# Autism Parenting Magazine

Issue 72

## Enhance Your Child's Capacity for Self-Love

## Simple Ways to Use ABA Intervention in Family Routines

## EVIDENCE VS. SPECULATION: How to Know Which ASD Therapies Work

## Sensory Enrichment Therapy: A New Approach

## SENSORY SOLUTIONS FOR LIFE

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# Autism Parenting Magazine

Do you have a story to share? Perhaps you have information that would be helpful to other parents with ASD kids and want to share the info. Why not share your story/info with us? Autism Parenting Magazine wants parents and caregivers to unite to help each other. Our writing guidelines are simple.

Ideally, the topic needs to be relevant to the magazine. Any topic that is related to parenting a child with autism or being a person on the spectrum that is parenting would be a relevant topic. Released on a monthly basis, the magazine features the latest news, tips, and advice for parents of children with autism. With helpful advice that covers subjects like: behavioral tips, sensory processing issues, mitigating meltdowns, special education needs and getting access to services, we are confident that the magazine will become a must read for parents of children with autism.

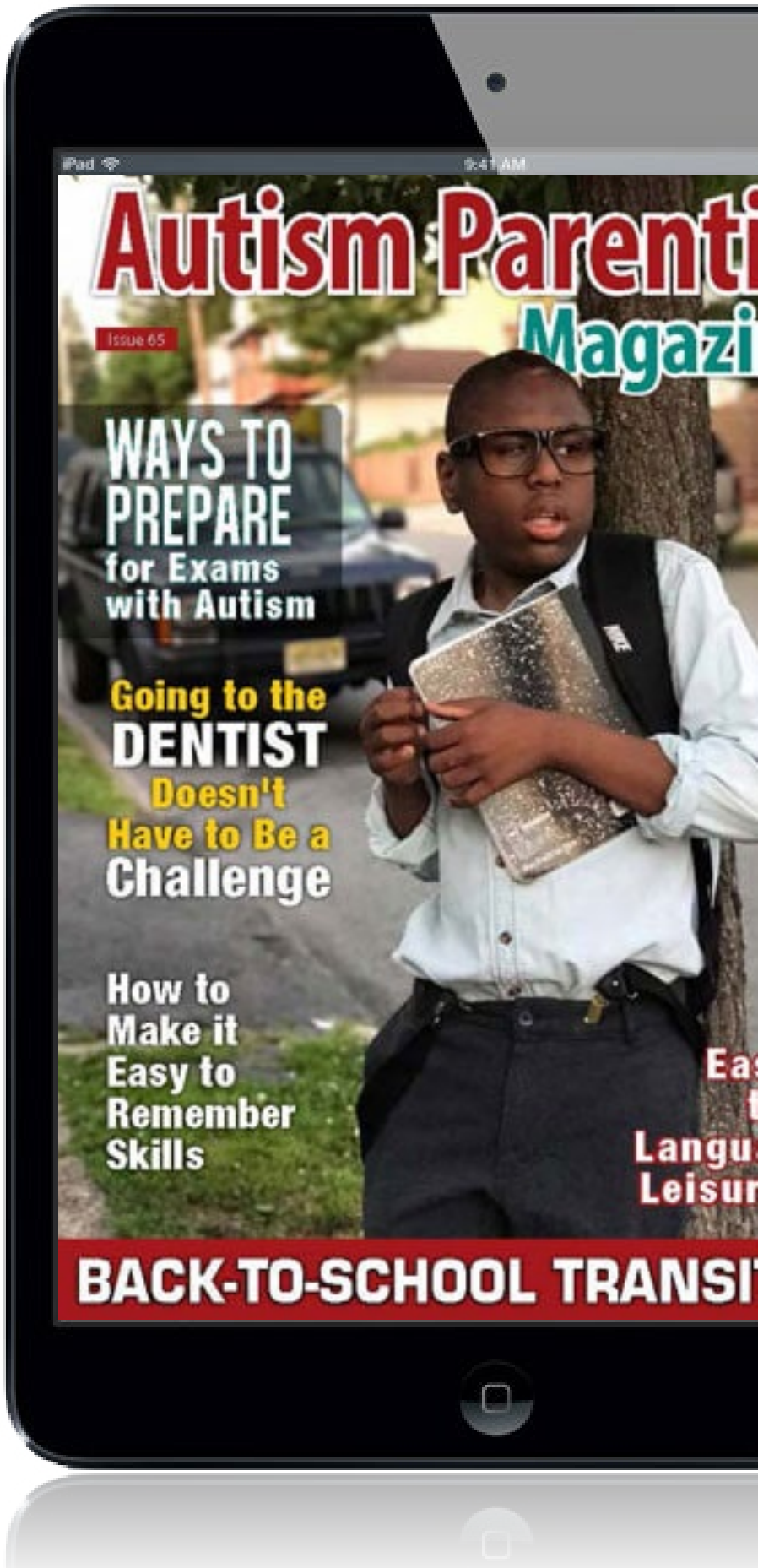
We do ask that you submit a topic, title or idea of the article to make sure that someone hasn't already covered the same thing by emailing the editor. You may use a blog post that you have posted on your blog already.

THE ARTICLE SHOULD BE A MINIMUM OF 300 WORDS. FONT DOES NOT MATTER. WE DO ASK THAT IF YOU USE SOURCES TO PLEASE CITE YOUR SOURCES AT THE END OF YOUR ARTICLE TO AVOID PLAGIARISM.

At the end of your article please include a few sentences about yourself and your writing or autism related background with links to your site or products.

Please note that we cannot post your article without a small bio. So please do not forget to send a few sentences about yourself with your article.

If you have something interesting or informative to share please email editor@autismparentingmagazine.com.



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# Top Strategies to Enhance Your Child's Capacity for Self-Love

By Connie HAMMER, MSW, PCI Certified Parent Coach®

**Self-love is something all human beings struggle with regardless of age or ability. But when children perceive themselves as flawed—either from an autism label they have been given, or a negative comment from a bystander, or an expectation they cannot realistically meet—the ability to love themselves can be very difficult.**

The book *The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism* is written by Naoki Higashida about a 13-year-old nonverbal boy with high-functioning autism. When I read the book, I was struck by this young author's insight, maturity, and wisdom beyond his years as he responded to the question, "Would you like to be 'normal?'"

He stated, "For us, you see, having autism is normal—so we can't know for sure what your 'normal' is even like. But so long as we can learn to love ourselves, I am not sure how much it matters whether we're normal or autistic." How profound for such a young mind!

How does a child learn to love himself or herself? Unfortunately, our current media-saturated society bombards children with messages and images of unrealistic perfection to which they constantly compare themselves. This makes it difficult for children to get in touch with and accept their true and precious selves. On Valentine's Day, the focus is all about showing our love to others, which is great! Unfortunately, loving others means giving from the inside, and if nothing substantial or positive exists within, there's nothing to draw from and share with others.

Helping your child explore how he/she feels about himself physically, mentally, emotionally, and spiritually will help him/her fulfill a sense of self and supply him/her with something to send out to others and have it returned in greater measure.

So where does one start? How do you teach a young child to love himself or herself enough to have a positive sense of self, and yet not develop an inflated ego that makes one feel so entitled it leads to indifference?

I believe there is a connection between self-talk and self-love. Regardless of your child's challenges and abilities, ALL children benefit from learning to listen to the positive voices inside their heads, and if your child doesn't have many, you need to help him/her develop some.

**“One way to practice self-compassion is to treat yourself kindly by increasing the amount of positive self-talk and minimizing your negative inner voice. Studies also show that when we think soothing thoughts about ourselves, oxytocin and opiates are released, which makes us feel good.”**

Self-compassion is a good first step to take. It is something Kristen Neff, author of the book *Self-Compassion – the Proven Power of Being Kind to Yourself* is passionate about. Her research counters the argument that loving yourself makes you self-centered and unmotivated.

Dr Kristin Neff, associate professor in human development and culture at the University of Texas in Austin, has completed a study that shows how self-criticism undermines motivation. Negative self-talk is an attack on our self-concept, and we feel threatened. “With self-criticism we are the attacker and the attacked,” which is a double whammy according to Dr. Neff [1]. As a result, the fight-or-flight response takes over and releases large amounts of adrenaline and cortisol, and stress levels increase. And if you are a constant self-critic, your body will eventually shut down to protect itself and depression can easily set in, making both love of self and love of others more unlikely.

One way to practice self-compassion is to treat yourself kindly by increasing the amount of positive self-talk and minimizing your negative inner voice. Studies also show that when we think soothing thoughts about ourselves, oxytocin and opiates are released, which makes us feel good.

So get that voice inside your child’s head to practice compassion and focus on the positive. The power of positive self-talk for children on the autism spectrum will help override any existing negative self-talk that may be keeping them from loving themselves.

Here are two activities you can do to ban the self-critic inside your child’s head and paint a more affirmative self-portrait.

## Activity 1

Have your child list some positive traits he/she has such as honesty, kindness, patience, care, intelligence, etc. Add to the list of characteristics you believe he/she possesses as well. Then take several sheets of blank paper and write one trait on the top of each. Leave the rest of the page blank for writing down examples of how this trait is displayed. Your child might be able to identify and voice a positive thought, like, “Mom told me I was kind when I shared my ball with my brother.”

If your child struggles with this, prompt him/her by pointing out how you see these positive attributes displayed. Tell your child what you observe regarding each trait and write it down: “You were patient when you waited for your turn at the slide.”

Repeat this with other family members and friends so your child can see his/her positive traits from as many perspectives as possible. A sibling might write, “You were kind when you told me I could play with you.”

As each page grows with examples of how your child demonstrates each quality, a visual picture will begin to emerge that is full of positive, loving energy. Post these sheets in your child’s room and review one

each morning before he/she starts his day and another at night before you tuck him/her into bed. This will program your child's brain with thoughts that trigger self-love and help create more of the same.

## Activity 2

Some children with autism are visual and think in pictures. Look for pictures that signify the affirmation you want him/her to absorb and cut them out. Have your child look for pictures of what is important to him/her and what he/she's good at, or wants to be good at.

You can then create a vision board with your child using the photographs and pictures. Doing this positive activity together will not only increase your connection with your child, but it will also give you insight into his/her likes and dislikes, passions, and interests.

Why not spread the wealth and promote self-love for all family members? Consider doing these activities for each member of the family highlighting a different individual each week or month. Then stand back and watch the self-love grow!

[1] http://www.self-compassion.org

*Connie Hammer, MSW, PCI Certified Parent Coach®, and author of Autism Parenting: Practical Strategies for a Positive School Experience - Over 300 tips to help parents enhance their child's school success. Hammer coaches and supports parents facing the challenges of raising children with autism, or other special needs, by helping them deal with the diagnosis and empowering them with time-saving tactics and resources to positively impact their children's potential.*

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# Autism and ADHD: Do You Know How to Help with Co-Occurring Conditions?

By Alexis ANDERSON


Among school-aged children, an estimated 11 percent are diagnosed with attention deficit hyperactivity disorder (ADHD). What most parents, teachers, and school counselors may not realize is that children with ADHD may also manifest symptoms of autism spectrum disorder (ASD). Having two or more co-occurring diseases or disorders is defined as being comorbid or having comorbidities. A 2014 review of studies looking at comorbidity found that "between 30 and 50 percent of individuals with ASD manifest ADHD symptoms (particularly at pre-school age), and similarly, estimates suggest two-thirds of individuals with ADHD show features of ASD." Researchers also determined that children with this comorbidity often had more severe levels of dysfunction—which is why early and accurate diagnoses and effective treatments are so important for parents to help these students succeed.

The good news is that many of the treatments for one disorder can be helpful for the other—which is highlighted in *Strategies for ADHD: How School Counselors Can Help Today's Students Succeed*, a recent post by Counseling@NYU, which offers online masters in school counseling from NYU Steinhardt. Here, we'll look at strategies, like behavioral therapy, as well as the similarities and differences of both diagnoses and how they often overlap.

