ISSUE 31

FOR PARENTS & PROFESSIONALS

AUTISM ADVOCATE

PARENTING MAGAZINE


ADHD
Aggressive Behavior
Art Therapy
Affection
Amygdalas in ASD
Electronic Addiction
Apraxia
Communication
DIRFloortime
Anxiety
ASD Severity Over Time
Diagnosis
Autism in Young Children
College/University Transition
Developing Skills
Cerebral Folate Abnormalities
Cognitive Behavioral Therapy
Dating/Romantic Relationships
Executive Function
Fragile X
Detox
Embracing Differences
Gastro Intestinal Issues
Family
Employment
Enzymes
Financial Resources/Planning
Tics
Gender Differences
Genetics of Autism
Gut-Brain Axis
Feeding/Oral Development
GI and Behavior
Therapy and Medication
Topics Covered
IN AUTISM ADVOCATE PARENTING MAGAZINE
Visual Schedules
Theory of Mind
Gluten-Free & Casein-Free
Hyperbarics
Global Perspective
Happiness
Social Stories
Technology
Integration
Hygiene
Teaching at Home
Medication
Mindfulness
Healthy Lifestyle
Independence
Learning Difficulties
Yoga
Hypersensitivity
Lyme Disease
Microbiome
Sibling Support
Motivation
PECs
Literacy
Nutrigenomics
Mitochondrial Dysfunction
Self-Care
Neurobiology of Autism
Mycotoxins
Music/Sound Therapy
Play Therapy
Safety
Occupational Therapy
PANS/PANDAS
Positive Reinforcement
Sensory Processing
Probiotics
Pre-Diagnosis Checklists
Selective Eating
Relationships
Self-Determination
Self-Injury
Thinking Traps
Self-Esteem
School/IEP
Sexual Abuse
Sports
Supplements
Severity of Autism Over Time
Stress Regulation
Taking Turns
Toilet Training
Transition to Adulthood
Visual Strategies
And so much more!

AUTISM ADVOCATE
PARENTING MAGAZINE

AAPM strives to foster a broad perspective on all topics regarding autism. To this end, we attempt to be as inclusive as possible with the views we present. These views may or may not reflect our own, but we include them in order to add to the reader's diverse knowledge and education on autism.

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.

EMPOWERING *Parent* ADVOCATES

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

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AUTISM ADVOCATE
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IN THIS ISSUE

Features

Research

Printable Resources

IMPROVING SENSORY ENVIRONMENTS for Autistic Children

Anna Hamlet, BSc Occupational Therapy, MSc Autism, PGCert Sensory Integration

Sensory processing differences are common in autistic children. They can experience hypersensitivity, or over-responsiveness, and hyposensitivity, or under-responsiveness, to a wide range of stimuli. Many autistic children experience both.

Autistic children are exposed on a daily basis to a variety of environments that have been designed by and for neurotypical individuals. Given the challenges that this reality implies, it is worth asking how we can contribute to improving sensory environments for autistic children.

First of all, it is important to remember that each autistic child is unique and that sensory processing differences can affect him or her in different ways. Wherever possible, we want to hear children's voices and to be guided by them. Some children are able to tell us about their sensory likes and dislikes and how they experience the environment around them. When children are not able to tell us, we have to be detectives and carefully observe their responses to sensory input.

Parents usually have a very good understanding of their child's sensory likes and dislikes. An Occupational Therapist can work with a child and a family to clearly describe the child's sensory needs, to support any environmental adaptations, and to utilise sensory strategies.

When supporting autistic children, we need to consider the sensory environment at home, school and in the community with the goal of helping children participate as fully as possible in all areas of life.

HOME

There are a number of steps that you can take to improve the sensory environment for your child at home. When evaluating and making changes to the sensory environment at home, consider your child's hypersensitivities and hyposensitivities across seven senses.

Visual (Sight)

- Does your child find bright daylight uncomfortable? Would blinds help reduce this effect?
- Does your child find bright artificial lights uncomfortable? Would a dimmer switch help?
- Do your lights flicker? Can they be replaced with LED lighting?
- Does your wallpaper have a distracting or busy design? Would plain wallpaper or paint be a better choice?

Auditory (Hearing)

- Can external sounds, such as traffic or dogs barking, be heard in your house? Would background white noise help to block these out?
- Are there distracting internal sounds in your house, such as the TV, music, bathroom fans, or a refrigerator hum? Can these be reduced? Are ear defenders available to your child?
- Is your child's bedroom located in a quieter area of the house?
- Can you create a quiet zone in the house?

Tactile (Touch)

- Does your child dislike the textures of certain household furnishings, such as carpet or wood floors? Can you replace the furnishings with a more tolerable option?
- Does your child find deep pressure calming? Can you use weighted items, such as lap pads, shoulder wraps and weighted teddies, with your child?

Olfactory (Smell)

- Does your child dislike certain food smells?
- Can you use a fan when cooking or open your doors and windows?

Gustatory (Taste)

- Does your child only eat foods with a limited range of flavours?
- Can you provide choices for snacks and meals that will reduce anxiety?
- Do you always have a stock of accepted or preferred food items on hand for your child?

Vestibular (Movement)

- Does your child need movement to self-regulate?
- Can you create space for your child to pace, run and jump?
- Can you provide an opportunity for your child to swing in a hammock or a rocking garden seat?

Proprioception (Body Awareness)

- Does your child seek body awareness input to self-regulate?
- Can you create a small space that your child can squeeze into? This could include a cosy corner or play tent with beanbags or cushions.

In addition to considering the sensory aspects of the family home, creating sensory zones/areas within the home is another useful way of helping children avoid sensory input that they find uncomfortable and seek the sensory input they need to self-regulate.

Create a Calm, Quiet Area

Creating a quiet, calm space at home can provide a place for children to retreat to when they feel overwhelmed. This should be a "low arousal" space where sensory stimulation is reduced or controlled. It should have minimal background sounds by being located away from busy areas of the family home and by offering options to block out sounds through the use of white noise, ear defenders or earplugs.

The space should have minimal visual distractions and be free of clutter or busy wallpaper or posters. Lighting should be dimmable, and curtains and blinds should be available to block out bright sunlight.

The space should also contain the resources that your child uses to help self-regulate. While the resources will vary depending on the needs of each child, the space could include items that will provide calming deep tactile and proprioceptive feedback, such as a large squishy bean bag, a weighted lap pad or weighted teddy.

The quiet calming area could also contain a small bag or box of tactile sensory tools, including a bubble pop or stress reliever ball.

Create a Sensory Movement Area
If you have a garden, it can provide a range of movement opportunities to meet your child's vestibular and proprioceptive needs. Ideas for activities in the garden could include a trampoline, climbing frame, slide, swing, basketball hoop and swing ball. Children may also enjoy digging in sand or playing with water.

In the absence of a garden, or if weather conditions prevent you from using the garden, your child may benefit from indoor options to meet their sensory movement needs. These needs could be met by a rocking chair used for gaming or relaxing, a small indoor trampoline or jumping mat, a peanut ball or therapy ball, and a ball pit or a paddling pool filled with balls.

School can be a challenging environment for autistic children. Some children may be overwhelmed from a sensory perspective by busy wall displays, smells from the school kitchen, crowded corridors and noisy playgrounds.

The environment at school may cause some children to experience sensory overload, which can negatively affect their well-being and reduce their access to learning. For some children, difficulties in coping with the sensory environment at school can result in refusal to attend school.

Some children "mask" very well at school. They may push through the discomfort of the sensory environment at school and only talk about how it feels at home. This negative experience may lead to emotional outbursts at home.

Improving the Sensory Environment at School
Work with the school Special Educational Needs Coordinator and your child's class teacher. Share Occupational Therapy reports with them. This will give them a better understanding of your child's sensory needs and how this affects his or her participation at school. Work with your child's Occupational Therapist, Special Educational Needs Coordinator and class teacher to create a "One Page Profile". The profile provides a simple summary of what is important to your child and how your child needs to be supported. It should describe elements of the sensory environment that might be distracting, uncomfortable or overwhelming for your child, as well as environmental factors that help your child to stay calm and participate. For example, the school may wish to provide a quiet, calm space that the child can access when feeling overwhelmed.

Ask your child's Occupational Therapist, Special Educational Needs Coordinator and class teacher to complete a sensory classroom audit such as that created by the Autism Education Trust. This enables the team supporting your child to assess the sensory environment and to plan adaptations to benefit your child's well-being and learning.

There is a growing understanding of the need to make public spaces "autism-friendly." Many cinemas now offer screenings in which adjustments are made to reduce anxiety and sensory overload by lowering lighting, reducing sound and allowing movement during a screening. Some supermarkets offer autism-aware shopping sessions with dimmed lights and speakers turned off.

A few towns, including Clonakilty in Ireland and Channel-Port Aux Basques in Newfoundland, Canada, have worked to become autism-friendly towns. Examples of autism-friendly practices in these towns include the provision of autism training for staff in local services and of quiet times in local businesses, as well as dedicated quiet spaces and access to relaxation boxes that contain sensory tools.

Consider what you can do to help your child cope with the sensory environment in the community.

Use Social Stories™ (Gray 2015) to prepare your child for the sensory environment of places you plan to visit. The social story can also explain how your child can ask for help if needed, and can detail sensory strategies to use to help self-regulate.

Colchester Zoo has provided social stories to prepare children for their visit. Although these would need to be adapted to the individual needs of each child and the specific details of the trip, they constitute a helpful resource. The following is an example of one of the social stories.

> *Some of the animals are very loud. I may hear animals making noises like: roaring, chirping, growling, trumpeting, and squawking. This is just how the animals talk to each other. There might be other loud noises at the zoo. Some loud noises I might hear are: microphones, the trains, and other people. If I do not like a noise, it is okay to cover my ears. If it is too loud, it is okay to ask to move away from the noise.*

You could also prepare a bag of sensory resources for your child to take out in the community. Of course, the contents will depend upon your child's individual sensory needs and interests. The bag could include the following:

- ear defenders, headphones, earmuffs or earplugs to reduce uncomfortable sounds
- a cap or sunglasses to reduce discomfort from bright sunlight
- a healthy snack that is chewy or crunchy to provide calming oral proprioceptive input, such as a raw carrot or a breadstick
- a sports water bottle with a straw lid to provide calming oral proprioceptive input
- tactile tools to provide calming proprioceptive and tactile input, such as stress reliever balls or a sensory bubble pop
- weighted items, such as a weighted lap pad, shoulder wrap or weighted teddy.

Autistic children need home, school and community environments to be as sensory-friendly as possible in order to reduce anxiety and to aid participation. Since each child is different, we need to work towards making sensory-friendly environments that are flexible and adaptable. Our progress in this effort will have a positive effect upon the lives of all autistic children and their families.

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Anna Hamlet, BSc Occupational Therapy, MSc Autism, PGCert Sensory Integration, is a Clinical Specialist Paediatric Occupational Therapist who specialises in working with Autistic children.

Anna has over 20 years of experience as an Occupational Therapist. She founded her company My World Therapy based in Hertfordshire, UK, to provide individualised, timely, highly specialist Occupational Therapy for children with sensory processing differences and/or motor skills difficulties.

Through thorough assessment, Anna builds a profile of each child's strengths and needs. In addition, she recognises the importance of understanding what the world feels like to children and also what motivates them. This enables Anna to formulate an individualised therapy plan. As a Mum of two children, Anna understands the importance of therapy being fun and of working closely with parents to understand their priorities for their child.

https://myworldtherapy.co.uk/

My Name

Zachariah

What others like & admire about me:

I am kind and helpful

I am good at making models with Lego

I have a lovely smile

I know lots about dinosaurs

What is important to me:

My family

My pet cat Marmalade

Going to the play park

Lego

My dinosaur collection

How best to support me:

I need everyone to give me space. Please don't sit or stand too close to me.

I need you to help me go to my quiet calm space in school if I am overwhelmed.

I need you to help me have a movement break for 10 minutes every hour. I like to play basketball or to kick a football.

I need you to make sure that I have my ear defenders for music lessons and assembly.

I find it painful to have the top button of my school shirt fastened. Please do not ask me to fasten it.

My Name

My Photo Goes Here

What others like & admire about me:

What is important to me:

How best to support me:

Allergies and Chemical Sensitivities in Autism

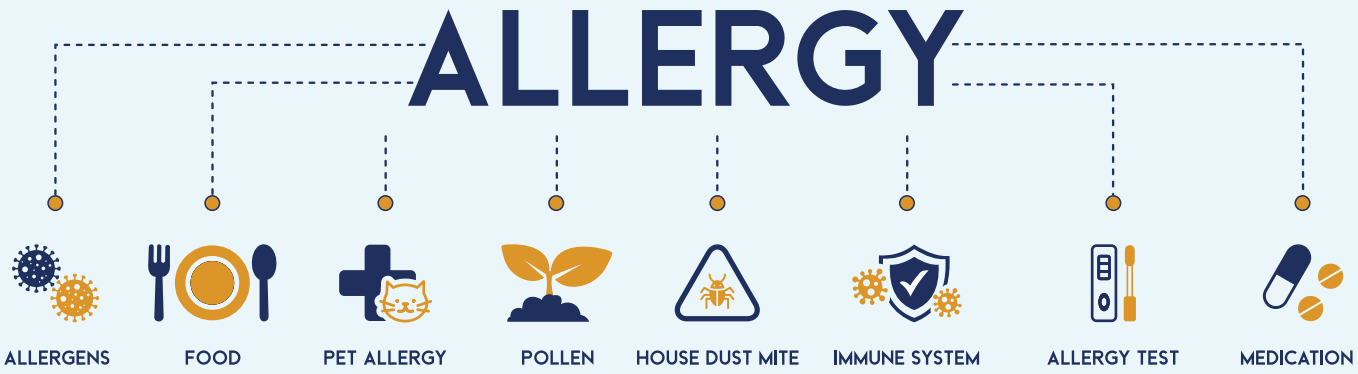
Jerry Kartzinel, M.D., F.A.A.P.

It is well known that many autistic individuals have underlying or co-occurring medical conditions. As someone who manages a practice that cares for children with special needs and undiagnosed issues, I have seen many of these children present with environmental allergies, chemical sensitivities and food sensitivities. Parents should be aware of the signs and symptoms of a child who is experiencing allergic reactions so that they can quickly and appropriately address the situation and alleviate the child's distress and discomfort.

When it comes to allergies in general, the typical *physical* signs include hives, rashes, dark circles under the eyes, puffy eyes and skin irritations. An allergic child who cannot express discomfort could also present an allergy through a variety of behaviors, including extreme or uncontrolled actions, difficulty concentrating, food cravings, fatigue, hyperactivity, difficulty performing tasks, or irritability.

