

Autism Parenting Magazine

Issue 118

Teaching Private vs. Public Behaviors

Do Schools Have the Right Model for ASD Kids?

Online Autism Therapy: Does it Work?

Police Officers and Kids on the Spectrum

Grandparents Diagnosing Autism

REFRAMING EDUCATION IN THE NEW NORMAL



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Do you have a story to share? Perhaps you have information that would be helpful to other parents with ASD kids and want to share the info. Why not share your story/info with us? *Autism Parenting Magazine* wants parents and caregivers to unite to help each other. Our writing guidelines are simple.

The topic needs to be relevant to the magazine. Any topic related to parenting a child with autism; or being a parent on the spectrum will be considered. Released on a monthly basis, the magazine features the latest news, tips, and advice for parents of children with autism. With helpful advice that covers subjects like: behavioral tips, sensory processing issues, mitigating meltdowns, special education needs and getting access to services, we are confident that the magazine will become a must read for parents of children with autism.

We do ask that you submit a topic, title, or idea of the article to make sure someone hasn't already covered the same thing by emailing the editor. You may use a blog post you have posted on your blog already.

The article should be a minimum of 600 words. Font does not matter. We do ask that if you use sources to please cite them at the end of your article to avoid plagiarism. If providing images with your article, please ensure you have permission for them to be published.

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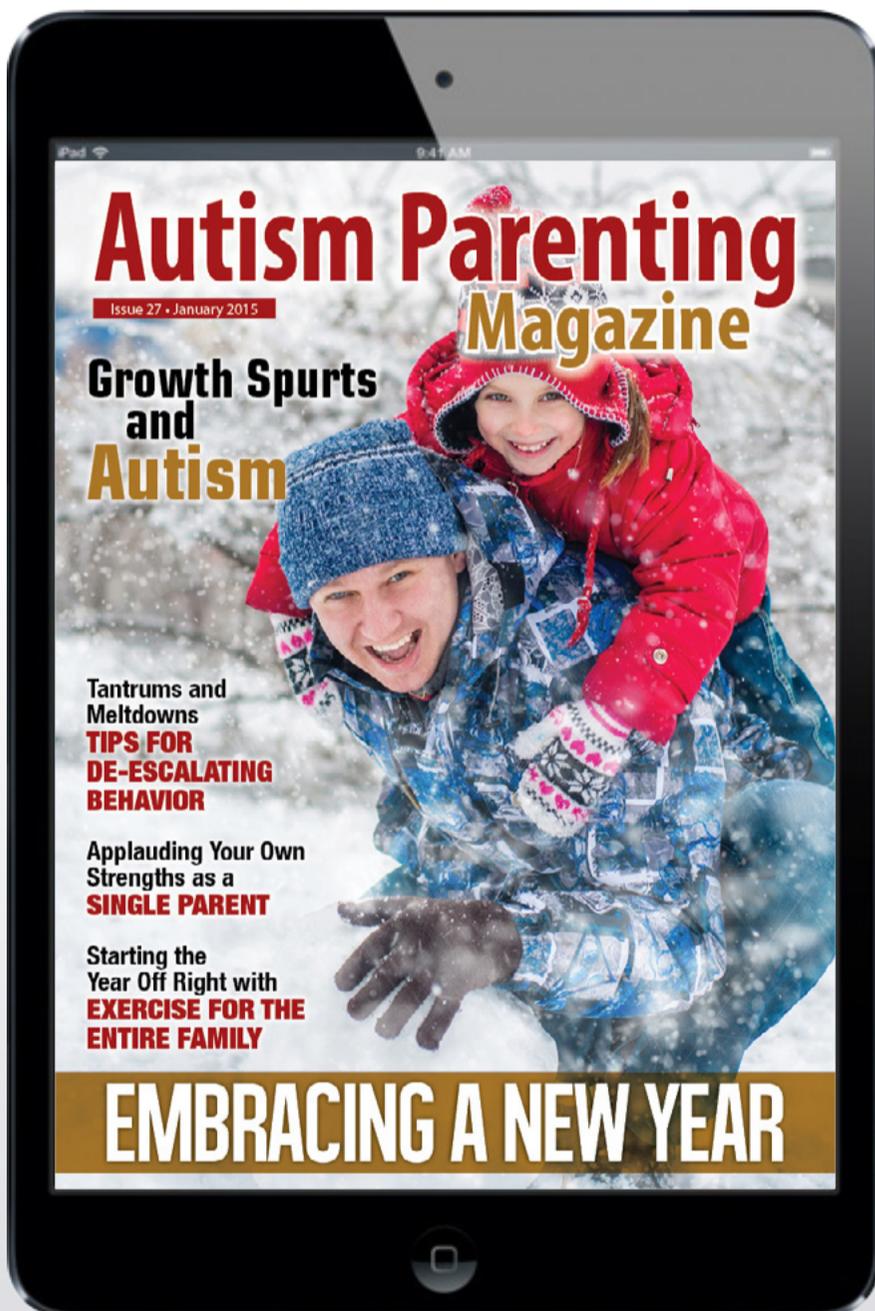
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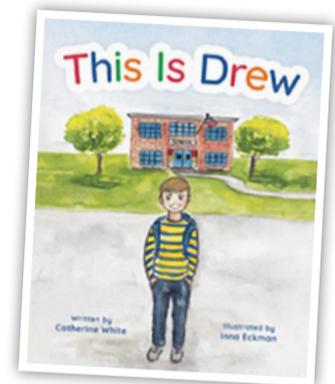
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As I write this month's Editor's Letter a new strain of COVID-19 is making its presence known. The UK has been plunged into its third national lockdown, restrictions have tightened across parts of the USA, and other countries including South Africa are facing new challenges as the world continues with its efforts to beat the virus.

With more school closures and constant changes to daily living, we decided to run with the theme "Reframing Education in the New Normal" for our February issue. The magazine is packed full of content to help parents and caregivers as many continue to take on the role of teachers for their children.

Sarah Allen OTR/L SCSS and Megan Huggins OTR/L have co-authored *Supporting Home Learning Through Movement* which looks at homeschooling from a sensory perspective and outlines how movement breaks can boost children's learning performance.

Meanwhile, Marcia Eckerd, PhD, has penned a thought-provoking article questioning whether schools have the right model for autistic kids and asking what can be done to improve their learning experiences.

We're also pleased to include some heartwarming content from two autism moms - Lauren Gebel and Lisa Maloney - who have shared personal narratives about their families' journeys through home education during the global pandemic.

Plus, we're discussing the concept of online therapy for children with autism. Choosing an online



approach not only helps with social distancing and lockdown rules, it can also be a more budget-friendly option - but how effective is therapy when it's conducted online? Karla Pretorius' article *Online Autism Therapy: Does it Work and How?* weighs up the pros and cons.

There's all this and so much more in February's pages. We hope you find this issue useful and take some of our contributors' suggestions onboard.

Keep calm, carry on, and stay safe!

Emily Ansell Elfer

Editor

Autism Parenting Magazine

Disclaimer:

Autism Parenting Magazine tries to deliver honest, unbiased reviews, resources, and advice, but please note that due to the variety of capabilities of people on the spectrum, information cannot be guaranteed by the magazine or its writers. Medical content, including but not limited to text, graphics, images, and other material contained within, is never intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of a physician with any questions you may have regarding a medical condition, and never disregard professional medical advice or delay in seeking it because of something you have read within.

Do Schools Have the Right Model for Autistic Kids?

By Marcia ECKERD, PhD

A look at whether the mainstream education system is doing the best it can for children with autism.



To decide if our schools are using the best model for our children, we need to think of the environment, the interventions, and the impact of both on our children.

Most school interventions in the US are based on the model of autism in the American Psychiatric Association diagnostic manual (DSM-V). The traditional medical understanding of autism is that it's a neurodevelopmental disorder diagnosed by observable behavioral characteristics. This is a challenge-based or pathology-based model.

If autism and its manifestations are pathological, it makes sense to try to "fix" them so the children behave in ways that are generally seen as more acceptable. "Evidence-based" gold standard treatments aim to eliminate autistic behaviors.

What's particularly important about the pathology model is the criteria describing behaviors are based on outsiders observing them. The conclusion that a behavior or routine of an autistic child is "non-functional" is not based on the experience of the autistic child but rather on the ideational framework of the "neurotypical" observer.

There is an alternate model. Increasingly, researchers are talking about neurodiversity—the idea there is more than one way for brains to develop, that biodiversity itself is not a negative, and each different kind of neurodevelopment comes with strengths and challenges. The neurodiversity model is to recognize autism as a legitimate, neurodivergent way of processing experience with autistic behavior as an authentic expression of autistic experience.

Atypical vs neurotypical

According to DSM-V, autistic behaviors such as having routines, special interests, and “stimming” are seen as non-functional rather than as meeting the needs of someone who processes differently. If you navigate the world differently and at a different pace than the majority, it helps having things be expectable, so you know how to react. Transitions and novelty are difficult, and routines are functional in that they provide a sense of being in control. Stimming is a self-calming behavior for someone who can be overwhelmed by the sensory and social environment. Taking a deep dive into understanding behavior means working to understand the perspective and experience of individuals on the spectrum of all ages.

Most non-academic school interventions focus on behavior. Behavior is often described as avoidant, attention-seeking, oppositional, manipulative, or a variety of negative attributions. That’s because the behavior gets attention and isn’t what we might want the child to be doing. In trying to eliminate the behavior, we often don’t consider what underlies it—what need or experience is being expressed. Instead of understanding and providing empathic support, we are critical of the behavior. According to autistic adults, autistic children experience this kind of misunderstanding and criticism frequently.

Let me give an example with excerpts from an article written by Lisa Morgan, a certified autism specialist and consultant.

Looking through the eyes of an autistic student

First, think of an elementary school classroom. The room is bright and colorful with pictures, charts, a calendar, and completed assignments on the walls. Some colors bother me but there’s enough of my favorite color to be OK. There are desks arranged in a familiar pattern. There are 18-22 kids, one teacher and an aide.

The desks are arranged in configurations designed by the teacher. They are changed several times during the year—a surprise to the students. Most students walking in on Mornings of Change get excited and the regular noise level is much higher.

For me, those mornings are extremely hard. The change is so abrupt. I see the chairs have been moved all around, and I stand still by the doorway, not sure it’s my classroom. My anxiety rises. I panic—I want to find my calming color.

Still standing by the doorway, I start to tune into the sounds of students talking at different speeds, at different decibels, changing topics, with a squeal or two thrown in along with an argument here and there. It’s so hard to think. There are 22 desk chairs squeaking on the floor, pencils being sharpened, the teacher giving directions, and students finding their new seats. Minutes later, I’m still standing in the same spot. I stand rooted by panic brought on by the change, the noise, and the confusion about where to sit. I wish I could find words to explain. My teacher tells me she wants me to move.

She wants me to get ready for the day. If I don’t soon, she said she will help me move. What? Does that mean she’s going to touch me? I don’t want her to touch me. My feet are even more firmly rooted by the doorway. The teacher has on a perfume that the other students say smells real nice, a sweaty student walks by who forgot to put on deodorant.

“ The neurodiversity model is to recognize autism as a legitimate, neurodivergent way of processing experience with autistic behavior as an authentic expression of autistic experience. ”

“ Repeated stress can result in a pathological stress response, in which the body’s level of arousal and stress hormones don’t return to a relaxed baseline. ”

The strong smells are all around me and I can’t get away from them. Anxiety! Still, I can’t move.

The teacher warns me again to go get ready for the day. Now I might be in trouble too! I want to get ready, but don’t know where to go. I can’t think. I need to move. My teacher’s voice reaches me again out of all the other voices and it’s not comforting. It sounds different—angry, I think. She wants me to say something to her. I have no words. There’s too much to think, feel, and figure out.

What do I do? I still don’t know where to go. My teacher asks if I can see the bright tags on the desk with the students’ names on them. There are tags on the desks?

The teacher’s voice is rising and it’s hard to know why. Is it me? I’m trying so hard! I move towards the desks, high anxiety, heart still pounding, hearing noises all around me, the strong perfume smell. A student bumps me, the sudden touch makes me forget everything I was doing and I stand very still once more.

My panic rises again. My skin crawls. I continue walking slowly around the desks and find a tag with my name on it. I’m there! My head hurts from the smells; I’m overstimulated, overwhelmed, so I sit down and gently rock back and forth to calm myself.

My teacher walks over to me and says, “See how easy that was? Why aren’t you excited like the other students! Now sit up straight and stop rocking in your chair.”

Education is not linear

Let’s consider a typical school Individualized Education Program (IEP). We can imagine this child has a behavior plan that includes, “With one prompt, the student will follow a teacher’s direction.” Another part of the plan might be “The student will not rock

in her seat and will use appropriate coping strategies.”

Is the best answer to this situation for this child to stop rocking? Or do we need to understand her shock, confusion, and sensory experience? Does the child feel increasingly anxious and threatened when she perceives the teacher’s voice to be irritated? Does she feel supported when the teacher says how easy it is to find her seat? Most of all, does the child experience school as a safe, empathic environment?

The body has a physiological stress response called the “fight or flight” response that activates the sympathetic nervous system and makes it difficult to focus and listen. Repeated stress can result in a pathological stress response, in which the body’s level of arousal and stress hormones don’t return to a relaxed baseline. With frequent stress, would we expect the child to be able to focus on learning? How can we expect a child to be resilient? Having a deep and accurate understanding of triggers is extremely important.

Returning to Lisa Morgan’s story, we could anticipate an autistic child would have difficulty with the sudden change in the classroom; it would trigger stress. If it’s predictable the class is typically excited and noisy on these mornings and we know this child has acute auditory hypersensitivity, we’ve identified another trigger. If we know odors can also be problematic and the child needs to get away from strong ones, we have a third trigger. Add confusion, the perceived need to find words to explain, and anxiety about the teacher’s response, the child’s panic is understandable.

What might we do differently? We might ease the transition by alerting the children to the change in seating and handing out a seating chart ahead of time. It’s easy to put tennis balls on chair legs to quiet sound and require “inside voices” even when everyone is excited. A teacher with an autistic child in her class might not use perfume. Critically, we would understand any child rooted in one spot is probably struggling—not avoidant, attention-seeking, or manipulative. Occupational Therapists (OTs) are often experts in sensory calming tools; the question

is whether a tool preferred by the child is available where and when it's needed.

My point isn't to criticize school staff. They intend to be helpful. They address aberrant autistic behaviors according to their understanding of autism and framework for intervention. Since our focus is on the behavior, the legitimacy of the child's experience isn't considered.

Let's be mindful

Taking into account the importance of the experience of the child and the legitimacy of behaviors in terms of experience would constitute a huge paradigm shift in understanding these children and therefore in responding to their behavior. There would need to be acceptance of their autism and thoughtful consideration of the environment they face.

Children often use "stimming" to self-calm. "Stimming" is a movement such as rocking or flapping hands. If a stim isn't harmful, why do we need to eliminate it? I know a teacher who works with some students who stim. If the student prefers to use a self-calming stimming behavior that might be distracting, he might decide to sit in the back of the classroom, so the behavior isn't disruptive.

If our concern is that a stim is destructive to the child or property, an OT could help the child find a workable variation. [AutismLevelUp.com](https://www.autismlevelup.com) is a wonderful website that goes into depth about understanding sensory experiences and strategies for handling arousal. It provides free downloadable tools that can be used at home or school.

An IEP plan might encourage an autistic child to use some kind of communication strategy (verbal, using a signal, or pointing to a picture) to indicate sensory problems, to request sensory materials, or to ask for a break. Speech and language therapists ideally can both help script responses and come up with alternate modalities of communication. We would not expect a child panicking or melting down to use language to explain himself/herself or to stop be-

“If the student prefers to use a self-calming stimming behavior that might be distracting, he might decide to sit in the back of the classroom, so the behavior isn't disruptive.”

ing overwhelmed; that's basically asking the child to stop being autistic.

The Americans with Disabilities Act (ADA) requires accommodations for students with disabilities. We take having wheelchair ramps as normal. They benefit non-disabled students as well—someone with a rolling book bag or on crutches temporarily can also use the ramp. The ADA covers "invisible" disabilities as well; this could include accommodations for the extreme sensory sensitivities of an autistic student. An autistic student can go to a "lunch bunch" in a counselor's office instead of a noisy cafeteria, but one could say this is stigmatizing. Why does someone who needs quiet need a counselor? Why can't there simply be a quiet lunch space like there's a quiet car on a train, where anyone who wants a respite at lunch might sit?

Re-modelling education—a teacher's account

If this seems like a lot to do, consider this Facebook post by Karen Hope Blacher. It went viral and she was on *Good Morning America* to discuss it.

"All of my students are neurotypical, but my classroom looks very much like a special education classroom. I teach mindfulness and emotional literacy. I provide fidgets and sensory toys. I have a calm corner and use it to teach self-regulation.

“If our concern is that a stim is destructive to the child or property, an OT could help the child find a workable variation.”

"My students are thriving. And that made me realize something. When we treat autistic children the way the world tells us to treat neurotypical children, they suffer.

"But I have never encountered a single human being, of any age or neurotype, who doesn't thrive when treated like an autistic person. And that got me thinking that maybe neurodiverse people aren't the only ones who've been misunderstood and mistreated all this time.

"Are we worried about how other students might react? We could do a much better job modeling and teaching acceptance of those with differences, whatever the differences might be. Students shouldn't be acceptable only to the degree that they can fit in by being someone they're not."

Conclusion

The school environment and behavior plans can reflect this neurodiversity paradigm of understanding autistic experience. As Karen Hope Blacher says, all students could benefit from having sensory tools, recognition of their emotional states and, I would add, help with transitions, executive function, and clear directions. Most schools have goals of enhancing self-acceptance and resiliency. We can make our schools more difference-friendly for all students to enhance learning and everyone's ability to develop positive self-esteem and resilience.



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TEACHING PRIVATE VS. PUBLIC BEHAVIORS

By Lorna HECKER, PhD, LLC

Jason, age six, was admonished by his father for picking his nose in a public bathroom when they were at Target. However, Jason was very confused because his father had told him that if he needed to pick his nose, he should do it in private, like in the bathroom. So here he was in the Target bathroom (there were toilets and sinks, it looked like a bathroom!), but he was now being told not to pick his nose here. How was he ever going to figure out when it was okay to do this?! He had already gotten in trouble at school for picking his nose, so that is why his father told him to do it in the privacy of the bathroom! Jason just wanted some relief from a crusty nose brought on by a cold...



There are social rules around what we can do in public versus what we can do in private. For children on the autism spectrum, these rules can seem obscure and difficult to learn. If we really stop and think about it, they are complicated! There are rules around WHERE you can do or say certain things, there are rules around WHO you can and can't say certain things, and WHAT you can or can't divulge.

These are a lot of rules to navigate for a child on the spectrum whose internal guidance system does not immediately pick up on these socially constructed

rules. It can also be nerve-racking for parents to teach the idiosyncrasies of these rules, such as what Jason's dad encountered in teaching his son he could only pick his nose in the bathroom. Jason's dad failed to mention the nuance of either being in one's OWN bathroom, or perhaps behind the restroom door stall in a public restroom. The nuances neurotypicals take for granted are a lot to think about.

Additionally, certain behaviors can land a child or teen in hot water or even legal trouble if social norms are not adhered to. It puts a lot of pressure on parents to teach very specifically about things they them-

“ Children need to understand there are certain behaviors that can only occur in private places such as their bedroom or bathroom (with doors closed). ”

selves likely take for granted. It also is not a one-time lesson; these rules change as a child gets older and according to context, including cultural norms.

The WHERE

There are four spheres of life where we spend time, and parents can educate their child about what is appropriate and inappropriate behavior in each sphere.

Adapted from Organization for Autism Research (n.d.):

Private place behaviors

Children need to understand there are certain behaviors that can only occur in private places such as their bedroom or bathroom (with doors closed). This can include picking one's nose, getting undressed, bathing or showering, passing gas, and going potty. These are easier to understand because there are firmer rules around these behaviors if you do them outside of a private place.

Public place behaviors

Like private behaviors, these behaviors are easier to understand as you see everyone doing them. This includes saying hello to friends, waving, laughing together, playing, eating, and so on. What you do in public you can do in private (but not vice versa).

There are strict rules about not doing private things in public spaces; these are typically more readily understood. However, the spheres of semi-private and

semi-public are more nuanced and will require more attention and explanation both in identifying the place itself and deciding what behaviors are appropriate in these places. Additionally, what is appropriate may depend upon the type of other people within these spheres. It is these “gray areas” that may cause more problems for children on the spectrum as they struggle to understand what you should and should not say in these environments.

