

September 2022

FOR PARENTS & PROFESSIONALS

# AUTISM ADVOCATE

PARENTING MAGAZINE

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Regression**

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 Supplements Severity of Autism Over Time  
 Sports Stress Regulation Taking Turns Toilet Training  
 Transition to Adulthood 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 therapies 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 **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 a child on the spectrum:**

### *Current Research*



We present the latest research in the field of autism. We share current research in a way that is clear and easy to understand.

### *Expert Advice*



Autism experts from around the world share their knowledge and expertise. They will keep you informed about the latest therapies, treatments, diagnostic tools, nutritional plans and more.

### *Resources*



In every issue we provide FREE printable resources, guides and tools that will help you support your child.

### *Parent Advocating*



Our children are extraordinary and have unlimited potential. We want to join you on your autism journey and share stories of hope, advocacy and inspiration.



We are autism parents 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](mailto:admin@autismadvocateparentingmagazine.com). We want to make your life easier, because we know how hard it can be.

Please note: The articles we provide do not represent the views of Autism Advocate Parenting Magazine. However, we feel it is our obligation to provide you with relevant information so you are informed and can make the best decisions for your child and your family.

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

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# CHILDHOOD APRAXIA OF SPEECH (CAS) and Autism

Meredith White, M.ED. CCC-SLP, COM



Parents of children with autism have so many concerns and questions. They wonder why their child with autism is not talking, and if there is something they can do to help their child communicate. They may question whether or not their child with autism also has childhood apraxia of speech (CAS). It can be difficult to get clear answers. I've asked these questions myself as an autism mother, and many families come to my clinic in hopes of finding answers and help.

## **Childhood Apraxia of Speech (CAS)**

The leading non-profit organization that supports best practices in research and intervention for CAS, Apraxia Kids, defines the condition as a neurological childhood speech sound disorder in which the precision and consistency of movements underlying speech are impaired in the absence of neuromuscular deficits, such as abnormal reflexes or abnormal tone. The American Speech-Language-Hearing Association (ASHA) indicated in 2007 that CAS is characterized by the following three features:

- inconsistent errors on consonants and vowels in repeated productions of syllables and words;
- lengthened co-articulatory transitions between sounds and syllables, such as choppiness, intrusions, lack of fluency and stuttering; and
- inappropriate prosody, especially in the realization of lexical or phrasal stress.

A CAS diagnosis can be made when these three essential elements are present. Other speech features associated with CAS include omissions, which are the most common; substitutions, which typically involve pre-vocalic voicing; distortions, which can be difficult to transcribe; additions, such as saying “balue” for “blue”; and the presence of vowel errors.

## **Prevalence of CAS**

More research is needed in order to provide us with information on both the incidence and prevalence of CAS. Some sources estimate a low incidence of CAS of between one and 10 children in 1,000 as being affected, or three to five percent of speech-impaired preschoolers. While some researchers believe that the incidence of CAS may have increased in recent years, there are no published scientific studies to support this general sense of increased incidence.

## Comorbidity of CAS and Autism

In October 2017, researchers assessed 30 children aged 15 months to five years old. The follow-up testing showed that *64 percent of the children initially diagnosed with autism also had apraxia, and 37 percent of the children initially diagnosed with apraxia also had autism.*<sup>1</sup>

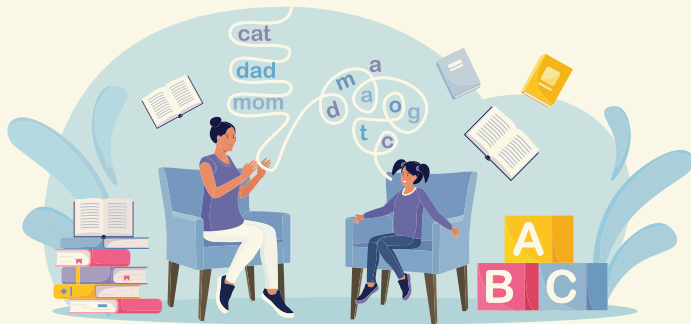
Given the study's findings, parents of a child with autism may now wonder if their child also has apraxia. Many children with autism are either "non-speaking" or "unreliable speakers." While they try to communicate verbally, they can't execute what they intend. Many children are also not tuned into the world of communication. They aren't yet aware that they are expected to participate in the string of sounds that form words. As a result, they are not yet ready to benefit from CAS intervention. These children first need work on imitation, both physical and verbal.

How do we determine the best approach in such situations? As a general rule, children who "script" by saying random words, such as "Universal Studios" or other frequent or perseverated words or phrases likely do not have CAS. On the other hand, children who don't say many words at all are more likely to have CAS. They are not yet fully aware of how to physically and verbally imitate speech.

## A Diagnosis of CAS

The only person qualified to make a CAS diagnosis is a certified speech-language pathologist (SLP) who specializes in CAS. Experienced pathologists can make a diagnosis in children as young as 18 months old. Your SLP will conduct a thorough receptive and expressive language assessment, a motor-speech assessment and an augmentative and alternative communication (AAC) assessment. A good motor-speech assessment will examine all the sounds children can make volitionally. Speech will then be analyzed for breakdowns, such as whether or not children can produce a variety of consonant-vowel (CV) sounds and use the same sounds to produce vowel-consonant (VC) sounds. Further analysis determines if children can use their speech-sound inventory to produce syllable shapes of increasing complexity. Knowing where speech breakdowns occur lets us know where therapy should begin. The results from the assessments will then be compared to the three essential criteria to determine if CAS is present.

- Are speech attempts consistent, or do they come out differently with successive attempts?
- Can sounds in a child's inventory be expanded easily into a variety of syllable shapes?
- Is the flow/prosody of speech natural or unusual?



## The Best Course of Intervention for CAS

Apraxia Kids recommends more frequent short visits to therapy as opposed to fewer long visits. In an ideal world, a child would receive therapy from an experienced SLP approximately four times per week for 20 to 30 minutes at a time. If this is not feasible, parents should try to secure two visits per week with an experienced SLP. They can then try to work with their child on their own using strategies learned from the SLP to cover the other two days per week.

In cases when CAS is present and significant, several interventions should be considered. Children who aren't effective communicators when almost four years old should supplement speech with an Augmentative and Alternative Communication (AAC) device. Research shows that use of an AAC device promotes verbal speech. While many people are concerned that children will stop talking if they use an AAC device, in fact research has shown the opposite to be true.

If a child's case is more severe, it is recommended that an evidence-based intervention style known as Dynamic Temporal and Tactile Cueing (DTTC) be used. This intervention targets five expressive speech goals that are important or salient to the child, and then uses a cueing hierarchy to establish speech-motor plans. For children with less severe CAS, other interventions based on the principles of motor learning are recommended. Multi-sensory cueing is best. This means that the SLP tries to build children's speech through the DTTC hierarchy, using touch cues if necessary, and then fading those cues quickly for children's independence.



There are many programs available to address CAS. Ideally, your SLP will be trained in a variety of approaches in order to adapt, as necessary, to the needs of your child. Typically, a number of approaches are used and then customized for your child based on principles of motor learning. Since many children don't like to have their faces touched, be cautious about programs that require lots of touch to the face. The ultimate goal is to have your child speak without being dependent on touch cues.

## Final Considerations

A good evaluation will first determine which phonemes are within a child's repertoire and where speech breakdowns occur. Therapy should then focus on building or expanding syllable shapes with phonemes already within the child's repertoire, starting with a higher level of support and multi-sensory cueing that fades to independence. Therapy will target salient words and power phrases, such as, "Go away," "Help me," and "No way." It will use phonemes within the child's repertoire to shape intelligible approximations/utterances for a functional core vocabulary. Finally, it's key that a child be taught to use an AAC device effectively in order to provide essential communication until the child becomes an effective verbal communicator.

If your child has been diagnosed with CAS, rest assured that there are strategies and resources available that can make a difference.

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Meredith White, M.ED. CCC-SLP, COM, is a speech-language pathologist as well as special needs mother to children with autism and other learning challenges. She is recognized by "Apraxia Kids" for Advanced Training and Expertise in Childhood Apraxia of Speech and is certified in Orofacial Myology/Myofunctional Therapy (COM) by the International Association of Orofacial Myology (IAOM). She served as The Coordinator for the Atlanta Apraxia Walk in 2018 and 2019. Additionally, she regularly guest-lectures for Georgia State University graduate students on the topic of pediatric motor speech disorders, and is asked to present at various conventions on topics such as Childhood Apraxia of Speech, Autism, and Tongue-Tie. She also regularly presents on the topic of Orofacial Myofunctional therapy to Airway Centric medical partners such as dental study groups, dental practices, ENT, and sleep medicine practices.

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# VIRTUAL REALITY AND AUTISM

**Simon Wallace, Ph.D.**  
**Jeremy Parr, MD**

If the vision of the future presented in science fiction books and movies had been correct about virtual reality, we would all be walking around with headsets on, exploring imaginary dimensions and finding ourselves increasingly separated from reality. Of course, that vision has not been realized. In fact, virtual reality (VR) has struggled to reach mainstream audiences. It is used mainly in gaming, but there has recently been an increase in the number of successful applications in education and healthcare. Those of us in the field of autism have embraced VR. Our own work as researchers over the past decade has suggested that the untapped potential of VR can have significant benefits for our community.

## **What is VR?**

Virtual reality technology is a way to simulate an environment that a user can engage with on a screen. Some technologies involve wearing a headset, such as Microsoft's Oculus, while the user interacts with computerised scenes by the use of special gloves. Other technologies project animated scenes onto a large screen that surrounds individuals as they are taken on a journey through a new, immersive world. Another approach is a desktop virtual world, such as Second Life, in which users create their own interactive landscapes. These different approaches all have strengths and limitations in terms of user experience and immersion. Also, some are better suited than others for use by autistic children and adults. For example, some autistic individuals may find the sensory discomfort of wearing a headset too much to take.

## **Autism and VR**

Researchers and practitioners have been eager to explore the possibility of using VR with autistic individuals for a number of reasons. There is a common assumption that autistic people have a strong connection to technology and seek comfort in the predictability of computer-based interaction. As a result, there can be increased levels of engagement with and attention to things presented in virtual worlds. In addition, one of the benefits of VR environments is that they can be less confrontational than real-world scenarios. For example, an autistic individual who may have significant levels of social anxiety could exercise greater control over the intensity of social stimuli in a virtual scene. This would serve as a stepping stone to becoming more comfortable with real-life social interaction. Since many people with autism have difficulties imagining different scenarios, the use of VR can be an important strategy in representing such situations.



## Research Initiatives



Our interest in VR and autism came as we collaborated in research in the UK. We began by seeking to understand if autistic young people become immersed in virtual worlds in the same way as their non-autistic peers. Immersion is a sense of being embedded and present in the virtual experience. Since we planned to develop practical uses for VR technology, we needed to know the autistic experience was truly immersive. We used two different types of technology for our studies. The first was a VR room in which users were surrounded by four screens and they passively experienced the virtual world. The second was a desktop virtual world — built in Activeworlds — in which users navigated around a virtual town and interacted with other users. We found that autistic young people felt immersed in both technologies, shared their experience with other users, and had no negative sensory reactions, such as feelings of sickness or dizziness.



One of the strengths of autism technology research is how well it promotes “user engagement.” Autistic individuals and their families have often led research studies or been consulted on the design of projects. This certainly has been the case for our projects. For example, an autistic pupil from a local college gained work experience by designing the environment in our desktop virtual world. This not only gave the student greater confidence and heightened self-esteem, but it also improved our final product.



Since the first phase of research showed autistic individuals were equally comfortable with both VR room and desktop technologies, the next phase of our research looked at practical uses for VR room technology. We wanted to determine if immersive virtual environments projected onto screens could be used as a clinical treatment to reduce anxiety situations, specific fears and phobias. There is now an increasing awareness of the profound effect of anxiety on autistic individuals. Fortunately, a number of treatment options are now available, including cognitive behavioural therapy, mindfulness and psychoeducation. We felt, however, that using VR technology may present some unique opportunities. For example, exposure therapy for a phobia about dogs involves exposing the patient to increasing levels of dog stimuli. This would escalate from dog pictures, imagining dogs and seeing a dog toy, to seeing someone stroke a dog, to having the patient stroke the dog. VR gives us more control over the inputs and allows us to make small changes to pictures, thus moving easily up and down the exposure hierarchy. Utilising VR can also reduce the number of verbal commands and increase the use of visual prompts instead.



