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Autism Parenting Magazine

Issue 144

The Big High School Preparation

My Hangry Nine-Year-Old

When Puberty Comes Knocking

DATING *On The Spectrum*

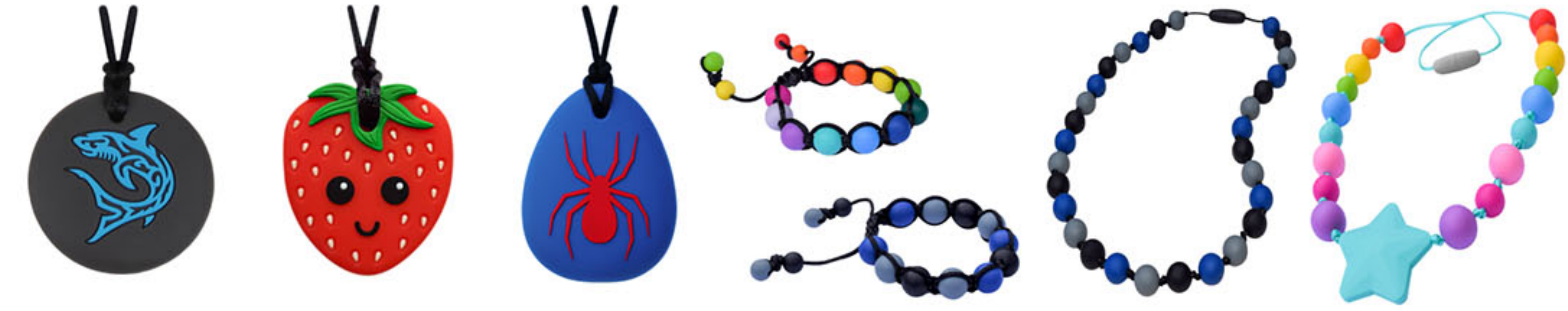
The Dreaded Haircut Made Easy

For The Love Of Music

Fun & Beneficial Sensory Games

The Pressures of Teenage Change

PUBERTY & SEX EDUCATION



Autism Parenting
Magazine

Editor's Letter

Dear Readers,

Did you know that puberty can start as early as eight years old for girls and nine for boys? Your child will experience both physical and emotional changes that won't happen overnight, of course, but it might be time to start preparing yourself (and them) for what's to come. After all, we can't stop these changes from happening.

In this issue, we deal with the topic of puberty, and we hope this is helpful in opening some discussion or relieving some of the cringing that often happens when having one of these talks. Rachel Anderson provides some good information in her article called "*Autism and Puberty*," and you'll want to read Karen Kaplan's informative piece, "*Puberty and the More Severely Challenged Teen on the Spectrum*."

With puberty comes additional challenges for autistic teenagers. Hormones begin to fire in a way that don't make sense, and the social awkwardness that comes with attraction is only amplified for teenagers on the spectrum. Donnesa McPherson covers this topic in her interesting piece, "*Autism Dating: An Honest Dating Guide for Autistic People*," and Yolande Loftus provides some great information in her look at "*Sexuality in Neurodivergent Individuals* ."

Between homework, after-school activities, and therapies which have to be attended, teenagers have so much going on in their lives. Having to then deal with puberty and relationships can feel very overwhelming. Nykele Asemota enlightens us with her article, "*Four Ways to Help Your Neurodivergent Teen Prepare for High School.*"

Of course, it is the season for many festivities and a whirlwind of activities and fun. However, sometimes the holidays can be overwhelming for all of us, especially for our little ones on the spectrum. With the overstimulation that can occur from lights and music to parties and an abundance of gifts and food, it might be a good idea to take some short breaks throughout the events to help with all the excitement.

Wherever you and your ever-changing children may be this holiday season, may you have many moments of good cheer and communication, enlightening thoughts as bright as the twinkling lights, and peace that transcends all the flurry of activity.

Enjoy!

Mark Blakey
Founder
Autism Parenting Magazine

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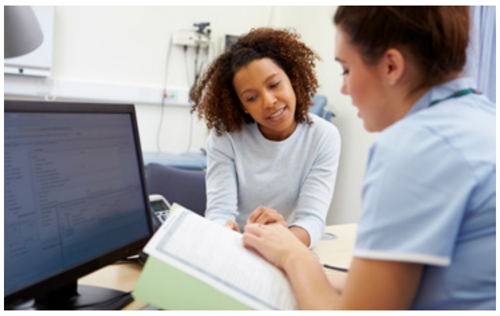

Autism Parenting MAGAZINE

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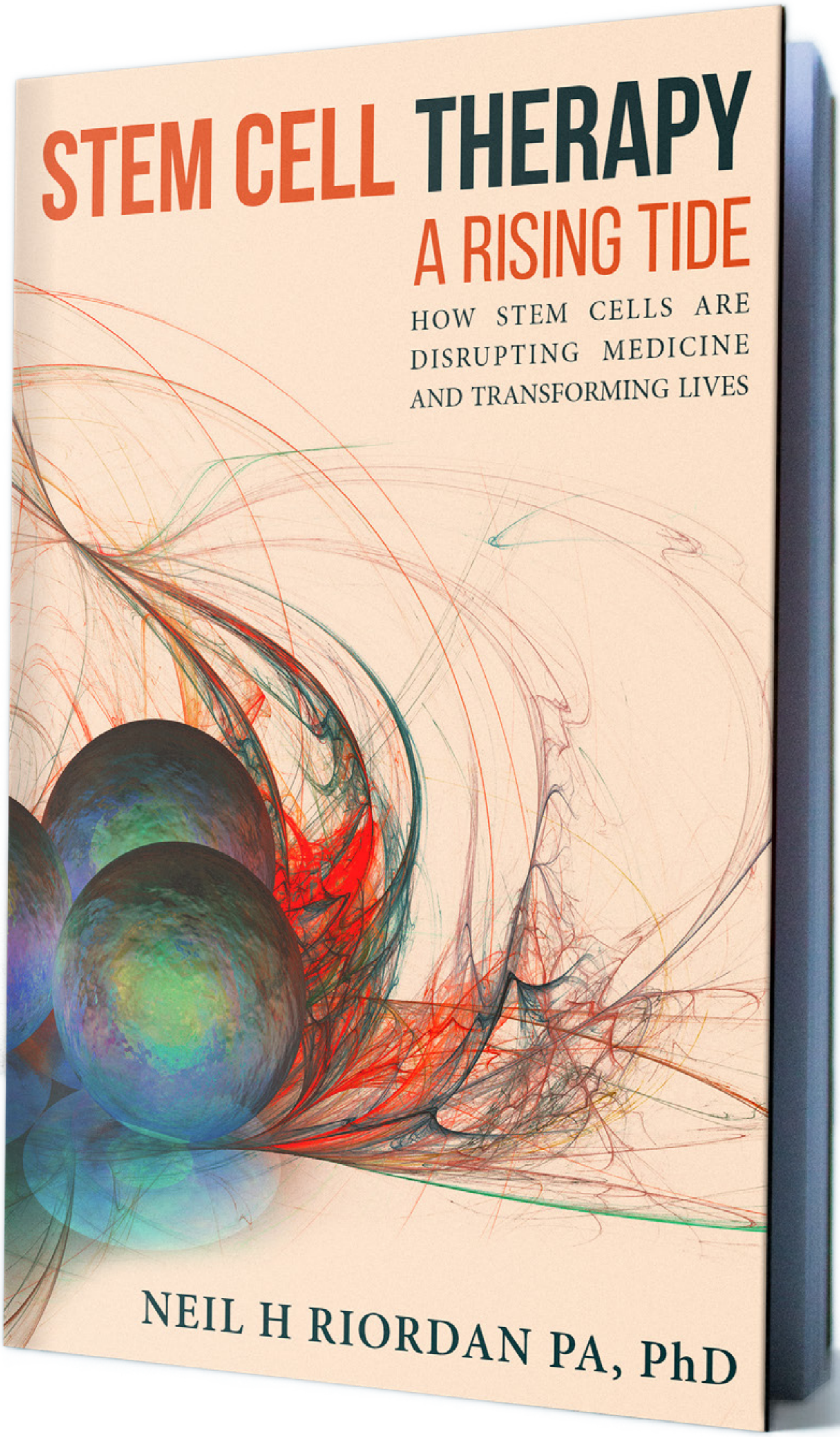
STEM CELL THERAPY
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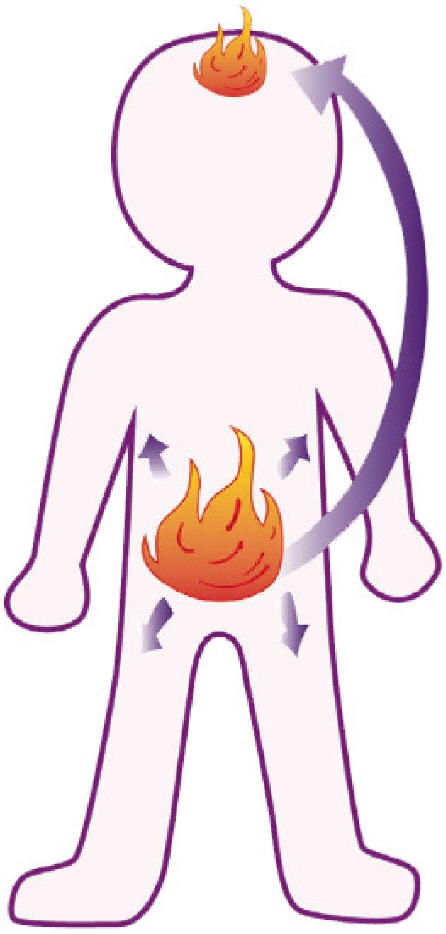

Me and My Tuba

By **Rosemary SZABLEWICZ**

A GRANDMOTHER REFLECTS ON THE INCREDIBLE ACHIEVEMENTS HER GRANDSON HAS MADE, AND HIS LIFE FROM HIS ASD DIAGNOSIS AS A BABY TO NOW.

It was Mother's Day and my oldest grandchild, Michael, was visiting. As he walked into our condo, he presented me with two large bouquets of vibrant-colored spring flowers. One from him, and one from his girlfriend Melissa, who was visiting her mom and grandmother in another town.

Since he will be graduating soon, Michael and I chatted for a while about his remaining days at college before he had to leave to go pick up Melissa. As always, it was gratifying to have a conversation with my grandson.

While chatting about his studies at university, Michael said he would be going forward in his chosen career with a degree in secondary education alongside a focus in music. His hope is to obtain a position in a high school which would include demonstrating, as well as teaching how to play and care for an instrument. Michael would like to share his love for and teaching music, as well as playing the tuba, which has been his choice since attending elementary school.

Michael hopes to assist in leading, and eventually heading, a school's marching band or orchestra. He also shared another aspiration of his; to play the tuba in a Broadway orchestra pit or late-night talk show. I commented that he definitely has the education, talent, and enthusiasm, along with a plan for himself, adding that "Grandpa and I wish you success, but be patient." Michael laughed, saying he always is.

As Michael was about to depart our condo, he turned to me and asked, “Are you and Grandpa coming to my music performance next week at the college? It’s early in the evening so you don’t have to drive in the dark.” This thoughtful statement brought tears to my eyes.

A blast from the past

I looked at Michael’s 21-year-old face, and at that moment I saw his countenance at 18 months old when he was diagnosed as having Autism Spectrum Disorder (ASD). It was a worrisome diagnosis for my daughter and the family to understand and accept, at first.

Apart from extreme manifestations of the condition, not much was known about the diverse levels of autism in 2002. Nevertheless, my daughter persevered to learn everything available about the syndrome, and she succeeded in locating the appropriate doctors, therapists, and educational systems to help Michael.

Through love, understanding, patience, education, counseling, guidance, training, medical care and determination, my grandson was about to graduate from college. During his four years at the university he worked part-time at the college while attending classes. As a member and officer of the school’s pep band, he was afforded the opportunity to travel to various colleges and has marched twice in the Macy’s Thanksgiving Day Parade.

Recognition for his achievements in music have also been awarded to him, for which he is very humble. He loves his family and his girlfriend and has many friends. He enjoys sports and being part of the community and whatever is available to him to become better at what he does, as well as paying back to those in need.

> “Michael graduated *cum laude* and proudly wore his academic cords. He was also recently informed that he received his certificate for teaching.”

It’s all thanks to the interest he showed and learned while playing the euphonium, a brass instrument, in fifth grade. Michael was resolute to learn the tuba, which he did, and kept it up over the years, becoming the kindhearted person he is today.

Before leaving, Michael beckoned me back from my reverie, and asked once again if Grandpa and I would be attending the performance. I asked if he was playing with the band. He replied, “No Grandma. It’s just me and my tuba.” A tear rolled down my cheek as I once again remembered Michael as a toddler.

Of course, we were present in the recital hall at Michael’s tuba solo concert.

Epilogue:

Michael graduated *cum laude* and proudly wore his academic cords. He was also recently informed that he received his certificate for teaching. Since then, Michael was offered and accepted a position as a music educator which he started in September 2022.

He is about to share his knowledge by developing a new music programme for the Kindergarten through eighth grade students. He is looking forward to imparting his skill of playing the tuba, along with teaching his soon-to-be students.

Michael is set to embark on life's passage to witness his dreams come true. We are thrilled for him and value all that he has achieved.

***Rosemary Szablewicz** has worn many hats over the years: Student, organizer, developer, property manager, coordinator, nursery school founder, president of various civic organizations including the PTA, interior designer, company manager, company comptroller, activist, volunteer, writer of first person and travel essays, creative nonfiction, short stories, and whatever captivates the mind. Rosemary, now retired after 30 years employment, has been published in New York and South Carolina newspapers, Newsday and Post & Courier respectively; Good Housekeeping, Travel Holiday, House (Lifestyle of the Island), and Long Island Pennysaver. Rosemary received an Honorable Mention in a group of 350 applicants for her essay on time passing, but remaining viable as we age. Her work appeared in the online "Dear Reader" publication. She is a daughter, wife, mother, grandmother, sister, aunt, niece and friend. Rosemary wears all hats worn under one chapeau known as Woman. She is a member and Moderator of the Nolan's Ridge Writing Group and the Roxbury Public Library Writers Workshop. She expresses her gratitude to these groups, family, and friends for their inspiration and support. Rosemary and her husband, Bill, formerly longtime residents of New York, now reside in New Jersey to be in close proximity to their three grandchildren.*

Tips for Holidays

By **Angela CHAPES**

LEARN FROM AN ADULT ON THE SPECTRUM ABOUT DIFFERENT HOLIDAYS, AND TIPS AND TRICKS FOR WAYS PEOPLE ON THE SPECTRUM MAY CHOOSE TO PARTICIPATE.

Any kind of holiday can bring a lot of joy or conflict because you are around a lot of family or friends. If you are alone, it can be hard. Sensory issues can happen.

I am providing an explanation of these holidays, how they are typically celebrated, and how those on the spectrum may choose to celebrate. I hope these help.

Tip 1: Martin Luther King Jr. Day – Held in January, this holiday is celebrated for a great man wanting equal rights for persons of color. Many people celebrate Martin Luther King Jr. for his work.

Tip 2: Groundhog Day – Held in February, a groundhog located in western Pennsylvania, Punxsutawney, Phil predicts the weather. If he sees his shadow we get six more weeks of winter.

All those on the spectrum can celebrate this holiday. My mom used to make groundhog logs out of rice crispy treats. It was fun. This is celebrated in Canada too.

Tip 3: Valentine's Day – Held on February 14, chocolate, flowers, and dinner are big on this holiday. Those who are on the spectrum can share a special day with a valentine.

If someone does not have a special someone, celebrate with a friend, family member, or pet. Go to a movie or do something else fun.

Those who don't want to celebrate don't have to. I have always curled up in my house with my cat and have been perfectly content.

Tip 4: Presidents' Day – Held on the third Monday in February, this holiday celebrates past and present presidents who made the United States what it is. Everybody on the spectrum can celebrate.

Tip 5: Mardi Gras – Held the day before Ash Wednesday, also known as Fat Tuesday, everyone eats all the fatty or rich foods in the house. It is one big holiday before the start of Lent.

During Lent, people who celebrate avoid meats and fatty foods. Lent lasts till Easter Sunday. During Mardi Gras, people celebrate with lots of food and parades; in New Orleans people on floats throw beads and trinkets. Sensory issues may happen; use your best discretion.

Tip 6: Saint Patrick's Day – Traditionally held on March 17th, this is a celebration of Saint Patrick which comes from Irish traditions. People wear green, often eat corned beef and cabbage, and drink green colored beer.

Some on the spectrum probably don't drink, like me. Drinking is not required. You can wear green, eat special food, and have fun with friends.

Tip 7: Easter – Held in the spring, it is about going to church and celebrating Jesus' Resurrection. Many celebrate the secular side of this holiday with the Easter Bunny and Easter eggs.

Families hide eggs and candy for their children to find. Kids may have their picture taken with the Easter Bunny. Adults on the spectrum may enjoy this holiday by going to church, eating candy, and just having a good day.

Tip 8: Cinco de Mayo – Held on May 5, Mexico won the Battle of Puebla which became a symbol of resistance to foreign powers, celebrated in Mexico and by Mexican Americans. Family and friends celebrate with dancing, music, balloons, and flowers. Sensory issues may happen - use your best discretion.

Tip 9: Mother's Day – Held the second Sunday in May, it's all about mothers. Moms on the spectrum can expect a special day with loved ones, family, and friends.

Children can make their mothers breakfast and bring them flowers and gifts. Since moms are working, it is an excellent idea to recognize them on a special day.

Tip 10: Memorial Day – Held on the last Monday in May, this holiday celebrates women and men who have died serving their country in the military. Many on the spectrum served their country in the military. Everyone can commemorate members of their families who died in wars.