Semi-private

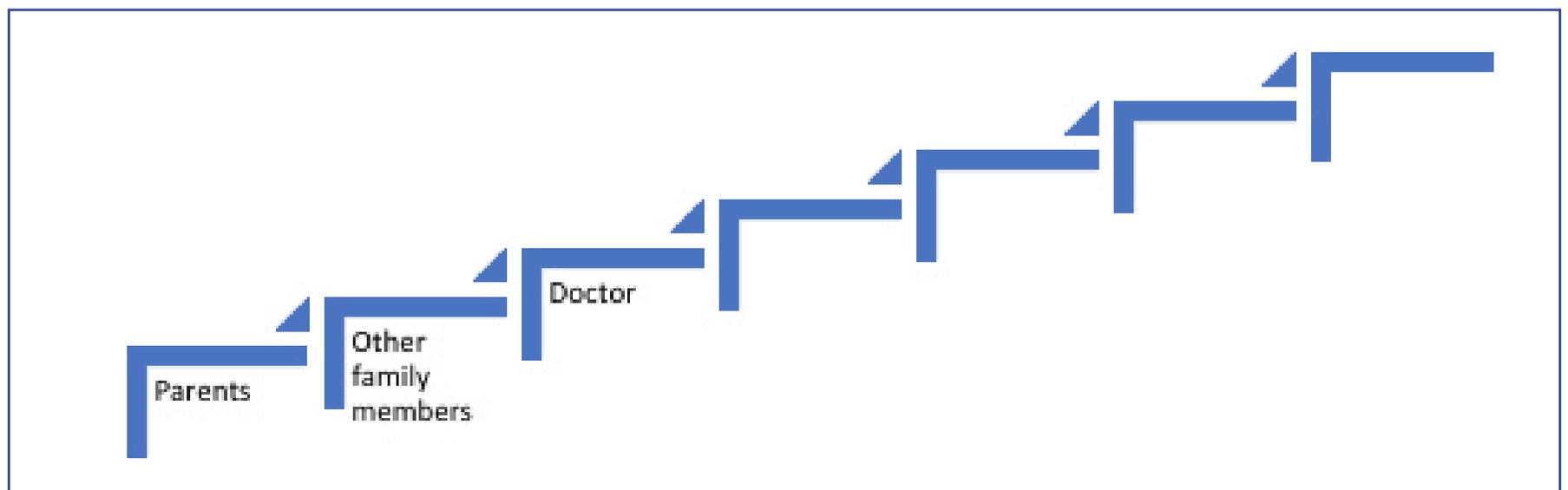
While it may be okay to undress in the doctor's exam room, the door must be closed and the doctor must have asked for the undressing. As in our case scenario, what may be okay in the home bathroom may not be acceptable in a restroom in public.

Semi-public

These are typically shared spaces that are not fully public, but also not fully private, such as the office where a parent works. There may be a bit of privacy, but different rules of behavior are required than in more private situations.

The WHO

As we look at the *Information Sharing Stairs*, we will find there are some people children should feel comfortable sharing almost anything with, but as you move up the stairs, a child should become less comfortable sharing information and learn to ask parents if he/she is unsure if he/she should share information with these individuals.



Information Sharing Stairs

A child can understand there are some people he/she is freer to share information with, but as he/she moves up the stairs, he/she needs to be more careful about what information is shared. Using a visual such as stair steps may be helpful.

The WHAT

Parents also need to help their children understand what *personal information* or behaviors are appropriate to share (that is what can become *public information*). The more private the information, the less likely it is it should be shared with others on the upper end of the *Information Sharing Stairs*.

Personal information typically refers to data or behavior that is about hygiene or grooming, medical information, some financial information, and information of a sexual nature. But it also includes phone numbers, addresses, birthdays. Parents need to be able to explain to their information what NOT to share.

Summary

Teaching children the difference between public and private behaviors is critical and challenging. It is important to remember:

- Children need to know the difference between private and public places, as well as the gradations between semi-private and semi-public variations
- Children need to know what private information is, and what they can freely share in public
- Children need to know whom it is appropriate to share information with, and whom they should not share information with

More nuances on the HOW to communicate topics (e.g. voice tone) and WHEN it is appropriate may also need to be explained by parents. With patience and clear instruction, children with autism can become socially competent.

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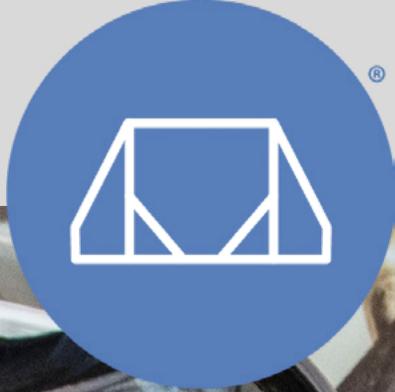
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Police Officers and Kids on the Spectrum

By Joseph PANGARO

A veteran police officer shares an on-duty interaction with an autistic teen that inspired lifelong efforts to bridge special needs knowledge gaps in law enforcement.



Many years ago, when I was a new police officer, I was sent to the home of a woman who was having trouble with her 16-year-old son. That was all the information I received from dispatch. This was a normal type of a call; we often found ourselves going to people's homes when their children were refusing to go to school or acting up in other ways. It's part of what cops do in most communities in America and falls under the "Community Caretaking" role.

I arrived at the house and knocked on the door. The woman was very nice, but obviously upset. She said her son was upstairs in his room and refusing to eat his lunch or come down to go outside. While we respond to calls from parents a lot, this call seemed very odd because the conflict seemed to be very benign.

I said: "Okay, let's go talk to him."

The mom and I went up to a bedroom and went in. Once inside I saw a very tall and very large 16-year-old man standing in the corner. He had to be at least

“ In New Jersey (NJ), in the late 1980s, autism was not something most people understood, and police officers received very little training on interacting with people on the spectrum. ”

six feet tall and 240 pounds. He saw me and started smiling, I smiled back and said: “Mom says you don’t want to eat or go outside today. What’s going on?”

The young man tensed up and stopped smiling. It was at this point I realized there was something more to this young man than just defiance, but I had no idea what it was.

His mom was behind me telling her son the police were here to make sure he did what he was supposed to do. I was confused and didn’t recognize the signs of autism; I had not been trained on what to look for or how to interact with people on the spectrum.

I was not sure how to proceed, but I knew something was off about the young man. I spoke to him gently and asked if he wanted me to eat lunch with him, but he didn’t answer. He was non-verbal, but I had no idea that was part of a condition. I spent the next three or four minutes trying to convince him to go downstairs and do what his mom asked to no avail. Instead of responding to my request he started twisting and flapping his arms. At the time I didn’t know this was “stimming,” or self-comforting, and part of his autism. His face looked like he was going to cry but no tears came. I turned to talk to his mom when he ran at me from behind and knocked me to the floor, then began choking me. Like I said, he was a very large guy and I was fighting for my life at that point—he caught me off guard and had the advantage of size and strength.

As I lay on the ground trying to get him off without hurting him his mom was screaming at him to get up, but he just got more upset. I felt I was going to have to use very severe force to stop him. At that moment, his mother hit him with a lamp from a desk in the room. He stopped choking me, got up, and ran down the stairs, now crying very hard.

I was in shock trying to put all of this into perspective, my neck hurt and I knew I had to go after him. I got up and radioed Headquarters to send me additional officers, figuring we would have to restrain this young man. I went down the stairs and found

him sitting at the kitchen table eating a peanut butter and jelly sandwich.

He saw me and smiled like nothing had happened, so now I was really confused. In our town we had a mobile mental health crisis team. They responded to the call and a counselor talked to me, the mom, and the young man. When we were done the counselor told me about the young man’s autism and wanted to know if I was going to arrest him for the assault. I asked the counselor what he thought, and he said he didn’t think a criminal arrest was the best idea since the young man didn’t realize what he had done was illegal, so I agreed not to make an arrest. Instead, the counselor planned to provide additional services to the mom and her son.

That event was a watershed moment in my career and my life. In New Jersey (NJ), in the late 1980s, autism was not something most people understood, and police officers received very little training on interacting with people on the spectrum. There have been reports of officers injuring or killing people on the spectrum because they didn’t understand the condition or how to properly deal with situations like mine.

That encounter could have gone very badly for everyone. I knew we had to get someone to teach us how to safely and respectfully perform this interaction so we could be a positive force for the kids and families of these special needs communities.



“ **Police agencies should ensure their officers are properly trained on understanding the signs of autism and how to interact with people on the spectrum as well as with people with other mental conditions.** ”

Since then I have tried to help police departments and the parents of our kids set up outreach and contact so when there is an interaction between the two groups it goes smoothly.

Here's what I suggest:

- Police agencies should ensure their officers are properly trained on understanding the signs of autism and how to interact with people on the spectrum as well as with people with other mental conditions
- Police agencies should create an outreach to the community so families with kids on the spectrum can get to know the officers in a controlled environment before they have to respond to a home for a call for service
- Parents should take the initiative to reach out to the police chief or sheriff in their community and set up a meeting so they can get to know the police leadership and the police can get to know the families
- A registry should be set up so if a call for service is at a home of a special needs family, the officers will know before they get there and can interact appropriately. These kinds of registries can be done easily with computer aided dispatch systems (CAD Systems) and when a location is entered for the call, it can be flagged with information for the officers
- Police agencies should encourage their officers to get to know the kids before they have to interact in a law enforcement capacity. As each child is different, so too can the meetings be different. Officers could visit the classroom or stop by the house and wave or talk with the children in a non-threatening environment so the kids get to see the officers in a benign way and become familiar with them

- Police agencies should encourage police department visits for kids who are open to the idea

These suggestions are just the start of a dialogue between our police officers and our special needs families. Developing a bridge between these two groups in a way that fosters understanding and creates a safe and friendly relationship can go a long way to providing the service every resident needs and can help our families feel comfortable when they interact with the police.

I once spoke to a police officer whose son is on the spectrum. He said he and many parents fear potential danger when their autistic children have to interact with an officer who doesn't understand and may misinterpret their children's actions as dangerous or aggressive. This can result in an officer using force; even deadly force, when it could have been avoided had the officers been properly trained and the families knew their local police.

This is my goal: to help create that bridge between my brother and sister officers and the kids and families we serve. Make the call today to your local police and ask if they have a program like I described. If not, ask them to start one. We all know we have to be our own advocates. Take this article with you and if I can do anything to help feel free to reach out to me.



Lt. Joseph Pangaro is a 27-year veteran law enforcement officer and former Director of School Safety and Security. He is currently the owner of True Security Design, a company that provides training for law enforcement, schools, businesses, and houses of worship on safety and security issues. Lt. Pangaro is also an award-winning writer, receiving two awards from *Autism Parenting Magazine* for columns on safety, security, and our kids on the spectrum.

Email: Pangaro.Training@Comcast.net

A young girl with glasses is shown from the chest up, playing a piano. She has her hair in a braid and is wearing a white top. The background is a textured blue wall with white musical notes and a treble clef. The text is overlaid on the image in white serif font on dark red rectangular backgrounds.

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Shaping the Future: Grandparents Diagnosing Autism

By Alison SINGER

With more experience and less exhausted eyes, grandparents often play a huge role in bringing autism symptoms to the attention of new parents.



“It takes a village to raise a child”—just hearing this phrase might evoke images of a bygone era, in which extended family, neighbors, and regular citizens all had a hands-on role to play in shaping the next generation. While today’s children are of course still shaped by their communities, attitudes around parenting have become fiercely individualistic, and honest questions and well-meaning advice may be met with hostility rather than openness. The internet is rife with advice columns featuring worried grandparents who

are concerned about their grandchild’s routine, diet, education, and the like. The exact source of the anxiety varies, but the advice is almost always the same: [butt out](#).

There’s a grain of truth in all this, of course—no one likes a busybody, much less when that person is your own flesh and blood. But there are times when a more experienced perspective is not only acceptable, but crucial to a child’s long-term development.

As President of the Autism Science Foundation, I’m here to say grandparents have a vital role to play in



Grandparents bring a unique perspective to the parenting experience because they have done it all before—and in many cases, they've done it multiple times.



diagnosing and treating autism, and I encourage them to make their voices heard in appropriate situations. The impact they make in this area should be recognized and discussed, as continued vigilance will lead to improved outcomes for the next generation.

There are still so many mysteries surrounding autism, but one thing we do know is that early intervention is critical to getting children the support they need and ultimately setting them up for the best possible outcomes down the road. A [study](#) shows that addressing deficits early in life is key to maximizing developmental gains.

This can't happen without early detection, and that's where grandparents have a vital role to play. Grandparents bring a unique perspective to the parenting experience because they have done it all before—and in many cases, they've done it multiple times. They also may have experience watching nieces and nephews, other grandchildren, the children and grandchildren of friends, and so on. Often, they are more attuned to childhood development milestones than new parents and can draw upon their years of experience to identify traits or quirks that may be worth discussing with a professional.

There's also the simple fact that most parents of young children are in a perpetual state of exhaustion. Even the most attentive parent can easily miss an early warning sign of autism, and a fresh set of eyes can make all the difference in the world.

In a [study](#) of over 2,600 grandparents of children with autism spectrum disorder (ASD) by the Interactive Autism Network; the data illustrates that 30% of grandparents said they were the first to notice signs of an ASD, while an additional 49% supported others who noticed a problem. In addition, a [study](#) from Mount Sinai Hospital in New York called *Grandma Knows Best: Family Structure and Age of Diagnosis of Autism Spectrum Disorder* indicates maternal grandmothers and teachers are often the first people to have concerns.

"Many parents avoid seeking help to find a diagnosis for their child, even though they know something might be wrong," says study co-author Nachum Sitcherman, PhD. "They often ignore signs of a larger problem and look the other way, making the role of close family members and friends vital to accelerating diagnosis and helping a child's condition."

The study also found frequent interaction with a grandmother reduced the age of ASD diagnosis by 5.18 months, and frequent interaction with a grandfather reduced the age of diagnosis by 3.78 months.

As the mother of a daughter with an autism spectrum disorder (ASD), I have firsthand experience with a teacher being the first person to bring symptoms to my attention. In my case, early signs were first spotted by my daughter's preschool teacher. When she brought her concerns to my attention I did not respond well. I started yelling at her and used words that don't belong in any preschool. But years later, after my daughter was thriving in a special education preschool, I went back to her, bagels in hand, and thanked her. Your child, or especially a daughter-in-law, may not react well at first if you express concerns, but I promise you, down the road he/she will be very grateful.

Even if armed with the facts and the right attitude, grandparents may still feel apprehensive about broaching the subject, but the stakes are too high not to act. That voice in your head saying: "It's not my place," has no place here. When it comes to a child's future, it's always better to be safe and sorry, even if it takes you out of your comfort zone.

It can be useful to educate yourself on some of the early warning signs, even if your grandchildren appear to be developing typically. The CDC has produced an [extensive list](#) of early warning signs. These warning signs vary widely among different children and across different age groups, but many of them relate to responsiveness, speech, and physical development. With many of these behaviors, professional intervention is often a good idea even if it doesn't result in an autism diagnosis.

My message to grandparents is one I will borrow from the Department of Homeland Security: if you see something, say something. Your years of parenting experience and outside perspective are invaluable tools for parents of young children, and they can play a big role in helping future generations reach their full potential. The world may be changing, but this is one arena in which you can always make a difference in the lives of your loved ones.

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Grandma knows best: Family structure and age of diagnosis of autism spectrum disorder, Nachum Sichernman, George Loewenstein, Teresa Tavassoli, and Joseph D Buxbaum



Alison Singer is the co-founder and president of the Autism Science Foundation. Alison manages the foundation's strategy and directs it to fulfill its mission of supporting autism research and educating the public to increase awareness of autism and the needs of individuals and families affected by autism. Alison served on the federal Interagency Autism Coordinating Committee (IACC) for 12 years. She currently serves on the executive boards of the Yale Child Study Center, the Seaver Autism Center at Mount Sinai School of Medicine, the Marcus Autism Center at Emory, and the Autism Research Center at the University of North Carolina at Chapel Hill. Alison is a member of the board of directors of the International Society for Autism Research where she chairs the communications committee. She graduated magna cum laude from Yale University with a BA in Economics, and has an MBA from Harvard Business School and an honorary ScD from Emory.

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Parent Skill Acquisition through Video Modeling

By Maria GILMOUR, PhD, BCBA-D, LBA, and Bryan DAVEY, PhD, BCBA-D, LBA

Discover how video modeling has had a positive and empowering influence on parent-child therapy interactions.



In recent years, the use of telehealth services in the field of Applied Behavior Analysis (ABA) has grown substantially. The current health crisis related to COVID-19 and social distancing recommendations shifted many ABA providers toward telehealth to deliver services remotely to children and their family members.

From our recent experience as behavior analysts using this method as the sole means for service delivery, we have witnessed an escalated adoption rate and unique evolution of video modeling for parents and caregivers. The use of video modeling within telehealth programming allows practitioners to not only continue providing treatment to individuals and their families while following social distancing

guidelines, but it also allows for parents and caregivers to acquire skills from viewing video modeling assignments with their children.

Adapting to the new world

Since the onset of the pandemic, we have increasingly integrated parents and caregivers into the delivery of ABA in novel ways. Parent or caregiver mediated therapy naturally increased with limited face to face therapy. Interestingly, we have observed a change in caregiver behaviors in how they interact with their children during virtual therapy visits. Specifically, parents are watching video models with their children and actively imitating skills demonstrated in the video model. In this manner, parents have also

undergone behavior shaping contemporaneous with their child. Numerous observations from our own practices testify to this process.

Parents' engagements

For instance, we have observed one parent change the way she provided prompts and directions to her child after viewing a video model targeting a specific request provided to a child by a therapist. Having observed the parent's words, volume, tone, and cadence of her language had drastically changed, we asked her why she thought her communication with her child was different now. She said she was imitating the videos her child watched and he was responding to her just like he responded to us when we were in the home prior to transitioning to telehealth-only services. Some of these responses from the child included looking at the parent in the face, imitating her actions, having fewer challenging behaviors, and following her vocal instructions to complete one-step actions.

As a further benefit of the video modeling sessions, the parents are not only developing their own ability at modeling appropriate behaviors, but are increasingly becoming more active participants in their child's therapy. We have observed this spike in engagement by parents to be empowering. Parents view themselves as gaining some measure of control over a sometimes challenging or chaotic situation.

Introduction to Gemiini systems therapy

In response to limited face to face therapy sessions, we boosted our use of Gemiini Systems' therapy software. Gemiini provides on-demand "discrete video modeling" presenting repeated learning opportunities, similar to a behavior therapist providing repetition of concepts via flashcards, objects, and modeling actions. Discrete video modeling provides clear examples with minimal words. In the example with the parent above, her child watched a discrete video model of the concept "stand up" and the child watched this video on a loop daily in the morning and in the evening. During our telehealth session we observed the parent clearly say to her child, "Stand up," after getting his eye contact while providing the model to stand up as seen in the discrete video model.

Our behavior therapy team members have shared their observations of parents and caregivers changing the speed, repetition, number of words, and tone they

use when providing directions to their child. We have also seen caregivers are more successful in gaining their child's attention by modeling skills in the same way they are presented during the video models, increasing the number of appropriate and functional interactions as well as providing positive reinforcement in the form of improved eye contact and more frequent social smiles between the child and caregiver. In addition, we have used video modeling showing the child's actual engagement in the skill, and later integrated those videos into the child's assignments.

Although we have observed gains in engagement and skill acquisition from video modeling in caregivers, further research is needed in this area. Given the growing need for non-face to face therapy modalities, both at the present and continuing after the crisis, we look forward to parents and therapists working together to better understand the most effective strategies for family involvement via telehealth service.

Bryan Davey, PhD, BCBA-D, LBA is Board Certified as a Behavior Analyst at Doctorate level (BCBA-D) and a Licensed Behavior Analyst in AZ and MI. His clinical expertise includes training organizational personnel in the application of behavioral principles and procedures, functional behavioral assessments, assessment and treatment of severe and complex behaviors, intervention implementation, and effective teaching practices. Dr. Davey's professional experiences include being an administrator, past certified special education teacher, consultant to schools, businesses, health plans, state agencies and behavior analytic agencies nationwide, as well as an agency owner.

