

FOR PARENTS & PROFESSIONALS

AUTISM ADVOCATE

PARENTING MAGAZINE

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Developing Skills Cerebral Folate Abnormalities
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Fragile X Detox Embracing Differences Executive Function
Employment Family Enzymes
Financial Resources/Planning Tics
Gender Differences Genetics of Autism Gut-Brain Axis
Feeding/Oral Development GI and Behavior
Therapy and Medication

Topics Covered

IN AUTISM ADVOCATE PARENTING MAGAZINE

Theory of Mind Visual Schedules Hyperbarics
Global Perspective Gluten-Free & Casein-Free Happiness
Integration Hygiene Mindfulness Healthy Lifestyle Teaching
Medication Independence Learning Difficulties Yoga Hypersensitivity
Motivation PECs Literacy Microbiome Sibling Support
Nutrigenomics Mycotoxins Mitochondrial Dysfunction Self-Care
Neurobiology of Autism Music/Sound Therapy
Play Therapy Safety Occupational Therapy PANS/PANDAS
Probiotics Pre-Diagnosis Checklists Positive Reinforcement Sensory Processing
Relationships Self-Determination Self-Injury Thinking Traps
Sexual Abuse Self-Esteem School/IEP
Sports Supplements Severity of Autism Over Time
Transition to Adulthood Taking Turns Toilet Training
Visual Strategies

And so much more!

Dear Parent Advocate or Reader:

We are excited to share Autism Advocate Parenting Magazine with you! As caring parents, we love our children and want the very best for them. We want to go to bed every night knowing that we have given them the best support and resources possible. Sometimes it can be difficult to know where to start, what supports are best for our children and what the latest autism research has uncovered. This is where we can help.

Autism Advocate Parenting Magazine's primary purpose is to **empower** parents. We work closely with doctors, therapists, specialists and experts in the field of autism. Their expertise and experiences will give you the ability to stay up to date, **ask** questions, to **advocate** for your child and to **search out** information that can benefit you on your journey.

In our magazine we focus on four key areas that will empower YOU while raising your autistic child:

Current Research



Summaries of current autism research giving you vital information without the need for reading through complex medical journals.

Expert Advice



Gain valuable insights from leading experts in the autism field, including top doctors, researchers, and professionals. Their wealth of knowledge and expertise will provide you with up-to-date information on the latest supports and resources available to parents.

Resources



Access a wealth of game-changing printable resources, guides, and tools that are designed to assist you in supporting your child. We offer an abundance of these invaluable resources to empower you on your journey.

Parent Advocating



We recognize the extraordinary potential within every child and are committed to joining you on your journey. We share stories filled with hope, advocacy, and inspiration, fostering a sense of community and support.



We are parents, raising autistic children, sharing this journey with you. We know all about the frustrating days, the exciting moments and the long nights. We also know that time and energy are limited, and that seeking out information on autism is challenging and time consuming. We are here to help. If you would like us to find an expert or investigate a topic that can benefit your child, please reach out to us by email: admin@autismadvocateparentingmagazine.com. We want to make your life easier, because we know how busy life can get.

Please note: The articles we provide do not represent the views of Autism Advocate Parenting Magazine. AAPM strives to foster a broad perspective on all topics regarding autism. To this end, we attempt to be as inclusive as possible with the views we present. These views may or may not reflect our own, but we include them in order to add to the reader's diverse knowledge and education on autism.

Dr. Tom O'Bryan, an autism expert, said it best: "Take one hour a week to learn more about autism and before you know it, you will be an expert in many areas of autism."

We value, embrace and advocate for neurodiversity. We admire each of you — whether you are a seasoned parent advocate or just starting on your autism journey. We love hearing about your success stories, as well as your hopes and dreams. We are honored to be a part of your family's journey, and grateful to have you be a part of ours.

Parent Advocates

Autism Advocate Parenting Magazine

"Take one hour a week to learn more about autism and before you know it, you will be an expert in many areas of autism."

- Dr. Tom O'Bryan

AUTISM ADVOCATE

PARENTING MAGAZINE

A Note on Perspective

At Autism Advocate Parenting Magazine, we pride ourselves on providing our readers with a diverse range of perspectives and expertise from the autism community. We actively seek out renowned doctors, experts and professionals in the field of autism to contribute articles to our monthly publication. We value their perspectives. Our suggested article guidelines encourage authors to use terminology that is widely accepted within the autism community, and to also be mindful of the ever-changing landscape. We understand that some experts may continue to adhere to traditional medical model terminology, and we value their contributions and years of dedication to the autism community. We also acknowledge that there can be diverse opinions and perspectives among autistic contributors on preferred terminology and symbols. It is important to point out that the terminology used by various contributors does not reflect the express viewpoint of our publication. In today's world, we know that the challenges posed by cancel culture can hinder open conversations and understanding. We firmly believe that no one's best interests are served by a divided community. Instead, we encourage the community to come together, bridge the gaps and embrace differing viewpoints with a view to promoting mutual understanding and growth.

At Autism Advocate Parenting Magazine, we believe in creating an inclusive space where all voices are heard and respected. We seek to foster a broad perspective on all topics related to autism. To this end, we try to be as inclusive as possible with the views we present. While these views may or may not reflect our own views, we include them in order to educate and inform our readers on the wide range of viewpoints on autism.

We value the expert doctors and researchers who have dedicated their careers to serving and advancing the autism community. We also deeply appreciate and acknowledge the essential role of parents who devote their time and energy to supporting their children. Their contribution is at the core of our publication's origin. We also highly value the unique insights and experiences shared by autistic individuals, as well as the involvement of others who actively contribute to and show interest in the community. By acknowledging the different voices and diverse perspectives within our community, we strive to foster a collaborative and inclusive environment that benefits everyone.



AUTISM ADVOCATE

PARENTING MAGAZINE

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Autism Advocate Parenting Magazine strives to include a range of perspectives and relevant expertise that can help parents who are raising a child or children with Autism Spectrum Disorder. This magazine includes articles authored by third parties. The views, findings, recommendations and opinions (collectively, the “**content**”) expressed in each article are that of its author and do not necessarily reflect the opinion of Autism Advocate Parenting Magazine. We do not endorse and are not affiliated with these third party authors and we assume no liability or responsibility for the content. Given that research in this field is rapidly evolving, the content expressed herein is subject to change at any time and you should use your best skill and judgment to evaluate the content. It is important to consult a trusted medical professional for advice to help you make informed decisions. The information in this magazine is of a general nature, is not medical advice, and should not be relied upon as a substitute for medical advice.

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Top 10 Rules

for Parents
Raising an
Autistic Child

**Maja Toudal, MSc.Psych.,
Author, Autistic Advocate**



I am an autistic psychologist from Denmark. I was diagnosed with autism at the age of 16, which means that I went through primary school without a diagnosis and the supports that come with it. I experienced a lot of bullying and the challenges that come with it on a mental health level, such as anxiety, depression and even suicidal ideation. Although I didn't have a diagnosis as a child, my mother knew that something was different about me even when I was young. She knew that she couldn't relate to me, nor understand the world I was in, the way I played, the games I came up with, or why I phrased things a certain way. I am grateful that, despite her lack of understanding, she tried her best to accept and accommodate me in my childhood. For example, when I was about eight years old, I wanted a lock on my door so I could have total privacy. I wanted a place where I could relax and recharge, and know that no one would be able to enter unless I allowed it. I didn't just want to close my door, I wanted to lock it. Even though my mother did not quite understand my need for a lock, she acknowledged that it was important for me and helped me to put a lock on my door.



When I was a young adult, my former psychologist prompted me to speak with groups of parents raising autistic children. After several sessions, I began to recognize that these parents valued my personal perspective. I was able to tell my story; I was able to tell them what being autistic is like for me; I was able to share my autistic voice – just one of many. From these experiences, and with the encouragement of my mentor and friend, Dr. Tony Attwood, I wrote a book titled, "What Your Autistic Child Wants You to Know: And How You Can Help Them." In this book, I share Ten Rules, or foundational pillars, that I feel could benefit parents raising an autistic child. These are based on answers I give most frequently to questions posed by parents in these group sessions and are aimed at debunking myths about autism. I don't pretend to know everything. However, with my own experiences and those that other autistic people have shared with me, as well as my clinical work, I hope I can lift up the voices of autistic individuals and raise awareness about the autistic experience.

Ten Rules

1. I am a human being, no matter how different I seem.

While autistic people can be different from non-autistic people in some very specific ways, overall we are more alike than we are different. We are human beings. We are people just like everyone else. We don't need to be approached as a mystery to be solved or like an alien from another planet. Sometimes we think and approach social interactions differently, but we are human beings like everyone else. It is important to remove the thoughts of "otherness." I have spoken to many parents who feel they cannot possibly understand the autistic perspective because it is "so different." The fact is, however, that autistic human needs are not all that different; they are just expressed differently.

2. There is something in this world that I am great at.

There can be a tendency to focus on the challenges and difficulties of autism, on all the things we *can't* do. In view of what professionals have said or of depictions of autism in the media, parents might feel that their child can't have friends, shouldn't expect to get married, probably won't have a job, or won't have a life that is anything like "normal." I feel that this is a terrible message to give to someone. It's not motivating, and it's also not true! There are so many autistic artists, athletes, researchers and technology experts. After all, we are everywhere in society. If you look, you will find something at which your child excels. There is something that he or she has that is wonderful. Stop focusing too much on the things your child can't do and highlight the things your child is great at.

3. I am different from every other person on the spectrum.

When I received my diagnosis, I was placed in a social networking group by my municipality. I was in the group with four or five other autistic teenage girls to help us build connections with one another. None of us, however, shared the same profile or interests. The only thing we had in common was our autism diagnosis. While autistic people can connect on that level, true connections often happen when they have a shared interest, goal or match in some other way. Just because your child is autistic doesn't mean he or she fits into a special autism box. The experience of autism is very different for each person. The willingness or desire of autistic individuals to engage socially can be very different; the kinds of routines that are important to them can be very different; their interests can be different; their individual sensory sensitivities can look very different. Just like every other segment of the population and every other box that people can be put in, autistic people are going to be very different from one another.

4. I need love.

There is a myth that autistic people don't want to be social, don't want interactions and don't want community. This can very easily transform into a misconception that they do not want love. Autistic people want to connect; they just might not want to do it in the same way that other people do. They might not need quite as big a tribe as other people do. It doesn't mean they don't need or want love, connection or community. Figure out a way that your child receives love that is not overstimulating. It might involve just being in the same room as your child, or receiving a very controlled hug - not too tight, not too long and not by surprise. When I meet with my trusted friend and colleague Christian Stewart-Ferrer, we bow to greet each other at his request. He is not being rude. This is what he is comfortable with, and I respect that. What is more, I recognize the love and respect that are implied in the bow. Try not to impose your signs of affection on your child if he or she finds them uncomfortable. Accept the expressions of love, care and respect that are given to you in your child's way. Then, try to mirror those in the same way to your child.

5. I need space.

The world is constantly overstimulating for most autistic people. The result is that autistic people need to withdraw. They need to put themselves in a space where they are not being overloaded with social and sensory stimulation. They need a controlled space where they can recharge. Sometimes that space is nature, a private bedroom or the beach, or playing video games. It's different for every person. Needing space is not a rejection: it's simply a need to recharge from a chaotic world.

6. I am trying.

I truly believe that all people do their best at life. If people know how to do something better, how to meet a challenge in a different way, or how to change an approach to be less destructive or more accommodating, they usually will do it. When individuals don't look like they are giving enough or not trying to improve, it's usually because they do not have the capacity for some reason or another. Your child is trying and is doing his or her best! When parents begin to acknowledge that their child is trying and that the effort is more important than the success, their child's confidence and development will grow.

7. Sometimes I need a day off.

Everyone needs a break sometimes. Your autistic child occasionally needs a day off from the pressure of expectations, performance, challenges and perfectionism. A break will allow your child to relax. It's important to take a step back and let your child have a day free of the constant challenges and difficulties.

8. My energy is spent quicker.

There are many things that use up an autistic person's energy. These include stressors that non-autistic people do not even notice, such as sensory processing differences, social challenges and more. The autistic brain processes information in such a way that more energy is required to manage the constant stimulation. This causes exhaustion, overload and burnout. An autistic person's energy is spent quicker, so it is important for parents to be realistic about what their child can manage and when breaks and space are required to recharge.

9. I need you to catch me, not carry me.

Parents naturally want to protect their child. It is important for parents to protect, teach and nurture. However, it is also vital for parents to give their child opportunities to meet challenges at his or her level and ability. Parents should not fix every problem their child encounters, but allow their child to learn skills and confidence to overcome problems. I sometimes explain this point with a cheerleading analogy. In cheerleading there are flyers, the athletes who are tossed in the air to do tricks and flips, and there are bases, the athletes who catch the flyers. Autistic children who are flyers will only feel comfortable doing tricks and developing their skills if they know they have a base or a parent to catch them, support them, and cheer them on. Without these things, flyers will not want to go up in the air. It is also true, however, that if the bases never let go of the flyers, they are held on the ground and cannot even attempt to develop their skills in the air. All children, including autistic children, need to know that their parents will catch them when they fall. Parents need to be ready to catch their children as they work through difficulties, not carry them through every difficulty. Be their base, but do not keep them on the ground.

10. Chill out.

It is natural for parents to worry. Parents of autistic children might worry what their child's life is going to look like in five or 10 years, or when they are gone. They might wonder if they are providing all the supports needed for their child to reach his or her full potential. They might worry about education, employment or independence. My advice for parents is to chill out! It's going to be fine. Life is difficult. It comes with challenges, but you will overcome them. When parents are worried and stressed, their child picks up on that energy. Worrying too much is not productive. Meet your child with confidence. Tell your child that you believe in him or her. Tell your child - and yourself - that you believe everything is going to be okay. Reassure your child that, together, you can deal with life's challenges. I have met so many parents who tell me, "You cannot know; you are not as challenged as my child is." In many ways that is true, but these parents are not seeing me as a child but as an adult. My challenges as a child were not the same ones as I have today because I have learned strategies and developed. We mature, too. When you, as a parent, are with your child every day through the most difficult times, it is hard to see a future when maturity and strategies will give your child a better quality of life, a life that works for him or her. I urge you to believe me when I say that a bright future is possible.

