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

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BASKETS BY A PEDIATRIC OCCUPATIONAL THERAPIST
It’s human nature for most of us to want to love and be loved in return. The majority of people on the autism spectrum are no different from neurotypical people in this regard—but the dynamics of getting there can be extra tricky. Many of us have had to navigate awkward dates, trying our best to read any romantic signals, flirt successfully, and engage in appropriate conversation. Just imagine trying to do all that with autism also in the mix!

That’s why, in this issue of the magazine, we’re running with the theme *Autism and Romantic Relationships*. Our pages are packed full of practical advice for parents to share with young people starting to explore relationships, attraction, and all the confusing moments and emotions that come with them.

Among our themed content, we have an article from Karen Kaplan, MS which offers a comprehensive guide on sex education to help parents create comfortable, informative dialogue with their children. Lt. Joseph Pangaro has also penned a piece on understanding sexual identity to help caregivers accept and welcome their children’s relationship preferences.

We also have an article from Dr. Rachel Schwartz, PhD, BCBA-D on the concept of teaching “love” as a life skill. She points out that while parents and therapists focus on building skills such as communication, money management, cooking, etc., it’s important they don’t forget “learning love” is just as important.

Dr. Schwartz comments that, for far too long, conversations around sexuality, love, and the right to love have excluded neurodiverse individuals. This has resulted in many individuals being unprepared and ill-equipped to explore healthy relationships on their own. Scary stuff. It’s time to make a change!

Taking a slightly different slant on the relationships theme, autism coach Deanna Picon, BA has authored some content to help parents revitalize and strengthen their relationships with each other as the world slowly recovers from the Covid-19 pandemic.

We also have an array of articles exploring topics such as Behavior Intervention Plans, the autism assessment process, pathological demand avoidance, sensory solutions, communication, and so much more. We hope you dive in and enjoy the read!

**Emily Ansell Elfer**  
Editor  
*Autism Parenting Magazine*
Putting Love into Life Skills

By Rachel SCHWARTZ, PhD, BCBA-D

AN ARTICLE ABOUT HOW PARENTS AND EDUCATORS CAN TEACH NEURODIVERGENT CHILDREN LOVE AS A LIFE SKILL.

My early days in special education were a rollercoaster. I was excited, terrified, overconfident, and underprepared. All of my supervisors and trainers had instilled in me the importance of building student independence and involvement in their community and education. To that end, I was extremely focused on building essential life skills (e.g., communication, money management, cooking, etc.). I was proud of the work I was doing and excited by the growth and independence I saw in the individuals with whom I worked.

Then one day, a female student came up to me and whispered in my ear: “Guess what?” I leaned in and whispered back: “What?” She said, with a smile on her face: “I have a crush,” and pointed to a boy nearby. My face got red. I stared at her feeling embarrassed and uncertain and responded quickly with: “I don’t need to know that,” before turning away.

Over 15 years later, I still go back to that moment and cringe at my response. I was so focused on building life skills that I was unprepared to teach the more intimate and equally important “other”
life skills. That moment helped bring a simple yet crucial awareness to my practice: love is a life skill.

The importance of teaching love skills

I wish I could go back in time and say to that student: “Tell me more!” rather than abruptly shutting down the conversation. For far too long, conversations around sexuality, love, and the right to love have excluded neurodiverse individuals.

Social stigma and fear have perpetuated barriers to educational opportunities, leaving many individuals unprepared and ill-equipped to explore healthy relationships on their own. This has resulted in high numbers of neurodiverse individuals experiencing social isolation, mental health concerns, and sexual exploitation and victimization throughout their lifetimes.

Through more education and heaps of experience, I’ve learned that while teaching essential life skills enhances independence, they don’t always build happiness or teach the basic aspects of loving yourself and loving others. Close human relationships including love and friendship are essential to a person’s quality of life and overall well-being. Developing life skills that facilitate partnership, choice, community, and relationships are just as important as the life skills of laundry or cooking. It is through these “other” life skills that a person can foster self-love and companionship with others.

It is easy to talk about the other life skills, but how do you teach them? The answer is comprehensive sexuality education. Sexuality education reduces risk and encourages positive self-expression and self-determination.

It encompasses so much more than discussions on pleasure and sexual identity. Comprehensive sexuality education includes human development, relationships, personal skills, sexual behavior, and sexual health (SIECUS, 2004). Beyond these domains, sexuality education helps individuals establish a foundation of self-confidence and self-esteem.

Tips for supporting access to information

1. Provide sexuality education at home

Parents are the number one educators. You can use natural opportunities such as watching television or reading books.

Jump in with open-ended questions like: “What do you think about…?”, or “What would you do if…?” or “How do you feel when you see…?” based on what you just saw or read. These questions allow you to see what your child already knows about the topic and provide further information and clarification.

It is easy for kids (and you) to get embarrassed. Keep reminding them that it is ok, there is nothing to be embarrassed about, and that you are there to

“Developing life skills that facilitate partnership, choice, community, and relationships are just as important as the life skills of laundry or cooking.”
help them. The more your child trusts your openness and honesty, the more your child will come to you with his/her questions and concerns. Conversations about sexuality education may seem scary, I know. But it is through these conversations that your child will learn safety, advocacy, and a sense of belonging.

2. Encourage questions

When I turned away from my student, I unfortunately gave her the impression that her words did not matter, her desires were uncomfortable, and even trusted adults did not want to talk to her about her feelings. Since then, I have learned to lean into these moments. If your child or student comes to you, first and foremost embrace the opportunity. For example, if your child tells you: “I have a crush,” you can say, “How do you feel about that?” to start probing what your child may be trying to ask or tell you. When a child brings up a question or statement, it usually means that there are more questions or concerns behind it.

3. Find a class

Parents are the primary educators, but it doesn’t hurt to bring in reinforcements. Pediatricians and disability organizations often have sexuality education recommendations or classes available. These classes will provide another safe space for your child to learn and ask questions. Classes may also provide an opportunity for broader peer relationships and community for you and your child.

4. Be aware of your body language and tone

Be aware of how your face or body responds to the questions or statements from your child. You may want to interrupt or correct your child, but doing so may accidentally shut down the conversation. Keep your facial expressions encouraging (smile and nod) and your body open to your child (not turned away or distracted). This is the time to put the phone away, turn off the television, and face your child. Grab some popcorn and make the environment comfortable, safe, and even fun.

5. Overcome your fears

You need information just as much as your child. There are resources and classes that can help you overcome your fears. Reach out to local sexuality educators, pediatrician offices, and disability organizations for information on groups (or classes) you can join.

6. Professionals can do this, too

Even though the information above is geared towards parents, professionals in the field can follow the same advice. Be open; find resources and experts to support your students’ questions and concerns. Be mindful of not inserting your own values or attitudes about sexuality into the learning space. I always recommend finding a mentor who has experience in teaching sexuality education to support and supervise your work.

Teaching life skills can and should include skills of daily living and sexuality education. You as a parent and professional should not need to choose just one area of focus. Both curricula provide a pathway for an independent and fulfilling life.
I can’t tell you how many times I have heard parents say “I just want my child to be happy.” Happiness goes hand in hand with equitable access to information. It is difficult to achieve happiness if your life is focused on your limitations. It is difficult to achieve happiness when knowledge is withheld. Information leads to empowerment which leads to agency, and that agency facilitates choice and control over your life.

REFERENCES:

Rachel Schwartz, PhD, BC-BA-D has worked internationally creating and supervising programs for individuals with developmental disabilities. With over 15 years of experience working with special education teachers, administrators, students, and families, Dr. Schwartz is passionate about sharing her experience and empowering parents and professionals.
Tips to Revitalize and Strengthen Your Marriage

By Deanna PICON, BA

THE CHALLENGES OF PARENTING A CHILD WITH SPECIAL NEEDS CAN PUT A STRAIN ON RELATIONSHIPS. HERE ARE A FEW IDEAS THAT COULD HELP REVITALIZE YOUR MARRIAGE OR PARTNERSHIP.

“So what are you buying John for your anniversary?” my girlfriend Jean asked me.

“It depends on which John you’re talking about, because I think I married a man with multiple personalities. During this pandemic, I’ve seen so many different sides of John, I don’t know who I’m living with anymore,” I said with a huge laugh.

“Half the time, I want to give him the biggest hug and kiss for being the most considerate and loving husband and dad. The other half, I want to lock him in the closet and throw away the key, because he drives me crazy.”
Stresses of life and the pandemic

Many couples probably felt this way about their partner at one time or another during the pandemic. Spending more time than we normally would with our significant other allowed us to see “the good, the bad, and the ugly” in them and ourselves. And there may have been a few occasions when we had doubts about our relationships.

If you’ve ever thought this way, you’re not alone. Managing a fulfilling relationship while raising a child with special needs has been, and will always be, a challenge. Between work, family responsibilities, and taking care of all aspects of a child’s life, parents are left with hardly any time for themselves, much less a spouse.

The pandemic probably added more pressure, including financial insecurity, job uncertainty, and health concerns. On top of all that, there’s full-time caregiving, remote learning, and managing challenging behaviors of kid(s). So it’s completely normal to feel exhausted, overwhelmed, or stressed out.

Fortunately, things are improving as many places around the world emerge from the worst of the COVID-19 pandemic and we slowly adjust to our new normal. Like everything else in life, nothing stays the same, but it’s important to get back on track, especially with your partner.

So how can you become a couple again while dealing with challenges and responsibilities? How can you make your relationship a priority again?

Don’t worry! By following a few important steps, my hope is that you can revitalize your relationship and keep it strong.

A few ideas to revive your relationship

1. Give yourself some space

After isolating with your family during the pandemic, it’s time to think about your personal needs for a change. Give yourself some “breathing room” and try to get back to being “you” again, and don’t feel guilty about it.

Participate in activities that make you feel good. For example, go back to the gym, start a walking/running program, dance, get a mani/pedi, meditate. Doing what makes you happy is beneficial for you, your relationship, and the entire family.

2. Keep in mind you’re both human

Remember this the next time your partner says she/he is overwhelmed with working from home while managing a kid’s virtual learning schedule.

- Take over or help out with a task if you can
- Give each other permission to vent and “blow off steam” whenever you need to
- Don’t be critical or take anything to heart in the heat of the moment
- Be understanding of your spouse’s feelings so you avoid fostering anger and resentment

By allowing each other to be open and honest, you’ll build goodwill, trust, and respect within your relationship and deepen the bond between the two of you.
3. **Take advantage of your support team**

Ask family members or close friends (well in advance!) to watch your special needs child and/or other children for a few hours or a day or two. They will feel good knowing they can help. You’ll have peace of mind because your kid(s) are safe and well cared for. Best of all, there are no child care costs.

4. **Plan enjoyable dates**

Every couple needs and deserves some time alone together to reconnect and keep the emotional, physical, and communication bonds strong. And don’t feel bad for doing so. It’s the best way to prioritize your relationship.

- Schedule “fun” dates for yourselves on a weekly or monthly basis. Enter them in your cell phone or computer calendar. After living in sweatpants for a year, it’ll probably feel great to put on a nice outfit for a change.
- Your date doesn’t have to be a “night out on the town.” A blockbuster, summer movie, or quick bite at a local restaurant is fine. Participate in some of the hobbies, activities, and events you enjoy.
- Summer is a perfect time to relax outdoors. Have an old-fashioned picnic at a park or beach or go swimming.

Most importantly, focus on your partner. Put down all the electronic devices and talk and listen to each other. And as hard it may be, don’t discuss the kid(s). You’ll have time to do that when you get home!

“Remember, affection and attention for your partner doesn’t have to be set aside for just date nights and special occasions. Romantic evenings can be created anytime.”

5. **Keep the spark alive**

Remember, affection and attention for your partner doesn’t have to be set aside for just date nights and special occasions. Romantic evenings can be created anytime. After your kid(s) are asleep, have some wine, munch on chips and dips, or have a scrumptious dessert by candlelight. Snuggle on the sofa while you stream some Netflix movies. It’s a cozy way to wind down from a stressful day.

A little extra effort from both partners can generate ongoing intimacy and maintain a loving atmosphere at home. A tender kiss, hug, or smile in the morning or evening is a wonderful way to start or end the day. A simple “thinking of you” message by email or text can mean so much.

Tell each other: “You look beautiful in that dress,” or “your cologne smells great.”

Hearing those compliments can really make your spouse happy. And looking at each other as attractive partners can make you feel desired and positive about your relationship.

6. **Surprises are welcome**

Showing you care, even when there isn’t a special occasion, is one of the most romantic things you can do. Don’t wait for Valentine’s Day, birthdays, or anniversaries to do something thoughtful for your partner. An unexpected gift or gesture is a fantastic way to enrich your relationship. Give him/her a balloon that says: “You’re Amazing!” Buy something your partner really wants, like jewelry or athletic clothing.
7. **Appreciate each other**

Despite the negative aspects of the pandemic, it has taught us some important lessons. Life is unpredictable. It can turn upside down in an instant. We should treasure our loved ones.

Now, perhaps more than ever, it’s important to express gratitude for your partner. Don’t forget to say: “I love and need you,” or “thanks for taking care of that for me.” They’re simple words, but on a tough day, a few heartfelt expressions could make all the difference.

**A gift of a lifetime**

After speaking with Jean, I thought about my lovable, handsome, stubborn, and thoroughly impossible husband. What would be the perfect gift for the only person who knows exactly what I’m going through? Who loves my child as much as I do and is on the same life-long journey?

Dinner at John’s favorite restaurant is fine. But I also want to give a meaningful present. I’ll buy John a heart-shaped frame and put a picture of us on our favorite rollercoaster ride. It was taken shortly after we married, when life was carefree and uncomplicated. It brings back such happy memories.

And now, when I look at it, I realize it’s representative of our current lives. Raising a child with special needs is like riding an emotional rollercoaster, encompassing unpredictable highs and deep lows, with major twists and sharp turns along the way. But in the end, we always arrive safely on the ground with a huge smile on our faces.

Despite how crazy John makes me, he’s my pillar of strength and main source of comfort. And, after all these years, with the ups and downs of our marriage, he’s still the one!

**Deanna Picon, BA** is the founder of Your Autism Coach, LLC, which provides comprehensive support programs and seminars for parents of special needs children. Her personal mission is to empower parents as they advocate for their children while balancing productive work and family lives. Deanna is a parent of a nonverbal young man with autism.

Her academic credits include a Bachelor of Arts degree in psychology and a Bachelor of Arts degree in broadcast journalism from Syracuse University. She is the author of *The Autism Parents’ Guide to Reclaiming Your Life*, available from Amazon and through her website. This life-affirming guide provides parents with proven techniques and a clear-cut action plan to build a good life for themselves and their families.

Deanna is a regular contributor to *Autism Parenting Magazine*. She is the recipient of both the 2020 and 2018 “Top Parental Advice Writer” and 2015 “Top Life Coach Writer” awards.

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Help Your Child Respond to His/Her Name Through Positive Associations

By Maritza (Mitzy) PARDO, MA, BCBA

HERE ARE SOME IDEAS FOR HOW YOU CAN INCREASE YOUR CHILD’S RESPONSENESS TO HIS/HER OWN NAME.

Dale Carnegie said: “Names are the sweetest and most important sound in any language.” I agree, but there is much more to it. Parents take great care in choosing their child’s name; initially it may reflect their own personalities or desires for their children. For example, parents often give their children meaningful names like “Faith” or “Hope.” Only later will a child come to identify or associate themselves with their name. What will the association be? A sweet sound motivating your child to respond, or avoidance? In order to better understand the process, a look back at the initial stages of development may be useful.
The Mayo Clinic reports that a fetus can hear sounds and may recognize their mother’s voice 23 weeks after conception. Auditory development continues throughout the remaining weeks. Once born, a baby will typically receive a hearing test before discharge (or within three weeks). Assuming a baby’s hearing is intact, by six or seven months, they should be able to follow sound or respond to their name.

Responding to one’s name is one of many important milestones that children are supposed to reach. As a matter of fact, not responding to one’s name is typically a red flag often identified in children with autism. However, it is important to note that children vary in their development, so it may not necessarily indicate a developmental delay or disorder.

I have observed several children with perfect hearing display inconsistent responding simply for the sake of avoidance. Early on, children develop associations between words and other events which follow (positive or negative). Studies have confirmed higher rates of responding to words that have a positive connotation.

Use affirmations when calling your child

Ever notice a child respond to their name following “ice cream” or some other treat? Yet, the same child may ignore the speaker when hearing their name called right before bedtime or some other non-preferred task. Children are very perceptive and quickly catch on to the context in which their names are used. So rather than wait for concerns to surface, I urge parents to set their child up for success early on. This means once you have decided on your child’s name, whether in the womb or after birth, take steps towards creating positive associations or pairings to your child’s name.

By pairing your child’s name with a pleasant tone, affirmation, or praise, you are creating the initial positive experience your child will associate his/her name with, thus increasing the likelihood of a response.

One way is to repeat your child’s name with affirmations or praise, such as, “Rose, you have a beautiful smile”, “Lily, mommy loves you so much,” or “Matthew, you’re eating so well.” The benefits of receiving affirmation are well-documented, so it only makes sense to pair your child’s name with positive statements and a pleasant tone.

