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Autism Parenting Magazine

ISSUE 193

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EMOTIONAL REGULATION: SUPPORT WITHOUT STRUGGLE

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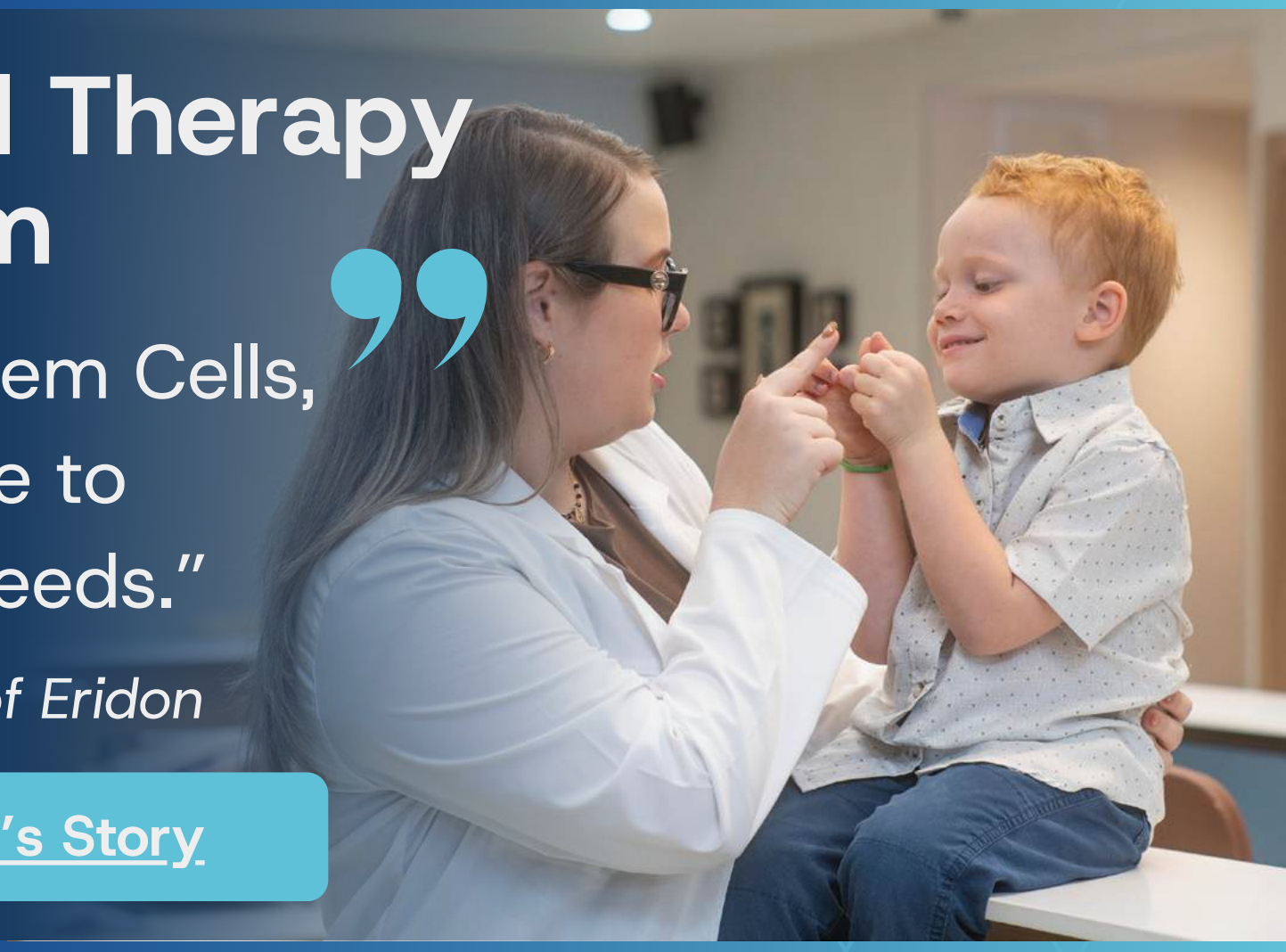

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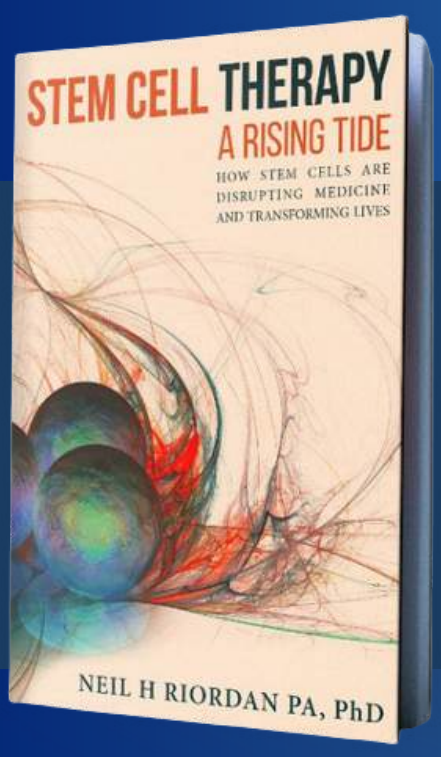

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Editor’s Letter

Dear Readers,

As the temperature rises in July, so can some people's emotions. Feeling hot, sticky, or uncomfortable can be challenging. The loss of a school routine can bring uncertainty or boredom. For children and their parents on the spectrum, those rising and falling emotions can be like a rollercoaster, but without the thrill.

Our theme this month is “Emotional Regulation: Support Without Struggle”. Supporting a child, teen, or adult with autism comes with an array of challenges. We cover many topics that should help bring down the heat, along with strategies and examples from lived experience for loved ones of all ages.

As you and your family work toward regulating the many emotions you may be experiencing, take time for some fun and festivities. While the temperatures may be uncomfortable and oppressive, remember that a diamond is created with heat and pressure. Help your diamonds sparkle, but don’t forget to cool off in the pool or air conditioning!

Happy reading!

Sharon Longo

Editor
Autism Parenting Magazine

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An award-winning publication on a mission to improve the quality of life for families impacted by autism worldwide.

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Reducing Meltdowns with Mindset Shifts

By Lisa Candera, Esq., CLC

Here are ways parents can change how they view and approach meltdowns.

Some parenting moments just get seared into your memory: the first time you hold your kid or see them take their first steps. Or, the first time you football-hold your child out of a birthday party while they kick and scream.

When this happened, I felt more than mortified. I was frustrated. I had done everything I could leading up to the event: I prepped my son, packed his favorite snacks, and built in breaks.

Yet, when the overload hit, we were the family making a loud exit, again.

That was thirteen years ago, and I spent most of the years that followed believing moments like that meant I was failing. If I just tried harder, planned better, and anticipated more, I could prevent meltdowns.

I was wrong. The problem was never that I wasn't doing enough. The problem was that I was focused on the wrong things.

I see this pattern all the time. We pour so much energy into researching, planning, accommodating, and staying one step ahead of every possible trigger. Then a meltdown happens anyway, and the question immediately becomes, "What did I do wrong?"

That cycle is exhausting. It also keeps you focused on the wrong thing. Here are three mindset shifts that can change the game.

Meltdowns are neurological

Every autism parent must have this foundational understanding to make sense of meltdowns in the first place. There is a lot of confusion around them, and that makes sense.

From the outside, tantrums and meltdowns can look almost identical: screaming, hitting, dropping to the floor, throwing things. The difference is what is driving the behavior.

While tantrums are goal-directed (a child trying to get or avoid something), meltdowns result from an overloaded nervous system. As a result, if you treat a meltdown like a behavior problem and respond with traditional discipline or old-school parenting, you will usually make it worse.

Instead of addressing the dysregulation driving the meltdown, you add to it with your words, your tone, and the pressure of consequences.

Once you understand the behavior as overwhelm rather than defiance, your job shifts. You stop trying to turn every behavior into a teachable moment and start focusing on bringing the temperature down.

Meltdowns will happen

Meltdowns will happen. Does that mean you throw in the towel and let the behaviors ride? Absolutely not. Everything you do to understand your child's triggers, preview transitions, or notice early signs of dysregulation is important. The problem is making prevention the goal.

> If you treat a meltdown like a behavior problem and respond with traditional discipline or old-school parenting, you will usually make it worse.

Autism can affect communication, sensory processing, executive functioning, impulse control, emotional regulation, and other areas, which can leave a child more vulnerable to nervous system overload and meltdowns.

That means you can do a lot right and still end up with a meltdown. Your child is not choosing it, and you are not causing it.

The real problem with the prevention mindset is what happens to you when a meltdown happens anyway. Every meltdown starts to feel like proof you missed something. You start asking, "What did I do wrong? What did I miss? Why is this happening again?"

Meanwhile, the meltdown is already underway, and your child can feel your panic, urgency, and frustration.

By contrast, when you accept that meltdowns will happen, you can pivot more seamlessly from "What did I miss?" to "What do I do now?" when things go sideways.

Control yourself, not your child

Most parents go into a meltdown trying to manage the child: stop the behavior, contain it, and get back to normal fast. But the harder you try to stop the behavior and control your child, the worse it usually gets.

Why? More words, more intervention, more intensity is like adding fuel to a fire.

The better question is: How do I support regulation?

Instead of trying to stop the meltdown, you focus on what is still in your control: your breathing, tone, words, and the pressure you bring into the moment. In other words, you become the anchoring force in the room.

The result: your child has less to react to because you are calmer, your presence feels safer, and you are no longer adding fuel to the fire.

What these shifts actually change

These mindset shifts will not make meltdowns disappear, but they can absolutely reduce their frequency and intensity.

First, parents must understand what is happening and stop making prevention the goal. You can learn how to regulate yourself in the moment and stop adding pressure to an already overloaded nervous system.

Then, you can have a clearer, more effective way to reduce meltdowns and respond with confidence.

> “Instead of trying to stop the meltdown, you focus on what is still in your control: your breathing, tone, words, and the pressure you bring into the moment. In other words, you become the anchoring force in the room.”

Lisa Candera, Esq., CLC, is a single mom to a young adult with severe autism and OCD, a practicing attorney, and a life coach for autism moms. She founded The Autism Mom Coach as the answer to the question she asked herself during her son’s most volatile years of acute aggression, school crises, and hospitalizations: “How do I stay steady and grounded when my child is constantly melting down?”

The answer became the foundation of her coaching program, in which she teaches autism moms to regulate first so they can respond with steadiness and lead with confidence.

Lisa hosts The Autism Mom Podcast, has contributed articles to Autism Parenting Magazine, and is a presenter on parental self-care, emotional regulation, and meltdown de-escalation strategies for Autism Services and Resources, Connecticut.

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Understanding the ‘Why’ Behind Behaviors

By Dr. Brett J. Novick, MS, EdD, LMFT

Understanding their child’s behavior can help parents strengthen the parent-child connection.

An autism “label” might suggest traits and characteristics, but it doesn’t provide the reason behind certain behaviors.

Why behavior happens

All behaviors occur for a reason and to meet an unmet need. We might not realize how a child’s behavior relates to what they are trying to fulfill. Behavior is a form of communication just as much as spoken words.

What is our child trying to communicate through their behavior?