The last piece of advice, or the last rule, is the one that I end most parent-focused presentations or events with because it is the one I most want you to remember. I want to leave you with hope and excitement for the future. I know that life with a child who has any handicap is stressful and full of worry, and that it brings many sleepless nights. I know that the struggles to even get access to support are exhausting. Sometimes, it must feel like screaming into a void as you ask for someone — anyone — to help you and your child. And this is the case regardless of what your child's support needs are. I see it across the board.

In those desperate moments, whether short or long, I hope that you remind yourself that your child will find a way through those challenges. Your child can do it, just as the many adult autistic advocates have done who came through immense challenges and have blossomed into capable, skilled and wonderful people. I implore you to believe it. Rest assured that a bright future that works for your child is in store.

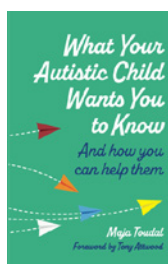


Maja Toudal, MSc.Psych, is an autistic psychologist, speaker, self-advocate and author from Denmark. She has worked in autism communication since 2010, primarily as a speaker at conferences, parent groups and local networking groups for people with Autism Spectrum Conditions. Maja has worked closely with autism experts Dr. Tony Attwood and Kirsten Callesen for many years, gaining clinical experience and helping to run social groups for teenage girls with ASD.

In 2016, she published her first book, *What Your Child With Asperger's Wants You To Know*, combining her personal and professional knowledge to educate and advise parents on the inner life of their children. This book was re-published in 2022 under the title, *What Your Autistic Child Wants You To Know*.

These days she focuses on a combination of clinical work and future book projects, as well as the podcast *Autistic Tidbits and Tangents*, which she hosts along with Dr. Kara Dymond.

Access Maja's book here: https://uk.jkp.com/products/what-your-autistic-child-wants-you-to-know?_pos=1&_sid=4e19e2347&_ss=r



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Autism and Bone Health

Ann Neumeyer, MD



Autism is a complex condition that comes with many associated challenges, including difficulties with social communication, language development, sensory differences, anxiety, gastrointestinal issues, sleep difficulties and more. One topic that is often not considered but has emerged as an important area of research is bone health in autistic individuals.

Bone formation and development begins around the sixth week of embryonic development and continues throughout childhood and adolescence. Through diet and exercise, we help our bones become as dense and strong as possible until we reach peak bone mass in early adult life. As we get older, however, bones start to become less dense. The goal is to have bones that are as strong as possible so that when bone mass loss starts to happen, bones don't become so weak that they break easily, such as occurs with osteoporosis.

There are many factors that contribute to overall bone health. Genetics, exercise, diet, intake of vitamin D and calcium, and hormones all contribute to strong bones. On the other hand, certain medications, diseases and some genetic conditions can predispose a person to have weak bones.

Autism and Bone Health

Over the past decade, a number of research studies have shown that autistic children have bones that are weaker and less dense than children without autism.¹ There are a number of possible reasons for this difference.



Exercise

Statistics show that autistic children are less active than non-autistic children. Exercise plays a key role in building strong bones, and children who are less physically active tend to have bones that are not as strong as those who routinely engage in physical activity.



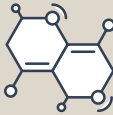
Medications

Some medications can affect bone health. Many autistic children take medications needed for anxiety, depression, reflux, irritability or other conditions, and this can affect bone density.



Diet

Diet plays a critical role in bone health. Eating foods with calcium, protein and vitamin D affects bone density. It is commonly known that many autistic children are selective eaters and may not be consuming the proper nutrients to support bone health. Also, many autistic children are on a gluten-free or casein-free diet, and not all alternatives have calcium and vitamin D added to them. In fact, research shows that vitamin D deficiency is common in autistic children and is likely contributing to poor bone health.^{2,3}



Hormones

Children with autism often have higher cortisol levels than non-autistic children, and higher cortisol levels have deleterious effects on bone density and strength.

Current Research

Since bone health in autism is a relatively new area of research, a large population study has not yet been done that looks at bone health in autistic children. Several smaller studies have been conducted, and these have shown that many autistic children have statistically lower bone density than non-autistic children.^{4,5,6} The studies tracked exercise, diet and medications, and used a medical imaging technique known as a dual-energy x-ray absorptiometry (DEXA) scan which measures bone density. The DEXA scan uses very low levels of x-rays and is quick and painless.

In further studies, researchers were able to use large databases to look at the number of children and adults who presented with bone fractures in the emergency room. The results showed that autistic children and young adults aged three to 22 years old and older autistic adults aged 23 to 50 years old were more likely to have a hip fracture than those without autism.⁷ The study also showed that autistic women aged 23 to 50 years old were more likely to have a forearm or spine fracture than non-autistic women.⁷

Other research on bone health in autistic adults is limited. However, results from studies done on children, as well as information on fracture risk in children and adults, lead experts to believe that bone health in many autistic adults may be poor and could lead to significant problems.

When to Seek Help

If your autistic child has even one fracture, you should consider getting your child's bone density tested. It's also important to have your child's vitamin D levels checked. This is particularly true if you live in a location where exposure to the sun is limited in the wintertime, your child is on a selective diet such as a gluten-free or casein-free diet, or your child is a very selective eater.

Improving Bone Health

Bone health can be improved by physical activity and the consumption of adequate amounts of vitamin D, calcium and protein through diet or supplements.

As parents, we all do our best to get our children active. Autistic children, however, may have challenges and restrictions that prevent them from being as active as other children. My best advice is to get them to walk, and to walk with them. Park a little further away from the school or the grocery store so that you have to take a few extra steps. Make little changes to increase your child's activity level. Find activities that your child likes. They do not have to be traditional group or team sports, but could include martial arts, swimming or gardening.

It is important to continually work on improving your child's restrictive eating. If your child is on a gluten-free or casein-free meal plan, ensure that the alternative products being consumed have adequate vitamin D and calcium. Work with a dietitian to ensure your child is getting the necessary vitamins through diet or supplementation.



Treatment

Treatment for low bone density in autistic children and adults is currently being investigated. One novel treatment that is showing promise is the use of oxytocin. Oxytocin is a hormone that is produced primarily in the hypothalamus and plays a critical role in romantic relationships and social bonding. Research shows that if oxytocin is missing in mice, they have significant osteoporosis. However, giving these mice a controlled treatment of oxytocin improves their bone density, which means their bones become stronger.⁸ A preliminary study on autistic children also showed that bone density increased after oxytocin treatments. In fact, a clinical trial to study the effect of oxytocin on bone density in autistic children is just beginning at Massachusetts General Hospital. For more information, please see: https://rally.massgeneralbrigham.org/study/oxt_in_asd

Another potential treatment involves the use of bisphosphonates, a series of drugs that are often prescribed for osteoporosis. If a child with autism has both low bone density and a concerning history of bone fractures even with minimal trauma, some pediatricians will treat the child with a bisphosphonate after optimizing the child's calcium and vitamin D levels.

Bone health is extremely important. Our bones provide the structure for our body and allow us to move. They also protect our internal organs from injury. The healthier our bones are when we are children, the longer they will be able to remain strong and healthy after peak bone density. If you are concerned about your child's bone health, seek a qualified professional who can help you get the supports that your child needs.

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Ann Neumeyer, M.D., is a pediatric neurologist with over 25 years of experience in the diagnosis and treatment of children with autism and of children with neurodevelopmental disabilities at Massachusetts General Hospital in Boston. Dr. Neumeyer is the MGH Lurie Family Endowed Chair in Autism, Medical Director of the Lurie Center for Autism and an Associate Professor of Neurology at Harvard Medical School. As a member of the Massachusetts Autism Commission and the immediate past co-chairperson of the steering committee of the North American Autism Care Network, she works to develop better clinical care for children both in Massachusetts and in North America. Her clinical observations have fueled a strong interest in medication trials and investigations of metabolic and bone development issues in children with autism. As Medical Director of the Lurie Center, she also works to improve hospital systems to ensure quality of care for children with autism as inpatients and outpatients. Dr. Neumeyer attended Dartmouth Medical School and trained in pediatrics at Montreal Children's Hospital and Boston Medical Center before completing her Neurology/Pediatric Neurology training at Massachusetts General Hospital where she continues to practice.


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Proactive and Preventative Behavior Strategies for Children with Autism Spectrum Disorder

INTRODUCTION TO A SIX-PART SERIES

Sonja R. de Boer, Ph.D., BCBA-D

Photo credit: Treasure4Life Photography and the Hotta Family

A photograph of a woman and a young girl sitting on a grassy field, high-fiving each other. The woman is wearing a red shirt and a colorful skirt, and the girl is wearing a green and white patterned shirt and khaki pants. They are both smiling and looking at each other. The background is a blurred park setting with trees and a fence.

I have worked with children with autism spectrum disorder (ASD) for the past 30 years. For 10 of those years, I worked as a behavior analyst consultant in families' homes. I designed behavior intervention programs and helped families create a home environment in which the entire family — including siblings and parents — could thrive and enjoy daily life together. When I first start working with families, I offer training to help us assess the family's current daily routines, and identify all the proactive and preventative systems and strategies that can be put in place to help both the child with autism and the whole family. Over the next few months, I will be providing five more articles for publication in Autism Advocate Parenting Magazine. This introductory article lays the foundation for the proactive and preventative systems and strategies that I will be discussing.

As a behavior analyst, my goal is to help families, teachers and other professionals build a scaffold in their approach to planning and preparing for daily work with children with autism. The key structure of the scaffold is made up of two strategies: *being proactive* and *being preventative*.

Being proactive involves teaching children the skills they need in order to reduce problem behaviors, participate in daily activities and learn from parents as well as current and future teachers. Being preventative entails setting up an environment with clear routines and boundaries so that children are motivated to learn and develop necessary academic, social interaction and communication skills in order to function successfully in the home, the community and at school.

The methods and principles used in the evidence-based practices of Applied Behavior Analysis (ABA) are the basis for setting up each family's proactive and preventative scaffold of systems and strategies. A crucial component of this process is *improving the social significance* of the individual's behavior. In other words, the change in behavior needs to be observable, meaningful, and important. For example, it could include teaching an individual to read, add and subtract numbers, not to hit other people, to follow the instructions of a parent or teacher, or to improve social acceptance within the community. In order for a change in behavior to be socially significant, the individual must also demonstrate *independence* and *generalization* with the skills and behaviors that he or she has learned.

These methods offer families and professionals an evidence-based and systematic process for teaching skills and changing behavior in a way that allows individuals with ASD to understand and learn efficiently and effectively. All ABA procedures involve understanding and changing one or more components of a three-part paradigm: antecedent, behavior and consequence.

A Antecedent	B Behavior	C Consequence
The stimulus which causes a behavior to occur.	An action that occurs in response to an antecedent.	A response that follows a behavior that will either increase or decrease the behavior.

Using this paradigm lets us analyze behavior that occurs in any environment. Reviewing the occurrence of a behavior and the events that happened immediately before and after it allows us to evaluate the cause, or antecedent, and the effect, or consequence, of a behavior. This approach helps us focus *most* of our energy on changing things in the environment by looking at the antecedents to behaviors with a view to preventing inappropriate or undesirable behavior before it occurs. This is a positive and proactive way for families to view their efforts to help their child function successfully within everyday family routines. We can then plan how to reinforce the appropriate or desirable behaviors when they do occur, and how to avoid reinforcing the undesirable behaviors.

B Boundaries set boundaries and limitations	V Visuals provide support with visuals	R² Rules and Rewards teach rules and give rewards	R Routine provide structure and routine	O Organization provide organization of materials and specific timeframes	S Sensory provide a space for children that meets sensory needs
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In upcoming articles I will discuss the following *proactive* and *preventative* strategies and how parents can use them in their everyday lives and routines. These strategies connect and strengthen the scaffold that each family puts in place within the home.

I look forward to sharing more information on each of these strategies in future articles.



Sonja R. de Boer, Ph.D., BCBA-D, is a Board Certified Behavior Analyst-Doctoral (BCBA-D) and obtained her Ph.D. in special education and psychology and research in education at the University of Kansas, with an emphasis on early intervention for children with Autism Spectrum Disorders (ASD). She has approximately 30 years of experience working in early childhood special education, early intervention services, Applied Behavior Analysis (ABA), with students with disabilities, and specifically children with ASD. For children with ASD, she has designed and supervised in-home intervention programs (ages 0-10), preschool programs (ages 3-6; both intensive ABA and inclusive preschools), as well as elementary school educational and behavioral programs (ages 5-12).

For more than half of her career, she has focused on serving students with ASD and their families and educators in rural communities. She has also worked as an adjunct professor and regularly provides consultation and training around the nation regarding interventions for children with ASD. Besides the United States, she has worked with professionals, universities, non-profit organizations and families with children with ASD and other disabilities in Australia, New Zealand, Ireland, Russia, Nigeria, China, Chile, Abu Dhabi and Dubai. She is the author of the book *Successful Inclusion Practices for Children with Autism: Creating a Complete, Effective, ASD Inclusion Program* (Preschool through 6th grade); *Discrete Trial Training, 2nd edition* (part of the How To Series on Autism Spectrum Disorders); and is one of the original co-authors of the first edition of *Autism Spectrum Disorders: Interventions and Treatments for Children and Youth*.

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Strategies for a Successful and Enjoyable

Holiday Season

Dr. Kellie Band, DBH, LBA, BCBA

The end of the year is in full swing and so are the holiday preparations. While this is supposed to be a fun time of the year, it can also bring a certain level of stress to families, especially to those with an autistic child. Many things contribute to this stress, including changes in daily routines, not having to go to school, potential travel, contact with lots of different people, new sights, sounds and smells, and more. Sleeping in an unfamiliar bed is stressful, as is being presented with new foods or foods that look and smell different from what is normal at home. Festive decorations or a crowded room with unfamiliar people can also be overstimulating.