Tip 11: Father's Day – Held on the third Sunday in June, dads on the spectrum can expect lots of love from their loved ones. Children on the spectrum cherish their dads by giving special gifts.

Tip 12: Fourth of July – Held on July 4, it is about America's independence. There are fireworks, hotdogs, and hamburgers. Since fireworks can be loud, parents will decide if their kids can watch.

Adults on the spectrum can judge what they can handle. You might bring headphones to block loud bangs, or watch the fireworks on television. I always enjoy watching fireworks on television.

Tip 13: Labor Day – Held on the first Monday in September, it is about hard-working Americans. Those on the spectrum who work can enjoy their celebration. This holiday is a three-day weekend celebrated with picnics or short trips.

Tip 14: Halloween – Held on October 31, this is a fun holiday for people to dress in costumes. People can go to Halloween parties and trick or treat for candy with kids and adults. Pets can go trick-or-treating too.

People in the old days dressed up to ward off spirits. It is fun for kids to get candy, and if they get overwhelmed, parents can take them home to eat candy and watch movies.

Adults can go to costume parties. If parties are wild, some on the spectrum can be overwhelmed. Parties should be sensory-friendly.

Tip 15: Veterans Day – Veterans Day is celebrated on November 11. There are parades and concerts honoring those who serve or have served in the military. Many on the autism spectrum have served their country in a branch of the service.

Tip 16: Thanksgiving – Held on the fourth Thursday in November, this is a holiday sharing gratefulness. It celebrates when pilgrims and Native Americans shared the first harvest.

Families and friends celebrate with a turkey dinner. Many individuals celebrate with their families by traveling home.

Tip 17: Christmas – Traditionally held on December 25, it is a Christian holiday celebrating Jesus’ birth. The secular way of celebrating Christmas is with Santa Claus. Gift giving is central.

Families with members on the spectrum can celebrate by going to church and/or opening gifts and being together. Grandparents, aunts, uncles, and close friends often gather on Christmas Eve or another day. Individuals who do not celebrate Christmas may gather with family or go on vacation.

Tip 18: Hanukkah – Hanukkah, the Jewish festival of lights, is held in December. It is a celebration of a miracle when a meager amount of oil in a lamp lasted for eight days. Families celebrate with gifts and special foods on each of the eight nights of Hanukkah.

Tip 19: Kwanzaa – Kwanzaa is celebrated from December 26 through January 1 by African Americans. It is a celebration of African heritage, unity, and culture. Kwanzaa is not a religious holiday; it’s a cultural one with spiritual quality.

Tip 20: New Year’s Eve and Day – Held on the last day of December and first day in January, this holiday brings in the New Year and says goodbye to the old. This is a time for people to stay up at least until midnight partying, drinking, snacking, or watching television and hanging out with friends.

Some on the spectrum can handle all the excitement; others may not be able to handle what is going on. For these individuals, I recommend staying home and having a quiet celebration. The Chinese New Year is celebrated in February.

Tip 21: Family Conflict – Families often encounter difficulty on holidays because of long-standing or recent disagreements. When people are hurt, it is difficult to enjoy get-togethers.

Some families might decide to forgive and start healing. Others might gather with awkward conversations. Holiday celebrations offer an opportunity to heal wounds.

Many of these holidays are celebrated in other countries with different names and dates. I hope these tips have helped those on the spectrum.

__Angela Chapes__ is an autism and mental health advocate. She is an autistic adult with anxiety and OCD. She has also had depression in the past. Angela was not diagnosed with autism until her late 20s. It was years later that she started to figure out who she was, thanks to the positive and supportive people in her life. Angela has two encouraging jobs and feels she is transforming and growing at lightning speed. She is learning all she can about leadership, advocacy, and organizations that can help shape her future. Angela wants to be a strong voice for individuals with autism and mental illness. She loves being busy, writing, and speaking.

Four Ways to Help Your Neurodivergent Teen Prepare for High School

By **Nykele ASEMOTA**

HERE ARE FOUR WAYS YOU CAN HELP YOUR NEURODIVERGENT TEEN BE READY FOR HIGH SCHOOL.

Preparing for high school can be daunting for any teen, but for teens with neurodivergence, it can feel especially overwhelming. As a parent, you want to do everything you can to help your teen succeed in this new environment. High school is a time when teens are expected to start taking on more responsibility for their own lives, and for neurodivergent teens, this can be a challenge.

It can also be hard for parents to know how to best support their neurodivergent teen during this time. You want to give them more independence, but you also don't want to leave them feeling unsupported. It's important to find a balance between giving your teen the space they need to grow and providing the support they need to thrive.

Here are four ways you can support your neurodivergent teen as they transition into high school.

1. Help them develop a support system

A big part of preparing for high school is feeling like you have someone who has your back. Encourage your teen to build a strong network of friends – both at school and beyond. These friends will become an invaluable resource during the highs and lows of high school life.

Friends they have in elementary school and middle school may not be the right fit for them in high school, so encourage them to branch out and find new friends who share their interests. People change and grow, so neurodivergent teens may find it helpful to have a variety of friends to rely on in their niche.

Start by helping them explore their interests. What clubs and extracurricular activities does their school offer? What are their hobbies? What do they like to talk about? From there, it will be easier for them to find like-minded people with whom they can connect.

Help them work on their social skills by role-playing different scenarios, coming up with some conversation starters, or attending social events together. The more comfortable they feel in social situations, the easier it will be for them to make friends.

2. Provide them with a planner or calendar

As a teacher and coach, one of the biggest challenges I see neurodivergent teens face during high school is staying on top of their assignments. A planner or calendar can be a great tool for helping them stay organized and on track. If your teen is neurodivergent, consider purchasing a planner specifically designed for neurodivergent students.

> “People change and grow, so neurodivergent teens may find it helpful to have a variety of friends to rely on in their niche.”

There are plenty on the market. Make sure the planner includes a calendar, to-do list, and space for recording homework assignments.

Most planners can help your teen keep track of their classes, homework, extracurricular activities, and social events all in one place. A planner specifically for neurodivergent teens can also contain:

- IEP information and progress trackers
- Daily student activity trackers to keep parents informed
- Parent/teacher communication pages
- Rewards systems to encourage positive behavior

3. Encourage your teen to ask for help when they need it, and advocate for them when they can’t

High school can be tough for anyone, neurodivergent or not. There will be times when your teen doesn’t understand something in class or feels overwhelmed by their workload. That’s ok.

Encourage them to ask for help from their teacher, classmates, or other adults they trust. If they’re feeling lost, a little guidance can go a long way.

When your neurodivergent teen can't advocate for themselves, be their voice. Talk to their teachers, counselors, and administrators about what they need in order to succeed.

Let them know about your teen's neurodivergence and how it affects them in school. Advocate for accommodations or modifications that will help your teen thrive in high school.

4. Help them build a positive self-image

Most neurodivergent teens struggle with self-confidence issues at some point during high school. It can be hard to feel good about yourself when you're constantly dealing with obstacles that other teens don't have to face.

Help your teen develop a positive self-image by praising their accomplishments, big and small. Point out the things they're good at, and remind them of their strengths.

Let them know that you believe in them and that you will support them through everything high school throws their way. Building a positive relationship with your teen will go a long way in helping them to develop a positive self-image by themselves.

Every neurodivergent teen is different, so what works for one may not work for another. As a parent, it's important to find what works best for your teen and help them navigate the waters of high school. With your support and encouragement, neurodivergent teens can succeed in any environment.

Summing up

High school can be a challenging time for any teen, neurodivergent or not. But with a little bit of parental guidance and support, neurodivergent teens can thrive in high school and beyond. Remember to encourage your teen to explore their interests, stay organized, and ask for help when they need it. Most importantly, build a relationship of trust and communication so they know they can always come to you for advice and support. Thanks for reading!

__Nykele Asemota__ is a certified mindset coach, educator, and parent who builds teens and kids into confident leaders by helping them develop unshakeable confidence and intrinsic motivation. You can read more about her work and her Boost Mindset Coaching System online.

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https://www.boostmindsetcoaching.com/boostkids

READ IT NOW

READ IT NOW

READ IT NOW

READ IT NOW

READ IT NOW

Poetry Corner

Why Is Everything Too Much?

By **Renee BOLLA**

Sun shining.
Too bright for my eyes.

Fuzzy sweater.
Too itchy on my skin.

Time for shoes.
Squishing my feet.

Bike around town.
Too fast for my tummy.

Pink popsicle treats.
Hurting my teeth.

Music to rest.
Too loud in my ears.

Snuggle with hugs.
Just right for my heart.

***Renee Bolla** is a retail executive turned children's picture book writer. After 20 years in corporate retail, Renee made the decision to resign. As a mother of three daughters, she wanted to be more present, spend more time with her family, and discover more about herself. With the luxury of time and space to let her creative mind wander, she decided to explore writing. Her journey started with creating a keepsake book for each of her children with each story being unique to their personalities and real life experiences. While writing started as a hobby, it has evolved into much more. She is a self-taught writer, inspired by motherhood and she enjoys sharing her stories with others.*

Childhood Disintegrative Disorder:

Does it Relate to Autism?

By **Donna McPHERSON, AAS**

A LOOK AT CHILDHOOD DISINTEGRATIVE DISORDER, ITS EFFECTS, AND HOW WE CAN HELP KIDS ON THE SPECTRUM WHO MAY EXPERIENCE IT.

What is childhood disintegrative disorder (CDD)? Is my child at risk? How might it affect my child? These are questions parents of children on the spectrum might ask when first seeing CDD written out in front of them, perhaps alongside the word "autism."

Being a parent and watching your children develop, wondering whether they are reaching their milestones, can be stressful. It is natural to worry if your child has previously met some developmental milestones and they appear to start regressing.

If regression of previously acquired skills occurs at any time, it is always a good idea to talk to your child's doctor. They can do an exam and order additional assessments and tests, if necessary. Try not to panic; a skills regression can happen for many reasons and is not always a sign of CDD.

In this article we will be discussing CDD, what it is, diagnosis, and how CDD differs from autism spectrum disorders (ASD). At first glance, both CDD and ASD seem to have a lot of similarities, but they also have many notable differences.

What is childhood disintegrative disorder?

Childhood disintegrative disorder (CDD) is a rare condition characterized by the occurrence of developmental delays after a child is two or three years old. These developmental delays are found in language skills, social skills, and/or gross and fine motor skills.

The other two names that CDD is known by are, Heller's syndrome and disintegrative psychosis. The condition was first reported and described in 1908 by Austrian educator Thomas Heller.

The disorder is sometimes grouped with other, better understood, conditions like pervasive developmental disorders (PDD) or autism spectrum disorders. However, most children with PDD or autism will not also experience CDD. CDD affects many different areas of a child's development, and that is the main reason it can sometimes be found with these other conditions.

> “The disorder is sometimes grouped with other, better understood, conditions like pervasive developmental disorders (PDD) or autism spectrum disorders.”

> “Childhood disintegrative disorder (CDD) is a rare condition characterized by the occurrence of developmental delays after a child is two or three years old.”

Childhood disintegrative disorder is thought to affect one in 100,000 boys. The typical ratio of boys to girls is estimated at about eight boys to one girl. Regression usually starts around two to three years old but can continue up to around the age of ten.

Autism is much more common than CDD and is believed to affect one in 44 eight year olds, according to the Centers for Disease Control (CDC).

What are the symptoms of childhood disintegrative disorder?

When a parent starts noticing their child has late onset regression and starts losing developmental milestones and skills they previously had, it is probably a good time to discuss the possibility of CDD with a doctor.

The child's doctor can check and rule out any other possibilities during a routine exam. If the doctor is concerned, they might refer the child to a psychiatrist who will conduct further assessments and make the diagnosis of CDD, if applicable.

In order to diagnose CDD, the child must show regression in at least two of the areas listed below, after they turn two years old:

- understanding language that is spoken to them (receptive language skills)
- being able to express thoughts through language (expressive language skills)

- social skills and/or ability to regulate behavior (adaptive behaviors)
- interactions with others their age/peers
- development of fine and gross motor skills
- toilet training or loss of previous bowel or bladder control

Along with the regressions noted above, the child should also exhibit anomalous function in at least two of the following areas:

- difficulty interacting with and making social and emotional connections through nonverbal behaviors
- difficulty with social skills and situations like starting and maintaining conversations with others
- repetitive stereotypical patterns and behaviors, like hand flapping and other types of repetitive movements. These are typically not caused by general medical conditions and/or other diagnosed medical conditions

What causes childhood disintegrative disorder?

There is no definitive research that pinpoints the cause of childhood disintegrative disorder. There are hypotheses that point to the condition possibly stemming from neurobiology or how the brain and nervous system are formed and function.

A study by Johns Hopkins Medicine of children diagnosed with CCD revealed about half of the children had abnormal electroencephalogram (EEG) readings. Seizures have also been associated with childhood disintegrative disorder and can indicate the occurrence of abnormal neurobiology.

What are the differences between CDD and autism spectrum disorder?

The main difference between CDD and ASD seems to be that, with CDD, the child followed a “normal” development of skills compared to their neurotypical peers until they were at least two years old and started losing those skills around three and four years old, up to ten years old. Whereas, with ASD, the child typically misses some developmental milestones or meets them later than their neurotypical peers.

What does this mean for my child?

If you have concerns about your child’s development or regression, it is always advisable to reach out to their doctor. Your child’s doctor will have access to different resources and information and might be able to put your mind at ease.

The doctor can also examine and determine whether your child needs further evaluation or if there are therapies that can be used.

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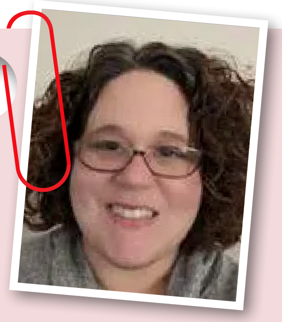

Donna McPherson, AAS *is a Writer for* *Autism Parenting Magazine**, a wife, a special needs homeschool mom, and a nature photographer. She has a degree in Early Childhood Education and is dedicated to helping people better understand autism, sensory processing disorder, and homeschooling. Donnesa is an avid advocate for her children and enjoys spending time with her family playing games, reading an array of books, exploring all that nature has to offer, and participating in National Novel Writing Month (NaNoWriMo).*

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As My Son Giggled in His Dreams...

By **Tulika PRASAD**

A MOTHER SHARES WHAT HER SON'S GIGGLES IN HIS DREAMS REVEALED TO HER.

I was riding through a field of daisies, on a lemon yellow bike, with a bunch of flowers sitting in the basket up front. A stream somewhere close by sent out the soothing sound of its water playing with little rocks on their way down, while the mountains in the far distance poked teasingly at the clouds.

The gentle breeze tickled my face, and the sun was a perfect shade of gold. The birds chirped stories of faraway lands, and butterflies and bees flew all around me like worries leaving my mind.

As I was savoring the moment, a faint giggle, like the sound of bells, filled my ears. I looked around for the source, confused. It was my dream after all, and this giggle was not supposed to be a part of it. As I focused more on the giggle, it sounded more and more familiar…it was my son's…and it was coming from right next to me.

My son was giggling, and he was clearly having a lot of fun in his dream. It woke me up from my own beautiful dream, but to watch him giggle with such abandonment was a more beautiful sight!

What does he dream about?

I wondered what it must be about — was he being tickled in his dreams? Was he tickling someone back? Was he on a swing or a roller coaster and could feel the butterflies in his tummy, or was he giggling as he rode a wave on the beach?

Was he sharing a joke or maybe laughing at one? But hey, he cannot talk and has a language processing disorder, so jokes don't make sense to him.

Can he still be laughing at those in his dreams? I wondered and gently stroked his hair as he drifted back into his sleep and his soft snores replaced the giggles.

My dreams for him

My son is autistic and cannot communicate and express himself. I tend to think for him, speak for him, and assume things for him. Sometimes I am right where he wants me to be, and probably most of the other times I am way off, but he has no way of telling me that. So I arrogantly keep going as if I am his savior.

In my mad rush to constantly be his advocate and voice, I sometimes forget to stop and watch him be himself, with no demands from the people around him or me. In all this craziness, I also forget that he can have his own dreams too. I found him giggling in his dreams, so I know he dreams and that he dreams of happy things.

But while I claim to be the know-all for my son, I couldn’t even guess what exactly it was that made him giggle in his dreams. However, here I was claiming to know and work towards making his dreams come true! It made me wonder what else he might be dreaming of, and if my dreams and his align at all.

Over the years I have always wanted him to have neurotypical friends, to be called to playdates and birthday parties, or just have friends visiting him. I never stopped to think if that is what he wanted as well. Like so many people, he might not really want the company of others.

He might enjoy being with himself. Maybe he likes to sit and watch and observe people but not really interact with them. He might dream of enjoying the silence of his own company and his thoughts, with no other distraction.

In my ignorance, I might be constantly pushing him to say hi to everyone he comes across, shove him towards other kids so that he can mingle, or just keep asking him to socialize more. Maybe I am doing the exact opposite of what he prefers, imposing my expectations on him.

Maybe his dreams are different from mine

I keep pestering my son to bike, run, or play with a ball. I have enrolled him in different special needs sports and keep pushing him to be more active. He prefers a more sedentary lifestyle. Maybe that’s what he prefers, or maybe that’s what his body allows him to do. I have seen him enjoy watching nature — the clouds floating by, the raindrops falling, and the trees and grass swaying in the wind. Maybe he dreams of sitting in a lush green field by a lake, just enjoying the breeze on his face and watching the squirrels search for nuts.

> “Maybe he likes to sit and watch and observe people but not really interact with them. He might dream of enjoying the silence of his own company and his thoughts, with no other distraction.”

