, she crosses her arms. She then sternly tells him, "Stand up," and "Stop." When he continues screaming, she gives in and buys him the stuffed animal so he stops.

When Chris responds in this manner, she often finds the situation gets worse. She then usually feels guilty and unhappy in the way she responded because it does not align with her values of learning and wellness. She reflects on what she can do instead that aligns with her values. She thinks, I can pause, take a deep breath, get down to my son's level, and offer him choices of what he can have that I packed in my purse instead of buying the stuffed animal or disciplining him. By responding in this way, she is responding based on her values. She is promoting her own personal wellness by pausing to take a deep breath to ground herself. She is also promoting learning as she teaches her son to accept and cope with the difficult feelings he faces when told, "No," by seeking available choices.



How I react or behave in response to the difficult thoughts and feelings:
Cross my arms
Give in
Sternly say, "Stand up."

How I CAN behave or respond to difficult thoughts and feeling that aligns with my values:
Pause
Deep breath
Offer choices

Thoughts and feelings that arise in difficult situations:
Fear
Frustration
Are other people looking?
Do I look like a bad parent?

My values:
Learning
Wellness

ACTIVITY #4

Find a piece of paper and a pen. Draw four squares to create the frame of the ACT matrix. Think about a stressful situation you were in recently that you wish you responded to differently. Fill in each box to reflect on how you felt, how you responded, and how you can respond to that situation in the future.

KEY TAKEAWAY!

Identifying how you feel when you experience stressful situations, how you respond to those feelings, and how you would like to respond to those feelings creates an opportunity to practice how you would like to respond to those stressful situations.

REFLECTION #4

Picture the last time you found yourself caught in a stressful situation where you responded in a way that was not aligned with your values. How did you feel?

After filling out the ACT matrix and thinking about how I want to respond to the stressful situations I often face, I am still having a difficult time pausing to think before I respond to highly stressful situations. What can I do in high stress or unexpected situations?

Now that you have learned a strategy to reflect and create opportunities to practice changing the way you respond to stressful situations, let's learn a strategy to help move you into a state where you can take control of your behaviors to better respond to high-stress situations.

Think of all the feelings you identified in the reflection activity the last time you were in a stressful situation. Think of these feelings as an "emotional storm," with you being the boat in that storm. When a boat is in a storm, the goal is to get the boat back to shore and drop the anchor as quickly as possible to avoid floating out to sea. Dropping anchor helps to restore a sense of calmness while bringing you back to the present moment, allowing you to pause before reacting or responding to the stressful thoughts and feelings you experience. How can you drop your anchor when you are weathering an emotional storm?

First, acknowledge your thoughts and feelings. You cannot control them and, as a result, you cannot make them stop. Instead, focus on labeling how you are feeling in the moment. Once you acknowledge how you are feeling, you can begin to work on what you can control—your actions. You can come back into your body by moving: stand up, walk, take deep breaths, tap your fingers against each other, etc. Finally, after acknowledging your feelings and coming back into your body by purposefully moving it, redirect yourself by engaging with your surroundings. Look around the room. Focus on your senses and what you can feel, see, hear, smell, and taste.

Dropping Anchor with ACE

Acknowledge our thoughts and feelings

Come back to our bodies

Engage with our surroundings

You can practice dropping your anchor any time. Practice in easy contexts first so that when you encounter difficult situations, you can more easily drop your anchor and regain control over your actions. In the final activity, you will practice dropping your anchor. This activity can be modified based on how much time you have. You can drop your anchor in one minute or take as much time as you need to work through this exercise. By practicing dropping your anchor both quickly and slowly, you can learn to adapt this approach to situations where you must quickly respond as well as situations that allow time for you to reflect before responding.

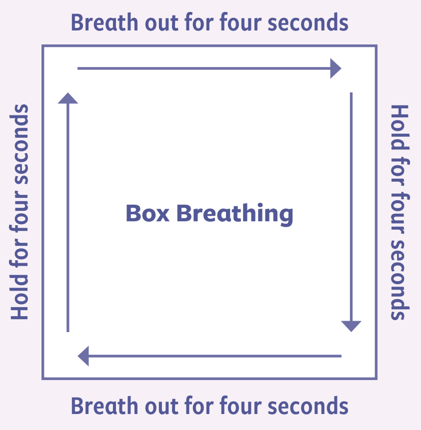
ACTIVITY #5

Acknowledge how you are feeling. What are you thinking as you feel that emotion?
Practice coming back into your body. Take a deep breath. Tap your fingers against a table or your legs. Push your arms into your chair or your feet against the ground. Feel the sensation of touch as you move your body.
Engage with your surroundings. Look around the room. What is one thing you can smell? What are two things that you can hear? What are three things that you see? What are four things that you can physically feel?

REFLECTION #5

Reflect on how you feel after that exercise. Do you feel different than you did before completing the activity?

There are other strategies to help you work through the mental and physical characteristics of stress. Box breathing is a technique that can be used to help settle a racing heart and can help with anxiety and stress. It can help you feel more relaxed and grounded during moments of high stress. To practice box breathing, find a comfortable quiet place to sit or lie down. You can close your eyes to help you focus. Breathe in slowly through your nose for four seconds. Hold that breath for four seconds. Slowly release your breath through your mouth for four seconds. Hold for another four seconds before starting to breathe in again. Repeat until your heart rate lowers.



For persistent negative thoughts or feelings, guided meditation can be helpful to connect you to the present moment. Guided meditation consists of a speaker guiding the listener through exercises that evoke soothing mental visualizations, such as placing your thoughts on a leaf and letting them float down a river. Breathing and mindfulness exercises may also be incorporated into guided meditation. Guided meditations are accessible at no cost on a variety of platforms including YouTube, phone applications, and through internet searches. Consider exploring guided meditations on websites such as tarabrach.com and uchlahealth.com, or apps such as Headspace and Aura. You can also search for guided meditations that cover specific topics such as parenting, stress, anxiety, grief, relaxation, and happiness.

Progressive muscle relaxation is another strategy to manage the mental and physical characteristics of stress. Progressive muscle relaxation first begins with tensing a group of muscles. As you tense the target muscles, you learn to better identify the sensation of tenseness. The muscles are then relaxed. As the muscles relax, you feel the tension release. You learn to recognize what the target muscle group feels like when it is relaxed. Through dedicated practice of this exercise, you can learn to better identify when your muscles begin to tense up in your daily routines so that you can focus on relaxation techniques in those moments.

KEY TAKEAWAY!

You can pause before reacting or responding to difficult thoughts or feelings by dropping anchor, box breathing, guided meditation or progressive muscle relaxation.

Stress management for caregivers of profoundly autistic children is imperative in maintaining a high quality of care for the autistic child. As caregivers increase their ability to skillfully respond to stressful situations, they can better control how stress impacts them and the child they care for. As you continue your journey to manage stress, continuously reflect on what strategies work for you and build your skills by expanding the use of those personally effective strategies. If you are interested in additional resources to dive deeper into stress management, try seeking out parent support groups, further exploring the resources referenced in this chapter, or identifying a professional trained in Acceptance and Commitment Therapy.