There are many ways to increase the likelihood that your child enjoys the holiday season and that you not only survive but have a happy and relaxing time. Consider using the following strategies to help deal with the stress of the holiday season.



Be Flexible

Be flexible and give yourself some grace. This will allow you to make adjustments when needed in situations that arise. For example, if there are more people at grandma's house than originally planned and your child gets overstimulated or anxious, you can go back to the hotel to take a break and return for dinner.



Have An Exit Plan Ready

Be sure to have an exit plan ready for occasions when your child is close to being overwhelmed. Pick a code word or sign that your child can use to let you know that he or she needs a break or to step outside. You can also sit in the car and listen to some music or do something that your child finds soothing. Discuss possible places to go when your child needs some time to decompress.



Plan Ahead

It is always helpful to plan for outings ahead of time. Talk about the food that will be there, the number of people present and whether or not they are known to your child. Depending on your child's needs, you may have to offer reassurance that there will be alternative food for your child or discuss what is acceptable behavior when food smells funny or different. You can prepare your child for behavioral expectations with specific relatives, such as who to hug, where to sit during dinner and what activities are planned for after dinner. Perhaps everyone will talk in the living room while the children decorate the tree. It may be helpful to discuss the location if it is one that is unfamiliar to your child, as well as the types of decorations that may be present. Some children may need more details while others may be fine with less. Using visual aids may also be helpful for some children. Make a point of discussing all of these details in the days, and even weeks, leading up to the holiday.



Ask For Help

Ask for help from family and friends. In the same way that you prepare your child so that the holidays can be successful, be sure to also prepare the environment, including the people who will be present. Share your child's special interests with your family and friends. Let your family and friends know if your child tends to be abrupt. For example, if your child protests over an unwanted gift, let your family know that your child is not being rude but had different expectations.



Prepare for the Transition Back to School

Once you've gotten through the big day and are now moving through the rest of the holiday break and the transition back to school, be consistent. Routine and structured time help you and your child be successful. If your child uses a visual schedule throughout the school day, continue with one at home. If your child has a particular reward system, maintain it at home. While you may need to modify expectations on how to earn rewards to fit the current environment, the more consistent the routine, the smoother the transition. It can be helpful to ensure a balance of preferred activities and neutral tasks or chores. Children who do whatever they want all day during holiday breaks find it challenging to go back to school where days are structured and they have to engage in less preferred tasks. Finding a happy medium will help ease your child back into that setting.

Consistency and predictability are key to getting your child through the holidays, while you will need to demonstrate grace and flexibility. By preparing for the transition from school to the holiday, and then back to school again, your child and family can ensure a relaxing, fun and successful holiday season for everyone!



Dr. Kellie Band, DBH, LBA, BCBA, is the Clinical Director at Lexington ABA Solutions. She has been in the field of Applied Behavior Analysis since 2005. During her career, Dr. Band has evolved from pediatrics to Organizational Behavior Management and business development. Before joining Lexington, Kellie spent the last few years assisting in the growth and development of a pediatric therapy clinic that now serves children across the state. She believes culture, accountability, and transparency are of the utmost importance and a foundation to success in any business. She holds a Doctorate in Behavioral Health, which focuses on integrated care, and has served on the Arizona Association for Behavior Analysis board, holding a variety of roles ranging from Treasurer to different committee chairs. Kellie has been a graduate professor with Arizona State University, Grand Canyon University, and Purdue Global University teaching in the Psychology department. This has helped her to grow her knowledge and skills with performance management and the dissemination of Applied Behavior Analysis in various capacities.

When Kellie is not working, she stays busy with her two boys and husband. She enjoys going to the zoo, hiking, being with friends and family, and catching up on true crime podcasts.



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What is Twice Exceptional?

Gaining Understanding and Perspective

Julie Skolnick, M.A., J.D



Julie Skolnick is a frequent speaker and prolific writer on the topic of twice exceptionality. She is the Founder of With Understanding Comes Calm, LLC, through which she guides parents of twice exceptional kids, mentors 2e adults, and trains teachers around the globe. She is the author of the book, *Gifted and Distractible – Understanding, Supporting and Advocating for Your Twice Exceptional Child*. She serves as the Secretary to the Maryland Superintendent's Gifted and Talented Advisory Council, is an advisor for the Masters of Education Program in the Bridges Graduate School of Cognitive Diversity, and an advisor for "The G Word" full feature film. Julie is trained in the suite of tools "Putting the Person into Personalized Learning" through the 2e Center for Professional Development at Bridges Academy. Julie is also the mother of three twice-exceptional children who keep her on her toes and uproariously laughing.

She spoke with Cindy Lentz, Creative Director of Autism Advocate Parenting Magazine, about what it means to be twice exceptional and the best approaches and strategies for parents of twice-exceptional kids.

AUTISM ADVOCATE PARENTING MAGAZINE: What is twice exceptional?

Julie: The term twice exceptional — commonly abbreviated to 2e — is used to describe a child or individual who is highly gifted in reading, math or other area of academia, but who also has another exceptionality. This exceptionality could be a number of different things, including a learning difference, Autism, ADHD, dyslexia, dysgraphia, dyscalculia, working memory difficulties, processing

speed differences or social-emotional challenges. The combination of being gifted and having one or more of these differences is known as 2e.

AAPM: What is gifted?

Julie: Unfortunately, there is no universal definition of what it means to be gifted. There are different definitions depending on what country or state you live in, and some countries do not even recognize it at all. However, most people think of a gifted person as someone who is smart, bright, and has high potential and ability. Although this is a part of giftedness, there is so much more. To truly understand giftedness, imagine a three-layer cake. The frosting above and around the three layers is the assumption of giftedness, which is being bright, smart, and having potential. Under the frosting are three layers of cake, or giftedness characteristics. These include: asynchronous development; perfectionism, which can bring anxiety; and intensities, or what's known in gifted parlance as overexcitabilities.



Frosting – Assumption of Giftedness

This refers to individuals who are smart, bright, have potential and high abilities in specific academic areas such as math, reading, writing, music and science. They may also excel athletically, artistically, and even charismatically.



Layer 1 – Asynchronous Development

Asynchronous development represents uneven development in the intellectual, physical and emotional domains. For example, gifted or 2e individuals may be advanced in music, reading or critical thinking, but might lack social skills or emotional maturity, or be identified with a specific learning difference.



Layer 2 – Perfectionism and Anxiety

Perfectionism is the drive to meet high expectations. Unhealthy perfectionism is when expectations are inappropriately high, and it is often accompanied by a fear of failure, unrealistic standards and anxiety.



Layer 3 – Intensities and Overexcitabilities

Overexcitabilities are neurological responses to stimuli that can give individuals great pleasure or discomfort. The five areas of overexcitability are intellectual, emotional, imaginal, sensual/sensory and psychomotor.¹

Typically, giftedness is assessed by an IQ test. An average IQ is 100, and a score of 130 or greater typically indicates giftedness. It is worth noting that the IQ test may not accurately identify all gifted or 2e individuals. It takes an evaluator who is well-versed in giftedness and twice exceptionality to tease out strengths from struggles. Other assessments are being explored by researchers.

AAPM: What are the characteristics of twice-exceptional children?

Julie: Although each person is unique, here are some common characteristics of 2e children.

- They are existential and deep thinkers. Their deep thinking often goes beyond their chronological age. For example, a three-year-old 2e child once asked his mom, “Do we *need* to live, or do we *want* to live?”
- They may appear to have slower processing speeds. Due to the amount of data gifted and 2e people notice, assess, and process, their processing is often slowed down by the sheer amount of information they are considering.
- Parents of 2e children sometimes experience intense power struggles with their children, even over simple requests. Such children may challenge rules and suggest better ways. In my experience, brushing teeth is often a task that commonly leads to power struggles between parents and 2e children.
- They can be intense, and may have a lot of meltdowns.

- Some 2e children have very large vocabularies. Sometimes, they learn to read without any formal instruction.
- They tend to ask a lot of questions, and these questions do not always have answers.
- They often have difficulty relating to peers.
- In the school setting, 2e children might be resistant to completing and turning in work or assignments. Also, they might complete the work but then forget to turn it in, or not see the point of turning it in. Children might also refuse to complete work, even though they understand the assignment and could complete it easily.
- They usually have a lot of energy, especially if there is psychomotor overexcitability or ADHD.
- They tend to engage in a lot of negative thoughts. Unfortunately, teachers and parents often pay more attention to children's negative behaviors and deficits than to their abilities. When children notice only their negative qualities, they might say things like, "I'm bad," or "I wish I wasn't here."

AAPM: What are some strategies to support twice-exceptional children?

Julie: Given 2e children's unique strengths, challenges and perspectives, it is important to support them in the best way possible. I have organized my suggested strategies into the acronym **P-R-A-I-S-E**.

P Personal Connection

A personal connection with your child is extremely important. Understanding and gaining perspective starts from a strong relationship. Children respond and work hard when a parent, teacher or caregiver values and appreciates them for who they are. I advise parents to take at least 15 minutes every week and to spend time one-on-one with their child. In this time, do something the child wants to do. Ask questions. Do not judge your child or try to teach a skill. Just be with your child. Do not have phones or distractions. Spend this 15-minute block with only one child at a time.

R Reframe

It can sometimes be difficult to understand a child's behaviors or perspective. Instead of seeing a child who only took one bite of dinner and then left the dinner table without asking as defiant or rude, try to focus on the positive behaviors exhibited. The child came to the dinner table when asked, chatted with siblings and shared something learned at school, and the child tried a bite of food. Focus on the positive things that your child does. Tell your child you notice his or her actions, and then take baby steps to make improvements. Most of the time, children know what they are supposed to do. Perhaps they left the dinner table or walked out in the middle of class because they were overwhelmed and needed to remove themselves from the situation. Don't always think the worst. Try to understand the reasoning behind children's actions and behaviors.

A Anticipate

Every child has different triggers: specific people, environments or subjects can cause stress and anxiety. If you know that your child is an excellent athlete, has ADHD and has trouble with math, you might be able to anticipate that math class could cause some difficulty. Perhaps the teacher can share the lesson plan ahead of time so the child can have a preview. What are your child's triggers? Look at life from the child's perspective. Why is this particular task hard? What can we do ahead of time to make challenging parts of the day a little easier?

I Incentives and Choices

Incentives and choices are an important part of supporting a 2e child. Effective incentives occur when children compete against themselves and not against other children. For example, the pomodoro technique, or tomato timer, lets you set how much time you are going to work, and then how much time you will have for a break. The break is the incentive. During this break, go for a walk, get a snack or a glass of water, or go outside. Have children try to beat their best time for getting ready at night. These are healthy incentives. Do not use incentives such as stickers or treats as these encourage competition and focus on external motivations. When a child who is identified with ADHD can earn a sticker for standing in line, the expectation to stand in line for a prolonged period may be inappropriate. This type of incentive is counterproductive as it rewards or punishes children for their neurology. Instead, consider the child's needs. Ask this child to go to the office and deliver a message, and to then meet the class at the final destination. Giving a child choices is very effective. Choices allow the grown-up to define the expectation but allow the child to choose when, where and how. Ask if your child wants to do homework before or after a snack? Does your child want 10 or 15 green beans? Does your child want to walk the dog before or after dinner? Parents are still requiring that the child complete a task, but the child has control and choice.

S Sense of Humor

A sense of humor is extremely important. Twice-exceptional individuals often have a lot of heavy thoughts and feel a responsibility about humanity's well-being. Having a sense of humor is a great inoculation against perfectionism. When grown-ups laugh at themselves, it's great role-modeling. Improvisation classes are also effective with 2e kids as they require higher-level thinking, sharpen social skills, and teach empathy and group dynamics.

E Exercise

It is well known that exercise has many benefits. It can serve to reset an exhausted brain, provide an outlet for excess energy, release endorphins and reduce stress, anxiety, and depression. Physical activity can also improve concentration, increase attention span, and enhance executive functioning. Exercise does not have to mean a traditional work-out, going to a gym, or even playing a sport. An obstacle course or scavenger hunt can be lots of fun for 2e kids, and 2e kids can coordinate the activity for younger siblings.



AAPM: How can twice-exceptional children be supported at school?

Julie: Communication between parents and teachers is essential. By following some simple tips, teachers can gain an important perspective on a child's needs and interests, and parents can help a teacher to gain positive feelings about their efforts with their child.

Teachers

- Find out what the 2e child loves to do and hates to do. In essence, what makes the child tick and what ticks the child off?
- Integrate the child's interests into class lessons. Allow the 2e child to be a leader or share expertise. This is different from having the child help or teach others. 2e kids need time to shine for their own self-confidence. When 2e children do share their interest, acknowledge the depth of their thought and recognize their desire to share. Instead of thinking of children as disruptive or trying to show off, celebrate their knowledge and abilities.
- Call on gifted children. They want to share what they know!
- Share with parents when their 2e child does something positive, whether it's consistently volunteering to help pass out papers, integrating a new child on the playground, or acknowledging the child's curiosity and deep bank of knowledge. Sharing these anecdotes helps the parent-teacher relationship because parents know you see their child's strengths.

Parents

- Take pictures of your child in action, such as when reading a book, building Lego, volunteering at a homeless shelter or any other moment when your child is engaged and in the flow. Share these pictures with your child's teacher. The teacher only sees your child in school, often when your child is not at his or her best.
- When your child talks about something he or she learned at school, share it with the teacher. Let the teacher know the impact he or she is having on your child's growth and learning.

AAPM: In closing, do you have any final words of advice for parents?