Generally, our children’s behavior is influenced by multiple potential motivators.

Escape and avoidance

One purpose of behaviors is to avoid or escape a real or imagined situation. For example, a child might throw a temper tantrum to skip going to sleep at a set time when they are involved in an activity they enjoy.

Attention-seeking

Often, a child seeks more attention through negative behaviors because they yield a bigger response. In a class where all students are sitting quietly and working correctly, one child gets no more attention than anyone else. If they scream,

cry, or flip a desk, they will quickly and effectively draw everyone's attention and focus.

For a desired reward

When a child wants access to an activity or item, they may show certain behaviors. These might be negative ways of trying to get what they want. For instance, if a child receives a candy bar each time they throw a tantrum at the store to avoid public embarrassment, they will probably repeat that behavior to get the reward again.

Sensory input

If a behavior provides relief from sensory overload, a person might seek this input to feel more regulated and balanced. This could include actions such as making loud noises to drown out other irritating sensory stimuli, engaging in repetitive behaviors, or seeking touch.

Common underlying causes

Certain behaviors occur for various reasons:

Avoidance of sensory stimuli

Glaring lights, loud sounds, or annoying textures may lead to covering the ears or eyes, or refusing certain clothing or foods.

Lack of sensory stimuli

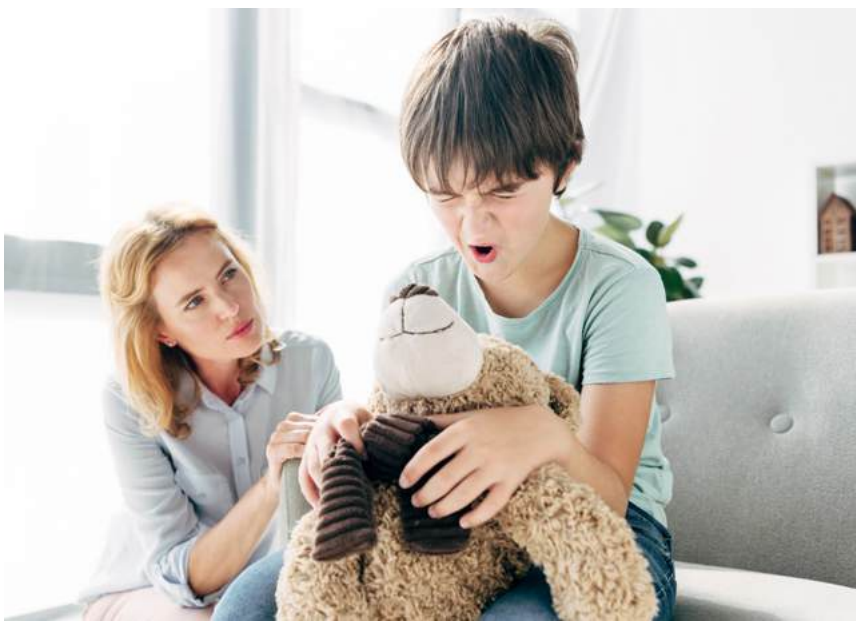
When an individual has too little stimulation, they may attempt to self-stimulate by spinning, rocking, chewing on objects, etc.

Anxiety or fear-based

Tantrums, repeated questioning, or refusal to participate in an activity may stem from fear or anticipation of the activity.

Frustration or dysregulation

After a day of "holding it all together" at school, a tantrum at home may be a way to relieve the pressure from the day's events.



Change in routine

Children associate predictability with safety. When a routine change occurs, it can lead to anxiety or frustration.

Difficulty with expressive or receptive language

Frustration from challenges in understanding or expressing oneself can lead to reliance on behaviors to communicate needs.

Strategies for understanding and supporting

Dealing with constant behaviors can test the patience of the most well-meaning parent or family member. However, the behaviors serve as an alternative form of communication.

As infants, our children communicated by crying. We had to determine if it was hunger, a dirty diaper, or illness. Similarly, these behaviors convey a message. The question is, what message?

When observing behaviors, consider the following:

Observe first, then ask why

When we first observe behaviors, we might respond more reactively than rationally. This can only worsen the situation. Be aware of your own thoughts and feelings about the problem and why it has caused you to act emotionally.

Ask questions

Asking questions can help uncover the root causes of behavior. Is there a pattern? What is your child trying to communicate? Are they motivated to do something or avoid it?

Ask better questions

Rather than asking questions like, "What is the matter?", ask, "What is happening to cause this specific behavior?"

Focus on strengths

Look past the perceived negative behavior. Concentrate on the child's potential positive qualities whenever possible.

Observing and identifying behavior patterns

When analyzing behaviors and patterns, try these techniques:

- **"A-B-C" technique:** When analyzing behaviors and patterns, remember the A, B, C's. The **A**ntecedent is what happened right before the behavior occurred. The **B**ehavior is what your child did as a result. The **C**onsequence is whether your child reached their goal or avoided something they didn't want to do.

- **Take a "S-E-A-T":** After identifying the antecedent, behavior, and consequence of a specific behavior, choose one of four possible functions for the behavior.

  Sensory: the behavior was done because it either felt pleasant or to relieve something that did not feel good.

  Escape: the objective is to escape from a person, situation, or task that one did not want to do or found unpleasant.

  Attention: the goal is to gain attention or leave a scenario that offers too much attention.

  Tangible: the primary notion in this pattern of behavior is to get some object or do a preferred activity.

> "Rather than asking questions like, 'What is the matter?', ask, 'What is happening to cause this specific behavior?'"

Use of visual supports, routines, and calming strategies

These strategies can also be helpful:

- **Visual or pictorial schedule:** Helps the individual know what to expect throughout the day and understand their routine. It creates predictability, thereby reducing anxiety about the unknown.

- **First-then charts:** Show that if a person does the unpreferred activity, it will lead to the desired activity.

- **Consistency:** The more predictable the routines, the less anxiety arises. Repetitive schedules and activities foster trust.

- **Use of manipulatives:** Sometimes, manipulatives such as a fidget spinner can help achieve the necessary calm**.**

- **Removal from sensory stimuli:** Moving from overly stimulating situations due to sight, noise, or crowds to a calmer environment can be very beneficial.

- **A calming space:** Providing an area in a classroom or home containing soothing toys and tools offers a safe place to retreat and practice self-soothing and calming techniques.

- **"Grounding":** Shifts focus to the five senses, asking them to find five things they can see, four they can hear, etc.

Collaborating with professionals

It is always okay to ask for help, even after trying all the techniques to manage behaviors. Reach

out to mental health, educational, or medical professionals during your journey. Ask for recommendations and referrals to find quality providers who can address behaviors and offer suggestions for parental enrichment. You are not alone.

Knowing why for a stronger connection

Parenting involves managing many different areas at once, such as schedules, carpools, and medical appointments. When our children's behavior prevents us from checking items off our seemingly endless "to-do" list, it can be frustrating. We might also view these behaviors as intentional and manipulative.

Instead, we could view these behaviors as different ways to communicate needs, recognizing that our children are not trying to disrupt our routines but attempting to connect, ask for help, or both.

Doing so, we can work with our children toward a common goal rather than engage in conflict. We can view these behavioral episodes as teaching moments that prepare our children for the challenges society will present long after we are gone.

Our children are always watching and learning, mirroring our behaviors. Instead of reacting, we can model the empathy and patience we hope

they will someday adopt. This can be easier said than done, so take care of yourself to be at your best for them.

When you understand the why, you can better develop the how to address the behaviors your child may exhibit. The combination of both will lead to fewer behaviors, better understanding between you, and an even stronger parent-child bond.

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Dr. Brett J. Novick, MS, EdD, LMFT, holds a Master's degree in Family Therapy and post-degree certification in School Social Work and Educational Administration. He earned his EdD in Educational Leadership. He has worked as a school social worker and counselor for the last 23 years and is an adjunct instructor at two universities. Brett has also spent over 25 years as a licensed marriage and family therapist in private practice, community mental health, and substance abuse settings. He has supervised family and school counseling, centers for abused and neglected children and adults and children with developmental disabilities, and has been a licensed foster parent. He authored educational, self-help, and children's books and created therapeutic games for youth. He has also won numerous awards for his work in education.

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Q&A With Dr. Temple Grandin

This month, Dr. Temple Grandin answers parents' questions about an autism evaluation and hyperactivity.

Q

Linda of Chandler, Arizona, asks, "What would be the benefit of pursuing an evaluation for autism for a child (girl, age six in kindergarten) who tested gifted with an IQ of 130 at age five? She has an IEP for speech only and was evaluated at age three and diagnosed with ADHD. She has sensory challenges with clothing, food textures, and noises. She also has some extreme emotions that can last 20 to 30 minutes."

A

ADHD and autism get mixed up all the time because a lot of the behaviors and the genetic parts are the same. In most places in the United States, you need a diagnosis to get services.

In some places, you can have a two-year wait list, which is unacceptable for a young child. Then you've got to wonder, "Is insurance going to pay for this or not?" It's very expensive if they don't pay for it.

So this child is six years old and tested gifted with an IQ of 130 at age five, and they have an IEP for speech. If she is getting speech, that's good.

She might need an occupational therapist (OT) to work with her on sensory things. Given the sensory issues, much of what an OT does can be helpful: balancing activities, pressure, and swinging activities.

Q&A

In my book, “Autism and Adolescence,” I’ve got a lot of information on sensory issues. Even though it’s for adolescents, the principle is the same. Also, my book “The Way I See It” has sensory information.

I always ask, “Is the child improving?” That’s one of the most important things.

I’m not a big fan of loading up young kids with lots of medications. I’ve seen six-year-olds, and the doctor had them on six different medications. When I asked why they used each medication, it seemed like they were just writing prescriptions to control behavior. That’s bad.

What is this kid good at? Let’s build up the child’s skills. She’s gifted. Is she good at art, music, or mathematics?

Let’s take what she’s good at and build on those strengths. That might help her focus because then she’ll be interested in these things. There are also activities you can do with other people.

I’m a big proponent of developing strengths because, when the child grows up, they can turn those strengths into a career.

Also, is she getting enough exercise? My mother used to say, “Go outside and run the energy out.”

Then, when it comes to the people providing services, I can’t emphasize enough how important good teachers are. Some people just have the knack to work with these kids.

Is her speech improving? She has an IEP for speech, but is it improving? If it is, then you’re doing something right. It’s that simple. Sometimes these things get overthought.

> “My mother used to say, ‘Go outside and run the energy out.’”

Q Ravindra of India asks, “How do we control an autistic child with predominant signs of hyperactivity, such as running around aimlessly?”

A First, exercise. Also, the sensory integration techniques that the OTs do could be very helpful. There are simple activities, such as swinging, deep pressure, and balancing. Nail a board to the floor and walk the “tight rope” on it.

There’s also something called environmental enrichment, which is an effective treatment for autism. There is a paper called “Environmental Enrichment As An Effective Treatment for Autism.” It’s an add-on to other therapies.

What you do is you stimulate two senses at the same time. For instance, you might smell peppermint and hold a cold bottle, so you’re stimulating two senses.

You’re going across the senses, so it’s called cross-modal. You might be looking at one thing while smelling something else. There might be a lot of emphasis on touch and smell, and you’re always changing the pair of stimuli.

