# September 2021 AUTISM ADVOCATE PARENTING MAGAZINE

### The Molecular Blueprint of Autism

# **Videogame Addiction**

PAGE 9

# **Supporting Siblings**

PAGE 20

### How to Promote Positive Behavior and Reduce Stress

PAGE 14

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Dear Parent Advocate or Reader:

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

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



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### AUTISM ADVOCATE IN THIS PARENTING MAGAZINE September 2021







# ISSUE

#### **Features**

- HOW TO STAY CALM WHEN YOUR CHILD IS b HAVING A MELTDOWN Kate Lynch
- THE MOLECULAR BLUEPRINT OF AUTISM 9 Dr. Rene Anand
- HOW TO PROMOTE POSITIVE BEHAVIOR AND 14 **REDUCE STRESS IN THE HOME** Dr. Brian McClean
- EARLY DETECTION AND EARLY INTERVENTION -17 WHAT EVERY PARENT SHOULD KNOW Lisa Kota
- THE SUSCEPTIBILITY OF CHILDREN, 20 ADOLESCENTS AND YOUNG ADULTS WITH AUTISM TO VIDEOGAME ADDICTION Dr. Jay H. Berk
- INTEGRATING YOUR CHILD'S ASD DIAGNOSIS 23 INTO YOUR FAMILY - SUPPORTING SIBLINGS Dr. Leslie Speer
- TRAVELING WITH AUTISM 26 Andrea Auger
- ADVICE FOR PARENTS RAISING A CHILD ON 29 THE SPECTRUM Murphy Lynne
- PARENT ADVOCATE ADVICE

#### Research

- THE RELATIONSHIP BETWEEN SLEEP AND 32
  - SENSORY SENSITIVITIES IN CHILDREN WITH AUTISM
- 34 THE TEMPLE GRANDIN GENOME

#### **Printable Resources**

37

HOW TO USE VISUALS TO SUPPORT YOUR CHILD'S PLAY SKILLS Melissa Yapp

- **GLUTEN-FREE & CASEIN-FREE: 40 OVEN PANCAKES** 
  - SOCIAL STORY: GOING OUTSIDE FOR RECESS
- 48 **MY NEXT STEPS**

# How to Stay Calm when your Child is Having a Melteom

FIVE MINDFULNESS STRATEGIES To find your own center During the storm

Kate Lynch

It is possible to maintain empathy and harmony in the most challenging moments. I've done it. I don't always succeed but I have done it, so I know it is possible.

I'm a meditation coach and an inclusive yoga teacher. I've been advocating for my autistic son for nearly 10 years and teaching atypical families for 20 years. I specialize in using breath patterns, mindfulness and gentle yoga to build resilience to anxiety. My practice has helped me become more present and patient with my family, and with myself.

How do you stay calm when your child is having a meltdown? Avoiding a child's triggers is ideal, but we all know a meltdown will happen eventually. If you can learn emotional self-regulation and some mindfulness tools, I believe you will be happier and less anxious. You will also be better able to handle the emotional outbursts when they happen. My hope is that the crises won't feel so dire and debilitating.

#### Your Child's Meltdowns

Can you remember the last time your child had a meltdown? How did you feel? Is it a blur? Did you go numb? Did you freeze, scream, grab, run and hide, or hold your breath?

I've done all of those things and it didn't go well. I have come to realize that when my child has a meltdown, I need to change the one person which I do have control over: myself. I've slowly trained myself to call upon mindfulness and compassion during a meltdown.

Mindfulness means paying attention, on purpose, without judgement. Compassion encompasses mindfulness, as well as caring and an urge to relieve suffering.

#### Mindfulness and Compassion: The Two Pillars of Awareness

Try the following in order to practice mindfulness and compassion.

First, recognize what is right in front of you, without trying to change anything. Accept what is true in the moment, taking it in without judgement. Detachment doesn't mean complacency. Accepting the truth is a first step towards change. When you see what's happening, you have a chance to shift the dynamic.

Have you ever stared out a window without really seeing the window? Have you had that moment when you focus on the window and notice a smudge or something distorting your view? That moment of focus is something you can't undo. What if you didn't judge the smudge or wipe it away immediately? What if you simply noticed the effect it had on your view? Would you be able to see a little more clearly? That clarity is an example of mindfulness, which isn't for escaping our feelings or shutting out the world. Equanimity happens when we can be with what is, without judgement.

Second, recognize how much you care. The reason that your child's meltdowns are stressful to you is because you care so deeply about him/her. I care about my family and long for harmony. I dare to desire joy and contentment for our atypical family, including for myself. In your moment of recognition, you might place a hand on your heart and remind yourself, "This isn't my fault," or "I am not alone." When we feel common humanity with other parents, we can eradicate shame. Nothing is beyond the reach of our compassion.

#### **Apply Mindfulness Techniques During Challenging Parenting Moments**

A regular self-care practice will build neural pathways you can rely on during a crisis. Then, your child can rely on you to help them co-regulate.

Practice mindfulness techniques when things are calm. Then, practice when you feel slightly triggered or annoyed. The next step is to practice after a meltdown when the dust has settled. Finally, the day will come when you can call on simple mindfulness techniques at the peak of your child's meltdown.

Once I had mastered this process, I was surprised by how close I felt to my son in the moment of a meltdown. I had feared that distancing my emotions from him would cause me to feel cut off from him. Surprisingly, that was not the case. I was able to be with him with more tenderness and perspective because I held on to my center. I was fully present.

# **5** Simple Mindfulness Strategies

I have found the following five mindfulness strategies to be helpful in dealing with meltdowns.

### Affirmation

Repeat a short phrase that resonates with you and which reminds you of your **parenting values**. For example, "We've got this," "It's not an emergency," or a single word like "Patience" "Kindness" or "Love." Choose your affirmation. Say it out loud. Write it down ahead of time, and put it somewhere you will see it often. Remember what's most important.

# **3** Self-Regulate

Self-regulation is not always easy. Name what you're feeling right now. Notice where you feel it in your body. Then, think of something for which you're grateful. See if that can help you shift your own energy to calm. Remember that you are the adult, and your child relies on you to co-regulate.

### Move

Ground yourself in your body. Reach up, rock, jump up and down, shake your hands out, hug yourself, rub your shoulders, tap your chest or wiggle your toes. Do **something** to ground yourself in your body.

### Self-Compassion

Recognize that this is hard and that the meltdown will be over soon. Remind yourself that you're not alone. Other parents also feel this way. Remember that it isn't your fault. Put a hand on your heart. Be as kind to yourself as you would be to your best friend.

### 5 Breathe Out Slowly

Paying attention to your breathing can shift your nervous system. Imagine you are fogging up a mirror as you slowly exhale. Take twice as long to exhale as you do to inhale. Put a hand on your belly if it helps you connect to your breathing. If you remember nothing else during your child's meltdown, remember to breathe consciously.

Remember that these are for **you** to practice, not your child. If they are curious and want to try also, that's fine. Please keep the focus on yourself.

Along with these five strategies, consider the following principles to be nonnegotiable.

- **Safety** Remove everyone from harm's way, including yourself. Stop your child from hurting anyone. Deep down, your child really doesn't want to cause harm. In public, *"walk, don't talk"* to get away from judgment and misunderstanding. Shielding your child from ignorant onlookers might be a higher priority in some communities than in others.
- **Respect** You and your child are partners in life and can learn from each other. You both matter. Model using a respectful voice. If your child says something rude, remember that he/she may have difficulties communicating in the same way you do. Try not to take what is said personally, especially in the middle of a storm. When an individual is dysregulated, his/her brain cannot process language as well.
- **Trust** Your child wants to do what's right. With your help, he/she will learn to self-regulate within his/her developmental ability. It can help to know that other families have these challenges too. Trust that, over time, the trend is moving in the right direction.

#### After the Meltdown: Repair

During a meltdown is **not** the time to teach. **After**, when the dust has settled, you can soothe, touch, take responsibility, apologize and forgive. Then, see what you can **both learn** from the event together. Whatever arises, no matter how challenging, can help us grow.

It might seem easier to not think about what happened until the next meltdown. In the long run, however, talking about what happened can be healing for everyone involved. This doesn't mean assigning blame. We can listen to each other and see what solutions come up. We can model taking responsibility for our part in the situation.

Anything that is mentionable can be more manageable. When we can talk about our feelings, they become less overwhelming, less upsetting, and less scary. The people we trust with that important talk can help us know that we are not alone.

—Fred Rogers

In my family the meltdowns have reduced in frequency and duration over the years. There have been occasional surges, when our stress levels are high, but I can see a trend of more self-regulation.

Awareness has helped me so much in my parenting. Its components, mindfulness and compassion, help me gain perspective and understanding. I hope that practicing these simple tools will help you find empathy and harmony during your child's meltdowns.



Kate Lynch is a meditation coach and inclusive yoga teacher (Healthy Happy Yoga). She has been teaching and cultivating community since 2002. In her role as Ocean's mama, she continues to learn about advocacy, emotional balance and neurodiversity. Kate specializes in supporting anxious parents of atypical kids with the mindfulness, resilience, and self-care tools that help her get through the day.

Mindful Meltdown Cheat Sheet: <u>https://healthy-happy-yoga.ck.page</u>

Please check out Kate's podcast: Mindfully Parenting Atypical Kids

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#### 8 / SEPTEMBER 2021 AUTISM ADVOCATE PARENTING MAGAZINE

# THE MOLECULAR BLUEPRINT OF AUTISM

Dr. Rene Anand, Ph.D.

Autism spectrum disorder (ASD) is a complex mixture of clinical conditions in neurodiverse individuals. While research has determined that hundreds of genes are associated with autism and that co-occurring conditions are common, genes do not entirely determine one's health destiny.<sup>1</sup> Despite the common elements of autism, no two children will have the same symptoms or benefit from the same treatments.

Scientific research and statistics are vital for uncovering the complexities of any condition, disease or disorder. They can lead to more effective treatments and a better understanding of the condition. Help can seem distant, however, for parents who have to deal with the daily challenges of their child's picky eating and self-injurious behavior, or their own exhaustion. I want parents to know that there is hope. Researchers and scientists around the world are discovering new ways to change the trajectory of autism. Parents with neurodiverse children are some of the most dedicated parents I have ever met. By learning how to better take care of their children in the present, they can make real change and build a better future.

#### **Three Pillars of Health**

To understand the complexities of neurodiversity, parents need to learn more about what I call the Three Pillars of Health: genetics, nutrition and environment. The pillars are all interconnected and can help determine what future medical conditions and diseases could develop. It's important to note that the impact of each pillar will vary from person to person.



#### **1. GENETICS**

Genetics is where everyone begins. We get one half of our genes from our mother and the other half from our father. Our genetic makeup determines such things as the color of our hair and if we will be short or tall. How our genes are expressed is complex and depends on many factors. Consider a severely malnourished child. While the child may have the genetic potential to be six feet tall, he/she may never reach that height because of a lack of optimal nutritional support during periods of growth. Our genetic makeup largely determines how we respond to the environment and to nutrition.

This also applies to individuals with autism spectrum disorder. For example, many children with autism have a genetic makeup that makes it difficult to detoxify heavy metals from their body.<sup>2</sup> While genetic makeup is determined at conception, we do have some control over the environment, such as exposure or not to heavy metals. Although autism may have a significant genetic component, a child's exposure to nutrition and the environment may determine many clinical outcomes.



