

AUTISM ADVOCATE

PARENTING MAGAZINE



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ADHD Aggressive Behavior Art Therapy
Affection Amygdalas in ASD Electronic Addiction
DIR/Floortime Anxiety Apraxia Communication
Autism in Young Children ASD Severity Over Time College/University Transition Diagnosis
Developing Skills Cerebral Folate Abnormalities
Cognitive Behavioral Therapy Dating/Romantic Relationships
Fragile X Detox Embracing Differences Executive Function
Employment Family Enzymes
Financial Resources/Planning Tics
Gender Differences Genetics of Autism Gut-Brain Axis
Feeding/Oral Development GI and Behavior
Therapy and Medication

Topics Covered

IN AUTISM ADVOCATE PARENTING MAGAZINE

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

And so much more!

Dear Parent Advocate or Reader:

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

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

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

Current Research



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

Expert Advice



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

Resources



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

Parent Advocating



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



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

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

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

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

Parent Advocates

Autism Advocate Parenting Magazine

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

- Dr. Tom O'Bryan

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A Note on Perspective

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

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

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



AUTISM ADVOCATE

PARENTING MAGAZINE

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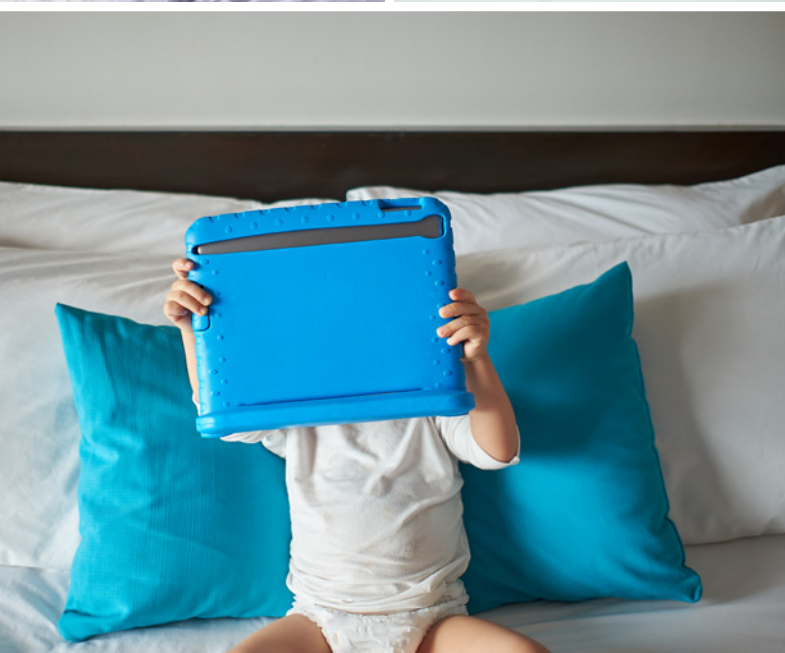
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From time to time, this magazine may include our review of other articles or publications that we think may be of interest to our readers. We have no affiliation with the original author or publication. We are providing the reviews for interest and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

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Benefits for Autistic Individuals of Outdoor Play in a FOREST AND NATURE SCHOOL

Pat Andrews, BPHE, B.Ed. BCTF

“Breathe in, breathe out, eyes closed, ears open, senses alive... breathe in, breathe out. Smell the earth in the morning after a rainfall. “

Grounding myself to start a day at forest school with Natural Pathways Learning Centre connects me to the land and sparks my enthusiasm for the day ahead. As an educator, as well as former executive director and now board chair of the centre, I am grateful for the opportunity to touch the lives and support the development of people who are drawn to this kind of inspirational and holistic approach to learning in a natural setting. Natural Pathways Learning Centre is a non-profit charitable organization located in Essex, Ontario, Canada, and has been offering forest and nature school programs since 2016. I am part of a group of educators at our organization who have seen tremendous growth and valuable learning for autistic individuals that take part in our forest and nature school programs.

What is a Forest and Nature School?

Forest schools began many years ago and are based on a Danish early-years method of taking children into the outdoors throughout all seasons. The pedagogical approach was adopted in the UK, and eventually spread to North America and the rest of the world.

The Child and Nature Alliance of Canada offers the following definition of this approach.

We define Forest/Nature School as an educational ethos and practice that centres the Land and the child at play. Children and educators build a relationship with the Land through regular and repeated access to the same outdoor space over an extended period of time. Educators support learning through a pedagogical framework that is rooted in place and play, directed and inspired by the child (emergent curriculum), and driven by a process of inquiry. Forest/Nature School is founded on three pillars: Trust, Reciprocal Relationships, and Freedom.¹



Benefits

As the popularity of forest schools increases, a growing body of research and evidence shows the benefits of these programs for the health and well-being of children. Time spent in nature promotes mental health, physical and cognitive development, and social skills development. The following are just some of the benefits and characteristics of a forest school approach to learning.

Individual Strengths and Needs

In his book, *Forest School and Autism – A Practical Guide*, author Michael James states: “Although there is a growing evidence base to show the benefits of increased contact with the natural world for people in general, there is not currently a strong evidence base to indicate any benefits of outdoor education specific to autistic learners.”² While this may be true, it is worth exploring how the forest school approach can support the health and well-being of autistic individuals. Since autism is a spectrum condition, there are a broad range of individuals diagnosed as being autistic. Many other individuals who may meet some of the criteria for sensory processing issues or social communication barriers are not diagnosed. Accordingly, when we consider how best to mentor individuals with neurodivergent needs in a forest school program, we need to keep the individual at the centre of our practice, seek information from others, and build relationships based on our own observations and what the individual communicates to us.

Inclusivity

The individuals who participate in forest school programs are often of different ages, come from diverse cultural communities, and are neurotypical or neurodivergent. By establishing relationships with the individuals in a group, we can develop an awareness of their particular needs and offer activities that engage and accommodate them. Creating inclusive spaces helps reduce the impact of perceived disabilities and allows individuals to share their strengths and gifts. This, in turn, allows for the holistic development of a community of learners.

Curiosity and Experimentation

Another benefit of forest schools for both neurotypical and neurodivergent learners is the opportunity to challenge assumptions about how learning happens. For example, individuals who may display certain characteristics and tendencies in a typical indoor setting may become more curious and experiential when outdoors. The child-led approach taken by forest and nature schools expands the opportunities afforded to the learners and strengthens the relationship of trust between mentors and learners. This approach also encourages learning new skills and promotes independence through opportunities to make choices and self-advocate.

Health Benefits

One of the many health benefits for individuals with autism is the exercise from walking and the other activities that expend energy in the forest school program. Author Michael James says, “Research shows that autistic people have differences in the way they regulate the stress hormone cortisol and that exercise is effective in helping to counteract this imbalance.”²



Students Can Take Risks

Risky play is an integral part of the forest school experience. With the support and guidance of practitioners and mentors, individuals learn to assess risks and work through challenges that may stretch their comfort zone. The opportunity to take risks in an inclusive environment can empower individuals with autism and increase their feelings of well-being and competency. Having positive shared experiences with others helps raise self-esteem personally, as does receiving recognition from others. Safe, inclusive and flexible spaces support all learners and are particularly important for those with autism.

Sensory Stimuli

Learning in the outdoors offers a rich range of sensory stimuli. Neurodivergent learners who are sensitive to indoor spaces may find outdoor stimuli to be less intense. Leaders need to develop a good relationship with learners to know what will be a supportive environment and what might be overwhelming. For example, the need for vestibular stimulation can be addressed through swings or hammocks and rolling down hills, all activities that are typically included in a forest school offering. Learning about each individual's sensory triggers and preferences is helpful for offering accommodations and working together to create a positive experience where calming strategies are known and used when needed.

Social Interaction

Having fun and interacting socially are vital parts of a forest and nature school experience as they break down barriers and create compassionate relationships. This can be particularly important for individuals with autism who have impairments in communication. Neurodivergent learners can be supported and feel included when they participate in an inclusive and autism-aware program with educators who are sensitive to the challenges in social communication and expression. Such an approach values the differences that we each bring to the group.

There are many other benefits of outdoor play in forest and nature schools for individuals with autism that could be enumerated. There is also much more to learn from future research in this field. However, our practical experiences with our Forest School programs at Natural Pathways Learning Centre have shown us the positive impact that this approach offers to individuals with neurodivergent needs. We are committed to continuing to grow and learn how we can create inclusive spaces and opportunities to explore, have fun, connect and deepen relationships to each other and to the land.



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Pat Andrews, BPHE, B.Ed. BCTF, is grateful to be living, working, learning and playing on the unceded territory of the Qualicum First Nation on Vancouver Island. This part of Canada has been her home for three years. Drawn to the land of mountains, lakes, ancient forests, and oceans, she and her husband moved from Amherstburg, Ontario, to Vancouver Island in order to be closer to their three adult sons.

Inspired and enchanted by summer months spent on a remote Georgian Bay island in her youth, her connection to nature is deep and reverent. From adventures by bicycle through Europe, Australia, New Zealand and Canada, to kayaking/canoeing adventures in remote parts of BC and Ontario, and hiking adventures in Canada, Europe, Australia and New Zealand, the travel bug has become a symbiotic part of her life. In between some of these travel adventures, she began her teaching career. She has worked in public education in Toronto, Kitchener-Waterloo, Essex County, Australia and, most recently, B.C.

Just as rivers and streams meander across landscapes, teaching for Pat has been shaped by the flow of many educational paths. Her experiences have included being a homeschooling mom, public school teacher, music educator and small business owner (Kindermusik), Montessori Music and Movement teacher, Waldorf Learning Support teacher, Forest and Nature School Practitioner, Executive Director of Natural Pathways Learning Centre, President of Natural Pathways Learning Centre, and co-facilitator for The Child and Nature Alliance of Canada.

In her spare time, she enjoys sailing, hiking, yoga, Pilates, biking, cooking/baking, reading, travelling, knitting and enjoying time with friends and family.

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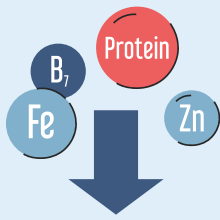
Common Health Issues of Autistic Individuals

Kurt N. Woeller, DO

Autism is a complex condition that manifests in various ways and impacts a person's social interactions, communication and behavior. While much of the focus continues to be on the behavioral and cognitive aspects of autism, it is essential to consider some of the underlying health issues frequently observed in autistic individuals. Recognizing the prevalence and diversity of these health concerns is key to gaining a comprehensive understanding of the challenges that face autistic individuals.

Common Underlying Health Issues

In my experience, some of the most common underlying health issues for autistic individuals include nutritional deficiencies, food sensitivities, gut dysbiosis and unique biochemical imbalances. Let's look at each of these in turn.



Nutritional Deficiencies

Most autistic children, teens and even adults have some type of nutritional deficiency.¹ This can include a deficiency in certain vitamins, antioxidants, minerals or other nutrients. These deficiencies are often a result of selective eating. Selective eaters tend to prefer processed foods and dairy items, and may choose foods that are void of nutrients. This puts added stress on the body and causes nutrient imbalances.



Food Sensitivities

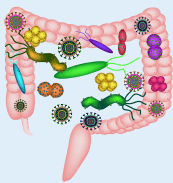
Many autistic individuals have extreme food sensitivities. The most common sensitivities are to dairy and gluten.² Food sensitivities can not only cause an adverse immune reaction, such as inflammation, bloating or gas, but also a chemical reaction to certain compounds in the food that can have a neurological effect. Such a chemical reaction could influence cognition, language, attention and behavior.