This chapter concludes with one final reflection activity to reset your perspective on supporting a profoundly autistic child.

REFLECTION #6

Welcome to Holland by Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this…

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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13

Safety Considerations

As a parent of a profoundly autistic child, it is important to be aware of common issues that can affect the safety of your child. Because of their communication challenges, profoundly autistic children are more vulnerable than their neurotypical peers, especially in situations such as those we describe in the pages that follow.

This chapter will discuss important safety concerns and provide suggestions for how to prevent them, how to educate/alert your child, and how to respond should you find yourself in such a situation. Additionally, we will provide suggestions for preparing for interactions with first responders.

Safety preparation

When it comes to keeping your child safe, preparation is the key to success! One of the most important things you can do is to develop a safety plan that is readily available in case of an emergency. Your child's safety plan should include important details about them, such as appearance, behaviors, medical conditions and medications, and emergency contact information. It's a good idea to also alert local law enforcement that an autistic child resides at your address. Doing so will allow police to better address an emergency at your home, should one occur. For example, if police know your child is sensitive to bright lights and sounds, they can plan to arrive with their lights and sirens off. To inform law enforcement, call your local non-emergency police station line and ask them to register your child within their system.

It is also a good idea to ensure your neighbors know you have an autistic child, especially if your child tends to wander from you or the home. Finally, having your child wear an identification bracelet with their name and your contact information, or a tracking device, will aid in locating them should they get lost or elope.

KEY TAKEAWAY!

You can never be too prepared when it comes to emergency situations. Be sure to update your safety plan regularly and have it readily available.

Elopement

Elopement is when a dependent child wanders from a safe space. Elopement is common among profoundly autistic children. In fact, approximately 49% of autistic children engage in wandering behavior (Anderson et al., 2012). Wandering poses safety risks for this population, and significant stress for caregivers. Although elopement tends to peak around the age of five, some autistic individuals engage in elopement throughout their lifespan (Anderson et al., 2012). Because profoundly autistic individuals are drawn to water, drowning is a major concern (water safety will be discussed later in this chapter).

Most autistic children who wander do so from their own home or a friend or family member's home (Anderson et al., 2012). Some children wander from safety because they are trying to avoid something unpleasant, while others wander with a specific goal in mind. Understanding if your child is wandering to avoid an uncomfortable sensory experience (e.g., loud noises, crowds, bright lights, discomfort) or if they are interested in seeking out something specific (e.g., playground, toy) will help you develop specific strategies to address the behavior. For example, if your child is eloping to avoid loud noises, you can teach them to put on headphones. If they are seeking out the neighborhood playground, you can work on teaching them to ask to go to the playground.

To determine why your child is eloping, you'll want to collect data (see example below). Gather information about what occurred right before they attempted to elope, who was there, what sensory triggers were present and, if possible, where they were trying to go.

ELOPEMENT LOG

Date & Time	Who was present?	What happened right before?	Elopement Event	What happened right after the elopement event? For example, do you know where the child was going? Were they trying to avoid something or get to something specific?
Ex: 10/22 at 9:35 am	Mom, Dad, Johnny	Mom asked Johnny to clean up his toys.	Johnny tried to leave the house.	Johnny attempted to leave the house through the front door to avoid cleaning up his toys.

- See APPENDIX G for Elopement Log

KEY TAKEAWAY!

Collecting data on elopement events will help you understand why your child is eloping, which will allow you to better address the behavior.

How can I prevent my child from eloping?

While you are addressing why your child is eloping and teaching skills to communicate those wants and needs, you can also take precautions to prevent elopement. Ensure your home has deadlocks on all doors, and that window locks are functioning. Consider installing alarms to deter or, at the very least, delay elopement. You can also use a visual, such as a stop sign, to remind your child not to leave the area. Additionally, be sure to communicate with neighbors, teachers, and others who supervise your child about the risk for elopement. If you know your child tends to elope, strongly consider a personal GPS tracking device. Most often these devices are bracelets that transmit your child's location in real time. When choosing a device, ensure that it has a locking mechanism so that your child cannot independently remove the item.

What should I do if my child elopes?

If your child has eloped, immediately call 911. Inform the responder that your child is autistic and has eloped. If your child engages in any self-stimulatory or challenging behavior, be sure to inform the first responders so they are aware. Additionally, if your child is sensitive to loud sounds or bright lights that may cause them to hide, ask the first responders to turn them off as they approach. Because autistic children are drawn to water, be sure to search areas near water as soon as possible. Finally, have your safety plan readily available when first responders arrive so that you can provide them with vital information to help them find your child.

KEY TAKEAWAY!

If your child elopes, immediately call 911 and search areas near bodies of water.

Water safety

Drowning is the number one cause of death among autistic children (Denny et al., 2021). Drowning is silent, takes less than 30 seconds, and can occur in as little as two inches of water. Autistic children are often attracted to water and may not know how to swim or understand the danger of downing. It is therefore critical to teach basic water survival skills, such as how to flip onto your back or to get to the nearest wall should they fall into a pool.

How can I prevent a drowning incident?

Enroll your child in swimming lessons. It's never too early (or too late) to learn how to swim! Contact your local recreation centers, CARD (Centers for Autism and Related Disabilities), or YMCA for information related to adaptive swim lessons. Be sure to choose a pool and instructor that are a good fit for your child and have experience working with profoundly autistic children.

Develop clear water rules and present them in a way your child will understand. For example, "no swimming alone" and "no running near the water." In addition to stating these rules verbally, creating a visual reminder for them might also be helpful. Be sure to always supervise your child near water and be within arm's reach in case they need assistance. Additionally, if you have a pool, install a pool fence, pool alarm, and door chimes. It's also a good idea to talk to your neighbors if they have pools. Explain that autistic children are drawn to water and often wander. If they have a fence, ask that they keep it closed and locked if possible. Informing your neighbors that your child is profoundly autistic and may engage in these behaviors can help reduce risks. Finally, ensure that all adults in your home are CPR certified.

KEY TAKEAWAY!

Your child is never too old to learn water safety skills.

Pica

Pica is the repeated ingestion of nonfood items (e.g., paper, soap, rocks), and is relatively common among profoundly autistic children (Fields et al., 2021). If left untreated, pica can lead to choking, gastrointestinal parasites, nutritional deficiencies, poisoning, and intestinal obstruction or perforation (Fields et al., 2021). The reasons why autistic children engage in pica aren't always clear. Some possible reasons include inadequate nutrition, lack of awareness of what is and isn't edible, to relieve stress, to get attention, to escape a task or demand, or for sensory stimulation.

How can we manage pica?