You might be listening to classical music while touching something warm or smelling something. They use about six different strong but pleasant odors, such as cinnamon, peppermint, or whatever the child likes.

I think it desensitizes the sensory, and it's been helpful. It is evidence-based and uses simple household items for about 15 minutes a day.

Also, get the child out doing things. When you go shopping, take them to the market and have them help you find what you need. Put all that activity to work.

Those are all things that might help.

Resource:

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Dr. Temple Grandin, PhD, is a Distinguished Professor of Animal Science at Colorado State University. Many companies around the world use facilities she has designed for handling livestock. She has also been instrumental in implementing animal welfare auditing programs used by McDonald's, Wendy's, Whole Foods, and other corporations. Temple has appeared on numerous TV shows, such as 20/20 and Prime Time. Her books include Thinking in Pictures, Livestock Handling and Transport, and The Autistic Brain. Her books, Animals in Translation and Visual Thinking, have been on the New York Times Bestseller List. Temple was inducted into the National Women's Hall of Fame in September 2017. In 2022, she was named a Colorado State University Distinguished Professor, and in 2023, she was inducted into the Colorado Authors' Hall of Fame.

Helping Your Teen Resist Peer Pressure

By **Carol Tatom Nentwig, BA.HSE, CHW**

When teens have tools for social skills, they build resilience.

The teenage years are difficult for any parent. When your child is on the autism spectrum, the social realm of high school can feel like an obstacle course. For many autistic teens, the desire to fit in is met with social processing challenges.

While their neurotypical peers might intuitively know when a "joke" is actually a manipulation, an ASD teen may miss those subtle cues. This can make them vulnerable to peer pressure. Understanding this social atmosphere is the first step in empowering them.

Understanding the ASD-peer pressure connection

To help our teens, we must understand why they are often targeted for social influence. It isn't a lack of intelligence; it's how their brains process social data differently.

- **Literal thinking:** If a peer says, "Everyone is doing this," an autistic teen may take that as a fact or non-negotiable rule of social conduct instead of an exaggeration used to persuade.

- **Theory of mind challenges:** The ability to understand that others have different perspectives, intentions, or motives. An ASD teen might struggle to realize that a "friend" has a hidden agenda or is trying to get them into trouble for a laugh.

- **Social cues and context:** A teen with autism might miss the subtle eye-roll or mocking tone that accompanies a suggestion. They may believe a situation is safe when it isn't.

- **Masking:** Many autistic teens spend their day "masking" or mimicking neurotypical behaviors to blend in. This constant effort to perform can cause "social exhaustion," making them more likely to agree to things to keep the peace or maintain the facade of belonging.

The desire for friendship often outweighs their internal warnings. After spending years feeling like an outsider, the promise of inclusion can be a powerful, and sometimes dangerous, motivator.

Recognizing the warning signs

Because social challenges can be internalized, peer pressure doesn't always look like a confrontation. It often shows up as subtle changes that differ from your teen's usual behavior. As a parent, you are the expert on your child's "normal." Watch for these red flags:

Shifts in their identity

Has your teen suddenly lost passion for a "special interest" (like trains, coding, or art) for something they previously disliked?

While some exploration is normal, if you notice a total personality change to match a specific group, this can indicate peer pressure.

Increased social anxiety

If your teen seems uncharacteristically stressed before school or "shuts down" after social interactions, they may be handling a high-pressure situation they don't know how to escape.

"Scripted" responses

When you ask about their day or their new friends, do they sound like they are reciting a script? This could be a sign they are being coached or are afraid of saying the "wrong" thing.

Uncharacteristic behavior

If you notice your teen engaging in risky behaviors, using new slang words that feel forced, or a sudden drop in their academic performance, this could indicate an outside influence.

Building resistance skills: the "social toolbox"

We can't be with our teens throughout the day, but we can give them a mental "toolbox" to use when we aren't there.

Role-playing and scripting

Abstract advice like "Just say no" is often too vague. Instead, practice specific scenarios. Use "If/Then" logic: "If someone asks you to skip class, then you say: 'I can't, I have a project due.'"

Having a pre-rehearsed script can reduce trying to think of what to say during a stressful moment.

Identifying core values

Work with your teen to identify what actually matters to them. If they value "honesty" or "being kind to animals," use those as anchors. Then, if a peer suggests something that violates a core value, it becomes a logical "error" in the teen's mind, making it easier to reject.

The "exit text" strategy

Create a "safe code" via text. If your teen is in an uncomfortable situation, they can text you a specific emoji or word (like "pizza"). This is your cue to call them and provide a "socially acceptable" excuse to leave: "Hey, I need you home right now for a family emergency (or chore)."

This saves face for the teen while ensuring their safety.

Assertiveness training

Teach the difference between being passive-aggressive and assertive.

Practice the "broken record" technique, calmly repeating the same refusal without offering new excuses for the peer to argue against.

Creating a supportive home environment

At home, help your teen develop and strengthen their sense of self-worth to resist negative peer pressure. If a teen feels truly accepted by their family, the potential rejection from peers doesn't carry the same weight.

> "High self-esteem is built when a teen feels their authentic self is valuable."

Here are some ways to support your teen:

- **Have open, non-judgmental communication:** Create a "no-consequence" zone for honesty. If your teen admits they tried something they shouldn't have because of a peer, focus on the why rather than the punishment. If they fear your reaction, they will hide the pressure they are under.

- **Celebrate the "uncool":** If your teen loves stuffed animals or vintage vacuum cleaners, celebrate that unique passion. High self-esteem is built when a teen feels their authentic self is valuable.

- **Use a strengths-based approach:** Focus on what they are good at. Are they incredibly logical? Great at spotting patterns? Use these strengths to help them "analyze" social situations the way they would solve a puzzle.

- **Establish clear family values:** When expectations regarding safety, substance use, and etiquette are clear and consistent, they provide a blueprint the teen can refer to when they are confused by peer behavior.

Ready to resist peer pressure

Understanding the social world with ASD might be challenging, but with the right guidance, your teen can find their way. Building social resilience is a gradual process.

Every time your teen makes a choice based on their own values rather than someone else's whims, they are strengthening their "independence muscle."

Helping Your ASD Teen Resist Peer Pressure

- **Prepare scripts:** Practice specific "If/Then" responses for common social pressures.
- **Maintain safety nets:** Use code words to provide an easy exit from uncomfortable situations.
- **Validate the struggle:** Acknowledge that wanting to fit in is natural, but staying safe is the priority.
- **Focus on autonomy:** Empower them to see their unique neurotype as a strength in making independent decisions.

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Before the Crisis: Planning for the Child Who Will Always Need You

By **Malkie Scher, Esq.**

Plan for your child's future with financial and legal decision-making documents long before they turn 18.

There are two types of phone calls I receive. The first kind is calm from parents who want to plan ahead. Their child is 8, 12, or 17 years old. They've heard about special needs trusts. They want to understand guardianship. They're thinking long term and want to be responsible.

The second kind of call is very different. It's from a hospital room or after a parent passes away. Or when a simple oversight has just disqualified a child from Medicaid. The sentence I hear most often is: "We didn't know. Why didn't anyone tell us before?"

As someone who works in special needs planning and guardianship, I can tell you with certainty that most crises I see are preventable.

The inheritance that hurts

Parents of children with special needs are usually extremely careful. They know their child can only have a limited amount of money in their name to qualify for government benefits like Medicaid or SSI. They work hard to keep assets out of their child's accounts.

What many families don't realize is this: If you don't leave clear legal instructions for when you pass away, your child will automatically inherit

from you. Not because you intended it. Not because you were careless. But because the law fills in the blanks when you don't.

When that inheritance goes directly into your child's name, it can immediately disqualify them from the very benefits they depend on for medical care, therapies, housing, and daily support.

Getting those benefits back can be exhausting. It can involve lengthy delays, paperwork battles, and navigating Medicaid and Social Security offices at a time when your family is already grieving. I see this happen far too often.

There's a common misconception that estate planning is for the wealthy. It's not.

Anyone with children needs a will.

If you have a child with special needs, you need a will and a properly structured supplemental needs trust. Both provide a legal loophole that allows you to leave them money without affecting their benefits. Not "someday," or "when things settle down," but now.

Planning is not about how much money you have. It's about protecting your child.

The day your child turns 18

Another moment families are often unprepared for is when their child turns 18. Legally, the law now assumes the child can make their own medical, financial, and personal decisions. For many young adults, that's perfectly appropriate.

For others, particularly individuals with more significant disabilities, it creates a serious gap. Suddenly, no one has the legal authority to step in and act on their behalf.

One of the most common questions I hear is: "Isn't it automatic that I can keep making my child's decisions? I'm the parent." The answer is no. Parental authority ends at 18. By the time many families realize this, they are already in crisis.

To continue making decisions, you need to seek guardianship, the legal process by which a court appoints someone, typically a parent, to continue making decisions for the child after age 18.

Here is an example: A worried father is frantic. His son, who just turned 18, is scheduled for open-heart surgery. Everything is prepped and ready to go.

As they bring him into the operating room, the doctor suddenly stops. After reviewing the chart, the doctor looks up and says, "I'm sorry. We cannot proceed without proper consent.

"Now that your child is legally an adult, you no longer have the authority to consent on his behalf. Because he cannot advocate for himself, you will need guardianship papers before we can move forward."

The father is stunned. Panicked, he calls my office and asks, "Can you get me guardianship by next week?"

Unfortunately, the answer is no. Guardianship is a court process that takes months to complete.

While I would like to say that this is an unusual situation, it is not. We receive calls like this regularly. Families mistakenly assume they have authority when they don't.

But there's one more critical question: When something happens to you, who steps in?

Naming standby or backup guardians ensures continuity. It ensures your child is never left in legal limbo.

When guardianship may not be the right fit

Not every individual needs full guardianship.

Some young adults are higher-functioning; they may be employed, manage certain aspects of their lives, and value their independence, while still relying on parental guidance and support.

In those situations, guardianship may not be appropriate or granted by the court.

Instead, parents should explore alternatives such as HIPAA authorizations, medical proxies, powers of attorney, and supported decision-making agreements. These tools allow you to assist your child while preserving their independence.

The key point is this: When your child turns 18, there must be a plan in place to ensure you can continue to protect and support them in a legally recognized way.

> Planning for a child with special needs is not about fear. It's about responsibility and taking action. It's about ensuring benefits remain intact.

Take action today

The most dangerous sentence I hear is: "We'll deal with it later." Later is unpredictable.

Life is already challenging when raising a child with special needs. Don't add unnecessary legal uncertainty. Don't leave decision-making authority or the inheritance structure to chance when they can be clearly established now.

Later can mean sudden illness. Later can mean an accident. Later can mean a hospital refusing to share information. Later can mean benefits being disrupted.

These are not dramatic hypotheticals. They are everyday realities in my practice.

Planning for a child with special needs is not about fear. It's about responsibility and taking action. It's about ensuring benefits remain intact. It's about ensuring trusted individuals have legal authority. It's about preventing avoidable emergencies.

Protect your child's future

Special needs planning, through a will and a well-structured supplemental needs trust, protects your child's financial future and ensures government benefits remain intact, regardless of age.

Guardianship, or other appropriate decision-making documents, protect your ability to continue caring for your child once they turn 18.