By pairing your child’s name with a pleasant tone, affirmation, or praise, you are creating the initial positive experience your child will associate their name with, thus increasing the likelihood of a response.

Pair your child’s name with a preferred activity

Try pairing your child’s name with a fun activity: “Matthew, it’s tickle time.” Again, the association is positive and fun. A child who frequently hears their name alongside what they find to be positive or pleasurable will begin to look forward to hearing their name and be motivated to respond in anticipation. So in essence, you as a caregiver are creating a pattern of responding. The benefits of increased response from your child will go a long way and will also be the foundation for other skills, such as the ability to follow directions.

Now, I understand if the recommendations seem unnatural or disingenuous. However, the effort will produce long-lasting benefits. Of course, there will be times when as a parent, you will have to call out their name to deliver an instruction or reprimand.
However, by that time, a pattern of frequent responding will have been ingrained, making it easier to gain their attention.

Keep in mind, if a child is not in the habit of giving their full attention upon hearing their name, the rest will fall on deaf ears. In addition, your child will have gotten used to hearing their name followed by affirmations and praise, making it easier to associate your requests, directions, or reprimands with happy feelings and experiences.

So, along with careful consideration of your child’s name and all that you want it to mean, carefully consider the initial words that follow. Phrases of affirmation, love, and praise just might make all the difference in your child’s choice to ignore or love hearing the sweet sound of their name.

REFERENCES:

Maritza (Mitzy) Pardo, MA, BCBA is a Latin American clinical assessor and CEO for the non-profit Shades of Motherhood Inc. With a Master’s in Education and board certification in Behavior Analyses, her background includes developmental assessments, caregiver, and social skills training as well as educational consulting. She continues to focus her energy on supportive services for both the typical and special needs community.

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— Steve Silberman, author of NeuroTribes: The Legacy of Autism and the Future of Neurodiversity

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Let’s Talk

Sex Education

By Karen KAPLAN, MS

A COMPREHENSIVE GUIDE FOR CREATING DIALOGUE ABOUT RELATIONSHIPS, SEXUAL MATURITY, AND CONSENT WITH YOUR AUTISTIC CHILD.

R elationships are tricky for everyone, especially those with autism. There are many questions such as: How does love feel? How does a real friend act? How does a lover act? How do relationships really look? Was I flirting? Was he flirting? What does sexual attraction feel like?

Many on the spectrum are confused and have limited insight into these areas. They need help understanding how to relate to others and how to have healthy relationships. The myth that autistic individuals are not interested in romantic relationships is simply not true; the truth is that they may need a little more guidance with communication, emotional response, and how to respond to (appropriate) intimate touch.
Activities for interacting with others:

Circles of Relationships

- On a piece of paper make five circles. Put your child with autism in the center circle. Then draw four more circles around. Have them list their families and close friends in the first circle. In the second circle, they list casual friends, classmates, workmates, and acquaintances. In the third circle, they list their doctors, teachers, police, and store clerks. The fourth circle is for strangers.

Next, hold discussions:

1. Family and close friends

   Ask your child...
   
   - “What are some of the feelings you have for your family and close friends?” (Love, trust, enjoying each other’s company, dependability). Make a list of the feelings.
   - “How do you act around your family and close friends?” Some examples: We share personal thoughts and feelings. We trust them. We speak with them when we’re upset.

   Now your discussion moves to, how do you touch the people in the first circle?
   
   - Share some ideas with your child: handshakes, hugs, brief hugs, kisses on the cheek, hand holding, and hand on shoulder.
   
   Then make sure they understand that even with people in the first circle, all touch must be consensual. This means both people agree to and want the touch; both people say YES.

2. Casual friends

   Next, talk about circle two: casual friends.
   
   - “What are some feelings you have for casual friends and groups you are in?”
   - “Who are these friends?” Make a list of friends and feelings they have for them. (Maybe trust, enjoying each other’s company, having fun)
   - “How do you act around casual friends and groups?”

   Perhaps you are friendly but not friends yet. Remind your child that you might not share personal information and/or personal feelings with just casual friends. You might feel comfortable around them but not close.

   Once again, have a discussion on how we touch the people in the second circle (emphasizing consent). For example, friends may give handshakes, high fives, or fist bumps. If someone in the second circle doesn’t want to give you a handshake, high five, or fist bump, you do not do it.

   Let them know that a person in the second circle might move to the first circle. Their feelings can change as they get to know someone better.

3. Professionals

   Your discussion moves to the third circle, which is about professionals we engage with (doctors, teachers, etc.).
   
   - “What are some feelings you have for professionals who help you?” Your child might say friendliness and appreciation.

   The following discussion topics may help:
   
   - Understanding their emotions and those of others
   - What do they feel for different types of people they meet?
   - How do they act with different types of people they meet?
   - What is flirting, dating, or sexual harassment?
   - What is masturbation and intimacy?
   - What protection do they need so they do not get pregnant?
Next, discuss how they might act around helping professionals:

- Discuss that you are friendly with them but not friends with them. Discuss that you might share personal information and feelings with a doctor, teacher, social worker, or police officer. They might feel comfortable around them but not close to them.
- They may express that they are happy to have helpers like doctors, teachers, and police officers.

Move your discussion to how they might touch the people in the third circle. Handshakes and waving are appropriate.

- If someone in the third circle doesn’t want to give you a handshake, you don’t!
- Remember, all touch must be consensual. This means both people agree to and want the touch.
- Explore the possibility of someone moving from the third circle to the first or second circle.
- Remind them that a person can change as you get to know them better.
- Sometimes teachers get to know you really well and may give a hug good-bye.

4. Strangers

Now, it’s time to talk about the fourth circle—the stranger circle. Have your child think of places where they see strangers, such as the bus, subway, street, or store.

“Talk about how strangers are different from other people. Some are nice, and some are not nice. Emphasize that we don’t accept a ride in strangers’ cars.”

- Discuss with them that some strangers may be friendly, but it is important not to hang around with them.
- Other strangers may make them feel uncomfortable. When that happens, they must get away from them quickly.
- Make sure you ask them if this has ever happened to them. Has a stranger ever made them feel really uncomfortable?

Next, talk to them about how we act around strangers—we are polite, but cautious.

- Talk about how strangers are different from other people. Some are nice, and some are not nice. Emphasize that we don’t accept a ride in strangers’ cars. The same applies to accepting gifts. Talk about the reasons behind not accepting rides and gifts.

Then, talk about the idea of touch with the people in the fourth circle.

- Let your child know that there is no touching.
- When you are introduced to a stranger by someone you know and trust, then you can shake the stranger’s hand (but only if you want to).
Remind them that you don’t have to be mean to strangers, unless they make you feel uncomfortable.

Activities for understanding emotions

The next conversation you might have could be around dating and relationship skills. Those on the spectrum often find the world of emotions to be overwhelming and puzzling. They have problems labeling and recognizing their emotions and understanding the emotions of others.

- Identifying and labeling emotions in photos

Using the camera or phone, take photos of people displaying emotions, both positive and negative. Print out the photos. Label them and discuss these emotions. Have your child recall incidents when they have felt such emotions. They could put the photos in an album with emotions labeled to refer to in the future.

- Identifying and labeling nonverbal clues

With the photos above, ask them to look for nonverbal clues in the facial expressions or body language that help them label an emotion. Have them list the nonverbal clues.

- Using role-play to identify and label emotions and nonverbal clues

Role-playing is a great tool to help high-functioning kiddos recognize their emotions and the emotions of others. Take turns role-playing and guessing each emotion. Have each person freeze halfway through his/her role-playing turn so others can point out facial expression, tone of voice, and nonverbal clues.

- Brainstorm as many different feelings (above) as they can

Group similar feelings (for example, angry, mad, furious, etc.). Draw a four-columned table on another sheet of paper. Label the tops of the columns with these terms: Feeling, Situations, Physical Cues, and Body Language. Take each feeling or group of feelings and put them in the chart.

Other topics: sexual maturity

Every person needs to learn practical information and skills related to puberty, body changes, different types of relationships, modesty, and appropriate displays of public behavior. It is important not to assume what your child knows or will pick up instinctively, or how well they comprehend what they are hearing and seeing. Because of the high risk of sexual abuse in autism, it is important they be taught how to take care of their bathing and hygiene needs themselves.

Talk about puberty before their body starts developing. Otherwise, a girl may think she is bleeding to death when she has her first period and a boy may think he is “wetting the bed” when he has his first wet dream.

They may not be ready for some information about intimacy and sexuality, but they will need to have some sex education to reduce risk of behaving inappropriately or being sexually abused. Teens and adults who work or engage in the general community will be hearing their peers discuss the subject and need to be aware of what it all means.

Discussing sexual maturity with your autistic child

How and when you decide to discuss different topics will depend on how much understanding the young teen or adult has. Explain to the person as if they understand, then back it up with visual and auditory input in the form of social stories.
If necessary, do a task analysis (step-by-step routine) of sexual activities or use a word or picture schedule for hygiene activities.

Getting down to the real talk

Provide reassurance about feelings and wanting to be close to someone, but emphasize that any expression of feelings has to be consensual. Talk about appropriate and safe ways in which building of a sexual relationship occurs. Sexual feelings are private, but can be spoken about to your partner.

Here are some ways you might want to explain things to your child:

- On masturbation

This is sometimes called “playing with yourself”. This is when you touch your own genitals. Sometimes two people touch each other and that is called mutual masturbation.

- On sexual intercourse

Sexual intercourse usually follows kissing and touching and cuddling (but you can also kiss and cuddle without then having intercourse). The man fits his penis into the woman’s vagina, sliding it in and out. After a while, sperm might travel from the penis into the woman’s vagina and uterus. It might then fertilize an egg and a pregnancy can occur.

For sex to be legal and enjoyable, both people have to want to have it, and there should never be pressure to have it. Sexual relationships should involve good communication between the couple. They need to be able to talk to each other and let each other know what they like and enjoy and feel.

It is important to make sure protection is used (rubber or oral contraceptives) so that intercourse doesn’t produce a child until the couple is ready. Sometimes people do not want to have sex; this is called celibacy. Virginity is when the woman or man has never had sexual intercourse. First-time sex can sometimes be uncomfortable; some bleeding could occur.

Some extra information you could share

- The age of consent is usually 16, but differs in certain places around the world.

- Different families/cultures and religions have different thoughts about sex; it’s always a good idea to get to know the people in your child’s life

- Sex is private

- Sex shouldn’t ever be forced upon anyone

- Discussion about sexual abuse and rape

Resources

- Sexuality: Your Sons and Daughters with Intellectual Disabilities by Karin Melberg Schwier and Dave Hingburger

- The Growing Up Book for Boys: What Boys on the Autism Spectrum Need to Know! by Davida Hartman


- Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger’s Syndrome by Sarah Attwood
Karen Kaplan, MS just completed ten years as Executive Director of Wings Learning Center, a school for children 5-22 years old with Autism Spectrum Disorders, located in Redwood City, CA. She served as an instructor in the Autism Spectrum Certificate program at Alliant University. She completed her BS and MS in Speech Pathology from ASU. She minored in Special Education and holds an Educational Administrative Credential and Moderate to Severe teaching Credential.

Karen has sat on non-profit boards to help build capacity for those with special needs. She founded and directed a residential school for nearly 20 years in Sacramento. She is an author and speaker. She spent time globally helping non-governmental agencies in Indonesia and Africa. Currently she is consulting with families, schools and adult programs.

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

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Autistic Health and Medical Info
What is a Behavior Intervention Plan?

By Carol TATOM, RBT

A behavior intervention plan, or BIP, is used by schools and therapists to help families alter or change maladaptive behaviors in children into more appropriate and functional behaviors. A behavior intervention plan works by using a reward system and the use of positive reinforcements to increase the occurrence of more acceptable behaviors.

BIPS often form part of therapy plans for children on the autism spectrum. Behavior intervention plans also work well with neurotypical children who are having problems with behavior at school and at home.

How do professionals determine if a behavior intervention plan is needed?

Behavior health professionals look at many factors that could impact behavioral patterns. When
a behavior negatively impacts the child’s ability to learn, interact with peers, or function appropriately in social settings, steps are then taken with parents and teachers to discuss the implementation of a behavior intervention plan.

Behavior health professionals will use a variety of methods for collecting data when creating a behavior intervention plan. The professional may interview the parents to see what types of behaviors are happening at home and if there are any significant events in the child’s life that might contribute to behavioral issues.

Teachers with whom your child interacts may also be interviewed so that the behavior health professional can see what is happening at school and in their classrooms.

Functional behavior assessments may also be used in addition to the collection of data from the interviews. The functional behavior assessment is a tool that is used by behavior health professionals to figure out why a child is misbehaving.

All behaviors serve a function or purpose. It is the behavioral health professional’s job to figure out what purpose or function the negative behaviors serve. In that way, a personalized behavior intervention plan can be created and put into place, to start making positive changes in behaviors.

A behavior intervention plan is divided in three sections

- The first section defines what the problematic behaviors are. This comes from the data collected from parents, teachers, or the functional behavior assessment tool

"Behavior health professionals will use a variety of methods for collecting data when creating a behavior intervention plan."

- The second section provides an insight into why the behaviors might be happening. This section addresses the function or purpose the negative behaviors might be serving

- The third section details the supports, resources, or programs that will be implemented by behavior health professionals, teachers, and parents to decrease the occurrence of the unwanted behaviors and alter such behaviors. This will enable the child to be successful in a variety of different settings without behavioral problems

BIPS should be reevaluated for effectiveness

Behavior intervention plans, or BIPS, should be reevaluated often to ensure effectiveness. Sometimes the purpose or function of a negative behavior is not accurately portrayed during an assessment, which can hinder the programs or supports put in place.

For example, if you have a child who consistently acts up during group assignments, a logical assessment might conclude that the negative behaviors are serving the purpose of seeking attention. A behavior intervention plan might have that child serve as the group leader or presenter of the project to fulfill the child’s need to have the extra attention,
therefore decreasing the negative behaviors in the classroom when working on group assignments.

If the behaviors do not change or increase, a reassessment might show that attention seeking was not the purpose or function of the behavior. The child may have shown negative behaviors because they were academically challenged and unable to keep up with his or her classmates. Engaging in negative behaviors would then fit the purpose of avoiding embarrassment or ridicule from classmates.

If the behavior intervention plan was not reevaluated, such new perspectives could have been overlooked. As you can see from this example, had the behavior intervention plan continued as originally written, having the child serve as the group leader or presenter of the project would have magnified the academic challenges and the teachers would have seen an increase in behavior problems from the student (in an effort to avoid embarrassment or shame).

**SUMMING UP**

If you have concerns regarding your child’s behavior at home or at school, seek out a behavior health professional or BCBA therapist to discuss putting a behavior intervention plan in place. Having an assessment done opens the door to a variety of different supports and resources for both the child and parents or caregivers.

Getting the right type of help can increase the quality of life for your child as well as increase social interactions and opportunities for personal growth. The type of behavior your child may need will change over time as they grow and mature.

Other factors like graduating from elementary school to middle school or middle school to high school can add new stressors and possibly new behaviors. Having a team of behavior health professionals to help you monitor and address situations, as they arise, can help eliminate unnecessary stress and promote healthy coping skills for both child and parents.

“**If the behaviors do not change or increase, a reassessment might show that attention seeking was not the purpose or function of the behavior.**”

**Carol Tatom, RBT** is a mother of four children, including a child with autism. She works as a behavior technician for Autism Response Team Texas and has served on the committee for the Dallas Chapter of Autism Speaks for three years. Carol is currently finishing her bachelor’s degree in Human Services with a concentration in Child and Family Services. When Carol is not working, she is often found volunteering within the autism community.

"**My son is so happy with himself, you can see the joy!**"

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"**He advanced from 3.4 to 5.8 score in reading!**"

"**His teacher said he has never seen a student advance so quickly, especially in math!**"

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Autism Assessment: What Parents Should Know

By Wendi L. JOHNSON, PhD, Olivia KING, Jasmine HAMMER, Hannah HAGLER, and Briana PAULMAN

FOR PARENTS WHO MAY BE WONDERING ABOUT THE PROCESS OF OBTAINING AN AUTISM DIAGNOSIS FOR THEIR CHILD AND WHAT FollowS AFTER A DIAGNOSIS, THIS ARTICLE COULD HELP.

When parents first wonder if their child is on the autism spectrum, feelings of concern may arise along with questions as to what to do next. This review provides an overview of what criteria are examined by clinicians, as well as what the initial assessment process entails. If a diagnosis is made, guidance is also provided for parents to access services to help support their child’s continued success.

Diagnostic traits of autism
There are several areas to be evaluated by clinicians based on the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) criteria for autism spectrum disorder. The two main areas are deficits in social communication and restricted, repetitive patterns of behavior (American Psychiatric Association [APA], 2013).
First, deficits in social communication must be seen across multiple settings (e.g., at home and at school). This includes deficits in social-emotional reciprocity, such as limited sharing of emotions or interests or failure to engage in back-and-forth conversation (APA, 2013).

The child may also approach social situations in an unusual way or fail to initiate social interactions altogether. Additionally, deficits in nonverbal communication will be seen, such as poor integration of verbal and nonverbal communication (APA, 2013). This can look like poorly modulated eye contact, lack of facial expressions, or difficulty understanding and using communicative gestures.