Gut Problems

The high prevalence of gut problems in autistic individuals is well-documented.³ Such problems can include constipation, loose stools, bloating, gas and many other issues. It is important to note that these gut issues have been linked to behavior difficulties, such as aggression and even self-injury.⁴ Digestive problems are often driven by a microbial imbalance, such as the presence of pathogenic or opportunistic bacteria or fungi. For example, *Candida* is a type of yeast that lives naturally in the digestive system. It is usually kept in check by the “good” bacteria in the gut, but an imbalance can allow for an overgrowth of *Candida* which may affect energy levels, cognition, digestion and even mood.

Many autistic children with digestive problems may also have poor digestive enzyme production and are unable to digest food appropriately or optimally. This can lead to further imbalances in the digestive tract. These issues can also contribute to the nutrient deficiencies already mentioned.



Gut Dysbiosis

The gut problems mentioned above are often caused by gut dysbiosis, an imbalance in the gut microbial community. It is worth noting that this dysbiosis does not just cause problems in the gut. During digestion, the organisms that reside in our digestive system metabolize the food we eat. During this process, the bacteria and fungi that reside in our gut produce by-products. If the bacteria and fungi are unhealthy microorganisms, the by-products may be toxic compounds. When these toxic compounds are absorbed from our digestive system, enter the bloodstream and circulate throughout the body, they eventually cross the blood-brain barrier and influence the brain. This can affect attention, awareness, language and behavior. Such two-way communication between the central and enteric nervous system is known as the gut-brain axis. An overgrowth of *Candida*, for example, can cause an excess of silliness such as is seen when one is under the influence of alcohol. Another example is an overgrowth of *Clostridium*, which may cause negative effects in the digestive tract. It can also cause a neurological effect and result in irritability, agitation, aggression and self-injurious behavior. Given the prevalence of gut issues, it is also possible for autistic individuals to have multiple overgrowths of various intestinal pathogens.



Unique Biochemical Imbalances

Unique biochemical imbalances can result from the body's inability to detoxify environmental compounds and chemicals. Such substances include herbicides, pesticides, mold, mycotoxins, heavy metals, and even perfumes or strong scents. Many autistic children do not process or eliminate environmental compounds efficiently. This often occurs because of nutrient deficiencies, food sensitivities and gut-related issues.

The conventional medical model sees autism as solely a neurodevelopmental condition. However, a broader perspective shows that nutrients, food sensitivities, the immune system and the gut all influence the brain. If food sensitivities were addressed and overall gut function improved, it would make sense that there would be a positive influence on the brain as well.

Mitochondria Function

In order to understand many of the common health issues seen in autistic individuals, we need to take a closer look at what is happening at the cellular level in our bodies. The mitochondria are known as the “powerhouse” of the cell because they play a crucial role in producing adenosine triphosphate (ATP), the primary energy source for the body. At any moment, our bodies are producing billions of ATP molecules. This energy allows us to talk, our hearts to pump, our immune system to work, our bodies to digest food and our brains to make complex decisions. The mitochondria are always working and need to be fed constantly with proper nutrients to function properly and appropriately.

Nutrient deficiencies, food sensitivities, gut problems, dysbiosis and environmental toxins will negatively affect mitochondrial function. When the organ systems in our body that are most dependent on mitochondrial function become compromised, they do not work efficiently. The largest organ systems in our body that use ATP is the brain, heart, and nervous system.

Improving mitochondrial function is a multipronged process that entails addressing the five common health issues listed above. In other words, it involves eliminating nutrient deficiencies, addressing food sensitivities, reducing gut problems, balancing the gut and eliminating environmental toxins.



Testing

Different doctors and professionals may recommend various tests to identify common health issues in autistic individuals. While there are many to choose from, I often recommend the following as important entry-level tests.

Organic Acids Test

This is a urine test that assesses various organic acids produced by the body's metabolic processes. It helps evaluate how well the body is functioning at the cellular level. There are many kinds of organic acids tests on the market. I highly recommend the MOSAIC Diagnostics Organic Acid Test (<https://mosaicdx.com/test/organic-acids-test/>). It is the most comprehensive test for autistic individuals and is the one test that should not be missed.

Food Sensitivity Test

This is a diagnostic tool used to identify specific foods or substances that may trigger an adverse reaction in an individual's body. It includes measuring the levels of immunoglobulin G (IgG) antibodies in response to specific foods, as well as a person's immune sensitivity to foods. It is an especially important test for any patient with a seizure disorder. MOSAIC Diagnostics has an excellent Food IgG MAP test (<https://mosaicdx.com/test/igg-food-map/>).

Hair Analysis

Also known as a "Hair Metal Test," this method is used to assess and detect certain toxic elements, such as heavy metals, within the body. It also provides an indication of a person's mineral levels. It involves analyzing a sample of hair to measure the concentrations of various minerals and elements deposited within the hair shaft. I recommend the test offered through MOSAIC Diagnostics (<https://mosaicdxinternational.com/products/mx-heavy-metals-test-hair>) or Doctor's Data (<https://www.doctorsdata.com/hair-elements>).

Comprehensive Stool Analysis

Children with significant gut issues should have a comprehensive stool analysis in order to determine what is going on in the gut. Issues could be related to the presence of parasites, inflammatory markers or bacterial or fungal matter. This test complements the organic acids test.

For those seeking assistance in obtaining or interpreting a lab test, a website called Lab Tests Plus (<https://labtestsuplus.com>) provides access to testing from MOSAIC Diagnostics and other labs, such as Doctors Data.

Treatment

As a practitioner, I often place great importance on percentages and probability in my work. For example, we know that a large percentage of autistic individuals have suboptimal nutritional intake that can result in nutrient deficiencies. Given this prevalence, I recommend a *multivitamin* for almost every autistic individual. While a healthy diet is important, foundational supplements could be started while changes are being made in the diet. It is an easy place to start before testing has begun.

Dietary changes can also be implemented right away. I recommend a whole-food or real-food diet. Since up to 80 percent or more of autistic individuals have adverse reactions to gluten and dairy, I recommend eliminating these substances. I also suggest the elimination of refined sugar. These two changes — adding a vitamin supplement and eating a whole-food diet — will result in positive changes in most cases.

The treatment for dysbiosis of the gut depends on the *offending agent* and will be addressed based on what the tests show. The intervention for an overgrowth of *Candida* and yeast will be different from that taken in response to an overgrowth of bacteria. Seek guidance from a qualified professional to know the next steps in this treatment.

Conclusion

Improving a child's diet, expanding the variety of foods eaten, and incorporating more nutrients into the diet all contribute to improving the child's underlying health. In my experience, autistic children who slowly make these changes are less hyperactive, agitated and erratic, have improved focus and awareness of the environment, and enjoy improved sleep. They have better comprehension and are more present, and will seem calmer and more social. There will be less bloating, gas and constipation, as well as better bowel movements.

While these changes may not be easy and will take time and effort, they could make a significant difference for your child. As a parent or caregiver, think of yourself as a detective and monitor your child's symptoms. Empower yourself through education by asking questions, researching and reaching out to others. Your efforts can change the trajectory of your family and your child.

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Helping Parents Engage Their Children in **Personal Hygiene Self-care**

Beth L. Raiola, MS, EdS, BCBA, IBA

Autistic children are as diverse as any other children. There are some commonalities, however, among children and adults who experience sensory-related challenges. While these challenges can take many forms and some sensory responses may seem pleasurable, each individual's reaction to such stimuli is unique.

Let me offer a few personal examples. I cannot tolerate seeing people's mouth foam when they brush their teeth. I enjoy playing with my hair, but I cannot tolerate labels on my clothing. I am sure we can all relate to different reactions to various stimulatory sensations to some degree. We may have had to learn how to tolerate some of them, especially those related to hygiene.

In order for autistic children with strong sensory-related feelings of aversion to allow parents to brush their teeth or give them a bath, they must feel that it is worth it. The challenge may be that children don't yet recognize the value of having healthy gums and teeth or of refraining from being dirty and having body odor, and feel that is not important. This article outlines ways in which parents can engage their children in taking care of their own personal hygiene.

Short-term and Long-term Goals

Parents need to distinguish between short-term and long-term goals. Most children do not see the long-term benefits of brushing their teeth or engaging in personal hygiene. In the hierarchy of priorities, parents must pick and choose their battles. I recall one caregiver who did not force her child to sleep in her own bed, but who would not allow her child to go to school with messy hair. The child ultimately tolerated this condition as it was a losing battle.

Getting children to adjust to unpleasant sensory experiences related to good hygiene may be a process that takes time. When trying to get a child to do something that requires work or stress and that may feel intolerable, there are strategies that can make the exposure bearable. The goal is to prepare children for the activity in advance, help minimize potential anxiety associated with the non-preferred or aversive task, and make it worth it. While the long-term reason may not be developmentally relevant, the short-term benefit must serve as a motivator.



Motivation

Everyone requires motivation in order to act. We might do things for personal gratification, for fun or for the chance to earn something meaningful. I am motivated to brush my teeth because I want a beautiful smile and hope to avoid dental procedures. I could take a job cleaning bathrooms because I see the value of the money it brings me, or I may feel a sense of purpose because of my work. What motivates you?

When it comes to autistic children, we need to consider what will motivate them to engage in personal hygienic self-care. Using the principles of behavioral science and keeping in mind the developmental ability of the child, we can use the following guidelines to help achieve that goal.

- Use a preparation strategy to mitigate the anxiety over the task or the transition.
- Show developmentally appropriate references to the activity through videos, books and other media.
- Model the activity.
- Do the activity as a family, if appropriate.
- Create a schedule with a routine surrounding the schedule.
- Put in place a self-monitoring system of rewards.
- Develop and use a self-monitoring scrapbook.

Meet Children Where They Are

The key points to remember are the following: meet children where they are; prepare for the activity; reward attempts; allow children to earn something for trying or completing the task; maintain a schedule since many children are comforted by routines; and remove any added stress or negativity associated with the activity. Build on existing family routines, such as bath time at 7:00 p.m., brushing teeth at 7:30 p.m., story time at 7:45 p.m. and bedtime at 8:00 p.m. All children benefit from a visual schedule. When you are requesting or explaining a task, remember that less is more. Children tune adults out when things lead to auditory overload, or are repetitive, demanding or authoritarian. Children with autism or sensory processing issues, or who are oppositional, can be particularly sensitive to auditory overload. Break the tasks down, and provide a sticker or a point that adds up to a larger reward. That reward can be ice cream, 10 extra minutes on a favorite activity or some other motivator. Keep it simple and pleasurable.

When children see their photo associated with a task, they tend to connect with it. I typically use a photo of the child engaging in the task and enlarge it into a poster to which stickers, stars or points can be attached *by the child*. If it makes sense, have children keep their own scrapbook with the schedule, the visuals of the task, photos of children engaging in the task and tallies of how many stickers or points have been earned. Some children enjoy having their own clipboard with pictures of the steps that they can check off as they advance toward the goal. A strategy is only useful if the child is motivated by it. Remember that the goal is to shape the behavior using motivators. The child will learn the expectations over time, and the importance of the motivators to the child may fade. The time frame for each child will be different.



Prepare for the
activity.



Reward attempts:
allow children to
earn something for
trying or completing
the task.



Maintain a schedule
since many children
are comforted by
routines.



Remove any added
stress or negativity
associated with the
activity.