Be sure to inform your child's physician if your child has eaten or often tries to eat inedible items. The physician will likely check for anemia, test their lead levels, and check for parasites. If your child has eaten something inedible or appears to be in gastrointestinal distress, contact your physician, 911, or poison control immediately. Your child's medical provider can order an x-ray to rule out a blockage.

If your child is diagnosed with pica, be sure to inform teachers, therapists, and any other care providers and alert them to the dangerousness of the behavior. Work with your child's care providers to develop a plan to prevent pica. First, identify if there are certain items that your child usually targets (e.g., hand sanitizer, chalk, coins, paper) and keep those items in places that are inaccessible, such as a locked cabinet or drawer. Visually and physically "sweep" the environment regularly to remove pica items. Create a checklist for each area of the home where your child spends time so that you know you have checked all the areas. Don't forget to do regular sweeps of the car before your child gets in as well as in the homes of people your child visits regularly. There is some evidence that offering edible items that are similar in look to the inedible items may be effective in reducing pica. If your child does ingest something harmful, poisonous, or dangerous, immediately call 911 so that your child can be assessed.

KEY TAKEAWAY!

Inform all caregivers if your child engages in Pica and be sure to remove all Pica items from the environment.

Household toxins

Autistic children are significantly more at risk for poisoning than their non-autistic peers (Cornell et al., 2022). Autistic children, especially those with profound autism, often do not understand that cleaning supplies or other household toxins are dangerous. Research reveals that most poisonings occur while caregivers are home (Cornell et al., 2022). The most dangerous household toxins include cleaning products, medicines, batteries, and pesticides. Being aware of the risks, having safeguards in place, and knowing how to respond in an emergency can help reduce serious injuries.

How can I keep my child safe from household toxins?

Be sure to store all household toxins, such as cleaning supplies, medicines, and pesticides in their original packaging, locked up and out of sight and reach of children. Ensure all medicines are in bottles with child-resistant caps, and never refer to medicine as "candy." It can be tempting to convince your child to take their medicine by calling it candy, but it may also lead them to seek out the medicine independently. If your child ingests a household toxin, follow these steps:

1. Take the item from your child. If your child has some of the item in their mouth, have them spit it out. Do not make your child vomit.
2. If your child is not breathing, is convulsing, acting disoriented, or exhibiting any other symptoms which may suggest an immediate threat to their health—Call 911

If your child is not exhibiting any of these symptoms, call Poison Control at 1-800-222-1222, and they will guide you through the appropriate next steps.

Fire safety

Autistic children, and profoundly autistic children in particular, are more vulnerable in a situation involving fire. This is because they are less likely to recognize the danger or respond to first responders, and they are more likely to retreat to a familiar hiding place. Also, autistic children are more likely to try to reenter the home, so it's important to ensure an adult always has eyes on the child. If you have multiple children, it's a good idea to plan for who will be specifically responsible for your autistic child in the event of a fire

How can I prepare for a fire-related incident?

Reach out to your local fire department and inform them that you have an autistic child. Ask them if they can record this information in their records in the event of an emergency. Also, ask if they have any resources for autistic children. Some fire departments have decals that can be placed on your child's bedroom door, making it easier to locate them. Create a visual evacuation plan and designate a meet up spot. Practice evacuating and meeting at your designated location so that your child is familiar with the plan. Be sure to install smoke alarms in all bedrooms and on every level of your home. Test your smoke alarms often so your child knows what the sound means and becomes accustomed to it. Additionally, have a fire extinguisher accessible on every level of your home.

It's also a good idea to plan a visit to your local fire station so that your child can see a firefighter in their protective gear. Allowing your child to become familiar with the gear will make any future interactions less scary. You can use videos, stories, and songs to teach your child basic fire safety skills (e.g. stop drop, and roll), and teach your child to respond to their name when the alarm goes off. If your child is non vocal, teach them to blow a whistle when they hear the alarm. Finally, keep matches and lighters locked up, and out of reach of your child.

KEY TAKEAWAY!

Designate a meet up spot and practice evacuating when you test your smoke detector, so your child knows what to expect.

Preparing for interactions with first responders

Interactions with first responders can be scary for anyone, but especially for a profoundly autistic child with limited communication abilities and sensory sensitivities. Often, interactions with first responders take place during an emergency, so there are loud noises, bright lights, and protective gear that might be frightening. Unfortunately, it's not uncommon for autistic children to avoid or hide from first responders during an emergency. It's important to teach your child that first responders are community helpers who want to keep them safe. You can do this by reading books, watching videos, and most importantly by exposing your child to first responders during non-emergency situations. To do this, you can reach out to your local police station and fire department and ask if they offer tours or programs specifically for autistic children.

KEY TAKEAWAY!

Introduce your child to first responders in fun ways by reading books, watching videos, and attending local events.

◻ See APPENDIX F for Safety Information Sheet

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14

Choosing and Collaborating with Providers

As the parent of a child with profound autism, you will seek out assistance from a variety of professionals for support with educational, clinical, and medical needs. From working with the school team to address educational and clinical needs, to getting support with speech therapy, occupational therapy, and other specialists, to finding physicians and dentists in the community—it's a full-time job!

In this chapter we discuss steps for collaborating with providers and other professionals who support your child. We include strategies for working with them to ensure you get what you and your family need and are satisfied with the supports your child is receiving. In all likelihood, children with profound autism will have multiple providers, either at the same time or over a period of time, to address their needs as they develop.

How do I find a good provider?

You suspect your child has a cavity, or is slow to develop language, or appears to have motor difficulties—all of these situations require you to seek out an expert who can provide the assistance needed. Profoundly autistic children require specialized care and providers that understand autism and your child's specific developmental needs. Below are several steps you should take before reaching out to a provider for help.

1. **Assess Your Child's Needs**

   The first step in finding a provider is to understand your child's specific needs and challenges. Think about your child's day and identify the issues that they struggle with. At the end of the chapter is a checklist to help you identify and prioritize needs and goals. For each area, write down your concerns—think about what your child is currently doing, or not doing, and your goals for them. Prioritize each item. This is important because, although you may have many concerns, they all cannot be addressed simultaneously. Figure out what is most important for your child, you, and your family, and begin there.

2. **Research Providers**

   Search for providers with specific expertise in treating autistic children and, if possible, profoundly autistic children. Your child's pediatrician, school, or other providers may have referral sources. It can be helpful to call the provider to determine their areas of expertise and what issues they treat. It is important that you feel comfortable with the provider so you can communicate effectively and share your family's priorities. Other parents of autistic children may be a valuable resource for identifying providers. Note that some services are now available via telehealth. Telehealth can be a great option if you are unable to locate providers near you.