Put these in place now so that you stop worrying about “what if.” You stop second-guessing emergencies. You gain peace of mind knowing everything is in place and ready when you need it.

That calm is not automatic. It is the result of planning well today.

Malkie Scher, Esq., is a dedicated attorney who works at the Moskowitz Legal Group in Hewlett, NY. Her area of expertise is helping parents navigate legal matters pertaining to their loved ones with intellectual or developmental disabilities.

Malkie assists families in obtaining legal guardianship to ensure lifelong protection and advocacy for those who cannot manage their own affairs. Recognizing that long-term security is equally vital, she also specializes in creating Special Needs Trusts. These specialized tools are designed to enhance a beneficiary’s quality of life while carefully preserving their eligibility for essential government benefits.

Malkie’s deep commitment to this field is rooted in her previous experience as a Special Education attorney, where she fought for parents in tuition lawsuits against the NYC Department of Education. Her passion for this work began long before her legal career; for years, she has actively worked and volunteered with various organizations dedicated to supporting individuals with developmental disabilities.

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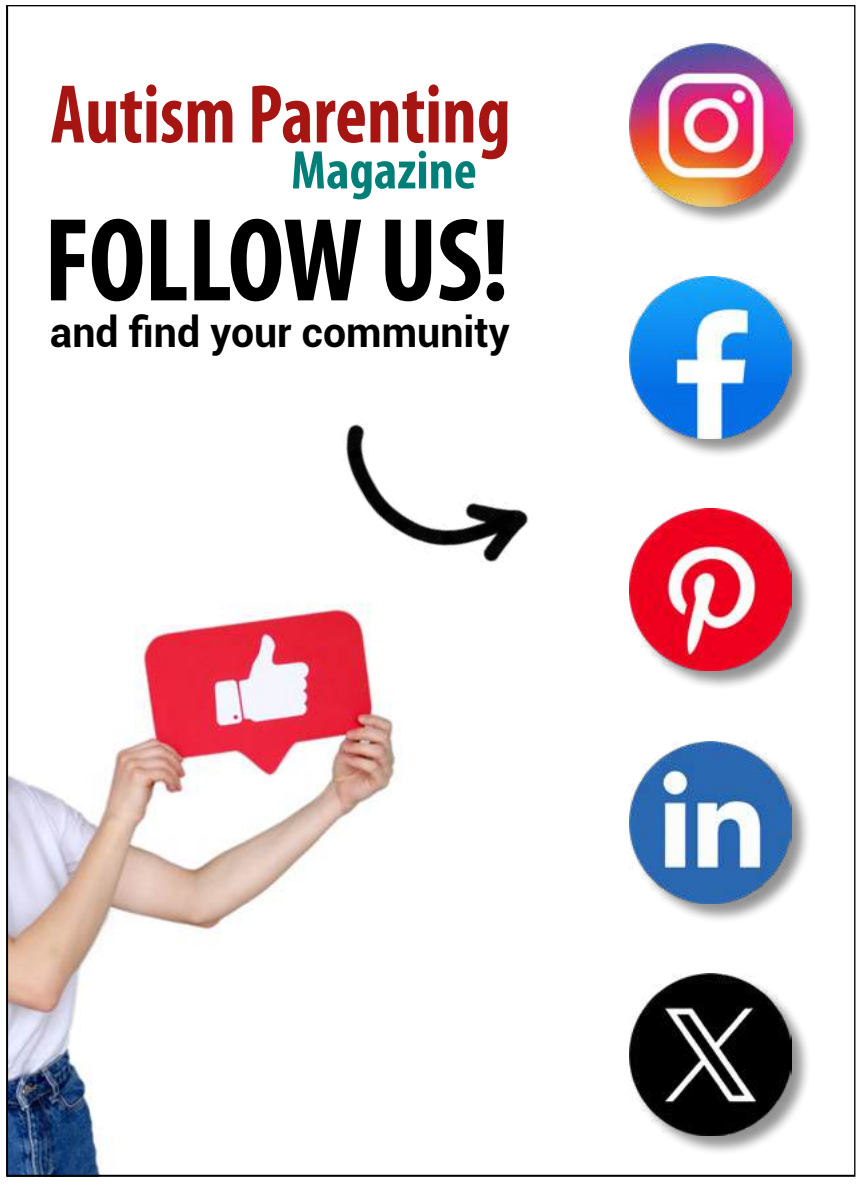


Success Story:
What I Learned Between Appointments

Danielle Romano shares her son's progress through biomedical care. Have a success story you want to share? Click here.

I am a mother of three, sharing our family's experience navigating autism, ADHD, and neurotypical development while affirming my son's neurodiversity.

I'm not offering medical advice or a promise for a certain outcome. I want to share the questions we asked and what resulted when we began listening to my son's body.

Most of our story happened between routine appointments, after pediatricians reassured us that things were "normal" and before the next referral arrived.

Like many families, we visited specialists who focused on a single body system, while my son lived in a body where everything was connected.

Allergies were treated separately from behavior; feeding challenges from neurology; and sensory distress from biology.

As parents, we were standing at the entrance of the woods without a compass.

I didn't set out to question the system. I was simply trying to understand my son.

He was a bright-eyed little boy who met every milestone on time, often early. He connected

deeply with me, and nothing felt out of the ordinary.

I was a working corporate parent alongside my husband. Together, we had a daughter, followed by fraternal twin boys, which felt like a family dream.

Our eldest showed early signs of ADHD, so we were familiar with evaluations and neurologists. By comparison, our twins appeared to be thriving.

Signs of concern

The first signs of concern emerged around food. As the boys transitioned to solids, one of my sons developed severe, plaque-like eczema that was a deep inflammation and covered much of his body.

Our pediatrician suspected a dairy allergy and referred us to an allergist. After skin testing came back negative, we were dismissed.

Shortly after, our long-time pediatrician retired, and we found ourselves starting over with a provider unfamiliar with our history.

Over the following months, we noticed a gradual change. There was a retreat from our son's eyes. His twin and his older sister played together, but he drifted away.

He ran back and forth repetitively, often carrying objects and fixating on light through the corner of his vision.

> "I remember looking at the neurologist and saying, bluntly, 'You realize now I can't die. I can't leave him in this world without me.'"

He stopped responding to his name.

Spinning behaviors emerged.

Sleep disappeared.

Night after night, I watched him pace his room on the baby monitor, repeating the same phrases until exhaustion finally overtook him. Sleepless nights became sleepless months.

At a breaking point, our new pediatrician suggested daycare, hoping stimulation might help. Two weeks later, I received a call that my son had slipped out of the classroom unnoticed and briefly left the building. He was unharmed.

When the state investigator asked to speak with him, I found myself saying aloud what I had been avoiding internally: he couldn't communicate.

Soon after, we secured a neurological evaluation. The diagnosis was autism.

After the diagnosis

I had promised myself I would remain composed. Both my husband and I had worked with autistic children previously.

I remember looking at the neurologist and saying, bluntly, "You realize now I can't die. I can't leave him in this world without me."

The doctor reassured us, reviewed therapy options, ordered extensive bloodwork, and recommended an IEP.

As we left the office and headed straight to the lab, our journey truly began.

The bloodwork results revealed significant immune responses to multiple common foods. At the same time, my son's diet had narrowed almost entirely to the foods contributing to inflammation.

Through research, I came across an approach I hadn't known existed: biomedical intervention. This approach looked at neurology, immunity, nutrition, and metabolism together.

Additional testing revealed biological stressors and infection that were contributing to his discomfort and intensifying his behavior.

Our goal was to reduce our son's physical distress so his body felt safer, not to erase his diagnosis.

Through the public school system, we pursued speech, ABA, and occupational therapy.

Under biomedical care, we addressed allergies, supported gut and metabolic function, and treated infection and inflammation through dietary changes.

The process was slow, variable, and at times exhausting. Feeding became restrictive, and progress required patience.

Yet, gradually, his skin healed, and the dark circles under his eyes faded. Eye contact returned. Words began to emerge, first intentionally, then spontaneously. His ability to engage, focus, and participate increased as he became more comfortable.

Ten months later, his teachers described a child with comprehension, awareness, and emerging conversation. His report card showed mastery in areas we once feared were out of reach.

At home one day, he tugged on my shirt, looked directly into my eyes, placed his hand on his chest, and said his name.

We are still in the woods, but now we have a compass.

I'm not sure where my son's path will ultimately lead, but I no longer need to know.

I do know that parents deserve to ask questions, follow patterns, and advocate for care that treats their child holistically.

Sometimes the path forward doesn't begin with answers. Sometimes it begins with the courage to trust what you're seeing in the space between appointments.

Safeguard a loved one!

Have you ever wondered what could happen if a family member with autism were to answer the front door of your home and be confronted by a member or members of law enforcement?

Intended to lessen the possibility of a negative outcome when a person with autism has an unplanned or unusual encounter with strangers, a symbol/sign has been created by SzantorDesigns.

Available either as a vinyl decal or as an aluminum plaque, these communication devices are easy to install on glass or other smooth, flat surfaces as well as on typical construction materials that may be adjacent to your home's front door.

For more information, please visit:
www.etsy.com/shop/SzantorDesigns

Navigating Meaningful Conversations

By **Maggie McGarvie, SLP**

How can parents create trust and connection that leads to true conversation?

Many parents of autistic children long for deeper conversations. They want to know what their child is thinking, feeling, or dreaming about, but they aren't always sure how to begin.

Traditional ideas of conversation often center on back-and-forth verbal exchanges, quick responses, and eye contact. When those expectations aren't met, parents may worry that connection is out of reach.

Meaningful conversations don't need to look neurotypical to be real. Connection isn't forced communication; it's validating your child, loving them, and building trust over time.

Start with what matters

One way to engage in meaningful conversation with your child is to begin with what already matters to them. Stimming, special interests, routines, and sensory preferences can lead to connection.

If your child loves video games, elevators, maps, animals, or a specific TV show, those interests can become shared language. You might ask open-ended questions like, "What do you like most about this animal or game?" or "Can you show me how this works?"

It's just as important to accept that yes-or-no answers, gestures, or showing rather than telling may feel more comfortable, and that's okay. Even if a child is just letting you into their space or play, that is the first step.

Let your child teach you, and be willing to learn. Watch the videos they love. Listen to the same facts repeated again and again. Participate without rushing to redirect or expand the topic.

When children feel their interests are respected and enjoyed rather than tolerated, they're more likely to invite others into their world.

It's also important to respect your child when they choose not to talk. Communication is not an obligation. Honoring their "not now" builds trust and can lead to future connection.

Sometimes the most meaningful message you send is: "I value you even when you're quiet and love you even if we don't communicate the same way."

Create low-pressure communication environments

For many autistic children, sensory overload makes conversation difficult, even when they want to connect. Bright lights, loud noises, crowded spaces, or emotional stress can drain the energy needed for communication.

Before initiating a conversation, consider the environment. Is the space calm? Are sensory needs supported? Communication comes more easily when a child feels regulated.

Low-pressure settings often work best. Side-by-side conversations during car rides, walks, or quiet activities allow children to talk (or not) without feeling watched or evaluated.

