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Editor's Letter

o you have people in your life who provide the unconditional support you need? Sadly, not every family member or friend fully understands an autism diagnosis, which can add to holiday stress. It doesn't have to be this way. So, let's find some ways to fill your heart with love, peace, and joy this season.

All kids need to feel a sense of belonging—so why not form a group of friends this year to include other autism families in your community? Perhaps you can connect with friends from a local playgroup or a special needs' support group. Or maybe you can unite with fellow parents on an autism-centered social media page? You know what works best for your child and family—so celebrate YOUR way.

People often ask us for advice on how to explain autism to friends and family. Too often, children who find it hard to engage or respond to social cues are overlooked at family gatherings. And many people don't know how to react when a child with autism vocalizes or engages in self-stimulatory behavior. Erica Crowley, BCBA, has provided us with an excellent piece on ways to help people in your life develop fun, loving connections in *How to Help Family and Friends Build Relationships With Your ASD Child*. Her guidance will help broaden everyone's understanding.

According to Chris Abildgaard, LPC, NCC, NCSP, it can be twice as complex to plan for the holidays when one of your children has an autism spectrum disorder (ASD) or another developmental disability. If you are feeling overwhelmed, be sure to read his article, *5 Ingredients You Need for Holiday Success With Special Needs* to help make your holiday celebrations a little more manageable.

While social media has the potential to bring people together, it's easy to hurt someone unintentionally. You may be cautious when posting, but not everyone understands the long-lasting impact of careless words. Margaret M. Quinlan, PhD, Dan Grano, PhD, and Bethany Johnson, MPhil, MA, a team from the University of North Carolina, Charlotte, has put together a piece called 5 *Tips for Posting About Special Needs Parenting on Social Media* for you to share to ensure posts are kept inclusive and positive.

According to Alfred Chavira, research shows families raising an individual with special needs are at a higher risk of stress compared to other families. When left unresolved, tensions can turn into anger, frustration, or resentment, which may affect how family members interact with one other. Take a look at *Top Ways to Manage Stress When A Loved One Has Autism*, to learn about three major factors causing the rise in stress levels: perception, expectation, and fear.

Have you talked to your child about his/her autism diagnosis? Parents may be hesitant to tell a child he/she is on the spectrum because they fear the child might not understand it fully or become discouraged. As Emily Daniels, MSW, RP, Med, says, parents know their children best and will know the most meaningful ways for them to process information





about themselves. For top guidance, look at her piece *How Can I Explain an Autism Diagnosis to My Child?* as Emily shares five points to consider when trying to help your child understand and develop acceptance for who he/she is as a valuable member of the autism community.

Is your child having a hard time getting a good night's sleep? Studies indicate a majority of children with autism experience sleep issues. If your child is struggling to get to sleep and stay asleep, you will want to read Melissa Doman's article, 3 Simple Tips for a Restful Night for Your Child With Autism, to discover new ways to help your child sleep longer, better, and healthier. Some kids with sensory issues have difficulty sleeping alone. We recently received a letter from a mom in search of advice on how she can move her son back to his room. Take a look as Kelly Beins, BA BHScOTR/L, explains why some children with autism struggle to sleep and provides sensory supports you can use in HELP: My Child With Sensory Issues Won't Sleep In His Own Bed.

Does your child with autism wander or run away from safe spaces? This is a common concern for families. If you want to learn technological ways to help keep your child safe, read *Five Smart Tech Ideas for Parents with Kids on the Spectrum* by Hilary Thompson.

Finding the most up-to-date information you need to help your child can be challenging; that's why we make such an effort to respond to our readers' requests. This month we have articles on a variety of key topics such as how you can help kids with ASD reduce bullying, how to best manage financial gifts so they don't affect government benefits, as well as a great listing of toys to help your child develop coordination, emotional maturity, social skills, and confidence.

For continuous advice and encouragement, check out the <u>Autism Parenting Magazine</u> Facebook page, as well as our membership page called <u>Autism Support Groups for Families</u>, which provides a unique opportunity to come together with other families.

Wishing you love, joy, and acceptance this holiday season as you celebrate with the people you love.

Amy KD Tobik Editor-in-Chief

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

5 Ingredients You Need for Holiday Success With Special Needs

By Chris ABILDGAARD, LPC, NCC, NCSP

Preparing for the holiday season is difficult for any family. We spend a lot of time trying to answer questions like "Is it my turn to host?" "What do I get him that he doesn't already have?" or "I hope my sister-in-law remembers my kid's allergies!" We can all relate to these questions to some degree.



ased on my work with families over the years, I know it can be twice as hard trying to plan when one of your children has an autism spectrum disorder (ASD) or another developmental disability. It makes an already demanding time of year more complex. If you are feeling stressed, here are five small ingredients to help make your holiday celebrations a little more manageable.

Ingredient 1: Be mindful of traditions

In my work as a mental health counselor, I can't tell you the number of times a client has come in after the holiday and said, "Mr. Chris! My mom dragged me to my aunt's house for Christmas; then, she didn't even have _____ like she usually does!" Traditions, or routines, are very important to people on the specBeing around a lot of people, possibly in a new(er) environment, can be overwhelming for a person with ASD regardless if he/she has been there before. Planning with your child as to where he/she can go to take some space or have some downtime is extremely important for sensory needs and the overall ability to self-regulate.

trum. Think ahead to ask about the setup of the holiday this year: will there still be ____, how many people will be there, is grandma making ____?

If there are going to be some different aspects to the holiday, explain them to your child using phrases like, "We have to be flexible this year," "What if....," or "It's important to...." These phrases address core deficits in ASD, such as perspective-taking and executive functioning. Yes, these are not easy ideas to understand, and it may take some time for your child to accept the changes. With repetition, review, and support of the new plan, he/she will feel more at ease. The more aware you can be as a parent of what the plan will be for this year's holiday, the better prepared you can be to help your child.

Ingredient 2: Make an escape plan (for you and your child)

Passage of time is a hard concept for many young people to understand. What does, "We will leave when everyone else is ready to leave" really mean? Being around a lot of people, possibly in a new(er) environment, can be overwhelming for a person with ASD regardless if he/she has been there before. Planning with your child as to where he/she can go to take some space or have some downtime is extremely important for sensory needs and the overall ability to self-regulate. Think of it like this: when we are at work, and we need a break, we get up and change our environments (we get a cup of coffee, we walk over to a coworker's desk, we leave to use the restroom). Here is the crucial part—we come back. Part of this plan with your child has to be the "coming back part" and helping the child to know and feel when his/her body is ready to "come back" into the setting which was left. Using phrases like, "When you are feeling calm," "When your mind is not racy," or "When your body feels ready to be a part of things again," can help. Let your child know you will check on him/her in 5 min, 10 min, 15 min. If, after 15 minutes, the child is still not ready, you can say, "Well, I need to take a break too, so I'll stay with you until you are ready." What this is doing is slowly introducing another person back into his/her world so the child can start to readjust to having people around.

This idea of taking a break is essential for a child's body and can teach him/her to identify when his/her body is feeling ready to reenter a social situation.

Ingredient 3: Talk about the "what ifs"

We have all been there. We have all gotten that gift we really didn't want or that obvious "regift" from our distant, or not so distant, relative. What do we do in times like that? We think to ourselves, "Oh man, what am I going to do with this?" and then we smile and say thank you. For children who are rigid thinkers, who get stuck in their plan, who maybe are blurters, this concept of holding things in their thought bubble can be difficult. This topic is critical for parents and professionals to address with kids and adolescents this time of year. Giving them a plan or a script of what to say if they don't get that perfect present from their aunt may be a good thing. Sitting close to them as they open the presents may also be a smart idea in case they need a little "hand on the knee" prompt. I often talk with our families about reinforcing positive social behaviors. For example, if Brendan can hold that "Oh man," thought in a thought bubble and move on from the gift he really didn't want, he can earn "X." We all need and use reinforcers in various ways. I believe strongly in reinforcing individuals for using their social competencies, ESPECIALLY when in a social situation like family holidays. :)

Ingredient 4: Stress management—for you, not them

I talk with parents all the time about putting themselves in "time out" for just a little bit. This tip is vital for a successful holiday season. Make a plan to visit with your girlfriends, go to the movies with your spouse, do a cookie exchange...do something for YOU. If you are not in a good place, you will not be able to support your child during this crazy time of year. Your own mental health and stress management are so important to acknowledge and plan for during the holiday season. Parents are their children's best model. By making time for your mental health, even during stressful times, you are modeling how to self-regulate and modulate your emotions for your child. Let your child know why you must get out of the house for a little bit. Let him/her know what the "why" behind you baking cookies for others is (this would also be a terrific perspective-taking exercise). By modeling how you self-regulate your emotions when under stress, you are teaching your children that stress is okay, as long as you know how to cope and move through it.

Ingredient 5: Presents—this is always the sugar of this time of year

Getting presents can be stressful for a child or adolescent with ASD. Often, my clients will share with me, "Mr. Chris, if my mom and dad don't get me what I want, I am just going to lose it." I come back to them and say, "Lose what? What would you lose if you don't get what (or don't get everything) you wanted"? To my surprise, more often than not, that question makes them pause and think. As a parent, grandparent, or family-friend, when thinking about what to get that special someone, remember two things:

1. It doesn't always have to be the biggest present. As adults, we sometimes want to give the largest or best gift. However, even though we think something is the best, it does not always mean the person you are buying for will think it's the best. Think a small to medium-sized gift. The one "big present" may be something they know is coming.

2. Think enthusiasm, not practical (there are other times of year for the practical). I worked with a family for years around this topic, and they always wanted to buy their son new undershirts. As we talked and processed this present, it turned out they were buying the undershirt more for them instead of him. As people get older and can better appreciate those "practi-



cal" gifts, that's when to go for them. As a child and even an adolescent, the idea and meaning behind undershirts are at a one on a 1-10 excitement scale (this ranking holds true even into adulthood, to be honest). This time of year should be about one's enthusiasms and loves. And there is nothing wrong with buying dinosaurs if your son or daughter loves dinosaurs! Embrace the gifts you know will bring joy and excitement to the day.

The holidays are a magical time of year, but also one of the most stressful. If we can prepare both ourselves and those we love, we can have a more successful and enjoyable holiday season.

Chris Abildgaard, LPC, NCC, NCSP is the owner and director of the Social Learning Center, LLC. located in Cheshire, CT and an Adjunct Professor at the University of St. Joseph located in West Hartford, CT. He has been in private practice for over 13 years. Chris is a Nationally Certified School Psychologist, a board-certified national counselor, and a licensed professional counselor with a specialization in autism spectrum disorders. Chris earned a Graduate Certificate from the University of Massachusetts Lowell in Behavioral Interventions in Autism and is currently pursuing his doctorate of Education (EdD) in School Psychology from Loyola University.

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8 Toys That Will Help Your Child With Autism Build Skills

By Megan BREAULT, MS BCBA, LABA

A child's job is to play. The act of playing helps children develop physical coordination, emotional maturity, social skills, and the self-confidence to try new experiences and explore new environments.



or children with autism, it is essential to provide toys and activities that are designed to foster these skills. By learning critical play skills, children with developmental disabilities can increase the complexity of their language, imagination, and creativity. Learning appropriate play skills also provides opportunities for observational learning, increased social interactions, and aid in decreasing self-stimulatory behavior.

"Children and adolescents with developmental or mental health issues often have a variety of complex sensory and motor challenges," says Tina Champagne, occupational therapist and Chief Executive Officer at The Cutchins Program for Children and Families, a member-school of the Massachusetts Association of 766 Approved Private Schools (maaps). "These challenges can impact the ability to demonstrate safe behaviors and functionally perform daily activities and routines, such as school participation, in addition to being barriers to social and emotional learning."

One way to counteract these challenges is by selecting toys and activities that involve similar skills to Matching games can be found in many forms, but all function similarly in helping a child with disabilities strengthen fine motor and visual perception skills. Games like 'Letter Match,' 'Match Me,' or 'Letters on the Loose' are all great for classroom or at-home use and can be played individually or with a group.

those children are working on at school. If you are looking to have your child work on academic skills, below is a brief list of toys beneficial for children with autism.

Jumbo Magnetic Letters

Jumbo magnetic letters are one of the simplest toys for teaching letters and simple words. They can familiarize children with the alphabet in an interactive way and demystify potential frustrations that come with learning a language. Learning activities include sorting the letters in alphabetical order, spelling names, identifying and naming each letter, and pronouncing the sounds each letter makes. For less word-centric activities, try sorting by color, counting the letters, or playing a game of "Hide and Seek" with the letters magnetized around the house. The bright colors and shiny or foam texture of the letters make them easy to see, hold, and understand.

Matching Games

Matching games can be found in many forms, but all function similarly in helping a child with disabilities strengthen fine motor and visual perception skills. Games like "Letter Match," "Match Me," or "Letters on the Loose" are all great for classroom or at-home use and can be played individually or with a group. The games require coordination to select different cards, letters, or numbers, which strengthens the dexterity of children who struggle with fine motor skills or muscle development. In forming a match, children exercise their retention skills for future learning.

Number Pegboards

Pegboards, or number pegboards, are typically wooden counting games that use small, colored pegs and indentations to help understand number concepts and counting. By placing the proper amount of pegs into the corresponding holes, children grasp the association of numbers to quantities, numerical orders, and simple addition or subtraction. Pegboards are ideal for understanding the concepts of tallying and calculating—all of which are disguised by the joy of play.

Piggy Bank

A different type of counting is best done through a piggy bank, which teaches a young child the beginnings of financial literacy and money management. Children can learn to identify the different types of coins, how much they are worth, and how to tell them apart. Certain piggy banks provide better features for these lessons, such as providing clear storage or showing the sum of the coins put into it. Other toy piggy banks provide colored or numbered plastic coins for better identification of denominations.