Common Allergens

The substances that cause allergic responses, known as allergens, can range across all types of food and a vast array of environmental agents. The most common food allergens and intolerances in children with autism are gluten, wheat, dairy, soy, corn and citrus products. Animals such as dogs and cats can also cause allergic symptoms. House dust mites and mold are common causes of environmental allergies. Sensitivities to various chemicals are also common, such as to food additives and dyes, chlorine in swimming pools, formaldehyde which can off-gas from pressboard wood like that found in kitchen cabinets, and fragrances such as those in candles, "plug-ins," hair spray and perfumes. These sources can all lead to allergic symptoms.

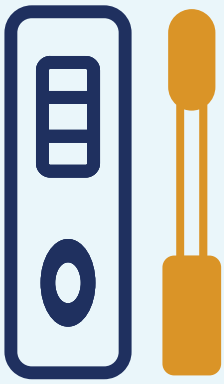


Initial Evaluation

If you notice any of the signs or symptoms of allergy in your child, you should seek an evaluation from a health care provider. During an allergy evaluation, it is important for a practitioner to take a careful history of the child's health and behaviors. This history should cover the period from when the child was an infant to the present. The following questions could be part of the assessment.

- ☑ How did the child tolerate formula and/or breastmilk, and were multiple formulas needed?
- ☑ Did the child have prolonged colic?
- ☑ Did the child have abnormal stools, diarrhea, constipation or a bloated belly?
- ☑ Did the child have delays in growth and development?
- ☑ Did the child meet social and gross motor milestones?
- ☑ Did the child have reoccurring ear infections or sinus infections?
- ☑ Does the child have eczema now or have it in the past?
- ☑ Are there dark circles under the child's eyes?
- ☑ Does the child have dry cheeks or red ears?
- ☑ Is there a family history of food sensitivities or seasonal allergies?

Answering in the affirmative to some or many of these questions would indicate the need for further evaluation and an allergy workup.



Testing

With the combination of the child's history, signs and symptoms, a clinician can decide if an allergy workup is warranted. This could include an immunoglobulin G (IgG) and/or an immunoglobulin E (IgE) blood panel looking at food and environmental allergies, skin testing or just a trial eliminating common suspected allergens such as gluten and foods containing dairy.

Treatment

The following treatment options and approaches should be pursued if a problem is identified.

FIND THE OFFENDING AGENT

It is important to find the agent or agents causing the child the allergic reaction. Typically, this will begin with food items. As mentioned, the most common food allergens and intolerances in autistic children are gluten, wheat, dairy, soy, corn and citrus products. By eliminating these items, you may be able to relieve your child's symptoms. I will often suggest to my clients that they also eliminate sugars, dyes and processed foods as these can be irritants as well. While I understand that this task can seem overwhelming and even impossible, with persistence and patience it can be done. Think for a moment of Secretariat, a champion American thoroughbred racehorse. He was magnificent and strong, and regarded as one of the greatest racehorses of all time. What do you think the owners fed this racehorse? Aren't our children more precious to us than a racehorse? We can optimize our child's health, brain and function by providing the best foods available while removing heavily processed foods loaded with sugar. If we are trying to help our children's brain recover, we can't do it just with junk food!

If the child is still reactive after common food possibilities have been eliminated, the healthcare provider should start an investigation of environmental and chemical offenders. Testing can focus on mold, formaldehyde, heavy metals, and other substances that are common. While some children are allergic to the chlorine in drinking water, others may be allergic to dust mites in mattresses or to the polyurethane foam in household seating. The possibilities are endless. One child I worked with had severe seizures. Doctors would have to put him in a medically induced coma to stop the seizures. After a thorough investigation, it was determined that new carpet installed in the house and a yeast overgrowth were causing the trauma. After the synthetic carpet and underpadding were removed and the child was put on anti-fungal medication, the seizures became few and far between. My own son is very sensitive to formaldehyde, which I learned is found in many kitchen cabinets and re-manufactured wood. These products can off-gas formaldehyde for up to 10 years!

I had another client who had skin that looked like scales. His eczema was very itchy, and he found it to be almost unbearable. I conducted a thorough search for the source of his allergen. We cleaned out his room and took a complete history. It turned out that he was sleeping with a 200-year-old quilt that was used by his grandma. After the blanket was removed, his eczema cleared up. Unfortunately, blankets and favorite stuffies are often the allergic culprits.

CREAMS ARE NOT A PERMANENT FIX

Hydrocortisone creams are often recommended for relief of skin irritations. Although they can be an effective short-term strategy, they are only a Band-Aid solution and do not address the root cause of the irritation. Think of your skin like the red warning light on the dashboard of your car. It tells you when something deeper down is wrong. Using hydrocortisone on the skin is like putting black masking tape over that red light. The fact that you don't see the red warning light anymore doesn't mean that the underlying problem is solved. It is important to get to the root cause of the problem.

PND AND ALLERGY SHOTS

Provocation, Neutralization and Desensitization (PND) has been shown to be an effective way to treat allergies. Allergy shots are also a traditional way of managing hay fever and some food allergies. You should speak to your doctor to see if these options are right for you.

OVER-THE-COUNTER MEDICATIONS

Natural allergy medications can be very helpful in treating symptoms in many children. However, since they are meant to be swallowed in capsule form, they may not be usable due to their very strong taste and smell. My preference is to suggest a combination of Quercetin, Vitamin C and probiotics. Most practitioners have their own favorite combinations. There are also too many books on natural allergy elimination to discuss in this article.

Many children do experience relief of allergy symptoms with over-the-counter medication, such as diphenhydramine, which should be dye-free, Zyrtec™, Claritin™, and Allegra™. If the child will tolerate a nasal spray, Flonase™ is another possibility. These products will provide relief until more definitive testing and desensitization can be performed.

Prevention Strategies

The following preventive strategies can be helpful in addressing allergies and chemical sensitivities.

- Given the high levels of off-gassing in new houses and new building materials, **consider going green when moving to a new house or renovating** by using zero-VOC (volatile organic compounds) paints and materials that are non-toxic and do not off-gas.
- You may wish to install a **water system** in your house to take out the chlorine and other harmful chemicals that your child may react to.
- Consider a high-quality **air filtration system** for your home.
- Use products that are **hypoallergenic**, and never use dryer sheets.
- When renovating or considering the purchase of a new home, try to **minimize carpeting**.
- **Encase mattresses with allergy or dust mite covers** that keep the dust mites in the mattress and out of the air.

If you suspect that your child is allergic, seek an integrative or biomedical doctor who is specifically experienced in allergies. Addressing your child's allergies could improve their symptoms and even behaviors. Once you take care of the underlying issue or issues, you will be able to make more progress in ongoing therapies. I know that this journey can be long, difficult, isolating, exhausting and expensive. The symptoms of allergies and chemical sensitivities, however, can be greatly improved with the support and guidance of a qualified professional. That's when tangible, real improvements can be experienced by all!

Dr. Jerry Kartzinel, M.D., F.A.A.P., is an internationally known author, lecturer, and clinician who has been featured on TV and radio and has helped numerous children recover from chronic debilitating diseases. He is board certified in pediatrics and is passionate about helping children and families regain health by some of the most natural means possible.

Both national and local media have featured Dr. Kartzinel's approach to health and nutrition, including Larry King Live!, 20/20, and The Today Show.

Dr. Kartzinel received his Doctorate of Medicine at St. Louis University School of Medicine and completed his pediatric training at Keesler Air Force Base. Following Desert Storm, Dr. Kartzinel practiced traditional pediatric medicine until his fourth boy was diagnosed with Autism and all its related chronic diseases (immune system dysfunction, chronic inflammatory bowel disease, chronic constipation, etc.).

Dr. Kartzinel quickly realized that the traditional approach to medicine was limited to treating a disease state with a medication, but with little thought about why the disease state occurred in the first place. Many times in medicine, this approach works well. The problem lies with chronically reoccurring diseases, or conditions of the human being that just will not improve with traditional approach. Realizing most disease states share in common toxin exposure (and the body's inability to detoxify these exposures), inflammation (as commonly seen in most chronic illnesses), oxidative stress, and the particular genetics the individual has (this determines "how" the disease process will manifest), Dr. Kartzinel turned to the field of nutritional and preventative medicine for answers. This new approach has demonstrated marked clinical improvements in his patients — way beyond what he had initially hoped for!

His clinical approach is to treat the whole patient by carefully obtaining a full and complete history and based on this history, obtaining very detailed laboratory evaluations. Individualized plans are implemented integrating the very latest medical interventions that include both traditional and complementary medicine approaches.

Early Signs of Autism

Lonnie Zwaigenbaum, MD

Both parents and professionals agree that receiving an early diagnosis of autism is important so that supports and services can be put in place as soon as possible. Studies have found that such supports can help children make significant gains in cognition, language and adaptive behavior.[1] These services are also helpful in reducing frustration for parents and children, helping parents manage their children's challenges, and improving communication in families.

Early Signs of Autism

In the past few decades, researchers and clinicians have learned much about the early signs of autism. Most of the information has come from the experiences of parents and from autistic individuals reflecting on what life was like when they were younger. A number of research groups have followed infants who were more likely to develop autism. The combination of what parents have reported, what clinicians have observed and what research groups have discovered has shed considerable light on some of the earliest signs of autism.

Features to look for in infants as young as six months

Low muscle tone and difficulty holding the head up or keeping the back straight.

Tendency to focus on the sensory aspects of toys, such as the way they look and feel.

Features to look for in infants as young as 12 months old

Not making eye contact.

Not responding when called by name.

Interested in playing but not in sharing interests with others.

May not focus on the parent's attention.

May get stuck on particular activities and interests.

May exhibit social and communication differences.

There are questionnaires and lists available on the Internet that can help parents determine if their child might be at risk for having autism. It's important to keep in mind, however, that these questionnaires cannot be used to make a diagnosis. Rather, they serve as a guide for parents to know if they should seek a further evaluation from a qualified professional. Speaking to friends who have an autistic child and to local autism organizations can also be helpful in determining if a child warrants an evaluation.

Should I Wait and See?

It is generally not in the child's best interest to wait and see if the challenges develop into a diagnosis. If a doctor suggests waiting, parents should know that it is always reasonable to ask what they can do now to help. For example, if your child is not speaking, have a hearing test administered, obtain a referral to an early intervention program, and connect with a speech language pathologist. There is usually some type of support that can be helpful.

It is worth noting that a number of clinicians have shifted from exclusively looking at early identification to looking at **timely** identification. The goal is not only to push the envelope to earlier and earlier diagnosis, but also to make sure that the system addresses the individual's needs across the lifespan. Some autistic individuals have differences that may not become apparent until they are a bit older. We need to remain vigilant and open-minded, and recognize that the earliest signs may actually vary. While some children may show obvious differences at six months of age, others may not do so until later in childhood or even adulthood. The key is to not delay seeking help for your child's specific challenges at whatever age they came to your attention.

Latest Research on Early Identification

There is exciting progress in understanding what autism looks like early in life and how the biology of autism might lend itself to tests to identify autistic individuals at a very early stage. Some interesting research shows that brain wave patterns in response to hearing speech or looking at faces may be different in individuals with autism compared to those without autism.[2,3] The electrical signals of the brain may give some clues about how different regions of the brain are connected and could be used to identify someone with autism. Brain scans might also be able to show differences in growth and how various areas of the brain are connected in those with autism.[4]

Other researchers are showing that there might be subtle differences in how infants who later go on to develop autism explore their world, what they prefer to look at, how long they focus on one object and if they tend to shift more or less often. This can be detected with eye-tracking technology.[5]

This exciting research is still in its early stage and is not yet being applied to clinical practice. It is worth asking, however, if we should be identifying signs of autism before a child has specific developmental challenges. Were we able to detect that a three-month-old has specific brain waves that indicate autism, what supports could be put in place based on this information? This topic is the subject of thoughtful and passionate discussions by those working in the field. It is important to find a balance between making sure infants and families receive the supports they need at the earliest stage, and not jumping to conclusions about a child's diagnosis before outward features and challenges can be seen.

When Parents Suspect Autism

If you suspect that your child has autism, consider taking the following actions.

- Talk to your child's physician. Ask if your child would benefit from further assessment. If your physician does not take your concerns seriously, seek another health care provider. Seek a physician who is knowledgeable about what autism looks like early in life.
- Contact your local autism organization and advocacy groups to find out how the system works. Find out how to receive an evaluation, what services are provided by the public health system, and who the go-to people are in the community.
- Find out if there is a specialty autism center in your area. When parents call such centers, they can often receive valuable information on appropriate steps to take. It is not only about getting a specialized autism assessment, but also about identifying what's available in the community to support children's development even prior to a diagnosis, and how these supports and services can be accessed.

In most areas, you do not need to wait for a diagnosis before receiving supports for your child's challenges. If your child is not communicating at an appropriate level or is having difficulty connecting socially, seek support. During the pandemic, the array of online supports was expanded. Parents are now able to incorporate early support strategies into their everyday activities. They can educate themselves on their child's different learning styles, and research ways to both engage with and help their child discover self-expression. Parents should trust their instincts and not be dissuaded from seeking help for their child. When it comes to early identification, my experience has been that the parents are the experts when it comes to their children, and we need to take their concerns very seriously.

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M-CHAT-R

Instructions for Use

The M-CHAT-R/F is valid for children 16-30 months old. The M-CHAT-R can be administered and scored as part of a well-child care visit, and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R is to maximize sensitivity, meaning to detect as many cases of ASD as possible. Therefore, there is a high false positive rate, meaning that not all children who score at risk will be diagnosed with ASD. To address this, we have developed the Follow-Up questions (M-CHAT-R/F) (Available at: http://www.mchatscreen.com and usually administered by a professional). Users should be aware that even with the Follow-Up, a significant number of the children who screen positive on the M-CHAT-R will not be diagnosed with ASD; however, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive. The M-CHAT-R can be scored in less than two minutes. Scoring instructions can be downloaded from http://www.mchatscreen.com.

Scoring Algorithm

For all items except 2, 5, and 12, the response "NO" indicates ASD risk; for items 2, 5, and 12, "YES" indicates ASD risk. The following algorithm maximizes psychometric properties of the M-CHAT-R:

LOW-RISK Total Score **0-2**	If child is younger than 24 months, screen again after second birthday. No further action required unless surveillance indicates risk for ASD.
MEDIUM-RISK Total Score **3-7**	Administer the Follow-Up (second stage of M-CHAT-R/F) to get additional information about at-risk responses. If M-CHAT-R/F score remains at 2 or higher, the child has screened positive. Action required: refer child for diagnostic evaluation and eligibility evaluation for early intervention. If score on Follow-Up is 0-1, child has screened negative. No further action required unless surveillance indicates risk for ASD. Child should be rescreened at future well-child visits.
HIGH-RISK Total Score **8-20**	It is acceptable to bypass the Follow-Up and refer immediately for diagnostic evaluation and eligibility evaluation for early intervention.