Our two research studies demonstrated that most of the participating autistic youth, who were between seven and 14 years of age, saw a reduction in their anxiety associated with situations, individual phobias and fears. Psychologists were trained in the use of the technology as a therapeutic aid and adopted it quite readily. Over four sessions of 20 to 30 minutes each in the VR room, children were gradually exposed to the fear-provoking stimulus, such as getting on the bus, shopping, or pigeons, and were taught techniques to control their anxiety. Once the VR sessions had finished, we saw a real-world reduction in phobic responses to triggering stimuli as reported by both children and their parents. This positive effect was found not just in the short term but also many months later.<sup>1,2</sup> A similar but smaller study showed a positive effect for some autistic adults.<sup>3</sup>

## VR or Traditional Treatment

Research in this important field needs to continue. We have yet to determine whether or not our VR treatment is more effective or economical than traditional treatment approaches. Since relatively small numbers of children and adults have taken part in the studies, we need to increase our understanding of why it works for some children and not others. To address these limitations, Newcastle University and Cumbria Northumberland Tyne and Wear NHS Foundation Trust have begun to explore the commercialisation of this technological approach to autism and anxiety treatment through a spin-off company called XRTherapeutics ([Home - XR Therapeutics](https://www.xrtherapeutics.com)). The company is now providing anxiety treatment to children and adults with autism, as well as to neurotypical people, through the UK National Health Service (NHS) and privately.



The tremendous potential for the use of technology for autism has yet to be fully exploited. It tends to create excitement about projects, and is one of the few areas of autism research in which we engage with a wide range of partners, such as developers, researchers, autistic individuals and their families, businesses and investors. By building on these partnerships, we hope to make significant advances in coming decades and ensure that VR is regularly used in clinics, schools and the workplace to support autistic individuals.

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Jeremy Parr, MD, is a Professor of Paediatric Neurodisability at Newcastle University, UK. He works in the UK National Health Service (NHS) seeing children and young people with possible autism. Jeremy leads clinical research focused on understanding autism across the lifespan and, based on the findings, designs and evaluates new interventions with the aim of improving physical and mental health and well-being. Jeremy led the research into VR use for anxiety, and is the lead Academic Founder of XRTherapeutics, as well as a Director and Shareholder.

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# “A Happy Journey Through Life”

## 13<sup>th</sup> Autism-Europe International Congress

Cracow, 7-9 October 2022



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The **13th International Autism-Europe Congress** is the first full online Congress with **high quality access to its sessions, presentations, workshops, discussion panels and more**. You can **join in person as well, in the historical city of Cracow**. The Congress brings expertise from around the world to promote a positive vision for autistic people and their families.

“**Happy Journey through Life**” is the theme of the Congress – to highlight the importance of taking a **lifespan perspective** on autism research and practice, with the **promotion of wellbeing** for all being the focal point.

The Congress is unique in terms of its **history, scale** and that it **provides a platform** for researchers, practitioners, students, autistic people and family members to come together.

The **scientific programme** includes keynote presentations, a diverse range of symposia topics, interactive poster sessions, workshops run by leading practitioners and moderated sessions to discuss challenging questions.

During the Congress **autistic people and caregivers** will be central to proceedings, providing a platform for their voice to be heard and to advocate for change.

We celebrate this diversity of perspectives to ensure a “**Happy Journey through Life**” for everyone.

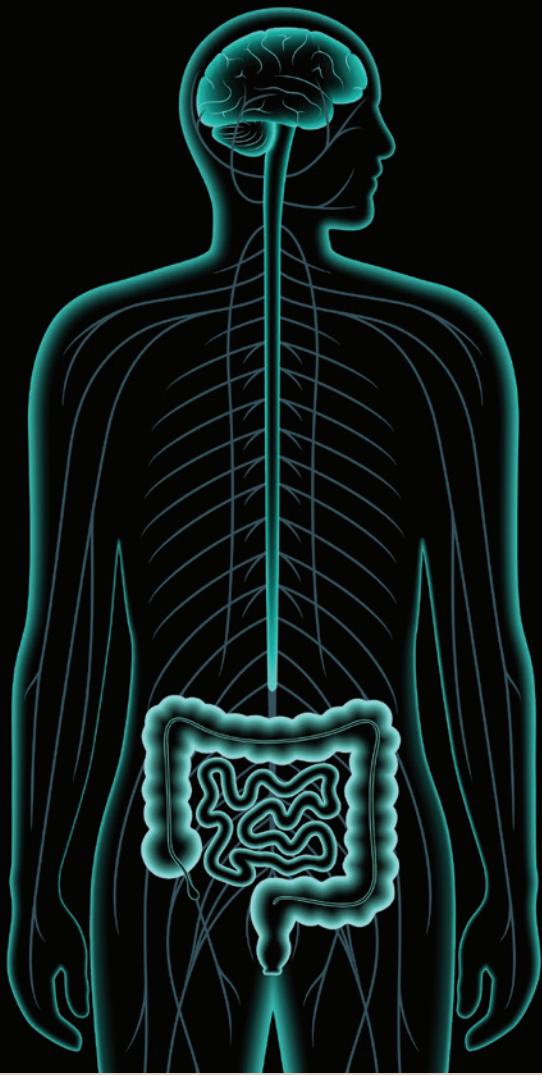
The Congress has the ambition to showcase three perspectives on the newest scientific trends in the autistic community:

- Perspectives from researchers
- Practitioners
- Autistic people, their family members or caregivers

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# THE ROLE OF Neurotransmitters in Gastrointestinal Disorders RELATED TO AUTISM

**Kara Margolis, MD, AGAF**

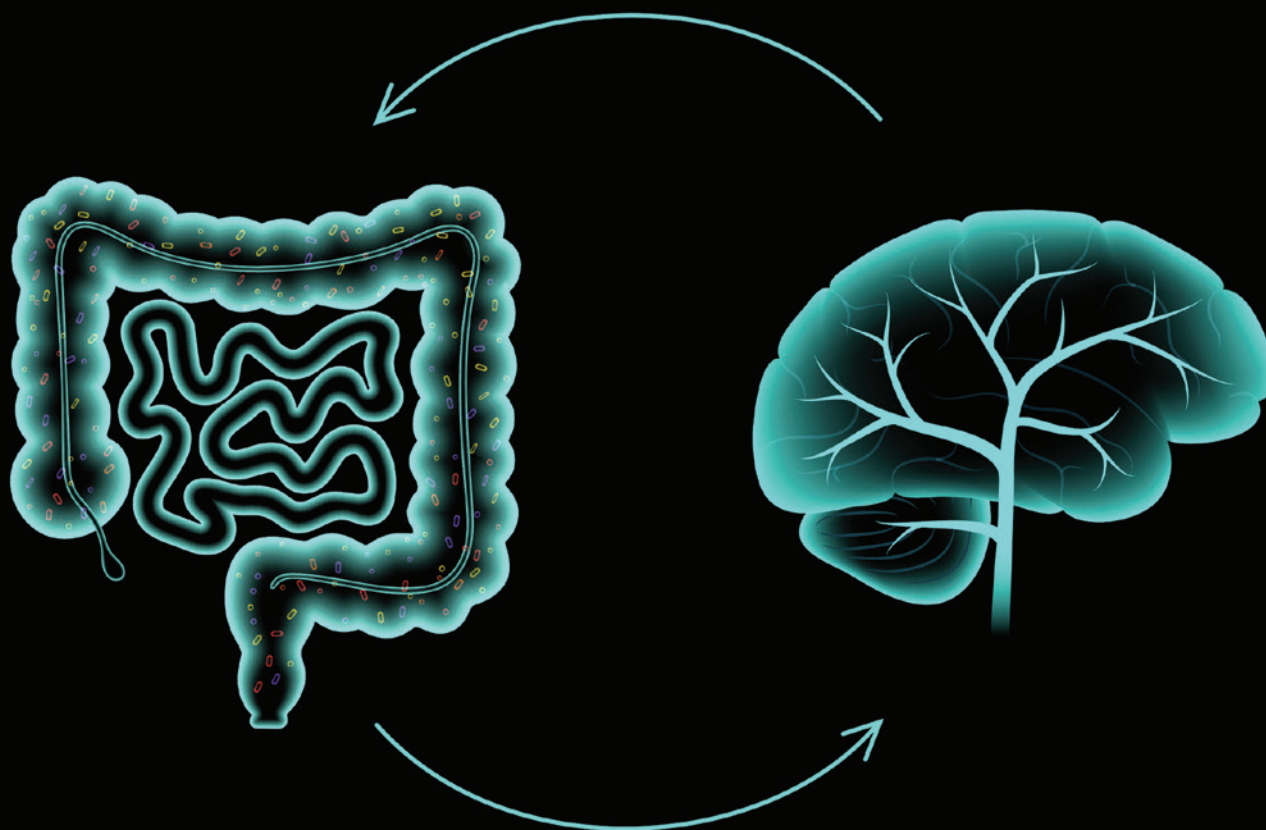
It has become increasingly clear that gastrointestinal (GI) issues are more common in children with neurodevelopmental conditions than in those without such conditions. Multiple studies show that GI disorders are two to three times more prevalent in these children, and a recent meta-analysis showed that they can be up to four times more likely.<sup>1</sup>

Children with autism spectrum disorder (ASD) who experience GI issues often suffer from constipation, diarrhea and gastroesophageal reflux. In fact, constipation is the most common disorder in the majority of studies. The way children with autism present with these conditions can vary. Many children with autism have challenges with speech and cannot verbalize pain in direct ways. Even for those who have high levels of speech, the ability to localize and verbalize pain or discomfort can be challenging. These difficulties can lead children with ASD and GI issues to present with challenging behaviors, including self-injury, aggression, sleep difficulties and worsening of the core diagnostic features of ASD itself.<sup>1-9</sup>

## **The Gut-Brain Axis**

A key reason for the high prevalence of GI problems in ASD is the presence of abnormalities in communication between the brain and gut. Communication on this “gut-brain axis” is constant and bi-directional, which means that the brain communicates with the gut and the gut communicates with the brain. An example of the former is the fact that the gut can respond to specific emotions. Some individuals get abdominal pain, butterflies in their stomach, or diarrhea when they have anxiety or are nervous about something. On the other hand, an example of the gut communicating with the brain is seen in the effect of foods on the brain. Processed foods have been shown to be associated with higher incidences of mood disorders, while fiber-rich foods have been shown to potentially have anti-depressive and anti-anxiety effects. Studies have shown that the vagus nerve, which is the main channel of communication between the brain and the gut, serves as a conduit for this exchange of information. Given the high level of communication between the gut and the brain, it is likely that gut health plays an important role in autism-associated behaviors and in other comorbidities commonly associated with autism. This is why it’s important for parents and caregivers to consider this connection, and to be familiar with the potential effects that gastrointestinal issues may have on their children’s behaviors.

# GUT-BRAIN CONNECTION



## The Enteric Nervous System (ENS)

Just as the nerve cells in the brain connect to and communicate with one another, the nervous system in the gut functions in a similar way. Known as the enteric nervous system (ENS), it can function independently of the brain and communicate in ways that help the gut to function. One of its primary roles is to control gut movement. Problems with the ENS can lead to constipation or diarrhea. One of the best ways to evaluate the ENS is to look at the neurotransmitters of this system.

## Enteric Neurotransmitter — Serotonin

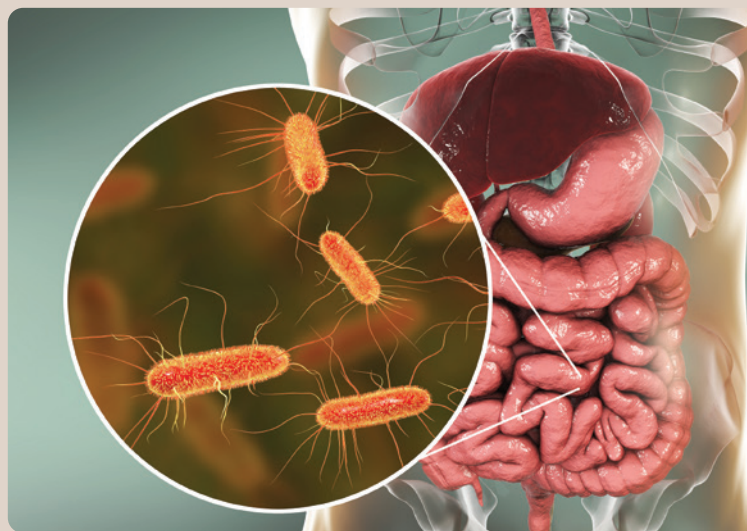
Serotonin is a prominent neurotransmitter in the ENS. It is often called the “feel good” chemical because it contributes to happiness and mood. While serotonin plays many roles, it is particularly important in the ENS for **gut function**. It helps regulate how fast or slow the gut is moving. It may also impact **abdominal pain pathways**. Selective serotonin reuptake inhibitors are sometimes used to treat individuals with comorbid mood disorders and disorders of gut-brain interactions. In addition, serotonin can **signal through the vagus nerve**, facilitating messages being sent between the gut and the brain.