#### 2. NUTRITION

Good nutrition is important for everyone. Nutrition includes the food we consume, as well as how the nutrients found in our food affect our body. Having too much or too little of certain nutrients can severely affect how our body functions and its susceptibility to disease.

Nutrients can be broken down into macronutrients and micronutrients.

Macronutrients are typically consumed in large quantities. They can be divided into carbohydrates, proteins and fats.

- CARBOHYDRATES include sugars, starches, and fiber. They are the main source of energy, and aid in digestion. They provide fuel for our brain, kidney, heart and central nervous system.
- PROTEINS are important for growth and development. They help repair cells and aid in the process of creating new cells.
- FATS are important in preserving brain health, reducing inflammation in the body and lubricating joints.

**Micronutrients** are essential in small quantities. They include vitamins and minerals. The essential vitamins a body needs to function are A, C, D, E, and K and the B vitamins (thiamine, riboflavin, niacin, pantothenic acid, biotin, B6, B12, and folate). All play different roles in body function and are required at different levels.

The following are some of the most important minerals.

- POTASSIUM enables the kidneys, heart, muscles and nerves to function properly.
- SODIUM maintains nerve and muscle function.
- CALCIUM forms bones and teeth, and supports the nervous system.
- PHOSPHORUS contributes to the health of bones and teeth.
- MAGNESIUM is involved with muscle and nerve function.
- ZINC aids in the growth of healthy cells, maintaining an optimal immune system and wound healing.
- IRON is crucial for the formation of red blood cells and of connective tissue, and also aids in hormone production.
- MANGANESE aids in the production of energy, as well as supporting blood clotting and the immune system.
- COPPER is vital in the production of connective tissues and blood vessels.
- SELENIUM plays a crucial role in immunity, reproduction and thyroid health.

In most cases, a balanced diet can provide all of the essential nutrition that our body needs. However, research has shown that many individuals with autism have nutrient deficiencies. Low levels of vitamin B1(thiamine), vitamin B6, vitamin B12, vitamin A, vitamin D, folate, zinc and magnesium have all been reported in children with autism.<sup>3,4,5,6</sup> The molecular blueprint of autism often includes vitamin deficiencies that can severely affect function and growth. Fortunately, the use of supplements can lead to significant changes in a child with deficiencies. Parents should determine if their child has any deficiencies and seek help in supplementation through a nutritionist with experience in autism.



#### **3. ENVIRONMENT**

The environment we live in today differs considerably from that of 100 years ago. Pollution is a worldwide problem, pesticide use is rampant, and many toxic chemicals are found in our daily health products.

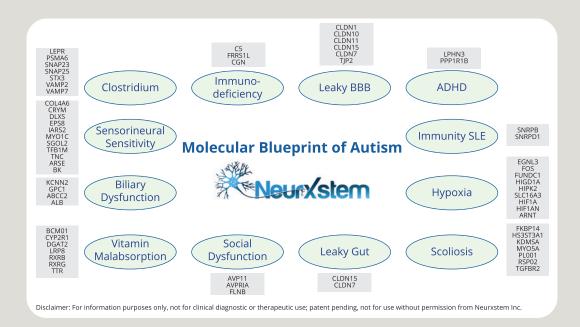
A systematic research review by Drs. Rossignol, Genuis and Frye showed that toxins implicated in individuals with autism include pesticides, phthalates, polychlorinated biphenyls (PCBs), solvents, toxic waste sites, air pollutants and heavy metals, with the strongest evidence found for air pollutants and pesticides.<sup>7</sup> Our environment is changing, and neurodiverse children do not have the molecular basis to manage the level of toxins they are exposed to. That's why it is important for parents to provide an environment that is as toxin-free as possible.



#### **Molecular Blueprint of Autism**

In addressing autism, we should be guided by molecular science. Instead of treating surface problems, we should be more focused on uncovering the root of the problem. Autism presents itself in behavior, but what are the underlying conditions causing the behavior?

Research has shown that some common underlying conditions seen in individuals with autism include gastrointestinal issues, seizures, immune dysregulation, mitochondrial impairment and vitamin/mineral deficiencies. To further complicate matters, research and genetics confirm that autism spectrum disorder has many overlapping and closely related conditions (see below).



It is clear that there is a molecular basis for autism. It's important for clinicians, who evaluate behavior, and scientists, such as geneticists and molecular biologists, to build a bridge between their respective data. Both groups can look at the data together to determine what molecular and behavioral similarities exist in groups of individuals. This combination can improve therapies and, ultimately, outcomes.

#### Current vs. Future

In view of the *Three Pillars of Health* and the *Molecular Blueprint of Autism*, it is worth asking: what we can do now to make a difference in our child's life, and what we can do in the future to change the trajectory of autism.

#### **Improving Your Current Situation**

#### IDENTIFY VITAMIN/MINERAL DEFICIENCIES

It is vital to understand why a child is deficient in a vitamin in order to implement an effective supplementation strategy. Have your child tested for vitamin deficiencies. The molecular blueprint of children with autism shows some very common nutrient deficiencies that should be addressed early in life. Parents also must understand the nature of the deficiency. For example, many children with autism are deficient in vitamin B12. However, giving your child a B12 supplement will not resolve this deficiency. Research has shown that these children lack the enzymes involved in the methylation, or production, of B12. They are likely getting enough B12 in their diet, but need the "machinery" to process it. This machinery is known as methylation of B12. Supplementing children with Methyl-B<sub>1</sub>, means they will be able to process and use the B12 they are already consuming. Another example is the enzyme pyridoxine 5'-phosphate oxidase (PNPO) which helps convert vitamin B6 into its active form, pyridoxal 5'-phosphate (PLP). In individuals with genetic variants of this gene, vitamin B6 is poorly converted into its active form. Thus, it would be more appropriate to use a dietary supplement of PLP in those with autism and PNPO deficiencies, rather than vitamin B6.8





#### **HEAVY METALS**

Have your child tested for heavy metals. Many children on the spectrum cannot detoxify as well as other young people, and they accumulate an excess of heavy metals in their body. Heavy metal toxicity can lead to muscular, physical and neurological degeneration in the body. It can affect mood, behavior, aggression, sleep habits and other No Heavy Metals symptoms commonly seen in children with autism.



#### **ELIMINATE TOXINS**

Eliminate as many toxins as possible from your environment. One of the most important considerations is your drinking water. In most areas of the world, the regulations for "safe" drinking water do not meet the needs of neurodiverse children. Take action to ensure clean, filtered water in your home. Eliminate toxic beauty products, cleaning products and pesticides. This will not happen overnight, but can be done over time.



Diet

#### NUTRITION

Eliminate packaged and processed foods, as well as food dyes, as much as possible. Consider a gluten-free/casein-free diet, and identify any food allergies your child might have.



#### IMMUNITY

Our molecular blueprint predicts that many with autism will also be immunodeficient. Have your child tested for immunodeficiency, including severe combined immunodeficiency (SCID). This could be the cause of persistent and repeated infections that affect both health and well-being.

#### **Take Notes**

Document when your child has lots of energy or no energy. Notice when your child is sensory sensitive or self-injurious. Are there triggers? Are there commonalities? Are there certain foods that cause different reactions? Parents spend the most time with their child and notice when even the slightest differences in behavior occur. By documenting these changes and differences, you can start to pinpoint what environmental or nutritional factors trigger certain behaviors. We are all susceptible to things in the environment, even things that might be recreational. Your child may be affected in a way that you would not expect.

#### Changing the Future

#### **OPTIMAL MATERNAL CARE**

When a fetus is in utero, there is enormous growth and brain plasticity. Most of the cells required for the formation of the fetal brain are generated within the first *five weeks* of development in the womb.9 It is not common to know the genetic makeup of a child before birth. Will the child be able to detoxify from heavy metals? Will the child have a neurodiverse genetic makeup? This is a time for mothers to ensure optimal environmental and nutritional support, especially if close relatives have been affected by autism. Such action may change the trajectory of the newborn. A mother can ensure optimal care by doing all of the things listed above in "Improving your Current Situation." This includes identifying nutrient deficiencies and any excessive heavy metals, eliminating toxins, focusing on a healthy nutrition and taking notes.

Lead seems to be a particularly dangerous toxin for neurodiverse individuals. When it was released, Neurxstem's molecular blueprint of autism predicted that those with autism and a deficiency of the protein hemoglobin epsilon-1 would not be able to detoxify even low levels of lead. The role of lead in autism was confirmed in a subsequent study



involving twins.<sup>10</sup> One twin was diagnosed with autism, while the other was not. The study looked at the composition of the baby teeth that fell out at age five or six. It is worth noting that the teeth of the child with autism had high levels of lead, while the teeth of the other twin did not. Since tooth buds develop in utero, the researchers suspect that the high amounts of lead started accumulating while the baby was in the mother's womb.

It is hard to overstate the importance of maternal care. You should take such measures as avoiding toxins and providing personalized nutrition in case your child is genetically predisposed to be sensitive in these areas. It can change the trajectory of autism. Providing optimal personalized nutritional and environmental support to unborn children that are potentially neurodiverse can ensure that their developing brains will reach their greatest potential.

#### 12 / SEPTEMBER 2021 AUTISM ADVOCATE PARENTING MAGAZINE

#### Conclusion

It is important for parents to understand that molecular science plays an important role in autism. It will help determine what environmental and nutritional factors are dangerous for neurodiverse individuals. I hope that knowing the molecular basis can help us in making environmental and nutritional decisions. With these decisions, the trajectory of autism can be changed for the better.

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# How to Promote Positive Behavior and Reduce Stress in the Home

Brian McClean, Psych.D.

Darragh has two ways of alleviating stress. On rainy days, when we can't get out of the house — Darragh doesn't like the rain — he has so much energy, he bounces and whoops. From a crouched position near the floor, he stretches until he almost touches the ceiling. He sort of whoops while he is doing it, and some days he can be pretty loud. Then he calms himself back down again by pouring water into a dishcloth and wringing it out slowly, watching every drop. There are days when I no sooner finish mopping the kitchen than he is back at the sink!

Raising a child with autism spectrum disorder can be really stressful, and it's a bit of a vicious cycle. The child's behavior can cause stress for the caregiver, and the stress of the caregiver causes stress in the child. How can the cycle be broken? How can parents promote positive behaviors *and* decrease the stress of the family? Here I offer some strategies for both.

#### **Promoting Positive Behavior**

As a clinical psychologist, my background is in the multi-element behavior support model of Gary LaVigna and Tom Willis. Every time I visit a family that has a child with autism, I ask the following five questions and always in the same sequence.



#### 1. Is your home a low-arousal environment?

Many children with autism struggle to soothe the level of arousal that they often experience in their bodies. A low-arousal environment is a calm environment. It's a place where families feel comfortable and relaxed. Every home should have a place of sanctuary, a place where a child can go to feel safe and where a child's alarm signals can begin to calm.

Most challenging behaviors happen because children are struggling to keep up; words fly by them too quickly. Adults change the subject or switch activities, and the child isn't ready for such changes. When emotions surge in the body, the child isn't clear where they came from. Creating a low-arousal environment for children who are easily overwhelmed usually means doing less. Try not to use so many words. Give children time to process what we are trying to say. Reduce background noise. Speak slowly and use visual clues to help them see what we mean.