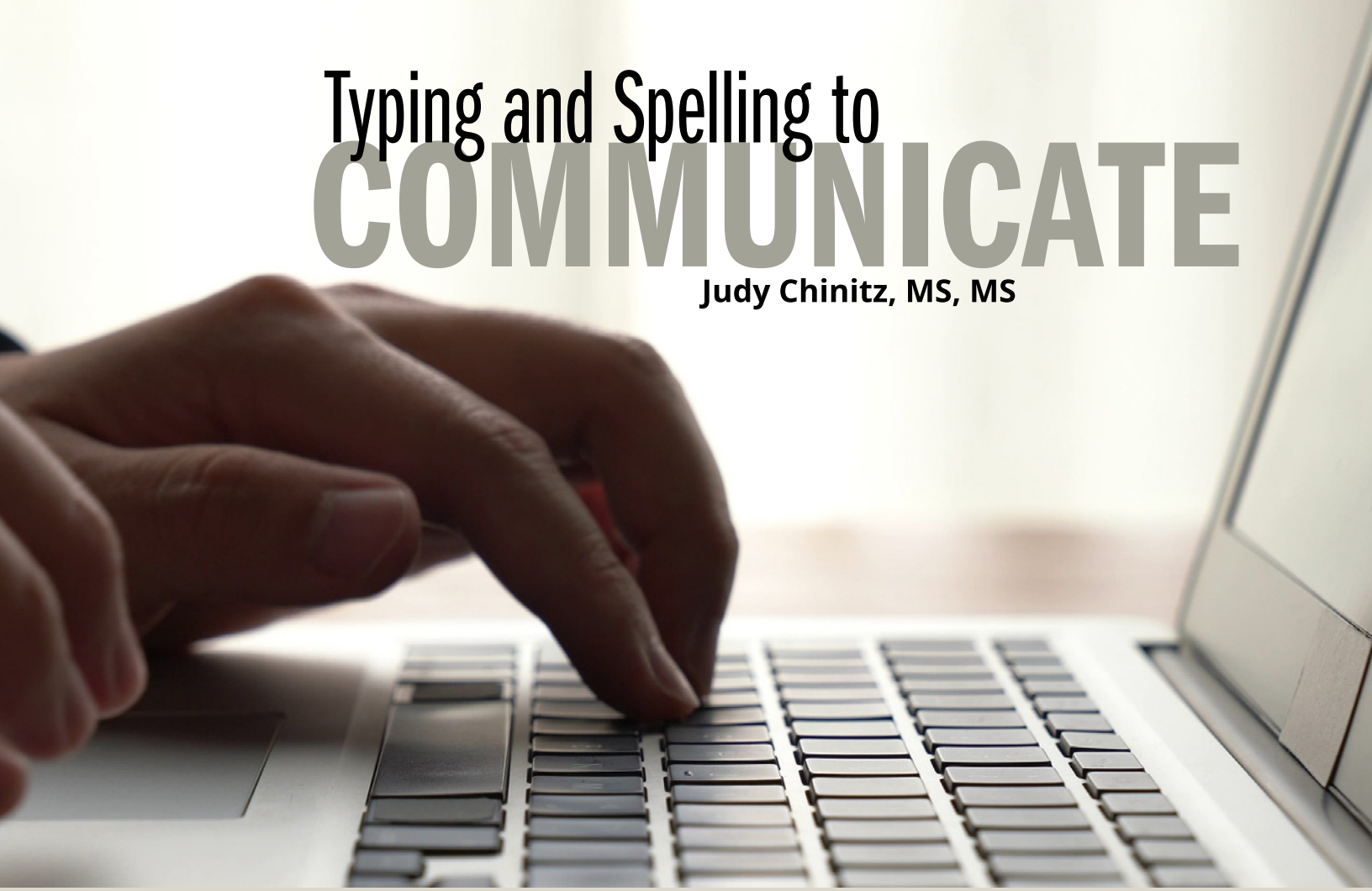
M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

1.	If you point at something across the room, does your child look at it? (**FOR EXAMPLE**, if you point at a toy or an animal, does your child look at the toy or animal?)	Yes	No
2.	Have you ever wondered if your child might be deaf?	Yes	No
3.	Does your child play pretend or make-believe? (**FOR EXAMPLE**, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?)	Yes	No
4.	Does your child like climbing on things? (**FOR EXAMPLE**, furniture, playground equipment, or stairs)	Yes	No
5.	Does your child make unusual finger movements near his or her eyes? (**FOR EXAMPLE**, does your child wiggle his or her fingers close to his or her eyes?)	Yes	No
6.	Does your child point with one finger to ask for something or to get help? (**FOR EXAMPLE**, pointing to a snack or toy that is out of reach)	Yes	No
7.	Does your child point with one finger to show you something interesting? (**FOR EXAMPLE**, pointing to an airplane in the sky or a big truck in the road)	Yes	No
8.	Is your child interested in other children? (**FOR EXAMPLE**, does your child watch other children, smile at them, or go to them?)	Yes	No
9.	Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (**FOR EXAMPLE**, showing you a flower, a stuffed animal, or a toy truck)	Yes	No
10.	Does your child respond when you call his or her name? (**FOR EXAMPLE**, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?)	Yes	No
11.	When you smile at your child, does he or she smile back at you?	Yes	No
12.	Does your child get upset by everyday noises? (**FOR EXAMPLE**, does your child scream or cry to noise such as a vacuum cleaner or loud music?)	Yes	No
13.	Does your child walk?	Yes	No
14.	Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her?	Yes	No
15.	Does your child try to copy what you do? (**FOR EXAMPLE**, wave bye-bye, clap, or make a funny noise when you do)	Yes	No
16.	If you turn your head to look at something, does your child look around to see what you are looking at?	Yes	No
17.	Does your child try to get you to watch him or her? (**FOR EXAMPLE**, does your child look at you for praise, or say “look” or “watch me”?)	Yes	No
18.	Does your child understand when you tell him or her to do something? (**FOR EXAMPLE**, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket”?)	Yes	No
19.	If something new happens, does your child look at your face to see how you feel about it? (**FOR EXAMPLE**, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?)	Yes	No
20.	Does your child like movement activities? (**FOR EXAMPLE**, being swung or bounced on your knee)	Yes	No

Typing and Spelling to COMMUNICATE

Judy Chinitz, MS, MS



My world shifted on its axis on March 22, 1996, when my son, Alex, was diagnosed with autism at age two. The previous year, I'd watched my baby boy regress physically and mentally. I had received my MS in special education just a few years before but did not understand what was happening because "regressive autism" was not yet taught in graduate school. On the day he was diagnosed, the world as I had known it was gone. I refocused all of my energy on helping my child, including trying everything I knew and didn't know in order to teach him. I invented every kind of educational material you can imagine! As far as I could tell, for the next 25 years or so I failed abysmally.

Fast forward to July 1, 2019. At the emphatic insistence of one of my very dear friends, I made a trip with Alex and my mom to visit a speech pathologist who was working with individuals diagnosed with autism and related disorders who are nonspeaking, minimally speaking, or unreliably speaking (like scripting). She had developed a methodical system of teaching "spelling" for communication to these individuals. She also explained to me that they were not at all what we had been told they were. "Your son has perfect language in his head," she explained. "He is not cognitively impaired. He is unable to respond to your questions or to talk because he suffers from apraxia."

Dyspraxia

I had been told by various speech pathologists and occupational therapists over the years that Alex was apraxic or dyspraxic. The former is a term commonly used by speech pathologists, while the latter is a synonym that is more commonly used by occupational and physical therapists. While I had a vague idea that it meant he had difficulty with "motor planning," it turned out that I didn't **really** know what this meant. An article in Psychology Today defines dyspraxia as "a neurological disorder that affects the planning and coordination of fine and gross motor skills."[1] That is, it is an impairment — signified by the prefix "dys" — of the volitional motor system, or "praxis." What exactly does this mean? The word "volitional" refers to things done of one's own will or choosing. For example, when I choose to type, I think about it and make my fingers perform the necessary actions on the keyboard to make my will a reality. We engage our praxis system when we learn to do any new activity.

Since this concept is critical to understanding why spelling for communication works, let's look at another example. Think about learning to drive a car. During your first days behind the wheel, you think about every single detail: where your hands are on the wheel, determining if your foot is on the brake or the accelerator, remembering to signal, checking your rearview and side mirrors. Now that you are an experienced driver, you can usually arrive at the grocery store and not remember how you actually got there.

The motor skills have gone from being volitional, in which you had to think about performing them, to being automatic in which little or no cognition is required.

I often think as I drive around the New York tri-state area that the drivers around me are definitely not engaging their cognitive brains!

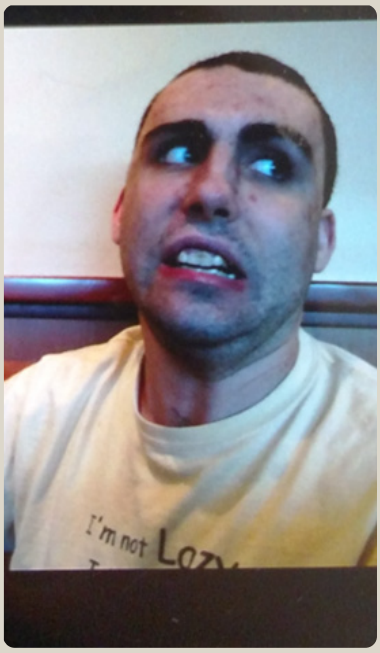
Speech and Dyspraxia

Why is speech so difficult for individuals with severe dyspraxia or apraxia? Speech is the single most complex motor skill we perform as humans. It involves muscles of the lips, tongue, cheeks and throat, as well as the chest and diaphragm as we push the air up past our vocal cords. The coordination required is simply too much even for the "unreliable speakers," or those who can sometimes enunciate perfectly but say nothing. Once their cognitive brain kicks in to formulate their thoughts into the motor movements of the mouth, dyspraxia also kicks in. Remember that it is a disability of the volitional motor system. As soon as you *think* about doing something, you can't do it anymore.

The following will really help you understand dyspraxia! When I give talks, I always show a slide with three photos of my son. The first picture is of Alex smiling in a completely normal way. It's one of those lucky pictures that you finally capture after taking 100 others. The second is a picture of a weird, strange smile that clearly signals to all "autism" parents that I must have said, "Say cheese!" This is the worst thing you can do, right? The third picture is of Alex completely distorting his face as he desperately tries to smile, but is, of course, unable to do so. I think now you are getting it!

Alex and me: His beautiful "automatic" smile. When he's not thinking about smiling, he can smile.

Alex: Unfortunately, someone told him to smile. Now he's thinking about it and can't do it normally!



Alex: Oh, no! Now I am really, really trying to smile! The harder I try, the less I can do it!

Remember that this exercise simply involves using the muscles of the lips and cheeks at will. Now think about the level of complexity in speech. Twist and turn your tongue around in your mouth. Now you're saying – "Wow!" We still haven't gotten to all the many other muscles involved.

MOTOR SKILLS

Speech vs. Language

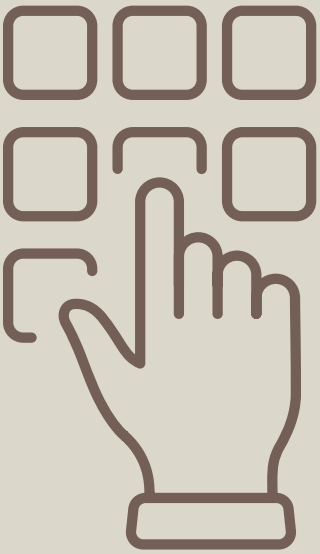
If you take nothing else from reading this article, remember that speech is 100 percent motor skills, but language is 100 percent cognition. Also, keep in mind that the majority of those with autism have motor issues that they never outgrow.[2] In fact, many professionals that work with this population believe that the high prevalence of motor deficits should make them a part of the autism diagnosis. By the way, one of the most important things to know about dyspraxia is that it also affects the eyes! It causes problems with both tracking, which means following an object as it moves or moving your eyes smoothly to read a line of text, and relocation, or refocusing when looking from one thing to another.

I encourage you to visit the website of the Dyspraxia USA Foundation. Take a look at the list of symptoms in children and adults. If you're anything like me, it will be an "aha" moment you won't soon forget.

Let's think for a moment about the repercussions of not being able to control the volitional motor movements of your body. In response to a request, you say,"Yes, of course I understand that you want me to point to the letter A! I've been reading since I was three years old!" You think about making your hand move to the card on the table but it just won't listen to you. Then, your own hand betrays you and picks up the letter C instead. The harder you try, the less able you are to pick up the letter A. You want to nod when your teacher asks if you know the letter A, but your head doesn't listen to your brain. Instead, your body jumps out of the seat and runs across the room. You ask yourself, "Why the heck is my body running across the room? I was just trying to nod yes!" Many of my students tell me that it feels like being an outside observer of their own body.

Think about it! All communication requires volitional motor movements. If you cannot control your own body, how can you communicate to show anyone what you really know? It is worth asking if the ability to nod or speak with your mouth is a measure of intelligence or comprehension. I point out to all the new students when they first walk into my practice that the brilliant physicist Stephen Hawking suffered from ALS (amyotrophic lateral sclerosis), a devastating neurological disease, for 55 years. It left him a quadriplegic, unable to communicate verbally for about the last 30 years of his life. While he needed an alternative communication resource, no one questioned his intelligence! Of course, he could talk for the first decades of his life so he was able to demonstrate his intellect. Our children, though, are not so fortunate in that respect.

Our children, who have impaired motor function and are acknowledged to be suffering from apraxia and/or dyspraxia by both the medical and educational communities, are said to be cognitively impaired. Unfortunately, they can't prove otherwise. Thus, they spend their lives in special needs classes that operate far below their intellectual abilities. They are consigned to spend their lives in silence unless we give them an **alternative communication method**.



Spelling or Typing for Communication

What is it we are teaching to the nonspeakers with such severe dyspraxia/apraxia? Through a regimented, methodical system, we teach them to coordinate their eyes and hands to get to the letters they want so that they can spell to communicate. This involves the use of a letterboard or a keyboard.

When I refer to spelling and typing for communication, I do not mean what many of you may be thinking. I am not talking about simple requests like "bathroom" or "I want water." I mean regular conversational English. It allows them to chat, yak, joke, talk, jabber, chatter and gossip just like the rest of us. I mean writing stories, essays, poetry and songs. It is all in their heads; they just have no means of expressing it.

This concept is already present in the medical and educational literature. A 2007 article in the journal *Developmental Medicine and Child Neurology* states that, "...praxis in children with autism is strongly correlated with the social, communicative, and behavioral impairments that define the disorder, suggesting that dyspraxia may be a core feature of autism or a marker of the neurological abnormalities underlying the disorder."[3] In other words, impairment of the volitional motor system may be at the core of what we call autism.