Dr. Maria Gilmour, PhD, BCBA-D, LBA, is a BCBA-D, licensed in WA and OR. She has been working in the field of autism, behavior disorders, traumatic brain injury, and ABA for the past two decades. Dr. Gilmour is the CEO of Wynne Solutions and the CCO of Gemiini Systems. She has been using telehealth methods since 2007, after graduating from the University of Georgia with her doctorate in special education. Dr. Gilmour focuses her clinical support on building capacity of care with parents and educators through parent education programs and multi-disciplinary collaboration. Her research interests include using technology to teach individuals with exceptionalities, specifically video modeling methods. Currently Dr. Gilmour resides in the Pacific Northwest where she supports families and clinicians across the world via telehealth.

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Reporting vs Tattling: *Teaching Kids With Autism When to Tell a Trusted Adult*

By Leanne STRONG

A young woman with autism offers her perspective on what instances children should share with a trusted adult and what small infractions, if reported, could lead to being known as a “tattletale”.

Hi, my name is Leanne, and I am a young adult who is on the autism spectrum (my diagnosis used to be known as asperger’s syndrome). I know some people with disabilities struggle to know when they should attempt to address a situation on their own, and when to seek help.

Some individuals might seek help over even the most minor infractions, because they want to make sure

everybody is doing exactly as they are supposed to. This is likely to eventually cause a rift between the individual and their fellow students, teachers, and later, their coworkers, supervisors, and/or managers. Other individuals might take it to the other extreme and not inform an adult about even the most serious incidents, because they think doing so is tattling. If a serious issue occurs and an adult is not informed about it, significant injury or other problems can result.



I hope this article will help people on the spectrum and their parents with learning when and how to report situations. If you choose not to use terms such as “reporting” or “tattling,” you can use terminology such as, “I **should** tell an adult if...” or “I **do not need** to tell an adult if...”

REPORTING (I should tell an adult if...):

- I am being made to feel unsafe or uncomfortable
- Somebody else is being made to feel unsafe or uncomfortable
- Somebody is doing something harmful or destructive
- Somebody talks about doing something harmful or destructive
- I am sick or injured
- Somebody else is sick or injured
- I have tried several times to address the issue, and have been unsuccessful
- There is no other way to handle the situation

TATTLING (I do not need to tell an adult if...):

- I am not being made to feel unsafe or uncomfortable
- Nobody else is being made to feel unsafe or uncomfortable
- Nobody is doing anything harmful or destructive
- Nobody talks about doing anything harmful or destructive
- I am not sick or injured
- Nobody else is sick or injured
- I have not tried handling the situation myself, or some of the strategies I have tried have been successful
- There is another way to address the issue

Here are some examples of **REPORTING** (times when you **SHOULD** tell an adult):

- “Kyle is running toward the road, and I am worried he might get hit by a car.”

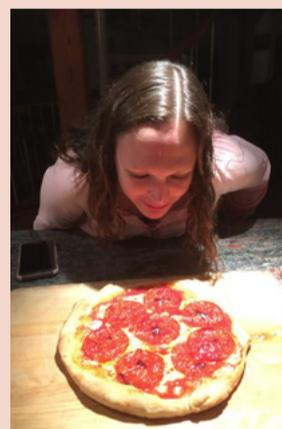


- “Brianna touched me in an area where she’s not supposed to.”
- “Dan tried to get me to touch him in an area where I don’t feel comfortable touching him.”
- “I overheard Joan and Lynda talking about how they are planning on going to the mall this weekend, and ‘accidentally’ take some very expensive items without paying. I told them, ‘No, girls! That’s stealing!’”
- “David keeps saying this, and I don’t like it. I have asked him several times not to say it, but he keeps saying it.”
- “Courtney keeps cutting in line. I have reminded her to wait her turn on several occasions, but she won’t stop cutting in line.”
- “Greg just threw up over there.”
- “Holly hit me and Brian threatened me.”
- “Ashleigh told me her mom hurts her physically.”
- “Brandon threatened Jason.”
- “Noelle keeps teasing me. I have asked her to stop several times, but that just seems to make it worse.”
- “Mike is showing parts of his body we do not need to see.”
- “Nicole is trying to get me to show parts of my body I do not feel comfortable showing.”
- “Charles just fell down and Melissa got hit in the head.”
- “Jake is taking more than his fair share of the brownies.”
- “Lisa is hogging the ball, and won’t give anyone else a turn.”
- “George won’t share.”
- “Susan is doodling on her paper instead of doing her work.”
- “Bob is doing his work the wrong way.”
- “Jessica took my pencil.”
- “Kevin and Adam won’t let me play with them.”
- “Sarah and Brittini won’t let me sit with them at lunch.”
- “Mark cut in line.”
- “Stephanie said a bad word.”
- “I couldn’t get a drink, because Mikey took too long at the drinking fountain.”

In closing, I want people with autism spectrum disorder or other challenges to understand it is a good idea to tell a trusted adult about serious incidents, but coming to trusted adults about minor issues should be avoided. As I mentioned earlier, if someone informs an adult about minor infractions, it may eventually cause people not to want him/her around. On the other hand, if someone witnesses a serious incident and doesn’t tell an adult about it, someone could get hurt, or there could be a problem.

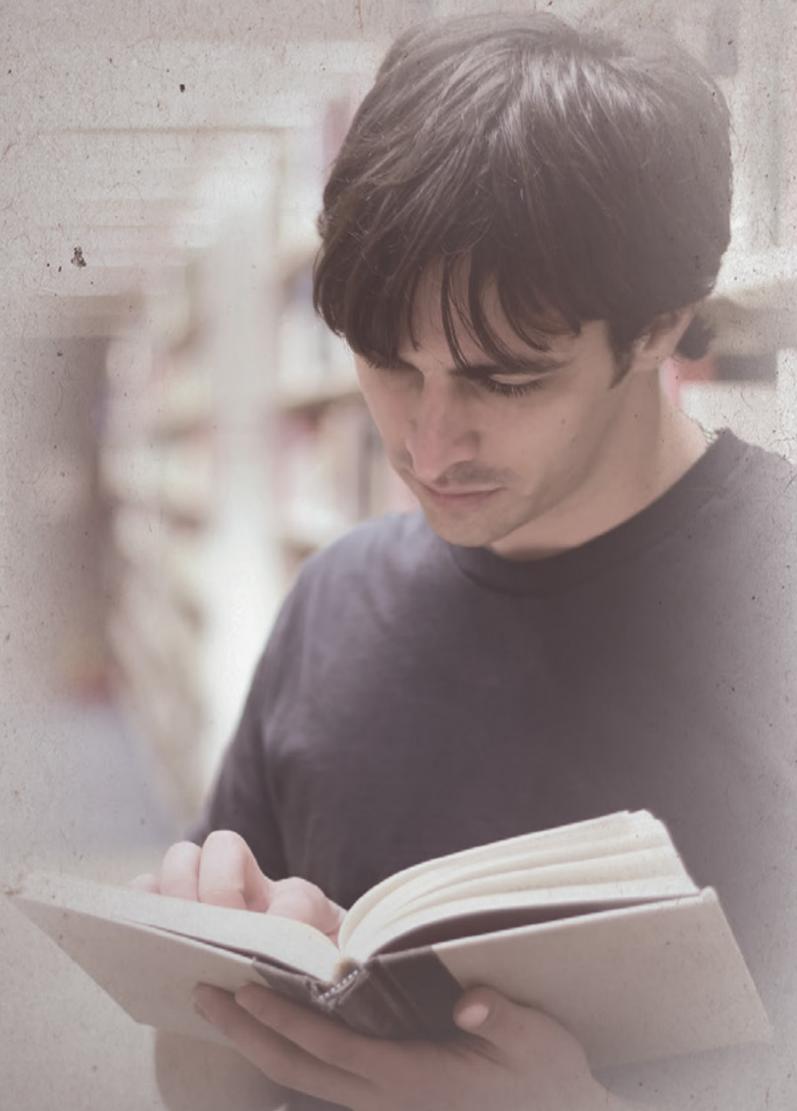
Here are some examples of **TATTLING** (times when you **DO NOT NEED** to tell an adult):

- “Sharon took the last of the mint chocolate chip ice cream, and Diane wanted it. We begged and pleaded with her to give it to Diane, but she won’t give it.”
- “Fred said this, and I didn’t like it.”
- “Maggie is in the wrong spot.”
- “Connor didn’t save me a seat on the bus, like he told me he would.”
- “Hayleigh won’t let me have one of the muffins she brought with her.”



Leanne Strong is a young adult from Upstate New York. She was first diagnosed at age two-and-a-half with a language disorder, as well as sensory processing issues but, after further testing, it was determined she had an autism spectrum disorder then known as pervasive developmental disorder-not otherwise specified (PDD-NOS). However, her parents felt this diagnosis did not fit her, as she never had any significant delays in verbal communication or cognitive skills. At age 15 or 16, she was rediagnosed with a form of autism then known as asperger’s syndrome.

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AN AUTISM INTERVIEW

with

Ava Hart

By Derrick HAYES

Encouragement Speaker Derrick Hayes gives an AUTISM Interview by asking six questions through each letter in the word AUTISM to give readers an insightful perspective from parents, experts, entrepreneurs, and other leaders in the field.

Ava Hart was born into a family of singers and performers and has been singing since the age of 12. She has taught music, and for the past 14 years has worked as a vocal coach and instructor to academics, dance studios, and theaters. She is the mother of a young child with autism and this is the basis of her song, *Mothers Day—The Mother's Tale*. For additional information about the song and Ava, go to <https://www.davidarn.com/>.



is for Awareness—When and how did you first become aware something was different?

Maybe it was my ignorance, since this was my first child, but I didn't really notice anything. Friends would make comments about lack of eye contact or "Why isn't he talking yet?" It was finally our pediatrician who pointed out he was missing big milestones. He was sent for many assessments, while I was still in denial.



is for Unique—How has this experience been unique for you and your child?

I had many opinions on parenting before I had kids. I would look at a child misbehaving and think I would never allow my child to act like that. I knew nothing really. I have learned what works for one child doesn't



work for every child. We have seen growth over the years, with therapy, but our experience looks different than the next person's. Each child is unique and you have to find, and keep finding, new ways to work with him/her.



T is for Tools—What tools are there now that were not there in the beginning that could help other parents?

Support groups — find other parents who have walked this road already. You will gain friendship, support, education, and even a shoulder to cry on.



I is for Inspire—As a parent, when you look at your child or children, what inspires you?

I celebrate everything with my son. It has been a long road to get where we are now and we are still learning. Many may see his growth as slow or behind, but being his parent, I know what huge strides it took to achieve each new milestone.



S is for Support—Are there things you struggle with or have struggled with and what types of support do you still need?

I still struggle with wanting him to be accepted by everyone. Kids can see the differences and can be

cruel. Inclusion education for children is progressing, but I wish there was more.



M is for Manage—What keys to success can you leave with parents so they can better manage their day to day efforts?

Take a breath. Every day may be different. You may have great days or days where you just need to cry. Sometimes people, trying to be helpful, will say things that upset you. Try to remember you know your child better than anyone else — you are his/her advocate. Speak up when your child can't and don't let the opinions of others get the best of you. You're doing great!

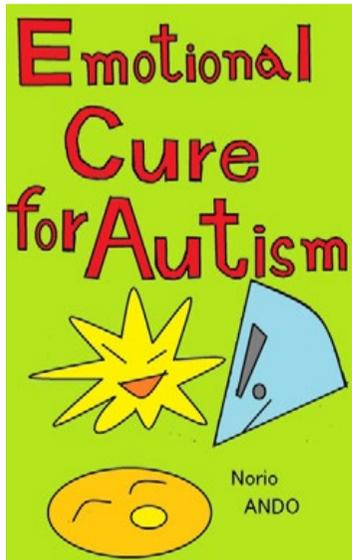
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DID YOU KNOW YOU CAN IMPROVE AUTISTIC BEHAVIORS BY ENCOURAGING RELAXED PLEASURE?

EMOTIONAL CURE FOR AUTISM:

Unknown Contribution of Relaxed Pleasure

By Professor Norio Ando



Autistic children tend to express tensioned pleasure which promotes a rigid mind and narrow range of consciousness. Look as Professor Ando explains how to elicit relaxed pleasure and ease tensioned emotion in this book in detail.

Norio Ando is a certified clinical psychologist and professor at Uekusa-Gakuen University, in Japan. He has treated autistic children for 37 years focusing on emotional development.

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Reframing Tips: *Defiant or Holding Strong Beliefs*

By Karen KAPLAN

How to support children on the spectrum who may have difficulty understanding why others do not share the same opinions and beliefs.

PROBLEM FOCUSED	SOLUTION FOCUSED
bossy	natural leader, manager and director
defiant	holds strong beliefs, bold, determined
demanding	knows what they want, outspoken
dramatic	expressive, passionate
fearful	cautious, careful, protective
fussy	has strong preferences
hyperactive	energetic, enthusiastic, on the go
impulsive	spontaneous, instinctive
inflexible	prefers order and predictability
oppositional	advocates for a different perspective
stubborn	persistent, tenacious, steadfast
talkative	enjoys communicating, articulate
tattletale	seeks justice, respects rules
unfocused	multitasks, pays attention to many things
just wants attention	seeks connections

How wonderful it is for a child, teen, or adult to have strong opinions and not be afraid to express them. A commitment to accomplishing something can be admirable, but how do we help those on the spectrum not get labeled as simply defiant for their strong commitments?

How do we help them understand each of us is likely to have strong beliefs and we must be respectful and tolerant of others' opinions? How do we help them accept others may not agree with our beliefs?

How do we help them not to become hostile, combative, or resistant to others' thoughts, ideas, and feelings and be labeled defiant?

Ideas

I suggest we start with teaching the concepts of sharing and taking turns. We start with teaching how to listen to others' stories. We read books to our children about different people having different ideas and making contributions in our world. We teach how to be respectful to mothers, fathers, grandparents, brothers, sisters, and classmates. We teach greeting people, thanking people, and valuing others.

Also label people's feelings to them — point out facial expressions and what they mean. Talk about inside and outside voices, standing too close to others and allowing others to finish what they have to say.

Have them explore debate clubs — there are always two sides presented at a debate meetup. Each side must develop sound arguments for each position. Let them see there are at least two sides to every argument.

Use the dinner table to discuss topics and encourage each member of the family to express his/her perspective about the topic. Show your child there are always different feelings and thoughts about a topic.

Write down how it feels when someone disagrees. Point out to him/her that others' feel the same way as they do when they are disagreed with.

Teach effective conversation skills. Teach how the intonation and volume of their voice affects others and may turn others off to their ideas and beliefs.

Watch films of lawyers presenting cases. See if the audience can see what types of communication skills the lawyer is using.

Help them see how there are different styles of talking to different kinds of people in their lives. What kind of respect will they need to develop when speaking to their grandmother or grandfather? What about a classmate? boss at work? What about someone younger? A man versus a woman? What about an expert in the field of their topic?

Persuasive techniques should be researched. Alert them to the fact some people are convinced through reason, logic, and research; while others are more swayed by emotion. They need to know that just because they believe a certain way does not mean someone else is going to. They have to see that arguing with the other person may not get the oth-

er to respond in the desired way. After offering their thoughts and ideas to support their strong belief, they might have to accept the other person has a different strong opinion and move on. Screaming louder, demanding, or becoming aggressive will not move a person into accepting a different opinion—it is more likely to only push them further and further away.

According to language experts, generally we learn these things naturally, but a person on the spectrum may need to be taught social perspective, conversation skills, and etiquette. He/She will need to learn how his/her words affect others, that everything isn't black or white, right or wrong. He/She will need to learn about collaboration, cooperation, and how different ideas help build businesses, laws, and scientific discoveries, even when finding answers to medical issues.

Individuals with autism will need to know there are many ways to resolve and solve problems. Therefore, it's okay to hold strong opinions and it's okay to have determination, but we all must be taught socially appropriate, effective communication and emotional strategies in delivering our opinions and using our determination.

Defiant? No.

Sharing strong ideas? Yes.



Karen Kaplan just completed 10 years as Executive Director of Wings Learning Center, a school for children five to 22 years old with autism spectrum disorders, located in Redwood City, CA. She served as an instructor in the Autism

Spectrum Certificate program at Alliant University. She completed her BS and MS in Speech Pathology from ASU. She minored in Special Education and holds an Educational Administrative Credential and Moderate to Severe teaching Credential. She has sat on non-profit boards to help build capacity for those with special needs. She founded and directed a residential school for nearly 20 years in Sacramento. She is an author and speaker. She spent time globally helping non-governmental agencies in Indonesia and Africa. Currently she is consulting with families, schools, and adult programs. Connect with her at www.karenkaplanasd.com or send her an email: karensupportsu@comcast.net

Online Therapy:

Does it Work and How?

By Karla PRETORIUS



To be completely honest I had my doubts when we introduced online services at AIMS Global. We, just like the rest of the world, had to adapt to a “new normal” and thus created training workshops to help our current therapists transfer their amazing “in-home” support to a virtual platform. With any change, anxiety increases in us all, but this change was especially stressful for our parents.

Parents with neurotypical children felt uneasy with schools being closed and education needing to be conducted at home. Our parents who have special needs children felt overwhelmed, understandably so. Not only were they now expected to work from home, but they were without their therapists, who have always been able to “manage the behaviors”

and provide input the child possibly craved. I do believe the change of employing more virtual or online therapists is inevitable and of course exciting in many regards. Let’s discuss some of the benefits.

Five benefits of online therapy:

- 1.** You can generalize skills immediately—if you have an online therapist you will most probably need a *therapy partner* at home who can guide your child through the session. This is an excellent way to pick up strategies from the online therapist to the home environment and ensure generalization (which usually takes a bit of time) occurs almost instantly! It also provides you, the parents, with the power to “manage” your child’s behaviors and urges by yourself.

“ You don’t have to drive to various therapists, sit in traffic, go to crowded spaces, etc. ”

2. You are able to fade some hours of therapy out. Most organizations will suggest eight hours of ABA therapy per day, five days a week. If you do online therapy for a couple of hours a day and then generalize these strategies to the rest of your child’s day with the people in his/her life utilizing these, you are providing him/her with the therapy tools he/she would receive from his/her therapists.

3. You don’t have to drive to various therapists, sit in traffic, go to crowded spaces, etc.—Most of our families are doing an exceptional job in driving from one place to another to include all the different therapies and activities. Imagine doing therapy online and then having time to enjoy your mornings or afternoons relaxing or going on an outing with no expectations placed on you or your child.

4. It is affordable! Unlike paying three different therapists per day to do hourly-rate sessions with your child (in many cases), online therapists are charged per month and prices should be lower than going to a therapist.

5. You are changing, adapting, and evolving with the world. We know life is much more virtual now and this was the case even before all the different lockdowns were put in place. Change is always difficult, yet it is inevitable for growth. Most schools now ask learners to work on iPads and laptops and to type rather than write. We want our kids to always feel they are evolving with their peers and thus provide them the

same opportunities their siblings and friends are receiving.

Great, but how does online therapy actually work?

I also understand if you are working from home or may have to in the future, you rarely have hours to dedicate as a *therapy partner*. I want to assure you the end-goal of any good online program is for your child to work independently, as much as he/she can, and for you to have a break or time for your work or being with your other children. I am going to write about a typical online program and detail the process, but these requirements might differ to various organizations.

1. Usually the organization will require your child’s latest reports and any other information you feel is important together with some videos of how he/she communicates, plays, reacts in various environments, etc. It is important any organization or therapist requests this type of information as it is crucial to always try and make the best possible fit of a therapist’s experience and passion with your child’s personality, needs, and strengths.

2. You, as the parent, will typically receive a short-list of candidates who you can choose from to interview and get to know before you make the decision of who you want to work with as your child’s therapist. It is important too that you feel empowered by the organization and are able to make these decisions together. You ultimately know your child best!

“ You are changing, adapting, and evolving with the world. We know life is much more virtual now and this was the case even before all the different lockdowns were put in place. Change is always difficult, yet it is inevitable for growth. ”

3. Once you have chosen your therapist, you can start therapy—easy, right? The first week is an important time for your therapist to get to know your child and will entail more observations, where you can do fun activities and the therapist will use Zoom or Google Meet to do a video call. Once your child and the therapist have established a positive rapport, the therapist will include **daily** lesson plans that include the concepts (from the Individual Educational Plan created within the first week) into fun and interactive activities.
4. Your role as the *therapy partner* will be to guide your child to engage in the activities, but you should receive training to feel equipped to do so. Typically, organizations will offer an initial training workshop to the *therapy partner* which will provide strategies to generalize what the *online therapist* does to the home environment. At AIMS Online we provide parents with a [free starter pack](#) which includes strategies they can implement immediately to ensure a conducive environment for learning.
5. Typically, within the first 10 days, children are willing and perfectly able to do sessions almost independently with their online therapist and will only need assistance here and there with loading of videos or imitating dance moves.