Offer Choices

Another key way to engage children with autism or related diagnoses in performing a typically unmotivating task is to provide choices. For example, let them choose which toothbrush or toothpaste to use, whether to use the potty or the toilet, and which color hairbrush they prefer. If you ask a simple “yes” or “no” question, chances are good that you will get a “no.” Rather than asking such a question when requesting completion of a less-than-pleasant task, offer a choice. Peer mediation has also proven successful. If there is a friend or sibling that the child connects with, have that individual engage the child by saying such things as, “Let’s go brush our teeth, and then we can watch TV together.” A parent may say, “Do you want to brush your teeth with me or with Suzie?”



I encourage parents to be consistent, keep it simple, use visuals, offer rewards, and try to make it fun. Combine a favorite song with the activity and use it *only* for that activity. Offer a special book for potty time and keep it *only* for toileting. Try blowing bubbles during bath time. The most important thing you can do is be patient. Every child's timeline is different. While you're at it, don't forget to take care of and reward yourself because you are doing your best!

Use these sample charts to create ones that are personalized for your child. While these are viable examples, using images of your own child or making charts that are more personalized might be more relevant.



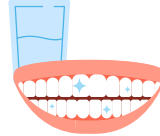
Washing Hands

1		Turn on water
2		Wet hands
3		Put on soap
4		Scrub hands for 20 seconds
5		Rinse hands
6		Turn off water
7		Dry hands

Shower Chart - Wash Body

	Wet Body
	Soap on Sponge
	Wash Arms
	Wash Shoulders
	Wash Legs
	Wash Face
	Rinse Body

Brushing Teeth

1		Squeeze toothpaste onto your toothbrush.
2		Hold toothbrush under the tap.
3		Brush your teeth.
4		Spit the toothpaste into the sink.
5		Rinse your mouth and smile.



Beth L. Raiola, MS, EdS, BCBA, IBA, an international behavior analyst, graduated from the American College of Education with an advanced degree as an Educational Specialist (EdS) and is currently completing a doctoral dissertation in Early Childhood Education Leadership. She earned her Master's at Post University in Human Services, Clinical Counseling. Ms. Raiola did her post-graduate work in Applied Behavior Analysis at the Florida Institute of Technology, leading to becoming a Board-Certified Behavior Analyst, with licensure in multiple states. Ms. Raiola is a published author of articles on parenting, ADHD, and autism. Ms. Raiola taught Autism Studies, Applied Behavior Analysis, and Human Services at Marywood University in Scranton and Vargas University in Florida, where she sat on their Advisory Committee in Mental Health and Human Services studies. Ms. Raiola currently sits on the Human Services Advisory Board of CSU Global.

Ms. Raiola designed and operated a successful behavioral health agency in Monroe County, PA, dedicated to children with autism, ADHD, and other co-morbidities. Ms. Raiola is a trainer and supervisor for students and professionals in the behavioral health field. She has worked in clinical and operational leadership roles after owning her own agency, has provided workshops and devised coursework and curriculum for RBT and BCBA accreditation, and is a coach for parents and teachers on positive behavioral supports.

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AUTISM SKILLS @ WORK

Part 1

ADVOCATING for Self and Others

Jonathan Pierce, PhD

This article is based on Dr. Pierce's dissertation case study at Aspiritech, an organization in the greater Chicago area that hires and supports employees on the autism spectrum since 2008.¹ The results of this study revolve around eight emergent themes, each of which is worthy of its own article. The hope is that parents find these themes and topics useful in preparing their autistic children for employment, independence and fulfilling lives. This article discusses how to advocate for yourself and others.

Advocating

The theme of advocating for self and others came about as a direct result of studying a workplace that was already supportive of autistic employees. Leaders at Aspiritech established the importance of accommodating autistic employees to such a degree that other individuals within the organization would speak up on behalf of individuals who faced various struggles.¹ In fact, the workplace culture saw autistic employees advocating for their fellow autistic employees and even for themselves. By creating a work environment in which employees can advocate for their specific needs, the leaders at Aspiritech were able to foster higher productivity in workers while simultaneously securing the rewards of their labor. This process is described in labor process theory.²

Disclosing Autism

Disabled employees are generally reluctant to disclose the full nature of their disability and the accommodations they need in the workplace, which can limit their contributions.³ Accordingly, an organization that focuses on employee support and accommodation needs will likely achieve higher performance from its employees. Self-advocacy and advocacy for others can prompt leaders to create an environment in which employees who need support and accommodation are not only identified but are put on a path toward receiving the support needed to maximize their potential.

Self-advocacy

Self-advocacy involves employees with disabilities informing their managers of specific supports or accommodations they need to manage their daily tasks. While individuals with disabilities are required to disclose their disability under the Americans with Disabilities Act and its associated regulations, many disabled employees do not disclose the full nature of their disability.^{3,4,5} Self-advocacy

Checklist for Employers

- ✓ Establish the importance of accommodating employees
- ✓ Create an open work environment where employees know their concerns will be heard
- ✓ Focus on employee support
- ✓ Ensure an environment in which employees are comfortable disclosing autism
- ✓ Ensure an environment in which employees are encouraged to advocate for their needs
- ✓ Do not dismiss supports that are requested

remains an important facet of obtaining the requisite support or accommodations necessary to maximize productivity.⁶

Establishing Supports

Once disclosure has occurred, it becomes the responsibility of organizational leaders to assess what supports and accommodations are appropriate and necessary in the workplace.⁷ When leaders create a work environment that is inclusive and accepts employees with disabilities, the latter feel empowered and experience fewer negative psychological effects.^{8,9,10} Employees also feel they belong and are appreciated. In essence, they feel like they are valued members of the team. This highlights the fact that leaders need to create a work climate and environment that are conducive to self-advocacy on the part of employees.¹⁰ Positive and accommodating work environments flow from an organization's mission, vision and values, and its overall stance on social responsibility.

Conclusion

To help optimize the contributions of autistic employees in the workplace, leaders need to create an environment that welcomes and supports those employees. When appropriate supports and accommodations are put in place, autistic employees feel a sense of empowerment, appreciation and belonging, which leads to higher levels of productivity and a more engaged workforce. A work environment that allows for and appreciates self-advocacy and advocacy for others will result in a workforce that is more content, well-balanced and able to exceed expectations.

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Benefits of allowing employees to advocate for their needs

- ✓ Employees feel empowered
- ✓ Positive work environment
- ✓ Higher productivity
- ✓ Feelings of belonging and appreciation
- ✓ A more engaged workplace



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Quality Assurance, Accessibility, and Data Services

Excellence Powered by a Neurodivergent Team

A child is sitting on a bed with white pillows and a blue blanket. They are holding a large, blue, rectangular communication device with a screen and buttons. The device has a blue, textured cover with small bumps. The child is wearing a white t-shirt.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

Transforming Communication for Nonspeaking
or Minimally Speaking Children

Hannah Williams, BSc (Hons), MASLTIP, Cert RCSLT, MHCP

In my work with the families of autistic children, I hear from parents every week about wonderful communication moments they have had with their children. A mother discovered her five-year-old nonspeaking son could spell when he typed “Disney” on his iPad. A nonspeaking boy was delighted to ask for ice cream at school using his iPad. An autistic boy said “I love you” to his mother for the very first time by selecting the three words on his iPad. These are all moments to celebrate, but first words like these are just the start.

If your child is autistic and is nonspeaking or has minimal speech for communication, you should consider the use of a communication app. A robust augmentative and alternative communication (AAC) app could transform your child’s communication when you introduce it to your child with the right help.

AAC is anything we use to help us communicate that isn’t speech. You may have already used symbols or signs with your child. An AAC app lets children explore words in a new way that works for them, and can be especially effective if your child already uses a tablet or iPad.

Facts About AAC

There are still many myths about AAC that make parents fearful and uncertain about its use. The following are five important facts that parents should know about AAC.

- 1. You do not need to make a choice between AAC or speech.** You can do both! Using AAC can give a child a means of communication while still allowing the development of speech if that is possible for the child.
- 2. It is not necessary to start with paper-based AAC before moving on to high tech devices such as a communication app.** You can go straight to an AAC app and use paper-based AAC at the same time.

- 3. Use of a Picture Exchange Communication System (PECS) is not required.** In fact, we now know that a robust AAC app is more neurodiversity-affirming and has better outcomes for language and communication than such a system.
- 4. There are no prerequisites for getting started with AAC.** This means that your child is never too young to be introduced to an AAC app. If your child doesn't use a tablet yet, you can still get started by using the AAC app when you talk to your child.
- 5. It is not necessary to "teach" AAC.** Rather, it should be integrated into your everyday life as a way that you communicate. This allows children to see the power of what it could do for them.

Getting Started

When parents tell me they are scared about starting an AAC journey, I advise them that they shouldn't be intimidated by it. When you break down the steps, you can celebrate each milestone. It can be a joyful and exciting experience for you and your child.

While it's easy to get started straight away, there are a few things that parents should consider. It's best to seek some specialist advice to get on the right path.

Here are a few important points to help you get started.

- Your AAC app should be on a device that is only used for communication. This helps your child come to recognize that it can be his or her "voice."
- Most apps have a free trial period, including the following: Proloquo; TDSnap Lite, the free trial version of TDSnap; Coughdrop, which can be used on almost any device including Android devices; and Touchchat with Word Power 60.
- Don't instruct your child with phrases like, "You do this," "Point to this," "Show me this," "Where's this?" or "What's this?" This will slow down your child's progress towards using AAC for communication. There should be no expectation initially that your child will use the communication app.
- Value all communication. If you understand what your child means, do not ask him or her to say it with the iPad. All ways of communicating are valid.
- Give yourself and your child time. When you begin this journey, you and your child are starting on the path to communication success. Trust the process, but don't put pressure on yourself or your child. You've got this!

When you hear your child's first words or new words — however they are expressed — you will realize that AAC is not so scary after all.

Resources

- Follow me on Instagram [@hannahjoycommunication](#) and message me with any questions.
- You can ask for help from your SLT service for an AAC assessment.
- Look out for free AAC courses (e.g. <https://www.aacscotland.org.uk/modules/>).
- Check out the "Talking with Tech" podcast all about AAC!
- Join my 12-week individualized parent coaching programme 'Communicate with Joy.'



Hannah Joy Communication offers specialized support to families with children who are Autistic and have no speech or minimal speech for communication. The service, available online across the UK, focuses on helping children communicate effectively using innovative Augmentative and Alternative Communication (AAC) technologies.

The "Communicate with Joy" individualized parent program helps a child learn new words and communication skills within a dedicated three-month time frame. Hannah Joy Communication provides expert coaching aimed at transforming the lives of families dealing with communication barriers, using AAC solutions as a first line of intervention rather than a last resort.

Hannah has helped children and families with complex communication needs for 18 years within the NHS and now independently with her business Hannah Joy Communication helps parents transform communication for their child.

Hannah Joy Communication - Independent Specialist Speech and Language Therapist
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5 Possible Reasons Why Your Autistic Child is Not Sleeping

Lindsey Clark, BA (Hons), QTS



If you have an autistic child who struggles to fall asleep and stay asleep, you know it puts stress on the entire family. Studies have found that up to 80 percent of autistic children have issues with sleep. There can be many reasons for such issues, but rest assured that it has nothing to do with your parenting. You haven't done anything wrong and should not feel that it is your fault.

As the parent of an autistic child, you've probably wondered if it's even possible to have your child cooperate at bedtime or get a full night's sleep. In fact, this thought may cross your mind every day as bedtime approaches. You might have tried traditional sleep training techniques, exhausted Google, and turned to family and friends but found that nothing works. You may have been told that poor sleep is something that you just have to accept for your child and family.

