ISSUE 37

FOR PARENTS & PROFESSIONALS

AUTISM ADVOCATE

PARENTING MAGAZINE

Photo Credit: Avery at Red Hill Toyota

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
Embracing Differences Executive Function
Fragile X Detox Family Gastro Intestinal Issues
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
Medication Hygiene Mindfulness Healthy Lifestyle Teaching at Home
Independence Learning Difficulties Yoga Hypersensitivity
Lyme Disease Microbiome Sibling Support
Motivation PECs
Nutrigenomics Literacy 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 supports are best for our children and what the latest autism research has uncovered. This is where we can help.

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

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

Current Research

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

Resources

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

Expert Advice

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

Parent Advocating

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

EMPOWERING *Parent* ADVOCATES

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

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

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

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

Parent Advocates

Autism Advocate Parenting Magazine

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

AUTISM ADVOCATE
PARENTING MAGAZINE

A Note on Perspective

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

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

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

EMPOWERING
Parent
ADVOCATES

AUTISM ADVOCATE
PARENTING MAGAZINE

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

From time to time, this magazine may include our review of other articles or publications that we think may be of interest to our readers. We have no affiliation with the original author or publication. We are providing the reviews for interest and information only and we encourage you to read the original publication for more information.

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Looking Beyond

APPLIED BEHAVIOR ANALYSIS THERAPY

Next Steps and Alternative Treatment Options

Dr. Myah Gittelson, PsyD

Applied Behavior Analysis Therapy may or may not be the right treatment approach for your child. Dr. Gittelson, a clinical psychologist who specializes in evaluating, diagnosing, and treating Autism Spectrum Disorder (ASD), spoke with AAPM about how to determine if ABA is working and what other possible treatments are available.

The Use of ABA

Let's first address the elephant in the room: ABA Therapy has been surrounded by controversy, and its efficacy has been questioned by many in the community. The ABA model, originally developed for young children ages two to six years old, is helpful for tantrum behaviors. It can also help when a child lacks the internal motivation to learn a skill or, once it is learned, apply that skill. While ABA continues to be the frontline intervention for the ASD population, no two children are the same. Some are not as responsive, and others may reach their ceiling potential through ABA sessions but then might need to pivot. Parents, therapists and teachers need to work as a team and watch for such moments.

Is there more than ABA?

Since all children move through different developmental stages, the treatment approaches may need to shift as well. ABA Therapy focuses strongly on behavior, and parents should also consider the developmental, social-emotional and cognitive levels of functioning for their child. Additionally, they should consider the wide variety of presentations found across ASD profiles and the fact that each child has unique strengths and challenges. This explains why one child may see success in ABA, and another may not. Such awareness helps parents understand that a one-size-fits-all approach does not always apply when it comes to the ideal therapeutic course of treatment, unlike other conditions where there is a single cure or medication. Many psychiatrists, clinical psychologists and even ABA therapists agree that a new, more individualized approach is needed.

My Therapeutic Style

In my own private practice, I have introduced connecting to emotions through color and the Cognitive Behavioral Therapy (CBT) model to provide insight into thoughts, behaviors and feelings. I take the time to understand the client's specific profile and design a personalized treatment plan accordingly. I work together with the child and parents to develop agreed-upon weekly plans that include clear boundaries but that give choices to the child. This approach helps to hold families accountable for their plans to accomplish the best outcome. When treating pre-adolescents and adolescents in particular, I find that gaining their buy-in is critical to success.

I frequently recommend that school-aged children and teenagers enroll in enrichment classes or programs, or in team sports, as a means of targeted intervention to improve deficit areas and foster social skills. This gives them a chance to learn, grow and practice via trial and error in an environment where all peers are working together towards common goals.

Other Treatment Approaches

In my experience, children with ASD have multiple developmental, behavioral and medical diagnoses. Some factors playing a role in treatment planning may include the following: coexisting mental health symptomatology, such as anxiety and depression interfering with peer relationships; food-related concerns, such as pickiness or restricted dietary preferences; sensory processing dysregulation making it uncomfortable to be in noisy or crowded situations; and sensory-seeking behaviors impacting age-appropriate types of play, interaction with peers and adults, and attentional skills.

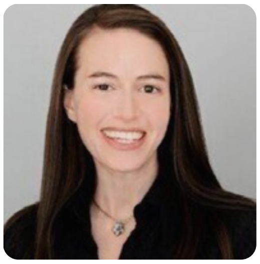
To address these various presentations, parents can turn to professionals skilled in other areas of expertise, such as occupational therapy, speech and language, child development, psychology, neurology and others. In seeking out such related services, parents should ask professionals about their experience working with autistic individuals. They should also seek to form a multi-disciplinary team that includes teachers to ensure consistency across the home, the therapist's office and the school setting.

Cognitive Behavioral Therapy is an alternative method gaining more acceptance. Research has shown its efficacy and effectiveness in treating anxiety disorders, including post-traumatic stress disorder, obsessive-compulsive disorder, panic disorder, generalized anxiety disorder, social anxiety disorder, and specific phobias. Journaling about one's thought-feeling-behavior cycle throughout the day is one of many ways to confront and modify behavior.

Parents can also take advantage of emerging digital technologies to accelerate their child's progress. Neurofeedback therapy, which has been around since the 1990s, is one example. It offers brain enhancement training via computer-based exercises while measuring brainwaves with non-invasive sensors. Supporters of neurofeedback therapy claim it can help autistic people by improving their social skills, communication, speech and ability to focus.

Final Words

As our understanding of autism continues to evolve, so will the forms of treatment interventions. It is important for parents to recognize that they can play an active role in deciding which therapeutic approach, or combination of approaches, works best for their child. As they do so, they should carefully consider the recommendations of family physicians, therapists, Individualized Education Plan teams and teachers.



Dr. Myah Gittelson, Psy.D., earned her Psy.D. in Clinical Psychology from California School of Professional Psychology, Los Angeles campus. She has over a decade of experience in the field of Autism. She has been a consultant for multiple Regional Centers in southern California conducting evaluations within the intake eligibility process. Dr. Gittelson also has a private practice located in Studio City, CA, providing diagnostic evaluations and treatment, as well as social-emotional peer groups and parent workshops. Read more at www.drmyahgittelson.com.

Using Social Thinking in the Mainstream Classroom

A Way for **ALL** Kids to Learn Social Concepts Together

Michelle Garcia Winner, MA, CCC-SLP
Pamela Crooke, PhD, CCC-SLP

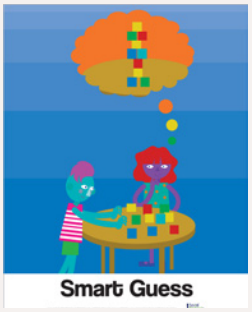
The Social Thinking Methodology originated in schools over 25 years ago in response to a lack of common sense and practical ways to explain different aspects of the social-emotional world to both neurotypical and neurodivergent students. Michelle Garcia Winner, founder of the Social Thinking Methodology, continues to update core strategies and tools in response to ongoing and valuable input from individuals with a range of social-emotional learning differences, disabilities and/or difficulties, as well as from mainstream teachers and learning specialists. Dr. Pamela Crooke joined forces with Michelle almost 17 years ago to further evolve components of the methodology. Michelle and Pam speak in communities across the United States and globally. Tools from the Social Thinking Methodology have found their way into inclusion-based or mainstream classrooms since ALL students can benefit from a common vocabulary and understanding of the social and emotional world together.

Teaching Tools for the Classroom

Over the years, many students and clients have shared their dislike of being rewarded or punished based on their social behaviors. As an alternative, we created a core set of *Social Thinking Vocabulary* (STV) phrases to explain "why" we use our social competencies. In general, we use them to meet our own social goals. These vocabulary terms are not about right or wrong but instead teach concrete ways of describing the many ways we participate socially to work and learn in the presence of others, as well as form relationships if we choose.

Social Thinking Vocabulary is made up of simple and clear phrases used to help teachers and students understand abstract aspects in the classroom. The key to using STV phrases in a classroom setting is to teach them proactively and not reactively to belittle or shame or correct. It is also important to teach with empathy, understanding that neurodivergent students often spend large amounts of cognitive and emotional energy trying to figure out how the social world works and how to use their tools or strategies within that world, when they choose to do so.

Table 1 features a few examples of how a teacher might use these terms for all students in the classroom. Please note, there are many other STV terms not included in this short article.

Situation or Classroom Event	Social Thinking Vocabulary Ideas
 Announcing or talking about the "schedule" for the day. Transitioning to small groups or lining up to move as a group.	Use the term "**group plan**" instead of schedule. This helps students remember that they are part of a bigger whole and that there is a difference between following their own plan and a group plan. Try the following: • "The group plan is to_____." • "You can be part of the group plan by______." • "We are ____ together. Everyone is following the group plan."
 Encouraging students to notice when you are holding something up in front of the classroom. Encouraging students to figure out, for themselves what is happening now or what will happen next.	Use "**think with your eyes**." This helps teach that there is a purpose for looking around the classroom to gain information through observation. *Instead of saying, "look at me" or "pay attention," try:* • "Use your eyes and ears to think about what I'm showing. I have information to share." • "Think with your eyes. Let's notice what the group plan is right now." • When writing on the whiteboard, say, "Wow, I know you all are thinking about what I'm teaching because you are thinking with your eyes!"
 Bringing students together to sit in a group. Encouraging students to show they are part of a working or social group. Helping students transition to line up.	Rather than saying, "It's circle time" or "line up," use the term "**body in the group."** • "Put your body in the group, it is time to line up." • "When your body is in the group, we can walk to lunch." • "When your body is in the group, it shows others you are interested/ready to learn."
 Encouraging students to figure out what is happening and infer meaning in a work of literature; predict what might happen next; and/or figure out what others mean by what they say and do in groups.	Many students see guesses as random and inaccurate. Instead, teach that guesses can have a process, like math, where we gather information using our eyes/ears/brain to make a **Smart Guess.** Rather than saying, "estimate or predict what will happen next," try: • "Let's all gather clues to make a smart guess." • "I wonder what the writer meant by that sentence. Let's make a smart guess." • "Make a smart guess about what we will do next. What clues can you find?" • "What materials do we need for science? Let's make a smart guess based on what the experiment is about."

Teaching ideas from Kari Zweber Palmer, Social Thinking Collaborative Trainer

The STV helps to teach, in a literal and meaningful way, the “thinking” underlying what we “do and say” in classrooms and groups. Make sure to notice when students are *thinking with their eyes*, following the *group plan*, or *making smart guesses*. If you find yourself simply redirecting behavior or the vocabulary terms are not a fit for your classroom or students, then please don’t use them.

The second tool is a visual teaching framework called the *Four Steps of Communication*. In this framework, we explore how face-to-face communication involves far more than just talking.

https://www.socialthinking.com/Products/social-thinking-teaching-frameworks-set-2

Step 1: Thinking about who is around us in specific situations.
- What do we know about the people?
- Is this a good time to approach? If so, then....

Step 2: Showing our intention to communicate with our body.
- Our body can convey who we want to talk to, if we want to join a group or just listen, or our intentions.
- When working in peer groups, our body conveys that we are part of that group.

Step 3: Using our eyes to consider perspectives and what is happening with others.
- Avoid teaching simple “eye contact.” Instead, eyes help us gather clues about the people and the situation, as well as the emotions, interests, or possible lack of interest of others.
- The eyes of others can also help us figure out what they might be thinking based on where they are looking, such as at their cell phone, other people, a teacher or a peer.

Step 4: Using our language to relate to others.
- We ask questions to learn about thoughts, feelings and perspectives of others.
- We listen with our eyes and ears to determine what people mean by what they say.
- We add our own thoughts to connect our experiences and knowledge to the interests or comments of others.

Sum it Up

What started as a way to teach a few concrete concepts has now evolved into hundreds of lessons to support social-emotional learning and organizational skills. We continue to evolve and share this process via workshops, online training, developmental books, posters, and games. Our work has also expanded to help teach how to make sense of our feelings, how our feelings shift throughout the day, and how our awareness of our feelings leads to a better understanding of our reality. With that understanding, we are better able to self-regulate to meet our own goals.

Ultimately, we hope our work will help people recognize that ***to be social*** is more than just talking or being polite or making friends. The social world is complex, and many of the social competencies we teach form the foundation for learning and participating across the academic day. We all desire to be included and appreciated for who we are, and helping all students access their own tools to meet their goals is a first step. We also feel strongly that learning should be accessible to all. That’s why we provide free webinars, articles, and downloadable materials on our website www.socialthinking.com.

What is the Social Thinking Methodology?

The Social Thinking Methodology was developed for social learners ages four to adulthood with solid language and learning abilities, in other words, those who are using their language to learn versus those who are learning to develop basic language skills. The curricula and materials may be helpful for any person whose social goals or desires are unmet due to a lag in social and/or emotional competencies, motivation, learning difference, or disability. They are also intended for those who are simply interested in how the social world works as they can help them navigate to regulate within it. The strategies and tools are not specific to one diagnosis.

Individuals who might benefit from tools within the methodology include neurodivergent students with documented diagnoses*, learning differences, or disabilities, as well as neurotypical individuals.

*Possible diagnoses: autistic spectrum (levels 1 and 2), ADHD, language or learning disabilities, twice exceptional (2E), gifted and talented, social anxiety, developmental language disorder, and traumatic brain injury. Others who may benefit include those with learning differences and/or difficulties with sensory regulation, executive functioning, or other behavioral and emotional disabilities.

Michelle Garcia Winner, MA, CCC-SLP, is the founder and CEO of Social Thinking and a globally recognized thought leader, author, speaker, and social-cognitive therapist. She is dedicated to helping people of all ages develop social-emotional learning, including those with social learning differences. Across her 30-year career she has created numerous evidence-based strategies, treatment frameworks, and curricula to help interventionists develop social competencies in those they support. Michelle's work also teaches how social competencies impact people's broader lives, including their ability to foster relationships and their academic and career performance. She and her team continually update the Social Thinking® Methodology based on the latest research and insights they learn from their clients.