He probably dreams of reaching high up into the clouds on his swing and dipping his feet in their fluffiness. Maybe he dreams of these and not of being an athlete. I might be getting it all wrong, trying to make him imitate what his peers are doing.

I push for him to be included. Inclusion is the buzzword in the special needs world. I want him to sit with his neurotypical peers, study with them, perform with them, and play and eat with them. I want him to be a part of everything they do.

Maybe our dreams are the same

I never ask him if that is what he also wants. Does being with people who don’t understand him or how he feels really make him happy? Does he want to be in a room filled with people who are too noisy for him and do not appreciate his sensory needs?

Maybe my push for inclusion is not his desire. Maybe he likes being with those like him. His dream might be to be in a world that has people who are like him.

Like everyone else, he might want to be with like-minded people and not with those who operate very differently from him. Maybe inclusion is my dream and not his.

I wonder if in his dreams he talks to us, shares his thoughts, and has a conversation about things that excite him, or is he still non-verbal in his dreams, struggling to make himself understood and seen? Does he even dream about being able to talk, or do words seem insignificant in a world that he visits in his dreams? I wish I could know if it's just me obsessing over his need to communicate or if he wants this as much as I do.

To fit in this world, I have tried hard to change so many things in my son — make eye contact; don't flap your hands; don't make that sound; don't laugh for no reason; stay in one place; don't fidget so much; don't listen to nursery rhymes anymore, you're too old for that; there's no reason to be anxious when no one else is; sit down with everyone… the list goes on!!! I'm always correcting him, trying to change him, and asking him to fit in.

I never paused to think maybe he wants none of these. Perhaps he wants to flap, jump, laugh, and watch Old McDonald on a loop. Maybe he wants to be different.

Maybe his dream is to be himself and to be happy about it. Maybe he dreams that one day we all will be ok with him being him. He might want us to stop dreaming for him and dream with him instead. Maybe he was giggling in his dreams because he was in a world that was just this — a world of his dreams, not mine.

__Tulika Prasad__ and her husband are parents to Vedant, who was diagnosed with autism when he was three years old. She is an Autism Speaks Volunteer Advocacy Ambassador, a member of Regional Autism Advisory Council and also volunteers in various capacities for autism awareness and acceptance.

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Autism Warrior

Marcus Boyd

By **Emily Ansel ELFER**

MEET MARCUS BOYD, THE VOICE FOR THE VOICELESS, AND THE CHAMPION FOR CHANGE FOR AUTISM FAMILIES.

Marcus Leonardo Boyd is an accomplished man. He is a four time award-winning autism activist. His accolades include 13 awards and seven Grammy nominations as a producer and composer.

From a collection of clothing and a line of shoes to a coloring book called *Marcus the Superhero*, and founding the Autism Music Festival, he uses his talents to reach those in power. For the past five years he has worked to effect change.

He fights all over the world for new laws, rights, and programs for low income families. He has made it his passion-fueled mission to be a voice for autism and to pave the way for the next generation to have a better life.

As the voice to the voiceless, he has committed his life to overcome challenges such as people in high places refusing to listen, lack of funding, lack of support, and the struggles involved in getting the word out about autism and autism families' needs.

Accomplishments

Marcus' accomplishments include a bachelor's degree in journalism and mass communications from Ashford University. He is the first African American in the United States to win awards as an autism activist. He will be attending a dinner in his honor at the Library of Congress in 2023 and has been inducted into the history books for his activism in South Carolina.

Inspiration

Many people have inspired Marcus throughout his life, including his family; the families he works with; his case worker, Dorothy Carr; his behavior aid, Bob Ordner; his best friend, Gary Sinatra; his friend, Queen Carter; his sister, Cassandry Burse Boyd; his sister, Brandi; and his grandmother, who is in heaven now.

He shares, "I know my journey and my walk is not about me; it's about the millions of voiceless individuals who don't get to fight or have their stories heard. I have to fight and stand up for them, so they are my inspiration."

Goals

Within the US, Marcus is currently working with several state governments to advocate for new programs and activities for autism families. He is also working toward the same goals with other countries.

He plans to work with autism families worldwide to bring all communities together for three days at the Autism Music Festival. There they will celebrate, encourage, and love one another.

Future endeavors include an autobiography book, a TV series centered around "The Boy with No Voice," and many more speaking engagements to raise awareness about autism.

Advice

Marcus would advise parents, hearing of the child's autism diagnosis, that what they are feeling is okay. He wants them to refuse to give up, and walk through with faith. He encourages them: "You just have to show them an unlimited amount of love, affection, patience, and understanding. Their first lesson in life is you, so how you treat them will affect how the rest of the world treats them. Never give up on your child."

Additional thoughts

Marcus shares what he is thankful for: "I want to thank the world famous Autism Parenting Magazine for this historic and life changing opportunity. I want to thank my team and my supporters for always supporting me and having my back."

"I want to thank every mayor, governor, city council members, state senators, and democrats that have listened and are working with me to make new laws and rights for autism and to make it better for the next generation. Just be looking out for more from me, and know that I believe in you. I stand with you, and I love you."

Marcus is an award winning autism activist who can be found on [Instagram]() and [Facebook]()

Benefits of Sensory Games for Children With Autism

By **Miriam FRANKEL**

AN OCCUPATIONAL THERAPIST SHARES VALUABLE INFORMATION ABOUT SENSORY GAMES AND TOYS.

Children with autism are children first and foremost. They may have wonderfully rich imaginations, a standard (and sometimes additional) set of needs, yet there is much they can learn through play.

Every child gravitates towards certain types of toys and types of play. What is interesting to one may not be interesting to another. As any parent of a child with autism knows, these particularities can be very intense. Children with autism often have strong sensory needs, as well as a strong sensory sensitivity, and that combination makes for every individual's likes and dislikes in terms of toys.

It's always beneficial to try to meet a child where their interests lie. In order to give someone the capability of theory of mind, i.e. the capability to

come out of their thoughts and perspective and see someone else's thoughts and interests, you first need to join them in their interests. Then you can gradually bring them out into a middle ground.

Play builds connections

Meeting your child on their level and engaging with what they're interested in is absolutely essential to making a meaningful connection.

Regardless of where your child may "fall on the spectrum," so to speak, one of the challenges parents with autism face is building connections. If your child is nonverbal or not very communicative, play is a beautiful way to bridge the gap between traditional verbal communication and relationship building.

There are so many wonderful ways to build strength into your connection with your child, and as you dive into this article further, you will get a picture of how many options you have.

What are sensory toys and games?

Sensory toys and games are specially designed to stimulate one or more of the senses. Children on the spectrum enjoy these as they provide the sensory input that they need.

As a parent, you may have heard about sensory toys and games in the toddler or preschool years. "Sensory play" has become something of a buzzword in early education, and it's a great way to facilitate tactile exploration of the world.

> "Sensory toys and games are specially designed to stimulate one or more of the senses. Children on the spectrum enjoy these as they provide the sensory input that they need."

If your child is in occupational therapy, your therapist has probably used some of the toys we'll talk about here.

Here are some examples:

Textured items

Think about contrasts: bumpy versus smooth; scratchy versus soft. Textured items can include sensory tubes, squishy balls, sandpaper, bubble wrap, slime, spiky balls, and more.

Sensory lighting

Light and shadow, mood lighting, colorful lights, lava lamps, LED color strips, twinkle lights, and more can be used in sensory play.

Fidget items

These are easier than ever to get, and popular options include poppers and spinners. Repetitious, constant movement can satisfy a child's sensory needs.

Scratch and sniff or scented items

Scented playdough, scented markers, even the scent of nature-based crafts that use leaves and flowers can soothe a child whose sensory system is out of balance.

Many of our examples aren't things you have to run out and buy. You can create sensory items from things you already have in your home, such as items used to wash dishes, shower, and paint. This is also a good way to model for your child how to seek out appropriate sensory experiences, making it clear that these things are accessible and not hard to find.

Let's go through some examples of how your child, who may experience ASD symptoms or be diagnosed with autism, can play sensory games to feel good.

Visual stimulation sensory play

ASD is often typified by an intense need for visual stimulation. This is why children with autism may spin in circles or spin their toys around and around. Repetitive movement has a calming effect, helping them regulate their sensory system.

It's important to pay attention to how your child responds to lights and various types of visual stimuli.

Often, a perfectly balanced environment will leave them feeling at rest, whereas one where a light, color, texture, or sound is "off" to them will promote anxiety.

Visual sensory play can include things like this:

- Decorating or doing crafts with glittery papers or materials
- Sticking colorful alphabet letters to a felt board
- Playing with a light projector or different colored lights
- Color painting in high contrast paper colors and paint colors
- Using flashlights to do a scavenger hunt
- Creating a kaleidoscope, paper windmill, fan, flag, or wind sock

Think about what sights are highly stimulating and interesting, then follow your child's lead on what makes them feel happy and at ease.

Sensory games and the vestibular system

Sensory games that provide vestibular input are a powerful way to help your child feel more focused and alert. One of our favorite ways to play with this is to use a balancing board.

The amount of focus a child has to exercise to stay upright can be helpful. There are plenty of fun games you can play once your child is confident and balanced. If the balance board is too challenging for your child at their age or level of gross motor development, you can use a BOSU ball, or even just a folded towel on the floor to give them some “early stage” attempts at balance.

Another whole-body option is compression vests, which provide deep proprioceptive input and calm the body. Try using them to help your child increase their body awareness.

With improvements in body awareness, your child will have a better understanding of where their body is in space, and how one part of their body moves in connection to another part.

You may discover that your child’s gross motor movements, like jumping or kicking a ball, will improve with heightened body awareness.

If you are a parent of a child with autism, we know that you live day in and day out wanting nothing more than for your child to feel calm, to feel peaceful, and to feel at home.

***Miriam Frankel** (formerly Manela) is a highly sought-after Occupational Therapist who specializes in treating mental and behavioral challenges in both adults and children. She is the founder and director of an online learning platform, Bloom, where parents, caregivers and educators can access the tools they need to help their struggling children, be it struggles with anxiety, fears, ADHD, SPD, ODD or developmental issues. Miriam is also the author of the **Parent-Child Dance**, and founder of Thrive Occupational Therapy.*

🌐 https://www.childrenbloom.com/pages/membership-plan

The Connection Between Physical Strength and Mental Wellness

By **Melanie K MILICEVIC**

A MOTHER SHARES THE MEANING OF DEVELOPING A STRONG BODY AND MIND FOR HERSELF AND FOR HER CHILDREN.

For the last six months, I've been working diligently on my body. It's amazing what you can accomplish if you focus only on one thing: yourself. It's something I have been neglecting for almost thirteen years. Since my son turned 13 this month, I figure it's time to finally shed the baby weight and reclaim some part of my old self. Time to rediscover a new self, and my body recovery is part of that.

Weight for women is such a touchy thing. I was bigger than my body could take, and I knew this. But truthfully, I had a hard time paying attention to my figure once I became a mom.

I allowed for bad eating habits and emotional eating to take over, and I gave up on myself a bit. It seemed too hard to work on my figure when I was mothering and caring for others. Balance was key, and of course I understood this but couldn't grasp it.

I was not at all in sync with myself physically or mentally. I fell into habits like late-night eating, eating in bed, and the most destructive, eating when angry or depressed.

I felt my children needed me more than I needed myself

In the midst of all that eating came an autism diagnosis and a dyslexia diagnosis, and caring for myself seemed unfair when my children needed so much help. I could not do it then.

I could not focus on me when all they needed was me. I sacrificed myself, but it was worth every pound, every wrinkle, and every scar I've endured mentally and emotionally from advocating for them.

They were and are worth it. My children are my legacy and greatest rewards.

Now, it is time to focus on me

Now they are older and more capable, and it would be foolish not to focus on myself. My health has suffered enough. I've given up enough of myself physically and emotionally, and now we enter the stage when we need to find balance once again.

However, this time it's about letting go of the parenting remote control and diving into my own self care and development. There's still a little bit left of me I would like to develop. There's more I want to become before I retreat into another phase of life with my husband.

My body is just one part of this. Creating a strong body is something I'm just beginning to discover–but I've started. I've lost ten pounds and have seen a dent in what I want for myself.

“The stronger I become physically, the better I feel mentally. My mental health hasn't always been consistent because I've had so much to accomplish these past 13 years.”

I recognize my face again, not the bloated, scared woman I saw looking back at me in the mirror for the last 13 years. My little bit of confidence is returning, yet I remind myself to remain humble and not to get too excited because I have a long way to go both physically and mentally.

Today I am celebrating my beginning. It's something I have craved for many years, yet something always halted my work. This time, I hope I can achieve my physical goals and grow stronger mentally as well. The connection between the two is obvious to me now that I'm feeling the rewards.

The stronger I become physically, the better I feel mentally. My mental health hasn't always been consistent because I've had so much to accomplish these past 13 years. But I'm determined to find the tranquility that waits for me as I physically become the woman I want to be for myself and for my truly beautiful family.

__Melanie K Milicevic__ is a graduate of UCLA and a former 5th grade teacher for the Los Angeles Unified School District. She worked mostly with second language learners and collaborated with special needs families to meet the unique needs of her students. She now advocates for her own special needs children and continues to work with schools to help educate them about ways to include children of all abilities in the classroom. Melanie is a passionate writer and hopes to be a voice for special needs families in her community. She lives in San Diego with her husband and two children.

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Opinion:

Is Systemic Racism Delaying Autism Diagnosis of African American Children?

By **Cherisse WATTS, MSN RN PHN**

DELAYING DIAGNOSIS AND SERVICES TO AFRICAN AMERICAN CHILDREN WITH AUTISM COULD BE A RESULT OF SYSTEMIC RACISM.

One in 44 children aged eight years old in the United States were diagnosed with autism spectrum disorder (ASD) in 2018 (Maenner, 2021). While screening for ASD has increased, and the disparity gaps have narrowed over the years, African American (AA) parents are found on average to experience a three-year delay in diagnosis from when neurodivergence is first recognized (Dattaro, 2020).

In a study of 584 AA children, AA parents became aware of developmental delays around 23 months; however, it was not until six months after the observation that the concern was expressed to a healthcare professional. Once concerns were shared, an official ASD diagnosis was not received until after the age of five years old (Constantino, 2020).

Delays in services

Not only are there delays in identification, but racial inequities in access to services for ASD (Broder-Fingert et al., 2020), once diagnosed, have also been identified. What might the reasons be behind these delays in parental reporting, diagnosis, and access to services?

Several systemic flaws are impacting the timely diagnosis of ASD in AA children and use of services (Broder-Fingert et al., 2020). Factors that can lead to delays in parental reporting may include:

- Distrust of the primary care provider (PCP) and overall dissatisfaction with the healthcare system. This can be for a variety of reasons such as perceived discrimination, feeling judged, feeling unheard, disability stigma, and concern about familial and societal acceptance
- A lack of diversity amongst neurodevelopmental pediatricians, as only 2% identify as AA (Broder-Fingert et al., 2020). At times, there can be a disconnect between AA families and providers of a different ethnicity due to providers' lack of cultural competence and humility
- Life stressors, such as poverty (which can affect insurance coverage), and lack of transportation
- Not having specific information pertaining to developmental milestones and what delays may look like

Factors that can cause a delay in diagnosis may include:

- Parental hesitancy to report to a health care professional
- PCPs that suggest wait and see when a delay or delays are observed, as opposed to implementing preventive measures early on
- Refusal of PCP to provide a referral for early intervention services
- Wait lists to see specialists if a referral is obtained

Factors in AA communities that hinder enrollment and use of services may include more of the same issues as mentioned above: poor insurance coverage, lack of referrals to specialists, PCP wait and see approach, life stressors such as lack of transportation or needing to prioritize work commitments, and parental dissatisfaction and distrust of the healthcare system, overall (Flores, 2005). AA families are more likely to live in medically underserved areas that lack ASD specialists (also due to issues of systemic racism in housing policies) and are more likely to depend on Medicaid for health insurance.

Medicaid is structured so that low rates of reimbursement are offered to providers, making expansion of services difficult for the clinics that serve low-income communities (Broder-Fingert et al., 2020). These low reimbursement rates make it especially challenging to support and maintain a high-quality workforce.

Prevalence of dual diagnosis

Additionally, AA children are found to have a higher prevalence of a dual diagnosis of ASD and intellectual disability (ID), as 47 percent of AA children are found to have ASD and ID compared to 27 percent of white children (Dattaro, 2020). Could later diagnosis of ASD in AA children be a factor in this? Are some dual diagnoses erroneous?

Previous studies have also discovered that AA children had higher chances of also being diagnosed with an adjustment or conduct disorder than white children (Mandell et al., 2009). This becomes dangerous territory, as AA children with ID, learning disabilities, and/or behavioral disorders experience a school suspension rate two to three times higher than white students from elementary through high school, are expelled at a rate three and a half times higher than white students, and are at a higher risk of being truant, arrested, and becoming part of the pipeline to prison (Green, 2012).

The pipeline to prison refers to the high rates of AA children entering the juvenile justice system for offenses that could have been handled in a different manner. Once these children re-enter traditional classrooms, statistics show that approximately 65% end up dropping out of school and face other discouraging obstacles in life (Green, 2012).

Lack of workforce preparation and high unemployment rates are examples of such obstacles. The unemployment rate among individuals with disabilities was 10.1% in 2021. For AA individuals with disabilities, it was even higher at 15.1% (U.S. Bureau of Labor Statistics, n.d.).

> “Once these children re-enter traditional classrooms, statistics show that approximately 65% end up dropping out of school and face other discouraging obstacles in life (Green, 2012).”

> “The pipeline to prison refers to the high rates of AA children entering the juvenile justice system for offenses that could have been handled in a different manner.”