Alternatives to spoken conversation are just as valid. Drawing, texting, typing, using AAC, sharing memes, or pointing to visuals can all be meaningful ways to connect. The goal shouldn't be **how** the message is shared, but that your child feels safe sharing it.

Tools that help

Parents often ask, "What should I say?" There is no single right answer, but there are practical strategies to support autistic communication.

- Use clear, concrete language.
- Avoid broad questions. Instead of "Tell me about your day," (which can feel overwhelming), try, "What was one thing you liked today?" or "Did you go to the gym today?"
- Give time to respond. Silence doesn't mean disinterest. Count to ten in your head before repeating or rephrasing a question. That pause can make all the difference.
- Offer choices to give control and reduce pressure. "Would you like to talk about school or your trucks right now?"
- Use visual supports to help children organize their thoughts and reduce anxiety. (A feelings chart, a written list of topics, or pictures that support understanding.)

- Avoid rapid-fire follow-up questions. Multiple questions in a row can feel like an interrogation. One thoughtful prompt is often enough. Try to give more wait time and stop asking so many questions!

- Use parallel talk. Describe what your child is doing without expecting an answer. “You’re lining up the cars by color.” This can make communication feel more natural and less pressured.

Respecting boundaries and communication differences

Parents need to recognize that silence is communication. Not speaking can mean your child is thinking, tired, uncomfortable, or just content.

Consent matters in conversations, just as it does in other areas of life. Asking, “Is now a good time to talk?” or “Do you want company or space?” teaches children that their boundaries are respected.

Common challenges, such as shutdowns, scripting or echolalia, and sudden transitions, are often misunderstood.

Shutdowns are a nervous system response, not defiance.

Scripts and echolalia are meaningful communication tools, not meaningless repetition.

Difficulty with sudden transitions is often related to shifting attention, not rudeness.

When parents view these moments as communication styles rather than problems, interactions become more compassionate and effective.

Celebrate small wins. A shared glance, a typed sentence, a repeated script used in a new way, or simply sitting together comfortably are all meaningful steps toward connection.

> “Parents need to recognize that silence is communication. Not speaking can mean your child is thinking, tired, uncomfortable, or just content.”

More meaningful conversations are possible

Meaningful conversations with your autistic child are absolutely possible, even if they don’t look like traditional dialogue.

When parents focus on connection over compliance and curiosity over control, relationships deepen naturally.

By honoring your child’s pace, preferences, and communication style, you create space for trust to grow. From that trust, real conversation can emerge in its own time and its own beautiful way.

Maggie McGarvie, SLP, is a neurodiversity-affirming pediatric speech-language pathologist with 16 years of experience specializing in helping families connect and understand their autistic child(ren). She shares insights on sensory needs, language, play, and behavior on her YouTube channel to help families who feel lost.

https://www.instagram.com/yourathomeslp/

https://www.youtube.com/@YourAtHomeSLP/playlists

Creating a Supportive Space for Meaningful Play

By **Teresa L. Boggs, PhD, CCC-SLP**

Creating an intentional play space can positively impact a child's play and engagement.

Darting from room to room, a child dumps out toy bins without choosing any one activity. He lines up blocks without building. He starts a puzzle but doesn't place a piece.

Play feels chaotic and short-lived, and nothing seems to hold his attention.

For many families raising a child with autism, encouraging meaningful play feels overwhelming. Yet, there are practical ways to help at home.

Why the home environment matters

I conducted a home study to see how changes in space and toy access affected engagement and challenging behaviors.

One child who rarely stayed with a toy began stacking blocks and playing for longer stretches.

Another child, who often wandered during play, became more engaged when activities took place in a more structured space. The parents described feeling in control, confident, and connected.

This simple tent setup becomes a favorite retreat for a child needing a break.

These small environment changes involve simple tools most families already have.

For children with autism, a space's setup can impact how they play, interact, and regulate their emotions. Overwhelming environments with cluttered toys, unclear boundaries, or unpredictable sensory input can lead to distress or disengagement.

Supporting your child at home is about creating simple, intentional spaces that:

- Reduce visual and sensory overload
- Offer predictability
- Promote independence

Defining a play area or limiting toys can increase engagement, support self-regulation, and lead to peaceful, connected moments in daily life.

Five practical ways to support play through the home environment

Play becomes more meaningful and manageable when a child's environment supports rather than overwhelms them.

The following simple and affordable strategies, taken from research and real family experiences, can help your child stay regulated and engaged.

Simplify and rotate toys

Parents often offer too many toys, hoping to spark an interest. Yet, too many choices at once can overwhelm children with autism. Instead of encouraging exploration, clutter can lead to jumping between toys without focus or avoiding play.

Why it helps: Fewer toys can help your child focus, make choices, and use materials purposefully. It can also reduce sensory overload and make transitions less frustrating.

> "Children with autism benefit from knowing where things happen. When play can happen anywhere, it can start to feel unstructured, leading to wandering, dumping toys, or avoiding play altogether."

What to try:

- Keep 4–6 toys out; store the rest in bins or a closet.
- Rotate toys weekly or biweekly for renewed interest.
- Use open shelves or clear bins so toys are visible but tidy.
- Label bins with words and pictures to build language and independence.
- Group similar toys (e.g., pretend play, building, puzzles, or sensory tools).

You're not limiting play. You're helping your child discover deeper ways to play with what's available.

Create a defined play or learning space

Children with autism benefit from knowing where things happen. When play can happen anywhere, it can start to feel unstructured, leading to wandering, dumping toys, or avoiding play altogether. A clearly defined space helps make play feel more organized and predictable.

Why it helps: Defined spaces help your child understand "this is where play happens" or "this is my space to build". These physical boundaries create a sense of predictability, support focus, and reduce distractions.

What to try:

- Choose a consistent area: a living room corner, bedroom nook, or space by the kitchen table.
- Mark the area with a rug, a low shelf, or even painter's tape.
- Frame the space with furniture: a table and chair, a cushion, or a beanbag.
- Keep a few play materials in this area, stored neatly and within reach.

Children may still move around. Starting from a familiar space builds a routine, eases transitions, and gives them a clear place to return.

Set up a calming area

Children with autism need a safe place to reset when their environment feels loud or overwhelming. A calming area is meant to be a comfort zone, not a punishment space. It gives your child a place to step away, regulate, and return to play or routines when ready.

Why it helps: A consistent, cozy spot for calming can reduce meltdowns, support emotional regulation, and teach your child to recognize their own needs. It also helps prevent overstimulation before it escalates.

What to try:

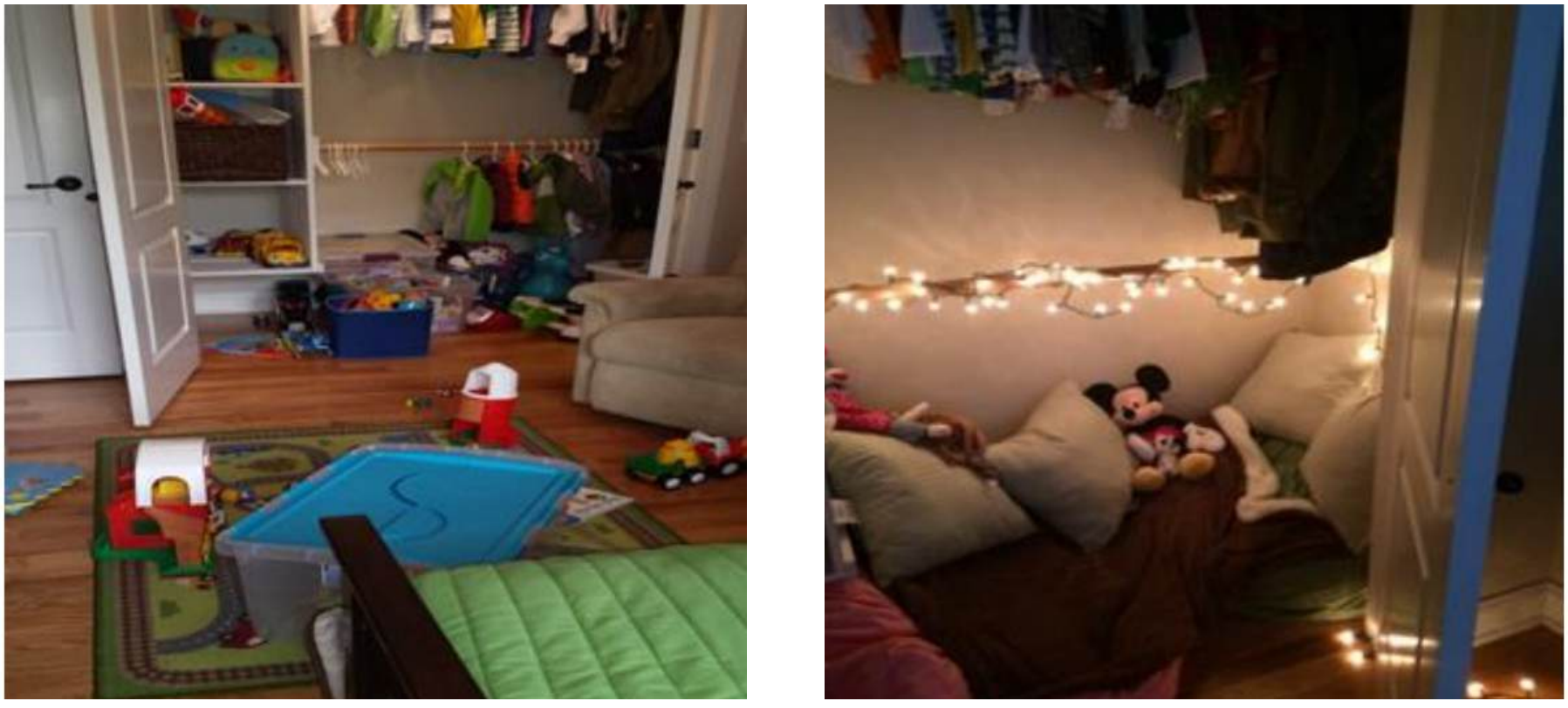
- Pick a quiet spot: bedroom corner, behind the couch, or even a pop-up tent.
- Add cozy, familiar items: blanket, stuffed animal, beanbag, or pillow.
- Include sensory tools: a chewy necklace, fidget, weighted lap pad, or a glitter bottle.
- Use soft or dim lighting if possible.

Treat this space as a positive option. Over time, your child may start using it independently when they need a break, which is a big step toward self-regulation.

Minimize visual and sound clutter

Many children with autism are highly sensitive to their surroundings. Bright lights, background noise, or visual clutter may be overwhelming. Even rooms filled with toys, posters, or bins can cause overload.

Why it helps: A quieter, simpler environment makes it easier for your child to stay calm, focused, and more engaged. Reducing competing sensory input can make transitions easier and support regulation.



Before and after: A small closet was repurposed into a calming area with minimal changes to provide predictable, cozy, and child-chosen comfort.

What to try:

- Turn off distracting TV and background music.
- Use soft lamps or natural light when possible.
- Cover or tidy shelves with fabric bins or closed containers to reduce visual busyness.
- Choose soft or neutral colors for rugs, curtains, and furniture.

Joy can become more accessible in a calmer environment.

Encourage interaction by adjusting access

If toys are within arm's reach, children don't need to communicate with others for help. While independence is important, parents want to encourage meaningful interaction.