As an autism and anxiety sleep specialist, I am committed to helping families get the sleep they need because I know it is possible. I've seen the detrimental effects that lack of sleep can have both physically and mentally on children and parents, and I refuse to accept that for your family.

In order for your autistic child to sleep well, you need to first figure out the root cause of the sleep issues. The following are the top five reasons why children struggle with sleep.

1 Over-connection Research has found that some of the brain pathways in autistic children are more widely connected with other parts of the brain than those in neurotypical children. This over-connectivity means they experience certain things with more intensity, which can make everyday situations feel overwhelming. Processing of information also takes longer for autistic children, and it is not easy for their brains to filter out unwanted information. The result is their brain swirls with information and can feel quite chaotic by bedtime. Naturally, this makes it much harder to fall asleep and stay asleep.

2 Stimulation Many autistic children experience sensory overwhelm or high anxiety, and this can build up during the day. If they haven't had opportunities to regulate and bring these levels back down again, they will be at their peak by bedtime. Children will be so overstimulated that they can't switch off and stay asleep. Sleep can also be affected when children have too much of one activity or not enough of another to meet their sensory needs. Every child's needs are unique. With autistic children, we need to think about what happens during the day before the bedtime routine even begins. Consider what you can put in place to ensure your child's sensory needs are met throughout the day so your child isn't seeking that input at night. Focus on activities that will help reduce the build-up of anxiety during the day so that your child is ready to sleep by bedtime. Discovering what works for your child can be the difference between a good night and a terrible night.

3

Circadian Rhythm

Autistic children's sleep patterns are often not typical for their age. They may wake up much earlier or fall asleep much later than expected. This is because their internal "body clock" - also known as the circadian rhythm - is not programmed in a typical way. While most people naturally feel sleepier at night and more awake during the day, this isn't always the case for autistic children. Their body interprets the exposure to day and night in a different way. As a result, it can feel like they are wired to a completely different time zone! This makes it quite a challenge to form day and night sleep patterns that are socially appropriate.

4

Environment

Your child needs to be relaxed and calm in order to sleep well. Most autistic children have very specific sensory sensitivities. If these triggers haven't been considered when designing their sleep environment, it's unlikely they'll be able to relax enough to fall asleep. Do a sensory check of your child's room to make sure it's not too cluttered, that there's nothing visual that will stop them from sleeping, and that they are comfortable with their bedding and clothing.

5

Melatonin

You may have heard that most autistic children produce lower levels of melatonin than neurotypical children. There is evidence to suggest that this is true. You might also know that melatonin top-ups can be given in supplement form. Melatonin production in most children starts to build in the late afternoon, so by evening they're ready to fall asleep naturally. However, this isn't the case for many autistic children. Since their melatonin levels are lower, they struggle to settle at night. You may also find that they are very restless, they fight sleep and they just can't seem to relax and switch off, which can be frustrating for everyone! If you are thinking about trying melatonin with your child, contact your pediatrician for advice and a prescription. Keep in mind, however, that melatonin supplements may help *some* children sleep better but they won't solve the root issue and are not a long-term solution to the problem.

Parents find it heartbreaking when their children are clearly exhausted but there's something stopping them from sleeping. They desperately want to help them but don't know how.

The root cause of your child's sleep problems could be one or more of the points mentioned above. Since sleep is complex, particularly in autism, it can be difficult to figure out the best approach. Being the parent of an autistic child is wonderful, but it also comes with many challenges. These are even harder to face when you're surviving on poor sleep. Recognize that you are doing the best you can, and remember to take care of yourself, too.

Conclusion

Parents of autistic children should try to identify the root cause of the sleep difficulties, contact a sleep specialist, provide sensory activities during the day so that children aren't seeking input at night, create a calm sleeping environment, and consider using melatonin under the direction of a healthcare professional. Rest assured that you don't need to power through this and accept that sleepless nights are part of the package for your family. There are specialist sleep solutions that can ensure your whole family gets a good quality night's sleep.


If you'd like help with your child's sleep, reach out to me and get in touch. We can have a chat about what's happening, and I'll let you know a bit more about how I can help you and your family get the sleep you deserve!



Lindsey Clark, BA (Hons), QTS, is Founder of Peaceful Sleep Secrets. Based in Hampshire, England, she has been working with young children and babies her whole life and is a former deputy headteacher of a large infant school. After having her own children, who both struggled with sleep, Lindsey retrained as a sleep consultant and launched her own sleep consultancy. After she realised the lack of support available for parents of autistic children and saw her eldest child on the pathway to diagnosis, she made the decision to train as an autism and anxiety sleep specialist. Her expert knowledge and first-hand experience mean she is able to support families using gentle, bespoke approaches so that autistic children get long-lasting quality sleep. She has successfully helped improve sleep for hundreds of families worldwide through her 1-1 packages, group support programs, courses and workshops.

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A close-up photograph of a hand holding a black pencil, writing on a lined notebook. The background is softly blurred, showing more of the notebook and a warm, golden light source, possibly a lamp, creating a cozy and focused atmosphere.

Dear Parents, Your Child Is Waiting to Surprise You

Amanda Harrinauth

I am writing to you as a 34-year-old autistic adult. I spent the first 26 years of my life oblivious to what was really happening. I was diagnosed with retinopathy of prematurity and congenital hydrocephalus, or water on the brain, at birth. Growing up with both of those conditions made life challenging.

The hydrocephalus demanded so much of my attention. I was in and out of the hospital for the first 18 years of my life. There was nothing I could do to avoid the many brain surgeries. In fact, I required 21 brain surgeries to save my life.

I also dealt with frequent visits to the eye doctor to check my vision. As you can imagine, growing up legally blind was frightening. I was constantly anxious and crying. Navigating my way through the educational system was a recurring nightmare. After graduating from high school with a diploma and completing three years of college, I thought life would slow down.

I was mistaken. Nothing could be more frightening than hearing the words, "You have autism." Even though I wasn't a child anymore, I wept as I waited for my parents and older sister to make it better and possibly make it go away. Reality hit me hard and fast because I learned there was no cure for autism. I was officially in this community.

I decided to jump in. I began watching videos of mild cases of autism, and then I viewed some more severe cases. I cried while watching the videos of kids hitting their heads because they were unable to vocalize, dress themselves or feed themselves. Looking back now, I see autism as a blessing. Autism comes in many different forms.

At one point, I reached a fork in the road. If I turned right, it meant I was just going to be another stereotype; if I turned left, it meant the possibilities were endless. I stood at that fork in the road for about three months. I was officially diagnosed on April 16, 2016, and I was just waiting to see what my future held. By June of that year, I was still crying about my diagnosis.

After those three months of standing still, my life began to make sense. It was like putting the pieces of the puzzle together and seeing a picture take shape. One morning before work, I found myself crying on my bathroom floor. Instead of grabbing a box of tissues, I grabbed my phone and began to write.

I was releasing my pain and shame. I turned my pain into poetry.

Many parents are probably wondering why I am telling my story or why it is important. I want parents to know that every autistic child has a gift. It's a gift like no other. When I found mine, it was like finding the key to a beautiful golden locket. It was finally time to open it and read the inscription. I think that inscription would read:

Hi, Amanda!

It's nice to finally meet you. My name is autism and we are now lifelong partners.

Sometimes, it is going to be difficult and emotional. Other times, it will be filled with joy and inspiration. I will help you write beautiful poems and speak to millions.

Sincerely, your friend Autism

It's important to remember that every child is different, and everybody's future is not determined by this diagnosis. Yes, there are stories of autistic children going through difficulties, but there are many other stories of triumph and victory. Just like Dr. Steven Shore says, "When you've met one person with autism, you have met one person with autism." Autism does not determine people's future unless they allow it to.

Last year, I thought I would never write again. I experienced severe grief after the passing of a very good friend. In addition, another male friend was hospitalized for an extended period of time, and one of my best friend's began to experience seizures. I struggled so much emotionally that I stopped writing. My heart felt heavy. My two friends who were hospitalized had always been the ones encouraging me to keep going. It was a very long and emotional road. While my friend was recovering at home, he asked me a very simple question: "Did you ever think about starting to write about your grief and pain?"

I had never thought about it. I figured that if I wasn't forced to confront it, it would just continue to consume my soul.

I wanted to begin writing again. Later that night, I composed my poem called, "It Happened All at Once." The poem was earth-shattering to write but cleansing for my soul.

Dealing with these experiences was extremely difficult, but it feels like it is 100 times worse with autism. Our emotions are all over the place, but we must find our calm space. In my case, I would seek out God and become immersed in my Bible. The autism journey is like a roller coaster with ups and downs, and twists and turns. But let's face it, we can all enjoy this ride if we choose to.

Dear parents, your child might have autism but he or she is just waiting to surprise you.



Amanda Harrinath lives in the San Francisco Bay Area. She works with the Special Olympics North America, where she is the representative for the Southwest region of the United States. For work, she is a freelance writer. She has written for various autism publications and continues to share her story on various mediums including podcasts.

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It Happened All at Once

It happened all at once.

To my first friend, I woke up one day to realize you were gone and I couldn't handle it.

We had eight years of magic and friendship.

I feel it wasn't enough time for us.

Your beautiful smile still remains in my heart and your Brooklyn accent will forever be a part of the legacy that you created for those with disabilities like me.

I feel like a shadow of my former self, not being able to text you anymore.

To my second friend, when I received your text, it was too much for me to deal with.

My heart shut down to hear that you were being hospitalized once again,

not knowing if you would ever regain your speech.

Although we never said "I do," I don't want to go through life without you.

And finally, I have words for my third friend.

The pain remains in my soul, to surrender to the aches and pains that you are feeling from illness.

You are cancer-free, thank God. I love you so much.

I am so glad I can still feel you here with me.

You are my sister.

I cherish what's happening with my friends because they are more like my family.



The Benefits of **BodyWalking** for Autistic Individuals

**Tod Miller, BFA, LMT, Founder,
BodyWalking Institute**

BodyWalking is an enhanced therapeutic extension of massage therapy in which practitioners use their calcaneus (heel), metatarsal head (toes) and lateral longitudinal arch (sole of the foot) to BodyWalk a client. It uses six different foot positions for specific therapeutic results and is based on ischemic compression therapy, or trigger point release massage. Trigger point does have some attributes of BodyWalking. BodyWalking uses site-specific therapeutic compressions with each compression lasting 15 to 20 seconds. The client is clothed during the BodyWalking session, and the BodyWalking practitioner wears BodyWalking socks.

All BodyWalking patented steps are designed for the specific therapeutic purpose of relaxing muscular contractions. Each compression causes a slight decrease in blood flow in the part of the body being BodyWalked. When the BodyWalking practitioner moves to another part of the body, the release causes a major enhancement in circulation in the area that was just BodyWalked. The result is overall muscle relaxation. While the same effect occurs with regular massage, the intensity is slightly reduced while the releasing of the muscle is increased.

One major benefit of BodyWalking is what is known as the “weighted blanket effect.” The pressure from a weighted blanket is believed to simulate the feeling of a gentle hug, which triggers a release of serotonin and dopamine that can contribute to increased relaxation. BodyWalking provides the same effect. By compressing site-specific muscles for 15 to 20 seconds, BodyWalking allows clients to relax during the session. The relaxation is so effective that the client will often fall asleep. BodyWalking has a unique ability to get very deep into the muscle which allows for overall muscle and body relaxation.