## Serotonin and Autism

Studies have shown that many individuals with autism have high **blood** serotonin levels.<sup>2</sup> These high levels have also been associated with GI problems.<sup>3</sup> The origin of these abnormalities in serotonin is not clear, nor is the full extent of the associated symptoms. Parents should be aware of the role that serotonin plays in the gut and the possible gastrointestinal side effects of taking a medication that alters serotonin levels.

## Serotonin and Gut Microbiota

Serotonin not only affects gut function, but also interacts and communicates with the microorganisms that inhabit the gut.<sup>4</sup> Although the organisms that have been studied the most are bacteria, it is worth noting that viruses and fungi are also present. The gut microbiota has been shown to play important roles in health as it aids with digestion, helps control the immune system, and affects brain health.



Just as serotonin influences which gut microbiota is present, the microbiota can regulate gut serotonin levels. Research has shown that many children with autism have altered gut microbiomes. However, there is no one "autism" microbiome, and no microbiome test that will identify someone with autism versus someone without. Preclinical studies have shown that specific microbiota may be linked to specific neurobehaviors and/or mood. The microbiota is significantly affected by diet and medications, however, and it has recently been suggested that differences in the microbiota in some individuals with ASD may be linked to limited variety in dietary intake.<sup>5</sup> As in many other medical conditions, some future treatments for ASD may lead to a personalized, medicine-based approach, dependent in part on microbiome analysis. More research is needed in this area before conclusions can be drawn.

## Autism and Diet

Diet is very important to the health of an autistic individual's microbiota. Studies have shown that various nutritional interventions can make a difference in the GI symptoms and behavior of a child with autism. In order to improve gut health, consider making the following important changes.



### REMOVE ARTIFICIAL SWEETENERS

Artificial sweeteners have been shown in preclinical studies to make the gut barrier more permeable and may lead to inflammation.



### AVOID PROCESSED FOODS

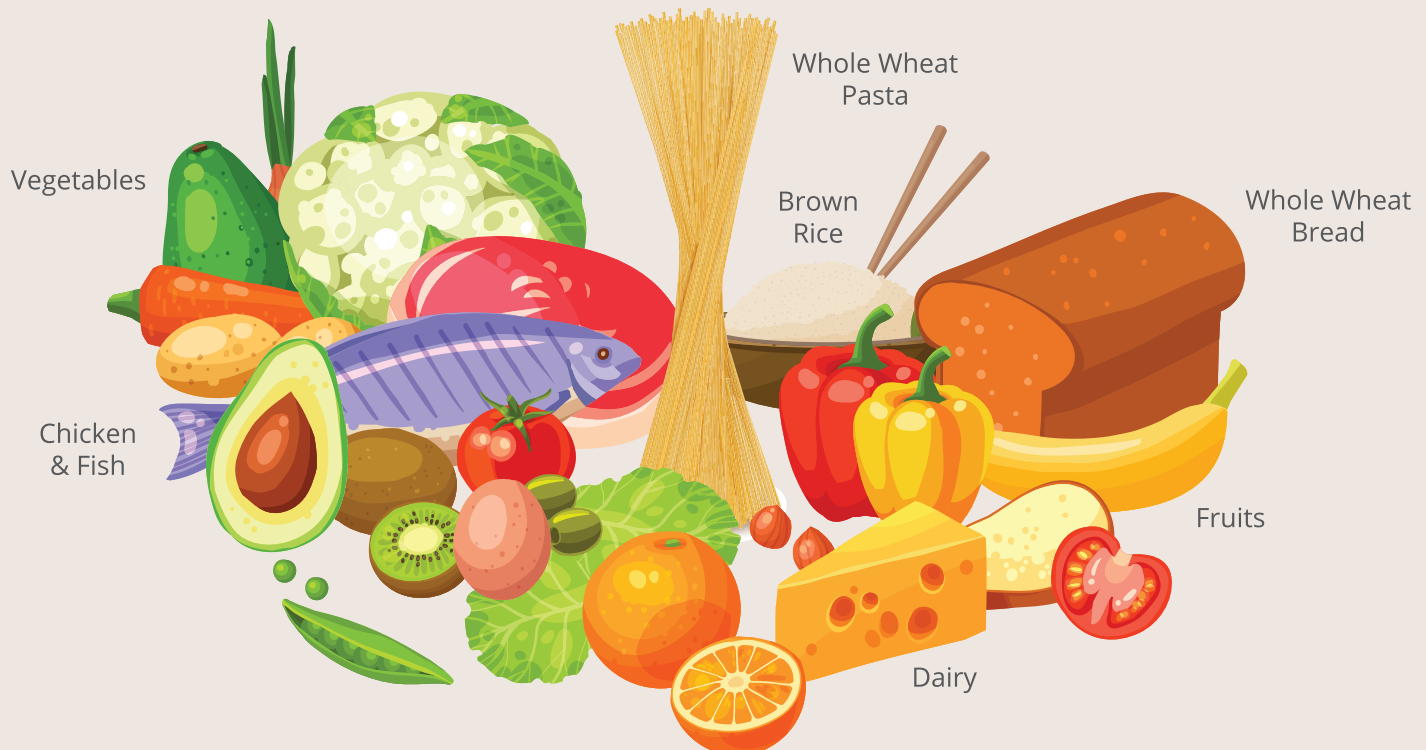
Processed foods are filled with preservatives, which are known to be unhealthy for the gut.



### FOLLOW A HIGH-FIBER DIET

Fruits and vegetables are high in fiber and have consistently been shown to shift the microbiome in a positive direction.

## TOP FOODS FOR A HEALTHY GUT DIET



Although there are many other dietary interventions for improving gut health, families must be able to manage these nutritional interventions. Children with autism often have difficulty with changes in food due to their food selectivity and aversions. In researching these interventions, it is important to determine what nutritional plans support an autistic individual and how to effectively implement these plans.

## Next Steps

The following are some important next steps that doctors and scientists are currently pursuing in the research fields.

### 1. *Personalized Approach*

An individual's gut microbiota is as unique as a fingerprint, and this is true for individuals with and without autism. If it eventually becomes possible to understand and treat autism based on microbiota differences, it will likely require a more personalized approach for each individual. As researchers begin to elucidate more precisely how the gut microbiota is linked to behaviors, other medical comorbidities and neurotransmitters, it will be important to consider other factors when evaluating treatments above and beyond the microbiota blueprint. This could include, for example, determining the challenging behaviors that are present, serotonin level, nutritional deficiencies that are present, and the diet that will best support the microbiome.

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### 2. *Nutritional Studies*

More rigorous studies on nutrition are needed to identify how specific parts of the diet relate to the microbiome and the brain, who benefits from certain dietary interventions and who does not, as well as the reason for such differences. Further studies should also include manageable nutritional plans for autistic individuals and families, particularly since most children with autism will likely find a non-processed and high-fiber diet very challenging.

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### 3. *Fecal Microbiota Transplants*

A fecal microbiota transplantation is the transfer of stool from a "healthy" individual into someone with an "unhealthy" microbiome. A preliminary study showed that a significant improvement was made in both GI difficulties and challenging behavior in children with ASD after a fecal microbiota transplant, and that the positive effects persisted for two years after the transplant occurred.<sup>12,13</sup> Although these results are exciting, this study was open-label and was not placebo-controlled. A similar study that is double-blind and placebo-controlled is necessary to confirm these initial findings.

## Conclusion

GI abnormalities exist in many children with autism, and these can be linked to behavioral challenges. The increase in research in this important area is likely to lead to novel biomarkers and interventions. In order to move forward in our understanding, however, significantly more research is required.



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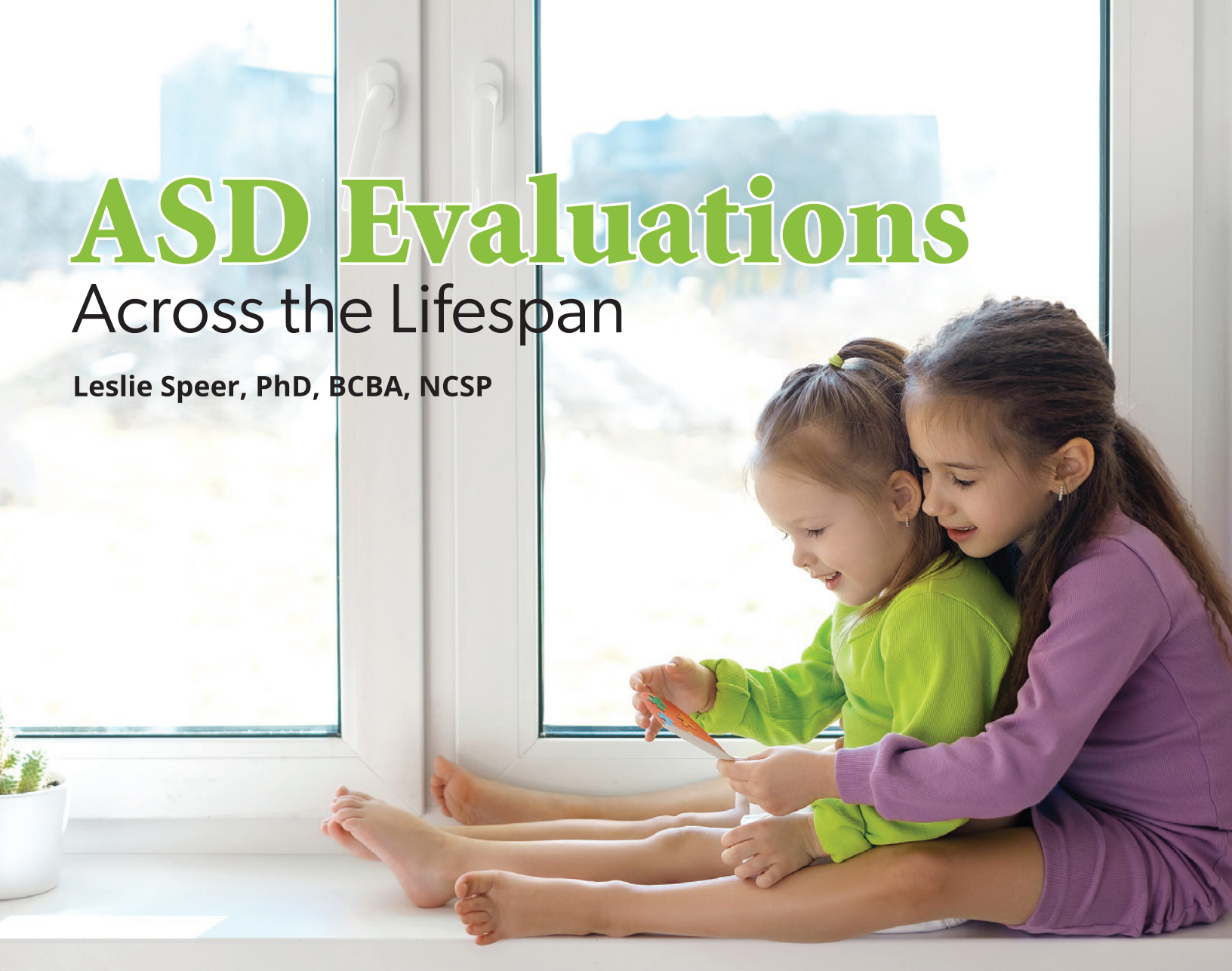
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# ASD Evaluations

## Across the Lifespan

Leslie Speer, PhD, BCBA, NCSP



I have been conducting autism evaluations with individuals of all ages for fifteen years. Through this work I have had the opportunity to meet so many incredible people and families. This is what drives my commitment to provide quality evaluations to individuals of all ages, and to make sure individuals have access to appropriate supports following the evaluation, regardless of diagnosis.