## What's the Difference?

Experts noted that it can be difficult to isolate a diagnosis of ADHD or ASD since the symptoms often overlap. What's more, the symptoms of ADHD are often the same behaviors exhibited in typical childhood development—except that they persist and worsen over time.

Here are a few similarities between ADHD and ASD:

- Difficulties with attention
- Difficulties communicating with peers
- Impulsivity
- Various degrees of restlessness or hyperactivity
- More common in boys than in girls
- Present, at least partially, at preschool age
- Have a known genetic pre-disposition
- Cause significant behavioral, academic, emotional, and adaptive problems in school, at home, and elsewhere

As far as what's different, one study says, "ADHD is defined by impaired functioning in the areas of attention, hyperactivity, and impulsivity, whereas ASD is characterized by core social dysfunction and restrictive-repetitive behaviors." These ASD traits include behaviors such as:

- Unresponsiveness to common stimuli
- Intense focus and concentration on a single item
- Repetitive movement
- Avoiding eye contact
- Withdrawn behaviors

## More Than One Diagnosis?

Available research on the comorbidity of ASD and ADHD is still scarce because prior diagnostic standards made the diagnosis of one an exclusion for the other. However, the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), published in 2013, included criteria that allowed clinicians to diagnose an individual with both disorders at the same time.

With the ability to better understand the impact of ASD and ADHD as comorbid conditions, more accurate diagnoses, and more effective treatment options may be available. For students with these conditions, such insight gives educational professionals such as school counselors a better understanding of what strategies they can use to help these children and their parents to succeed.

## Strategies for Success

Partnering with school counselors is an important way for parents to help their children with these co-morbid conditions succeed. A common approach that counselors use for helping kids with ADHD is through the use of evidence-based interventions (EBIs), which include behavioral techniques that are effective for children with ASD, too. Specifically, Dr. Chacko says school counselors can implement strategies that address organizational skills and the transition across settings:

"It is important that treatment should focus on outcomes and processes, not diagnosis. A child with ADHD and/or ASD can benefit from EBIs that focus on the outcomes that are problematic and focus on tailoring the EBIs to meet the unique needs of these children."

Additional strategies parents can use at home to help their children dealing with this dual diagnosis include things like:

- Providing positive communication and reinforcement
- Creating and maintaining as much structure in their day-to-day lives as possible
- Posting lists, rules, and schedules to help with organization
- Encouraging physical exercise as a release
- Learning more about available behavior parent training programs

Experts note that "whereas both ADHD and ASD include behaviorally oriented parental intervention, the role of the family is conceptualized similarly; for ADHD and ASD 'parent training' often involves teaching parents to manage the behaviors of their children; in addition, ASD 'parent education' also places emphasis on individualized treatments that provide parents with tools to promote their child's (social) skill development."

Although the presence of comorbid conditions presents students—and their parents—with additional challenges, the good news is that there's help available. By accessing expert resources, like school counselors, parents can learn how to use effective strategies to help their children succeed.

*Alexis Anderson is a digital PR coordinator covering K-12 education at 2U, Inc. Alexis supports outreach for their school counseling, teaching, mental health, and occupational therapy programs.*

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# The End of Me

By Victoria BAKER

It was an unusually warm spring day. Ian bounced out of the van ready for a quick stop at our local Whole Foods. The after-lunch crowd was quieter, less sensory overload for both of us. Our excursion was an excuse for me to pick up much-needed groceries. For Ian, it was a welcome break from homeschooling and a chance to move around a bit. My idea of getting the wiggles out had a totally different meaning for Ian!

The emotional and academic challenges of public middle school were daunting. Without the school's acceptance of Ian's autism spectrum disorder (ASD) diagnosis, there were no educational or behavioral plans in place. It is difficult enough for typical students transitioning into this period of their lives, much less for one wrestling with tremors, motor tics, irritable bowel syndrome, and food allergies, to name a few. Ian experienced bullying. He was hit, and anxiety attacks resulted in meltdowns and academic regression.

*"The Lord is my Shepherd; I shall not want."*

Years of advocates, lawyers, mediation conferences, court petitions, school meetings, medical appointments, hospital stays, holistic doctors, metal detoxifications, vitamins, supplements, and therapies all seemed to feed into one cold March afternoon. It was the third time his school case manager phoned to tell me Ian had been hit. At home, he wrote notes saying, "I want to die." He chose to motion his needs instead of speaking, slipping into selective mutism. Fearful he would further regress, I researched homeschooling as an alternative, which soon became our only option.

Two months after that call, Ian, Danny, his younger brother, and I moved through the tears and the trauma of those incidents. Homeschooling, we were amidst healing, having fun, and at last, enjoying life. Ian and I were learning together. Juicing, walking in our neighborhood, exercising with Brain Gym®, snuggling, and reading replaced some of the exhaustingly emotional effects of his autism, daily vomiting ep-

isodes, and frequent meltdowns. Ian walked into the market that day happy, beaming.

*"He makes me to lie down in green pastures. He leads me beside still waters."*

*On your mark, get set, go!* was one way to describe Ian's entrance into the produce section. At 13 years old with facial hair, his gait still awkward, he stood as tall as my five-feet-two frame. Without hesitation, Ian began to skip. Yep, I said it: skip! Ian was having the time of his life, laughing, smiling, singing, and skipping! "Hey, guy," I said, "stay close to me." Yeah, that didn't happen. My eyes darted between shelves grabbing what I could to keep up with Ian who glided up and down each aisle. With each new turn, scouring, judging faces met my glance, void of compassion.

*"He leads me in the path of righteousness for His name sake."*

"I can't believe this," I thought to myself. My guy is having a wonderful day, he's happy. No one is hitting him; he's not being made fun of or throwing up—he's *talking* for God's sake! "Look away, please! Stop with your condescending stares," I wanted to shout.

*"Yea, though I walk through the valley of the shadow of death, I shall fear no evil: for thou art with me."* My spirit ached.

Scooping up this and that, another scowl greeted me in each new aisle. More thoughts stifled: "I am going to make a T-shirt. It's gonna read, 'This is autism too!' How can people be so cruel? Oh, wait, I know, a big A with a line through it. That will do it!" I contained myself—barely.

*"Thy rod and thy staff they comfort me."*

"He's eating strawberries for the first time in his life without gagging. Maybe they were jealous that he could skip without wearing Depends. Oh, I must be a mean momma," I decided during this internal conversation with myself.

I let Ian know it was time to check out. My heart whispered to my Creator. "Father, why do I feel such anger?"

*"Thou preparest a table before me in the presence of mine enemies."*

"Ian has been through so much. Lord, I can't stand the glares. Please, Father, help me. Ian doesn't seem to notice. But for me, oh Jesus, I may be walking, but I'm on my knees on the inside. I need you."

I was wearing myself out, or maybe Divine Love was provoking me, teaching me, *to let go*.

Free and unaware of his own wonderful distraction, Ian picked a checkout and stopped to a halt. There was a lot of action going on in this aisle. And, it was loud.

*"Thou anointest my head with oil; my cup runneth over."*

That wasn't the only thing running over. Tears greeted us as we settled into the checkout.

First, we saw an adorable but screaming toddler in the shopping cart ahead of us. He was inconsolable. Right in front of their full cart, we found his mom, cradling her infant. The little one's pitch was piercing. Time and the waiting cashier stood still. This sweet woman was paralyzed looking at her two screaming children with what I knew was an all too familiar look of defeat. I was sure her own meltdown was seconds away.

Ian and I looked at each other, and I whispered, "Ian, we have to help." Taking *all* things literally, that was the cue Ian needed to hear. Quickly, we unloaded the cart onto the belt. As I moved closer to bag the items, I turned to see Ian speaking to the toddler, "There, there, it's going to be okay." Those words were the few spoken during our encounter. The infant was crying so hard the mom motioned; she couldn't move. Reaching the end of her rope, perhaps herself, she was unable to open her handbag.

The cashier and I found her wallet and gingerly removed payment for her groceries. Perfect strangers were entangled in this personal transaction. I gave her reassuring smiles above the cries. As Ian playfully leaned into the cart, the little boy began to laugh. A sigh from the frazzled mom filled the atmosphere. Her tension released, her baby at last snuggled into his mother. I held back my tears. It was beautiful and intimate. For a moment, we were drawn by a tender Love that boldly connected us. The mom, restored and strengthened, left the store with her peaceful little ones.

*"Surely goodness and mercy shall follow me all the days of my life."*

It was our turn. The cashier watched this boy of mine (the skipper with hair and clothes in usual disarray, no

matter how I tried, really) calm the storm around her. Silently, without as much as a glance, she checked and bagged our groceries.

Just then I realized I didn't need to make a T-shirt. There was no longer the need to scream or shout about anything. Fear and frustration cannot remain in the presence of Love, the One and Only, Divine Love and Grace. I saw Ian in place of stares. My shortcomings were invaded by mercy. For this mom and me, comfort was realized. Our portion was not withheld. "Thank you, Father." Love soaked into my being and spilled into my deepest cracks. And oh, there's plenty of them.

I beamed in awe of this Relentless Love as I watched Ian sing his way out of the store. Raw, powerful grace, you might even call it organic, healed my aching.

*"He restoreth my soul."*

Let's say partnering with the Almighty is an evolving habit for me. Forgetting and surrendering my worries and yes, even myself sometimes seems unnatural. Yet, when I do, on purpose, my energy and intention seem to change for the better. I pray it's for the highest good. It wasn't the first time Divine Love showed up when I reached my end. There wasn't room for my pride and disappointment in that checkout line. Those enemies of my soul seemed to fall away.

Ian thrived in his special education homeschool program. Along with nutritional and therapeutic supports, his academic levels soared five grade levels in three years. During year two of homeschooling,

I went back to the school district, faced my so-called giants, and at last, secured an appropriate education for Ian, 12 years in the making. On December 12, 2012, his multiple disabilities were placed in writing, and we looked for a therapeutic high school to meet his needs.

My brave heart began high school at the age of 17. He stumbled upon a film job during a dual enrollment program in our community college while attending his last year of high school. At the same time, Ian's school was speaking with the same film production company which led to an internship for him. This fall Ian began a new life at college in an east coast film school. Talk about serendipity.

In my lifetime, I may reach the end of me hundreds, even thousands, of times. But I know when *all* that remains is Love, the end of me is the beginning of infinite, magnificent possibilities.

*"I will dwell in the house of the Lord forever."*

- Psalm 23 The Holy Bible, (NIV)®

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# Evidence vs. Speculation: How to Know Which ASD Therapies Work

By Stephanie BATES, BCBA

Search online for "autism therapy for children," and you will get more than 90 million results offering information on everything from applied behavior analysis (ABA), equine therapy, restricted diets, hyperbaric chambers, speech therapy, occupational therapy, and alternating tactile stimulation, to behavioral therapy, chelation, electroconvulsive therapy, and so much more.

Parents want the best for their children and are willing to try anything that might help, but identifying a therapy that will help can be confusing. With so many options available, how can parents tell which therapies actually work?

The answer is "evidence-based therapy." Simply put, "evidence-based" refers to a treatment that scientists have found to be effective at helping people with specific problems. Looking for evidence of a therapy's results can help you tell the difference between therapies that have been shown to help many kids with autism and therapies whose impact is unknown.

## What is Evidence-Based Therapy?

Evidence-based therapy may sound complicated, but the basics are simple. First, it means scientific research has been conducted with enough participants who have shown statistically significant improvement. Scientists use advanced mathematical

tools to determine whether participants improved due to the treatment, random chance, or something entirely unrelated.

Evidence-based also means a panel of experts has reviewed the experiment and its results from various fields, and it has been duplicated by other qualified researchers.

The bottom line: An evidence-based therapy for autism spectrum disorder (ASD) is one the scientific community has deemed effective for a large number of children.