Michelle maintains a private practice, The Center for Social Thinking, in Santa Clara, California, where she works with clients who continue to teach and inspire her. She travels globally presenting courses on the Social Thinking Methodology, an evidence-based approach she created that she continues to evolve and expand on. Michelle helps to develop educational programs, consults with and trains families and schools, and is a guiding presence with a wide range of professionals, politicians, and businesses on the topic of social-emotional competencies. She is a prolific writer and has written and/or co-authored more than 40 books and over 100 articles about the Social Thinking Methodology.

Michelle receives accolades for her energetic and educational conference presentations, as well as her down-to-earth approach to teaching social competencies. The strength of Michelle's work is her ability to break down abstract social concepts and teach them in practical, concrete ways to help people improve their social problem-solving abilities and social responses.

Pamela Crooke, PhD, CCC-SLP, is Chief Curriculum Officer and Director of Research, Content, Clinical Services, and the Social Thinking Training & Speakers' Collaborative at Think Social Publishing, Inc.

Prior to joining the Social Thinking team, she coordinated the Autism interdisciplinary clinical services at the Tucson Alliance for Autism, served as a clinical faculty member of three universities, and worked as a speech-language pathologist in the Arizona public schools for 15 years. She is on the board and/or is a member of a wide range of organizations related to autism and speech/language and has been the recipient of several foundation and community grants. In 2011, she received the Outstanding Achievement Award with Co-recipient Michelle Garcia Winner from the California Speech, Language and Hearing Association (CSHA).

Pam is a prolific speaker both in North America and abroad and has co-authored five award-winning books related to Social Thinking with Michelle Garcia Winner. Their book, *You Are a Social Detective!* was the Autism Society of America Literary Book of the Year in 2012. The recently released 2nd Edition (2020), won the 2021 Creative Child Magazine Preferred Choice Award, the 2021 Mom's Choice Gold Medal Award, the 2021 Best Book Awards Finalist, and the 2022 International Book Awards Finalist. They co-authored the companion *You Are a Social Detective! Teaching Curriculum and Support Guide*, (2022).

Pam and Michelle collaborate on writing articles and blogs that appear on the Social Thinking website and in a wide array of publications. Her most recent publications focus on using practice-based research to examine how educators, mental health specialists, and parents utilize strategies within the Social Thinking Methodology. Pam maintains an active clinical practice for both adolescents and adults.

Treating Fear and Anxiety in Autistic Youth

Lauren Moskowitz, Ph.D.
Nathalia Benitez, B.A.
Ashley Smith, B.A.

Anxiety is one of the most common problems for autistic youth. When we see our children afraid or anxious, the most natural thing to do as parents is to try to rescue them: to help them to avoid the things that make them anxious or reassure them that the things they fear will not happen. This makes sense since we are hardwired as parents to try to make our children feel better and prevent them from experiencing distress. The problem, however, is that when we avoid what makes us anxious, we never learn that it likely won't be as bad as we fear. We also won't come to realize that, whatever happens, we can handle it. The key to treating fear or anxiety in autistic youth is to teach them that they *can cope* with whatever makes them afraid or anxious.

Gradual Exposure

The most critical intervention for treating anxiety is "gradual exposure" to the feared situation, or "facing your fears." For example, a child who is afraid of pools should not be thrown into the pool or forced to jump into the deep end. A better approach is to encourage the child, through rewards, to first dip a toe into the shallow end of the pool, and then the whole foot and, when ready, the leg, the stomach, the chest, until the child is finally in the pool. While the water might feel very cold at first, this feeling diminishes after a while once we get used to it. If we keep repeating an anxiety-producing activity rather than avoiding it, we usually learn that our anxiety will eventually diminish, or we habituate to it as we get used to the situation. That said, we focus more on anxiety tolerance than habituation, which means we emphasize *coping* with fear rather than *reducing* fear.[1] In other words, we are trying to send this message: "we can feel afraid and still cope with it – we can still live our lives."

Consider the following example. Jane was a nine-year-old girl with autism who had a phobia of thunder. Her previous therapist had recommended she wear headphones whenever it thundered so that she did not have to hear it. This approach would not help Jane learn to cope with it in the long run. Although at first Jane listened to music on her headphones when it thundered, she was later encouraged to do exposures, or "brave challenges," in which she gradually lowered the volume of her music so that she could hear more of the thunder. Eventually, she removed her headphones so that she could hear the thunder at full volume.

It is worth noting that *not every fear needs to be faced*. A fear may not be worth targeting if it does not interfere with the quality of life of the child or the family. If a fear of spiders makes a child afraid to go camping because of the possibility of seeing a spider, there may be no need to target that fear. However, if the child once saw a spider in the bathroom at school and is now having accidents in class because he or she is too afraid to use the school bathroom, that phobia seems like an important one to target.

Although it can be challenging to get children to face their fears, there are several other strategies that can help them do so.

Positive Reinforcement

Children should never be *forced* to engage in an exposure to what they fear. Rather, they should be *encouraged* or motivated to face their fear by rewarding, or reinforcing, them for doing so. If you are trying to motivate your children to face their greatest fears, you have to use the most potent or powerful reinforcer. Consider what your child likes to do the most. If it is watching a particular YouTube video, for example, then reserve that video as the reward for attempting exposures and *only for exposures*. Your child will not be motivated by a particular reward if it is available all the time whenever requested; it will lose its power. Keep your child's favorite thing or activity for the most difficult or anxiety-provoking situation. While some parents may not agree with this approach, we all need rewards to do things that we find challenging. Facing our fears is the hardest thing that we can possibly do, and that's why it deserves the biggest reward.

Incorporate a Child's Special Interest

Autistic individuals often have very intense interests or passions known as **"special interests."** One way to modify exposures for autistic youth, particularly those with a co-occurring intellectual disability, is to incorporate the special interests into the exposure itself. For example, a dental exam could be conducted with the child seated in a *Frozen* chair while listening to a song from *Frozen*. The special interest could also be used as a reward for doing an exposure. Both approaches can help motivate children to face their fears. For example, to help an autistic child who is afraid of birthdays but loves Sesame Street, we could incorporate Sesame Street into the exposures by showing a video of Ernie singing happy birthday to Bert, or using Sesame Street candles in the birthday cake. A Sesame Street toy could also be used as a reward for approaching the cake.

Coping Self-Talk

One component of treating anxiety is **"cognitive restructuring."** This involves identifying and challenging anxious thoughts, and replacing them with more accurate or helpful thoughts that promote coping with anxiety-provoking situations rather than avoiding them. In other words, we teach children to use "coping self-talk." In a study on fear of the dark, one group of children was taught self-talk that focused on the dark being positive rather than scary, while another group was taught self-talk that emphasized the child's control or competence through phrases such as, "I am a brave boy/girl; I can take care of myself in the dark."[2] The study found that "competence" self-talk was more effective: kids who were taught that they could cope with the dark did better than kids who were taught that the dark wasn't that scary.

One way that we modify cognitive restructuring for autistic youth is by simplifying it. Depending on a child's developmental level, we might teach the child simple coping self-talk such as, "I've done it before, I can do it again," or "I can handle it," or "I can do it." A second way to modify cognitive restructuring is to make it more concrete and visual. We can illustrate coping self-talk with pictures or video models, or use lists of unhelpful versus helpful thoughts that the child can choose from to craft coping statements. A third way to help autistic youth is to incorporate the child's special interests into the coping self-talk, just as we incorporate them into the exposure itself. For a boy who had an intense interest in *Harry Potter*, for example, we named his anxiety "Voldemort" — the villain in *Harry Potter*. We used the metaphor of fighting Voldemort to make facing his anxiety more concrete and salient. We also taught him to confront Voldemort with phrases like, "Back off Voldemort! You can't tell me what to do anymore," and to tell himself, "When I feel afraid, I can conjure the Patronus Charm by thinking about a happy memory; this will help me face my fears just like Harry!"

Providing Choices or Control

When people have opportunities to make choices, it increases their sense of control over their environments. Too often, autistic individuals are not given any choice or control over their lives, which can cause anxiety. Rather than letting children choose *whether* or not to complete a disliked or anxiety-provoking activity such as homework, provide the child with two to three fixed choices between *how*, *when* or *where* to complete the activity. For example, they can choose whether to do spelling or math homework first, what pencil or pen to use, and whether they want to complete it in the bedroom or at the kitchen table. Let them also choose which rewards they want to receive for engaging in the activity. For example, individuals who are afraid of a medical exam might be allowed by the doctor to choose whether to have their ears checked or their blood pressure taken first. This gives individuals some control over the situation.

Increasing Predictability

Another way to reduce anxiety is to provide information proactively about what will happen next. While people in general feel calmer when they know what to expect, those with autism often need more predictability than neurotypical individuals.

There are a range of ways to make things more predictable for autistic youth. One such way is through the use of a ***visual schedule.*** It lets children know about the upcoming sequence of events. If your child is afraid of running errands, for example, you can provide a portable dry erase board that contains pictures of your itinerary, as well as anchor pictures of the home fastened with Velcro to each end of the schedule. As you go about running your errands, remind your child where you are going next while pointing to the schedule.

Another helpful tool is ***priming***. This entails having children preview future events so that they become more predictable. For example, an autistic child we worked with previewed a video-recording of what it looked like to transition from one classroom to another. We then rehearsed these transitions with the child one-on-one, under relaxed conditions, when school was not in session.

The use of a ***social story*** can also help make things more predictable for the child.[3,4] This is an individualized narrative that visually depicts the sequence of events involved in a situation and describes appropriate behavior for that situation. An autistic child we worked with was afraid of taking car rides, so we created a social story that included information about what would happen on the car ride, how to behave, and coping strategies to deal with the ride, including positive activities that could be done while riding in the car.

A final way to increase predictability is to provide ***advance warning*** of an upcoming transition or other anxiety-provoking event. This gives the child time to prepare for changes by making them gradual rather than abrupt. It can also signal how much time is left until the anxiety-provoking activity ends.[5] Such warnings can be verbal, visual or both, and could include countdowns, picture prompts, and visual representations of time. For example, a timer could visually show how many seconds the child will have to hold an arm still for a blood test.

Reduce Accommodation

Accommodation refers to anything you do or don't do in order to avoid, escape, reduce or "give in to" your child's anxiety. Although accommodations may reduce anxiety in the moment, they do not help your child deal with the anxiety in the long run but rather maintain the child's anxiety. While it might seem helpful in the moment to accompany your child to every room in the house, for example, this accommodation actually makes the separation anxiety worse because your child never learns that he or she can be alone.[6] Part of treating your child's anxiety is to eliminate, or at least reduce, accommodations. For example, an autistic child named Sam was afraid of left or right turns. His parents had been accommodating his anxiety for years by driving straight as much as possible and making as few turns as possible. This meant it took twice as long to make every trip as it should have taken. Once we started treatment, we encouraged his parents to no longer accommodate his anxiety by altering their driving route in combination with aforementioned intervention strategies such as gradual exposure, incoropating special interests and providing choices.[7]

In some cases, accommodation can take the form of offering excessive reassurance to a child. For example, an autistic child with obsessive-compulsive disorder (OCD) that we treated engaged in the ritual of repeatedly asking his mother if he was sick or healthy. His "brave challenge" involved not asking these questions. If he did ask these questions, his mother was encouraged to stop providing reassurance by repeatedly answering the questions, and to reply with the following: "I can't tell you if you're sick. That's just your OCD *(nicknamed 'The Undertaker')* talking. To help you fight the Undertaker, I'm not going to answer that question."

Rather than responding to your child's anxiety with criticism, excessive reassurance or by minimizing the anxiety, it is better to respond with honesty and empathy, and to show confidence in your child's ability to cope with the anxiety. Instead of saying, "Don't cry, there's nothing to be afraid of," convey acceptance and validation, as well as confidence in your child, by saying something like, "I understand how scary this is for you, but I know you can do it," or "It's hard, but you can do it." Ultimately, your job as a parent is to build up your child's sense of competence and confidence.

We are hopeful that the concepts and strategies outlined in this article will help parents and caregivers address the fear and anxiety experienced by autistic young people.

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Resources

Books

Books designed for autistic youth and their parents:

- **Facing Your Fears: Group Therapy for Managing Anxiety in Children With High-Functioning Autism Spectrum Disorders / Facilitator's Manual / Parent Workbook / Child Workbook**
  by: Judy Reaven Ph.D., Audrey Blakely-Smith Ph.D., Shana Nichols Ph.D., Susan Hepburn Ph.D.