To address this, several things need to happen.

- There should be continued efforts to recruit and retain ethnically diverse health professionals, as an ethnic and culturally diverse workforce can help impact how care is delivered, as well as adherence to plan of care (Gilliss et al., 2010)
- There needs to be more outreach efforts by health professionals within areas that are traditionally medically underserved and low-income
- Increased collaboration and engagement with Nurse Family Partnerships program, Early Head Start programs, and other local community health non-profits
- Holding educational seminars about ASD and other developmental and intellectual disabilities
- Following up with families when needed

Culture and language must be incorporated into developmental assessments. Are ASD screening tools culturally competent? Are screeners taking language practices within the home into consideration (Gold et al., 2012)? They should!

Research on ASD must continue, especially as it pertains to the experiences of AA children and adults, as well as genetics.

Questions to consider: What are the trends in ASD presentation experienced? What are the similarities seen with other ethnicities, and what are the differences? Further research on long-term outcomes is also needed, especially in children who had late diagnosis and whose families fought their way to a diagnosis and supports through the education system.

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Dream Big

By **Kimberlee Rutan McCAFFERTY**

A MOTHER SHARES HER SECRETS FOR PREPARING FOR THE DAY WHEN HER CHILD MUST LIVE APART FROM HER.

Dear Justin,

The letter with our non-profit's 501©(3) status arrived last week, the final piece me and my friends have been waiting for to move forward with the best adult residence ever created for any autistic adult anywhere.

Yes, we dream big.

Now we begin the challenging journey of acquiring funding, land, a residence, and an amazing team of people who will care for you 24/7 when you are no longer living with us. This is a dream I've held dear to me for many years, and it all finally came to fruition a few years ago when I gathered together my girlfriends of a decade or more, and we decided to give this a try.

And yes, I selected them carefully. Our families will be intimately involved with each other and with your care for decades. I wanted to make sure I liked them all.

To be truthful, I waited as long as I did to get things going because part of me didn't see how I could do it — how I could have you live anywhere other than in my home. Rationally, I know I won't live forever, and you will probably see three or more decades on this earth without me. But emotionally, when you were little, it was too difficult to contemplate.

As you've aged and matured, and your needs have changed, it's become an easier prospect to envision you with a measure of independence from us. Honestly, it needs to be done. Your father and I will die someday, and I'm not leaving your care to your little brother.

As my grandma always said, it is what it is.

Although it's been complicated to anticipate your leaving the nest, one short month ago at 19 you exceeded all our expectations and successfully slept for an entire week at an overnight camp, one you had only been to three years prior during the day. You accomplished this, and I'm told even looked like you were having fun, after never having spent a night outside of your home without your family.

Nope, not one night.

It was time to try this. Many arguments about this ensued between me and your father. He was worried you'd think we'd left you there forever. I knew our bond was strong enough that you wouldn't. I worried you wouldn't sleep and they'd send you home, but you slept beautifully, albeit waking up very early a few days.

I pushed your father because deep down I knew I could never send you to a residence and have that be your first night away from family your entire life. I couldn't do it. We had to try.

And it worked.

And my point, dear boy, is that if we hadn't kept trying things with you your whole life, no matter how difficult or heart-wrenching those decisions were, you would not be the man you are today. It wasn't easy.

Out-of-district placements where we knew you'd never interact with neurotypical kids. Trying horseback riding which you initially hated but then loved for years. Sleeping. Getting you into a pool. Braving the beach and the boardwalks. Medications. Eating food other than carbs. Potty training. Riding in a car.

Hell, just transferring you to a crib.

But we persevered, and eventually all obstacles were conquered, even if the outcome didn't always look like we'd anticipated it would. I feel you're living your best life now — eating well, sleeping well, loving school, enjoying activities outside of the home, and entertaining yourself when within.

You are happy. That was my dream, too.

And after seeing your success last month, I know in my heart that when you move out, you'll be okay.

Here's a little secret — I now know my heart will be too.

I am so proud of you, and so fortunate I will have a hand in helping you continue your best life as you want it to be.

I love you.

> “As you've aged and matured, and your needs have changed, it's become an easier prospect to envision you with a measure of independence from us. Honestly, it needs to be done.”

Kimberlee Rutan McCafferty *is mother to two sons on the autism spectrum and an Autism Family Partner at the Children's Hospital of Philadelphia (CHOP). Kim is also the author of a blog. Kim's book* ***Raising Autism: Surviving the Early Years*** *is on sale at Amazon.*

http://autismmommytherapist.wordpress.com/

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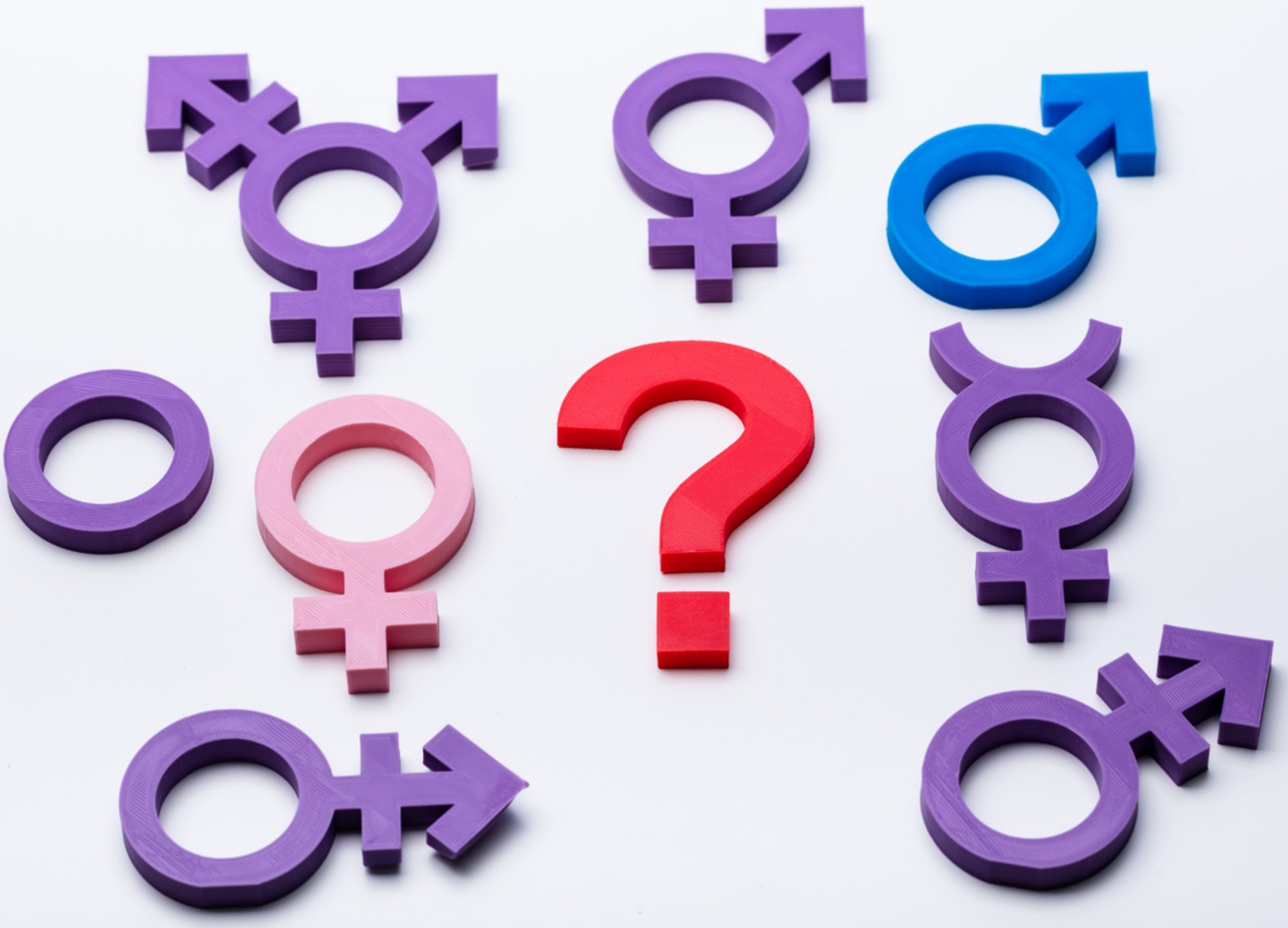
Sexuality in Neurodivergent Individuals

By **Yolande LOFTUS, BA, LLB**

AN ARTICLE IN A PARENTING MAGAZINE ABOUT INTIMATE OR ROMANTIC RELATIONSHIPS… GROAN. IN THIS CONTEXT, MANY PARENTS WOULD RATHER NOT TALK ABOUT SEX. BUT OPEN AND HONEST CONVERSATIONS ABOUT SEX, SPECIFICALLY WHEN IT COMES TO SEXUALITY IN NEURODIVERGENT INDIVIDUALS, IS A CONVERSATION THAT COULD KEEP YOUR AUTISTIC ADOLESCENT SAFE—AND MAKE THEM FEEL SEEN.

Your neurodivergent child is growing up; you've put every effort into ensuring their transition to adolescence or adulthood is as smooth as it can be. You've spoken at length about physical and mental health, education, and job opportunities. These heavy topics seem tame, however, at least in comparison to the things that need to be addressed in equal depth: sexual orientation, gender identity, sexual health, and sexual activity.



From bees and storks to blushed avoidance, we've all thought about not talking about topics that seem odd to discuss with our kids. When my son asked a detailed question about his birth during a car journey, I saw my husband's eyes dart about wildly. In all likelihood he was contemplating the distracting power of a very light fender bender.

Dealing with kids' questions is actually the easy part. Educating ourselves and learning to handle sensitive topics in a knowledgeable, judgment-free, honest, and open way may be even trickier, especially when talking to kids on the spectrum. Sexuality, particularly when it comes to neurodivergent youth, goes far beyond sexual education.

Parents have to be prepared (by talking to autistic adults, researching, and educating themselves) to listen and converse about sensitive topics like gender identity, sexual attitudes, sexual intercourse, and also the applicable legal rights protecting these. When children on the spectrum become teenagers, they may want to talk to parents about sexual relationships, but beyond typical questions, they may want information pertaining to the relation between specific autism characteristics and sexuality.

How do you address questions about physical contact when your child has an aversion to touch? How do you determine if the time is right to explain what a sexual relationship is when your non-speaking child just does not seem interested in certain topics beyond their interests?

> “Dealing with kids' questions is actually the easy part. Educating ourselves and learning to handle sensitive topics in a knowledgeable, judgment-free, honest, and open way may be even trickier, especially when talking to kids on the spectrum.”

Many parents feel—rightly so—that there are more questions than answers. Unfortunately, sexuality in autistic people is a topic which is still in its infancy when it comes to research and literature.

Sexual education for children with autism spectrum disorders

The *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM–5; American Psychiatric Association, 2013) identifies and explains one of the core characteristics of autism: persistent challenges in social communication and interaction. Even as we salute advocates trying to change the deficit-model of autism, parents recognize that a differently wired brain may require a sex education that is tailored to the neurodivergent mind's communication differences.

Many parents say their autistic kids do not receive sex education at school. Considering how diverse the autism spectrum is, educators may not be equipped to tailor a message about sensitive information—like sexual health and sexual orientation—appropriately to the varying needs of children with developmental disabilities. With more resources they could. Realistically speaking, however, the burden falls on parents and other caregivers to ensure sexual education is customized and appropriately delivered for their children with autism spectrum disorder (ASD).

One article (Davies et al., 2021) offers recommendations to support more inclusive approaches to sex education, appreciating that a one-size-fits-all approach is not appropriate for children and adolescents with autism spectrum disorder. Acknowledging and supporting differences, rather than focusing on deficits, should be emphasized to help children feel comfortable and safe in their skins.

Before having conversations about sex with your young adult, child, or adolescent, you should research and educate yourself about social and romantic functioning on the spectrum; autistic adults are often the best source of honest and accurate information. Without knowing more about sexuality on the spectrum, any conversation you have about intimacy may feel alienating to your child. Most of the information out there is tailored to the neurotypical, heterosexual experience. Parents who want to converse openly and honestly with their kids may have to do their own research and reach out to other parents on support groups.

Autistic adults and romantic relationships

Answering your child's questions about a sexual relationship will be difficult if you've never considered intimacy from a neurodivergent perspective. When explaining the motivation behind flirting, with associated behaviors like extended eye contact and passionate kissing, a neurotypical child may be curious and grossed out in equal measure. For kids on the spectrum with sensory issues, romantic relationships and the accompanying intimacy could sound frightening or bizarre.

> “Sexual expression involves so much more than just sexual behavior; it's how we express our sexual selves. In literature and academic articles, sexual expression includes all sexual activity with and without a sexual partner.”

If eye contact is impossible and kissing is a nightmarish sensory experience, how will sexual interest be shown? Parents should be prepared to answer questions like these, not only about the possible interaction between autistic individuals and a neurotypical romantic partner, but also an intimate relationship between two adults on the spectrum. Interestingly, it seems many individuals on the spectrum may prefer a partner who is also on the spectrum (Nordsletten et al., 2016).

Sensory stimuli and sensory sensitivities

Sexual expression involves so much more than just sexual behavior; it's how we express our sexual selves. In literature and academic articles, sexual expression includes all sexual activity with and without a sexual partner. Sexual activity is difficult to separate from sensuality and sensory processing.

Research tells us an estimated 90% of individuals with autism have atypical sensory experiences (Marco et al., 2011). Talking to autistic youth about romantic relationships while ignoring the different ways they may experience intimacy will set parents up for failure.

For autistic individuals, sensory features impact sexual and relationship experiences in potentially negative and positive ways (Grey et al., 2021). Hypersensitivity may mean any sensory input such as tactile stimulation or smells, and even the feel of someone's breath may be too much. Hyposensitive individuals (those who seek or crave additional sensory input) on the other hand, may be under-responsive to touch. Sensory-seekers may need additional sensory input or sensory integration therapy.

For those with sensory issues (which includes most individuals on the spectrum), physical contact and sexual activity may be uncomfortable. Societal expectations and neurodivergent sexual expression do not always align; autistic people should feel acceptance when it comes to their approach to social and romantic functioning.

Parents play a major part in raising confident children. If your child feels uncomfortable with touch, or if they handle emotional intimacy in a unique way, be encouraging and help them realize that it is not necessary for them to conform to the sexual expression of neurotypical people.

Helping your child with self-acceptance means they will be more accepting of others. Accepting and respecting the choices and boundaries of others may also contribute to your child's understanding of consent.

Consent and legal rights

Sexual practices, consent, and legal rights are interconnected; every parent should educate their child and have conversations about these important topics when the child is ready. It is a strange myth that all adults with Asperger syndrome (which is no longer a diagnosis but many people still use the term) are either hypersexual or asexual and nothing in between.

> “Helping your child with self-acceptance means they will be more accepting of others. Accepting and respecting the choices and boundaries of others may also contribute to your child's understanding of consent.”

Research does indicate that individuals with autism spectrum disorder (ASD) may be more likely than those without ASD to self-identify as asexual (Bush et al., 2021). Studies also suggest males on the spectrum may have more hypersexual fantasies and behaviors (Schöttle et al., 2021).

Just like neurotypical people, autistic individuals could fall anywhere on the sexual spectrum. However, because communication deficits often render them vulnerable to abuse, it is especially important to ensure the safety of children and adolescents on the spectrum.

Research tells us that children with intellectual disability are particularly vulnerable to abuse. For autistic women, sexual exploitation is a worrying reality. Girls on the spectrum may be oblivious to danger and eager to fit in, which makes them an easy target for predators.

Studies show that in females, ASD was linked to an estimated threefold increase in risk of coercive sexualized victimization, while attention deficit hyperactivity disorder (ADHD) was associated with a doubled risk (Ohlsson Gotby et al., 2018). The authors' speculations go as far as suggesting sexual predators may actively target individuals with neurodevelopmental disorders.

As a parent, you know your autistic child best, and it goes without saying that possible asexuality, hypersexuality, hypersensitivity, and hyposensitivity are factors demanding a customized sexual education. Consent should also form part of the majority of conversations relating to sexual activity. Neglecting to converse about consent leaves your child open to abuse, but it also means your child may unknowingly act in ways which could compromise the safety of others.

Sex education is no longer only about warning teens against sexually transmitted infections and unwanted pregnancies. When our kids are ready, they need all relevant information to ensure they stay safe, physically and emotionally. This means beyond sexual education and sexual health talks, sensitive topics like sexual orientation and gender identities should be discussed when your child is ready.

Gender dysphoria and autism

According to the DSM–5, gender dysphoria could be defined as a "marked incongruence between their experienced or expressed gender and the one they were assigned at birth." Previously known as "gender identity disorder", there is an increasing amount of research pointing to a link between autism and gender dysphoria.

In fact, exclusive data from *Autism Parenting Magazine* showed (in the sample surveyed) close to 6% of autistic children have some form of gender dysphoria. In comparison to DSM–5 data stating gender dysphoria is present in 0.005–0.014% of biological males and 0.002–0.003% of biological females globally, it would seem gender dysphoria is higher in the autistic community in comparison to the general population.

According to a large study (Warrier et al., 2020), examining the connection between autism and gender diversity, transgender and gender-diverse individuals have higher rates of autism in comparison to cisgender individuals. In research and literature, we often find the term gender-diverse, which is a broad term inclusive of individuals who are nonbinary, transgender, and gender-queer.

Mental health support for gender-diverse individuals on the spectrum

Results from a study (George & Stokes, 2018) suggest that autism introduces a unique experience to the development and consolidation of gender identity. Furthermore, results showed that for some autistic individuals, their sexual orientation is linked to their gender experience. Most importantly, the authors encourage awareness of gender-diversity for clinicians working with ASD, to ensure the necessary support (for healthy socio-functioning and mental health) is offered.