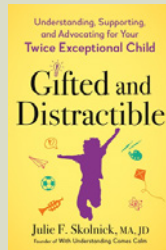
Julie: Gifted children and individuals are found in every group, culture, race, gender and economic level. Although it is unclear the exact prevalence of gifted children in the autistic population, what we do know is that it is underreported. What is most important is for parents of autistic children — whether officially gifted or not — to focus on the child's strengths and to use these strengths to support the child's struggles. Focus on the child in front of you, not on what others say your child should be doing. Celebrate your child's wins. When your child is not meeting your expectations, assume that your child needs support or that the expectation is not clear or appropriate.

Resources



This website has podcasts, blogs, and a free newsletter all on the topic of the 2e profile.

<https://www.withunderstandingcomescalm.com/>



Book: *Gifted and Distractible – Understanding, Supporting and Advocating for Your Twice Exceptional Child*, Julie Skolnick, MA, JD

[GiftedandDistractible.com](https://www.GiftedandDistractible.com)



Supporting the Emotional Needs of the Gifted (SENG) is a non-profit organization that empowers families and communities to guide gifted and talented individuals to reach their goals: intellectually, physically, emotionally, socially, and spiritually. SENG provides support through a variety of programs, all aimed to be inclusive and accessible.

<https://www.sengifted.org/>



National Association for Gifted Children

<https://nagc.org/>

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Julie F. Rosenbaum Skolnick, M.A., J.D., Founder of With Understanding Comes Calm, LLC, passionately guides parents of gifted and distractible children, mentors 2e adults, trains educators and advises professionals on how to bring out the best and raise self-confidence in their 2e students and clients.

Julie's studies at Colgate University, Boston College and Cornell Law School allowed her to take a deep dive into sociology and why people do what they do. Her advocacy focus orients her toward seeking what individuals need based on who they are and how they show up in the world.

Her community involvement mirrors her passion for the gifted and twice exceptional community serving as Secretary to the Maryland Superintendent's Gifted and Talented Advisory Council, Advisor for the Masters of Education Program for the Bridges Graduate School of Cognitive Diversity, Maryland liaison for Supporting the Emotional Needs of the Gifted (SENG), Committee member for the National Association for Gifted Children (NAGC) and as an advisor to "The G Word" feature documentary currently in production.

Julie produces Let's Talk 2e! virtual conferences, hosts *Let's Talk 2e! Empowerment Groups*, and publishes "*Gifted & Distractible*," a free monthly newsletter. Her book, *Gifted and Distractible: Understanding, Supporting, and Advocating for Your Twice Exceptional Child*, is due out in October 2023.

Julie and her husband Eric are parents of three twice exceptional children who keep them on their toes and uproariously laughing. Julie's therapist is a red standard poodle named Tigger.

IG - [@JulieSkolnick](#) | Twitter - [@JulieSkolnick](#) | FB - [@withunderstandingcomescalm](#) | YouTube: <https://www.youtube.com/@JulieSkolnick>

Facebook groups - Let's Talk 2e! Adults | Let's Talk 2e – Parents | Let's Talk 2e – Teachers' Lounge

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Talking to Your Kids about **HEALTHY SEXUALITY**

Peter Gerhardt, Ed.D.
Jessica Cauchi, Ph.D., BCBA-D, CPBA-AP

Healthy sexuality is a broad term that covers a range of attitudes, actions and experiences. It includes: the ability to discuss feelings and values related to relationships and sex; being able to initiate and say no to sex; engaging in consensual sex and enjoying sexual experiences; being able to manage oneself in a safe way with regard to others; understanding personal needs and desires; and establishing healthy independent habits.

Concerns about safety and protection with regard to sex are often discussed but rarely addressed when it comes to individuals with disabilities, including those with autism. Less discussed is the fact that sex can also be fun and pleasurable, and can contribute to a healthy romantic relationship. Since many autistic individuals, especially those who are nonspeaking, may have difficulty articulating their wants and needs, many parents - and even professionals - mistakenly assume that autistic teens and young adults are not interested in a sexual relationship. They may also feel that their teen or young adult does not have the maturity for or social interest in a relationship.

Despite these misconceptions, sexuality is at the core of our biology. As children mature, it is very likely that they will be interested in a sexual relationship with others or with themselves. They have natural sexual desires and may already be engaging in some sexual activity, including covertly. Parents need to educate their children and to advocate for education from school and other service providers on healthy sexuality and relationships.

Sexual Education

Sexual education should be provided to autistic children for two main reasons: to ensure safety and minimize the risk of involvement in a sexually abusive situation; and to promote healthy sexual habits and relationships.

Unfortunately, autistic children do not receive the same sexual education from their peers that other children might receive due to their social and communication challenges. Also, sexual education provided at school is often delivered in group-style, didactic learning, which can be a challenge for many autistic children. At school, sexual education is often taught with allusions, indirect language and metaphors that many people with autism find confusing and difficult to understand. If sexual education is assessed at all, it is often done in a language-based way to assess knowledge but not skill acquisition.

Since autistic children are not receiving appropriate sexual education from either their peers or from school, a significant burden of responsibility falls on parents and families to fill in the gaps. Parent-directed sexual education starts at home, and should be continued through childhood and adolescence. At the same time, parents must advocate for appropriate and adapted sexual education for their child at school. Parents can request sexual education goals to be a part of their child's Individualized Education Plan (IEP).

Sexual education for autistic teens needs to be carefully designed and planned, and to be evidence-based as much as possible. Information should be meaningful, functional, and individualized for each learner. Practising skills in the environment in which they will be needed is more effective than language-based instruction alone. For example, practising applying a sanitary pad to underwear, putting on a condom, or rehearsing what to say when asking someone out on a date is better than just talking about what to do in these situations. Carefully consider how your child learns best and work with your team of professionals to make a plan for successful education on the topic of healthy sexuality.



When and How to Start Educating

The following guidelines can help you know when and how to start educating your child.

- **Sexual education starts in early childhood.** Neurotypical children naturally learn about sexuality from family interactions. They learn such things as appropriate ways to be held and touched; whose lap it is appropriate to sit on, such as a parent's but not a teacher's; who kisses whom and if you kiss on the lips, the cheek or the hand; and who it is appropriate to snuggle with at night. Parents may need to teach these things more directly to their autistic children. Diagrams or other visual supports can be used to explain important information. The topics and skills taught to children at a young age will serve as the foundation for more complex skills that keep children safe as teens and young adults. Don't assume that your child will naturally pick up skills related to appropriate boundaries and healthy sexuality. They need to be taught.
- **Use anatomically correct words for body parts from the beginning.** These are good words that we are supposed to use. The more naturally these words are used, the more comfortable you and your children will be with them.
- **Some topics will be more difficult to talk about than others.** Before talking to your child about masturbation or ejaculation, practice using the words in private or with a trusted partner so that you are comfortable with them by the time you speak with your child about them.
- **Include various aspects of sexuality in your daily conversations.** Casually talk about menstrual cycles and body hair. As you have conversations around healthy sexuality and development on a regular basis, such discussions will become more natural and evolve as your child grows and matures.
- **Use the same teaching techniques for sexual education that you use in other aspects of your child's life.** If your child learns best from visuals, written words or repetition, use these techniques in your teaching efforts on this topic. As professionals, our experience has been that it is best to use materials that are as realistic as possible. For example, if you are teaching your daughter how to use pads and panty liners, practice with the ones that she will actually be using.
- **As soon as the topic of sexual health crosses your mind as a parent and you think it might be time to start talking to your child or teen about these complex topics, do not delay.** This is the right time. Either initiate these conversations with your child or seek help from a professional who is qualified to help you in this area.
- **The challenge of teaching these skills evolves over time.** Parents will constantly have to revisit these skill sets because they change with age and situations. Deciding what is appropriate and necessary to say about social skills, functional skills, consent, independence in washroom routines, and sexual preferences will vary depending on the age and maturity of the child or teen.

Essential Topics

There are many topics related to healthy sexuality that can be difficult to talk about with a developing teen, including menstruation, orgasms or masturbation. It is important for parents to navigate all components of healthy sexuality with their autistic children and teens, and to seek guidance when necessary. The topics to cover with a child to ensure healthy sexuality will differ for each family. If your child is very sensitive to clothes and touch, for example, ensure that you discuss body hair, and try out various menstrual pads before they are actually needed. Provide children with information on the topics that are most salient and relevant for them.

The following are some critical topics that should be covered with children.



Body parts - While it is vital to use the correct term for body parts, it's also important to teach the slang terminology that your child is likely to encounter.



Saying "No" - Being able to say "no" in a way that will be heard and that is appropriate for the situation is key. It can range from politely saying "no" to screaming the word when needed. For example, when children are asked if they want another piece of bread, they can politely say "no." In situations of danger, consent or privacy, however, children need the skills to forcefully and loudly shout "NO!"



Personal Space - Children need to understand that people cannot come into their personal space and that they cannot go into someone else's personal space without permission. Be sure to demonstrate this for your child.



Independent Self-care - Parents need to spend significant time on such topics as showering, toileting and dressing to ensure children's safety. The sooner children can demonstrate these skills independently, the sooner they can dispense with help in these personal and private matters.



Online Safety - Although parental controls can be effective for a time, your child will learn a way around them at some point. Teach your child how to safely navigate the online world, including why it's important not to share personal information, how to monitor the amount of time spent online and what to do if inappropriate ads pop up. Teach your child that pornography is an unrealistic depiction of sexuality and relationships.

Complexities of Sexual Education for Autistic Individuals

Social behaviors associated with human sexuality get increasingly complex as we get older. If these concepts are even complex for non-autistic adults, imagine how difficult they are for those with added social and communication challenges. What makes this even more challenging is the fact that many of these skills cannot be assessed or taught in the moment when they are actually required due to the personal and private nature of sexuality.

The following are some important questions to consider when providing sexual education to your child.

- Does your child have the ability and maturity to be in a consensual intimate relationship with another person? Have you talked to your autistic teen about sexual and relationship desires?
- Have you discussed gender diversity with your child?
- Does your child understand the various levels of sexual relationships, from casual to lifelong partnership?
- Does your child have the skills to adapt to a situation when hormones, adrenaline, and arousal come into play? How can you prepare your child for these situations?

The answers to these questions can help guide the topics and strategies you use to provide comprehensive sexual education to your child.

Who Can Help?

While there are educators and professionals with specific training in the area of sexuality education, they tend to be few and far between. This means there may not be one specific professional who is qualified to educate your child in healthy sexuality. In fact, many professionals are not comfortable teaching sexual education or do not have the proper training and tools to know how or what to teach to a child with autism. Our advice is that you speak with the professionals that are already involved in your child's education, such as the clinical supervisor at your child's therapy or the special education team at your child's school. Wherever you have people involved in the education of your child, ask those educators to also include sexual education. Work with these professionals and reinforce at home what is being taught in the clinic or school.

Conclusion

We know that sexuality is a difficult subject. You may find it scary and stressful to talk with your child about sexuality, but it is important to do so. Such education is key to abuse prevention, healthy relationships and a positive quality of life as an adult. Use your sense of humor as you talk about sexuality, and don't be too rigid. Your child will do or say things that are embarrassing or even mortifying. You will likely say the wrong thing too on occasion. It's okay. Sexual education is all about quality of life. That's why it is imperative that you advocate and work to provide your child with the best sexual education possible.



Peter Gerhardt, Ed.D., is the Executive Director of the EPIC School in Paramus, NJ. Dr. Gerhardt has over 40 years of experience utilizing the principles of Applied Behavior Analysis in support of adolescents and adults with autism spectrum disorders in educational, employment, residential and community-based settings. He is the author or co-author on a number of articles and book chapters on the needs of adolescents and adults with ASD and has presented nationally and internationally on this topic. Dr. Gerhardt serves as Co-Chairman of the Scientific Council for the Organization for Autism Research and is on numerous professional advisory boards including the Cambridge Center for Behavioral Studies. He currently serves as adjunct faculty in the Institute for Behavioral Studies at Endicott College. Dr. Gerhardt received his doctorate from Rutgers, The State University of New Jersey's Graduate School of Education.



Jessica Cauchi, Ph.D, BCBA-D, CPBA-AP, is a behaviour analyst that has worked with people on the autism spectrum for over 20 years. She resides in Ontario, Canada, and is the Clinical Director of Atlas Behaviour Consultation. Jessica received her Ph.D. in Applied Behavior Analysis from Endicott College and is a doctoral level Board Certified Behaviour Analyst, as well as a Certified Progressive Behaviour Analyst – Autism Professional. Dr. Cauchi is interested in research and clinical practise in curriculum development and effective teaching practises in sexuality skills for persons on the autism spectrum, meaningful programming, rapport and assent, and progressive ABA. She has published work in these areas, as well as presented on these topics across Canada and North America.

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Resources

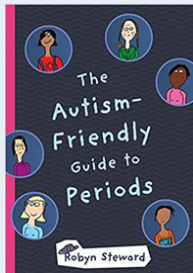
Websites

<https://researchautism.org/self-advocates/sex-ed-for-self-advocates/>

<https://siecus.org/>

<https://www.aasect.org/>

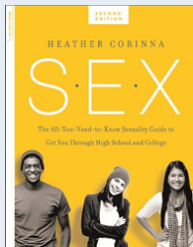
Books



The Autism-Friendly Guide to Periods – Robyn Steward

<https://www.amazon.com/Autism-Friendly-Guide-Periods-Robyn-Steward/dp/1785923242>

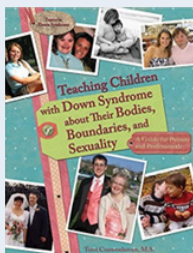
Written by autistic author Robyn Steward, this is a detailed guide for young people aged nine to 16 on the basics of menstruation. Created in consultation with young people and a group of medical professionals, and in response to an online survey, this is a book that teaches *all* people about periods, which can be a scary and overwhelming issue. Promoting the fact that everyone either has periods or knows someone who does, the book reduces the anxiety girls face in asking for help. It offers direct advice on what periods look and feel like and how to manage hygiene and pain. It also organizes information using flaps and step-by-step photos of how to change pads and tampons. It discusses alternatives to tampons and pads, and gives information about possible sensory issues for people with autism.