Books written for parents of children without autism but that still would be useful for youth with autism:

- **You and Your Anxious Child**, by Anne Marie Albano, Ph.D.
- **Freeing Your Child From Anxiety,** by Tamar Chansky, Ph.D.
- **Freeing Your Child from Obsessive Compulsive Disorder**, by Tamar Chansky, Ph.D.
- **Helping Your Anxious Child,** by Ronald Rapee, Ph.D., Ann Wignall, Susan Spence, Vanessa Cobham, and Heidi Lyneham

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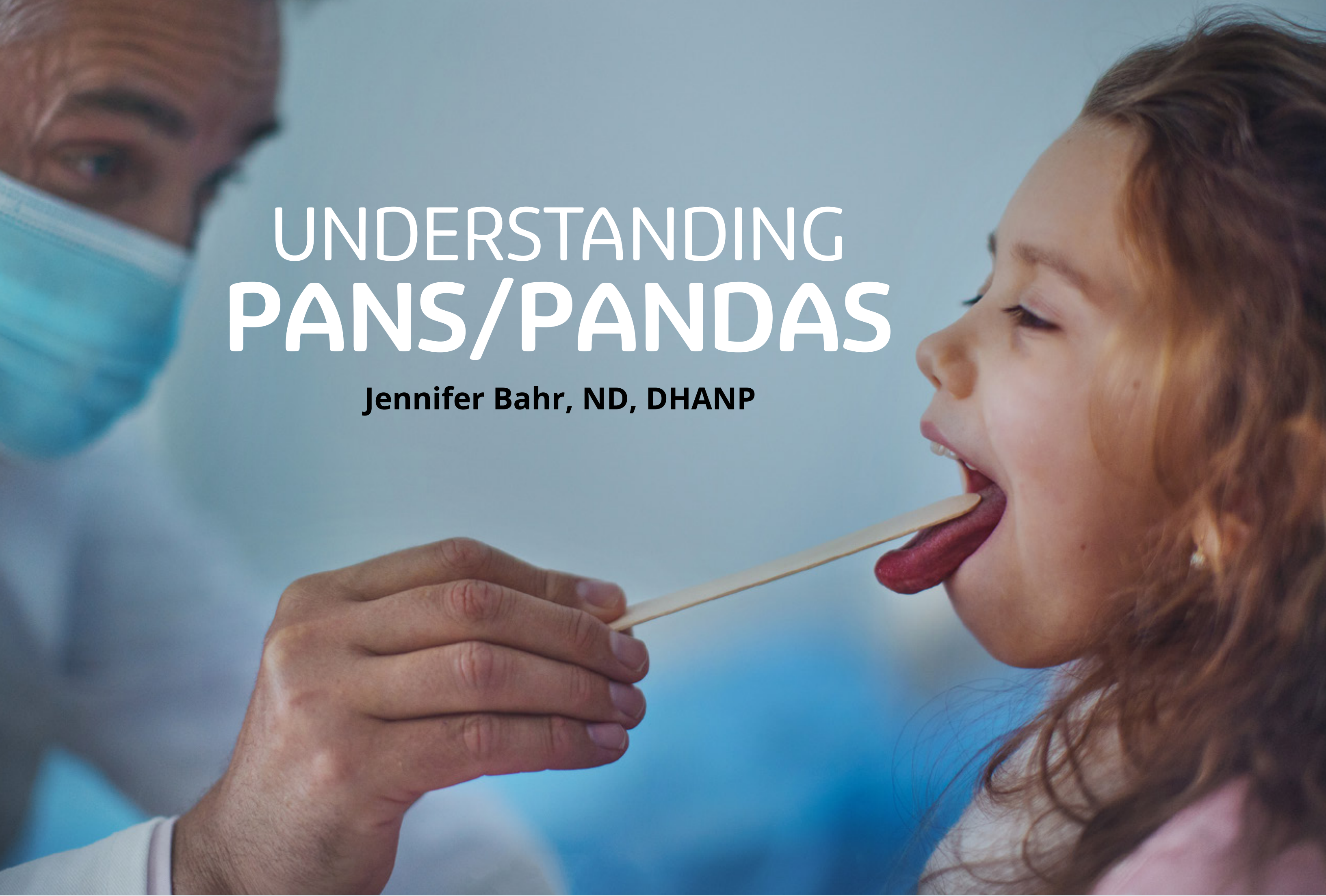
Websites

- Facing Your Fears (virtual groups available for autistic youth and their parents)
  https://medschool.cuanschutz.edu/jfk-partners/clinical-services/facing-your-fears-program
- Children's and Adult Center for OCD & Anxiety
  www.worrywisekids.org
- The Child Anxiety Network
  www.childanxiety.net
- Anxiety Disorders Association of America
  www.adaa.org
- Parent Training Resources for Anxiety
  http://www.copingcatparents.com/
- Meg Foundation for Pain (empowering families with strategies to manage pain and medical anxiety)
  www.megfoundationforpain.org
- Modular Evidence-Based Practices for Youth with Autism Spectrum Disorder (MEYA) (clinical training for providers who want to learn to treat anxiety in autistic youth)
  https://meya.ucla.edu/public/
- A Parent's Guide to Evidence-Based Practice and Autism
  https://nationalautismcenter.org/resources/for-families/
- Free Online Intervention Study to Treat Fear/Anxiety in Autistic Youth for Parents of Children with Autism and Intellectual Disability (see FLYER and contact Dr. Moskowitz at moskowil@stjohns.edu if you're interested and have a child with autism and ID between the ages of 4 and 12 years old)



UNDERSTANDING PANS/PANDAS

Jennifer Bahr, ND, DHANP

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcus (PANDAS) are medical conditions that occur when a person acquires an infection that triggers an abnormal immune response. Instead of, or in addition to, classic symptoms of an infection such as a fever or a rash, a person may present with behavior changes, such as obsessive-compulsive disorder (OCD) behaviors, tics and restricted eating.

PANDAS is diagnosed if streptococcus, or strep, was the cause of the infection, while PANS is diagnosed if a trigger other than strep was involved. Some triggers for PANS can include a range of different viruses, including cytomegalovirus, mycoplasma and Avian pneumovirus (APV), Lyme disease and other tic-borne illnesses. It can also be triggered by toxins such as black mold.

Medical professionals determine if a person has PANS/PANDAS based on the presentation of symptoms or clinical diagnosis. The literature commonly reports that individuals with PANS/PANDAS have a sudden onset of symptoms, most commonly OCD behaviors and tics in the case of PANDAS, or OCD and restrictive eating in the case of PANS. However, some research has suggested that these symptoms do not always appear suddenly.[1,2] While research suggests that the prevalence of PANS/PANDAS could be as high as one in 200 children, this is probably an underrepresentation because the condition is not fully understood.[3]

Common Symptoms of PANS/PANDAS

- OCD behaviors
- Tics, which are more prominent in PANDAS than in PANS, but can be present in both
- Separation anxiety, especially if it wasn't present prior to the infection or is no longer developmentally appropriate
- Restricted eating, or avoidant restrictive food intake disorder (ARFID)
- Bed wetting or urinary difficulties, including changes in the urgency and frequency of going to the toilet, or having phantom wetness in which children feel like they are still wet even if they are not
- Handwriting changes
- Rapid fluctuations in moods
- Rage
- Acquisition of new fears
- Cognitive and behavioral regression, such as when children who were doing well in school are suddenly no longer doing well, or 10-year-old children who suddenly act like they are five years old
- Hallucinations
- Depression

While the symptoms of PANS/PANDAS can vary for each individual, the following are some of the most common symptoms.

- OCD behaviors
- Tics, which are more prominent in PANDAS than in PANS, but can be present in both
- Separation anxiety, especially if it wasn't present prior to the infection or is no longer developmentally appropriate
- Restricted eating, or avoidant restrictive food intake disorder (ARFID)
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- Acquisition of new fears
- Cognitive and behavioral regression, such as when children who were doing well in school are suddenly no longer doing well, or 10-year-old children who suddenly act like they are five years old
- Hallucinations
- Depression

The symptoms of PANS/PANDAS tend to appear in a pattern of flare-ups. While the symptoms may lessen after the flare-up, the individual's baseline tends to get progressively worse until the symptoms are persistent over time.

PANS/PANDAS and Autism

It can be difficult to distinguish PANS/PANDAS from autism because some of the symptoms may overlap. For example, stimming behavior could be a tic. A child's rigidity or need for sameness could be diagnosed as autism when, in fact, the OCD behaviors could be brought on by PANS/PANDAS. The overlap can be confusing and lead to misdiagnosis. In reality, there could be some children diagnosed with autism who actually have PANS/PANDAS and some children with autism who may miss receiving a PANS/PANDAS diagnosis because their symptoms were attributed to autism.

PANS/PANDAS Diagnosis

Since there is currently no single test that can confirm PANS/PANDAS, a diagnosis is based on symptoms, medical history and lab tests. As PANS/PANDAS will be slightly different in each person, it is important for a qualified professional to take a thorough behavior history, family history, physical exam and lab workup.

A clinical professional will seek to determine if the patient is known to have recently had an infection. If a strep or other infection was not recently verified, clinicians may do a blood test to look at antibodies that would indicate a recent infection. These tests would include an Antistreptolysin O (ASO) titer and anti-DNAse B titer.

In addition, the patient must meet certain behavior criteria. The typical symptoms of PANS/PANDAS are OCD, tics, restricted eating, and separation anxiety. The presence of a few of these main behavior changes, in addition to a recent infection, would likely lead a qualified professional to diagnose the patient with PANS/PANDAS.

Treatment

Given the complexity of PANS/PANDAS and the fact that each child's presentation of symptoms is unique, there are various treatments and protocols that can be used. The following are some of the most common treatments.

Conventional Treatment

The conventional treatment is a three-pronged approach in which a specialist typically treats the initial infection with antibiotics, addresses the child's inflammation with anti-inflammatories, and prescribes a psychiatric medication to manage the OCD behaviors. Also, the specialist will often recommend various behavior therapies to manage anxiety, aggression and regression of skills, depending on the child's unique needs. When this three-pronged intervention fails, a doctor might recommend IVIg, tonsillectomy, plasmapheresis, or other intensive therapies.

Integrative Treatment

An integrative approach generally uses natural antibiotics and antimicrobials to fight an infection, anti-inflammatory herbs, and high doses of nutrients to aid the body's abnormal immune response. This approach may also investigate genetic components and food sensitivities in order to reduce factors that contribute to inflammation and that might be causing flare-ups.

Homeopathy

Homeopathy is based on the principle of "like cures like." By way of illustration, a very low dose of a single substance found in nature is given to a patient with PANS/PANDAS. This ultra-diluted substance contains nanoparticles that, when given to a healthy person, stimulate a response similar to that experienced by the PANS/PANDAS patient. It is important to note that it also creates a secondary, opposite action rebound response in the body that allows the body to begin the healing process. When we take something into our body, we experience a primary action and a secondary reaction. The primary action involves the biochemical force of the substance, while the secondary reaction is the body's response to that biochemical force. For example, consuming coffee leads to the primary action of a stimulating response. The caffeine gives you energy, keeps you alert and makes you feel restless. The secondary reaction is known as the caffeine crash, when you feel fatigued, drained and generally worse than you did before you consumed the caffeine.

When very small amounts of a natural substance are given to stimulate a primary action that is similar to the symptoms presented in a PANS/PANDAS patient, it also naturally provokes a secondary healing response in the body. Many experts have found that, over time, homeopathy leads to improved outcomes in which PANS/PANDAS children can be exposed to agents that have previously triggered a flare-up and not react. They can be free of medications and supplements because their own body has created a secondary response that addresses their unique, specific and individual symptoms and susceptibility. Our goal is to make PANS/PANDAS a thing of the past, and to make homeopathy the medicine of the future.

The Road to Recovery from PANS/PANDAS

Treatment can take many years and depends on many factors. Treating an individual with PANS/PANDAS typically has many ups and downs. The body may become less sensitive to the antibiotics being used until a new one is prescribed. There can be experimentation to see which medications are right for your child and at what dose. There can be similar fluctuations with homeopathy. For every two or three steps forward, there is one step back as you work towards recovery from PANS/PANDAS. The specific changes seen after treatment begins will depend on your child's individual symptoms. The goal is to see fewer and less intense flare-ups over time. The road to recovery will take time and patience.

Finding Help

Parents who suspect their child might have PANS/PANDAS should seek a doctor who is experienced in assessing and treating these conditions. When seeking homeopathic care, we recommend a medical professional who is trained in managing medications, side effects and supplements, and who has homeopathic expertise such as that of a naturopathic doctor. The specific type of professional will depend on how the parents choose to treat their child, whether through conventional, natural or homeopathy treatments.

Resources

Parents and caregivers can find a qualified professional through the following organizations.

- **PANDAS Network:** https://pandasnetwork.org/
- **ASPIRE:** https://aspire.care/
- **Facebook Support Groups:** There are several large, national and world-wide groups on Facebook. There are also local groups who can suggest providers in your area.
- **Homeopathy for PANS & PANDAS Facebook Group:** https://www.facebook.com/groups/PANDAShomeopathy
- **YouTube channel:** https://www.youtube.com/@resiliencenaturopathic7877
- **Resilience Naturopathic:** https://resiliencenaturopathic.com/

Conclusion

The root of PANS/PANDAS is a susceptibility to an atypical response to infections or other immune triggers. Many people believe that autism has some similar underlying causes, and that the two conditions can present with many overlapping symptoms or that both can be present in the same child. Experts do not fully understand why some children are more susceptible to PANS/PANDAS than others. Parents should recognize that treating a child with PANS/PANDAS and/or autism can be a long and challenging road, and that PANS/PANDAS PTSD for parents is real! Taking care of yourself *is* taking care of your child. As we learn more and as research uncovers clues about why some children are more susceptible to PANS/PANDAS, we will be able to better treat and understand these complex conditions.

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The Importance of Social-Sexual Education to Reduce the Risk of Sexual Abuse

Amy Machado, M.A., BCBA

A universal truth for all parents is that we want our children to be healthy, happy and safe. Of course, this truth also applies to parents and caregivers of children and adults with autism. Many parents, however, are unaware of the danger of sexual abuse for individuals with disabilities. The rates of sexual abuse of individuals with disabilities is disproportionately high for this population, yet many caregivers are unaware of how and why this is happening.

Research indicates that the risk of sexual abuse is four times higher for children with intellectual disabilities than children without such disabilities.[1] It is estimated that between 39 and 68 percent of female children with a disability and between 16 and 30 percent of male children with a similar condition will be sexually abused before they are 18 years old.[2]

Rates of sexual abuse are often difficult to calculate accurately because many cases go unreported or are dropped due to a dysfunctional system that doesn't support the disability community. The testimony of individuals with autism and intellectual disabilities is often discounted, and their credibility is questioned when interviewed or asked about their abuse. Law enforcement and first responders may lack the training needed to interview a person with a disability. This means most cases of abuse are not investigated. One study noted that three out of four cases are never reported to authorities when they involve a child with intellectual disabilities.

Most people within the disability community are not aware of the rates of sexual abuse affecting those with autism and intellectual disabilities. It is vital that we raise awareness of this silent epidemic and take action to reduce the risk of sexual abuse.

Contributing Factors

There are a range of factors that contribute to the increased risk of becoming the victim of sexual abuse. These include the following: a lack of knowledge regarding sexuality, relationship awareness, and social boundaries; dependence on others; trained compliance; and social isolation. Perpetrators know how to manipulate children in order to place themselves in positions of power where they can build a false sense of trust.

Additional factors may also come into play. Autistic individuals are often groomed to accept and tolerate high levels of physical prompting and manipulation during daily care routines. Such individuals are often easily controlled without physical force. In addition, professionals working with these children are not teaching and practicing assent with their clients and students on a daily basis.