Parents are understandably swayed when they hear another parent talk about how much a therapy helped their child. Without scientific evidence, however, it is impossible to know what worked and why. One child's improvement with an autism therapy does not necessarily transfer to another child.

Most unproven therapies will not hurt your child. The biggest risk is wasting time. The hours you spend each week on an untested autism therapy could be spent on an evidence-based therapy program that has been proven to work. In the meantime, your child has missed opportunities to make progress.

## Evidence-Based or Not?

Figuring out whether an autism therapy is scientifically proven and is likely to help your child does not have to be complicated. Asking a few simple questions can provide the information you need to make an educated decision.

1. Is this therapy evidence-based? It may sound obvious, but you should ask this question about any therapy you are considering. A "no" answer is not necessarily the end of the conversation, but it can help you decide whether the therapy is worthwhile and where it might fit in your child's treatment plan.
2. How many studies have been conducted on this therapy? There is no exact right answer, but you should look for therapies with at least five to ten studies for each skill area or behavior being measured. For example, more than 600 research studies have proven that Applied Behavior Analysis (ABA) is effective for children with autism.
3. What types of children participated in the studies? As parents know, most children with autism need help in a number of areas. Evidence that proves a therapy works for children who have difficulty speaking is only valuable if that is a challenge facing your child. Ideally, you are looking for studies that show results among children whose needs are similar to your child's.
4. Have experts from other disciplines confirmed the results? If a panel of speech therapists, behavior analysts, and teachers have all confirmed the quality of a study, you can be more confident in the findings.

Additional resources can also be valuable. The National Autism Center published a 2015 report titled *The National Standards Project, Phase 2*, which is the largest review of autism research to date.

The report includes a list of groups that provide systematic reviews of autism research, such as The National Professional Development Center on Autism Spectrum Disorder and the Agency for Healthcare Research and Quality.

## Watch Out for Red Flags

Not all autism therapy research is conducted with the same level of scientific quality. You do not need to become an expert in research methods or statistics, but a little skepticism can help you avoid therapies whose evidence is questionable.

Start by asking a trusted teacher, board-certified behavior analyst (BCBA), speech-language pathologist, pediatrician, or another clinician to help review the literature about an autism therapy you are considering.

Watch out for red flags:

- "Sales" Research

  One or two studies that support an autism therapy may have been designed to produce positive results—especially if the research was conducted or sponsored by the company that is selling the therapy. Many people selling autism therapies are eager to get more business, so they may state that their treatments are evidence-based even if there is poor evidence or no evidence.

- No Data

  The data and research methods behind a study should always be published so other researchers can review and duplicate the results.

- Overpromising

  Be wary of any research showing that one autism therapy delivers more and better results than any other therapy. Outcomes that seem too good to be true usually are, no matter how much you would love to see your child make that progress.

- Unestablished Therapies

  A few large reviews of autism research provide lists of "unestablished interventions." According to panels of autism experts from multiple disciplines, these autism therapies do not have enough evidence to show whether they are effective. The research that exists may not meet accepted standards, show no treatment effects, or even show negative effects.

  See *The National Standards Project, Phase 2*, page 72 for a list of unestablished therapies for autism.

## Evidence-Based Therapy in Action

The evidence-based approach to autism treatment covers more than proof of working for kids with autism spectrum disorder (ASD). It also includes how that therapy is delivered, which professionals sometimes call "evidence-based practice."

For example, a therapy provider should collect data during treatment. You may notice changes in your child's behavior, but the provider should constantly gather data and share it to demonstrate progress. If the data does not show results after several months, it may be time to switch to a different evidence-based therapy.

It is important to remember that each child with autism has unique needs, so the fact that a therapy is evidence-based does not guarantee it will provide the best results for your child. Other evidence-based therapies may be more effective.

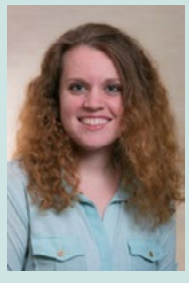
Professionals who use evidence-based practices should also talk with you about how the therapy works, how much follow-up is required at home, and other considerations to help choose the evidence-based therapy that will work best for your child and your family.

## Making an Educated Decision

The list of treatments for autism is almost endless and grows every year. The good news: There are always new ideas to help your child learn and improve. The bad news: Many of these ideas are untested and unproven.

The dilemma for parents is figuring out which therapies will help children reach their full potential. Therapies backed by scientific evidence are the best place to start and should be the foundation of your child's treatment plan. Unestablished therapies without evidence behind them might help, but they are a gamble.

There are many ways to evaluate autism therapies, including word of mouth and online anecdotes. Examining the evidence supporting a therapy is one of the most powerful tools and one that can help you make the best decisions for your child.



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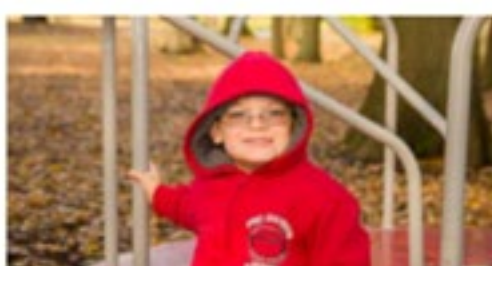

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The app is developed by See Beneath, a San Diego-based nonprofit co-founded by autism experts with years of experience in autism research and intervention.

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# Calming Self-Injurious Behavior with a Simple Touch

By Tal BADEHI

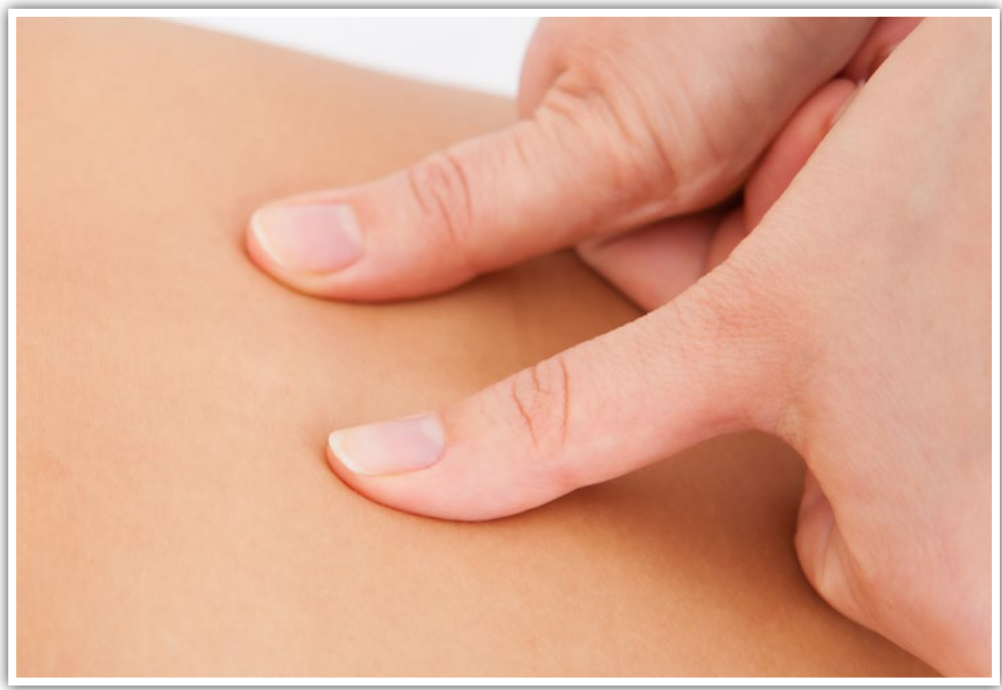
**The hardest part of treating people with autism spectrum disorder (ASD) is observing self-injurious behavior. It is especially difficult for the individual's family and carers to witness self-harming with such aggression when they do not always understand the reason or cause of the trigger.**

Therefore, I take my clients' needs very seriously, and I work on a one-on-one basis, using personalized techniques to help identify the cause, lessen the distress, and prevent self-injury. Mary (not her real name), is one of my clients. She has an ASD diagnosis complex-needs. Before Mary attended my sessions, she would often display reparative self-injurious behavior, involving hitting herself incessantly around the eyes and temples. The hitting was affecting her vision and could eventually lead to blindness. Mary's carers had no choice but to make her wear a protective helmet (made from foam-like rubber). It covered most of her head, leaving only a small opening at the front of the face, and causing Mary to sweat a lot.

## The Shiatsu treatment

Mary takes part in weekly Shiatsu sessions. As she comes to the treatment and lies down on the Shiatsu mat, she keeps banging her head. During the Shiatsu session, Mary becomes relaxed, and the beating stops for short moments. Therefore, I remove Mary's helmet during the sessions so she can get some relief from it and I can get to treat her around the head and neck. I place myself in a position that allows me to protect Mary's head if she tries to hit herself.

I have noticed Mary sometimes lift her hand towards her head but holds herself and stops the movement before the strike. Witnessing this made me think that her self-hitting might not be voluntary and that she is trying to stop herself, with little success. I wondered how I could assist her in taking control of her movements.



As I had already learned, people with autism experience different sensory-regulation than neurotypical people do, so I thought Mary might hit herself to pacify some sensory stimuli around her eyes and temples. Assuming so, I tried placing my hands on Mary's temples and forehead and just stayed there, seeing what happened. I was astonished to see the self-hitting immediately stop. Not only did it end, but Mary started smiling and laughing! She seemed to enjoy the touch on her sore temples very much.

## What happened here?

In my understanding, either Mary felt pain around her afflicted temples and eyes, or she required the stimuli of touch in those areas. She was not able to satisfy these need without hitting herself forcibly and perhaps exacerbating the situation in the process. The relaxing effect of Shiatsu, combined with placing hands on the sensitive areas, probably

calmed this urge and allowed Mary some relief from her self-injurious behavior.

I am glad to have found a way to help Mary. It required out-of-the-box-thinking, as in the beginning I assumed Mary could control her movements. Realizing her actions were involuntary took me on a different approach and helped me find a possible solution for her problem.

*Tal Badehi is a Shiatsu and acupuncture practitioner based in London. He works with autistic people with complex needs for many years and is proficient in allowing this group of people to enjoy the benefits of therapeutic touch and holistic treatment. Tal works in autism services and private clinics in Central and North London.*

*Website: www.atouchbetter.co.uk*

# Simple Ways to Use ABA Intervention in Family Routines

By Meme HIENEMAN, PhD, BCBA

**Applied behavior analysis (ABA) interventions have been proven to be extremely effective for children with autism spectrum disorder (ASD), increasing their skills and reducing problem behavior (National Autism Center, 2015). There are a variety of ways ABA can be provided, but the way it is often delivered, through intensive 1:1 therapy, has come to be viewed as the primary, if not only, option. This article will describe how ABA can be used within typical family routines to improve quality of life for children and families.**

## Issues with Delivering Intervention

Intensive 1:1 ABA therapy has the advantage of changing behavior quickly under controlled situations. It can, however, have drawbacks for some children and families. First, the skills developed can sometimes seem rote or not fit the circumstances. For example, a child may learn specific words or problem-solving strategies that other children do not typically use, setting him/her apart from same-aged peers. Second, some children resist participating in repeated learning trials, resulting in an increase in their problem behaviors. Third, the impact of 1:1 therapy may not "generalize" across time, people, and/or circumstances. A child may perform well for his/her therapist only. Finally, when poorly planned, ABA therapy can interfere with valued family routines. Parents may find themselves rearranging

daily activities to accommodate professional schedules. For these reasons, ABA therapy can increase stress rather than make family lives better.

It is important that parents understand that ABA strategies can be embedded in typical family routines. This approach can improve day-to-day interactions and activities, thereby improving family quality of life. Current early intervention and family support programs emphasize aligning goals with family values and needs, empowering parents and other typical caregivers, and focusing on strategies that can be easily maintained in natural settings (Division for Early Childhood, 2017). Recent research in routine-based ABA, also known as "positive behavior support" (Bailey & Blair, 2015; Fettig & Barton, 2013; Lucyshyn et al., 2015; Sears, Blair, Lovannone, & Crosland, 2013), suggests it offers a great alternative or supplement to direct intensive treatment.