Jenga

The classic game of Jenga is a hands-on game that requires concentration, body awareness, and fine

Pegboards, or number pegboards, are typically wooden counting games that use small, colored pegs and indentations to help understand number concepts and counting.

Typically, a tooth-brushing buddy is a stuffed animal with a plastic set of teeth that comes with an enlarged toothbrush to help simulate the act of teeth brushing. Tooth-brushing buddies help children follow directions, learn proper brushing techniques, and appreciate oral health and self-care.

motor skills. The game's structure helps with social learning and turn-taking, and the game's design and conclusion also help with tolerating loud noises and disruption. Alternative versions of the game have questions on each block like "What's your favorite color" or "What's something that smells good?" to prepare children with conversation skills.

Tooth-Brushing Buddy

There are many tooth-brushing 'buddies' on the market, but all of them serve the same purpose: to promote hygiene in a fun and easy to understand way. Typically, a tooth-brushing buddy is a stuffed animal with a plastic set of teeth that comes with an enlarged toothbrush to help simulate the act of teeth brushing. Tooth-brushing buddies help children follow directions, learn proper brushing techniques, and appreciate oral health and self-care.

Lacing Kits

Lacing Kits, also known as String Alongs, come in a variety of shapes and configurations, all designed to strengthen self-care skills like shoe lacing, knot tying, and buttoning a shirt. By practicing lacing a string through the holes in a variety of arrangements, a child is developing his/her hand-eye coordination, fine motor skills, and pattern recognition skills.

Sensory Tables

A sensory table is a small table filled or covered with different materials such as water, sand, rice, beans, or other substances. They serve as a contained and clean environment for children to explore different touches, smells, and consistencies, and familiarize themselves with different textures. They make an excellent setting for finger painting or other arts-andcrafts lessons, and learning activities can involve mixing two substances together, separating different materials, or trying to guess the items on the table based on only touch or smell.



Megan Breault, MS BCBA, LABA, serves as RCS Learning Center's Clinical Director. Megan joined RCS in 2010 as a Behavior Therapist/Floater and was promoted to the role of a Clinician in 2013. Megan became the Clinical Director of the Learning Center in 2015. She received her Bachelor's of Science in Elementary Education and Sociology from Stonehill College and obtained her Master's of Science in Behavior Analysis from Simmons College. *Currently, she is pursuing her Doctorate in Behavior* Analysis from Simmons University. Megan is also an adjunct faculty member for Simmons University's online program, teaching behavior analysis graduate courses, and has served as a mentor to graduate students from Simmons since 2013. Megan's areas of interest include errorless instruction and staff and parent training.

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Top Ways to Manage Stress When A Loved One Has Autism

By Alfred CHAVIRA

Raising an individual on the autism spectrum comes with its challenges and blessings. Parents have to process the diagnosis and determine what approach to take regarding their child's health. They have to learn how to navigate the medical care process, schedule therapy providers and plan for special education with their school districts. Their plate is full! With all the planning can come pressure, emotions, and worries. What can parents do to help manage and cope with their stress levels? How can couples work through the difficulties of raising a child with autism?



esearch shows families raising an individual with special needs are at a higher risk of stress compared to other families. Stress is seen as the beginning of issues amongst couples, families, siblings, and caregivers. Unresolved stress levels may turn into anger, frustration, and resentment, which in turn can affect how family members feel about and interact with each other. After reviewing over 20 research articles and determining commonalities, I have been able to compile three major factors that

tend to cause stress levels to rise amongst families raising an individual with special needs: perception, expectation, and fear. Take some time and participate in a few exercises that can help you understand, acknowledge, and process stress.

Step 1: What is your current and present perception of life?

Begin by looking at your life as a big picture. Are you happy in general? Do you feel satisfied? Slowly begin

Changing or adapting your expectations is not failure; it is adapting to life and what life gives you. We use communication to overcome expectations.

"

to think more specifically. For example, are you happy with daily things like work, home, or your health? Do you tend to be more pessimistic and negative or optimistic and positive? Our first step is to take a good broad look at your perception of life. Why do you have a negative perception and how does this affect your daily moods? When stress levels rise, you may tend to view any small speedbump in life as a major obstacle.

For example, you may wake up late on a Monday morning and rush to work. While rushing to get ready, you stub your toe on the corner of your dresser. As you speed to work you get pulled over by a police officer. When you finally get to the office you forget you had a meeting that already started. All these events make you think you are doomed for a bad day. But why? Here is where Step 1 begins. This is where we need to be able to recognize we are basing the mood of our entire day on a few morning emotions rather than using those same negative emotions to remind us to be grateful and mindful. We woke up late, BUT we are grateful to have employment. We got a speeding ticket but are grateful there were no accidents due to the speeding. The point is to be able to recognize when your perception is negative, use the negative emotions to produce grateful responses, and continue your positive thinking by being mindful of your day, who you interact with, and how you can be a positive influence on others. This tactic can be used with any negative perception. Try it!

Step 2: What is your current and present expectation of life?

Begin by looking at your life as a big picture. Have you accomplished your goals and dreams? Slowly begin to think more specifically. For example, does your spouse or partner live up to your expectations? Do your children? Does any of your stress come from failed expectations? Our first step is to take a good look at our expectations in life. When our expectations do not pan out, we tend to see it as a personal failure, or if someone fails to reach our expectations we feel disappointed. Both of these instances will eventually turn into resentment towards ourselves for failing or towards other people for failing us. Here is where Step 2 begins. This is where we need to recognize our expectations in life were set by ourselves, not someone else. We also need to recognize that expectations in life can change and adapt based on our current situation. Changing or adapting your expectations is not failure; it is adapting to life and what life gives you. We use communication to overcome expectations.

For example, you have been at work all day and can't wait to come home to a cooked dinner. You get home, and there is no dinner, the house is a mess, and the kids are running around. You are disappointed because there is no dinner and all you wanted was peace and quiet. This is a perfect time to think about communication with your spouse or partner. Instead of thinking about yourself and the disappointment you feel for him/her not having dinner ready for you, think about him/her and the potential day he/she had and how tired he/she may be. Communicate with each other and see what can be done so things can be accomplished. Remember, expectations are our own, and we can't put our expectations on someone else. We need to communicate to better understand rather than get angry. A conversation amongst couples can help shed light on the situation. Are there things that can be done prior to or done together to assure dinner gets done? Does one person need help more than the other? By communicating your thoughts, feelings, and emotions, you are removing your own expectations and starting to learn to be open to others' needs and to communicate with them.

Step 3: What are your present fears in life?

Begin by looking at your life as a big picture. What fears are the strongest? Slowly begin to think more specifically.

For example, what is your biggest fear regarding your kids? Does any of your stress come from fear?

PARENTAL ADVICE

Our first step is to take a good look at your fears and how they tend to originate from the unknown. For instance, how will your child do in school? How will your child adapt to new environments? Will your child be safe as he/she gets older and moves to new schools? What happens once your child turns 18? Will your child be able to work and live on his/her own?

Here is where Step 3 begins. Fear tends to start with the unknown. For you to combat the unknown, you must work on getting informed. As you get informed, you build confidence and reduce your fears. When you reduce your fears, you tend to focus more on the important things in life. If you feel worried about the unknown of school and your child, then you can inform yourself about the policies the school has on parents visiting the school and classroom. If at any point you feel uneasy, you know that as parents, you can pop in and pay a visit to the school. If you are afraid of the future and your child being able to live on his/her own, then you can prepare by seeking resources regarding employment placement for individuals with special needs. You can start looking into housing for adults with special needs. You can work with organizations and social workers within your

community to inform yourself of the resources and programs available to you and your child. Prepare for things you have control over so the unknown is less scary. Prepare for the benefit of your child, so your stress levels stay low. Become an advocate for your family by informing yourself of what you can plan for, so you feel better prepared.

The American Psychological Association defines stress as the feeling of being overwhelmed, worried, or rundown. Stress can affect people of all ages, genders, and circumstances and can lead to both physical and psychological health issues. Our biggest weapons against stress are our own minds, our own perspectives, and our own psychological wellness.



Alfred Chavira is the Wellness Services Program Director for Any Baby Can of San Antonio, Inc. For the last nine years, Alfred has worked on adapted fitness, nutrition education, family wellness, and advocacy and

inclusion for individuals on the autism spectrum.

Websites: <u>achavira@abcsa.org</u>, <u>www.anybabycansa.org</u>

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How Can I Explain an Autism Diagnosis to My Child?

By Emily DANIELS, MSW, RP, Med



fter getting a diagnosis, parents often ask me how they should tell their child that he/ she has autism spectrum disorder (ASD). Many people struggle with how outsiders will view their child, worry the information will be confusing or upsetting, fear their child might use ASD as a crutch, or simply wonder just how useful (or potentially limiting) knowing the diagnosis will be. Most parents express they want their child to know, but don't know when to tell him/her or what words to use.

Parents know their children better than anyone and recognize the most meaningful ways for them to best process information about themselves. There is no right way or single answer. Yet, over time, I have seen some parents frame their child's autism in beautiful ways, allowing their kids to take ownership and pride in their differences while recognizing their unique challenges.

Here are five points to consider when trying to help your child understand and develop acceptance for who he/she is: a valuable member of the autism spectrum.

1. Developmental Readiness

Age and cognitive development matter when deciding when and how to share your child's diagnosis. In my son's early childhood years (ages two to four), we didn't feel this knowledge would be useful for him. I know other parents who were open and direct with their child as soon as they got the diagnosis, but this was not something we felt would help our son. ASD In adolescence, self-awareness becomes even more critical. Having the right vocabulary is very affirming at a time when life feels so fragile. This can be tricky, as teens don't want to stand out or appear different.

"

was something we kept between teachers, service providers, close friends, and family.

As soon as he entered primary school, we monitored our son's readiness for self-understanding. When he entered kindergarten, we began to notice the developmental gaps between him and his classmates. This was when we started talking to him about his unique brain. We pointed out his strengths and abilities, and empathetically supported the things that were more challenging for him. We emphasized that all kids are better at some things than others. While some may need extra help with math or reading (which he didn't), others (like him) benefited from support with speech and understanding emotions.

In 4th grade, we noticed that not only was he ready to understand his diagnosis, but the vocabulary could serve him as he related to others. It is hard having an 'invisible' disability, and we wanted to provide him with tools to help him navigate his world (and help others know that just because he was the spelling bee champ, doesn't mean he could easily tie his shoes). He became the voice of his autism and helped educate classmates through presentations and self-advocacy.

In adolescence, self-awareness becomes even more critical. Having the right vocabulary is very affirming at a time when life feels so fragile. This can be tricky, as teens don't want to stand out or appear different. Yet, when framed well, significant relief can come from realizing their struggles are not their fault. Moreover, this can be an affirming way to make sense of their experience of the world.

Many young adults come to me after receiving a later diagnosis. Not one has ever said they are glad their parents withheld information or didn't get an evaluation earlier. Similarly, they were all relieved to have an explanation for their differences and struggles and could now begin the process of healing years of self-beratement.

2. Strengths-Based Focus

The folks I meet with who have the most positive, optimistic outlook for their child with ASD have always viewed autism as a remarkable strength that comes with some challenges. They value their child's amazing brain, which allows the child to focus on his/her enthusiasm, observe the world through a unique perspective, dismiss the confines of social norms, and develop brilliant thoughts and ideas. These parents also teach self-compassion about challenges, helping their kids understand that some things that seem easy for their peers might be hard for them (though the reverse is also often true). They also recognize that ASD makes some things MUCH harder, like processing sensory information, reading social cues, flexibility of thought, maintaining reciprocal relationships, managing anxiety, and anything related to executive functioning. And as these challenges are significant and difficult, parents help their children recognize they can ask for support with things that don't flow as well. They can receive therapy, get accommodations at school or work, advocate for themselves with others, and help those around them learn how to be supportive. They can find others on the spectrum (and their families) who get it, who understand the meltdowns and idiosyncrasies, and where they can safely be themselves.

3. Time and Place

It's helpful to think about a comfortable scenario for telling your child. Where does he/she feel most at ease? What time of day is your child most receptive to receiving information and having conversations? Are there upcoming events where sudden knowledge may lead to stress or anxiety? Parents have described different scenarios about how they've successfully shared the diagnosis. One family talked to their daughter right before bed and after storytime. Another shared the information on a morning walk around the neighborhood. A third did it in their therapist's office, knowing their son would grasp it better with a professional to help answer questions. While the initial discussion may seem especially important, it is also good to remember autism self-awareness is a life-long process that changes over time and that the conversation is open-ended.

4. Language

So, what language do you use? How do you help your child fully understand the complex diagnosis that is autism? What is going to make sense?

Focus on strengths: "You know how you're really good at...?"

Describe behaviors: "It can be hard for you when schedules change..."

Provide vocabulary: "Lots of people on the *autism spectrum* have repetitive behaviors like flapping their arms. It's called *stimming*..."

Address who might benefit from knowing: "Who do you think ought to know?"

Let him/her ask questions: "Is there anything you want to ask me about autism?"

5. Use Examples

Role Models

I have also seen families help their children see their strengths through the eyes of others who have accomplished much before them. Would your child be *wowed* by learning that the creator of *Pokemon*, Satoshi Tajiri, is on the spectrum? Might your animal lover be inspired by Temple Grandin's contribution to large animal welfare? Or how about knowing that Dan Harmon, co-creator of humorous, cult TV shows like *Rick and Morty* and *Community* says ASD has helped his writing? Having successful examples of people on the spectrum can be empowering and open minds to the infinite possibilities that lie ahead.