Possible Indicators of Abuse

When parents learn about these statistics, they want to know what signs to look for as indications of abuse. Although some signs might suggest sexual abuse, caregivers should realize that such indicators, when taken in isolation, could be related to other issues. According to the Rape, Abuse, Incest, National Network (RAINN), some signs of abuse can be more difficult to identify than others. It is important for caregivers to be aware of these signs and to use their instincts to determine when something seems “off” with their child.

The following are some of the most common physical, behavioral and emotional signs of abuse.

Physical Signs

- Sexually transmitted infections (STIs)
- Signs of trauma to the genital area, such as unexplained bleeding or bruising, and blood on the sheets, underwear or other clothing

Behavioral Signs

- Excessive talk about or knowledge of sexual topics
- Keeping secrets
- Not talking as much as usual
- Not wanting to be left alone with certain people or being afraid to be away from primary caregivers, especially if this is a new behavior
- Regressive behaviors or resuming behaviors that children had grown out of, such as thumb-sucking or bedwetting
- Overly compliant behavior
- Sexual behavior that is inappropriate for the child’s age
- Spending an unusual amount of time alone
- Trying to avoid removing clothing to change or bathe

Emotional Signs

- Changes in eating habits
- Changes in mood or personality, such as increased aggression
- Decrease in confidence or self-image
- Excessive worry or fearfulness
- Increase in unexplained health problems such as stomachaches and headaches
- Reduction or loss of interest in school, activities and friends
- Nightmares or fear of being alone at night
- Self-harming behaviors

Steps to Take if You Suspect Abuse

If you suspect abuse is occurring, professionals recommend taking the following steps.

- If your child has indicated that abuse is taking place, immediately contact law enforcement and Child Protective Services (CPS) or Adult Protective Services (APS). Trained professionals who specialize in childhood sexual assault should speak with and examine your child. Be sure to remain calm and reassure your child that you believe, love and want to help him or her.
- If you see less obvious signs, such as regression or behavior changes, seek to rule out any medical issues before assuming abuse. Talk to your child’s pediatrician about the behaviors so that any medical reasons for your child’s change in behavior can be eliminated as a possible cause.
- Keep track of any information that might lead you to believe your child is being abused. Record as much information as possible, including dates, times, locations, who was present, and any observations about how your child’s behavior has changed. Write down what you have noticed, how long it has lasted, and if there is one particular person your child is uncomfortable around. Have mental health professionals that are familiar with your child document any changes to the child’s behavior or mental health.
- We discourage parents from starting their own investigation. It is important to have someone experienced in interviewing children in such situations speak with your child. Caregivers may inadvertently taint an investigation by attempting to get information from the victim or discussing details about the incident.

Reducing the Risk

Many well-intentioned parents, caregivers and professionals instinctively want to keep children in a bubble as they think it will protect them from the world. They assume that sheltering children from society and relationships will protect them from perpetrators. They may teach such outdated concepts as "stranger danger," and restrict access to communities or relationships to keep them safe. Unfortunately, this protection model has been failing our kids for decades. Statistics show that abuse rates have not decreased. While it is true that there are dangerous people and strangers who will cause harm, it is far more likely that children will be abused by someone they know and trust. Of all the people that will come into contact with your child, it is acquaintances, including staff and peers, who are the most likely to be the source of abuse. Keeping a child in a bubble and not teaching the child how to recognize when someone is crossing a boundary means the person sitting next to the child in that bubble is more likely to be the abuser.

The sad reality is that we can't stop perpetrators from abusing. There's no effective way to prevent abuse, but we *can* reduce the risk by giving our children the tools they need to recognize when someone is manipulating them.[3] The most critical factor in reducing the risk of sexual abuse is education. Teaching children about relationships and the boundaries associated with each relationship gives them the ability to discriminate between safe and unsafe people, and appropriate and inappropriate interactions. When children know what coercion looks like, what consent is, and how to be assertive and access their trusted people, they then have the tools to confidently navigate social situations across their lifetimes. Children and adults need to learn about the different types of relationships, social boundaries, their bodies and puberty, and they need to receive sex education from well-informed, trusted adults. Teaching social-sexual education builds children's confidence and promotes their social autonomy.

Please note, however, that educating students isn't enough! Social-sexual education must go beyond the student by reaching everyone around that child, including the child's peers. Students learn best from each other. Social-sexual education should be a part of every educational environment so that peers learn to interact with each other appropriately and practice appropriate social skills. Furthermore, all support staff, family and caregivers must be trained and speak the same language when referring to relationships and boundaries. When you insist that professionals and educators who work with your child be trained in appropriate interactions, boundaries and ways to identify coercion, you are building a network of people who not only advocate and model appropriate interactions with your child but also a team that can recognize when a perpetrator has entered your child's orbit.

It is never too late to start educating your child! Even if your child has already gone through puberty, is interested in or engaging in romantic relationships, or is even engaging in sexualized behaviors, education can still play a key role. Foundational skills can be taught to young children, teens and even adults who never received education when they were young. Social-sexual education addresses fundamental life skills that can change and evolve with them across all phases of life.

The following are some strategies that you can use to start educating yourself, your child and others on this important topic.

Educate at Home

Start educating your child early and often. Remember, sex education does not start with sex! Teach your child the foundational skills needed to understand healthy relationships. These include the proper names for body parts; privacy as it relates to public versus private body parts, places and talk topics; relationship discrimination, including the difference between family, friends, acquaintances, strangers, and couples; social boundaries; consent; personal space and how to protect it; and assertiveness, with regular practice of how to speak up. Having age-appropriate conversations with children that build on prior knowledge as they grow will help them get ready for the tougher conversations when they come of age. In addition to using proper names for body parts, start incorporating language about personal space, the difference between public and private, and how to advocate for themselves and build bodily autonomy when they are little.

Emphasize Consent

The concept of consent or assent should also be taught at a very young age. Parents and other caregivers can practice consent by asking children before giving hugs and kisses, not requiring them to show affection to other family members or acquaintances, and listening to and honoring them when they say “No,” or show discomfort with touch. By teaching children about consent, we allow them to have agency over their own bodies and teach them to recognize and advocate for their own safety.

Compliance training is a common therapeutic intervention for autistic children. From a very young age they are taught to tolerate high levels of physical intervention and touch from a never-ending cycle of staff. Goals related to compliance and following directions are commonplace, and assent is rarely acquired by the adult giving the directive. While learning to follow directions is an important part of the learning process for any child, placing too much emphasis on compliance teaches children with autism that they must follow every adult directive and that their opinions and comfort do not matter. If we teach children to comply without question, how will they learn to trust their own instincts? Children will not recognize when a person crosses a boundary and know how to say “No” to an adult or peer in such a situation. No person should be expected to comply 100 percent of the time. Support staff, educators and caregivers need to put more emphasis on gaining assent and less on compliance. Find support staff that know about and practice assent, or educate them on this concept and promote it within your network.

Have Your Child Participate in Social-sexual Education Classes with Adapted Materials and Instruction

While social-sexual education should be a part of every learning environment, it is not the case in most educational settings. Many parents don’t know how to educate about social-sexual topics and rely on the school to provide this information. Unfortunately, most schools are not equipped to address these topics adequately. Many parents opt out of their school’s sex education courses because they are not adapted to individuals with autism and intellectual disabilities. School programs are often science-based courses full of statistics and data, and are not adapted to learners with disabilities. These courses are fast-paced and don’t include basic foundational social skills that children with autism and intellectual disabilities need.

As a parent or caregiver, ensure that your school and school district are providing social-sexual education with adapted materials and instruction to suit the learning style of your autistic child. This instruction should be evidence-based and include things like video modeling, visual supports, technology-based instruction, social narratives, scripting and role-playing. Be sure to include social-sexual education in your child’s Individualized Education Plan (IEP). Advocate for social-sexual education in your child’s behavior therapies, speech therapies, occupational therapies and day programs. Don’t allow your school to assume that your child does not need or want this type of education.

Educate Everyone in Your Social and Professional Networks

The best thing that parents can do is to educate themselves, their children, and their entire support system, including family members, teachers, aides, therapists, siblings and peers. Be sure that your child’s teachers and day program facilitators are trained. Require all staff and professionals working with your child to take the *Caregiver Training* or another similar training to ensure they understand boundaries, consent and other important caregiver practices.

Know Your Staff

Know the people who are working with your child and ensure that they are trained. I acknowledge that most staff members are wonderful, caring people who have the best of intentions, but we cannot ignore the fact that they are often the most likely perpetrators. In fact, some perpetrators seek out these positions so they can abuse the vulnerable. Be involved in your child’s education and therapies. Conduct background checks on the people who work with your child. Train them, observe them and ensure that appropriate boundaries are being followed and modeled for your child.

Model Appropriate Relationship Boundaries

Although you may want your child to be comfortable and build a relationship with staff members and teachers, he or she needs to understand that they are staff members and must maintain certain boundaries. Parents often refer to their child’s staff members as friends or, in some instances, as “girlfriends” or “boyfriends.” This can be very confusing and opens the door to those who want to cause harm. These individuals are paid to work with your child. They may be nice people who care deeply about your child’s safety and well-being, but they have a code of conduct and ethical guidelines they must follow. Being a friend is not included in that code. Help your child understand these boundaries. Refer to staff members as such, not as your child’s friends.

Conclusion

Being aware of the rates of abuse for individuals with disabilities is just the first step in protecting children in this population. Caregivers must recognize the danger and work to provide their children with education on fundamental social-sexual concepts such as relationships and social boundaries. Individuals both young and old can be taught these concepts by using a variety of methods to tailor instruction to their particular learning style and abilities. With proper education and practice, you can reduce the risk of sexual abuse for your child. By raising awareness, demanding change in our educational and therapeutic settings, and holding our community accountable, we can create a system that promotes education and safety, and that prepares our children for a lifetime of dynamic social interactions and healthy relationships.

Resources

Caregiver Training

SEEDS Therapy Center

RAINN - Crisis Hotline
CALL: 800.656.HOPE (4673)
https://www.rainn.org/

RAINN

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Amy Machado, M.A., BCBA, has worked with individuals with Developmental and Intellectual Disabilities for over 20 years in home, school, community, and clinic settings. She earned Bachelor's degrees in Health and Education, and a Master's degree in Teaching with an emphasis in Special Education from Belmont University. Additionally, she earned a post-graduate certification in Behavior Analysis from Florida Institute of Technology.

Amy has extensive experience working directly with individuals with disabilities of all ages and has spent the latter part of her career creating innovative programs to assist young adults with the transition into adulthood. Amy has authored the *Rooted In Connection* curricula that teaches comprehensive sex education with an emphasis on relationships, social boundaries, assertiveness, and abuse prevention for individuals with disabilities of all ages (youth through adult).

Amy's drive to reduce sexual exploitation stems from her direct work with countless individuals and families who have shared their personal stories of exposure, assault and sexual abuse. Throughout her career as a Behavior Analyst, she has worked with many families seeking information about relationships and how to connect with others. From their experiences and their desire for social autonomy, she is dedicated to making SEEDS Therapy Center (STC) an inclusive place for people with disabilities to learn invaluable information about connecting with others appropriately and safely.

In addition to handling STC operations, Amy conducts training and workshops throughout the state for parents and professionals on social-sexual topics including abuse awareness and risk reduction through education.

Socialization and Autism

Fostering Belonging for Neurodivergent People

Lori B. Vincent, Ph.D., BCBA-D
Jason P. Harris, M.S.

Socialization is a complex process by its very nature. Although we have societal norms that are commonly accepted, it is worth considering when and how these were created and if they are still appropriate. There is great variability in people's social behaviors and practices both within and across cultures. When discussing social skills, we are often talking about adapting to social norms or "fitting in." This involves changing to be like everyone else in order to be accepted. Belonging, on the other hand, is being accepted for who you are.[1] The latter does not imply giving no consideration to the views of others, especially since relationships are reciprocal and may require compromise and similar views or ideas of sociality. However, it does imply that people feel accepted as they are. A sense of belonging and community is associated with improved health and well-being.[2,3] It is worth asking how we can help neurodivergent people feel that they belong in a society with "rules" that often exclude them from many places and interactions.

Changing Societal Norms

It is important to recognize that our societal norms were developed within our society, which means they may benefit some groups of people more than others. Ableism has been defined as a system of discrimination where people with disabilities are viewed as less valuable or as having less potential than non-disabled people. This influences how people talk about and perceive disabilities such as autism whether or not they are aware of it.[4] Ableist ideology that exists within our social "norms" should be evaluated. This involves considering why social norms exist and who may not be considered in the establishment of these norms. Another consideration could be whether or not these norms help keep people safe. For example, it is considered socially unacceptable by many people to hit or physically harm others or to call people by certain derogatory terms. These societal rules seem targeted at the safety and well-being of all people. Other norms, such as expecting people to maintain appropriate eye contact during an interaction, are not about safety but about preferences of some people within certain cultures. A key step towards identifying ableism is considering why societal rules and expectations exist and whether they are supportive of the natural diversity, including neurodiversity, within our society. This is also relevant when considering social skills interventions and supports. Social targets should be truly beneficial to the person and respectful of his or her way of being. One way to help identify appropriate social targets is to include the person in the process.

Self-Determination

Self-determination is a basic human need that includes autonomy, motivation and agency for action.[5] It entails self-knowledge, identifying wants, and being able to act in accordance with personal values. When it comes to socialization, some people like to be surrounded by other people and have large social groups. Others prefer to be alone or have a small number of close social relationships. These desires and social preferences are all acceptable and appropriate. Helping neurodivergent individuals determine what socialization looks like for them is crucial.[6] Who do they like to interact with, around what activities, and in what settings? What supports are needed to help them be successful in achieving the interactions and relationships they want? These are questions that should be asked and discussed, or that can be observed through non-verbal behaviors for those who are unable to verbally advocate for themselves. We can note the setting that the person gravitates towards, the activities that are of interest, how this person interacts socially now, and what social situations are sought out or avoided. The fact that individuals do not interact socially with others does not mean that they do not want to interact with anyone. There can be many reasons other than a lack of interest for someone to be socially isolated. This should not be used as an excuse for failing to create opportunities for socialization. Creating social opportunities should not be dependent upon individuals appearing neurotypical but should allow them to be themselves and to utilize their strengths and preferences in social interactions.