The overall effect of BodyWalking is to increase circulation, reduce stress and allow the entire nervous system to relax. This, in turn, can reduce symptoms of anxiety, improve sleep quality and relieve symptoms of depression. Numerous clients report that it helps them to “just let go.” BodyWalking allows the body to let go of any pent-up physical and emotional stress held in the muscles and soft tissue.

As a therapeutic practitioner since 1989, I have had the wonderful experience of working with many clients with autism, as well as those with Parkinson’s and PTSD. One mom told me that, before starting BodyWalking, her son would never lie still. After the therapy, her son’s response was, “BodyWalking, let’s do it again!” When I received my first therapeutic massage at age 19, I personally felt the tremendous benefits of a skilled therapist and the power of touch. As someone who has completed over 30 Ironman competitions, I have found that BodyWalking offers highly therapeutic results for my enhanced muscular recovery and helps me live up to my committed daily performance.

If you think your autistic child could benefit from BodyWalking, please visit: <https://www.bodywalkinginstitute.com/>



Tod Miller, BFA, LMT, received his first massage at the age of 19 and knew it could change the world, at least it could change Tod’s world. Therapeutic massage and other healing modalities have helped Tod accomplish 30+ Ironman competitions and live day to day pain-free while also increasing his overall wellness. As the Founder of the BodyWalking Institute, he was working with a swim club mom and she asked if Tod would work on her Autistic son. Long story short, the son loved it and Tod’s work opened up to helping autistic individuals. Tod has two children and a wife of 24 years. He is a proud University of Arizona graduate and the owner of multiple spas in the Scottsdale, AZ, area.



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Research Shows LITERACY ABILITIES in Many Nonspeaking Autistic Individuals



This article is a review of the following research: Jaswal, V. K., Lampi, A. J., & Stockwell, K. M. (2024). Literacy in nonspeaking autistic people. *Autism: The International Journal of Research and Practice*, 13623613241230709. Advance online publication.

The latest research indicates that 25 to 30 percent of autistic children are nonspeaking.^{1,2} Many of these children use other communication strategies, including the Picture Exchange Communication System (PECS), gestures, letter boards and communication apps. It is not entirely clear why about one-third of autistic children are nonspeaking. Some experts suggest it could be due to motor differences, sensory or emotional overload, or language-processing differences.

When individuals are nonspeaking, many societal assumptions come into play. Unfortunately, some might assume that nonspeaking individuals do not understand what others are saying to them, or that their cognitive abilities are low. This leads to nonspeaking autistic children being underestimated and excluded, which can also limit their educational, employment and social opportunities.

In recent decades, many cases have been documented of nonspeaking individuals who are able to read and are highly intelligent. One such example involves the nonspeaking adult son of Judy Chinitz, a special education teacher. When Judy's son was 25 years old, she discovered that her son actually had normal language and exceptional intelligence despite her belief that he had a severe cognitive disability (<https://www.mouthtohandlearning.com/>).

Researchers from the University of Virginia conducted a study to investigate the literacy abilities of nonspeaking autistic individuals.

Study

This study recruited 31 nonspeaking autistic adolescents and adults, almost all of whom were currently participating in speech therapy.

For the study, each participant was required to play a game on an iPad in which letters were highlighted one at a time. As soon as a letter was highlighted, the participant was asked to tap on that letter as quickly as possible. Some trials had letters of the alphabet that spelled out a sentence, while others involved meaningless letter sequences.

A	B	C	D	E	X
F	G	H	I	J	!
K	L	M	N	O	?
P	Q	R	S	T	.
U	V	W	X	Y Z	Done

The researchers identified three indicators that would show a person is able to spell. Such a person would: tap the highlighted letter faster when the letters spelled out words and sentences; tap the highlighted letters faster when the letters usually go together in the English language, such as the letter “h” which is more often followed by the letter “e” than the letter “s”; and pause before tapping the first letter of a new word, which indicates the person knows when one word ends and a new one is beginning.

RESULTS

16
of the 31 participants
showed a pattern
consistent with literacy

The results showed that 16 of the 31 participants showed a pattern consistent with literacy. They tapped highlighted letters more quickly when words and sentences were being spelled, tapped highlighted letters faster when it involved two letters that commonly co-occur, and paused at the end of words.

The authors felt it was important to note that the 15 participants who did not show patterns of literacy could still have an understanding of literacy but were just not able to demonstrate it on this particular task.

Conclusion

These findings suggest that nonspeaking autistic individuals are likely underestimated in their literacy abilities. Although they may not be able to speak, they are able to learn and understand the foundational skills of literacy, as well as the conventional spelling system of a language, in this case, English.

The results of the study point to the need for changes in our approach to teaching literacy. The current methods of teaching it rely heavily on speech. For example, teachers show students how to sound out letters and words. If professionals were to take as a given the fact that nonspeaking autistic children are literate, they could use different approaches that would allow such children to communicate their thoughts, feelings and ideas. One emerging approach is known as “Spelling to Communicate” (S2C). It is specifically designed for individuals with significant speech and motor challenges, such as nonspeaking autistic individuals. With advanced and specific instruction and support, many nonspeaking individuals could be able to communicate more effectively and shed the stigma of having low cognitive abilities.

It is worth noting that autistic individuals were involved in designing and carrying out this study. Autistic informants, family members of autistic people and experienced clinicians who support non-speaking individuals were also involved in the study to ensure neurodiversity-affirming practices.

This research highlights the societal issue of underestimating the literacy abilities of nonspeaking autistic individuals. Moving forward, it is vital that professionals explore and implement communication approaches that empower these individuals, dismantle societal assumptions, and foster inclusive opportunities for education, employment and social engagement.

The study that has been reviewed in this article can be found here:

<https://journals.sagepub.com/doi/10.1177/13623613241230709>

Written by Autism Advocate Parenting Magazine

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1. Brignell, A., Chenausky, K. V., Song, H., Zhu, J., Suo, C., & Morgan, A. T. (2018). Communication interventions for autism spectrum disorder in minimally verbal children. *The Cochrane Database of Systematic Reviews*, 11(11), CD012324.
2. DiStefano, C., Shih, W., Kaiser, A., Landa, R., & Kasari, C. (2016). Communication growth in minimally verbal children with ASD: The importance of interaction. *Autism Research: Official Journal of the International Society for Autism Research*, 9(10), 1093–1102.

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TANDEM REPEATS

New Insight into the Genetics of Autism

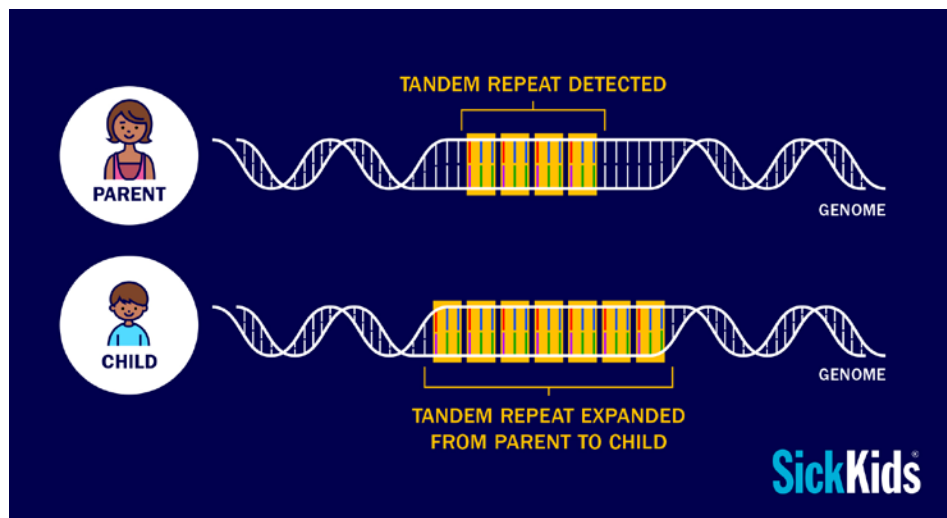
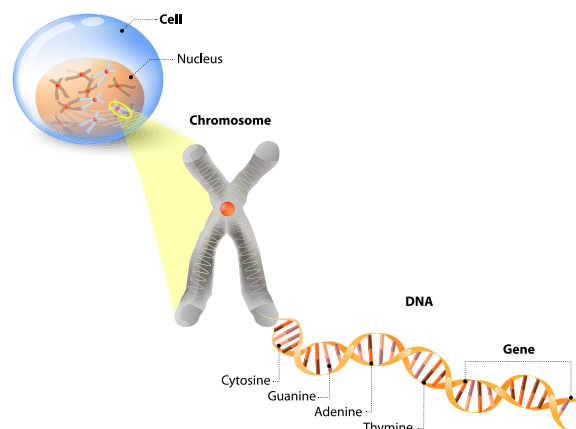
This article is a review of the following research: Trost, B., Engchuan, W., Nguyen, C.M., et al. Genome-wide detection of tandem DNA repeats that are expanded in autism. *Nature*. 2020 Oct;586(7827):80-86.

Research led by Dr. Ryan Yuen (The Hospital for Sick Children, Toronto, Canada), has unveiled genetic insight into autism.

DNA is constructed of building blocks called nucleotides. There are four nucleotides: Adenine (A), Cytosine (C), Guanine (G) and Thymine (T). These nucleotides are joined together one after another.

A *tandem repeat* in the DNA occurs when a group of nucleotides is repeated over and over again (e.g., CGG CGG CGG CGG, etc.). While tandem repeats are common in our DNA, a tandem repeat sometimes can be expanded when parents pass their genetic code to the child.¹ This expanded tandem repeat can cause functional complications.

For example, there is a region of tandem repeats on the *FMR1* gene. This repeat (CGG) normally occurs 5 to 45 times. However, if the CGG repeat is passed from the parent to the child and repeats 200 times or more, this will result in a genetic condition known as Fragile X syndrome.² Fragile X syndrome is characterized by hand flapping, poor eye contact, impulsive behavior and anxiety, and is often accompanied by autism.



This image is a demonstration of tandem repeats found in DNA and how they can be expanded from parents to children. *This image was re-printed with permission. <https://www.sickkids.ca/en/news/archive/2020/sick-kids-scientists-discover-novel-genetic-contributors-to-autism/>

The Study

Dr. Ryan Yuen and his team wanted to further investigate the relationship between tandem repeats and autism. Up until now, it was only possible to look at tandem repeats in one gene at a time. With over 30,000 genes and an estimated 1 million tandem repeats in the entire human genome, this would be a very difficult and tedious task. However, Yuen's team developed an analytic approach that could find tandem repeat expansions in the entire genome.

The research team applied the approach to 1,558 autistic individuals, 3,636 families with one or more autistic individuals in the family, and 2,504 control individuals.

RESULTS

The data revealed 2,588 rare tandem repeat expansions that were more prevalent in autistic individuals than in their unaffected siblings.

While 57.7 percent of the tandem repeats were already known to be present in the genome, the other 42.3 percent had not been previously reported.

The new genes identified included those involved in the development of the nervous system, the cardiovascular system and muscle tissue. These include the following genes: *DMPK*, *FGF14*, *CACNB1*, *FXN*, *CDON*, *MYOCD*, *MBOAT7*, *ILIRAPL1*, *FMR1* and *IGF1*.

The individuals with expanded tandem repeats in the genes listed above were associated with intellectual and adaptive disabilities.

Future Directions

Genetic testing is becoming more common for those diagnosed with autism. With Yuen's new analytical approach, genetic testing can be improved and more questions can be answered. With better answers, support for autistic individuals can be improved and individualized.