Some families have also introduced their children to other people on the autism spectrum in their community. Social groups, slightly older mentors on the spectrum, and community events can be helpful in 'normalizing' the diagnosis, learning from the experiences of others with ASD, and helping kids find people who they can identify with well.

Books

Stories help kids make sense of the world. Books can be especially helpful for understanding the meaning of autism and allowing kids the opportunity to learn from the experiences of others. There are numerous stories for children of all ages that present different perspectives of autism. It's helpful for young people to know these examples share one view of autism and that their experience may be different.

Psychoeducation

Knowledge is power. Use local agencies and online ASD support sites to find information that will connect with your kid. Many of my literal thinkers appreciate a direct explanation for autism, and the resources are out there.

Finally, I would say, trust your gut. Don't rush it. Don't slow down too much. Expect to keep this conversation open and repeat often. Just help your child understand, accept, and celebrate who he/she is in a way that feels right for him/her.



Emily Daniels, MSW, RP, Med, is a psychotherapist and social worker in private practice in Fort Collins, CO, who supports families with children with disabilities. Emily runs groups for young people on the spectrum

and provides individual, sibling, parent, and partner counseling using a strengths-based approach. In addition, Emily is the mother of an 11-year-old, super-enthusiastic boy on the autism spectrum.

Websites: <u>www.danielscounseling.com</u> and <u>www.thesociallearningproject.com</u>



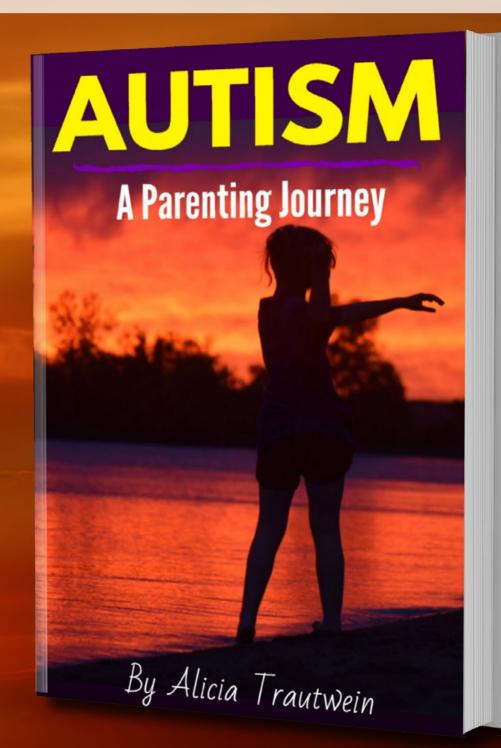
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HELP: My Child With Sensory Issues Won't Sleep In His Own Bed

By Kelly BEINS, BA BHScOTR/L

My six-year-old son won't sleep in his own bed, so we have been letting him sleep with us. How can we work on moving him back to his own room? He has sensory issues and always wants to be near me.

—Jenny

Dear Jenny,

his problem of children with sensory issues not being able to sleep on their own is a common one among children who have sensory differences. Sleeping is one of the physical tasks of self-regulation, and when any one or combination of a child's sensory systems is not working efficiently or effectively, sleep is likely to be disrupted.

One of the most common ways sensory differences impact sleep is from what we call tactile/touch processing differences. Some children need more touch input so they can feel where they are in space (their own body awareness is poor), and other children have touch sensitivities (their sense of touch is over-responding). In both cases, having a parent close to them offers the warm, firm pressure that helps to calm touch sensitivities OR it gives them the added feedback about their own position so they can rest and relax into sleep. The other factor that can contribute to these challenges from a sensory standpoint is that many children with sensory differences have a dysregulated nervous system. Parents are typically the "safest" relationship a child



has, and this sense of safety supports a more regulated nervous system, which helps the child rest and fall asleep. Touch plays a significant role in self-regulation from birth onward, and touch from a parent, even passively received while sleeping, can support a child remaining in an even state of arousal that allows for sleep.

Some sensory strategies to support a child sleeping in his/her own bed include:

- Touch inputs such as warm towels (warmed from a dryer before sleep time), a body pillow, positioning stuffed animals around him/her, or use of compression sheets or certain fabrics he/she likes around him/her (fleece, flannel, fuzzy soft pillows, etc.).
- Visual inputs such as ambient lighting (white Christmas lights, a soothing projector on the wall, nightlight(s), or glow in the dark star stickers).
- Auditory inputs such as a white noise machine, soft music, or use of the iLs Dreampad pillow that plays calming music while a child falls asleep (www.integratedlistening.com).
- Cozy spaces are sometimes helpful for children with sensory differences because these help them feel more secure. Cozy spaces can limit visual input, help children feel more secure in their bodies, and create a warmer space while they sleep. Some parents I have worked with purchase a bed-tent, a canopy, or create a tent on bunkbeds by hanging a blanket down the side from the top bunk. I had one child sleep with a giant cardboard box at the head of the bed to place the pillow in to feel more secure.
- Avoid the use of screens within at least an hour before bedtime. Many children with sensory differences are hyper-responsive to visual input and thus may be more hypersensitive to the impact of screens. A child may look calm and relaxed while watching a screen or while scrolling through YouTube, but the brain is far from quiet. Studies show some children are more impacted by active screen-use than others and that scrolling has a stronger impact than simply watching a TV show. Being selective about the type of screen-time and the

timing of it may play a large role in supporting better sleep.

Working with an occupational therapist (OT) to address any sensory challenges that may be complicating your child's ability to self-calm is highly recommended. An OT may recommend specific strategies in addition to the above that could be helpful, but he/she may also look more comprehensively at how to calm your child's nervous systems overall, not just at sleep time. OTs will also make <u>suggestions</u> for environmental, activity, and routine modifications to support better self-calming and independence around bedtime.

Finally, sometimes tackling sleep difficulties may need a combined approach of sensory support and counseling because there can be social-emotional difficulties contributing to sleep troubles, or parents may need help in managing the push-back that comes with bedtime for some children. There are <u>private</u> <u>sleep consultants</u> who may also be beneficial.

If sleep and falling asleep become an ongoing challenge, it is worth discussing with your child's pediatrician to make sure all physical causes of sleep difficulty are ruled out, and then some of the above solutions may be helpful.



Kelly Beins is a seasoned therapist with over 25 years of experience in occupational therapy. Kelly received her BA in Psychology and her Bachelor of Health Sciences in OT from McMaster University in Ontario, Canada. She received

her certification in Sensory Integration in 2005, and has an extensive clinical background combining OT and sensory integration with behavioral health interventions. Kelly is a published children's author of a book series about a young sheep with sensory processing disorder (www.ovisthesheep.com) and she approaches her work with an intuitive, empathic, and playful style while implementing the most evidence-based interventions available. Kelly co-coordinates the <u>Screen-Free Frederick Initiative</u> and also owns and operates her own group private practice in Frederick, MD, where she lives with her husband and two daughters.

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AUTISM SAFETY



By Hilary THOMPSON



arents of children with autism spectrum disorder (ASD) often use physical devices like gates, locks, and helmets as ways to <u>keep their kids protected</u>. But an increasing number of parents are also turning to smart tech to help. In fact, today's ASD parents have plenty of options for keeping their children safe. Here are five smart tech ideas to try if you have a kid on the spectrum.

1. Smart Sensors

Many children with ASD wander, bolt, or run away from safe spaces (known as "eloping"). Eloping puts

children at a higher risk of bodily injury. And nearly <u>half of children with ASD</u> engage in eloping, so it's a big concern for parents.

But today, parents are using <u>smart home sensors</u> for doors and windows to alert them to any small escape artists. When a sensor triggers, it sends an alert to your connected mobile device. An app can notify caregivers anywhere—at work, at the store, or while mowing the lawn.

You can also connect sensors to other smart devices to customize your home's safety. For example, if your child has trouble with light switches, connect your Smart video cameras are an effective way to track your child's whereabouts inside and outside the home. Most smart cameras are self-contained and easy to install. They connect to the internet and store data to the cloud, giving you access to a video from anywhere at any time.

smart sensor to a smart bulb. It will turn the light on when the door opens or when someone enters the room. This design can make dark hallways much safer and less scary. Virtual assistants like Amazon Alexa also work with door sensors. You can create an <u>Alexa</u> <u>Routine</u> with your front door sensor to have Alexa announce, "The front door is open."

Smart sensors range from \$15 to \$60, depending on the features. But the total cost will depend on how many sensors you need to cover all doors and windows.

2. GPS Tracker

While smart sensors can alert you if your child starts to wander away, what happens if he/she is successful? GPS trackers are on almost every digital device today, from our smartphones to our cars. But some trackers are built with children with ASD in mind. The Angel-Sense tracker has many features that will help locate your child in almost any situation. If your child wanders into an unfamiliar outdoor location, the AngelSense will alert you through a map on your smartphone. You can also activate the tracker's alarm to locate your child within a crowd or when he/she is hiding nearby.

The tracker also works at school or daycare. If your little one misses the bus or is late leaving school, you will receive a late departure warning. The tracker is also a one-way and two-way radio, allowing you to talk to or with your child for directions or as a comforting presence. The AngelSense attaches to your child's clothing, so it works well for children who are sensitive to wearables.

Unfortunately, the price for the AngelSense runs around \$230, and it requires a monthly (\$39.99) or annual (\$400) plan. So, it's not for every family budget, but it can make a big difference for children prone to eloping.

3. Smart Cameras

Smart video cameras are an effective way to track your child's whereabouts inside and outside the home. Most smart cameras are self-contained and easy to install. They connect to the internet and store data to the cloud, giving you access to a video from anywhere at any time. And most models let you live stream from your smartphone, so you can remotely monitor your child from work or the next room.

Some cameras also offer night vision, which is helpful if your child suffers from seizures, sleepwalking, or nightmares. And children with autism are <u>three</u> <u>times more likely</u> to experience life-threatening injuries like drowning compared to neurotypical children, so smart cameras are a must-have for families with indoor or outdoor pools.

Smart cameras also help with needs other than safety. For example, you can record your child's behavior for teachers, therapists, and medical professionals, and they can use the footage to inform their diagnosis. Video footage can also be an excellent tool for monitoring in-home therapy sessions or tracking behavior problems. Standalone security cameras cost around \$100 to \$250 each.

4. Leak Detectors

Often, children with ASD leave water faucets running. But the implications are more than a flooded home and sky-high water bill. Children can slip, scald themselves, or drown in bathtubs. Smart leak detectors alert you when water pools around them. Water detectors are internet-ready, so you get real-time alerts pushed to your mobile device. Use them around bathtubs, showers, kitchen floors, and basements. Detectors will run you anywhere from \$30 to \$70. They're an inexpensive investment that could save you everything.

5. Smart Locks and Doorbells

The front door is a common challenge for parents of ASD children. If you have many therapists or caregivers coming into your home, a smart lock can simplify your life. Instead of making extra keys, give each person a PIN code that will unlock your front door. Or if you're away from home, you can unlock or lock your door with your smartphone, which is great for forgotten keys or emergencies.

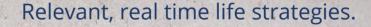
Smart doorbells are another handy device for safety and convenience. Smart doorbells have video cameras that detect when someone's at your front door. Certain doorbell models can even learn and recognize faces and announce the person's arrival. Some children with ASD will let strangers into your home, thinking they're being helpful, and deadbolts may not prevent this if they know how to unlock them. Smart doorbells can announce the name of the person, so your child will know if it's okay to open the door.

Smart locks and doorbells are pricey. Expect to pay around \$200 to \$350 for a lock and \$150 to \$230 for each doorbell.

Although these five smart devices alone can help protect children with ASD, their real power comes when they're combined. Efficient smart homes have central hubs that connect all devices. Use them to program your smart doorbell to turn on your lights when it identifies your child at the front door. Or if your child has a favorite song that calms him/her, tell your virtual assistant to play it when he/she attempts to open a door or window. It could distract him/her long enough to keep him/her from wandering. Connectivity lets you get creative and customize your home's security to your individual needs—a feature every parent of a child with ASD can use.

Hilary Thompson is a small business owner and freelance writer who writes on a variety of subjects from health to business, tech, and parenting. She is the mother of two small children and an intrepid little French Bulldog—and she runs on coffee and fumes.

LIFE AWAITS.....



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One Mom and Seven Children on the Spectrum

By Michelle L. MYERS

I was born on a cold winter's day in November. Other than some sleeping issues and my being quieter than my brother, I was a healthy baby. According to the medical community in the early 1970s, my developmental milestones were all met. As I grew, my mother says I had a lot of anxiety, preferring to play alone or with my sibling only. Though I could talk, it was very literal and sometimes sporadic. People often remarked I was an unusual child, and sometimes I was seen as "strange" for my age. But they were always astounded that I was intelligent beyond my years.



eading advanced books and classical music fascinated me. My parents were surprised when, at the age of four, I began to play the piano without having had a lesson. That same year, I began to verbalize that my body hurt, especially my tummy. They carefully watched my diet, noticing I had the propensity to stick to the same foods. Concerned, my mother continued to take me to various physicians. I was diagnosed with spastic organs, later called irritable bowel syndrome (IBS). As far as my social skills go, they told her I was highly intelligent, just awkward.

School life proved to be significantly challenging. Throughout elementary, junior high, and high school, though I got excellent grades, I found it difficult to relate to my peers. My entrance to college life was easy academics-wise; however, living away from the routines of home was overwhelming. I began to live a secret life, hiding my anxiety and frustration. I struggled with context in conversations, and just never felt connected to people like everyone else seemed to be.

