

# Autism Parenting Magazine

Issue 90

**BEHAVIOR  
SUPPORT  
STRATEGIES**

**Top Tips on  
Transitioning  
a Child Back  
to School**

**How To Get  
the Social  
Skills Class  
Your Family  
Wants and  
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**Building  
the Road to  
Independence  
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**How to Help a Child  
Struggling With Sensory  
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**Medical Cannabis,  
Autism, and the  
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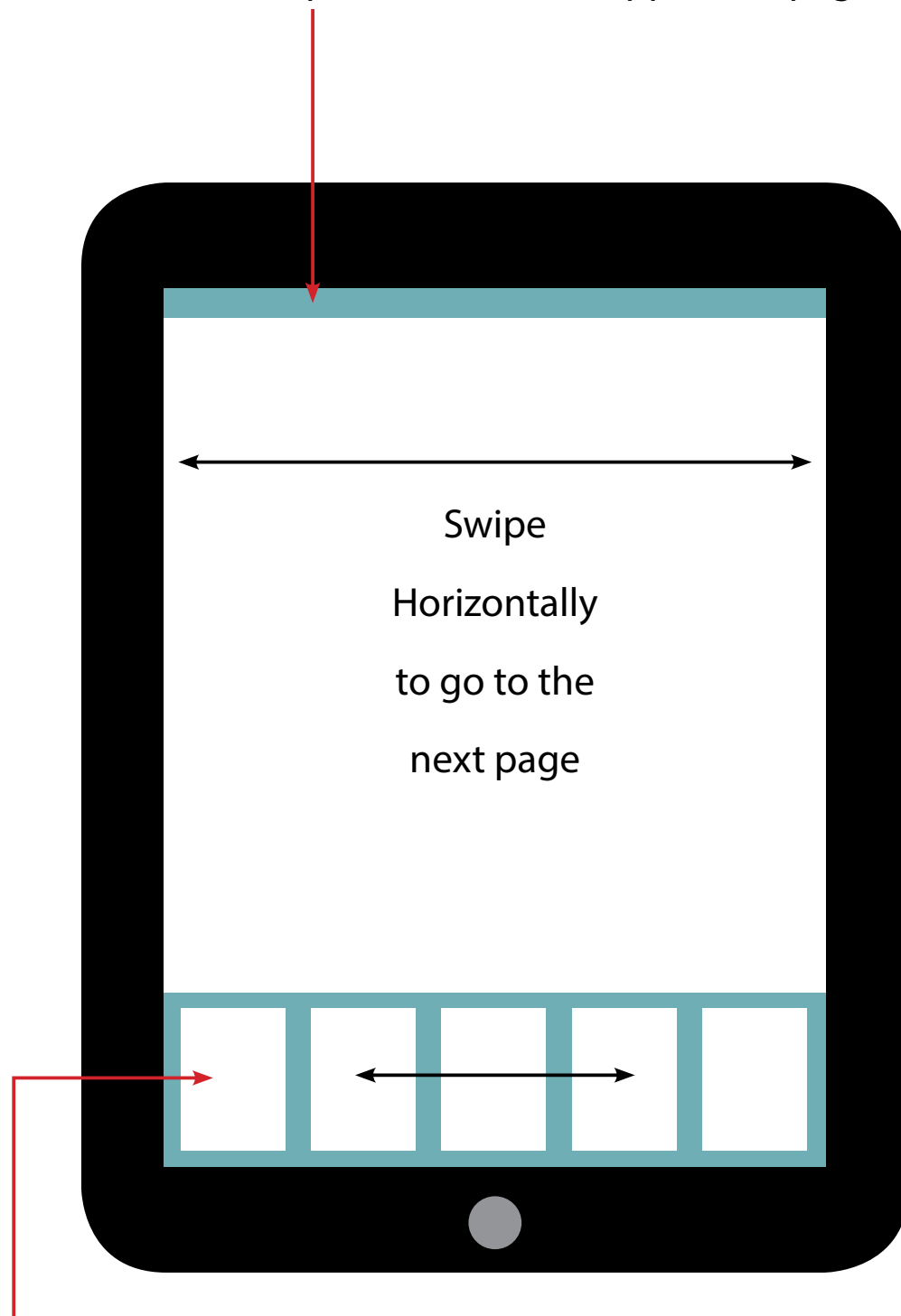
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## Editor's Letter

**A**s the long summer days gradually come to an end, do you find yourself apprehensive about the new school year? We all know unfamiliar classrooms, teachers, peers, and programs can be overwhelming. Are you stressed with the thought of new schedules and beginning the transitioning process with your child with autism? Do you feel like no one understands your fears? Well, you don't have to feel this way anymore.

One of the highlights of my job since I joined as Editor-in-Chief five years ago has been connecting with and guiding an extraordinary autism community. Parents, siblings, grandparents, teachers, advocates, and people on the autism spectrum all reach out to our team each week with their biggest concerns. Many times, we offer guidance by assigning a specialist to tackle the topic in an upcoming issue, and other times, our staff directs them to a previously published piece. We take pride in supporting families affected by autism spectrum disorder (ASD).

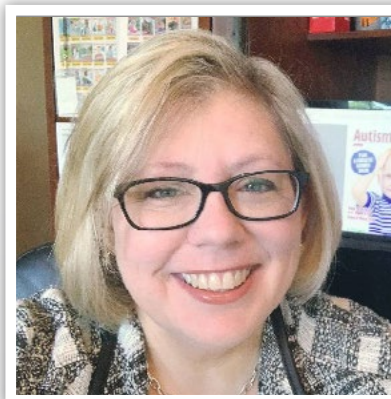
This month's issue is jam-packed with guidance. From advice on social skills programming and behavior support strategies to improved transitioning and ways to gain independence, you don't want to miss this issue as we focus on practical ways to build skills for a lifetime.

One concern always at the forefront this time of year is the transition back to school after a summer schedule. As many of us know, kids with ASD crave routine and predictability, which makes preparing for the first week of school key. Take a look at **Top Tips on How to Transition a Child With ASD Back to School** by Annette Nunez, PhD, to discover specialized strategies for transitioning a child with autism to a new environment. From taking a tour of the school to reviewing your child's Individualized Education Program (IEP), Annette's advice will prepare your family and hopefully relieve some stress.

Since socialization is an integral part of the school day, another apprehension often revolves around mastering social skills. This is an ongoing endeavor for kids on the autism spectrum as they change so much as they develop. If your child could benefit from a social skills class, please read **How To Get the Social Skills Class Your Family Wants and Needs** as Rachel Bédard, PhD shares easy ways to secure the supportive social skills programming your child needs to thrive.

Numerous children with ASD have difficulty with conventional behavior expectations as autism often comes with many neurological differences. The need to transition into new environments and schedules can only amplify behavioral challenges. Take a look at **Behavior Support Strategies for Children With Autism** by Elizabeth Ives Field, MEd, CCC-SLP as she shares the common characteristics of autism, which can lead to behavioral conflicts. Her article also includes specific strategies to fit each child's situation.

Does your child quickly go into a fight-or-flight response when bombarded with confusing sensations and become disoriented by it? If so, please read Nancy Peske's piece called **How to Help a Child Struggling With Sensory Issues and Self-Control** to find new ways to help kids develop important self-regulation skills.



Have you considered Applied Behavior Analysis (ABA) to help boost targeted skills? While typically applied in the home setting, its use outside the home in a clinic/center is proving to have specific advantages according to ABA expert Joseph Laudadio. Please read Joseph's piece called **Is an ABA Center the Right Place for Your Child on the Autism Spectrum?** as he explains what to look for when seeking therapies for your child and what to consider when choosing an ABA center.

Finding new ways to improve health is always at the top of the list when we plan an issue. We are thrilled to feature a piece this month on ways nature can be used to improve physical, sensory, social, and emotional wellbeing. Take a look at **The Remarkable Ways Sensory Gardens Can Help People With Autism** as Amy Wagenfeld, PhD, OTR/L, SCEM, FAOTA, and Marlene Sotelo, EdD, BCBA-D, MT-BC, introduce you to The Sensory Arts Garden at The Els Center of Excellence in Florida. This 13,000-square foot therapeutic and educational destination has been thoughtfully designed with children and adults with autism in mind. The grounds are gorgeous as they are filled with a variety of plantings, hardscaping, and water features that offer varying levels of sensory experiences. When people with autism participate in nature, they not only broaden their interests, but can develop social skills as well.

We know it's hard sometimes to focus on tomorrow amid life's daily stressors, but fostering independence and preparing for the future is vital. According to Karen Kaplan, who has more than 35 years of experience working in the field of autism, from the moment a student begins an educational program, the school should be preparing him/her for the future. Be sure to read her piece **How to Build the Road to Independence With Autism** where she provides key questions to ask when thinking about transition goals, objectives, classroom lessons, and family supports to reach independence.

Be sure to take a look at our other informative pieces this month, from an article on emotional self-regulation to easy ways to teach perspective taking to an ASD child. We also have an excellent article by David Berger, MD, a board-certified pediatrician and leading US authority on medical cannabis, on how using medical cannabis can help facilitate the treatment of children with chronic conditions.

Please reach out to us—together, we form an exceptional autism community that will meet today's and tomorrow's challenges.

**Amy KD Tobik**  
Editor-in-Chief

### Disclaimer:

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# Top Tips on How to Transition a Child With ASD Back to School

By Annette NUNEZ, PhD

The time has come! Summer is winding down, and it is that time of year when your kids need to start preparing to go back to school. As a parent, you have mixed emotions about starting the new school year. On the one hand, you are excited to have some “me” time again. However, on the other hand, you dread this time of year because, as with any big transition, it often comes with your child’s anxiety going through the roof and sparking difficult behaviors.



**E**ven though your child has gone to school before, the beginning of the school year is filled with newness and a lot of unknowns. Your child has a new teacher, new classroom peers, and a new routine and schedule. This change is difficult for any child, but for a child with autism, it can be 100 times more

difficult. Imagine the stress and anxiety you would feel if you were thrown into a new job with no training. It would feel pretty uncomfortable. So take that uncomfortable feeling and pair it with the inability to express yourself. Can you understand a bit more why your child may exhibit increased difficult behaviors during the new school year?



**You will have to change your relaxed summer schedule and engage in activities that have some structure. Structuring up your child's schedule will help reduce the stress and anxiety he/she is feeling about going back to school.**



Children with autism like routine and predictability. It is essential for you to begin some routines and predictability a couple of weeks before your child starts school. You will have to change your relaxed summer schedule and engage in activities that have some structure. Structuring up your child's schedule will help reduce the stress and anxiety he/she is feeling about going back to school. I have created a list of five strategies that have been extremely effective with my clients. These strategies have proven to be helpful to many parents when transitioning a child from summertime to a new school year.

### **1. The Final Countdown**

Create a calendar that marks the date of when your child is going to start school. Mark this day with a HUGE star that reads, "First Day of School!" two weeks before school starts, then have your child cross out each box at the end of his/her day and count how many days he/she has until the first day of school. This calendar is a predictable visual for your child that lets him/her know when school will start and how many days are left of summer vacation. This calendar is tangible, visual, and predictable...everything your child loves!

### **2. Practice Makes Perfect**

Two weeks before your child starts school, begin your morning and evening school routines. Have your child wake up at the time he/she regularly would for school, get dressed, eat breakfast, etc. Then leave the house to go on a walk, go to the park, or do another activity outside the home. In the evening, have your child follow the evening school routine such as eating dinner, taking a bath, reading a book, and going to bed at a specific time. By following these routines a couple of weeks before school starts, your child will be less resistant to waking up and going to bed because he/she will have practiced this routine. Practice makes perfect and helps with behaviors.



### **3. Prepare, Prepare, Prepare**

Show your child pictures of his/her teachers, the classroom, and classmates if you can. Contact your school a week before the first day and ask if you and your child can take a tour of the classroom. You can also create a social story that includes pictures of your child's teacher, names and pictures of kids in the class, pictures of the classroom, etc. This way, your child knows who his/her teacher is, what the classroom looks like, and what to expect on the first day of school. This step will decrease his/her stress and anxiety, as well as yours.

### **4. Review Your IEP**

It is essential for you to review your child's Individualized Education Program (IEP) and make a copy of it to give to your child's teacher while highlighting any special accommodations. Many parents assume that the new teacher and aide will have read their child's IEP, but they often haven't. Also, review all the services listed in the IEP and call the school to ensure your child's aide is in place on the first day of school. Informed people make for an easy transition.



## 5. It's All About Me

Create a simple and easy flyer that contains information about your child. Include things such as what your child likes, what sets your child off, what reinforces your child, what your child is allergic to, what your child did over the summer, etc. Make this flyer easy to read and make multiple copies to hand to everyone working with your child.

The beginning of the school year can be an exciting time. It is a time of growth and change and a way for your child to learn new skills. Keep in mind that your child feeds off of your energy, so if you are calm about this transition, he/she will be too. Remember, the end of summer leads to a child's success and a parent's sanity.



*Dr. Annette Nunez, PhD, is the founder and director of Breakthrough Interventions, LLC and Breaking Through Autism. She is a licensed psychotherapist and has worked with children with ASD and other related disorders for over 22 years. As part*

*of her doctorate work at the University of Denver, Dr. Nunez developed the Children's Social Competence Scale (CSCS). The CSCS is an early intervention evaluation tool that measures social competency in young children. She served as the program director for Connect Us, a non-profit organization that helps children cultivate positive relationships through facilitated play. Her research interests include the mainstreaming and socialization of children with high functioning autism.*

*Dr. Nunez co-wrote and self-published the Friendship Is... book. She conducts many seminars both nationally and internationally and has consulted with many schools in China and South Africa. Dr. Nunez also consults and supervises the therapists at the Breakthrough Interventions site in South Africa. Dr. Nunez has been featured in the Huffington Post, NPR, The Jenny McCarthy Show, and FOX News. You can listen to her on her weekly podcast Behind the Breakthroughs.*

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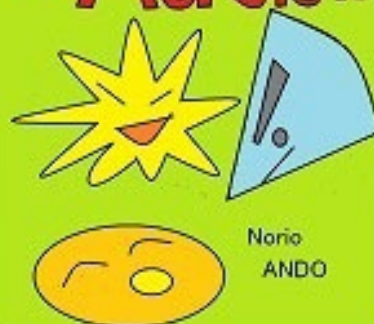
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Norio Ando is a professor of Uekusa Gakuen University in Chiba, Japan and a certificated clinical psychologist. He has treated autistic children for 37 years based on the emotional development.





# How To Get the Social Skills Class Your Family Wants and Needs

By Rachel BÉDARD, PhD



**S**eriously, what child really wants to sign up for social skills class? In my storied career, I've actually only heard one child bemoan, "But Mom, I really *need* social skills!" The rest of my clients have been coaxed, cajoled, and bribed into attending the initial session, generally to discover the class wasn't that harrowing, but also maybe wasn't that helpful. (As for adults? There is a reason why so many elementary school groups are full and why many young adult groups are on the brink of extinction.

Adults don't *have* to attend!) So, how do you get the programming you want? Here are some ideas:

- **Talk to the people who seem to be in charge**

Find the decision makers and offer some creative suggestions (more on that below). Directly suggest programming you might like to see. Sometimes the people in charge have been there for a long time and have not considered updating their programming. Your request might be a gentle prod to update of-



ferings. Alternately, “Geez, I don’t know...that is how it has always been” is the phrase you might hear. In which case...

- **Talk to the people who *don’t* seem to be in charge**

You know who I’m talking about: the young, hip ones who know which organizing apps you should have on your phone—and how to install them! These young adults are open to new ideas and will probably welcome your suggestions. They also have the energy to pull this off and are not yet accustomed to the status quo.

- **Ask for a group that includes an *interest***

Before you roll your eyes back so far that you resemble a teenager, consider: what social skills groups do you know are based on an INTEREST of some sort? Interests that easily come to mind include crafting, art, knitting, board games, gaming, drama, writing, and rather specific animals. Ends up, you CAN learn about social skills while also discussing specific interests with your—wait for it—future friends!

- **Ask for a group that is an *activity***

I’m currently obsessed with the notion of Yoga for Gamers. Everyone needs exercise—why not try a little yoga with people who also game? Make some new friends, chat about your favorite games...you can see where this is headed. Not interested in yoga or gaming? How about pottery, poetry, or website design? Get specific, and make your request.

- **Ask for a 4-week group**

It often seems that social skills classes run for 8 to 16 weeks. Who can realistically commit that long? Ask for a one month group, and for the opportunity to sign up again and again. If you pitch the most amazing programming ever, the group will fill, so reserve your spot!