Finally, the child may exhibit relationship deficits with difficulty developing, maintaining, and understanding relationships (APA, 2013). For example, the child may not be able to engage in imaginative play with peers or may have no interest in interacting with peers at all.

The second criterion is restricted, repetitive patterns of behavior. This can include stereotyped or repetitive movements (e.g., lining up toys, flipping or stacking objects) or speech (e.g., echolalia, idiosyncratic phrases) (APA, 2013). Additionally, the child may exhibit a strong, inflexible adherence to routine (APA, 2013). For example, the child may become distressed at minimal changes to his or her routine, have difficulty with transitions, and eat the same food each day. Highly restricted or fixated, abnormal interests may be observed, such as preoccupation with or excessive interest in unusual objects or topics (APA, 2013).

Direct testing consists of tasks or activities that a clinician will ask children to complete and observe their performances. Finally, this can include hyper- or hypo-reactivity to sensory input from the environment (APA, 2013). For example, the child may have an adverse or excessive response to certain sounds, smells, or textures, or visual interest with lights and/or movement. The child may also experience an indifference to pain or changes in temperature (e.g., wearing shorts and sandals in the middle of winter).

The assessment process

The assessment process can consist of direct or indirect measures to evaluate the child’s abilities. The process can be finished in one day or broken up across multiple sessions. Depending on the child’s age, a parent may be able to sit in the room during this process. However, portions of the evaluation may be completed in the testing room with just the evaluator(s). Depending on the site, there may be one or more people conducting the evaluation, such as a psychologist, speech language pathologist, and/or occupational therapist.

The testing process allows clinicians to measure a child’s abilities and performance in comparison to other children their age based on standardized norms. The assessment process can consist of both direct and indirect tools.

Direct testing

Direct testing consists of tasks or activities that a clinician will ask children to complete and observe their performances. These measures can consist of specific autism measures, developmental/intelligence assessments, and measures of language and social/behavioral functioning. The autism-specific tools evaluate symptoms of autism such as social skills, communication, and restrictive and repetitive behaviors.
Depending on the age and functioning level of the child, some assessments can be a combination of play-based tasks with toys and/or structured questions. Examples of these tasks can include the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) and the Monteiro Interview Guidelines for Diagnosing the Autism Spectrum, Second Edition (MIGDAS-2). The assessment process can also include measures of overall intellectual or developmental abilities depending on their age.

The most common assessments used for direct testing can include, but are not limited to, the Bayley Scales of Infant and Toddler Development, Fourth Edition (Bayley-4), Mullen Scales of Early Learning (Mullen), Woodcock-Johnson Tests of Cognitive Abilities, Fourth Edition (WJ COG-IV), Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V), and the Wechsler Preschool and Primary Scale of Intelligence, Fourth Edition (WPPSI-IV).

Regarding language measures, clinicians may examine pragmatic use of language, as well as receptive and expressive language functioning. Common language measures can include the Comprehensive Assessment of Spoken Language, Second Edition (CASL-2) and the Clinical Evaluation of Language Fundamentals, Fifth Edition (CELF-5).

**Indirect testing**

In addition to direct testing, an autism assessment may include indirect testing where people who know the child well can provide information from their perspectives, such as parents/caregivers and teachers. Examples of indirect measures may include rating scales (i.e., specific question probes with various answer options such as never, sometimes, often, or always) and an interview.

Many of these measures will ask for information about the child in a number of areas, such as when/if developmental milestones were met, current social interaction, sensory sensitivities, communication abilities, and restricted areas of interest. Some of the most common indirect measures used in autism evaluations include the Autism Spectrum Rating Scale (ASRS), the Autism Diagnostic Interview-Revised (ADI-R), and the Childhood Autism Rating Scale, Second Edition (CARS-2). However, each evaluation is individualized and may include different measures that address various concerns related to autism.

After the assessment is completed, the data are compiled into a report and the diagnostic criteria are reviewed to determine applicability to the child. Results are reviewed in a feedback session where the parents meet with the evaluator to discuss the results, observations made during the evaluation, and diagnostic conclusions. The evaluator will also discuss recommendations with the caregiver regarding concerns that were identified during the evaluation.

**After obtaining an autism diagnosis**

Should a diagnosis be obtained, the next step would be to consider the options for services and interventions. According to federal law, public school districts are required to provide services to children with disabilities that can impact their educational needs, including autism.

> Should a diagnosis be obtained, the next step would be to consider the options for services and interventions.
Children under the age of three years are provided services through state-run Early Childhood Intervention (ECI) programs, and children over the age of three years are served by the local public school districts. Children do not have to be a current student at the district to seek services, so children who are homeschooled may also be eligible for services.

Services through ECI are income-based and individualized based on the family’s resources; whereas there is no charge for school services. The school district may choose to conduct their own evaluation to determine the needs of the child, or they may choose to accept an evaluation from a private practice or clinic.

Schools can provide a variety of services through special education programs provided by the Individuals with Disabilities Education Improvement Act (IDEIA) or through the Section 504 program, and such services may include accommodations in the classroom (such as preferential seating or extended time), access to special education classrooms, social skills training, parent training, transportation, and speech, physical, and occupational therapy.

For more information about school-based services, parents can contact the local school district’s special education department. Intervention services may also be provided through home health (i.e., speech therapist coming into the home), walk-in clinics for Applied Behavior Analysis therapy, and/or occupational, physical, or speech/language therapy needs.

Private therapies are often covered by insurance. Parents can check with their provider to see how many sessions or what type of services would be covered.

If concerns arise related to a possible autism spectrum disorder, parents should obtain a comprehensive assessment to determine the need for intervention services. While the assessment and diagnostic process may seem daunting, parents are encouraged to advocate for their child and seek support through local providers. Early intervention to target social and communication needs is crucial to provide support for long-term success.

REFERENCES:


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Choosing the Best Educational Option For Your Autistic Child

By Ronald I. MALCOLM, EdD

A DETAILED OVERVIEW OF THE DIFFERENT EDUCATIONAL OPTIONS AVAILABLE FOR CHILDREN ON THE SPECTRUM.

It has often been said that if you’ve met one child with autism, then you have met one child with autism. Parents can easily become overwhelmed with trying to address all the needs of their child with autism.

Anxious parents often worry about deciding on the most appropriate educational setting for their child. The educational program that is best for your child may be totally different for another child on the spectrum.
Public schools

PUBLIC SCHOOL CLASSROOMS

There used to be a time when students with autism did not attend public schools. The term “autism” was misunderstood by many individuals, including educators. The term had educators envisioning a child with no speech or language, sitting on the floor, repetitively spinning plates. Thankfully, we have seen a radical change in the view of most educators and also an improvement in the services that are available for children with autism.

Not every child with autism presents with academic challenges or delays. Many are able to attend the same educational programs as their peers. While some students with autism require an Individual Educational Plan (IEP) or a 504 Plan, others may not require any of these services. There are many students with autism who are able to successfully attend their public neighborhood school system.

One of the greatest benefits of attending a public school is that your child with autism will have the opportunity to interact socially with many different kinds of students—neurotypical and possibly neurodiverse.

“ Not every child with autism presents with academic challenges or delays. Many are able to attend the same educational programs as their peers. ”

PUBLIC SCHOOL WITH RESOURCE ROOM SUPPORT

You may want your child to attend the public school system, but he/she may still require specialized instruction to meet academic, social, and behavioral needs. Your child with autism may require additional support with reading, writing, or math skills.

Children on the spectrum sometimes require assistance with peer relationships or behavior regulation. Other children with autism may require
speech and language therapy, occupational therapy, adaptive physical education services, or physical therapy to be successful throughout the day.

Some special education teachers may do “push-in” services. This will involve the special education teacher going into the regular education classroom and working with your child in that setting. Other special education teachers may provide “pull-out” services. This will involve your child leaving his/her regular classroom and going to the special education classroom for individual or small group sessions.

PUBLIC SCHOOL WITH FUNCTIONAL SUPPORT

Your child with autism may have various health-related needs, severe behavioral needs, an intellectual delay, or he/she may be nonverbal. If your child is attending a public school, he/she may require the services of a functional classroom either all day or for a part of the school day.

Some children on the spectrum require support with alternative communication methods, toileting skills, feeding skills, etc. Many of these students may still enjoy going to art, computer class, physical education class, or music with their peers.

Others may enjoy interacting with peers during library time, recess, or in the cafeteria during lunch. These are all great environments for children with autism, who may have a functional need to practice conversational skills.

PUBLIC SCHOOL WITH ABA SUPPORT SERVICES

Some students with autism may be fortunate enough to qualify for Applied Behavior Analysis (ABA) services. Individuals trained in ABA therapy, such as a Board Certified Behavioral Analyst (BCBA), can come into the school and assist educators with different ways to work positively and productively with children on the spectrum. Some children with autism may be on a modified schedule at school to attend outside therapy at an ABA Center—or even within their own home.

Private Schools

Some children with autism attend private schools. This may be the most appropriate choice for a variety of reasons. Some parents prefer private schools due to smaller class sizes; others want their children with autism to attend private school with their siblings. Keep in mind that private schools are not under the same mandate to provide your child with autism specialized instruction (or services) as the public school system is.

It is important for parents to share the fact that their child has autism with the staff at the private school. This may help them understand some of the specialized needs of your child, such as the use of noise-canceling headphones, access to fidgets, how to make transitions occur smoother, etc. Some private school teachers have had experience with other students with autism. They just need to be aware of your child’s diagnosis.

PRIVATE SCHOOLS FOR CHILDREN WITH AUTISM

A parent may want their child to attend a private specialized school for children with autism. These schools deal specifically with students on the spec-
trum. The staff employed at these schools are generally specialists that have been trained to deal with the academic, social, and behavioral needs of students with autism. Of course, a possible drawback of this type of educational setting may be that your child will be attending school only with other children with autism.

**Homeschooling**

Some parents may want to keep their children with autism at home. This can be done for a variety of reasons. Some parents homeschool for religious reasons, while others simply homeschool because they have always homeschooled and want to keep their child in the same program at home with his/her siblings. Others may have tried public school and been dissatisfied with the results.

The biggest benefit of homeschool is that you have direct input into the daily instruction of your child, as well as being able to see his/her daily progress. If you are homeschooling your child alone, it will be important for you to involve him/her with other homeschool families so that he/she can practice social skills with other children.

**Home-public school combination**

You may be homeschooling your child with autism. However, your child with autism may have a specific skill in an area that you are not comfortable providing. This could be anything from music to chemistry. Even though you are homeschooling, you can still approach your public school system to inquire about the possibility of having your child attend for a portion of the day. This could allow your child to become a band member, sing in the school choir, or take an advanced math or science class.

**Day treatment programs**

Many school districts have established day treatment programs. These programs generally deal with children with severe autism and/or children with emotional disturbance. These programs have specialized staff who work with children with severe behavioral needs in a small group setting.

Some of these students struggle daily with self-regulation, as well as exhibiting aggressive behaviors towards themselves or others. One of the main goals for students attending day treatment programs is to provide them with the academic, behavioral, and social skills necessary when returning to their public school programs with their peers.

**Residential settings**

Some children with autism present with serious behavioral and emotional needs. They may exhibit self-injurious behaviors or become extremely difficult to maintain in their own home for safety reasons. Some parents may select a specialized residential setting. This will be a program with trained staff members, teachers, and nurses.

This type of schooling may involve the child living at the school and receiving all their specialized instruction during school or within a dorm during evening or weekends. Parents can often visit their child at the residential school throughout the year, or he/she may be granted home visits for short periods of time.

Parents have a wide variety of options available to them to effectively educate their child with autism. Each child will have his/her own unique needs, and each option should be considered and researched. The goal is to provide the best education for your child as they navigate the world to become as independent as possible.

Ronald I. Malcolm, EdD is an Assistant Director of Special Education for a public school district, an Associate Faculty Member with the University of Phoenix, and a Special Graduate Faculty member at the University of Kansas. He has Bachelor Degrees in English and Special Education. He holds Master level Degrees in Counseling, Special Education and School Administration. His Doctorate Degree is from Northern Arizona University in Educational Leadership. His Post Graduate Degrees are in Positive Behavior Supports and Autism Spectrum Disorders. He has worked for the past 37 years with students between the ages of 3-21 with autism in various school and community based settings.
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An Autistic Man’s Point of View on Self-Stimulatory Behavior

By Michael TANZER

There are several opinions on self-stimulatory behavior, also known as “stimming”. This article considers the first-hand view of an autistic person.

I have heard varying definitions and reasons why self-stimulatory behaviors occur in people with autism spectrum disorder (ASD). The explanations are frequently from those in a position of treating or serving the ASD community, instead of coming from an individual who is diagnosed with autism.

I am not discounting the many years of medical expertise and knowledge from professionals, instead, I’m asking parents and professionals to also consider the point of view (POV) of someone on the spectrum. I am a young adult with autism who was first diagnosed around the age of three. I share my perspective on this topic with the hope of shedding some light and understanding on this puzzling subject.

What is self-stimulatory behavior?

To better understand self-stimulatory behavior, we must first attempt to define it. As a simple explanation, self-stimulatory behavior is an action that someone does repeatedly. For example, pacing, twirling hair, spinning things, lining up objects, rocking, biting their fingernails, flapping their arms, etc. Not only do these behaviors present in different ways, but the level of intensity also varies.

Some individuals can spend hours engaging in repetitive behavior, while others may do it sporadically. My POV is that every child diagnosed with
ASD (and even those without a diagnosis) may engage in some form of self-stimulatory behavior.

Why does self-stimulatory behavior occur?

Some people call it stimming. For me and many of my friends (who also have ASD), self-stimulatory behavior occurs because people on the spectrum may be “sensitive” to the world around them. These repetitious behaviors can help soothe and provide a sense of relief.

Stimming may calm a person down because it allows them to focus on just one thing and helps to take away some of the sensory overload they may be experiencing. In my case, stimming aids in managing anxiety. Believe me, there can be a lot of sensory things going on!

For others, stimming may be an opportunity to get into a rhythm that allows them to express a feeling of enjoyment. Another reason why stims may happen is because people with autism are trying to feel comfortable in their environments. My POV is that everyone is different and has their own unique sensory needs, so the reasoning behind stimming will also be highly individualized.

What are other reasons why people with autism stim?

There are so many different POVs on this topic. If you do not believe me, Google it and you will find out. I have heard some people say that they think a person with autism stims because they do not have good social (or play) skills. This was sort of true for me.

As a parent, it is important to determine why your child is self-stimming and if there is anything you can teach them to do instead.

When I was younger, I did not really know how to play or socialize all that well. My therapists spent many hours teaching me how to play independently and with other kids. Some self-stimming behaviors stayed with me and I continue to do them today when I am bored or anxious, but others have stopped.

I have learned to replace some stims with other behaviors and have learned how to change some of my self-stims, so they do not look too obvious when I do them in public. I cannot explain why some are easier to control than others.

Is self-stimulatory behavior ever a problem?

There may be circumstances where certain stims are uncontrollable, occur excessively in inappropriate settings, or can harm a person. Examples of problematic or harmful stimming can include hair pulling, biting, hitting oneself, hitting the head against something in a harmful way, or picking/nail-biting to the point of injury. My POV is that dangerous stims should be interrupted and stopped. Remember, not everyone on the spectrum does harmful stimming.

What can parents do about self-stimulatory behavior?

As a parent, it is important to determine why your child is self-stimming and if there is anything you can teach them to do instead. Over the years, my family and therapists have helped me manage my stimming to ensure that it did not become a problem for me in public (like when I am volunteering, out shopping, or at the movies).
You might have a different POV on stimming. Some people believe that you should never let people stim and others believe you should not stop a person from stimming. Well, if that is what you think, then okay, that is your POV. But do not forget to ask the person with autism what it is doing for them.

So, my POV on self-stimulatory behavior is that it may be a coping mechanism that can serve a variety of purposes. It really depends on the person you know!

Michael Tanzer is a young adult with autism. He is an autism advocate and has written articles for Autism Matters magazine (Autism Ontario). He has also written a book called MICHAEFLISM: My POV on Life With Autism based on his own personal experiences. He is sharing his Point of View (POV) on life with autism; he hopes that readers will gain a better understanding of individuals with ASD.
Henry appeared to be a happy baby and did all the things a baby would do. However, when he was about four years old I noticed that he wasn’t talking—not even saying simple words—yet his three-year-old sister was talking. He didn’t answer to his name and he would bump into things when walking or running. I had to keep a constant eye on him; I couldn’t relax because I was afraid something would happen to him.

The breakthrough moment

I ignored my fear for a while because children develop differently, but as time went on, I got very worried and decided to take him to Child Find for an evaluation and to get him into a preschool to help with speech. They were able to enroll him in school with a great autism teacher who was very kind and patient with him.

She was ready to work with him. I told her about the way he takes off running without warning; she said that she was ready with her shoes to run, too.

"He didn’t answer to his name and he would bump into things when walking or running. I had to keep a constant eye on him."
She was wonderful. She devoted a lot of time to him and helped him to learn new skills. I was so proud! She always kept in touch to let me know how he was progressing. She also informed me of anything he learned and made me feel very comfortable that he was in good hands.