Depending on your child's needs and your preferences, you may seek services from different types of professionals. Professionals who often work with autistic children and their families include:

Type of Professional	What They Do	Credential(s)
Developmental Pediatrician	Provides diagnostic evaluations, makes recommendations about developmental issues, medication, or therapy	MD or DO and state licensure
Behavior Analyst	Develops behavior support plans, provides ABA therapy addressing behavioral challenges and teaching new skills	BCBA or BCBA-D
Registered Behavior Technician (also referred to as a Direct Therapist, Behavior Technician)	Provides one on one services in the home or a center	RBT Note: not all states require a credential for this position
Psychologist	Provides diagnostic assessments, provides parent/family support and therapy, helps with concerns around sleep, mealtimes, and anxiety	MA/MS or PhD, sometimes also BCBA and state licensure
Speech Therapist or Speech and Language Pathologist	Helps children improve language and communication skills; can also help with social skills	Master's degree or doctorate in Speech and Language Pathology and state licensure
Occupational Therapist	Helps children learn skills needed for daily living; addresses sensory concerns and fine motor skills	Master's degree in occupational therapy and state licensure
Special Education Teacher	Provides specialized educational services in schools for children with disabilities; develops individualized education plans and provides educational support	Bachelor's or Master's degree in special education or related field and state certification/licensure
Psychiatrist	Provides mental health services and prescribes psychiatric medication	MD or OD State licensure

3. Verify Credentials, Expertise, and Experience

It is important to verify a provider's credentials. If a potential provider has the appropriate credentials, the next step is to verify that they have expertise in working with profoundly autistic children and experience working with the particular challenges that concern you. You will be able to get some of this information from a provider's website. You can also schedule an appointment to talk to a potential provider to learn more about their expertise, experience, and background. Some potential questions to ask are:

- Do they provide services in a clinic, in a family's home, virtually, or in some combination?

  Any of these are fine and it is important to choose an option that will work for you and your family.

- How many hours per week do they typically work with children and families?

  Look for a match between your availability and what is being recommended.

- What are their general goals for profoundly autistic children and what assessments do they use to identify those goals?

  If the therapist talks about things like "curing" or "healing", this is a red flag that they do not understand autism as a neurological condition. Goals should include helping children learn strategies to be as autonomous as possible, developing skills, and helping parents learn ways to support their children.

- Ask how they typically approach treatment planning in the areas you have identified as priorities.

  Be sure that the approaches discussed sound acceptable and reasonable to you and that you are comfortable with what is being described. If you feel uncomfortable or uneasy, it could be a sign that this may not be the right provider or type of treatment for you and your child.

- What if I don't see any improvement in my child?

  Be sure to ask how the provider will evaluate improvement in your child. This will preferably be based on data rather than on a more subjective measure of improvement. Understanding this process is critical to help you hold the provider accountable for their services. Remember progress can be slow, may occur in fits and spurts, and is not always immediately obvious.

KEY TAKEAWAY!

Be sure you are comfortable with the provider and the approach they recommend. Always ask specific questions about the process and what will happen if you do not see improvement or change.

Special considerations for medical providers

As the parent of a profoundly autistic child, your child is likely to face medical, academic, behavioral, and mental health challenges. Some of the most important decisions you will make involve selecting the right pediatrician and other healthcare providers. The first question to ask any potential provider is whether they have experience working with profoundly autistic children. Identifying someone who understands the exceptional needs of your child is critical to getting good care. For some types of services (e.g., psychiatry), you may be able to access the provider via telehealth. This can be particularly useful if your child has difficulty with transitions to and from appointments.

Special considerations for therapies

As noted, many autistic children need specialized therapies such as occupational therapy, speech therapy, or behavior therapy (sometimes referred to as Applied Behavior Analysis, or ABA). For behavior therapies, it may take some time to identify which type of therapy is a good match for you and your child. When your child is initially diagnosed, it is important to have a conversation with the person conducting the assessment to determine what type of therapy would be most efficacious for your child.

We recommend that you look for evidence-based therapy. That is, the intervention approach has research and scientific evidence behind its use. One resource to identify evidence-based interventions is the National Standards Project published by the National Autism Center at May Institute (https://nationalautismcenter.org/national-standards/). The National Standards Project summarized the autism literature and treatment interventions and identified the degree to which an intervention is evidence-based.

You may also want to find out more information about the following:

- **How well trained is the person working with my child and do they have adequate supervision? This is especially important with home-based therapy.**
- **How will goals be set for my child, and do they reflect and support the goals I am interested in?**
- **What will a session look like for my child?**
- **What will they do if my child is unhappy or doesn't want to participate?**
- **Do they provide parent training so that you can continue therapy at home?**
- **How often is progress monitored?**
- **If my child is not making progress, what changes will be made?**

Ultimately, you must ask yourself: Do you feel that you will be able to work well with this provider? Do they understand your child and their needs?

You will likely have additional resources available to you through your pediatrician, your child's school, and your state developmental disability and/or autism programs. Most states provide individuals who have disabilities with a case manager to help families access services at different points across the lifespan. There are also many online resources. For example, in Massachusetts, the website Mass.gov has resources for individuals with disabilities, including the Department of Developmental Disability Services, that provide information about resources such as the Childhood Autism Waiver program for eligible families.

Begin gathering information about adult services well in advance of the date that your child will "age out" of children's services. The transition to the adult system of care can be difficult. The resources and service options for adults are much more limited than they are for children. Beginning your research early will provide you the opportunity to work with your state developmental and autism waiver services well in advance of your child aging out to ensure you have sufficient time to line up the services your child needs as they transition to adulthood.

Beware of non-evidence based treatments

As the parent of a profoundly autistic child, you need to be wary of promises by providers to “cure” your child. It is important to research a therapy or intervention to ensure it is evidence-based. Over the years, there have been recommended therapies for autistic individuals that were found not to be the “miracle” treatment that was initially described. Below is a table listing examples of treatments that were shown to lack scientific evidence of effectiveness when studied by researchers.

Type of Intervention	Reason for Use	Examples
Dietary Interventions	Eliminates certain food products that may cause gastrointestinal issues such as constipation, diarrhea, and abdominal pain	Gluten-free or casein-free diet, raw camel milk
Supplements	To address dietary insufficiencies, improved body functioning and gastrointestinal regulation	Omega-3s, vitamin B6 and magnesium, megadoses of vitamin C, digestive enzymes and probiotics
Animal Therapies	Aimed at improving communication, social skills, motor skills, and help manage external stimuli that may be overwhelming	Dolphin-assisted therapy, therapeutic horseback riding, pet therapy

KEY TAKEAWAY!

It is critical to make sure there is scientific evidence supporting any type of intervention for autism. Refer to the National Standards Project published by the National Autism Center at May Institute for more information on therapy you are considering (https://nationalautismcenter.org/national-standards/).

The table below includes examples of issues you might consider when prioritizing your concerns.