#### 2. Is your child in rapport?

Once a low-arousal environment is in place, or at least there is a place of sanctuary in the environment, the next thing I look for is rapport. When the caregiver speaks, does this register with the child?

For example, I call the child to the dinner table, but she is watching TV. She does not respond. This could be one of those tricky tugs-of-war for the child's attention unless I make a connection. I have to follow the child's focus of attention. Where is her interest? I then try to name what she is doing: "I see that you are watching TV." Wait for a reaction from her so that you have a moment of joint attention.

These moments are as precious as gold. We celebrate them with smiles, praise and recognition.

When you name what the child is doing, it is like using words as scaffolding for the child's experiences. You are entering your child's world and participating in what has captured her attention. As you celebrate each moment of social interaction, you will find that it starts to come easier for the child and that the rapport is growing stronger.

Don't assume that the rapport you developed an hour ago is still in place. When it comes to a child with autism, you must constantly try to create those moments of joint attention. Think of it as an emotional deposit. Try to keep track of the number of emotional deposits you make with a child as they will determine the number of emotional withdrawals, such as requests or demands, that you can make. As a general rule of thumb, try to have the emotional deposits exceed the number of emotional withdrawals by a factor of three. In other words, if I make three requests, I need nine social connection moments. You will see that it starts to add up quickly!



#### 3. Are activities predictable?

Children without a predictable routine have to expend an enormous amount of mental energy to figure out what is going to happen next. Predictable sequences, routines and rituals reduce stress and confusion. The more predictable the sequence of activities, the less effort children have to make to figure out both what is expected of them and what they can expect of others.

It's a little like the effort of cycling. When you are cycling up a hill, you wonder if you will ever get to the top and be able to coast or freewheel. Some children are so overloaded that they are just holding out for when they can coast. Familiar rituals and routines allow the child to freewheel. The child may still be pedaling but shouldn't have to work so hard all the time.

It's worth looking at family routines from the perspective of the child. Could we have a predictable morning routine, or a predictable sequence of activities before bedtime? Could we signpost the sequence to the child through a series of pictures posted on the refrigerator? Get the child to take down a picture of the activity once it's done, which will help the child see the sequence as it unfolds. Weekly calendars can also help the child know when favorite activities are coming up. This creates less confusion.



#### 4. Can your child communicate the message of the behavior?

All behaviors communicate a message and something about what the child needs in a given situation. Our research tells us that when children with autism engage in challenging behaviors, such as outbursts, most times they are trying to communicate "No" or "Go away." The best way for a parent to stop such outbursts is to teach the child a better way to communicate that message. I remember working with Brendan, a fifteen-year-old boy who could not communicate verbally. When he wanted something to stop, he would lash out by pulling hair or hitting. I used to approach him with a guitar, even though I can't play the guitar, or a request for him to do something unusual. As soon as he lifted his hand, and before he could reach me, I would interpret his movement and say "No?" He learned that all he had to do was lift his hand to tell me to stop.

When working with children with autism, I spend most of my time as a "meaning detective." Once we figure out what message the behavior is intended to convey, setting up a fun way of teaching is the easy part. The teaching takes place once the child is in a relatively low level of arousal, is in rapport, and has some sense of the sequence of activities.



#### 5. Why should the child bother?

The last question I ask is whether there is an incentive for the child to get it right. While some therapists start with this question, I think the child needs to be calm, connected and collected, and to know how to get it right. Only then do rewards for getting it right make sense.

The reward aims to harness the child's attention. In order to capture the child's interest, we use such items as rocket ships to the moon, Bob the Builder climbing a ladder, favorite players arriving on the football pitch or Elsa crossing the mountains of ice.

#### **Strategies for Reducing Stress**

A few years ago, I was working in a community as part of a Behavior Support Team. I had the privilege of working with four young men who often displayed extreme levels of aggression when in distress. I have mentioned two of them already, Darragh and Brendan.

We were able to show that this sequence of interventions — low arousal, rapport building, activity sequencing, communication training and incentive — was very effective, even for long-standing severe behaviors.<sup>1</sup> We noticed that 85 percent of all aggressive and self-injurious behaviors reduced after just the first two steps of low arousal and rapport. I began to wonder what would happen if we put more of our energy into creating environments in which families experience lower levels of stress and into teaching rapport-building. Would we achieve most of the desired reductions in challenging behaviors.<sup>2</sup>

As I visited family homes and group homes, I also noticed that some parents and staff just seemed to be able to exude a sense of calm and to know intuitively when to reduce arousal and how to build rapport. I wondered what would happen if we just taught parents and staff the skill of mindfulness instead of spending hours and hours in behavioral assessment.

Mindfulness is being able to pay attention purposefully to the present moment, without judgment or fear. When we are fearful or stressed, our reasoning changes. We are not able to attend to all that is here, or see the opportunities for reciprocation and rapport.

Dr Nibhay Singh, a Professor of Psychiatry at Augusta University, has been studying mindfulness in parents who are raising children with special needs. In one study with three adults with profound intellectual disabilities, he found that caregivers who practiced mindfulness for ten minutes a day were less stressed. In addition, the three adults had higher levels of measurable happiness, including smiles, laughs and vocalizations. When parents of children with autism practice mindfulness, their children show lower levels of aggression and higher levels of cooperation.

When we practice mindfulness, our compassion increases, burnout reduces and we are better able to provide love and kindness, even during challenging situations.<sup>1,2,3</sup> Mindfulness directly helps us notice and manage our stress levels, which allows us to handle difficult situations in a more positive way.

#### **Back to the Basics**

Caring for a child with special needs can sometimes be so challenging that we forget the basics. The following are some of the most important aspects of reducing stress and managing challenging situations.

- Make sure you are getting enough sleep. Enlist the help of grandparents and friends so that you can get a good night's rest.
  Make sleep a priority in your home, and establish effective bedtime routines.
- Exercise and strenuous activity are known to reduce stress. Find ways with or without your children to move your body and exercise every day.
- Learn to breathe in response to stress. An effective technique is called "7/11 Breathing." Breathe in as you count to seven; breathe out as you count to eleven. This will encourage you to breathe deeply and slowly, which can help you avoid a panic attack. If you feel your body starting to escalate into "fight-or-flight" mode, breathe slowly.
- Try a little mindfulness. We use the Headspace app a lot for guided meditations. A little every day goes a long way.

Stress is a global issue and a significant health concern for many parents, especially those raising a child with autism. It creates a cycle of arousal in which parents and children can both be caught. My advice to parents is to try to take care of themselves by sleeping, exercising and practicing mindfulness to create a lower arousal environment for themselves and their children. Let's start at home and create a sanctuary of calm, health and happiness.

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Brian McClean, Psych.D, qualified as a Clinical Psychologist from the University of Surrey in 1989. His doctoral thesis was on Outcomes of Behavioural Support for 138 people with challenging behaviour. In 1994, he founded The Callan Institute for Behaviour Support and developed it as a national consultation and training agency. In 2001, he established a Behaviour Support Service in County Roscommon, Ireland, which supported community living and real lifestyles for people with behaviour support needs.

Dr. McClean has over 25 years' experience working with children with autism and with behaviour support needs, designing and implementing behaviour support plans. Brian has spoken extensively, nationally and internationally, about autism. He is currently Principal Clinical Psychologist with Acquired Brain Injury Ireland.

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Mindfulness is being able to pay attention purposefully to the present moment, without judgment or fear.

#### 16 / SEPTEMBER 2021 AUTISM ADVOCATE PARENTING MAGAZINE

# Early Detection and Early Intervention

What Every Parent Should Know

Lisa Kota, MADS, BCBA

https://mb.cision.com/Public/2874/2931520/b29d56c94c278076\_org.jpg

There is still a lot that we don't know about autism. We don't know exactly what causes it, nor can we predict the effects of autism over a lifetime. However, in recent years there have been some interesting and exciting developments in autism research, such as the use of eye tracking technology and the social motivation theory of autism. These developments reaffirm what every parent should know: early detection and early intervention are key to a good outcome.

#### **Eye-tracking Technology**

There is no biological or neurological test to confirm a diagnosis of autism. Expert clinicians use checklists and observation in an effort to diagnose autism in infants as young as 18 months old. Unfortunately, an autism diagnosis is often not made until the child is three years old or older. All that could change with a new and exciting diagnostic tool that is on the horizon. Eye-tracking technology could provide a quick and easy way to diagnose autism in infants. A baby can sit on their mother's lap and watch a short video while infrared light is used to see where their eyes focus. The assessment can be completed in 12 minutes. While eye-tracking technology is not yet a widely accepted method of diagnosing autism, several research groups around the world are investigating its utility in early detection of autism. It can identify differences in visual focus between infants with autism and typically developing infants, and in confirming the positive effects of early intervention.

#### **The Social Motivation Theory**

Thirty-five years ago, cognitive developmental psychologists Baron-Cohen, Leslie and Frith conceptualized autism as a disorder of cognitive impairments, including a lack of theory of mind that caused difficulty with social interactions. Then in 2012, Coralie Chevallier et al. authored a paper titled *The Social Motivation Theory of Autism*. It constituted a paradigm shift toward the idea that autism is actually a deficit of social motivation that could limit learning opportunities and thereby cause cognitive impairments, rather than the other way around. This new theory of a lack of social motivation is supported by retrospective studies of home movies and by eye-tracking technology research. The latter has



collected data showing that typically developing infants look toward eyes, faces, human bodies and biological movement, while infants who were later diagnosed with autism preferred to look at objects and object movement, such as doors closing, balls bouncing, and mouth movement rather than eyes. The early experiences of infants build the neural circuitry of the brain. Infants who are developing typically look toward their parents, imitate them, and learn how to think, feel and act. These early social experiences build a brain that will be able to navigate the social world as an adult. The preference of an infant to attend to the physical world of objects can interfere with social learning opportunities. Parents can take action by learning to interact in such a way that the infant will begin to enjoy looking at and interacting with people. The critical implication of the social motivation theory of autism is that children who are more interested in objects aren't watching people. That means they are missing out on thousands of learning opportunities every day. Without early intervention, their development will continue to fall further and further behind their peers.

#### The Importance of Parent Involvement

Naturalistic developmental behavioral interventions are treatments for infants and toddlers that essentially blend behavioral and developmental approaches, and that focus on promoting engagement between the adult and the child. Such treatments can be implemented by a therapist who is certified in one of these toddler interventions, such as the Early Start Denver Model (ESDM). However, these interventions also emphasize parental involvement and can be done completely through a parent-training model. It makes sense to train parents as they are with their child all day long, and can learn to use engagement and teaching strategies throughout regular daily activities. The teaching strategies involve some easy adjustments that can have a profound impact on a child's development. Such adjustments include making sure that you are face-to-face, following the child's lead, smiling and being animated, creating back-and-forth reciprocal interactions, and modelling appropriate language. These strategies change children's experiences and actions, which in turn can change how their brain develops. More information on learning these strategies can be found on the Autism Navigator website (https://autismnavigator.com/). It offers a free course and many free materials on what autism signs to look for, and how to create learning moments. Since early intervention is so important, every parent should become familiar with the signs of autism and how to intervene. There is no harm in using these strategies for children, with or without autism. You certainly don't need to wait for a diagnosis to intervene.