## Process of Routine-Based Intervention

The following sections of this article will describe how ABA can be used within family routines, providing an example during sibling play. The process includes identifying goals, assessing patterns, designing strategies, using the plan, and monitoring outcomes.

### Identifying Goals

The ABA process begins with identifying child and family goals, considering ways in which the child's quality of life needs to be enhanced, and focusing on the routines the family most wants to improve. A family might choose getting ready for the day, hygiene, meals, playing with siblings or peers, or participating in extracurricular activities, for example. The specific goals of intervention, including skills to develop and behaviors to decrease, are selected based on the routines and goals desired.

***Example:*** *More than anything, Savannah would like Tristan and Emily to be able to play together nicely so she could have a little time to herself and the children could learn to enjoy one another's company. Unfortunately, play times are often shortened by Tristan's tantrums. Savannah's goals are for her children to be able to share their toys and take turns playing games for at least 45 minutes, without Tristan screaming, throwing items, or striking his sister.*

### Assessing Patterns

Once the goals are clear, an assessment is conducted to determine patterns that may be affecting the child's behavior within the routine. Specifically, we would want to know what happens before the child's behavior (e.g., who is present, when and where it occurs, what is expected, what is happening), both when he/she is successful and when his/her behavior during the routine is particularly challenging. We would also want to know what the child gets or avoids through his/her behavior such as attention, items, activities, or breaks from the situation. This information is collected with the family through interviews and observations and is summarized to guide intervention.

***Example:*** *Paying close attention to play time, Tristan's behavior specialist helped Savannah sort out what circumstances were contributing to his behavior. They found that Tristan played cooperatively when the rules of games were clear, and when he had more personal space. He had the most difficulty with new toys and games—and when he was tired or hungry. Savannah would typically stay away when the children were getting along. When Tristan screamed or got physical, she would counsel him about his behavior and often asked Emily to let Tristan have the toys to make peace.*

### Designing Strategies

Using the patterns from the assessment, we can develop strategies that (a) work given the patterns affecting the child's behavior and (b) fit with the family lifestyle. Strategies fall into three categories and the specific strategies chosen are tied to the patterns. Proactive strategies involve preventing problem behavior and prompting positive behavior by rearranging environments or establishing expectations. Teaching strategies focus on building skills a child can use to replace his/her challenging behavior and participate more successfully in the routine. And management strategies focus on consequences, specifically providing reinforcement for positive behavior and withholding it for problem behavior.

***Example:*** *Based on the patterns, the following strategies were developed for Tristan and the family.*

| Proactive Strategies | Teaching Skills | Managing Consequences |
|---|---|---|
| • *Organize play areas to provide more space, including an area for breaks from the action*<br>• *Create a list of playtime rules, using pictures to illustrate*<br>• *Introduce new games by going over the steps and rules*<br>• *Create plans for sharing toys (who gets what, for how long)*<br>• *Provide snacks/meals before play and schedule playtimes when Tristan is well-rested* | • *Teach Tristan to ask for what he wants using pictures or pointing to items*<br>• *Teach Tristan to share the toys, taking turns or setting a timer*<br>• *Teach children to get a parent when frustrated (with Tristan signing "help")*<br>• *Teach Emily to prompt Tristan to use his words* | • *Join in when the children are playing cooperatively, praising positive behavior*<br>• *Change toys and games after every 10 minutes of cooperative play to maintain novelty*<br>• *Remove toys if children are fighting over them*<br>• *Limit conversation following problem behavior, while still keeping children safe* |

## Using the Plan

Once the strategies have been developed, it is important to carefully plan how they will be put in place and maintained. If professionals are involved, they should serve as coaches, rather than implementing the interventions themselves when possible so they are building the capacity of the family. If children's skills cannot be established without additional practice, it may be helpful to conduct additional "trials" (e.g., having Tristan practice using picture cues to request items), while continuing to support the routines. Really, the emphasis is on teaching—arranging the environment, prompting skills, and rewarding children for increasing success and independence.

***Example:*** *To put the playtime plan in place, Tristan's behavior specialist helped Savannah reorganize the family room and landing between the children's bedrooms. They put the games into plastic bins so that all the pieces were together and created a "time-out box" for toys that caused arguments. They bought a "sharing timer" and created rules with pictures of the children playing cooperatively. They made picture cards for Tristan's favorite activities and toys. They selected five of the children's favorite activities and reviewed and practiced their steps and rules with the children. They reviewed the plan with Grandma, who watches the children regularly. The behavior specialist modeled some of the strategies at first, but then quickly removed herself and simply provided support and feedback.*

## Monitoring Progress

It is important to objectively track whether children's behaviors are improving—making sure that skills are increasing and problem behavior is decreasing, as well as whether overall goals are being met. With objective information, families are more prepared to tweak aspects of plans that are not working—and celebrate successes. Monitoring by behavior specialists and other professionals can be pretty complex (e.g., recording every time a behavior occurs), but monitoring progress may be simplified in everyday family life by using something like a rating scale.

***Example:*** *To monitor the plan and outcomes, Savannah decided to record how long her children were able to play cooperatively (without screaming or aggression) each day. She noted the times on the family calendar. She also rated how well Tristan adhered to each of the playtime rules each day using smiley (good), straight (OK), and sad (poor) faces using the following chart. She reviewed these data with the behavior specialist and other family members every week.*

| | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday | Sunday |
|---|---|---|---|---|---|---|---|
| **Use words** | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ |
| **Share toys** | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ |
| **Gentle hands** | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ |
| **Put away** | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ | ☺ 😐 ☹ |

*Initially, Tristan was only able to play nicely with Emily for about 5-10 minutes. By using the plan, this time was gradually extended to almost an hour, with most rules being followed consistently.*

The ultimate goal of any ABA program is to improve not only behavior but also the lives of children and their families. By focusing on valued routines and designing strategies that fit in the contexts of family lives, we can achieve this goal.

Resources:
Family Routine Guide
APBS Families Page


*Meme Hieneman, PhD, BCBA, is a consultant with Positive Behavior Support (PBS) Applications and co-principal investigator on a National Institute on Health-funded research study. Meme works with organizations to improve their adoptions of evidence-based practices in PBS at individual and systems levels. She has published a variety of articles, chapters, and three books, including Parenting with Positive Behavior Support: A Practical Guide to Resolving Your Child's Difficult Behavior, as well as the parent training video series available: Video Package.*

## Capital Keys Autism Families, Inc

is a new nonprofit that connects with Autism Families nationwide with fun drawings weekly plus an Autism Birthday Club where mothers of autistic children submit membership info.

The Autism mom also qualifies for a $25 Amazon Prime gift. 150 current members since October debut of my company. We are seeking paid memberships to our Autism Fun Delivery Services.


Our website is
**https://goldkeys-autism.org**

**300 paid members at $10 recurring allows for 40-50 drawings a month on Facebook Live.**
I was diagnosed with Asperger's Syndrome in 2015 and then invented my board game Keys to the Capitals which sells on Amazon. Many Autism families enjoy the game.

# How To Be The Hero In Your Life

By Thomas W. ILAND, CPA, DTM

**There are countless stories out there about youth with autism spectrum disorder (ASD) struggling during the process of transition and other times of change. Whether it's moving out of Mom and Dad's house, going to a new school, or finding work, just to name a few scenarios, all of them have one thing in common: they have the potential to make you a better person.**

New things can be especially hard if you do not know about your diagnosis or how it affects you both positively as well as constructively. Maybe you find it impossible to accept yourself as a person, thinking you might not be worthy or capable of love. Or how about living the life that YOU want as opposed to the life that others want for you?

These matters warrant the need for the critical "prequel to transition" process of self-discovery for youth with autism. Transition plans for a person with autism and all the work associated with them will not have meaning or importance if the person with autism doesn't fully understand himself or herself first and foremost. The steps to self-discovery are summarized by the mantra "Know Yourself. Love Yourself. Be Yourself." You can become your best self by knowing about your diagnosis (parents can check out *Tom's Tips for Telling*) as well as the strengths and opportunities for improvement that come along with it, by realizing that your diagnosis doesn't have to define you, and by being open to the opinions, considerations, and suggestions of others!

Speaking from experience, it can be difficult to foster the courage to get out of your comfort zone or to do the things that are needed for you to get answers to

the questions you need to take your life to the next level. For example, there was a young man in college who was afraid to go to his professor to ask for help. This young man, however, liked Marvel Comics, and the X-Men are part of Marvel Comics. This man was told, "Pretend you're an X-Man and that you're going to see Professor Xavier for help." His face lit up instantly, and he mustered up the confidence and the courage to go and get the help he needed. A great deal of guidance can be found in studying superheroes and other characters in movies, TV shows, etc. that are on a journey to accomplish something bigger and greater than themselves and who must help themselves overcome their internal conflicts before they can help others.

Batman, for example, may only be one man, but he constantly and consistently puts in the work to gain more knowledge, make himself stronger, and adapt to new situations to remain at least one step ahead of his enemies. As a result, he is very effective and creates a reputation for being a skilled crime fighter that makes a difference for the better in the lives of others. Also, Batman has teammates, or "allies" as they are called in *Come to Life! Your Guide to Self-Discovery*, who help him accomplish his missions and make a bigger difference. They also help him when he feels down emotionally or experiences failure. Bruce Wayne's butler, Alfred, once asked him, "Why do we fall?" The answer is, "So we can learn to pick ourselves up."

This is an example of being the hero in your life: Knowing what you do well AND where you can improve, accepting that once you love yourself, others will love you in return, and that hearing what others have to say so you can make the best decision for yourself will help you see that getting out of your comfort zone and embracing change rather than avoiding it can be and often is good for you. You don't have to go through this journey alone. There are people in your life who want you to succeed and will help and guide you to get there. Similar to playing "make-believe," you can pretend you are a hero on a journey to bigger, better things. See what happens when you apply this approach; you might be amazed at the results.

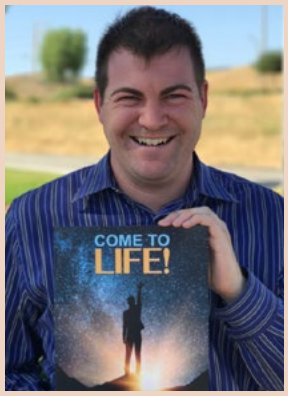
It all starts with asking yourself, "Who's my superhero?" More specifically, ask yourself, "Who do I look up to?" or "Who do I want to be like?" Your superhero can be a real person or a character, alive or dead. After you have chosen your superhero, list the following about him/her:

- His/Her superpowers (what he/she does very well)
- His/Her mission (Why is he/she here?)
- Special tools he/she uses (Batarangs and grapple guns, in the case of Batman)
- Allies your hero works with to get the job done
- The hero's weaknesses or things that distract the hero from his/her mission

Finally, after looking at your answers to these items, ask yourself, "How is my superhero a good role model for me?" In other words, what are the good things that your hero does that you do or can do, too? Once you get an idea of what your hero has going for him/her, you can start to look at your skills, talents, and people that care for you, and figure out what you have going for yourself.

Lastly, remember a hero does not complete his/her mission sitting at home feeling sorry for himself or herself—a hero ventures out into the unknown with his/her head held high ready to take on new challenges. It is crucial that you know that life doesn't come to you…it's up to YOU to come to life! So, get up, get out there, and see how you can be the hero in your own life!