Parents should receive feedback, video observations notes, ongoing reports, and recordings of the sessions from their therapist’s supervisor. A good online program will make you feel in control of your child’s program and progress. It will take you along the journey of supporting your child in a fun and functional manner.

I am more than happy to answer any questions or discuss any concerns you might have of online therapy. I feel privileged to be in the position where a form and type of therapy has even surprised me after all the years of working in the field.



Karla Pretorius is one of the two directors of AIMS Global and co-developer of AIMS support system. She started working in the field of autism in 2002 and has played an instrumental role on an international level in advocating for autism awareness, acceptance, and understanding. Karla received a double Honours degree in the US and South Africa as well as completed her Masters degree in Psychology through the University of Stellenbosch as a Research Psychologist.

Karla, together with her colleague, Nanette Botha have presented in many countries, such as Denmark, Indonesia, Singapore, South Africa, and the US. They have collaborated with autism advocates and adults on the spectrum by providing a holistic support system that evolves as our understanding of autism does too. She is a major role player in the autism revolution. Karla currently resides in Portugal but travels all over the world to work with clients. Her passion for autism drives her to continue learning from her amazing clients, their parents, adults on the spectrum, and professionals in the field.

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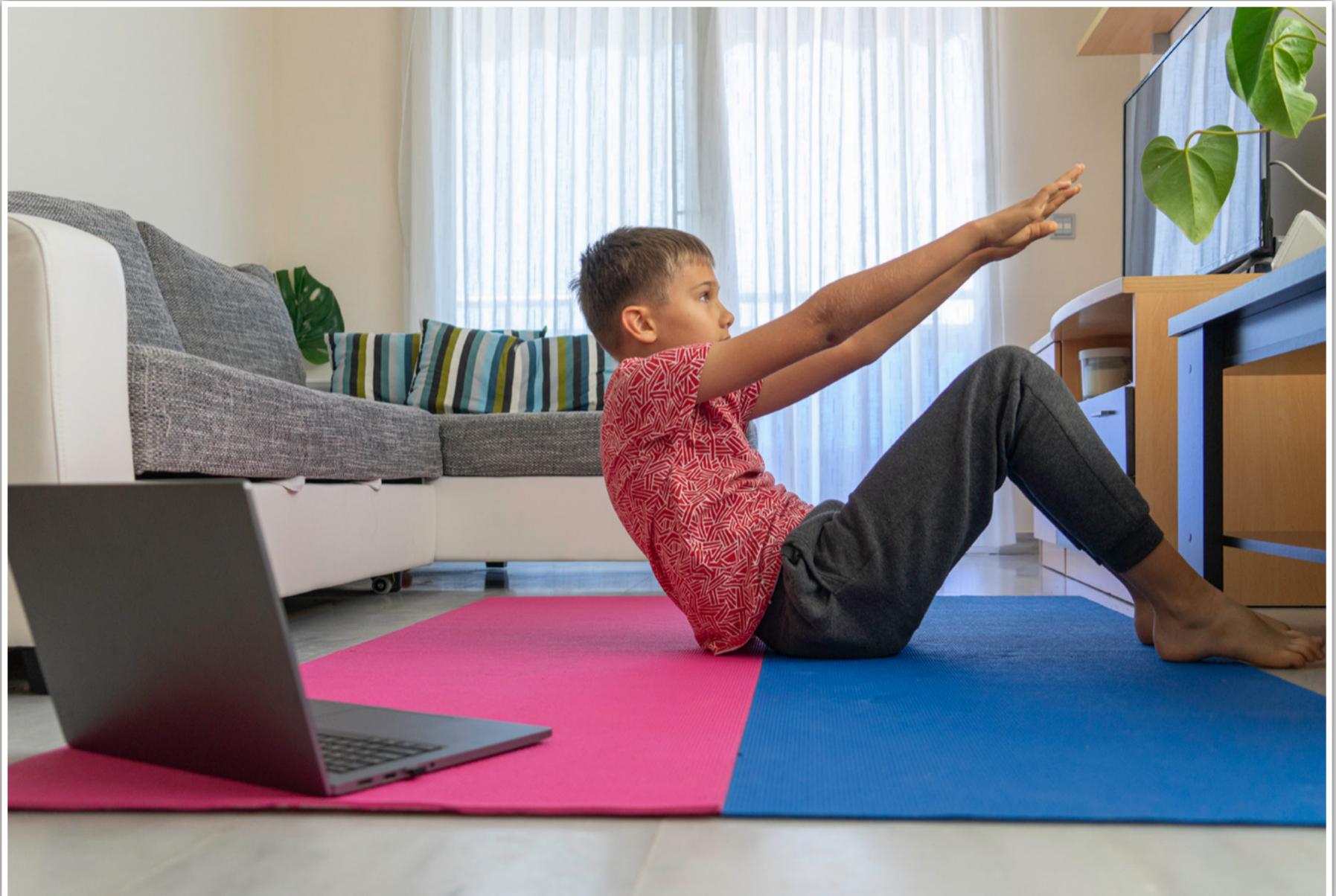
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Occupational Therapist Viewpoint: Supporting Home Learning Through Movement

By Sarah ALLEN, OTR/LSCSS and Megan HUGGINS OTR/L



The COVID-19 Pandemic has led to significant changes in daily life for children, youth, and their families. According to [the BMC Public Health](#) children in the United States performed less physical behavior and increased their sedentary behavior.

The pandemic has changed how children access their education. Different options for school now exist: remote models (students stay home and learn), hybrid models (students go in part time), or in person models (students come in for in person learning full time). These new models have brought with

them changes to children's routines and, for many, an increase in screen time and sedentary behavior.

Children and youth with autism tend to be less physically active compared to the general pediatric populations. Due to these circumstances, it is important to highlight the significance of movement throughout your child's day in order to sustain their focus and attention and promote positive mental and physical health. In this article we will provide simple ways to embed movement in your child's day.

Let's talk about movement.

What is a movement break?

A movement break is a brief interval of time that allows children to move their bodies and should be done throughout a child's school day. Breaks as short as two to five minutes can be beneficial, when implemented throughout the day. Movement breaks are a strategy commonly used by school-based occupational therapists. These breaks may be implemented as a whole-class activity or the occupational therapist may create an individualized plan to meet a student's specific needs.

Why is movement important?

Research has shown physical activity can increase brain activity. Brain plasticity and cognitive function are significantly improved by physical activity. Simply put, the brain reacts positively when the body is physically moving. One [study](#) demonstrated students who had aerobic exercise in their day performed better academically than their peers who were sedentary. Providing your child with regular movement breaks throughout their day can increase their participation in physical activity and other productive occupations. One study found that children in classrooms that utilized movement breaks were 75% more likely to meet the recommended amount of daily physical activity. Movement breaks were also associated with more on-task behavior, fewer behavior problems, and fewer students demonstrating decreased effort.

The Center for Disease Control (CDC) gives the following recommendations for physical activity:

- Ages three to five: Physical activity everyday throughout the day. Active play through a variety of enjoyable physical activities
- Ages six to 17: 60 minutes or more of moderate to vigorous activity daily
- As part of the 60 minutes, on at least three days a week, children and adolescents need:
 - Vigorous activity such as running or soccer
 - Activity that strengthens muscles such as climbing or push ups
 - Activity that strengthens bones such as gymnastics or jumping rope

For more information on physical activity, visit the CDC website [here](#).

Later, we describe ways to provide movement opportunities for your child at home. We have also included an example schedule of when to incorporate movement into your child's school day routine when learning from home.

Movement and mental health

Occupational therapists understand the importance of movement on children's mental health and seek to promote children's participation in meaningful activities. Meaningful movement activities can include academics, play, and social participation. The COVID-19 Pandemic has significantly impacted the way children are able to engage in their typical daily occupations. Virtual learning may lead to an increase in screen time and sedentary activities.

Parents, practitioners, and educators alike have expressed concerns with the impacts of the COVID-19 Pandemic and how the resulting changes in our children's lifestyle and schooling may impact their mental health. Changes in routine, loss of social support, and added fears and anxiety have the potential to detrimentally impact our children. Fortunately, incorporating movement into your child's day is one simple way to promote positive mental health.

According to the World Health Organization (WHO), physical activity has been associated with the development of healthy behaviors, opportunities for self-expression, and the building of self-confidence. Studies have also found that less screen time and more physical activity are associated with a lower risk of symptoms of depression, anxiety, low self-esteem, and life dissatisfaction. While screen time is necessary for your child's education right now, even moments of stepping away from the screen and engaging in physical activity could decrease these risks!

Helping your learner

Not only can incorporating movement into your child's day promote positive mental and physical health, but it can also help improve their school performance. It is important to be mindful of reasonable expectations for sustained attention, based on age. [Illinois State Guidelines](#) recommend the following:

In addition to setting age-appropriate expectations for screen time and sustained attention, incorporating

Grade Level	Minimum Screen Time	Maximum Screen Time	Recommended Length of Sustained Attention
Pre K	20 minutes /day	60 minutes/day	3-5 minutes
K	30 minutes /day	90 minutes/day	3-5 minutes
1-2	45 minutes /day	90 minutes/day	5-10 minutes
3-5	60 minutes /day	100 minutes/day	10-15 minutes
6-8	Class: 15 minutes/ day	Class: 30 minutes/ day	1 subject area
	Total: 90 minutes/ day	Total: 180 minutes/ day	
9-12	Class: 20 minutes/ day	Class: 45 minutes/ day	1 subject area
	Total: 120 minutes/ day	Total: 270 minutes/ day	

movement in your child's day can also promote improved attention and behavior. According to multiple studies, even adding just ten minutes of movement to your child's school day has been linked with increased on-task behavior and motivation, decreased reports of negative classroom behavior, and improved cognitive functioning. These component parts lead to improved overall academic performance.

Many children with autism exhibit differences in their sensory processing and behavioral responses to sensory input. These differences can impact classroom behavior and academic performance. School-based occupational therapists often suggest sensory strategies and movement breaks to aid in participation and attention in the classroom. Strategies are personalized depending upon the child's preferences of sensory input.

Keep it simple and fun! Movement breaks do not require a significant amount of space or equipment but

should be incorporated into their regular routine. For example, a movement break could be as simple as jumping in place or taking a break to stretch. Other examples include, having your child help set the table or get items out of the fridge for mealtime. Changing position while your child is completing school tasks can also be beneficial. Instead of sitting your child could stand or lay on their stomach. Whether your child participates in chores, changes positions, or completes a more structured movement activity, it is just important he/she moves!

Sample schedule for movement breaks

You know your child best and what helps him/her stay focused. Use this schedule as a model of when you could incorporate these movement breaks into his/her day. Think of movements that are already a part of your child's natural routine as well as activities or exercises your child enjoys. Replace the activities in the sample schedule as appropriate for your child.

Wake up 7:30 AM	Start your day off with jumping on the bed or dancing to a song
Breakfast 8:30 AM	Have your child help set the table and put dishes away
Movement break 10:00 AM	Pick three yoga poses
Lunch 12:00 PM	Crab walk to and from lunch—no screens if possible
Movement break 2:00 PM	Wall push-ups or regular pushups
Movement Break 4:00 PM	Arm circles or hopping in place
Dinner 5:30 PM	Frog jumps to and from dinner table—no screens if possible
Movement Break 7:30 PM	March in place

The COVID-19 Pandemic has led to significant changes in the way that children are educated. As children transition to virtual learning, they also face a loss of predictable routines, social supports, and participation in meaningful activities. Movement breaks are

a simple way to prevent detrimental effects on children’s physical health, mental health, and academic performance. Movement breaks can be implemented easily by parents without the need for any special equipment or supplies. Let’s get our kids moving!

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Empowering Pediatricians to Diagnose Autism

By David HAPPEL



Nearly 80 years after psychiatrist Leo Kanner became the first physician to use the term “autism”, children and families with autism still face critical gaps and unnecessary delays on their way to a diagnosis.

Rather than diagnosing children themselves, pediatricians typically refer children with suspected developmental delays to specialists—setting off what is often a long and arduous path toward diagnosis—a necessary first step to receiving treatment. In most cases, initial parental concerns are expressed at around [14 months old](#), however, the average age of autism diagnosis has remained unchanged at [4.3 years](#) of age for [over 15 years](#). In the current system, families often experience long specialist waitlists for diagnoses resulting

in precious treatment time being lost—potentially impacting the child’s developmental progress and making it more difficult to achieve optimal long-term outcomes. Further complicating a timely diagnosis, significant [disparities](#) exist when it comes to autism diagnosis for girls and ethnic and racial minorities. On average girls are diagnosed 1.5 years later than boys while one in four children under age eight living with autism (most of them Black or Hispanic) are not being diagnosed at all.

Cognoa’s Autism Diagnostic aims to change this reality. Soon to be submitted for approval by the U.S. Food and Drug Administration (FDA), the AI-powered device is specifically designed for use by pediatricians—enabling accurate diagnoses in the primary care setting to enable early intervention. Cognoa’s mission?

A transformative approach to autism care to improve lifelong outcomes for children and their families by enabling equitable access to early intervention.

A new model for autism diagnosis

As research published by the American Academy of Pediatrics (AAP) [notes](#), pediatricians “can significantly affect the outcome of children with autism by making an early diagnosis and providing referral for evidenced-based behavioral treatment.”

Serving as the first line of care for the [one in 54 American children](#) affected by autism, pediatricians are perfectly positioned to assess and diagnose potential cases. Making it easier for pediatricians to diagnose autism could slash the months—or even [years-long delays](#) that many families experience waiting for a diagnosis.

Autism-specific early intervention—defined as the initial onset of treatment before the age of six—can be a gamechanger for children and their families, with children who receive early diagnosis and treatment experiencing [twice the cognitive gains](#) of children who do not. Children diagnosed and treated earlier in life are also more likely to [integrate into mainstream schools](#). Simply put, when physicians are empowered to act during critical neurodevelopmental windows, children have the opportunity to receive better, more effective care.

Augmenting the role of the specialist

Where does this leave the specialist?

Rather than referring the majority of children with suspected behavioral health concerns to specialists for assessment, pediatricians can begin to rule out or diagnose autism, removing the easier-to-diagnose children from specialist caseloads. Relieved of these bottlenecks, specialists can train their focus on more complex, harder-to-diagnose cases. This will accelerate and streamline the autism diagnostic journey—to the benefit of children with autism, their families, pediatricians, and specialists alike.

Cognoa’s Autism Diagnostic

Where does Cognoa’s autism diagnostic solution fit into this picture?

Cognoa [recently announced](#) that it would be submitting its solution for FDA approval following the

results of a pivotal study that surpassed all targeted benchmarks. The solution is now on course to be the first FDA-cleared digital solution for pediatricians to diagnose autism.

The study, which ran from July 2019 through June 2020, examined 425 U.S. children aged between 18 months and 72 months, evaluated the ability of the diagnostic device to aid in the diagnosis of autism by comparing its diagnostic output with the clinical reference standard, a diagnosis made by a specialist clinician, based on DSM-5 criteria and validated by one or more reviewing specialist clinicians.

Harnessing AI technology to evaluate a range of data points—questionnaires filled out by pediatricians and caregivers, analysis of video of children in their natural environment – the device was shown to be highly accurate. Built to embrace gender, racial, ethnic and socio-economic diversity, Cognoa’s algorithms are not restricted by the inherent biases in the current system and the device demonstrates accuracy across population groups.

With its imminent submission to the FDA, Cognoa’s diagnostic device is one step closer to transforming the standard of care for children with autism. Earlier diagnosis, more seamless coordination in the health-care system, and a commitment to improving equitable access to care will all be needed to make progress, and if cleared, Cognoa’s device will mark a key milestone in this journey.

David Happel is the President and CEO of Cognoa, the leading pediatric behavioral health company developing diagnostic and therapeutic solutions to improve the lives and outcomes of children and families living with behavioral conditions. Prior to joining Cognoa, Happel served as President, CEO, and Director at Chrono Therapeutics, a biopharmaceutical company focused on treatments for neurologically debilitating conditions. He also previously served in senior roles at Horizon Therapeutics, Raptor Pharma and Allergen Research Corporation. With over 25 years’ industry experience, Happel has an extensive track record of improving clinical and commercial outcomes for cutting-edge health-tech companies.

Sensory Needs and Sleep for Your Child with Autism

By Melissa DOMAN

A look at how addressing your child's sensory needs could help him/her get a better night's sleep.



In the special needs community, I know sleep is a very important topic. Many parents are aware their kids are desperate for more sleep, but they just can't seem to get these precious hours. For children with autism, a good night's rest can be especially tough to achieve. In my years of working with kids just like yours, I have learned a few things:

- 1.** Incredibly long wake-ups (three to five hours at a stretch) in the middle of the night are very common for kids on the spectrum. Three out of four of my children with ASD struggle with this exact issue

- 2.** Taking three or more hours to get to sleep at night happens...a lot

- 3.** If a child struggles with one or both things, it makes it really hard for him/her to regulate the next day.

When sleep training a child with autism, or any kind of sensory processing issues, knowing what that child needs to stay regulated is key. When a child is struggling to get the long stretches of sleep he/she so desperately needs, it's his/her brain telling you it needs more stimulation!



When sensory needs are addressed in the right way, my kids are starting to fall asleep faster, sleep through the night more consistently, and waking more rested and ready to tackle the day—that's because their brain is happy.



I've learned time and time again the traditional methods of sleep training only go so far until you've helped address the sensory needs. These two things go hand in hand. And, why is that?

The area of the brain that controls sleep is right next to the area of the brain that processes and integrates all the "input" coming into the brain through the eyes, ears, nose, mouth, and skin. If one of these areas is not running as efficiently as it should, there will be negative ripple effects—chances are you've seen this! Parents will tell me when their child hasn't slept well that they'll stim more, be more hyperactive, etc. That's going to affect his/her sleep the next night.

It's a vicious cycle. But, it's a cycle that can be reversed!

When sensory needs are addressed in the right way, my kids are starting to fall asleep faster, sleep through the night more consistently, and waking more rested and ready to tackle the day—that's because their brain is happy. It's gotten everything that it needs to do the work it has to at night. If your child with autism just can't sleep, here's my top recommendations to help address their sensory needs at home:

1. Tactile needs: whether your child is a seeker or an avoider, I first recommend incorporating joint compression massage specifically in your child's bedtime routine and during the day. Very often, just a few minutes of this before bed can help your child's brain to wind down and their body to relax. I find it's a great way to release any built up tension or stress from school, daycare, therapy, etc. And, it can be very helpful to reset things if your child has been up for a while at night. Try to incorporate even more sensory play, brushing techniques, and more with your child throughout the day.

In addition to this, make sure that your child's bedroom is cool at night. Many kids run hot, and this will prevent them from getting into a

deep sleep. Make sure that your child's room is no hotter than 70°F (22°C).

2. Auditory needs: in most cases, the kids that I work with struggle with being too sensitive to sounds. Signs of this are: certain sounds bother your child, they struggle in crowded places, they're distracted easily, or tune out a lot. They will make constant noise either with their voice or with other objects, or wake with the slightest creak of the floor boards. Some children may be hearing many sounds at once, and much more intensely than you and I. Imagine trying to sleep through all that racket! My recommendation is to cut out sounds as much as possible. For kids over 5 years old, I recommend that they sleep with silicone ear plugs that are usually used for swimming. These simply sit over the ear canal, and can be comfortably molded to the shape of your child's ear.

I don't usually recommend sound machines for my hypersensitive kids, as they can make it harder to settle. However, from time to time they can be helpful. At most, try to find a machine with a pink noise setting which has a calmer frequency. Or, simply run a fan at night.

3. Visual needs: if your child hears and feels things differently than they should, chances are they're seeing lights in a more intense way as well. Even the tiniest little bit of light in the bedroom can throw your child's sleep off. It's important that your child's room is as dark as possible at night. My rule is if you are standing in your child's room, you should not be able to see your hand extended in front of you. That means, putting up black out shades and blacking out the windows. You can do this by taping thick paper or aluminum foil over the windows. If your child needs a night light, use something that is red, orange, pink, or yellow and put it

behind another piece of furniture to dampen it. Avoid anything with a blue tinge.

Finally, avoid TV, tablet, smart phones, laptops, etc. at least one hour before bedtime. The light that these devices emit tricks our brains into thinking it's daytime and delays the natural dump of melatonin into the system.