Children, adolescents and adults come to my office for many different reasons. Younger children often come with some type of developmental delay, such as a delay in speech and language development. They may exhibit atypical behaviors, including limited eye contact or hand flapping. Adolescents participating in a first-time evaluation often have difficulty connecting with peers and forming social relationships. This can lead to symptoms of anxiety or depression. Many of the adults that I see experience stress from the loss of employment due to difficulties getting along with co-workers and supervisors, a strain in their marital relationship, or limited social interaction and relationships. These experiences, and others, prompt them to seek out an evaluation. The symptoms of Autism Spectrum Disorder (ASD) are different for each individual and vary at different ages across an individual's lifespan. The autism spectrum is expansive. As a result, evaluations of individuals at different ages, with different symptoms and needs, should be both different across the lifespan and individualized.

## YOUNG CHILDREN

Multidisciplinary evaluations for young children typically include a psychologist, a medical provider, such as a developmental pediatrician or neurologist, and a speech pathologist. Caregiver input on development and behavior serves as an integral part of the evaluation process. As such, evaluations usually involve a caregiver interview, as well as direct observation of the child while playing and engaging with the caregiver and evaluation team. Gold standard assessment tools for this type of observation include the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2), and Childhood Autism Rating Scale, Second Edition (CARS-2). A standardized speech and language evaluation, and a physical/medical examination are also conducted. Often, caregivers are asked to complete questionnaires about their child's development, communication, socialization and behavior. Since obtaining information from many different sources helps with diagnostic clarity and the formulation of treatment recommendations, all aspects of the evaluation process are important.

- ✓ Psychologist
- ✓ Medical Provider
- ✓ SLP
- ✓ Standardized Testing
- ✓ Direct Observation
- ✓ Caregiver Input/  
Questionnaire

## ADOLESCENT

While very similar to the process outlined above, an evaluation for an adolescent may be different depending on referral concerns and current needs. Absent medical concerns and developmental delays, an adolescent may not need to see a developmental pediatrician. Rather, they may benefit more from having a psychiatrist involved in the evaluation process to help assess possible comorbid symptoms, such as anxiety, depression or Attention Deficit-Hyperactivity Disorder (ADHD). In addition, an evaluation with a speech language pathologist may not be necessary if there are no concerns regarding speech and language development. However, given the fact that deficits in social communication, or pragmatic language, constitute one of the core symptoms of ASD, assessment of an individual's ability to communicate socially needs to be a part of an ASD evaluation. A caregiver's involvement continues to be vital to the evaluation process and typically includes an interview and questionnaires, as previously noted. Adolescents being evaluated should also have a voice and the opportunity to provide input regarding their own symptoms and difficulties. The way in which this information is gathered will vary with each individual. Some methods of gathering information may not be possible for individuals who are nonverbal or who have a significant intellectual disability. As outlined above, direct observation and standardized testing continue to be important aspects of the evaluation process.

- ✓ Psychiatrist
- ✓ Assessment of Social  
Communication
- ✓ Direct Observation
- ✓ Standardized Testing
- ✓ Direct Input from  
Adolescent
- ✓ Caregiver Input/  
Questionnaire



## ADULTS

While there are many challenges in evaluating adults, these can be addressed through flexibility and problem-solving. An important part of an autism evaluation is obtaining information about the early developmental period. Since gathering this information in adults can sometimes be difficult, if not impossible, it is vital to include in the evaluation process parents, caregivers and others who were a part of the individual's youth. Even if someone who can speak to early development is not available, it is very helpful to have a collateral source to provide information on social interactions, communication and behavior. Some aspects of what is considered to be part of an autism evaluation can be difficult for the individual being assessed to fully describe or address, such as eye contact, facial expressions and social reciprocity. Other individuals who can be helpful in the evaluation process include spouses, siblings, close friends, or extended family members. As is the case with adolescents, comorbidity is common. This makes assessing a broad range of symptoms beyond those of autism important. As a result, it can be very helpful and appropriate to have a psychiatrist as part of the multidisciplinary team. As noted above, standardized testing, direct observation of the individual being evaluated, and input from that individual are all essential.



Information on Early Development



Include spouse, siblings, friends in evaluation



Psychiatrist



Direct Observation



Direct Input from Adult

## GOALS AND NEEDS

Parents and caregivers who seek evaluations for their children, as well as adults seeking to be evaluated, have many different goals and needs. Providers should be aware of these at the onset of the evaluation process, and strive to achieve these goals and provide support and recommendations around areas of need. I always tell families and patients that the goal of an evaluation is not simply to make a diagnosis, but to outline a plan and suggested next steps. Seeking an evaluation has typically been prompted by a concern or a struggle, and our goal is to address that concern or struggle in one way or another. While diagnostic clarity assists with the development of a treatment plan, it should be just the starting point. The recommendations that follow an evaluation should be as individualized as the evaluation process itself. Knowledge is power. The more we understand our child's learning style and development, the better equipped we will be to outline next steps and to identify needed resources. We will be better able to determine which people should be involved in our child's treatment, such as speech therapists, occupational therapists, behavioral therapists and others. This also applies on a personal level if we are the one seeking treatment. We are on a journey, and having a road map is essential. A diagnostic evaluation helps us develop that road map in an informed way, while acknowledging there will be many bumps and forks in the road in the course of this journey. We will be better prepared to handle those challenges, however, if we have built our starting point on a solid foundation.



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# Say Good Night to Sleep Problems

Addressing Sleep Disturbances in Children  
with Autism Spectrum Disorders

Cheryl Tierney-Aves, MD, MPH  
Lucy Emery

Healthy sleep is important for both children and parents. Identifying sleep problems early may prevent negative consequences, such as daytime sleepiness, irritability, behavioral problems and learning difficulties.<sup>1</sup> Multiple studies have been conducted on the prevalence of sleep problems in children with autism. A large study in 2019 found nearly 80 percent of preschoolers with autism have disrupted sleep.<sup>2</sup> This suggests sleep problems are twice as common in children with autism as in their neurotypical peers. Additionally, autistic children need an average of 11 minutes longer to fall asleep, and many wake up frequently.<sup>1,3</sup> If you're a parent of a child with autism who has sleep issues, rest assured that you are not alone!

Parents must create an environment conducive to healthy sleep by establishing routines and removing sleep barriers.

## Sleep Rules

Establishing good sleep hygiene is the critical step in helping a child with sleep problems. Sleep hygiene doesn't mean showering before bed. It refers to the sleep habits or behaviors necessary for a good night's sleep, and includes avoiding caffeine, and going to bed and waking up at the same time every day.<sup>4</sup>



### BEDTIME ROUTINE

The goal is for children to sleep through the night in their own bed. Establishing a short, consistent, and reproducible sleep routine that happens **every night** before bed can greatly improve the chances that children will fall asleep quickly. An example of a healthy routine includes: taking a bath/shower; putting on pajamas; brushing teeth; and reading from a book or listening to some music. The bedtime routine should take place outside of the bed, last less than 30 minutes, and end with being tucked into bed.



### TURN OFF ALL ELECTRONICS

It is important to avoid all electronic devices, including TVs, computers, phones, and tablets, for 60 to 90 minutes before bedtime. The light emitted by these devices — even with the night filter on — suppresses our body's melatonin, our natural sleep hormone. This exposure can inhibit sleep for several hours.



### SLEEP IN YOUR BED ONLY, AND USE YOUR BED ONLY FOR SLEEP

If children frequently fall asleep on the couch or in their parents' bed, it can disrupt their sleep. The brain has a unique signal that allows us to "check" our environment throughout the night. It triggers a night awakening if the circumstances under which we fell asleep are different.

Children and teenagers with autism often spend a lot of time in their room. They may use their bed as a place to play video games, do homework, or hang out. For many young people, however, the brain cannot distinguish when the bed is for activity or for falling asleep. If the bed is used only for sleep, children are better able to register that when they get into bed, it is time to fall asleep.

## When Will I See Improvement in My Child's Sleep?

Since each child is unique, it is hard to say exactly when things will improve. However, if you are consistent, you should see significant improvement in just a few weeks.

Once you have established good sleep hygiene, it is important to avoid behavioral sleep disorders. Known as "behavioral insomnia of childhood," they include sleep-onset association disorder subtype, limit-setting subtype, and combined subtype.

**Sleep-onset association disorder** is a condition in which a child associates falling asleep with something in the environment or with a person. This could include, for example, being held or rocked, or eating and drinking before bed. It is easy to find yourself lying down with children who don't want to fall asleep on their own, say they are scared, or climb into your bed. Sleep associations can lead to children waking up because they have moments throughout the night that they "check" their environment to determine if the circumstances when they fell asleep are still the same. If you let children fall asleep in your bed, cuddle with them, or rub their back until they drift off, this can be perceived as different and they will wake up and look for that same comfort to fall back asleep. This can occur throughout the night, causing children to awaken multiple times. Teaching your child to self-soothe at bedtime will lead to a restful night's sleep without night awakenings resulting from a behavioral cause.

**Limit-setting subtype**, or what I call "jack-in-the box" syndrome, involves refusal to go to bed with repeated requests that delay bedtime. Asking to use the bathroom, requesting one more story, or getting out of bed repeatedly are examples. I call this "jack-in-the box" syndrome because parents are constantly returning their children to bed and watching them get out again.

## What Can Tired Parents Do?

We often see tired families at their wit's end, but there are solutions. It is important to follow *all* the sleep hygiene recommendations listed above. To promote a good night's rest, remember to first remove those items that might interfere with sleep. After you tuck children into bed, you can follow one of two methods that work to help them fall asleep.



### Option 1 — A Bad Case of Laryngitis

Tuck children in after their bedtime routine and say good night. Then, pretend to have a serious case of laryngitis and make sure you don't talk after this point. Talking when children get out of bed will only prolong the process. When children get out of bed, calmly return them to bed and leave the room. Continue this until children fall asleep in their bed, then offer reinforcement in the morning, such as a high five, verbal praise or a sticker. Remember that while it might have been a rough bedtime for you, children don't have a concept of time so the praise in the morning is for falling asleep in their own bed.

### Option 2 — The Chair Method

Put a chair next to children who might not have an easy time falling asleep on their own yet. Sit next to the bed, but don't talk since you have horrible laryngitis. Once children fall asleep in their own bed in less than 30 minutes for three nights in a row, the chair can be moved away from the bed. If children get out of bed, put them back in bed without talking, and return to the chair. Again, success is when children can fall asleep in their bed in less than 30 minutes on their own without you. Finally, move the chair to the door as the last step in this process.



The key steps are to stay silent, remain calm, and use reinforcement in the morning when children fall asleep in their own bed on their own.

Children with healthy sleep hygiene who fall asleep on their own but continue to wake up overnight may suffer from a medical sleep disorder. The two most common disorders are obstructive sleep apnea and periodic limb movement disorder. These are treatable, but require seeing a pediatrician or a sleep specialist. Your child may also need lab work and a sleep study for a proper diagnosis. Since these conditions are often overlooked and can cause poor sleep in children with autism, consultation with a medical professional is important, especially if you have not had success working on sleep habits.

If you have a child with autism who struggles with sleep issues, follow the strategies outlined above. If you don't see progress over time, be sure to consult a medical professional.

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# AUTISM AND REGRESSION

## What Parents Need to Know

Kourtney Christopher, M.Ed.

Christina Toolan, Ph.D.

Catherine Lord, Ph.D.



It is amazing to watch toddlers grow and gain new skills. They have a seemingly effortless ability to learn and develop. When the opposite occurs, however, and previously obtained skills are lost, it can be a terrifying experience for parents. Such a loss is known as “regression” and refers to the loss of skills that had previously been reliably established. While there are normal ups and downs in children’s development as they grow, a consistent loss in skills for at least one month is cause for concern. In autism spectrum disorder (ASD), a regression can occur in many different areas, including language, social, self-help, or motor skills. Parents most often report losses in children’s language and social skills. While regression is not common in typically developing children, it is reported to occur in about one-third of children diagnosed with ASD.<sup>1</sup>

## The When and Why of Regression

Rather than following one path, regression appears to have several trajectories. In most cases of autistic regression, parents report that the loss begins mid-way through their child's second year of life.<sup>1</sup> While cases of sudden loss of skills have been noted, it is more common for children to gradually lose social interest over time. This loss plateaus in the first few years of life.<sup>2</sup> Since the onset of regression coincides with the time when children typically receive the measles, mumps, and rubella (MMR) vaccine, some have wondered if there is a causal connection between the two. A great deal of evidence, however, has shown that the MMR vaccine does not cause autism.<sup>3</sup> The cause of regression in ASD is not well understood at this time, but it is likely linked to interactions between biological and environmental factors.<sup>4</sup>

There are very rare situations in which regression is noted in children at around three to four years of age. These cases tend to be related to losses in motor functioning, such as hand coordination, and can involve the loss of other skills, including toileting. If children experience a loss of motor skills around that age, especially the purposeful use of their hands, parents are strongly advised to seek assistance from a neurologist. The loss could be related to a number of very rare disorders, such as Rett syndrome, Landau-Kleffner syndrome, or other degenerative conditions.<sup>4</sup>

## What to Do if Children Regress

We know that children should learn, grow and develop new skills. At the same time, it is important to remember that children are undergoing significant changes, and that their skills can vary from day to day or week to week. However, if parents feel that their child is consistently losing skills, particularly those related to social interaction or communication, they should recognize that this is not part of typical development and seek medical advice immediately. Parents may wish to track skills they are concerned about by writing down examples or recording videos to share at upcoming visits with their pediatrician or family physician. They could also request a referral to a specialized provider, such as a developmental-behavioral pediatrician.