I cried for about two years because I didn’t want to accept that he had autism. I didn’t know much about autism, so I did some research, and as time went on I had to accept it. I was still very afraid that he may never speak or do things that other children could do.

I always wondered if I would ever be able to hear him speak and tell me what he wants and likes (or what he doesn’t like). I had to guess all the time, but he proved me wrong. Now, at the age of 11, Henry can talk and tell me what he wants, he can ask questions, and he can dress himself. He can ride a scooter, which took him a long time to learn. He is still learning to read and write, but I know he’ll get there. He has come a long way and I’m so so happy—he continues to progress every day.

I just wanted to share Henry’s story and let parents of autistic children know never to give up hope. Progress may be slow, but they’ll eventually get there. But to get there, they need a lot of love and patience.

Eunice Obinim is a mother of four. She was born in Ghana and immigrated to the United Kingdom at the age of seven, before moving to the United States at the age of 19. Eunice was a professional hairdresser and became a homemaker about 11 years ago in order to care for her autistic son. She likes writing, reading, and spending time with her children.
Stephanie Smith: A Woman Driven by the Passion to Create Change

By Andréas RB DEOLINDA, BA, BSc

MEET STEPHANIE SMITH, A WOMAN DRIVEN BY HER PASSION TO CREATE CHANGE IN THE AUTISM COMMUNITY THROUGH EDUCATION.

Stephanie Smith is the recently appointed Deputy Headteacher at The Cavendish School, a state-maintained special free school for young people with autism in the UK—and the world’s first International Baccalaureate (IB) special autism school. Stephanie has been involved in the autism community for over 10 years. Her experience ranges from working within mainstream primaries, secondaries, and special needs schools.

Stephanie trained in Mathematics at Stanground Academy before going on to complete a national award for special educational needs coordination. Prior to joining The Cavendish School, she worked at Medeshamstede Academy in Peterborough, with almost 100 autistic students ranging between the ages of four and 16 years.

Stephanie shares that her journey within the autism community started because of personal interest. She attended a variety of autism courses, such as the National Autistic Society Early Bird course, and says: “Through this, I realized I wanted to become part of the solution for the educational difficulties that I could see around me in the autism community... I wanted everyone to be able to see the beauty and positives...”

Stephanie was inspired by a local Special Educational Needs & Disabilities Coordinator to become a teacher and pursue her ambition.
A challenge Stephanie says she faces within her work is the prejudice and judgment within the world of autism education. She believes The Cavendish School is important to challenging stereotypes and building a strong and diverse community.

**Accomplishments**

Stephanie's accomplishment is centered on how empowered her students become.

“I enjoy seeing my students grow to be happy and successful young adults who are engaging with their communities, further education and work, and knowing that I have given students the ability to be able to express their own voice and advocate for themselves,” she says.

Stephanie is also proud to have nurtured, trained, and supported other professionals within her field to understand how autism affects young people and their families.

**Inspirations**

Stephanie is inspired by students and young people every day. This inspiration, she says, “stems from how hard they work to be a part of their communities and achieve their goals.”

She adds: “They don’t have the option of giving up to make the world a better place for them to live in and neither do I.”

**Goals**

Stephanie’s focus is to manage The Cavendish School the right way, with a holistic curriculum focused on the individual needs of each student.

Stepahnie explains: “The Cavendish School holds the student at its heart, and this includes providing a community and understanding safe space for the whole family.” As part of her role, she aims to support families through the complexities, struggles, achievements, and joys of raising a young autistic person.

“The purpose of The Cavendish School is to create a safe and nurturing environment so that the young child can be themself and thrive.” Stephanie concludes. “This allows the focus within the home to be about family life.”

**Advice for families affected by autism**

Stephanie encourages families affected by autism to not manage everything on their own as there are wonderful support groups and communities out there, including The Cavendish School.

Her message is to take one day at a time and celebrate all successes—especially the little ones.

**Andréas RB Deolinda, BA, BSc** is an advocate for children with special needs, especially those on the autism spectrum, and serves as an Editorial Assistant for *Autism Parenting Magazine*.

She was born in Congo, Brazzaville, and grew up in South Africa where she pursued her studies. Andréas holds a BSc degree in Biochemistry and Psychology, a BA Honours degree in Drama Therapy, and a BA Honours degree in Psychology. Professionally, Andréas has taught at two remedial/special needs education schools as well as running workshops for children in neurotypical schools in South Africa. Her passion is writing and impacting the lives of children with special needs through education.

She is also a poet and runs an Instagram account where she shares her writings in both French and English.
Supporting Parents of Children with Autism and Pathological Demand Avoidance

By Sandy TURNER BEd (Hons) NPQH and Judy TURNER BEd (Hons) Adv. Cert. Child Focused Therapy

Pathological demand avoidance (PDA) is characterized in children by a continual resistance to everyday demands through social manipulation which has, at its root, an anxiety-driven need to be in control. This inability to cooperate with simple requests can make everyday family life a battlefield.

It’s unfortunate that motherhood is subjected to external opinions/judgment; this is often the case for parents raising a child with PDA. This article offers some tips for parents experiencing “bad press”.

Pathological demand avoidance (PDA) is characterized in children by a continual resistance to everyday demands through social manipulation which has, at its root, an anxiety-driven need to be in control. This inability to cooperate with simple requests can make everyday family life a battlefield.
Parents have to make constant adjustments to get through the routines of the day, and this is exhausting. In the long term, this becomes such a normal way of living that parents forget what it is like to live an ordinary family life.

The stresses of living this way are enormous, and most parents have felt at one time or another that they have reached the end of their resources, and they don’t know where to turn for help. As friends, wider family members, or professionals, we need to be the support mechanisms that parents need to adjust successfully to the complex situations they find themselves in.

“One of the hardest things I find about parenting a child with demand avoidance is that sometimes they appear so normal that others think there isn’t a problem—but I know I can never relax—others don’t see the groundwork and the thinking I have to do to make the simplest thing a success; it is completely exhausting,” says the parent of a child diagnosed with PDA.

Common negative experiences

Parents of children with PDA tend to have some common experiences when dealing with professionals in the formative years. Knowledge of the condition is still limited amongst early help providers. This often translates to parents being told that there isn’t a problem with their child but that their parenting style and a lack of consistency is at fault.

Many parents have attended parenting courses where they have been taught to put in stronger boundaries with a series of rewards and sanctions for wanted or unwanted behavior. This approach tends to increase the anxieties in children as a direct result of the increased demands, and therefore the need to resist is stronger. This leads to exacerbated avoidant behaviors and a sense of confusion for the parent.

Many parents begin to believe such “bad press” when they cannot get their children to conform, however hard they try. In many cases, this has led to a deep-seated fear that their children will be taken away from them because they cannot help their children comply with societal norms and behavior. This may include being unable to prevent aggressive outbursts in the community, anti-social behavior such as stripping in public, not being able to get to school on time, or even being able to attend school at all.

By the time parents find a professional that knows about and understands the condition, they can be in a very precarious position with strained family relationships and a sense of despair that things will never be any different.

“I have tried everything that professionals have suggested to me and have been on so many parenting courses. Nothing works and I don’t know where to turn. I can’t go on like this” says the parent of a child with a demand avoidant profile attending a parent open day at The Link School.
Key support strategies

Thankfully, practitioner research on PDA has helped professionals and parents make discoveries about best practices for supporting families affected by this condition.

It is vital that professionals understand PDA presentation and the different ways it affects individuals, rather than assuming a parenting course will be the solution. Parents need to be listened to and their experiences recognized without prejudice.

Doctors should acknowledge the strategies that parents have discovered along the way to pacify and lower their child’s anxieties. Parents have often found some innovative and exceptional strategies that, when pointed out to them, will help them realize what extraordinary parents they are.

“I feel so much better about myself these days—I know I’m a good Mum and I can see that what I do every day is making a real difference to my son,” says a parent from the PANDA support group at The Link School.

Giving parents permission to try out unconventional parenting techniques can provide a huge sense of relief, particularly when these techniques prove (very quickly) to have a positive impact. Strategies like reducing/disguising demands, or depersonalizing demands to make an authority figure responsible for unpopular decisions, are easy to put into place and tend to be effective.

Being able to ignore rather than punish undesirable conduct can be very freeing, particularly when doing so prevents escalation of more challenging behavior. Positive interactions—such as parents exploring their child’s special interests—in combination with role play can often encourage the child to perform routines that must be done as a matter of urgency or safety.

It is helpful for parents to realize that they don’t have to work on every issue at the same time. Learning to prioritize concerns and choose appropriate battles to work on, with the support of a professional team, can give a sense of hope. Having other people to celebrate with on good days, and for commiseration on dark days, helps parents to maintain their efforts and even introduces humor and optimism into their lives.

“Thank you for always seeing the best part of my son, whatever he does. I no longer dread picking my child up from school because I know that even when he has had a bad day, you will say, ‘it’s a new day tomorrow,’” says the parent of a child with demand avoidance who attends The Link School.

Top tips for supporting parents

1. Research PDA so that you know challenging behaviors come from a place of anxiety rather than bad parenting
2. Give parents hope by valuing the child for the personality that is hidden behind the anxiety
3. Be honest about children’s difficulties, but always believe there is a solution
4. Understand that parents’ energies are often exhausted by looking after their child; they need support to advocate with professionals that may not understand the PDA condition.

5. Keep up with a child’s motivations and interests so that you have a way to engage successfully with them.

6. Allow parents to be more involved in their child’s individual learning programs if it helps reduce their anxiety and improves access to learning.

7. Be resolute through the tougher times to help parents overcome exceptional challenges.

8. Consider setting up a bespoke parent support group so parents know they do not have to manage alone.

Conclusion

Recognition of the PDA condition is improving among professionals and therefore, support for parents is more likely to be forthcoming in the future. It is vital that parents are not made to feel that their child is “just naughty” or that their child’s complex behavior is their fault.

There is evidence that, when given the right support, parents can recognize their strengths, overcome their negative past experiences, and develop the new skills they need to successfully parent their extraordinary children.

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Judy Turner BEd (Hons) Adv. Cert. Child Focused Therapy is a nurture group teacher and practitioner researcher at the same Academy. Sandy leads a team of staff committed to child-centered learning approaches and solution-focused interventions aimed at overcoming learning barriers, in order to impact positive futures for young people with special needs.

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https://linkprim.org.uk

Autism Parenting Magazine

READ IT NOW

READ IT NOW

READ IT NOW

READ IT NOW

READ IT NOW
Mirrored Stranger

A poem about mirror-touch synesthesia.

By Andréas RB DEOLINDA, BA, BSc

A clone to your touch.

Innocently,

As if enslaved to you,

I share what you feel.

Behind this glass,

I am invisible to you,

Yet somehow,

You tempt me with every touch.

You limp, I limp.

You scream, I am your echo,

As you melt into the hand of your dear one,

I too perceive that touch.

I don’t choose it,

If only you knew!

Andréas RB Deolinda, BA, BSc is an advocate for children with special needs, especially those on the autism spectrum, and serves as an Editorial Assistant for Autism Parenting Magazine. She was born in Congo, Brazzaville, and grew up in South Africa where she pursued her studies. Andréas holds a BSc degree in Biochemistry and Psychology, a BA Honours degree in Drama Therapy, and a BA Honours degree in Psychology. Professionally, Andréas has taught at two remedial/special needs education schools as well as running workshops for children in neurotypical schools in South Africa. Her passion is writing and impacting the lives of children with special needs through education. She is also a poet and runs an Instagram account where she shares her writings in both French and English.

@andy_deolinda
When I was writing my first novel, my editor told me that an ordinary child narrator and/or protagonist was not enough for an adult audience. A child, he said, needed special, even supernatural qualities to keep a reader’s interest.

Strangely, this same rule seems to apply to fiction about autism. The popular portrayal of autistic protagonists is of men and women who struggle with ordinary, daily life, but who can replay an entire Mozart sonata after hearing it once or win a chess game in a few deft moves.

The savant myth took wings with Rainman and continued with Motherless Brooklyn, The Curious Incident of the Dog in the Night-Time, and dozens of other novels. While these books delivered autism...
into a broader pool of understanding, they have also warped the collective imagination.

Many people believe that just below the surface of any autistic person, a genius is waiting to be freed. This myth has become so pervasive that when I tell people that my autistic son can only do basic math or barely unriddle which shoe goes on his right foot, I have heard: “He must still think like an encyclopedia?” or “when you do find out what he’s good at… you might be rich.”

For the exceptions where an autistic narrator doesn’t have some special super-talent, they are, at least, high-functioning. They can read, write, take public transportation, live independently, and date.

High-functioning people with autism or aspies (from asperger’s) comprise a very slim fraction of people on the autism spectrum, but they take an inordinate amount of space in the literary imagination, public conversation, and resources designated for the middle or low-functioning.

In fact, advocates for the middle and low-functioning have drawn a line in the sand with: “If you can read this, then you don’t have autism.” Unfortunately, the contention between the defenders of high- and low-functioning has become as contentious as our political system, turning every attempt at policy into theater.

My son’s world

My autistic son stands right in the middle of the spectrum. The very definition of autism is someone with impaired communication, so for him dialogue is a Herculean task; chit-chat is overwhelming; connecting with other teens casually is (after a lifetime of speech and social therapy), nearly impossible. Often turning inward, he has become a teenager who constantly talks to himself, has imaginary friends, listens endlessly to all kinds of hip-hop, makes drawings of anime women, and loves going fast whether it be on a sled or a scooter.

Unfortunately, I have been teaching him for years how to turn on the shower, wash his hands, clean his face, put his shoes and shirt on correctly, brush his teeth, etc. He learned to read at the age of 13, and is still at a very basic level. He can’t comprehend time and asks me every day: “When does school start?” He has an extraordinary ear, especially for music, but instead of being a savant, he is more obsessed, like the protagonist in *High Fidelity*.

While I regularly stumble under the emotional, existential weight of having a child who might never be independent, my son gets up every morning smiling, singing to himself, and maintaining a warm disposition throughout the day. Unlike the stories of high-functioning children with autism who get picked on in school or don’t necessarily fit in social circles, my son has been turned away from dozens of schools, simply because they do not know how to educate him. Worse, most kids, even the quirky outcasts, simply don’t understand his constant utterance of verbal associations; his indecipherability sends them fleeing with flustered back-glances.

His mind is fuzzed, his inner-balance wobbly. Every day, he fights strange impulses, tantrums, and ran-
dom prickles from his autistic brain. He will show up with all his clothes backward and inside out or freeze in humiliation when someone yells at him: “Can’t you read the sign?”

I become incensed when someone cuts me off in traffic or we run out of orange juice for breakfast. His autism has shortened my fuse. But I have also come to realize that my temper is weighted by pessimism and has become my shackles, while my son’s enduring optimism, his persistent glow, is a kind of superpower.

I went to school during a time when our textbooks were full of Jack London’s Alaska and Hemingway’s symbolism of fisherman reeling in giant fish. We had Dorothy Parker’s African-American maids working on the frigid Upper West-side and Zora Neale Hurston’s African-American maids working in the oppressive Floridian heat. Literature was driven by the struggle of the common man and woman against daily indignities. My high school teacher quoted the line from Eliot’s The Love Song of J. Alfred Prufrock: “With a bald spot in the middle of my hair —” exasperatedly and excitedly, concluding, “The everyman against the daily is heroism.”

Movies like the Peanut Butter Falcon are doing what Rainman did, to bring disability into a more realistic light. But the shift to reflect the experience of the majority of people with autism is still distant.

When I set out to write a novel modeled after my son, I made the conscious decision not to have either a high-functioning autistic protagonist or one with special talents. The protagonist is a boy, like my son, whose challenges are interior, whose daily struggles with a body and mind work against him, and who, through it all, still holds hope for a brighter future.

His mental stamina, his incredible will to learn, his ability to get out of bed everyday in the face of great odds makes him and those like him worthy of admiration and praise, especially within the pantheon of fiction. The struggle with autism or any disability should be championed for precisely what it is: man and woman against nature and the character revealed in the struggle.

Erik Raschke was born and raised in Colorado, and received his Master’s in Creative Writing from City College of New York. He now lives with his wife and three boys in Amsterdam.

Finding a dentist for children can be a struggle, but it poses additional concerns for parents of children on the autistic spectrum. Nationwide, more than 52 million people in the U.S. have special needs. Unfortunately, less than 10% of dentists treat patients with disabilities because of their lack of training and the patients’ adverse reactions to standard dental procedures. For this reason, access to specialized care such as dentistry is among the leading healthcare concerns for people with special needs.

As the parent of a child on the autistic spectrum, I can attest that the search for a dentist who would make my son comfortable was not an easy one. I want to help parents in a similar situation better
navigate the process of finding their child the right care—and also how to prepare him or her for a trip to the dentist.

Why children with special needs require special care

Going to the dentist can be incredibly overwhelming for children with sensory issues or autism spectrum disorder (ASD). The bright light, the feeling of the cleaning, the loud noises, or even X-rays (if necessary), can create not just anxiety but physical discomfort.

“One of the most common facets of care for patients on the spectrum includes the use of desensitization visits,” said Dr. Mallory Marquie of Tooth Works. Tooth Works is a female-led pediatric dental practice located in the Upper West Side of Manhattan. They specialize in providing comprehensive dental care for both children and special needs patients.