In order to fund college, someone suggested I enter pageants. By this time, I had developed intricate coping skills to hide my daily struggles. In 1994, I became Miss Black Austin Metroplex, with no one having any idea of my challenges. Overwhelmed by the social requirements of attending a university, I delved into the world of music. Music was the one thing that was never a struggle, and life moved forward.

I was married in my early twenties, and by the age of 36, I had seven children. My mother offered to assist me in raising them. The routine she provided was familiar and welcomed. My first child was quiet, with much of her behavior mimicking my own. The second child was born premature, and she, too, was quiet. Just after my third child was born, my eldest daughter went to school. It was then I realized how unlike the other children she was, but everyone chalked it up to her being extremely shy or like me.

Never had I heard the word "autism" until my youngest son turned 18 months old. Unlike my two older children, he developed significant communication issues after a round of immunizations. The very night he had them, his face swelled, and he ran a fever of 103. When I called the nurse line, I was told to give him Tylenol.

The next morning, I awoke to behavior I had never seen. He was rocking, gazing off to the side, and seemingly incapable of staying still. Though he had no fever, his face was swollen. After evaluation, I was told it was a mild reaction to his shots. Over the course of a year, my son went from bad to worse, becoming nothing like the little boy who smiled and giggled.

As the years passed, I had four more children. By that time, all of my children were having noticeable sensory issues. One day I was crying outside of the school building while my son moaned and rocked on the step next to me. I had no idea what to do and couldn't understand why some of my children struggled with communication far worse than I did. A very benevolent woman walked up and spoke to me. Her daughter was in the same special education class as my son. She told me about a group of therapists who could come into our home and help us figure things out.

A neuropsychologist evaluated them all and told me they were all on the ASD spectrum. I had no idea what that was and was then surprised when he asked if it was okay to test me. Though our IQs were significantly elevated in some of us, everyone had serious social issues. Some of the diagnoses were: severe autism, high functioning autism, pervasive developmental disorder, Asperger's syndrome, adult attention-deficit/hyperactivity disorder (ADHD), attention deficit disorder (ADD), auditory processing delay, and social anxiety.

Though the task ahead seemed daunting, occupational therapists, speech therapists, neuropsy-

chologists, and others helped our family. Though challenged myself, as an author and composer, I immersed my children in literature and music. They were constantly read to, taken to studio sessions, and given instruments at a young age. For some who lacked the ability to verbally express themselves, music became their voice and books their passion.

One year, after a vicious virus went through the household, one child and I just never seemed to fully recover. I ended up having a transient ischemic attack (mini-stroke), which permanently altered my speech. I am one of less than a hundred people now diagnosed with foreign accent syndrome. Upon further evaluation, doctors discovered we all have a rare connective tissue disorder called Ehlers-Danlos syndrome.

It has now been 15 years since I first heard the word autism. My children are now young adults and teens who have progressed significantly. Though I am still challenged by some issues in regard to not being neurotypical, after a profound encounter I awoke to using more of the executive function of my brain.

Often, when families are diagnosed with autism, they are only given a poor prognosis. We are a very loving family, full of empathy for humanity, and focused on achieving our goals. The children aspire to publish literature, model, work in media, sing, dance, attend college, and more. We hope our story encourages others to be confident about the future possibilities that exist. We love the way our minds work. Autism is a word that does not define us—we define it.



Michelle L. Myers is a single mom of seven, residing in Arizona with her mom, Grace. She is a published author, composer, and inspirational speaker. She wrote about her family's lives in her latest book, <u>The Cross of Chronic Pain and The</u> <u>Nail of Invisible Illness</u>.

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"One of the biggest takeaways...is understanding how to help autistic kids to comprehend and absorb information." —Susan George, parent

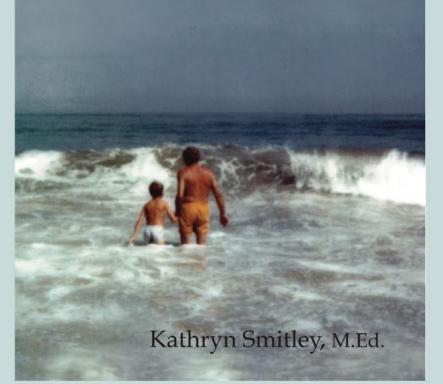


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Making the World Make Sense

A Parent's Guide to Helping Their Child with Autism



How You Can Help Kids With ASD Reduce Bullying

By Louis CARTER, MA soc/org psychology

Bullying has become a heated issue of debate among the autism community. When assessing specific types of disabilities, bullying prevalence rates differ: 35.3 percent of students with behavioral and emotional disorders, 33.9 percent of students with autism, 24.3 percent of students with intellectual disabilities, 20.8 percent of students with health impairments, and 19 percent of students with specific learning disabilities face high levels of bullying victimization (Rose et al., 2012).

ccording to *TIME Magazine*, "Many people with autism have trouble recognizing social cues, which makes them awkward around others. They also often engage in repetitive behaviors and tend to be hypersensitive to environmental stimuli, all of which makes kids with the disorder ripe targets for bullies." However, bullies are not always other children. From *The Courier Mail*, "More than 44 percent of bullying cases against students with autism examined by the Autistic Family Collective were found to have been started by the students' teachers and other school staff." What are some ways to combat this disturbing trend in behavior?

One suggestion is for parents of children with autism to practice emotional connectedness. Emotional connectedness is the state of being appreciative of and "in-tune" with the feelings, experiences, and perspectives of others.

The practice of emotional connectedness requires changing interactions to active questions, set in



a more positive tone with a focus on progress. It is less stressful and thereby produces less cortisol for everyone—parents and children. Cortisol is the hormone in our bodies that becomes elevated when we are stressed. It can change neural pathways over time and prevents neural bundling (connecting the two sides of the brain). Changing neural pathways and reducing neural bundling can also lead to lower myelin sheath levels. Children with autism tend to have lower myelin sheath levels than those who are typically developing. Myelin sheaths are vital because they are the cover for neurons in the brain and help perform tasks and submit signals efficiently. Scientists have recently observed that the fewer myelin sheaths an individual with autism has, the more difficulties he/she will have with social interactions

BULLYING

and daily functioning. In children with autism, who often already have diminished neural connections, increased stress only harms their development. It is reasonable to assume active questions promote more neural bundling and pruning, eliminating unproductive neural connections in a neurotypical child's development process.

Developing emotional connectedness requires vigilant work in practicing self-awareness for parents. When using active questions, we ask ourselves and others: did I do my best today to:

- Help my child find a safe place when he/she was feeling or acting atypically?
- Provide teachers with an understanding of my child's trigger points?
- Fully understand how my child experienced interactions with "typical" children?
- Find ways to advocate for my child?
- Ensure my child felt safe to communicate with teachers and fellow students and to actively participate in class?

After 79 studies with 2,537 participants, author of *What Got You Here Won't Get You There* and *Triggers*, Marshall Goldsmith, created the list of six Active Daily Questions. In every study, participants were asked to use the active daily questions at the end of each day. After two weeks, 37 percent of respondents said they were better at everything, and 65 percent said they had improved on four out of the six questions. Only 12 percent didn't change.

Active daily questions should be posed at first by the parent. Then, the questions should be directed toward the child as an activity to build self-awareness. The question process will also assist with external validation of positive daily practices. Because of the focus on positivity, active daily questions form a deeper emotional connectedness between parents and children, enabling a greater amount of connection and performance in school and outside the house. With this increase of emotional connectedness, it is reasonable to suggest the bullying behaviors mentioned above are far more likely to reduce over time.

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Louis Carter, MA soc/org psychology is founder and CEO of Best Practice Institute, a research consortium, think tank, and advisory company for Chief Talent Officers and Chief Human Resources Officers of Fortune 500 and mid-sized companies globally. He is the author of 10 books on leadership and organization development, including <u>Change Champions Field</u> <u>Guide</u> and <u>Best Practices in Leadership Development and Organizational Change</u>. His new book is <u>In Great Company: How</u> to Achieve Peak Performance by Creating an Emotionally Connected Workplace.

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How to Help Family and Friends Build Relationships With Your ASD Child

By Erica CROWLEY, BCBA

Parents often worry friends and extended family don't spend time getting to know their children with autism spectrum disorder (ASD) and tend to overlook them at gatherings and parties.



any adults aren't sure how to engage with a child who isn't verbal or doesn't respond to social cues. They might be uncomfortable when a child vocalizes, jumps, or flaps his/her arms. As a result, adults often focus on neurotypical kids instead.

That's unfortunate. Kids on the spectrum have the same feelings as other children, and it hurts to be left out. They're also just as much fun.

Extended family and friends probably don't realize that getting to know a child on the spectrum isn't much different than getting to know any child. By offering some guidance, parents can help adults build rewarding relationships with their kids who have autism.

Choose the right time to connect

The excitement and activity of parties can be a lot of sensory input for children on the spectrum. So it's Neurotypical kids usually have a wide range of interests, which makes it easy for adults to connect with them. Children on the spectrum tend to have more narrow and deep interests, from letters to cars, numbers, dinosaurs, or almost anything.

always best to approach a child when he/she is calm and comfortable.

Look for a time when a child is playing alone in the sandbox, petting the dog, or building something with Legos. Try sitting down and saying hi. A gesture such as high-five is an excellent way to break the ice. Most kids know it and will respond.

Then follow up with a question. It can be as simple as, "What are you making?" or "What's the dog's name?" Or you can offer a comment along the lines of "Nice tower you're building" or "I love dogs, too."

Don't worry about your exact words or whether the child answers. What's important is you're acknowledging the child and including him/her in the party.

If a child seems anxious or agitated, wait a while or until the next time you're together.

Find shared interests with the child

Neurotypical kids usually have a wide range of interests, which makes it easy for adults to connect with them. Children on the spectrum tend to have more narrow and deep interests, from letters to cars, numbers, dinosaurs, or almost anything.

Ask the parents what interests their child and find ways to share it. If a child loves dinosaurs, ask which dinosaurs he/she likes and why. Bring a dinosaur coloring book and crayons to the next event and spend a few minutes coloring together. Find an age-appropriate dinosaur puzzle and invite the child to work on the puzzle with you or sit and encourage him/her while he/she does it.

The child's interests may change or expand as he/ she gets older. Or they may not. By asking the parents and making a little effort, you can always find fun ways to spend time with a child, regardless of whether he/she has autism.

Create a ritual to build a relationship

Doing a special thing each time you see a child is a great way to build a relationship. A secret handshake, a goofy riddle, or a simple magic trick will delight both of you. Creating a ritual helps a child recognize you're interested in him/her and look forward to seeing you at gatherings and parties.

A greeting or hello that's just between the two of you also helps a child feel included. Kids with autism are often passed over in social situations and may have a hard time identifying cues that help them play with other kids or connect with adults.

Taking the time to engage a child in something fun means a lot to the child and his/her parents. It's also an easy way to help a child practice social skills, which are usually a priority for kids on the spectrum.

Talking is not needed to communicate

Some kids with autism don't speak. But that doesn't mean they don't communicate or that you can't connect or have fun with them. Talk to a child while he/she plays or try a gesture game such as rock-paper-scissors.

Some non-verbal kids communicate by using cards with pictures on them called the Picture Exchange Communication System (PECS), a voice-output device, or sign language. Parents can tell you more about these methods and how you can encourage the child to communicate with them. If a child uses sign language, it's easy to learn to say hi and ask simple questions.

Keep in mind that kids on the spectrum who don't speak usually *do* understand. You can help a child feel special by telling him/her what you like about him/ her. Compliment the child when he/she does something well. Let a child know how much fun you're having. Kids with autism rarely hear this kind of praise, and they need and deserve it as much as any child. Parents will also appreciate hearing what you enjoy about their child. They'll likely be delighted that you're making an effort and value their son's or daughter's unique qualities.

Rocking and flapping are okay

Everyone uses repetitive movements all the time. Whether it's drumming your fingers, sighing loudly, tapping a pencil, or biting your nails, these self-stimulatory behaviors help release tension.

Children with autism are no different, although their behaviors are often more noticeable. Kids on the spectrum may rock, spin, shout unexpectedly, flap their arms, repeat a word, and so on. Adults often find stimming disruptive, but it's nothing more than the way a child copes with sensory overload or adapts to a new place.

If you're playing with a child who starts stimming, let it go. Offer the child a toy, start a game, or ask a question. If the child isn't hurting himself/herself, there's no need to try to stop or change the behavior.

Start small and recognize success

Don't get discouraged if a child with autism doesn't immediately respond to your efforts. Most kids need time to warm up to adults they don't see regularly, and children on the spectrum often take longer to adjust to new people and situations.

Starting small and being consistent will help a child get comfortable with you. Over time, if you spend a few minutes saying hi, asking about his/her interests, and doing your secret handshake, a child will learn that you're a friend and be glad to see you.

He/She may come up to greet you, smile when you approach or even start your special ritual. Maybe a child will enjoy spending 15 minutes coloring with you instead of 5 or 10 minutes.

Adults expect these behaviors from neurotypical kids, but kids with autism usually make progress more slowly. Take the time to acknowledge and celebrate those successes. Praise the child, offer a high-five or a hug, or tell the child how happy you feel when he/she spends time with you.

Accept, connect, and enjoy

Acceptance is essential to building a relationship with any child. Most adults don't think twice when neuro-

typical children have unique personalities, interests, and behaviors. Children on the spectrum are the same. Kids with autism experience the world differently, but they need and deserve the same acceptance.

Equally important, children with autism have the same emotions as other children but may not be able to express them. Most adults will go out of their way to avoid hurting a child's feelings but may not realize that overlooking a child with autism in favor of neurotypical kids is hurtful. It's also unnecessary.