If your autistic teen is struggling with gender identity, you should ensure they have access to appropriate specialized mental health care. While parents know their kids best, the combination of autism and gender dysphoria may present unique challenges, especially for parents who are still learning about gender diversity.

Finding someone with no agenda, except the well-being of your child, may be a challenge. But considering the risk of depression in autistic individuals with gender dysphoria, it may be crucial to have mental health support available if your child is struggling.

A study (van der Miesen et al., 2018) reported individuals with autism who endorsed the response: "I wish to be of the opposite sex," reported higher levels of anxiety and depression. Trying to fit into a world created for neurotypical individuals while dealing with gender dysphoria could increase anxiety; anxiety which is already present in more than 40% of the pediatric autistic population (Matilla et al., 2010).

An autistic child simultaneously struggling with gender identity and neurotypical social norms and expectations—with possible impairments in expressing and communicating such emotions—deserves appropriate medical intervention.

Less talk

When researching sexuality in neurodivergent individuals, I found most studies and literature referring to high-functioning adolescents or high-functioning adults on the spectrum. Besides the fact that the autism community is advocating for the term "high functioning" to be abandoned, I found a shocking lack of information about sexual health and sexual education in the nonspeaking autistic pediatric population.

> "Trying to fit into a world created for neurotypical individuals while dealing with gender dysphoria could increase anxiety; anxiety which is already present in more than 40% of the pediatric autistic population (Matilla et al., 2010)."

Many studies are survey based, meaning autistic individuals with advanced verbal skills may facilitate the interview or survey process. But where does this trend of focusing on a single side of the spectrum leave parents of nonspeaking autistic kids? Where do they seek advice about sensitive conversations?

Considering that nonspeaking children with autism may be especially vulnerable in sexual contexts; their parents need support to address sensitive topics in a way that makes sense for kids who communicate differently.

A literature review (Solomon et al., 2019) deduced that providers should use the specific characteristics of autism when developing sexual education curriculum. The authors highlight the social communication and sensory profile of autistic individuals—as these appear to relate specifically to the way in which information is accessed, the "motivation to engage in healthy sexual activities, and the development of skills needed to engage in healthy sexual behavior."

This review (Solomon et al., 2019) and the conclusions reached may highlight the way in which parents should approach conversations about sexuality with their neurodivergent kids—wherever they fall on the spectrum. By taking their specific needs and characteristics into consideration, important information can be shared in a way that makes sense.

If your child does not speak but uses technology or visual aids to communicate, you could follow their cue and use these methods to educate them and learn about their needs. Social stories may be used to present crucial information to assist autistic individuals and their parents or caregivers in preparing for a safe, healthy, and satisfying sexual future (Tarnai & Wolf, 2008).

It seems the best way to talk to and educate autistic children about sexuality in neurodivergent individuals includes: finding appropriate information from autism research and the experience of autistic adults; paying specific attention to their autism characteristics and using this information to customize our conversations about sexuality; but, most importantly, finding a way to help them communicate their questions, needs, and emotions in a way that makes them feel safe…and seen.

Yolande Loftus, BA, LLB *is a journalist, content creator, and legal researcher. She's lived in Dubai and France but currently calls South Africa home. She received her journalism degree from the University of Johannesburg, and her law degree from the University of South Africa. She hopes to promote autism awareness in developing countries, breaking down the stigma and cultural misperceptions brought about by a lack of education.*

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Humps, Lumps & Undulations:

Hurdles of Parents with Individuals Who Learn Differently

By **Karen KAPLAN, MS**

SUGGESTIONS FOR PARENTS WHO MUST GO THROUGH THE OBSTACLE COURSE RAISING A CHILD WITH SPECIAL NEEDS.

As I took my 6000 steps today, I noticed these sign posts. I stopped.

It made me reflect on the humps, lumps, and undulations parents of children with learning differences must hurdle through. These signs indicate it is key to slow down when going over them. It reminded me how important it is for parents to take care of themselves so that they can get over hurdles coming their way, their child's way, and perhaps their siblings' way.

I suggest they find it like tribe parents who have also traveled the lumps, bumps, and undulations. Relate, connect, and share resources.

I suggest parents find ways to bring some calmness to going over these lumps and bumps. Exercise, meditate, take walks, and find time, not to hold their breath, but to breathe deeply.

Sometimes it is the system that is slow; slower than a mother or father wants to travel. Learn the laws, policies, and procedures for engaging in each system.

Humps

Sometimes it is a hump they face, such as getting the diagnosis and then acquiring the knowledge about the differences and strengths of their son or daughter. Sometimes the hump is learning how the special education system works in order to obtain the most effective educational supports.

Sometimes the hump is identifying resources, such as speech therapists, occupational therapists, physical therapists, reading specialists, and perhaps behavior specialists, to help their son or daughter reach his or her potential.

Lumps

Sometimes it's a huge lump, such as finding out their individual may develop seizures, has to live in a wheelchair, or may never marry, have kids of their own, or drive a car. There is a heaviness here. There are feelings of loss. I thought of that lump in the throat we feel at times. We find it hard to swallow.

Then another powerful lump comes along the way, and families become more and more stressed as they wonder who will take care of their individual when they are no longer able. They must now learn about special needs trusts and find ways to help their communities develop positive living alternatives. They must create a team, perhaps led by a sibling, aunt, or uncle to look over their individual when either something happens to them or they pass away. This LUMP sits right in parents' hearts and never goes away.

Undulations

Sometimes parents meet undulations and must ride those waves, up and down, over, and over again. First they learn about the school systems, and then their individual turns 22 and needs additional support, so they must learn about the Regional Center System. When school is over, they must know about the rehabilitation system, and of course supported living and supported employment systems.

These families never seem to get a break from the undulations. The hope is that they can ride those ups and downs at a more even pace and find the resources.

I then think, how lucky I have been in my life. My three adult sons can take care of themselves. My humps, lumps, and undulations regarding them have never been extreme. I am grateful.

RESOURCES:

Parents Helping Parents: Parents Helping Parents
Support for Families:
Support for Families | Support for Families
Autism Society of America: Autism Society
United Cerebral Palsy: United Cerebral Palsy (ucp.org)
California State Department of Education/Special Education:
Special Education Division - Organization (CA Dept of Education)
Individual Disability Education Act:
About IDEA - Individuals with Disabilities Education Act
California Regional Centers: Regional Centers - CA Department of Developmental Services
Living Unlimited: Living Unlimited (living-unlimited.org)

__Karen Kaplan, MS__ has served as an instructor in the Autism Spectrum Certificate program at Alliant University. She completed her BS and MS in Speech Pathology from ASU. She minored in Special Education and holds an Educational Administrative Credential and Moderate to Severe teaching Credential. She has sat on non-profit boards to help build capacity for those with special needs. She founded and directed a residential school for nearly 20 years in Sacramento. She is an author and speaker. She spent time globally helping non-governmental agencies in Indonesia and Africa. Currently, she is consulting with families, schools and adult programs.

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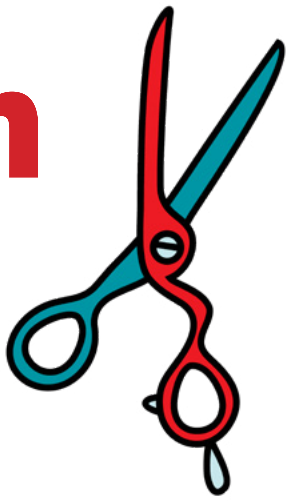
A Haircut With A Difference



By **Craig HENDERSON**

A BARBER SHARES HIS COMMITMENT TO SERVING THE COMMUNITY THROUGH MAKING HAIRCUTS A BETTER EXPERIENCE FOR CHILDREN WITH ADDITIONAL NEEDS.

The loud buzz of the clippers, the strong scent of products, the scrape of the comb, all part of getting a haircut. As a hair professional, I feel everyone deserves to look and feel their best. However, a trip to the salon can be overwhelming for people with sensory processing difficulties.

I've been using the days my shop is closed to go into the community and visit a specialist nursery and secondary school that works with children and young adults with additional needs. Most of the children have non-verbal autism. I spend my time helping to get the children and young adults desensitized to the experience of getting their hair cut in a comfortable setting where they feel safe.

Sensory aspects of a haircut

I've been working on the sensory aspects of the experience at each visit. This involves spending time getting them used to the equipment, touching the combs and brushes, feeling the water spray mist, and getting familiar with the vibrations of the clippers.

When I perform the haircut, it's all about being patient. It can be a sensory overload for the children, so I make sure to take time with each child and wait when needed, as each child has a different way of processing the experience.

Craig Henderson

Stress free as possible

I aim to make this stress free for them, whether this involves me taking one hour or even four if it helps the child to build up an understanding of the experience of getting a haircut. I want them to feel that they had a complete experience without being judged or discriminated against because of their additional needs. Hair salons are part of the community, and we should serve the community that includes these amazing human beings.

A parent of one of the children I work with described taking their four-year-old son to another barber for his first haircut after lockdown as "awful and traumatic." Now, having her son in calm, respectful hands is a huge relief.

Something special

I've had the privilege of working with around 100 children and young adults so far. Being able to make such a difference to them and their parents is amazing.

I feel like I've achieved something special: making these children look fantastic while helping to build their confidence with hair professionals. The time they have spent together will make it easier for each child, as well as help their parents not suffer from stress and anxiety worrying that their child is going to be judged on visits to a salon in the future.

A lot of the children I have worked with in these settings now visit the barbershop that I run with my partner Sarah Timmins. I've set up a small sensory corner that is not too overwhelming and a chalkboard wall to help them with literacy skills.

I run a small shoe box salon with Sarah called Craig's Barber Shop. We run the salon entirely by appointments. This eliminates any of the customers with additional needs being interrupted during their allotted time, and in turn, prevents them from being overstimulated. I'm the only member of staff in the shop, so that helps massively also.

I'm aware that not a lot of them will always be okay on the first visit, but parents or guardians need to remember, getting them into a shop is already a huge win – even if all I manage to do is comb their hair or even just get into their personal space and play with their hair.

It all takes time and patience. A haircut is not a sprint, it's a marathon.

FUTURE PLANS

Looking ahead, I've got plans to not only keep up this service, but I'm working on PEC cards, a children's book in future to explain the process, and a training program for hair professionals to be able to understand and accommodate these fantastic humans with additional needs.

***Craig Henderson** has been a hair professional for over 10 years. "I have four wonderful children between my amazing fiancée Sarah and myself. We run the little shoe box salon, Craig's Barber Shop, in Bolton together.*

Puberty and the More Severely Challenged Teen on the Spectrum

By **Karen KAPLAN, MS**

TIPS AND TRICKS FOR THOSE ON THE SPECTRUM WHO MAY STRUGGLE MORE WITH PUBERTY.

What if your son or daughter is non-verbal, doesn't understand the need for good hygiene, needs constant supervision and support to live daily, and does not understand the changes in his or her body?

How can you help them move through those sensitive times? How can you help prepare them?

Here are some tips and suggestions you might try.

You could start teaching privacy early

Teach them to complete hygiene with doors closed. Going to the bathroom and always keeping the door closed can help. Teach them to only undress in their bedroom or bathroom. This will establish a good safe routine.

Model hygiene actions for your individual

Have them watch you put deodorant on, shave, wash your hands after toileting, or shower. If they enjoy watching YouTube, then videos of hygiene tasks could be helpful. If they connect to their siblings, having them see their brother or sister complete tasks could be helpful.

Help support the start of menstruation

As menstruation approaches, there are things you can do to help prepare your child before it begins. There are special pants now that are specifically designed to make menstruation easier, and having your child wear them for a few days each month can help.

Demonstrating how to use a pad or other menstrual products is a good way to model good hygiene and avoid confusion. Teach your child to point to their belly if it hurts so you can support with pain medication if necessary. A conversation with a doctor can provide birth control and vaccination options, as well as additional counseling.

“Teach your child to point to their belly if it hurts so you can support with pain medication if necessary. A conversation with a doctor can provide birth control and vaccination options, as well as additional counseling.”

Remember, puberty can be a challenging time

There could be an increase in anxiety, depression, irritability, mood swings, and maybe even aggression during puberty. Yoga and meditation might help. A positive diet and exercise plan definitely will and is very important, as is ensuring a good night’s sleep every night.

It is good to work with a trusted therapist or psychologist to see if medication or specific strategies are advised.

Start early to get your child comfortable in a bra

Modeling how mom puts on her bra can be helpful. At first, purchasing soft and comfortable bras, which are easy to put on and wear, is great for those who have tactile sensitivities. As your child develops, add more supportive bras with easy fasteners.

Educate them about touching their private parts

This is a sensitive area and depends on the beliefs of each family. For all, it is important to redirect touching private parts in public. For some families it is never okay and must be re-directed everywhere. For others, teach your son or daughter to only touch their private parts in their bedroom.

> “Build a social story around friendship vs strangers — the people we talk to versus the ones we DON’T! The people we can ask for help and those we DON’T!”

Engage with your school

Communicate with the school your teens go to in order to help your son or daughter engage in hygiene tasks. Send deodorant to school to be applied after exercise. Send a toothbrush and toothpaste to be used after snacks and lunch time, or perhaps some dental floss which might be easier if they’re rushing back to class.

Have your school explain the good hygiene — cleaning themselves after each toileting incident and washing their hands after lunch, art, or an outdoor activity. Send a brush and comb so the school can help teach your son or daughter to maintain their hair.

Make sure your school is also aware of your daughter’s period and will help remind her to change pads during the day. Also make sure the occupational therapist is helping to work on the motor planning by getting involved in the process of good hygiene, too.

Make sure to also teach your kids about strangers. You might have pictures taken of all family members, friends, and perhaps doctors, therapists, and teachers.

Build a social story around friendship vs strangers — the people we talk to versus the ones we DON’T! The people we can ask for help and those we DON’T!

Prepare for missing kids

Some families worry about their son or daughter leaving safe areas, thus becoming a target for sexual assault. Each family will need to process their individual’s safety issues and develop a safety plan.

Are alarms needed on doors? Can the individual wear a device of some sort? Do clothes have names and contact numbers?

Can the individual wear a jewelry piece around their neck or wrist? Can the individual learn where police stations or fire stations are in the neighborhood and whether they can make it to one if needed? Families must work with their school program to design a plan which makes teens aware of the dangers of the above.

The teen with greater cognitive, communication, and sensory challenges will benefit from establishing routines early. Use visual supports to teach them, as well as social stories, modeling, and video teaching.

***Karen Kaplan, MS** has served as an instructor in the Autism Spectrum Certificate program at Alliant University. She completed her BS and MS in Speech Pathology from ASU. She minored in Special Education and holds an Educational Administrative Credential and Moderate to Severe teaching Credential. She has sat on non-profit boards to help build capacity for those with special needs. She founded and directed a residential school for nearly 20 years in Sacramento. She is an author and speaker. She spent time globally helping non-governmental agencies in Indonesia and Africa. Currently, she is consulting with families, schools and adult programs.*

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HELP:
My Nine-Year-Old is Not Eating and is Angry

By **Beatrice (Bea) MOISE, MS, BCCS**

Q

Hi,

I have come across your article about tantrums and cursing in autistic children. We live in the UK and have a nine-year-old daughter who was only just officially diagnosed as autistic. I am her father.

She is very high functioning, disguises it well, fairly bright, and for a long time, a lot of her characteristics were manageable - whether it was sensitivity to smells, preference of wearing just a few items and materials, attachment to only one parent, or anxiety when being the center of attention. These were all manageable things, and we only had to deal with stubbornness and controlling behavior at times.

However, in the last six months or so, she was called fat by someone at school (she's not) and began to obsess on diets and exercise. She initially decided to rule out eating meat, and then her calorie intake had progressively declined to a very low amount.

We cannot reason with her, and lack of food has contributed to her tantrums, which come on regularly. Before the extent of her anger may have included phrases like "shut up," but she now curses with the worst possible words and doesn't care who they are directed at - us or her siblings.

She lacks any empathy or remorse at what she says, and it's usually brought on by something very specific to her, yet very irrational to us. It's usually worse in the morning and following a period of reduced food intake, but it's very frequent now - several times a day.

My relationship with her has become very difficult - she tells me to go away, to shut up, or much, much worse, almost with every interaction now. She is unpredictable and seems to push the boundaries unimaginably further every day.

Since we had her assessed, the school has not been very helpful. We have received no advice and just have a doctor referral on her eating.

The more education and advice she receives on how she should do something (eating, socializing etc...), the more she turns the other way to become much worse. She may read on the Internet that rice is fattening and then decide she will no longer have it. It's very concerning and a very real issue.

So I'm at a loss. I fear for her future and for her siblings. We are trying our best, trying to leave her alone, trying to discipline, trying to ignore at times - and we have no idea if what we are doing is right or what's best. I'm sure every child is different, but if you have any advice or suggest where we can get it, I would be very grateful.

Thanks,
Louis

A

Dear Reader,

Thank you for reading our past article on tantrums and cursing. ASD individuals can become hyperfocused on a particular thing that causes them to feel bad about their esteem. At age 9, most children become more aware of their body image, and that can cause healthy eating habits to become disrupted.

The current situation you are dealing with is developmentally appropriate; however, the lack of social awareness makes it more challenging to deal with because, as a parent of a neurodivergent child, you simply can't discuss their healthy eating habits with them.

Currently, you are at a difficult intersection, and it sounds like your child is highly verbal and may appear to be at the same developmental capacity as neurotypical peers. However, that's not likely. Neurodivergent children are a few years behind their chronological age, and educating them on social norms needs to address that need first. Her level of understating might be closer to a child that is 5, and when she is reading information, she may not be making the necessary adjustments to make sense of all the information. But processing from her level of understanding can be delayed.