“While a neurotypical patient may be able to complete an exam, cleaning, and X-rays all in one appointment, children on the spectrum may require several appointments to work up to just one aspect of our check-up. These shorter, focused visits help build trust with the provider and establish familiarity with the patient regarding various dental experience components.”

“Perhaps the most important factor in tailoring our treatment approach involves taking cues from the patient to help create an environment that eases any anxiety surrounding the visit,” she adds. “Modifications in lighting, the use of headphones and sensory-stimulating toys, the presence of weighted blankets, and even just the consistency of returning to the same room each visit are some of the various ways we approach care for children on the spectrum.”

Dr. Marquie further explains: “Parents, caretakers, and therapists are our greatest resources for making these visits successful, so their knowledge of the child’s responsiveness to prompting and modeling and how the patient tolerates flavors, textures, and touch is immensely helpful in making progress as a team.”

Dr. David Jourabchi, DDS of The Pacific Dental Services® (PDS) Foundation Dentists for Special Needs, agrees. PDS Foundation is committed to making oral healthcare more accessible and provides individualized care through a first-of-its-kind dental clinic in Phoenix, AZ, with future clinics, training, and advocacy.

“The obstacles to care for individuals on the spectrum can vary greatly,” said Dr. Jourabchi. “However, they typically include varying speech levels, tolerance to sounds, lights, and new sensory stimuli. When patients arrive, they are introduced to our sensory room. We have sensory stimuli that can be modified for each individual’s preferences, including sensory tiles, fish tanks with bubbles, and galaxy lights. The sensory room allows patients to
interact with team members and prepare for their dental experience. Following introductions in the sensory room, we show our plans to visit the patient and parents through pictures and words. This helps relieve some fear of the unknown as we embark on our dental journey.”

Both dentists stressed how vital communication with the parents or caretaker is. Questions include the following: Do they dislike certain sounds, textures, feelings? Do they like certain songs? Or does watching a certain show help them get more comfortable?

“With our individualized approach, we anticipate obstacles to care for each patient and modify our approach to providing care,” Dr. Jourabchi shared. “We celebrate all goals and accomplishments and understand that all individuals learn at a different pace. Our goal is to allow the patient to become desensitized to the dental office, and we work with the patient to know their comfort level and help them achieve the next step.”

Dr. Marquie also recommends employing symbolic imagery, also referred to as the picture exchange communication system, for patients with limited communication abilities. If you are a parent, she recommends creating picture boards for patients. This can help outline the visit’s objectives, include images of various parts of the office and tools to be used, and create a streamlined visual order of the appointment for the patient to follow along. She also encourages children who communicate through soundboards to use them during their visits.

“With our individualized approach, we anticipate obstacles to care for each patient and modify our approach to providing care.”

A dentist’s training and experience matters

While any dentist can treat children or patients on the spectrum, it doesn’t mean they have the understanding or the skills required to handle special needs patients optimally. For example, the doctors at Tooth Works all completed an additional two-year residency in a hospital-based program.

Their specialty training incorporated care of medically compromised and special needs patients, vast experience addressing dental emergencies and traumatic injuries, and completion of dental procedures in both the operating room and clinic using advanced sedation techniques.

The PDS Foundation Dentists for Special Needs have specially trained staff and an integrated sensory facility. They also host a residency program for pediatric residents from New York University Langone Dental Medicine. The program provides residents with one-on-one training focused on providing comprehensive oral health care to special needs patients. The program also offers pediatric residents training on special needs advocacy and guidance. Programs like this are crucial in helping dentists feel more confident in treating special needs patients.

When asked why so few dentists are prepared to work with those who have special needs, Dr. Jourabchi answered: “Providing dental care for individuals on the spectrum requires attention to detail, patience, effort, and the ability to think a little out
of the box to achieve a successful visit. Behavior modification protocols can help increase our patients’ tolerances to unfavorable stimuli, and most dentists learn them through their professional education. However, these interventions require flexibility, time, and patience.”

“I think it comes down to a lack of experience for many providers,” Dr. Marquie explained. “The curriculums and clinical training vary widely amongst dental schools, so a large percentage of new practitioners might not have gotten the opportunity to care for any patients on the spectrum before graduation. With the rise of pediatric dentistry and general practice residencies, doctors obtaining additional education can garner wide-ranging skills and broader knowledge caring for different populations, ultimately expanding access to care for special needs patients.”

Advice for parents and patients

Early visits to the dentist (six months after the first tooth erupts or by 12 months old) and oral motor stimulation are vital for all individuals, especially those with special needs. These experiences can help kids learn about the different stimuli they can expect at the dentist early on from a playful perspective.

Dental providers also play an integral role in evaluating dental-facial development and providing feedback on individualized home care, diet, and lifestyle goals. Starting early helps develop healthier long-term habits.

“When searching for a dentist, you can reach out to their pediatrician, therapists, and support groups who may have providers that they can recommend,” Dr. Jourabchi suggests. “Your dental provider may recommend scheduling more frequent dental visits (i.e. three month or four-month exam/cleaning) in place of six month recalls to allow kids to become more familiar with the office and provide your dentist more opportunities to closely monitor your child’s oral health and provide timely feedback.”

Dr. Marquie also recommends speaking to other parents of children on the spectrum. “The process of establishing a dental home for your child may take time, but completing multiple consultations with different offices is a great way to gauge each doctor’s approach and your child’s response, if you can do so. Many offices will also allow your child’s occupational or ABA therapists to accompany your family to the office, as they can be a great help in guiding the visits!”

Dentists should also provide you and your child with items and methods to prepare for the appointment at home. Ask for samples of the materials used during the appointment to work with your child at home, so he or she can become used to them—practice sitting in a chair, laying back, and opening the patient’s mouth. If there are any verbal queues used at home to calm or engage the patient, communicate those.

For those old enough who understand their sensory limitations, Dr. Marquie advises you to convey your preferences and needs to your doctor in any way that you can. “Verbalizing or giving cues regarding your sensitivities can start your relationship with
your doctor off on the right foot,” she said. “The
doctor-patient relationship is a collaboration, and
any provider who has experience with patients on
the spectrum will gladly accommodate your needs
when providing care.”

Dr. Jourabchi concurs that communication is crit-
ical. “Work with the office to make them aware
of your limitations,” he recommends. “And real-
ize that everyone deserves the best care, so don’t
settle. There are many great videos and pictures
on what to expect at a dental visit to help you feel
more prepared. Realize that your dentist is here
to help make your mouth and the rest of the body
healthy, and they will have tips and tricks to make
your visit more comfortable.”

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She is a Forbes Women Con-
tributor and has had piec-
es included in Time magazine,
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cy, relationships, parenting, being the mother
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As an infertility subject matter expert, she has
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contributed a chapter in the book, Women Un-
der Scrutiny by Randy Susan Meyers and per-
formed in the Cover Girl’s Stand Up for Beauty
with Aisha Tyler.

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Parenting the Hormonal Autistic Adolescent

By Eboni Jarvis

IDEAS FOR SUPPORTING CHILDREN ON THE SPECTRUM AS THEY ENTER PUBERTY, NAVIGATE HORMONES, AND EXPLORE RELATIONSHIPS.

As a working mom of three children, ranging from ages four to 15, it is safe to say that I have a lot on my plate. The thing is, all parents have a lot on their plates. We must be the therapist, the referee, the chef, the housekeeper, and too many more things to name. But, I believe that wearing those different hats is what it takes to be a great parent. Parents of children on the spectrum must be all of those things while supporting the social, emotional, and developmental differences in their children.

My oldest child was determined to be high-functioning on the autism spectrum around the age of four. He is smart and well-spoken about his interests. However, he has difficulty expressing his feelings and is awkward in social situations.

We had it kind of tough in his early years, as I was a single mom trying to navigate the unknown while still trying to support his health and development. As difficult as it was for me to learn the ins and outs of what was happening with my child, he still managed to be the sweetest, kindest, and most well-behaved child I had ever known.

My son made it easy for me to be a mom. Even as a pre-teen, we rare-
ly had many outbursts that couldn’t be resolved with some therapeutic conversation and breathing strategies we had learned from ABA therapists.

Now, he is a huge 15-year-old with high intelligence and an even higher level of hormones. I never got around to planning for raising a teenager. Furthermore, I never realized that my baby would not always be my baby and that his interests would change. Who knew?!

Meet my son

To understand my struggle, you must first understand my son’s personality. At a whopping six feet and 220 pounds, my son is a gentle giant. He would give the shirt off his back to anyone in need. He is an avid reader of non-fiction literary works and has a photographic memory. While not the type to spark up a conversation, when you spark his interest he will give you all the greatest facts about just about any topic. My son is shy, kind, and just all around a great guy.

Which makes it all the more difficult to handle situations regarding hormones, relationships, and sex. The average teenager his age will begin to show interests in sex and relationships while pursuing such mutual relationships in high school. An adolescent on the spectrum will likely have more trouble gaining those types of emotional connections with the objects of their affection.

While not the type to spark up a conversation, when you spark his interest he will give you all the greatest facts about just about any topic. My son is shy, kind, and just all around a great guy.

Keeping the door open for communication is essential during this time in your child’s life. They may feel misunderstood.

It can be difficult for them to understand and lonely for them to go through. Often, that level of loneliness they experience can lead to less-acceptable behaviors such as viewing pornography. This can be a slippery slope for teenagers on the spectrum because their understanding of sex can be greatly misconstrued.

As adults, we know that pornography does not provide a valid interpretation of what sex is. Our children are even more misguided as they don’t understand the emotional connections and the safety precautions that are required when engaging in such activities. How, then, do we carefully navigate this stage in autistic adolescent development without tarnishing our teen’s ideas or experiences with relationships?

There aren’t enough books published or blogs posted or articles written on this earth to help parents navigate each and every possible scenario. However, I have taken a few steps to help my son navigate his own personal experiences thus far, and I must say it has shown great promise.

The following steps helped my son navigate his personal experiences:

1. Communication

Keeping the door open for communication is essential during this time in your child’s life. They may feel misunderstood. So, reaching out to the child and initiating the conversation may work better than waiting for him/her to come to you.

One way to open the door to the conversation would be to purchase helpful books or magazines.
that will help explain hormonal changes and what is happening to his/her body. Sex is not a bad word and your adolescent should not feel bad about thinking about it or talking about it.

2. Therapy

Contacting a therapist or enlisting therapists already in your child’s life to help navigate through puberty and beyond is a great way to help both the parent and the child understand what is happening. It is not an easy task having conversations about sex and relationships with an adolescent on the spectrum. In some cases, it is best to get a professional to help guide the conversations effectively.

3. Reading

As mentioned above, supply your teen with plenty of literature to refer to. Give them options on ways they can find out more about sex and relationships. I would steer clear of having them search online as this can lead to more confusion than clarification. A good practice is to read the materials with your kids and even pick chapters or sections that are most relevant to your child and use them as talking points while discussing the book.

4. Support groups

Both parent and teen support groups can effectively help you get through this time in your child’s life by providing a shoulder to lean on when times get difficult or confusing for either of you. My son and I were in a group that supported both parents and teens in their own respective groups. I found out through that group that my son was not the only child struggling with understanding sex. It feels better knowing you are not alone.

5. Safety

Regardless of all the effort we put into teaching our children, while they are in this stage of their lives, it is likely that they will still be curious. That is normal. However, it is imperative that we keep them safe. Monitoring cell phone activity is important. Using parental controls on all devices will help reduce their chances of finding unsavory content or even coming in contact with online predators.

Utilize your TV provider’s parental security to minimize the possibility of your teen watching inappropriate programs and movies.
“ Our babies will always be our babies, but we are raising them to be productive adults in a world that does not always understand them. ”

Utilize your TV provider’s parental security to minimize the possibility of your teen watching inappropriate programs and movies. Children are resourceful and will likely find ways around many of these security blocks. The idea is that once security has been breached, you will likely be alerted. This will give you the opportunity to initiate the conversation about what is happening, how they are feeling, and what is safe and unsafe.

Our babies will always be our babies, but we are raising them to be productive adults in a world that does not always understand them. As parents of children on the spectrum, it is our job to stay in the know and, and even more importantly, to keep our children in the know. “When you know better, you do better”.

Eboni Jarvis is a Revenue Cycle Specialist for an independent laboratory in Chicago. She has worked in the healthcare field for over 12 years. With an education in both Healthcare Management and Psychology, she often uses her professional and educational experiences to help navigate motherhood and relationships. Aside from the daily hustle and bustle of work life, she enjoys spending a great deal of time engaging in fun activities with her family.
Jeanne Simons devoted her career as a social worker and educator to the study, treatment, and care of children with autism. In 1955, she established the Linwood Children’s Center in Ellicott City, Maryland, one of the first schools dedicated to children with autism. Her Linwood Model, developed there, was widely adopted and still forms the basis for a variety of autism intervention techniques. Incredibly—although unknown at the time—Jeanne was herself autistic.

Behind the Mirror reveals the remarkable tale of this trailblazer and how she thought, felt, and experienced the world around her. With moving immediacy, Jeanne tells her life story to developmental psychologist, friend, and collaborator Sabine Oishi. Jeanne’s unique experience is supplemented by commentary from Dr. Oishi, who explains the importance of key biographical details and fills in additional information about the diagnosis and treatment of autism. The story is enhanced with a photo gallery, a look at new approaches to the education of children with autism, and a history of Linwood since its founding. Demystifying the experience of autism, Behind the Mirror is a groundbreaking account of possibilities and hope.

Jeanne Simons, LCSW, ACSW (1910–2005), earned her degree in clinical social work from Boston College. In 1955, she founded the Linwood Children’s Center for children with autism in Ellicott City, MD, where she went on to pioneer a highly successful treatment approach. She is the author of The Hidden Child: The Linwood Method for Reaching the Autistic Child.

Sabine Oishi, PhD, was educated as a teacher and a child psychologist at the University of Geneva. She earned her PhD in child development and family therapy from the University of Maryland. Alongside Jeanne, she is the co-author of The Hidden Child.

For more information and to purchase, visit: https://jhupbooks.press.jhu.edu/title/behind-mirror

Use code HTWN at check-out for 30% off your order.
Autism hearts have very special gifts,
Mothers and fathers made a wish on a star, for their very unique child to go very far.
My child acts differently, they flap their arms.
My child loves to smile and loves talking about planes, trains, and cars, too.
My child, so kind, always ready to make friends.
My child's heart, so pure.
The courage comes from a place of love.
Their autism heart, what a wonderful gift to explore.

Amanda Harrinauth was diagnosed with autism in 2016 and started writing poems shortly after her diagnosis to cope. Her goal is to become a life coach and empower others with autism. She is a Special Olympics athlete who believes poetry has the power to change the world.
Importance of Understanding Behavior and Teaching New Skills

By Dr. Camille BRANDT

HAVE YOU REALLY CONSIDERED THE POSSIBLE CAUSES BEHIND MALADAPTIVE BEHAVIORS AMONG AUTISTIC CHILDREN?

Many children on the autism spectrum have difficulty regulating their emotions. Outbursts, acting in defiance, or fleeing a situation are examples of behaviors of children experiencing stressful situations that result in feelings of anger, frustration, or anxiety. Behavioral science suggests that all behaviors serve the function of either gaining something sought (attention, an object, an event, a sensory experience, etc.) or avoiding something unwanted (a task, something sensory-provoking, a person’s attention, etc.).
Learning to understand the behavior of a person on the spectrum will aid in identifying both skills to teach and strategies to put into place that best match the function of the child’s actions. While examining emotional responses, it’s important to understand a child’s language skillset and his sensory profile.

What do we mean by this? It’s not unusual for a person with non-typical development in language skills to develop a uniquely individual approach for expressing wants and needs. Similarly, a person with intense sensory needs may develop a repertoire of behaviors for either seeking or avoiding specific experiences or sensations.

**Tips to understand the behavior**

Careful and consistent observations across living and learning environments should reflect these questions:

1. What behavior am I looking at? Carefully describe the exact behavior.
2. What times of day is this behavior occurring?
3. What spaces and places does this behavior occur within?
4. Are there any people (adults or peers) associated with this behavior?
5. What appears to initiate the behavior?
6. What does the student gain or avoid from the behavior?
7. What are the immediate outcomes, or consequences, of the behavior?
8. What skill (or skills) does the student have in his/her strength skillset that could be targeted for teaching a more appropriate emotional response?
9. What skill or skills does the student not yet have that could be taught towards the development of a more appropriate emotional response?
10. What role do the student’s communication and sensory needs play in his/her emotional response pattern?

“Strategies to explore should center on teaching the child how to best indicate needs and wants through a total communication approach that works best for the individual child.”

**Behavior due to sensory stimuli**

Once a behavior is better understood and a child’s communication and sensory needs have been examined, a decision on the direction of intervention scope and purpose needs to be addressed. First of all, it must be determined if a behavior is motivated by a sensory need. If this is the case, a review of the student’s methods of communication should signal an instructional focus: what weak skill should be strengthened, or what missing skill should be taught that would enable a child to gain what is needed?

Strategies to explore should center on teaching the child how to best indicate needs and wants through a total communication approach that works best for the individual child. This may include a system to prompt communication such as using key words, picture or symbol cards, modeling, or giving choices either verbally or through a choice board array.