Most of my students clearly display motor abnormalities. They have abnormal gaits, cannot adeptly use silverware, and cannot write. Some even struggle to form a point with their finger. What is unusual is that some of my students can write, and a few can even type when they first come to see me. What they write and type, however, is rote memorization. It is not conversational English. My own observation in working with my own son and many nonspeakers is that there seems to be a disconnect between the language that's in their brain and the motor skills necessary to express that language. The system I use to teach them the motor coordination skills to volitionally get to the letters they want on a letterboard or keyboard eventually turns into an automatic movement. This allows them to access their cognitive brain and express themselves.

What does the system look like? We start with three large stencils and break the alphabet up into bite-sized chunks. This gives the students less visual material to sort through. The idea is to make pointing to letters as basic a motor movement as possible: moving the hand forward with the shoulder. As with any new skill, there are prompts at first to move to the correct letter. As the student improves, prompts are dropped. At first, many students struggle to even point or hold a pencil, let alone signal the letter of their choice. Depending on the motor challenges of a particular student, it may take anywhere from weeks to years for the nonspeaker to be able to smoothly tap out letters on either a laminated letterboard or on a keyboard. Once students have achieved a reasonable level of open communication and can say anything they want, I move them on to independent typing.

To the Skeptics

The common features of my students are that they have all been diagnosed with autism and are also labeled as cognitively impaired. They are nonspeaking, minimally speaking or unreliably speaking, and have all been placed in special needs classes for the cognitively disabled. Once they talk by spelling or typing to communicate, however, I have found that they are highly intelligent individuals, with their own wonderful personalities, just like the rest of us. Some are quite funny; others are serious; yet others are creative; and some are analytical. All are empathetic to a degree that I have never seen in the speaking population.

I know that many reading this article will be highly skeptical. I, too, was skeptical for many years. I am a licensed New York State Special Education teacher with a deep love of science, and did not believe a word of it either. **Then, I finally saw it.**

I have seen my son and my students spell or type without my assistance other than to hold a laminated letterboard or keyboard. Once they master this, many start to type on keyboards that are not being held as the final step in this process. This is completely independent communication. I observe that they are highly intelligent and have normal, or sometimes advanced, language skills. They are self-educated to a remarkable degree, and are empathic with no social deficits other than those brought about by impulses in their bodies over which they have no control. Just as those with Parkinson's disease cannot control their tremors, the impulses of these individuals, such as jumping out of their chairs at inappropriate times, flapping their hands, or making "mouth noise" as they call it, are simply beyond their control.

A paper published in 2020 by researchers at the University of Virginia in the scientific journal, *Scientific Reports*, looked at communication in nonspeakers who volunteered to participate in the study. The researchers were able to track the eye movements of nonspeakers outfitted with special glasses as they spelled out responses to questions about which they had no prior knowledge. The scientists were able to see that the nonspeakers looked for their letter of choice and tapped on it with the same speed and accuracy as a neurotypical speaker. The paper concluded that the "...participants pointed to letters they selected themselves, not letters they were directed to by the assistant. The blanket dismissal of assisted autistic communication is therefore unwarranted... Recent research has shown that the cognitive abilities of nonspeaking autistic people have been significantly underestimated."[4]

"Recent research has shown that the cognitive abilities of nonspeaking autistic people have been significantly underestimated."

My Story

I would like to share with you a bit more of my story. In July 2019, I agreed to observe my son in a session with the speech pathologist I mentioned earlier to objectively look at spelling for communication. I firmly believed that my son did not even know the alphabet. I observed enough that day to convince me that it was worth a six-month trial. I would try to teach him. I saw that after several months of daily work, his motor skills improved. At four months, he proved to me that he could not only read, but could talk using this methodology. I had many special educators, speech pathologists, and physicians observe this progress as well. Their observations coincided with my own.

Later, my son worked with a math tutor and continued studying with me. In June 2020, he was tested by a well-known PhD psychologist in my area, who put his IQ at a minimum of 150, the 99th percentile of intelligence. This was 110 IQ points higher than his school records indicate. In August 2021, I saw him undergo three days of rigorous testing to earn his high school diploma. He then applied for and was accepted to college. He will be starting college in the near future.

It is important to note that spelling or typing for communication does not just involve the nonspeaker. This is a family endeavor. You must learn to be an effective communication partner for your child or student. You must learn how to work with and teach your child. It is not like other therapies or school where you drop your child off with the professional and run out to get the shopping done. You have to work with your own child daily to practice, practice, practice. By way of illustration, consider the following example. If you had a child who was deaf, would you not want to learn sign language so that you could communicate with your own child? It would serve no purpose to teach deaf children sign language and for them to be unable to communicate with anyone in their own home and family.

Learning to communicate by typing and spelling is not a way to change the fundamental issues in autism. My son and my students will still require extensive assistance throughout their lives. So did Stephen Hawking, but look at what he accomplished. Spellers are now graduating from colleges across the country and are working as artists, writers, lawyers and advocates. Consider Elizabeth Bonker who ended up giving the valedictory address at Rollins College, in Florida. In graduating the University of Southern California, Hari Srinivasen and David Teplitz had a perfect 4.0 GPA and a 3.8 GPA respectively. Hari has now gone on to pursue his PhD in neuroscience at Vanderbilt University. Woody Brown graduated from UCLA with highest writing honors. The list goes on.

A Paradigm Shift

Learning to communicate by spelling has helped to free the minds and souls of individuals who have been trapped inside a world of hopelessness and silence. The time has come for a complete paradigm shift. Parents, educators and others who work in the field must change how we perceive and educate the millions of nonspeakers **around us**. I saw what was possible, and I changed everything I was doing for my son. I changed my entire life, quit my job, and opened up my center to teach as many nonspeakers as I can how to finally be able to communicate. Change is hard and can be scary, but we must change. As President John F. Kennedy said, "Change is the law of life. And those who look only to the past or present are certain to miss the future."[5]

To quote one of my students, 15-year-old Edison: "Educate your child believing in his intelligence. I am only now able to talk because my Mom didn't believe everything the so-called experts told her." Be a part of the future. In so doing, you will be giving your child a future. As my son, Alex, says, "We are not cognitively disabled. And we can do great things if you give us a means of communication."

Resources

1. The International Association for Spelling as Communication (I-ASC) | https://i-asc.org
2. Communication for All | https://communication4all.org
3. United for Communication Choice | https://unitedforcommunicationchoice.org

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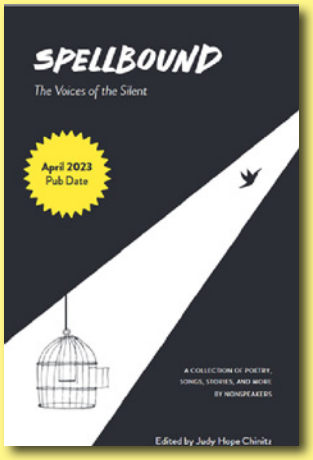
Judy Chinitz, MS, MS is the founder and director of Mouth to Hand Learning Center, Inc.

Judy has been actively involved in the world of autism, both biomedically and educationally, since her son, Alex, was diagnosed 27 years ago. With a Master's degree in nutrition, she has worked with many of the top physicians in the field, authoring numerous book chapters, articles and her own book on diet *(We Band of Mothers: Autism, My Son and the Specific Carbohydrate Diet)* and other biomedical treatments. She also has a blog, *The Biome Buzz*, on which she follows research on the human biome and health.

On the educational front, she spent 27 years trying to find ways to teach her own son, as well as other students with nonspeaking autism, but until 3 years ago, believed herself unsuccessful. In July of 2019, when she was introduced to Spelling to Communicate (S2C), everything changed for both Judy and Alex. He went on to pass the GED exam with distinction, and was recently accepted early decision to the Script and Playwriting Program at the State University of New York, Purchase. Once she saw what spelling/typing for communication could do, Judy changed her entire career path, and in May of 2020, opened up the Mouth to Hand Learning Center, where she teaches many other nonspeaking students.



SPELLBOUND: The Voices of the Silent

A ground-breaking collection of creative works that will change the way you listen to those who cannot speak.

An estimated 31 million people with autism are classified as 'nonspeakers'. For too long, this silent community has been marginalized and misunderstood, frustrated and forgotten. But thanks to the pioneering work of organizations like *Mouth to Hand Learning Center*, nonspeakers are breaking free from their silent cages.

Each startling piece in this collection has been painstakingly spelled out by pointing to letters on a board or typed on a keyboard. Whether it's a lyrical vignette about falling in love, a spirited ode to pizza, or a haunting ballad about holding onto hope, these anthems are as varied as the individuals who wrote them. United by a common thread, each affirms a joy for life and a desire to make the world a better place.

By turns poignant, inspiring, and laugh-out-loud funny, *Spellbound* celebrates the magic of a community finding its voice and using it to advocate fiercely for the millions of nonspeakers who still suffer in silence.

All profits from the book go to* Mouth to Hand Parent Association*, whose mission is to enrich the lives of their students, both socially and educationally.
Click here to be notified when the book is available for purchase: https://docs.google.com/forms/d/e/1FAIpQLSe6m3h-qswjYkWsTtCrwEFj_yHXznkZr5EvDA6SZD3K00dL4Yw/viewform

Strategies and Interventions for

Improving Listening Skills

Dawn Aerts, Au.D.
Angela Loucks Alexander, Au.D., CCC-A, MNZAS
Vanessa Rentschler, Au.D., CCC-A, C.A.S.

Many parents of children with Autism Spectrum Disorder (ASD) wonder if their children are not hearing them correctly. This is one of the first signs that can lead parents to bring their children to a pediatrician. Children with ASD might be more likely to have speech or language delays and less likely to respond to their name, both symptoms that are often consistent with hearing problems. Even when they do have typical speech and language abilities, they may still be easily distracted, find it hard to follow verbal instructions, or not respond when someone speaks. Several studies show that most individuals with autism* have some degree of difficulty processing auditory information.[1]

If you have concerns about your child's hearing, it's important to see an audiologist for a diagnostic hearing evaluation. Even if the results show that your child's hearing sensitivity is normal, he or she could still have difficulty listening or processing auditory stimuli. Studies have found that one possible cause of this challenge could be the fact that people with ASD tend to have a neurologically immature hippocampus, a key area of the brain for learning and memory.[2]

Children with ASD may have difficulty processing what is heard, which can cause them to misinterpret what was said or appear not to have heard anything at all. This can be especially challenging in noisy environments like classrooms and playgrounds, two environments that are critical for developing academic and social communication skills.

Parents and educators may assume that children who struggle to understand or remember what they hear are just not paying attention. Recent research suggests, however, that these difficulties can be indicative of a treatable underlying disorder called auditory processing disorder. You can help your child improve his or her auditory processing skills with specific strategies and interventions.

**For reference, the authors have chosen to use person-first language for this article for the purpose of discussing clinical information of interest to parents. We respect and appreciate identity-first language and neurodivergent advocacy since our goal is to provide tangible and effective strategies and interventions for improving listening skills.*

STRATEGIES TO HELP YOUR CHILD'S BRAIN PROCESS SPEECH AND SOUND

- **Be at eye level** with your child as *visual cues* from your face and lips can help connect what your child is hearing to what he or she is seeing.
- **Counting out instructions** on your fingertips, such as "Get your shoes, hat, and gloves."
- **Slow your rate of speech** to allow your child's brain *time* to process what you are saying.
- **Reduce your distance** from your child and speak from within a few feet.
- **Eliminate background noise** from devices such as the television.
- **Simple sign language** can *visually supplement* what your child is hearing.
- **Auditory training** can teach the brain how to process specific speech sounds and improve listening.
- **Using remote microphone technology** can give your child's brain a *clear auditory signal* and help it focus on speech by reducing background noise.

Auditory Processing Disorder

Auditory processing disorder (APD) is an umbrella term for a wide range of difficulties that individuals may have with processing auditory information.

Individuals who experience APD often find it challenging to understand or remember speech, even when it is loud and clear. They may have difficulty understanding what is said in noisy environments or distinguishing between similar-sounding words, such as "bat" and "cat." Other challenges include poor short-term memory for verbal information, trouble integrating what they hear in each individual ear, and an inability to sequence the sound they hear.

The disorder can be caused by a variety of factors, including hearing loss, learning disabilities, head injuries, neurological disorders, genetic syndromes, and developmental disorders. Diagnosis requires an evaluation by a specialized audiologist who will assess the individual's listening abilities in quiet and noisy environments, and will test other auditory skills.

Researchers are studying different types of auditory interventions that can enhance the neural connections in the brains of those identified with APD and enable them to process sound better. Two such interventions that have shown positive results are auditory training and the use of a remote microphone system.

Auditory Training

Auditory training is a targeted approach to improve the brain's ability to enhance sound connections. Such training is similar to the physical therapy exercises done by those seeking to overcome an injury. The programs are often tailored to the individual's needs based on the results of an auditory processing evaluation. They are delivered by a specialized audiologist or speech-language pathologist as a series of listening exercises that can be repeated and practiced regularly to increase auditory skills. While computer-based and self-directed programs are available, there are also therapy options that can be delivered one-on-one or in group settings by specialists in-person or by telemedicine.

Each approach applies different techniques to help individuals improve their listening abilities in both quiet and noisy environments, and enhance other auditory skills, such as sound discrimination, attention and memory. As is the case for many disorders, the better the intervention matches a person's specific problems, the greater the possibility of achieving the desired outcome. For example, children who have difficulty with speech sound awareness or hearing in background noise may benefit from therapy based on the Buffalo Model.[3]

Parents should note that not all clinics are equipped to test or treat children with APD. They should seek a specialized clinic (www.apdsupport.com/apdmap) that can meet their needs.

AUDITORY TRAINING CAN:

- improve phonemic awareness, or speech sound knowledge
- improve working memory
- improve attention, sequencing, decoding
- improve listening in noisy environments

Remote Microphone System

A remote microphone system allows speech or sound to be delivered directly to a child's ear. This removes the challenge of background noise and distance. It can be helpful in noisy places where it is difficult to filter out speech from unwanted noise, and can address safety concerns as parents can speak to a child from a greater distance than if the system is not used. Parents could communicate simple words like "stop" if a child gets too close to the street. Parents report that children can participate and focus on instruction and activities that they were not able to do before using a remote microphone system. Alicia, a mother of an 11-year-old boy with autism, shared her experience while her son used the remote microphone system for his equine therapeutic horseback riding lesson. She said, "We noticed an increased focus on instruction and accuracy on follow-through. This allowed his therapist to provide clear instruction further away to allow more independent thought and action, which was a goal he had been trying to achieve for a long while. It was also amazing that the earpiece was so small and lightweight that no sensory concerns were present."

She also reported that her son was able to participate in Special Olympics basketball camp for the first time because he was able to process what his coach was saying in a noisy environment.