Getting to know a child with autism isn't much different from getting to know any child and is just as rewarding. Spend time focusing on the child. Engage in his/her interests. Celebrate the child's unique qualities. Praise the successes. Those are the keys to building a fun relationship that's a source of joy for everyone.



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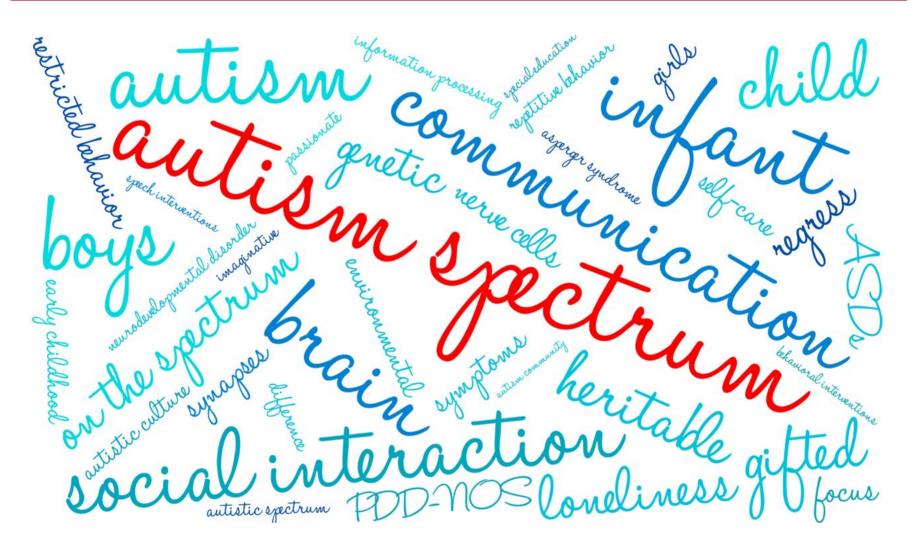
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Teaching Adulting to Children on the Spectrum

By Rita ROEM

Because more adults on the spectrum are giving voice to their experiences now than in the past, those of us with younger children on the spectrum are benefiting from their wisdom and advice. The biggest take away I have from what I read and see by these adults is that being an adult on the spectrum does not look the same as being a child on the spectrum, which means I must look to what my child can become and start parenting in a way to guide him towards that adulthood.



n the early years of his diagnosis, adulting was an unimaginable goal for us to have for him. We believed he would remain the dependent child he was. We even made plans for our basement that would accommodate our adult child living with us, and I changed my career to one that would allow him to work with me someday. We now believe he won't even want to stay with us, which is a bit frightening, honestly, but positive.

He is nine and capable now of learning to adult even if he isn't aware of it. I've settled on four skills to build in young kids that will prepare them for adulting because they are on my mind right now. There is a plethora of them. There are other skills we've already introduced, and more still that will come as he develops and shows us what he can handle.

Flexibility

Stop laughing. Or crying. From the ages of three to five, our son was rigidly routine-driven, so we became the most flexible we have ever been, pulling on stores we didn't know existed. His security depended on

EDUCATION

routine, having desired behavior depended on routine, and being able to learn depended on routine. He will probably always carry this need for routine with him, and it can serve him well, but we are seeing areas now where we can ask for and receive flexibility from him, and we must nurture that. Areas where we have slowly been able to create more flexibility:

- Clothing
- Food
- Leisure activities
- Travel

Volunteering

His older brother needed to log volunteer hours for his black belt, and we brought our autistic son along. He was happy to pick up the trash on the trail around the lake and in the woods. Eventually, he will understand why we are doing these things. He has already been on the receiving end of volunteerism and may be for the rest of his life, so giving in return is something we can train to become natural in him.

A job well done

It wasn't long after our son started to respond to Applied Behavior Analysis (ABA) that we realized if taught how to do it right the first time, he'd do it that way every time. With our neurotypical child, we often taught and still teach him things in stages or with the shortcuts we've already learned. However, our autistic child can't understand why some dishes that come out of the dishwasher can go straight into the cupboard while others must be wiped dry first, so we've taught him to wipe them all. The result is he is the best at this job of anyone in the house.

Taking the initiative

Picture schedules plant the seeds for this. Once our son realized what they meant, he often took the initiative in his day, especially when a preferred activity was up next. When we stopped the picture schedules at home, we moved to verbal "first, then, then, then" schedules and found he would take the initiative. When our neurotypical child was three, he came up with a system for making friends at the playground: introduce himself, give his age, and ask to play. Thus, he was never without a playmate. Now that our autistic son's language can be understood by all, we are teaching him to use the same system, but not just for playtime. When he arrives for a therapy session, he now greets the receptionist by name, says "Hi," gives his name, and tells the receptionist he's ready.

If your child is young, you may not be ready to think about adulting. You may still be in the state of wondering if he/she will ever just 'child' in a recognizable manner. Put this in a file for when you are ready because you will need to start thinking about adulting sooner than you expect. You're doing what's required to make that happen. That you are reading this is proof. You're doing a great job. If your child is older, you've got this. Help him/her be the adult you've become. Awesome.



Rita Roem is a lifetime writer recently turned author. She was a high school English teacher for 20 years but left teaching not long after her youngest son was diagnosed with autism. She

spends her time caring for the whole family along with helping other parents of children with autism find resources and cope. She lives with her family of four in Northern Colorado.

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Excellent Ways to Maximize Language With Your ASD Child

By Kate C. WILDE

The most powerful insight I have gained during my 30 years of inspiring our beautiful children to verbally communicate is the knowledge that all growth starts with acceptance of our children as they are. This cannot be overlooked or bypassed.

t is the wings upon which all change occurs. If you want your child or the child you are working with to learn and grow, this is the place to start. It lies in the belief that *the love you already have for your child does not have to be put aside as you begin or continue your journey to help him/ her.* Rather, it must be the place you start and must fuel every action you take.

Spiritual leader Matt Kahn began one of his workshops asking participants to say these two lines out loud:

I see you.

And I like what I see.

Doesn't that quote bring a smile to your face?

Imagine if our children on the autism spectrum saw this smile each time they reached out and looked at their teachers, caregivers, and educators. A smile that says, "I see all of who you are, and I like it, all of it. I like you when you talk me, and I like when you don't talk to me. I like you when you respond to me, and I like when you don't. I like you when you play just like the other children, and I like you when you make sounds and movements that look very different."

This accepting and welcoming attitude gives our children no reason to move away, and every reason to continue to reach out and communicate with us. Don't we all move towards people who delight in us and show us they enjoy all of who we are? Unfortunately for our children, their experience of people is often the opposite. The people in their lives spend the majority of their time looking at them with the



focus of "fixing," changing and/or stopping them. Although this is done in a sincere effort to help our children, you know how this feels when you're treated that way. It certainly doesn't feel like help.

If you implement the four strategies below with an attitude of loving acceptance and enjoyment of everything your child does and is, the doorways of communication can swing open!

1. Love what they love

Making a true connection with our children is a key part of inspiring them to want to verbally communicate with us. Most of us are more likely to connect with someone we have something in common with. "

Whatever your child likes, you can like, too. Whatever he/she is doing, you can do it with the child. Make his/her interest your interest.



For example, wouldn't you be more likely to gravitate towards a person who wears a T-shirt with the name of your favorite band scrawled across it? Our children with autism are no different. They, too, will gravitate towards people who like what they like. The only difference is our children tend to have unusual interests not mirrored in our society.

Maybe your child really likes to dangle a piece of string or watch something that spins, or talk about volcanos or washing machines. Whatever your child likes, you can like, too. Whatever he/she is doing, you can do it with the child. Make his/her interest your interest. If the child likes to talk about washing machines, become an expert on washing machines! If your child likes to line things up, make that your next hobby. If trains are popular, numbers, Dora the Explorer...whatever it is, enjoy it, too.

In my three decades of working with our children, this is the number one connection creator. Love what they love. Do what they do.

2. Listen to your child

When we think of teaching verbal communication, our instinct is to talk more. But the opposite is true. The key is to talk *less* and listen *more*.

No matter whether your child has yet to say a word or is already speaking in sentences, he/she is probably saying a lot more than you realize. If we are busy talking and filling in the silence, we don't give ourselves the chance to fully listen to what our children are already saying. When our children begin to talk, they may start by whispering and talking under their breath. This talking is very hard to hear if we are talking. When our children make sounds or say sentences that do not make immediate sense to us, we can easily turn off our listening without realizing this is what we're doing. Why would our children continue to grow their verbal communication skills if we are not listening?

Next time you are alone with your child, experiment with listening rather than talking. Cut the amount you talk in half. Once you've done that, cut it in half again. I think you will be surprised at what you hear.

This silence will give our children the chance to practice talking.

If we are taking up all the space with our talking, we are unintentionally telling our children to listen to us versus talk to us. But if we are listening (not pretending to listen—but *really* listening), we create a language space our children can fill.

3. Celebrate <u>all</u> verbalizations

It's important to celebrate our children's *current* level of communication. Celebrate all sounds, all words, and all sentences, even if you do not understand them and even if you've heard it a million times before.

What we focus on grows. Our celebrations communicate to our children that we are listening to and enjoying what they are saying. This will encourage our children to continue to talk to us. That is what Let your child know the power of his/her sounds, words, and sentences by responding super quickly to him/her. We want the child to know all his/her vocalizations are useful.

we want! The more our children vocalize, the more practice they will get, and the more likely it is their communication skills will grow.

The key to celebrating is to be joyful and verbally specific. For example, when your child makes a sound, you could say, "You just said, "mmm," that's a great sound!" When he/she says a word, you could say, "You said "ball" amazingly-when you do that, I know what to get you!" When he/she shares a comment with you, you could say, "I really like it when you talk to me, I love knowing what you are thinking!" Say it in your own way. The thing to keep in mind is to be specific about the fact it is his/her verbal communication you like. That way the child will know what it is you like and do more of it. The more we highlight what children are saying now, the more they will talk. It is impossible to over-celebrate, so become a celebrating maniac! Bring on the exclamation marks! You will be rewarded with more vocalizations, words, and sentences from your wonderful child.

4. Respond quickly

Once we have listened and celebrated, it is time to take action. An important reason we speak to another person is because that person responds and takes action based on our words. If he/she didn't, we would find another way to communicate, such as drawing or using gestures.

Again, our children are no different. When their verbal communications are not responded to, they use crying, pulling people by the arm, and hitting to get our attention. Sound familiar?

Let your child know the power of his/her sounds, words, and sentences by responding *super* quickly to him/her. We want the child to know all his/her vocalizations are useful.

This applies whether your child is saying simple sounds, full words, phrases, or paragraphs. The key is

to *respond quickly*. Not after you finish cleaning. Not after you finish tying your tie. *Right now*.

If your child says "eee," run and get him/her something to eat (or sing him/her a song or slide a stuffed animal down a slide). The particulars of what you do matter less than doing it with speed and excitement. If your child asks what time it is (for the hundredth time that hour), enthusiastically tell him/her the time! We want to help our children see the connection between *their* sounds and *us* moving.

Of course, these four strategies are not the whole story. That would take up an entire book (which is why I wrote one). But, if you follow the approach here, I think you will be very, very excited about the response you get from your child. I know you might sometimes feel overwhelmed or lost (don't we all!), but every journey begins with a single step, and now you have the first four!



Kate C. Wilde has literally spent all her life doing exactly that: thousands and thousands of hours working with countless individuals and families from all over the world, in countless countries. She trained with Dr. Rachel Pinney in London, who pioneered therapeutic approaches to children's development in the 1960s. Kate then moved to train at the Autism Treatment Center of America, where she became director of The Son-Rise Program.

The Autism Language Launcher:<u>www.amazon.</u> <u>com/Autism-Language-Launcher-Parents-Conver-</u> <u>sations/dp/1785924826</u>

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3 Simple Tips for a Restful Night For Your Child With Autism

By Melissa DOMAN

It comes as no surprise to the parents and professionals reading this article that many children with autism have sleep issues. At least 50 percent, and as many as 80 percent, of children on the spectrum struggle to sleep well¹. To have these struggles on top of developmental issues can be wearing on any child, parent, or family.



t may take your child hours to get to sleep. Your son may wake twenty times a night or start his day at 2 a.m. Maybe the only way your daughter can sleep is by being cradled and bounced on a physioball. Do any of these sound familiar? Whatever the struggle is for your child, I know you're struggling too. When your child doesn't sleep well, it affects not only his/her attention and cooperation but also just how well he/she does in therapy and how well the brain absorbs the information it is given. Your child is more prone to temper tantrums, sensory meltdowns, hyperactivity, a weakened immune system, and more.

Being a parent of a child who has developmental issues presents its own set of challenges. Your child's poor sleep is something so many parents just like you are facing. Parents who reach out to me often feel they've exhausted all possibilities. They've tried melatonin, weighted blankets, essentials oils, supplements, medications, etc. only to find their child still cannot get a good night's rest. When your child isn't sleeping, it makes you crankier. You have a harder time dealing with stressful situations and controlling your emotions. This can cause rifts between you and your partner and put a strain on the whole family.

You cannot be at your best when you are defeated, overly exhausted, and only getting a couple hours of sleep a night. Your child doesn't deserve this situation, your family does not deserve this situation, and neither do you.

It does not have to be this way. In learning about sleep training, I had a profound realization. Children with autism did not have difficulties resting well solely because of their diagnosis, which is so often assumed. They could not sleep well because they had never been given a chance to develop good sleep habits. It was the child's diagnosis professionals would use as an "excuse" for why a child slept poorly.