Website: www.thomasiland.com




*Diagnosed with autism at 13 years old, Tom Iland, CPA, DTM, has worked hard to achieve his goals: learning to drive, living on his own, graduating from college, obtaining full-time employment, becoming a Distinguished Toastmaster (DTM), and having a girlfriend. Tom recently left his career as a certified public accountant (CPA) to educate, inspire, and motivate people affected by autism. His mantra "Know Yourself. Love Yourself. Be Yourself." has been featured in keynote speeches and is among the topics in his Amazon #1 Bestseller book, Come to Life! Your Guide to Self-Discovery. Tom currently lives in Santa Clarita, California, with his dog, Bridget.*

# 7 MYTHS ABOUT AUTISM That Parents Want You to Know

By Robin LaBARBERA, PhD


As an educator of future special education teachers, my job is to present the best research-based strategies that are designed to meet the academic and social needs of children with autism spectrum disorder (ASD). I find, though, that it is just as or more important to teach my students to know and love the *people* they will teach (the children and their families) more than know the *interventions* they employ. "The best way to love the children you serve," I tell them, "is to develop a sense of understanding and empathy for the family."

I have researched considerably to promote an understanding of the parent perspective in raising a child with autism because it is something I care about very deeply. Concerned parents have expressed their frustrations and joys over the years, and here I present just a short list of what some of the parents in my research have shared. Parents want their chil-

dren's teachers to demonstrate care for the students and families they work with rather than maintaining an exclusive focus on implementing the strategies they've learned about.

Teachers have probably heard lots of things about autism—some truths and some myths. The top seven myths that parents of children with autism want their child's teacher to know about and work to combat are:

## 1. My child is purposefully disruptive or defiant

Every act seeks an end—a person gets something out of performing a behavior. This is true for everyone. We do things for a reason, and every behavior has a purpose. Most of the time, children either get something or avoid something by engaging in certain behavior. Things they might want to "get" include attention, an item, an activity, or some form of control over a situation. Things they might want to avoid can include attention, tasks, demands, or unwanted activities. If the child is using a behavior to get something, try and figure out what he or she is hoping to gain. If the child is trying to avoid something, try and figure that out, too.

Children need the consistency of a reliable adult to provide support and guidance. The child is not purposefully disruptive or difficult. Find out what message the child is trying to send. Understanding why the behavior might be happening is necessary to select more appropriate behaviors to replace the challenging ones.

## 2. My child should be able to perform the desired behavior with instructions given once

Sometimes, things that other people are quick to learn might take considerably longer for the child to learn or become comfortable with. It isn't that the child isn't listening, or that he/she doesn't understand, or that he/she isn't trying hard to grasp a concept. You might have to *show* the child how to do something (because children are so visually-oriented), and then be prepared to show him/her *many times*. Lots of patience is needed, and please don't give up. He/She won't be great at everything immediately. The child is worth it!

## 3. I should seek to address my child's weaknesses exclusively

The child doesn't need any help feeling that he/she is not good enough, or that he/she needs to be fixed to do well in your classroom. The child doesn't need any more criticism. Look for his/her strengths (there are many), and capitalize on those strengths to teach new things. Knowing the child's strengths will be the key to unlocking his/her potential. Utilizing strengths can provide motivation and success in learning something new.

Some examples of strengths commonly associated with autism include exceptional memory for facts and figures, high motivation in topics of interest, excellent attention to detail, ability to follow instructions and rules, skills in arts and music, innovative approaches to problem-solving, and honesty, just to name a few. They are also very visual learners, so anything you can present in visual form is important for unlocking potential. You might find that some of the "deficits" associated with autism are diminished when children are engaged in their specific areas of interest.

## 4. My child is broken and needs to be fixed

Children are sensitive to environmental stimuli, so they might react to changes in routine and get frustrated easily, but they are not broken. You don't have to try and fix the child. You might not be able to stop some of the behaviors you don't like. I believe that instead of fixing him/her, you would benefit from taking the time to understand and respect him/her. The child will likely never "behave" in the way you've come to expect from other children in your class. But his/her behaviors are not wrong. The child deserves your understanding.

## 5. My child doesn't listen to spoken instructions

It is important to know that visual learners prefer written language or diagrams and charts

that illustrate concepts. Many children with autism cannot process verbal instructions; they need to be shown the steps, sometimes many times over before the patterns and expected behavior can occur. The child might not take in information if it's presented verbally. If it's not written down or visually presented through graphics or pictures, he/she will not retain it. Flashcards, pictures, and words are all excellent tools for students who learn visually.

If you give an endless string of oral directions, you might be tempted to think the child is not paying attention, or that he/she is defiant or troublesome by not listening. Many children with autism find it difficult to understand and follow spoken directions. Think about ways you can present directions visually, rather than expecting him/her to try harder to understand your verbal directions. Please don't presume the child is not trying or try and convince him/her to try harder.

## 6. My child should be able to pick up social skills easily

It might look like the child doesn't want to play with other kids at recess, but it may be that he/she just doesn't know how to initiate a conversation or join in play in ways that are understandable to others. Most children with autism desire to have friendships, but they need help to develop the social skills necessary for interacting with their peers. Children with autism find it extremely difficult to interact with their peers. They have trouble reading body language and understanding social cues from others. Promoting positive interactions with peers is important for the child's development.

Teach the child how to play with others, and encourage other children to invite him/her into their activities. The child might long to be included but just doesn't know how to engage. Model appropriate ways for him/her to join peers. Provide structure and support in social interactions. Developing social skills will help with language and cognitive development as well.

## 7. My child needs more stimulation

The child's brain is constantly working overtime to accommodate overwhelming environmental stimuli, from noise to lights, to social cues, to changes in regular activities and routines. If he/she seems tired, it's because…well…the child is tired. He/She doesn't fall asleep easily. At night it can sometimes take two hours to get to sleep because the child gets out of bed a lot and the parent has to tuck him/her back in numerous times before he/she finally goes down. The child goes through a lot every day. So if he/she seems tired, don't try to pep the child up.

Not only can overstimulation make bedtime and sleeping difficult, but it can result in shutdowns or meltdowns during the day. Look for ways to help the child deal with the overstimulation, rather than providing consequences for "misbehavior." The child is not defiant or misbehaving on purpose—he/she is merely coping with the overstimulation in the only way he/she knows how. Find ways to help the child cope.

This list is not exhaustive. I've heard many parents express their desires for teachers to understand their perspective, and this list is a just a summary of the most frequent responses. Educators, if by some fortunate circumstance you have students with autism in your classroom, take the time to get to know your students' strengths and areas of need, and be intentional about doing all you can to encourage and support your students and their families. Be a part of dispelling the myths commonly associated with children who have autism.

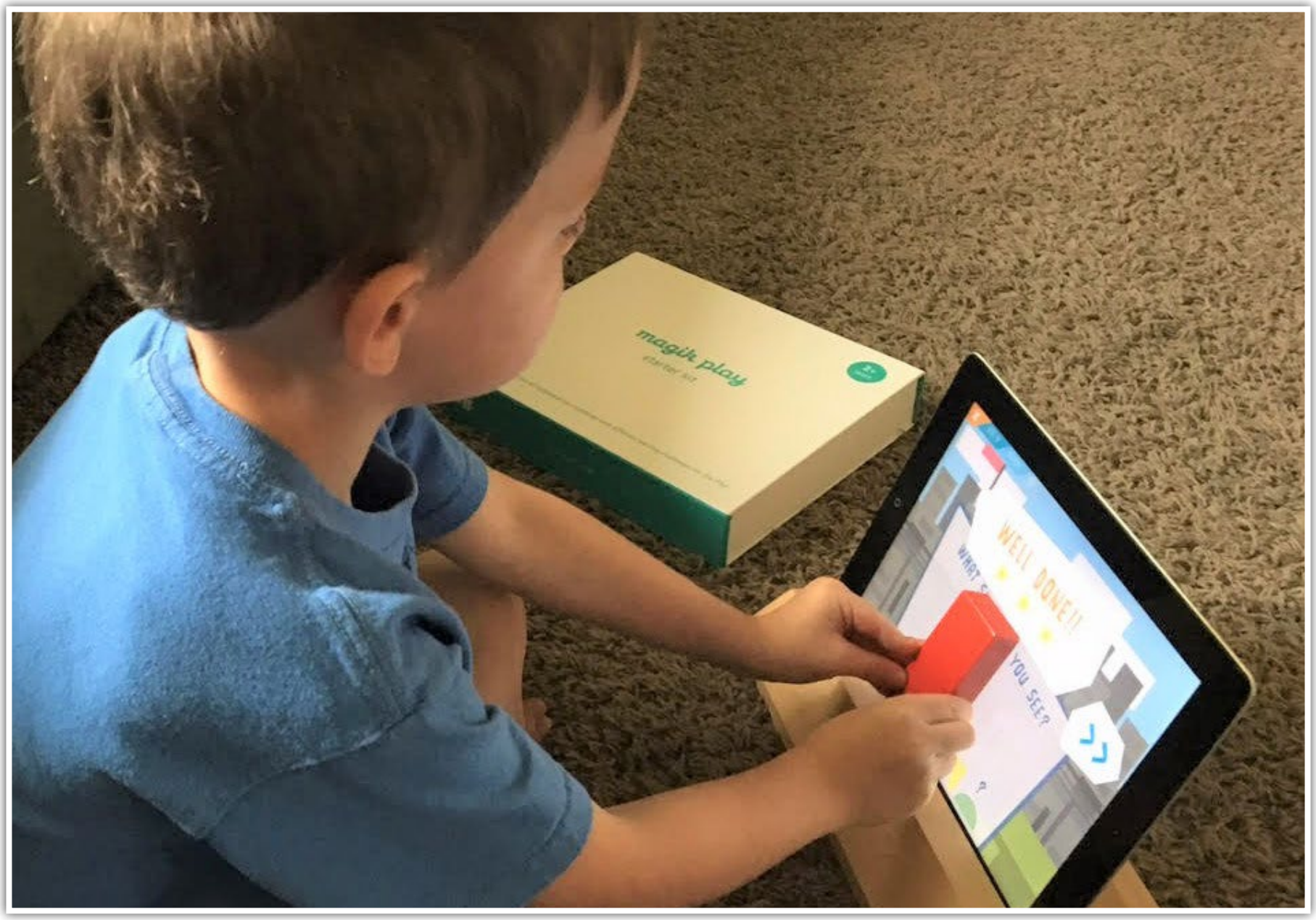
*Dr Robin LaBarbera, PhD, is a professor of special education and the director of the online special education credential program at Biola University. Her research interests include the experiences of stress, resilience, and coping among caregivers of children with autism. Her textbook, Educating students with autism spectrum disorders: Partnering with families for positive outcomes with Sage Publications, will be available in January 2018.*

*Program: http://education.biola.edu/grad/programs/credentials/special-education-credential/*
*Twitter: https://twitter.com/doktarobin*

# New Game Helps Young ASD Boy See the World Differently

By Amy Elisabeth BEAM

**Dylan is a special little guy diagnosed with autism spectrum disorder (ASD). He sees the world through a differently colored pair of sunglasses every day. Days are spent trying to take what he sees in his mind and comprehend it in the real world. Imagine always missing one piece when you are trying to put together a puzzle—the frustration, confusion, the constant feeling of disorder. Dylan finds these struggles in most activities he does.**




Through all this, I found only a few games or activities where he can get beyond these obstacles. Magik Play is an iPad building block game that has accomplished something unique for Dylan. First, he started with finding shapes, but these shapes are hidden in your everyday objects, like a ramp for a bike. Dylan learned and understood his first abstract thought; a ramp is not just a ramp but a shape that I can hold feel and see the direct impact in real life. Dylan has struggled seeing anything more

than black and white in life (a square is square). Magik Play has never frustrated him like most activities. Next, Dylan made a simple house with blocks to match the house on the iPad. We went outside later that day, and he looked back at our home and expressed, "Mommy, our house needs two squares." He put what he learned in the game into his outside world.