- **Ask for a short and focused group**

We once ran a series of 4-week classes for adults related to executive functioning. We met hourly for a week, focusing one month on writing appropriate goals, another month of prioritizing and motivation, and another month of goal achievement. (Well, mostly achievement. Not all goals were met.) The participants were asked to commit to making

changes every week. Most everyone signed up month after month, but some people took a month off due to scheduling or other factors. Low pressure, clear skill building, accountability, and lots of laughing. To translate that into a more social skill related group, ask for a group that is about joining groups, texting, posting on social media, first dates...

- **Ask for a group that *you* would want to attend**

Sometimes as professionals, we get so caught up in growth and measurable progress that we forget that social interaction is supposed to be *fun*. Ponder what type of group would be fun for you (or your child, I suppose, since this is supposed to be about your child) and see what elements of that jump out at you. Where is the group, how long do they meet and how often, and how many other people are there? What are you doing during the group, and are people sitting/milling about/focused on their knitting—or also communicating in some way? Ask for a fun group that is meaningful in some way.

As a parent, do you have a right to ask for a group that meets your child’s needs? YES! You may have to ask a few different providers in a few different ways, but asking is probably the first step in getting others to roll out some more creative programming ideas that build skills and are also actually interesting and fun! Must you settle for the status quo? No! And given the creative brains and divergent thought processes in your household, you are probably the person to help solve the boring.social.skills group crisis! Go, you! And when you get a minute, drop me a line about the awesome group you pitched to your team. Who knows, maybe I’ll use your idea, too!

*Rachel Bédard, PhD is a licensed psychologist practicing in Fort Collins, Colorado. She uses a strengths-based approach, and her clients note that she has the ability to help them laugh about even the most stressful or embarrassing events in life. Dr. Bédard has co-written two books with her favorite Speech Language Pathologist, Mallory Griffith. Their most recent book is You’ve Got This! The Journey from Middle School to College, As Told by Students on the Autism Spectrum and Their Parents.*

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# Amazing New Web Series Captures the Challenges of Autism

By Crystal RAMOS



**T**he web series *Oh Jordan* follows the Spinola family as they navigate the extra twists and turns their child with autism, Jordan, brings to their lives. Each five-minute episode focuses on a different aspect, ranging from an explosive family gathering to a therapy session for the entire family. More than just simply following Jordan as he goes through his struggles, we wanted to show how autism impacts everyone around him. With anger and frustration, there is also laughter and love.

Many of us involved in the series have family members on the spectrum or worked with children with autism. The actor who plays Jordan even has autism,

a casting decision we all felt strongly about. Too often in the media, you see an abled or neurotypical actor portraying someone who is not abled or neurotypical, and we refused to fall into that same Hollywood trap. Often, people with autism are made to feel like they can't do things, and we wanted to show through our casting that anyone can do anything if they put their mind to it and work hard enough. Just recently, my three-year-old son got diagnosed with autism, and I hope that *Oh Jordan* will help him see that he can dream big and, with enough hard work, make those dreams come true.

In addition to my oldest son, one of my younger brothers has struggled with autism and sensory is-

sues his entire life. So, when we were brainstorming ideas for *Oh Jordan*, I brought up an incident that had happened between my brother, his aunt, and a shirt. For neurotypical people, putting on a random shirt for a family picture poses no problems. But for my brother, the texture of the shirt overloaded his senses, and he could not put it on. The fallout from that moment still reverberates through the family today.

Sometimes, the people closest to us are the ones who are the least supportive. Their voices saying things like, "He only acts that way because you spoil him" are also the most painful to hear. They don't understand how things that come so easily to them can be so difficult for someone with autism. How can someone list all 809 Pokémon but refuse to read a fiction book because it's "lies"? How can someone throw a violent tantrum when he/she hears a doorbell? How can someone refuse to eat yogurt because it feels like slime?

That's why we showed things from Jordan's perspective as much as possible with the shirt transforming in "Scratchy Shirt" and the girl's makeup in "Sleepover." People with autism experience the world differently, but it's hard sometimes for others to understand that without seeing it. By showing things from Jordan's perspective, we hope those people who don't understand will finally be able to show the support and understanding we all desperately need.

It's not just family members who can misunderstand someone with autism. In "Poodles," we show Jordan at school, where he is the victim of teasing and even perceived as someone instigating it. People say they want the truth, but it's only when confronted with unfiltered reality do people realize they didn't actually want it. To Jordan, a classmate's hairstyle reminds him of a poodle, and it takes a therapist to make him understand how hurtful that comparison can be. She reminds him of the other boy's hurtful comments, and Jordan finally begins to understand how his words can hurt someone else.

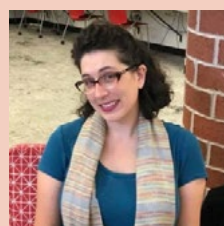
In this case, he has a chance to make himself understood more clearly, but it is a lifelong battle he will have to fight. By showing how Jordan doesn't understand his friend's hurt feelings, we hope people watching will realize that people with autism aren't trying to be mean. They lack skills in identifying emotions and social cues, and just as Jordan has to work

on constantly reminding himself that his words can hurt others, we have to remind ourselves that Jordan is not purposefully hurting anyone. He is simply telling the truth.

While in our series the unfiltered truth in "Poodles" and "Sleepover" gets laughs, it doesn't usually play out like that in reality. It's so easy to say the wrong thing or react with anger when we are hurt. It's harder to pause before the words come out of our mouths or we attack, but the laughs remind us that perhaps anger isn't the best response.

I was afraid my family would be upset and angry when they watched *Oh Jordan*. After all, I was sharing my brother's story with the world, and it's not the perfect, shining moment I want everyone to see. But after watching *Oh Jordan*, my stepmother called me in tears thanking me for telling my brother's story. Even though I only directly borrowed from his life once, she saw my brother echoed in every episode. Far from being angry, she expressed gratitude and a desire to turn a negative experience into one which could shine light into other families struggling with the same issues.

Earlier I mentioned my son has autism. Unfortunately, I did not know my son had autism when I started working on the series. Suspicions, yes. After all, it runs in families, and there are only so many times in a day he can line his cars in a straight, even row throughout the house before you begin to wonder. Now that I know he has autism, I only hope one day I'll be able to tell his stories and help others like him and their families as they struggle through life.



*Crystal Ramos graduated with an MA in Professional Writing from Kennesaw State University. She writes many different forms and genres but is especially taken with screenwriting at the moment. Her two boys, however, do their best to stop her from getting words on the page. She is the screenwriter of Oh Jordan! Episode 102 - "Scratchy Shirt."*

Scratchy Shirt Video: [https://youtu.be/qrFC\\_BupZt8](https://youtu.be/qrFC_BupZt8)  
Website: [www.oh-jordan.com](http://www.oh-jordan.com)

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# Behavior Support Strategies for Children With Autism

By Elizabeth Ives FIELD, MEd, CCC-SLP



**B**ecause autism comes with neurological differences, it is almost certain these children will have difficulty with conventional behavior expectations. Among the common characteristics of autism, which often lead to behavioral conflict, are the following:

- Significant, atypical difficulties with understanding and using language. This is especially demanding in group situations where several people are conversing, or a teacher is leading a discussion.
- Often, an overly reactive sensory system that makes ordinary noise, smell, or touch intolerable.
- Problems with shifting attention or transitioning from one activity to another. Leaving a favored activity is hard, but stopping an assigned task before it is finished can also be stressful.
- Very little ability to recognize another person's perspective or opinion or to empathize with another's feelings. It is certainly challenging to empathize if you cannot readily identify the feelings of others.
- A need for predictability and routine, and a tendency to respond based on associated memories that can lead to repeating familiar behaviors even if they produce negative results.



- Poor recognition of public vs. private behavior and limited embarrassment or apparent concern about other people's impressions of them.
- Emotional responses that are apt to be extreme and are often based on immediate events, leading to rapid changes from smiling to screaming. Immediate recovery may or may not occur if the problem is "fixed."
- Considerable difficulty organizing themselves to do something productive in undirected play activities, in stimulating public situations, or when waiting.

Remember, these are not the result of poor parenting or teaching, nor are they deliberate, willful, or manipulative behaviors. They are simply common characteristics of children with autism spectrum disorders, and they aren't anyone's fault. The child is probably doing the best he/she can to cope with an extremely confusing and unpredictable world. However, these characteristics do result in problems of many sorts, including such diverse behaviors as:

- Poking another child to hear him/her squeal
- Refusing to stay in circle groups
- Ignoring or automatically resisting teacher directions
- Coming out of the bathroom with pants at half mast
- Becoming very upset by changes in routine
- Saying things that are considered rude
- Having outbursts in public places

We want to help the child modify problem behaviors and fit into society better, but how?

Generally, I suggest first trying whatever methods the teacher or parent would use with other children, especially in a group setting where the expectations are the same for all the children. However, traditional methods often don't work for children with these issues, especially if they involve explanation, loss of privileges, discussion and/or reasoning, or appealing to empathy, self-image, or guilt. For instance, time-out might work; but in school, it can become a desirable escape. Rewards can be very helpful if they are clearly connected to a specific positive behavior

that is well within the child's ability—such as staying seated on the bus—but not if they are tied to a vague generality, like "being good on the bus." It's important to realize that adults will have to modify the environment and their expectations in addition to helping the child modify his/her behavior. Also, this child will not automatically generalize a new behavior to similar situations and will be unlikely to discover and interpret social expectations intuitively. Learning to set his/her cup on the table does not guarantee that the child will not throw the plate on the floor.

Keeping in mind that these are children who need considerable individualization in all aspects of learning and that specific strategies must be designed to fit each child's situation, the following are some general guidelines I've found to be helpful:

- Talk less. Use demonstration, visual cues, and physical prompts, shortening, and simplifying language in stressful situations. Repetitive or predictable language is also helpful in a crisis, such as saying "Eight steps to the door; 1-2-3-4-5-6-7-8-open!" as you physically help the child move in that direction.
- Use routine, structure, schedules, and predictability to provide a comfortable, less alarming situation for the child, but keep including small variations to help develop flexibility. "We need to change the plan today. One game and one book instead of two books. I will write it on the schedule."
- Ease transitions by shortening the gap (present new materials as you remove the old ones; don't come to a circle group until it's ready to start), provide transitional objects to carry from one place to the next (especially if the object is useful in the next activity), and keep language simple and familiar ("All done with \_\_, now it's time for \_\_").
- Distract and redirect the child to something more acceptable, such as a toy someone else isn't using, the sound of an airplane going over, or a small fidget toy in circle group or when waiting in line. When you do explain, keep it clear and simple: "Liam's turn with the train. We will wait and do the puzzle."
- Change the location or environment to remove yourselves from things that trigger or pro-

long the problem. If the cafeteria is too loud or smelly, eat somewhere else, with a friend or two if possible. Move away from group situations when you see agitation increasing. "It's too noisy here. Time to go for a walk."

- Prevent recurring problems that may quickly become negative rituals by changing the format, altering your language or behavior, or temporarily avoiding the situation and gradually reintroducing it. If a child always shrieks and collapses on the ground as you transition from the playground to the car, have a favorite toy or treat in the car, and instead of telling the child you have to go get a sibling, say "It's time to get the (treat or toy)."
- Teach rules that are clear, simple, and concrete ("sit on the carpet square," not "sit nicely") and reward improvement toward acceptable behavior, even if it was brief or adult-assisted at first. In the playground example above, the child gets the reward when he/she is buckled in the car seat even if it was a struggle to get there; say something like, "You're in the car seat; here's the..."

- Teach competing acceptable behaviors such as appropriate self-help skills and social routines to replace problem behaviors. Feeling competent and knowing what to do in a situation reduce the anxiety that often underlies inappropriate behavior.

Expect progress but not an immediate cure. Try to see the problem from the child's perspective and gradually help him/her cope in ways that are more socially acceptable.

*Elizabeth "Betsey" Field, MEd, CCC-SLP, lived in Maine until 2015 and had a rewarding career as a speech-language pathologist working mostly as a consultant to school teams and families working with children and young adults diagnosed on the autism spectrum with a focus on increasing communication, independence, and appropriate social behavior. She has also worked in a state institution, community agencies, schools, a university, and private practice. Betsey now lives in Massachusetts, where she works part-time, maintains some consultation services, and enjoys having four grandchildren nearby.*

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# A Flight of Love and Understanding With ASD

By Frank SEMMENS

The red-eye from Quito to Miami was delayed for two hours. Most of the passengers had been waiting near the boarding gate for more than four hours—many milling about in the aisles, a few reading, talking on their cell phones, or squirming in their plastic seats. Some were sprawled out on the tile floor—a few sleeping and some snoring.



**A** mother and her little boy who looked to be about 10 or 11 years old sat next to each other two rows in front of me. The child was neatly dressed in a white shirt, beige trousers, an aqua blue Miami Dolphins cap, and matching sneakers. In his hands, he held a computer game board, and every 10 seconds or so he would yell “WHOA, YEAH, OH NO, WOW” so loud that heads turned to find out what might be

wrong. The child’s exclamations were annoying everyone within earshot. I quietly fumed from within, wondering why his mother wouldn’t make him shut up or at least lower his voice. She just sat there with a blank face, never uttering a word. She seemed to be completely unaware of the commotion he was causing. I thought about admonishing her for being a bad mother. I wanted to get up and leave, but there were no other seats available. So I sat there anxious-

ly, thinking, "I hope they don't sit anywhere near me on the plane. God forbid, I'm exhausted and need to sleep on the flight home."

Before long, boarding began. I was in zone 5 and had been diligently searching to see if the mother and child were still in line. They were nowhere in sight, so I assumed they had boarded the plane before me. Parents with young children typically get priority service.

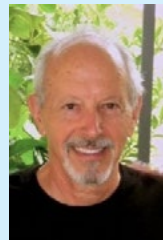
Upon entering the plane, I made my way to my aisle seat. No one had yet taken the middle or window seats. It was a large aircraft, more than 40 rows deep. I couldn't see to the back of the plane, so I assumed they had taken seats in the last rows. I stowed my carry-on under the seat, sat back, and let out a sigh of relief. A minute or two later, I heard familiar sounds coming from the front of the plane: "WHOA, YEAH, OH NO, WOW." "This can't possibly be," I said to myself. "Dear God, don't let them sit next to me." My mini prayer was to no avail because the mother approached my row, and with a slight smile, motioned for me to let them in.

Meanwhile, the boy continued with his commotion while clutching the device. The mother placed her child in the window seat, secured both of their safety belts, and sat with her eyes closed, completely ignoring the ruckus going on beside her. I was going out of my mind thinking that I'd never sleep. I had a mid-morning business meeting in Miami regarding a major marketing campaign and needed to be alert and focused. If the meeting went awry, my career would be in jeopardy.

I felt tremendous relief when I heard the flight attendant's announcement to turn off all electronic equipment. My relief was short-lived, however, because the child let out a horrific howl when his mother took the device and put it in her handbag. All of the passengers around us peered over their seats to see what was causing the commotion, many of them scowling. I felt like a prisoner in my seat, with nowhere to go. The boy's howl turned into screams. I looked to my left and saw the mother unbuckle the boy's seat belt, lift him into her arms, and place his head against her heart while humming a quiet tune. The boy's sobbing suddenly softened and eventually stopped altogether. His body went limp, and in what seemed like several seconds, he fell asleep. The mother arranged some pillows, placed him back into

his seat, and secured his safety belt. Then she turned and looked at me with a tired smile. I realized then the boy was autistic. I had seen similar behavior in my extended family. I tried to imagine how it would be to live like this every waking hour, every day for more than 10 years. I felt a mixture of compassion for her and shame for my selfish reaction to the boy's behavior. I was making this matter about me and not about her, a mother who had been dealing with this for all of these years and would probably continue caring for him for the rest of her life. The exhaustion in her face was sad and riveting.

I settled into my seat, closed my eyes, and thought about the moment the mother hummed a tune and placed her son's ear against her heart. I saw love, and I understood.



*Frank Semmens is a US Navy Veteran, former Peace Corps Volunteer in Bolivia, SA, former producer/director of documentary films, and current owner of Translation Services International.*

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# Medical Cannabis, Autism, and the Transformation of Medicine

By David BERGER, MD

In 1987, during my freshman year at Lehigh University, our first English assignment was to write a letter to an elected official advocating for a controversial issue of our choosing. I decided to write my United States congressman to express why I believed marijuana should be legalized.



**W**hat was supposed to be a three to four-page paper evolved into 11 pages, with each fact properly cited. I argued that people would be less likely to get marijuana laced with pesticides or other toxins; it could be taxed to generate much-needed revenues for the government, and it would lower the crime rate and the overall cost to society. Besides being the

most popular paper in the class, I received my first 'A' in college!

After that, I transitioned through a pre-med curriculum, medical school, and pediatric residency, not thinking much about medical cannabis until California passed its first law in 1996. That was also the first year I started using *wholistic* therapies in my medical practice. Since California was more than 3,000



miles away, I didn't pay much attention to what was happening there. I did, though, start using medicinal herbs to treat children.