#### **Parents – Staying Motivated**

Many parents find the thought of being the interventionist overwhelming. Infants may fuss or move away when the parent attempts to join in, and it may be difficult to capture their interest. This is because many infants with autism experience interactions with people as less interesting or less fun than interactions with objects. For those who have already parented a typically developing child, the differences will be noticeable. Typically developing infants react to those around them in ways that make parents want to stay close and interact. The lack of encouragement experienced by many parents who are teaching infants with autism makes it hard to keep trying. Parents should note, however, that making a few simple changes to how they interact with their children during daily activities can change their learning trajectory.\*

\* Inspiration to keep going can be found in the Autism Navigator free course called *About Autism in Toddlers*. Slide 16 has videos that highlight the significant progress of eight children and their families, including before and after videos. It is impressive that the children's good outcomes resulted entirely from the efforts of the parents as interventionists. Such experiences can help motivate other families.

Since early intervention is so important, every parent should become familiar with the signs of autism and how to intervene.



#### The Importance of Early Intervention

In many respects, autism continues to be somewhat of a mystery. We know that autism is present from birth, but that early detection and intervention can help a child stay on the same developmental trajectory as his/her peers. We know that children with autism do not seek out interaction with their caregivers to the same degree as typically developing children do. Since we know that brain structure and function are built from experience and action, we want children with autism to have similar experiences, engage in similar activities, and have all the same learning opportunities as their peers. An ideal solution is to train parents to engage their children during regular daily activities. For more difficult cases and for children who are three years old or older, ABA therapists can take the lead in collaboration with parents. The important point is that parents not delay intervening.

The treatment of autism is moving in a new direction. We do not want to cure autism. Learning about the physical world isn't a bad thing for young people with autism. Students with a strong interest in the physical world but who also learn to thrive in the social world can become engineers and scientists. A developing child who only has a strong interest in the physical world and doesn't receive intervention to learn how to talk and socialize, runs the risk of a lifetime of dependence on others. It doesn't have to be that way. Continued advancements in the future hold the possibility of all children reaching their full and balanced potential.

Early detection and intervention can help a child stay on the same developmental trajectory as his/her peers.





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# The Susceptibility of Children, Adolescents and Young Adults with Autism to **Videogame** Addiction

Jay H. Berk, Ph.D.

As a psychologist and coach located in Beachwood, Ohio, I work nationally and internationally with clients who have gaming overconsumption and/or addiction issues. I have seen such issues be a particular problem for individuals with autism.

Parents need to know that individuals with autism often seek an escape. The Internet and gaming can be healthy outlets for many individuals. However, they can be thought of as being on a continuum that ranges from healthy Internet activity, to problematic usage, to addiction.

Parents may wish to consider how susceptible their child is to gaming and electronic overconsumption. The use of electronic devices is thoroughly embedded in our society. From a very young age, school children have laptops, a cell phone, an iPad and more. The most important piece of advice I can give parents is not to focus on managing your children's use of electronics, but to teach them to manage it for themselves. The goal is a collaborative effort at helping them learn to manage electronics. However, this may not be attainable if they are past the point where they are able to control themselves. Symptoms of this loss of self-control include: rage-quitting; destruction of property; staying up in the middle of the night; refusing to turn in the games; focusing solely on games or when they will be able to get on the games again; and a lack of social connection to others.

Gaming and the Internet pose a particular challenge for individuals with autism because they provide an easy escape and surge of emotion. For many individuals with autism who have compounding social anxiety, depression, or other social interaction issues, the Internet offers an opportunity to meet people with similar interests. It is also easy to be attracted to the image that people present in gaming forums or online, even though they may not be the people they say they are. The high interest area of individuals with autism is easily remedied by finding a server, such as Discord, where others share the same interests, such as fans, bugs, etc.

Dopamine feels good! Winning games provides a forum where children can succeed in ways they may not have been able to succeed in their day-to-day life. For example, they may not be great at in-person sports, but they "rock" at esports (electronic sports).

Here is my advice to parents on ways to address gaming and Internet use by young people.



**Start early.** Prevention is key. Do collaborative learning with your children. What is a reasonable amount of time to be playing? What happens if they get off the games, and what happens if they don't? State your expectations up-front. That way, you are not taking the games away. Ultimately, they are choosing to keep them or not based on their own ability to manage their use of the games.



**Pay to play.** This is my favorite strategy. Select an amount of time per day for the use of electronic devices that you find acceptable. Then the child, adolescent or young adult can earn extra gaming time by getting off the game when asked, or by seeking out in-person experiences, such as joining clubs or exercising.



**Educate your child about game construction.** Gaming is often designed to be similar to gambling. There are many commonalities, such as the "near-miss phenomenon" in which you keep playing because you almost won. Games are also constructed so that players want to level up, have the best "skins" and be part of a group.



**Know when to get help.** If your child has gone from healthy gaming to problematic usage, and is moving toward an addiction, get help early from a professional. Don't get to the point where you are taking drastic measures, such as throwing games out.



**Don't just manage children's gaming; teach them to manage it themselves.** Otherwise, when your children become young adults and move out for college or to live on their own, they will not have the skills to manage gaming themselves. Our goal is to help them create a balance of social interaction, exercise, healthy eating, "in-person" friendships, and more.



**Recognize that addressing this issue takes energy.** Many parents give in to their children. They are held hostage by a child who is angry, breaks things, screams, yells, or disturbs the whole household. While I understand this feeling, I would reiterate that early intervention is key. If you find yourself in this situation I encourage you to read my book <u>Parent's Quick Guide to Electronic Addiction</u> (available on Amazon). It will give you much more information than I can provide in this short article.



**Esports continue to grow in popularity.** In fact, your local high school and college likely have electronic sports teams. If your child wants to participate, insist that the school provide training to the teacher who is the "coach" and the students who are on the esports teams. This can be a great opportunity for your child to learn socialization and self-management skills, too.



**Ensure consistency on the part of other adults in the house.** Inconsistency always leads to problems. When adults are inconsistent in outlining or enforcing the rules, children will often rebel. Agree on the rules, and get every adult on board.



**Remove the games from the house, if needed.** This ensures that children will not steal from you, or break into rooms and try to get them.



Ensure that your credit cards and PayPal account are not linked to games.



**Know your software.** If you don't know anything about the software, your child probably does. There are many programs available that can help limit time spent on games and on the Internet. Be aware, however, that there are also many YouTube videos that show how to get around these same controls. Check your child's browsing history, and don't forget to take electronics away at night.

Our children are capable of achieving amazing things in their lives. Unfortunately, children with autism often turn to excessive gaming as an escape and a rush. It is imperative that parents teach their children balance and how to manage time spent on electronics.



PARENT'S AUICK CUIDE ELECTRONIC ADDICTION JAY BERK, Ph.D.

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Jay H. Berk, Ph.D., is a licensed psychologist, coach, author, speaker and an expert in working with children, adolescents and families. He is adept at treating children/adolescents in outpatient and residential programs. His experience includes working at several area children's homes and in private practice. In his private practice, he conducts therapy with children, adolescents, families, couples and adults. His specialties include: clients with Stress, Anxiety, Depression, Social Issues, Learning Disabilities, Electronic and Gaming Over-Consumption, Attention Deficit Disorder, Autism, and Tourette's Syndrome, as well as treatment of those individuals who have multiple impairments.

In addition to providing therapy, Dr. Berk is a highly sought-after speaker. Dr. Berk has provided training and workshops throughout the USA, Canada, New Zealand, Australia, and Bosnia to schools, agencies, mental health therapists, speech therapists, occupational therapists and a variety of parent groups. He functioned as a special consultant to the Screen Actors Guild in New York City and for UNICEF. He will speak privately for groups of any size and also contracts with businesses, seminar companies, schools and universities to provide in-service training. Dr. Berk is also author of "Parent's Quick Guide to Electronic Addiction" and "Codeswitching: Social Skills in the Screen-Age" - both available on Amazon. He is also the clinical director of INTENTA, a training program for therapists working with gaming challenges.

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# Integrating Your Child's ASD Diagnosis into Your Family

SUPPORTING SIBLINGS

Leslie Speer, Ph.D., BCBA, NCSP



I am one of those lucky people who love the work that they do. Over the years, I have been inspired and humbled by all the incredible patients, and their families, that I have had the privilege to meet. You will never meet more determined and passionate parents than those who have children with special needs. Often, the siblings of the child with special needs are compassionate, patient and mindful. Of course, families will still face challenges in finding balance and understanding how the diagnosis of autism fits into their family.

Parents worry not only about how to support siblings in understanding the needs and challenges of their brother or sister but also about processing the impact some of these needs can have on the sibling and the family as a whole. What can the parents do to foster positive relationships between siblings? There are no simple answers to these questions as all children are different, and the nature of sibling relationships evolves and changes with time and age. However, there are some general strategies and resources that families can use to address these issues.

# The Basics

**START NOW!** - It is never too early to start. Adapt your language and the information you share to be age-ap-propriate.

**REFLECTIVE LISTENING** - Truly listen, and reflect back what siblings say about their brother or sister. We all want to be heard.

**VALIDATE** - Validate the feelings, concerns, guilt, frustration, love and worries of siblings. Validating a sibling's frustration does not diminish the love you feel for your child with autism. It simply acknowledges some of the challenges that the sibling and the family can experience around symptoms of ASD. Validation is important.

**NORMALIZE** - By listening and then sharing some of your own feelings, you start to normalize the siblings' feelings and experiences. This can help them feel like they are not alone, and that others are experiencing the same thoughts and feelings.

**REPEATED CONVERSATIONS** - This will not be a one-time conversation. The discussion should be ongoing. A clearer picture of the diagnosis and its implications can be built by siblings as their cognitive ability, understanding, and relationship with their brother or sister change and evolve over time.

**OPEN THE LINES OF COMMUNICATION -** Make it safe and comfortable for siblings to ask questions and talk about their feelings and needs at any time.

#### **Fostering Sibling Relationships**

Parents should do all they can to promote strong and healthy sibling relationships. The following suggestions can help.

Find activities that all of your children can do together. As a family, create a "menu" of activities. For each activity, determine: how much structure is needed; how much supervision is required; and when is a good time for children to play together.

Teach and empower siblings to interact with their brother or sister. They need to know how to set limits, communicate, feel safe, and have some control.

Remember that teasing, name-calling, arguing and other forms of conflict are common among most brothers and sisters, even when one has special needs. Sibling conflict is part of normal social development.

Typically-developing siblings deserve a life in which they sometimes misbehave, get angry and fight with their siblings just like other children. Set normal expectations for siblings. The personal safety of siblings deserves to be given as much importance as that of the family member who has special needs.

#### **Finding Balance**

When so much time and effort are needed to work with the child with autism it can be challenging to find an appropriate balance. Here are some ideas on meeting that challenge.

- Set high and consistent expectations for both the typically developing child and the sibling with autism. To the extent appropriate, have the sibling with special needs do chores and have responsibilities.
- Remind everyone that "fair" does not equal "same."
- Reserve one-on-one time for you and the typically-developing sibling.
- Ask for help. Reach out to family members and friends.