S.E.X. – Heather Corinna

https://www.amazon.com/X-second-All-You-Need-Know-Sexuality/dp/0738218847/ref=sr_1_1?crid=35BH44G54Q-5UZ&keywords=S.E.X.&qid=1680802833&s=books&sprefix=s.e.x.%2Cstripbooks%2C200&sr=1-1

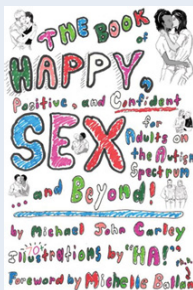
The go-to sex ed guide for teens and young adults, this book tackles everything you want to know about sex, from consent and safe sex, to emotional health and more, from the founder of scarleteen.com. As a teen or emerging adult, dealing with all the changes going on in your life, body, and mind can be mighty overwhelming. When it comes to sex, everyone seems to have strong feelings and opinions about who you should be and what you should or shouldn't do. How do you decide who to listen to? Heather Corinna and Scarleteen have provided sex education and information to millions of young people, parents, and mentors since 1998.



Teaching Children with Down Syndrome about their Bodies, Boundaries and Sexuality. – Terri Couwenhoven

https://www.amazon.com/Teaching-Children-Syndrome-Boundaries-Sexuality/dp/189062733X/ref=sr_1_1?crid=2F715C6SLH5EP&keywords=sexuality+and+down+syndrome&qid=1680802977&s=books&sprefix=sexuality+and+down+syndrome%2Cstripbooks%2C167&sr=1-1

Although this book was initially written for children with Down Syndrome, much of the information has a solid base and is easily generalized to children with autism.



The Book of Positive, Happy, and Confident Sex for Adults on the Autism Spectrum...and Beyond – Michael John Carley

https://books.google.ca/books/about/The_Book_of_Happy_Positive_and_Confident.html?id=017WzQEACAAJ&redir_esc=y



APA Handbook of Sexuality and Psychology

<https://www.apa.org/pubs/books/4311512>

Sexuality is a fundamental component of human psychological experience, yet it remains relatively underrepresented in the history of the psychological sciences. The *APA Handbook on Sexuality and Psychology* marks a turning point in the status of sexuality within the discipline of psychology. This comprehensive, two-volume handbook provides an overarching review of current empirical research on sexuality and a synthesis of the dominant theoretical perspectives that have guided both research and clinical practice. While this handbook is pricy and not autism-specific, it is probably the most comprehensive overview of human sexuality available.



MENTAL HEALTH

in Individuals with Intellectual Disabilities

Lauren Elder, Ph.D. ABPP

Current research estimates that about 30 percent of autistic individuals have an intellectual disability (ID). This means they have challenges in both cognitive skills and adaptive behavior.^{1,2,3} In addition, an estimated 70 percent of autistic individuals with intellectual disabilities have co-occurring mental health disorders. These estimates highlight the dire need for improved mental health treatment for individuals with intellectual disabilities.^{4,5,6,7} Unfortunately, mental health issues are often overlooked in this population due to general challenges in identifying mental health issues in those with intellectual disabilities and a lack of knowledge of how to address such issues.

Signs of Mental Health Concerns in Intellectual Disabilities

Changes in mood or behavior may indicate the presence of mental health issues, such as anxiety and depression. Other signs to watch for include:

- changes in sleep or appetite
- tearfulness
- avoiding experiences that were previously enjoyable
- low energy
- increases in repetitive or self-injurious behavior
- agitation, aggression or irritability

If you see any of these signs in your children, including adult children, it is important to first rule out any potential medical or sleep issues. Once such physical factors have been eliminated as possible causes, it is then time to consider the presence of potential mental health concerns.

Why Mental Health is Often Overlooked

Mental health concerns are often overlooked in individuals with intellectual disabilities. Unfortunately, this can occur for a range of reasons, including the following.

- **Communication Challenges** – Some individuals with intellectual disabilities are unable to effectively communicate how they feel.
- **Interoception and Alexithymia** – Interoception is the ability to identify and interpret body cues. Alexithymia is when someone has difficulty identifying and expressing emotions. Many autistic individuals have challenges identifying their internal feelings.
- **Confusion with Sensory Processing Challenges** – It can be difficult to determine if challenges are the result of being sensorily overwhelmed, which is best addressed by an occupational therapist, or are due to emotional regulation. Often, it can be both.
- **Assuming Mental Health Treatment is Not Necessary** – Many providers assume that applied behavior analysis (ABA) therapy is sufficient. However, ABA providers are not trained to address significant mental health challenges.
- **Lack of Access to Services and Trained Providers** – It is often challenging for families to access appropriate care.

As a psychologist who specializes in mental health treatment for individuals with developmental disabilities, I find that a lack of trained providers is one of the most significant issues. It is often challenging to find appropriate referrals when I'm unable to take on a client. Since I am willing to see adults with intellectual disabilities, I end up treating almost everything from eating challenges, psychosis, anxiety and mood concerns, to behavior issues and more. Mental health providers seeing clients with intellectual disabilities need to be generalists in everything related to mental health. Additionally, there is often a lack of appropriate training in mental health and intellectual disabilities, and what is available tends to be superficial or does not provide the depth necessary for providers to take on clients with intellectual disabilities. While a wide range of treatments are outlined in various manuals, many providers find that these protocols are not sufficiently adapted for clients with intellectual disabilities. Parents can help advocate for additional training for providers, such as school counselors.

Role of the Mental Health Provider

Despite these challenges, mental health therapy can be helpful for individuals with intellectual disabilities. This therapy will initially focus on emotional regulation. Clients can be taught to better identify and communicate their feelings, and practice coping skills. Behavioral activation, which uses schedules to increase activity and pleasure, and other similar interventions can help with depression. Exposure therapy can be used to help clients with anxiety slowly face their fears.

Therapy may need to be adapted for individuals with intellectual disabilities. For example, the course of treatment could be longer, or the intensity of treatment higher. The therapist may need to use nonverbal therapeutic techniques such as play, expressive arts or movement. The therapist should communicate in the way preferred by the client, whether verbally or using an augmentative and alternative communication (AAC) device. Extra visual supports related to feelings can also be helpful to explain situations.

When seeking mental health providers, it is best to look for those who specialize in autism or developmental disabilities. Ask questions about how they might be able to modify their treatment approach to fit the needs of your child. Inquire about the ages they treat, their approach to treatment, and their experience treating individuals with intellectual disabilities. The local university psychology department or children's hospital will often have lists of providers, and many autism support agencies keep local resource guides.

Questions to ask a Mental Health Provider

- ☐ Do you specialize in autism, developmental disabilities, and ID?
- ☐ What ages do you treat?
- ☐ What is your approach to treatment?
- ☐ How can you modify your treatment approach to suit my child?
- ☐ What is your experience treating individuals with ID?

Role of the Parent

Parents can play a key role in therapy. When I treat individuals with intellectual disabilities, I often have family sessions or parent coaching sessions even when the client is an adult. This is especially important when clients still live at home. There are many things that parents can do to modify the environment in support of their child's mental health.

- **ADDRESS THE SENSORY ENVIRONMENT** – Sensory processing issues contribute to many challenges in emotional regulation. Parents can limit sensory overwhelm, whenever possible, through the use of headphones, sunglasses, fidgets, alternative seating, and breaks from busy environments. An occupational therapist can help to customize a sensory plan for your child.
- **MODIFY THE SCHEDULE** – Many autistic individuals need a lot of downtime, and some can get overwhelmed by busy school and therapy schedules. Make sure children have adequate time to rest, play and pursue their interests.
- **IDENTIFY TRIGGERS** – Keep a journal to document times when your child seems distressed. Make notes about what happened before and after. Try to determine what triggers your child and avoid those situations when you can.
- **SUPPORT COMMUNICATION AROUND FEELINGS** – Ensure that there are feelings buttons on your child's AAC or picture communication system, and model their use. Talk about the feelings of your child's favorite characters from books and movies. Label how you think they might be feeling. Label your own emotions whenever possible.
- **MODEL COPING SKILLS** – Make sure your child sees you practicing coping skills. You could tell your child that you're going to take a break when you feel upset. Let your child see you taking deep breaths or meditating. Ask your child to take a walk with you or give you a hug when you have been feeling overwhelmed. Make a visual display of things that help your child calm down, and teach your child to look at the pictures and pick a coping method to use.
- **EMOTION COACHING** – Help your child connect with his or her feelings by empathizing. Avoid saying such things as, "You're okay!" Instead, say something like, "I can see you're sad. That's hard! Do you need a hug, or should I give you some space?" If language overwhelms your child, try something simpler like saying, "Sad?" and opening your arms for a hug. Be sure you are communicating in the way your child communicates, whether verbally, through a picture system, AAC device, sign language or other method.
- **PRESUME COMPETENCE** – Almost everyone can learn to improve his or her emotional regulation skills and mental health with the correct supports.



Treating individuals with intellectual disabilities for mental health concerns can be a bit more complex and challenging than treating some other populations. However, I know that it can be done successfully. Parents and professionals need to work together to ensure that this underserved population has improved access to quality mental health care.

Resources

<https://www.nami.org/Your-Journey/Identity-and-Cultural-Dimensions/People-with-Disabilities>

<http://www.aamr.org>

<https://skillssystem.com>

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Lauren Elder, Ph.D., ABPP, has over 20 years of experience as a psychologist, consultant and public speaker. Dr. Elder provides consulting services in the U.S. as well as internationally. Clients include families, clinics, foundations, agencies and corporations with behavioral products in development. She has diverse experience including helping to develop a prototype for a digital autism intervention, guiding clinics in the development of their service offerings, transforming an early intervention program to be neurodiversity- and trauma-informed and helping families evaluate and choose from a variety of early intervention services.

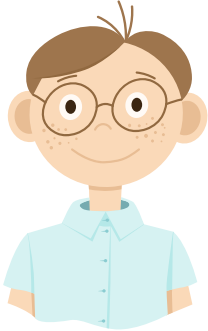
Dr. Elder is highly sought after to deliver training on a variety of early intervention, neurodiversity, and mental health topics. Recent training has included *Parenting Neurodivergent Children in a Neurotypical World* and *Best Practice in Early Intervention for Developmental Disabilities*.

Dr. Elder uses a client-centered and neurodiversity-affirming approach to help clients from infants to adults. She offers individual, parent coaching and dyadic therapy options. Her practice focuses on autistic individuals and those with ADHD or Down Syndrome, Fetal Alcohol Syndrome or Intellectual Disabilities. She also offers psychological assessments across the lifespan.

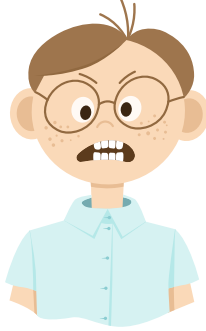
For more information or to contact Dr. Elder directly, please see her website: www.ascentpsychologicalservices.com

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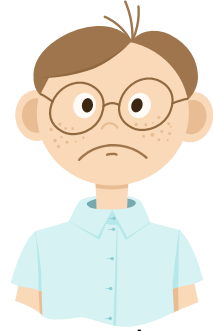
How Am I Feeling?



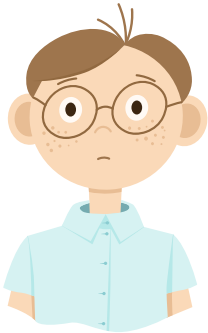
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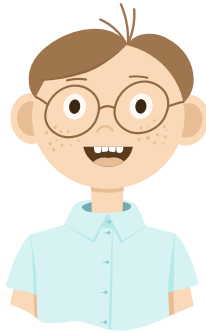
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Sad



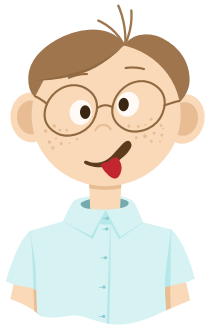
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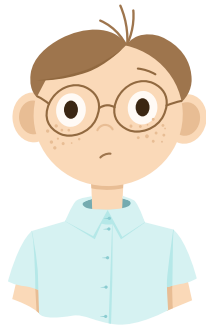
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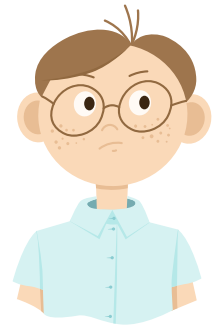
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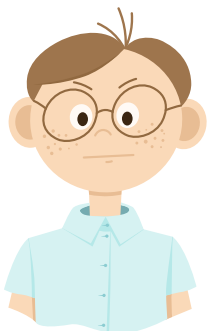
Silly



Scared



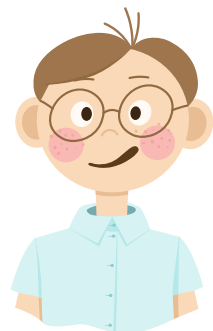
Disappointed



Frustrated



Relieved



Embarrassed

I Need A Break

I would like:



music



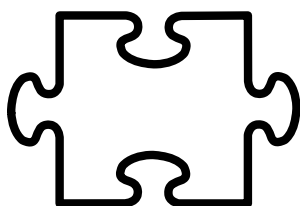
playdoh



comfy chair



book



puzzle



draw



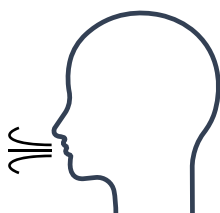
fidget toy



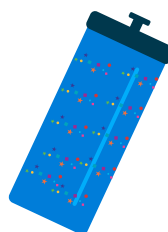
weighted blanket



**noise-canceling
headphones**



deep breathing



sparkle bottle



stretching

My Story

with Autism



Fatima Alsarayreh, M.Psyc.

My story with autism began in 2010 when I noticed that my child engaged in behaviors that I did not understand. These included such behaviors as stereotypical movements, not responding to his name, not communicating, being very anxious all the time, crying a lot and even laughing hysterically for no apparent reason.