## Supporting Children Who Regress

Parents of children who regress should seek out behavioral treatments that address the areas of need. These could be interventions such as naturalistic developmental behavioral interventions (NDBIs), which are play-based and mediated by therapists or parents. NDBIs are behavioral treatments that are child-led, implemented in natural settings, and use contingent reinforcement to teach children developmentally and behaviorally appropriate skills, such as joint attention, play, and social communication.<sup>5</sup>



Children who experience a regression, particularly in language, do not necessarily have worse developmental outcomes than children without regression.<sup>6</sup> It is important to note that children with regression can regain some, if not all, of their lost skills. For example, one study found that over 75 percent of the children who regressed did regain their lost skills.<sup>7</sup> Children who lose their skills early in life and regain them quickly also tend to have better outcomes.<sup>8</sup> However, in the case of later regression between three and four years of age, children are less likely to regain their skills. Though it is rare, some children will never regain lost skills.<sup>9</sup>

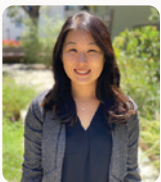
It can be very challenging and stressful for parents if their child is experiencing a regression. That's why it is critical to address and support parent well-being and mental health. Practitioners should be aware of these needs and prepared to help both children and other family members find the appropriate resources and manage expectations. Parents who are supported are more likely to be able to help their children access much-needed resources.

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# Improving Healthcare Transitions

for Autistic Individuals

Brittany Hand, Ph.D

Healthcare systems can be complex and difficult to navigate, particularly for autistic individuals and their family members. While supports and services for autistic individuals vary, they commonly include speech language therapy, occupational therapy, psychology, pediatrics and many others. A pediatrician often guides the care for an autistic child. After many years of working together, autistic children and their families may develop a close and trusting relationship with their pediatrician. Over time, the pediatrician comes to know and prioritize a child's needs. A significant challenge arises, however, when a child becomes an adult and no longer qualifies to be seen by a pediatrician. How does medical care change when an autistic individual transitions from pediatric to adult healthcare?

This transition time is sometimes referred to by researchers as “the services cliff.” The supports and services that were in place for the autistic child and family rapidly disappear when the child turns 18 or 21, depending on the service. This leaves many autistic young adults and their family members at a loss as to what to do and where to go for support.

More people are now being diagnosed with autism. The healthcare needs of autistic people do not stop when they reach age 18 but carry on into adulthood. The most recent data from the Centers for Disease Control and Prevention (CDC) estimate that there are about 5.5 million autistic adults in the USA.<sup>1</sup> This is a little over two percent of all adults in the country. We also know that each year, about 50,000 autistic individuals turn 18 and are in need of adult services.<sup>2</sup> By the year 2050, there will be an estimated 5.8 million autistic individuals in the USA.<sup>1</sup> It is clear that falling off “the services cliff” is a national problem that must be addressed.

## Main Challenges

To advocate for change and to give parents the tools to ease the transition for their teens and young adults, it is important to be aware of some of the main challenges. These can include the following barriers.

- There are too few healthcare providers who are knowledgeable about autism, and who are willing and able to provide evidence-based, patient-centered care for autistic adults.
- Autistic adults are more likely to be unemployed or underemployed than non-autistic adults, which means they often have inadequate access to health insurance to cover their medical expenses.
- System level barriers can be an issue, including offices and clinics that do not provide sensory friendly environments.
- The health care system can be very difficult to navigate, especially for autistic individuals who may have multiple specialty providers for different healthcare needs.
- The stigma and ableism that are ingrained in the US healthcare system can be a challenge for many autistic individuals.

## Receiving the Best Care

Ideally, when an autistic person approaches the age of 18, the pediatrician will connect that individual to a **local adult primary care physician** who would be an effective and qualified provider. If such guidance is not forthcoming, it is important for parents to advocate for their pediatrician to make this recommendation.

A **team-based approach** is becoming a popular and successful route of care for autistic adults. This involves a group of healthcare providers that is led by a professional, such as a physician or psychologist, who has expertise in working with autistic adults. In a complex and segmented system, this could provide autistic young adults with a “one-stop shop” for many of their healthcare needs. While this is the standard of care in some areas, in others the infrastructure for this type of care has not been put in place. Parents should look for local clinics that use a team-based approach as it will simplify the healthcare process for their young adult.

If parents and teens cannot find a clinic with a team-based approach or an adult primary care physician in the area who has experience working with autistic people, they may need to discuss their needs with their local adult provider. A particularly helpful starting point for this discussion with the provider might be the personalized accommodations report from Academic Autism Spectrum Partnership in Research and Education (AASPIRE). The AASPIRE website also has information for healthcare providers, such as a guide for caring for patients on the autism spectrum (see resources below). Parents and teens could also direct the physician to these resources.

Unfortunately, we know there are too few adult healthcare providers who have experience working with autistic individuals. Our research group and others are working on developing autism training for physicians and other healthcare providers. In the future, we expect there will be more providers who can provide high-quality care for autistic adults as such training becomes more widespread and embedded into healthcare provider education programs.



## Setting Young Adults Up for Success

It is vital to start thinking about the healthcare transition early. When children become teenagers, they should be encouraged to increase their involvement in healthcare skills. This can be difficult for many parents and caregivers as they have taken full responsibility for their children's care for so long. Giving teenagers the opportunity to take on some of that responsibility will build important skills of independence and prepare them for transitioning to adult healthcare. Consider using the following strategies to prepare teenagers for this transition.



**Medication Management** — When age-appropriate, help teenagers become more independent about taking medication. Set a timer to know when to take the medicine, and allow teenagers to assist in dividing the medications into daily portions. Teach teenagers how to get a medication refill.



**Communication with Providers** — Encourage teenagers to participate in doctor's visits, and have them ask questions of the provider. Also allow them to answer questions, as appropriate. Before the visit, practice making a list of questions and talking points that they want to discuss with the provider.



**Word-of-mouth Referrals** — Connect with other individuals in your local autism community. Ask autistic young adults and their families what doctor they see and how satisfied they are with their provider's knowledge and experience in autism. Connecting with these families early can help you be prepared for your child's transition to adult healthcare.



**Appointments** — Provide opportunities for teenagers to practice scheduling their own healthcare appointments. This might mean having them make a phone call or learning how to schedule an appointment online.



**Accommodations** — Think about what types of accommodations might benefit your teen, and ask potential adult providers about their ability to provide them. For example, it may be helpful for some teenagers to stop by the office before their actual visit to help them know what to expect, or to be taken straight to an exam room when they arrive for the visit. A great tool for identifying other possible accommodations for visits is the AASPIRE personalized accommodations report highlighted below.

## Looking Ahead

It is well known that the prevalence of physical health conditions, such as high blood pressure, diabetes and epilepsy, and of mental health conditions, such as depression and anxiety, is higher in autistic adults than it is in non-autistic adults.<sup>3</sup> When such conditions are unaddressed or under-addressed, there can be serious consequences. Using available supports and accommodations can help autistic people get the medical care they need to thrive and succeed as they transition into adulthood. I encourage parents and caregivers to research and read about the ways that they can set their young adults up for healthcare success as they transition from pediatric to adult healthcare.

## Resources

### Asperger/Autism Network (AANE)

Here you will find a list of supports and services for autistic adults.

<https://www.aane.org/resources/adults/>

### Autistic Self Advocacy Network

This is a list of resources including a number of toolkits and educational materials that are relevant to healthcare.

<https://autisticadvocacy.org/resources/>

### Academic-Autistic Spectrum Partnership in Research and Education (AASPIRE)

This is an excellent website with resources for autistic individuals and their supporters, including worksheets to help identify accommodations for healthcare. There is also information for healthcare providers to learn more about providing care for autistic adults.

<https://autismandhealth.org/>

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# BALANCING WORK, HOME, LIFE AND SELF

Chisato Hotta, DSW, LPCC, LMFT

When my twin boys were diagnosed with autism spectrum disorder, my husband, Yuki, and I agreed that we would do everything in our power to help them reach their potential and become the best adults they could be. We weren't sure what that would mean for the boys, but we were committed to supporting them and helping them grow.

In 2019, my husband decided to go back to school. He enrolled in a master's program in statistics at California State University Long Beach. He wanted to show the boys the importance of setting goals and working towards them. He worked very hard at balancing school, a part-time job, and family life. At that time, I was working two jobs and decided it was important for me to also focus on my education. As a result, I enrolled in a doctorate of social work program at the University of Southern California.

To add to our chaos, we suffered a great loss in December 2020. A person who was a key part of our support system passed away suddenly. We had to switch gears. Yuki found a full-time job and continued his studies, while I found a more flexible full time job. We did all of this while grieving.

Life can be hard. Trying to balance work, home, our relationship, the boys and everything else, stretched us to our limits. As a licensed marriage and family therapist and a professional clinical counselor, I know all about the importance of self-care and balance. I don't just teach others about these topics, I also try to practice them in my own life. Here are some things that my husband and I do in order to find that balance.

**Take time for yourself.** Both my husband and I take time to exercise every day. We take turns leaving the house to go biking or walking. We make time to reset and ground ourselves.

**Breathe.** It is important to pay attention to our breath. Is my breathing shallow, fast, slow or deep? Am I breathing from my chest or my stomach? I also set aside a few minutes to sit and take some deep, mindful breaths. After placing one hand on my stomach and one hand on my chest, I concentrate on breathing in for four seconds, holding it there for three seconds and breathing out for six seconds. As I do so, I move my bottom hand and keep my top hand as still as possible.



**Sing!** When I notice myself getting flustered or annoyed, I sing instead of yelling at the boys. It can be a song that I like, or even one that I've made up. For example, I could sing "The boys are about to get in trouble, trouble, trouble; the boys are about to get in trouble..." The boys often take over at this point and sing something like, "no, no, no" or "I don't want to get in trouble, trouble, trouble..." I usually end up laughing.

**Laugh.** I know this is hard to do when you are overwhelmed. I try to find funny videos, even if they are just short clips, or talk to people who are funny. I will also laugh at my own mistakes.

**Practice gratitude.** I start every day by thinking of three things that I am grateful for. They can be small or big things, like sunshine, my purring cats, the boys' laughter, or the gift of another day.

**Practice mindfulness.** It can be easy to think of all of the things that we have planned for today or for the next week, month or year. However, this tends to take away from the here and now. Many times, planning and worrying about those things can be a source of stress. I try to focus on what is happening right now, in this moment. What am I feeling right now? If that is hard to figure out, I do five senses meditation. I look around the room and quickly name five colors that I see, four things that I hear, three things that I feel on my body, two things that I smell, and one thing that I taste.

**Spend time with your partner.** If you have a partner, spend time together as partners, not just as parents. After the boys have gone to bed, my husband and I have dinner together and compare notes on the high points and the low points of the day. It helps to just check in with each other and to look at the good and bad together. We also make a point of not talking about the boys when we spend time together. It is too easy to get swept up into just being parents. While it is an important role, it is not our only role in life. Encourage and grow those other parts too.

**Learn how to say "no."** I used to say "yes" to everything. I noticed that when I did that, however, there was a cost to me and to my family. I could not help my boys and my family if I was tired and burned out. I learned to consider my own interests, and those of my family, before responding to any request. I would reflect on whether I wanted to do what was asked of me, and if the request was realistic. Would I find something in this activity that I would like or love? If the answer was "no," then my response would be in the negative. On the other hand, if I did agree to the request, I would find a way to set some realistic boundaries.

While there are many other things that we do as a family, these steps are a good place to start. Doing the little things every day that help us find balance moves us toward being whole. Each one of us is important, and it can be so easy to forget that. Balance is key.



