

Profound Autism: A PARENT'S GUIDE



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

National
AutismCenterSM
at
MayInstitute

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FOR A LIFETIME OF LEARNING

National Autism Center at May Institute | Randolph, Massachusetts



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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.

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

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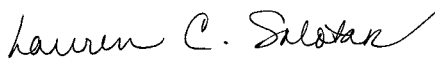
Creating this guide was a collaborative effort and we are deeply grateful to everyone who contributed their time, insights, writing, and research.

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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.

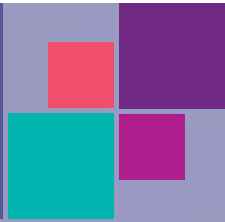


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Navigating Challenging Behavior

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.

M 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: <i>Kicking</i>	+++ +++ 	+++		+++			
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	<ul style="list-style-type: none">■ Conversation■ Hugs
Items	<ul style="list-style-type: none">■ iPad■ Snacks
Escape	<ul style="list-style-type: none">■ Loud Noises■ Hard Work
Sensory	<ul style="list-style-type: none">■ Rocking■ Twisting Hair

FILL IN YOUR CHILD'S WANTS AND NEEDS

Attention	<ul style="list-style-type: none">■ _____■ _____
Items	<ul style="list-style-type: none">■ _____■ _____
Escape	<ul style="list-style-type: none">■ _____■ _____
Sensory	<ul style="list-style-type: none">■ _____■ _____

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.

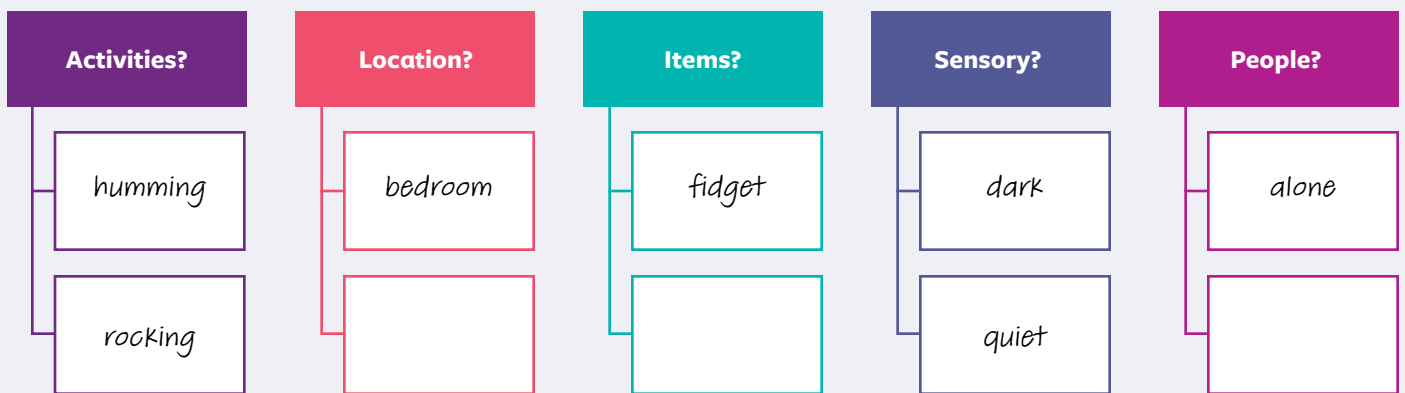
Finally, remember not to skimp on the paycheck for your child's hard work in practice! Make sure that you give tons of praise and access to good things to make practice worth it. Just like most people wouldn't go to work every day without getting paid, we can't expect kids to work hard for free.