There is considerable evidence-based research showing improved word recognition in noisy settings, improved listening and communication, better classroom behavior, enhanced general attentiveness, and lower stress levels while using a remote microphone system.[4,5]

A remote microphone system is made up of two parts: a microphone and a receiver.

The microphone is worn by a parent, caregiver, teacher, therapist, coach or friend.

The receiver consists of a small, discreet earpiece that is worn in the ear, or headphones.

The following are some of the situations in which a remote microphone system can be helpful.

At the Playground or Bike Rides

Shopping Trips

Family Dinner Time at Home or in a Restaurant

Therapy Sessions

Car Rides

Sports (e.g. basketball or horseback riding)

Classroom

Discuss your child's specific needs with an audiologist to determine if remote microphone technology is a good fit for your situation. It may not be effective for every child, especially for children who are hypersensitive to sound. However, a trial period is available to evaluate if it could be an appropriate strategy to help your child's brain process what it hears.

Conclusion

Supporting children with autism in a safe and respectful way can be a challenge for families. It is often made more complicated by the wide range of services and resources that parents must navigate. Better access to these interventions and strategies offers a concrete way to support communication and education. Consult with an audiologist to learn more about ways to improve access to speech and enhance the brain's ability to process what it hears. Taking such steps can ultimately help your child to thrive.

USING A REMOTE MICROPHONE MAY:

- improve listening, attention and social interaction
- improve focus and on-task behavior
- improve listening in noisy environments
- reduce physiologic stress and listening fatigue

Resources

www.helpful-hearing.com
www.APDsupport.com
www.audballpdx.com

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Dawn Aerts, Au.D., is an audiologist and founder of Helpful Hearing. She is an expert in pediatric hearing technology and recognized the need to increase awareness and access to assistive listening technology. Dr. Aerts received her Doctorate of Audiology in 2007 from Salus University and draws on years of clinical and hearing aid industry experience. She worked as a Pediatric and Educational Audiologist for a non-profit Speech and Hearing Center in Illinois for five years. Following her clinical practice, Dr. Aerts worked for a hearing aid manufacturer as an expert in pediatric hearing technology for 13 years. From these experiences she cultivated a passion for educating professionals on the benefits of assistive listening technology. She recognized that families of children with listening challenges are unaware of this technology, and her goal is to educate and support these families to help their children succeed.

Angela Loucks Alexander, Au.D., CCC-A, MNZAS, Audiologist, has spent 15 years specializing in diagnosing and treating Auditory Processing Disorder (APD), a hearing difficulty that has less to do with the ears and more to do with the brain. Despite significantly affecting potential and well-being, many of those affected are unaware of the condition, let alone their treatment options. Her talk "Escaping the Hidden Prison of Auditory Processing Disorder" was the most-watched TEDx worldwide in September 2021. https://www.ted.com/talks/angela_loucks_alexander_escaping_the_hidden_prison_of_auditory_processing_disorder. She is the host of the Between Two Ears podcast and founder of Auditory Processing Institute, where she trains audiologists and speech-language pathologists to provide APD services. She has also created an online, searchable map to help clients find the help they need at www.APDsupport.com/apdmap.

Vanessa Rentschler, Au.D., CCC-A, C.A.S., has been a clinical audiologist since 2004 and is a Certified Autism Specialist with training in educational advocacy. In addition to typical audiology diagnostics/treatment, Dr. Rentschler has obtained specialized training in Auditory Processing Disorder (APD), Tinnitus Retraining Therapy (TRT) for sound tolerance disorders, and Auditory Rehabilitation for Interaural Asymmetry (ARIA). Her interest in supporting auditory features in autism has grown along with her autistic son, as well as her heavy involvement within the Neurodiversity community. As a science communication enthusiast, she presents at national conferences to spread awareness and engage relevant stakeholders on this largely unmet need. She values collaboration with providers, educators, patients/families, and academics, in an attempt to bring what is known to work from the research lab into the standard of care. She currently provides consulting and clinical services in Portland, Oregon. www.audballpdx.com

Best At-Home Strategies for DISRUPTIVE BEHAVIOR

Rachel H. Fein, PhD, BCBA
Emily Jellinek-Russo, M.Ed

As parents, we can find it frustrating and stressful when our children have tantrums, don't listen to us or engage in disruptive behavior, such as hitting, biting or other physical aggression. When we think about our children's bad conduct, we often focus on the behavior itself. However, it is more important to pay attention to what happens right before the child's behavior, or what is known as the antecedent or trigger. This allows us to implement prevention or antecedent management strategies that either remove or change the trigger for the challenging behavior. Ultimately, we may be able to prevent the challenging behavior from happening in the first place.

The following prevention strategies can help you address disruptive behavior in your home.

Respond to Children's Cues

Some children engage in what are known as precursor behaviors which signal that more serious disruptive behavior is about to occur. Families may benefit from paying closer attention to children's cues and responding accordingly in order to avoid an escalation. For instance, if children start pacing around the room or becoming more irritated or noisy when family or friends are visiting, parents could encourage their children go to their room or go outside briefly in order to calm down. If children appear more irritated while doing homework and start sighing heavily or making negative comments about themselves, parents might want to offer more assistance with homework that night.

Take a Break or End on a High Note

Rather than completely avoiding situations or people, families can reduce the likelihood of disruptive behaviors by limiting a child's time in a specific setting or with a specific person. If your child tends to yell, throw things and hit people in loud situations, such as at birthday parties, or in stressful situations, such as at homework time, consider reducing the amount of time your child spends inside. Perhaps your child only stays inside at a birthday party for 30 minutes instead of the two-hour duration of the party. Before any problem behaviors occur, end on a high note. Allow your child to leave the party and play outside or in a quieter space for the remainder of the party.

Take Control of the Environment

Though it is not always possible, some families prevent behavior problems by controlling the environment. For instance, if a child constantly tries to leave the house, a parent might add a lock to the door that the child cannot reach. If a child is always trying to access a tablet, a parent might keep it out of reach and set aside certain times of the day when it will be accessible.

Use "First-Then" Statements

Most children become upset or annoyed when told to stop engaging in an activity that they really enjoy, such as playing on a tablet, and told to switch to a less preferred activity, such as taking a bath. It can be helpful for parents to first request that their child engage in the less preferred activity before taking up the preferred activity. You might even say, "First you need to take a bath, then you can play on your tablet." In some cases, parents may wish to supplement the statement with a visual aid, such as a "first-then" board. More information on visual supports is found below.

Offer Choices

It is common for children to respond negatively or to overreact when they are told "no." Instead of immediately saying "no" when a child asks for something that may not be an option or that is unavailable at the moment, try offering choices that would be an option or that are available. For instance, if you are about to get ready for bed and children ask to make muffins, you could say, "Let's find a time to do that later this week. For now, do you want to read a book or play with your doll house?" This approach could also be supplemented by the use of a choice board or other visual support.

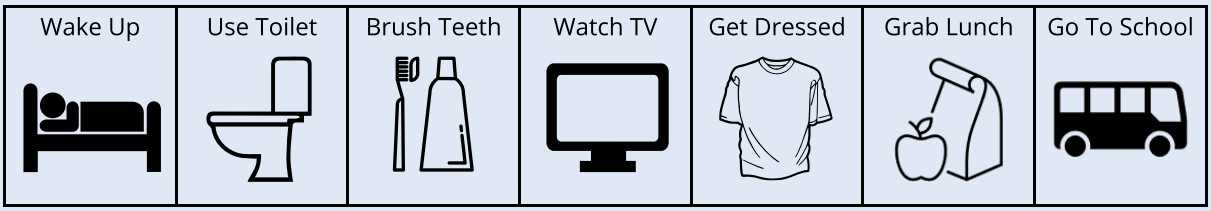
Change How You Give Instructions

When parents see their children doing something they don't like, it's natural for parents to immediately say "Stop it" or "Don't do that." However, children often tune out their parents when they hear these words. They may even respond in a disruptive manner. Instead of telling children to stop what they are doing, try giving positive instructions that clearly tell them what they should do. For instance, rather than saying, "Stop jumping on the couch," try saying, "I need you to put your feet on the ground." Also, keep in mind the importance of giving instructions in an effective way. While most parents think they are giving clear direction, they often give instructions in the form of a question. When parents phrase direction in this way, it sounds like they are asking for a favor. If children hear parents ask whether they are ready to take a bath or ready to put on their shoes, they might think they have a choice. Be direct and clear when you offer direction. Say things like, "It's time to take a bath, so make your way to the bathroom," or "It's time for school; go get your shoes."

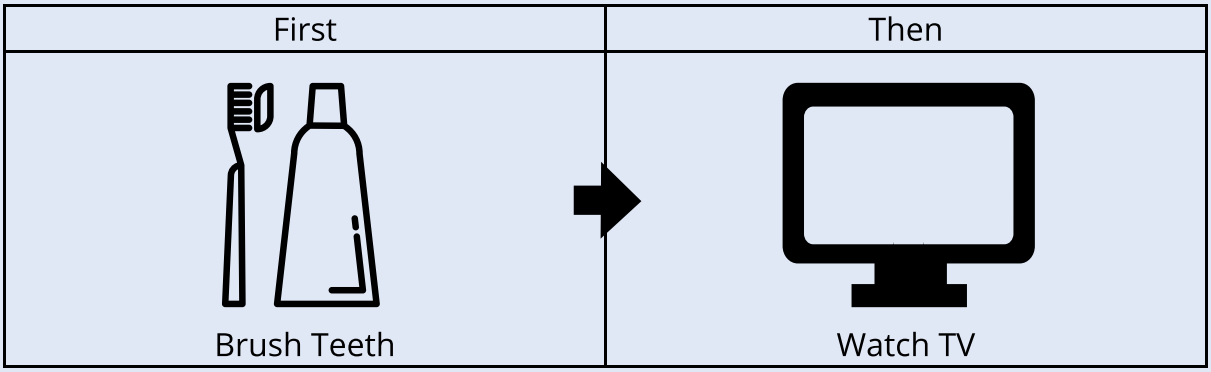
Use Visual or Auditory Supports

Visual and auditory supports, such as visual schedules, "first-then" boards, checklists, timers or verbal warnings, can help provide clear expectations about a child's day and what will happen next. They can be particularly helpful in preventing disruptive behavior by children who struggle to transition from one activity to another, in managing changes in their routine, or in processing information related to their schedule. While you may find that one type of visual or auditory support is needed in some situations, in others you may use a combination of supports. When children struggle with transitions, it may be helpful to show them a visual schedule at the beginning of the day. About five minutes prior to a transition, you could also use an auditory cue, such as a timer. In addition to advising them verbally that they need to brush their teeth in five minutes, be sure to set a timer. Although a child may request additional time, do not add more time to the timer. Once the timer goes off, show your child a "first-then" board and say, "First brush teeth, then you can watch TV."

Example of a Visual Schedule:



Example of a "First-Then" board:



Limit Demands on Challenging Days

Both children and parents are more irritable and can become frustrated when the schedule changes, when someone is feeling sick, or when they don't get enough sleep. On days that are more challenging for you or your family, consider offering more help or limiting the number of requests you make. For example, if your child is sick and normally has a difficult time getting dressed independently, you may need to provide more assistance in dressing.

Catch Your Child Being Good

One of the most powerful prevention strategies for parents is to use their attention strategically. Whenever you see your child engaging in positive rather than disruptive behavior, be sure to provide positive feedback. Praise should be specific and given immediately after the desired behavior. For example, if your child normally screams when unable to do something independently, when toys break, or when he or she can't do something independently without help, offer praise when you see your child playing calmly when a tower falls over. You could say, "Wow, I liked how you stayed so calm when your tower fell over." Other expressions of praise could include the following: "Great job keeping your hands to yourself," or "I appreciate you using your inside voice."

Expect Pushback

Any time parents use a new strategy, it is normal to experience pushback. For example, when you use the timer or the "first-then" board for the first time, it's common for children to continue their disruptive behavior. This is normal, and does not mean the strategy doesn't work. Rather, your child is communicating that you are doing something different, and he or she does not like it. When this occurs, it is important to hold the line that you've established and to ride out the disruptive behavior. If you said that you'd turn off the tablet when the timer went off, then turn off the tablet. Children need to know that you will hold to your boundaries.

As you consistently use the strategies listed above, you can help prevent disruptive behaviors!

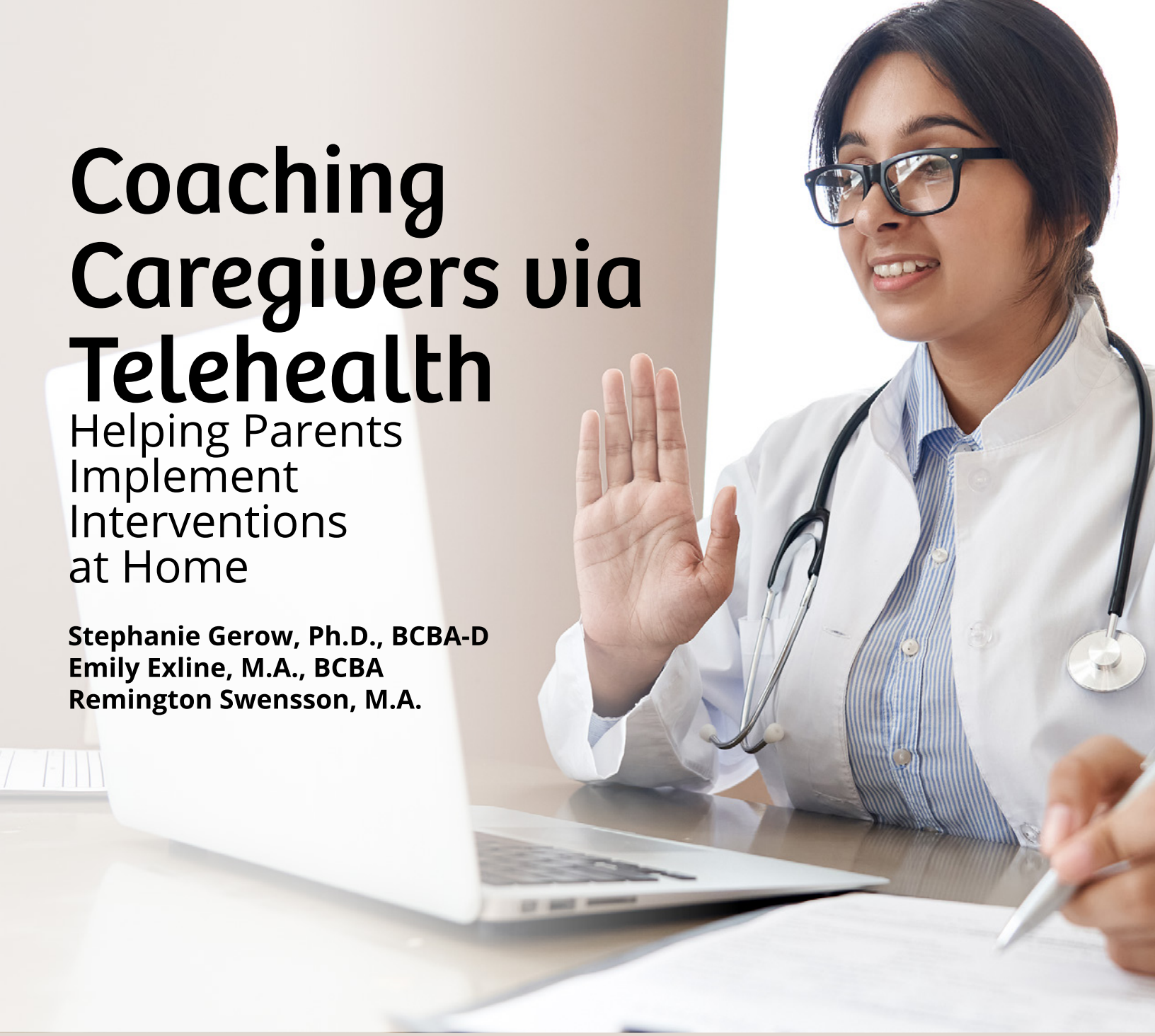
Rachel H. Fein, PhD, BCBA, works as an Assistant Professor in the Section of Psychology within the Department of Pediatrics at Baylor College of Medicine (BCM). She is also a licensed psychologist working within the Autism Center at Texas Children's Hospital (TCH). Dr. Fein provides clinical assessments and treatment to patients within the Autism Center. In addition to specializing in the assessment and treatment of Autism Spectrum Disorder (ASD), Dr. Fein specializes in working with preschool-aged populations and children with disruptive behaviors. Dr. Fein utilizes evidence-based practices in working with these populations, including applied behavior analysis, parent management training, and culturally responsive assessment and treatment. She is trained to research reliability in the Autism Diagnostic Observation Schedule, Second Edition, and is a Board Certified Behavior Analyst. Dr. Fein's research interests broadly surround ASD with an emphasis on parent management training for families of children with ASD and comorbid disruptive behaviors.