**Other possible causes for the behavior**

If it is determined that the behavior is not linked to a sensory need but instead is related to (a) avoidance or (b) gaining something desired, a review of current communication skills should yield, again, insight into what skills the child is applying in order to meet her needs and what skills need to be strengthened or taught altogether. Chances are, anticipating a child’s wants and needs within an environment will allow a parent, caregiver, or teacher to prompt the student’s response and pre-teach approaches through strategies that prevent frustration, anger, or anxiety.
If a student is beginning to demonstrate an emotional response, a consistent plan should be followed. Understand the source of the child’s reaction, determine if the anticipated behavior is related to gaining or avoidance, prompt communication that works best for this child, and remain calm and supportive.

The frustration of being misunderstood by those around them, paired with an inability to successfully communicate wants and needs, can lead to challenging behaviors in children on the autism spectrum. Embracing this core truth can allow the adults in the child’s life to center teaching skills that help to prevent behaviors linked to anxiety, frustration, and anger. The keys to success are to know the child well and to respond to individual needs through mindful observation and the consistent use of strategies that match the child’s demonstrated skill set, teaching what is necessary across environments.

REFERENCES:


“...The keys to success are to know the child well and to respond to individual needs through mindful observation...”

Dr. Camille Brandt frequently provides consultation to parents and caregivers with young children impacted by ASD. She is a Montessori educator and a university professor. Her areas of expertise include autism spectrum disorder, inclusive education, and curriculum and instruction. She has provided professional development on these topics and presented on related themes at state, national, and international education conferences.
How to be a True Friend: A Reflection on Belonging and Relationships

By Marcelle CIAMPI, MEd (aka Samantha Craft)

“Once, at the ANCA World Autism Festival in Vancouver, B.C., Canada, a very sweet and gentle Japanese lady—no older than her early-twenties—sat next to me during the screening of a documentary film. We sat together for the stretch of an hour, as complete strangers, shoulder to shoulder, her leaning down every so often to rest her head gently near mine. As if I was a long-lost aunt whom she was trying to remember.

She’d lift her head up, look at me, run her fingers through her shoulder-length hair and smile sweetly, before turning her eyes back to the film. Minutes
would pass. And then again, she’d grin, and repeat. She spoke without a single sound. Never a word. Not one. And it was one of the few times in my life that I felt entirely seen and heard.

Social scientists teach that a sense of belonging—the act of being a part of something outside of self—allows for the capacity to feel safe, valued, accepted, and supported—is an intrinsic part of one’s psychological and emotional well-being… A sense of belonging enables us to be part of something greater than self. Belonging signifies accessibility and invitation and the ability to find cultural references that confirm your value.”

The above prose is an excerpt from my new manuscript and soon-to-be book: *Autism in a Briefcase: Straight talk about belonging in a neurodiverse world*. The six-year writing project is based on my years of advocacy work for the autism community and on my role as a Senior Manager of Diversity, Equity, and Inclusion (DEI) at Ultranauts Inc. In my international teachings, I joke that I use the “B” word a lot: Belonging. Why? Because belonging is essential to feeling included—essential to feeling valued as a human being.

**The desire to belong**

Autistic individuals often struggle with multiple aspects of belonging. Throughout modern history, a disproportionate amount of blame has been pointed in the direction of autistic people. They are criticized for their “abnormal” presentation style and their general way of being.

A sense of belonging enables us to be part of something greater than self. Belonging signifies accessibility and invitation and the ability to find cultural references that confirm your value.

Agony Auntie, an autism advocate, shares the following about our communication: “...[it] comes across as abnormal (fixated, obsessed, rigid thinking, oppositional, manic)...The next stage is for people to really understand what the medical pathology narrative has done to this community. In that it has doctored your viewpoints of us. We have been looked at, down a microscope, for the last 60-70 years, and when you look at a community, as if they are mice, and study them, as if they are mice, you will make mice out of them.”

Research is citing the sociology theory of “double empathy problem” to counter social misconceptions and myths surrounding autism. Double empathy draws meaning from sociological theories.

Senior Lecturer in Psychology Brett Heasman presents a strong case in favor of the autistic experience through the lens of double empathy. Heasman successfully demonstrates that non-autistic people have challenges putting themselves in the shoes of autistic individuals and in understanding their perspectives, just as autistics have trouble putting themselves in the mindset of neurotypicals.

This information supports the thousands of anecdotal reports I have heard from those on the autism spectrum: non-autistics having trouble interpreting the autistic perspective. Both parties, the autistic and the non-autistic, have difficulty adequately interpreting what the other is thinking.
Heasman’s research also points out that autistic people have psychological awareness of themselves in conversation and that any “social impairment” is the result of others’ expectations and assumptions about their behavior.

Autistic people, like most humans, long to be included and part of relationships. There are numerous ways to engage in a relationship. For example: intimate relationships (romantic partner, confidant), work relationships (colleagues, schoolmates), community relationships (neighbor, church), supportive relationships (coach, doctor), activity-based relationships (gaming, hobby club), and service relationships (barber, book store clerk).

Each type of relationship involves unspoken rules and communication norms; and, for those on the autism spectrum (who are by nature not wired to instinctively tap into the social norms of Western society), each type involves social challenges.

For a person with autism spectrum condition (ASC), layers upon layers of complexities might arrive in simply approaching the idea of a relationship, let alone engaging in a relationship! For instance, when approaching a potential friend, there are complexities like small talk, past rejection and the reality of potential hurt, prioritizing and identifying a relationship, and bullying. Then there are matters of misunderstanding and assumptions, sensory overload and recovery time, anticipatory anxiety and self-doubt, acceptable topics, and finally, moving a relationship too fast or too slow.

### Ideas for building relationships

1. **Open dialogue**

   An effective way of building relationship knowledge involves opening up dialogue about unspoken rules and norms. Looking at other cultures, like the American Indigenous People, is a great place to start—notice that within some Native American nations eye contact is avoided, and no such word as disorder or disability is a part of their language.

   In conversation, consider asking: When have unspoken rules caused you trouble in trying to make a friend? What is difficult for you about unspoken rules at the park or school playground? Share your personal story of navigating unspoken rules. Other great questions to open dialogue are: What do you think is important in nurturing a friendship? Where do you struggle getting along with or understanding me?

2. **Ensure safety**

   Another important aspect of relationships is ensuring safety. Reflect on the ways all individuals are vulnerable to predators and dishonest people. Most autistics have great difficulties understanding boundaries.

   I wrote a piece on boundaries on my [Everyday Autistic WordPress Blog](http://example.com). Seeing it as an essential well-being issue, a university in Canada has published my boundary tips in their mental health handbook for college students. Boundaries can be confusing for anyone. Share what you’ve learned about boundaries and how they help with personal safety. Present scenarios of inappropriate friendship requests.
3. **Understand yourself**

Essential to nurturing a relationship is understanding yourself. To participate in healthy relationships, we need to self-reflect. We need to understand our own interests, passions, and dislikes. Building criteria for what makes a good friend is oftentimes a foreign concept to autistics. I didn’t realize I had the right to have criteria for friends until I was in my forties! I tend to think everyone could be a potential friend.

A part of understanding yourself is becoming aware of how you process emotions and present to others. To avoid misunderstandings and judgment, it’s wise to explore aspects of how those on the spectrum present differently in behavior than the majority of society. Discuss ways your child can feel seen and still be their true self. Talk about masking (suppressing autistic traits) and how that makes your child feel.

4. **Some friendships can break down—and that’s okay**

Other topics for conversation might include the transient nature of relationships. While some of us carry our childhood friends over into our adult lives, that’s not always the case. It’s a smart idea to talk about the stages of friendship grief or loss and to express it’s okay to feel sadness and regret over the loss of a potential or long-standing relationship. Distinguishing between emotions of sadness, guilt, and shame is advisable.

Pointing to autistic role models is a way to empower autistic youth to know life does oftentimes get easier. Remind your child that we all gain life skills through life experience.

Above all, continue to treat your child with dignity and respect. Be the advocate who understands the complexities of life on the spectrum. Let autistic children know their way of being is valued. Connect them with like-minded individuals who reinforce the validity of their personhood. Teach them by example to state their personal needs. Take your own self-inventory. Show them, through your behaviors, how to be a true friend.

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**Marcelle Ciampi, MEd (pen name Samantha Craft)** is a respected autistic author and worldwide advocate. She is best known for her writings found in the well-received book *Everyday Aspergers*. Her resources have enabled thousands of adults to receive an ASD diagnosis. A former school teacher, she has been featured in various literature, including the Stanford University project: ND GiFTS, ICare4 Autism, and *The Art of Autism*.

Considered an expert in the field of neurodiversity in the workplace, Marcelle has been quoted in multiple books and research studies. She serves as the Associate Director of DEI at Ultraauts Inc., an engineering firm with an autism-hiring initiative.

[www.myspectrumsuite.com](http://www.myspectrumsuite.com)
Understanding Sexual Identity

By Lt. Joseph PANGARO, CPM, CSO, MOI

UNDERSTANDING YOUR OLDER CHILD’S SEXUAL IDENTITY AND DESIRES ISN’T ALWAYS EASY. MEET ONE FAMILY THAT HAS SUCCESSFULLY NAVIGATED THIS JOURNEY.

Understanding our place in the world is difficult enough; trying to understand our human sexuality can make it even more difficult. This article is designed to help families of young people on the spectrum gain understanding of what they are thinking and going through as they go from young children to young adults—especially as it relates to their developing sexuality and identity, and in particular, their identity as a gay individual.

I met a family that has handled this situation really well, and I thought that sharing their story would be helpful for readers.

Meet Chris

Chris is a 23-year-old man on the spectrum. He is bright, articulate, and attends college.

Chris’s parents are Mike and Sheila, and he also has a brother and a sister. They are a loving family that interact with each other in very positive ways.

When I approached them for this article they all immediately agreed to participate and share their experiences to help others. Chris’s parents are good role models for effectively discussing sexuality with young people.

To get a sense of how a young person experiences their developing sense of sexuality, I asked Chris some questions about his life:
JP: Chris, how old are you?
CK: I am 23.
JP: How would you define your sexuality?
CK: I am a gay man.
JP: When did you first sense your identity as a gay individual?
CK: I began having feelings for boys around middle school. Looking back, I remember being entranced by yearbook photos of guys and wanting to kiss them. I realized I was gay when I was in high school. Some good indicators for me would be me constantly wishing I had a boyfriend, being uncomfortable with the idea of having a girlfriend, and how I had crushes on different guys while other guys would be talking about girls.
JP: Was it difficult for you to tell your parents and family how you were feeling?
CK: Yes and no. It was harder for me to say so in the sense of finding a way to tell them. I’m not really the best at speaking up, so trying to gather the words was not easy for me. I knew my parents would accept me because I know they were very accepting of the LGBTQ+ community and when I did tell them, it was one of the best things I ever did.
JP: Was it difficult for you to tell your parents and family how you were feeling?
CK: Yes and no. It was harder for me to say so in the sense of finding a way to tell them. I’m not really the best at speaking up, so trying to gather the words was not easy for me. I knew my parents would accept me because I know they were very accepting of the LGBTQ+ community and when I did tell them, it was one of the best things I ever did.
JP: How can the conversation about your feelings and developing sexuality take place with family?
CK: I think it is important to be honest about who you are. When you feel ready, I would say to sit down with your family and talk about your feelings. Coming out is your own personal journey that you can start and finish (whenever you feel that you are ready for it), and it is up to you when you feel comfortable sharing it with other people.
JP: What if your parents don’t understand your feelings, what would you suggest to other young people?
CK: I would say to try and help your parents understand. Describe your feelings so they can understand how and what you feel. If they are unaware of what you are feeling, ask if they have any questions so you can help them understand where you are coming from and clear up any confusion.
JP: What helped you to define your feelings and identity?
CK: For me personally, it was reading stories online that had characters going through an identity crisis and figuring out that they are gay, or romantic stories of a male character falling in love with his best friend. I would find myself relating to these characters without completely realizing it at the time. What helped me completely confirm that I was gay years later was having my first kiss with a guy and enjoying it.
JP: What is the hardest part of understanding your sexuality?
CK: For me, it was pretty easy to understand, but for other people, I would say it can be hard because there are so many different feelings in the world. Sexuality is something very complex and it takes time to figure out who you like. You just have to figure out who you are in your own time.
JP: What can parents do to help their children define their feelings and sexuality?
CK: I feel that a very important thing that parents should teach their children is that different sexualities exist and that it is valid if a child’s sexuality is different. I think children should also be reminded that they can tell their parents anything, so they have somebody to turn to in times of figuring out who they are; and guide them in the right direction.
JP: What should parents NOT do when they learn of their child’s sexuality?
CK: I do not agree with the idea of disowning a child or acting homophobic towards them. We are all equal and human, regardless of who we like. A different sexuality is not something that is wrong or should be looked down on. It is important to remember that everybody’s feelings are valid.
JP: Do you feel acceptance in the larger community?

CK: Ever since I came out, I have had nothing but support and love from everybody. I remember getting spammed with comments of love and acceptance from family and friends on Facebook when I came out over the span of three days and how much it touched my heart. It has helped me to become more confident in myself and free to be the person that I know that I am. I feel very accepted in my community and I am happy that I can express myself!

JP: What three things would you tell a young person on the spectrum about how to understand their feelings as they define their sexuality?

CK: I would tell them:

1. Take your time

Something important to keep in mind is that learning who you are takes time. Everyone has their own journey and will figure things out at a different pace. I discovered who I was when I was a teenager, but people can find themselves at an earlier or later age than that. What is more important is knowing who you are, not when you know.

2. Don’t try to force yourself into a label

In the LGBTQ+ community, there are many labels to describe the different sexualities and feelings that someone may feel. There seems to be a pressure to try and put a label on people within the community, but I believe it is more important to know who you are, with or without one. If you don’t know the exact word for who you are, it is perfectly valid!

3. Love yourself

It can be hard to find out who you are, but a very important message to remember is to love yourself. You deserve to be loved as the person that you are. Your feelings and identity are valid no matter what. You are special just being you, and you are just as equal and important as everybody else!

Meet Chris’ parents

Chris’ parents have made a difference for him in how they supported his sexuality and helped him understand his growing feelings of attraction. I asked Chris’ mom and dad, Mike and Sheila, a few questions too:

JP: When did you first understand Chris’s identification as a gay individual?

Mike/Sheila: Probably around age 16. Christopher did not prioritize sex or romance as a feeling until recently, but at that age, he began talking about boys as being cute or attractive so that’s what tipped us off.

JP: Did you see any signs of Chris’s developing sexuality?

Mike/Sheila: Only beginning around age 20, and more in a romantic sense than anything sexual.

JP: Were you surprised by his identification as a gay man?

Mike/Sheila: Not at all. He’s never mentioned a female as being attractive or interesting to him, so it did not come as a surprise.

JP: How did you come to understand Chris’s identification?

Mike/Sheila: He came out and told us very matter of factly that he liked boys. No big reveal or any-
thing like that, he just told us as part of a conversation one day.

**JP:** Was this understanding something you had considered earlier?

**Mike/Sheila:** Certainly, yes. We believe he was more than likely gay before he told us.

**JP:** How was Chris’s revelation taken by your family?

**Mike/Sheila:** It was not a big deal. We accepted it readily, happy that he was comfortable in revealing it and have always celebrated it since.

**JP:** If you could offer other parents any advice on helping their child on the spectrum to identify and define their sexuality, what would you tell them?

**Sheila:** To be accepting, open, and communicative and just to love them for who they are and not try to change them.

**JP:** What made the conversation easier or harder?

**Mike/Sheila:** It was an easy conversation, nothing awkward or uncomfortable.

**JP:** As Chris’s parents, did you have any concerns for him once he identified his sexuality and accepted it?

**Mike/Sheila:** We did, but not merely for his sexuality. We were more concerned for his safety and wellbeing due to outside forces in society. Also, it makes for a more complicated life for him. Being on the spectrum narrows his social abilities and the availability of friends/love interests. His being gay narrows the availability of love interests further...the candidate pool is more shallow for him.

**JP:** What would you tell other parents in a similar situation about how they can help their child live their best life?

**Mike/Sheila:** Accept your child for who they are genuinely, acknowledge the courage it takes to be their true self, and always support them and put your own preconceptions aside for the good of your child. Welcome and embrace their relationships. Love is love.

Mike and Sheila were there for their son Christopher to help him express himself and be who he is. They were accepting of him as a person regardless of his sexual identification, and I think that is the real message for any parent.

Our special needs kids are the same as any other child, they want love, acceptance, and understanding, and many have a desire to be with others. As parents and guardians, we have to be open to them and listen to them talk about their feelings.

We can give them guidance and help them decipher their feelings and beliefs, but ultimately, just like every one of us, they will make their own decisions. What should remain is love.

“To be accepting, open, and communicative and just to love them for who they are and not try to change them.”

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

- [www.ipvideocorp.com](http://www.ipvideocorp.com)
HELP: My nine-year-old cannot speak

Q

I have a nine-year-old girl who is not able to speak fully. She can spell some words when we teach her, but I want her to get better in her speech. Any suggestions, please?