I told myself that these behaviors would disappear over time, but the opposite occurred. The behaviors continued to increase, and I felt as if the child I had known was slowly disappearing. I took my child to a doctor who told me that my son needed several tests, including a hearing test, to determine if there were medical reasons for his behavior. All of the tests came back normal.

The same medical professional then told me that my child had symptoms of autism and recommended an evaluation by a psychiatrist and a neurologist. Hearing the word autism was a shock for me. I didn't know what autism was. I asked the doctor if there were any medications I could give my son to help with his behaviors. I was desperate for my child to talk and to play, and I so wanted to connect with him. The doctor told me that autism was something my son would have his whole life and that I should have him start behavior therapy as soon as possible.

This was the beginning of a very dark time in my life. I struggled with feelings of denial, trauma and depression, and isolated myself from society for the next eight years. During this time, my mental health was affected. I didn't allow anyone to come to our house for fear that they would judge me and my son.

In 2018, I made a decision that would change my life. I realized that if I didn't save my child, no one else would. I could see in my child's face that he was sad for me. I knew that I needed to change my situation. The next day, I mustered up the courage to register for a bachelor's degree in psychology. It took all of my strength to do so. Once I began the courses, I started to understand my own psychological state of trauma and depression. As I learned more about autism, I also came to

"I made a commitment to do my best to understand autism rather than to fear it."

accept my child and love his world. I started to feel comfortable talking about my son's autism in front of professionals and other students. I made a commitment to do my best to understand autism rather than to fear it.

That's when I started to see changes. I introduced my son to music. When he hears music, he laughs and dances like an angel. He now enjoys playing with his sister. He loves her and misses her when she is gone, and we have now learned how to recognize when he is expressing these feelings. I started holding my son's hand and helping him to learn that escaping behavior is not helpful and can be dangerous. I'm proud to have a beautiful autistic child who fights every day to grow and succeed.

I have come to realize that the key to my son's treatment is me. I truly believe that parents are the first and most important specialists for their child. Parents understand their child better than anyone else. I may have been late in realizing this, but I am happy to say that I am fully aware of it now and that I am succeeding.

My experience with autism has taught me more than I could ever teach my son. He has taught me to be patient and accepting, and to educate myself. He showed me that I can be a mother who is proud of her child in every sense of the word, even though he may see the world differently than I do.

My child, Salem, and all autistic children are magical. They have a positive energy that can change your way of thinking for the better. My life with my autistic son is beautiful. I have become a stronger person, and am able to confront anything negative and drive it out of our lives.

Thank you, Salem, my angelic child.



Fatima Alsarayreh, M.Psyc., is the mother of Salem and is an autism advocate. Thanks to her son, she has succeeded in obtaining several internationally recognized certificates. She completed her master's degree in psychology and works as a shadow teacher with autistic children in schools. She is now working towards her master's degree in sociology in family counseling.

She received several honors for entering her child in the first fashion show to support autism (Shein for Fashion). She also coordinates community workshops for mothers on the importance of promoting mental health. She also wrote her story in a book titled (translated), "Fatima in the World of Autism," and has written three books discussing psychological disorders.

Fatima's path continues as she aspires to complete her doctorate degree in psychology and sociology so that she can continue to help autistic people and build community awareness of autism.

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Research Shows a Link Between **AUTISM & EAR, NOSE & THROAT ISSUES**



This article is a review of the following research: Hall, A., Maw, R., Iles-Caven, Y., Gregory, S., Raj, D., & Golding, J. (2023). Associations between autistic traits and early ear and upper respiratory signs: a prospective observational study of the Avon Longitudinal Study of Parents and Children (ALSPAC) geographically defined childhood population. *BMJ Open*, 13(3), e067682.

Ear, nose and throat issues are common in children and encompass a range of conditions that can affect a child's overall health and well-being. Such issues include frequent ear infections, tonsillitis, sinusitis, sleep apnea, hearing loss and allergies. Recognizing and addressing these issues promptly can help alleviate discomfort and ensure a child's proper development.

It is interesting to note that the connection between autism and ear, nose and throat issues is a topic that has gained significant attention in recent years. Research studies have found a higher prevalence of problems such as recurrent ear infections and sleep-disordered breathing among autistic individuals, especially children.^{1,2,3} Although some connections have been made, the relationship is complex and not fully understood.

More research is needed to gain a better understanding of this complex field. Collaborative efforts involving medical professionals, researchers and autism specialists are essential to further explore this connection and to develop appropriate interventions and treatments.

A team of researchers from the University of Bristol (Bristol, UK) used a large birth cohort to further investigate the relationship between ear, nose and throat issues and autism.

Study

More than 10,000 children were followed from birth to the age of four years old, with data on these children collected from the Avon Longitudinal Study of Parents and Children (ALSPAC). In addition, parents completed questionnaires when their children were 18, 30 and 42 months old. The parents recorded the frequency of children's ear, nose and throat issues. They also completed questionnaires when their children were three, six and nine years old. These looked at children's social and communication abilities, repetitive behaviors and emotionality. Based on the results, individuals were identified either as having an autism diagnosis or as having many autistic traits but not necessarily an official diagnosis.

Results

- A total of 177 children had a probable diagnosis of autism.
- Autism was associated with all ear, nose and throat signs, except for symptoms of sleep apnea. This included mouth breathing, snoring, pulling or poking ears, discharge from the ears, worse hearing during or after a cold, and reddened and sore ears.
- Pus or discharge from the ears was associated with autism and with poor speech.
- The most prominent results were seen when the children were 30 months old.
- There was a particularly strong association between pulling, scratching or poking at ears and autism.
- Overall, autistic children and children with high levels of autistic traits had more ear, nose and throat symptoms than would be expected by chance.

Conclusion

This study adds further evidence to the findings of previous studies that young children with ear, nose and throat issues had a higher likelihood of being autistic. The authors warn, however, that these results should be read with caution and do not indicate that the ear, nose and throat issues cause autism. They also point out that ear, nose and throat symptoms are very common in childhood. Although the symptoms might indicate a higher risk of autism, there are many children with such issues who do not go on to have autism.

The relationship between ear, nose and throat issues and autism is complex. Medical professionals need to recognize these complexities and receive the proper training to understand and support children who face these issues.

Researchers are particularly interested in determining why ear, nose and throat issues might be more prevalent in autistic children. It could be related to the fact that these children are at increased risk of having immune abnormalities. There may also be physical differences in the actual structure of the ear. Researchers will continue to seek answers to this and other questions. In the meantime, parents and caregivers should seek the care and support that their autistic children with ear, nose and throat issues need.

Written by Autism Advocate Parenting Magazine

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Ear, Nose and Throat, and Hearing Questions in the ALSPAC Parental Questionnaires

- ☐ Has anyone thought there may be a problem with your child's hearing?
- ☐ Has your child had ear infections or earaches?
- ☐ Does your child breathe through the mouth rather than through the nose?
- ☐ Does your child snore for more than a few minutes at a time?
- ☐ When your child is asleep, does he or she seem to stop breathing or hold his or her breath for several seconds at a time?
- ☐ Does your child pull, scratch or poke at his or her ears?
- ☐ Do your child's ears go red and look sore for a long time?
- ☐ Has pus or a sticky mucus that is not ear wax ever leaked out of your child's ears?
- ☐ Is your child's hearing worse than usual during or after a cold?
- ☐ Generally, does your child listen to people or to things that happen nearby?

Hall, A., Maw, R., Iles-Caven, Y., Gregory, S., Rai, D., & Golding, J. (2023). Associations between autistic traits and early ear and upper respiratory signs: a prospective observational study of the Avon Longitudinal Study of Parents and Children (ALSPAC) geographically defined childhood population. *BMJ Open*, 13(3), e067682.

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Research Shows a Relationship Between **INFANT SLEEP & AUTISM**

This article is a review of the following research: Begum-Ali, J., Gossé, L. K., Mason, L., Pasco, G., Charman, T., Johnson, M. H., Jones, E. J. H., & STAARS Team (2023). Infant sleep predicts trajectories of social attention and later autism traits. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 64(8), 1200–1211.

Autism is a neurodevelopmental condition characterized by a range of social communication deficits, repetitive behaviors and sensory sensitivities. One area of research in the field of autism is the intricate relationship between autism and sleep challenges. The latest research suggests that up to 80 percent of autistic children have difficulties with sleep.¹ Such difficulties include, in particular, falling asleep, frequent nighttime awakenings, sleep apnea and shortened sleep duration.

These sleep challenges not only affect the overall well-being of autistic individuals but can also potentially exacerbate core symptoms of autism. Parents and caregivers often wonder why their autistic child is having sleep difficulties. Experts agree that the mechanisms underlying the link between autism and sleep disturbances are complicated. The relationship between autism and sleep disturbances is thought to involve a complex interplay of neurobiological, genetic and environmental factors, but the main causes are thought to be sensory sensitivities, alterations in melatonin production and circadian rhythms, and heightened anxiety.

One research study showed that children who have more night awakenings at 12 months of age are more likely to receive an autism diagnosis.² Another study showed that children between six and 12 months of age with serious sleep problems were more likely to have Attention-Deficit/Hyperactivity Disorder (ADHD), a neurodevelopmental condition closely related to autism.³

A team of researchers from the United Kingdom, led by Dr. Jannath Begum-Ali and Dr. Louisa K Gossé, decided to investigate early sleep patterns in children who later went on to be diagnosed with autism and/or ADHD. They also investigated links between infant sleep patterns and early visual attention, later cognitive skills and social adaptive skills.

Study

Between 2013 and 2019, 164 infants and their caregivers participated in the study. Of this total, 80 infants had a first-degree relative with autism; 34 infants had a first-degree relative with ADHD; 21 infants had a first-degree relative with autism and ADHD; and the 29 infants in the control group had no family history of autism or ADHD.

When the infants were five, 10 and 14 months of age, parents completed the “Sleep and Settle Questionnaire” and the “Infant Behavior Questionnaire” to evaluate their infant’s sleep patterns. This included day/night sleep duration, number of naps in the day, frequency of night awakenings and sleep onset difficulties. In addition, eye tracking technology – the Tobii TX-300 eye tracker – was used to measure visual attention, and behavioral measures were evaluated.

When the children were three years of age, developmental evaluations were conducted of each participant by a licenced clinical psychologist. The evaluations included the ADHD subscale of the Child Behavior Checklist — Preschool (CBCL-P) and the Social Responsiveness Scale 2 Preschool Form.

Results

family history of autism

70 minutes less sleep per night

Infants with a family history of autism slept an average of 70 minutes less per night than infants without a family history of autism.

later diagnosed

100 minutes less sleep per night

Infants who were later diagnosed with autism slept on average 100 minutes less per night than the other children in the study. They also woke up in the night twice as much.

autistic relative

LOWER night sleep scores

At age 14 months, infants with an autistic relative showed lower night sleep scores due to shorter sleep duration, increased night wakings and more difficulty settling to sleep.

lower sleep scores

HIGHER risk of autism

The infants with lower sleep scores had a higher risk of receiving an autism diagnosis, showed decreased cognitive abilities and had more social challenges at three years old.

The researchers found no difference in sleep when it came to infants with a family history of ADHD.

Conclusions

This study shows a noticeable correlation between sleep and autism, a finding that is in line with many other previous studies.⁴ The results of this study indicate that infants who later receive an autism diagnosis are experiencing notably reduced nighttime sleep compared to their peers. This undoubtedly has an impact on mood, behavior and overall development. These sleep disturbances in infancy also pointed to cognitive and social challenges at the age of three.

It is worth noting that the researchers did not find a relationship between infant sleep and ADHD. They suggest this could be due to the fact that ADHD is not typically diagnosed until mid-childhood or later.

It is also important to note that this research does not prove a causal effect. In other words, this research cannot prove or disprove that poor sleep in infancy causes autism. The researchers suggest, however, that poor sleep could be a contributing factor in the developing attention system.

Parents and caregivers agree that the entire household can be affected when infants and children are not sleeping well. The family will face heightened stress levels, poor emotional regulation and disrupted routines. The resulting sleep deprivation can lead to challenges in mood, productivity and overall well-being for all family members. When families are affected by autistic children with sleep challenges, parents should seek support as quickly as possible. They may wish to look for professionals who can provide strategies to help children sleep better, or to find others who can support them in getting some much-needed sleep.

Further research is needed in this area to determine if childhood sleep challenges contribute to the development of autistic traits, and to evaluate sleep past the age of three. We look forward to learning more about the relationship between autism and sleep in the future.

Written by Autism Advocate Parenting Magazine

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Autism Advocate Printable Resources

Building Emotional Regulation Skills

Autistic individuals sometimes find it difficult to effectively regulate their emotions. Emotional regulation refers to the capacity to monitor, understand and manage one's emotions in different situations. This means that autistic children who are angry or upset might be more likely to engage in emotional outbursts, to have more temper tantrums, to yell or scream, or to become aggressive.

Experts suggest that many autistic people struggle with emotional regulation because of sensory sensitivities, communication difficulties, and challenges with understanding their emotions. For example, an autistic child with profound sensory sensitivities can be in a constant state of high alert. Since our minds and bodies are naturally designed to safeguard us from potential threats, a brain that remains in this perpetual state of alert can have a heightened reaction to the slightest change or emotional stimulus.

Consider the following example. Think about a time when you were driving and had to turn the radio off to concentrate on finding a house address or to deal with the stress of rush-hour traffic. In normal driving conditions, the radio is a welcome background noise. However, during a stressful or challenging time on the road, the added noise of a radio or of children fighting in the back seat could cause you to have a strong emotional reaction. Autistic individuals can feel like they are always dealing with “rush-hour traffic,” which means that emotional dysregulation is understandable.

Developing effective strategies for emotional regulation is crucial to helping autistic individuals navigate social interactions, build relationships, and cope with the challenges of daily life more effectively. To assist children in regulating their own emotions, parents and caregivers may wish to use some of the strategies listed below.