- 4. Oral needs:** every once in a while, I will work with a child whose mouth sensitivity (or lack thereof) will keep him/her up at night. This makes it especially difficult to drop bottles and pacifiers, and I'll work with kids who are still using these at age six and older! In order to ease this sensitivity, you can use different oral sensory therapy tools. My favorites are the NUK brush and Z-Vibe brush. If your child needs this, use these tools right before a meal or snack.

Whether your child's sensory issues are mild or severe, giving the brain the stimulation it needs will make it easier for your child to go to sleep calmly and satisfied. In addition, with all the information your child gets during the day, the brain can process it and learn how to see, hear, and feel the world more consistently. The great thing is a little bit can go a

long way! Consider focusing on one or two areas at first and see how it helps your child. Then, dive into some of these other sensory pathways for a better night's rest.



Melissa Doman is a pediatric sleep consultant for special needs families who've had it with sleepless nights, anxiety, stress-filled days, and doctors who say their child's sleep issues can't be fixed. Melissa helps children sleep better

and independently so parents can see them grow, thrive, and use these sleep skills for years to come. Melissa has worked with children diagnosed with Cerebral palsy, Trisomy 21, Autism, ADD/ADHD, developmental delays, and more. She loves coaching parents to get their kids sleeping well and independently.

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Q&A

Do you have a question for our “Agony Aunts”?

Send your problems to editor@autismparentingmagazine.com for the attention of one of our experts:

- Occupational Therapist Rebecca Connick, MOT, LOTR
- Co-founder of AIMS holistic therapy, Karla Pretorius
- Behavior Technician and autism mom, Carol Tatom
- Psychologist Rachel Bédard, PhD
- Speech-language pathologist Mallory Griffith, MA, CCC-SLP

The advice provided in this column is for general information and should not be treated as a substitute for face-to-face therapy, counselling, or medical advice. The guidance provided is not endorsed by Autism Parenting Magazine or any of its employees.

HELP: My Child bites and hits himself

Q My son is seven years old and has special needs with the inability to communicate through speech. He is not diagnosed as autistic but he has sensory issues and is unable to walk and carry out his frustrations. He bites and hits himself and we have tried many things for intervention. What are your thoughts on how we can keep him from biting, pinching, or hitting himself? Thank you.

Valerie.

A Hi Valerie,

As an occupational therapist, I would like to address your concern from the sensory processing perspective. I am not sure what interventions you have tried for your son already, so please know there are many approaches, and your child’s physicians and therapists who are most familiar with his case are the true experts of his care.

Children with sensory processing difficulties often have a hard time maintaining a “just right” state of being. A child may be easily overwhelmed by the input around him/her, or on the flip side, need a larger amount of input than others in order to be at his/her optimal arousal level. Children can often tell us with their actions what their sensory needs are, and it is important to look at your son’s

behaviors as a detective would to figure out what sensory “need” he may be trying to meet for himself when hitting, biting, and pinching.

Proprioception is the sense responsible for perceiving body position and movement, and also has a huge role in regulation of the sensory system. Proprioceptive input can be very calming, which is why we swaddle, bounce, and pat our infants to help them calm from crying or fall asleep. When children are upset, sometimes they instinctively know what input helps them feel better, but they might seek this input out in inappropriate ways such as by hitting, pinching, or biting.

Is it possible your son is trying to give himself calming input when frustrated or upset? Or, due to his limited mobility, he may not be getting as much proprioceptive input as his sensory system needs? For my patients who engage in self injury, I often

problem solve with parents in order to find other ways to provide their child with proprioceptive input throughout the day. Do they like deep pressure massage? Clapping their hands/stomping their feet along to songs? Banging on a bongo drum? Getting a bear hug? Towel squeezes after a bath? Think of any enjoyable activity that would provide input to his muscles and joints. There are many ways to provide children with proprioceptive input, but it is important to be that detective and see if providing this input more regularly throughout his routine is helpful in decreasing his self injury. I highly recommend finding a pediatric occupational therapist familiar with sensory integration to guide you through this process.

Sending love and hugs, and I hope this response was helpful!



Rebecca Connick, MOT, LOTR, is a pediatric occupational therapist and the OT Program Coordinator at Crane Rehab Center for Behavior, Language, and Learning in New Orleans, LA. Rebecca has extensive

experience in treating children with ASD and feeding disorders as part of an outpatient interdisciplinary therapy program. Rebecca also authors the blog *Fingertips: Pointers from a Pediatric Occupational Therapist*, where she posts content on a range of topics relevant to all parents.

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How My Autistic Son Transitioned to Independent Living

By Dottie DAVIS

An autism mom shares her son's journey to adulthood and provides suggestions for other parents of children on the spectrum.

When my son, John, was diagnosed with autism at age three, all my focus was on early intervention and educational goals that would hopefully prepare him for a regular school setting. Once he entered the special education program in the public school system, the years quickly went by with education goals as our main focus. It wasn't until John reached eighth grade that it hit me. "What is he going to do after school? What if he can't get a job? What am I going to do with him during the day? What kind of adult life is he going to have? I can't care for him by myself for the rest of his life!" I knew I needed to immediately refocus his Individualized Education Program (IEP) on plans for his transition to adulthood. What I realized was that after school ended, there were very few services available for adults with autism. John was about to fall off a cliff.

I was very fortunate to become involved with a local non-profit organization called STARC of Louisiana (providing a lifetime of Services, Training, Advocacy, Resources, and Community connections). Their programs include early intervention, daycare, respite care, work training, vocational employment, home care, and residential living to help move individuals through a lifelong process toward greater well-being and independence.

I worked with John's IEP team to make daily living skills, social skills, and vocational skills his main goals, while continuing to maintain his current level of educational goals (since we knew he had reached his maximum level of comprehension on those). Now, it was time to prepare him for life after high school.



The school coordinated transportation and a staff member to accompany John three times a week to the local STARC day program center, where he spent one hour doing different kinds of tasks – shredding, filing papers, etc. It also gave him an opportunity to learn more about the center and become more familiar with the staff. Our goal was for him to attend the day program every day as his "job" once he finished school.

I also got John approved for ABA (Applied Behavioral Analysis) sessions at home. A therapist came twice a week and spent time working with John on social

skills and safety skills. They did a lot of role-playing such as reacting to someone knocking at the door who he didn't know, and walking to a stop sign, stopping, looking both ways, then crossing if it's safe. They would role play "conversations" where he learned to ask questions of others like "How was your day?" or "What do you like to watch on TV?". This really helped him be more comfortable and know what to expect in social situations.

But my biggest obstacle was John's need for independence as a young man, while also being in a place that was safe and with 24/7 supervision. As a single parent, I knew I wouldn't be able to care for John by myself for the rest of his life. STARC of LA came to the rescue again. They reached out and shared they had raised enough money to open another men's residential home, and wanted to invite John to live there with seven other men. This was an answered prayer from God. On July 25, 2018, I moved John into the home, where he has his own room with all of his Disney movie collections with him. The home is staffed 24/7 with loving, compassionate people who are there to support him, but also continue to teach him how to live independently. They're transported to the day program center Monday-Friday, where they do vocational work, exercise, and art projects, and go on frequent outings in the community.

Since John moved into his home, he has thrived. He loves his independence (he hasn't asked to move back home once!), and we go out to dinner once a week and talk over Skype. I'm seeing my son live a life that I never thought he would have a chance to. And he's becoming the man he was created to be.

Here are some suggestions that may help you in your child's transition journey:

1. Seek out any organization in your area that may have programs for younger children. They may be open to expanding it to include adults.
2. Reach out to local autism chapters or community groups to see what other parents are doing. There is strength in numbers, and a group of families who need the same type of services holds a lot of weight.
3. Reach out to your local state representatives and senators. Let them know about the lack of services that are available in your area, and ask them to work with you and local/state organi-

zations (Office of Citizens with Developmental Disabilities, Department of Health, etc.) to make these programs available. I found that several of these elected officials have children with disabilities as well, and they become eager to help. Take local chapter representatives with you so they can share their knowledge and support.

4. Consider making daily living skills, social skills, etc., priorities in your child's IEP beginning at the junior high level. You can maintain the current educational skill levels while focusing more on the skills he or she will need to live as an adult in society.
5. If your school offers internship opportunities for students, ask if you can create one for your child that would take him off-campus to a local shop, gym, or day program to practice social, vocational, and living skills.
6. If a residential home is not available in your area, find (or start up) social activities for young adults. You can have scheduled movie nights, go bowling together, board game nights, etc. Anything that will give these young adults interaction with each other.

I know the opportunities John's been given are not available to everyone. I know how blessed I am to have found them for John. I want to encourage you to not to give up. Keep asking. Keep looking. Find support from other parents like you. Get help from your local officials. The more we shine the light on this issue, the harder it will be for others to ignore. I want to thank *Autism Parenting Magazine* for allowing me to share my story with you.

STARC of LA can be found at www.starcla.org.

Dottie Davis lives in Mandeville, LA, and is a mother of four children, with her youngest, John, having autism. She served on the Parent Teacher Association (PTA) at her son's school in order to stay involved with administration, teachers and staff. Dottie also served as Parent Liaison for the Special Education Department for St. Tammany Parish School System for three years. She helped to facilitate communication between parents of special needs and/or gifted students and school administration and teachers. Dottie is happy to be contacted by other autism parents via email: 8016liz@gmail.com

There is No How-To Guide for Autism Education

By Ryan KELSALL

Learn about UK-based specialist autism school, The Cavendish School, and its important mission.



Education is all about listening to those around you. From the start of our journey to opening The Cavendish School, the world's first International Baccalaureate (IB) special autism school, we have been working extremely hard to ensure we are engaging in relevant conversations with the autism community and actively talking to all of our stakeholders, from prospective students and their parents to teachers and educational researchers. From these discussions, we have been able to create a space, as well as develop a curriculum and teaching methodology that will support each individual student, building on his/her skills and allowing him/her to achieve, make progress, experience success, and thrive.

Within the current context, Cambridgeshire County Council has to place a significant number of children and young people with autism in independent or out-of-county provision. So, to say we are proud to be Cambridgeshire's first state to maintain special free school for young people with autism is an understatement! We believe it is important for us, as educators, to provide the opportunity of an enriched and fulfilling education for all young people within their local community.

Throughout the development of The Cavendish School, removing barriers to education has been our sole focus. At the heart of our new school will be relationships and the important ways in which

they support the growth of each child. These relationships include those between each student and the staff he/she works with, other students in the school, and his/her family. Right from the outset, we will be involving the whole of the family in the child's time at the school. There is no "how-to" guide when it comes to supporting a young person with autism; therefore, we will hold constructive conversations with an open and enquiring approach, collaborating with families, teachers, and teaching assistants to provide cohesive support and find out how we can best tailor each student's education to meet their needs as they grow.

These important conversations also translate into all of our school planning, including development of the curriculum model through to the hiring of staff; we are currently recruiting for a headteacher, and students and their parents will form two distinct panels of the recruitment process.

We're extremely proud we will be the world's first special autism IB World School and with this, we will develop in our students 10 human attributes that go beyond academic success. These will teach our students to be: inquirers, knowledgeable, thinkers, communicators, principled, open-minded, caring, risk-takers, balanced, and reflective. Known as the IB learner profile, we believe these characteristics should be developed in all students regardless of neurodiverse or neuro-typical development. IB programs enable students to become globally aware citizens, make connections between their learning in different subjects, and develop the skills and confidence to succeed. The IB focuses on a broad and balanced curriculum and all frameworks of learning pay close attention to the development of the whole child, both at school and beyond.



Implementing our curriculum strategy

Our curriculum model also allows for a wide range of activities, including forest school, Lego therapy, and life skills—all supporting the idea of what it means to be inclusive. Here at The Cavendish School, we will celebrate diversity; we are accepting, respecting, and recognising neurological and developmental differences. We are committed to removing barriers to inclusion for young people with autism within and beyond the school community. Through active conversations and an individualized approach for each child, The Cavendish School will identify students' needs and look for the very best ways we can support them. We believe through our curriculum, our students will be able to achieve a range of accredited qualifications, which represent excellent progress for that individual and allow them to move on after successfully reaching their chosen destination.

Following the IB's world-renowned programs allows us to forge strong connections with Imping-

“

Here at The Cavendish School, we will celebrate diversity; we are accepting, respecting, and recognising neurological and developmental differences. We are committed to removing barriers to inclusion for young people with autism within and beyond the school community.

”

ton Village College (IVC), our co-located mainstream school, and Impington International College (its Sixth Form), which will provide excellent opportunities for our students through the use of facilities, support staff, and bespoke extra-curricular activities. IVC has around 40 young people with an autism diagnosis and we have worked with these students and their parents to gather their views about the facilities, curriculum, and additional support, all of which we will implement at The Cavendish School.

Testimonial from a parent

One parent whose son moved from a special school in Year 7 to study at IVC, commented: "The transition [for Harvey] was very challenging but worked so well due to the empathy, professionalism, and excellent strategies put into place by the team at IVC. My son grew in confidence and self-esteem with the support given. He was truly understood and all his achievements were celebrated. He went from a child who was anxious and didn't have trust in school, to a young man who was able to give a presentation about autism to a group of 400 other students and who advocated for other students with additional needs. The communication was fantastic and we felt we were working together with the team and were always consulted, welcomed, and included in his education."

The type of young people I envisage benefiting from The Cavendish School are those students who are academically and cognitively able to access a mainstream curriculum but who, through the structures and systems set out, aren't able to reach their potential. Often, the size, structure of the day, and the mainstream school environment, alongside the needs of the individual, mean they don't have access to a curriculum they are academically able to achieve with. The Cavendish School will provide the right environment for every student who walks through our doors.

Our vision

Our aim for The Cavendish School is to provide a safe, nurturing space, alongside inclusive and comprehensive support, so all of our students can flourish. Through listening to the needs of parents, knowing what is currently available, engaging with the community, and initiating those often difficult conversa-

tions that will be key in driving our school forward, we want to build a sustainable educational offering and provide a unique environment that will be life changing for young people with autism.



Ryan Kelsall is the Deputy CEO of Eastern Learning Alliance, a new role he took on in September 2020, following five extremely successful years as the Principal of Impington Village College (IVC). During his time as Principal, IVC consistently ranked in the top performing schools in Cambridgeshire and the top 10% nationally, while remaining true to its inclusive ethos, annually supporting over 90 students with Educational Health Care Plans (EHCPs). In 2020, IVC was crowned East Anglia State School of the Year by The Sunday Times. Ryan's commitment to inclusive practice is well known locally, having chaired the East and South Cambridgeshire Inclusion Partnership (ES-CIP) for the last four years, ensuring no students in the area have been permanently excluded and the most vulnerable receive the additional support they require to succeed; based on this success, he has recently taken on a similar role for the Cambridge city schools. In 2019, Ryan was nominated and short-listed for Headteacher of the Year. Ryan is also chair of the Local Governing Body of TBAP Cambridge, the county's alternative provision school for students at risk of exclusion and has helped them improve the educational provisions and opportunities for students not adequately provided for by mainstream education. Ryan's new role incorporates the responsibility to deliver the promise of outstanding education for students with autism in Cambridge by recruiting and supporting an excellent Headteacher and staff body as well as opening The Cavendish School in 2021.

Website: <https://thecavendishschool.org.uk/>

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Three Great Shows for Children with Autism and Their Parents

By Rebecca CONNICK, MOT, LOTR

Ask any occupational therapist, and they could point to a moment that inspired them in a way they cannot forget. A few years ago, I worked with a little boy who was nonverbal. One day, while assessing his fine motor skills, he was clearly getting frustrated but did not yet have a way to effectively communicate his frustration to me. His mother, being the amazing mother she was, got down on his level and began singing a song to him. I did not have children, so the song was not familiar to me. However, it changed the little boy instantly. I watched him calm down as he listened to his mother's singing, mesmerized by the co-regulation happening before my eyes. After he settled, I asked her what song she sang. She said it was from a favorite show of theirs, *Daniel Tiger's Neighborhood*.

"When you feel so mad that you want to roar, just take a deep breath and count to four."

A catchy TV show song cueing a child to regulate himself with breathing strategies? I had to know more about this show! I began watching *Daniel Tiger* and quickly fell in love with the amazing themes, songs, and emotional intelligence strategies that it effectively provided to a preschool audience. Better yet, the show was actually loved and well-received by many kids! As it's produced by Fred Rogers Productions, it's no surprise that the show carries on Mister Rogers' legacy of quality and holistic children's programming. Inspired, I sought to find other children's shows that I could recommend to parents for their children with autism.

Below are the top three shows I've found that can provide therapeutic benefit for your child.

Daniel Tiger's Neighborhood

Daniel Tiger's Neighborhood centers its plot around socio-emotional themes that are relatable for all



children. The show presents these themes through the experiences of Daniel Tiger and his friends, very clearly working through the lens of child development.

During each episode, the characters demonstrate simple and meaningful examples of real-life challenges, problem-solving, and friendship. Each episode also includes catchy songs with titles such as "When

You Have To Go Potty, Stop and Go Right Away!” and “When We Do Something New, Let’s Talk About What We’ll Do!” While its lessons are intended for children, Daniel Tiger’s Neighborhood also provides wonderful parenting strategies and songs for use at home to help with routines, common struggles, and working through emotions. Check out the latest special “Won’t You Sing Along with Me,” which features themes relevant to children due to the Coronavirus pandemic.

Caitie’s Classroom

Caitie’s Classroom is a show produced by Super Simple, a company whose mission is to make learning and teaching easy and fun. Caitie is an adult who guides children in a sort of preschool “circle time” through play, song, and even field trips. Each episode focuses on a theme and provides a very routine learning sequence. For example, it starts with the “hello” song, moves through a few activities relevant to the theme, and then ends with the “goodbye” song. Her music is simple and repetitive, clearly written with child development and learning in mind.

Caitie also provides great crafts and activities that parents can reproduce with children to promote hands-on learning. The field trips she includes are also wonderful, often presented in a social-story format to places meaningful to children, such as trips to the dentist or to get a haircut.

Bluey

An Australian animated series, *Bluey* is unique in that the themes and lessons it provides during its programming can be much less direct. The show is centered around Bluey, her sister, and her parents as they go on adventures through imaginative play. The main characters are often shown during their everyday life, but unlike many shows, the parents are just as invested in the shared game as the children.

Not only is it great for children with autism to view these models of creativity and imaginative play, but it is also helpful for parents to see the examples of ways that they can get on the floor, play, and connect with their children. The silliness is shared, and this representation of the value of play between parent and child is a welcomed one. Videos such as “Bluey Games to Play Indoors” are especially invaluable, as they provide parents with imaginative play ideas



as well as what you’ll need to carry out these games in your home.

If your child loves screen time and you are looking for productive content, each of these shows offers valuable tools and lessons for children with autism spectrum disorder (ASD). While they are aimed at preschoolers, there is something to gain for every age – including parents.



Rebecca Connick, MOT, LOTR is a pediatric occupational therapist and the OT Program Coordinator at Crane Rehab Center for Behavior, Language and Learning in New Orleans, LA. Rebecca has extensive

experience in treating children with ASD and feeding disorders as part of an outpatient interdisciplinary therapy program. Rebecca also authors the blog “Fingertips: Pointers from a Pediatric Occupational Therapist,” where she posts content on a range of topics relevant to all parents.

Website: <https://fingertips.blog/>

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Navigating the Uncharted Waters of Remote Learning

By Lauren GEBEL

An autism mom shares how she managed shifts in routine and transitioned to remote learning during the COVID-19 pandemic.



As we navigate these uncertain times with remote learning, it is my hope that I can impart some positivity for all by sharing my experience helping a child on the spectrum adjust to a drastic shift in routine. I'd also like to share what I've found to be helpful while I navigate the overwhelming nature of the pandemic.

I am a firm believer in manifesting what outcome we want in life. I lead life with an attitude of gratitude. My son, Liam, is enrolled at Spectrum Center and I am beyond grateful for the wonderful support the center has provided us during this time. I am grateful that I can have transparent conversations about what I should prioritize, such as mental health, and what I can shift away from, such as a heavy workload, while Liam is struggling to regulate.

Creating a schedule

It has helped me to ask Liam's occupational therapist for added hands-on activities to implement at home. I like to look at anything in life as a lesson. Ironically, remote learning and this pandemic has taught me the power of positivity. We can't control external circumstances in the present time. We can't erase the inevitable triggers our children are facing. However, we CAN find the strength within to greet each day with an intention to set and manifest it.