Emily Jellinek-Russo, M.Ed., is a 5th-year doctoral candidate in School Psychology at the University of Houston. Emily spent the past year training as a practicum student with Dr. Fein providing parent management training at the Autism Behavior Consultation Clinic and conducting consultative Autism evaluations using the Autism Diagnostic Observation Schedule, Second Edition, at the Autism Center at Texas Children's Hospital. Emily's clinical interests include the assessment and treatment of Autism Spectrum Disorder. Broadly, her research interests surround multi-systemic treatment approaches that emphasize the relationships between school, home, and family, to support children with Autism Spectrum Disorder and co-occurring challenges.

Coaching Caregivers via Telehealth

Helping Parents Implement Interventions at Home

Stephanie Gerow, Ph.D., BCBA-D
Emily Exline, M.A., BCBA
Remington Swensson, M.A.



Many families are starting to access health services remotely through distance technology. The broad term for this approach is telehealth. One of the primary benefits of telehealth is that families can have access to services from their homes without families or professionals having to travel. It can be useful when families are unable to access in-person services or would prefer to receive in-home services.

By using technology and software such as Zoom, professionals can provide services to individuals without being in the same location.[1] Telehealth has been used to provide a range of services, including counseling and speech therapy.[2,3]

The availability of applied behavior analysis (ABA) therapy through telehealth has been increasing. When engaged in such therapy, the parent and child are usually in the family home and talk to the ABA therapist using a phone or computer. The parent often works with the child to teach new skills, while the ABA therapist watches and provides support. Recent research has shown that coaching parents in ABA strategies over telehealth is effective in improving children's performance in specific skills, such as hand washing, using a fork, communicating preferences and needs, and reducing challenging behavior.[4,5,6]

One Family's Example

Our team worked with Parker and her mom, Violet (pseudonyms). Parker is a six-year-old girl who had been diagnosed with autism. We conducted all of our sessions with Violet and Parker over video call, with the therapist at home or a university building, and Violet and Parker in their home. During our initial meetings with Violet, we identified goals that Violet felt were important for improving Parker's life and interactions with family. The goals included teaching Parker how to: brush her teeth; put on her shoes; and identify feelings. The therapist taught Violet research-supported interventions based on ABA for each of these goals. This included arranging the environment to set up Parker for success, providing structured help that was gradually reduced over time, and providing encouraging responses after Parker used her new skills. After 22 weeks of sessions with the therapist, Parker mastered two of the goals, and showed improvement in all three. For example, Parker was not brushing her teeth independently prior to the intervention and would complete at best one of the steps required for the task. After the intervention by Violet and the therapist, Parker independently completed 77 percent of the steps needed to brush her teeth. Given this success, we have recommended that Violet continue to practice the interventions she learned during the program with Parker. We anticipate that this will lead Parker to futher improvements in each of these goals.

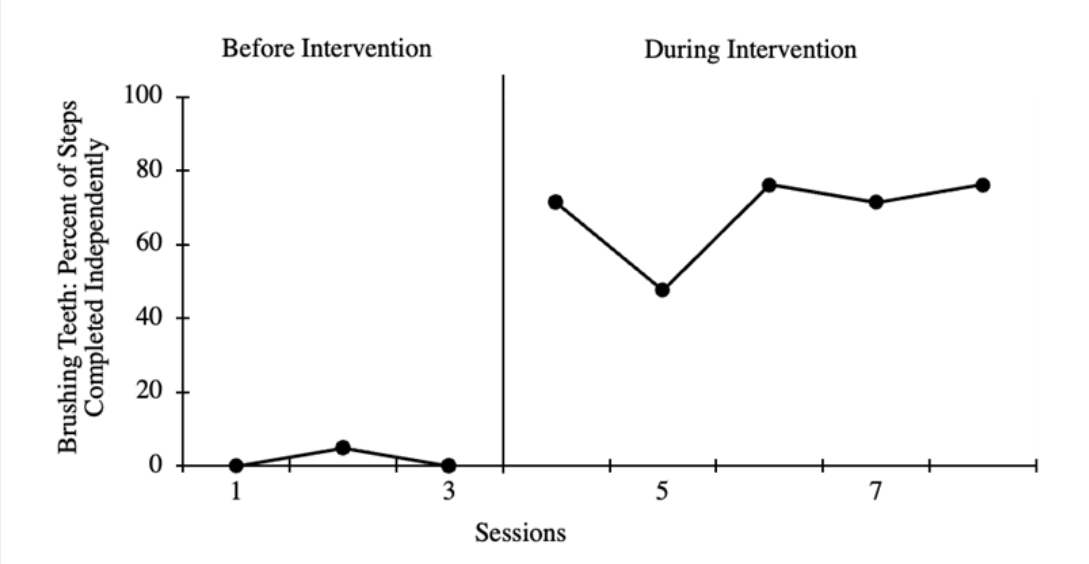


Figure 1. Graph Showing Parker's Improvement in Independently Brushing Her Teeth

Tips for Successful Telehealth Sessions

There are a number of things that parents or caregivers can do to prepare for telehealth services for their child. It can be helpful to talk to the telehealth provider to determine the technological requirements for the sessions. You will likely need to use technology that has video and audio capabilities, as well as access to internet or cellular service. Many laptops, tablets and cell phones meet these requirements. You may also need to download a specific type of software, depending on the type of telehealth technology used by your provider. It may be helpful to use a device that can be aimed at a particular spot in the room without having to be held by the user. If either the technology or the software is new to you, be sure to access the first session early, or conduct a practice call.

Consideration should also be given to such matters as scheduling, the location to use in your home, and differences related to conducting sessions without a professional present. When it comes to scheduling sessions, consider what routines you would like to practice during the sessions and the best time of day to practice them. For example, if you would like to work on eating, it may be useful to plan sessions around a mealtime. The presence of other adults and children in the home may also influence the specific time you choose. For example, we have worked with families that prefer to schedule sessions when two adults are home to help the child receiving services, or when siblings are not present to decrease distractions during the session. It is helpful to pick a place in your home that has good internet or cellular coverage. You should also choose a location in the home that is most appropriate for those routines or skills you would like to work on during the session. With telehealth services, of course, you will not have a professional available to set up the room or help you support your child. Your health provider can help you determine if telehealth is appropriate for your family. These tips are some of the things we've learned from our work with families. Your telehealth provider may have additional recommendations on preparing for telehealth sessions.

Quick Tips:

- Find out the technological requirements for the sessions (video, audio, internet, cellular service).
- Use a device that can be aimed at a particular spot in the room without having to be held by the user.
- Be sure to access the first session early, or conduct a practice call.
- Consider what routines you would like to practice during the sessions and the best time of day to practice them.
- The presence of other adults and children in the home may also influence the specific time you choose.
- Pick a place in your home that has good internet or cellular coverage.
- Choose a location in the home that is most appropriate for those routines or skills you would like to work on during the session.

Choosing a Telehealth Provider

When choosing a telehealth provider, it is important to first select a type of service that will benefit your child and family, such as ABA therapy, physical therapy or speech therapy. Telehealth services are only useful if the intervention is effective in improving the skills you and your child would like to improve. Also make sure that your provider has the required qualifications for the specialty, such as being certified or licenced. This information can often be obtained or verified online through such sources as the state licensing board website. In the case of telehealth services, providers should also be able to describe their experience delivering interventions via telehealth since this type of service can require additional skills. As is the case with all providers, those providing telehealth services should include the family and the child in the development of goals and intervention strategies. It is key to have a qualified provider who listens to your family's priorities and works collaboratively to achieve meaningful outcomes for your child.

Summary

While telehealth can make interventions more accessible, determining whether or not it is an appropriate approach for individual families depends on a number of factors, incuding those listed above. In cases in which telehealth is appropriate, it has been shown to be effective in producing improvements in the lives of children and their families.

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I AM A SUPERHERO EXPERT

Josh Stehle

MY NAME IS JOSH STEHLE AND, BY ALL ACCOUNTS, I AM A SUPERHERO EXPERT.

I admit that this is an incredibly deceiving way for me to begin this article. When compared to an actual expert, I know almost nothing about conventional superheroes. Sure, I understand the basics. I've read plenty of comic books in my 21 years of life, and I've seen almost every superhero movie. However, I don't completely understand the intricacies of the Marvel Cinematic Universe, nor have I memorized the DC Universe storylines and their many villains. Sadly, I probably couldn't even name the original seven members of the Justice League even if Batman held me by my ankles off the side of a building. Honestly, I still confuse the Joker with the Green Goblin on a regular basis. I truly have no conventional superhero expertise.

DESPITE ALL THAT I DON'T KNOW ABOUT SUPERHEROES, WHAT I DO KNOW IS THAT I, JOSH STEHLE, AM A SUPERHERO EXPERT.

You see, when it comes to true comic book expertise, my brother, Zach, reigns supreme. He knows everything there is to know about superheroes, from the worlds they live in, to the writers and studios that created them. Stacks of meticulously kept comics surround his bed and are piled on his bookshelves. In fact, my brother never goes a day without reading his favorite Batman or Spiderman issue, and he always remembers exactly where to find a particular issue in his massive comic book collection.

I should mention that Zach is also on the autism spectrum. Compared to some people with ASD, Zach's autism symptoms are relatively mild. He works full-time as a grocery store cashier, has several friends, and maintains a perfect credit score. In his free time, he enjoys reading his comic books and watching countless superhero shows on his computer while cuddling with his pet cat, Piper. Piper's cat food and litter box may be the bane of Zach's existence due to his cripplingly weak gag reflex, but he still loves that cat more than life itself, and he treats her like a queen.

Zach is my older brother by two years. If you were to see him in public, you likely wouldn't even know that he's on the spectrum. However, unlike *most* twenty-three-year-olds, he has difficulty making decisions about what we refer to as the "gray area." Black and white decisions, such as where to cross a street, when to wash his hands and when to brush his teeth, are easy for my brother to understand. In fact, Zach thrives in these situations because he knows exactly the rule he needs to follow. It's in situations that may require flexible rules or making an exception - the gray area - that Zach struggles. Additionally, Zach's speech is not as fluent as it could be. He has trouble remembering the letters of the alphabet and distinguishing left from right. He insists on following every rule and becomes flustered when that isn't possible. At times, he also has difficulty expressing interest in topics other than superheroes and fiction. To many individuals, these challenges would be inhibiting, and they can be for Zach, at times. But I also think that autism has given Zach something extraordinary.

I BELIEVE THAT AUTISM HAS GIVEN ZACH A SUPERPOWER.

Zach is one of the nicest people you could ever have the pleasure of meeting. His boundless kindness is contagious, and he makes the world a better place. He's always willing to lend a hand to whoever needs it no matter the circumstance, and he never asks for anything in return. He cares more about the well-being of his family and co-workers than about his own happiness. I can't imagine a scenario in which he isn't helping someone or trying to make someone's day just a little bit better. Whether it's family, friends, strangers or even people he will likely never see again, it doesn't matter to my brother. He'll always be there. This is Zach's superpower: it's simply who he is.

Zach does all of this without having the ability to fly. He doesn't have super strength and can't run at the speed of sound. He sometimes has trouble opening the pickle jars that have been sitting in the back of the fridge for a little too long, but who doesn't? Zach has limits, like us all. Unlike so many of us, myself included, Zach is actually inspired by his limitations. He strives to make life better for everyone who comes into contact with him. It doesn't matter to Zach. If there is a need, he will be the first in line to selflessly lend a hand. Isn't that what superheroes do?

Zach Stehle is my best friend. We talk every day about superheroes, and the world, and school, and work, and video games, and books, and movies, and life. I have spent my whole life learning from my brother, my superhero. He has taught me more than any book, teacher or life experience ever could.

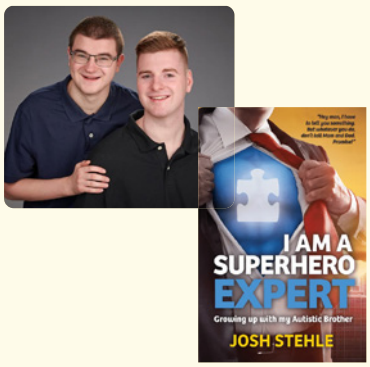
ZACH IS A SUPERHERO. THAT'S WHY, AS I HAVE SAID, I CONSIDER MYSELF A SUPERHERO EXPERT.

Now, you may be wondering where Zach's comic book is if he is a superhero. That is a question that I am delighted to answer! In my debut book, *I Am a Superhero Expert*, I explore my incredible relationship with my even more incredible brother. *I am a Superhero Expert* was released in 2022, and is now available on all online platforms.