Yuen's research shows that rare tandem repeat expansions play a role in autism. Yuen's research opens a door to further understanding the complexities of autism in hopes of providing more answers and optimizing supports.

Written by Autism Advocate Parenting Magazine

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1. Bahlo, M. et al. Recent advances in the detection of repeat expansions with short-read next-generation sequencing. *F1000Research*. 7, 736 (2018).
2. Hagerman, R. J. et al. Fragile X-associated neuropsychiatric disorders (FXAND). *Frontiers in Psychiatry* 9, 564 (2018).

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Autism Advocate Printable Resources

The Benefits of Coloring Mandalas

Given the heightened levels of anxiety that many autistic children experience, it is important for parents to use effective strategies and coping mechanisms to navigate the challenges that come with their children's anxiety. One strategy that can be helpful is coloring and tracing mandalas. Mandalas are intricate geometric designs that are common symbols in Buddhism and Hinduism. These visually appealing creations can help manage anxiety, calm an overstimulated child and promote the development of fine motor skills.

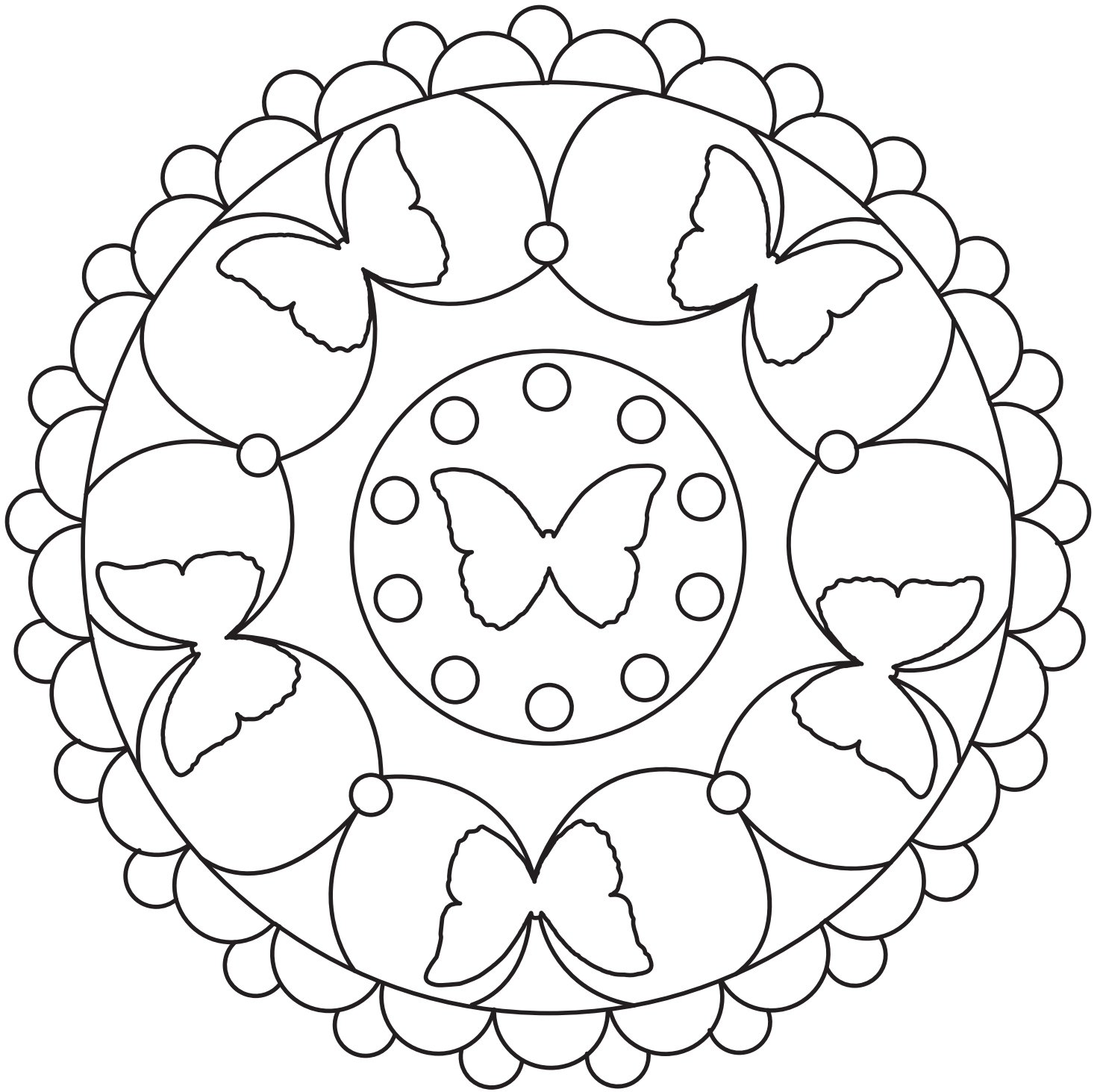
There are a number of reasons why mandalas can be effective coping tools for autistic children.

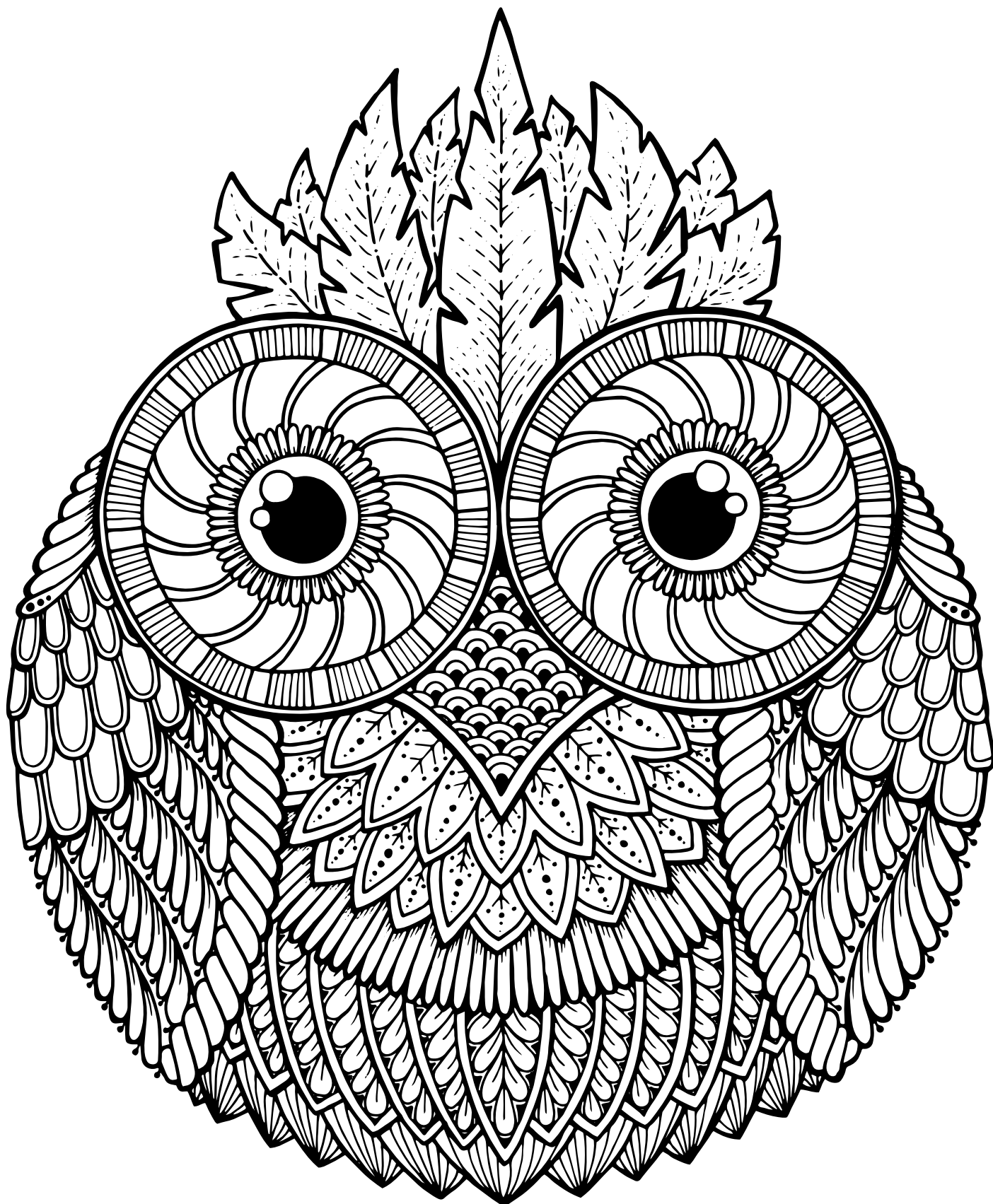
- Autistic individuals thrive on structure and predictability, and mandalas inherently provide these elements. Engaging in the repetitive, rhythmic motions of coloring or tracing mandalas can have a calming effect and can help regulate arousal levels and reduce anxiety.
- As visual learners, autistic children are often drawn to the geometric precision of mandalas. They find peace and calmness in the structured activity of coloring or tracing these designs.
- Mandalas can provide a soothing sensory experience, especially when combined with tactile elements like textured paper or specialized coloring materials. Put a drop of essential oil on the paper and make the sensory experience even more exciting.
- Mindfulness is a technique used by many autistic individuals. Mandalas can promote mindfulness by encouraging focused attention on the present task, such as coloring or tracing intricate patterns, thus facilitating a meditative state. This mindful practice promotes relaxation, stress reduction and emotional regulation.
- The act of creating mandalas offers an opportunity for the development of fine motor skills. As children manipulate coloring tools and navigate intricate designs, they are able to refine their hand-eye coordination, grip strength, and precision.
- Completing a mandala instills a sense of accomplishment and mastery, which can build self-esteem and confidence in autistic children. Witnessing the transformation of a blank circle into a vibrant, colorful design serves as evidence of the child's efforts and creativity.