Why it helps: Placing favorite items out of reach or in containers that require help to open creates natural opportunities for your child to communicate, seek help, or share attention. It encourages back-and-forth interaction without pressure.

What to try:

- Put a favorite toy or snack in a clear bin that your child needs help opening.
- Place a few high-interest items on a shelf above their reach.
- Remove batteries from electronic toys so your child asks for help.
- Store puzzles, art supplies, or building toys in a drawer your child can't open.
- Stay close and respond to gestures, sounds, or looks. Each is communication.

With these actions, you're helping your child make a request, ask for help, and build connections that can lead to meaningful interactions.

Cover shelves with curtains or closed, no-see-through containers to reduce visual busyness.

Small changes, lasting impact

With a few simple strategies, you can support your child's growth. Simple changes, such as fewer toys or softer spaces, can lead to calmer days and more meaningful play.

You know your child best. These ideas are tools to help their environment become one for more positive and meaningful play.

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Teresa L. Boggs, PhD, CCC-SLP, is a speech-language pathologist and professor at East Tennessee State University with more than 25 years of experience working with children and families. She specializes in early communication and feeding challenges and has spent much of her career supporting families in their homes, clinics, and communities.

Dr. Boggs helped launch ETSU's Autism Clinic and developed the Positive Eating Program, a child-centered approach to sensory- and behavior-based feeding disorders. She provides clinical services and mentors graduate students in speech-language pathology as they learn to support children.

Her work is rooted in real-life strategies that help families feel more confident and connected, and she believes that small changes can make a big difference.

Homeschooling: Learning Beyond the Classroom

By **Heather Anderson**

How can homeschooling help a child with autism thrive?

When I began homeschooling my nonspeaking autistic son, I knew I didn't want to limit his education to functional skills and a certificate of completion. I wanted him to access the same rich, age-appropriate academics as his peers and earn a high school diploma.

Today, he is a homeschooling freshman studying biology, modern world history, and literature because we built his education from the ground up. I'm not alone.

Homeschooling enables us to move past the narrow definitions of what autistic children should learn and embrace what they can learn with the right foundation, supports, and opportunities.

Why homeschooling can work well for autistic children

Traditional classrooms often confuse motor challenges with intellectual disability. Many of our kids can read words but struggle with ocular motor function, or eye movements that make tracking a line of text difficult. They lose their place or repeat lines, so educators assume they don't understand the material.

That's not a cognitive problem; it's motor. Holding students back academically isn't the solution.

Providing accommodations, such as audiobooks, is. That way, they can access the same content as their peers.

Homeschooling allows us to make those accommodations naturally, without waiting for administrators to approve changes to an IEP.

At home, we start with the foundational skills every child needs: phonics, number sense, early reading, and basic math. We expose our kids to all subjects and focus on clear proof that they've mastered foundational skills.

For example, my son first learned beginning consonant sounds and one-to-one correspondence. He had already taught himself to read by memorizing the order of letters, but he didn't understand that those symbols also meant something.

By building foundational skills systematically, starting with beginning consonant sounds, then word families, then consonant blends, we created a structure where each skill prepared him for the next.

This is how he moved from being underestimated in special education to thriving as a high school freshman.

Learning opportunities outside the traditional classroom

Real life reinforces academics in ways no worksheet ever could. Learning beyond the classroom doesn't just mean life skills. It's academics through experiences.

Cooking becomes applied math and science through measuring, sequencing, fractions, and observing chemical changes.

Grocery shopping is an exercise in reading labels, one-to-one correspondence, and rounding up to the next whole dollar.

A trip to the playground is an opportunity to add and use new words on an AAC device.

We also use episodic learning, tying academics to meaningful events. Decorating our homeschool space for holidays is fun and also builds episodic memory, making abstract concepts like time, seasons, and history more concrete.

A Halloween-themed month might include a pretend-play pumpkin patch with signs to read, tickets to purchase, and opportunities to practice skip counting or primary and secondary colors.

These experiences are easily remembered because they're tied to novelty and joy, not rote drills.

Social occasions matter too. Homeschool co-ops, therapies, or community outings provide students with opportunities to practice communication and executive function, while academics remain central.

Last fall, we joined another homeschool family on a trip to a local candy shop where the owner demonstrated how candy canes are made. We learned sugar changes from a solid to a liquid and back again, and how "pulling" candy incorporates air into the sugar, changing its color and texture.

Learning happens everywhere and is expanded into applied, meaningful academics, not watered down into life skills.

Creating a flexible, supportive learning environment

At home, we focus on making academics accessible, predictable, and engaging. Visual schedules, consistent routines, and organized materials reduce anxiety and free up mental space for learning.

However, while we have structure, learning isn't rigid. If my son is absorbed in a history project, I let him keep going. If he wants to learn lying down on the floor, that's where we do it. Flexibility allows learning to support his regulation rather than undermine it.

We also account for motor differences that may look like behaviors. For example, many autistic students struggle to stop an action before it feels finished.

A child asked to count five bears may move all 25, not because they lack 1:1 correspondence skills, but because their motor system compels them to complete the pattern.

Errorless learning also allows students to fully understand the assignment before asking them to demonstrate mastery expressively. This type of learning reduces anxiety and resistance to schoolwork.

By understanding these challenges, we can design lessons that reduce frustration and still assess true intelligence.

A flexible homeschool environment is more about philosophy: presume competence, support the body, and trust that every child deserves rigorous academics.

Celebrating progress and redefining success

For too long, autistic students have been defined by what they can't do. Homeschooling lets us flip that script and measure success by academic growth.

For my son, that means still cutting his math worksheets into individual problem squares, allowing him to focus his eyes on just one problem at a time. Or we'll use a vertical whiteboard instead of a horizontal desk.

I still create 9th-grade vocabulary flashcards that allow him to match each word to its definition and demonstrate intelligence without a pencil.

Yes, sometimes he matches flashcards on the floor while draped over a yoga ball. Sometimes he throws his schoolbook across the room. That's unintentional motor, not intelligence.

My son is still completely nonspeaking. However, after years of working with age-appropriate academics and robust AAC with access to all the buttons, he has developed strong communication skills.

Because we homeschool, he's able to engage with current events as they unfold.

So many parents wish they knew what their nonspeaking children were thinking. Even though my son lacks spoken words, I know his likes, dislikes, hopes, and dreams because I presumed

his intellectual competence and focused on academics instead of life skills.

Progress occurs when students are allowed to show academic mastery and share intelligent thoughts and beliefs while still being autistic.

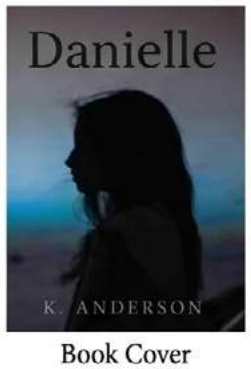
Home is the best place to support that.

Heather Anderson, a former journalist, created Nonverbal Autism Homeschool during the 2020 pandemic. She partnered with Ken Sims, a special education teacher who worked with her son when they first began homeschooling through a charter school. Today, nearly 1,000 nonspeaking, minimally speaking, and other struggling autistic students in all 50 U.S. states and around the world are participating in this program.

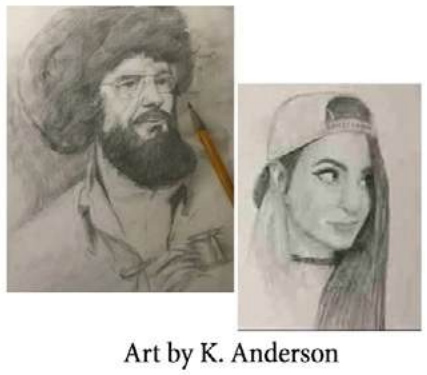
'Danielle' by K. Anderson

Author K. Anderson

Born in Vallejo, CA, K. Anderson is a new published author reaching for his dreams after being diagnosed with autism at age 10. He graduated from Spectrum Center in Fairfield and attended Futures Explored Film School in Sacramento. He loves writing and art. 'Danielle,' about a teen girl with uncontrollable power created from his imagination, is his debut book.



Book Cover



Art by K. Anderson

For more details about his book please check out his website: https://christianfaithpublishing.com/books/?book=danielle. For more information email: Loulavella@yahoo.com.

Making Travel More Predictable

By **Rafaela Hoffmann Correa, CATP**

Here are strategies for traveling with a child with autism.

For many families, vacations are an opportunity to step away from daily responsibilities, reconnect with loved ones, and create memories that children carry throughout their lives.

Travel is a way to explore the world, develop independence, and expand perspectives. However, for neurodivergent families, especially those raising autistic children, travel can also be stressful and unpredictable.

Why is travel so difficult?

Children with autism often experience sensory sensitivities. They often have difficulty with transitions and a need for predictability, making simple trips feel overwhelming.

Many families follow structured routines that include therapies, school support, and carefully planned schedules. Stepping outside of that routine can feel risky. Some parents worry that disrupting structure may negatively affect their child's progress.

Travel often comes with sudden changes to plans, long wait times, and crowded environments. This unpredictability in unfamiliar settings can make it difficult to help children regulate their emotions.

Having access to accommodations or tools that enable families to communicate their child's needs while traveling can make trips easier for both children and parents.

Planning, visual supports, and flexibility are important when traveling with autistic children. However, families often feel unsure about how to apply these strategies in real-life situations.

As a mother of two autistic children, I understand that travel is more than leisure. When planned thoughtfully, travel can offer real-life opportunities to practice communication, flexibility, emotional regulation, and independence.

With a structured approach, travel can be a bit more predictable, supportive, and meaningful.

Limits of the "autism-friendly" label

In recent years, many destinations, hotels, and attractions have begun promoting themselves as "autism-friendly." This reflects important progress toward inclusion and accessibility. However, many families still encounter barriers even in environments that claim to support neurodivergent individuals.

Often, inclusion is seen as providing physical accommodations, such as a sensory room or a quiet space. However, if the experience leading up to that moment involves loud environments, long lines, and confusing instructions, the child may already feel overwhelmed.

Inclusion also requires ongoing learning, empathy, and adaptation. Continuous staff training, clear communication, and thoughtful planning are important for a truly inclusive environment.

Predictability in travel

Parents notice that their children feel more comfortable when they understand what to expect in advance. Having predictability when traveling helps reduce anxiety and allows children to adjust to new environments more easily.

Visual preparation

Visual preparation involves introducing the child to elements related to the destination or the travel process before the trip.

Examples may include:

- Social stories with real images
- Videos of the destination
- Visual maps
- Simple travel schedules
- Objects related to the destination

Providing visual references helps the child build familiarity with the experience, reducing fear of the unknown and increasing confidence.

Sensory mapping

Autistic children often have unique sensory sensitivities. Identifying possible sensory triggers in advance allows families to better prepare for the travel experience.

Sensory mapping may include considering:

- Loud sounds
- Crowded spaces
- Bright lights
- Waiting times
- Food preferences

- Temperature changes
- Need for movement breaks

Parents often find that situations such as sitting for long periods or moving through crowded environments can be stressful during travel.

When families anticipate these challenges ahead of time, they can plan breaks, look for quieter spaces, and prepare sensory tools to help children stay regulated.