#### **Plan For The Future**

In the whirlwind of daily life, it can be hard to find time to plan for the future. Make sure to involve siblings in planning for your child with special needs.

Make concrete plans for the future of children with special needs. Involve and listen to siblings as you make plans. Often siblings take on the responsibility of caring for their sibling in their adult years. Remember that their attitude toward the extent of their involvement as adults may change over time, and that any future involvement is a choice rather than an obligation.

Send the message early that the sibling has your blessing to pursue his/her dreams, as well as the basic right to his/her own life. Be guided by the motto, "Nothing about us without us." After all, self-determination is for everyone, including brothers and sisters.

Despite the many challenges, families can build strong bonds between children with autism and their siblings.

# How to Talk to Siblings

The best approach to answering questions will vary depending on age. Here are some general guidelines to follow.

#### **Two to Three Years Old**

Concrete short explanations are best to talk about the sibling's difficulties. Describe behaviors that siblings can easily see or observe, such as: "Talking is hard for Johnny," "Sally has a hard time playing with toys," or "Tim has trouble falling asleep."

#### **Three to Six Years Old**

Children this age ask a lot of 'why?' questions. This provides an opportunity for parents to discuss the reasons behind a sibling's behavior. They can say such things as: "He has a hard time using his words when he is mad," or "He finds it hard to pretend with toys like we can."

#### Six to Nine Years Old

Build on previous explanations and examples, but add more abstract concepts. For example, parents could say: "Billy finds it hard to understand how other people feel," or "Mary sees, hears or feels things differently."

At this age, siblings can understand that all of these difficulties taken together are called 'autism.' Talk about the specific symptoms of autism seen in the sibling. It is also important to proactively answer such questions as, "Is autism contagious?" or "Did I do something to cause my sibling's autism?" Children often do not voice these concerns, so addressing such misconceptions can be helpful. Explain that autism is caused by differences in the brain from when the sibling was very young. Reassure your child that you love and value your children equally.

#### Nine Years Old and Older

Children can now understand more detailed written information about an autism diagnosis. Parents can talk about the specific behaviors displayed by the sibling, and how this fits with the characteristics of the diagnosis. It is useful for parents to consider how they would respond to such questions as:

"When will he get better?" or "Who will care for him when he gets older?"

Parents should provide reassurance that they are planning for the child with autism's future, that siblings will have a choice and that they can still live their lives.

Parents should openly communicate about autism with their children, foster healthy relationships and find balance. Siblings will grow to be strong, compassionate and resilient.

### Resources

Sibshops: Events for kids who have a sibling with special health or developmental needs. It is a fun-filled event with recreation, discussion and peer support activities. <u>Sibshops.org</u>

Autism Speaks provides families with a list of resources on autism spectrum disorders, including general information, diagnosis and early intervention, therapeutic and behavioral intervention, social skills, family, and special education. This list provides guidance as to what resources would be appropriate for parents, siblings, professionals, and peers, as well as children/individuals on the autism spectrum. It can be found at: <a href="https://www.autismspeaks.org/directory">https://www.autismspeaks.org/directory</a>



Leslie Speer, Ph.D., BCBA, NCSP, is a Nationally Certified School Psychologist (NCSP), as well as a licensed clinical psychologist. Her areas of specialty include Autism Spectrum Disorders, Anxiety, Behavioral Concerns, Developmental Delay, Sibling Support, Whole Family Wellness/Support, Parent Coaching, Understanding your rights/your child's rights in school (IEP, 504 Plans, etc.) and how to advocate for your child in the school setting.

As Program Director at the Cleveland Clinic Center for Autism, Dr. Speer oversaw and coordinated multidisciplinary evaluations of children, adolescents, and adults suspected of having an autism spectrum disorder. Dr. Speer also coordinated a sibling clinic, medication monitoring clinic, and parent support groups, as well as offered consultation services regarding behavioral difficulties, treatment planning for individuals with an autism spectrum disorder, school difficulties, special education law, IEPs, 504 Plans, and advocating for student's needs in the classroom/school. Dr. Speer now works at the MetroHealth Autism Assessment Clinic (MAAC) and provides support for individuals diagnosed with autism spectrum disorder and their families.

Dr. Speer has presented at various conferences and spoken at local organizations. Dr. Speer has been active as a member of the Milestones Autism Resources conference planning committee and regularly presents workshops for this conference. In her free time, Dr. Speer enjoys spending time with her family, especially outdoors. She loves to garden, read, run, and go on bike rides.

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Vacations are often the moments in our lives that create lasting memories. You share experiences with those that you care for the most and can reflect back on those moments for years to come. What comes to mind when you think of your last vacation? Perhaps an unexpected wrong turn led to the most incredible and unplanned adventure. You may have finally seen an iconic landmark that has been on your bucket list. My family enjoys collecting ornaments from our travel destinations. Each year when we decorate the Christmas tree, we "revisit" our trip. This ensures that the memories are passed down, in addition to being forever stored in our photo books.

Many people find the anticipation of a vacation almost as enjoyable as the vacation itself. However, families who are traveling with a member with special needs may feel overwhelmed at the thought of a vacation. Many families that would like to travel opt not to do so because of the additional challenges faced in making sure the trip will be enjoyable and safe for everyone in the travel party. This may be the result of needing to bring too many items to keep the special needs member comfortable. There may be medical necessities that are too cumbersome for travel. Would you consider taking that long-awaited trip if you had a resource person who could assure you that each member of your travel party would be safe and have a good time, and that you would still have all the items you require without having to bring everything from home?

As a travel advisor and a Certified Autism Travel Professional, I help families with special needs book vacations that will meet all of their needs, and work to make their vacations run smoothly. One of the companies that I use to book vacations provides many of the items you may typically need to take from home. This can include items used in the bedroom or bathroom, for mobility and more. These items can be ordered and available in your hotel room or your stateroom on several cruise lines. Special Needs at Sea is an organization that has numerous items to make travel lighter and easier for you while providing items that are required for your travel party. I have helped hundreds of families with a child on the spectrum have a safe and happy vacation. It is possible.

I offer the following tips to help you be successful on your next vacation.



#### Plan Ahead

Before you go on a vacation, do your research. A good place to start is at <u>IBCCES.org</u>. This website lists numerous activities, at zoos, water parks, museums, and theme parks, and accommodation at hotels and resorts that are all Certified Autism Centers. This means that these facilities are dedicated to serving individuals with autism, that at least 80 percent of their staff members are trained and certified in the field of autism, and that they are committed to ongoing training in autism. Finding places like this can give peace of mind to your travel party. The website can also be a springboard for ideas if you are starting to plan a vacation.



#### **Create a Storyboard**

A storyboard is a visual representation of your trip. Include pictures to represent each day or each activity. Creating a storyboard, prior to traveling, is a great way to involve your family in the planning. It will help your child see when you will be leaving, where you will be staying and the sites you will be seeing on the trip. This will help your child feel comfortable with the planning and can alleviate some anxiety.



#### **Navigating the Airlines**

Some airports offer an opportunity to "test drive" the check-in process through what is known as the "flying rehearsal program." You could consider this option if it will ease the stress on the actual day of travel.

If you are traveling by air, be sure to bring your child's favorite comfort items, within the limits set by airlines. For instance, we always bring a favorite blanket and soft toy, books and activities. It is also helpful to have headphones and something to chew on while taking off and landing. You may wish to have new items and snacks to unwrap throughout travel. Of course, you will have more freedom if you are driving to your destination.

Talk to your pediatrician about options available to calm your child, if necessary. Always be sure to try out what is recommended prior to your flight as each person reacts differently to medications.



#### Stick to a Schedule

If you decide to travel by car to your vacation spot or to take a scenic roadtrip, it's important to stick to a schedule. This is another opportunity to make a storyboard of the journey so that your child knows what to expect. My advice is to keep the schedule reasonable and doable for all those traveling in the car. When researching your vacation, be sure to add all the things you want to do to the agenda, but don't overdo it. This is not the time to add extra stops that were not on the storyboard. Be sure to plan bathroom and snack breaks. Bring entertainment that is suitable for your child in the car, as well as snacks, and items that bring comfort. Don't try to do too much in one day. For everyone's sake, keep the driving reasonable, and take a break at a park or other place where you and your child can relax and play before hitting the road again.



#### **Booking a Hotel Room**

If you decide to make your own hotel or resort reservations, prepare a list in advance of the items you require in your room and at the resort. Go through a typical day at home noting things that may not be readily available when you are on vacation. You may be surprised by how many adjustments you make, and will need to make, on your trip. Once you have the list in hand, you can request these items when you make your reservation. If the hotel cannot meet all your needs, staff may be able to suggest how to get the items from outside vendors. If you plan to utilize the resort's childcare services, ask about the training of the on-site childcare staff. Make sure they are certified to work with your autistic child. If they cannot accommodate you, it is better to find out before you arrive at the resort.



#### **Start With a Short Trip**

Taking a short trip as a practice run may be beneficial for your family. Follow the same steps as you would for a longer trip: create a storyboard, bring comfort items and stick to a schedule. A shorter trip will give you an idea of the kinds of things to plan for on a longer trip.



#### **Plan According to Your Child's Interests**

Since you know your child best, consider what activities might be suitable. If your child prefers a quiet environment, plan on visiting places that are calm, such as museums or outdoor exploration centers. If your child loves excitement and adventure, plan a trip to a waterpark or an amusement park. Keep in mind how long your child can reasonably enjoy these outings and make time for breaks, naps, if needed, and food.

As a Certified Autism Travel Professional, I update my content and renew my certification annually. This is how I help my clients find the best travel destination for their family's needs, whether it's a cruise, a theme park or some other destination. I assist my clients in making sure that they are well taken care of and that all of their concerns are met. This ensures that when they arrive at their destination, they can have a worry-free time.



Andrea Auger is a Travel Advisor specializing in Disney, Universal, Hawaii, Alaska, cruises and more. She is a Certified Autism Travel Professional and is also Special Needs at Sea certified. Andrea is a homeschooling mom and a senior dog rescuer.

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# Advice for Parents Raising a Child on the Spectrum

**Murphy Lynne** 



My name is Murphy Lynne, and when I was 13 years old I was diagnosed with PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified). I was not exactly sure what that diagnosis meant, but I was glad to have a name for what I was experiencing. As I have gotten older, I have become more aware of my diagnosis and continually look for ways to adapt better to the world around me. When I graduated high school, I knew I had a story to tell. I recently completed my book, "Am I Invisible?: Things I Wish Teachers Knew." This book is to help parents and educators understand individuals on the spectrum, individuals who walk a different path and the parents who are walking with them. Since I often felt invisible in school, it made all the difference to have parents who were consistently supportive and encouraging. Every child has his or her own unique voice, and children on the spectrum need their parents and caregivers to help bring that out in them. Encourage, support and love your child through the challenges. Do your best to learn and grow as a parent. This is vital to your child's success. If your child is still in school, below are some tips on how to help the road be a little less rocky from someone who has been there.