The most incredible thing Dylan has gained from playing Magik Play is his first understanding of cause and effect. On the game, he built an escape route for the bird and then knocked it down so the bad guy couldn't get to his bird. Dylan was proud he saved the bird. Later that same day, Dylan stated very profoundly, "I hug you, you're happy, I hit you, you're sad." For the first time, he truly understood his actions had a direct impact on the world around him!

Dylan has also improved drastically on his fine motor skills, the ability to manipulate shapes, standing on end, lying flat, or turned sideways. In the beginning, he dropped them; now he can stack, turn, and do anything he sets his heart on. Magik Play has made a direct improvement in Dylan's skills and increased his ability to see the world differently.

Magikbee is an education technology startup based in Braga, Portugal, with an ambition to provide kids with fun and educational ways to use digital devices. Their first product, Magik Play, is a "phygital" kids' toy that seamlessly connects traditional building blocks with tablets in a series of fun puzzles and games.

*Amy Elisabeth Beam is the mother of three amazing boys. She is a nursing student and wife to a great husband of 15 years. Amy's kids are her absolute world.*

# Sensory Weighted Blanket and Miracle Cape Created with Love

By Marna PACHECO and Susan HICKOK

Sit down for a cup of coffee with Marna Pacheco, and she'll tell you that grocery shopping can be tough. But it's not the weekly scavenger hunt for this obscure ingredient or that hard-to-find brand that makes food-finding missions tough.

It's a combination of things, in fact. For starters, Pacheco's 11-year-old daughter, Millie, often acts out when she finds herself in an unfamiliar environment. Chaos and loud noises can trigger outbursts. This is especially tough because other store patrons—even other parents—don't seem to understand what it's like to parent a child with special needs. The judgmental stares rub Pacheco the wrong way.

Millie continues to experience the lasting effects of emotional trauma stemming from her early experiences in a Chinese orphanage. She has lower than normal cognitive abilities, she is mostly nonverbal, and she struggles with sensory processing disorder. Simple outings can be a real struggle.

Pacheco's friend Susan Hickok knows all too well what that is like. She adopted her daughter, Elsa, from the same Chinese orphanage, and the two girls have faced similar struggles over the years. Elsa has had to cope with a cancer diagnosis, as well, amplifying the family's need to find a viable way to mitigate her fears and frustrations.

## A Simple Solution

Pacheco and Hickok desperately wanted to help their daughters find peace. That's when Pacheco began researching the effects of abuse and neglect on the brain. She wanted to explore the science behind what was happening with Millie and Elsa, and she sought the advice of several professionals. Pacheco's occupational therapist suggested she look

into weighted blankets, which cause an involuntary calming sensation.

Pacheco soon discovered that there weren't many blankets to choose from. Big and bulky blankets with bold prints simply wouldn't do—she needed something that would allow her daughter to blend into a crowd rather than stand out.

The two moms decided to create their own line of blankets and wearables, doing two things that set them apart from other companies.

One, they created innovative designs that use positive deep pressure touch stimulation, prompting the brain to release serotonin, dopamine, and endorphins. CapeAble Sensory Products is the first and only company to incorporate micro-beading distribution in its weighted products, a process that ensures the recycled glass beads in the blankets disperse equally—even when someone has the blanket or wearable draped over their shoulders while standing up. Their

design—and the machine they built to manufacture the blankets—are both patent-pending.

Two, they created blankets and wearables that make a fashion statement. On-trend fabrics and patterns complement the décor of just about any home, and wearables complement regular clothing, just as a scarf or wrap would. Both the blankets and wearables provide a dignified and fashionable way to relieve discomfort and anxiety in any social setting.

"We started our business to create an aesthetically pleasing, dignified option that would both honor and comfort our customers," Pacheco said. "Our children deserve to be treated the same as other children. CapeAble Sensory Products help better ensure they won't be judged for behaviors they cannot control."

## A Booming Business

CapeAble Sensory Products found quick success. Though Pacheco and Hickok originally intended to help their daughters, they've discovered that the blankets and wearables help people with a variety of conditions, autism, including anxiety, ADHD, chronic pain, depression, Parkinson's disease, sleep difficulties, and more. Even adults feeling overwhelmed with the daily struggles of life benefit from their use.

As interest grows, Pacheco and Hickok are seeing an increase in the volume of orders. It didn't take long for them to realize that they would need to scale their manufacturing operation, so they found a way to make it happen. They modified their product designs, re-engineered the manufacturing process, obtained a Small Business Administration-backed loan, and leased their own manufacturing facility.

"The science behind the comfort of our weighted products is what sets CapeAble apart," Hickok said. "We wanted to ensure that the recycled glass beads within each blanket are dispersed equally and do not shift with prolonged use."

## Turning Heads

Pacheco and Hickok are certainly making a name for themselves in the weighted products industry.

At the 2017 SCORE Awards, SCORE chose CapeAble Sensory Products as the Outstanding Innovative Small Business of 2017. SCORE is an organization that mentors American small businesses, providing guidance and advice to entrepreneurs like Pacheco and Hickok.

Additionally, CapeAble Sensory Products is partnering with Parkview Hospital, the second largest hospital in Indiana, to study the effects and benefits of weighted products on traumatic brain injury patients. Findings from this study could influence the use of weighted products in mainstream hospitals and medical practices.

Although Pacheco and Hickok are proud of everything they've accomplished, they say the true reward comes from the smiles on their daughters' faces when they wrap themselves in their favorite CapeAble capes.

After all, they believe every person deserves to feel CapeAble.

*Marna Pacheco and Susan Hickok are the owners, designers, and manufacturers of CapeAble Sensory Products. The challenges faced by their children inspired the two mothers to create their own products to provide comfort, focus, and hope for their daughters and others with mental challenges. Today, CapeAble Sensory Products offers weighted blankets, weighted wearables, and sensory enrichment tools that deliver deep pressure touch stimulation, enabling the central nervous system to communicate most effectively with the brain.*

*Website: https://www.capeable.com*

# Thoughtful Advice for Parenting the Neurotypical Sibling

By Audrey S PARK

**Having a sibling with autism spectrum disorder (ASD) is very different than having a child with it. It's something that often makes us stronger, more patient, and more mature than others, but it can also be a struggle.**

While parents might have read a lot about how to treat their diagnosed child, they might overlook the fact that there are special conditions created for siblings without the disorder as well. I have put together a list with tips for parents on things they can do and think about concerning their children who don't have the diagnosis, to help them better understand us siblings and our roles in the family.

## 1. Talk to us about our sibling's disorder

This might sound obvious and very simple, but, many parents avoid talking to us neurotypical children about our siblings' diagnoses, updates on it, and hardships with it, thinking they don't want to bother us. You don't have to tell us every detail, but it's important to be open and to talk to us. We spend just as much time with our siblings as parents do, and we want to understand our siblings' disorder better so that we can be the best siblings we can be. If a child in a family has a disability, it affects all family members, and because the sibling is affected, he/she also needs to be educated and prepared. And yes, talking about our siblings' autism can be emotional, and it might be hard, but that is why it is important not to let it become a stigmatized topic.

## 2. Teach us to go against the flow

Especially when you're younger, it's easy to give in to group pressure. Some studies suggest that children with autism can be at a higher risk of being bullied than other children. They may also be unable to communicate this to parents and other adults. Children often act and speak before they think, and are often quick to question, or even taunt, behaviors that, to them, seem unnatural. Teach us to put our siblings and their special needs first so that we are prepared to stand up for them. Teach us that it's wrong to use the R-word, and it's wrong to use mental diagnoses as derogatory terms. Teach us what to do in situations where we might be torn between siding with our peers or with our siblings.

## 3. Don't assume we know less than you

We've had our siblings with autism our whole lives, or at least for a large part of it. Autism will always be a part of our lives, and we would be different people had our siblings not had it. Unlike most parents, who have had to educate themselves at a later age about something they perhaps knew very little about before, we learn how autism works at an early age from seeing our siblings—we see how our siblings are different and we develop our own strategies for coping with it. Maybe we haven't read all the parenting books, but we know our siblings, just like any siblings do, so let us teach you, too, sometimes.

## 4. Sibling workshops

Sibling workshops are great because they give us the chance to discuss what can feel like a personal and sensitive topic and meet others in the same unique situation. Even if everyone has a unique family situation and siblings are on different places on the spectrum, it can be very liberating just to be able to talk about things in a safe space with others who understand what we are going through. There are also many online groups and support networks, and those can be just as helpful. Parents, do suggest to your neurotypical children to go to these kinds of meetings, because there are many things about our siblings and their disorders that only we see as siblings, and it can make us feel less lonely in our situations.

## 5. Tell us we don't have to be superhuman

Siblings of neurotypicals usually mature and become more autonomic and independent much ear-

lier than their peers, as parents often have less time and energy to spend on us. Parents also expect more from us, and many of us easily fall into thinking that becoming overachievers in school, work, or other activities is the only way to get our parents to see us, too, but it can easily also become a pressure and do much damage to our self-image. Just tell us that we don't have to be perfect, and we don't have to "earn" your love and attention by our actions. But also don't feel sorry for having to spend more time with our siblings than us, because we understand, even if we think it's unfair sometimes.

## 6. Don't neglect our mental health just because we're "the unaffected one"

Studies have shown that siblings of people with autism are more than twice as likely to suffer from a psychiatric condition than the rest of the population. Siblings also have a large chance of developing autism themselves, and even if they don't develop it, many struggle with developmental difficulties commonly found in those with autism. Neurotypical siblings who struggle with mental disorders might find it hard to talk about it, and we might even feel guilty, not wanting to cause our parents more hardship than they already have with our siblings. If you suspect that the unaffected child might have a problem or disorder, pay attention to his/her mental state, talk to the child, and share ways to get help. Just look at him/her as your child, not your "unaffected" child.

## 7. Don't stigmatize negative thoughts

Parents have them. Siblings have them. Yet, it's a very stigmatized idea to have negative thoughts about it. Sometimes we, too, get so mad at our siblings' disorders, and we get angry and sad and feel confused and helpless as well. We hate that the world is an unfair place to live in and that others can be so ignorant and cruel towards people with disorders. Tell us it's okay to feel this way and that it's not our fault. It's okay to be jealous of other people and other families who, bluntly speaking, have an easier life. Parents definitely struggle a lot, but it can be extremely hard for us siblings, too, sometimes, and now and then you just need to vent all these emotions, and it should be okay to do that.

## 8. Encourage us to seek out friends

Especially at younger ages, having siblings with disorders might make us reluctant to bring friends home, thinking our siblings might act weird. Encourage us to defy these thoughts. Also, try to give your child some space and alone time with friends, either if the sibling with autism can be out of the house, or offer to take the neurotypical sibling and his/her friends somewhere to spend time by themselves. This advice also applies to children with the disorder. For people on the spectrum, having understanding and accepting friends, whether they are personal assistants, autism support groups, or friends at school or work for the more high-functioning, can be huge helps in their personal development.

## 9. Spend some alone time with us

Every child just wants to spend some time with their parents alone sometimes. This is the same for all families with more than one child, with or without family members on the spectrum. Every now and then, just make some time for just us to do something together. We, siblings, tend to end up in the shadow of our siblings' needs much of the time. So let us be the center of your attention, too. Try to set this kind of separate time aside for us on a regular basis, because as siblings, we need to be reassured sometimes that we are equally loved and important, even if we don't get as much attention as our siblings on a regular basis.

## 10. Encourage us to make our own free choices

A special needs sibling will always remain a big part our lives. Even if parents need someone looking after their neurotypical children when they no longer can, don't tell us we have to be around our siblings 24/7. The best thing parents can do is to encourage us to live our own lives and do things we want because we will always love our siblings, and we will always be there for them even if we live our own lives, too. Don't let our lives be consumed by our siblings, but encourage us to make choices for us, and to have our own dreams and aspirations. Most importantly, tell us that it's okay to talk to you about these dreams so that we don't stay silent, thinking what we want is inferior to our siblings' needs.