Kavitha

A

Hi Kavitha,

Firstly, saying a letter in isolation can often be easier than saying a whole word with multi-syllables or saying a phrase or sentence.

This little girl could have auditory processing challenges (not hearing all the sounds correctly).

She could have articulation challenges (not able to pronounce certain sounds), or she could have oral motor challenges (not able to use her articulators efficiently).

These possibilities should be evaluated by a certified, licensed speech therapist. Then, special articulation and auditory processing strategies can be put in place.

Language comprehension is most important. Can she follow simple directions? Can she name things, request things, make a choice with one word clearly? Can she imitate sounds or words well? Does she respond to music and could singing songs be a motivator to support speech?

Does she like to be read to? Reading to her and having her point to and name objects could be a motivator. Some songs are also great where kiddos have to repeat sounds of animals; this, in particular, could help her.

Acknowledge all communication attempts. Then provide good modeling.

When she is calm and non-resistant, ask her to repeat if she is not clear. Children get frustrated when they are not understood. Try to not stress her out.

Some parents get a talking device to help support clear communication. Having a voice output talker can help relieve frustration and also provide modeling for the child.

I hope some of these thoughts and ideas help.

Karen

Karen Kaplan, MS just completed ten years as Executive Director of Wings Learning Center, a school for children 5-22 years old with Autism Spectrum Disorders, located in Redwood City, CA. She served as an instructor in the Autism Spectrum Certificate program at Alliant University. She completed her BS and MS in Speech Pathology from ASU. She minored in Special Education and holds an Educational Administrative Credential and Moderate to Severe teaching Credential.

Karen has sat on non-profit boards to help build capacity for those with special needs. She founded and directed a residential school for nearly 20 years in Sacramento. She is an author and speaker. She spent time globally helping non-governmental agencies in Indonesia and Africa. Currently, she is consulting with families, schools, and adult programs.

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* The advice provided in this column is for general information and should not be treated as a substitute for face-to-face therapy, counseling, or medical advice. The guidance provided is not endorsed by Autism Parenting Magazine or any of its employees.
Roxy and Maliboo: It’s Okay to Be Different

By Hillary SUSSMAN, MSPT

Today, it is important to share the messages of inclusion and being yourself with children.

Hillary Sussman’s new book, Roxy and Maliboo: It’s Okay to Be Different does just that.

In this super cute and playful read-aloud picture book, Roxy is a loveable dog who has lost a leg because she was sick, and is now faced with accepting this difficult new change. She dreams of going to the dog park to play. When she is healed, her mom finally takes her to the dog park. Once there she sees a dog in the distance sitting all alone, looking sad. His name is Maliboo and he is different too. Roxy goes over and tells him about her own experiences and insecurities. Hearing this helps Maliboo overcome his fears. He works up the courage to play with Roxy and the other dogs. The other dogs accept them just fine, despite their unique features. The lesson they both learn is that it’s okay to be different.

Roxy’s story is meant to give children the confidence to be themselves and not let any differences dictate their self-worth.

Hillary Sussman is a physical therapist, who uses her experiences in the field to help tell Roxy’s story. After working with many clients with disabilities, she was inspired by her dog Roxy, who has gone through four surgeries, to help kids who are different gain more confidence and overcome their physical limitations.

The idea just made sense… kids would identify with Roxy and realize, like her, that they should not let those limitations stop them from having a full and exciting life. This is Hillary’s first book, but she is planning a whole series featuring Roxy’s adventures, with the delightful pup learning something new in each book, meeting new friends and facing new challenges.

For more information visit: https://www.adventuresofroxy.com

Hillary Sussman is a physical therapist with Southeastern Home Health Care Services Inc., who studied at Penn State University, and later got her masters degree in physical therapy at Beaver College, now Arcadia University. She has been serving southeastern Pennsylvania as a physical therapist for 23 years.
The Fireboy:

With a Side of Autism

By Lori AACH

AN AUTISM MOM SHARES HER SON’S REALITY OF LIVING WITH AUTISM AND LENNOX-GASTAUT SEIZURE SYNDROME; AS WELL AS HIS PASSION FOR FIREFIGHTERS!

What happens when you have a son who thinks he’s a fireman and a stressed-out mother who innocently tries out a Groupon for an hour of sanity? You have the life journey of my medically fragile, 27-year-old son with autism, Eric, and my path of self-discovery converging.
The Fireboy: With a Side of Autism is my candid memoir of short stories about Eric’s love for all things fire-related: fire trucks, fire stations, fire extinguishers, and, yes, fire ants, as he continuously battles an evil monster called Lennox-Gastaut seizure syndrome along with the challenges of autism.

During Eric’s early years life was consumed by his seizures, autism, and severe behavior, as well as being mom to my younger neurotypical son, Brian, and wife to my husband, Joel. Life was hard. I was stressed, depressed, and lonely. Yet, it was only after I started taking aerial arts classes in 2012 and found the “old Lori” that I began seeing my Fireboy in a new light: a funny person with a great imagination and a quirkiness I loved. This outlet helped me discover what I wanted to be: a writer. As therapeutic as it was for me to write my “Fireboy” stories, I hoped to raise awareness of persons with autism, seizures, and behavior, as well as show parents they weren’t alone on this unforeseen path.

Eric’s journey was a rough one that included medical regressions, 911 calls for seizures and behavioral aggression, major brain surgeries in 2016, moving into a medical group home, and now COVID-19 quarantining.

Yet, he was at his most joyful during his almost thousandth fire station visit with his stuffed pals, Froggy and Ellie Elephant. He became an Honorary Fireman for both the City of Orlando and the Orange County Fire Rescue Department—making him part of their brotherhood.

Although times were challenging, I chose to focus on things that made me laugh and bring out the love for our “Make A Wish” son, who once had over 300 seizures a day at four years of age.

I’ve included a few short stories from my memoir. These stories are sometimes silly, sometimes humorous, sometimes heartbreaking. I hope the stories are also somewhat insightful. Most importantly, I hope you, too, will realize that life does go on when you’re thrown a curveball… or two or three. But you can find acceptance, loving support, and wonderful resources along the unforeseen way.

Bathroom 911

I dream of the day when I can leisurely walk into my Zen-like master bathroom, light scented candles, turn on classical music, and take a luxurious bubble bath. Of course, I don’t have a spa-like bathroom now. My bathtub needs the jets cleaned and the shower door and floor tiles are not in the best shape.

Besides, it’s not very spa-like when the Fireboy rushes in, turns ALL the lights on, and places a police chase scene in the shower stall. When there’s an arrest to be made, you’re told to exit the bathtub so the cops can move in quickly. Not my idea of a relaxing time, but at least one more bad driver will be taken off the road.

Eric’s work resume with David, his favorite lawn man

Since recently getting his toy chainsaw, Eric is looking for seasonal work.

Eric’s lawn and landscaping resume:

- Works only when he feels like it
- Follows David around nearby lawns with his handy-dandy chainsaw. Specializes in making trimmer, lawnmower, and blower sounds. When David is taking a break, Eric’s expert noises are sure to make you think your lawn is being tended to at all times
- Locates every fire ant mound, introduces himself to the ants, and spends his break time telling them about his day. 60% success rate
in convincing the ants to find a new place to live when this treatment is used

- Excavates large holes in lawns using his CAT Machine toy digger. If you need a deep hole dug, then he’s your man! So, any takers?

Eric went up to a tall man and said with a smile: “Excuse me please. Move out of my way!”

I think we’ll be working on understanding social nuances for the rest of the month.

Good news?

Yesterday, I got the call that I’ve been waiting for. Eric’s brain surgery was moved up to next Wednesday. His seizures have become far worse, especially this past month with him having seizures every day. Calling 911 and rushing to the hospital are now daily occurrences. I wonder if Eric can hold on until the scheduled surgery date. Thankfully, our prayers are answered and next week, he will start a new journey.

So, it finally hit me. We have exactly one week with our Eric before he goes in. I keep wondering, will he come out of this as our same Fireboy? Chances are, he will not be the same.

It all depends on what surgeries are done and what parts of the brain are affected. I pray so hard that his seizures will be gone. But I wonder if I’ll still have the same boy who gets so excited visiting Fire Station #10 and wearing his fire shirt proudly. Will he remember his love for CSX hopper trains or his cats Dexter and Stella? Will he yell out “Komatsu”, “Hitachi”, or “John Deere” when driving by a construction site?

It’s a bit scary to wonder whether you’re going to end up with the same child or not after brain surgery. I try focusing on the fact that the damaging seizures will stop, and Eric will have some peace to develop to be the best that he can be. Hopefully, I’ll still have my Fireboy, but if not, I pray for him to be happy and much healthier.

Autism across the pond

Since Eric was doing well at his medical group home, I joined Joel on a business trip. Having a day to myself to discover London, I came upon the Parliament building. Looking for a tour, an officer told me to follow the path through the security and head towards the House of Commons.

I learned they were debating the funding needs for autism. I couldn’t believe my good luck.
Select MP’s (Members of Parliament) were discussing the challenges their constituents with autism were facing. I sat completely enthralled, listening to every word. It felt like I was taken back some 10-20 years, since they were describing everything my family and I went through with my Eric.

Desperate families needing respite help. More autism awareness training for police officers. The need for support and job training after school years. Two MPs described how a person with autism worked in their offices, how it was a positive experience. I sat there relating to so much of their discussion/debate.

It was getting late, so I needed to leave, but I’ll never forget that particular experience one Wednesday in March. It just reinforced to me how autism affects not only a person and their family, but their community as well, no matter where they live.

**Lori Aach**, an aspiring author and mother to 27-year-old Eric and 24-year-old Brian, started her career as a speech-language pathologist in 1988. She became a full-time mom when Eric became chronically ill with seizures at 18 months of age and was later diagnosed with autism. She focused on fundraising for autism for many years when her son attended school.

Lori participated in the Orlando International Fringe Festival where her poem from the contemporary dance show, **LUNA** by (famed choreographer and Patron’s Pick) Ana Cuellar was spoken live in 2018. In addition, she wrote the poem for **Addiction**, performed at Immerse Creative City Project, 2018. Lori’s song lyrics from the show, **HOMBRE** by Ana Cuellar were performed live by a Latin Grammy singer in 2019.

Lori has a love for aerial arts, such as aerial tissu and flying trapeze, but currently stays closer to the ground taking pilates and baking loads of goodies for son, Eric and the residents at his group home.

Lori is hoping for her memoir, **The Fireboy: With a Side of Autism** to be published in the near future.

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ISSN 2633-1004

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One Family’s Journey to Create Financial Security for Their Autistic Son

By Mark LYONS

FINANCIAL PLANNING FOR YOUR AUTISTIC CHILD’S FUTURE CAN BE SCARY. LEARN ABOUT SAMUEL AND HOW HIS PARENTS TOOK THE INITIATIVE TO START A BUSINESS TO SUPPORT HIS FUTURE.

Samuel is 24 years old. He was born in Round Rock, Texas. He was diagnosed with PDD-NOS at age four. He began speech and physical therapy soon after. He was homeschooled by Sally, his mother, until the seventh grade. Samuel attended middle and high school in Hutto Independent School District. He graduated from high school in 2017 and attended the Hutto ISD 18+ Program until 2020.

Samuel received some job training through the Hutto ISD 18+ Program, along with other students with differing abilities. Some of these students held part-time jobs out in the community through the 18+ program. Several had job coaches.

Samuel is very verbal with us, his parents, but not around other people. He has many OCD behaviors and is quite rigid in his daily routines. He responds well to instruction but needs constant prompts and reminders to stay on task. Samuel is also very distractible. Samuel does not like change. He does not like strangers. He gets along better with women. Samuel does not like loud noises or to be touched.

Samuel has quite a few interests. He likes trains, elevators, toilets, video games, bells, clocks, and Walmart, to name a few. He really likes the Walmart in Clifton Park, New York. We have visited it three times in the last four years. He also likes the Walmart on the west side of Flint, Michigan. Both Walmart stores have a unique feature to their public address system. A sound like a train horn is emitted before each announcement. Samuel really likes this.

Samuel likes to take rides in the car. He likes to listen to music on the radio while riding. He is fond of Katy Perry. Samuel has the ability to “mash-up”
songs. He knows which songs go together. One song will be playing on the radio and Samuel will be singing another song along with it at the same time.

In 2017, Sally and I started thinking about what Samuel’s life would be like after he aged out of the public school system. We were concerned about his future. We were both getting older and worried about Samuel having enough money once we were no longer around.

I retired from being a teacher in 2020. Not a lot of money there. We wanted to provide Samuel with a safe and secure place to work that allows for his needs as a person with differing abilities. We also wanted to try to earn money to put aside for his future.

Financial planning for Samuel

We started thinking about starting a business in 2017. I was still working full-time as a teacher. Initially, we thought we would have Samuel make a product which we would then sell. This proved to not be Samuel’s “cup of tea”.

We researched more options, finally hitting on the idea of offering socks for sale online through a website. We used nights, weekends, holidays, and summers to research and lay the groundwork for SammySocks Etc.

“We started thinking about starting a business in 2017. Initially, we thought we would have Samuel make a product which we would then sell.”

We started SammySocks Etc. in September 2020. We are quite small currently. Samuel puts together our information packet. He puts a candy treat, a discount coupon, a poem, a Sammy Saying, and a card explaining our story into a baggie. This baggie goes with every order. He also puts together our Bells and Whistles Bag. Sally or I serve as his job coach.

We also wanted to possibly include other adults with differing abilities. We realized that as we grow, Samuel might need a job coach, separate from either Sally or myself, to help provide onsite assistance with the various tasks associated with working at the business. Other adults that we might employ would also benefit from a job coach. We spoke with people involved with the Hutto ISD 18+ program and they were receptive to the idea of some of their students working at our business and of offering job coaches, if needed.

We have not done a lot of business yet, so Samuel has not worked a lot. As we grow, this will change. Also, as we are able, we hope to employ other adults with differing abilities. Additionally, we hope to offer other apparel items. That is why there is the “Etc.” in our name.

As we continue on our journey, I wanted to share some ideas with other parents considering work options for their children with autism.

Tips for creating work opportunities for a family member with autism

1. Use local high schools and see if they have a program for students with differing abilities for vocational training and job support.
2. Use your local church or house of worship for help and support. You can network for possible job opportunities there as well

3. Plan on spending a lot of time finding training, a job, or setting up a business

4. For your own business, start small. We spent about $10,000 on inventory, equipment, furniture, and supplies to get started

5. Expect to make mistakes

6. Keep good financial records. Consult with a Certified Public Accountant and a Business Lawyer

7. Get business insurance if you are starting your own business

8. Advertise your business

9. Have a presence on social media for your business

10. Seek advice from retired small business people to help with your business

11. Have your business become a member of your local Chamber of Commerce

12. See how any government assistance benefits (SSI and/or Social Security) may be affected with either a job or starting a business

13. Contact local colleges and/or universities to inquire about help with job coaches. Students may need to “intern” at a business to get credit for courses they may be taking

14. Don’t get discouraged

Mark Lyons is a retired educator. He taught for 44 years in both parochial and public schools in Texas, USA. He ended his teaching career as a dyslexia teacher. Mark resides in Hutto, Texas, with his family.

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AN AUTISM INTERVIEW

with ROSE MORRIS

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.

Rose Morris is the founder and president of Abram's Nation and a mother who was driven by the relentless pursuit to keep her son, Abram, who is on the autism spectrum, safe at night. When she could not find a suitable solution, Rose designed and developed The Safety Sleeper™, the first and only enclosed bed system of its kind.

Recognizing many others deserved the same freedom to sleep without fear for the safety of their loved ones, Rose began her mission to make a meaningful impact for others through Abram’s Nation. For more information about Rose and Abram’s Nation please go to https://www.abramsnation.com.

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

I first became aware that something was different when Abram was around 12 months old. You are told not to compare your child to others, but as a mother, you trust your instincts. Abram was still crawling at 12 months and had not attempted walking. He started babbling, but it was not in the expected way of trying to mimic our speech.

At the one-year check-up with our pediatrician, I voiced my concerns about Abram’s development. Our doctor did not think anything was really wrong, but she referred us to a speech therapist. From there we learned that my instinct had been correct.
is for Unique - How has this experience been Unique for you and your child?

Unique is the very definition of autism. The saying is that if you have met one person with autism, you have met one person with autism. Just as everyone has a unique personality, the autism diagnosis is part of Abram’s personality. He has a desire to be around people, but not necessarily engaged.

When he goes to work with me, Abram knows the exact schedule and what time everyone leaves for the day. He stands outside and waves to everyone as they head home. He would never engage with those same people one-on-one, but he wants to feel like he is part of the community. It’s an endearing personality trait. Abram is not anti-social, he’s just unique in the way he socializes.

is for Tools - What tools are there now that weren’t there in the beginning that could help other parents?

There is more awareness and understanding of autism than there was when we first received our diagnosis. There are more voices speaking up and people have the courage to speak openly and candidly about their experiences with autism.

We are at a place now where we can have a conversation about the difference between a temper tantrum and a meltdown and people are receptive to that conversation. People are less likely to make judgments about a child’s behavior now than they used to be, though there is always more work to be done to educate and promote understanding.

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

Abram is now 15 and I am inspired by the progress he has made. At age two, I was filled with worry and uncertainty about Abram’s future. While that worry about the unknown will always exist, I cannot dwell on that.