The best way to get a child to hear the message you are trying to tell them is to listen and learn from their perspective. So start with some of these guidelines.

- *Ask her what her fears are about food.*
- *Ask her about what healthy choices look like from her perspective.*
- *Model nutritional food intake for everyone; the whole family should be involved.*
- *Educate her on the importance of eating all the food groups, encouraging her to take a bite from all but not forcing her to eat all of it. Encourage the attempt and then, leave it alone.*

> “Educate her on the importance of eating all the food groups, encouraging her to take a bite from all but not forcing her to eat all of it. Encourage the attempt and then, leave it alone.”

Lastly, have a conversation with her pediatrician about her physical health and if she is still thriving and growing. This phase will pass, and the more time you spend focusing on it, the longer it will last.

If the pediatrician is not worried, and you are educated through creating a healthy emotional bond and connection, this may not last long.

Beatrice (Bea) Moise, MS, BCCS *is a Board-Certified Cognitive Specialist, parenting coach, national speaker, and author of Our Neurodivergent Journey. Her UNIQUE parenting channel on YouTube is dedicated to educating individuals on neurodiversity.*

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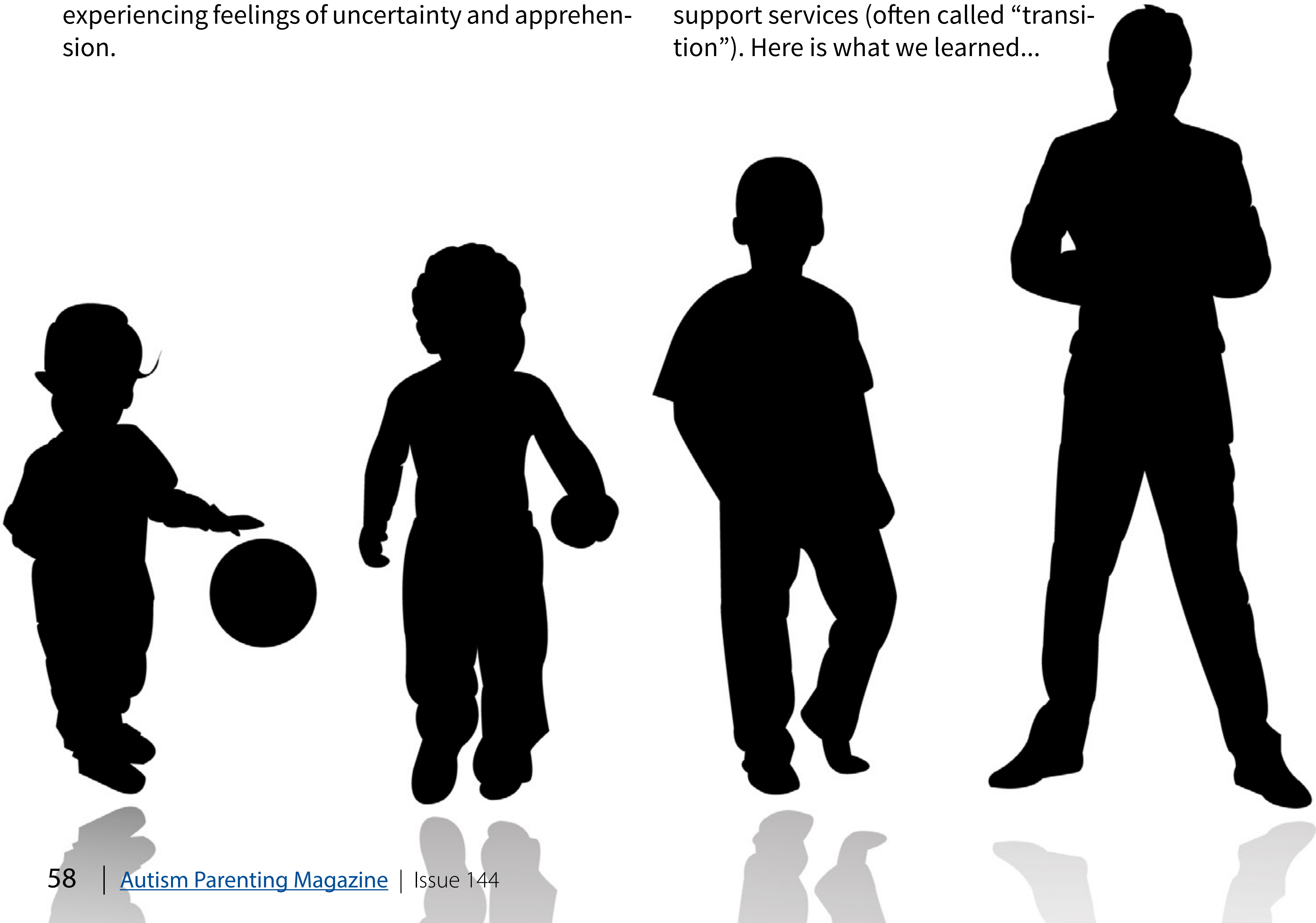
Insights into the Transition to Adult Services, From Those Who Have Done It

By **Rachael DODGSON**

THE TRANSITION TO ADULTHOOD INCLUDES MAKING DECISIONS FOR ONE'S FUTURE, AND THERE ARE WAYS TO MAKE THIS EASIER FOR THOSE ON THE SPECTRUM.

Families with loved ones who have undergone the transition from a residential school or college to adult social care services will know how complex the process can be. We know that families whose children will leave specialist education in the next few years may be experiencing feelings of uncertainty and apprehension.

Dimensions recently hosted a free webinar to bring these two groups together, providing insight from family consultants, support providers, and experts by experience, to equip as many families as possible with the tools to make the most of their loved one's move from education into adult social care support services (often called "transition"). Here is what we learned...



Getting started

Each local authority (LA) is responsible for managing the transition out of school for pupils with an Education, Health & Care Plan (EHCP). While they can vary between different local authorities, provisions need to be put in place.

Families can therefore ask their council to perform an eligibility assessment for their child before they turn 18. They can outline their loved one's needs in a fully person-centered way, allowing the local authorities to advise the different types of support available – depending on the local eligibility criteria.

Provision of support may sometimes differ from what the individual and their family would prefer. In this instance, the LA should take the person's wishes into consideration. If, however, they fail to do so, then the person will be eligible for support from advocacy groups such as Mencap, NYAS, VoiceAbility, POhWER, and Disability Rights UK, to ensure that their voice is properly heard.

In addition, it is worth noting that many residential schools are owned by organizations that also run large adult care homes. Families should be aware of this so they can avoid being pushed into their existing support provider's adult social care provision, which may not necessarily suit their loved one.

> “Most adults with learning disabilities and/or autism prefer supported living, where they can live in their own home with as much or as little support as they need, often fairly close to where they grew up.”

Help with housing

Differentiating between the various models of support is key to securing a move that is tailored to the individual's needs. While people without direct experience sometimes view adult social care as synonymous with residential care in permanently staffed homes, many people – even those with complex health needs – can enjoy the greater independence of support living.

Most adults with learning disabilities and/or autism prefer supported living, where they can live in their own home with as much or as little support as they need, often fairly close to where they grew up. They can choose to live alone, with friends, or with a partner, and they can choose to change their living arrangements as they go through life, even those with complex health and communication needs.

Different models of support have differing financial implications. People in supported living are usually eligible for housing benefits to cover rent costs, while the cost of residential care is usually met by Health or Social Services. There are, however, other monetary matters to consider when organizing someone's transition to adult social care services.

Money matters

Back when most people with learning disabilities and/or autism lived in residential care on a small weekly allowance, there was a certain simplicity about financial matters. Now, though, many people are far freer to make their own choices about how they spend their money, often a combination of benefits and personal budget, and thus how they spend their life.

Upon turning 16, someone with learning disabilities and/or autism has the same right as anyone else to claim benefits such as Universal Credit and Employment & Support Allowance (ESA). The Direct Payment of a Personal Budget, which the LA will allocate on assessing a young person's needs, is not a welfare benefit but a support needs budget.

Personal Budgets should be reviewed annually. They are available to anyone aged between 18 and 64 who qualifies for having their needs for care or support met and are paid directly to individuals to purchase their own services. Families can support with finances with the young person's permission, as an appointee to manage benefits (having been assessed as suitable by the Department for Work & Pensions), as a court-appointed deputy to manage all financial affairs, or through Power of Attorney granted by the young person.

> “Personal Budgets should be reviewed annually. They are available to anyone aged between 18 and 64 who qualifies for having their needs for care or support met and are paid directly to individuals to purchase their own services.”

Family consultant: Leveraging the law

Liz found out about the Mental Capacity Act (MCA) just as her daughter started secondary school, and she used the principles of the MCA to support her daughter's own decision-making during her transition to adult life.

The MCA is designed to empower people who may be unable to make some decisions by themselves. It recognizes that while some people may lack capacity to consent to medical treatment, for instance, they may be more than capable of making smaller decisions such as what they would like to eat. The MCA ensures that any decision made on an individual's behalf must be in the person's best interests.

Liz used these principles in her parenting, starting with everyday choices, so that now her daughter is regularly able to make much bigger decisions by herself. Her decisions may not always be wise (which the MCA prescribes for) and in that sense she is no different from any other young person – but, crucially, these decisions are hers.

Acting in her daughter's best interests, moreover, is often about limiting her freedom as little as possible. Managing her daughter's finances, for instance, does not remove her daughter's right to spend her disposable income how she chooses. Within the parameters of the support she needs, she is free to live her life the way she wants.

Expert by experience: Owain's own place

Owain knows a thing or two about living with more freedom, having moved into his own flat during the pandemic. Aged 18, he had virtually no belongings and needed support to tie his shoes. But now, with support from Dimensions, he has developed skills such as cooking and cleaning, and is currently planning a trip to Blackpool with friends for his 21st birthday.

Looking back on the last couple of years, Owain acknowledges that it has not always been easy, but he is immensely proud of the progress he has made. He is thriving in adult life more than he ever thought possible.

Owain's story is a great example of what people with additional needs can achieve when supported to live in the community. Indeed, every individual will benefit from a transition to adult services – and adult life – that has been tailored to meet their specific needs.

This isn't necessarily straightforward, and can certainly take time. But hopefully families will take something from the considerations highlighted here, and in our resources, which include a comprehensive Q&A for those going through transitions now, by those who have already done it. We hope to share this knowledge to benefit as many people as possible.

***Rachael Dodgson** is Chief Executive of Dimensions, one of the UK's largest not-for-profit support providers for people with learning disabilities and/or autism. With more than 30 years' experience in the social care sector, Rachael's previous roles include Dimensions' Managing Director, Group Operations Director at Care Management Group, and Head of Adult Social Care Policy for the CQC. Rachael's priorities for the sector include improving workforce pay and esteem, addressing the ongoing failure to get more people out of ATUs, and continuing to prove that, properly supported, more people can lead better lives as part of their community.*

🌐 *https://dimensions-uk.org/*

THE SECRET MISSION: Ben & Nana's Big Adventures

By **Susan ROOKS**

The Ben & Nana's Big Adventures series was born December 4, 1990. These are the real-life stories about Matt, who was diagnosed with autism at age three, and his four-year-old nephew Ben. Matt is a gentle giant who loves Legos, Chaz is service dog, and playing with his nephew Ben. Ben loves to ask questions to learn about life. Ben didn't notice that his Uncle Matt was different from other adults except that Uncle Matt likes to watch cartoons, play Legos, and spend lots of time with Ben. This all changed one day when he overheard his Nana talking about Matt and autism. Curious, Ben asked, "Nana, what is au-dis-m?" Not quite sure what he meant, she replied, "Ben, do you mean au-tis-m?" He replied, "Yes, Nana! That's it!" Nana had no idea how to explain the medical diagnosis of autism to a four-year-old. So, she put on her thinking cap and went to work!

Nana, an artist, wanted to paint a word picture story to help Ben better understand what autism really is. Her first story called, The Secret Mission is about an Egg Family who wants to bring another Egg into their family. Nana used the issues of family life to help Ben so that he could fully comprehend what autism truly is and what that means for his Uncle Matt.

Ben had many more questions for Nana about his Uncle Matt, autism, and autistic behaviors. As Ben asked each question, Nana wrote them down and tried to create more word picture stories for him to understand. All these questions have now become the Ben & Nana's Big Adventure series. Come along for the adventure and learn with Nana, Ben, and Matt!

You can visit with Susan, Ben, and Matt and share your egg artwork from The Secret Mission at the Ben & Nana's Big Adventures Facebook page. The Secret Mission is available on Amazon.

Susan has always been a gifted storyteller, and her love for children and love of art have come together helping her to create word picture stories about autism. Her goal is to help other children around the world to understand the difficult concepts of autism.

https://www.amazon.com/dp/0578361280?ref_=pe_3052080_397514860

https://www.facebook.com/Ben-Nanas-Big-Adventures-101383192714906

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dBud volume adjustable earplugs are the ideal solution for children suffering from noise sensitivity issues related to disabilities like Autism, ASD, Asperger's, ADD, ADHD and more. People with the above disabilities have a very high likelihood of having noise sensitivity issues and dBud helps manage these issues and allows a comfortable level of sound to be received in different settings.

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Noisy situations can be a problem for nearly everyone, but for specific people it can be a clear trigger for discomfort, distress, anxiety, frustration and avoidance, just to name a few. The type of noise that individuals are sensitive to differs from person to person, and traditional earplugs that people use to block out these noises also block out the noises that they are not sensitive to. dBud earplugs have volume settings of -12dB and -24dB, which allows the person using them to adjust the sound input depending on how sensitive they are to noise in any given situation. They can also be left in one setting when an individual is trying to find calm and control in a generally noisy scenario like a shopping center, classroom or public event, where dBud helps lower the sensory input.

dBud especially helps with lowering the effect of different types of frequencies, whether high frequency from things like horns, or low frequency, being things like background noise which can be triggers for noise sensitive people. By providing balanced attention across all frequencies, dBud dulls distracting noise, thus allowing individuals to focus on sound that matters, whether it be important conversations with parents and friends or instructions from teachers and carers.

dBud comes with 8 different types of interchangeable ear tips to ensure a comfortable and secure fit for everyone, including small children, as well as a detachable leash that goes around your neck and is connected by magnets in the dBud themself, to ensure they are not easily lost.

dBud comes with a 30 day money back guarantee, so there is no risk in giving them a shot and seeing if they make a big difference in your child's and your own life.

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Is There a Link Between PCOS and Autism?

By **Yolande LOFTUS, BA, LLB**

AS MORE CHILDREN ARE DIAGNOSED WITH AUTISM, RESEARCHERS ARE EXAMINING A VARIETY OF POTENTIAL "CAUSES" INCLUDING MATERNAL HORMONAL DISORDERS LIKE POLYCYSTIC OVARY SYNDROME (PCOS).

One of the most debated autism theories may just be the "extreme male brain" theory. The theory suggests that autism may be an extreme manifestation of the male brain (Baron-Cohen, 2002). The theory remains controversial, receiving support and scoff from the scientific community. Whether the theory is accepted or not, it has raised many questions about exposure to prenatal sex steroid hormones, elevated maternal testosterone levels, and most relevantly, the link between (maternal) hormonal disorders like polycystic ovary syndrome and autism.

Maternal hormonal disorder

For women contemplating pregnancy, the effect of prenatal hormones on a developing fetal brain may be of importance. Especially when some studies (Auyeung et al., 2013) suggest exposure to prenatal sex steroid hormones may predict autistic traits in children. These concerns are especially relevant for women with hormonal imbalances or hormonal disorders like polycystic ovary syndrome (PCOS).

What is PCOS?

PCOS is a health condition that affects a woman's hormonal levels. The condition, which affects millions of women of reproductive age, is also sometimes referred to as Stein-Leventhal syndrome. It is characterized by the ovaries producing an abnormal amount of hormones related to male reproductive health and traits (referred to as androgens).

The name polycystic ovarian syndrome originally came about to describe small cysts in the ovaries, but it's now realized that polycystic ovaries actually have a high follicle number (with the follicles resembling cysts). Diagnosis usually comes from scans showing this high follicle count and from a hormonal blood test.

While the cause of the condition is hard to pin down, medical experts believe a combination of environmental and genetic factors may be responsible. The cause may be unclear, but the symptoms are often overpowering and debilitating. Some of these include:

- High testosterone levels
- Insulin resistance
- Weight gain
- Thinning hair (male pattern baldness)
- While hair thins on the head, excessive hair growth on face, chest, and back (hirsutism) is also common
- Infertility or trouble conceiving
- Other symptoms like acne, fatigue, low sex drive, and irregular periods are also often experienced

> “The name polycystic ovarian syndrome originally came about to describe small cysts in the ovaries, but it's now realized that polycystic ovaries actually have a high follicle number (with the follicles resembling cysts).”

PCOS and autism

When looking at a link between autism and androgens, specifically elevated levels of testosterone, the science is confusing. Some research (Geier et al., 2012) mentions evidence—supported by multiple studies—of an association between hyperandrogenism and individuals diagnosed with autism. On the other hand, a contrasting study (Kung et al., 2016) suggests their findings augment prior research which found “no consistent relationship between early androgen exposure and autistic traits”.

PCOS is fundamentally a disorder of androgen excess or hyperandrogenism (Azziz et al., 2006). Women with PCOS have reason to be confused when looking at the contradicting research; they may wonder if there is a concrete association between hyperandrogenism and autism. More relevantly, is there scientific proof of a link between PCOS—a hormonal condition characterized by androgen excess, including elevated testosterone levels—and autism?