PRIORITIZING YOUR CONCERNS

	Low Priority			Critical/Very High Priority	
	1	2	3	5	6
Mealtime Issues *Example:* Justin refuses to sit at the table and only eats standing up and walking around. He eats a limited number of foods. I'd like him to join us for meals and be willing to at least try more foods.				X	
Bedtime and Sleep *Example:* Lillah gets up very early every morning and doesn't seem to need more than 5 hours of sleep.				X	
Independence (e.g., dressing, toileting, bathing) *Example:* Ben is 10 years old and still wears a pull-up. I would love for him to get toilet trained.					X
Meltdowns/Tantrums (e.g., crying, whining, throwing items) *Example:* When we ask Marvin to put his iPad away, he has terrible tantrums. Sometimes I give in and give it back to him and other times I just wait him out.				X	
Severe Challenging Behavior (e.g., aggression, self-injury, property destruction, pica, elopement) *Example:* When Isaac is out in the yard, he sometimes puts leaves, twigs, and mulch in his mouth. We have to watch him constantly when we are outside.				X	
Safety (at home and in the community) *Example:* Alex has no sense of what is and is not safe. He tries to run across the street whenever we are out and can't be alone except when he is sleeping.				X	
Transitions *Example:* Kai has a lot of difficulty with the morning routine and getting ready for school. He wants to play with his toys, and it is difficult getting him dressed and out the door to the bus.			X		
Communication *Example:* Ethan does not communicate except by pulling me when he wants help or bringing over an item. We've tried for years to help him learn to speak or use a tablet, but it has not worked.					X
Medical Concerns/Illness *Example:* Ian does not speak but he seems uncomfortable a lot, holding his stomach. I wonder if he has reflux or gas. How can I figure out how he is feeling?			X		
Educational Concerns *Example:* Kenetra is behind her peers in preschool. I know she has autism but is she delayed academically too?					X

PRIORITIZING YOUR CONCERNS

	Low Priority			Critical/Very High Priority	
	1	2	3	5	6
Lack of interest in play and other children *Example:* Jayson sits by himself on the playground. He refuses to join the other children even to just play beside them.		X			
Social skills *Example:* I cannot get Evan to respond to me or other people.			X		

15

Medications Prescribed for Autistic Children

Medications are prescribed to autistic children to address a variety of symptoms and behaviors associated with autism, such as behavioral concerns (e.g., aggression and self-injury), impulsivity, anxiety, attention deficit hyperactivity disorder, and depression. In this chapter, we discuss how medications are typically prescribed and strategies for talking to your child's provider and monitoring medication effects.

How are medications prescribed to autistic individuals?

Medications can be a useful treatment option to help address symptoms and behaviors related to profound autism. Understanding how medications are typically prescribed to autistic children can help you make a more informed decision on whether medication is right for your child. For medication to be prescribed, it must first be thoroughly tested in clinical trials for the intended population and approved by the US Food and Drug Administration (FDA). Providers then use the treatment guidelines outlined by the FDA to identify potential medication options for their patients.

Unfortunately, there aren't many clinical trials conducted with autistic children, so it is rare for the FDA to approve medications specifically for this population. To date, the FDA has only approved two medications for autistic children and adults, specifically to treat irritability: Risperdal (risperidone) and Abilify (aripiprazole). Irritability may be displayed in specific challenging behaviors such as self-injury, aggression (verbal and physical), tantrums, or other outbursts. This doesn't mean that irritability is the only symptom related to autism that you can use medication to treat. Other symptoms can be targeted using medications that are prescribed "off label" (i.e., not tested for specific populations by the FDA).

This does not mean that no research has been done evaluating the effects these medications have on autistic children. It just means that there isn't enough research to get FDA approval specifically for autistic people. For these medications, providers rely on FDA guidelines for non-autistic children to inform their treatment decision. For example, anti-depressants are FDA approved to treat obsessive-compulsive disorder (OCD) in children but can also be helpful for repetitive and ritualistic behavior in autistic children. Providers can use prescription guidelines for children with OCD to determine a course of treatment for autistic children with repetitive behavior. Here are some medication examples that may benefit autistic children (Zarcone, 2020).

COMMON MEDICATIONS USED WITH AUTISTIC INDIVIDUALS

Class of Medication	**What is it used for?**	**Specific Medications**
Antidepressants	Depressive symptoms Repetitive/Ritualistic behavior (can also be used for anxiety)	Prozac®, Zoloft®, Lexipro®, Celexa®, Luvox®, and Anafranil®
Antipsychotics	Aggression and Self-injury	Risperdal®, Zyprexa®, Seroquel®, Abilify®, and Geodon®.
Anticonvulsant	Seizure disorders Mood stabilizer	Depakote®, Tegretol®, Lamictal®, Neurontin®, and Topamax®
Benzodiazepines	Anxiety symptoms	Ativan®, Xanax ® and Klonopin®
Beta Blockers and Alpha Agonists	High blood pressure and anxiety	Inderal®, Kapvay, and Catapres®
Stimulants	Hyperactivity and Inattentiveness	Ritalin®, Concerta®, and Adderall®

KEY TAKEAWAY!

There are many different kinds of medications available for a variety of conditions. It's hard to know what might help and what won't without trying them. Working with a provider with expertise in autism is ideal, but your child's pediatrician or PCP can help you get started too.

How should I talk to my child's providers about medications?

Before deciding if medications are the right choice for your child, it is important that you have a thorough discussion about the medication with your child's provider. You want to be sure that you make an informed decision about the risks and benefits of the medication.

Here are some potential questions to ask your child's provider about the medication they want to prescribe (or are currently prescribing) (Schall, 2002):

- Why are you recommending this medication for my child?

  You want to understand why this specific medication has been selected given your current concerns.

- Has this medication been tested for use in children with profound autism?

  You want to know how this medication has affected other children similar to your child.

- What symptom or behavior changes can we expect if the medication works?

  You want to know exactly what the medication is being prescribed to treat and how you will know if it is working.

- How long does it typically take to see a change after starting the medication?

  Some medications can take a few weeks before any symptoms or behavioral changes occur, so it is helpful to know this before starting the medication.

- What side effects are common with this medication?

  Understanding the potential side effects of a medication can help you weigh the risks and benefits for your child. It is also important to know what to look out for if your child is prescribed the medication, especially if they are nonverbal or nonspeaking.

- What should I do if my child has side effects or an adverse reaction to the medication?

  Medications can cause side effects or adverse reactions that range from mild to severe. Talk to your child's provider about how to handle any potential reactions.

- How often do I give a dose of medication?

  Knowing the dosing in advance can help you align your daily schedule with the medication dosing.

- What happens if they miss a dose?

  Even with planning, it is possible to miss a dose of medication. It is important you know what you should do when this happens. Should you give the dose as soon as you remember, or should you just wait until the next scheduled dose?

- Should my child avoid certain foods or activities while on the medication?

  Some medications can cause symptoms such as drowsiness or gastrointestinal issues that might impact your child's ability to do certain things. Your child's provider can help you determine if there are things you should have your child avoid or do while on the medication.

- What information should we collect at home and at school to help determine if the medication is working or not?