*Audrey S Park grew up with one younger sibling with autism, and she wants to see a world where mental disorders are not looked down on by society and to spread awareness about what it's like to be a sibling of autism. She is currently balancing her studies while attempting to pursue a career in freelance writing.*

*Twitter: https://twitter.com/a_s_park*

# Sensory Enrichment Therapy: A New Approach

By Claudie POMARES

**Children with autism spectrum disorder (ASD) often have sensory issues. They may be sensory-seeking, or they may be sensory-avoiding or even a little of both. For children living with autism, some textures can be very irritating. Sounds, crowds, lights, or smells can upset them.**

Many sensory approaches already aim to help in this area, and that is great. It is a good idea to develop a sensory plan for your child to help him/her be more comfortable. One approach is to keep the child isolated from the sensory stimulation that is upsetting. Another approach is to give the child what seems to soothe and satisfy him/her. Some sensory approaches also try to expose a child to different sensory stimulations repeatedly so he/she can get used to them, hoping to reduce the child's negative response over time.

## New approach for improved brain function

Sensory Enrichment Therapy (SET), not to be confused with Sensory Integration Therapy, is a new sensory approach that comes from an entirely different perspective. Although SET is effective at helping children with autism regulate their sensory-seeking and sensory-avoiding behaviors, that is not the

only purpose of the therapy. Instead, it is designed to help improve brain function, which then results not only in improved sensory processing, but also in improved IQ, attention span, eye contact, speech, social skills, and many other of the core symptoms associated with autism.

SET can be traced back to an accidental discovery made during research on animals by Donald Hebb in 1947. Pet rats would outperform lab rats in problem-solving tests. Why was that? Did the pet rats learn things from the humans? Hebb did not draw conclusions at that time. It was not until 1962 that Mark Rosenzweig discovered that it was the enriched environment the rats were exposed to, whether or not they were pets, which would result in larger, healthier brains.

To be the right kind of stimulation, the enrichment activity should involve the senses or movement and combine more than one sense or motion at a time. It is best when that combination is not normally found in a day-to-day experience and is interesting enough to capture the participant's attention. The stimulation should also be as pleasant and as free from distraction as possible.

SET has taken the research from Environmental Enrichment and "humanized" the protocols. It introduces the right sensory stimulation and movement in a pleasant way, combining multiple sensory inputs or movements at once. There are now hundreds of protocols that strike that balance and are put together like games that you can play with your child.

## Tips for sensory enrichment at home

Here are a few things you can do to introduce a little sensory enrichment at home:

1. Introduce a pleasant fragrance to your child several times a day while giving him/her a gentle, pleasant back rub with your fingertips. If the child doesn't like that, find a place he/she likes or where he/she will at least tolerate a gentle, pleasant touch, e.g., the cheek, forearm, forehead, or the palm.

2. At bedtime, play peaceful instrumental music while the child is falling asleep and put a scented cotton ball inside the pillow-case. Any safe scent that is pleasant will do.

3. Following a bath or shower, have a warm towel ready to wrap around your child. (You can put the towel in the dryer for a few minutes to warm it.) Give your child a foot massage and a hand massage with scented lotion.

4. Place mats of different textures in a place where your child may frequently walk without shoes.

5. Set up the environment with more textures, smells, music, art, and other pleasant passive sensory opportunities.

These are things which can be done for free and can make a difference. If you can make a daily habit of sensory enrichment, you can begin to see improvements.

## Structured Sensory Enrichment Therapy: Individual programs

Structured SET involves more than just good sensory ideas such as those outlined above. To create an individual program, SET begins with an assessment that gives an idea of which areas of the brain to focus on, and therefore which daily sensory enrichment exercises to follow. A set of three or four exercises make up a worksheet that is followed daily. The therapy takes about 10 to 15 minutes, once a day.

Here is an example of one of the exercises that may be done in Sensory Enrichment Therapy:

- Step 1: The parent prepares two large bowls. One has warm water, and the other has cool water.

- Step 2: The parent instructs or helps the child place one hand in each bowl simultaneously. For example, the left hand in warm water, and the right hand in cool water, at the same time. If possible, avoid touching the bowls. We want temperature, but not pressure.

- Step 3: The parent swaps the bowls, and now the hands will feel the opposite temperature. Continuing with the example, the left hand is now in the cool water, and the right hand is now in the warm water. (Note that the child does not cross arms, but instead the bowls are swapped.)

- Step 4: Repeat swapping bowls and dipping the hands two more times, for a total of four hand dips.

This exercise may be assigned, for example, if the initial assessment shows that it would be good to focus on improving the function of the corpus callosum, which is the main communication bridge between the two halves of the brain. Many complex functions require speedy interaction between both sides of the brain, such as speech, sensory processing, and math. Recent studies have linked issues with the corpus callosum and autism symptoms. This water exercise would be combined with another protocol intended to prepare the brain for growth and repair. So, with the combination of these exercises, the ideal results would be improved corpus callosum function and improvements in the corresponding symptoms.

This is just one example of hundreds of exercises that may be assigned depending on the results of the assessment.

## Powerful results for all ages

So, does it work? This is a very important question to ask of any approach. Some therapies, diets, or other approaches seem to work better than others, which is normal. The good thing about SET is that its effectiveness has been the subject of three studies published in peer-reviewed journals. This means that it is not just supported by research, or "based" on science, but is actually the subject of research itself. Here are the three studies measuring what happens when children with autism engage in SET:

- Study 1: The first study showed a nine-point increase in raw IQ on average. Forty-two percent of participants improved on the Childhood Autism Rating Scale by five points or more. Sixty-nine percent of parents reported that their children improved. The article published in the peer-reviewed scientific journal *Behavioral Neuroscience* won the D.G. Marquis award for best neuroscience paper of the year in 2013 from the American Psychological Association.

- Study 2: This study replicated the first study, showing an eight-point increase in IQ, 11-point improvement in sensory profile, seven-point increase in receptive language, and five-point increase in expressive language. What's more, 21 percent of the children no longer qualified for the autism diagnosis on the Autism Diagnosis Observation Schedule (ADOS), the gold standard for an autism diagnosis.

- Study 3: Results from 1,002 subjects showed on average a significant improvement in learning, memory, anxiety, attention span, motor skills, eating, sleeping, sensory processing, self-awareness, communication, social skills, and mood/autism behaviors. It was equally effective for all ages, including older teens.

The research concludes that SET and its new sensory approach to treating autism is effective for many children. Of course, the only measure that matters is if it works with your child.

Free program—just stick with it!

SET is done by the parent at home with the child and requires taking time every day to incorporate a new therapy. This is perhaps the "Achilles' heel" of the therapy. SET works, but like introducing a new diet or exercise into your life, it can be hard to stick to.

At the same time, many parents have expressed appreciation for the fact that they get to spend quality time with their children, and they don't have to drive anywhere for the therapy. Parents have also shared feelings of empowerment to be directly in charge of their children's recovery.

The full SET program can be accessed online for free. This free online version gives families everything used in the clinical studies, including a thorough online assessment in the form of a questionnaire, as well as video instructions for each exercise. For local support, parents can access over 200 professionals certified in SET. There is also currently an option to enroll in a platinum service plan and work directly with the creator of SET. You will find a wealth of information online.

Whether you are ready for a new therapy or not, SET looks like a new sensory approach that is here to stay!

*Claudie Pomares is the creator of Sensory Enrichment Therapy and an executive at Mendability.*

*Website: www.mendability.com/autism*

# Enhancing Fine and Gross Motor Skill with Creative Activity


By Maria ROHAN, RN, BSN

The sun rises and sets every day. It is a proven occurrence and can be documented by most human beings who live on this planet. Now, if you are 70 years old, you should have seen 25,550 sunsets and sunrises each during a lifetime, but at the same time, you most likely missed many of them.

Why? When the most breathtaking gift to our eyes can be seen every day, for free, how do we miss it?

When a child is diagnosed with autism spectrum disorder (ASD), the parent or parents are bombarded with a boatload of things they need to do to fit their child in this pretty little box called "normalcy." As the child grows, parents are constantly told where the child should be and what he/she isn't doing, and most of the time, it feels like even when you think your child is doing great, there is always something he/she hasn't measured up to. It's a race. Autism feels like a race—a race against nothing. No one really tells us to slow down, and that it is not a race; they just let us run. If one day you decide to pick your head up from the drowning of "not good enoughs," "we need to stop that," and "we need to work on this," you will realize that you have missed many sunsets and sunrises while you were gone and that your life is not an Individualized Education Program (IEP).

> **At first, you will have to prompt, asking where you should go next, or you may need to redirect. That is okay. This game requires some focus. This kind of focus is built; you will notice more as you play. Their focus will last longer as well. It will not be perfect at first. A lot of hand overhand may be needed at first, and that is okay. You will work up to independence.**

We have to remember our children need to be freed a little to become their own people, to let their intelligence shine, and to not grow into people we robotically want them to be. We are all guilty of it, parents and educators alike. When an educator can tell you everything on your child's IEP but cannot tell you five things your child likes or five things he/she is good at, we have let the diagnosis take over. How do we steer away from being like those who become blind to the sunrise and sunset? We take a step back and teach to the child, not a piece of paper.

Below is a fun lesson plan to work on with your child, one that allows for creativity and critical thinking that can be tailored to current needs of the child and hones in on fine gross motor skills. Modified versions for advancement will also be explained below.

## The Spider Web Lesson

**Step one:** Draw a large spider web with tape on the ground. If your child struggles with fine and gross motor skills, draw the lines of the spider web thicker, and as he/she conquers the skills, make the lines of the spider web thinner.

**Step two:** Place random bean bags all over the spider web where horizontal and vertical lines meet perpendicularly.

Here are the rules of the game: You and the child will stand at the bottom of the spider web, choosing a vertical line as your starting point. You will point to a bean bag the child has to obtain. Here is where creativity and critical thinking takes place. It is a maze. There are many ways to get to that bean bag, but the child gets to choose what route he/she wants to take. THERE IS NO ONE-WAY ANSWER. This allows the child freedom to think. To get to the bean bag, the child must walk one foot in front of the other, or try to. This will help with balance and fine and gross motor skills. At first, you will have to prompt, asking where you should go next, or you may need to redirect. That is okay. This game requires some focus. This kind of focus is built; you will notice more as you play. Their focus will last longer as well. It will not be perfect at first. A lot of hand overhand may be needed at first, and that is okay. You will work up to independence. When the child gets to the bean bag, he/she must pick it up and throw it to the center of the spider web, again catering to the fine and gross motor skills. Then the child will get on a route to get the next bean bag. When all bean bags are in the middle, REWARD!

Reward, reward, reward. What is a sufficient reward? Although this game doesn't seem like work, it is. In the world of autism, this is work. In any other lesson, when they achieve something they may get a timed opportunity to do something they want. That reward is sufficient when achieving the concept of this game.

## Advancements

Room to build and grow is the best kind of lesson plan. This game allows lots of room for creativity for the parent/teacher as well as for the child. If the child is learning letters, put letters on the bean bags. At the start of the game, instead of obtaining all the bean bags, prompt the child what letter to obtain a certain letter. You can do the same with numbers.

- **Spelling Advancements:** When working on vocabulary, put letters on the bean bags. Verbalize

**“Many children with autism have a connection to lines; therefore, a game of this sort is attractive to the autism brain. Like art, children with autism can easily express themselves from mind to hand. That is why PECS, communication devices, pointing, or even art works. We limit children by forcing them to communicate the same way we communicate.”**

the word you want them to spell. Have the child spell it by obtaining the correct spelling letters in order and throwing them in the middle of the spider web.