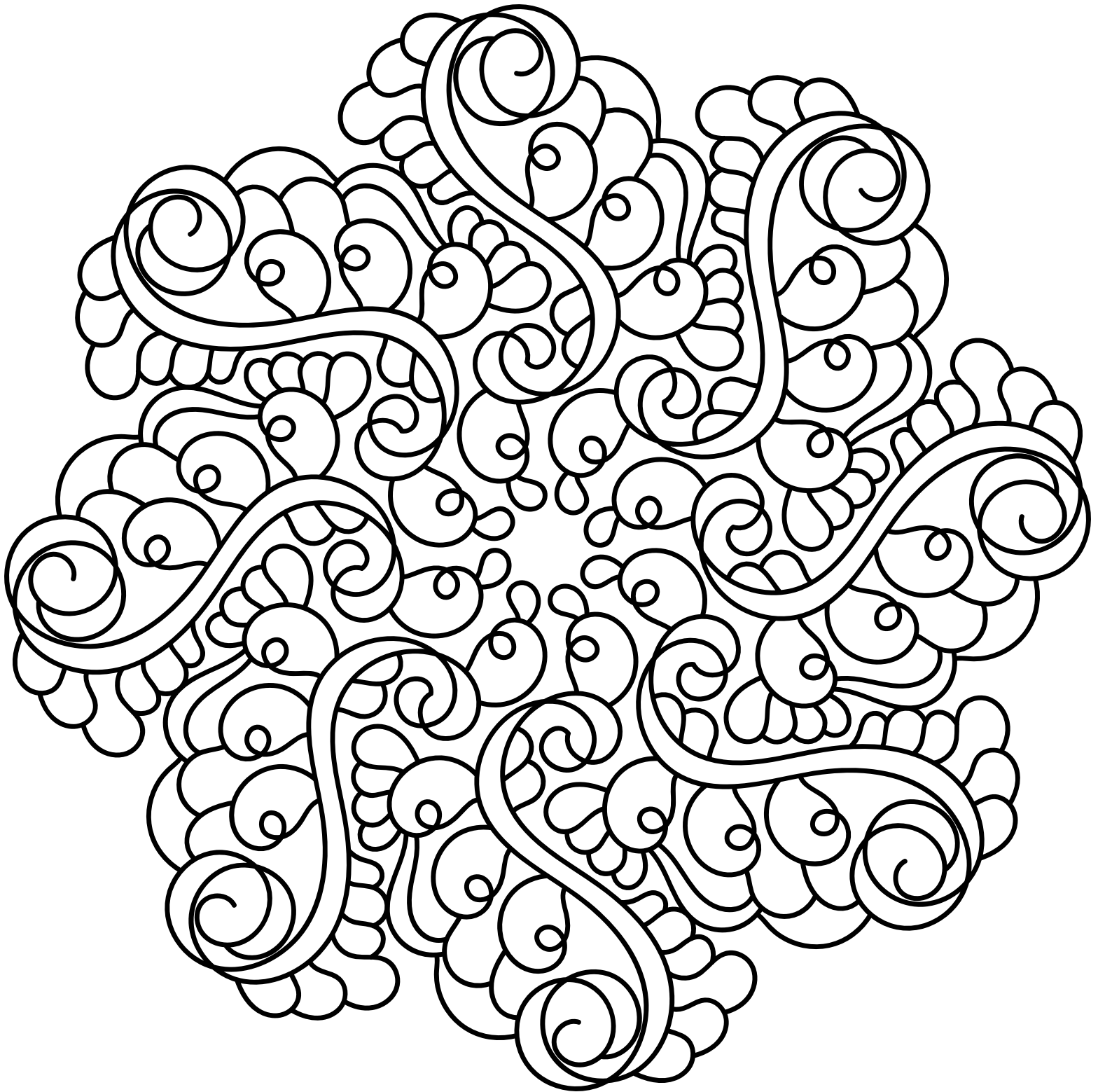
Instructions for Coloring a Mandala

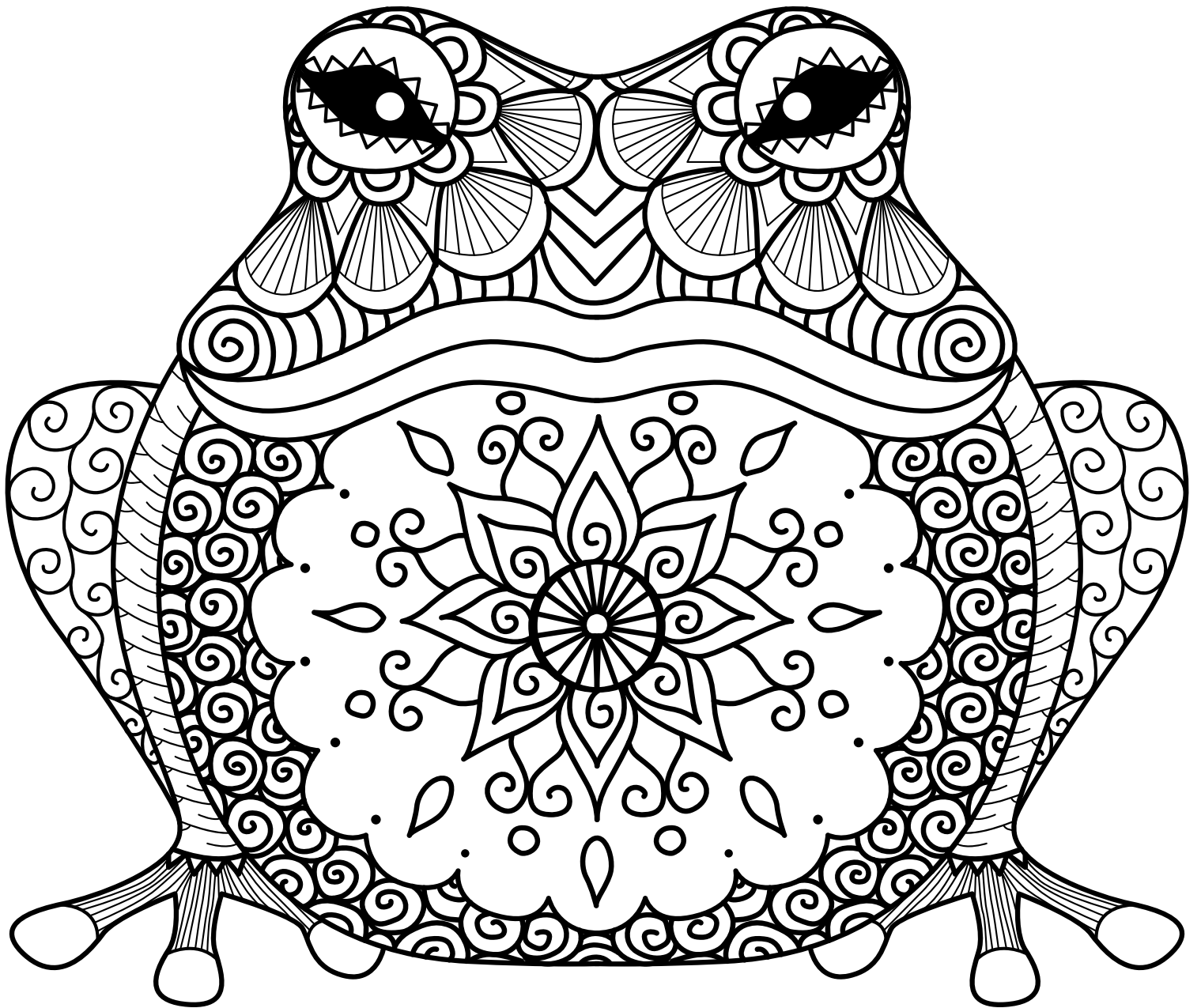
1. Print mandalas that match your child's abilities.
2. For a sensory experience, print the mandala on textured paper or put a drop of essential oil on the paper. Calming oils include lavender, orange, sandalwood or a serenity blend.
3. Provide a variety of coloring tools, such as markers, pencil crayons, crayons, colorful pens and sparkly pens. You could even use scented markers. Provide tools that are appropriate for your child's age and abilities.
4. Allow your child to color for as long or as short a time as he or she would like.
5. Once your child has colored a few mandalas, ask if he or she would like to try and make his or her own design.

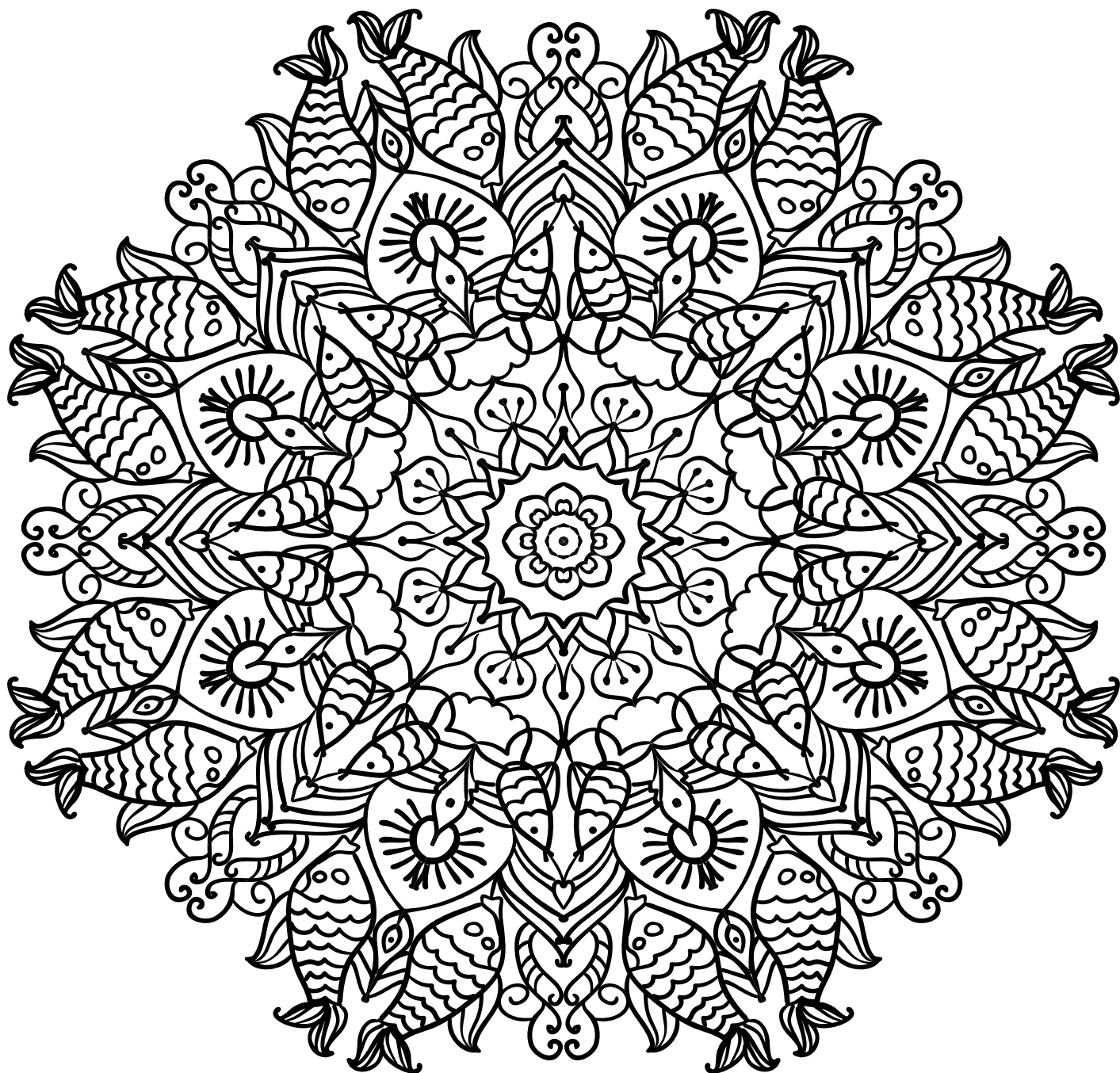
Mandalas offer a multifaceted approach to supporting autistic children's coping and development. Their structured format, sensory appeal, mindfulness benefits and manual dexterity opportunities allow mandalas to empower children to manage anxiety while enhancing their fine motor skills. By integrating mandalas into therapeutic interventions and daily routines, caregivers and educators can nurture resilience, relaxation and motor proficiency in autistic children.











AUTISM ADVOCATE

PARENTING MAGAZINE

Social Story Printable

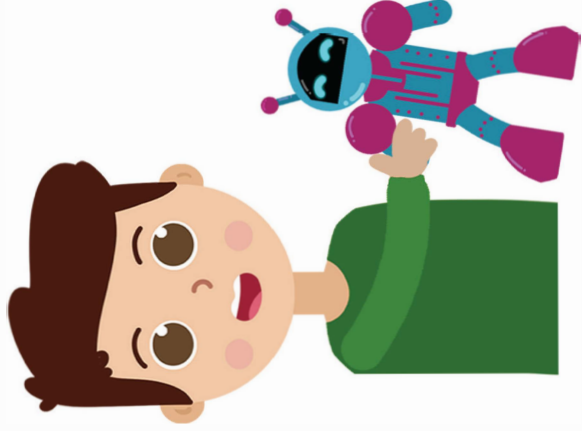
INSTRUCTIONS

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.