Create Diverse Social Opportunities

Finding social belonging is challenging for all people and takes work. It can be even more challenging for neurodivergent people. This is not due to a lack of interest or ability, but comes from a mismatch between social environments or expectations and neurodiversity. If the goal of social supports is belonging, then the focus should be on supporting individuals in finding social situations in which they feel accepted as they are rather than on changing them to fit the social context. Finding belonging requires trying different social environments, strategies and supports to identify the right fit for each unique person, and creating spaces for socialization in which diversity is appreciated.

There are many ways in which caregivers can help children foster social belonging. These include the following: observing social contexts in which a child appears relaxed and engaged; creating social opportunities, including helping schedule social activities with peers that a child has shown an interest in; trying new activities such as sports or clubs based on a child's interests; changing environments to create opportunities for social interactions of interest to a child; and providing adult support and facilitation as needed in social interactions to learn skills. An example of changing environments is adapting recess time. School playgrounds are often limited to motor activities and sports. If these activities are not of interest to your child, he or she may choose not to engage. Asking school staff to allow your child to bring out games and activities of interest for recess time can create natural social opportunities for your child and peers with similar interests. Also, adults who can help facilitate these activities foster the behaviors needed to initiate and maintain social interactions.[7] It is important to remember that people have different preferences related to how much socialization they desire and, therefore, some children may only want to interact for shorter periods of time and may need support in re-joining social activities when ready.

There are many ways in which caregivers can help children foster social belonging. These include the following:

- observing social contexts in which a child appears relaxed and engaged;
- creating social opportunities, including helping schedule social activities with peers that a child has shown an interest in;
- trying new activities such as sports or clubs based on a child's interests;
- changing environments to create opportunities for social interactions of interest for a child;
- and providing adult support and facilitation as needed in social interactions to learn skills.

Social preferences can change quickly. If children do not want to interact in an activity one day, it does not mean they may never want to do the activity again. Balance trying new activities to help children learn what they like and where they feel comfortable, with respecting when they consistently indicate that a social situation is not for them. When the latter occurs, seek to change the environment and situation by finding another activity or other peers rather than trying to change the person to fit in.

Summary

Socialization will look different for each of us, and we should allow people to determine what it looks like for them. At times we must step outside of our comfort zone and try something new to find belonging. Encouraging someone to try new activities and meet new people is important. It is also essential to listen when individuals say, verbally or nonverbally, that a social situation is not right for them. Learning about people's social preferences and desires is important to help them know themselves. Finding belonging takes work. In many cases, it takes more than just "fitting in." It is vital, however, since belonging can lead to improved physical and mental health.[3] As we create spaces that are more accepting of people's differences, it allows everyone the opportunity to be more authentic and to find their own belonging.[8]

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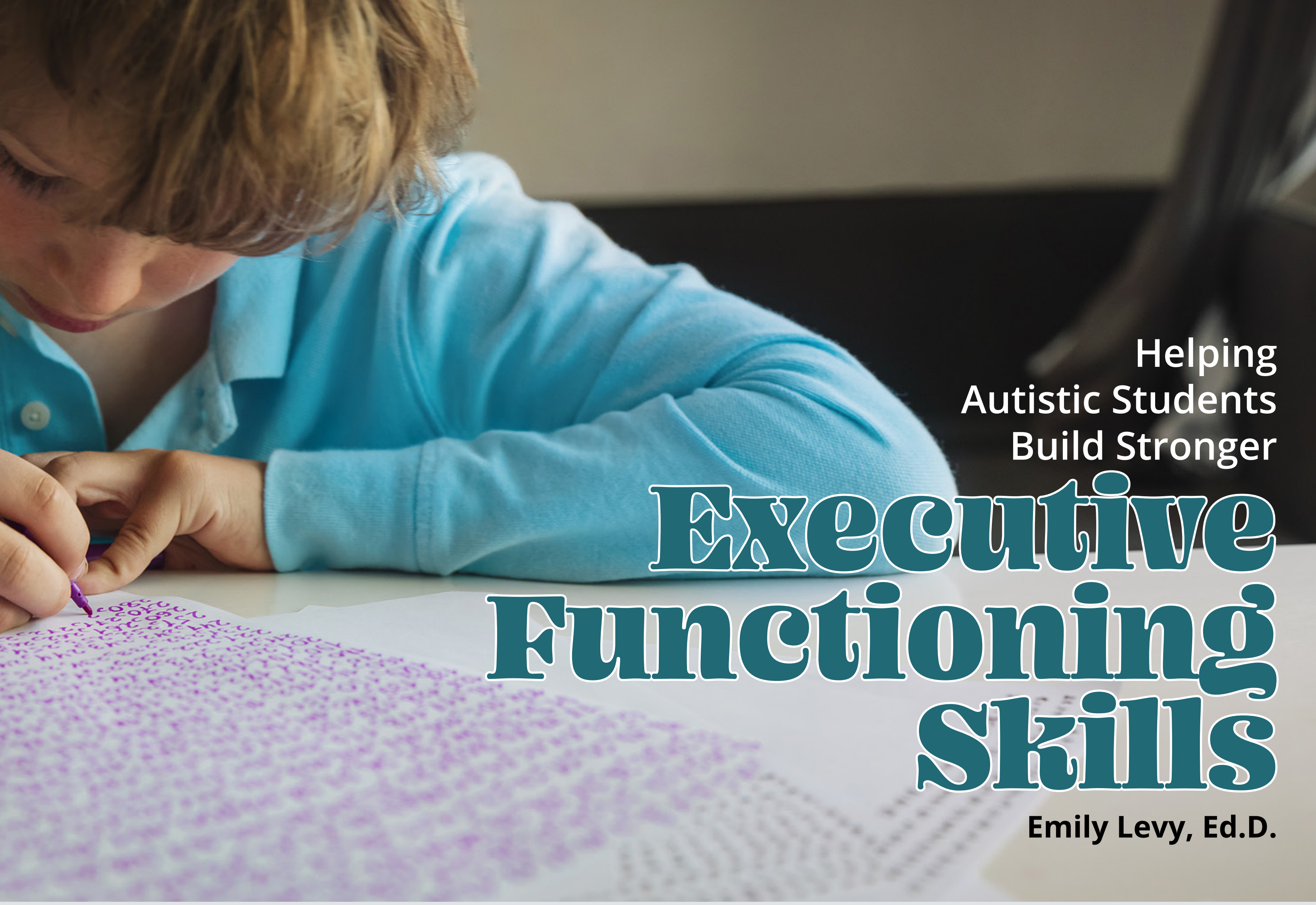


Helping Autistic Students Build Stronger Executive Functioning Skills

Emily Levy, Ed.D.

Many children with autism struggle to start and complete their homework assignments. They may lose papers, notebooks, and teachers' notes. Some may find it difficult to plan and prioritize their actions, and to self-monitor. When children struggle in these areas, it is often a sign of issues with executive functioning skills. These are skills that play a significant role in success at school, but many autistic children find them particularly challenging. The following are some strategies that you can use to help your child with autism build stronger executive functioning skills.

Time Management

Children with executive functioning challenges often need help with time management. They might procrastinate or not have a good sense of how long a task might take to complete. You can strengthen your child's time management skills with a time management strategy based on estimated time/actual time. When children have a task to complete, such as a math worksheet or a science packet, have them estimate how long they think the assignment will take to complete and write down the estimated time. Once the task is completed, have them note how long the assignment actually took to complete and write down the actual time. There will often be a big difference between these two times when students with time management issues start using this technique. Over time, however, the two times will become closer as they practice the technique and make more realistic estimates.

Task	Estimated Time	Actual Time

Organization

Poor organizational skills are a common characteristic of executive functioning challenges. If your child loses papers and has a messy backpack or a cluttered desk or room, you may want to consider this three-tier organizational strategy. Tier one involves designating a working notebook that your child will carry to school on a regular basis. It could be made up of one folder and notebook per class that ideally are color-coded, or a large three-ring binder divided by classes. One day per week should be designated as the time to clean out the notebook and remove papers that no longer need to be carried on a regular basis. Tier two entails filing these papers in an accordion file. The accordion file could have three sections for each class: homework, notes, and tests or quizzes. The papers from the working notebook are placed into the proper section of the accordion file and saved for the purpose of studying for a quiz or test. Tier three is a file drawer or cabinet for projects completed by your child or well-written essays that are worth saving for the long term.

Create a Schedule

Individuals who struggle with executive functioning skills often fail to create a well-organized schedule. They might jump from one task to another with little or no planning. To address this challenge, you can map out steps for your child for each part of his or her day when at home. For example, your child might have five steps to complete in the morning before leaving for school: wake up; get dressed; have breakfast; brush teeth; and check backpack to make sure it has all necessary items for the day. You may want a checklist for the backpack, too. You could also create a colorful poster to map out this routine with pictures or images that correspond to each step. A similar schedule could be created for after-school and pre-bedtime activities. It may be worth asking if your child's teacher would be willing to prepare one for the school day.

My Morning Routine


Wake Up ☐


Get Dressed ☐


Eat Breakfast ☐


Brush Teeth ☐

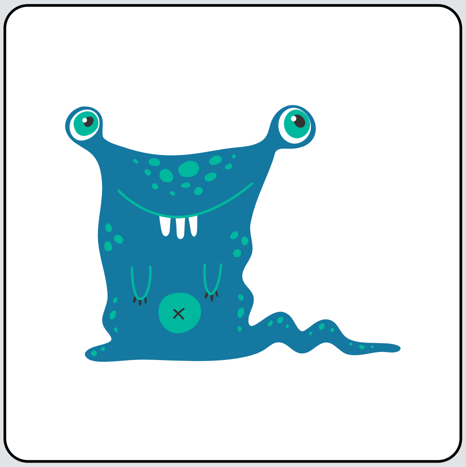

Check Backpack ☐

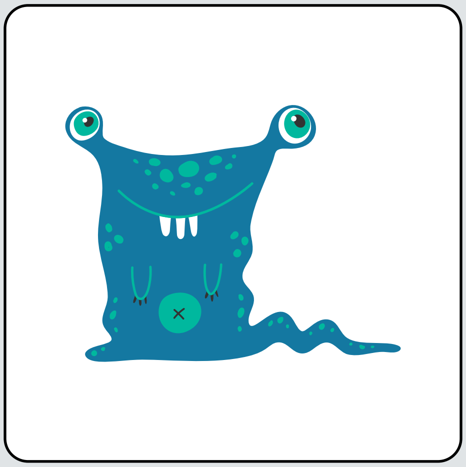
Play Games

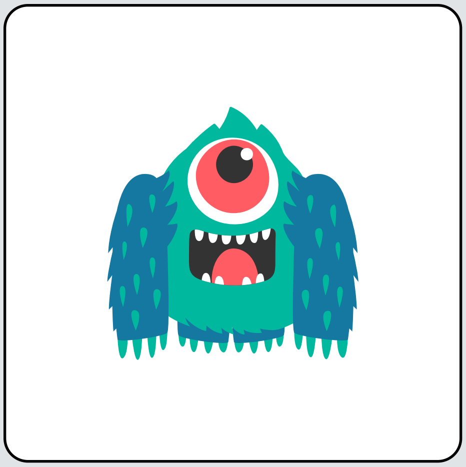
Playing games is a fun way to improve executive functioning skills that can involve the whole family. In the game Jenga, for example, players try to figure out what will happen if they remove a block from the tower. They need to determine if it will make the tower fall, and if they should try to pull the block out slowly or quickly. Thinking about strategies and the best way to proceed can help improve executive functioning skills. Other possibilities include playing a sequencing game in which a set of four to six pictures must be placed in the right sequence to illustrate the correct way to complete a task such as washing a car or making lemonade. The number of pictures can gradually be increased so that the game is more challenging. Playing a memory game is another great way to build attention and improve working memory skills, both of which are important aspects of executive functioning. A series of cards are placed facedown on the table, and players must turn over two cards and remember what they are in order to find future matches.

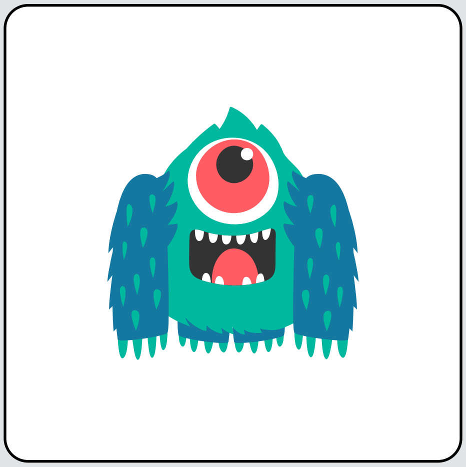
Memory Matching Game

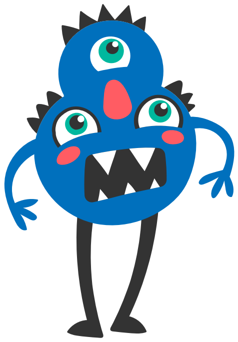
1. Print out this page on cardstock or construction paper. Cut out each card.
2. Lay the cards face down randomly on a table.
3. Player 1 will turn over two cards. If the two cards have the same picture, the player will keep the cards and go again. If the two cards are not a match, the cards are turned face down again and player 2 will take a turn.
4. The person with the most matches when all the cards are gone is the winner.