#### Grieve the Vision You Had for Your Child

An expectant mother often imagines what her child will look like. Will her child have blonde hair and brown eyes or blue eyes? Often this includes a vision of her child's personality. Will her child be outgoing or shy? Will her child be the popular kid or the video gamer? All of these exciting questions go through the expectant mother's mind throughout the pregnancy as she patiently waits to see if her vision is correct. The last thing a parent really thinks about is the possibility of the child having autism or another disability. It is perfectly normal to grieve the vision you had for your child. As a parent, it is important to deal with your feelings and the grief that come with the diagnosis so you can better embrace and advocate for your child. After acceptance comes the joy of getting to know your unique child.

#### Give Children the Space to Express Themselves

I was very lucky that my parents always gave me the space and freedom to express myself. From tolerating my stimming behavior when I was little, to supporting me in my writing and accepting my overall quirkiness, they have always supported me as much as they could. Some parents may be confused about why their child is stimming or engaging in odd behavior. It actually is necessary for autistic children to stim. Think of it as the nervous energy you sometimes have that leads you to go for a walk or even a run after

a stressful or frustrating event. Your autistic child does the same thing, just in a different way. Allow your child to dig deep into his/ her interests. I have a wide variety of interests, and my parents always embraced them even when I was talking their head off at the kitchen table. Putting children in activities that you are not sure if they will enjoy could actually lead to their fondest memories. My mom signed me up for cheerleading even though she was not sure I would enjoy it. It was actually one of the greatest memories of my childhood. Autistic children need to have some sort of outlet, and having parents that understand this fact makes all the difference.

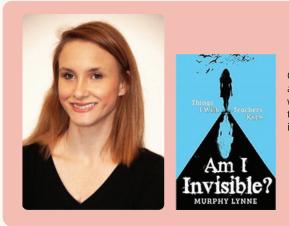


#### Advocate for Your Child in School and Public Spaces

I would not be in the place that I am today were it not for my parents, especially my mom who advocated for me in school. School was very difficult for me. I felt extremely vulnerable and would often shut down in classrooms. This made it difficult for teachers to get to know and understand me. During my Individualized Education Plan meetings, I needed my mom to advocate for me because I was not comfortable expressing my needs in a school environment. If most children with autism struggle to communicate what they need on a day-to-day basis, it is even more challenging in a school setting. As a parent, you need to let your child's teacher know about your child's autism diagnosis and personality. After I was diagnosed, I asked my mom to let all my teachers know about my diagnosis. These became key conversations to help my teachers understand and teach me in the best way they could. For many years, my teachers had to guess what they thought was best for me, which often made matters worse. Putting a name to a behavior made a world of difference for me as teachers could then find resources to help me.

Thank you for always being there for your children. Even though we may

not have the words to express how we feel verbally, we feel it on the inside and couldn't be more grateful.



Originally from Wichita, Kansas, Murphy Lynne is a twenty-something writer who, after graduating high school, had something to say, wanting to help teachers of kids who are different, parents of those kids and the kids themselves. She divides her time between completing college, spending time with friends and family, and playing with her dogs (wishing she had a cat). After all, all cats are on the spectrum!

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Jules Segura

When my son was first diagnosed with autism, I was afraid. I feared for my child's future and wondered if he would be able to be an independent human being and face everyday challenges by himself. If I could go back in time, I would tell myself to let go of the fear. I would tell myself to let go of the need to control everything and to accept my child as he is. I have learned that children on the spectrum may have different ways of communicating and socializing, but that in no way makes them less than others.

I used to be a people pleaser. I would say "yes" to almost everything. I would stay late at work whenever my colleagues or boss needed it. Unfortunately, it often came at a cost to my family. One of the most important things my son has taught me is to have the courage to say "no" to the things that that do not go along with our lifestyle, I have learned to make others respect my time. I have learned to let go of the need to control everything. Being an autism parent has taught me to use my voice! So, this would be my advice for other parents: speak up! Stand up for your child in every situation. Make your family's and your child's needs your priority, instead of the needs of everyone else. Our children are wonderful and deserve the very best. Let go of the control. Use the moments you have to appreciate how amazing your child is and everything that he/she has taught you.

Follow Jules Segura on Instagram: <u>https://www.instagram.com/julesamazinglife/</u> Visit Jules Segura's website: <u>http://www.julesamazinglife.com/</u>





Every child with autism is different and has unique strengths and challenges. My daughter's biggest challenges are speech, sensory sensitivities, understanding danger, and paying attention. But she also has the most amazing sense of humor, is determined, has a fantastic imagination, loves math and music, and is so caring and affectionate.

How do we get through the hard days? What can we say to ourselves to get us through the challenges? If I could go back and speak to myself at the beginning of our autism journey, I would tell myself to *pause*. When you are frantically trying to find a diagnosis, *pause*. When you receive an autism diagnosis, *pause*. When your child is having a meltdown, *pause*. Give yourself a minute to catch your breath and to think, instead of reacting. By taking time to pause, you can assess the situation and your child's needs.

My daughter is the one who gives me strength throughout this journey. I have to be strong for her. I have to keep fighting for her and be my best every day no matter how hard it is.

Follow Jessica Boyes-Korkis on Instagram: <u>https://www.instagram.com/love\_livi\_life/</u> where she sells fun themed sensory craft activity boxes for all children.

# THE RELATIONSHIP BETWEEN **SLEEP AND SENSORY SENSITIVITIES** IN CHILDREN WITH AUTISM

This article is a review of the following research: Manelis-Baram, L., Meiri, G., Ilan, M., Faroy, M., Michaelovski, A., Flusser, H., Menashe, I., & Dinstein, I. (2021). Sleep Disturbances and Sensory Sensitivities Co-Vary in a Longitudinal Manner in Pre-School Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 1–15. Advance online publication.

JOK

Sleep disturbances are common for children with autism. A recent study suggested that 50 to 80 percent of preschoolers with autism have some sort of sleep disturbance related either to falling asleep or staying asleep.<sup>1</sup> Children who do not get enough sleep show more severe repetitive behaviors, exacerbated social challenges, hyperactivity, inattention and aggressive behaviors.<sup>2,3</sup> Unfortunately, the underlying cause of these sleep disturbances in children with autism is understudied.

Researchers have suggested that the greater presence of sleep disturbances in children with autism could stem from sensory sensitivities, gastrointestinal problems or anxiety, all of which are common co-morbid conditions for an individual with autism spectrum disorder (ASD). For example, painful constipation may cause a child to wake up several times in the night, and severe sensitivities to light, sound and touch may make it difficult for a child to fall asleep.

Researchers from the National Autism Research Center of Israel (Beer Sheva, Israel) decided to take a more in-depth look at the relationship between sensory sensitivities and sleep disturbances in children with autism.<sup>4</sup>

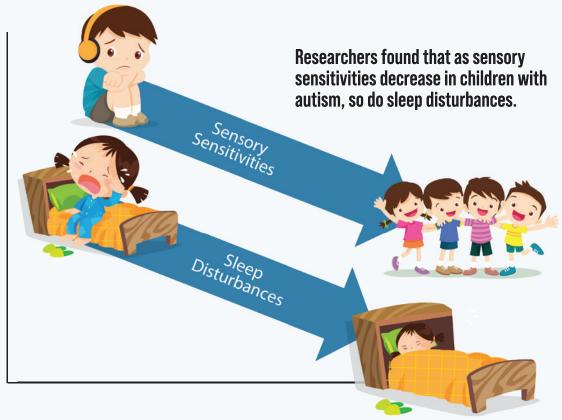
#### STUDY

- The research study included 103 pre-school children with ASD, and lasted 18 months.
- Parents completed a Child Sleep Habit Questionnaire (CSHQ) which measured bedtime resistance, sleep onset delay, sleep duration, sleep anxiety, night waking, parasomnias, sleep disordered breathing and daytime sleepiness.
- Parents completed the Sensory Profile (SP).
- Autism Diagnostic Observation Schedule Second Edition (ADOS-2) assessments were completed on children to assess the severity of ASD.
- Cognitive assessments (either Bayley scales of infant and toddler development, third edition [Bayley III], or the Wechsler preschool and primary scale of intelligence, third edition [WPPSI-III]) of children were completed.
- On average, children were three years old at the beginning of the study, and four and a half years old at the end of the study.

AUTISM REASEARCH

#### RESULTS

1. The researchers found that sleep disturbances were directly correlated with sensory sensitivities. Over time, as sensory sensitivities increased or decreased, so did sleep disturbances.



- 2. The researchers found that sleep disturbances in preschoolers with autism were not linked to their cognitive abilities.
- 3. The researchers found that sleep disturbances in preschoolers with autism were not linked to the severity of their autism symptoms.

#### What Does this Mean for Me?

Does your child have both sleep difficulties and sensory sensitivities? This study suggests that these events are linked. The more sensory issues children have, especially in the tactile and auditory domains, the more likely they are to have difficulties with sleep.

This research can give parents hope and direction. Interrupted sleep and lack of sleep can severely impact a family's emotional status and functionality. If the root of sleep disturbances is sensory sensitivities, working with professionals on this core problem could improve success with sleep. The researchers involved in this study will next investigate sensory processing interventions to see if sleep quality can indirectly be improved in children with autism. We await the results of their further research.

Written by Autism Advocate Parenting Magazine

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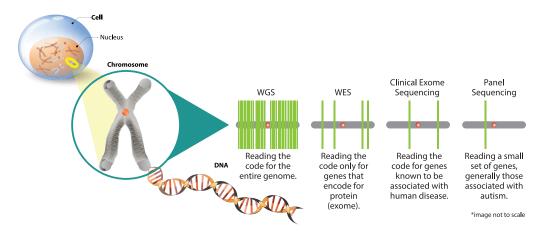
This article is a review of the following research: Vanzo, R. J., Prasad, A., Staunch, L., Hensel, C. H., Serrano, M. A., Wassman, E. R., Kaplun, A., Grandin, T., & Boles, R. G. (2020). The Temple Grandin Genome: Comprehensive Analysis in a Scientist with High-Functioning Autism. *Journal of Personalized Medicine*, 11(1), 21.

Temple Grandin is perhaps one of the most well-known individuals with autism. She is Professor of Animal Science at Colorado State University, a best-selling author in the United States, and a world-famous motivational speaker and presenter. She has appeared on television shows such as 20/20, 48 Hours, CNN, 60 Minutes, and the Today Show. She has been featured in People Magazine, the New York Times, Time magazine, and Discover magazine. In 2010, Time magazine named her one of the 100 most influential people.

Dr. Grandin was born with severe autism. She was non-verbal until she was three and a half years old, had difficulties making eye contact, and had many sensory sensitivities. She engaged in repetitive behaviors and was diagnosed with "minimal brain damage" at the age of two, but later diagnosed with autism in childhood.

It was recently proposed that Dr. Grandin undergo genetic testing. Such testing is often suggested for individuals on the spectrum as it is increasingly apparent that genetics plays an important role in autism spectrum disorder (ASD).<sup>1</sup> Genetic testing can lead to personalized treatment options that improve behavior, gastrointestinal symptoms, and social and communication issues. It could also identify hidden or underlying medical conditions or predispositions.

There are many different genetic tests to consider, including chromosomal microarray analysis (CMA), whole exome sequencing (WES), whole genome sequencing (WGS), and various gene panels. Finding an expert who understands both genetics and autism is extremely important. According to Dr. Richard Boles, an expert medical geneticist who specializes in autism, a diagnosis with beneficial treatments is found in 75 to 80 percent of individuals who undergo WGS.