Emotional rehearsal

Emotional rehearsal helps prepare the child to process and understand what will happen during the trip.

This process may include:

- Using simple and clear language
- Validating the child's feelings
- Involving the child in planning decisions
- Supporting autonomy in appropriate ways

Children often feel more confident when they can participate in small decisions, such as choosing activities or understanding the day's sequence.

Travel can provide meaningful opportunities to practice communication and emotional skills in real-life contexts.

> Children often feel more confident when they can participate in small decisions, such as choosing activities or understanding the day's sequence.

Applying the model in real life

In my own family experience, I saw how preparation could positively affect the outcome of a travel experience.

When one of my children was four years old, we traveled to a large themed entertainment park to celebrate his birthday. At that time, he had a strong interest in trains, so we chose an attraction on that theme to begin the day. After watching videos related to that experience, it seemed appropriate.

However, the ride was more intense than expected, and he became frightened. He also had to stay there until it ended, which caused emotional distress. After that moment, he was not comfortable participating in additional attractions that day.

Just because a child has an interest in something does not necessarily mean they are ready for an experience that includes that interest.

A few years later, we approached a trip to another theme park differently. We watched videos of the park, reviewed maps, identified quieter areas, and discussed possible activities in advance.

He participated in the planning process and had the opportunity to choose the attractions he wanted to try. As a result, the experience was calmer and more enjoyable for the entire family.

Benefits beyond travel

Thoughtfully prepared travel experiences can support the development of important life skills, including:

- Communication
- Adaptability
- Independence
- Emotional regulation
- Family connection

When children feel supported and prepared, they are often better able to engage with new environments and build confidence in unfamiliar situations.

Gradual exposure to new experiences can increase flexibility and independence over time.

What families can start doing today

Families do not need to begin with complex trips. Small steps can make a meaningful difference.

Here are some helpful strategies:

- Create simple visual schedules
- Show pictures of new environments

- Take short trips to practice transitions
- Observe sensory sensitivities
- Prepare sensory support tools
- Talk about emotions related to change

Short experiences can help both children and parents build confidence.

> “Reducing uncertainty and improving communication can significantly improve the travel experience for the whole family.”

What destinations and hotels can improve

Destinations that aim to be inclusive must understand that accessibility involves more than physical adaptations.

Important improvements may include:

- Ongoing staff training
- Clear communication
- Predictable processes
- Visual information guides
- Awareness of sensory needs
- Flexibility when possible

Reducing uncertainty and improving communication can significantly improve the travel experience for the whole family.

When destinations invest in inclusive practices, they create environments where more families feel comfortable traveling.

A positive travel experience

Travel is possible for autistic individuals and can be an opportunity for growth, connection, and discovery. Thoughtful travel preparation can lead to a positive experience.

Not every challenge can be avoided, but children should feel safe enough to explore new experiences with confidence. Then those positive experiences can support emotional development, strengthen family relationships, and expand opportunities for participation in the world.

When a child feels prepared and supported, travel can become a meaningful experience for the whole family.

Rafaela Hoffmann Correa, CATP, is a Certified Autism Travel Professional (CATP), travel consultant, and mother of two autistic children. With over 15 years of experience in tourism and specialization in family travel, she focuses on helping neurodivergent families plan more predictable and supportive travel experiences. Through her work, Rafaela advocates for practical accessibility strategies that promote confidence, inclusion, and meaningful participation in travel.

All Inclusive Trips

Ask Dr. Malcolm

By **Ronald I. Malcolm, EdD**

Dr. Malcolm answers parents' questions and concerns about their autistic children. You can submit your questions here.

Sylwia of Poland asks:

Can you please tell your point of view regarding speech development? Is it possible to evoke speech through some speech therapy exercises? Or rather, can a speech therapist only correct or develop speech once it has occurred?

My son is 5 years old and nonverbal. He says a lot of echolalia and has started repeating some sounds (mama, bam, tik tok, etc.), also from iPad songs (murmuring), and observing adults while producing sounds and putting his mouth to try to do the same.

Should I get some exercises (and from where)? Here in Poland, it is still common to believe we can only shape the speech if it occurs. There are not many speech therapists in my area who work with autistic children.

I remember an interview with Temple Grandin once in Poland, when she said she had two speech therapists who helped her develop speech. So my question is: Should I wait or practice with my son, and is there any online help for that?

The importance of speech

Children with autism who develop speech skills are better able to communicate their wants and needs. The use of speech allows all of us to control our environment better.

While all children with autism may not develop their speech and language skills, children with autism should receive the necessary services to develop them.

Early intervention

Children with autism need to be involved in early intervention programs. Some children may begin formal services at age 3 through their local school district. Others who were diagnosed earlier may receive services in a "Birth through Three" program at a childcare center or even at home.

Waiting until your child is ready to enter Kindergarten is not the correct approach. You need to seek out resources within your local community, doctor's office, and school district as soon as you become aware of a concern about your child's speech development.

Involving your pediatrician

One of the first things you should do if you are concerned with your child's ability to communicate is to consult your child's pediatrician. You'll want to rule out other issues than just their autism if their communication skills are being impacted.

For example, your child with autism should have a hearing evaluation by an educational audiologist. This will help rule out any hearing loss your child may be experiencing that could be negatively impacting their ability to communicate.

Peers

Look for ways to expose your child to same-age peers, such as the following:

- Developing "play dates" with other children in the neighborhood
- Joining a play group at the local YMCA
- Joining a T-ball team
- Taking swimming lessons
- Going to the local park where other children play
- Attending day care a couple of times a week

Each of these is a great way to expose them to typical speech development patterns.

Think of ways your child can be involved with other children so they are exposed to peers who consistently model speech and language skills.

Reasons for communication

Be certain you are giving your child a functional reason to communicate. Ask them to run upstairs and tell one of their siblings that you want them to come downstairs. Point out items in the grocery store and see if they can name them or receptively understand what you are asking for.

If they point to an item such as a cookie or a can of pop, encourage them to try to say the word or a sound associated with it. Even using phrases like "Hi" or "Bye-Bye" when greeting people is a good way to help your child develop their speech skills.

Make it fun!

Learning to use speech skills can be difficult for young children with autism. Try to make your attempts to communicate with your child fun. Sing songs to them, read nursery rhymes out loud, make animal sounds, etc.

If your child still does not make specific speech sounds, you can engage them in activities that will strengthen their vocal control or breath stream. Have them do the following:

- Blow out candles on top of a cupcake
- Blow bubbles
- Make a specific speech sound to move a toy train down the track
- Blow on a tissue to see who can keep it afloat the longest

Technology

Today, children with autism have many different forms of technology and augmentative communication devices available for them. Your child may have a specific interest in trains, animals, superheroes, and more. If so, look for online games that engage them and help build their speech and language skills.

Children's television shows might catch their interest and expose them to a specific speech sound they need to develop.

Start simple

Start with something "simple" for your child. This may mean simply responding to "Yes or No" questions. If your child doesn't yet have the skills to vocalize, use prompting to have them nod or shake their head. They can even use a smiley face for "Yes" and a frowning face for "No."

You can create a photo book of family members' faces to see if your child can identify Mom, Dad, siblings, and grandparents. Picture cards can also be used for activities such as eating, playing, and sleeping, as well as for favorite foods like pizza and chicken nuggets, and for various drinks.

Reinforcement

As your child begins to communicate, be certain to reinforce them. Even if the speech sound is a basic utterance or not entirely accurate, you'll need them to understand that you are happy with their attempt to communicate with you vocally.

Consistency and patience

For many parents of children with autism who want their children to communicate vocally, their patience may be tied to their own desire to hear their children do so.

Continue to work on the goals outlined by your child's speech and language pathologist. Give yourself plenty of breaks to ensure that you are not overwhelming your child. Finally, be consistent in your daily efforts to give your child a realistic purpose for using their speech skills.

Simply passing them items because they pointed may not encourage them to use their voice. However, pointing, combined with attempts to use vocal patterns, may be a better option.

Dr. Ronald I. Malcolm, EdD, is an Assistant Director of Student Services and Special Education for a public school district and a Special Graduate Faculty member at the University of Kansas. He holds bachelor's degrees in English and special education, and master's degrees in counseling, special education, and school administration. His doctorate in educational leadership is from Northern Arizona University, and his post-graduate degrees are in positive behavior supports and autism spectrum disorders. He has worked with students ages 3-21 with autism and various medical needs in school- and community-based settings for the past 41 years.

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Student Group Participation May Help Your College Student

By **Miriam Edelman, MPA, MSSW**

Joining some student organizations may be beneficial for your autistic college student.

Beginning and attending college can be difficult for some autistic students, especially if they are residing in their school dorms. These students may need to adjust to a new community, most likely with new ways of learning and different people.

Participating in some student organizations may help. The groups may provide an on-campus community, help build support networks, increase self-confidence, enhance the overall college life, and provide transferable work skills.

Challenges associated with college

College life can present challenges for any student, especially someone with autism.

Social life

Unlike in high school, college students may go weeks or months between seeing their family in person. E-mails, phone calls, video chats, and in-person get-togethers with family and loved ones are not the same as living day to day with close relatives.

Autistic students may spend time in a new environment with few (if any) familiar people.

Sharing spaces

Unlike at home, college students may not have their own space. Many students share dorm rooms, and it may be the first time doing this.

Not having a place where they can be completely free to be themselves may be challenging. They no longer may go to an area where they can do as they wish without judgment.

Academics

Academics are usually very different between high school and college. In high school, many students attend small classes for around seven to eight hours every weekday. Smaller classes allow teachers to know their students.

Students can excel academically by demonstrating that they learned what they were taught. They generally have many assignments, and there are sometimes opportunities for extra credit.

In college, students spend much less time in class, possibly only a few hours a week. Classes can vary in size, from just a few people to hundreds of students.

In large classes, professors often do not know individual students, although those courses may have teaching assistants who lead sections and know their students.

Often, college students are graded on how they apply what they study to new situations. Grades may be based on a relatively small number of tests and papers. Thus, students may not fully recover from performing poorly on a single assignment.

> “Academics are usually very different between high school and college. In high school, many students attend small classes for around seven to eight hours every weekday.”

Benefits of student organizations

Participating in student groups may be beneficial for autistic students for several reasons:

- Organizations provide social environments with planned activities, reducing social isolation and concerns about attending classmates’ casual get-togethers.
- Groups also provide natural discussion topics about common interests.
- Students may become friends with other group participants and see them outside of club activities.
- They may also feel that they belong somewhere in what may be their biggest school.

Participation, especially leadership in student groups, may have other benefits. Through groups, autistic students may gain transferable job skills, including:

- Working with others
- Keeping and using a budget
- Delegating assignments
- Planning and advertising events
- Public speaking
- Collaborating with other organizations

Additionally, through their group's events or publications, they may make meaningful contributions to campus life.

Club members may also gain access to special opportunities, such as performing at major campus events, landing career-launching internships, and more.

Special interests

Colleges usually offer a variety of student groups, some of which may align with the long-held interests of autistic students.

Clubs often relate to demographic groups (e.g., religion, ethnicity), academic fields (e.g., history, engineering), community service, and various activities.

Clubs also include student government, newspapers and media, sports teams, performing arts groups (such as orchestras, bands, and choirs), and fraternities and sororities.