Over the next 20 years, I collaborated with parents to develop individualized treatment protocols using mostly natural products. The goal was to help children with autism, and subsequently, many other chronic medical conditions. Parents would ask me (or tell me) about tests and treatments of which they learned. I began attending and eventually lecturing at conferences sponsored by the Autism Research Institute. The ability to order medical cannabis for children legally one day was never something I considered would become a reality.

## **Incorporating Cannabis Into Medical Treatment Plans**

Fast forward to 2016, when Florida passed its first medical cannabis law, which allowed for the use of liquid and capsule form cannabidiol (CBD) for people with cancer, muscle spasms, and seizures. Since quite a few of my patients with autism had either seizures or tic-like movements that included muscle spasms, I became a cannabis certifying physician so I could provide additional treatments for qualified patients. From there, I began treating patients with CBD and quickly saw clinical improvements. Reduction of anxiety and/or irritability was soon being reported. Kids were sleeping better. Some children stopped stimming. Tics improved. We were definitely on to something.

But not all children improved, and in 2017, "regular" cannabis, containing 9-delta Tetrahydrocannabinol (THC) became available. THC is what causes the euphoric/psychoactive effect typically associated with marijuana use.

## **Improvements to Medical Cannabis Laws**

Under the new law, licensed physicians who become certified by the state can authorize qualified patients to receive medical cannabis; this includes children, as long as a second doctor agrees. Certified doctors can also now authorize cannabis use for patients suffering from debilitating medical conditions similar to those listed in the statute, such as post-traumatic stress disorder (PTSD), Parkinson's disease, Crohn's disease, etc.

With the new law in place, I quickly concluded that, similar to patients with PTSD, many people with autism experience debilitating anxiety, panic attacks, insomnia, and aggressive behaviors. Others had difficulty speaking, as is common in people with Parkinson's disease, or had chronic abdominal issues similar to those associated with Crohn's disease. With fully-informed parental consent, the parents/caregivers are allowed to purchase, possess, and administer medical cannabis to the children.

To be clear, very minimal research has been conducted on the use of cannabis in children. There are concerns about memory and cognitive function, especially when a developing brain is exposed to THC. It is critical that parents take into account the potential benefits and risks, as well as the alternatives when deciding on any treatment for a child. Doing nothing is one alternative, but for most families, that is not an option. Pharmacological intervention is often considered. However, many families tell me they are considering medical cannabis because other medications either didn't work well enough or brought unacceptable side effects. Some also say they are uncomfortable placing their child on specific prescription medications because of the reported side effects.

## **Starting Medical Cannabis**

When I introduce medical cannabis to a patient, I recommend starting with a CBD/low-THC product (the lower the THC, the better) and gradually increase the dose. The effects are usually seen relatively quickly. Within two to three days, the responsiveness to a product and dosage should be apparent. Most patients begin taking medical cannabis three times per day. Others get satisfactory results using it as needed, once or twice a day, or by micro-dosing. With micro-dosing, very small doses are taken every hour or two or a transdermal patch is used.

## **Routes of Administration**

The various routes of administration available to patients have significantly expanded. While I firmly believe nobody should SMOKE anything (be it tobacco or banana leaves), inhaling cannabis is the most efficient way to produce the desired effect.

In Florida, certified doctors can now order inhaled products for patients to ingest through nasal delivery, asthma-like metered dose inhalers, or vaporized.

I know of young and low-functioning children who are being taught to inhale cannabis through these various methods.

## Smoking Versus Dry-Vaping

It is important to understand how vaporizing is different than smoking. The key distinction involves the temperature at which the cannabis is exposed. At a high enough temperature, a plant will burn. But at lower temperatures, the essential oils are released as vapor, and nothing is burned. Although vapor can be seen in the exhalation, which looks similar to smoke, no smoke is inhaled. When this is done with the flower of cannabis, it is called dry-vaporizing.

When cannabis is vaporized as an oil, several techniques can be used to isolate the cannabinoids (such as THC and CBD) and terpenes. Terpenes are the other main chemical type in cannabis that can induce different effects such as sleep, providing energy, pain reduction, and relief from mental health issues. The terpenes and cannabinoids are then brought back together, usually in MCT/coconut oil or cannabis oil, in various ratios. There are also high-pressure methods that “squeeze” out the oils that are then collected.

## Pediatric Medical Cannabis

As one of the first board-certified pediatricians in the state of Florida to specialize in pediatric cannabis therapy, I am relatively sure I have certified more children for medical cannabis treatment than any other doctor in Florida. Every day at my clinic I hear about another child whose life is improved and whose entire family has benefited because of medical cannabis.

For out-of-state families, I provide educational consultations where I consult on how to put together a protocol to optimize the use of medical cannabis. When requested, I also help families shop online if they tell me the dispensaries/products available to them.

As I look back over this 30-year journey, I am amazed at how far we have come. I look forward to hearing many more amazing and inspiring stories about people with autism and other qualifying conditions whose lives have been transformed with medical cannabis.

*An abbreviated version of this article was published in April 2019 as a blog on the Wholistic Pediatrics and Family Care website.*



*Dr. David Berger (“Dr. David”), a board-certified pediatrician with over 20 years of experience as a clinician, has developed a national reputation in wholistic pediatric primary care. Dr. David is considered the Tampa Bay area’s leading authority on medical cannabis for*

*adults and children and is one of the nation’s most experienced pediatricians in using medical cannabis to help facilitate the treatment of children with chronic conditions.*

*Dr. David graduated from The Medical College of Pennsylvania in 1994 and completed his pediatric residency at the University of South Florida/Tampa General Hospital, where he first began utilizing wholistic therapies. Dr. David has been in private practice since 1997 and in 2005 opened Wholistic Pediatrics and Family Care, his medical practice in Tampa, Florida. In 2010, Dr. David was appointed Assistant Professor at the University of South Florida College of Nursing. In 2016, he launched WholisticReLeaf to help qualified patients become certified to use medical cannabis.*

### About WholisticReLeaf

*WholisticReLeaf, founded in 2016 by Dr. David Berger of Wholistic Pediatrics and Family Care, empowers families and patients to choose the best treatment approach available for their medical condition. The mission of WholisticReLeaf is to evaluate and certify qualified patients who meet the state of Florida’s legal requirements for receiving medical cannabis and to provide medical cannabis management and dosing consultations to patients certified by other Florida physicians. WholisticReLeaf is committed to providing patients with the best possible care, while also complying with the ever-shifting legal landscape of medical cannabis in the state of Florida.*

*For more information, or to find out if you or a patient you know may be eligible to use medical cannabis as part of a customized treatment plan, visit [www.WholisticReLeaf.com](http://www.WholisticReLeaf.com).*

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# Autism Through My Eyes: A Successful Journey With Devereux

By Erin CLEMENS

In my first semester of college in the fall of 2007, I felt stuck. I was earning great grades, but it was a major struggle. I was confused and stressed out through the entire process, constantly feeling overwhelmed and overstimulated. I didn't always understand what people were asking of me. By the end of that semester, I was unable to continue my college education. The experience reminded me of my first few years in high school before I was diagnosed with autism spectrum disorder (ASD).

Sometimes, being on the autism spectrum means I can use my amazing memory to help others, like remembering where they placed a missing item or the directions to keep from getting lost. I see the world in a unique way, and this can help others to solve problems from a different angle. However, sometimes, it means I need extra help to function in the neurotypical world.

After I realized I was struggling with my college education, I wasn't sure how to move forward as an adult. That's when my parents found the Devereux Pennsylvania Community Adult Autism Partnership Program (CAAPP). At Devereux, I was paired with another adult, who I have referred to as my service person, to help me with everyday life. I have had several of these people paired with me over the years, and each one has turned into a successful partnership. We have worked together on many different goals. As each goal is mastered, I feel more independent.

The first thing Devereux taught me was how to take public transit. Then, they assisted me in volunteering at my local library so I wouldn't be stuck at home all day. When I got my driver's license, they helped me work on expanding my routes by showing me the back roads to places (I get overwhelmed on most major highways). They even helped me get a part-time job through Devereux Pennsylvania Center for



Autism Research and Education Services (CARES), where I print, laminate and cut out picture communication icons for students. My service person helped



me get started, and now, I'm almost completely independent at work.

Then, after many years of working on coping skills, the people from Devereux Pennsylvania CAAPP slowly helped me start going back to school. This was a big step, as I wasn't sure if I was ready to face the challenges college would bring. But, my services have carefully walked me through the process.

I'm currently studying Early Childhood Education. My original goal with Devereux was to attend one class at a time. My service person sat with me through the class, helping to take notes or reminding me of my coping skills when I would get stressed. He/she would go with me to meetings with my advisers and help me better understand how to communicate my needs. That one class turned into another. Before I knew it, I completed four classes over four semesters. I now nearly have a certificate.

While I've decided I may no longer work in the Early Childhood Education field, I am looking forward to transferring the skills I've learned into a career with animals. My dream career is to be a service dog trainer, and Devereux CAAPP is helping me start on that path, too! My current service person has even trained

to become a volunteer at the Brandywine Valley SPCA so that he/she can help me volunteer there as well!

With a lot of hard work and help from my services, I've come a long way. I still struggle with some daily tasks, such as communicating with others or maintaining a safe and healthy living environment. I'm also working on how to budget my money. However, the services I receive through Devereux Pennsylvania CAAPP are continuing to help me with these issues. I don't think I'd be where I am today without them.

To learn more about Devereux Advanced Behavioral Health, click [here](#), or click on the following links to learn more about Devereux Pennsylvania [CAAPP](#) and [CARES](#).

*Erin Clemens is a woman on the autism spectrum. When she is not in school or working, she likes to spend her time volunteering and watching The Ellen DeGeneres Show. She is also the author of the book I Have Asperger's.*

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# How to Build the Road to Independence With Autism

By Karen KAPLAN

From the moment a student is placed in an educational program, the school should be thinking about how it's preparing him/her to travel on the road to independence.



**W**hile there is a wide range of cognitive, motor, and communication abilities among students on the autism spectrum, they all are on the road to acquire as much independence as they are able.

We are a culture rich in interdependence, so it is acceptable for those with autism to have coaches, mentors, families, and friends to help them on the road.

Here are some questions we suggest teachers and families ask themselves when thinking about transi-

tion goals, objectives, classroom lessons, and family support so they can continually prepare students to reach independence.

- 1.** How can we help students to understand vocabulary words they will need as they travel the road to independence?
- 2.** How can we help them remember personal information such as their names, phone numbers, addresses, birthdates, identification numbers, or people to contact in an emergency?



3. How can we teach and motivate students to gain effective communication skills?
4. How do we help them develop effective listening skills?
5. How do we teach them to understand gesture language and voice meaning?
6. What mathematical skills can we teach so they can function at the highest level (calendar, measurements, time, weight, money, thermometers)?
7. How can we help them understand their future educational opportunities (trade schools, community classes, colleges)?
8. How do we prepare students to determine their career interests and figure out if those jobs fit their interests, skills, and challenges?
9. How do we prepare them to search, apply, and interview for jobs, plus maintain them?
10. How do we teach them about salaries, budgets, payroll, and paychecks?
11. If they are readers, how do we teach abbreviations and what they stand for in a sentence or title?
12. How will we teach them phone skills, such as how to dial or find phone numbers?
13. How do we teach students to use computers?
14. How will we teach them all about all the other technology devices they will come in contact with during daily life (camera, TV, CD, and DVD)?
15. In what creative ways can we teach food vocabulary, including beverages and seasonings?
16. How will we teach restaurant vocabulary, package label information, and food preparation documents?
17. How will we teach food costs and nutrition?
18. What lessons can we create on reading clothing labels for size, material, and cleaning methods?
19. What lessons will we develop for learning how to search for places to live and how to complete rental agreements?
20. How will we teach our students about checking and savings accounts, credit, and retirement?
21. Will the school want to create lessons around medical and health issues? What about making doctor appointments?
22. Will the school discuss sexuality, birth control, or sexually transmitted diseases?
23. What will the school do about lessons on drug abuse?
24. How will you teach about transportation issues (traffic signs, traffic symbols, vehicles, driving licenses, road maps)?
25. What resources will your school introduce students to locally (libraries, post offices, recreation facilities, movie theaters, parks, sports centers)?
26. What lessons will your teachers create to teach warning signs and safety-related issues (terms like, "police," "explosives," "poison," "flammable," "emergency exit," "do not enter," "beware of dog," etc.)?
27. What lessons will teachers develop to teach the meaning of typical community signs (such as "taxi," "bus stop," "toilet," "open/closed," "hospital," "ticket office," "please wait to be seated," "cashier," "for rent," "no refunds," etc.)?
28. Will your school teach about voting?
29. How will you teach your students about self-advocacy?

The above questions are just a small representation of the types of transition skills schools should address if serving K-12 on their way to becoming independent adults. While all skills might not be attainable, parts of them may be. It is always important to perceive a student as capable and find ways to teach these key skills creatively. Make sure the families are part of the transitioning, planning, and implementing. It is a team responsibility.

In my opinion, it is never too early to be thinking of the techniques, strategies, and activities you can implement to help your son, daughter, or student to reach independence. I have seen many families reluctant to nurture independence, and then when the student turns 18 years old, they suddenly be-

come panicked and hope the schools will have the answers.

Whatever negative feelings a parent may have—whether it's fear, anxiety, guilt, or helplessness—I suggest finding a mentor, coach, counselor, or like-minded adult to help deal with those sensitive feelings and get unstuck.

## Tools for Building Independence

Here are three planning tools that parents or educational teams can use to begin to see the complexity of preparing a student for successful adult life.

### 1. THE CIRCLE OF FRIENDS

<https://www.friendshipcircle.org/blog/2012/01/11/circle-of-friends-a-type-of-person-centered-planning/>

Building connections is considered essential to foster a sense of belonging. How are we helping our students build connections?

Children are said to develop friendships naturally, but what about those who do not?

This tool can help parents and teachers identify students who need support by building a circle of support. Friends who may listen, give advice, or provide support when needed are those in this group.

The tool asks that we draw four concentric circles and label them 1, 2, 3, 4.

The first circle represents a **Circle of Intimacy**. These are people we cannot live without.

The second circle contains a list of good friends and is called the **Circle of Friendship**, and includes those who may not have made the first circle.

The third circle is the **Circle of Participation**. This is a list of people, organizations, and networks that we are involved with regularly (dance club, choir, sports team, technology club).

The fourth circle is the **Circle of Exchange**. This is a list of people who provide services to us (doctors, hairdressers, teachers, mechanics, etc.).

Some people can be in more than one circle.

Teachers might do this exercise in the classroom with all students in order to help them understand how it might feel to not have friends (lonely, confused, rejected, isolated, frustrated, unwanted, depressed, etc.), and then they might discuss what students might do if they feel this way (stay in bed, take drugs, isolate themselves, or try to make friends).

Sometimes other students may then want to help students at risk to develop friendships and connections. They become buddies and share how they are making connections, hoping it may help them.

When families of children with special needs do this type of work, they begin to see the need to help develop lists at each circle so their son or daughter may have connections established by the time they reach adulthood.

For example, if a student does not have friends, parents and teachers might identify groups or organizations he or she could join according to his/her interests (art, horseback riding, boy scouts, camp, computer clubs, etc.), thus helping them make connections in the Circle of Participation. Teachers might also identify classes within the school the student could join to develop his/her interests, thus enhancing group participation. At young ages, teachers can create group projects around lessons to further encourage group participation. Some schools develop lunch buddies or work buddies as well.

### 2. PATH

<http://trainingpack.personcentredplanning.eu/index.php/en/map-and-path/path>

This tool was developed by Jack Pearpoint, John O'Brien, and Marsha Forest in 1991. Facilitators are trained at the Marsha Forest Center for Inclusion-Family Community in Toronto.

The steps of PATH are:

- Create a clear picture or vision of where the student wishes to be
- Identify goals to focus on the next year to keep grounded



- Identify the people to enroll in the journey
- Recognize ways to build strengths
- Chart actions and steps to achieve the goals

The **PATH** asks that a circle of support be created. This is a group of people who agree to meet regularly to help the person with a disability accomplish certain personal visions or goals. They help him/her overcome obstacles or open doors to new opportunities.

Parents can invite a variety of people to the **PATH** meeting. Family members, school staff, church members, or neighbors are often asked. The meeting can take three to five hours.

Meetings include the person with the disability. There may be a need to do some planning with the student. Help him/her express ideas for the future and how to agree or disagree with what other members are offering.

There are generally six or more people to encourage varied experiences and perspectives.