I don’t know whether he will ever drive or live on his own, but I focus on everything he has accomplished and how he has grown beyond what I initially thought possible. He is truly a joy and could live with me forever!

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

I struggle with the thought of what will happen to Abram when I get old or when we lose people who are close to him. Abram has a very close relationship with my father, and I do not know how I will be able to help Abram process his emotions when his grandfather dies. The thought guts me. Abram thinks linearly and everything is black and white to him, so knowing that I will someday have to explain death and help him through the loss truly makes my heart ache.

“Just as everyone has a unique personality, the autism diagnosis is part of Abram’s personality. He has a desire to be around people, but not necessarily engaged.”
M is for Manage - What keys to success can you leave with parents so that they can better manage their day-to-day efforts?

The most important thing I learned was how to manage the meltdown. I learned that a meltdown could be two hours or 20 minutes, and that my reaction was a major factor. During a meltdown, Abram would get physical, like a monster expelling evil energy from inside himself.

I learned that I had to be the complete opposite of that because otherwise the monster would feed off of me. I had to channel inner peace, stay cool, and speak matter-of-factly without any emotion. This exact approach may not work for every child, but the key is to learn that you can impact the situation more than you may realize.

Most importantly, I want to speak from experience, it gets better. Very early on, one of Abram’s therapists told me that it would get better. I believed her only because I had no other choice. Autism is a journey and you will face different challenges, but you have to hold onto that hope—that it gets better.

Derrick Hayes the “enTIEtain-er” is a Professional Speaker, Consultant, and Entertainer who lives in Columbus, Georgia. For contact or booking information visit www.derrickhayes.com or call (706) 615-1662.

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“MOM!!” A louder whisper I can’t ignore. Here we go. I fly out of bed, through the dark (I’m a veteran to navigating the path between my spot in bed to my child’s) and reach out for his hand.

“What happened? Are you ok?”

“Something happened in my bed, I don’t know what, it’s all wet.”

You can imagine how fast my thoughts flash through my mind at that moment:

- Shoot, I didn’t think he was going to have this happen yet
- We didn’t even have any “talk” yet
- When I brought up sex and health education, he very maturely answered: “I’m not ready.” Why did I let him lead?
- Why am I the one to have to help him? I’m a woman!
“Ok, let’s take care of it, I’ll get a towel.”

I get to work. Going through the motions to “fix” a problem can be numbing—just DOING the task; let thinking be for later.

I have a son who at three years old was diagnosed with asperger’s syndrome (the label at the time for just one flavor on the autism spectrum). He was kicked out of pre-school, then tested and evaluated and tested some more.

My entire journey as a mother of this boy has been one of learning. I’m never without a book, blog, article, or conversation with a fellow mother with similar experiences. I am constantly learning and relearning how to be the best support I can for my son. I knew puberty would be the next big “known” hurdle for us, I just thought I had a little more time.

I’m also a divorced mom so I have a harder time relying on any male influence for him.

All in all, you can imagine I didn’t go back to sleep that morning. I laid there, percolating on how I would talk to my son about his experience. I ran through scenarios in my head and ran through my mental-Rolodex of what I’ve learned from others to inform my approach. I also knew I needed to lead with love and compassion, no matter what.

There’s one more thing you should know about how I parent my children: I am a TALKER. I want them to express themselves openly, so I lead with complete openness myself. I cry in front of them, I name my emotions in front of them, I validate, I reinforce, and yes, sometimes I just hide away when it gets to be too much.

Let’s talk about it

The time came and my son and I casually chatted on my bed about his experience. I asked open-ended questions like: “How did it feel?” “What did you think was happening?” And then I sat and listened.

I will tell you, sometimes he is my number one teacher. I am a TALKER. I want them to express themselves openly, so I lead with complete openness myself. I cry in front of them, I name my emotions in front of them, I validate, I reinforce, and yes, sometimes I just hide away when it gets to be too much.

I will tell you, sometimes he is my number one teacher. I asked open-ended questions like: “How did it feel?” “What did you think was happening?” And then I sat and listened.

I will tell you, sometimes he is my number one teacher. After I scientifically described as much as I could in a fact-based way (that appeals to his learning style), he said: “So okay, but my mind is not ready for this. I do not WANT this.”

Which led me to a beautiful response: “Sometimes our bodies are ahead of our mind. Sometimes they are informing us of what to pay attention to, what to look out for. Your mind will get there. Just let your body lead for now.”

The journey through puberty

It’s been about a year since then, and life through puberty for my son is just getting harder. From an observer’s point of view I can see he is overcome with hormones pumping through his body, hormones he can’t control. I can see his need to belong in overdrive. I was recently given a link to Maggie Dent and her point of view on boys through adolescence is spot on. She says:

“There are many masks—the smart alec, the clown, the jock, the bully, the cool dude, the shy mouse—usually with a long fringe hiding their face. They especially need this mask at school as it is really much like a war zone for boys—so many rules, expectations, different teachers, classes and being challenged to do tasks they are not sure they can conquer. Many boys are struggling with heightened levels of anxiety that they mask and have no understanding they even are having as they simply mask anything that may suggest vulnerability of any kind.”

Now imagine adding the unique struggles of our autistic babies on top of that! My son never did imaginative play, so the ideas that Ms. Dent brings up about masks puts into perspective how hard it must be for my son right now. Not only is he battling with all the chemical and physical changes, he is playing catch up to put “masks” on each day to try and fit in. It must be exhausting.

For every growth phase in my children, I see an opportunity for growth in me. I’ve written down some affirmations to remind myself, from my son’s perspective, how hard life is for him right now:

- Every time I smell his stench, instead of yelling to go put deodorant on, I’ll say in jest, “Boy do I love hugging you and being around you, but I’ll have to wait for my nose to clear up!”
Every time I need him to perform any self-hygiene (I know many of you will agree this was never easy!), I will try a checklist instead of barking commands.

Every time he grunts, or replies with “In your butt!” or simply ignores me, I will take a deep breath and remind myself that this is a mask and it’s hard for him to wear. Lead with unconditional love and we will both get through.

I was once told by a friend who had a son who was 13 when mine was three, that many of the behaviors of a 13-year-old mirror that of a three year old. Testing, experimentation, need for belonging, no sense of others. I reflect on what I learned from those years as a mother. For my son on the spectrum, routine was gold. Routine was a life savior. The better I could organize his day and communicate what to expect, the better day we had.

Recently, I had a perfect opportunity present itself to test my theory on routine. Bedtime is its own type of torture in my house, but it was over, lights out. I heard some commotion and went back upstairs to find my 13-year-old son in the bathroom with his iPad. I lost it!

“Control your pubescent urges because now is NOT the time!” I said in a huff. The next day provided a new talk track for us to connect on and I thought, what the heck, let’s try the routine approach now. When I was about to go to the grocery store and leave him home alone, I yelled down to him: “Now would be a good time for any of those bodily urges, honey!”

His response, “You can’t put THAT in my routine MOM, gosh!!”

I hope you are laughing by now because, what was I thinking? Live and learn, and always love. It can be a bumpy ride, but take as many moments as you can to pause, breathe, and reflect. You’re doing an amazing job!
Safe Schools for Those with Severe Autism Post-Pandemic

By Karen KAPLAN, MS

As students prepare to go back to school following the summer, the question is: How can we ensure they feel safe post-pandemic?

Some are saying: “What could schools look like for those with severe autism, post-pandemic?” Those students who are unable to wear a mask, stay a reasonable distance from another, follow directions without physical support, need help to eat their snack and lunch, need help in the bathroom with hygiene and toileting, and could have a seizure requiring, once again, physical support?

Some are asking: “How will our schools and families work together to create this safe, comfortable, and effective environment for students?”

I say, it is time for parents, teachers, therapists, and governmental organizations to find a way to work together to create this new learning environment—which is recommended, but not exactly mandated or supported by funding.
What policies and procedures might need to be put into place? What types of collaborations and understandings might need to be agreed upon between parents, special schools, school districts, the Commission on Teacher Credentialing, and the State and Federal Departments of Education?

Some considerations about policies and procedures that may need to be put in place:

1. Parents need to be sure they are doing everything to keep themselves and their students healthy. Colds, virus, flu, and disease tend to hit those who have greater health challenges harder. Professionals must also do everything they can to keep themselves healthy (nutrition, exercise, sleep).

2. Parents will have to find ways to help their son or daughter with autism not to become obese or acquire diabetes. Better meal planning will need to occur; addressing sensory challenges over food should become a priority. Replacing sugar food intake with nutrient-dense foods will be a must.

3. Better hygiene routines need to be established. Never before, in my 70 years of life, has it been so important to wash hands and be aware of risks. Hygiene routines need to be put in place at home frequently and completed at school many times a day. Each student needs to have their own hygiene tool kits at school and they need to be cleaned at the end of each day.

4. Parents need to find support to keep their students home from school when they have a cough, shortness of breath, runny noses, and of course any infections and fevers. I have seen those students come off the yellow buses with coughs and runny noses because their parents must go to work and send their son or daughter to school as long as they have no fever. The fever symptom can no longer define the precautionary action that must take place. New education codes may need to be written.

5. Communication challenges must be addressed. This should be one of the highest priorities. Assistive technology and devices must be readily available to all students with communication challenges. It is known that the better a student can communicate, the less anxious, frustrated, and confused they will be, and the less likely they’ll feel the need to use physical ways to get their needs and feelings met. When the student uses physical ways of communicating, everyone is at a higher risk for injury and now, of course, the spreading of a potentially deadly virus.

6. Toilet training must be addressed early. How do we make training accessible and not at such high prices to families? Many private businesses have been started, offering behaviorists to provide training. Can most families afford this (at $60, $75, $125 and more per hour)? How do we address this challenge?

7. Hygiene/toileting educational goals need to be written for home implementation and
parent training, for implementation in the home environment, to reduce school staff risks. There needs to be flexibility in program delivery.

8. Perhaps more outdoor education could be allowed and goals and objectives adjusted to be met in more creative ways. Sitting and receiving information at a desk in a classroom for six hours a day with other students and support staff may not be the healthiest way to receive an education, nor the most effective. There needs to be more flexibility in program delivery.

9. Parents need to work with their son or daughter on all self-help goals that occur naturally, in the home. No longer can the schools be totally responsible for teaching independent living.

10. The new paradigm must be more collaborative. This will be hard on families, but teamwork is imperative here.

11. Perhaps instructional assistants can be approved to train in the home? Perhaps teachers can be approved to observe in the home and train parents? Why is it that education can only occur on a school site?

12. Parents now understand that they need to teach their children to wear a mask from an early age. This is not the school’s sole responsibility. Children learn to brush their teeth, comb their hair and take a bath at home. Now they have to learn that a mask may need to be worn when an illness is present.

13. Students need to have their own set of education supplies and learn to keep them clean (pencils, pens, paper, erasers, rulers, books, crayons etc.). Schools need funding to support this action.

14. Students need a place to store backpacks and personal items that won’t come in contact with other students’ items. Schools need funding to purchase these storage units.

15. Will group seating (at one table) work now, or will the new paradigm require separate desks?

16. How can recess occur safely? Less students out at one time or planned recess activities with stations set up and visual schedules for the student to follow may work.

17. How will snack and lunch time occur safely? I imagine in their own classrooms with proper health standards met. Boxed lunches, not cafeteria style, delivered.

18. The occupational therapist’s gym will need to be cleaned after each student’s use. Perhaps more sessions need to be held outdoors with motor equipment like bikes, balls, and exercise equipment.

19. The speech therapist’s room will need to be cleaned after each session. All materials should be cleaned before the next student utilizes them. Perhaps more sessions will occur outdoors, which opens up the ability to build communication in more natural contexts. Making home visits could work. Holding sessions in the backyards of families. This could improve generalization from school to home. So, Education Codes will need to change.

20. Each school will need a safe room to support a student who has come to school with some type of unsafe symptom (diarrhea, fever, cough, etc.) where they can wait safely until a parent picks him/her up. There must be an agreement for a parent to pick up in a timely manner. I understand it is hard to leave work, but this is a high priority.

“Parents now understand that they need to teach their children to wear a mask from an early age. This is not the school’s sole responsibility.”
21. Each student in special education is required to have an individual education Plan (IEP) and, after 14 years, an Individual Transition Plan (ITP). These documents outline goals and objectives as well as supports and services. There needs to be flexibility in plans so that schools are not put in compromising positions to provide education that is at risk for their students or providers.

22. These students need a very different educational paradigm. Have we looked at other countries’ methodologies? Where in the world are there better and safer outcomes?

23. We are in a crisis in the US. We have less professionals interested in becoming teachers for challenging students. We have less speech therapists and occupational therapists coming out of our university system who are prepared to support these students. Why is this? Is it due to a system that is too narrow in scope, under-funded, and restrictive? We need a new paradigm so we can inspire people to move into these meaningful professions.

24. How do we begin to think out of the box? Have any of the schools sat down with families and brainstormed together? What was the outcome? Has there been any open dialogue for the safe expression of concerns with people actually, actively listening, not judging and not attacking? What was the outcome? Have educational leaders found a way to come together to brainstorm on a new paradigm? What will it take?

25. Media reports that more and more litigation is occurring. Media reports the frustrations of families and schools. There is a continuous search for additional teachers, therapists and assistants to help support in homes and schools.

26. Important discussions need to be held at the city level, state level, and federal level, now.

27. We all need to reach out to those who make policies, and help them focus on solutions.

After 40 years of passionately working in this field, trying my very best to direct schools and give hope to families, I must say, now is the time to change how we operate and to realize the old paradigms no longer fit. I know that I would be delighted to be asked to sit on a committee empowered to make change. Wouldn’t you?

Karen Kaplan, MS spent 10 years as Executive Director of Wings Learning Center, a school for children five to 22 years old with autism spectrum disorders, located in Redwood City, CA. She served as an instructor in the Autism Spectrum Certificate program at Alliant University.

She completed her BS and MS in Speech Pathology from ASU. She minored in Special Education and holds an Educational Administrative Credential and Moderate to Severe teaching Credential.

She has sat on nonprofit boards to help build capacity for those with special needs. She founded and directed a residential school for nearly 20 years in Sacramento. She is an author and speaker. She spent time globally helping non-governmental agencies in Indonesia and Africa. Currently, she is consulting with families, schools, and adult programs.

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“Each student in special education is required to have an individual education Plan (IEP) and, after 14 years, an Individual Transition Plan (ITP).”
Due to the fact that over 75% of adults with a disability live with their aging parents, and one million of those households in the United States are being managed by a parent over the age of 60, planning for the future needs to be discussed.

The obstacles to planning for the future can be many, but one of the most common is: “the status quo is working.” Parents enjoy having their adult child live with them, and the adult with a disability knows nothing different, and so all parties are comfortable with the situation.

When the status quo is shaken and a parent becomes ill or dies, underlying issues are exposed. Without a plan, chaos ensues and other family members, many times adult siblings, are forced to embark on emergency planning with no expertise and very little guidance.

Planning can be so overwhelming because the choices can seem endless, and the starting point is often unknown. When embarking on special needs planning, consider following these three steps.
1. **Identify your team**

   a. Select an expert guide: This person or organization will have the expertise, specialization, and knowledge to coordinate and manage the pieces of your plan to provide the best level of support for your loved one.

   b. Manager of daily life: This person, people, and/or organization will handle day-to-day life, including living arrangements, transportation, volunteer activities, employment, recreation, and more. This area is often multi-pronged and will involve family members who make final decisions and organizations that can carry out many of the daily activities.

   c. Financial management: This area may also require a team. You may have a family member that will make final decisions regarding money, but you will also have them supported by experts to help them in carrying out decisions in the proper way, especially when it comes to managing a Special Needs Trust and/or an ABLE Account.

   Financial management will also include managing the benefits from the government, which will include being a Representative Payee and keeping up with the associated paperwork and reporting.

2. **Financial and legal planning**

   a. As part of your plan, you will need to:

      i. Determine the cost of your loved one’s lifetime support needs.

      ii. Identify the available resources. These resources can be from the parents' income and assets, family members, the individual with the disability's income and assets, and government benefits.

      iii. Understand the risks associated with these resources, including the government changing the rules on their benefit programs, tax legislation changes, market volatility, and the increased cost of care.

   b. Designing the proper legal procedure

      i. Depending on the family situation, the legal structure will most likely include a Will, Special Needs Trust, Powers of Attorney, Health Care Power of Attorney, Living Will, and other legal tools that can assist the family in the proper management and execution of the plan.

3. **Share the plan**

   a. Write a Letter of Intent

      i. The Letter of Intent is a written document that describes your loved one’s daily life, activities, interests, behaviors, diet, medical history, prescriptions, people involved in their life, and the goals they have for their life (including preferred living arrangement situations).

   b. Team meeting

      i. Schedule a time to bring the team together (either in person or through technology). In this way, all members of the team will meet one another, and more importantly, this meeting will provide clarity as to each member's role and responsibility.

Planning for the (future) support needs of your loved one with autism can seem daunting, but it is possible and more achievable than you know.

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**Ryan F. Platt, MBA, ChFC, ChSNC**

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

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– Sara J. (California)
parent of a 4-year-old boy

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