What the above means to me is creating a schedule for Liam, plus tweaking his schedule and being flexible if it doesn't work one day.

Routine is uncertain in these times, so I create one. I write down the days we will attend the park, the library, and make a sensory craft, and I also accept when it may not go as planned and Liam is struggling with sensory overload. Every day won't be rainbows and butterflies, but we can find the small moments in every day that bring us joy.

Navigating remote learning

Remote learning has taught me to persevere through the lingering blues. To somehow find positivity, even on the days I may need to search harder. Though I don't find direct joy in remote learning, it has certainly taught Liam to get out of his comfort zone and it has taught me to tackle the challenges of seeing my son struggling. I could either break down and cry and give up, or find the teachable lesson.

When Liam cried and said "Mommy, I just want school," I told him how I do, too. I validated those feelings and I explained that we can still be joyful. It's not our choice that we can't go into a classroom right now, but we can wake up and make the choice to try our best, to play, to draw, to build Legos, to watch our favorite movie, eat our favorite food.

We mediated and incorporated yoga as well during this time, which has been helpful spiritually and very

grounding. I have never worked so hard on my mentality in my life. This pandemic and remote learning has taught me, above all else, how you can make lemonade out of lemons. It's not impossible to wake up, enjoy our children, and accept what we can't change.

When we accept things and lead with gratitude for the incredible teachers, occupational and speech therapists, and everyone working so hard to also provide for our kids, instead of dwelling on what we wish to change, it's then that we can truly help our children.

I hope my perspective here has resonated with fellow autism moms. You are strong, you are doing such a great job and, because of our wonderful kids, giving up is not an option. Instead, find those small joys

each day has to offer, leaning in to all the support available and get out of your own head. We need to remember that everyone is overwhelmed during this time and giving a piece of our heart, and not always our mind, is what will connect us all.

I wish everyone the best.

Lauren Gebel is a mom of two young boys, one of whom has autism. She navigates through problems and faces the daily challenges with positivity, always looking for ways to make life simpler for both her son and herself, as a parent, who deals with the unexpected triggers and meltdowns that often occur. Lauren's challenge right now is navigating remote learning.



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My World

By Navneet KULKARNI

*Let's Take You To World Of Mine
IT'S Very Beautiful Like Tree Pine
Very Tall And Thin With Long Leaf
Capture's Your Eyes Very Deep*

*MY World Is Very Natural And Pure
YOU Will Change Your Mind For Sure
NO Place For Anything Negative
There Is Place For Only Positive*

*My World Is Different From Others
BUT Good To Live Without Doctors
I Need More Love And Affection
NO Medication Only Connection*

*My World Is Full Of Imagination
Come And See With Observation
MY Brain Is Like Chip In Computer
ALL My Senses Work Together*

*MY WORLD Is Kind Of Galaxy
LOTS Of Stars You Can See
I Talk With My Brain Always
IT Help Me In Many Ways*

*MY World Is Very Fast And Denser
NO Competition, Conflict With Other
WITH Fragrance Of Love And Delightful
WHICH Makes My World More Beautiful*



Hi. My name is Navneet Kulkarni. I am a 16-year-old non-verbal boy on the autism spectrum. My mother's name is Neha Kulkarni and my father's name is Raghavendra Kulkarni. I'm from the Solapur district in Maharashtra State, India. I was diagnosed with autism when I was 2 ½ years old. I was very hyper, I had sleeping issues, and I was head-banging and biting. At that time there was not much awareness of autism where I lived, so I went to my grandparents' place in Bangalore for treatment. There, I was officially diagnosed with autism and we took therapies in Bangalore.

After a few months, we came back to Solapur with home programs given by a therapist in Bangalore, and my mother started doing the therapies at home because there was no therapy center. My mother homeschooled me and taught me life skills. My mother put much effort into my speech development but I was unable to speak so she tried the AAC method for communication. I communicate with my parents through typing and sometimes through gestures. I'm very happy the way I am and my parents have accepted me the way I am. I feel very lucky to have such parents who are always supportive for me.

I'm very passionate about writing – I write many poems, moral stories and many life quotes, and I want to continue writing as my career. Being special means I am not normal but very unique. I think and feel things differently, it doesn't mean I'm disabled. I'm a boy with different abilities, so through my writing I want to spread awareness of autism.

How Counting to 20 Can Help Your Child with Autism

By Colette McNEIL

Counting to 20 was my go-to strategy over my 30-year career working with children with disabilities. I used the 20-count to help children with many situations including waiting, transitioning, desensitization, and reinforcement.

Counting out loud has been a strategy used and taught in child-rearing and education for centuries. Many different counting approaches are regularly used when engaging children. Most of them focus on short counts from 3-10. Many plans focus on behavior management in a punitive fashion such as, "You better be cleaned up by the time I count to 3."

I chose to use counting more as a supportive, skill-building, and communication strategy. I further expanded my counting to 20 as opposed to lower numbers because I found this number gave me more flexibility in how, why, and for how long I use

the counting strategy. While lasting longer than the 3-10 count variety, it was also not so long that it inhibited use for quicker interactions.

I found that using 20 each and every time I need a counting strategy gave the children a consistent process which helped them make predictions about what was occurring. They knew that after 20 was spoken the activity would be over. Whether that was a relief or a disappointment depended on the activity. The consistency of the count was the key, and most of the time it yielded high levels of cooperative, calm engagement.

The interesting twist is that counting to 20 can be done at a variety of speeds, making the count last less than 5 seconds or up to 30 minutes. While the 20-count remains consistent and reliable in the actual spoken or written numbers, it can be widely varied in the length of time it takes or situations for which

it is used. The variability gives the 20-count greater flexibility than specifically-set timers or short counts. I am happy to share how I adjusted my use of the 20-count for waiting, transitioning, desensitization, and reinforcement.

Waiting

Help children tolerate waiting by counting in a rhythmic manner. You can use a variety of speeds depending on the length of the wait. If the wait is short, count quickly. If the wait is longer, count slower. If the wait is indefinite, count slower at first then quicken the pace towards the end. If an interruption or distraction occurs while counting, the speed and rhythm of the count can be adjusted to accommodate for the interruption.

Transitioning

Structure around cleaning-up or preparing to transition is often necessary for our autistic kids. A very rhythmic 20-count can be used to give kids the cue they need to focus their attention on making the transition in a timely manner. Adding a tap or a clap may help set the rhythm.

Desensitization

Helping autistic children learn to wear a new item, tolerate a new activity, or remain in a new location can be a challenge. Children with autism often become stuck in a habit of only wearing or doing the same things they already know. After investigating and concluding that their resistance is not sensory or health-related, it is understood that these children are resistant to the unpredictable nature of the new item, activity, or place.

In these circumstances, an escalating series of 20 counts can help the children become better able to accept the new situation. The following is an example of encouraging a child to wear a hat.



The novel situation

Place the hat on the child's head, not necessarily the right way. A new hat could just light touching the head. Hold the hat in this spot for the quickest count of 20 you can speak. You may say the numbers so fast they aren't very intelligible but always end with a clear "Nineteen, twenty." Celebrate the 20 by removing the item and indicating that you are finished with the interaction. Move on to something else the child enjoys without much attention to what just occurred. Remain attentive and positively engaged in what is happening next.

Repeated exposure

Approach the child again a little while later and repeat the process described above. Quick and harmless! Repeat this several more times until the child shows no distress over your speedy encounter. Then, repeat it again several more times but, begin to slow your count a little each time. You may say the first five numbers fast, then say the next seven numbers slightly slower, the last six numbers fast again, ending with a slow, clear "Nineteen, twenty." Mix it up, but always say a clear "Nineteen, twenty" to emphasize the counting is finished.

“

Help children tolerate waiting by counting in a rhythmic manner. You can use a variety of speeds depending on the length of the wait. If the wait is short, count quickly. If the wait is longer, count slower.

”

“ When you are done counting, speak your 20 clearly so the child knows you are finished and wait for the child to disengage from the activity or remove the hat independently. ”

Increasing expectations

Begin to have the child accept slightly more appropriate expectations. Place the hat actually around the head. Repeat this level of expectation with the quick-ish counting until the child shows no distress over the process. Then increase the expectation until he or she is actually wearing the hat correctly. Repeat several times until the child shows no distress at this level.

Encouraging distraction

Begin to slow your count more and use a consistent pace. As you develop a rhythmic count, begin to encourage the child to play while wearing the hat. When you are done counting, speak your 20 clearly so the child knows you are finished and wait for the child to disengage from the activity or remove the hat independently. Do not prompt disengagement or removal of the hat. You may find that the child independently adjusts to the new situation at this level.

Adapting and accepting

Place the hat on the child without introducing the 20-count and see how long he or she tolerates the situation. Usually by this time, the child is already desensitized and cooperatively accepts the now not-so-new circumstances. Focus your engagement and the child's attention on the play activity.

If the child begins to show a lack of tolerance, introduce a 20-count that matches their sense of unease. Help the child end the situation calmly, if possible. If you wait for a tantrum, you teach the child to throw a tantrum to get out of things. Let the 20 be the release, not the crying. If a child does begin to cry – that's okay! Still, end with the "TWENTY!" this will let the child know that the expectation is to wait for "twenty" and will give him or her the consistency and predictability he or she needs to understand the parameters. Follow up by focusing your interaction and the child's attention on the play activity.

Reinforcement

Reinforcement systems are most effective when the child is attentively engaged in each of the moments when he or she earns points towards a reward. Using the 20-count is an irregular system of reinforcement. It is not timed or rhythmical by design. Give the child points when the child needs some enticement to remain engaged. The points are given throughout the timeframe as needed. And when the points are given, pair a positive comment with each point. The following scenario is an example that could happen at school:

Reinforcing Brooklyn

"Wow Brooklyn, thank you for coming to the table. What are you working toward today? Oh, nice, you are choosing to play on the computer when we are done with our lesson. I like the way you walked over here (point 1), and you are sitting so nice in your chair (point 2) and I like how quickly you chose what you were working toward (point 3)." Mr. Berry has reinforced Brooklyn effectively for simply coming to the lesson and has positively primed the child with 3 points, right away, to cooperatively engage in the lesson.

After a few minutes of engagement, during a natural pause in instruction, Brooklyn receives another few points and has specific positive behaviors highlighted by Mr. Berry: "Brooklyn, I like how you are sitting in your chair (point 4), and you are looking at your paper (point 5). You wrote in the lines" (point 6). When the child answers a direct question, Mr. Berry gives point 7.

As Mr. Berry continues the lesson and interacts with other students, Brooklyn works quite well for another 10 minutes without any reinforcement. When Brooklyn begins turning away from the table and flapping his paper, Mr. Berry takes that as a cue that Brooklyn needs more reinforcement.

Instead of reprimanding the child for lack of participation, Mr. Berry redirects the child's attention.

“Wow, look here,” he says, directing Brooklyn’s focus to the number chart. “You have been doing so well for 10 minutes! (points 8 and 9), and you wrote one sentence (point 10), you are holding your pencil correctly (point 11), and I really like how you are listening to me now (point 12).”

“Let’s see,” Mr. Berry says, counting the rest of the points, “only 8 more points to go before its computer time. Can you write your name for number 13?” Brooklyn engages and Mr. Berry gives point number 13.

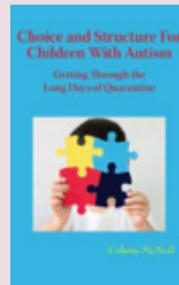
The lesson continues for another ten minutes, with Brooklyn receiving numbers 15-18 intermittently. As the lesson ends Mr. Berry specifically points out one more correct behavior and gives point 19 then asks, “Hey you did such a great job, can I have a high five?” Giving point 20, Mr. Berry releases Brooklyn to the computer.

This sort of intermittent reinforcement is very successful and allows for as many or as few support exchanges as are needed. It is preferential to allow children to get used to engaging in activities without looking for constant external praise. Extending the time between giving points but still using a full

20-count with points given intermittently worked wonderfully for me.

I hope using the 20-count in the ways discussed in this article will be a support to you and your children too.

<http://sharedperspectivesupport.com/>



Colette McNeil authored the award-winning book *“Understanding the Challenge of ‘No,’ for Children with Autism: Improving Communication, Increasing Positivity, Enhancing Relationships.”* Her newest book: *“Choice and Structure for Children with Autism: Getting Through the Long Days of Quarantine,”* was released in the summer of 2020.



Colette has over 30 years of experience working with children with autism in a wide range of educational, recreational, and caregiving settings. Colette aspires to develop confidence in children with autism through expanding the perspectives of their parents, families, teachers, and caregivers.

follow us



Changing the Landscape of Special Education Across the U.S.

By Kevin GERSH



Anyone who has worked with or, especially, parented a child on the spectrum knows no child is the same; each brings his/her own uniqueness, skill sets, and passions. There is no way to pigeon-hole the traits of a child, and, as any special education teacher will tell you, every day is a brand new one. Yet, for decades, schools have held the expectation that the student will conform to play a specific part in its overall operating system.

Gersh Academy was created to combat what was becoming an all-too-familiar method of instruction for those on the spectrum. Conversely, Gersh Academy was built with the belief that any student can achieve, given the right resources, circumstances,

and environment. It is the role of the school to bend to the student, rather than the other way around.

As we know, not every student has the ability to learn in a traditional school setting. However, every student does have the capability to succeed. With that in mind, Gersh Academy built its programs, and continues to innovate, in order to meet every student where he/she is in all aspects of his/her life.

Customized plans for every child

With that knowledge at the forefront of our curriculum design, each student at our school is offered an individualized approach to learning to meet every student exactly where he/she is with the goal to meet his/her potential. Instruction is therefore given

according to each child's learning style and specific needs. Often, those on the spectrum get lumped into one classroom and treated as a unified whole. Every day, we remind ourselves our students are on a literal spectrum of talents, capabilities, and skills, and it is our duty to adhere to that.

At the Gersh Academy, we offer three programs to our students, though the student's exact path is designed with the individual in mind. In our "I Am, I Can" Program, we meet the needs of those focusing on post-secondary opportunities. These students are prepared for state assessments, the college experience, and life outside the classroom. Though the scope and sequence mimics that of a public school district, our approach is specifically designed to meet each child at his/her level.

Another program we offer is our BASE Program (Behavioral, Academic, and Social Enrichment). This focuses more on the life skills, social skills, and more functional academics in order to promote independence. Most of our students are given an individualized plan with the two programs blended in a way that matches up with their capabilities. Each student's goals are customized and instruction developed based on those goals so that each child we encounter will succeed.

Preparation for success in and out of the classroom

When we think about our schools for those on the spectrum, we need to always be thinking about more than what's housed inside its walls. How will our students live independently and acquire the skills necessary to provide for oneself in society? The Gersh community understands true success lies in skill sets needed to fully participate in our world.

The vocational curriculum we offer our students exposes them to a variety of careers. They are led through the process of selecting a job they are interested in and securing that job. They are taught specific and individualized skills needed for the jobs they are interested in pursuing. On top of that, they are given the opportunity to participate in the workforce while still being a part of our program.

When you work with students on the spectrum, you know your job never ends on graduation day. We are keenly aware our job is to set up each student for

“ At the Gersh Academy, we offer three programs to our students, though the student's exact path is designed with the individual in mind. ”

success, and give him/her every opportunity to get there.

Within our schools, we place strong value on life skills. Many of our students learn to drive in a safe environment, cook for other students, and prepare to travel. In addition, we offer clubs: a unique experience to many on the spectrum, but essential to build social skills and possible passions.

Our Gersh Experience program for young adults houses students in their own apartments where they can build on all of these skills. They learn everything it takes to maintain a home and balance responsibilities with leisure time. Our students learn to navigate public transportation, pay bills, clean their apartments, and plan their days.





Our Employment Training Program pairs our students with Employment Specialists to help seek internships that will give them the skills they need to pursue employment post-graduation.



By offering all of these programs to our students, we are vehemently refusing to push the students through until graduation. We are holding ourselves to a higher standard, ensuring each student is given every opportunity and advantage in life.

Diverse offerings to reach every learner

As educators, it is our job to acquire a 360 degree view of each child. We want to know how he/she learns and what his/her interests are, as well as what triggers them. In addition, learn what ignites him/her, and how to overcome their triggers. We know, as different as our children are from each other, the ways to reach them vary just as much.

We provide each student with an individualized plan that includes the highest quality of autism therapy services. We offer ABA, Occupational Therapy, Physical Therapy, Speech Therapy, Counseling, Behavior Management, and the more recently popular and highly effective Equine Therapy. We pride ourselves, however, on going well beyond the typical offerings at schools specifically for those on the spectrum.

Our Employment Training Program pairs our students with Employment Specialists to help seek internships that will give them the skills they need to pursue employment post-graduation. Because our teachers start laying the foundation for these skills in elementary school, by high school they are ready to engage with the outside world.

Meeting a student where he/she is and discovering where he/she thrives is so inherent to our mission at Gersh Academy. For those reasons, in addition to our schools and residency programs, we host a day camp each summer for children on the spectrum or diagnosed with another neurobiological disorder.

Located on 18 acres, each camper is given a new way to express himself/herself and show off his/her tal-

ents. These campers are given constant support for development of social skills, life skills, and independence, as well as being surrounded by certified special education teachers. They are given the opportunity for an accepting, traditional camp experience that allows for the growth necessary to build on each child's progress.

As we look at the smiles of success, the achievements and strides made daily, and the grateful feedback from parents, we know we are on the right track. Partnering up with these parents and students and giving them essential tools, not only through schooling, but through life, has brought us great pride and, with it, motivation to continue to innovate for the benefit of these extraordinary individuals.

Kevin Gersh is the founder/CEO/Chief Autism Officer of Gersh Autism. He was raised in a time when ADHD, Dyslexia, and other similar disabilities were not diagnosed. These children were labeled difficult, lazy, and trouble. Kevin was one of them. The challenges he faced in his childhood would set him on a life-long path to help children.

Nearly 30 years ago, Kevin opened his first school, focused on creating a customized environment for children with special needs. Today his organization operates programs across the US and Puerto Rico: K-21 Schools, Therapeutic Programs, Day Camps, Post-Secondary, Vocational Training, Job Placement, Residential, and a Driving School.

Kevin has dedicated himself to making a difference in the lives of children. His experience and professional commitment continue to provide opportunities, inspiration, and guidance for every child to reach his/her full potential, regardless of the challenges faced.

Website: www.gershautism.com

Autistic or Toxic?

How I Unlocked the Mystery of My Son's "Autism"

By Scarlett SOUTH

What killed Luke's twin and left Luke in an autistic fugue?

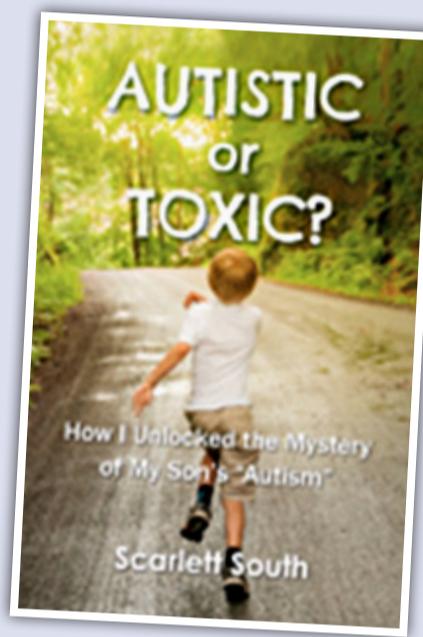
Luke was thrust into our world barely clinging to life, hastened in his arrival by his dying twin. The doctors scratched their heads and ventured guesses as to what had damaged them, but admitted defeat when their theories proved wrong.

At the age of three, Luke was completely nonverbal, and was labeled as having autism. As the years passed, Luke's behavior spiraled out of control, until the subject of institutions began to creep into conversations.

Then one day when he was seven, his mom, beaten down and broken by life, stared at the old well as they pulled up into their yard, after yet another confrontation with Luke's principal. Something clicked in her head, as if someone had just turned on a light, and she turned and gaped at Luke.

She realized then what killed Luke's twin, and what was really wrong with Luke.

Autistic or Toxic? is a true story about a mom and her quirky, but hilarious son, as they traveled down that mysterious road towards autism recovery, and the devastating lows and triumphant highs they met along the way.



Scarlett South is a registered nurse specializing in autism, a contributor to Autism Parenting Magazine and author of Autistic or Toxic? How I unlocked the Key to My Son's "Autism." But her proudest achievement is her awesome adult son, who started out in life labeled as severely autistic, and who is now an independent and productive member of society. Scarlett is based in Florida.