Sometimes the family unconsciously puts limitations on the possibilities of the person with challenges. They also may not be aware of many services and options. Assembling a team of varied perspectives can expand their beliefs, attitudes, and knowledge.

One or two facilitators can be a good idea. One person may draw people out to offer ideas while the other is recording information.

**PATH** is a place for brainstorming and sharing creative ideas. It is a safe, respectful, non-judgmental tool.

The meeting may begin with the history of the person, including strengths, interests, dreams, fears, and needs. Then, move on to identify resources, strategies, and supports, and finally, develop action plans to reach goals set by the team.

**PATH** is recommended for families who want to work together and friends and colleagues who want to make a difference.

Once the **PATH** team develops a vision with

goals and action plans, the parents can use the information to help work with the IEP and ITP team to build the transition plan.

### 3. MAPS

<http://www.inclusion.com/maps.html>

**MAPS** is a planning process used by educational teams to help plan for a student's future. It uses a person-centered approach. It's based on the person's dreams, interests, needs, and fears. The family takes the lead position at these meetings.

**MAPS** teams usually include the student, parents or guardians, one or more special education teachers, perhaps the assistant, a social worker, people from community-based agencies, any family members the parents feel should be involved, and advocates.

There is a facilitator and recorder at the meeting. The meeting may take an hour or more.

The facilitator will always ask the student to respond first, then family, and then other members.

All ideas are expressed in a positive manner.

Parents may help the student first talk about his/her life (where and when the child was born, brothers, sisters, school, friends, places visited, and things he/she enjoys).

Then the discussion focuses on the dreams (jobs, living, college, school, money, etc.) of both the student and parents. There are no judgments made at this time about dreams.

The student and parents are also asked to talk about fears and anxieties.

Members of this team are then asked to describe the student's strengths, likes and dislikes, and personal qualities, as well as favorite activities, friends, talents, etc.

Considering the student's hopes and interests, the team develops a list of activities, opportunities, and supports to address them. Finally, members begin reviewing all the information and start prioritizing. A list of needs is created to address priorities.

For example, some needs might be to complete a vocational assessment, begin job exploration, increase involvement in community activities, begin an exploration of living options, or develop skills in a specific area.

All ideas and thoughts are listed by priority, and goals and action plans are written for the most important ones.

The facilitators gather up all notes, summarize, and send them to all members of the team. The team meets yearly to check on progress towards goals.

## Resources

PACER CENTER: <http://www.pacer.org/tatra/resources/personal.asp>

MPACT: Transition to Empowered Lifestyles Project Person Centered Planning: <http://www.ptimpact.org>

Person-Centered Planning Education Site: <http://www.ilr.cornell.edu/edi/pcp/>

## Additional Transition Resources:

Asperger on the Job by Rudy Simone, Future Horizons, [www.FHautism.com](http://www.FHautism.com)

Brigance Transition Kills Inventory, Curriculum Associates, [www.CurriculumAssociates.com](http://www.CurriculumAssociates.com)

Developing Talents, Careers for Individuals with Asperger Syndrome and High Functioning Autism by Temple Grandin, AAPC, [www.asperger.net](http://www.asperger.net)

How to Teach Life Skills to Kids with Autism or Asperger's by Jennifer McIlwee Myers, Future Horizons, [www.FHautism.com](http://www.FHautism.com)

Learning a Living. A Guide to Planning Your Career and Finding a Job for People with Learning Disabilities, Attention Deficit Disorder and Dyslexia, by Dale Brown, [www.specialneeds.com](http://www.specialneeds.com)

Life Skills Activities for Special Children by Darlene Mannix, Jossey-Bass publishers, [www.josseybass.com](http://www.josseybass.com)

Taking Care of Myself. A Hygiene, Puberty and Personal Curriculum for Young People with Autism, by Mary Wrobel, Future Horizons Inc., [www.FHautism.com](http://www.FHautism.com)



*Karen Kaplan has more than 35 years of experience working in the field of autism spectrum disorders with children, teens, adults, and their families. She has engaged with schools, residential programs, vocational and nonprofit day programs, addressing the challenges of autism and other similar learning differences. She has joined faculty at universities to help mentor and educate teachers and therapists. Karen is the Executive Director of Offerings, a non-profit organization empowering communities locally and globally to build special needs programs. She also founded the Autism Lecture Series in 2009 and the Special Needs Resource Fair in 2010. She is currently the Executive Director at Wings Learning Center, a school for children 5-22 years old with autism spectrum disorders, located in Redwood City.*

Websites: [www.globalofferings.org](http://www.globalofferings.org),  
[www.wingslearningcenter.org](http://www.wingslearningcenter.org)

Facebook:  
[www.facebook.com/WingsLearningCenter1](http://www.facebook.com/WingsLearningCenter1)

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# The Remarkable Ways Sensory Gardens Can Help People With Autism

By Amy WAGENFELD, PhD, OTR/L, SCEM, FAOTA,  
and Marlene SOTELO, EdD, BCBA-D, MT-BC

*Experiencing nature improves physical, sensory, social, and emotional health and wellbeing; and a garden is an ideal space to engage with nature. While research has and continues to demonstrate these benefits, little has been done to study the impact on individuals with autism spectrum disorder (ASD). In time, we hope to fill the void and conduct some of this much-needed research.*



## Autism and Sensation

**W**hy a sensory garden? Sensory integration challenges are common amongst individuals of all ages with ASD. They can experience under and overreactions to sensory experi-

ences. Let's unpack sensory integration. Sensation is information received from the environment, like hearing the sound of a lawnmower, looking at bright red and orange tulips, tasting a tangy lemon, or the sweet smell of lavender. Integration is how we interpret and use sensation. For many, lavender smells



nice, bright colored tulips make us smile, a lick of a tangy lemon is mildly aversive but quickly forgotten, and the sound of the lawnmower can be a nuisance, but easily ignored. These small sensory “annoyances” are just that, nothing more and nothing less. Someone struggling with sensory integration challenges may have trouble processing sensation from the environment while maintaining self-regulation<sup>1</sup>. Staying composed and focused on tasks may be tough because the sensory systems are not processing in a typical way.

Some individuals with ASD may avoid certain sensory experiences, like messy play in the mud, while others may seek them out, like swinging for a long time. Some may be sensitive to specific sound frequencies or noises, lighting, motion, or touch, or seek out these experiences excessively. A garden may buffer the varied challenges that individuals with ASD experience<sup>2</sup>. Generally speaking, gardens provide children with important productive and holistic opportunities to be outside and exercise, socialize, learn, nurture their sensory systems, and improve their health. All children, regardless of skill or ability, deserve and need to participate in outdoor activities.

Professionals work tirelessly each day to develop strategies and interventions to address the needs of individuals with ASD and enrich their daily lives. With a significant rise in diagnoses, it is a necessity, rather than a luxury, to provide individuals with ASD with intentionally-designed sensory gardens that meet them where they are, enrich their daily lives, and bring solace, excitement, engagement, and learning all in one space. We would like to tell you about a sensory garden we helped to design for the Els for Autism Foundation at The Els Center of Excellence. Come join us on a tour!

The Sensory Arts Garden at The Els Center of Excellence is designed for individuals with ASD and their parents, educators, therapists, and caretakers who support and enrich their lives. The center, located in Jupiter, Florida, is committed to helping individuals with ASD realize their full potential to lead positive, productive, and rewarding lives through world-class educational, recreational, and therapeutic programming on its 26-acre campus. Although it is welcoming to people of all ages and abilities, we want to share how children are delighted by what the garden offers.



The 13,000-square foot garden supports and enriches children with ASD by providing opportunities to play, socialize, relax, and learn in a secure, fenced area that permits free movement and exploration. Much planning was devoted to making the spaces within the garden “autism friendly.” The results balance alerting and calming sensory experiences to decrease stress and anxiety and gently enrich the basic senses—as well as a sense of balance (vestibular) and position and movement in space (proprioception). To honor individual strengths and preferences while providing opportunities for shared enjoyment, the overarching intention of the garden is to offer a feeling of serenity, security, autonomy, and restoration. It acknowledges the realities of hypo/hypersensitivities that many individuals with ASD have, supports curiosity and meaningful engagement, and most importantly, always welcomes everyone, regardless of ability.

Who tells us that the garden is working? A parent shared this about the water wall: “I stood before it staring as I listened to the sound. It’s in a beautiful garden with lovely plants. It makes this place more special for birds and humans too. It lends a certain presence that captivates the view. While autism still confounds me and remains a mystery, this wall of pure, clear water will write its own history.”

Two teachers shared similar thoughts: “Peaceful, calming. Draws the kids in. It’s a wonderful sensory activity. Even the non-verbal kids can show their feelings on how much they love the water wall. It unifies the kids.” Another said, “It gives the kids a great sensory activity. All the kids gravitate toward the water wall—they all run towards it whenever they get to



the garden.” As to the impact of the water wall on staff, one teacher told us, “Feeling—visual and auditory aspects were very meditative. Combined together, brings on a nice, calm feeling and creates an opportunity to reflect.” Some of the children shared their thoughts about the water wall, saying things like, “I could take a shower with this!” and “It’s raining,” “It’s a waterfall,” and, “I can feel the water falling.” It is safe to say the water wall has become a popular destination in the garden! Other positive thoughts include a parent telling us, “My son loves the swing in one of the ‘Places Away’ so much, we bought one for him to enjoy at home. One of his rewards for working in his classroom is to go out into the garden for a break; he always makes a beeline for the swing!” A staff member said, “The garden is a place of peace and tranquility. It is a space that I go to in moments when I need to stop, think, breathe, and reset my intention for the day. It is truly a gift.”



For the garden design to capture the breadth and complexity of ASD, we knew that close collaboration between the landscape architect, the Els for Autism Foundation’s COO (Marlene Sotelo), and occupational therapist (Amy Wagenfeld) was necessary. We brought different ideas with a shared vision to the table. This approach worked well for us. We planned for predictable routines, patterns, sightlines, and wayfinding while at the same time maintaining a degree of openness in the garden to encourage discovery, autonomy, and flexibility. The transition spaces and movement patterns are understandable and inviting yet unobtrusive. Potential fears of the unknown or anxiety about what to expect during a garden visit are allayed at two neutral entry points that visitors use. These transitional spaces allow

for a pause before entering and the ability to see the entire garden. A densely planted perimeter encloses the space to subtly focus attention within the garden. Overhead, a majestic canopy of foxtail palms offers a sense of order, calming enclosure, and relief from the South Florida sun.

Everything in the garden was carefully considered for appropriateness, safety, durability, and therapeutic potential for children with ASD. “Sensory rooms” aligned on the garden’s long axis, with foxtail palms as bookends for each planter, discretely target each of the five basic senses. The planters’ varying heights bring sensory-appropriate plants to comfortable and easily accessible levels for both standing and seated visitors. Small, movable, musical sculptures activate the surrounding spaces with sound. Teachers and therapists (and yes, children!) move the instruments around to encourage cooperative exchanges and creative explorations.



Several nooks called “Places Away” along the perimeter provide calming counterpoints when children feel overwhelmed and need a moment of refuge. Smooth pebble seats offer playful and varied sensory experiences. Small water bubblers provide opportunities to touch and hear. The custom-built water wall provides immersive touch, sound, and sight experiences without the worry of curious children jumping into it. Large pebble pavers strategically installed in several of the “Places Away” heighten sensation and motor skills as children walk from smooth concrete to slightly uneven layers of rock. A bench swing tucked within the plants and trees offers vestibular stimulation and opportunity to swing with friends, parents, or teachers.





All plantings were thoroughly vetted for toxicity. An environmentally-sensitive coordinated maintenance program ensures chemicals are used only as a last resort. Trees, such as a gumbo limbo and a bay rum, were selected for their shape and shade capacity, visual, olfactory, and tactile features, and semi-permeability so that staff can see the entire garden. Repeated patterns of planting provide just the right amount of consistency and interest.

## Implications of a Sensory Garden

In establishing an enriching therapeutic and educational environment that is inclusive and welcoming for all, the Sensory Arts Garden further advances the foundation's position as a leader and broadens its influence within the ASD community. The garden invites children to feel whole and safe on their terms—becoming part of something bigger than themselves without feeling overwhelmed. Children experience respite in the garden's "Places Away" and enrichment through an exploration of the plants in the sensory rooms. Some have identified favorite spots and return daily to engage with them. The garden has become an established space for outdoor instruction, particularly for students who may be challenging to reach inside the classroom. High

school students work independently on laptops or with a teaching assistant at "tree stump" tables centered in round grassy areas. Music, yoga classes, and reading groups all benefit from this sensory-rich, living classroom. Within a lush and safe setting, the garden provides opportunity and choice for everyone to engage with nature on their terms, in their own way, and at their self-directed pace. From quiet and serene reflection by the water bubblers to active sensory involvement on the swing or smelling and tasting herbs in the sensory rooms, the garden offers various opportunities for both active and passive participation. Everyone takes from the garden what they need and want. And every day in the garden is a time to experience peace and joy.

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*Note to the readers: this work was adapted from an article to be published in Children, Youth, and Environments Journal.*

*Images provided by David Kamp, FASLA, LF, NA, President of Dirtworks, PC, Landscape Architecture and the Els for Autism Foundation.*



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# Employment Matters...

## Especially for Those on the Spectrum

By Gregg IRELAND

The job of “raising” a son or daughter significantly impacted by autism spectrum disorder (ASD) does not come to an end when your child reaches the age of majority. It just shifts to a new realm. Indeed, adulthood brings significant new worries and challenges.



**V**ital concerns for parents of emerging adult children with ASD include health/healthcare, safety, housing, and a good social life. But another component, employment, can be every bit as crucial for building a fulfilling life of purpose—the kind we all want for our offspring.

In our society, somehow, a job is more than just a way to make a living. At some level, it's an identity. Seemingly innate to the human spirit, people with or without disabilities want to be included and involved—they want to be contributors. They want that as their identity!



**“ Today, we have six business units, 55 employees, and a budget of around \$1 million—and yet we know we have only scratched the surface. Most important of all, our employees are working, getting paid, and being a part of an effort greater than themselves. ”**

Thus, having a responsible job can (and almost always does) lead to purpose, confidence, and pride, as well as personal growth in unexpected ways. On the other hand, being idle—unemployed, sitting at home, nothing to do—can be debilitating.

My wife, Lori, and I began to appreciate this when we started to look ahead to our son's adulthood several years ago. Right after worrying about where he might live, who would look after him if not us, would he be safe, etc., we broached the question of whether or not he would work, and if so, in what capacity.

In 2007, when our son was 17, we began networking with families in the same situation. One idea led to another, and eventually, Extraordinary Ventures was formed.

Initial ideas centered on advocating for our children with employers, but we decided that we knew our children well and would have a much better chance of creating jobs that matched up with their abilities if we did it ourselves. We also took note of the fact that the unemployment levels for people with disabilities in our area were very high. There were few jobs, and the ones that existed were often not compatible, or we knew the employers had finite patience.

Extraordinary Ventures was launched in 2008. The mission was to develop real job opportunities for people with autism and disabilities. We became a non-profit and raised funds to launch the organization, but we decided early on that we'd run the enterprise as a real, self-sustainable business—addressing one of our goals to have something that would finance itself and stand the test of time, rather than require us to raise money or ask for government help every year.

We started with a laundry business. A number of our early employees loved the pace, and we were able to break the process down so that everyone had work

they could do successfully. Later, we got into mailings and office services. What began as a small-scale sorting and stuffing operation turned into a profitable, automated business, turning out 50,000 letters/month with machines that our people have learned to master.

Once we learned that some of our employees were volunteering at the animal shelter, we decided we could launch a dog walking/cat sitting business. Another time, we used the fact that one of our employees loved to cook and follow recipes. We didn't want to get into food, so we created a candle-making business (along with a range of soaps and personal products) where we set the production up as a recipe-following endeavor. Today, our candles and other gifts are sold in stores and online.

Today, we have six business units, 55 employees, and a budget of around \$1 million—and yet we know we have only scratched the surface. Most important of all, our employees are working, getting paid, and being a part of an effort greater than themselves. Every day we learn new lessons about the skills of our people. I could write an entirely separate story about what our people have accomplished and what it means to them.

Last year, our success led us to fund a filmmaker to create a documentary about our people and our organization. The result is a short film called *Extraordinary People*. It highlights six of our employees, what they do, how they've experienced personal growth, and what their jobs mean to them.

It's a wonderful film full of ideas and inspiration for families looking for new ways to think about employment for their sons and daughters who don't have, and sadly won't have, the same opportunities as others for good jobs in the mainstream economy, mostly due to social skills.

We've shown the film in private screenings across the country and on Capitol Hill. The message is that it's possible to have a small business in any community dedicated to employing people with disabilities that does not rely on government funding but relies instead on providing necessary and valuable goods and services—being a part of the economy, rather than a burden on it.