So, what to do? How do you start righting the ship? Here are my top recommendations and the foundation of what I teach all of my families:

1. Get your child to bed earlier

If there is one thing you do, getting your child to bed earlier will make a big difference. Here's why: our energy goes up and down throughout a 24-hour cycle. This is called the circadian rhythm. The lowest dip in energy happens at night, and this is our "window of opportunity" when it comes to getting a great night's sleep. Mother Nature is giving us a little nudge, but we often ignore her. When we miss that window, it will take longer to fall asleep, we will wake up more frequently during the night, and will wake feeling out of sorts.

For children under the age of eight, this dip in energy happens around 7 to 8 p.m. Take advantage of that window! When kids are put to bed too late, they become overtired. Overtiredness makes kids do the total opposite of sleeping at night. Research has shown the areas of the brain that dictate sleep get completely disorganized when sleep deprived. Unfortunately, this same area of the brain also controls sensory perception, behavior, balance, coordination, and language. For a child with autism, overtiredness is a double whammy.

If your child is between the ages of eight and 15, my recommended bedtime is anywhere

between 8:30 pm-9:30 p.m. For older teens, a 10 p.m. bedtime would be appropriate. Even if you cannot stick to these ideal bedtimes consistently, a simple 30-minute adjustment can make a big difference.

2. Teach your child to sleep on his/her own

This is a little easier said than done (I know!), but this shift will make a "night and day" difference in the quality of your child's sleep. All of us have our own way to go to sleep. You need your pillow and blanket, you might flip to your left side, you may need your arms curled up to your chest. You may need to listen to white noise. Whatever it is, you have your own way of getting to sleep.

For the majority of kids I've worked with, the root of a child's sleep issues lies in that initial falling asleep for the night. Why? Because he/she is still dependent on mom or dad in some way. He/She doesn't have his/her own strategies to get himself/herself to sleep. And, your child will keep looking for that help during the night when he/she wakes up. Over and over again. This will affect the quality of his/her sleep, and everyone will wake up tired the next day.

If your child needs patting, rocking, cradling, someone lying next to him/her, a drive in the car, etc. to get to sleep, it's time to give him/ her the space he/she needs to figure it out on his/her own. Once he/she knows how to do it without you, he/she can use those strategies to get himself/herself back to sleep at night. This will make it faster for him/her to settle again, and those long wake-ups at 2 a.m. will get significantly shorter.

3. Reduce bright light exposure

For many children on the spectrum, they are much more sensitive to light exposure than we might think. Your child is experiencing lights much more intensely. This can delay the dump of melatonin in the system leading up to bedtime and can trick your child's brain into thinking it's still daytime.

My recommendation would be to first cut screens at least 1 hour before bed, and even earlier if you can. Many children on the spectrum might find watching videos before bed comforting, but it will affect their overall sleep quality. The strong, blue light from screens will delay the release of melatonin in the system and will cause middle of the night disturbances too.

In the afternoon, do your best to limit your child's exposure to strong, artificial light (fluorescent lights, for example). You might consider putting "blue light blocking bulbs" in certain fixtures around the house, as well. And, lead by example—if your child can't have screens an hour before bed, make sure you follow the no screens rule too.

I was recently contacted by a mother whose child was sleeping terribly. After attending one of my seminars, she got rid of screens before bed, took away the nightlight, and reduced light exposure in the evening. In three weeks, her child was not only sleeping through the night, but he was sleeping independently. With good sleep, her child started to try new foods, stopped toe walking, and began saying words. Look how great an impact some simple changes made!

These are just some of the strategies I teach my families to help their children sleep well. For a child on the spectrum, a careful look at sleep hygiene as well as



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factoring in physical activity, nutritional recommendations, and more, can pave the path to sleeping great for years to come! Any change, big or small, takes time to adjust to. However, with consistency and a little patience, your child can make these changes. Your child with autism has all the potential in the world to defy his/her diagnosis and sleep great.

Sources:

¹Lamm, Carin. *Establishing Good Sleep Hygiene*. Retrieved from <u>https://www.autismspeaks.org/sleep</u>



Melissa Doman is a pediatric sleep consultant, specializing in sleep training for children with special needs. She has a decade of experience teaching parents of children with a variety of diagnoses

and uses this knowledge to enhance her sleep training programs. She is passionate about empowering parents with the knowledge to help children reach their full potential. Melissa has worked with children diagnosed with cerebral palsy, trisomy 21, autism, ADD/ADHD, developmental delays, and more. She loves coaching parents to get their kids sleeping well and independently.

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Understanding Perspective With ASD: The Sally Anne Test

By Ryan LARSON

uppose there are two women, one named Sally and one named Anne. Sally puts a rock in her basket and goes off somewhere else, leaving the basket. While she's gone, Anne opens the basket, takes the rock out, and puts it in her own box. In this presentation, it's very clear Sally did not see Anne move the rock. So when Sally returns, there are two questions. Where is the rock now? And where will Sally look for the rock? The first question is easily answered correctly by anyone who was watching. But the second question is one most autistic children get wrong. It's a question I would have gotten wrong. If I saw Anne put the rock in her box, I would have said that's where Sally would look for it. If your autistic child fails this test, it means he/she doesn't understand Sally's point of view. So this brings up a third question. What else does your autistic child not understand?

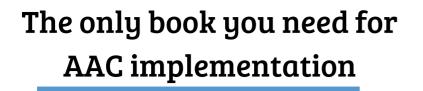
The Sally Anne Test is well known in the autistic community because it reveals how misunderstanding we can be. There is a colossal number of symptoms of autism. Some symptoms cannot be cured and are better left accepted, but some can be overcome. Which one is this? I don't have a simple answer for you. The fact I can pass the Sally Anne Test doesn't mean I understand other peoples' perspectives. For instance, one time I put my girlfriend's coffee mugs on the top shelf of the cabinets, even though she's almost a foot shorter than me. She asked me to bring them down. I laughed because I had forgotten I was dating a female Frodo Baggins; she laughed too and then told me to shut up. While putting the dishes away, I hadn't put myself in her shoes. And this is an issue not just for those of us who have autism. Sometimes, even neurotypical people cannot understand another person's point of view. For instance, politics, but let's not spend much time on that. Because we in

the autistic community don't understand other people as well as we should, we can come across as uncaring or even rude. One time in school, I was giving a speech, and I was asked to slow down because the other students had to write down all of the information I was providing. There will be times when your autistic child will accidentally be rude with something that he/she says as well.

So, what's the solution to this? I think your autistic child can understand people better by reading books and watching movies and TV shows. A TV show can work very well because there's far more time for character development that can be analyzed than in a movie. I don't have a list of which shows your family should watch. But if you just talk to your autistic child when he/she doesn't understand why one person said this and another did that, then I think that's time well spent.

Let me repeat, every person in the world fails to understand another person's perspective from time to time. But for those of us with autism, it is more of an issue that needs to be addressed. By being open and honest, you can teach your son or daughter how to relate to other people better, which is imperative to having a happy and successful life. And if your autistic child isn't there yet, I guarantee you one day he/ she will understand Sally will look for the rock in her own basket.

Ryan Larson lives in the Des Moines area. He graduated from Iowa State University in chemical engineering and works at Wells Fargo, helping customers over the phone. In his spare time, he loves to read, write, put jigsaw puzzles together, exercise, and spend time with friends and family.



Make the Connection!

A Practical Guide to Parents and Practitioners for Teaching the Nonverbal Child to Communicate - with AAC

Written by a SLP with more than 45 years working with nonverbal children with autism. Available on Amazon.



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Building Bridges Media was created by Building Bridges, a Portland-based ABA therapy clinic. The content was created by Dr. Melissa Gard, BCBA-D, LBA, and Emily Kearney, BCBA, LBA, in collaboration with Building Bridges.

"Wonderful videos to help support parents at home with autistic young children," one Facebook member says.

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5 Tips for Posting About Special Needs Parenting on Social Media

By Margaret M. QUINLAN, PhD, Dan GRANO, PhD, and Bethany JOHNSON, MPhil, MA

Il three of us are parents (each of us has two kids) and educators who are aware of the need for guidance when posting about parenting on social media. We have all found social media helpful when attempting to connect with others (e.g., family, friends, other parents) but have also been hurt by posts from other parents and caregivers. As a result, we have put together a list of concerns around social media posts parents with children on the autism spectrum may have and how to address them. The three of us have a complicated relationship with social media in terms of our parenting and discussed some of the issues parents face, especially as Bethany and Maggie worked on their chapter about better babies contests (early 20th century) and developmental milestones (e.g., crawling, talking, walking, pincer grasp, etc.) as documented on social media. Dan relates to social media challenges specifically as the parent of an autistic child. We believe this is a list you could share with people in your life who do not parent a child with autism.

1. Language is constantly changing and families approach language in various ways: Our personal language choice of "autistic" is in support of the preferences of many (but not all!) in the autism community, who emphasize that "autistic" acknowledges autism as intrinsic to an individual's identity. "Child with autism," on the other hand, separates the disability from the person in a way that often stigmatizes it. There are ongoing debates on this subject, and some parents may prefer "child with autism" or similar constructions. We are also using the word "neurotypical" throughout the rest of this list. For us, "neurotypical" does not mean "non-autistic," and it is not derogatory. It



means performing in a way that fits with dominant standards for "normal" neurological and cognitive functioning. In emphasizing the experiences of parents of autistic children, we do not intend to speak for the experiences of autistic individuals themselves. Relationships between autistic persons and their parents or caregivers are subject to ongoing debate and are ultimately too complex and diverse to be captured in a single article. What words do your friends and family use to describe the people they love? How do they frame their experience? Consider this carefully before posting during "Autism Awareness" weeks or months. Not everyone wants to "light it up blue," and that is okay.

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Parenting challenges are a frequent topic of social media posts. They have the potential to build community around the shared difficulties and worries of raising a child. They can also unintentionally alienate, isolate, and exclude your friends with autistic children.

2. Parenting Challenges: Parenting challenges are a frequent topic of social media posts. They have the potential to build community around the shared difficulties and worries of raising a child. They can also unintentionally alienate, isolate, and exclude your friends with autistic children. To be clear, this shouldn't be a competition of "who has it worse," and it isn't possible to always "get" or account for the experiences of your friends or family members with autistic children. But a good guideline for posting about your own parenting problems is to consider a taken for granted factor that comes with the difficulties of raising neurotypical kids. For example: managing after-school schedules, being pulled away to birthday parties on weekends, or taking your children out to dinner can all involve legitimate frustrations.

Compare this, however, with what it might be like to have children with motor planning or social challenges that limit their participation in sports, to never being invited to birthday parties, or dealing with stares and snickering from other children when you go out for pizza. When you post in an effort to commiserate with other parents, consider the benefits of building community with parents of neurotypical children against the costs of possibly alienating your friends with autistic children; is this a problem your friends with autistic children would "love" to have (e.g., "My child talks all the time!") or is it perhaps one they can sympathize with (e.g., a scare at the doctor's office)? Your friends with autistic children probably recognize you have legitimate struggles, but if you do the work of weighing and comparing what you face and the daily struggles they face, that work will show.

3. Developmental milestones: We live in a development-obsessed culture, where challenges like autism are often represented as realizations of parents' worst fears. This is largely because autism is treated as a medical pathology rather than as a diverse and legitimate way of being in the world. For this reason, some neurotypical parents of autistic children believe they must "fix" their children, while others try to un-learn associations with pathology to embrace autism as inherent to their personhood. Wherever parents of autistic children are in the process of addressing or accepting their child's disability, posts celebrating developmental milestones like first steps, first words, or graduations can often bring up feelings of loss over abilities or accomplishments they

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We live in a development-obsessed culture, where challenges like autism are often represented as realizations of parents' worst fears. This is largely because autism is treated as a medical pathology rather than as a diverse and legitimate way of being in the world.

It is also important to be aware of stereotypes, especially as autism is being represented more and more in popular culture. Common pop culture stereotypes include savantism, social awkwardness, lack of empathy, inability to communicate, and behavioral instability.

may never experience. For autistic children deemed "high functioning" (more on this as a problem below), the outside appearance of typical development may leave you unaware of substantial challenges around sensory sensitivities, communication difficulties, or pressures to appear "normal" to prevent bullying and stigmatization. Many parents of autistic children face the prospect of never having a conversation with their child or have to worry about serious injuries due to motor planning challenges. Remember: framing helps. Frame the announcement as something particular to your kid and acknowledge individuals are different with a range of experiences. Even a quick nod to the broader issues can help dispel some of the tension of milestone culture. For example, is your sweet kiddo walking now? That's amazing! Maybe a post with a caption like, "There are lots of different kids with different bodies and different ways of being. Today our kiddo took his/her first steps!"

4. Diagnoses, jokes, and stereotypes: Increased awareness of autism has also brought about an increase in the use of popular but sometimes problematic terms and images. For example, parents with autistic children are often asked whether their child is "high functioning" or "low functioning." This is very common language; doctors and therapists use it frequently when talking to parents of autistic children, and some parents may use it themselves. Just be aware these labels might reduce unique, complex individuals down to a list of what they can and cannot do. In addition, autistic individuals labeled "low functioning" are often underestimated, while autistic persons labeled "high functioning" are often denied necessary services and support. "High functioning" and "low functioning" belong to a longer list of common terms to be aware of when posting on social media. Glossaries of problematic and preferred terms and guides for language use are available online.