You can buy the book here: www.amazon.com/dp/B08JM1DTWK

Website: www.scarlettsouthauthor.com

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Reflecting on the Struggle of Virtual Schooling

By Lisa MALONEY

An autism mom reflects on the struggles her family faced when school came to a stop and virtual learning began.

“Having a child with autism can mess with your head. You feel like you can move mountains for them yet you’re powerless at the same time.” - Stuart Duncan

I am writing this article not as a columnist or reporter. I am simply known to my children as “Mom” or “Momma.” This mom is writing an article because I have a voice, as we all do, and this voice wants to inform you, the reader, about a problem that is affecting our children, whether they have a disability or not.

But first, let me introduce you to my son, Alex. Alex is a lovable, social, inquisitive 4-year-old boy. This little guy loves being outdoors, building things, playing with his siblings and cousins, and especially enjoying the water. Whether it’s the ocean, pool, or sprinkler, he loves it.

This is my story about how this pandemic affected not just my son, but other children with disabilities. When I learned that the COVID-19 virus had arrived in the US, I was like any other parent—I was nervous, but cautious. We had a trip planned to Walt Disney World in March, which we decided to go ahead with. But honestly, the virus was the least of my worries at that point. My biggest fear was Alex being on a plane. He had never been on a plane, but to both my surprise and my husband’s surprise, Alex loved the flight—he was calm, happy and very interested in everything going on. Once at Disney, he loved to walk around Magic Kingdom, and the mere sight of him hugging Mickey Mouse or Minnie Mouse was worth a million dollars. He loves anything Mickey Mouse.

Once we returned home, everything changed. Gone was the somewhat relaxing trip we had just had.



Now, we were faced with major changes, disruption, and stress. Everything was closed except supermarkets. Alex’s school went into remote learning almost immediately. Now I have an older daughter, Katelyn, 7, and she did remote learning but it was a challenge because she’s very social and didn’t fully understand what was going on.



Alex wanted nothing to do with remote learning. He would only sit for five to ten minutes. My complaints to his teachers, who offered to send material to work with him, fell on deaf ears. I was told repetitively, “I know this is hard.” Alex was offered a “virtual” summer camp for four to five hours a day but I declined. I have talked to a lot of people and most, if not all, said that “camp” didn’t work. I have said over and over that children like Alex, need all-day stimulation and reinforcement. I was worried, very worried, because I started to see signs of him regressing.

So, the duration of the summer he received no services. I called a bunch of places to get him home-based services and unsurprisingly, everyone was either unable to come due to the coronavirus or there was an extremely long wait list.

Unless you have a child who is disabled, you can’t fully understand how stressful it can be to see your child not progressing and actually going backwards. I spent many times so stressed that I would cry and I had many sleepless nights because I knew he needed help. I was powerless and couldn’t get it for him. No one would listen and my complaints again were falling on deaf ears. In early August, we learned that his school would go back to remote learning for six hours a day then move onto the hybrid method.

I was shocked. I was angry. I made several phone calls and emails to my local school committee – but yet again, I was told “that is the plan.” I made a few more calls to some other schools that specifically dealt with autistic children, and one of them was taking new students and could start in a few weeks – not “months” like I had been told by other schools

and home-based services. So, I’m happy to say he is enrolled in this new school and starts in a few weeks.

My advice to parents who are in the same boat as me is to remind yourself that this is temporary and it won’t last forever. Another strong piece of advice is don’t just sit back and let them dictate that “this is the plan” for your child’s education. This is your child and your child’s future—you have a say in what you think is best for your child. Fight for what you believe in and what you know is the best for your child. Not all disabled children fit the same mold; each is different and unique in their own way. Always question the teachers, school districts, politicians, anyone who is making decisions as to what they “think” is best for your child. You know your child and what works – they don’t. You have the right to question anyone if you feel they are not experienced in making decisions for children with special needs.

I hope that my article can give you an insight into my ordeal these past months. I am trying to get the word out that children with disabilities were left behind during the pandemic and helping them should be our top priority because we, the parents, are their voice.

“Never give up, for that is just the place and time that the tide will turn.”

Harriet Beecher Stowe



Lisa Maloney lives in Boston, Massachusetts with her husband, Brian, and their three children. Lisa is a stay-at-home parent, formerly a medical receptionist, who enjoys cooking, reading, writing, traveling, taking walks with the family’s two German

Shepherds, Bella and Cocoa, taking scenic photographs, and just being outdoors with her family. As her husband Brian would tell you, she makes an “awesome chicken pot pie.” She loves anything that has to do with history, especially Ancient Egyptian History and U.S. History. Her favorite TV shows are “Outlander,” and “The Crown.” One place she would love to visit is Australia.

Learning I Have Autism as an Adult with an Autistic Son

By Robert PLEASANT

An autism dad shares his journey towards discovering both he and his son are on the spectrum.

My name is Robert Pleasant. At 32 years of age, I was officially diagnosed with autism spectrum disorder (ASD). This diagnosis came after getting married, having a family, and facing career instability. The problems that I thought would end once I became an adult did not improve as I aged. I thought my social life would improve and communication barriers would begin to erode; it just didn't happen in the ways I thought any of it would.

My lonesome reality

My entire life, something felt off. Something was different, and whatever that something might be it was all-encompassing. I went to therapy for years, and my therapist referred me to a psychiatrist for medication to make my anger go away. It wouldn't be too much of a stretch to say there were well over 10 diagnoses I was medicated for that didn't fit.

I struggled with anger, hostility, agitation, irritation, frustration, insomnia, anxiety, social failures, and awkward moments – a range of emotions I had no explanation for and no one else seemed to have answers for. Therapy didn't help any of these feelings. Journaling didn't improve my thoughts or behavior. I just needed help fixing the problem, identifying the source, and writing out real solutions for real outcomes.

A major meltdown at work one afternoon led me to call my psychiatrist and ask for something to calm me down. I didn't know what was happening, and with no knowledge of what was wrong, I had resorted to taking medications for things that no one could provide a clear answer on. A new doctor would be talking to me for the moment while my primary doctor relocated. *Ok! Change! I can handle this!* I thought.



Finally, a breakthrough...

I spoke with a woman who was in the mix of things that afternoon; she would become the doctor who assigned me the title "autism spectrum." She knew before I knew, but I had already known, just not in a way I understood. What I mean to say is, during my 20-minute phone call with her in the parking lot at work, she already knew I am autistic. I had already been told and prescribed medication for it, and I still

“ I am mature for my age because I don’t enjoy immature humor. I also don’t have much of a sense of humor. ”

had no idea what I had going on. Then and now, I am often unsure how autism affects my daily life. It is a learning process for me just like it is for anyone else.

This is who I am

I am mature for my age. Thinking in abstract ways is soothing for me. Reading is my niche, as is writing. I cannot get enough of either and spend the vast majority of my days doing both. Each gives inspiration to the other. I spend my days researching, and that is partially why I am starting to understand myself more each day.

I am mature for my age because I don’t enjoy immature humor. I also don’t have much of a sense of humor. Preferring learning and information, I’ve avoided people most of my life and I don’t find what others do to be amusing. I used to think “maturity” meant I was more grown-up than other people. What “maturity,” for me, really means is that I have a dry sense of humor and I don’t like content aimed at younger audiences. I’m not so mature that I can communicate effectively with adults in social settings.

My ASD diagnosis was denied by my parents several times, starting at four years old. My mother, who has her own set of things going on, refused to believe there was anything “wrong” with her first-born son and therefore refused all treatments. Medication, therapy, counseling – she wouldn’t accept any of the options available. Later, I would discover as an adult that children on the spectrum initially get help where they can but, after the age of 18, there is a drop off. I know this from the research I’ve done, and my current therapist admits that I’m one of two adult patients she has; the remaining patients are children on the spectrum.

I’m learning how to accept who and what I am. The signs and symptoms are all there, with some people saying they wouldn’t have known until talking to me, and others saying they knew from afar for some time. About those who have known for some time, I wonder if that is their way of accepting something they don’t understand, or if I am unable to see myself as others do.

I understand now, through being married to a partner who is beyond patient with me, that I’m atypical. I have my own language; although the words don’t have meanings, they have suggestions. For instance, I may use one of my words in a stressful situation, and it is mutually understood between my partner and I as a code word, much like children do with parents when they are ready to leave a social event and need it to be mom’s idea, perhaps even fussing a bit over the desired outcome.

When I found out not everyone thinks in pictures and not everyone can repeat a conversation back to someone verbatim, I realized something is very different about me. I have sensory issues, which include aversion to bright lights, loud sounds, awful sounds like crinkling bags, and clothing that is too tight or too loose. I have no interest in small talk and I love a powerful conversation about a book someone has read or a topic that he or she is hyper focused on. I am learning about myself as an ASD parent while raising our son who shares identical and different struggles. I am raising a child on the spectrum while being on the spectrum and not quite understanding the spectrum.

I am not alone

Our son and I take things very literally. I just found out that there is no big picture, only a metaphor for an overall situation. Idioms are phrases neither of us may ever understand. We explore the world together, him and I, inside our home and outside our home. Wherever we go, it is certain we will be moving, distracted, focused, and looking at everything no one else sees in quite that way. Parent and child, each with little understanding of social cues, emotional context, and executive functioning, and lots of understanding of exploration, research, and creativity.

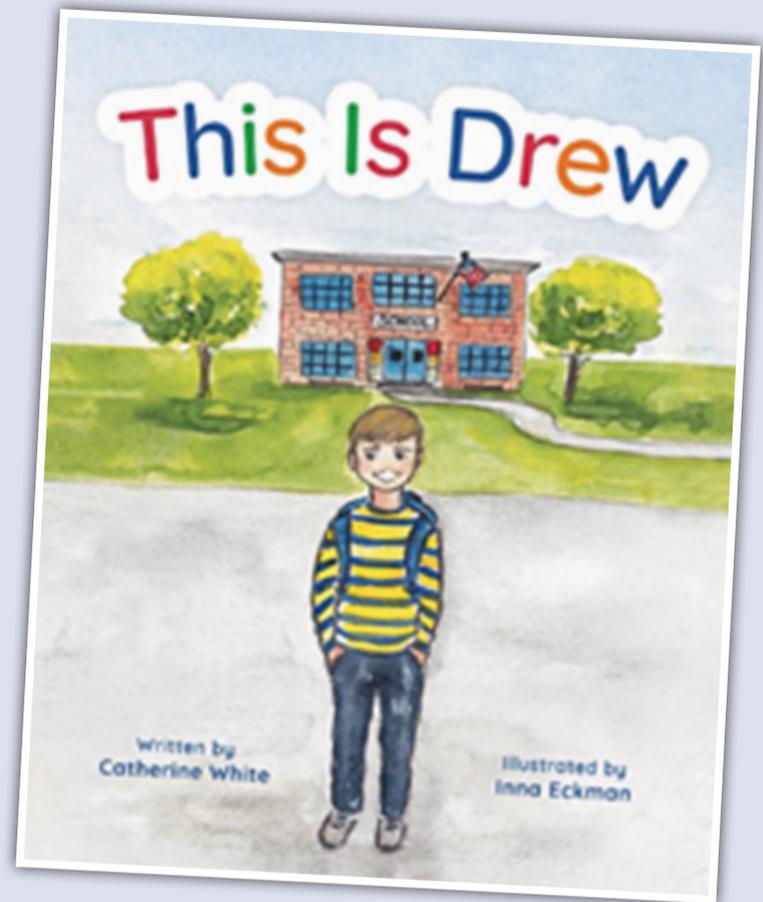
Robert Pleasant, aged 32, and his son Joshua, aged seven, are on the autism spectrum, each at their own idiosyncratic level. Robert writes daily blogs reviewing the events of the days before so the next day can promote a better quality of life, using life experience and education.

This Is Drew

By Catherine WHITE

Autism can be hard to understand, even for experts in the field. Join us as we meet Drew and teach his classmates about living with autism. Thoughtful examples illustrate differences in interpreting situations, allowing children to ultimately foster empathy and compassion for those who see the world a little differently.

Author Catherine White has seen firsthand how other children and even adults struggle to understand her son, Drew, who is on the autism spectrum. Drew wants and enjoys many of the same things as other children, but he expresses himself in different ways. For example, Drew wants to have friends, but he has trouble looking people in the eyes. Drew likes to go to school, but he has difficulty sitting still and paying attention. In accessible language, *This is Drew* helps guide children to better understand autism.



Catherine and her husband, Paul, have two children, Sarah and Drew, two dogs, Cricket and Pepper, and live near Washington, D.C. Catherine has served on the advisory committee for students with disabilities for her local school board, where she advocates for Drew and other children with disabilities.

For more information:

<https://mascotbooks.com/mascot-marketplace/buy-books/childrens/picture-books/this-is-drew/>

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Life with Maggie, Before College Algebra

By Susan RUSSELL

A determined mother shares her frustrations as she fights for her daughter's right to earn her college degree.

Life with Maggie, before college algebra, was one of remarkable focus and perseverance, because she is on the autism spectrum. Maggie is a mixed media artist from Gulfport, Mississippi, who uses the power of creativity to bring happiness and joy to herself as well as others. She was first diagnosed at age three with autism, and later with asperger's, dyscalculia, PTSD, and depression. In her world exists an array of dazzling, bold, and radiant colors that give her a positive outlook on life. Thus, she is not defined by who she is as a person with disabilities, but through the expression of her art. Creating art means days filled with optimism and contentment for Maggie. While loud noises disturb her and being around people is awkward and fearful, it does not prevent her from doing the things that people without disabilities do. Without a doubt, her first and undying love is for creating art and she gives it her full attention.

As her mother, Maggie and I are inseparable because we have been through all her ups and downs. We share everything: laughter, secrets, tears, hope, hugs, trust, and most especially love. Her father is our strength and protector. She tells me that I am her best friend, but I tell you that she is "my rainbow" in this world. Although life can sometimes be unkind, inhumane, and compassionless, one thing is clear: Maggie is my rock, and I am hers. As a family, we face



the world together, hand in hand, just like we are fighting her community college for Maggie's right not to take college algebra.

Earning and achieving a degree is part of the American Dream that many students strive to achieve. Ultimately, this was Maggie's dream, and she achieved it with a 3.60 GPA. She accumulated 93 semester hours

“ Maggie is my rock, and I am hers. As a family, we face the world together, hand in hand, just like we are fighting her community college for Maggie's right not to take college algebra. ”

“ In schools, Maggie was often ostracized, unfriended, and bullied just for being herself. Every day was a struggle, but it was through art that Maggie found a source of comfort. ”

for a 60-hour Fine Arts Degree. Her goal to achieve the impossible had just become a reality...until her degree was denied.

In schools, Maggie was often ostracized, unfriended, and bullied just for being herself. Every day was a struggle, but it was through art that Maggie found a source of comfort. It was like turning a magnificent bright light on in a very dark room, because she sees, thinks, and feels emotions through her art. This was life with Maggie before college algebra. The college made a deliberate and conscious decision to take from Maggie that once-in-a-lifetime opportunity to graduate with her friends, walk in a cap and gown, and make memories that last a lifetime, all because she can never pass college algebra.

When Maggie was in sixth grade, she was doing math on the fourth-grade level, and when she was in eleventh grade, she was doing algebra on the eighth-grade level. The college has refused to acknowledge Maggie's history of struggling in Algebra; she failed the Mississippi State Algebra SATP tests four times, and her MCT2 Algebra scores since second grade are below basic. Subsequently, she scored a 16 on the ACT.

Maggie did the work, earned the degree, and with four piercing words – “you are not graduating” – the administration turned her world upside down. They have committed a harmful act that has had detrimental psychological consequences on Maggie, and they did it through discrimination and lies.

Without hesitation, I have done what any other parent would do: advocate for my child against a community college whose bureaucratic discrimination is

motivated only by dictating the compliance of the students for a one-size-fits-all approach to education. They do not recognize students with disabilities in college algebra at all. Incomprehensibly, they do not even reduce the number of algebra problems on the exams. The outcome for many students is that they are forced to drop out.

Community colleges and higher-learning institutions are only concerned about their high enrollment, accreditation, and how much money they receive from the federal government. I would like to ask the administration at the college: “Who decided that algebraic expression, functions, and theory of equations are essential, and if so, to who or what?” I can assure you that it is not essential to Maggie because she is...an artist.

The disability law states, “it is within the constituent's rights to petition (name of college) to waive College Algebra and replace it with a comparable course.” Without my knowledge or consent, the OCR entered a “Resolution Agreement” with the college and offered Maggie four options:

1. Quantitative Reasoning
2. Physical Science, Visual Basic Programming, and Economics (must take all three)
3. Physical Science, Visual Basic Programming, and Statistics (must take all three)
4. College Algebra

Even when Maggie took the Physical Science and the Economics courses in Option 2, the administra-

“ Community colleges and higher-learning institutions are only concerned about their high enrollment, accreditation, and how much money they receive from the federal government. ”



Our education system is failing students with special needs because the administrations at colleges are self-serving and think that they are above reproach as well as above the law.



tion refused to waive the Visual Basic Programming Course. According to the course's syllabus, Maggie does not "qualify" to take Quantitative Reasoning, Statistics, or the Visual Basic Programming course. The prerequisites require Intermediate Algebra and College Algebra. They offered her nothing.

With extreme prejudice, Maggie's college has retaliated against her because I advocate for her rights and because I filed a complaint with the OCR. It is the Resolution Agreement itself that proves they are abusing their power. The one thing that institutions of higher learning have forgotten to take into consideration is that inflicting monumental pain on our children results in consequences.

Our education system is failing students with special needs because the administrations at colleges are self-serving and think that they are above reproach as well as above the law. They do not consider how being forced to take College Algebra affects these special needs students' lives, resulting in feelings of frustration, depression, and failure. According to Maggie's therapist, "what they have done to her amounts to torture." Where is the outrage?

While I am infuriated about the injustice done to Maggie, I do what I do out of a place of love. It is time to hold these community colleges responsible for their actions. We need legislators to change the laws that will protect students with disabilities from the institutions' abuse of power. Ultimately, they are responsible for destroying students' lives. There is no justification for acts of injustice in education. In the end, Maggie will have justice and her Fine Arts degree, because I keep my promises. Never give up, never surrender.



Some algebra-themed artwork Maggie did as a commission for her Algebra teacher.

Susan Russell is the mother of Maggie Russell and experiences the joys of raising a daughter on the autism spectrum. She is a stay-at-home mom who spends her time loving, nurturing, encouraging, and supporting Maggie through life's positive and negative experiences.

Before the birth of Maggie, Susan received a degree in Travel & Tourism from Phillips Jr. College, as well as from Chris' Beauty College. Later, however, she spent 20 years employed in the medical profession as a dental assistant, an admission, ER, and outpatient registrar, as well as a receptionist and transcriptionist.

Susan enjoys poetry, photography, and especially art with Maggie, because that is her colorful world. Several published photographs of Maggie can be found in the International Library of Photography Books: *Tapestry of Dreams*, *Memories of YesterYear* and *Clouds Across the Stars*. According to Susan, without a doubt, her sole mission in life is Maggie's happiness.

You can find Maggie's artwork at:

[Fine Art America](#)

Instagram: [@MagsterArt](#)

Twitter: [@MagsRussell1](#)

How to Help YOUR CHILD with AUTISM TRANSITION to ADULTHOOD

By Lisa LANE and Susan SACHS



“**W**hat do you want to be when you grow up?” This question is first posed to youngsters before they even reach first grade and continues in some form for years to come. Those words can make parents of children with autism cringe. We are not sure what lies ahead for our children in the years to come. In fact, we are often unsure of the status of next week. Our focus is simply to get through the day. But, too often, thoughts of the future wake us up in the middle of the night.

Action can be an antidote to worry. As the moms of two adults with autism, we suggest two avenues of action to help alleviate concerns: focusing on tran-

sition-readiness skills now, regardless of the age of your child, and advocating for systems that better meet the needs of individuals on the spectrum.

Start now

Although school systems typically focus on the transition to adulthood when students turn 16, parents can start building towards transition at an early age. Starting now, we need to build key skills that will help our children have as much autonomy as possible.

- **Exercise choice-making**

The ability to make a choice is crucial to self-determination for people with autism. This skill should be part of any intervention plan and practiced frequently in the home. Consider

choice-making to be a muscle that requires consistent exercise to become strong. Integrate small choices into every activity: *Do you want to put the cap back on the toothpaste before or after you brush your teeth? Do you want to button your jacket from the top or the bottom? Do you want to use your right hand or left hand to turn on that light?* Our goal is to help our children move beyond a simple choice between two offered options to an expression of their own preferences throughout their daily lives.