Another message is that with a creative approach and flexibility, people with disabilities can thrive. It takes patience and some investment, of course. But in the end, people who otherwise may exist on the edges of society are integral to it.

Indeed, at Extraordinary Ventures, we do not take government money and our employees are taxpayers! What's better than that?

*For the past seven years, Gregg Ireland has played a central role in the growth and development of Extraordinary Ventures, currently serving as an officer on the Board of Directors. Gregg is also Chair of the Autism Science Foundation, New York. Gregg is retired after 45 years in the investment business with the Capital World Investors, where he was an analyst, portfolio manager, fund officer, and partner of the organization.*

Website: [www.extraordinaryventures.org](http://www.extraordinaryventures.org)

Documentary Trailer: [www.extraordinarypeople-film.com](http://www.extraordinarypeople-film.com)

Facebook: [www.facebook.com/extraordinaryventures](http://www.facebook.com/extraordinaryventures)

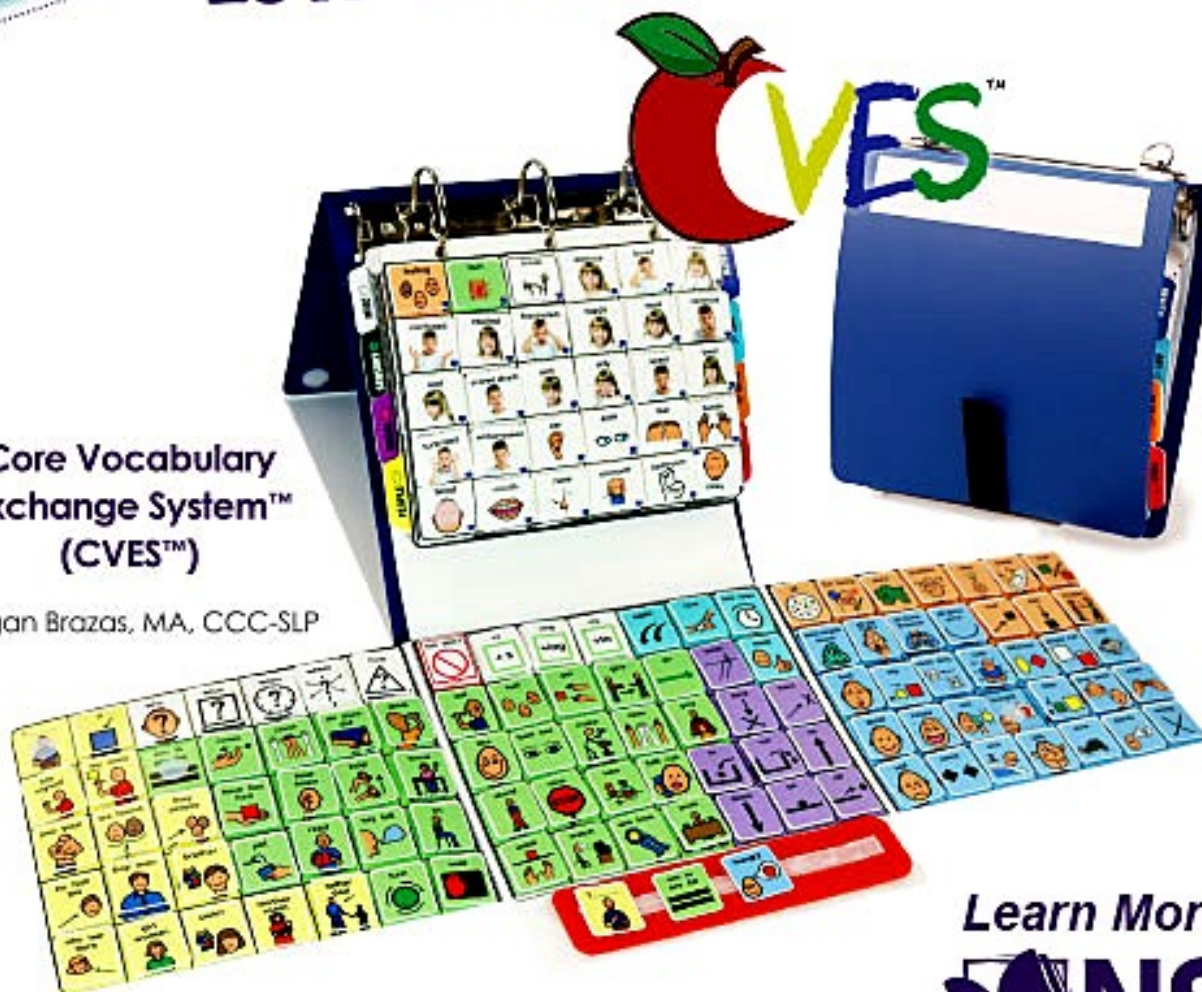
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# Ways Books, Reading, and Writing Helped Me As an Aspie

By Alan D.D.



Sometimes children diagnosed with Asperger's syndrome aren't always able to express or understand emotions like everyone else. As an Aspie, I can tell you we sometimes can find it hard to express how we feel at certain moments, or even know what it is that we feel.

Asperger's syndrome makes these processes more complex as if the person and his/her feelings are two different beings, handcuffed to each other and each of which speaks in a different language, always trying to learn what the other is saying or intending to say.

Many people have recommended that television and movies, or even music, could help in the process of understanding what an Aspie is feeling, but being an advocate of reading and its benefits, I agree with the following:

Reading helped (...) in terms of: their social well-being, by increasing personal confidence, reducing social isolation, fostering a sense of community and encouraging communication skills; their mental well-being, by improving powers of concentration, fostering an interest in new learning or new ways of understand-

ing, and extending their capacity for thought, verbalized and internalized; their emotional and psychological well-being, by increasing self-awareness, enhancing the ability to articulate profound issues of being, and making possible a shift in internal paradigms (or the telling of “a new story”) in relation to self and identity.<sup>1</sup>

Since I was a boy, I couldn’t understand how to establish a conversation, how to understand what others were telling me, and even took obvious jokes and sarcastic comments seriously. This happens to Aspies all the time. Where is the line between explicit and implicit when you understand all so literally?

For me, books of all kinds helped me to get a better understanding of how to express myself; while writing was and continues to be a tool through which I get to know myself better as if I were interviewer and interviewee at the same time.

When reading, people forget about the outside world to get immersed in a new one, a fiction that may have some similarities, yet is completely different. They have no control over what happens, but simply on how they feel about it, what they expect to happen. That’s the important part of reading for Aspies.

When reading, someone with Asperger’s doesn’t have to worry about any kind of interaction, so they can simply relax, take a break from reality, and discover how a character behaves, thinks, and expresses. The silence and calm that reading offers always relaxes me and helps me cope with reality; reading itself taught me what emotions were and how to express and understand them.

The same happens when I write. I’ve never been a talkative person, but a thoughtful person, always imagining and thinking about the impossible, fantasy scenarios, and with an endless list of what-ifs. Writing is an escape just as reading is, with the difference that doing it gives me full control of what’s happening in this world I just created, and I can come back to edit and change what I *said* as many times as I want, which cannot be done with spoken words.

I don’t feel confident speaking about certain topics, and I have embarrassed myself in doing it sometimes, but I feel safe and happy when writing, which also helps me to process and understand my sur-

roundings, even my feelings towards something or someone. I agree with this explanation:

Writing at least 15 minutes for 3-4 consecutive days (...) leads to positive changes on both physical and psychological health. Writing can be used as a self-help intervention in preventive health practices due to its cost-effectiveness, ease of application, and shortness. (...) In addition, WED helps individuals to restructure memories by changing their way of thinking about stressful or traumatic experiences until they reach more consistent schemas about themselves, others and the world.<sup>2</sup>

Writing and reading have been two powerful tools for me since I started with them. I cannot separate one from the other, and I don’t see the need in doing so. Instead of watching a TV show or a movie, I’d rather be discovering a book. It’s not that I don’t like audiovisual stories, just that, as contradictory as it sounds, written stories are a more complete experience.

<sup>1</sup>Billington, J. et al. (2010, p. 81)

<sup>2</sup>Acar and Dirik (2019, p. 75)

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*Alan D.D. is a writer, journalist, and blogger from Venezuela. After years of thinking he was just introverted and shy, he discovered he had Asperger’s syndrome while doing what he loves the most: reading. Since then, he writes about the topic whenever he can, and when not immersed in a book of his own or from his favorite authors, he can be found most likely at the movies or playing Heroes of the Storm.*



# How to Help a Child With Autism With Emotional Self-Regulation

By Sam KELLER



**T**he stressors of a typical school day are only compounded for students with autism spectrum disorder (ASD). They often struggle with emotional self-regulation or the ability to moderate feelings in situations that provoke intense reactions. Traversing a crowded lunchroom can flood heightened senses, and [difficulty understanding social dynamics](#) during group projects can spark panic. To ease potential anxiety in school situations, parents can work with children with ASD at home to further develop their emotional regulation skills.

Emotional regulation is one component of executive functioning, which also includes behavioral management skills such as planning, attention, and flexibility (essentially, all the steps you take to manage your everyday behavior). While many people might consider these innate brain functions, psychologists stress that these executive functions involve behavior, and [those with deficits can improve with learned](#)

[or modified behaviors](#). Emotional regulation, in particular, involves the ability to recognize a felt emotional state, evaluate the repercussions of reacting, and make a conscious choice to move toward a goal even with accompanying negative emotions. This is troublesome for students with ASD, who can have larger emotional reactions to stimuli and increased difficulty shaking off negative feelings.

Parents can help children with ASD manage their emotional sensitivity. It's vital to explain that a strong reaction is a feeling and that feeling will pass. Parents can work with them on [developing skills to initiate self-calming behaviors](#). Dr. Adel Najdowski suggests that [children with ASD can actively develop emotional self-regulation through an emotional levels chart](#), as detailed in a recent piece from [OnlinePsychology@Pepperdine](#), the [online Master of Science in Behavioral Psychology program](#) from Pepperdine University.

“With the multistep emotional skills chart method, parents show children how to connect to their emotional states and develop effective coping mechanisms to work through discomfort that may arise in different scenarios.”

With the multistep emotional skills chart method, parents show children how to connect to their emotional states and develop effective coping mechanisms to work through discomfort that may arise in different scenarios. Each step should be mastered before moving on to the next. First, parents should create a [two-column emotional skills chart \(PDF, 130KB\)](#), ranging from *very upset*, to *a little upset*, to *good*, to *very good*. The right column leaves space for children to describe situations that provoke each emotion.

After a child has assigned some of his/her lived experiences to the different emotional states, a parent can then teach them in what instances it would be useful to work toward having an adjusted intensity of reaction. For example, if a child says not being able to play a favorite video game because he/she has homework would make him/her very upset, a parent can gently inform the child this is a scenario to work toward feeling closer to “a little upset” about. The parent can then teach the child coping mechanisms—such as taking some time alone, asking for help, or initiating deep breathing to use when this type of situation arises to calm emotions.

Once coping skills are introduced, parents can encourage children to practice these skills in an imagined scenario that may provoke strong reactions. The parent and child can brainstorm potentially recurring upsetting events in typical daily life—such as a noisy playground, an unexpected assembly, or a substitute teacher—and write down a step-by-step coping plan for the child to use in each situation. The parent should ask the child how he/she would respond and what specific actions might ease an overly intense emotional reaction.

Learning emotional regulation is a process, and progress can be measured at each step over time. First, parents can check in on how well their chil-

dren are identifying their emotional experiences; then, as mastery progresses, they can analyze how coping mechanisms are wielded as an intervention. Remember that patience is key: Students with ASD experience anxiety as they face unexpected or upsetting events—particularly at school—and parents should do their best to make home a place they can depend on to find understanding.



*Sam Keller is a digital PR coordinator and supports outreach for 2U Inc.'s psychology and mental health programs.*

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# Parenting My Child With Autism Is a Valuable Full-Time Job

By Sue KERSTETTER

I don't have a job yet, but my calendar is filled with to-dos, appointments, and tasks required of me. I have a psychology degree hanging on the wall that everyone around me seems to have forgotten, collecting dust as I interact with therapists that often think of me as "just another special needs mom." I attend all the sessions from all the disciplines, whether it is physical therapy (PT), occupational therapy (OT), applied behavior analysis (ABA), or speech, all coming with a different approach on how to combat what they see as my child's deficits; and it is up to me to figure out which approach is working.

**M**y days at home are spent with therapists coming in and out and making sure my house is set up for each program to be run. I'm always double checking that all of the iPads are charged and ready to go. I make sure the bathrooms are accessible, equipped with liquid hand soap and clean towels (because my son is learning how to shower himself). My washer downstairs is always running, filled with extra clothes for when he has an accident because he has had a recent regression in potty training, and going back into pull-ups is not an option. When I have an autism-free moment, I take that as my chance to make that quick run to the store, without fear of a meltdown, to stock up on whatever food is being used as a reward during his session.

As the therapists work with my child, I am actively offering input or standing quietly in the doorway, observing so that after the therapists leave, I can carry through whatever behavior plan they have implemented. When I am not active in therapy, I am on my laptop or on the phone in the other room researching behavioral interventions that have worked for other children, or going round and round with insurance companies about our coverage (or lack thereof), and being placed on excruciatingly long wait lists for the therapies my child so desperately needs.



There is a science to what I do. It takes a lot of skill, focus, and perseverance to maintain not only the rigorous schedule that special needs parenting brings, but also to remain emotionally steadfast as you find yourself strapped into the roller coaster you never wanted to ride.

While many others look at me from the outside, they may think I am not contributing to society or that my role as a stay-at-home mom is in some ways insignificant—but I have been on the other end of the line. In my time of inpatient mental health, I laid witness to families that were struggling. I saw the bags under the caregivers' eyes as they tried to juggle the care of their loved one while working to maintain a job. I have seen the toll that autism (and any mental disorders) has taken on our society and its resources. Let me share with you what I have learned after my decision to walk away from my job to stay home.

It was not an easy decision. After all, I had done all that work for my degree and had 14 years in toward future goals. However, for over three months, I watched my son's behavior regress, and his siblings' grades decline, so I began to take another look at our arrangement. In trying to juggle everything, I was only giving a percentage of myself to each commitment. When I was home, I was just preparing for the next day; my focus was never solely on my kids. Likewise, when I was at work, my mind was at home. I began to look around and ask myself, as a mental health technician, what was it about certain patients that made them among my favorites to care for regularly. As my son is on the more severe end of the spectrum, I have accepted the realities of his prognosis. He will never live alone, and about two years ago, I made the switch in hoping for his independence to being as self-sufficient as possible to becoming the kind of person someone would want to care for every day. I had realized early in my dealings in mental health that the ones that had the most self-help skills were the ones who fared the best in these types of environments regardless of their mental capacities and received the "best" and "kindest" care.

As I sat at the end of the long hall of the unit, I had an epiphany, and the question I asked myself would forever change my mind about juggling work and special needs parenting: "While I am here working with these patients, who is at home working with my son? Where do my talents and my education have the opportunity to have the most impact?" I

sat in deep contemplation; after all, I loved my job. It was my passion. But then I realized that I also have a responsibility to those that would come after me to make my son as independent as he could be. Not only would it make their lives easier, but it would also free up the time of those out in the field to be able to do more for other special needs individuals that may need more help than my son.

I also thought about my other two "typical" children and what it would mean to their futures if they took on the responsibility of caring for my son, and how it would be different if he could even just shower on his own or make his own sandwich.

That evening, I turned in my resignation to a job I loved to care for a child that I loved even more. Now, two weeks later, I find myself writing this to you stay-at-home caregivers to remind you that your sacrifices at home and in your lives, while now seeming to go unnoticed, are having a vast impact not only on your child but also your entire community. While it may be hard to see sometimes, especially because society may tell you differently, I am here to tell you from both a professional standpoint and a fellow special needs parent standpoint that what you are doing in your home, in those therapists' offices and waiting rooms, is far more valuable than that paycheck with your name on it.

Not only are you opening doors for your child and supplying him/her with all that these therapies have to offer, but you are also making yourself available to grow with your child. You are helping in more ways than you could ever know, more than I could ever list here. And if people make you feel as if you are not "contributing to society" because they have the mindset to measure success in economic terms, tell them that every new skill your child learns now saves money on care in the future, and that the more we work together as a team, the farther the child can go.

*Sue Kerstetter is the mother of three children, one of which is listed as severe on the autism spectrum. She is a former mental health technician where she had served for 13 years in the inpatient setting with various forms of mental illness. Her goal is to bring more awareness and acceptance to those living with autism spectrum disorder and their caregivers.*



# Parental Support With Autism: The Secret of My Success

By John PAUL

Growing up with autism is challenging. As somebody who has Asperger's syndrome, I know this all too well.