- If you notice that your child's emotional outbursts are frequent, violent or uncontrolled, seek guidance and an evaluation from a qualified professional. Parents are not always able to manage such strong emotions on their own and should seek help if needed.
- Lead by example. Talk to your child when you are angry, frustrated, nervous, embarrassed or excited. Demonstrate to your child the coping strategies you use to stay calm. Do not react immediately when your child is emotionally dysregulated. Speak in a calm, reassuring voice and remind your child — and yourself — of positive coping strategies to use in stressful moments.
- Talk about feelings in your home. Talk about them at the dinner table, at bedtime or during a movie. Play games to help your child identify his or her feelings.
- Make time for breaks. As sensory overload often contributes to emotional outbursts, try not to over-stimulate your child. Give your child time to take breaks and escape the sensory world. Identify times in the day when your child needs breaks the most. This could be after a long day of school or after a social gathering.

By using these strategies and others, parents can teach their children how to effectively manage their emotions. Of course, this will not happen overnight. These skills will build slowly over time as you teach them in different environments. Eventually, your child will become comfortable expressing and regulating his or her emotions.



HELP THE FAMILY GET THROUGH THE FAIR TO THE CASTLE.

Instructions:

1. The youngest player goes first.
2. The first player rolls the dice.
3. Move forward the number of spaces shown on the die.
4. Follow the instructions on the square on which you land. A castle means you pick up a card.
5. If you pick up a card, answer the question on the card. If you need help, ask the other players.
6. The person seated to the player's left goes next.
7. The game ends when everyone makes it to the finish line. Everyone is a winner for learning more about their emotions!



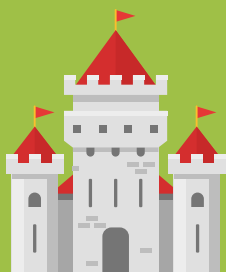
Talk about a time when you were very happy.



True or false: talking about emotions makes them worse.



Name one coping skill you like to use when you are angry or frustrated.



What does it mean to be "jealous"?



Describe a time when you had to be brave.



Act out the emotion of being nervous.



Describe a time when you were angry and how you handled it.



Make a silly face.



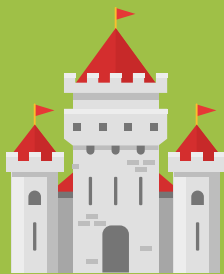
How do you feel
right now?



What is
something that
worries you?



Name a person
in a movie who
was sad.



What do you like
to do when you
are excited?



Describe a time
when you were
frustrated.



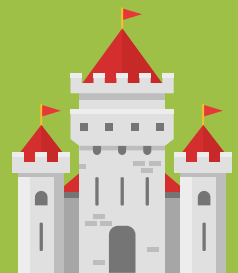
Name two
people that
you like to talk
to about your
emotions.

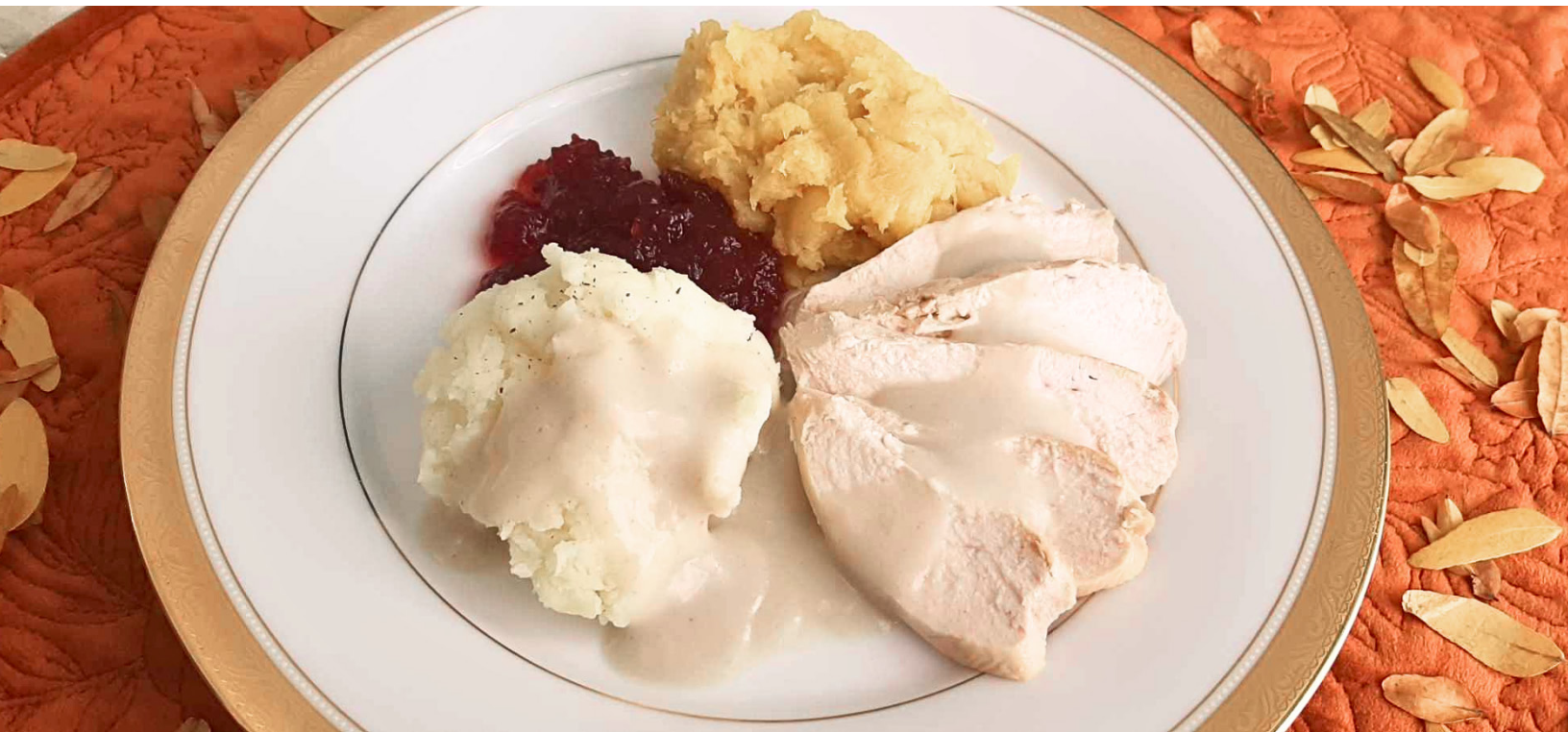


Describe a time
when you were
embarrassed.



What do you do
when you are
frustrated at
school?





Cauliflower Gravy

INGREDIENTS

cauliflower (chopped) 4 cups
 broth of choice 1 ½ cup
 pan drippings 1 cup
 cremini mushrooms (diced) (optional)... ½ cup
 celery (diced) ½ cup
 onion (diced) ¼ cup
 avocado oil 2 tbsp
 sage ¾ tsp
 salt to taste

INSTRUCTIONS

In a small to medium saucepan, sauté onion and celery in avocado oil on high until simmering. Reduce to medium heat and continue to simmer for two minutes. Add mushrooms and sage, simmering for two more minutes. Add drippings and return to a boil. Simmer to reduce for about five minutes. Add broth and cauliflower, simmer on low covered until fork tender. Transfer to high-speed blender and process until smooth. Add salt and pepper to taste.

Tip: Can also be used as a “creamy” soup base, thin with stock if desired. Add chicken, carrots, sliced mushroom, etc. Mushroom quantity can be increased or omitted, as desired.



Nutrient Nuggets from a Neurodiverse Nutritionist

Cremini mushrooms have anti-oxidants, vitamins, trace minerals, and potassium. Potassium helps to balance body fluids and nerve signaling. There is also evidence to show some mushrooms like the King Trumpet and the Oyster mushroom have a positive impact on gut microbiome and metabolic activity in children with autism.

[Reference](#)



Sarah Casburn is *The Autistic Nutritionist*. She is a certified Culinary Nutrition Expert, Registered Early Childhood Educator, Autism Therapist, and Sensory Enrichment Therapy provider. Sarah is also the founder of *Crown Family Wellness: Neuroscience & Nutrition for Neurodiversity* (www.crownfamilywellness.com).

As a neurodiverse wife and mother to neurodiverse children, Sarah brings professional and personal experience of over 25 years to her practice with a broad range of knowledge and passion. She currently consults virtually with adults, couples, families, daycares, camps, and ministries across Canada and the USA with fresh, effective approaches to complex challenges.

AUTISM ADVOCATE

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Social Story Printable

INSTRUCTIONS

This Social Story is provided as a template for parents and caregivers. This PDF is designed to allow you to replace the sample text with your own words, using language that is appropriate for your child. You can leave the text as is, replace it with your own, or print the pages with no text at all.

The sequence of images and words will help you teach your child important concepts. We hope you enjoy these Social Stories and have success using them in your daily living.

The Following Social Story Was Written by Robyn Weilbacher, M.S. CCC/SLP

Robyn is an award-winning ASHA Certified Speech-Language Therapist, Certified Autism Specialist, and Certified Hanen Centre Speech-Language Therapist for the *More Than Words Program*. She has been working with children ages two to six years old for more than 30 years.

Robyn established *RW Language Therapy and Consulting* (Specializing in Autism, Family Support, and Coaching) to teach families that have children on the Autism Spectrum how to build functional communication and social-language skills in everyday life experiences, activities, and interactions at home. She provides resources, therapy, strategies, and customized materials, such as social stories, core words, and visual supports.

Robyn teaches Hanen Centre's *More Than Words* evidence-based 8-week program for families having children ages two through five on the Autism Spectrum. By providing tools, strategies, and real-life videos, families can better connect with their child and expand purposeful, interactive communication and social interactions. Services are provided via video conferencing.

RW LANGUAGE THERAPY AND CONSULTING

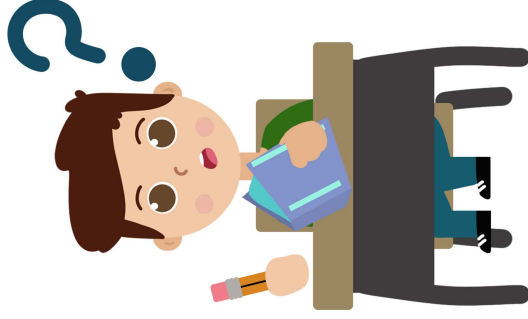
www.rwltc.com

robyn@rwltc.com

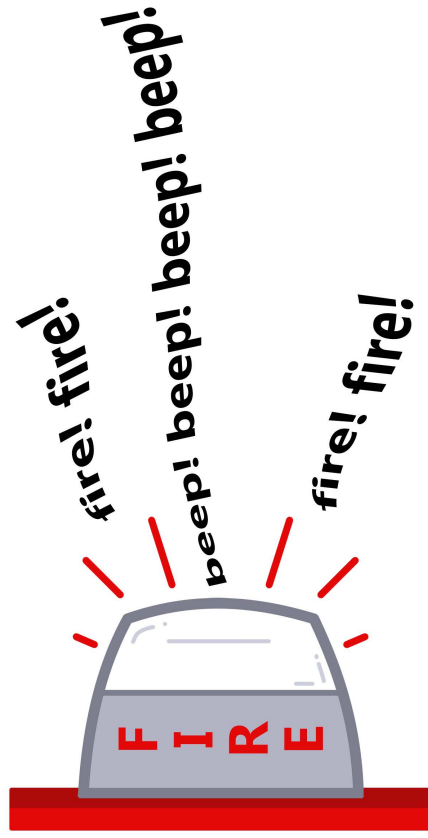


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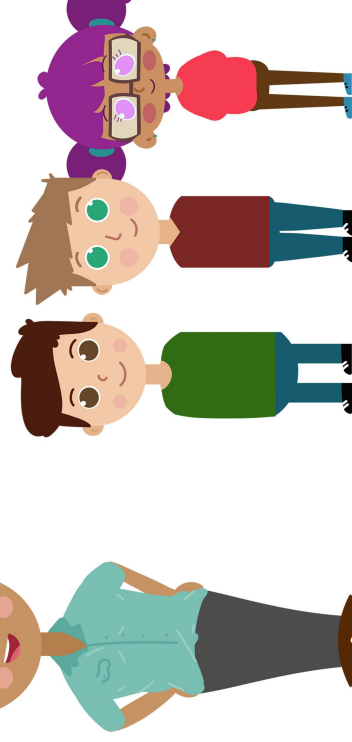
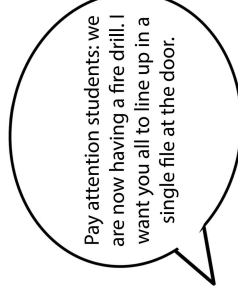
A Fire Drill!