As I grew up with Zach, I was aware that my parents were constantly involved in meetings with doctors and teachers. Zach was misunderstood and underestimated, and often ignored in his classrooms and during extracurricular activities. He found refuge in his books, and would take stacks of them with him everywhere he went. He didn't just read comic books, of course, but also fantasy books, adventure books, history books, and every book in between. As a family, we fought for Zach. His appointments with various therapists, doctors, and tutors took precedence over many other things. My siblings and I grew up knowing that we had to be a team. While I played basketball, Zach sat in the stands with his stack of books - his personal security blanket. When our sister was in a show, he sat in the audience with his ever-present books. When we had free time, we would take Zach to the library or bookstore and read books on the floor until they kicked us out.

So, when I knew I wanted to become an advocate in the autism community, I started by writing a book. *I Am a Superhero Expert* is my story of growing up with my brother Zach. It is a look at autism from a new perspective. It provides a glimpse into the challenges autistic people often face, while highlighting the indescribable beauty that autism can bring to siblings through the shared experiences of two brothers.

I love my brother, and I can't wait to share the rest of our story with you.



Josh Stehle is an author, speaker, and autism advocate from Philadelphia, Pennsylvania. His global autism awareness brand, The Stehle Bros, has received millions of views on TikTok and has been featured on ABC News, The Art of Autism, the Ausome Show, and several other national media outlets. (@thestehle.bros)

Josh's debut book, *I Am a Superhero Expert*, is a look at autism from a new perspective. *I am a Superhero Expert* was released on December 1st, 2022.

Follow Josh Stehle to learn more about *I am a Superhero Expert* today at www.Josh-Stehle.com!

ATTENTION-DEFICIT/ HYPERACTIVITY DISORDER AND AUTISM

Research Shows Genetic Similarities and Differences

This article is a review of the following research: Mattheisen, M., Grove, J., Als, T. D., Martin, J., Voloudakis, G., Meier, S., Demontis, D., Bendl, J., Walters, R., Carey, C. E., Rosengren, A., Strom, N. I., Hauberg, M. E., Zeng, B., Hoffman, G., Zhang, W., Bybjerg-Grauholm, J., Bækvad-Hansen, M., Agerbo, E., Cormand, B., ... Børglum, A. D. (2022). Identification of shared and differentiating genetic architecture for autism spectrum disorder, attention-deficit hyperactivity disorder and case subgroups. ***Nature Genetics,*** 54(10), 1470–1478.

Autism and attention-deficit/hyperactivity disorder (ADHD) are conditions that can have many similarities. They are both neurodevelopmental conditions that may include traits such as sensory sensitivities, difficulties with self-regulation, poor executive function skills, and poor social skills. However, they also have notable differences. Autism is characterized by repetitive behaviors and rigid thinking, while ADHD is associated with hyperactivity, impulsivity and a short attention span.

The relationship between these two conditions is quite complex. In many cases of comorbid ASD/ADHD, the challenges of ADHD may be attributed to an autism diagnosis or overlooked because of that diagnosis. Until recently, it was not possible to diagnose ADHD in a person who already had an autism diagnosis.

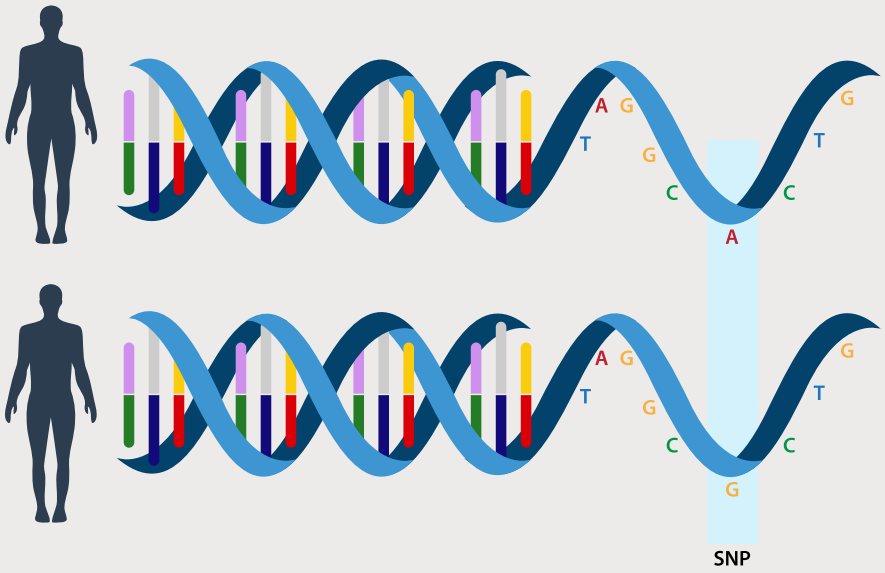
Studies have shown that autism and ADHD are also closely related at a genetic level.[1,2] In the past, scientists and clinicians debated whether autism and ADHD were in fact distinct conditions or simply the same condition with varying degrees of severity in certain traits.

A group of researchers from around the world, led by Dr. Anders D. Børglum (Aarhus University, Denmark), decided to investigate autism and ADHD at the genetic level to identify components that might be shared between the two conditions or that might be exclusive to one of the conditions.

Study

This study used patient information from the extensive databases of the Psychiatric Genomics Consortium (PGC) and the Lundbeck Foundation Initiative for Integrative Psychiatric Research (iPSYCH). The information covered 34,462 people diagnosed with ASD and/or ADHD, as well as 41,201 control patients. For each person, the researchers examined 8.9 million frequently occurring genetic variants from across the entire human genome.

The study looked for common single nucleotide polymorphisms (SNPs) in the DNA of patients with autism, ADHD, or both. SNPs are variations in the DNA sequence at a specific location in the gene.



Results

The researchers identified 263 SNPs in seven genetic regions (loci) that were **shared** by autism and ADHD.

SNP	Chromosome	Base Pair	Gene
rs7538463	1	44196416	PTPRF, KDM4A, ST3GAL3, MIR6079
rs4916723	5	87854395	MIR9-2(58.3)
rs2391769	1	96978961	-
rs9530773	13	78852243	-
rs138696645	20	21154234	PLK1S1, KIZ, XRN2
rs227293	4	103623491	MANBA
rs325506	5	104012303	-

Mattheisen, M., Grove, et al. (2022). Identification of shared and differentiating genetic architecture for autism spectrum disorder, attention-deficit hyperactivity disorder and case subgroups. *Nature Genetics*, 54(10), 1470–1478.

The researchers found SNPs in five genetic regions (loci) that **differentiated** autism and ADHD.

SNP	Chromosome	Base Pair	Gene
rs13023832	2	215219808	SPAG16
rs7821914	8	10805015	XKR6
rs147420422	2	104139422	-
rs3791033	1	44134077	PTPRF, KDM4A, ST3GAL3, MIR6079
rs9379833	6	26207175	HIST1

Mattheisen, M., Grove, et al. (2022). Identification of shared and differentiating genetic architecture for autism spectrum disorder, attention-deficit hyperactivity disorder and case subgroups. *Nature Genetics*, 54(10), 1470–1478.

The research showed that the SNPs which differentiated autism and ADHD often had opposite effects in the two disorders. For example, the participants with the "C" allele in the SNP rs3791033 were at greater risk for autism and increased cognitive performance. Participants with a "T" allele in this location were at risk for ADHD and decreased cognitive performance.

The seven shared genetic regions were all strongly associated with other psychiatric conditions, such as depression.

Discussion

The researchers found not just genetic similarities between ADHD and autism but also striking differences. Gaining a better understanding of the genetic basis of these two conditions will enable clinicians to do more accurate diagnoses and provide the best treatment possible. This is important because treatment can vary for each person and should be approached differently depending on the diagnosis. For example, social challenges are common both for individuals with autism and those with ADHD, but for different reasons. An autistic child may have challenges due to difficulties in social communication and social reciprocity. A child with ADHD, however, may have challenges due to impulsivity and hyperactivity. Improving social skills for these two individuals would take two very different approaches. With the help of genetics, clinicians can now determine more accurately the causes and underlying issues and if they stem from an ADHD or autism diagnosis.

The results of this study enhance our understanding of the complexities of autism and ADHD. They show that ADHD and autism are distinct conditions but that they share some genetic components. The next steps for such research would be to expand the range of test subjects to participants from other cultures and ethnic backgrounds.

Written by Autism Advocate Parenting Magazine

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HYPERLEXIA
Under Review

This article is a review of the following research: Macdonald, D., Luk, G., & Quintin, E. M. (2021). Early Word Reading of Preschoolers with ASD, Both With and Without Hyperlexia, Compared to Typically Developing Preschoolers. *Journal of Autism and Developmental Disorders*, 51(5), 1598–1612.

Hyperlexia is a condition in which children have advanced reading skills, learn to read without any formal instruction, and show a strong preference for books, letters and words from a very young age. Most hyperlexic children start reading between the ages of two and four, while some can read at 18 months of age. Even though children with hyperlexia can read well above what is expected for their age, they struggle with reading comprehension and the meaning of the words they are reading.

Hyperlexia is strongly associated with neurodevelopmental disorders, including autism, ADHD and Tourette's Syndrome. Current research shows that between six and 20 percent of autistic children have hyperlexia, and that 85 percent of children with hyperlexia also have an autism diagnosis.[1]

When typically developing children learn how to read, it involves alphabet knowledge and phonological awareness, or letter-naming and letter-sound correspondence. A recent study found that children with autism and hyperlexia don't follow the same process as typically developing children, rather they seem to be taking a unique approach in learning how to read.

There is very little research on the process used by hyperlexic children to learn how to read. It is important to gain a better understanding of this process as it would help parents, teachers and caregivers identify more effective ways of supporting these children.

Researchers from McGill University (Montreal, Canada) sought to better understand how children with hyperlexia learn to read. They compared the reading skills and pre-reading skills of three groups: typically developing preschoolers; autistic preschoolers; and autistic preschoolers with hyperlexia.

Alphabet Knowledge and Phonological Awareness:

- ✓ Understanding that each letter corresponds to a sound
- ✓ Breaking down words into individual sounds (dr – eh - sr)
- ✓ Breaking down words into syllables (DRESS – er)
- ✓ Breaking sentences into words

Study

Participants were between the ages of three and five years old. Each participant had an interest in letters and words, and/or the ability to read without formal instruction. Each participant was English-speaking, and was grouped into one of three categories. A total of eight participants had autism and hyperlexia; seven had autism alone; and 15 participants were neurotypical. As part of the study, each participant was assessed for reading skills, pre-literacy skills, phonological awareness and alphabet knowledge, reading comprehension, and oral language skills.

Results

Autism and Hyperlexia	Autism	Neurotypical
The participants with autism and hyperlexia showed: ★ **advanced** reading skills ★ **advanced** letter-naming skills ★ showed weak scores in phonological awareness, letter-sound correspondence and language skills	The children with autism demonstrated: ★ **advanced** letter-naming skills ★ age-appropriate vocabulary in terms of understanding and expression	The neurotypical children showed: ★ phonological awareness ★ language skills appropriate for age ★ appropriate letter-sound recognition ★ appropriate letter-naming skills ★ age-appropriate vocabulary in terms of understanding and expression ★ a lack of word reading skills

Discussion

This research confirms that preschoolers with hyperlexia have advanced reading skills, which is remarkable given that these skills often appear before any formal reading instruction has taken place. Hyperlexic children in this study showed advanced reading skills and letter-naming skills, but weak scores in phonological awareness, letter-sound correspondence and language skills. Given their weakness in the areas that are key to supporting reading skills in a phonological and language-based route, children with hyperlexia likely learn to read from a process that is unique and unlike that of typically developing children. The authors of this study suggest that children with hyperlexia may learn to read through strategies such as pattern detection, decoding, memory and other ways that rely less on phonological processing.

Although the sample size of this study was quite small, it points to the need for further investigation of the process that children with hyperlexia use to learn word reading skills. It also prompts a discussion about how parents and teachers can better support children with hyperlexia and their unique learning style, particularly since most education systems focus solely on alphabet knowledge and phonological awareness to teach this skill.

This study could lead researchers to find interventions that can support a child with hyperlexia. In fact, the same group of researchers that carried out this study designed a tablet application to teach reading comprehension to autistic children with hyperlexia that is tailored to their unique learning style. To date, the application has helped users make significant gains in reading and listening comprehension.[2] It is important to continuously support our children's unique learning style and to advocate for a reevaluation of the one-size-fits-all approach to learning used in the education system.

Written by Autism Advocate Parenting Magazine

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Autism Advocate
Printable Resources

Teaching Self-Advocacy

Parents and caregivers of autistic children are constantly advocating for their children's needs. They advocate for education, medical care, social assistance and equality. As children grow, it is important for caregivers to teach them how to advocate for themselves. Parents won't always be in the schoolyard when children need to stand up for themselves. Parents won't always be at a place of employment when a teenager starts a new job. It is important for parents to teach children how to communicate their goals, needs, desires, strengths, ideas and rights.

Teaching self-advocacy skills to children does not happen overnight. It takes time and preparation to empower children with the skills necessary to stand up for themselves and to advocate for their needs in work, relationships and in the community. The following are some suggestions on how to teach your child how to be an effective self-advocate.

- **Lead by example.** Your child will learn how to be an advocate by watching you. Advocate for yourself by speaking up when needed. Don't back down when you or your loved ones need an advocate.
- **Focus on fostering effective communication skills.** Children will not be able to advocate for themselves without communication skills. Do not assume that your child's lack of verbal skills means that he or she cannot be an effective advocate. Consult your child's speech language pathologist on the best ways to support communication. The use of small booklets could help your child advocate for his or her needs. (See printable below).
- **Let your child know to speak up and tell others about his or her needs, even if it is uncomfortable or awkward.** Just as someone in a wheelchair would ask for the wheelchair ramp or someone with diabetes would ask for candy or juice in the case of low blood sugar, your child also has specific needs. The fact that the needs are often hidden or misunderstood does not mean that they are any less important than a wheelchair ramp.
- **Help your child to be self-aware and to pay attention to his or her body.** Your child should understand the things that are triggers or that cause stress, as well as the tools that can help with coping. Use journals, printouts and worksheets to document your child's needs. This allows your child to see those needs, to write them down and to refer to them often. (See worksheet below)
- **If you and your child are comfortable doing it and feel it is necessary, teach your child to disclose his or her autism.** This can open doors for educational and workplace assistance and accommodations.

Give your child opportunities to be an advocate, even if it is easier for you to speak up at the time. For example, allow your child to order a meal at a restaurant, including any specific instructions, such as no onions. If the order comes back incorrect, have your child tell the waiter what was wrong and ask for it to be fixed.

Role-play possible situations. This might include helping your child know how to ask a roommate to turn the music down, or ask a teacher for permission to wear noise-cancelling headphones during a test or exam.