Parents with autistic children know there are many conditions that co-occur with autism. They may want clarity about the increased prevalence of PCOS in the autistic population; they may also want more information about statistics suggesting PCOS is associated with a higher risk of having autistic children.

Research and the link between PCOS and autism

Going by the results of a UK-based study (Cherskov et al., 2018), it seems that there is indeed an association between PCOS and autism. The study found austistic women in the UK have an almost two-fold increase in the risk for PCOS. The study also found that women with PCOS had a 35% greater chance of having firstborn children with autism.

The authors acknowledged certain limitations of the study (Cherskov et al., 2018) which should be taken into consideration when interpreting the research results. Due to missing information in the health records obtained from the Clinical Practice Research Datalink (CPRD), the researchers did not control for alcohol use, infertility treatments, marital status, and socioeconomic factors.

“When summarizing current research, the evidence strongly suggests a link between PCOS and autism. Women with PCOS are more likely to have an autistic child, and women with PCOS are more likely to have autism spectrum disorder (Katsigianni et al., 2019).”

Such factors could influence results. Women may rightly wonder whether it is PCOS or the subsequent treatment for infertility that increases the odds of having an autistic child. Unfortunately, asking this question may lead to further uncertainty as research seems to suggest a positive, but inconclusive, link between certain fertility treatments and autism (Robinson et al., 2020).

Reading between the links

When summarizing current research, the evidence strongly suggests a link between PCOS and autism. Women with PCOS are more likely to have an autistic child, and women with PCOS are more likely to have autism spectrum disorder (Katsigianni et al., 2019). Further studies taking other factors like infertility treatments and paternal influence into consideration are urgently needed.

When looking at the research, it is also important to note that, while mention is made of links or the association between PCOS and autism, the literature does not speak of PCOS causing autism. Lastly, it’s vital to note the conclusion of the study (Cherskov et al., 2018) mentioned above. The authors emphasize that their study’s findings are suggestive of the fact that autism in children of women with PCOS is still very rare.

This kind of research is not intended as scaremongering for women with hormonal imbalances. Rather, the studies are mostly undertaken to understand autism better.

Furthermore, the results of these studies should provide guidance to the medical community for better clinical intervention for both PCOS and autism. Studies should be asking vital medical research questions about women's hormonal health and the impact it has on pregnancy and the developing fetal brain.

Such goals, rather than stigmatization, should be the driving force behind autism causation research. These efforts should inform a better understanding of neurodiversity; the kind of understanding that shapes acceptance, education, and intervention to improve the quality of life of every individual on the spectrum.

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***Yolande Loftus, BA, LLB** is a journalist, content creator, and legal researcher. She's lived in Dubai and France but currently calls South Africa home. She received her journalism degree from the University of Johannesburg, and her law degree from the University of South Africa. She hopes to promote autism awareness in developing countries, breaking down the stigma and cultural misperceptions brought about by a lack of education.*

Autism and Puberty: How to Support Your Child

By **Rachel ANDERSEN**

SUPPORTING OUR CHILDREN THROUGH PUBERTY CAN BE CHALLENGING, BUT THERE IS HOPE!

As parents, our main focus is the health and happiness of our children. For our children with autism spectrum disorder (ASD), the list of needs to ensure those things can be a bit longer. Milestones are one aspect of our kids with autism's lives that we are particularly used to monitoring.

The milestone of puberty is one that I would like to discuss today. In this article, I will be exploring autism and puberty, how they affect each other, and how we can best support our children with autism as they traverse this complex time.

How does puberty affect people with autism?

Autistic children have enough going on without having to deal with the perils of puberty. However, it is something that they will have in common with their neurotypical peers. This time, as it is a normal part of growing up, they will be facing the "regular" symptoms, as well as the complications autism can bring to the "party".

Let's first explore puberty, its markers, and how autism spectrum disorder may or may not affect it.

Here is a list of some of the signs and symptoms of puberty in girls and boys.

Girls

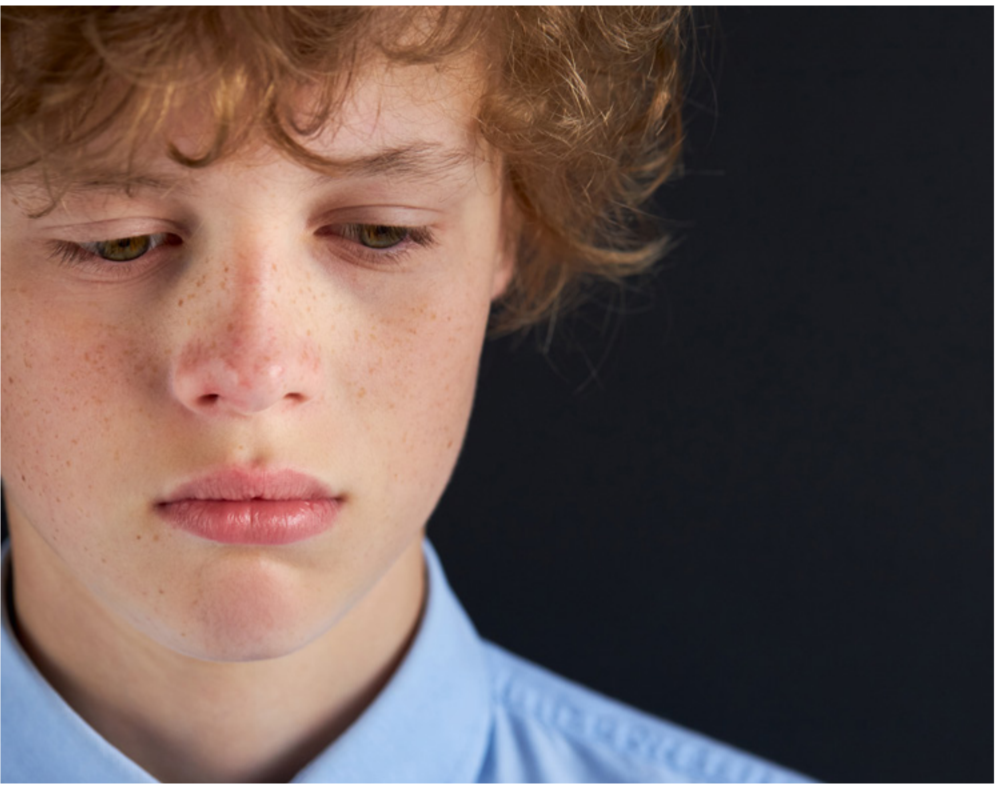
- breasts begin to develop
- growth of hair on body parts
- mood swings
- the beginning of menstruation
- acne

Boys

- voice changes
- wet dreams
- enlargement of testicles and penis
- acne
- muscle growth
- mood swings

Do kids with autism go through puberty faster?

Autism research has shown some variation between children with autism going through puberty and their neurotypical counterparts. Is this an indication that puberty will happen sooner for autistic children? Let's find out.



Precocious puberty

Precocious puberty is when the signs and symptoms appear in early childhood, before age eight in girls and age nine in boys. There is evidence to suggest that precocious puberty can occur more often in girls with autism. The research in the study titled, "Pubertal Timing During Early Adolescence: Advanced Pubertal Onset in Females with Autism Spectrum Disorder," we learn:

"Historically, precocious puberty (onset < 8 years in females and 9 years in males) or early puberty (onset between 8 and 9 years in females and between 9 and 10.5 years in males) can be considered a normal variant (Winter, Durand, & Brauner, 2019). A portion of the females with ASD would likely meet criteria for precocious puberty and an even larger proportion would meet criteria for early puberty. Due to the observed higher percentage of early onset in ASD compared to TD females, the findings would be hard to dismiss as a normal variant."

The same study also states: *"For males, there were no differences across the groups in pubertal timing to include genital or pubic stage..."*

So, it seems that autism can affect puberty's timing. Delayed puberty can also happen, but it isn't necessarily linked to autism.

Does autism get worse during puberty?

Autism does not "worsen". However, the changes that can occur can be more challenging for autistic children.

Children with autism often have trouble with social aspects, and these challenges can intensify during what is already a confusing and difficult time for many. Rising and changing hormone levels may also affect comorbid conditions, compounding the difficulty autistic children experience. Things such as:

- anxiety and depression
- attention deficit hyperactivity disorder (ADHD) symptoms
- seizure activity
- gastrointestinal woes

Social connections are often strained for children who don't usually struggle with social situations during puberty. The onset of acne and mood swings, as well as the comparison with their peers who may be further along in the process, can all take a toll on social function. For children with autism who already have differences in social skills, the time of puberty can pose extra concerns.

> “The ability to communicate and build trust is one way that can lessen the negative aspects of the transition to adulthood.”

Communication can also play a role in how autistic children fare during puberty. Some children with autism spectrum disorders have trouble communicating verbally, have a hard time reading body language, speak in a monotone, or have selective mutism. During puberty, this lack of skills can make everything more difficult for them.

They may struggle to build skills, understand how to interact with their peers, or be isolated from their friends and families at this vulnerable time. This can lead to worsening depression, anxiety, and tummy troubles. The ability to communicate and build trust is one way that can lessen the negative aspects of the transition to adulthood.

How to prepare your autistic child for puberty

In order to prepare our children with autism for puberty, we must first prepare ourselves. This can happen long before the first symptoms appear. In fact, the earlier we begin to prepare, the better.

Though we cannot anticipate every incident that may arise, we can be aware of the common issues, understand what to look for, set up support in advance, and most of all find out the fun things to look forward to. Younger children will need age appropriate preparation, while autistic teenagers who were prepared in advance will be much more ready to face the challenges.

Next, we can be available for open dialogue to be the standard for communications before, during, and after puberty. Our kids need to feel safe, informed, relatable, and celebrated, maybe more than ever during puberty. It is also important to note that we also need to feel that.

Here are some systems that we can set up for ourselves, as well as our children, as we prepare for them to enter puberty.

- therapy (for us and our children with autism)
- information collection (sources like *Autism Parenting Magazine*, your child's doctor, other parents, books, and podcasts)
- journaling (reflecting on our own experiences growing up and drawing wisdom from our own needs)
- alternative forms of communication and support (telehealth therapy, written communication, sign language, etc)

Feelings that can come from not being prepared can be negative and difficult to overcome while in the thick of it. We are not alone; our children are not alone.

Preparing our kids with autism for puberty begins with what every informed parent of a neurotypical child needs to prepare their own children. Additionally, it is helpful to understand how autistic children may struggle as their social skills, developmental needs, and comorbid conditions make the transition to becoming young adults more challenging.

Educating our children with autism about this transition is step one. Open, honest, straightforward, and non-emotionally charged exchanges are optimal.

> “Feelings that can come from not being prepared can be negative and difficult to overcome while in the thick of it. We are not alone; our children are not alone.”

In the aforementioned study we learn, *“While the challenges and long-term consequences are understudied, a recent study of autistic females, highlighted that young women would benefit from more education pertaining to menstruation before and during menses to assist with understanding factors related to health, duration, pain, hygiene and changes in mood status (Steward et al., 2018). Additionally, psychological and sexual education training such as the Tackling Teenage program (Dekker et al., 2015; Visser et al., 2017) may be beneficial.”*

Knowledge can make the differences that help our autistic children feel their most confident, connected, and celebrated selves throughout their lives. Age appropriate enlightenment about the changes coming, the assurance that what they will be experiencing being natural, and a heads up about what their autism may bring to the table can all be helpful.

How to help your autistic child during puberty

Once we have done all we can to prepare for puberty, we can turn our attention to what to do when it actually begins. Adolescence is a complex time and brain development is happening quickly. Parents can do a lot for their children with autism during this time.

Social stories can be a very useful tool starting at a young age and continuing through pre-teen and teen years. They can be an indirect way to address very personal, uncomfortable, or awkward topics. This time of transition can feel like a roller coaster. Understanding it from the perspective of someone else's experience can take some of the vulnerability out of it.

Most teenagers need more than they let on. They may not want to talk, though they need it. It is important to lay a good foundation, to explain that you are always there for them, and to make an effort to communicate with them.

It is also important to lead by example, modeling healthy emotional, mental, and behavioral coping skills.

Physical changes

The physical changes of puberty can be alarming for some. For other children, they may seem virtually unnoticed. It is important for each child to have an understanding of these changes. They need to know that these changes are natural, healthy, and though they can feel gross or unwanted, they are not bad.

Mental health issues

Children with autism are more prone to anxiety and depression. All children are at a higher risk for mental health issues during puberty, even if they are temporary. Mood swings, social complications, and new body changes can be scary.

> “The physical changes of puberty can be alarming for some. For other children, they may seem virtually unnoticed. It is important for each child to have an understanding of these changes.”

If they are not already attending, providing your child with mental health therapy can go a long way during this time. They may need extra support and treatment in the form of medication, telehealth visits, or an increase in session frequency.

Sexuality

Part of growing up is self-exploration. Puberty can bring new self-awareness. An increase in sexual urges, or lack thereof, can suddenly draw the child's attention to others in a way they have never experienced before.

During this time, it is important for our children to understand that we are there for them, that their sexual development is valid, and that we will love them and help them through this time in a non-judgmental way.

Romantic relationship training is important as it will ensure our children with autism are as equipped as possible to navigate relationships with their chosen partners. The need for privacy, the reality of autonomy over their bodies, and understanding the function of body parts are all crucial bits of information our children need.

Some things are private and should only happen with the door closed. However, things like wet dreams and masturbation should not be taboo.

Wet dreams happen because bodies are working properly. This is a good thing.

Autonomy over the body, education about relationship safety, and the knowledge of when and where it is ok to engage in sexual matters is important for all children. Children with autism may need extra communication as reading body language, missing social cues, and misunderstanding intentions can be areas of struggle.

School

School staff, though they deal with children all day every day, may not realize your specific student needs extra support. When supporting our children with autism through puberty, enlisting the aid of school staff can help. Reaching out to them to find out what they offer, teach, and protocols they provide can be a great resource.

School libraries may also provide resources in the form of books, audio books, and other materials that can help your child understand what is going on from a less personal perspective. Many children learn about these sensitive topics through books.

CONCLUSION

Puberty can be a terrifying time for anyone. There are ways we can make it easier.

Preparing ourselves and our kids beforehand, gaining an understanding of what the needs and challenges might be, and providing helpful resources can all make the transition easier. For our kids, knowing they are loved and understood, not judged, is key.

Reaching out to all available aids will meet many needs. From home, to school, to social engagements, our kids can practice what they learn and gain the confidence and love within themselves to take on the world.

The relationship we build with them from babyhood and adolescence will strengthen them. When provided with knowledge and love, they will come through it.

I hope this brief overview has helped. You are doing a great job!

RESOURCES:

Here are some resources you can check out. These are just my own recommendations.

Autism Parenting Summit

Celebrate Your Body (and Its Changes, Too!): The Ultimate Puberty Book for Girls (Celebrate You, 1) **Book.**

This book, *What's Happening to Tom*, I found had some controversial illustrations, however I believe that each parent has the right to decide for themselves what is best for their family. I would also like to offer, this could be a book that you use as more of a guide for yourself, not necessarily have to be read with your child. I wanted to include it because I also believe in taking a direct, realistic approach to sensitive subjects; this was that for me.

These, along with the links throughout this article, I hope will provide you with some ideas and encouragement as you prepare for this new life transition with your child.

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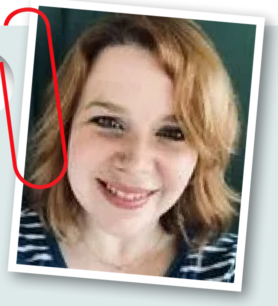

***Rachel Andersen** is a Writer and Copyeditor for Autism Parenting Magazine and is the author of Where Hope Begins: Decoding Depression for You and Your Loved Ones. Rachel lives with her husband and three children, two of whom have special needs. She hopes to be an encouragement to other parents and families through her work in the special needs community.*

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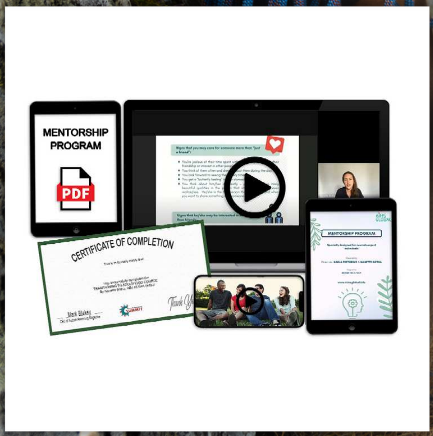

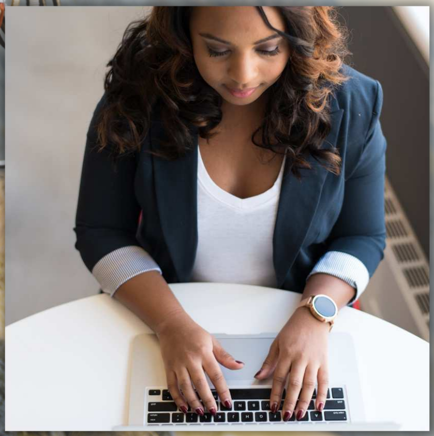

Transitioning to Adulthood Course

https://autism.ws/Adulthood

Autism Dating:
An Honest Dating Guide for Autistic People

By **Donnesa McPHERSON, AAS**

DATING IS NOT ALWAYS EASY, AND ADDING AUTISM TO THE MIX CAN PRESENT SOME CHALLENGES. HERE WE LEARN ABOUT WAYS TO KEEP DATING HONEST AND SAFE.

Autism dating can be quite a daunting and challenging part of growing up for people with autism and their parents. People that are on the autism spectrum often misread body language, lack scripting and appropriate skills to initiate relationships, and cannot always communicate what is on their minds.