It is also important to be aware of stereotypes, especially as autism is being represented more and more in popular culture. Common pop culture stereotypes include savantism, social awkwardness, lack of empathy, inability to communicate, and behavioral instability. Unfortunately, increased awareness of autism has also made these stereotypes popular. People often describe socially uncomfortable coworkers as "on the spectrum," or joke that people exceptional in math must be autistic. Such jokes are not merely limited to uninformed people; they're remarkably common and hurtful and should be avoided. For kids, try the book When Charlie Met Emma by Amy Webb on Amazon and check out her tips at the end of the book for navigating issues of bodily and social difference in public spaces with your children. Reading up on these problems doesn't guarantee you'll always use terms "correctly." Generally speaking, we advise trying to learn what terms are problematic so you can avoid them. Or, you can try to avoid labels and armchair diagnoses altogether.

Here are some tips you can share with caregivers who do not have a child on the autism spectrum:

- Before you post, pause!
- Follow, like, and comment on accounts that illustrate and celebrate neurodiversity
- Unfollow accounts that do not celebrate neurodiversity
- Be aware some parents of children with autism may feel isolated
- For some parents without children with autism, parenting "gets easier." However, some parents

have increased needs like more meltdowns, stronger bodies, and/or lack of accessibility, so it may be easier to stay home

• While some parents go out on dates (pay babysitters) or adult-only vacations, parents of special needs children spend a lot of money on medical bills



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Bethany L. Johnson, MPhil, MA, is an instructor in history and an associate member to the graduate faculty and research affiliate faculty in the department of communication studies at the University of North Carolina at Charlotte.

- Be aware some kids are not invited to birthday parties, etc.
- Some complaints are difficult to hear, like "My kid talks all the time!"

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The Joys of Horse Riding for A Boy With Autism

By Jackie MOORE and Olive PIH

Running, running, running, with a huge smile on his face. His eyes are focused on the door he opened with the flick of a switch. Ponies safely in their stables ignore the boy, more interested in chewing the hay. It is a hazy, lazy summer's day, where the cares of the world are forgotten.

itted out in his riding hat, the boy eagerly awaits the allocation of his horse. Gabriel is with Tansy today, with Lillian leading. "Yes!" exclaimed a jubilant Gabriel, jumping on the spot and raring to go. He is in high spirits as he goes with the leader to collect his pony, but he doesn't run or walk on the grass or do anything that will frighten the horses. In fact, he subsumes the calmness of the stables. Tansy is a fifteen-year-old grey mare, very gentle and docile, who is well used to the many different children who have learned to ride at the stables. The description of each horse is posted on their stable door along with any awards they have won. Gabriel strokes her coat and very carefully mounts his pony. "Walk on!" he says in an authoritative voice, feeling in control of his mount. He is now calm and controlled, ready to practice all the exercises he has been taught over the past few weeks.

What a transformation from the first lesson, when he ran in shouting, "What a catastrophe. It stinks in here!" Gabriel is now in proud possession of a first level star card, which sits in pride of place on his mantelshelf. He can now perform a rising trot, turn left and right, and, among other things, always remembers to thank the staff—mainly volunteers who have given up their time to help him. He says riding



is "awesome." He knows the names, ages, and heights of all the horses, but Tansy is still a favorite.

For an autistic child, horse-riding is certainly worth a try. He has learned independence, how to follow instructions, personal safety features, and how to treat animals with respect. Gabriel's confidence has grown, and he now talks to all the volunteers and other children with differing abilities and challenges. For example, one friend is a boy in a wheelchair who has lost the ability to speak. Gabriel talks to him and makes him smile. They end their conversation with a 'high five.' Parents and carers can watch the riding or take a welcome coffee and chat with others in similar situations to themselves. The staff is excellent, knowledgeable about horses, and aware of the difficulties children may face. They help the children to overcome their fears and tailor lessons to fit the group dynamics.

Gabriel's sister Olive watches her brother and sometimes goes with the group on their country walks. Here are her observations about the Chigwell Riding Trust, which was the first riding center for people with special needs in the world.

Olive's thoughts on Gabriel's riding

I watched Gabriel ride Toto, enthusiastically taking in all the sights and sounds of the environment. His name had just been called to ride in the gymkhana competition, and he was beaming with excitement. Toto walked proudly into the ring, Gabriel sitting confidently on his back. One of the workers read out Gabriel's interests. "This is Gabriel, he is eight years old tomorrow and his favorite horse is Toto, outside of riding he enjoys watching *Teletubbies*." Gabriel rode Toto round and round the ring, doing countless different tricks. He ended up finishing 5th and was voted Most Improved Rider. He won two rosettes and a giant cup, which we are going to get his name engraved onto!

I've loved seeing Gabriel's confidence grow throughout the time he has been here at the riding school, which caters specifically to disabled riders. It is a registered charity and an asset to the community, but is wholly dependent on that community's goodwill, the members of which volunteer in numerous ways to improve the lives of many people. The horses are chosen carefully. In selecting one, the leader of the school says, "We always look for kind eyes as this reflects their character, rather like people really." I asked the leader what her most memorable experience was of teaching disabled children to ride. She explained one little boy could not walk, but the motion of the pony was very much like walking, and through this, he was able to learn. For her, it was magical to watch him take his first few steps. In his time here, Gabriel has learned discipline, independence, and best of all, he has taken up a skill he will carry forever.

While I was talking to Gabriel about winning the cup, he told me this story:

Once upon a time, there was a shy boy called Shy Guy who loved reading books. Shy Guy went to Shy Guy Falls often and went horse-riding every day. His horse is called Toto. He rode Toto in a horse competition called "The Horsey Competition." He wanted to win a rosette and collect it. After racing against Roshi, a green dragon, Shy Guy came in first. He was still a little bit shy but managed to collect the rosette because it was for Toto. He had a big grin on his face. Toto makes him feel less shy because he must look after Toto.

Gabriel has the final words: "Horse-riding is awesome!"

Jackie Moore is married and lives in London. Her teaching career took her and her family to different parts of the UK and to Africa, which she describes as unforgettable. She divides her time between looking after her grandchildren and their dog, writing, and research. She relaxes by swimming or going for long walks in the country and contorting her body with yoga and Pilates. She lives life to the fullest and enjoys a challenge.

Olive Pih lives in Essex with her family. She is just eleven and is excited about going to secondary school, although she will miss her friends. Though she wanted to become an author, she now has developed a keen interest in drama and loves to act in theatre productions. She even starred in one! Her leisure activities take her into the countryside where she takes part in cross-country. She finds it energizing but exhausting at the same time!

Safety and ASD: Locked Down Like Fort Knox

By Kristina RADICIA

How many locks can one household hold? The answer for my household would take too many fingers and toes!

I can say now after spending years working with locks of all sorts that I used to underestimate a lock's ability. I would look at the basic use of a lock, and my mind would stop there, not taking into consideration the true power it holds.

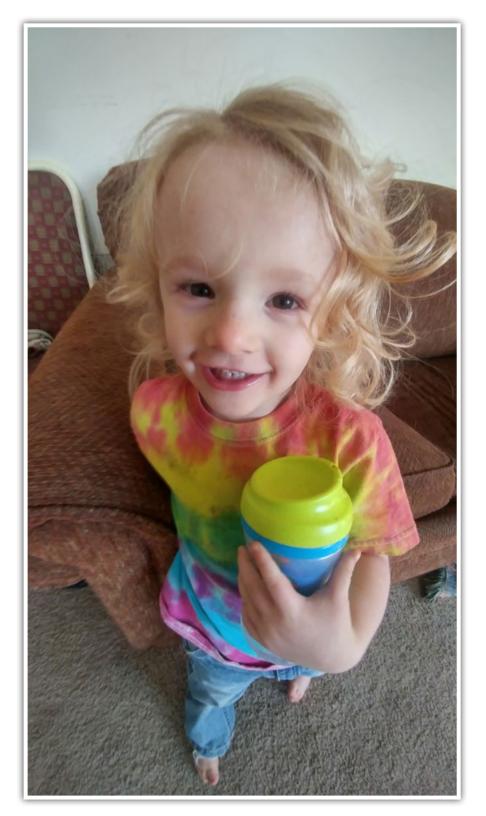
or most, a lock is something found on the door of your home. These door locks are used to keep your home, your valuables, and you safe late at night after the world has gone to bed. Otherwise, they are used to keep other people out of your home when no one is present.

If you think about it further, though, locks are found everywhere. On bank boxes and diaries, bikes and computers, cell phones, and cars. Door locks are just what we have socially accepted to be a lock's main purpose. If you come to my home, you will find locks doing so much more!

Living in a world run by my son's autism, we have found ourselves locking everything and anything he can use (or come in contact with): the oven, the fridge, the toilet, the cabinets, the doors, the windows, and, in some cases, desk and dresser drawers.

Lately, I have found even our Christmas tree has come under attack from his obsessions and compulsive behaviors; its hiding place in the back of the storage closet is no longer keeping it safe from his tiny fingers. We now must lock down the door that holds our year-round holiday gear behind it. I can't help but laugh and think to myself as I lock the door of how evil those elves must be...and you never know about that Easter bunny...we just better lock this one up!

As it is, my son's autism typically is "new" to most people as it is not something usually encountered daily



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We have a phrase that is stated quite often throughout my house by us, our patrons, and our family and friends: 'Locked down like Fort Knox!' Every time you need to use something you have to unlock it first.

or seen as a norm. When people are in my home and notice the uncanny amount of locking mechanisms we have on everything/everywhere, there is usually a discussion to be had!

We have a phrase that is stated quite often throughout my house by us, our patrons, and our family and friends: "Locked down like Fort Knox!" Every time you need to use something you have to unlock it first. That action in itself can catch anybody off guard. As a grown adult it is hard to retrain the eye to see something in a different light than usual, like a lock on a toilet bowl or dresser drawer.

I have other children and I cannot tell you how many times I have seen them run into my front door! They turn the handle, pull the door, and go to walk...but run right into the door! As they bounce off sighing and giggling to themselves, you can hear them mumble "Locked down like Fort Knox!" Then they look up and release one of the four (on bad days it's sometimes all four) locks that help hold my front door closed.

We laugh and we giggle at moments like those because they're funny and we can't help but notice the irony. Sometimes I think it is easier to pay attention to those things; if we look at the real reason those locks are placed, we will be reminded of a worrying truth.

My doors **NEED** locks: my son is a wanderer and if he got outside unsupervised who knows what could happen. At six years old he is not street trained. I don't even think he understands cars drive down the street we walk across. If a car came driving in his direction, I believe he would stop and stare blankly, slowly processing the situation but still not comprehending it enough to move. My son is also a runner. If he got outside, I don't know where he would go, but I know for sure he'd run. I have had too many scares where I ended up panting while clasping him tightly after finally catching him and his fast feet. My son is hyperactive and impulsive. He would dart every which way with no pattern, making him hard to trace and hard to keep safe.

My drawers **NEED** locks. In the kitchen there is a drawer of knives—those are locked. There is a bedroom dresser with a pocketknife and change (he puts it in his mouth and chokes)—that is locked. In the desk drawer there are small trinkets and glass. We lock that one too.

My fridge **NEEDS** to be locked. Imagine egg cartons full of eggs smashed around the house while you chase the culprit down (he always seems faster in these moments). He has the carton and is playing raw egg Russian roulette! The glass bottles of Worcestershire sauce, soy sauce, jelly, jam, and lemon juice get thrown and smashed, shattered glass covering wherever the episode occurs. A whole bottle of strawberry syrup will be dumped all over the living room floor, where your other older, neurotypical children will giggle over the stain and draw chalk body outlines.

The list goes on and on—I could go through them all and every day adds more. As we grow, we learn this is the only way. Some of the locks keep our things safe while the other locks keep him safe. It's baby proofing for a baby who no longer exists—physically. It's treating my house like a detention facility. Everything is accounted for and has a place and is always put back. It is giggling at strangers who cannot open my toilet after they excuse themselves and I forget to mention the toilet is locked. It is knowing he is safe and for that, I will do anything, even if means being "Locked down like Fort Knox!"

Kristina Radicia is a mother of three, with her youngest being on the autism spectrum. She has received her bachelor's degree in human relations and currently lives in Lincoln, Nebraska. **Poetry Corner**

I Like It Now

By Kenna J. JOSEPHENE

Laughing is all I hear and my tummy feels amazing and who knows what my face is doing? this movie is so funny

I am here alone and feeling happy

not that alone is better than *with* oh no

this is fun sometimes leaning forward sometimes touching my face sometimes squirming with pleasure

nobody cares, especially not me no not anymore

I am here alone and I am happy not that alone is better than with, oh no

but if someday I am *with* ever again, I hope it's with an Aspie like me

Kenna J. Josephene wrote this poem after scoring high on an online Asperger's syndrome screening quiz in 2007. Seeing herself on the autism spectrum enabled her to stop trying to be "normal," which created room for a huge amount of joy. Email: <u>verygoodmedicine@gmail.com</u>

Poetry Corner

The Princess and the Pea, Just Let Me Be Me

By Jayna Morgan ROBINSON

There was once a little girl who longed to be like you. She longed to be like others but was mistaken to be aloof. She struggled and struggled when it was time to go to sleep. Every little sound, every little peep; why, oh why couldn't she go to sleep?

Ah, but there was relief! Routine brought comfort.

And as long as it was there, she could repeat to her retreat.

Her mother referred to her as "The Princess and the Pea,"

Because she also knew about her sensitivity.

The world could be pretty demanding. Growing up and conforming seemed pretty challenging. Academically, school was never an issue. But socially, she felt like she didn't have a clue.

Being especially bright, she began to find a way to fit in.

She camouflaged her interests and joined right in. Life was never easy, always pretending to be... She began to get sick and wondered, "What is wrong with me?"

It wasn't until much later in life that she began to get an answer. ASD/High Functioning Autism—also known as Asperger's... Since the diagnosis, she could finally feel free. "Aha! I can finally be me!" For, you see, the "Princess" IS really me.