34 / SEPTEMBER 2021 AUTISM ADVOCATE PARENTING MAGAZINE

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A team of researchers from Lineagen, Inc. (Salt Lake City, UT), led by genetic counselor Rena Vanzo and Dr. Aparna Prasad, sought to identify the complex genetic architecture of Dr. Temple Grandin as an example to others on how genetic testing can benefit individuals with autism.

#### Study

The researchers performed a CMA — the first recommended test for people with autism and generally covered by insurance — WES, and WGS on Dr. Temple Grandin, and collected a comprehensive clinical and family history.

#### Results

#### Dr. Grandin's Medical History

Temple Grandin reported chronic myalgia, muscle rigidity, paresthesia (tingling or numbness of the skin), insomnia, a peculiar rash, and hyperesthesia (over-sensitivity to touch and temperature) of the feet. She described lack of coordination and being easily tired. She also disclosed that severe anxiety and panic attacks have been lifelong issues. Dr. Grandin also has microdontia (teeth that are smaller than normal) and hypodontia (the absence of many teeth), including six missing adult teeth, as well as ectodermal dysplasia, which presents as soft and brittle nails, hyperhidrosis (excessive sweating), and body hair loss.

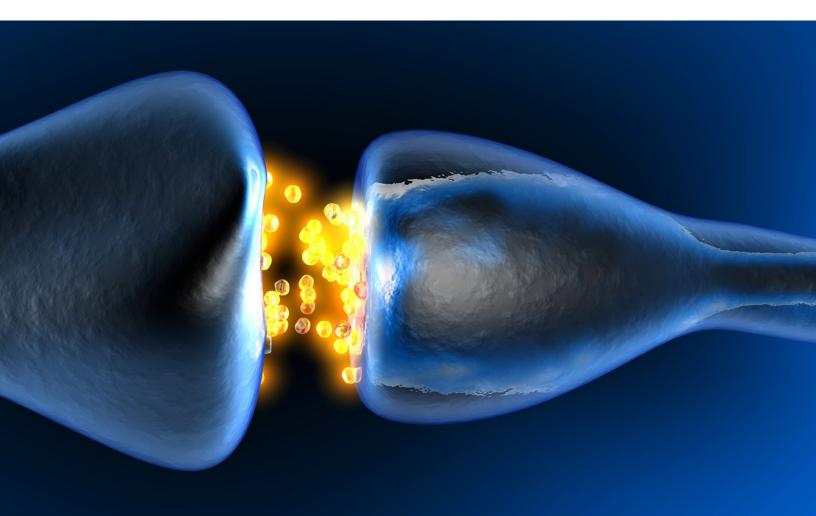
#### **Dr. Grandin's Genetic Results**

#### A POLYGENIC CAUSE OF AUTISM

The genetic results did not reveal a singular cause for autism in Dr. Temple Grandin. For this reason, the researchers suspect a "polygenic" cause, or multiple risk factors. This is common for individuals with ASD, and includes many factors such as genetic variants and environmental factors.

#### KNOWN ASD RISK GENES (SHANK2, ALX1, RELN)

Dr. Grandin's genetic results revealed several genetic variants in known ASD risk genes, including a very rare variant in the *SHANK2* gene. This gene is known to be involved in formation of the synapse, or the space between neurons. Research has shown that variants in the *SHANK2* gene are common for individuals with autism and result in decreased connections between nerve cells.<sup>2,3</sup>



Another ASD risk gene identified in Dr. Grandin's results was a variation in the ALX1 gene, which plays a role in development. Variants in the ALX1 gene have been shown in many individuals with autism.<sup>4</sup>

Dr. Grandin's results also revealed a variant in the *RELN* gene. This gene is involved in cell positioning and neuronal migration. Research has shown that variants in the *RELN* gene are common for individuals with autism.<sup>5,6</sup>

#### DISEASE-ASSOCIATED GENES (WNT10A, MEFV)

Dr. Grandin's results also showed a known disease-causing variant in the *WNT10A* gene. This gene is implicated in several developmental processes.<sup>7</sup> The variant likely explains her microdontia, hypodontia, excessive sweating, soft and brittle nails, and hair loss.

Another disease-causing variant was revealed in the *MEFV* gene. This gene is involved in inflammation response following an infection or injury. Many variants in this gene have also been associated with a disease known as familial Mediterranean fever, which is treatable.<sup>8</sup> The variant would explain Dr. Grandin's peculiar rash, muscle rigidity, and pain, tingling and numbness in her feet.

This article only discusses some of the DNA variants identified in Dr. Grandin's results. Additionally, Dr. Grandin has undergone optical genome mapping (OGM), a cutting-edge genetic test which could further inform her health. The results of the OGM are forthcoming and will be published in the near future. If you are interested in genetic testing for your loved one with autism, call Lineagen at 801-931-6200 or visit lineagen.com — testing can be done with a fast and painless cheek swab for DNA collection.

#### **Concluding Message**

The genetic analysis and results of Dr. Temple Grandin's testing serve as an example to other individuals with autism who are considering genetic testing. Testing revealed that Dr. Grandin's autism is likely polygenic, as is the case with many individuals on the spectrum. Dr. Grandin considered the testing to be extremely beneficial having learned much about her health and what to avoid in the future.

Genetic testing can reveal many important autism risk genes and disease-associated genes. In most cases, it can also lead to treatment recommendations that can vastly improve one's quality of life. In the case of Dr. Grandin, several results led to treatment recommendations to improve her pain, symptoms and prevent further medical issues.

As more and more children undergo genetic testing, it opens the door to improvements in treatment. Although waitlists may be long for genetic counsellors and tests are not always covered by insurance, professionals continue to identify the value of such testing and parents advocate for more cost-effective testing. Change will happen over time. We appreciate Dr. Grandin's willingness to share such personal information. We also share her goal of helping children receive the best care, treatments and quality of life.

Written by Autism Advocate Parenting Magazine

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### Autism Advocate Printable Resources

### How to Use Visuals to Support Your Child's Play Skills

### Melissa Yapp

The words "play" and "children" go together like bread and butter. As parents, we spend a great deal of time supporting and encouraging our children's play. We research toys, read story books, and look for merchandise that we know our children would love. We purchase complicated storage systems to store toys and activities. If you're like us, you convert your dining room into a playroom. Play must be pretty important when you're a kid! Do we really know, however, why play is so essential for children's development?

Play is often referred to as the work of childhood. Developing play skills is fundamentally important to support development in other key areas. These areas include:

- Communication learning new vocabulary, following instructions, making simple requests
- Social Skills interacting with others, turn-taking, joining in play
- Motor Skills manipulating objects
- Attention Skills focusing on activities, maintaining attention to activities, focusing on details

Children with additional needs, particularly children with autism, can have difficulties developing play skills. There can be a range of reasons for such challenges. Children with autism often prefer **solitary play** and sensory play. They are more interested in manipulating objects in a limited way rather than using the toys in the way they are intended. Children with autism can also have difficulties with **joint attention**. They may not engage with another person to actively share attention and response to an object or event.



Another reason for such challenges may be difficulties with **imitation**. Imitation, or copying others, is the perfect platform for learning opportunities in a child's own environment. Children with autism can often have difficulty with shifting their attention to other communication partners to observe or copy their actions. A final reason could be difficulties with **pretend play**. Children with autism can be less spontaneous and play more like a learned routine.

### **Using Visuals to Support Play Skill Development**

Visual supports refer to items, objects or pictures/symbols, including drawings, photos or images, that can help your child's communication process. There is substantial evidence to support the benefits of visuals for children with autism, particularly in the area of play development.

Visuals can support play development in a number of different ways.

**Visuals are permanent:** Unlike spoken messages, which disappear, visuals remain for your child to refer to, gain ideas and process the messages.

**Visuals teach new skills:** Visuals can show your child how to do new things with the play items, such as building a train track or building block towers.

**Visuals can support simple choice-making:** Visuals allow your child to make a choice between tasks or activities.

**Visuals can support attention skills:** Visuals can give your child ideas on how to play with items, encouraging them to focus their attention on the activity for a longer period of time.

**Visuals help teach new language:** Visuals can show your child what they can do with the toys. For example, when playing with playdough, we can *cut*, *press*, *roll*, *poke*, or *pat* the playdough.



A free visual resource "Things to Make with Playdough" is attached. To make the best use of this resource, consider doing the following.

- 1. Print and laminate for longevity.
- 2. When playing with playdough with your child, have the playmat visible on the table. Follow your child's lead. If you child looks at or points to the snake, say "Let's make a snake" or "Let's make a pancake." Use the support vocabulary ideas as you are making it.
- 3. Repeat with the other pictures on the playmat.
- 4. Encourage your child to remain on the task for "one more turn" by encouraging him/her to make another creation on the page.

To get more play ideas like this, go to www.theteachingspeechie.com

Melissa Yapp is a speech pathologist and a former special education teacher. When she's not working or spending time with her husband and two spirited children, she can be found creating resources for professionals and families. She is the author of *My Puppy's A Poo Magician!*, a story for children with toileting fears. For more resources, competitions and giveaways, visit <u>www.theteachingspeechie.com</u>, follow Melissa on Instagram and Facebook <u>@teachingspeechie</u> or send her a message at <u>melissayappwriter@gmail.com</u>

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# THINGS TO MAKE with Playdough



Suggested Vocabulary cut, pat, roll, press, poke, push



**Pizza/Pancakes** eat, slice, sprinkles, cheese, ham



**Snake** long, short, eyes, slither, baby

- Print and laminate for longevity.
- When playing with playdough with your child, have the playmat visible on the table. Follow your child's lead. If you child looks at or points to the snake, say "Let's make a snake" or "Let's make a pancake." Use the support vocabulary ideas as you are making it.
- Repeat with the other pictures on the playmat.
- Encourage your child to remain on the task for 'one more turn' by encouraging him/her to make another creation on the page.







**Balls** Roll, 1, 2, 3, big, little

39 / SEPTEMBER 2021 AUTISM ADVOCATE PARENTING MAGAZINE

### GLUTEN-FREE & CASEIN-FREE RECIPE



# Oven Pancakes

### INGREDIENTS

gluten-free flour2 cups	
coconut sugar <sup>1</sup> /3 cup	
tapioca starch $\frac{1}{3}$ cup	
baking powder4 tsp	
salt	
large eggs or *flax eggs2	
buttermilk or almond milk2 cups	
vanilla2 tsp	
unsalted or vegan butter melted½ cup	

### **INSTRUCTIONS**

- 1. Preheat oven to 425°F
- 2. Combine wet and dry ingredients separately.
- 3. Add the wet ingredients to the dry ingredients and stir until combined.
- 4. Line a baking sheet with parchment paper.
- 5. Pour the prepared batter onto the lined baking sheet.
- 6. Bake for seven minutes.
- 7. Check to see if the pancake is done by poking it with a knife. If the knife comes out clean, the pancake is ready.
- 8. If the knife does not come out clean, bake for another two minutes.
- 9. Serve with sliced strawberries or your favourite fruit with maple syrup.

\*To make a flax egg, combine 1 tablespoon flax meal with 3 tablespoons water and allow to set for 10 minutes.