## Pre-Diagnosis

**R**aised in a middle-class family in one of the nicest counties in the Atlanta area, everything was fairly typical for me in my day-to-day life as a child. My father is a pilot for UPS, and my mother is a retired flight attendant for American Airlines. I had a lot of friends, and I got along well with most of my peers in my earlier years.

My parents' experience during this time was mixed. One thing they noticed early on was my intellect. I tended to be quite knowledgeable about certain things, particularly animal life. I had a vast cranial database about a wide-ranging variety of animals, including snakes, sharks, and dinosaurs. Not only did my family notice this, but the people around us began to notice as well. I remember when my father would take me to the barbershop and how I would geek out about science. A lot of people in the shop were impressed by my expansive vocabulary, and they'd jokingly tell me to stop using such big words that people at a barbershop couldn't possibly understand.

## Signs and Awareness

My parents received word over the years from daycare owners and teachers that I always seemed to favor being alone. I usually played by myself at daycare during my toddler years, and as I grew older, I never really cared to work in groups and preferred to get things done on my own. I also liked to keep a bouncy ball on me, and I would bounce it around while deep in



thought. These were all signs of Asperger's syndrome, but my parents had never really heard of it. Around 6<sup>th</sup> grade, stuttering became an issue, and one of my teachers noticed the other signs and suggested my parents have me evaluated. Finally, I was diagnosed with Asperger's syndrome at the age of 11.

“

**My parents initially struggled to deal with my social issues at school (pre-diagnosis). When my mother first told me about my diagnosis, I remember being quite angry, and for a short time, I even rejected the idea and denied that I had Asperger's. Over time, I grew to accept being Aspergian.**

”

## Middle School

When I got into middle school, I began to struggle socially. I was only comfortable around specific people, and some of those who I previously called my friends were now antagonistic toward me. One example I remember quite clearly is being coldly dismissed whenever I tried simply striking up a conversation. I also remember trying to sit at the back of the bus and hearing the disapproving yells and curses of the other children telling me that weird kids sat at the front. Not helping matters was my tendency to be very serious about almost everything, which turned off some of my rather humorous peers. While this time in my life was turbulent, I did manage to get through it thanks to the unwavering support of my parents.

## Accepting My Diagnosis and Parental Support

My parents initially struggled to deal with my social issues at school (pre-diagnosis). When my mother first told me about my diagnosis, I remember being quite angry, and for a short time, I even rejected the idea and denied that I had Asperger's. Over time, I grew to accept being Aspergian.

During my adolescent years, my mother helped me succeed by having me attend classes to educate me about autism and help me understand my previous struggles with neurotypicals. I regularly met with counselors to assist me in improving my social skills and speech, and eventually overcame the stuttering. My mother also gave me tips as I grew older. She taught me how to interpret and simply be aware of tone of voice and body language. This ended up being very helpful by the time I entered high school. I ended up making a lot more friends than I ever did in middle school.

My father taught me how to identify when a person is serious or humorous, which really helped me



to stop taking everything literally. Thanks to him, I ended up developing a rather dry sense of humor of my own. My father also encouraged me during my adolescent years by showing me some notable celebrities that were diagnosed with Asperger's, such as Dan Aykroyd or Satoshi Tajiri (the creator of Pokémon). Information like that inspired me and boosted my confidence. These people likely had the same struggles I had. I realized that if they could go on to find great amounts of success, then there's no reason I couldn't pull off the same feats.

The two of them also noticed that my gift for writing stories was beginning to develop at this time. Their encouragement for me to develop my skills was the most amazing expression of support and had a huge impact. I began to develop so many ideas for stories as my teenage years continued, and they ended up being beneficial for the writing classes I took in college.



## College Years

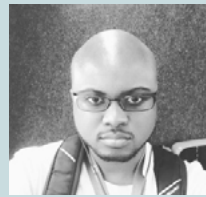
As I blossomed into adulthood and started college, I got a chance to reflect on how far I'd come from the adolescent that had a challenging social life during the middle school years. Throughout my college years, I had a nice circle of friends that shared a lot of the same interests as me and even went on a couple of dates. I started driving to different cities and states on my own and actually ended up joining a fraternity. In addition to this, I met a few people in college who also had Asperger's syndrome—one of whom remains one of my closest friends. It goes to show how valuable parental support and IEP's can be to students, helping them reach for the top and deal with unique circumstances.

## Message to Parents

Now, as an adult, I am proud of who I am, and I am even more proud to be Aspergian. Of course, I have my parents to thank for their amazing, steadfast support throughout my life. I share with hopes of reach-

ing and encouraging parents who may be struggling or feeling discouraged about their child's chances of success in adulthood. This extends to parents who are unsure if their efforts are even making an impact.

Your patience, support, and understanding are of vital importance. Instill the belief in your children that you will love and support them through every step of this incredible journey, help them power through any obstacle along the way, and help them build and maintain a strong mind and spirit to match.



*John Paul is a graduate from Georgia Southern University with a bachelor of arts in writing and linguistics with a minor in film studies. He has a keen interest in writing and photography and aspires to be a screenwriter.*

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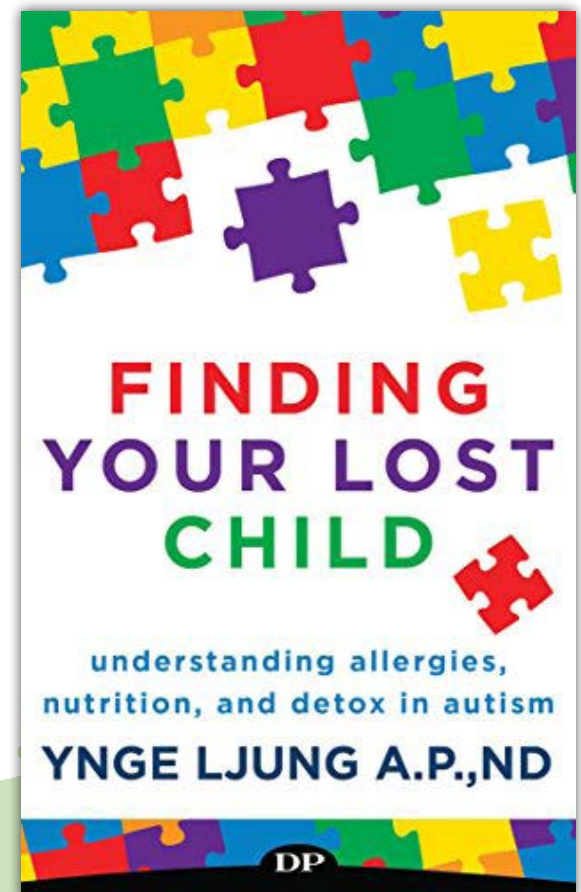
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# Easy Ways to Teach Perspective Taking to an ASD Child

By Connie PERSIKE, MS, CCC/SLP

Perspective taking is the ability to understand another person's thoughts, feelings, wants, and needs. Have you ever wondered how to begin helping your child with autism spectrum disorder (ASD) understand the perspective of others? Theory of mind deficits in individuals with autism is extensively documented in research, but where do we start? How do we break down this skill into a meaningful and systematic approach?



**P**erspective taking requires many skills, such as recognizing the emotions of others. However, in order to recognize the emotions of others, children must first learn to read facial expressions. This skill needs to be taught to all children, especially children with autism. This article intends to

provide you with concrete ideas and examples of how to teach the skill of recognizing facial expressions to children with autism, both in the home and school settings.

Let's be honest—many of us haven't had to think about what facial expressions look like. It's a skill, for



many of us, that comes naturally and doesn't require conscious thought. Therefore, we may have difficulty using language to describe a variety of facial expressions to our children. Taking some time to look at pictures of facial expressions may be helpful for both parents and professionals working with children with autism. When someone is angry, how can we describe the way their eyes look? If someone is happy, how does the positioning of their eyes change? What type of language can we use to describe this? Thinking about these questions will help give us the language we need before diving into activities and instruction. A useful resource to give us accurate descriptions of how faces look when people experience certain emotions is, [\*Test Your Emotional Intelligence: How well do you read other people?\*](#), published by UC Berkeley's *Greater Good Magazine*. The quiz will help you understand your depth of knowledge on the subject of facial expressions as well as provide you with explicit descriptors and language to use for each facial expression.

## Embedding instruction into children's literature

Reading to children is one of the best ways to help children experience different worlds, imagine different experiences, and see the world from different perspectives. This, in turn, helps us become more empathetic by helping us understand others' feelings and perspectives. While reading picture books to children, we can use the following prompts to teach them about the facial expressions portrayed by the characters:

"I notice (**describe nonverbal cues in detail**). This makes me think the character is (**name feeling**). I'm going to make my face/body look like that (**model nonverbal cues**)."

"It seems like (**character**) is (**name feeling**). I know this because (**describe nonverbal cues in detail**)."

"How do you think (**character**) might be feeling? How do you know?"

"I wonder how (**character**) is feeling? How can we tell? Make your face/body like that."

## Creating visual examples

"I think in pictures. Words are like a second language to me," said Dr. Temple Grandin (2006). When learn-

ing concepts, Dr. Temple Grandin needed to see a variety of pictures of a concept to generalize her knowledge. It may be helpful to create posters or visuals containing a wide variety of examples of each facial expression after reading picture books. Use pictures of the characters from the book and have the students imitate the facial expressions. This uses what we know about the neurology of individuals with autism to support their learning.



Images taken from the following children's books: *Llama Llama Red Pajama* by Anna Dewdney, *I Ain't Gonna Paint No More!* by Karen Beaumont, *Mouse Was Mad* by Linda Urban, and *Santa Bruce* by Ryan T. Higgins.

## Pass the Face game

Going through the motions of making a facial expression allows us to experience the associated emotion. Research has established that asking people to imitate certain facial expressions shows changes in brain activity that are characteristic of the emotion being imitated. In addition, we experience the same changes in heart rate, skin, and body temperature that are associated with the emotion we are imitating (Decety and Jackson, 2004). *Pass the Face* is a fun game developed by *Peace First* that involves children imitating nonverbal cues associated with specific emotions while still having fun! Think of the game telephone. This is a similar concept, except with the goal to pass on a facial expression instead of a verbal

message. Have children stand in a circle facing each other. Children will only see the face once when it is passed to them. Instruct the children that when they are tapped on the shoulder, it's their turn. At that time, they should look up at the face of the person next to them, imitate the face, and pass it on to the next person. As the face gets passed, each child should try to guess which feeling is being imitated, through facial expressions, without sharing it out loud. Once the face has been passed around the circle, the group should guess what emotion was being portrayed.

## Sorting facial expressions

Sorting tasks helps to remove language barriers for children with autism. Visually setting up the activities in an organized manner helps children understand what to do without needing to rely on additional language. Providing children with a variety of pictures of facial expressions and asking them to sort them into specific emotions supports their strength in visual processing and provides them with a large sample of visual examples.

Teaching perspective taking to children, especially children with autism, can feel like a daunting task. Hopefully, when asking yourself how to begin, you will now have a few concrete activities and examples to give you a place to start while working with what we know about the neurology of autism.

*Connie Persike, MS, CCC/SLP, is a highly experienced Speech Language Pathologist and Educational Consultant. As the founder of CP Consulting, Connie brings 20 years of experience to provide insight, guidance, coaching, and support to school districts, agencies, and families across Wisconsin needing expert direction in working with children. Connie has received extensive and in-depth training in several areas and educational models that inform her work with students across all grade levels, allowing her to customize the coaching, scaffolds, and supports she provides to help students succeed. From positive psychology and social thinking to functional communication training and integrated comprehensive service delivery models, Connie's mission is to help students increase their independence and improve their communication, social-emotional, self-regulation, academic, and adaptive skills. Connie is invited to present on a variety of topics. She is also a member of the American Speech Hearing Association, the Association of Supervision and Curriculum Development, and the Autism Society of Wisconsin. She has been involved in statewide workgroups to help develop and improve core programming in schools and is a published writer for Autism Parenting Magazine. Connie resides in Waunakee, WI with her husband and daughter. During her free time, she enjoys spending time with her family, reading, and cooking.*



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# How to Help a Child Struggling With Sensory Issues and Self-Control

By Nancy PESKE



**W**hen a child is having a tantrum or meltdown, we tend to say, “That child is struggling with self-control.” This description doesn’t quite capture what is really going on: poor self-regulation. A child might be able to control certain actions such as hitting oneself or others, even when upset, but what if the child can’t? If he/she is unable to do anything but experience distress and lash out, then the child has poor self-regulation of emotions. No amount of bribery or threats of punishment can get the child to stop because he/she simply *can’t*.

Kids with sensory issues have an especially hard time developing self-regulation skills when it comes to their emotions, focus, and activity level. Self-reg-

ulation and sensory issues commonly go together because kids with sensory processing disorder have brains that don’t process sensory information reliably. Children can quickly go into a fight-or-flight response when they are bombarded with confusing sensations, and in turn, become disoriented. Stack on top of that the pressure of people asking them questions or making demands of them, and it’s all too much.

It’s not always obvious how much kids with sensory issues are struggling. When they want to control their state of being, and it’s hard, they’re not available for learning, socializing, and taking on extra pressures. They have excess energy when we want them to be calm or are too relaxed when we want them to be energized. They have trouble with transitioning from

one state of being to another: asleep to awake, active to calm, and so on. Fortunately, by working on their self-regulation skills, we can help them to have an easier time functioning during everyday activities and situations at home, school, and away.

## How can a child develop self-regulation skills?

- **By practicing mindfulness**

By practicing mindful breathing, walking, listening, or eating, a child develops the part of the brain associated with self-awareness and focus. It's easier to stay focused on a task at hand when your thoughts aren't running away from you and turning into anxious ones: "If I try to eat an egg, it'll feel disgusting in my mouth. If I don't eat it, Grandma will get mad." A child needs to be able to control his/her emotional response of anxiety in order to be a good self-advocate, find his/her words, and choose the right tone of voice in which to say, "Grandma, my sensory issues make it super hard to eat eggs. Would it be okay if I eat something else?"

- **By using self-regulation tools**

At [www.zonesofregulation.com](http://www.zonesofregulation.com) you can access materials to help a child recognize and communicate his/her state of regulation: The Blue Zone is when a child does not feel very alert and perhaps feels tired, bored, sad, or sick. The Green Zone is when feeling peaceful, in a good mood, and focused—and there are other zones as well. The Alert Program and the Incredible 5-Point Scale are similar programs you can use as tools for helping kids to identify what state of being they are in and what they can do to shift into another zone. Having a picture to go with the abstract idea of feeling sad or overly excited can help both nonverbal and verbal kids to better identify and understand their state of being.

- **By developing emotional intelligence and words around emotions, activity levels, and focus**

It's easier for a child to learn to regulate emotions when he/she has words to express them. Labels for emotions, such as "frustrated" and "scared," can help a child gain a sense of control over feelings. Offer your child language that can help him/her identify and express what emotions he/she is ex-

periencing. Watch movies or videos together and point out where you see characters feeling and expressing themselves. You might say to your child who is watching *Frozen*, "Elsa looks anxious. She's stepping back a little like she wants to get away from everyone. People do that sometimes when they're afraid. What else do people do when they are afraid?" And you might say, "What could you do if you felt you were getting scared?" This way, you can help your child recognize what he/she is experiencing and self-reflect. That, in turn, helps the child plan for what to do the next time he/she gets in a situation where he/she is challenged to regulate emotions.

Words around activity level and focus can help your child, too. The Alert Program talks about kids whose engines are running too fast, too slow, or just right. This car engine metaphor can be very helpful for kids trying to understand why it's hard for them to sit still and participate in an activity at school when their bodies are telling them to run in circles. For focus, you might want to encourage your child to talk about his/her focus level and even about the brain needing more time to process information. What helps your child concentrate? What does concentration look like? Books and movies can also be helpful in these discussions.

The more self-awareness and tools kids develop for regulating emotions, activity level, and focus, the easier it will be for them to avoid meltdowns, tantrums, and other behaviors that can embarrass and upset them and others. Our kids are trying so hard to manage challenging situations. Knowing more about self-regulation and how to help your son or daughter develop self-regulation skills can help make your family life more harmonious.