My Social Story:

I CAN PICK UP MY TOYS



1



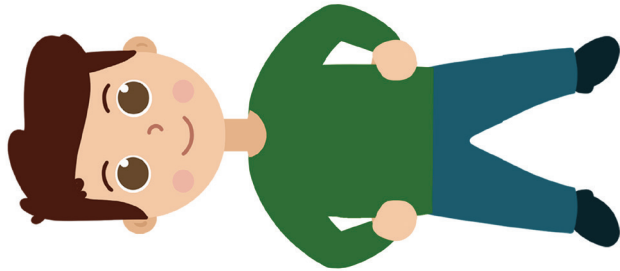
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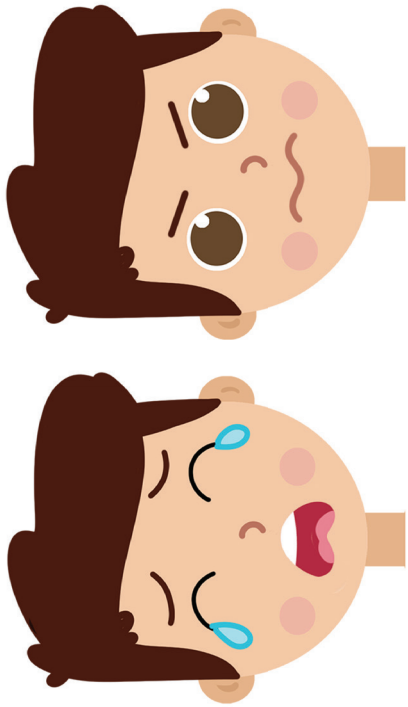


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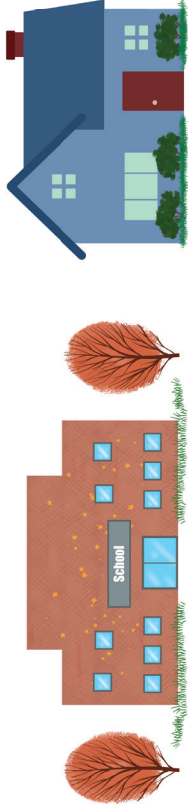
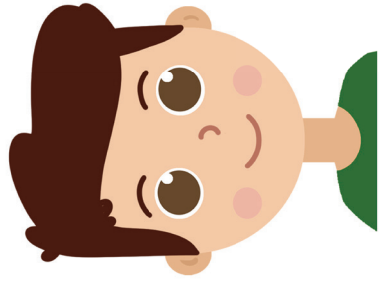


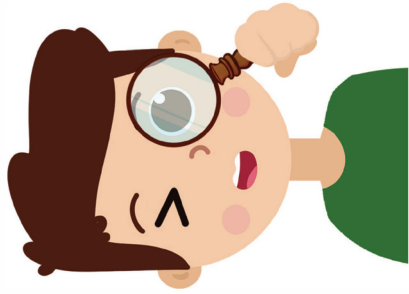
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4



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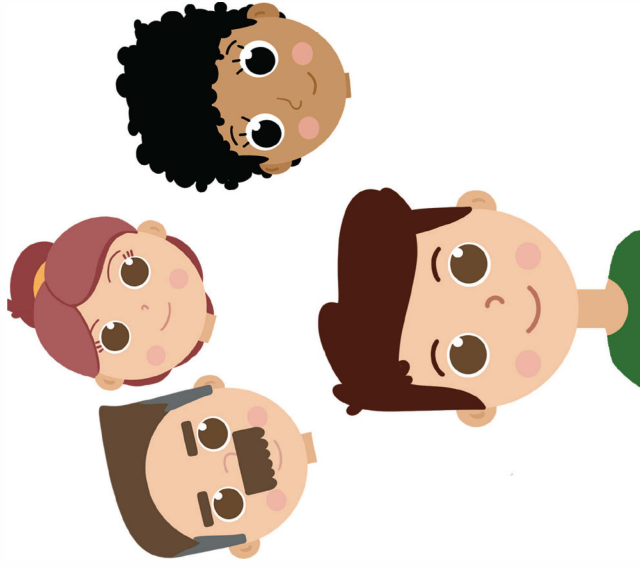
I like to clean, clean,
clean up my room.

I like to clean, clean,
clean up my room

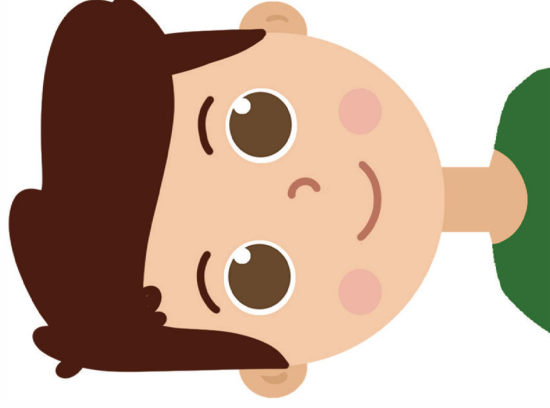
I like to tidy up my toys,
and clear up my clutter.

Yes I do!

9



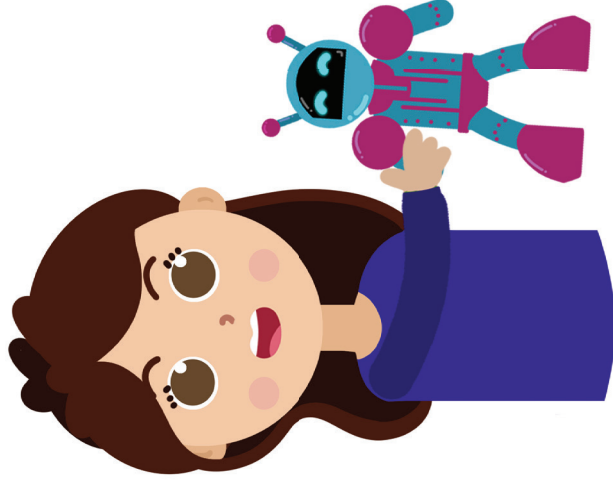
10



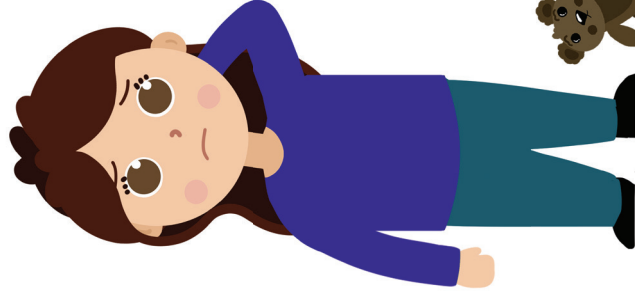
11

My Social Story:

I CAN PICK UP MY TOYS

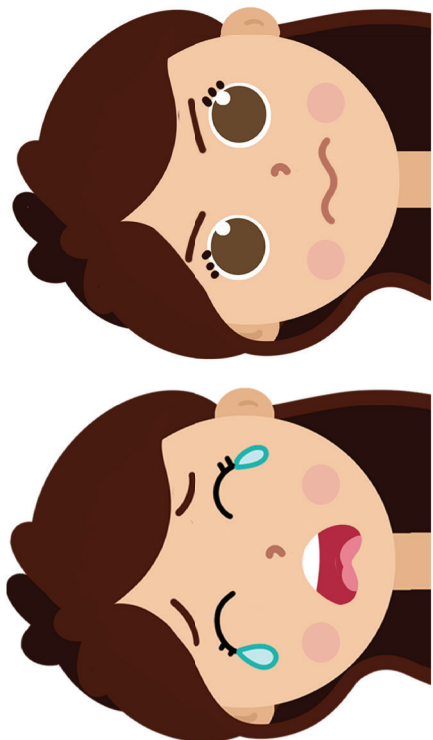
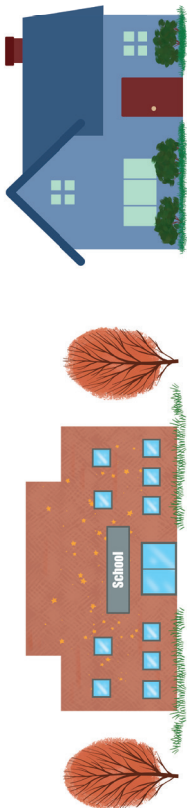
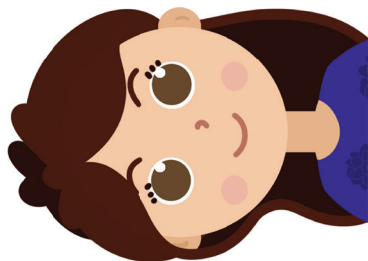


1



2

3





I like to clean,
clean,
clean up my room.

I like to clean,
clean,
clean up my room

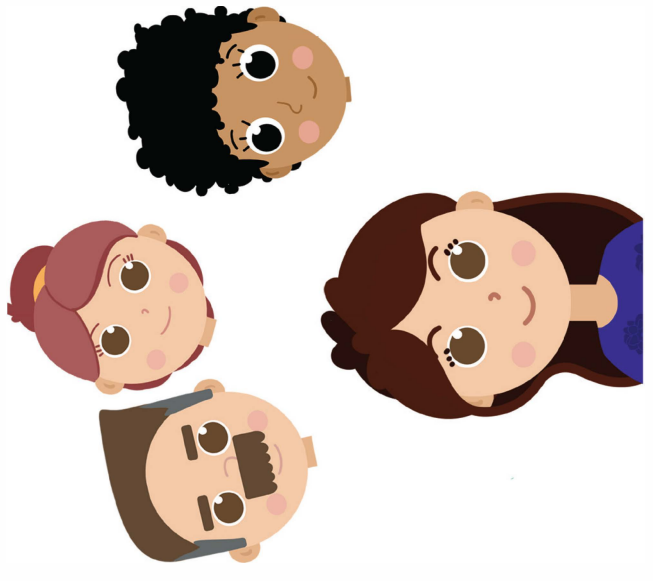
I like to tidy up my toys,
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Yes I do!

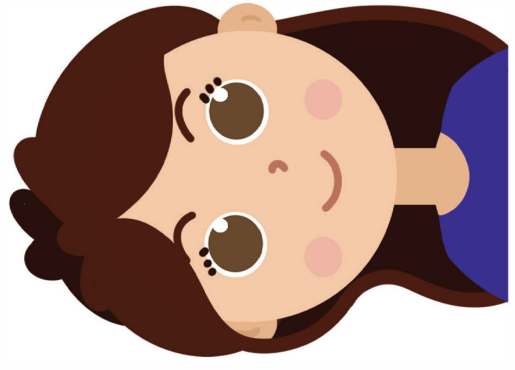


8

9



10



11

My Next Steps

Knowledge Combined with Action is a Key for Success.

What inspired me?

What is something new I learned?

Items I want to research further:

Items I want to discuss with my Autism Support Team:

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

Items I would like to implement/notes



You were not made to be
PERFECT.

You were made to be
AUTHENTIC.

Embrace your real life and
FIND JOY IN IT.

— Angie Kaffman



FOR PARENTS & PROFESSIONALS

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