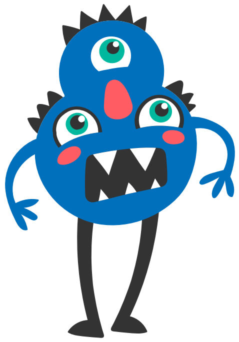


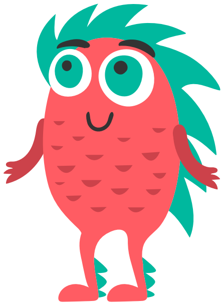


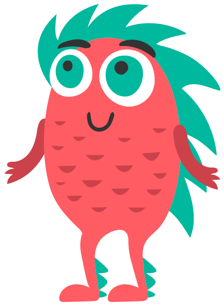


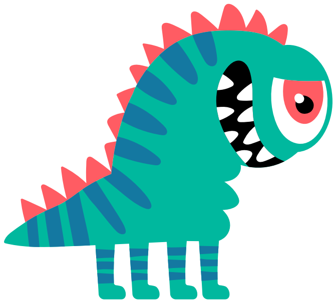


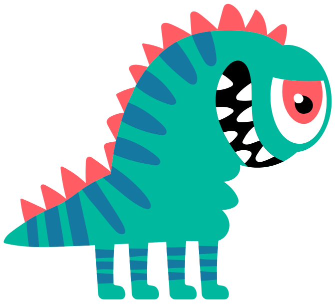


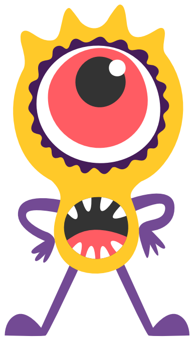


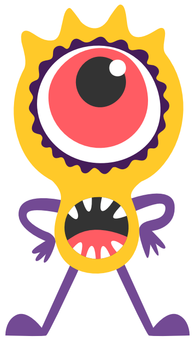


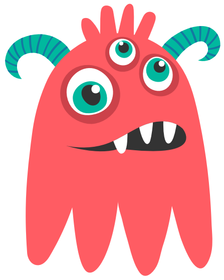


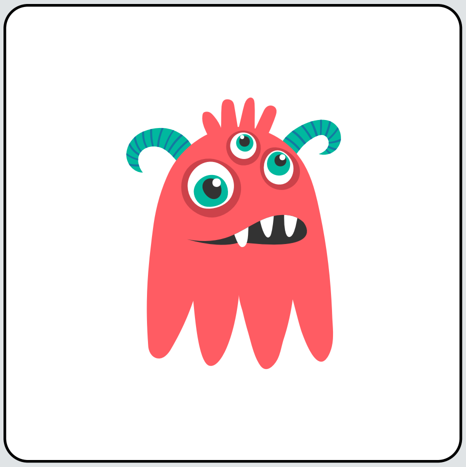


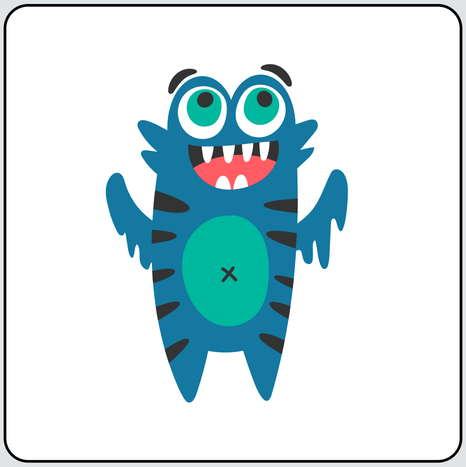


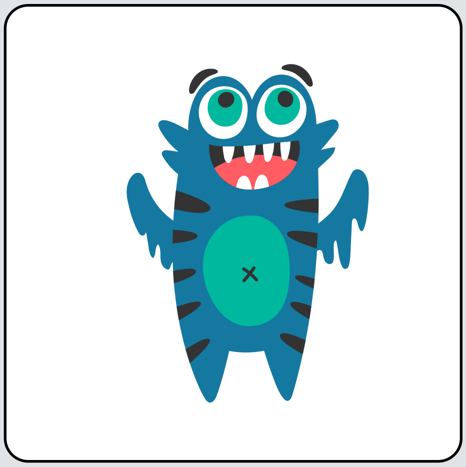












Executive functioning skills affect all aspects of life. I hope that you find the strategies outlined above to be useful in helping your child with autism strengthen these crucial skills. As you work on these skills with your child, you will see him or her thrive at home, at school, and in many other settings.

Emily Levy, Ed. D, is an educational expert, business owner, public speaker and author based near New York City. Dr. Levy holds both a Master's Degree in Special Education and Doctorate Degree in Education from Nova University. Dr. Levy owns and operates EBL Coaching, a specialized tutoring program offering individualized, research-based tutoring to children with specialized learning needs in grades pre-K to 12. Dr. Levy's five-year research study on alternative strategies for teaching reading comprehension found her winning a fifth place Westinghouse Science and Talent Award. In 2017, she was selected as one of Bergen County's Commission on the Status of Women Honorees during Women's History Month. She has spoken nationally and internationally on various education topics and writes regularly for education publications.

Autism and Co-occurring Conditions

There is **Hope**. There is **Help**. **Hold on Tight!**

Jan Stewart

I remember lying awake at night, anxious about my nine-month-old son Andrew. I was a first-time parent, and my husband and I were increasingly concerned about his behaviour. He never talked to himself, gurgled or played in his crib like our friends' babies. His hands and feet constantly moved in a circular motion. He had no self-regulation when it came to feeding. In fact, we did an experiment one morning when he was six months old and gave him as many bottles as he wanted. We were shocked to see him consume five bottles in a row. He would have kept going if we had let him, and he would not have been sick. He clung to me to the exclusion of everyone else, including my husband, who wanted to spend special time with him. Every time I contacted our doctor, he told me that Andrew was fine and that I just needed to calm down.

Andrew blossomed into a happy, outgoing toddler. While his speech was delayed, I tried to relax. When I had his speech and language assessed at two and a half years old, the therapist reassured me that he had no language or processing difficulties and that he would start talking soon. Indeed, he did: by age three, he was talking up a storm.

As Andrew started school, he learned to read, write and do simple arithmetic, and he was initially able to keep up with his peers. He thrived on rules and structure. His report cards, however, consistently noted his difficulties sitting still, focusing and paying attention. He couldn't hold a pencil or crayon correctly. He couldn't maintain eye contact, and he had a meltdown any time there was a change in activities for which he was unprepared. He became very anxious whenever he did something wrong, even if it was a small matter such as not immediately tidying up his area when asked. His doctor continued to downplay my ongoing concerns and told me that he was simply under "a bit of stress" that would pass.

By the time Andrew started grade 3, the gap between him and his peers had become increasingly obvious. He couldn't understand abstract concepts and started engaging in vocal and motor tics. He rocked back and forth. He had a major speech impediment that made it difficult for others to understand him. However, he continued to be chatty and social with neighbourhood friends. Our doctor kept insisting that he was just a highly sensitive child.

Shortly after he turned nine, however, he started engaging in frightening meltdowns for no reason that we could identify. These outbursts continued for up to two hours almost every day. Within one month, he also started engaging in non-stop, bizarre compulsive rituals. He couldn't walk through his bedroom door without repeatedly counting to 14. He hoarded garbage under his bed. He touched walls repeatedly for hours. The rituals then began to escalate: he rubbed his head against car mirrors and poles, and even put knives in his mouth to "feel" them. I was terrified.

While it may seem ironic, my husband and I were thankful that Andrew's symptoms got so severe because they led to him finally being properly diagnosed: autism, Tourette Syndrome, Obsessive Compulsive Disorder (OCD), attention-deficit/hyperactivity disorder (ADHD) and learning disabilities. We were told autism was his umbrella diagnosis and that the others were co-occurring conditions. These associated conditions have core symptoms that are different from autism, but they do often overlap.

Many studies have confirmed the prevalence of associated physical and mental health conditions with autism. Autism Speaks Canada, for example, cites findings from The Public Health Agency of Canada's 2019 Canadian Health Survey on Children and Youth (https://www.canada.ca/en/public-health/services/publications/diseases-conditions/autism-spectrum-disorder-canadian-health-survey-children-youth-2019.html) that "children and youth on the spectrum are three times more likely to have another long-term health condition compared to those without autism." While the following is not an exhaustive list, the survey noted that additional *mental health challenges* can include: anxiety, which affects approximately 22 percent of autistic children aged five to 17 in Canada; OCD, which affects about 17 percent of autistic children, although the actual percentage may be higher because it can be difficult to distinguish between autistic and OCD behaviours; and mood disorders or depression which affect six percent of autistic children.

> "children and youth on the spectrum are three times more likely to have another long-term health condition compared to those without autism."

The survey also found that common *neurodevelopmental disorders* include: ADHD, which affects approximately 36.5 percent of autistic children; intellectual disabilities, which affect about 30 percent of autistic children; learning disabilities; and apraxia or dyspraxia, the full or partial loss of speech. Additional *physical health issues* can include feeding and eating challenges; sleep disturbances; epilepsy and seizure disorders; and gastrointestinal problems.

We were relieved to finally know what we were dealing with. I naively thought that medications and therapy would "solve" Andrew's problems. We quickly learned, however, that certain medications had concerning side effects ranging from headaches and weight gain to dry mouth, shakiness, dizziness, lack of sleep and nausea, to name just a few. We also found out that the interactions between medications was cause for concern. They can play havoc with one another and have opposing side effects. For example, while certain medications helped Andrew's OCD and anxiety, they seemed to heighten his impulsivity and feelings of grandiosity. His psychiatrist explained that autistic children commonly experience frontal lobe problems associated with disorders like ADHD, such as executive dysfunction, insufficient screening of thoughts and actions, and the inability to stop, think or reflect. Neuropsychopharmacology is clearly an art, not just a science.

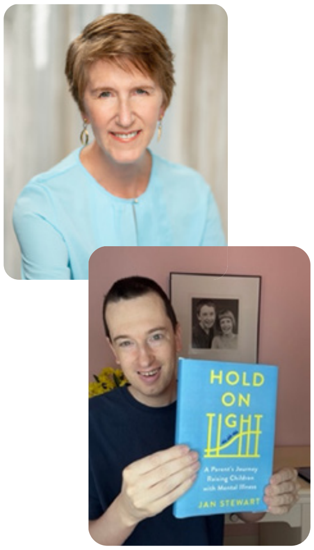
Andrew's therapeutic progress was also complicated by his co-occurring conditions. It was difficult to tell if he was stimming due to autism, engaging in a ritual associated with OCD, or displaying tics due to Tourette Syndrome. This continues to be a challenge today. His anxiety would heighten whenever there was a lack of clarity or closure on an issue. If he was unable to sit still in the classroom due to his ADHD, he became so stressed that he experienced panic attacks unless the teacher told him that she understood and that he was not in trouble. He constantly exhibited stimming behaviours by rubbing the top of his head in circles and massaging his shoulders to help himself stay calm.

Each of Andrew's conditions seemed to benefit from a different therapeutic approach. In addition to Applied Behaviour Analysis (ABA), Andrew learned to use Exposure and Response Prevention (ERP) for his OCD and Comprehensive Behavioural Intervention for Tics (CBIT) for his Tourette Syndrome. He benefited from social skills training for his autism, cognitive behavioural therapy for his ADHD and anxiety, and new learning strategies, such as organizing his work into more manageable pieces and learning to type because of severe graphomotor problems. He also needed speech therapy for his lisp, slurring and drooling, as well as occupational therapy. The list of therapies seemed never-ending.

While it took some time, I learned to stop worrying about which condition Andrew was exhibiting at any particular time and to simply work with him on strategies that targeted his symptoms. I have made many mistakes. That trial-and-error approach continues today. Of course, progress is not always smooth. There have been periods of backsliding, but the important thing is that we have seen a positive trajectory. Andrew's ability to function has improved significantly over time.

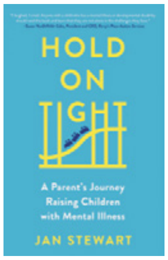
The good news for parents is that there are now so many health care providers who are qualified and trained to help autistic children with their co-occurring conditions, as well as additional resources. I have also found valued support and guidance from other parents of neurodivergent children, many of whom I have met at support groups and through Andrew's schools. We have formed a community of understanding and empathy, and we bolster and embrace one another.

Every autistic child is different and has unique strengths, capabilities and needs. Associated conditions can complicate matters, and they are not uncommon. As parents of autistic children with additional conditions, we are all on this roller coaster together. Remember that differences are not deficits. Persevere and remember that there is hope; there is help; hold on tight!



Jan Stewart is a highly regarded mental health and neurodiversity advocate and parent of a grown son with autism and co-occurring conditions. Her best-selling memoir *Hold on Tight: A Parent's Journey Raising Children with Mental Illness* is a recipient of the prestigious Mom's Choice Award® and describes her emotional roller coaster story parenting two children with multiple mental health and neurodevelopmental disorders. Her mission is to inspire and empower parents to persevere, have hope and know they are not alone, as well as to better educate their families, friends, health care professionals, educators and employers. Jan chairs the Board of Directors at Kerry's Place Autism Services, Canada's largest autism services provider, is a Today's Parent columnist on autism and was previously Vice Chair at the Centre for Addiction and Mental Health. She spent most of her career as a senior Partner with the global executive search firm Egon Zehnder. Jan is a Diamond Life Master in bridge and enjoys fitness, genealogy and dance.