Jayna Morgan Robinson grew up in a small town in Lauderdale County, Mississippi; she graduated high school with honors and completed college with a Bachelor of Science Degree in Business Administration from Mississippi State University. She is married with two children and currently employed with a local school district in metro Atlanta, GA.

An Exclusive Look at AUTISM with Chad R. MacDonald

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.

oday's AUTISM Interview is with Chad R. Mac-Donald, who is a writer, speaker, and autism advocate in New York who once stopped a crime in a superhero suit.

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

Liam had delayed speech. When he still wasn't speaking after he turned two, our pediatrician at the time referred us to speech therapy.

But even before then, I'd had more than an inkling something was up. Liam had (and still has) a habit of flapping his arms when looking at, say, a ceiling fan, or moving water, and sometimes would double over while flailing his arms. I didn't see this behavior in any other children.

I now know this is the phenomenon called "stimming" and why he does it. But at the time, it was this behavior that inspired me to press for further analysis, even when my family, my friends, and even our doctor kept assuring me I was worrying about nothing.

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

Liam was super focused on the wheels of vehicles and was reluctant to engage in imaginative play or to socialize. I used my love of superheroes to draw



him out of that, as the bright and colorful characters were impossible to ignore. And once he discovered how a cape would fly out behind him when he ran, Liam immediately became enamored with pretending to be a superhero.

So we became superheroes together. From the ages of three through five, Liam either had to be taken somewhere for therapy or stay at home while a therapist visited. That left us exactly one afternoon, on Wednesdays, for him to have free time to play. We both loved superheroes, so we would go to Central Park in full regalia, capes, masks, accessories, the whole bit. There, we would run and play and just have Dad and son time.

To this day, Central Park remains an Event Day for us, whenever we decide to go. Now other factors get involved, like baseball or stomp rockets, but we still break out the capes once in a while.

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

This depends upon where you are, of course, but here in New York, there is so much available to parents. Mind you, it takes patience and persistence to deal with the red tape, but if you stick to it and stay organized, the rewards are tremendous. Liam received speech therapy at home, as well as Applied Behavior Analysis (ABA) therapy. He met with occupational therapists to improve his core strength and fine motor skills. He would attend sessions at Educational Alliance on the Lower East Side with other children to help his socialization and to fine-tune his speech and ABA therapies.

As a result, when Liam reached pre-school and then Kindergarten, he hit the ground running. He was already used to the structure of a classroom and perfectly comfortable with listening to and respecting the instructions of his teachers. That meant he actually had a leg up in school and has even been a star student.

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

What inspires me is that he's happy. There is no greater measurement of success for me than to see him happy. He loves his life. He loves where we live. He loves his family. He loves going to school, or to camp, or swimming or skating. He creates art. He plays sports. He reads comic books. He builds robots!

Before Liam came along, I could measure my growth as a person by inches every year.

Now, I can see myself grow by miles every day.

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

Helping Liam would have been impossible if I hadn't transitioned to a stay-at-home Dad and then a workat-home Dad, to ensure he made all of those therapies and was ready for his visitors.

As a result, for a long time, I had a difficult time dealing with the fact I wasn't the primary breadwinner in my family. While I'm perfectly aware this is a gender stereotype, it would bother me that I wasn't contributing more financially.

Also, Liam craves motion and speed. Because of this, he's incredibly active, and always needs something to do, or to be occupied with. He has not napped since he was two years old, and even then, he fought naps tooth and nail, and he's always on the go. He literally runs circles around other children. He has three cousins, and he outlasts them all every time we get together. At the playground, other parents marvel at how he is in perpetual motion. I try to walk with him everywhere, and he usually runs ahead of me, runs back for a high five, and then runs ahead of me again. Repeat ad infinitum. I normally have him wear a backpack full of snacks and toys, and it does absolutely nothing to either slow him down or tire him out.

It. Is. Exhausting.

Still, the decision to stay home with Liam remains the best one I've ever made in my entire life. I would do it again.

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

Organization is key. Nobody likes homework, but in this case, you need to have it done. This is where my wife has been amazing.

Review your files often, and with your partner. Take the expression "get on the same page" quite literally. When it's time for a therapy session, a meeting, or a doctor's appointment, you'll be ready.

Create files for everything pertaining to your child, documents in a cabinet, and files on your computer. Put chalkboards or whiteboards up somewhere have a weekly schedule and a daily schedule. This will not only help your child adjust to transitions and feel more confident about the day's plan, but it will boost your own confidence as well.

Because if you miss some of these meetings, or are unprepared for them, you will set your child's progress back immensely. It will be your fault he/she isn't getting the help needed.

Derrick Hayes is an author, motivational speaker, and paraprofessional in the Muscogee County School District in Columbus, Georgia. Book or Interview Derrick Hayes the "en-TIEtainer" now by visiting <u>derrickhayes.com/entietainer/</u>.

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Connecting with Chad R. MacDonald Website: <u>www.gcandu.com</u> Facebook: <u>www.facebook.com/chad.macdonald.19</u> Twitter: <u>twitter.com/ChadMac19</u> Work: <u>citydadsgroup.com/nyc/2017/06/superheroes-cen-</u> <u>tral-park</u>

Charming Story Sends Powerful and Loving Autism Message

I'm a Little Big Brother

By Meshell BAYLOR

he book highlights the importance of unconditional love, yet demonstrates how autism can impact siblings within the home.

It sends a powerful message to parents, professionals, and children in the world of autism: siblings understand and feel the changes within the home environment

when a child is diagnosed with any disability. This book gives the reader insight on how two little brothers have the greatest adventures and how the youngest sibling learns what autism really means and how love can come in many shapes, forms, and sizes, even in the size of a younger sibling!

Having spent the last 10 years serving the special needs community, Meshell tells the story of two brothers who have magical adventures when the youngest sibling begins to ask questions about his older brother. The book covers an introductory way of introducing autism to a younger age range of children to help them comprehend what autism is.

Having read this book, children will walk away with a fun-loving understanding and warmth about family. It has a precious innocence and an altogether important message surrounding the roles of family members and how they can vary from the typical or ordinary. Its tone of tenderness makes it an ideal and easy way to communicate its concept to young children just beginning to learn what it means to be part of a family.



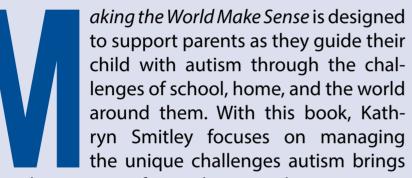
Meshell Baylor has over 10 years of experience serving the special needs community. She currently works as a case manager and community advocate helping those impacted by developmental disabilities. She obtained a Bachelor of Science Degree in Human Services from Springfield College. In 2016, her piece <u>Entering the World of Oz</u> <u>With Justin</u> was selected as the Editor's Choice by <u>LA Parent Magazine</u> in which she highlights how parents learn about navigating their way through the special education system through her personal journey with her son.

Amazon: <u>https://www.amazon.com/LITTLE-BIG-BROTHER-Meshell-Baylor/dp/179567704X</u> Goodreads: <u>https://www.goodreads.com/book/show/43789187-i-m-a-little-big-brother</u> Website: <u>https://www.imalittlebigbrother.com/</u>

New Book Bridges the Gap Between the Classroom and Home for ASD Parents

MAKING THE WORLD MAKE SENSE A Parent's Guide to Helping Their Child with Autism

By Kathryn SMITLEY

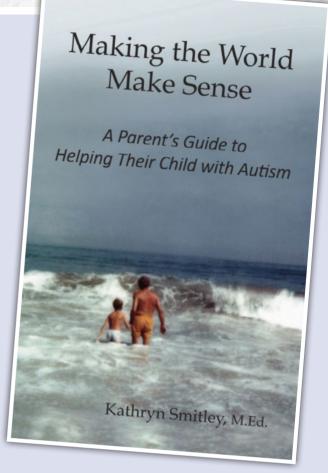


through instructive fun and creative learning activities at home.

As a veteran special education teacher, Ms. Smitley's strategies have been inspired and honed during her decades teaching children with autism as well as working with—and listening to—their families. She believes it is vital to connect and communicate with parents and caregivers who are on the frontlines of autism.

Building bridges between classrooms and home and connecting efforts at each end is a central tenet of this book. Spanning this gulf is increasingly important as new programs and approaches require schools to ask teachers to manage more administrative work, a trend that often takes them from the classroom to the conference room. Time teachers once spent working individually with children has been passed on to paraprofessionals. As this trend continues, teachers increasingly recognize the important contribution of parents at home.

With *Making the World Make Sense*, Ms. Smitley reaches out to families. She offers enjoyable and instructive



management strategies and activities that dovetail, behaviorally and academically, with many classroom goals. Additionally, she designs games and stories that help children with autism to enhance their communication skills and enable them to feel more comfortable in classrooms and social settings.

Now at Amazon:

http://tinyurl.com/MakingTheWorldMakeSense

Kathryn Smitley earned her MEd in Special Education at George Mason University in Fairfax, Virginia. She has spent 35 years in the autism classroom working with and learning from autistic children and their families. As a long-time writer on the subject of autism, her articles have been published in <u>Asperger's Digest</u>. She brings to <u>Making the World</u> <u>Make Sense</u> compassion, insight, and innovative methods to structure a successful and comforting learning environment at home.

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Will Monetary Gifts Affect My ASD Child's Government Benefits?

By Ryan F. PLATT, MBA, ChFC, ChSNC

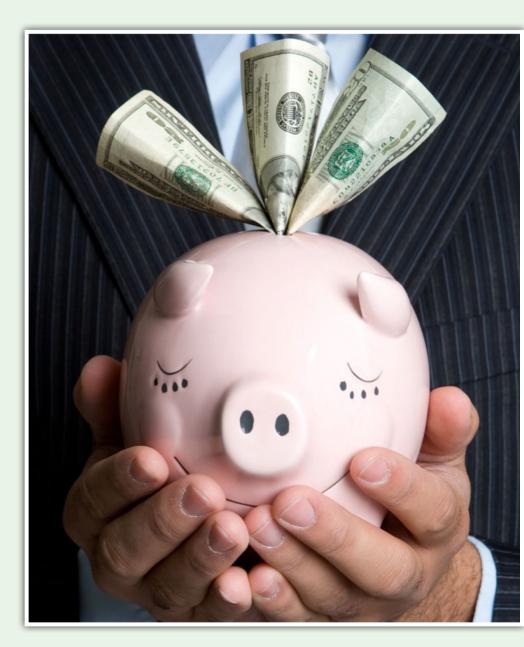
Question:

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As the holidays are upon us, my son will be receiving cash as holiday gifts from grandparents and aunts and uncles. We are currently preparing to ensure he can receive government benefits as he will be turning 18 in February. Will these gifts be a problem for him being able to qualify for government benefits?

our question has multiple layers to it, and unfortunately, cannot be answered with a simple "yes" or "no." Let me first begin by saying I am glad you are thinking about and being cautious regarding how to protect your son's eligibility for government benefits. The government benefits you will be applying for when he reaches age 18 will help provide him with a monthly income, health care, long term support and services, and possibly housing; however, you must stay within the rules. One of those rules is a maximum allowable resource allowance, which continues to be quite low. Your son will lose access to most, if not all, the benefits listed above if he is found to have more than \$2,000 in non-allowable resources. These resources can include the sum of checking, savings, investment, custodial, CD's, and even retirement accounts (if he has been working at all). Although this number is low, there is hope.

If the gifts your son receives will total more than \$2,000 but will be less than \$15,000, then you should consider using an ABLE account. ABLE stands for Achieving a Better Life Experience and is an account



If your son's gifts total more than \$15,000, you will not be able to use the ABLE account for any gift amounts over \$15,000. The ABLE account has an annual contribution limit of \$15,000, which means the maximum contribution in any calendar year can only be \$15,000.

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that is allowable in the eyes of the government. This means your son can have more than \$2,000 in his name as long as it sits in an ABLE account. Please be aware you will not be able to open an ABLE account at any and every financial institution. The legislation that made it law requires individual states administer their own state ABLE account. The legislation that created the account does, however, allow you to use any ABLE account from any state regardless of where you live. Each state's program offers benefits, and you will need to determine which one has the design that best suits the needs of your son.

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CAUTION: It is critical to understand the distribution rules of an ABLE account to ensure that when your son uses money from the account it qualifies as a disability expense. If it does not, it is possible the account (and/or the distribution) will lose its exempt status and be counted as income or as an asset against your son and place his qualification for certain government benefits in jeopardy.

If your son's gifts total more than \$15,000, you will not be able to use the ABLE account for any gift amounts over \$15,000. The ABLE account has an annual contribution limit of \$15,000, which means the maximum contribution in any calendar year can only be \$15,000. If this is an issue, then you will need to turn to a tool called a Special Needs Trust. This tool will require the services of a qualified attorney to design, write, and create this unique trust, and then once created, you are able to open an account at a financial institution to deposit money for your son's benefits.

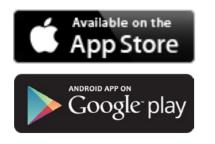


For more information on how to prepare for the future, be sure to contact a financial advisor who specializes in serving families with special needs. A Special Needs Plan is driven by their purpose of leading families to independence

through an ongoing multi-generational plan. A Special Needs Plan is passionate about families confidently moving forward.

101 N. McDowell Street, Suite 120 Charlotte, NC 28204 704-326-7910 Website: <u>www.aspecialneedsplan.com</u>

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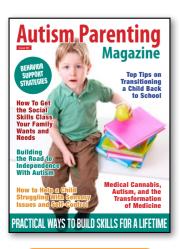
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