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



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

Activities?	Location?	Items?	Sensory?	People?
<div style="border: 1px solid purple; height: 50px; width: 100%;"></div>	<div style="border: 1px solid red; height: 50px; width: 100%;"></div>	<div style="border: 1px solid teal; height: 50px; width: 100%;"></div>	<div style="border: 1px solid darkblue; height: 50px; width: 100%;"></div>	<div style="border: 1px solid magenta; height: 50px; width: 100%;"></div>
<div style="border: 1px solid purple; height: 50px; width: 100%;"></div>	<div style="border: 1px solid red; height: 50px; width: 100%;"></div>	<div style="border: 1px solid teal; height: 50px; width: 100%;"></div>	<div style="border: 1px solid darkblue; height: 50px; width: 100%;"></div>	<div style="border: 1px solid magenta; height: 50px; width: 100%;"></div>

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

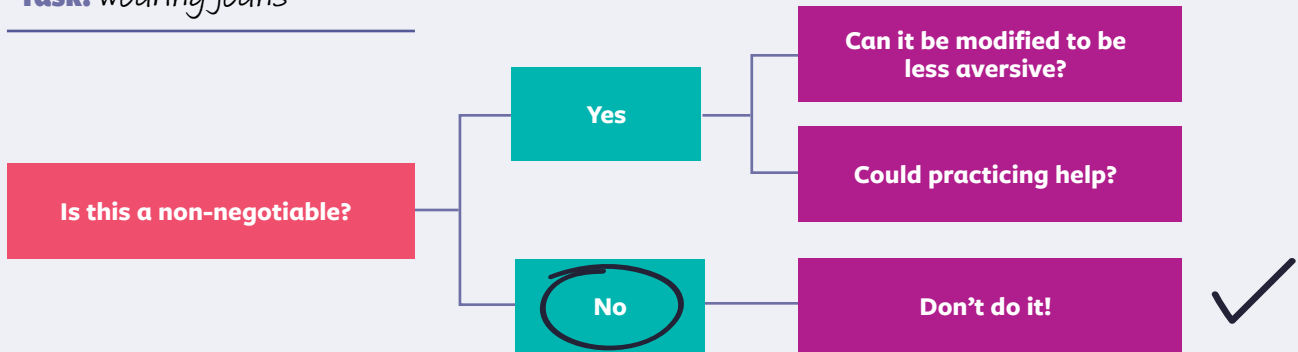
As noted above, it is important to do some self-evaluation of what you hope to achieve for you and your family. You might find that some challenging behaviors can be avoided simply by re-evaluating your expectations and focusing on your top priorities (Byrne et al., 2021).

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.

Task: *wearing jeans*



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

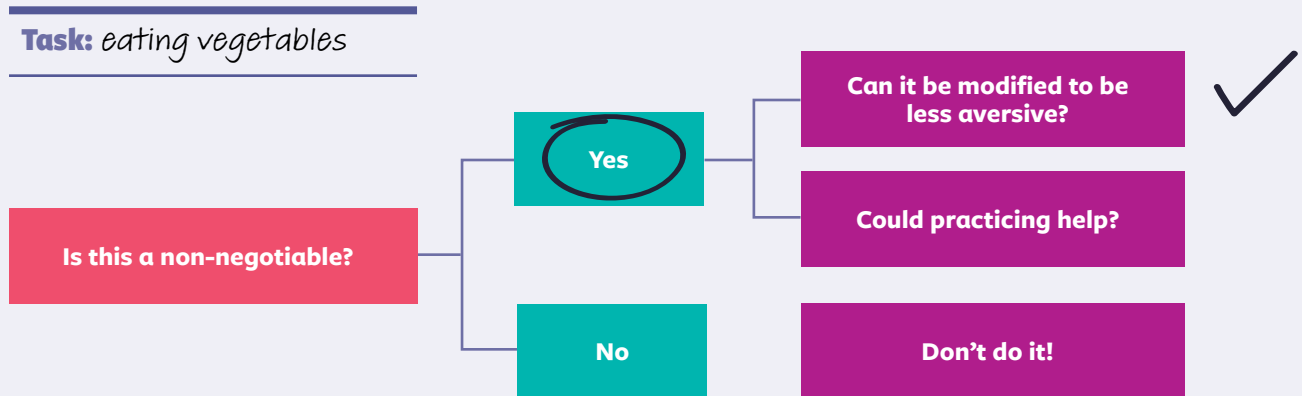
Unfortunately, endeavoring to complete these is sometimes at odds with the greater goals you hope to help your child achieve. There can be tradeoffs between short-term avoidance of challenging behaviors and long-term effects on health and well-being. For example, while your child needs to eat a balanced 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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