Website: janstewartauthor.com
Instagram and Facebook: @janstewartauthor
Book: Hold on Tight: A Parent's Journey Raising Children with Mental Illness which is widely available at Amazon, Indigo, Caversham Booksellers and Barnes & Noble

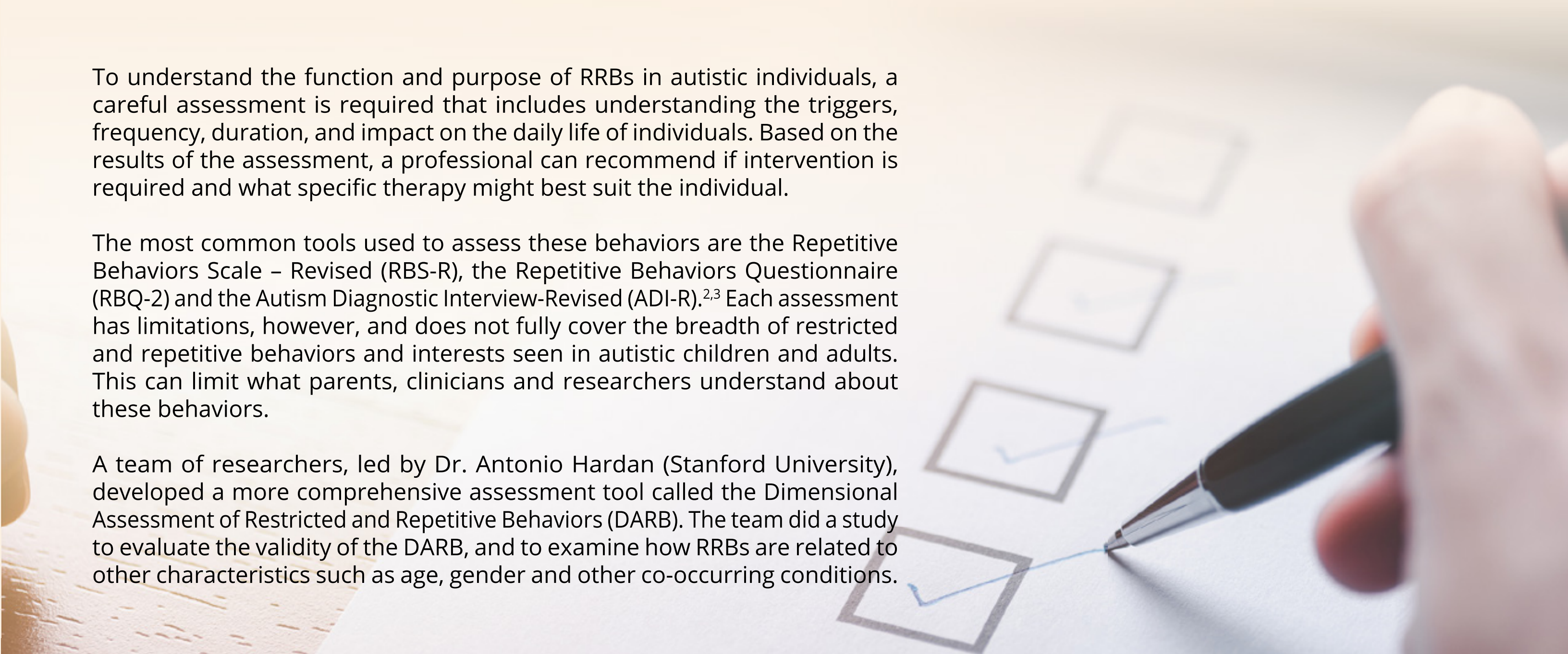


Researchers Develop a New Tool to Measure

RESTRICTED & REPETITIVE BEHAVIORS

This article is a review of the following research: Uljarević, M., Frazier, T. W., Jo, B., Scahill, L., Youngstrom, E. A., Spackman, E., Phillips, J. M., Billingham, W., & Hardan, A. (2022). Dimensional Assessment of Restricted and Repetitive Behaviors: Development and Preliminary Validation of a New Measure. *Journal of the American Academy of Child and Adolescent Psychiatry*, S0890-8567(22)01973-6. Advance online publication.

Restricted and repetitive behaviors and interests, commonly known as RRBs, are a core feature of autism.[1] Although they are primarily seen in autistic individuals, they can also be seen in those with other neurodevelopmental conditions such as attention-deficit/hyperactivity disorder (ADHD). RRBs can be highly variable in nature and intensity, and can include a wide range of behaviors, such as repetitive hand flapping, lining up objects, or following highly specific routines and rituals. These behaviors often serve as a coping mechanism for autistic individuals and help them manage overwhelming sensory and social environments. However, these behaviors can also interfere with daily life activities, academic progress and social interactions.



To understand the function and purpose of RRBs in autistic individuals, a careful assessment is required that includes understanding the triggers, frequency, duration, and impact on the daily life of individuals. Based on the results of the assessment, a professional can recommend if intervention is required and what specific therapy might best suit the individual.

The most common tools used to assess these behaviors are the Repetitive Behaviors Scale – Revised (RBS-R), the Repetitive Behaviors Questionnaire (RBQ-2) and the Autism Diagnostic Interview-Revised (ADI-R).[2,3] Each assessment has limitations, however, and does not fully cover the breadth of restricted and repetitive behaviors and interests seen in autistic children and adults. This can limit what parents, clinicians and researchers understand about these behaviors.

A team of researchers, led by Dr. Antonio Hardan (Stanford University), developed a more comprehensive assessment tool called the Dimensional Assessment of Restricted and Repetitive Behaviors (DARB). The team did a study to evaluate the validity of the DARB, and to examine how RRBs are related to other characteristics such as age, gender and other co-occurring conditions.

Study

The DARB was developed to encompass all types of restricted and repetitive behaviors and interests. Researchers analyzed the current assessment tools and reports, and established eight sub-categories of RRBs: repetitive sensory-motor behaviors (RSMB); insistence on sameness (IS); self-injurious behaviors (SIB); sensory sensitivity (SS); unusual interests (UI); obsessive-compulsive behaviors (OCB); repetitive language (RL); and restricted interests (RI).

A total of 1,892 parents of autistic children who ranged in age from three to 18-years old completed a series of questionnaires and surveys. They included the following:

- Dimensional Assessment of Restricted and Repetitive Behaviors (DARB)
- Repetitive Behaviors Scale – Revised (RBS-R)
- Repetitive Behaviors Questionnaire (RBQ-2)
- Sensory Experiences Questionnaire-3 (SEQ-3)
- Parent-Rated Anxiety Scale-Autism Spectrum Disorder (PRAS-ASD)
- Social Communication Questionnaire (SCQ)

In addition, cognitive test score data were collected.

Of the original participants, 450 parents completed the DARB after two weeks to evaluate the consistency of the retest results.

Eight Sub-categories of RRBs

1 **REPETITIVE SENSORY-MOTOR BEHAVIORS (RSMB)**
Hand flapping, rocking back and forth

2 **INSISTENCE ON SAMENESS (IS)**
Insisting on eating dinner at exactly 6:00 p.m. every day

3 **SELF-INJURIOUS BEHAVIORS (SIB)**
Hair pulling, skin picking, biting nails

4 **SENSORY SENSITIVITY (SS)**
Wearing the same clothes every day because they feel comfortable

5 **UNUSUAL INTERESTS (UI)**
A fascination with maps or the weather

6 **OBSESSIVE-COMPULSIVE BEHAVIORS (OCB)**
Checking excessively that doors and windows are locked

7 **REPETITIVE LANGUAGE (RL)**
Repeating words, phrases or sentences over and over again

8 **RESTRICTED INTERESTS (RI)**
Intense interest in dinosaurs, trains, or a certain animal

Results

- The DARB scores correlated well with the scores of the other RRB assessments, showing the DARB is a valid tool to assess RRBs in autistic children and teens.
- The test-retest scores were stable, which also indicates that the DARB is a valid tool for measuring RRBs.
- Autistic males had more intense repetitive sensory-motor behaviors and more intense repetitive language behaviors than autistic females.
- Autistic females had more self-injurious behaviors compared to autistic males.
- Autistic children with anxiety had more restricted and repetitive behaviors in every category. The most significant effects were in the categories of: insistence on sameness, sensory sensitivity and obsessive-compulsive behaviors.
- The social communication score was strongly correlated with restricted sensory-motor behaviors, self-injurious behavior, sensory sensitivity, unusual interests and insistence on sameness. This indicates that the greater the social communication difficulties, the more severe the RRBs.
- As age increased, there were decreases in repetitive sensory-motor behavior, sensory sensitivity, and unusual interests, while restricted interests increased.
- As cognitive function increased, repetitive sensory-motor behaviors and unusual interests decreased, while insistence on sameness increased.

The authors note that these findings should be considered preliminary.

Conclusion

This study shows the need for a novel assessment tool to fully evaluate restricted and repetitive behaviors in autistic children. It is heartening to see that this area of research continues to seek the best measures and tools to evaluate behaviors in autistic children. As every autistic child is different, it is important to have assessments that are as comprehensive as possible to understand the unique needs of each individual.

This study showed that the DARB is a promising new assessment tool. Previous assessments have not fully captured all aspects of RRBs, especially restricted language, unusual interests and sensory sensitivities.

The authors note that additional developmental and validation steps are still required in order for the DARB to be available for full use by clinicians.

Access the research article reviewed in this article here: https://pubmed.ncbi.nlm.nih.gov/36526162/

For more information and to access the Dimensional Assessment of Restricted and Repetitive Behaviors (DARB): https://med.stanford.edu/autismcenter/dimensional-assessment-of-repetitive-behavior--darb-.html

Written by Autism Advocate Parenting Magazine

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Using Technology to IMPROVE PICKY EATING

This article is a review of the following research: Kral, T. V. E., O'Malley, L., Johnson, K., Benvenuti, T., Chittams, J., Quinn, R. J., Thomas, J. G., Pinto-Martin, J. A., Levy, S. E., & Kuschner, E. S. (2023). Effects of a mobile health nutrition intervention on dietary intake in children who have autism spectrum disorder. *Frontiers in Pediatrics*, 11, 1100436.

It is well known that autistic individuals often have challenges when it comes to eating.[1] Such challenges can include being extremely selective eaters, or being rigid in their preferences with regard to the presentation of food. Many autistic children have such severe food selectivity that they omit entire food groups, with the most commonly omitted groups being fruits and vegetables. This can be a significant concern for parents as children may not be getting the nutrients needed to grow and thrive.

The reasons for such feeding concerns in autistic individuals are not entirely clear to researchers. Some researchers speculate that gastrointestinal issues may play a part, while others suggest that behavioral rigidity and sensory sensitivities are contributing factors.[2] Both rigidity and sensory sensitivities could explain why autistic individuals are more likely to eat processed or packaged food since it looks, tastes and feels the same every time it is presented. Fruits and vegetables may be less desirable as these food items can vary in texture, color, size and taste.

Researchers from the University of Pennsylvania (Philadelphia, PA) recognized that autistic children require specialized and novel techniques to address their feeding concerns. A team led by Dr. Tanja Kral developed a novel app, mHealth, that was designed to help autistic children make better food choices, specifically by increasing their fruit and vegetable intake and decreasing their consumption of snacks, pop and soda. In the study, the researchers tested this mobile health nutrition intervention to see if it could be used to help autistic children make healthier food choices.

Study

A mobile heath app, mHealth, provides remote coaching and skills training for parents who would like to address their autistic child's feeding issues. It addresses improving core behaviors needed for successful feeding, such as self-monitoring, goal-setting, stimulus control, positive parenting strategies, self-efficacy and self-management.

The children who took part in the study were between six and 10 years old. A total of 38 parent-child groups were involved in the study. Each child completed the Child Feeding Questionnaire (CFQ) and a short form Sensory Profile. Each group was assigned to be in the mHealth intervention group or in the nutrition education group that did not use the mHealth app. Each child's food intake was assessed at the beginning of the study and then again after three months.

Intervention Group

In this group, parents were encouraged to use the mHealth app daily with their child for three months. The app uses strategies such as visual aids and concrete descriptions to specifically address each individual's needs and style of learning. It also considers a child's individual food preferences and sensory sensitivities. A high level of parent involvement was required in this group.

The app aimed to increase consumption of fresh, canned and frozen fruits and vegetables, while decreasing the intake of less healthy foods, such as chips, popcorn, pretzels, ice cream, candy, cookies, cakes and pies, pastries, soda, fruit drinks and energy drinks. Even achieving small goals, such as touching or smelling food, was rewarded.

Education Group
A printed handout containing general information on healthy eating was given to the parents in this group.
They also received information regarding nutritional goals, targeted foods and less healthy food choices.
Parents were encouraged to promote healthy food choices for three months.

Results

The results did not show any differences between the mHealth group and the education group. It is worth noting, however, that both groups consumed more fruits and vegetables at the end of the three-month trial. Further analysis also showed that children who had high engagement with the mHealth app *and* consumed very few fruits and vegetables at the beginning of the study increased their fruit and vegetable intake by 1.5 servings per day.

	mHealth App		Education	
	Baseline	3 months	Baseline	3 months
Fruits and Vegetables (servings/day)	1.79	2.16	2.56	3.01
Fruits (servings/day)	0.82	0.84	1.48	1.54
Vegetables, not including French fries; (servings/day)	0.71	0.84	0.95	1.29
Salty and sugary snacks (kcal/day)	401.6	420.8	456.9	385.7
Savory snacks (kcal/day)	148.8	195.3	205.0	141.9
Sugar-sweetended beverage (oz/day)	7.8	7.6	7.1	7.3
Water (oz/day)	16.1	17.5	21.5	22.9

Kral, T. V. E., O'Malley, L., Johnson, K., Benvenuti, T., Chittams, J., Quinn, R. J., Thomas, J. G., Pinto-Martin, J. A., Levy, S. E., & Kuschner, E. S. (2023). Effects of a mobile health nutrition intervention on dietary intake in children who have autism spectrum disorder. *Frontiers in Pediatrics,* 11, 1100436.

Discussion

Picky eating or selective eating among autistic individuals is a complex issue. Sensory sensitivities may be a factor in such behaviors, and restricted and repetitive behaviors likely play a part. Interventions for selective eating in autistic individuals must take these differences into consideration.

The mHealth app designed by Dr. Kral's group aimed to address these challenges and improve the food intake by autistic children. Even though the results of using the mHealth app were not as dramatic as the researchers hoped, there were some positive outcomes. For example, there was a significant positive effect on autistic children who ate very few fruits and vegetables at the beginning of the study and who actively engaged with the mHealth app. This shows the app's potential to help those children who are the pickiest of eaters.

While all the children in the study increased their healthy food choices, there was not a corresponding decrease in unhealthy snack foods. This suggests that the app could be improved by using more strategies to decrease the consumption of unhealthy foods. Since a key step in promoting healthier eating is expanding food choices, running the intervention for a longer time period may have seen the unhealthy options be replaced by healthier options that became part of the child's repertoire.

The authors found it interesting that the education group also increased its healthy food intake. Simply knowing they were in a research study may have prompted the parents to make an extra effort to have their children increase their fruit and vegetable intake.