  Any information you can give your provider about changes in your child after starting a new medication will be helpful in determining if the medication is working. It is important that you know what changes to look out for so you can document them. The prescriber will primarily be relying on you to determine whether the medication is working or not, so use any information you can gather to inform that decision.

- When should we schedule a follow-up appointment?

KEY TAKEAWAY!

These questions can be used as a guide to facilitate a discussion with your child's provider about medication recommendations. The answers to these questions, and any subsequent questions, should help you make an informed decision about using medication as a treatment option.

How will I know if the medication is working?

When starting a new medication, it is crucial to monitor any changes in symptoms or behavior that may be due to the medication (Zarcone, Napolitano, & Valdovinos, 2008). This can help you determine if the medication benefits outweigh any risks (Schall, 2002). This is also true if there is a change in the medication dose, or if a medication is stopped or discontinued. There are several ways that you can monitor the effect of medication, in collaboration with your provider, to determine if it is working or not. During follow-up visits, your child's provider will likely ask you about any symptom or behavior changes you have noticed since starting the medication. This is an opportunity to share any data you or others (e.g., your child's teacher) have collected regarding behavior changes.

Changes in behavior

When your child is taking medication, you should keep track of any changes you notice in behavior. This information can be used to determine if the medication is working the way it was intended to work. There are many ways you can keep track of behavioral changes. For example, you can use a weekly data sheet to track the frequency of behavior the medication is prescribed to treat. Here is an example of what that might look like:

FREQUENCY OF CHALLENGING BEHAVIOR

<table>
<tr><th>BEHAVIOR</th><th>Week 1</th><th>Week 2</th><th>Week 3</th><th>Week 4</th><th>Week 5</th><th>Week 6</th></tr>
<tr><td>Ex: Hitting</td><td>𝍸 𝍸
|||</td><td>𝍸 ||</td><td>||||</td><td>𝍸</td><td>||||</td><td>|||</td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td></tr>
</table>

You can also use a daily data sheet to monitor changes in the severity of the behavior. Here is an example:

CHANGES IN SEVERITY OF BEHAVIOR

DATE:												
Behavior 1: *Self-scratching*	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1
Behavior 2: *Head Banging*	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1

- See APPENDIX H for Changes in Severity Data Sheet

You may also keep a journal log of any symptom changes or use a symptom tracking application on your smartphone (e.g., Best Behavior, BehaviorSnap). In addition, you can use a single data collection method or combine multiple methods. For example, you can use data sheets to monitor behavior while you are at home and take notes on your phone when you are in the community. If your child attends school or therapy, it may also be helpful to ask teachers or clinicians to monitor behavior changes due to the medication. Before follow-up appointments with your child's provider, you can have other service providers write notes or summaries of behavior changes they observed for you to share with the prescribing provider.

Your child's provider may also ask you to fill out a rating scale or questionnaire that is more specific for your child's diagnosis to monitor behavior changes. The exact measure used will depend on the information the provider is seeking. For example, if your child's provider wants to know if the medication has impacted your child's concerning behavior, they might use the Aberrant Behavior Checklist (Aman et al., 1985). This rating scale measures the severity of different behaviors such as irritability, aggression, social withdrawal, stereotypy, hyperactivity, and inappropriate speech. Other measures your child's provider may use include the Child Behavior Checklist (Achenbach, 1999), the Conners' Parent Rating Scale (Conners et al., 1998), or the Yale-Brown Obsessive Compulsive Scale (Goodman et al., 1989), depending on the child's symptoms and if they have a co-occurring mental health diagnosis.

KEY TAKEAWAY!

Make sure that the medication prescribed for your child is having the intended effects on their behavior. Gathering information, specifically collecting data on the targeted behavior, will allow you and your doctor to make informed decisions about how well it is working.

Physiological changes and side effects

Your child's provider will want to monitor any side effects or adverse drug reactions. A *side effect* refers to any unintended effect of the medication that occurs at normal doses (Kalachink, 1999). This effect may not necessarily be harmful or beneficial; it is just not the intended effect of the medication. For example, a common side effect of Risperdal is increased appetite and hunger (Siegel & Erikson, 2016). An *adverse drug reaction* (or "adverse effects"), on the other hand, refers to uncharacteristic or unexpected reactions to the medication (Kalachink, 1990). These refer to allergic or toxic reactions due to the medication itself or an interaction between this medication and another medication or therapy.

Once you have a list of potential side effects, it may be helpful to make a chart or checklist to monitor them. This can help you identify if your child is experiencing side effects, and the frequency with which they occur, to share with your child's provider. Here is an example of a side effect monitoring chart:

MEDICATIONS SIDE EFFECTS

0 = No Occurrence
1 = Little Occurrence
2 = Some Occurrence
3 = Severe Occurrence

POTENTIAL SIDE EFFECT	Week 1	Week 2	Week 3	Week 4	Week 5	Week 6
Ex: Fatigue	0	2	2	1	0	0

- See APPENDIX I for Medications Side Effect Data Log

Your child's provider may use rating scales to measure the presence and severity of side effects and adverse drug reactions. These rating scales can be comprehensive (measuring multiple potential side effects for many medications) or specific to a medication or side effect. For example, if your child's provider wants a comprehensive measure of a medication effect, they may use the Matson Evaluation of the Drug Side Effects (Matson et al., 1998). If your child's provider wants to measure a specific side effect, they may use the Abnormal Involuntary Movement Scale (Guy, 1976) which measures shakiness and other motor side effects of antipsychotic medication. When using these rating scales, your child's provider will ask you a series of questions about symptoms your child might be experiencing. For some questions, it may be helpful to refer to any notes you have regarding your child's symptoms.

Your child's provider will also monitor any physiological changes using various lab tests or measures depending on the information they are trying to gather. With some medications, providers can measure the amount of active medication in your child's body using a blood sample. This can help the provider understand how well your child's body is absorbing and processing the medication. This information can be used to ensure the correct dose of medication is prescribed. However, it is not necessarily helpful at determining if the medication is working or not without also looking at the behavioral measures you have been collecting. In addition to measuring how your child's body processes the medication, the provider can also use genetic testing to measure medication effects. Research shows that there are genetic differences that impact how a medication is metabolized in each person. If your child's body slowly metabolizes the medication, the normal dose of medication might be too strong. On the other hand, if your child's body quickly metabolizes the medication, the normal dose may be too weak.

KEY TAKEAWAY!

Many medications have side effects and it is important that you know what to look for and how to monitor them. Consider these side effects when weighing the risks and benefits of taking a specific medication.

Conclusion

Medications can be a beneficial treatment component for profoundly autistic children. While they do not address the core symptoms of autism, they can be used to treat related symptoms such as anxiety and irritability. When considering medication for your child, it is important to have a thorough discussion with your child's provider about the potential risks and benefits of the medications. We hope that the information and suggestions provided in this chapter will help you prepare for discussions with your child's provider as well as provide you with tools to monitor your child's symptoms and behaviors if medication is prescribed.