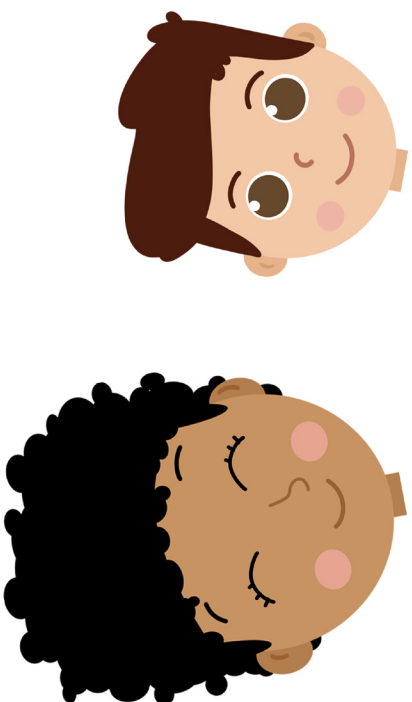
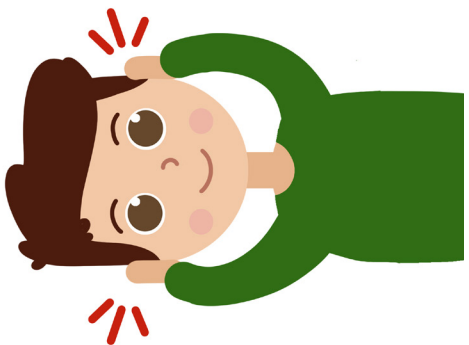
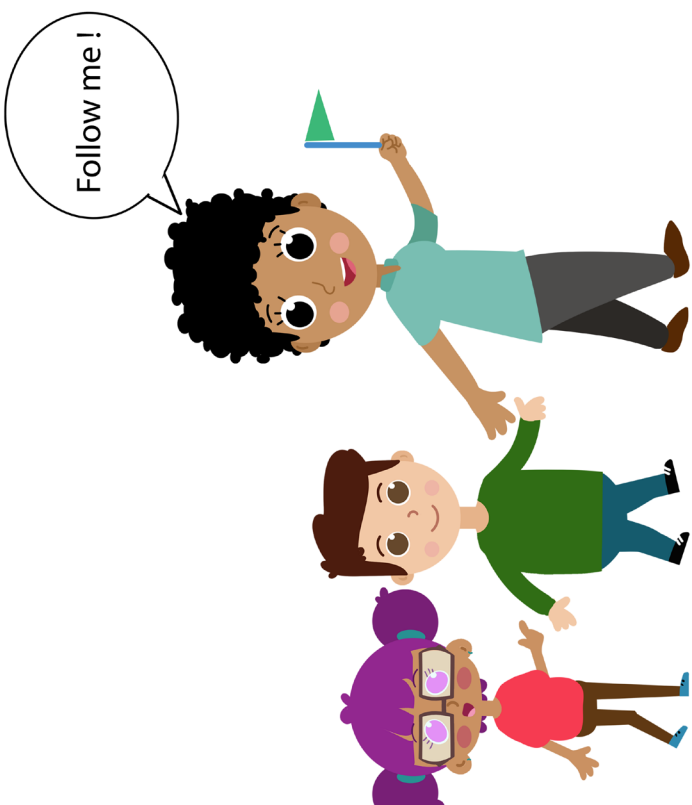
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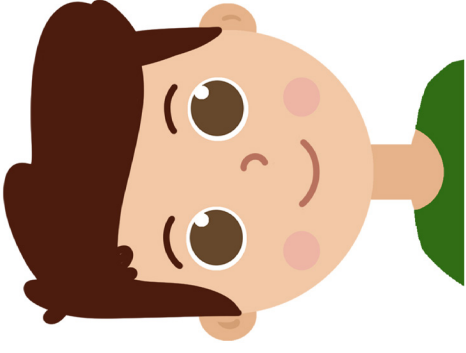


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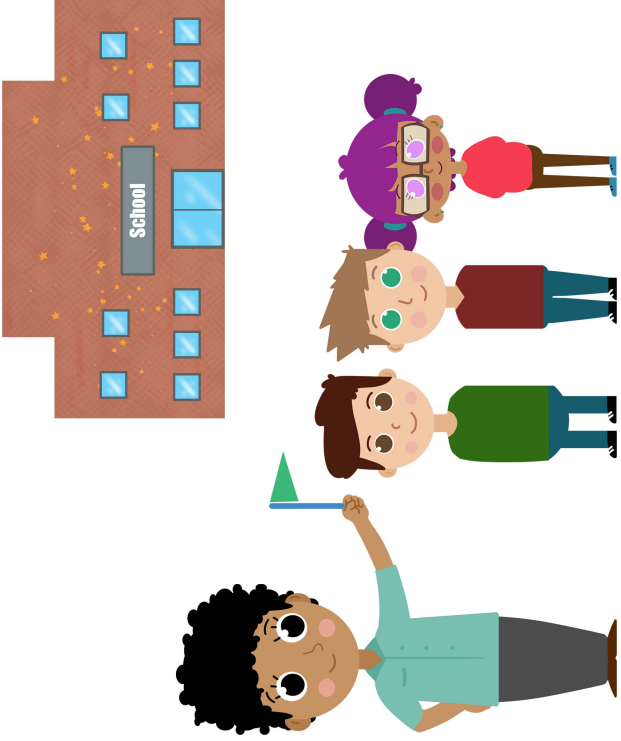




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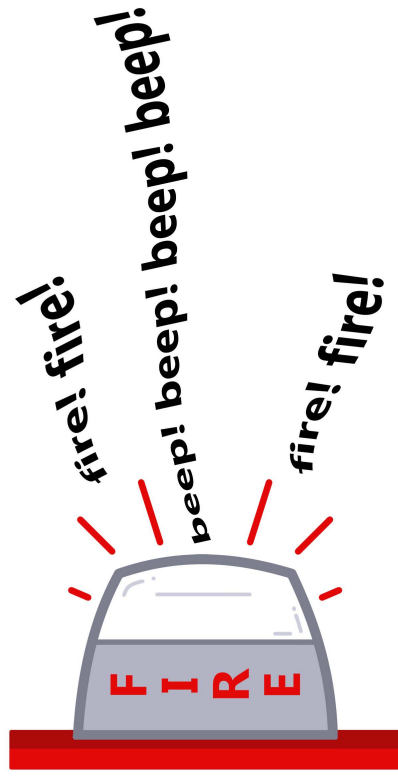
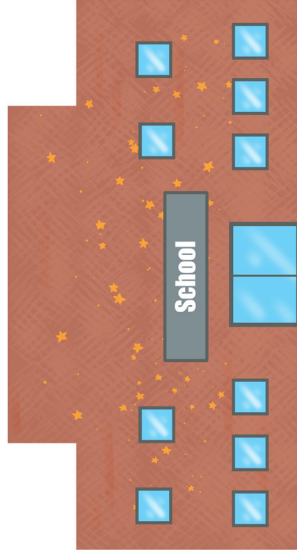
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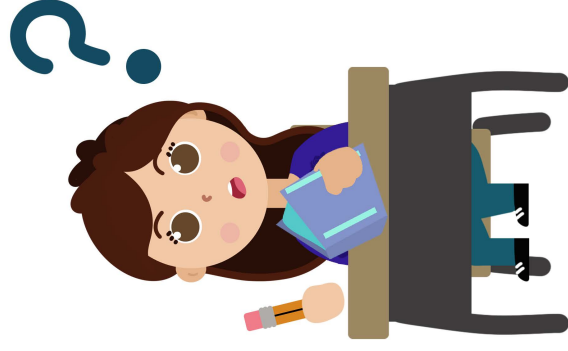
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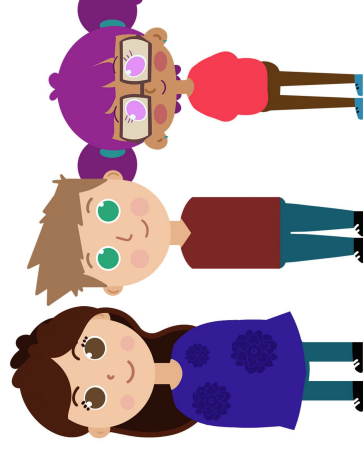
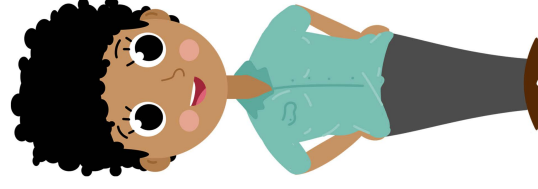
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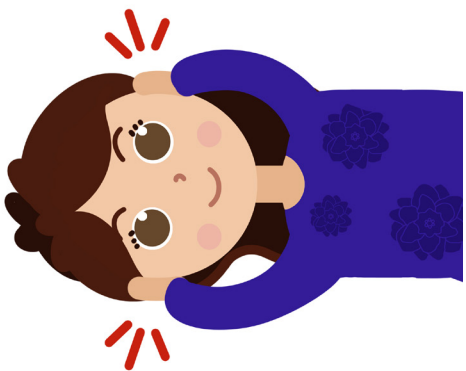
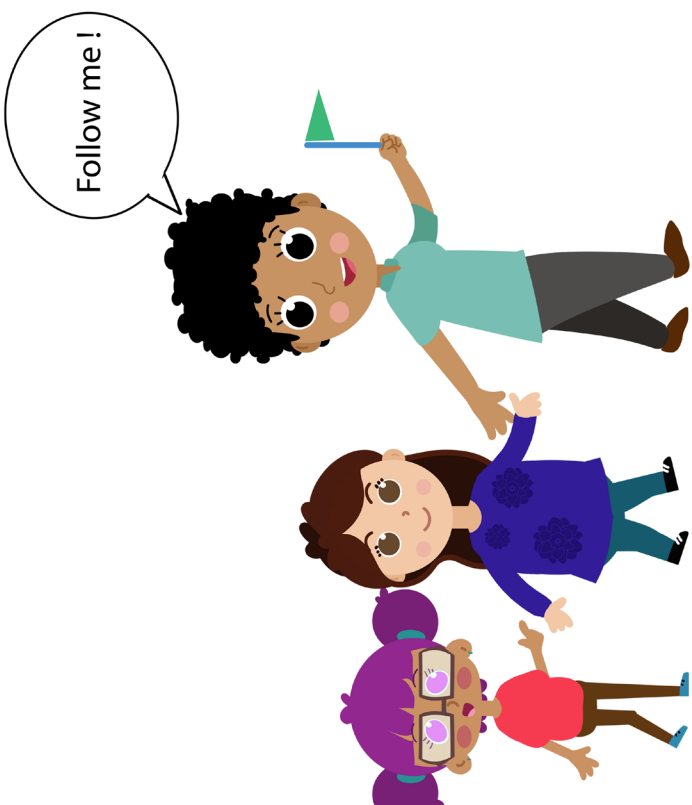
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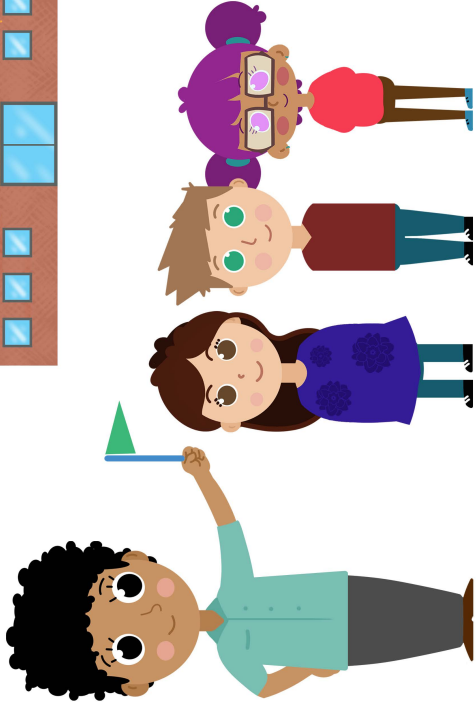
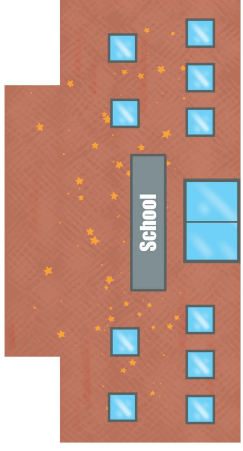


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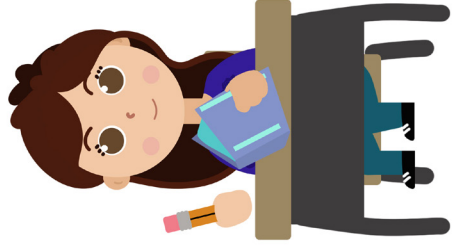


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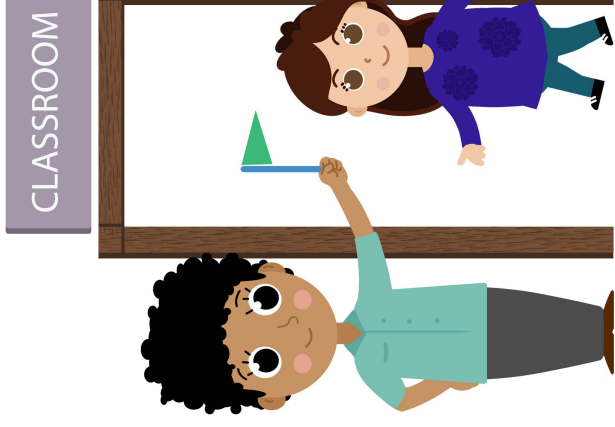




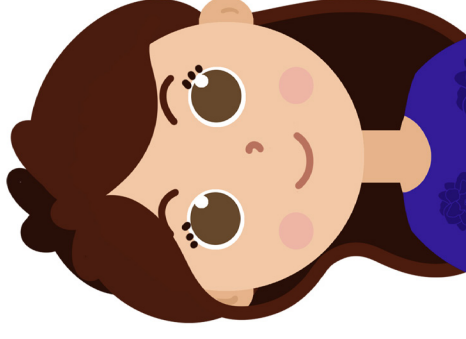
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My Next Steps

AUTISM ADVOCATE
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Knowledge Combined with Action is a Key for Success.

What inspired me?

What is something new I learned?

Items I want to research further:

Items I want to discuss with my Autism Support Team:

Doctors, Researchers or Professionals I would like to contact for more information:

Items I would like to implement/notes

AUTISM ADVOCATE



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Ambassadors for Autism Advocate Parenting Magazine

Ambassadors are individuals who passionately seek to provide quality education to the autism community through sharing content (expert advice, current autism research) found in Autism Advocate Parenting Magazine. These individuals seek to make a positive impact on other parents raising an autistic child.



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Monique Cain

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A photograph of a dirt path winding through a dense forest. Sunlight filters through the tall trees, creating a dappled light effect on the path and the lush green undergrowth. The trees are mostly deciduous with vibrant green leaves. The path leads from the bottom right towards the center of the image, disappearing into the woods.

*“The future is yet
an untrodden path
full of wonderful
possibilities.”*

— Lucy Maud Montgomery

FOR PARENTS & PROFESSIONALS

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