Reach out to autistic adults, either in person or through online support groups, and ask for advice on how your child can self-advocate. Autistic individuals will have a unique perspective that could benefit your child.

Learn about the laws in your country or region and what rights they confer on your child as an autistic person. If appropriate, share this information with your child.
Americans with Disabilities Act (ADA)

I Am Self-Aware

Things I am good at:	
Things that bother me:	
How I communicate:	
People I trust:	
Things that hurt my eyes:	
Things that hurt my feelings:	
Things that hurt my ears:	
Things that help me calm down:	

I feel sick.

My belly hurts.

My head hurts.

My ear hurts.

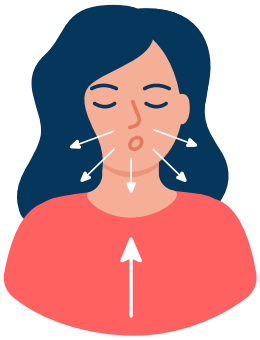
I'm really tired.

My nose is stuffy.

I have a cough.

I'm bleeding.

I need help calming down.



Take 10 deep breaths.

I want to listen to music.

I need a quiet space.

I need a fidget toy.

I need to go for a walk.

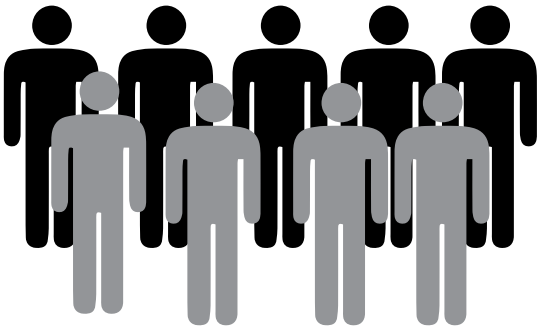
Something is bothering me.

It is too loud.

It smells funny.

It's too bright in here.

Someone is being mean to me.



There are too many people.

I don't understand what my teacher wants.

Creamy Potato Salad

INGREDIENTS

potatoes (yellow preferred)..... 3 lbs
vegan mayo .....1 cup
salt .....1 tsp
dry dill.....1 tsp
dry rosemary .....1 tsp
yellow mustard..... 1 tbsp

INSTRUCTIONS

Wash and chop potatoes into quarters, or eighths if they are very large. Skin can be left on unless you prefer to peel them. Fill a large pot with 5 to 6 cups of water, and boil potatoes until tender or for about 20 minutes. When potatoes are tender, drain water and rinse in cold water to cool. When potatoes are cool, add vegan mayo, salt, dill, rosemary and mustard, and gently stir to combine. Serve immediately.

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.

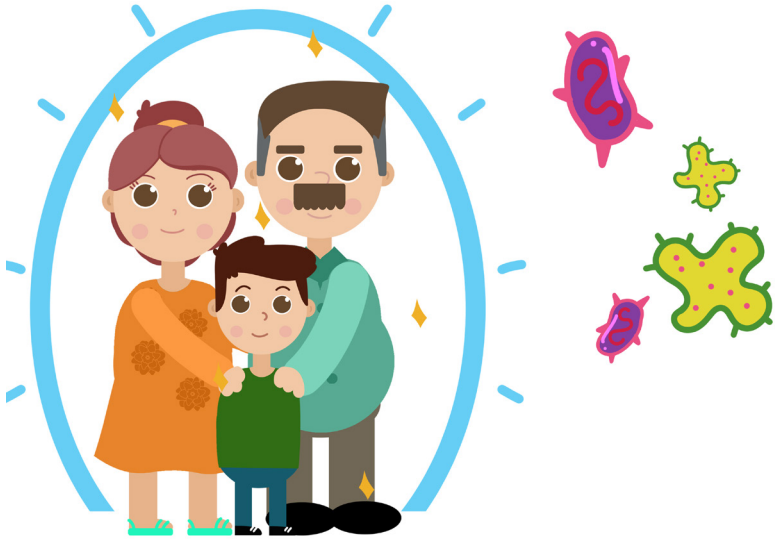
Robyn teaches Hanen Centre's *More Than Words* evidence-based 8-week program for families having children ages two through five on the Autism Spectrum. By providing tools, strategies, and real-life videos, families can better connect with their child and expand purposeful, interactive communication and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

RW LANGUAGE THERAPY AND CONSULTING
www.rwltc.com
robyn@rwltc.com

My Social Story:

I Can Take Care of My Body

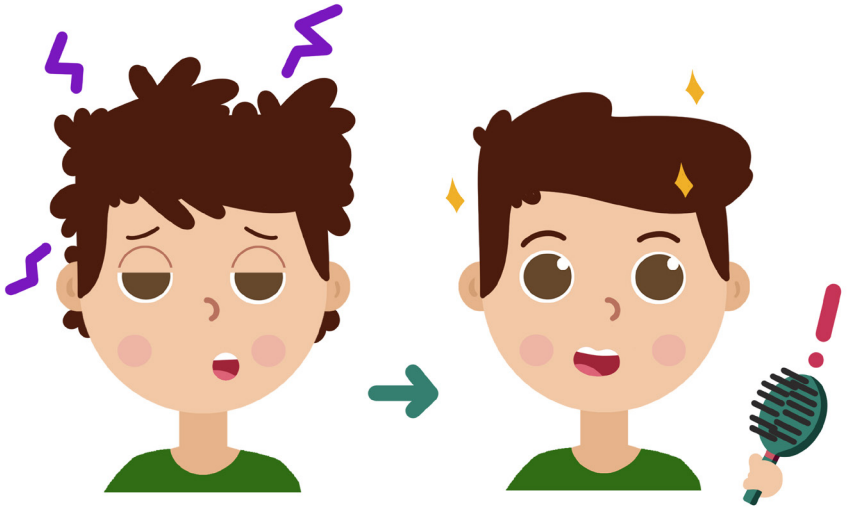
It is important to be clean and smell good, and to keep my body safe from germs.



I can keep my body clean and safe. My mom and dad are proud of me when I remember to do these things.

When I go to the bathroom, I need to wash my hands when I'm done so I can be clean.

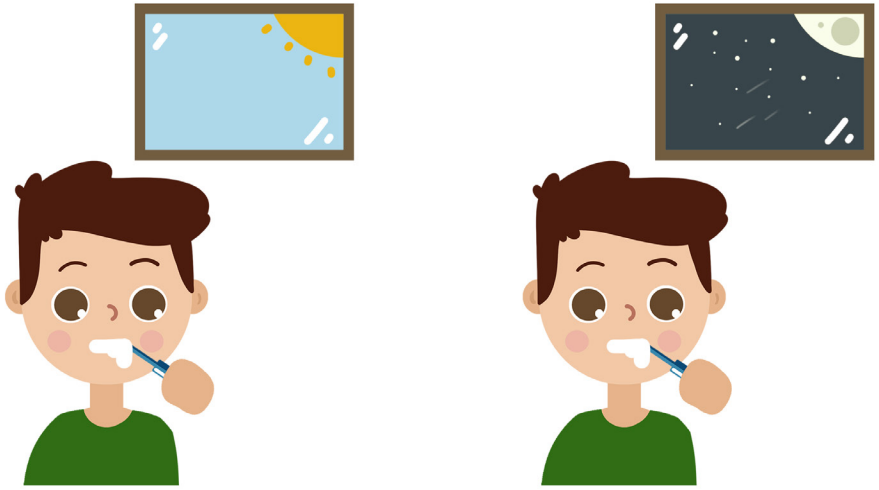
When I take a bath or shower, I wash my body with soap and my hair with shampoo.



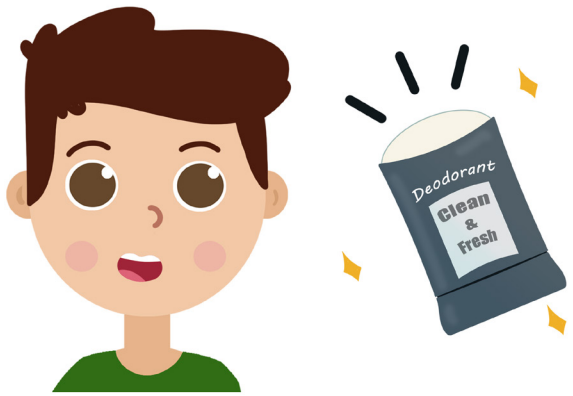
When I wake up in the morning, I need to brush my hair so it looks nice and not tangled.

If my nose itches or I think I have a booger, I can get a tissue and use it to wipe my nose so my hands stay clean.

I like to wear clean clothes. It makes me feel good.



I need to brush my teeth every morning and night to keep my teeth clean and healthy.



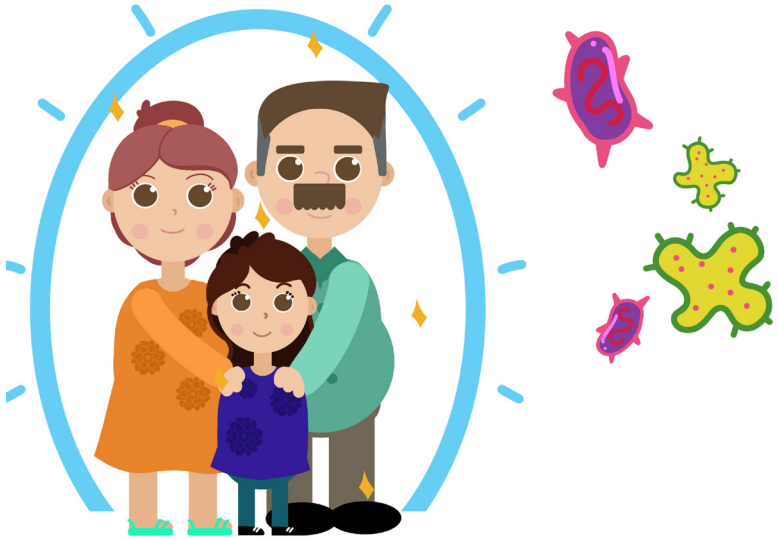
If my mom and dad tell me I am old enough, I can wear deodorant.

I’m so proud of myself when I keep my body clean and safe from germs.

My Social Story:

I Can Take Care of My Body

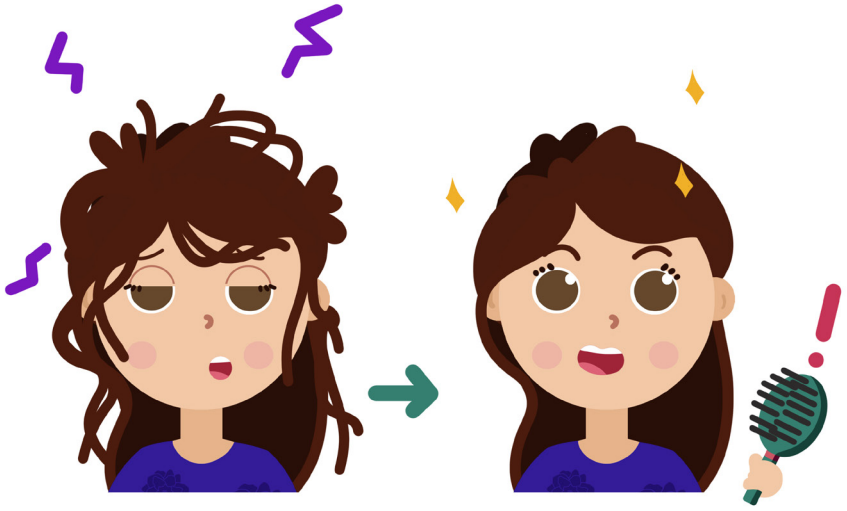
It is important to be clean and smell good, and to keep my body safe from germs.



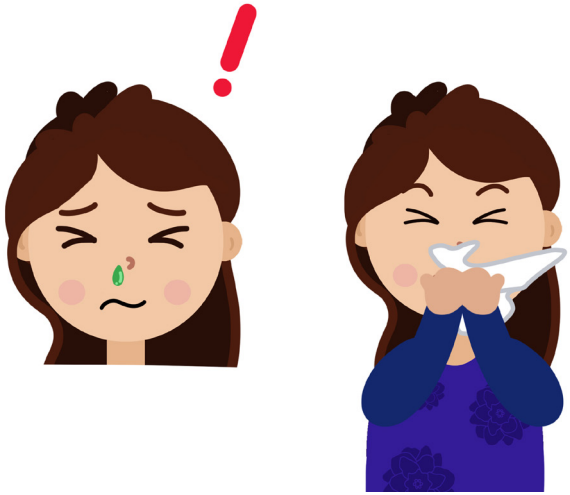
I can keep my body clean and safe. My mom and dad are proud of me when I remember to do these things.

When I go to the bathroom, I need to wash my hands when I'm done so I can be clean.

When I take a bath or shower, I wash my body with soap and my hair with shampoo.

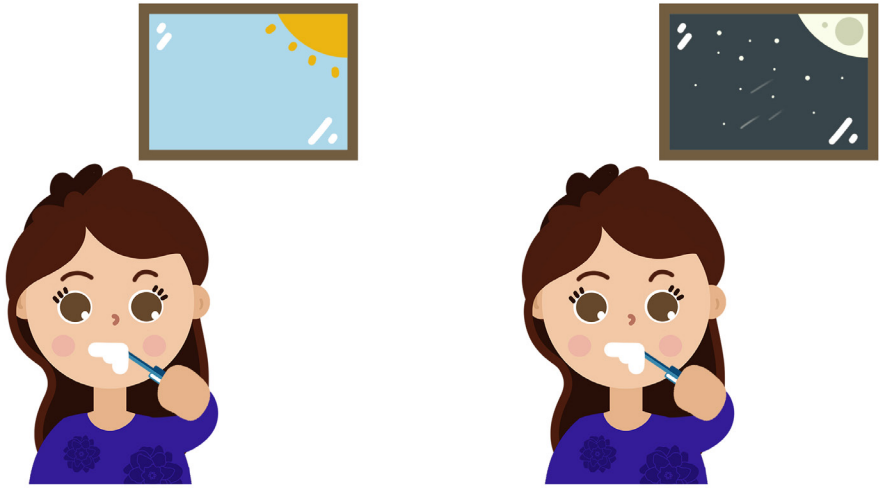


When I wake up in the morning, I need to brush my hair so it looks nice and not tangled.



If my nose itches or I think I have a booger, I can get a tissue and use it to wipe my nose so my hands stay clean.

I like to wear clean clothes. It makes me feel good.



I need to brush my teeth every morning and night to keep my teeth clean and healthy.

If my mom and dad tell me I am old enough, I can wear deodorant.

I’m so proud of myself when I keep my body clean and safe from germs.

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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:

My Next Steps

Items I would like to implement/notes

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Ambassadors

for Autism Advocate Parenting Magazine

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

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MORE THAN
YOU WILL EVER
TEACH THEM.
— Melissa Noelle Brown Oliveras

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