- **Increase independence**

For many parents of children with limited language, increasing a child's independence has the downside of potentially decreasing the motivation to communicate. We fear that if the child can get the juice himself, we will miss out on those precious words: "I need juice." We need to set aside those fears, however, because fostering the spirit of independence is critical to preparing for adulthood. At every opportunity, we need to build our child's habits of self-care. We can do so without losing communication skills if we, along with our intervention team, focus on continually adding new words to the repertoire.

- **Prioritize life skills**

As parents, we often want to focus our energy and interventions on academics to the exclusion of life skills, because we feel our window of time is limited. Many suggest teaching life skills at a later date, so their children can keep up with peers in the classroom. That tendency is not surprising, since our culture tends to value academic skills over self-help skills, even in our small children. We cheer if a child can count to ten in a foreign language, but we are less impressed if she knows how to blow her

own nose. Parents sometimes view building "functional skills" as giving up on academic skills, but those functional skills should be emphasized at every step of the way. Those are the skills that often determine the long-term quality of life.

Advocate for new systems

Existing systems for transitioning to adulthood are not designed to meet the needs of many individuals with autism. As parents, we need to advocate for opportunities that better match the skills and challenges of individuals on the spectrum.

- **Person-centered planning**

The use of person-centered planning is often a requirement in transition services. This individualized process is laudable, but, unfortunately, it requires a level of language that a significant segment of the autism community may lack. For language-challenged individuals with autism, completing this planning can be meaningless if the tool requires them to answer questions like "What are your dreams for the future?" We need to ensure the use of effective planning tools that are designed to discern the personal preferences of those who are unable to use language to express them.

- **Guardianship**

For some parents, guardianship is a necessity to allow for continued care for an adult with autism. The process of instigating a lawsuit against your child is draining, both emotionally and financially. Rather than fitting into legal systems designed to support people who have become incapacitated, we need new procedures that are more suitable for situations of maintaining legal support for adults with autism who require that significant level of help.

“ For many parents of children with limited language, increasing a child's independence has the downside of potentially decreasing the motivation to communicate. ”

“Housing opportunities for adults who need support remain too limited nationwide. Unfortunately, the regulations intended to protect individuals with disabilities can sometimes work against the specific preferences of individuals with autism.”

● Funding

Funding is extremely limited for adults with autism who need continued services. Most funding sources are only through Medicaid waivers. The reimbursement rates for these waivers are often based on a higher client-to-staff ratio than is workable for individuals with autism. Consequently, few organizations can design financially-viable programs that truly meet the needs of this portion of the spectrum. We need more funding options for individualized services for adults who need significant support.

● Employment

While the national focus on competitive employment in an inclusive environment is admirable, we need to consider that some on the autism spectrum may need another option to thrive. For some, the social demands and sensory input of a competitive workplace may be aversive, prohibiting them from working at a level that they could achieve in a workplace designed for them. We need to broaden the range of employment opportunities that are considered successful job placements.

● Housing

Housing opportunities for adults who need support remain too limited nationwide. Unfortunately, the regulations intended to protect individuals with disabilities can sometimes work against the specific preferences of individuals with autism. For example, requirements for distancing between housing and services may inadvertently decrease independence for adults with significant challenges. We need to advocate for housing models that meet the needs of individuals across the entire autism spectrum.

“What do you want to be when you grow up?” As parents, we generally have the same answer for our children: we want them to be happy, independent, and productive. We can lay the groundwork for their futures by taking action now to build self-determinative skills and advocate for autism-friendly options.



Lisa Lane and Susan Sachs are the Co-Founders and Co-Executive Directors of [Project HOPE Foundation](http://ProjectHOPEFoundation.org), a non-profit organization offering a lifespan of autism services. When they met in 1997, they were two moms desperately seeking autism services for their young sons. They couldn't find what they needed, so they created it together. Over the last 23 years, Project HOPE Foundation has grown from a small, inclusive preschool to a full-fledged center for autism services, with eight campuses across four counties in South Carolina. Project HOPE Foundation is broad in scope, providing a lifespan of services (from preschool-aged children to adults), across programs (education, therapy, adult services, life skills, family support, and community engagement), and across the autism spectrum. www.projecthopesc.org

The Letter Critters Talent Show (Mascot Books)

Pursuing Dreams through ABCs on the Autism Spectrum

By Chase TAYLOR

Today, the Letter Critters are putting on a Talent Show and you are invited! Travel to Letter Critters Town to enjoy the different talents of the Letter Critters from A-Z. A fun way to learn phonics!

Watch Letter Critter T perform a tremendous tap dance. Oh yeah, the Vowelettes are singing their latest song! Guess which Letter Critter's talent is cooking and Munching on the food? You guessed it, Letter Critter M! Oh, no! There is one Letter Critter who does not want the Letter Critter Talent Show to go on, which Letter Critter could it be?

Clap or wave your hands (sensory friendly) and get excited with everyone to see the Talent Show in Letter Critter Town!

The *Letter Critters Talent Show* is the third book in the Letter Critters Book Series, written and illustrated by Chase Taylor, who is on the autism spectrum. The author turned his fascination of letters and educational fun cartoons into a series of children's books that help children identify letters and words and learn challenging words.

The *Letter Critters* introduces the cute Letter Critters' personalities from A-Z. The second book, *The Letter Critters Biographies* is a fun tongue-twisting way to learn more about the Letter Critters' personalities and where they live. The Letter Critter B loves big,



bright, blue balloons. It features a simple glossary to help with challenging words and fun facts.

The Letter Critters series is a creative way to present the alphabet and phonics with adorable, cute woodland creatures like bears, foxes, and squirrels that represent the letters of the alphabet. Your child will giggle and laugh while learning the alphabet and brand new words!

Author/illustrator Chase Taylor is on the autism spectrum, very quiet and an introvert. One of his challenges is being social and conversational. The Letter Critters gives him a voice to share his love of letters and cute characters. This young sensational author and illustrator published his first book when he was 17 years old. Chase's dream is for his characters to become an animated series for children to enjoy!

For more information: www.thelettercritters.com

ADVERTISEMENT

Digital Learning Survival Guide for Children with Autism

By Angela WEST



Whether we like it or not, 2021 is here, and with it, the continuation of virtual learning. In many locales, this mode has been the norm for some time. In other places, as the COVID-19 pandemic persists, schools continue to pivot between in-person, hybrid, and fully-virtual models. There are varying responses to this decision throughout the nation. Some families are outraged while others are relieved. Some teachers are satisfied, while others are disappointed. There's one thing that most agree on, though, and that's the fact that this learning environment poses extra challenges for atypical learners.

Just as autism is a spectrum, children diagnosed with autism will likely experience a spectrum of challenges in the era of virtual learning. One major issue is the disruption of routine. Children thrive on structure in

general and for children with autism, routines may help ground their day and bring a sense of familiarity and comfort.

Another concern is the loss of specialized support. When attending school in an in-person setting, an autistic child likely has an established network of supportive professionals, such as a speech therapist, occupational therapist, one-to-one aide, and various teachers in the classroom who provide individualized education. This team specializes in providing appropriate accommodations and modifications to ensure educational gains are achieved. In the blink of an eye, parents have been forced into the role of parent, teacher, and therapist. Now that their children are home, parents are scrambling to support them in the best way possible with minimal help from the people who specialize in these fields.



Breaking things up into smaller steps and then gradually increasing difficulty is a way of scaffolding information that can lead to small, yet significant successes.



Despite these challenges, as families and caregivers continue through the school year, there are a number of steps one can take to empower children diagnosed with autism and set them up for success.

1. Set up a designated workspace

Create a quiet, organized, distraction-free space for daily work.

2. Build confidence by establishing reasonable goals and benchmarks

Breaking things up into smaller steps and then gradually increasing difficulty is a way of scaffolding information that can lead to small, yet significant successes.

3. Make time for fun

Add an engaging, screen-free activity into the daily schedule such as a craft, music, outdoor free play, or a game that your child likes and can look forward to. Don't be afraid to incorporate movement breaks as needed.

4. Prioritize

Determine which skills are most important to achieve this semester or this year. Focus on the things your child needs most right now, academically, physically, developmentally, and emotionally.

5. Modify as needed

For some, especially children who have more significant challenges, full-time virtual learning may not be feasible right now. Sitting in a room all day partici-

pating in Zoom calls may not be possible or healthy for some children with autism.

If this is the case, have your child participate in sessions that are most beneficial or most enjoyable for them. This could mean speech therapy, art, or science, rather than all of the core subjects. If possible, stay in touch with your child's teacher and other advocates to determine the best plan.

6. Manage expectations – of yourself

Remember that you are not the teacher, but instead a learning support person. Do the best you can to help your child complete school tasks but do not expect the impossible, especially if you are also working. Your ability to maintain a positive emotional state will positively impact your child.

7. Provide opportunities for frequent praise and feedback.

Children learn best when desired behaviors are reinforced and maladaptive behaviors are not rewarded. Take some time to identify what your child values most (toys, stickers, books, etc) and set up simple rules such as "First let's join math class for 10 minutes, then we can read a book together." Verbal praise also goes a long way. Make sure to pair verbal praise and social reinforcement with tangible items by telling your child what they are doing well.

Online learning may not be a complete disaster for everyone, and some could even be well-suited to a virtual learning environment. Telehealth has been around for a number of years and many members of the autism community are seasoned users of online



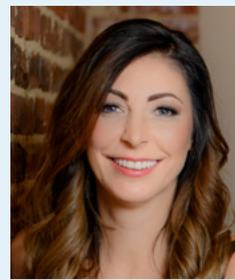
Remember that you are not the teacher, but instead a learning support person.



learning platforms to deliver behavioral and speech therapy.

Don't be hesitant to utilize outside resources and ask for guidance when tackling the digital morass of online learning. While using new channels could be intimidating to those who are less tech-savvy, those with prior experience may feel more comfortable trying out new platforms and online tools. Some families might even be able to cherish the special things they can do together this year. Being at home could allow for more opportunities to engage in domestic activities like baking, playing games, creating art, trying out new toys or materials, setting new routines, and exercising. The ability to do these things as a family will be more limited for some, especially those who are working while taking care of their children and managing household tasks.

For most, 2021 will be about survival – physical and emotional. Children may not reach every academic goal this year. Parents may grow a few new grey hairs and gain or lose a few pounds. While our standards for education and parenting may change, it's essential that all families, especially those with children diagnosed with autism, provide an environment that is loving, supportive, and flexible.



Angela West serves as Chief Clinical Officer of [Behavioral Framework](#), a company serving autistic children in Maryland and Virginia through the latest science and Applied Behavioral Analysis (ABA) therapy techniques.

Angela is Board Certified and licensed as a Behavior Analyst in both Virginia and Maryland. She has a long history of developing and expanding ABA programs in both Maryland and Northern Virginia. Angela's devotion further led her to meet with key local and state government stakeholders and lobby on behalf of ABA Medicaid funders to ensure ABA treatment reaches all families.

She began her professional career as a crisis unit therapist for homeless adults diagnosed with Schizophrenia and Bipolar disorder. While attaining her master's degree at Loyola University, Angela worked with children diagnosed with severe psychological disorders at risk for juvenile detention placement. During this time, she saw a need to assist the underserved population of children in Northern Virginia diagnosed with autism. Angela simultaneously developed a small platform ABA program that grew to a diverse and multicultural team servicing hundreds of clients around NOVA. She went on to work as a consultant in Virginia to strengthen in-home ABA programs and create a solid foundation for these agencies to provide optimal care while developing teams of dedicated ABA therapists. With over 15 years of mental health and ABA experience, Angela has a diverse knowledge of programming and behavior management.

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The Scent Guru Group, LLC

Product: MindScent® Smell. Discover. Connect. is a multi sensory tool kit for educators, occupational therapists, speech pathologists and parents who serve and who have children with ASD.

Cost: \$159.95

The Creator:

The Scent Guru Group LLC was founded by Ruth Sutcliffe, a professional scent designer in 2016. Ruth has personal experience with family members having Down syndrome and autism spectrum disorder (ASD) that inspired her to use her skills to develop sensory tool kits to help people living with learning disabilities, speech communication impairments and dementia. Her innovative kits seek to help educators, OTs & SLPs and parents who might be home-schooling during the pandemic. MindScent® is a patent-pending multi-sensory tool kit that has garnered attention from as far away as Australia.

MindScent® Facts:

- Has been tested with speech pathologists
- Being purchased by both occupational and speech pathologists and life activities directors
- Some suggested methods for use: increased engagement, establishing rapport, teaching vocabulary, increased length of utterance, increased use of descriptors, increasing socialization with peers
- Patent pending



- 100% made in the USA
- Formulas do not contain alcohol, are safe for the skin and have undergone all industry regulatory reviews
- The distinct scents are long lasting with each 0.5 ml. rollerball lasting more than 1,000 ½" swipes on the included paper scent strips
- Scent prompts are packaged in an easy-to hold rollerball & are recyclable!
- Before the pandemic, The Scent Guru Group hired local, non-profit organizations that employ people with disabilities to assemble and pack MindScent®.

Links: www.thescentgurugroup.com

How to Make Travel Fun for Your Child with Autism



By Gemma WINCHESTER

Looking after a child with autism can be a struggle at times. Since the autism spectrum is so diverse, what works for one child may not work for another. You really need to understand what triggers your child so that you can make accommodations for them.

I am not a parent, however, both of my brothers have autism. My father left us and I helped my mother raise them. One thing that really upsets me is when I hear families say that they avoid travelling with their child because they are afraid of how their child might react. I want to share with you some tips to get you out and about with your child, after the pandemic is over, of course.

I am by no means an expert, but I have worked as a flight attendant and a cruise ship staff member, and I have travelled to over 70 countries with my brothers. You shouldn't be afraid to take your autistic child overseas. Use the knowledge you have of your child's sensory needs and plan your trip accordingly—for example, if your child is particularly sensitive to noise, then of course you wouldn't bring them to a concert hall

Prepare for your journey

To start off, the first step of any trip is the transportation. I cannot stress how important it is to be prepared for the journey. Pack your child's favorite food, favorite books, some headphones, and a blanket.

My younger brother, Scott, loves to read. I always pack his favourite books, and when we get to a destination, I get him a brand-new book with pictures about the place we are visiting. This allows him to feel like he is involved in the adventure without overwhelming him. If a location gets too loud—and some of the major tourist hot spots definitely will—I give him his headphones and a book about the place we are in. This makes him very happy. Scott also requires a wheelchair, so I always do my research on a destination prior to arriving to ensure it is wheelchair accessible. Just imagine how you would feel if your family couldn't visit a place because you couldn't get around. It isn't a nice feeling for anyone.

Allow your child to choose their clothing

The next thing I will tell you is to let your child wear what they want to. This will save you a lot of heartache. For years, my mother and I would find it so hard to get Scott to wear what we thought was socially acceptable. Let me tell you, it doesn't matter what other people think. You know your child, you love your child, and you should allow them to express themselves in the way they want to. Sometimes Scott wants to wear a full suit and fedora to the zoo, and other times he wants to wear a frog onesie. As long as your child is dressed and covered, it will save you a lot of stress to just allow them to wear what they want. You travel to have fun and enjoy yourself, so don't let minor issues make your trip stressful.



Travelling with your autistic child isn't something that should be regarded as taboo. It should be a fun way to bring your entire family together. If you would like to reach out to me for any advice or tips, please don't hesitate to contact me and I can share as much knowledge with you as possible.



Consider activities and a comfort animal

I have spoken to many children who have autism and something all of them have communicated to me is that they feel different. They know they are different. It can be very damaging to your child's self-esteem when he or she feels like they don't belong. Let them try as many activities as you can; you will find out whether or not they enjoy it by trying it out. However, just assuming they won't enjoy it will make them feel left out. Feeling understood and accepted for exactly who they are is essential to your child's happiness.

You may also find it helpful to apply for a special needs assistance dog. Many dogs are trained to support people with anxiety. A comfort animal can make a world of difference when you travel. I have inside knowledge from working on airlines and passenger cruise ships that if you require an assistance dog, there is an allocated area for your family.

Pack comfort items

My family and I have travelled so much with Scott, we know exactly what comforts him during travel. We make him as comfortable as possible, picking places that are accessible for his wheelchair, packing his books, teddy and sometimes taking Ruby, his chihuahua, with him. Write a list of all the things that comfort your child and pack as many of them as you can. Involve your child in as many activities as possible, including the planning process. Do not stress—if you stress, then your child will stress.

Summing-up

Travelling with your autistic child isn't something that should be regarded as taboo. It should be a fun way to bring your entire family together. If you would

like to reach out to me for any advice or tips, please don't hesitate to contact me and I can share as much knowledge with you as possible.

Thank you for reading and I hope that I have inspired you to take that big inclusive family trip and not stress about it. Enjoy every moment; I wish you happy and safe travels for you and your whole family.



Gemma Winchester was born and raised in Singapore by British-Singaporean parents. She was the middle child; her older brother has autism and her younger brother has Down's Syndrome and autism. Gemma's younger brother and she are only twenty months apart. She went to school with him for years. In Singapore, schooling for children with special needs begins at six months. This allowed Gemma to be surrounded with children from all across the spectrum. She believes that having a deep understanding and connection to those on the spectrum allows her to be able to help parents and families today. She has been a professional writer since 2017, you can read her articles here <https://hive.blog/@vegoutt-travel#>

Four Steps for Planning for Your Autistic Child's Financial Future

By Ryan PLATT



2021

2021 is upon us, and with every new year comes hope. 2020 was a year full of surprises for the entire world, requiring all of us to change our habits, adjust our plans, and reevaluate how we live our daily lives. We were forced to think about the ways in which our actions not only impact our own future but how those actions impact the lives of others. For families with a child with autism this is not new. Families should always be concerned about how their decisions will impact everyone in the household and, of course, the future of their child with autism.

As this new year begins, we can take stock of the action items we completed and the action items that still need to be done. If this is the year that you promised to have a comprehensive financial plan completed for your child, but you still have not started, here are four steps you can take:

Create a letter of intent

A Letter of Intent is the “instruction manual” for your loved one. It will describe your child’s diagnosis, diet, sensory issues, therapeutic needs, behavioral items,

medical information, and prescriptions. You will also be able to detail the activities of daily life, the support services your loved one receives, other supporters in his or her life and their contact information, and government benefits your loved one receives. In the Letter of Intent, you will provide guidance on future care for your loved one based upon their needs, your wishes, and their desires.

Overall, the Letter of Intent is designed to give the next caregivers (after you) everything they need to care for your loved one in the same manner you had been.

You can find a template of a Letter of Intent and more information about it at www.HowtoSecure-theFuture.com

Develop your family's future vision

This process will take some time to think through because it will include a multi-generational timeline. This timeline should include a plan for the rest of the parents' lives and then a plan for the child with special needs.

This plan needs to include living arrangements, job possibilities, retirement goals for the parents, expenses for other children (such as education, weddings, etc.), an understanding of tax implications, and the inclusion of government benefits and services. It is critical to project a financial backdrop to your plan so that you understand the resources that will be necessary for your plan to be successful over two lifetimes.

Action. Action. Action.

The third step is usually the most challenging because this is when you must make decisions. You must decide how to use your financial resources, to save more money, to buy life insurance (or not), or to spend more on therapy or life skills training. You must decide to apply for government benefits, to create the proper legal structure to protect government benefits, and to ask others to be the next support people for your loved one when you no longer can or when you die.

Review. Update. Change.

This step is ongoing and continual. If 2020 taught us anything, it taught us that we must be able to adapt and change. The plan you create for your loved one with autism will not be a one-and-done event, because your life and your loved one's life does not behave in that way. We are living in a world that constantly changes, which means your plan must be fluid, and adaptable.

These four steps can seem overwhelming. We advise that you seek out professionals who can help you through them. These professionals should be able to assist you in all four areas. They should have the experience and knowledge to guide you through this process so that you can move from being overwhelmed to being empowered!

To continue to learn more about Special Needs Planning feel free to visit our Resource Library at www.ASpecialNeedsPlan.com



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This article is not a recommendation or an endorsement of any products. He is the founder of [A Special Needs Plan](http://www.ASpecialNeedsPlan.com).

For more information on how to prepare for the future, be sure to contact a financial advisor who specializes in serving families with special needs. A Special Needs Plan is driven by their purpose of leading families to independence through an ongoing multi-generational plan. A Special Needs Plan is passionate about families confidently moving forward.

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