Chisato Hotta, DSW, LPCC, LMFT, is a licensed marriage and family therapist, licensed professional clinical counselor and a doctor in social work. Dr. Hotta currently is a senior program supervisor at a mental health non-profit where she is able to support the amazing program directors, supervisors, clinicians and more. Dr. Hotta also works part time as an adjunct professor, therapist, and a consultant for a collaborative court program. She also gives trainings on mental health, autism, commercial sexual exploitation of children and more. Her husband, Yuki, has a master's degree in statistics and is an associate risk and data analyst. Dr. Hotta is also a mom to twin boys who are both on the autism spectrum and are her world and light. She tries to blend being a mental health provider and being a mama in her Instagram and Facebook.

Facebook: <https://www.facebook.com/465214584037700/>  
Instagram: @therapistmamabear

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# THE PLACENTA

## A POTENTIAL EARLY CLUE TO AUTISM

This article is a review of the following research: Zhu, Y., Gomez, J. A., Laufer, B. I., Mordaunt, C. E., Mouat, J. S., Soto, D. C., Dennis, M. Y., Benke, K. S., Bakulski, K. M., Dou, J., Marathe, R., Jianu, J. M., Williams, L. A., Gutierrez Fugón, O. J., Walker, C. K., Ozonoff, S., Daniels, J., Grosvenor, L. P., Volk, H. E., Feinberg, J. I., ... LaSalle, J. M. (2022). Placental methylome reveals a 22q13.33 brain regulatory gene locus associated with autism. *Genome Biology*, 23(1), 46.

Since autism is a behavioral condition, it is often not diagnosed until children are three or four years old.<sup>1</sup> Many believe, however, that children would benefit if intervention could begin before receiving a final diagnosis. If it were possible to identify autistic children at birth, parents would be able to intervene during infancy and the critical years of rapid development. Unfortunately, the lack of an “autism gene,” identifying physical features, or blood markers means that autistic children cannot be identified at birth. A team of researchers from the UC Davis MIND Institute decided to examine the placenta to gain clues about a child’s development while in the womb.

The placenta develops in the uterus during pregnancy. It is an organ that attaches to the wall of the uterus and then connects to the baby through the umbilical cord. In addition to regulating the supply of oxygen and nutrients to the baby and removing waste products from the baby’s blood, it also provides hormones and neurotransmitters that are critical for the developing brain.<sup>2,3</sup> During pregnancy, it is common for the fetus to experience oxidative stress, something that happens when an individual’s antioxidant levels are low. The placenta is important in regulating oxygen levels, but excessive oxidative stress can affect brain development in the fetus.<sup>4</sup>

By studying the process by which genes are turned on and off, or methylation, in important genes in the placenta, researchers can gain clues as to what happened during pregnancy, including any incidents of excessive oxidative stress. This allows them to identify critical events that happened in the womb and that may give molecular clues to a child’s future outcomes, including the presence of disorders such as autism.<sup>5,6</sup>

A research team led by Dr. Janine LaSalle examined the placentas of children who later went on to develop autism. The researchers hoped that identifying significant differences in the placentas would help facilitate early detection of autism.

## Study

### Part 1 - DNA Analysis

The researchers studied the placentas of 204 children who had at least one older sibling with autism and who were thus considered high-risk. They extracted and quantified DNA from the placenta tissue and used whole genome bisulfate sequencing (WGBS) to investigate the DNA of the placental samples.

### Part 2 - Prenatal Vitamin Investigation

The researchers were able to collect data for 77 participants to determine if prenatal vitamins were taken during the first month of pregnancy, a key developmental time period for the fetus.

## Results

### Part 1

- The researchers discovered a new gene, *LOC105373085*, which they renamed neuronal hypoxia inducible, placenta associated (*NHIP*). It is located on chromosome 22 (22q13.33) and is expressed in the brain. It responds to oxidating stress and also influences other known autism-risk genes.
- *NHIP* was **less methylated** in the placentas of children who were later diagnosed with autism. With less *NHIP*, the fetus would not be able to respond as well to oxidative stress and would be at higher risk for developmental delays.
- The team discovered 134 genomic regions (183 genes) — many of which are linked to autism — that had different methylation patterns in autistic children. Twelve of the regions with significantly low methylation levels were located in 22q13.33, the same region as the newly discovered gene, *NHIP*.

### Part 2

Mothers who reported taking prenatal vitamins in the first month of pregnancy had placentas with higher levels of methylation in 22q13.33 compared to mothers who did not take prenatal vitamins. Taking vitamins could provide essential elements to counteract the genetic differences that cause a person to have reduced *NHIP*.

## NHIP

- expressed in the brain
- responds to oxidative stress
- influences known autism-risk genes
- protects early fetal brain development
- less methylated in placentas of children with autism

## Conclusion

While genetic research, methylation, fetal development, and autism spectrum disorder are all complex topics, it is important that parents and caregivers stay up-to-date on the latest research initiatives. This research made some significant advances in increasing our understanding of autism.

Researchers in the study found a new gene that is linked to autism. Low levels of this gene in the placenta could indicate a child is at a higher risk of developing autism. Researchers also found that prenatal vitamins could increase levels of the newly discovered gene, *NHIP*, which helps to combat oxidative stress and improve fetal brain development while the fetus is in the womb. Prenatal vitamins are an essential consideration when planning a pregnancy.

More research is needed to gain a better understanding of the newly discovered gene. In the future, the placenta of every child could be analyzed to determine the child's risk of developing autism. Researchers will also investigate if *NHIP* could be given as a medicine to lessen the impact of excessive oxidative stress on the developing fetus.

Written by Autism Advocate Parenting Magazine

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# THE LATEST RESEARCH ON **AUTISM** AND **INTELLIGENCE** **QUOTIENT**



This article is a review of the following research: Katusic, M.Z., Myers, S.M., Weaver, A.L., Voigt, R.G. IQ in Autism Spectrum Disorder: A Population-Based Birth Cohort Study. *Pediatrics*. 2021 Dec 1;148(6):e2020049899.

The term Intellectual Disability (ID) is used to describe an individual who has deficits in intellectual functioning, adaptive living skills, and conceptual learning.<sup>1</sup> On standardized tests, ID is defined as an Intelligence Quotient (IQ) below 70. Research has shown that ID commonly co-occurs with autism. In fact, the Centers for Disease Control and Prevention estimated in 2021 that 35 percent of children with ASD were also diagnosed with ID, or an IQ of less than 70.<sup>2</sup>

Many experts assert that it is very challenging to distinguish ID from autism spectrum disorder. ID can come with significant developmental delays, including social differences — one of the core traits of autism. It can also be difficult to assess the intellectual level of an autistic individual who is minimally verbal or nonverbal. Since about 30 percent of children with autism are minimally verbal, one cannot assume that these children have below average IQs just because they perform poorly on standardized tests. In fact, a 2016 study reported that about half of minimally verbal children with autism have an IQ higher than would be expected given their communication difficulties.<sup>3</sup> These complexities have led many autism researchers to avoid distinguishing between the two conditions.

Despite such challenges, it can be important to identify if children have intellectual disability or an above average IQ in addition to autism. It will help professionals provide appropriate supports and resources that can assist children in their therapy and in the school system.

Dr. Maja Katusic led a research team that sought to find answers about the relationship between autism and ID. The aim of the study was to acquire accurate information on autism and ID using a range of data sets, including those on clinically diagnosed individuals.

## Study

The study looked at medical records, school records and behavioral records for 31,220 individuals born between 1976 and 2000 in Olmsted County, Minnesota. The researchers identified children who met the criteria for autism spectrum disorder (ASD) by analysing behavioral data and assessments, school records and clinical diagnoses.

A determination of Intellectual Ability was based on the last IQ score or on documented diagnoses of intellectual ability. Intellectual Disability was defined as a score of 70 or less on a properly administered and scored IQ test. The average range of IQ tests scored in the United States is between 85 and 115, with 86 being the average score. For the purposes of this study, average or higher IQ was defined as a score of 86 or more.

## Results

The research team analyzed the data of participants who were identified as having autism through medical and school records, as well as participants who had received an official diagnosis of autism from a clinician.

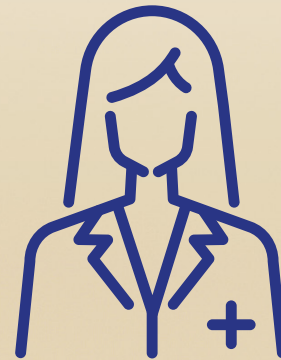
The following were the main findings of the study.

## Intelligence Quotient Levels

- Moderate to Profound ID (IQ < 50)
- Mild ID (IQ 51-70)
- Borderline ID (IQ 71-85)
- Average IQ (86-115)
- Above Average IQ (116-130)
- Superior IQ (>131)



Between  
**51%** and **59%**  
of those identified with  
ASD through **medical  
and school records** had  
average or higher IQ.



**43%**  
of those with a **clinical  
diagnosis** of ASD had  
average or higher IQ.



**BOYS**  
were more likely than  
girls to have average  
or higher IQ.

## Conclusions

Other recent studies showed that only 29 to 42 percent of autistic children had average or higher IQs.<sup>4,5,6,7</sup> This research, however, suggests that the number could be much higher. It is worth noting that this research found the percentage of autistic children identified by clinicians with average or higher IQs was only 43 percent. By comparison, the percentage of autistic children who were identified through medical and school records was as high as 59 percent. This points to the possibility that individuals with a below-average IQ are more easily identified by clinicians, and that those with higher IQs are more likely to be overlooked by clinicians and even parents.

This research also found that autistic boys are more likely to have higher IQs than autistic girls. It is possible, however, that many autistic girls with higher IQs are simply being overlooked or are able to mask their autistic traits.

Given that the measure of intellectual ability is commonly assessed through IQ tests, it is worth asking if these standardized tests are appropriate and reliable to make such assessments in those who are nonverbal or minimally verbal. It is important for intelligence testing to continue to evolve. Some research teams are developing an iPad-based tool for those with communication difficulties.<sup>8</sup> Others are investigating eye tracking technology as a means of answering questions on standard IQ tests.<sup>9</sup>

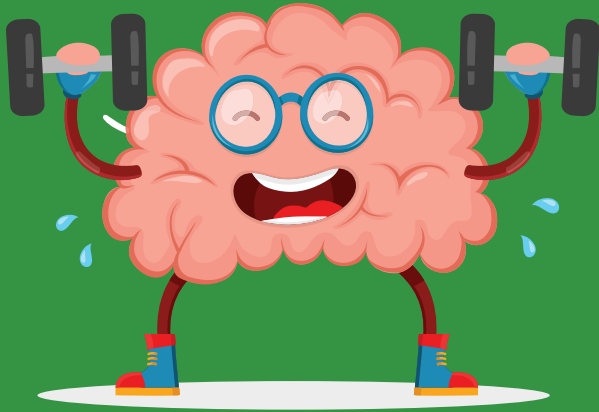
This research highlights the fact that there are likely more autistic individuals with average or higher IQ than previously thought. Such individuals may be unidentified or under-supported. Society and clinicians need to move away from the stereotypical image of an autistic individual seen in the past and move towards a broader vision. For their part, parents and caregivers should understand their children's intellectual ability since autistic children with average or higher IQs have the same need for social and emotional supports as those whose IQs are below average.

Written by Autism Advocate Parenting Magazine

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# Autism Advocate Printable Resources

## Developing a Growth Mindset

Autistic children, teenagers and adults all tend to be at higher risk for low self-esteem and a negative mindset about their abilities. This comes as no surprise since autistic children are constantly being reminded from an early age of the many challenges that accompany an autism diagnosis by being placed in therapies, support groups and special education classrooms.

It is common for autistic children to get stuck in negative thought patterns that are unhelpful and harmful. They sometimes spend too much time focusing on their challenges and not enough on their strengths. Parents should seek to create a positive mindset and teach their children how to be confident, how to manage mistakes and how to work towards improvement.

### What is A Growth Mindset?

The concept of a growth mindset was developed by Dr. Carol Dweck, a world-renowned psychologist at Stanford University. It aims to help children and teens — both with and without autism — look at problems and challenges with a positive attitude. Her work identifies what are known as **fixed** mindsets and **growth** mindsets. People with a fixed mindset believe that their intelligence and abilities are fixed traits that cannot be altered. This leads them to see mistakes as failures and to experience fear and anxiety when faced with new experiences. People with a growth mindset understand that their abilities can be developed through a combination of effort, persistence and the right strategies. A growth mindset fosters learning and a willingness to confront challenges and do hard things.