Activities like speed dating can cause an individual's sensory system to overreact. This could be due to potential loud noises and music, flashing lights, and abrupt changes.

Intense interests that are commonly found in autistic individuals can also deter a potential partner because they are based on the person's own needs and interests. A particular interest or topic could take over the conversation before they realize something is the matter because the other person will no longer talk or be interested.

The need to connect with others in this world is important to everyone, including those within the autistic community. While many people are able to spend time and really connect with a person while maintaining the social norms necessary to date, this can be difficult for an autistic person. However, this can be remedied quickly once they are made aware and can practice the skills necessary.

Relationship challenges for those on the autism spectrum

A common misconception by many is that an autistic person is unable to have a romantic relationship. It is thought that they are not self aware enough and lack the social skills to connect and make the big time decisions necessary for a potential date.

That is the furthest thing from the truth.

There are people on the autism spectrum that could make their main interest dating, focusing on the one person with whom they have a committed relationship. Individuals with high functioning autism may be interested in online dating or even a double date with a trusted friend.

It is important to talk to autistic people about online safety and have a protocol in place to keep them safe. This is true for autistic teens as well as adults. With all the electronic communication available, there are dangers that need to be taught.

Is it hard to date someone with autism?

There is a show on Netflix called *Love On The Spectrum*, which follows young autistic adults as they navigate relationships, dating, and falling in love. There are individuals that have a meaningful connection and form a committed relationship after their dating relationship takes the next step.

> “Difficult moments when making eye contact, understanding certain situations and feelings, and maintaining conversation were difficult.”

There were difficult moments when making eye contact, understanding certain situations and feelings, and maintaining conversation. There was one date where a cast member, Michael, went on his first date and was asking his date questions. She became overwhelmed, and the date ended, leaving Michael wondering if he did something wrong.

Having a level of self awareness and an awareness of the surroundings and the other person on the date is difficult, even for neurotypical people. So when it comes to people with autism, having romantic relationships can be a challenge. This can lead people to think that dating someone with autism is challenging.

An interview by Hurlbutt and Chalmers with an adult male on the autism spectrum indicated that the man felt he “drove away” women because of how often he called them, not recognizing their feeling that they were being harassed. It can only take a moment of misunderstanding feelings and body language that can lead to feelings of harassment, affecting the dating life of autistic people.

Things can change pretty quickly when boundaries have been crossed or interest has been lost. Keeping a partner interested is as simple as keeping the flow back and forth and listening to what the other person is saying.

Dating tips for people with autism

Please try to remember each autistic person is as different as a fingerprint and should not be generalized. Autism and dating can go hand in hand as long as both individuals understand the needs of each other, and good intentions are maintained.

Advice could be helpful from a trusted family member or friend. Even having a double date with a friend could help keep the focus on the date and the communication flowing.

Having a general education for a successful relationship, starting the education and training with elementary aged children, and moving up to understanding other people and what is considered appropriate and inappropriate are skills for life. This can start at home with families talking about how to treat a family member and how those relationships affect each other.

Moving forward, teaching autistic teens about the importance of good personal hygiene and how it affects their lives is a starting point. Also, how they interact with others and discussing their feelings helps prevent misunderstandings.

Explaining the changes they are experiencing and that they are normal helps alleviate the stress of the unknown. Also, having the knowledge that everyone in the world goes through changes makes going through them a little easier, for some.

> “Autism and dating can go hand in hand as long as both individuals understand the needs of each other, and good intentions are maintained.”

Some skills that could be taught and discussed with autistic adults, in reference to romantic relationships and dating, are to find a partner that is interested in the same topics they are. In addition to learning different cues and social norms, autistic people could learn and understand more about limits in love and, at the same time, interests of another person and a potential partner.

Autism flirting tips to keep people’s interest

Here are some top tips for people on the spectrum looking to ace flirting!

- Always be yourself
- Make eye contact, but don’t stare
- Smile often
- Talk to the other person and figure out their interests
- Be aware of your surroundings and stay in well-lit, public places
- Don’t expect too much from the first date; you’re still getting to know each other
- Don’t stress; relax and enjoy the experience
- Have fun

Dating websites and resources for people with autism

Relationships can be difficult enough without all the social pressures that are always present. Dating websites and apps are a way to help alleviate some of the stress a person with autism can feel when seeking a potential romantic relationship.

It is key to note the importance of safe interactions through the internet, apps, and in person. The individual should be aware of their limits, always pay attention to what is going on, go on a group date with someone they are just meeting, and meet in a public and well-lit area while they are getting to know one another.

Dating websites and apps

Some dating apps and resources potential daters on the spectrum might want to research and consider utilizing include (among others):

- https://autisticdating.net
- https://uneepi.com
- https://www.hikiapp.com/

The thought of romantic relationships and finding that one person can be a point of interest to a person on the spectrum. Before they start making use of dating websites and apps though, it is essential to make sure they have the skills necessary for interactions with other people, including a partner. Knowing boundaries, limits, and safety protocols while dating can keep the date light and fun.

> “Dating websites and apps are a way to help alleviate some of the stress a person with autism can feel when seeking a potential romantic relationship.”

Safe dating practices

There are many tips and tricks to stay safe during a date. They are simple and ensure that the autistic individual going on a date knows what precautions to take that can help maintain their safety and have a plan in place for the “just in case” scenarios.

Safety tips

- Tell friends and family where the date will be and who will be there – Letting people know where the establishment is and who all will be there is a great way to stay safe because then the family members and/or friends will know when to expect the individual back home and can check on them
- Ensure each person has their own transportation – Not needing to rely on someone else that a person hardly knows for transportation to and from a date can keep them safer, and having their own transportation allows for more freedom in the date
- Meet in a public, well-lit and safe spot – It is never a good idea to go to someone else’s home who they don’t really know or somewhere where there are not a lot of people. Being safe means staying where a person can be seen
- Always watch food and drinks – When around people, in general, it is always a good idea to keep check of food and drinks and to never leave them unattended

- Don’t drink too much – Staying sober, paying attention, and always knowing what is going on helps an individual stay safe
- Go with a trusted friend or group – Going with a group of people can keep intentions light and not add unnecessary expectations to the date
- Have mace or other personal protection – It is always a good idea to have a small can of mace (if you live in a country where it is legal), and know how to properly use it. A whistle, cellphone, or other loud alarm is also helpful in the event they are needed
- Always tell the truth about oneself – It is never a good idea or acceptable to lie about age or other attributes that a person may be expecting when they meet for a date
- Don’t overshare personal information – Not sharing an address, workplace, time when one is alone, etc. is important when getting to know someone
- Check the person out on Google or social media – There is a lot of free information available about a person through Google and social media outlets. It allows someone to get a feel for a person before meeting them

It can be a lot of fun to go out on a date, but making sure to maintain personal safety while getting to know each other is key. Following the simple tips and tricks above can help with safety, and always having a cell phone or smart watch can add more safety, allowing people to relax and have fun together.

> “Always tell the truth about oneself – It is never a good idea or acceptable to lie about age or other attributes that a person may be expecting when they meet for a date.”

Dating on the spectrum can be fun

Nerves and the unknown can really take away from the experience of dating for anyone. If an autistic individual has the right supports in place, like Applied Behavior Analysis (ABA) or social skills groups, and they are taught relationship-building skills like conversation and learning boundaries, dating can be a fun and safe way to meet a future partner.

Knowing what their interests are and what they have for goals will help an autistic person find a partner that could lead to more down the road. As long as they have the support they need in place and are willing to learn as they go when meeting people, there will be plenty of fun to be had.

Working on the skills and knowing goals and what they have planned for their future could help the individual with autism know what to look for in a partner. Being authentic with themselves and their date is the best way to start an experience and for it to be what they are expecting.

Always keep in mind the environment of the date and whether or not the other person has sensory aversions or is neurodiverse in their own way. Knowing these things and being ready for them before the date can help make sure that things are comfortable for everyone.

Sitting down and talking to a parent, counselor, ABA technician, or individual they trust can not only help the individual figure out what they are looking for, it can also help them build further on the social aspect of their being. As long as the individual knows about internet and date safety, knows what they are expecting, and is informed about what is and is not acceptable behavior and talk during a date, they can have the time of their lives and have experience with romantic relationships.

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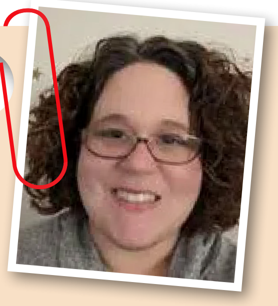

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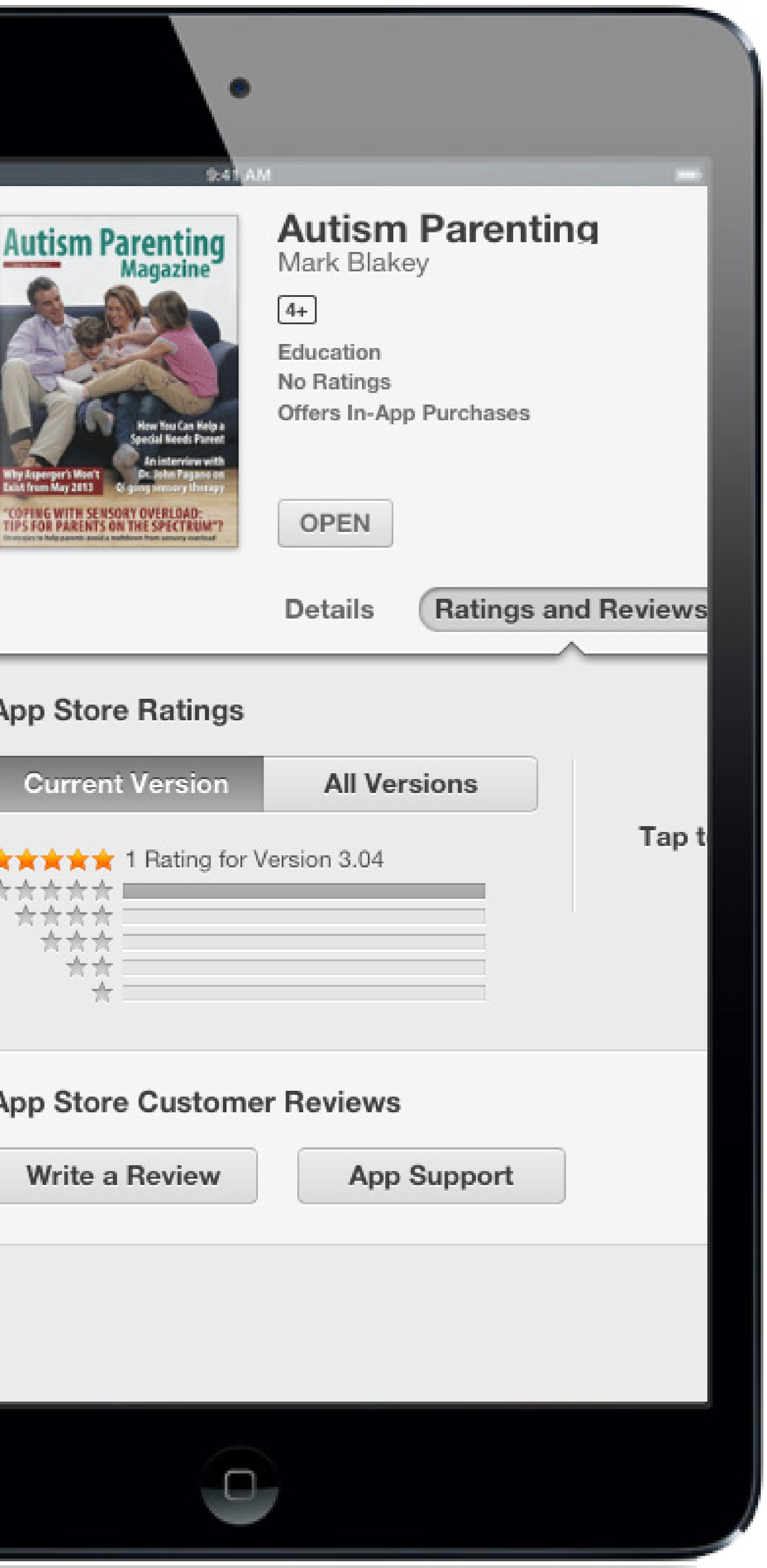

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Alternative Sensory Therapies

By **Heather COOK, ACC**

A HOLISTIC APPROACH TO SENSORY THERAPIES FOR ALL.

In our November issue we looked at some of the unintended effects of exposure therapy for sensory sensitivities, and why it doesn't actually desensitize as intended, but teaches the person to mask their visible reactions. What if there were a different way?

In fact, there are several alternative options that can help with different aspects of the sensory "issue," and a holistic approach often has the best chance of everyone being happy with the outcome. Here are a few other options.

Integration Therapy

Sensory integration therapies, when led by a responsive therapist, do what exposure therapy intends to do. It actually calms the nervous system so it becomes less reactive or more responsive, as appropriate.

The whole idea here is to teach the nervous system what calm feels like by engaging senses in combinations. This involves pairing one or more senses that are happy with one sense that is not.

The idea is that the senses that are happy will teach the other one that what they are experiencing is okay.

For example, someone may like heavy pressure and have no problem with scents, but their vestibular sense makes them nauseous at any movement. So we might put out some essential oils that they like and ask them to wear a weighted vest while they're bouncing on a big yoga ball.

As much as possible, the child should be able to participate in selecting the intensity of the therapy. If they are the one bouncing on a yoga ball, they can bounce a little or a lot, stopping when they need to, so that it activates their vestibular sense without making them nauseated. This kind of sensory integration helps the nervous system learn to process the external stimuli so that it's not as overwhelming.

Listening Therapies

Some autistic individuals have had some excellent results with various listening therapies. Each version is a little different, with different results, so look for one that meets your needs. I've personally experienced very good results from the Safe and Sound Protocol (SSP). It enhances vagal tone and helps bring the nervous system out of fight-flight-freeze-fawn activation and into a state of calm and safety.

Technology Aids

There are technological devices that may help.

- **Apollo Neuro** is a wearable wristband that gently vibrates in different modes to help your body rest and relax, sleep or wake up, get energized, or focus.
- **Dreampad** is a pillow that sends soothing sounds and sleep music through gentle vibrations to your body, triggering a natural calming response, helping you sleep.
- **Alpha Stim** is used to feed the brain alpha waves, which reduce anxiety and depression and enhance your ability to focus and learn.

DIY Aids

Stimming, weighted blankets, sensory toys, fidget toys, The Wilbarger Protocol of skin brushing and compressions, and more, are ways we can self-regulate our own bodies' needs throughout the day so that they don't become overwhelming.

Anxiety Management

Living with senses that are frequently overwhelmed or not stimulated enough; or senses that react without warning, not knowing when it's going to happen next but knowing that you can't avoid the situation, can create a lot of anxiety. Unfortunately, when anxiety levels rise, it heightens stress responses in the nervous system, which makes sensory processing even more challenging.

Sensory overwhelm is not the same thing as anxiety, but worrying that you're going to be overwhelmed is. Here are a few options to deal with some of the worries that add to anxiety.

Dr. Stephen Hayes developed Acceptance and Commitment Therapy (ACT) after struggling with anxiety himself. It teaches simple strategies for how to let go of the thoughts that won't leave us alone.

The Work of Byron Katie is a powerful, yet exceptionally simple, series of questions that help us find the truth in the thoughts that are causing us pain. It works in every area of our lives, and applied to sensory things, it might question beliefs such as, "It'll never get any better," "I can't deal with this," "I don't know how to help my kid," "It's not okay to be different," "No one will accept him the way he is," or "She needs to change."

Some of those thoughts above may apply to your kid or to you as the parent who's watching your child struggle and wanting the best for them.

Coaching

Working with a coach can give you personalized help in adapting your life to be a sensory refuge, or in working through those thoughts and expectations that you have that may be getting in the way of being your best self as you try to help your kid.

A coach who is themselves autistic or has sensory differences can offer the benefit of personal insights and perspectives that are often profound.

Acknowledge Sensory Differences

The hardest thing about living in the sensory minority hasn't been the sensory experiences themselves (and I am not in any way diminishing the pain of that), but feeling that I was wrong for having those experiences. That I was broken, disordered, not good enough, I would never be the way people expected me to be, and being told that I just needed to try harder when I was already trying my absolute best.

I wish my parents and teachers had used language like, "How does this feel to you?" or "What does your body need right now to feel good?" or "How can I make this better for you?" or "It looks like you're really struggling. How can I help?" or "What can we do so we both feel good?" or "If that doesn't work for you, that's okay. Let's find another way together."

> "Working with a coach can give you personalized help in adapting your life to be a sensory refuge, or in working through those thoughts and expectations that you have that may be getting in the way of being your best self as you try to help your kid."

Sensory Pleasures and Euphoria

So much of the conversation around sensory differences focuses on the difficulties and challenges, that we often overlook the parts that are truly wonderful.

Look for sensory experiences that your child loves, that help them to feel good, or that provides pleasure or euphoria. Add more of those good sensations into their daily routine, and focus on them whenever possible.

Remind your child that not all sensory differences are challenging. Also, bring up how other people don't get to experience those pleasures in the beautiful ways that they do.

Closing thoughts

What we need to feel good in our sensory bodies is not the same thing as the strategies we use to meet those needs. You might need to feel calm, but there are many ways to calm down, including deep breathing, stimming, using fidget toys, being alone, being with someone else, and more. The more strategies you have available to you, the more you can adapt as situations and needs change. I hope this helps you find a variety of strategies to meet your own family's ever-changing needs.

__Heather Cook, ACC__ is an autistic self-advocate, certified life coach, certified teacher, and an autism coach helping autistic individuals and their families to find ways to be themselves that work and feel better for all.

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