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Appendices

APPENDIX A] MORE GOAL WORKSHEET

DIRECTIONS: Complete the MORE table by determining a goal for your child. Fill in how the goal will be measured, observed, why it is relevant, and how it will be evaluated frequently.

Measurable	**O**bservable	**R**elevant	**E**valuated Frequently
There must be a system for measuring progress to assess how a child is doing. This could be as simple as counting how often something occurs.	To be measurable, goals must focus on observable behavior, what you see and observe.	Goals should be relevant to your child and family and result in meaningful changes.	Progress on goals need to be evaluated regularly. This means that progress data are collected frequently, even daily or weekly.

GOAL:

Measurable	
Observable	
Relevant	
Evaluated Frequently	

APPENDIX B] ABC DATA SHEET

DIRECTIONS: If your child has a meltdown or engages in other challenging behavior, write down what occurs before (antecedent) and after the target behavior (consequence).

Date & Scenario/Context	**Antecedent** (What happens before the challenging behavior)	**Target Behavior** (The meltdown or other challenging behavior of interest)	**Consequence** (What happens right after the target behavior)	**Notes**

APPENDIX C] BEHAVIOR FREQUENCY DATA SHEET

DIRECTIONS: Tally each individual behavior and/or episode behavior.

Week of: ____________________	**Monday**	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Challenging Behavior:							
Challenging Behavior:							
Challenging Behavior:							
Challenging Behavior:							
Challenging Behavior:							

NOTES
Monday
Tuesday
Wednesday
Thursday
Friday
Saturday
Sunday

APPENDIX D] CHALLENGING BEHAVIOR SAFETY PLAN

DIRECTIONS: Use the space below to fill in the steps you will take for safety during your child's challenging behavior episode. Share the plan with all family members and gather their input and ideas.

Consider the following questions:

- What will I do to protect my profoundly autistic child (e.g., change environment, time-out, protective equipment)?
- What will I do to protect other people in the environment (e.g., tell siblings to go to their room or other safe space)?
- What will I do to protect myself (e.g., tie hair back, put on protective arm guards)?
- What do I need to do to protect my home and immediate environment (e.g., put up temporary pads in areas, use blocking pads to protect child as well as the wall or table)?
- At what point do I call 911 (e.g., when I feel my child, or another person is in imminent danger.).

My Safety Plan

1. ______________________________________
2. ______________________________________
3. ______________________________________
4. ______________________________________
5. ______________________________________
6. ______________________________________

APPENDIX E] TOILET TRAINING DATA SHEET

DIRECTIONS: Collect data every time you take your child to the toilet. Circle whether they are dry or not, the result (**U** – urine, **BM** – bowel movement), and if the toilet visit was self-initiated.

Date	Time	Dry?	Result	Self-Initiated
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N
		Y N	U BM	Y N

APPENDIX F] SAFETY INFORMATION SHEET

Name of Child (and any nicknames):

Date completed:

PLACE CHILD'S PHOTO HERE

Date of Birth	Height	Weight	Eye Color	Hair Color

Diagnoses:

Medical conditions:

Current medication(s) & dosage:

Address:

Method of communication:

Identification worn (tracking device, ID card, jewelry):

Inclination of wandering behavior:

Favorite location(s) where child may wander to:

Characteristics that may attract attention:

Challenging behavior(s) that may occur:

Likes and dislikes (approach and de-escalation techniques):

Parent / Caregiver Information	Emergency Contact Infromation	Medical Care Provider Information
Name:	Name:	Name:
Address:	Address:	Address:
Phone:	Phone:	Phone:

APPENDIX G] ELOPEMENT LOG

DIRECTIONS: Gather information about what occurred right before your child eloped/attempted to elope, who was there, what sensory triggers were present and, if possible, where they were trying to go.

Date & Time	Who was present?	What happened right before?	Elopement event	What happened right after the elopement event? For example, do you know where the child was going? Were they trying to avoid something or get to something specific?

APPENDIX H] CHANGES IN SEVERITY OF BEHAVIOR DATA SHEET

DIRECTIONS: Fill in below the behavior(s) that is being targeted by the medication (e.g., physical aggression, verbal aggression, crying/tearfulness). Observe your child's behavior across the day and at the end of the day, circle the number that best matches the severity of each behavior from 1 (not severe) to 5 (extremely severe). Try to complete the sheet at the same time each day.

Date:							
Behavior:	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1
Behavior:	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1
Behavior:	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1
Behavior:	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1
Behavior:	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1
Behavior:	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1	5 4 3 2 1

APPENDIX I] MEDICATIONS SIDE EFFECTS DATA LOG

DIRECTIONS: For each side effect (e.g., lethargy, decreased appetite, constipation, etc), write the number that best describes whether it occurred or not. You can obtain information about common side effects to watch for from the prescriber, pharmacy, or the drug company website.

SCORING:

0 = No Occurrence
1 = Little Occurrence
2 = Some Occurrence
3 = Severe Occurrence

Date:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					
Side Effect:					

Glossary of Terms

A

ABC Observation: A direct observation that is typically conducted in the natural environment where the observer records what happens before and after the target behavior occurs (A– Antecedent, B– Behavior, C– Consequence)

Acceptance and Commitment Therapy (*ACT*): A type of therapy that focuses on accepting the negative thoughts and feelings we naturally experience as human beings and committing to responding to difficult thoughts and feelings in a way that aligns with our personal values.

Antecedent: An event that precedes the target behavior.

Applied Behavior Analysis (*ABA*): A research-based therapy implemented to improve social skills, communication, and daily living skills and decrease challenging behavior.

Augmentative and Alternative Communication (*AAC*): The replacement or support of speech with visual input. AAC encompasses a spectrum of approaches and systems from no-tech to low-tech to high-tech.

B

Behavior Support Plan: A document that outlines strategies to help replace or reduce challenging behavior as well as specific steps used to promote the child's success and participation in daily activities.

Board Certified Behavior Analyst: A behavior analyst who is nationally certified by the Behavior Analysis Certification Board.

C

Chaining: An instructional strategy in which a task is broken down into smaller steps. Each step is taught separately within the sequence before moving onto the next step.

Consequence: What happens after the target behavior occurs.

E

Elopement: Wandering, bolting, or running away from a safe environment.

Evidence-Based Therapy: Intervention approach that is supported by research and scientific evidence that has gone through rigorous studies.

Expressive language: How we convey meaning through any medium such as speech, sign language, gestures, and visual symbols (such as writing).

F

Fading: The gradual removal of prompts.

Feeding Therapy: Feeding therapy is typically provided by a speech therapist and focuses on helping children who engage in partial or complete food refusal, frequent gagging, and spitting out food due to sensory sensitivities or medical complications.

Focused intervention: An intervention or therapy that targets a specific behavioral, educational, or medical need for an individual. The goal of this type of intervention is to improve an individual's functioning.