**"A GROWTH  
MINDSET FOSTERS  
LEARNING AND  
A WILLINGNESS  
TO CONFRONT  
CHALLENGES  
AND DO HARD  
THINGS."**

### Developing a Growth Mindset

The following are simple strategies that you can use to change your child's negative thinking patterns into positive and productive ones.

#### 1. Language is Important

Surround yourself and your children with reminders of the growth mindset way of thinking. Post positive phrases on your fridge, and talk about them often. Encourage everyone in your home to use positive phrases, and ask your children's teachers and support workers to use them. Praise your children when they use them. Talk about the things you can control and the things you cannot control. This helps children understand the areas in which they should put added effort and those that do not need to be a focus of attention.

#### 2. Praise Effort

Praise your children for perseverance and hard work. Let them know that every time they practice, they are building their skills. Remind them that it's okay to make mistakes because that is how we learn. Show an interest in your children's efforts and ask questions about their progress and challenges.

#### 3. Give Positive Reinforcement

Create a reward chart so that recognition is given every time your children engage in positive self-talk, use growth mindset phrases, take a risk, try something new, or accomplish something difficult.

#### 4. Encourage Risk-taking

Encourage children to try something new and to see challenges as a learning experience. Remember that children will learn when they are out of their comfort zone, so don't be too quick to rescue them from a difficult situation. Give them time to consider the challenge and to ask you questions on how to move forward.

### 5. Model a Growth Mindset

Let your children know when you find something difficult. Try new and challenging things together. Set an example by avoiding fixed mindset phrases, and always trying to use growth mindset phrases. The actions, words and mindsets of parents have a significant effect on children.

### 6. Reframe Mistakes

Instead of getting upset when a child spills some milk, say “I’m proud of you for trying to pour your own glass of milk.” Help your children see mistakes as an opportunity to try again and to learn from the things that went wrong. Create an environment in which mistakes are accepted rather than assailed.

### 7. Take a Break

Changing your own mindset, as well as that of your children, can take a tremendous amount of effort. Be patient with yourself and your children. Take a break when needed.

Working towards developing a growth mindset in your home will make a big difference. Help your children turn negative thinking into positive and productive thoughts. You can do it!

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# DEVELOPING A GROWTH MINDSET

## INSTEAD OF SAYING....

## TRY THINKING ...

I can't do this → I'm still learning

I give up → I'll try a different way

This is too hard → It'll get easier with more practice

I made a mistake → Mistakes help me to learn and grow

I'm not good at this → I am not good at this yet, but I will learn

I don't know how → I can learn how

This is good enough → Can I do better?

They are better at it than I am → What can I learn from them?

I can't make this any better → I can always improve

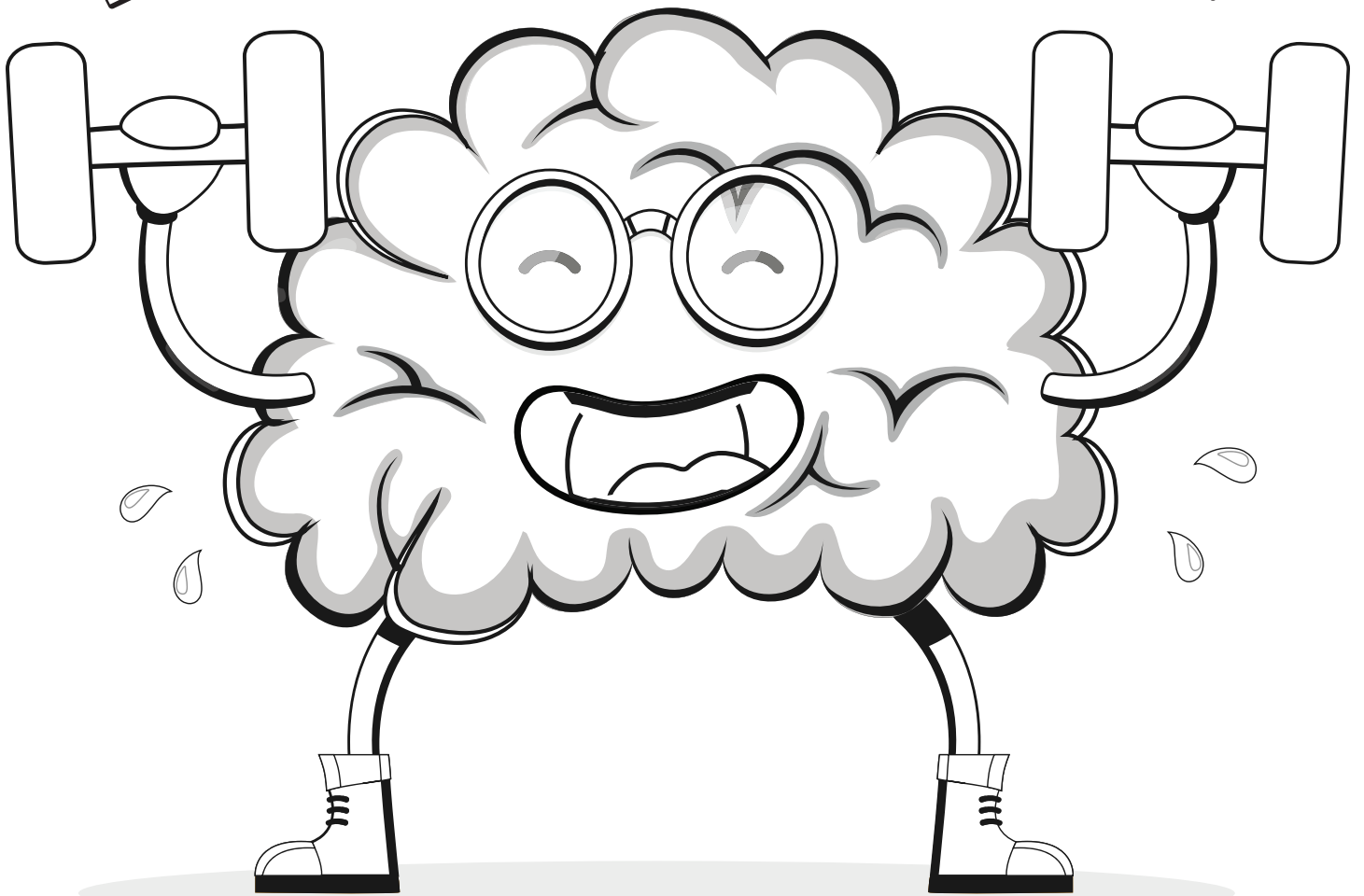
Plan A didn't work → There's always plan B



# THINGS I CAN'T CONTROL



I CAN GROW



MY BRAIN!



# Almond Cookies

## INGREDIENTS

vegan butter .....	½ cup
coconut oil .....	⅓ cup
brown sugar .....	½ cup
flax eggs .....	2
baking soda .....	½ tsp
salt .....	½ tsp
almond flour .....	3 cups
chocolate chips.....	1 cup

## INSTRUCTIONS

Set oven to 350° and allow to preheat. In a large mixing bowl, combine vegan butter, coconut oil and sugar, and mix until smooth. Add the flax eggs, and mix until just combined. Add the baking soda, salt and almond flour, and mix until a dough forms. Add the chocolate chips. Spoon 1-tbsp balls of dough onto a parchment-lined baking sheet and bake for 8 to 12 min. depending on how soft or crisp you like your cookies. You do not have to wait for the cookies to appear golden brown.

Remove the cookies from the oven and allow them to cool before eating.



I'm David Chapman and I am an artist, father of five kiddos, and the 'cook' at home. I prepare food that is healthy and tasty without gluten for my family and amigos. I like being in charge of the fridge and groceries, and I try to keep the best and freshest ingredients nearby for us and the kiddos.

The need to eat quickly turned cooking and baking into hobbies for me, and having family members with sensitivities to gluten while being picky eaters (some of them) challenged me to prepare food that is healthy for them while still being tasty.

Feeding a family three times a day can be daunting. For a while, I felt like a "stay-at-home-COOK!" But it doesn't need to feel that way. Cooking and baking without gluten or casein are really very simple. I like to share ideas and ways to prepare food that is healthy and, of course, tasty, without gluten. Follow me on instagram for more great recipes: @Tasty\_without\_gluten

*Happy Cooking!*

# AUTISM ADVOCATE

## PARENTING MAGAZINE

# 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](http://www.rwltc.com)

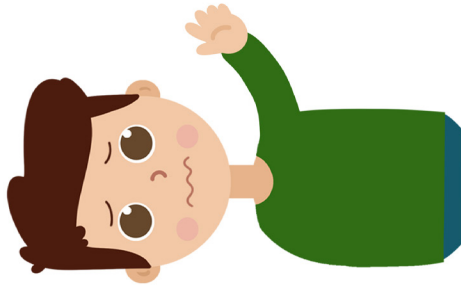
[robyn@rwltc.com](mailto:robyn@rwltc.com)



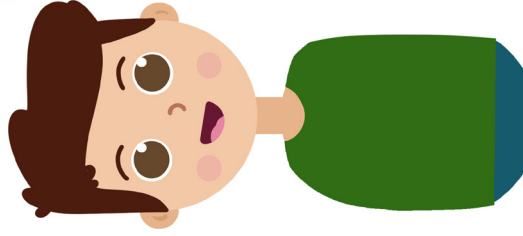


My Social Story:

**I Don't  
Always Get  
What I Want**

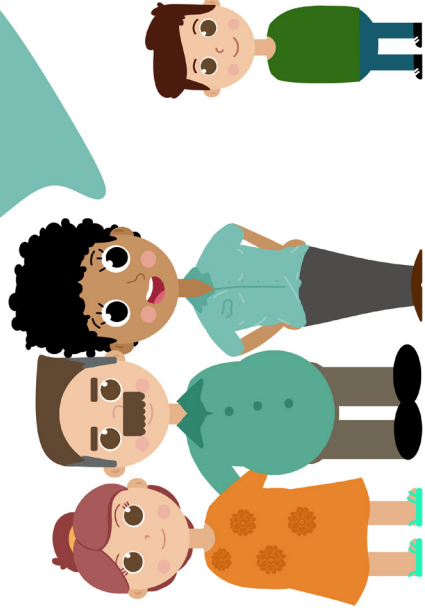


Can I please  
have it?



1

Yes, you can!

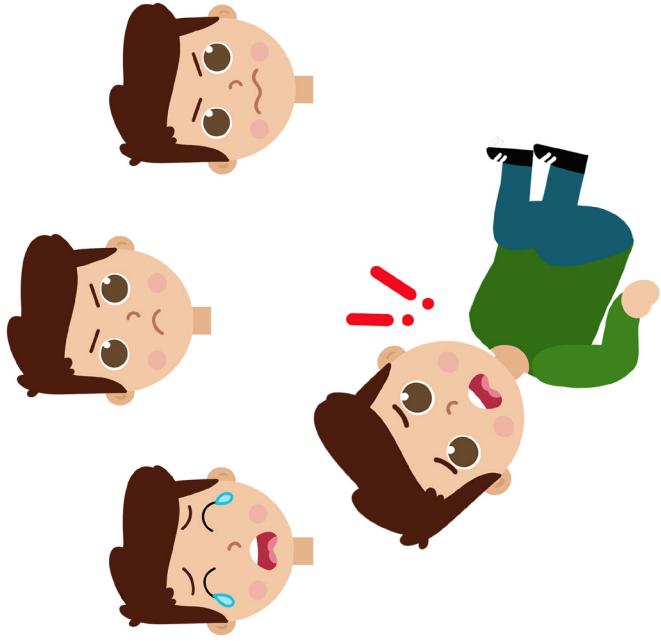


No, you can't.