*Nancy Peske is a freelance writer, editor, and consultant who has co-written or ghostwritten numerous bestsellers and award-winning books, including the newly updated Raising a Sensory Smart Child: The Definitive Handbook for Helping Your Child with Sensory Processing Issues, co-authored with Lindsey Biel, OTR/L. Nancy lives in Milwaukee, Wisconsin, with her husband and her son, who was diagnosed at age two with sensory processing disorder and multiple developmental delays.*

Website: [www.sensorysmartparent.com](http://www.sensorysmartparent.com)



# My ASD

By Amanda HARRINAUTH

*ASD, you have always been a part of me.*

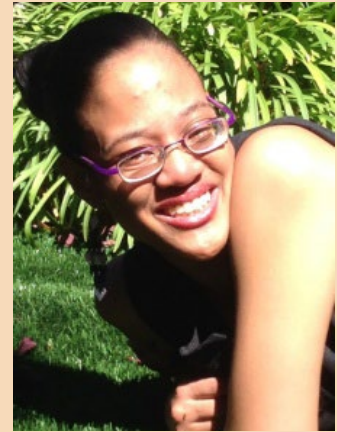
*You have been playing hide and seek with me, and let's face it, you won.*

*These fixations you give me night and day, they can't stay away from me.*

*ASD, you have freed me from myself, always afraid to be myself.*

*ASD, you have opened up a new world for me.*

*ASD, I am so happy you are part of me.*



*Amanda Harrinauth was diagnosed with autism in 2016 and started writing poems shortly after to help herself cope. Her goal is to become a life coach and empower others with autism.*

# For Sara

By Mary KANGAS

*Siblings of autistic kids,  
Are very special, you know,  
They teach their autistic siblings,  
The ropes of life to grow.*

*They interact  
And they help out,  
Any families with autism know what  
I'm talking about.*

*They deserve to be recognized.  
They deserve a lot of praise,  
For they are a helpful blessing  
In autism's intricate maze.*



*Mary Kangas is the mother of two children, Dennis and Sara, and has a great husband named Dennis who works very hard taking care of his family. Mary is a stay-at-home mom who likes to write poems and writes a lot about autism to unfold it all in her words. Mary's beautiful and smart son Dennis has autism and works incredibly hard on things. They are very proud of him. Their daughter, of whom they are also proud, is an honors student and a helpful young lady. They feel very blessed.*

# Is an ABA Center the Right Place for Your Child on the Autism Spectrum?

By Joseph LAUDADIO

It's no secret that autism diagnoses of children are growing. In a new study just published in the journal [Pediatrics](#), one in 40 children has autism spectrum disorder; and according to the Centers for Disease Control and Prevention, diagnoses of boys outnumber girls nearly four to one (1/37 boys versus 1/151 girls).

While there is an increasing range of options for helping individuals with autism—including everything from using laser lights to chiropractic adjustments—Applied Behavior Analysis, or ABA therapy, has become one of the most important methods of treatment.

ABA is a systematic approach that uses well-defined strategies to increase desirable, targeted behavior skills. Since it first emerged as a therapy for individuals on the spectrum in 1987, ABA has grown and matured into the only scientifically validated and most effective behavioral treatment for autism.

ABA therapy is generally used by two types of trained experts: Registered Behavioral Technicians (or RBTs), who often work one-on-one with children daily, and Board-Certified Behavior Analysts (BCBAs), who oversee RBTs. BCBAs are also responsible for reviewing the broad arc of how a child is progressing, how well the child and RBT are connecting, and what can help RBTs—and children—improve the learning process.

Although ABA therapy is often applied in a home setting, its use in a clinic or center is proving to have many more advantages. Here are a few of them:

- ABA centers have complete control of the environment with all professionals, including BCBAs, working together to support the child's needs, as well as different individuals available to help ensure generalization.
- Children learn to incorporate social skills with other children, compared to a home setting where socialization is limited to siblings or play dates (which can be quite challenging).
- ABA centers help improve attending to tasks in a busier environment but can also utilize the designated space for 1:1 discreet trials. At home, the only way to create a busy environment is to go out into the community where maladaptive behaviors often occur.
- ABA centers help children focus on making the transition between discreet 1:1 trials and group activities; they also provide “breaks” from difficult 1:1 work to help prevent boredom.
- Just as important, a good ABA center can offer access to a variety of reinforcers compared to a home setting where much of the reinforcement is always the same.





**“ If your child exhibits aggressive behaviors, a skilled, seasoned RBT won’t be intimidated. He/she will change the dynamic so he/she can steer the interaction with your child. ”**

However, all ABA centers are not created equal. Choosing the right one requires the evaluation of a wide range of crucial factors.

First and foremost, have a good feel for how well your child and his/her RBT interact. Is there a good rapport between them, or does the RBT seem hesitant when trying to connect with your child? If your child exhibits aggressive behaviors, a skilled, seasoned RBT won’t be intimidated. He/she will change the dynamic so he/she can steer the interaction with your child.

You should also be able to see progress quickly and consistently. In other words, is your child learning new behaviors that can be applied in and out of your home? If the answer is no, then maybe that particular ABA center isn’t the right one for your child.

A quality ABA center should be designed to offer a broad range of experiences and not be limited to a series of rooms or a set space. To that end, look for an organization that can offer a variety of environments.

For example, does the center have a partnership with an equine center where children can work with horses? This activity has proven to be especially effective for individuals on the spectrum. Is there a robust art studio or a pool? These different settings are particularly important because they provide a wider range of reinforcements to help children quickly improve and grow.

As you evaluate ABA centers, their ability to help your child grow and improve must be the number one priority. However, you should also consider whether the organization you’re considering provides additional services and resources to help you navigate what can be an extremely challenging journey.

For instance, are there resources dedicated to helping you with complicated insurance issues? Does the front office staff streamline the application process so you can quickly get support for your child?

Although ABA centers offer many advantages in helping children on the spectrum, they’re not right for everyone. For example, a child with significant attention deficits may find the stimulation of a center overwhelming and may not quite have the necessary attending skills.

The key for parents is to reach out immediately to start this critical process. Studies show that the earlier autism is addressed (as early as two years old), the more likely your child will be able to find ways that enable him/her to be fully integrated into a school setting—as well as society—as he/she grows.

*Joseph Laudadio, Regional Operations Manager for [Gersh ABA Services](#), has more than 20 years of Applied Behavior Analysis experience.*

**“ Although ABA centers offer many advantages in helping children on the spectrum, they’re not right for everyone. For example, a child with significant attention deficits may find the stimulation of a center overwhelming and may not quite have the necessary attending skills. ”**

# Special Program Provides a Safe Space for Kids With ASD to Play

By Ray WUNDER

Raising two sons on the autism spectrum, I knew I wanted to support an organization that focused on helping a wide variety of people—both kids and parents—who are navigating a similar experience. But when I started at my current role as senior director of digital partnerships at Deluxe five years ago, I never expected my career would play a central role in allowing me to support that cause while also directly impacting the development of my two sons and other children on the autism spectrum as well.

I grew up in Hawaii, working at a small family business. When I moved to Utah, I chose to work at Deluxe because it has a history of supporting small businesses. As part of a team that meets with and helps small businesses grow, I get to see small business owners realize their potential. I also began volunteering at the Melissa Nellesen Center for Autism (MNC) in Draper, Utah, but my volunteering was limited to my time away from work. That was until I was selected for Deluxe's 100 Hours to Make a Difference program, which allows select



employees to dedicate 100 hours of paid time off toward a cause they're passionate about. For me, supporting MNC was a perfect choice. It is in a unique position to make an impact locally and nationally for the autism community because:

1. It is part of a university; thus, the center has an inroad to shaping and changing education regarding autism. The center also supports individuals with autism in obtaining higher education and gainful employment.
2. It has a phenomenal leadership team with strong experience in the autism community and a track record for initiating change.
3. MNC supports grassroots ideas from the community, as evidenced by the sports camps my family and I started.



“ There is no shortage of need or demand in our community for help and support. In the past week alone, my wife has received requests to do camps quarterly, offer different sports outside of soccer and basketball, and have two groups from different states host a Moving Mountains Sports Camp. There’s a need, but when you have families and small groups trying to meet these needs, especially when those groups usually have their own needs at home, progress can be hard to come by. ”

I have served on the parent advisory board at the center for a few years. However, my support has been limited due to work and personal demands. The Deluxe Cares 100 Hours to Make a Difference program gave me dedicated time to meet with the center on creating sports camps for children on the autism spectrum, employment initiatives, and other activities.

There is no shortage of need or demand in our community for help and support. In the past week alone, my wife has received requests to do camps quarterly, offer different sports outside of soccer and basketball, and have two groups from different states host a Moving Mountains Sports Camp. There’s a need, but when you have families and small groups trying to meet these needs, especially when those groups usually have their own needs at home, progress can be hard to come by. The MNC can provide a platform to broadcast programs nationally, and Deluxe’s 100 Hours to Make a Difference program gave me time to focus on meeting some of these needs.

My wife and daughter are the driving forces behind the sports camps, which you can read more about [here](#). My daughter approaches local businesses for donations, talks with coaches and soccer teams about volunteering at the camp, and runs the pre-camp trainings on logistics, schedules, etc. My daughter’s soccer club, as well as her rival soccer club, are two of the main volunteer groups for the camp. My wife and her circle of friends do everything behind the scenes, which is another reason why having the dedicated time from Deluxe is such a blessing.

My boys can play in sports leagues, but to be honest, it is a struggle for them to deal with some of the sen-

sory overloads they experience. However, they LOVE sports, and camps like this give them a safe environment to start in a sport and grow to love it. So, it’s neat to do this together as a family.

As a parent, it’s hard enough to get a teenage girl, twin boys on the spectrum, and a toddler to be on the same page. But when the camp comes around each year, we get to work together. Whether we’re organizing 400 t-shirts in our living room or figuring out where to stash 200 soccer balls, it’s a ton of fun to see our family bond over making a positive impact through activities like this.

*Ray Wunder is a senior director of digital partnerships at Deluxe Corporation in Utah with a BS in Business Management and an MBA in Finance. Ray grew up in Maui, Hawaii working at a small family business, where he then met his wife of 20 years. The two now have four kids: 15-year-old Kylee, 11-year-old twins Jaron and Ethan, and four-year-old Brynley. After moving to Utah, Ray started his career at Deluxe and began volunteering at the Melissa Nellesen Center for Autism (MNC). With two twin boys on the autism spectrum, Ray and his family find great fulfillment in giving their time to the center as well as volunteering at a local soccer camp for children with special needs called Moving Mountains Sports Programs. Kylee and Ray’s wife Jen are the driving force behind these camps and dedicate significant amounts of time approaching local businesses for donations, running the pre-camp trainings on logistics, managing schedules, and more. Beyond work and volunteering, Ray and his family love trying new sports together and exploring musical hobbies such as piano.*

# Autism Expert Shares Helpful ABA Techniques in New Book

## Parenting Autism: Lighting the Way Forward: A Handbook for Parents & Caregivers

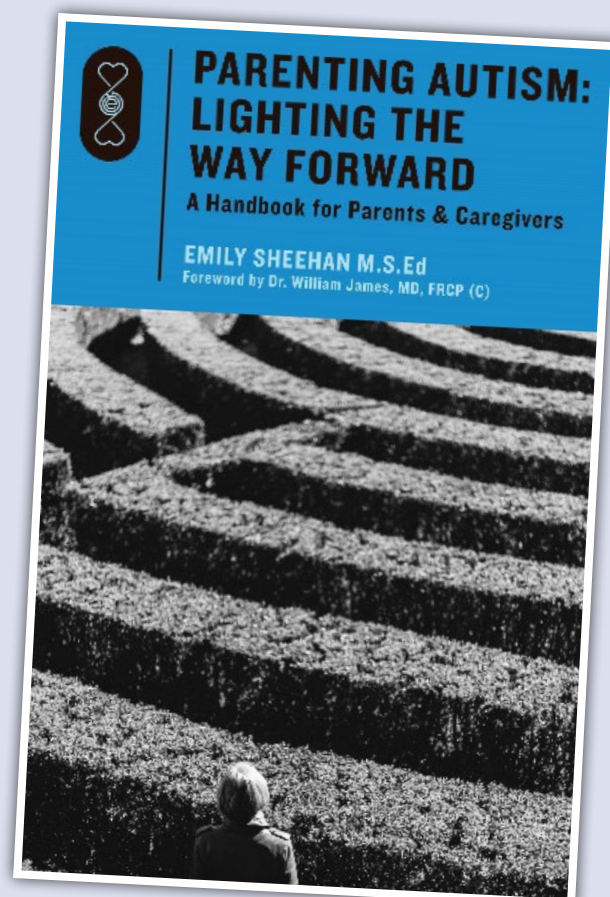
By Emily SHEEHAN, MEd

Foreword by: Dr. William JAMES, MD, FRCP (C)

**A**n autism diagnosis comes with uncertainty and many questions. Parents are left feeling unsure, confused, and helpless while navigating the maze, and autism services are costly and may be difficult to find. The solution? Empowering parents, caregivers, and educators to take a leadership role in providing the best possible care and becoming instrumental in the therapy of the child. Get informed and begin using these Applied Behavior Analysis (ABA) techniques to teach any child on the autism spectrum.

Written by an expert in the autism field with a foreword by a renowned pediatrician diagnosing autism, *Parenting Autism: Lighting the Way Forward: A Handbook for Parents & Caregivers* is an essential resource for anyone working with children on the autism spectrum. The book outlines principles, teaching philosophies, and therapy techniques to kick start/enhance anyone's ability to provide the best care possible for children on the spectrum.

Derived from the author's 15 years of experience in the autism field as a therapist and educator, this book has extensive real-life examples of common behavior situations and provides specific details on how to solve them.



The goal is to give parents and caregivers the tools they need to communicate, teach, and understand their children. Furthermore, these individuals may feel knowledgeable and much more confident after reading and utilizing this book.

*Emily Sheehan, MEd, is an educator specializing in autism therapy. She has worked with families in their homes as well as in schools. Emily drew inspiration for the book from the very first student she worked with who was moving to a country without any autism services. She wrote a handbook for the parents to take with them. Emily has worked with many families with whom she provided a handbook which is now available to everyone.*

For more information visit: [theraparent.ca](http://theraparent.ca)

ADVERTISEMENT



# New Book of Rhymes Reduces Stress Surrounding Autism

## You Don't Know My Story A Bedtime Book for Parents of Autistic Kids

By Elise R. JOHNSTON

If you have a child on the spectrum, you've likely felt that others have no idea what you go through...which just adds layers of stress! While we certainly get plenty of practice developing patience and unconditional love, we sure could use a little help in reducing our stresses, especially the unnecessary ones contributed by others around us.

This set of illustrated rhymes presents, with humility and humor, common struggles and challenging situations while offering supportive approaches to help manage our mindset, and thereby the stress of our children.

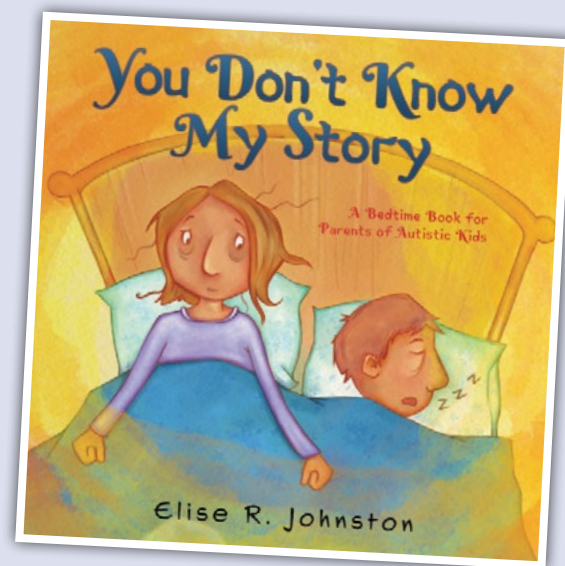
"In the following pages, I share the calming of my thoughts, reducing my stress, massaging out emotional knots. My hope is that you, too, can lay down in bed to slumber well, resting chaos that spins in your head."

### For more information:

<http://www.alivewithelise.com/autism>

<https://www.amazon.com/You-Dont-Know-My-Story/dp/0228806518/>

<https://www.barnesandnoble.com/w/books/1130574098>



*Lack of exposure to the autistic spectrum typically means that you just 'don't know.' You have no clue. Elise R. Johnston didn't and will be the first to admit to being critical of parents, even in general, before her child-rearing years! Her first-born made her re-evaluate many preconceptions, but she was reassured as all milestones were exceeded. Enter a second child who was actually easier as an infant, but over time, presented as delayed and explosive.*

*With next to no support or even awareness in the small island nation of Dominica, Elise struggled with parenting: shifting expectations, absorbing others' inputs, hospital visits, early education, and her own health issues stemming from increased stress.*

*Shift forward, away from her architectural career and into yoga and health coaching, Elise wants to share how mindfulness brought peace to her and her son.*

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# An Exclusive Look at AUTISM

with *Katherine Sanger*

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.*

**T**oday's AUTISM Interview is with Katherine Sanger, who is a mother with a son with autism. Katherine was a Jersey Girl before getting smart and moving to Texas. She's been published in various e-zines, and print, including *Baen's Universe*, *Spaceports & Spidersilk*, *Black Petals*, *Star\*Line*, *Anotherealm*, *Lost in the Dark*, *Bewildering Stories*, *Aphelion*, *RevolutionSF*, and she also edited *From the Asylum*, an e-zine of fiction and poetry.