Full physical prompt/hand over hand prompting: A type of prompt that involves taking your hand and using it to move the individual's hands to teach a skill or achieve a goal. Example: Putting both your hands over your child's hands and moving them up and down to demonstrate how to play the drum.

Functional communication training (sometimes referred to as functional communication teaching): Teaching an individual to use a communication response (e.g. vocal, assistive technology, signing) to replace unwanted behavior.

G

Gestural prompt: Involves using a gesture such as pointing to encourage the action. Example: pointing to a desired item (e.g. child wants to play the drum and learns to point to it).

I

Individualized Education Plan (IEP): A legal document that outlines a student's educational needs, plans, and goals as well as services or support they are required to receive from their school district.

Intellectual disability: Neurodevelopmental disorder that begins in childhood and is characterized by intellectual difficulties in conceptual, social, and practical areas of living (DSM-5).

Interoception: Internal body sensory system. It allows us to process sensations from internal organs such as when we feel hungry or have the urge to use the bathroom.

M

Mand: A demand or request to express needs and wants.

Modeling prompt: Involves demonstrating how to do the action for someone to imitate (e.g. hitting the drum with your own hands).

P

Partial physical prompt: Involves putting your hand on an individual's arm or elbow as a guide. Example: You put your hand behind your child's elbow and help guide them through the same up and down motion of playing the drum.

Pica: The repeated ingestion of nonfood items (e.g., paper, soap, rocks).

Picture Exchange Communication Systems (PECS): A communication system that promotes communication using pictural representations.

Preference Assessment: An assessment used to identify items that a person might prefer over other items, these items may then be used as reinforcers. This can be done as easily as holding up two items and let the child choose the one they want. This could also be done in other formats such as using pictures, spreading out an array of items, or offering one at a time and seeing how long the child interacts with the item to get a list of items from least to most preferred.

Profound Autism: A profoundly autistic person has a diagnosis of autism spectrum disorder (ASD), requires lifelong 24-hour care, has a significant intellectual disability, and is non-verbal or minimally verbal.

Proprioception sensory system: Sense of muscle and joint movement. The proprioception system is triggered when we exert force (e.g., running, jumping, pushing).

R

Receptive language: How we understand and comprehend language.

Reinforcement: A process that increases the likelihood of a behavior occurring again (e.g., providing praise after your child puts toys away).

Rumination: The deliberate regurgitation, chewing, and swallowing of stomach contents.

S

Self-injurious behavior (SIB): Any behavior that results in physical harm to one's own body.

Shaping: A teaching technique that uses reinforcement to gradually teach new skills or modify existing behaviors.

T

Target behavior: The behavior you are trying to change.

V

Verbal prompt: Involves saying what you would like another person to do (e.g. “play the drum”).

Visual schedule: A list that uses cues (e.g., pictures, symbols, words) that represent a sequence of tasks or activities.

Vestibular sensory system: Sense of balance and spatial awareness.

List of Contributors

Lauren Cyd Solotar, Ph.D., ABPP, President and Chief Executive Officer

Dr. Solotar is May Institute's President and CEO and holds a joint appointment as President of the National Autism Center. She is a licensed psychologist with close to 40 years of experience. Dr. Solotar is responsible for all aspects of both organizations and management of May Institute's senior leadership team. She also oversees May Institute's expansion to improve life outcomes for autistic individuals throughout the world. Dr. Solotar served as a senior advisor on this project.

Debra Blair, MBA, CMA, CPA, Chief Operating Officer

Ms. Blair holds a joint appointment as Chief Operating Officer for May Institute and the National Autism Center. She has more than 25 years of experience in nonprofit finance and operations, serving educational, healthcare, and human services organizations in various capacities. Ms. Blair served as a senior advisor for this project.

Cynthia Anderson, Ph.D., BCBA-D

Dr. Anderson was the Director of the National Autism Center from 2016 until 2024. Her research focused on the development and evaluation of interventions for children with or at risk for developmental disabilities and functional behavior assessments and function-based support, multi-tiered interventions within school settings; and factors necessary for high fidelity and sustained implementation of evidence-based practice. Dr. Anderson is currently the Chief Clinical Officer of Avela Health.

Karie DePaolo, Ph.D., BCBA-D, Assistant Director of the National Autism Center

Dr. DePaolo has more than 10 years of experience in early childhood education, and has provided behavior analytic services across school, home, and community settings. Dr. DePaolo's responsibilities include the development of the National Autism Center's webinar library and trainings for the Pathways for Parents virtual series, training teachers to implement evidence-based practices in their classrooms and developing continuing education events for behavior analysts.

Jenna Gilder, Ph.D., BCBA, LABA, Director of Clinical Services and Training

Dr. Gilder provides clinical support and training to the Day Habilitation and Residential programs across Adult Services at May Institute. Dr. Gilder develops and conducts trainings to meet the ongoing clinical needs of the individual clients and the programs.

Willow Hozella, Ph.D., BCBA, LABA, Divisional Director of Clinical Services and Training

Dr. Hozella is responsible for the overall delivery and integration of behavior analytic services into learning and behavioral programming within every program setting at May Institute. This includes supervising and coaching to support the development and implementation of universal and individual programming within an Applied Behavior Analytic (ABA) framework.

Rose Morlino, Ph.D., BCBA, Research Scientist

As a Research Scientist at May Institute, Dr. Morlino conducts school-based research, funded by the Institute of Education to support educators who work with autistic children. Her responsibilities include recruitment and implementation of research protocols.

Allie E. Rader Ph.D., BCBA-D, LABA, Executive Director, May Center School for Autism and Developmental Disabilities

As Executive Director of the Wilmington School, Dr. Radar leads a of team of teachers and administrators in the daily operations and clinical services in the school. Dr. Rader also serves as the co-chair of May Institute's Research Steering Committee.

Abigail Rix, MA, BCBA, LABA, Senior Program Director

Ms. Rix is the Senior Program Director for both the May Center for ABA Services and the May Center for Early Intervention in Western Massachusetts. She has been working in the field of applied behavior analysis (ABA) for over seven years. She has been working with children both with and without developmental disabilities for over 10 years.

Paul Simeone, Ph.D., CCC-SLP, ATP, Vice President of Allied Health and Supportive Technology
Dr. Simeone is responsible for overseeing Allied Health and Supportive Technology services across the organization. A specialist in assistive technology (AT) and augmentative and alternative communication (AAC) for people of all ages and abilities, Dr. Simeone has 17 years of experience in multiple settings at the individual and organizational level.

Jennifer Zarcone, Ph.D., BCBA-D, Former Chief Clinical Officer & Director of the National Autism Center
Dr. Zarcone oversaw the organization's Clinical Leadership mission which is responsible for developing, implementing, and leading clinical initiatives as well as setting standards and establishing indicators for excellence in service delivery, behavioral support, training, and research. She also held a joint appointment as the Director of the National Autism Center at May Institute.

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