It is heartening to know that experts from around the world are seeking to provide evidence-based and effective interventions to help parents and caregivers address the selective eating of autistic children and improve their healthy food intake.

Written by Autism Advocate Parenting Magazine

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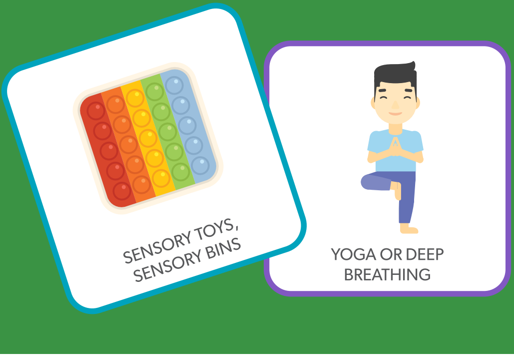

Autism Advocate
Printable Resources

The Value of a Sensory Diet

The "Sensory Diet" was first put forward in 1991 by occupational therapists Patricia and Julia Wilbarger.[1] The term sensory diet refers to a set of activities used to help individuals regulate their sensory experiences throughout the day. This can lead to a calmer state, improved attention and heightened overall well-being. The activities that individuals find calming will vary. For example, while one person finds deep pressure touch to be calming in a crowded and noisy gathering, another might find chewing gum or a fidget toy helps with focus during a test.

A sensory diet is especially helpful for children and adults with autism since they often have sensory processing differences. An occupational therapist or other professional experienced in sensory processing differences typically works with a child to create an individualized sensory diet. The types and timing of activities that are helpful will be different for each person. Some children need sensory input when they are feeling overwhelmed or anxious, while others need sensory input to feel alert. Understanding each person's unique sensory profile is vital to developing an individualized program.

Research shows that children who are engaged in sensory experiences throughout the day are more interactive, alert, calm and focused.[2] Establishing a sensory diet helps children avoid sensory and emotional overload and gives them the skills they need to find respite when they are feeling overwhelmed.

Would My Child Benefit from a Sensory Diet?

There are many online checklists that can help determine an individual's sensory profile and if that person would benefit from a sensory diet. The following are some of the key questions to consider.

- ☐ Does your child seem to be uncomfortable in clothes? Do tags, buttons or seams on clothes cause great discomfort?
- ☐ Does your child not notice pain, or is he or she slow to respond when hurt?
- ☐ Is your child extremely active and constantly moving or running?
- ☐ Is your child overly sensitive to stimulation, and does he or she not like touch, noise or strong smells?
- ☐ Is your child intense, demanding or hard to calm down?
- ☐ Does your child have difficulty with transitions?
- ☐ Does your child struggle to perform fine motor tasks, such as handwriting?
- ☐ Does your child have a hard time staying focused in class?
- ☐ Is your child obsessed with swinging or spinning?
- ☐ Does your child frequently chew on toys, pencil tops, and other objects?

If you answer yes to some or many of these questions, then your child may be helped by a sensory diet.

Creating a Sensory Diet

The strategies outlined below are a great place to start if you believe that a sensory diet would be beneficial for your child.

Consult an occupational therapist or other healthcare professional with expertise in sensory processing to discuss your concerns and observations.

Watch your child carefully throughout the day. Keep track of your child's behaviors as well as reactions to different sensory experiences such as touch, movement, sound and light. This record will help you identify which sensory experiences your child seeks and which ones are overwhelming.

After identifying sensory experiences your child seeks, **research** activities that can provide the required stimulation. For example, if your child likes deep pressure, activities such as massage, rolling a therapy ball over the body and using weighted vests or blankets may be helpful.

Write down times of day that your child seems particularly irritable. It may be beneficial to incorporate specific sensory diet activities at these times. These may involve sensory breaks, such as a quiet space, or sensory input, such as 10 minutes jumping on the trampoline.

Monitor and adjust the sensory diet as needed. As your child's needs and preferences change, you may need to adjust the sensory diet accordingly. Keep monitoring your child's behavior and reactions to sensory experiences to ensure that the sensory diet is effective and appropriate for your child's needs.

A sensory diet can be a useful tool to address dysregulation in those with autism. Be sure to consult a professional in coming up with a plan that will work for your child.

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My Sensory Diet

Name ____________________________________

EVENT	ACTIVITY/TOOL	COMMENTS
Wake Up	- Deep pressure hugs - 10 jumping jacks	
Breakfast	- Crunchy cereal	
School	- Sensory seat - Fidget toy during tests	
After School	- Jumping on the trampoline or swinging	
Bedtime	- Calming music - Lavender hand lotion - Weighted blanket	

My Sensory Diet

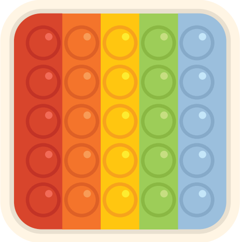
Name ______________________________

EVENT	ACTIVITY/TOOL	COMMENTS

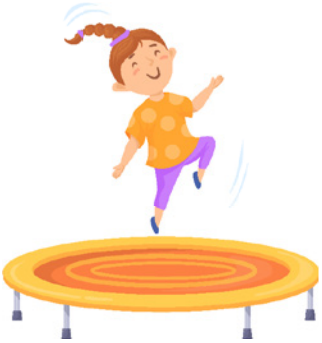
Sensory diet cards can be used at specific times of the day. Help your child determine if a calming activity or an alerting activity is needed.

My Sensory Diet Cards

ALERTING ACTIVITIES



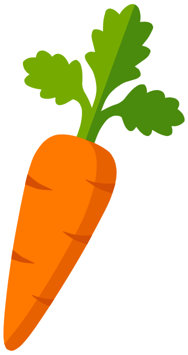
SENSORY TOYS, SENSORY BINS



JUMP ON THE TRAMPOLINE

SWING

SKIP ROPE



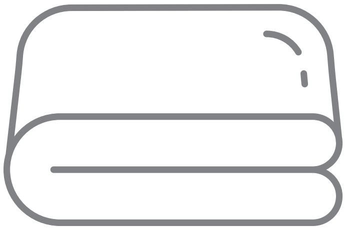
EAT CRUNCHY FOOD

BOUNCE A BALL

My Sensory Diet Cards

CALMING ACTIVITIES

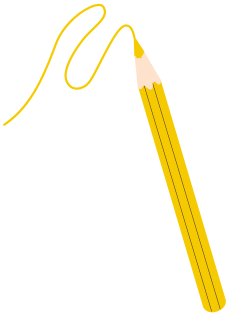
GLITTER JAR



WEIGHTED BLANKET

CALM MUSIC

QUIET TIME IN MY ROOM



DRAWING OR COLORING

YOGA OR DEEP BREATHING

My Sensory Diet Cards

Sensory Diet Worksheet

CHALLENGING TIME	POSSIBLE SENSORY ACTIVITY	WAS IT HELPFUL?
Focusing during a test	- chewing gum - sensory seat - fidget toy	
After school — temper tantrums, not listening	- 10 minutes on trampoline - calm/quiet space - relaxing music	

GLUTEN-FREE & CASEIN-FREE RECIPE

Pumpkin Fudge

INGREDIENTS

pumpkin (cooked, pureed)	¾ cup
unrefined coconut oil	⅓ cup
almond butter	¼ cup
maple syrup	¼ cup
sea salt	½ tsp
pumpkin spice (optional)	0 - ½ tsp

INSTRUCTIONS

Prepare a loaf pan lined with parchment paper or silicone molds next to stove ready for transfer. Pre-measure all ingredients into prep bowls. In a medium-sized frying pan, add coconut oil and turn on burner to low (1-2). As soon as the oil is fully liquid, add pumpkin, almond butter, and syrup, then whisk until mixture is well combined and smooth. Add salt and optional spice, to taste. Transfer mixture to desired dish or silicone immediately and place in freezer quickly, until set, to keep oil from separating This may take up to two hours. Remove from freezer when firm and cut into squares or use cookie cutters, if using a loaf pan. Place back in freezer until almost ready to serve as they soften at room temperature.

Tip: Almond butter, pumpkin, and coconut oil can be adjusted slightly for desired taste and consistency.

Nutrient Nuggets

from a Neurodiverse Nutritionist

Did you know that individuals with autism have lower levels of vitamin A and that this has been linked with autism severity?

Guess what's high in vitamin A?

Pumpkin!

References

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

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

AUTISM ADVOCATE
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
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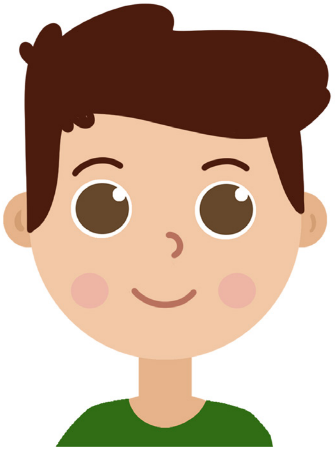
My Social Story:

HALLOWEEN

Soon it will be Halloween.

On Halloween, some people like to dress up in costumes.



Some costumes are scary, but I don’t need to be afraid. Halloween is fun.

On Halloween, lots of people go trick-or-treating. This means we walk from house to house and collect candy.

I will dress up in a costume and carry a bag or bucket.

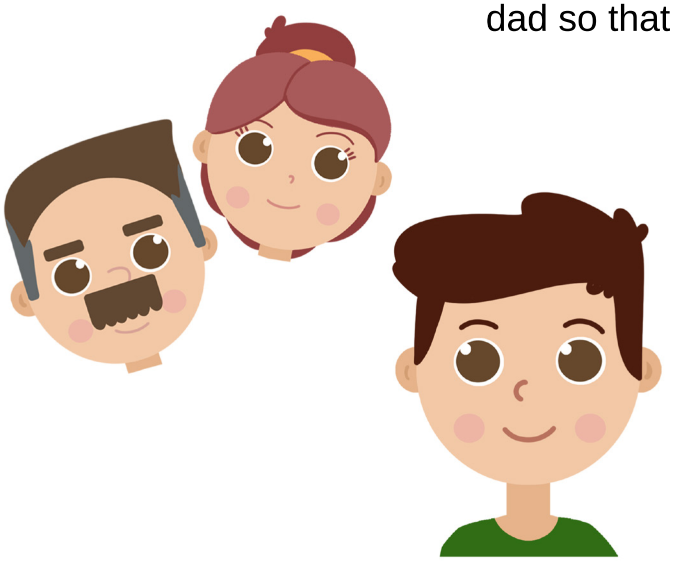
My mom and dad will walk with me to different houses.

I can knock on the door and say, “Trick or treat!”

When I hold out my
bag or bucket,
people will put a treat
in it. I will remember
to say, “Thank you!”

Mom and dad will then take me to the next house.

I always stay with mom and
dad so that I am safe.



Halloween is a lot of fun. Halloween makes me happy.

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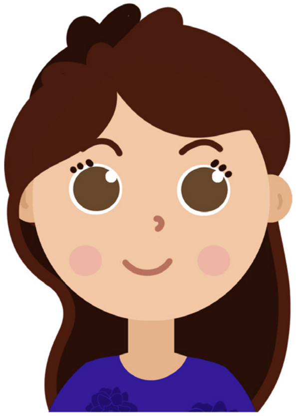

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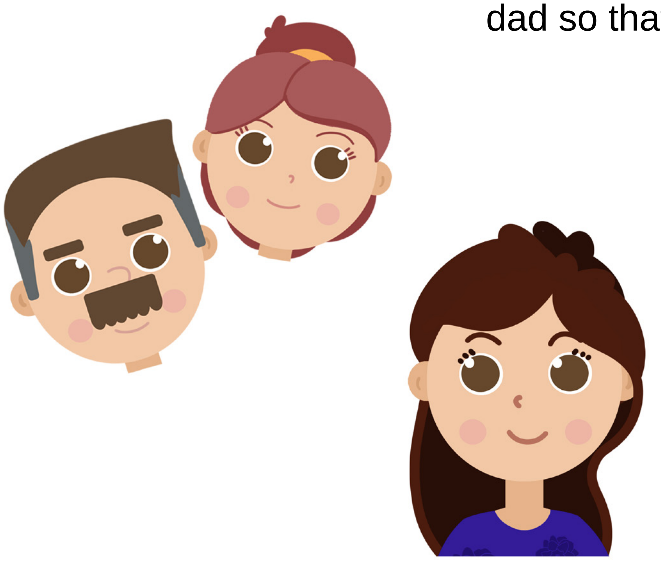

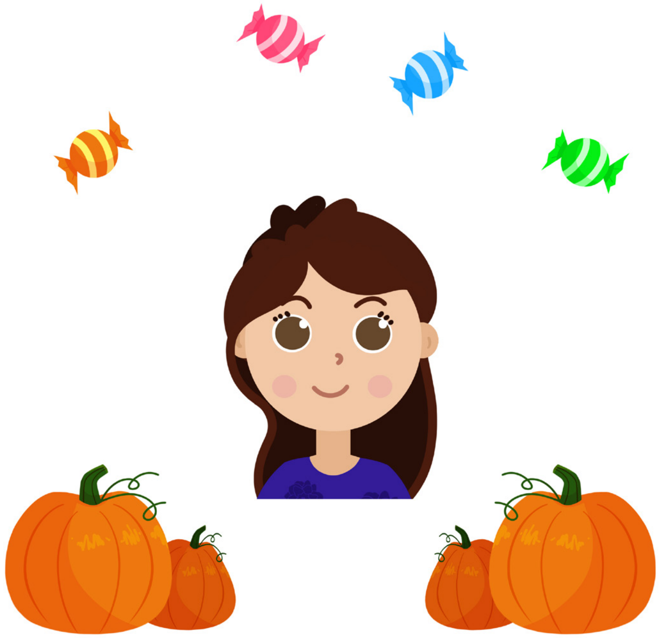

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My Next Steps

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

AUTISM ADVOCATE
PARENTING MAGAZINE

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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Love and kindness are never wasted. They always make a difference.

— Helen James

FOR PARENTS & PROFESSIONALS

AUTISM ADVOCATE

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