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

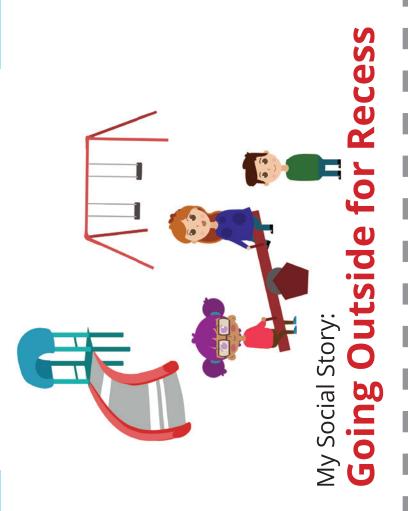
The need to eat quickly turned cooking and baking into hobbies for me, and having family members with sensitivities to gluten while being picky eaters (some of them) challenged me to prepare food that is healthy for them while still being tasty.

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

Happy Cooking!

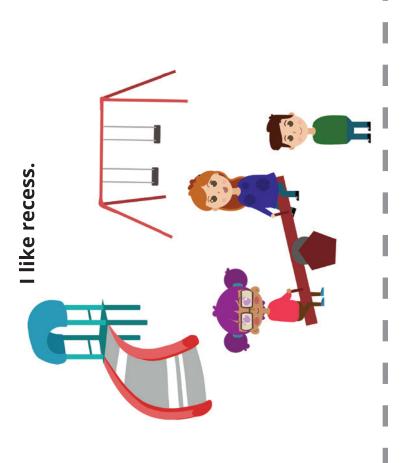
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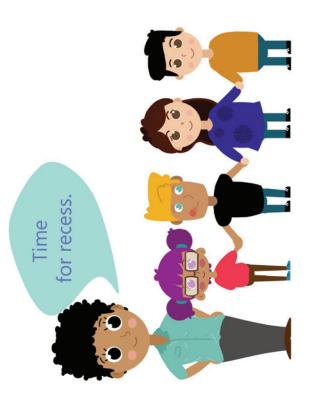


Recess is a break from schoolwork. Recess is a time to get some fresh air and exercise.

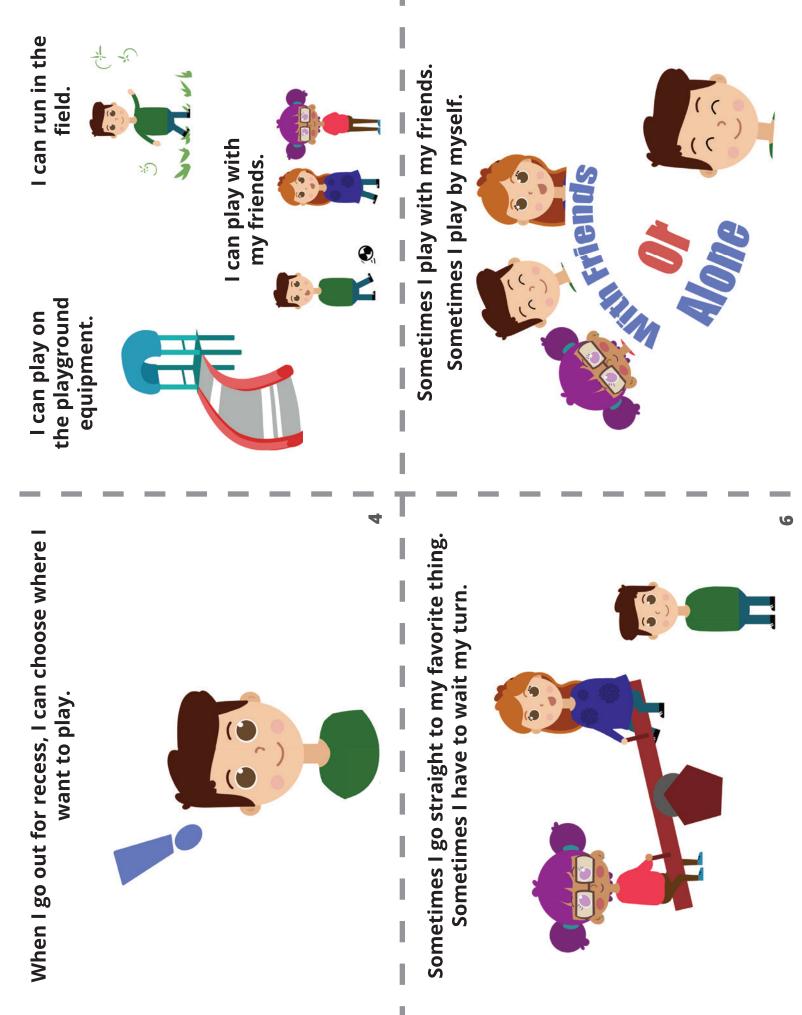


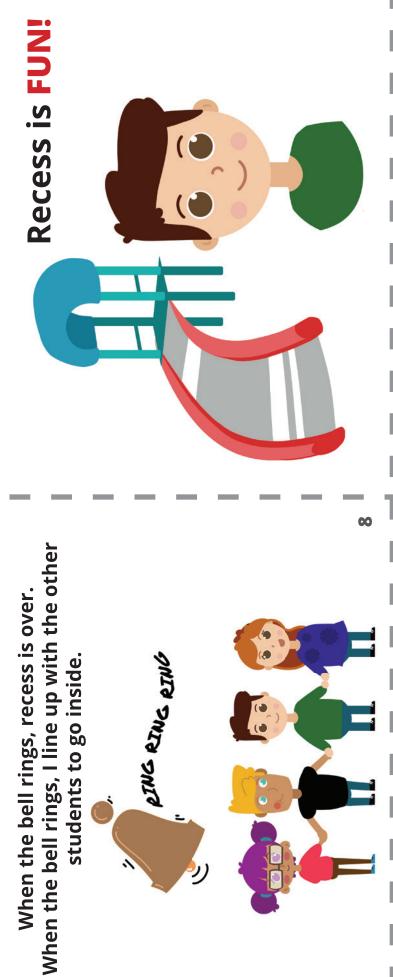


When my teacher tells me it's time for recess, I get ready to go outside. I get in line near the door.



2

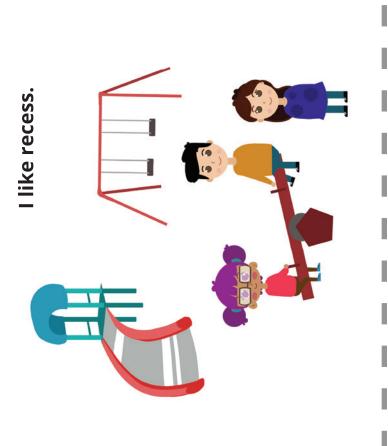




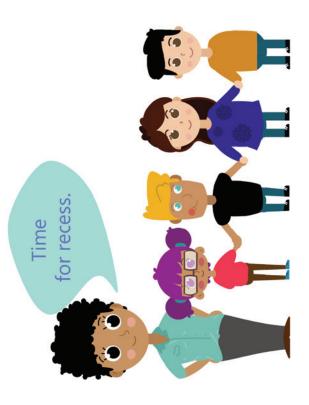


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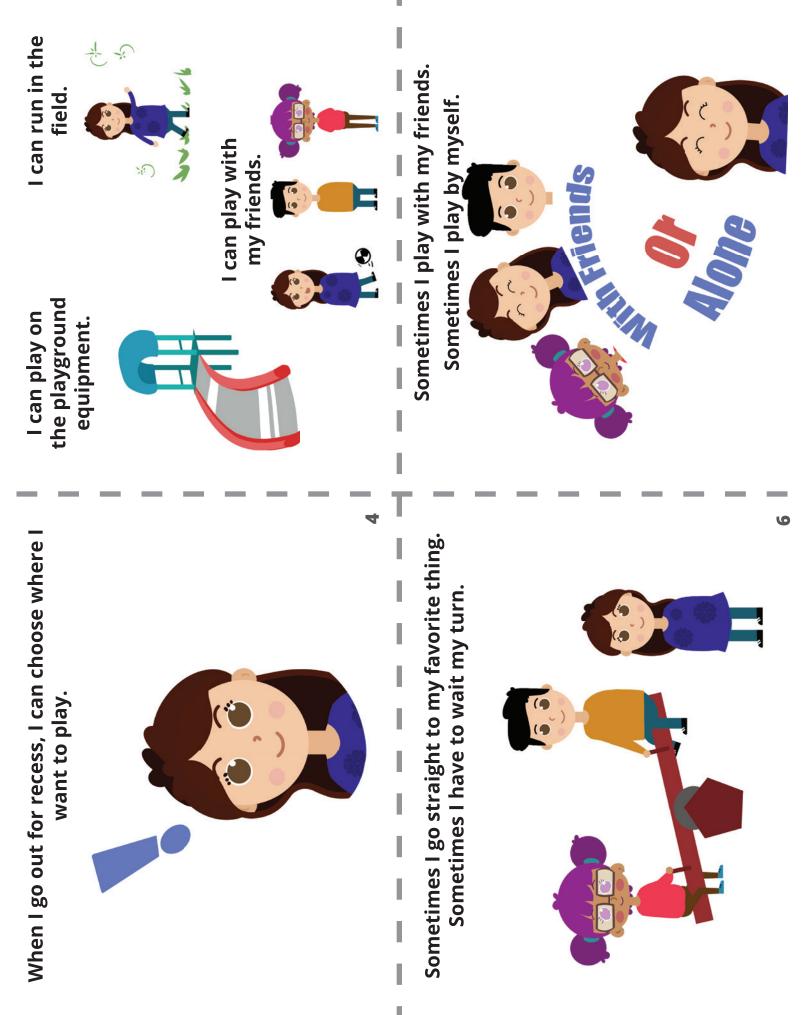


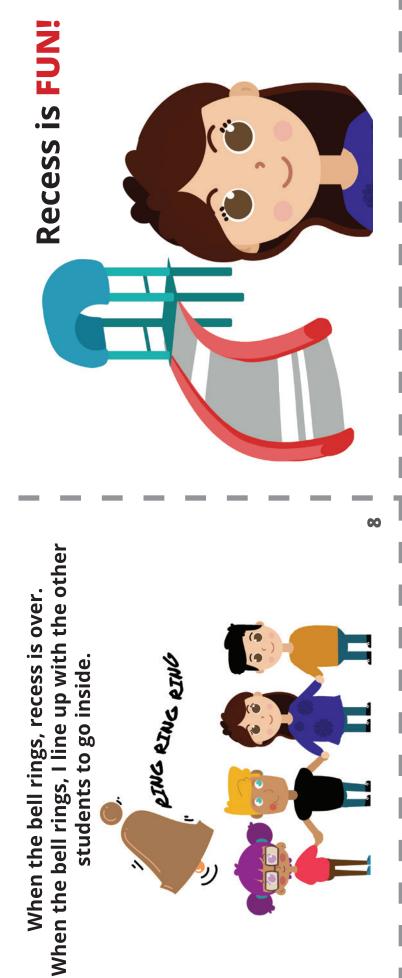


When my teacher tells me it's time for recess, I get ready to go outside. I get in line near the door.



2









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:	
Items I want to discuss with my Autism Support Team:	

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

www.autismadvocateparentingmagazine.com

The sign of great parenting is not the child's behavior. The sign of truly great parenting is the parent's behavior. – Andy Smithson

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