Her poetry has won numerous awards, including first place in Byline's *Autumn Poem* contest, first place in Lucky Thirteen contest sponsored by *Sol Magazine*, and Honorable Mention in The Houston Chapter Award, The Hap Fulgham Prize, and The Varoom-Va-room Award.

She writes non-fiction for various websites, including *Examiner.com*, *Hubpages*, and *Demand Studios*. She's a member of Broad Universe, Science Fiction Poetry Association, SFWA, HWA, Bay Area Writers League, and Gulf Coast Poets.

She's earned an associate of arts in general studies, a bachelor of science in information technology, a master of liberal arts, a master of arts in English literature, and a postmaster's certificate in education/college teaching, as well as 48 doctoral hours in post-secondary and adult education. She is currently working on her MFA in creative writing with the University of Tampa.



**A** **is for Awareness** - When and how did you first become aware that something was different?

We realized there was something different very early on. Simon did not meet milestones, including learning to talk at a year old. Luckily, we had an excellent pediatrician who called Early Childhood Intervention (ECI) when Simon was 15 months old. He worked with a speech therapist and an occupational therapist. He was diagnosed with PDD-NOS at the age of two.

It was only after Simon started working with ECI that I really became more aware of some of those differences.

The defining moment for me was when he and I were at a local library in the children's area. They had toys scattered around, wooden puzzles, Little People toys, and a huge stuffed Clifford. A little girl, probably no older than a year old, was playing with her mother. The girl put a chicken on top of a farmhouse, then looked up for approval. Simon was almost two at that point, and I realized that he had never done that. He played with toys, but whether or not anyone approved, or even acknowledged his actions, had never been a part of it. He had not purposely shared any of his experiences with me.

**U is for Unique - How has this experience been Unique for you and your child?**

Everything. I honestly believe that every human being's experience is unique, and that is especially true for people on the spectrum. They have a lens that lets them view the world in a way that we will never be able to do.

Specifically, however, one of the unique aspects of our life is Blue's Clues. Since Simon started watching it when he was two, he hasn't stopped. It has been 14 years of our life spent watching Steve (because no one likes Joe) and Blue. Simon carries a Handy Dandy Notebook everywhere he goes and can—and does—recite episodes any time he wants.

**T is for Tools - What tools are there now that were not there at the beginning that could help other parents?**

Facebook is an amazing tool. It's the place to connect with other parents, find local groups, and learn about events and conferences. I run a parent support group for local parents and have a Facebook page for my son. It's a great way to connect with people all over the world and share experiences. For any parents who haven't checked it out yet, do a search. Find people who are living similar lives and link up with them. They are your people. You are theirs.

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

The future is what inspires me.

Simon is 16 years old. He hasn't learned to drive. He hasn't gone on a job interview. He hasn't gone on a date. But he's 16 years old. He has his future.

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

Transition is, without question, the hardest thing we've had to work through. It wasn't that everything else was easy; there is nothing easy about seeing your son meltdown because he can't communicate, struggle because he can't understand that he has to wait or repeat a grade because he can't figure out the work. All those things, though, can be worked through. Time passes. The problem is that it keeps passing, and, right now, there are very few options to help adults with disabilities.

Simon needs options. He needs someplace to live, someone to live with, something to do. What are these things? We have limited time to find out, and we're racing towards the cliff of transitioning to adulthood. The drop is going to be steep.

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

The most important thing to remember daily: you are the best at what you do. Yes, some days you may feel like you're failing, but you're not. Write it on your mirrors, paint it on your walls, make it the background of your phone. You are the best at what you do.

Email: [ksanger@fromtheasylum.com](mailto:ksanger@fromtheasylum.com)

Blogs: [katsanger.wordpress.com](http://katsanger.wordpress.com), [katsanger.hubpages.com](http://katsanger.hubpages.com)

Twitter: [@katherinesanger](https://twitter.com/katherinesanger)

*Derrick Hayes is an author, motivational speaker, and paraprofessional in the Muscogee County School District in Columbus, Georgia. Book or Interview Derrick Hayes the "enTIETainer" now by visiting [derrickhayes.com/entietainer/](http://derrickhayes.com/entietainer/).*

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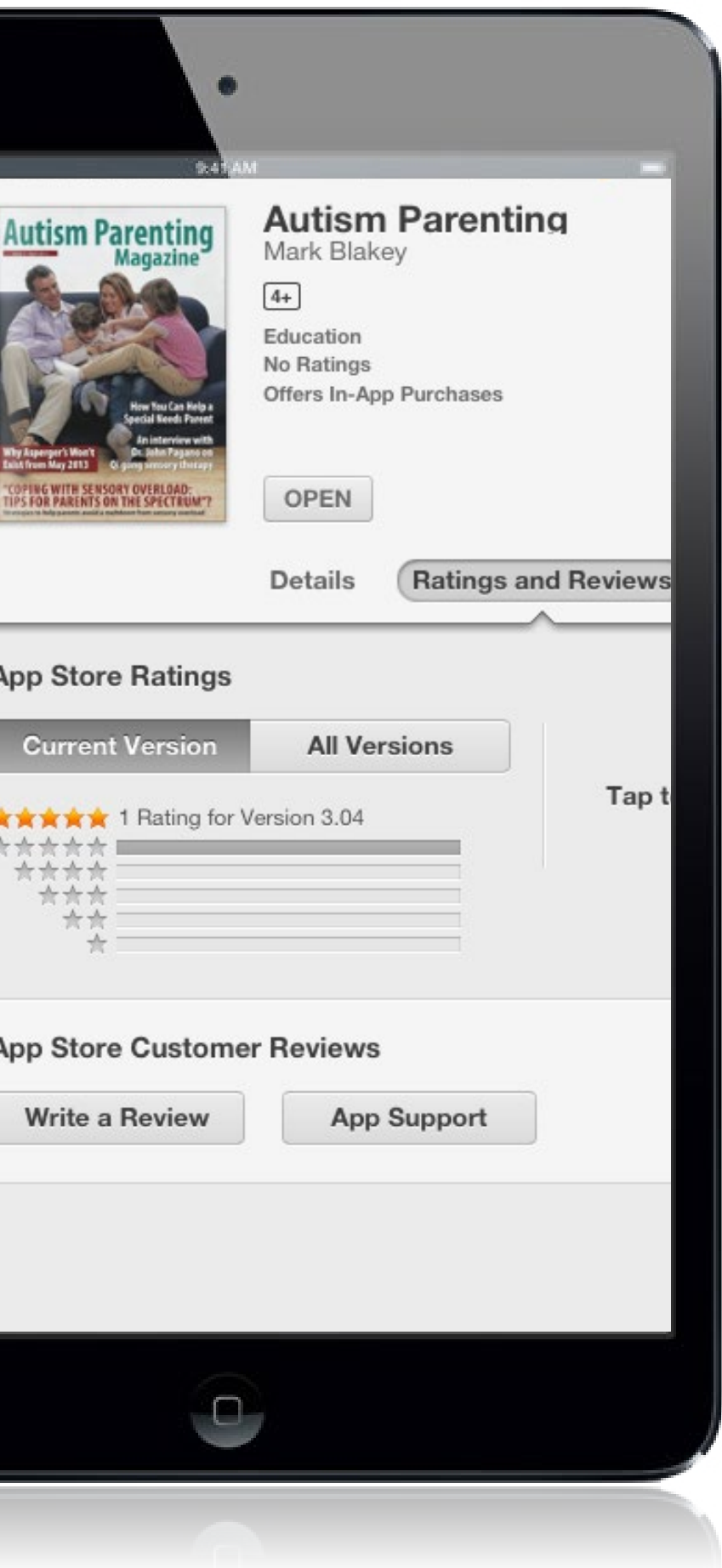
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# COURAGEOUS AUTISM BOOK PUBLISHER DEDICATED TO SOCIAL CHANGE

By Amy KD TOBIK



**J**essica Kingsley Publishers is a publishing house committed to social change. The autism list is foremost amongst its extensive publishing program across the social and behavioral sciences and is pre-eminent in this field. Specializing particularly in books on Asperger's syndrome (autism level one), the focus has always been on knowledge, demystification, and empowerment. Books are published for parents, professionals, researchers, and people on the autism spectrum, including books for children.

**Location:** JKP's main office is in London, UK, with a smaller office in Philadelphia, Pennsylvania, but the books are available all over the world, and many of them have been translated into multiple languages.

**Accomplishments:** Jessica names being part of changing the way people think about autism and helping make it part of the everyday world where people are different in a multitude of ways as her accomplishments. She also lists helping to get the world to understand that people with autism have incredible strengths as well as challenges. She is proud to have published some amazing authors including Tony Attwood, Kathy Hoopmann (*All Cats Have Asperger Syndrome*, etc.), and Luke Jackson (*Freaks, Geeks and Asperger Syndrome*) to name but three. "JKP has never dodged the difficult issues, but has always tried to publish books that open up the world to a better understanding of autism and appreciation of what creative and enlarging things people with autism have to offer the world," Jessica said.

**Inspiration:** Jessica's list of inspirations includes the courage, creativity, integrity, and sheer determination of people on the autism spectrum, the love and dedication of the people who understand, help, and support them, and the wonderful surprises that can come out of an autistic view of the world.

**Goals:** Her aim, she said, is to keep on working to transform the world into one that truly understands autism.

## AUTISM WARRIOR:

**Jessica Kingsley**

Formerly Managing Director and owner of Jessica Kingsley Publishers

**Advice for families affected by autism:** "Never give up! Fight for your child's right to be understood by the people they come in contact with. Remember you are not alone—there is an autism community out there rooting for you," Jessica said, "And remember if you can that if your child finds it impossible to express what they feel for you, it doesn't mean they don't feel it."

**Website:**

[www.jkp.com/uk/autism-and-related-conditions.html](http://www.jkp.com/uk/autism-and-related-conditions.html)

**Facebook:**

[www.facebook.com/JKPAutism/](http://www.facebook.com/JKPAutism/)

**Twitter:**

[twitter.com/JKPautism](http://twitter.com/JKPautism)

*Amy KD Tobik, Editor-in-Chief of Autism Parenting Magazine, has more than 30 years of experience as a published writer and editor. A graduate of Sweet Briar College in Virginia, Amy's background includes magazine, newspaper, and book publishing. As a special needs advocate and editor, she coordinates with more than 300 doctors, autism specialists, and researchers to ensure people diagnosed with autism receive the services and supports they need for life. She has two adult children and lives in the Carolinas with her husband.*



# Lovely New Book Told Through the Eyes of a Student on the Spectrum

## Artism and Me, Autism Within My Heart In Color

Written and Illustrated by  
Maggie RUSSELL

**T**he world of every artist is their own and is the very essence of who they are. In the children's book *Artism and Me, Autism Within My Heart in Color* written and illustrated by Maggie S. Russell, the simplicity and bold colors will astound you.

Maggie's journey into the autism spectrum began at age three. Subsequently, her world became a rainbow of an array of endless color because art, she discovered, was the media she could use in expressing herself to others. Maggie wants others to become aware that individuals who have been diagnosed with autism...are "special." This poignant book is filled with pictures of nature, landscapes, architecture, animals, and rainbows in vibrant shades of colors and hues in oil pastels.

Life with Asperger's has not always been fair, yet, Maggie has overcome these many obstacles through dedication, perseverance, family, and true friends. She "Never Gives up, and She Never Surrenders" no matter what life brings her way. "Art is my life, and I want to help others with disabilities like mine. The word 'autism' does not define who I am as a person because I define it through my art." Maggie takes the rain out of "rainbow," and she can take a gray day and turn it into sunshine. To know her is to love her.



*An excellent academic college student who achieved a GPA of 3.58, Maggie Russell was on the President's List once, the Vice-President's List three times, is an Honorary Member of Phi Theta Kappa, and the National Business Honor Society. Maggie was also the recipient of the Jackson Pollock Art Award for being "the most expressive artist," and she was also awarded the Henri Matisse Fauvism Award for her "use of bold colors." She also placed third in the Computer Art Category for her interpretation of Vincent van Gogh's "Starry, Starry, Night." "No day in my world will ever be without art."*

Instagram: [Magsterart101](#)

Twitter: [@MagsRussell15](#)

*Maggie's book can be found at any bookstore site; Amazon, Books-A-Million, Barnes & Noble, etc.*



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# Autism Parenting Magazine

**D**o 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.

Ideally, the topic needs to be relevant to the magazine. Any topic that is related to parenting a child with autism or being a person on the spectrum that is parenting would be a relevant topic. 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 that someone hasn't already covered the same thing by emailing the editor. You may use a blog post that you have posted on your blog already.

**THE ARTICLE SHOULD BE A MINIMUM OF 300 WORDS. FONT DOES NOT MATTER. WE DO ASK THAT IF YOU USE SOURCES TO PLEASE CITE YOUR SOURCES AT THE END OF YOUR ARTICLE TO AVOID PLAGIARISM.**

At the end of your article please include a few sentences about yourself and your writing or autism related background with links to your site or products.

Please note that we cannot post your article without a small bio. So please do not forget to send a few sentences about yourself with your article.

If you have something interesting or informative to share please email  
[editor@autismparentingmagazine.com](mailto:editor@autismparentingmagazine.com).





# State Medicaid Waiver Programs Can Pay for a Lifetime of Needs

By Ryan F. PLATT, MBA, ChFC, ChSNC

## Question:

*I heard a report that stated the Social Security trust fund will be extinguished by 2034. Is that true, and if so, how does that impact the plan for my adult son with autism?*

**B**y law, Social Security OASDI trust funds must be able to pay benefits for at least the next 75 years. The trustees for Social Security have projected that with no changes, the combined trust funds for retirement, disability, and survivors' benefits (OASDI) will pay full scheduled benefits through 2034, and then will need to be reduced by 21 percent to stay solvent. It is also important to understand that SSI (Supplemental Security Income) is not paid through the trust fund but is instead paid by general government revenues (taxes) on an annual basis.

It is clear that changes must be made to our system to keep it sustainable. SSI is a benefit that could be changed on an annual basis based upon government revenues. There has been chatter in Washington (nothing concrete) that SSI is an area that they need to research due to the reduction in revenue based upon tax law changes. It is also clear that changes will need to be made to Social Security to keep benefits at their current level. We understand that changes either mean an increase in some form of tax revenue, more stringent qualification rules for



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As you plan for your son with autism, it is critical that you consider the macroeconomic forces that will impact the benefits he receives in the future or the taxes you and he (or his Special Needs Trust) will have to pay. As you calculate his financial needs, you will need to have a contingency plan for a reduction in his government supported benefits, as well as an increase in taxation.

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SSI and SSDI (resulting in the reduction of the number of people receiving benefits), or the reduction of the dollar amount of these benefits by more than 20 percent in the future.

As you plan for your son with autism, it is critical that you consider the macroeconomic forces that will impact the benefits he receives in the future or the taxes you and he (or his Special Needs Trust) will have to pay. As you calculate his financial needs, you will need to have a contingency plan for a reduction in his government supported benefits, as well as an

increase in taxation. The adjustment in these two items will translate into more support being paid by you or your family, which means you need to have a good grasp on your asset picture, which ones you will use for your future or leave for his benefit, the taxation of those assets at different times, and compare those to your own financial needs and his financial support needs. By doing this, you will be able to have a more comprehensive projection of your family's multi-generational needs, which will allow you to make more informed and effective decisions today.



*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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*Ryan F. Platt, MBA, ChFC, ChSNC, is a registered representative that offers securities, investment advisory, and financial planning through MML Investors Services, LLC, member of SIPC. A Special Needs Plan is not a subsidiary or affiliate of MML Investors Services, LLC, or its affiliated companies. This article is not a recommendation or an endorsement of any products.*



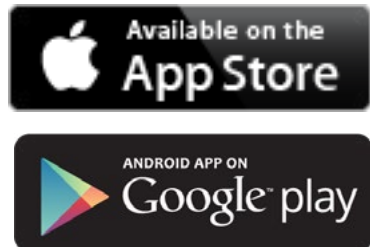
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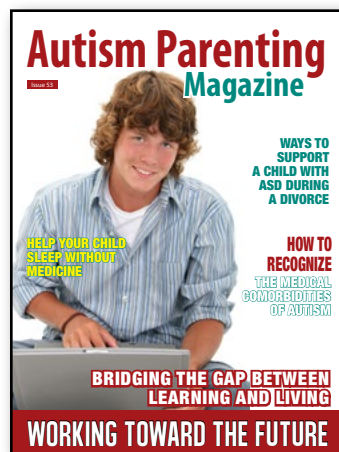
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