Finding or forming groups and time commitment

Students can learn about student organizations in several ways. To avoid becoming overwhelmed with so many changes after move-in, they can research their college's student organizations online. They can also learn more about these groups through their college's clubs fair, fliers, and conversations with classmates.

Many students join clubs during their first few weeks of college. They are not required to do so, nor to remain in the same groups throughout their entire collegiate career.

Time commitment varies by group and type. For example, sports teams and music groups may have weekly practice or rehearsals. Students may have to try out for certain clubs, such as a cappella groups.

Students should be cautious about joining many time-consuming organizations, as they still need to focus on their academics.

There are multiple ways to participate in student organizations. Students may initially attend organization events. Over time, they may volunteer, even taking on leadership and holding official positions.

Some organizations offer first-year representative positions, giving students opportunities to contribute early on. Board positions may help autistic students build meaningful relationships and feel more confident.

Some students may also decide to found their own student organizations. Rules regarding group formation vary by school. However, students typically must create an executive board, draft a club constitution, collect signatures from a certain number of students, and then apply for official school recognition.

Once a group becomes official, it may receive money from the school for campus activities.

Other methods of campus involvement

Students can be part of other types of communities in college. Colleges may offer

resources, such as social networks or support groups, for students with autism.

Through support groups, autistic students may discover that they have similar challenges and can help one another by learning best practices. They could also make friends with other participants.

Autistic students may form study groups with their classmates. Creating such groups may not be difficult, as students are sometimes assigned to groups for school assignments. Group projects may be useful but extremely difficult (with some members doing much more or less than their fair share of the work).

Autistic students may also have a part-time job on campus. These jobs can prepare students for the post-college workforce. Autistic students may be teaching, researching, serving as resident assistants, or working in other positions.

Lifelong benefits

Participating in and leading student groups may be especially beneficial for autistic students. Through these organizations, individuals can participate in on-campus communities and possibly form lifelong friendships.

They can also make valuable contributions to campus while gaining useful, transferable skills.

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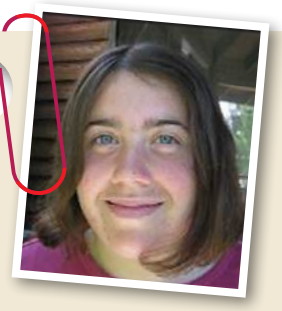

Miriam Edelman, MPA, MSSW, is a native Washingtonian and a Washington, D.C.-based policy professional. Her experience includes policy work for both the Senate and House of Representatives. Miriam's undergraduate degree is from Barnard College, Columbia University, with majors in political science and urban studies and a concentration in history. She holds a master's degree in public administration from Cornell University, where she was inducted into Pi Alpha Alpha, the national honorary society for public administration, and received the Cornell-wide Distinguished Leadership Award. She also has a Master of Science in social work (focusing on policy) from Columbia University. She is a commissioner on the DC Commission on Persons with Disabilities. Miriam aims to continue her career in public service. She is especially interested in democracy, civic education, the District of Columbia's autonomy, diversity, health policy, women's issues, and disabilities. Miriam has several cousins and friends on the spectrum and has also worked for an organization that helps people with intellectual and developmental disabilities, including autism.

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Visiting Theme Parks with Your Child

By **Jeremy Brown**

One dad provides suggestions for visiting an amusement park as a family.

Growing up, I loved to go to amusement parks. The thrill rides and roller coasters were always for me. It didn't matter whether it was a large theme park or a small, independent amusement park; I loved going on rides. I always wanted to share that with my kids.

While both of my sons have been diagnosed with autism, my younger son requires a lot more support. For a while, it seemed like theme parks were not in our future.

However, through a lot of effort and some excellent disability services, my family has bought season passes to our local theme park.

Amusement park issues

While amusement parks are designed to be fun for the whole family, the sad truth is they can be overwhelming for children and adults with autism spectrum disorder. There are a lot of bright lights, loud sounds, and even some strong smells that can send an autistic child into sensory overload.

Many people with autism also prefer a structured routine, but this can be thrown off since few people spend every day at a theme park. Even if you can go often enough to set a predictable pattern for your loved one, ride closures and higher-than-normal park attendance can throw off the best-conceived itineraries.

These disruptions and sensory sensitivities can cause anxiety and frustration, which can lead to meltdowns. This can turn any trip that's supposed to be fun for everyone into a stressful experience instead.

Our first trip

We had taken our older son, Jeremy, to the theme park a few times, as he doesn't require nearly as much support as our younger son, Joey. He loved the experience, but to do that, we would need a sitter to watch Joey all day.

As Joey developed to a point where he struggled to stay asleep outside his own bed, traveling became

more difficult. Eventually, we decided to try to take him to an amusement park in New Hampshire.

We checked what accommodations were available since autism qualifies for disability services at almost all theme parks in the United States.

We needed a doctor's note stating his autism diagnosis, but this allowed us to use a disability pass to skip lines for rides that Joey wanted to go on. He would not have done well if he had to wait too long, so this was a blessing for us.

We had a particular safety harness we knew would protect him. He wiggles a lot, so we were unwilling to take him on rides that only had over-the-shoulder harnesses or just a bar with no lap belt. Safety is top priority, and we had to work with him to find what he did and didn't like.

We made an exception with the log flume ride because of his love of water. I sat him in front of me and held on to him while we went down. He seemed scared at first, but was laughing and cheering when the flume hit the water, which sprayed everywhere.

We spent several hours at the park, taking breaks to sit and relax so he wouldn't get overwhelmed. After eating at a restaurant and heading back to our hotel, Joey fell asleep in the car, which led to trouble when he woke up the next morning.

Aftermath

Although Joey actually slept through the night in the hotel, he had one of his biggest meltdowns upon waking. Because he was in a different, unfamiliar place from where he had fallen asleep, he woke around 6 am and began screaming.

I quickly took him for a car ride, which he loves, as these sometimes serve as a coping mechanism for him. He was still screaming until we found his favorite fast-food donut shop.

Joey's favorite food is donuts, and he recognizes almost any donut shop sign, but especially his favorite. As I went into the drive-thru, he immediately calmed down.

After his treat and some juice, he was happy. We now knew we could take him to an amusement park, but with some issues afterward.

Theme park return

We had a decision to make: Return to the theme park or make it a one-and-done experience. We had numerous pictures of Joey smiling, but his reaction the next morning proved he was overwhelmed, either by waking up in an unfamiliar place or having too much stimulation.

We decided to visit another theme park, and since this one is closer to home, we thought we'd go for a few hours. We obtained the doctor's note and purchased the tickets.

Many of the rides were similar to the first amusement park rides, with the same frames and track movements. After finding out which rides he enjoyed, we had a path forward to do this again.

Much like the first trip, he spent much of the day laughing. He did have another meltdown on the drive home, but he eventually calmed down after we got him some food.

How to prepare for amusement parks

Visiting amusement parks can be fun, but tough without a plan to best accommodate your autistic loved one. There are some simple tips to help make the trip more enjoyable for everyone.

Research accommodations

While every amusement park in the US must meet specific standards for disability services according to the Americans with Disabilities Act, there is some wiggle room. Determine if the park you want to attend meets your child's needs.

Bring your own solutions

Once you know which accommodations are provided, you may be able to bring additional accommodations from home. We packed my son's noise-canceling headphones to help prevent sensory overload from the loud noises of some rides and the large crowds.

Plan for low crowd levels

A bright, sunny day can be one of the worst times to attend a theme park if your loved one gets overwhelmed in large crowds. Finding a time with lower crowd levels can make the park easier to navigate and possibly reduce the risk of overstimulation.

Stay hydrated

Amusement parks involve a lot of walking, so it's best to keep hydrated, especially during the hot summer months. Some parks provide free water for customers. Others allow the purchase of a cup for the day or season, which comes with free refills.

Water is essential to everyone, neurodivergent or neurotypical.

Don't overdo it

Amusement park fans love to visit every ride and attraction at the park, but doing that might be overwhelming for your loved one with autism. Don't push them beyond their comfort level.

If they don't want to go on a ride, even one they previously loved, don't force them. There may or may not be a reason for their reluctance. Just accept it. The park is more fun without overdoing it.

Fun for the whole family

The idea of an amusement park is family fun, but some aspects can be overwhelming for kids with autism.

Taking certain steps, such as choosing smaller rides or bringing some items from home, can help ensure your neurodivergent loved one has fun.

Just because your child previously loved an attraction doesn't mean they will feel that way next time.

Your child may be rigid, but if you're flexible, you can make it a fun day for everyone.

Resource:

https://www.ada.gov/

Jeremy Brown is a writer, editor, podcast co-host, Emmy-winning local news producer, husband, and father. His work in local TV news left him yearning for a more creative outlet, and the coronavirus pandemic and his wife's caregiver burnout presented an opportunity to stretch his creative muscles while also helping others. Jeremy and his wife, Sarah, launched the podcast Caregiver Chronicles together in August 2020. While Sarah is the lead, Jeremy co-hosts for many episodes and edits every episode of Caregiver Chronicles.

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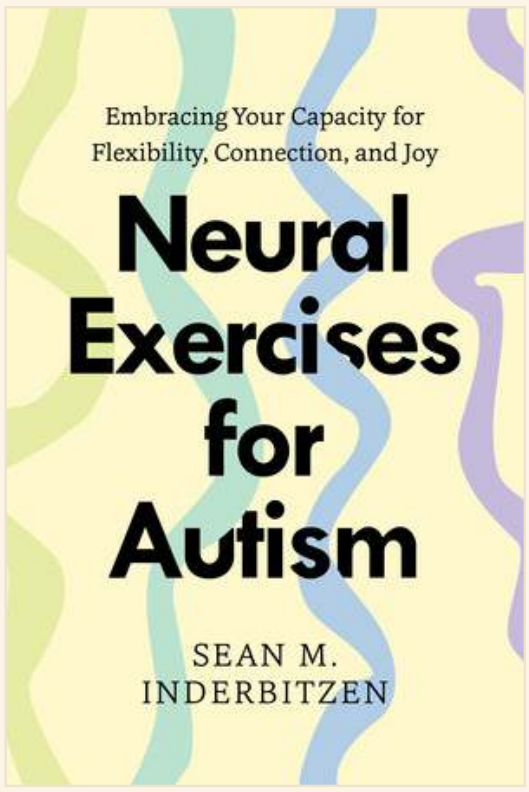
What's New
On The Bookshelf?

Neural Exercises for Autism

By **Sean M. Inderbitzen, DSW, LCSW**



There are ways to support your autistic child's nervous system.

In this revolutionary self-care book, autistic clinician Sean Inderbitzen presents exercises for autistic readers that focus on retraining the nervous system to access a state of safety more easily. These polyvagal-informed exercises draw on the body's intuitive wisdom to increase the reader's capacity for connection and flexibility, all while celebrating the inherent strengths of autists.

Neurology, mindfulness, somatic resources, and other fields are tapped to create these powerful practices for a more joyful, easeful, and connected lived experience.

Sean M. Inderbitzen, DSW, LCSW, is a psychotherapist and researcher through Mayo Clinic Health System, and the author of Autism in Polyvagal Terms. He regularly trains healthcare professionals to be more confident when working with people on the spectrum.

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