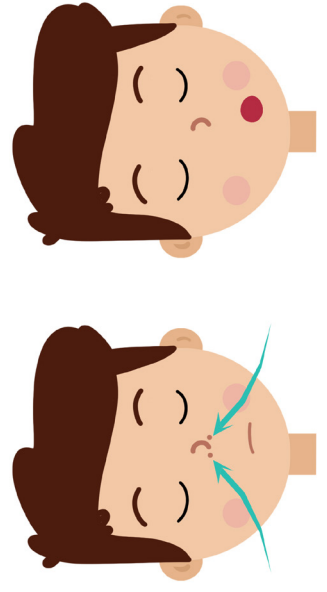
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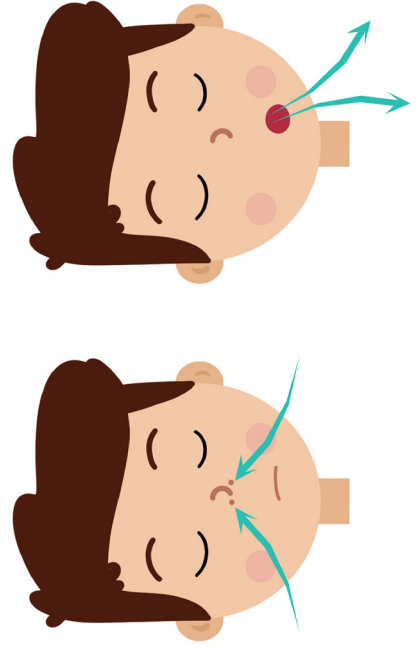


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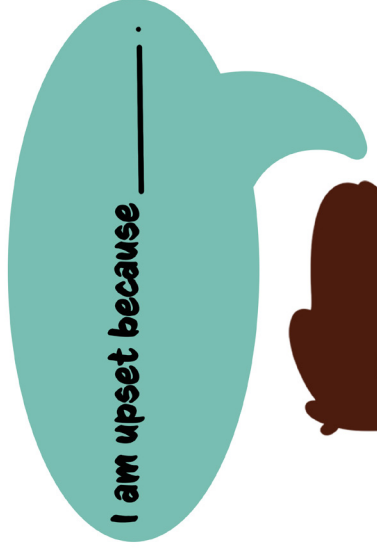
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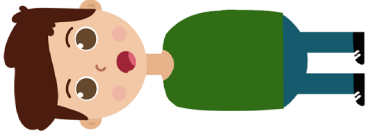
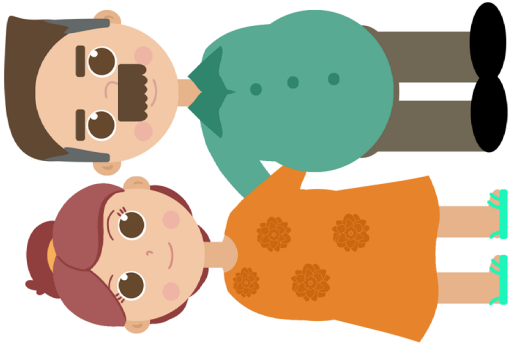


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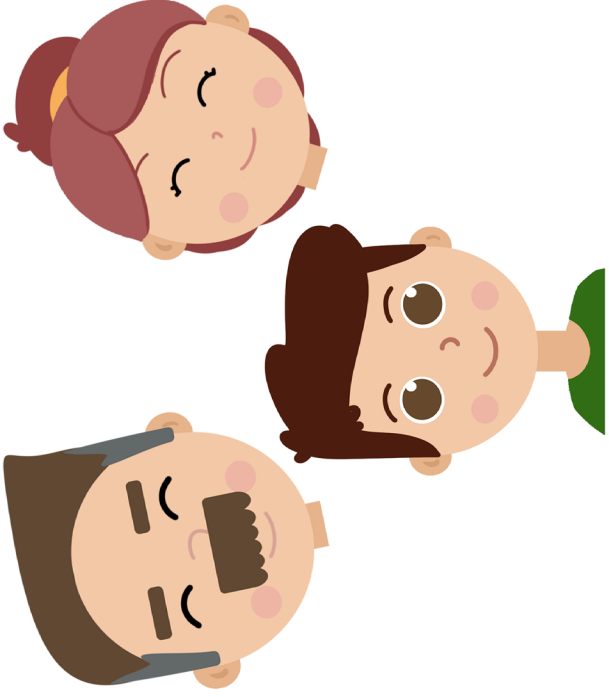


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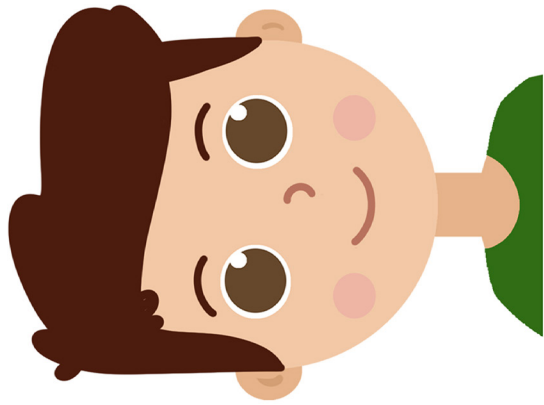
Can I have it  
later, please?



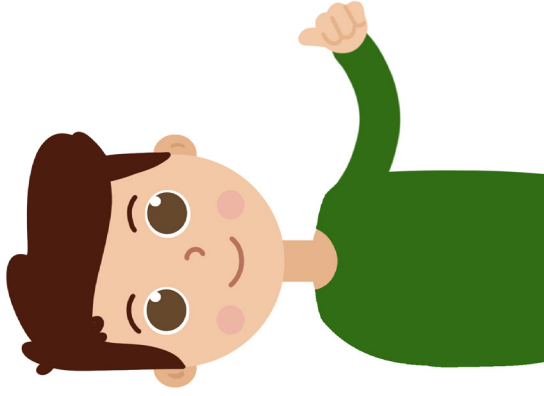
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My Social Story:

# I Don't Always Get What I Want

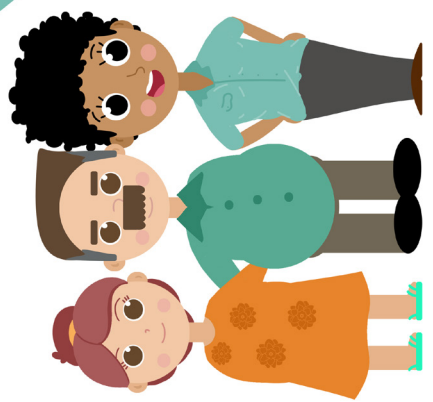


Can I please  
have it?

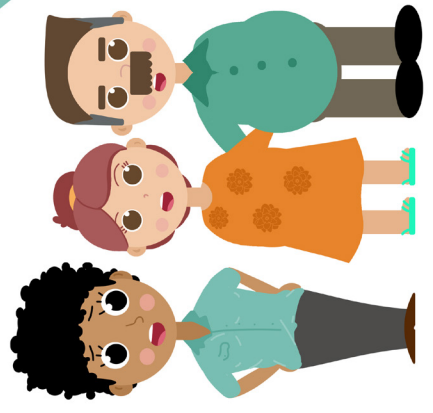
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Yes, you can!

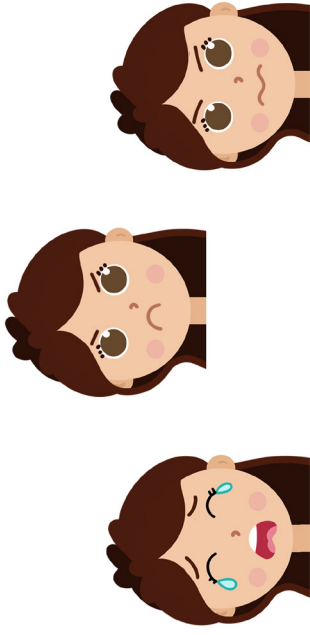


No, you can't.



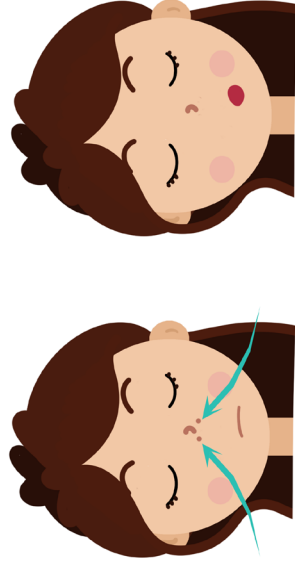
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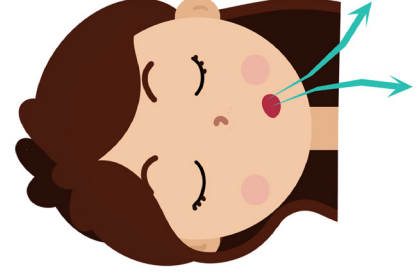
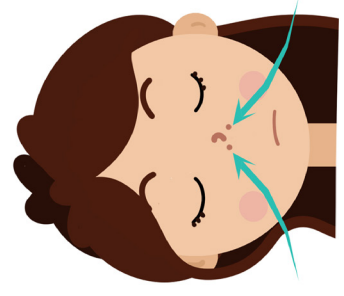


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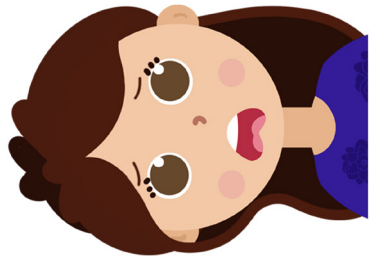
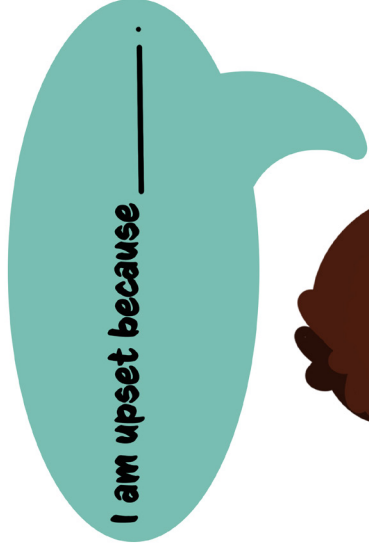
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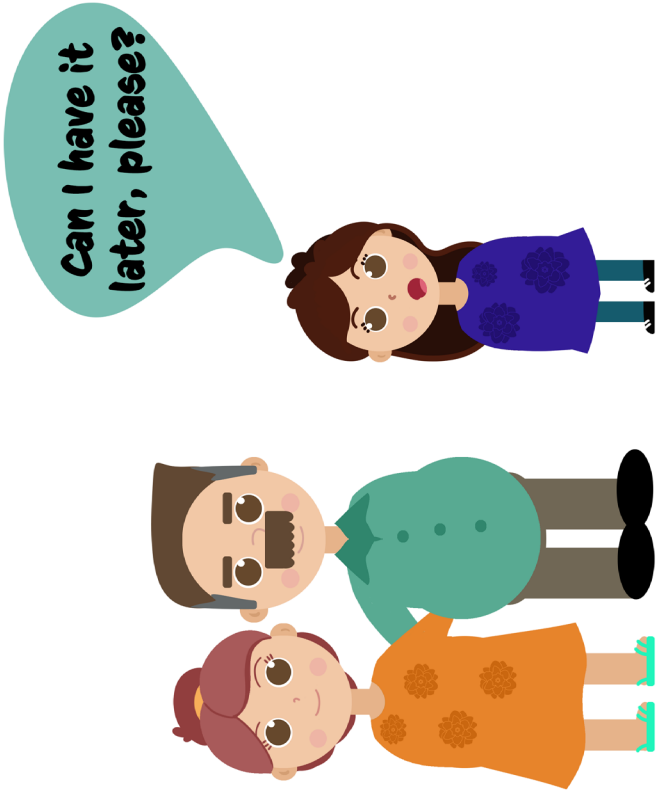
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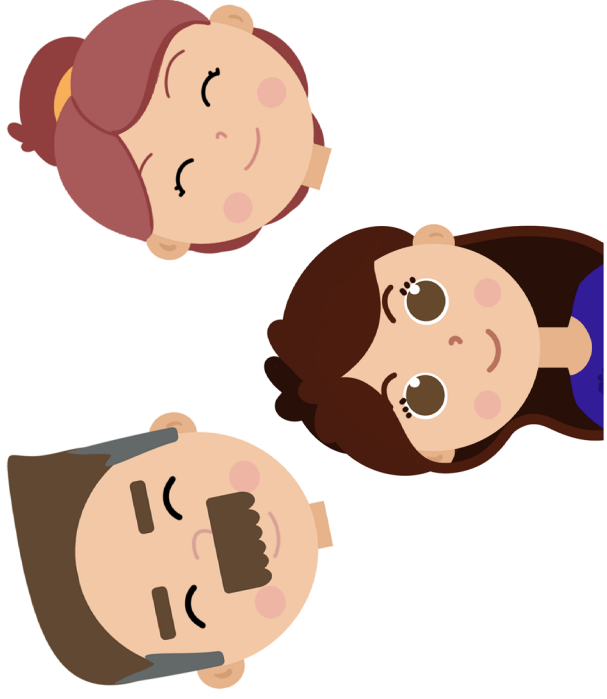
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11

# My Next Steps

*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

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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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"Believe You Can  
and  
You're Halfway There."

— Theodore Roosevelt



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