- **Math Advancements:** When working on simple math, put the answers to mathematical equations on the bean bags. Show the child a simple math problem, and prompt him/her to play the game and obtain the answer to the mathematical problem and throw it in the middle of the spider web.
- **Activities of Daily Living Advancements:** If you are a parent or an educator of a child with autism, you know that your house or your school is plastered with signs on how to complete tasks such as: going to the bathroom, getting dressed, brushing teeth, or getting ready for school. Here are ways to incorporate the Spider Web Lesson Plan with your older children/students. Put the same chronological pictures (PECS) you have used on your sheets on the beanbags to prompt the child to finish a task. Start the game with a question. What do you do first when you wake up in the morning? How do you brush your teeth? What do you do when you get dressed? This is a good test to know if your child has learned how to complete the task or just follows prompts.
- **Competitive and teaching waiting advancements:** Make teams!! Get two sets of colored bean bags and create competition with each other. This creates a real game atmosphere for your higher functioning children that forces the child to learn to wait.

How is this game tailored to the autism mind? Many children with autism have a connection to lines; therefore, a game of this sort is attractive to the autism brain. Like art, children with autism can easily express themselves from mind to hand. That is why PECS, communication devices, pointing, or even art works. We limit children by forcing them to communicate the same way we communicate. And then we measure their intelligence that way. This game allows them to acquire knowledge, express the knowledge, and advance that knowledge while not saying a single word. Although communication is needed and can be incorporated into this game, we can advance/test knowledge by hand-to-mind thinking. It also allows children with autism to be creative and think critically while strengthening fine and gross motor skills.

*Maria Rohan, RN, BSN, is a registered nurse at Rainbow Babies and Children's Hospital in Cleveland, Ohio. Outside of the nursing field, Maria has dedicated her life to working with and trying to give the most opportunity possible to children with special needs. Having worked with children with autism for ten years and having the autism diagnosis in her family, Maria writes interactive workbooks for children with autism, molding each workbook to their musical voice patterns, attention span, and likes. She currently sits on the PTO of STEPS Center for Excellence in Autism and continues to let her love for the children plant seeds of movement.*

# Check Out The Benefits Available for Families With Special Needs Kids

By Bret COLSON

**If you are the parent, caregiver, or representative of a child younger than 18 who has disabilities, there are many possible government benefits that you and the child could be eligible to receive. In addition, an adult who became disabled in childhood prior to age 22 might also be eligible for benefits.**


## Supplemental Security Income (SSI)

SSI makes monthly payments to people who have limited resources and low income and are 65 or older, blind, or disabled. If your child is under 18, he or she may be able to qualify if they have a physical or mental condition or a combination of conditions that meet Social Security's definitions. In addition, his or her income and resources must also fall within eligibility limits. Payment amounts may vary from state to state because some state agencies will add to a potential SSI payment.

To qualify as disabled, a child must have a condition or combination of conditions that result in "marked and severe functional limitations." In addition, the

condition(s) must have been disabling or expected to be disabling for at least 12 months, or the condition is expected to result in death.

Income restrictions for 2018 are that the child must not be working, or earning more than $1,180 per month. It should be noted that this amount changes from year to year and is based on increases in the Consumer Price Index.

State agencies review initial SSI claims and may take up to six months to determine if benefits should be awarded. However, if the child has certain medical conditions, payments may be made immediately. Some of those conditions may include HIV infection, total blindness or deafness, cerebral palsy, Down syndrome, muscular dystrophy, a severe intellectual disability (if the child is four years old or older), or a birth weight below 2 pounds, 10 ounces.

## Social Security Disability Insurance (SSDI) for adults disabled since childhood

The SSDI pays benefits to adults who have a disability that began before they turned 22 years old. It is considered a child's benefit because it is paid on a parent's Social Security earnings record. To receive this child benefit, one of the disabled adult's parents must be receiving Social Security retirement or disability benefits, or the parent must have died but worked enough to qualify for Social Security. The SSDI disabled adult benefit payments will continue for as long as the individual is disabled.

## Medicaid

In most states, children who receive SSI payments qualify for Medicaid. In some states, this benefit is automatic, while in others, you must sign up for it. Some children may qualify for Medicaid even if they do not qualify for SSI benefits. This will vary from state to state, so it is best to check with a local Social Security office or state Medicaid office to see if and how you can qualify.

## Medicare

This is a federal health insurance program for people who are age 65 and older, and for people who have been getting SSDI benefits for at least two years. However, a disabled adult child can get Medi-

care immediately if they have a chronic renal disease and need dialysis or a kidney transplant, or they have been diagnosed with Lou Gehrig's disease.

## Children's Health Insurance Program (CHIP)

CHIP allows states to provide health insurance for children of working families who have income that is too high to qualify for Medicaid, but too low to afford private health insurance. Criteria will vary from state to state, and it is best to contact your state Medicaid agency to get more information about this program.

## State Level Health Programs

Under the Children with Special Health Care Needs provision of the Social Security Act, state agencies provide some services through clinics, private offices, community agencies, or hospital-based treatment centers. Local health departments or social services offices should be able to help you identify and contact your local Children with Special Health Care Needs programs.

*Bret Colson brings more than 25 years of public and private sector experience to his role as senior editor at Eligibility.com. In his role as senior editor, Bret is responsible for researching and publishing news and information on a variety of public benefit programs with the goal of assisting the public in obtaining greater access to vital services at the local, state, and federal levels.*

# Potentially Dangerous Friends: How They're Made

By Dacia PRICE

**I am the mother of a child who is a little different. You probably wouldn't notice. He speaks, eats, runs, and jumps. He cries when he's sad and laughs when he's happy. He looks like all the other kids in his class, though they can see the difference, even if you can't.**

In kindergarten, he once hid under the table for hours. The teacher didn't know what to do. I had to crawl in with him and coax him out. In first grade, he refused to do his school work for almost the entire year. They thought he needed to be held back. In third grade, they put him in the gifted program. At home, he ate only peanut butter and jelly sandwiches. I tried to sneak in bananas when he wasn't looking, but he always noticed. When things didn't go his way, he'd throw himself on the floor and scream. When I would request that he brush his teeth or change his clothes, or that he take a bath, he'd slam his fists and feet. He'd bang his head. He was nine.

In fourth grade, he became so angry with his teacher that he wrote hateful things in his journal. When he was caught he blamed her for going through his personal things. He wrote of wanting her to die. The school took the threat seriously. They suspended him for two days.

He was devastated. He had erased it, he said. *It wasn't there anymore. Why was he still in trouble?* He wanted to know: *Why was everyone always so mean to him?*

When we got home, he cried and wanted me to hold him. This was nothing new. He's full of contradictions. Angry one minute, playing with my hair the next. He tells me he loves me at least a hundred times a day and follows me to the car when I leave. He stops to hug me every few feet. Sometimes I have to remind him that I need space, too. But he has a hard time remembering.

His anger seems more controlled now that he's older. He has a dog and two rabbits, and books. They help

him feel calm. He eats carrots and cucumber, pasta and avocado, and smoothies, though still prefers PB&Js to all of it. He's obsessed with computer programing and making YouTube videos. He's really into science and space and theories and discoveries. His hero is Neil deGrasse Tyson.

He's really smart.

But being smart doesn't make friends. Or community. Or build connections with other kids. In real life, they remember the boy who throws fits and uses

huge words and talks about astrophysics and politics. The boy who never does what he's told because he thinks he knows a better way. Who plays Lego and Minecraft and seems to be oblivious to their more grown-up interests. He's 11 going on nine while his classmates seem to be quickly approaching 14.

He's alone a lot.

And then, a few years ago he made a friend. *He liked Minecraft, too*, he told me. They played video games together, had Nerf wars in the woods, talked about the animals they each had. It seemed like a good fit. At first. But this new kid had the color of someone who hadn't been outside in a long time. His skin was like yellowed paper, fragile, and dirty. It made me sad. I wanted to give him a bath and take him to the beach.

After a while, little things crept up. He never took his shoes off unless I made him. When he spent the night, he never brought pajamas and next-day clothes and a toothbrush—even when the sleepover was planned. He always smelled a little like mildew and dust, and he never asked for things. Instead, he'd make statements: I'm hungry. I'm bored. I don't want to play anymore.

I stopped feeling so sad for him.

His family lived at the end of a meandering mountain road which was overgrown and unpaved. There were no utilities out there. A satellite connected them to the rest of the world—sometimes. Their water came from a well. It might have been quaint if the property hadn't also been littered with machine parts and broken vehicles, littered with bullet holes. There were five miles between their property and their neighbor's. I know. I counted.

I took the boys to the science center once. Later, after seeing where he lived, I wanted to show him the bigger world. We saw a show at the planetarium. My son was so excited, but his friend didn't care. He didn't even look up. He just sat there picking his nose and eating it. Slowly. Methodically. There was something deeply disturbing about the blank look on his face. About the way he licked his finger. He was 10.

I decided I didn't like him.

I may have actually hated him. I never imagined myself capable of hating a kid. But I did. He was weird. Rude. He smelled, and his dirty shoes on my carpet made me crazy, and his parents were also weird and awkward, and I began to form this idea in my head of the kind of home they had. Of course, for all I knew, they felt the same way about us. I'm a realist. I know we may not be top pick either, probably not even middle. But there was something else. Something beyond just weird. They made me uncomfortable. They set off alarms inside me.

Sometime around the end of fifth grade, I ran into the boy's mom in the grocery store parking lot. I don't think she and I had ever really spoken. Maybe it was the place I parked. Or the way I loaded the groceries. Whatever the reason, she was compelled to stop. To speak. To share with me a story I have never been able to shake.

Two men had robbed her recently, she told me. Right where I stood. They stole her purse. She used the term *conceal and carry*. And permit. Hers. Not theirs. *Conceal*, it turned out, was her bag. And *carry* was a handgun. She never left home without it, she said, and "felt naked now that it was gone." She laughed here as if it were a joke. As if having a gun helped everyone to feel clothed. She went on to complain about filing a police report. Expressed annoyance at their blame. Putting a gun into the hands of criminals wasn't *her* fault, she said.

In my mind, I tallied all the times my son may have been within reach of a gun. How many times had hers? I wondered how many other guns they had on that property. How many times had the kids almost stumbled into one? How many times did they not have to stumble at all? I began counting the bullet holes in all the rusted metal in my memories.

The alarm bells sounded a little louder.

I decided my son was no longer allowed to be friends with the kid. That was it. They were dangerous. And not the "kind of people we wanted in our lives." But then, how would I explain to my son that his one friend in the whole world was now off limits? These kids were caught in the middle of two conflicting ideologies. It wasn't fair.

But what *was* fair?

Was I expected to abandon my convictions about guns and gun culture so that my son could have a friend? Was that friendship worth the risk to his life? Whose beliefs trumped whose? It felt disproportionally weighted to their side. After all, a home without a gun poses no risk to their ideas about rights and

“She smiled. She seemed to be pleased with the arrangement. Her son was an A student, and she got to give him what he wanted: A semi-automatic weapon. An assault rifle. Designed for combat.”

bearing arms. But theirs…I wasn't telling them what to believe, but having firearms in a house with children wasn't okay with me. Especially if those guns were being carried, armed, and in a bag.

I began telling other parents about this concealed gun story but was met with tepid indifference. Sure, they'd say, lots of people have guns. I have one in my closet. Or my dad has a locked safe in his garage. Or we have a couple we keep just for emergencies. As though an emergency kit should come stocked with Band-Aids, aspirin, and a 9mm.

Ok, I thought. I hear you. But I politely disagree.

My son and I spent a lot of time doing activities that kept us too busy for friends that summer, and the following September marked the first year of middle school—a place with a hundred new kids who didn't know my son's more prickly side. I was convinced he'd meet someone new. Someone without guns. Someone who bathed and used tissues and who maybe liked to ride bikes.

But he didn't.

Instead, they reconnected despite not sharing any of the same classes or lunch hours. I relented and said yes to the boy coming over. I thought that was a good compromise. He could come to our house, and I wouldn't have to ban his openly. Win, win.

Except he talked only about getting his own rifle. About going hunting. About target practice in the yard. He was 12.

He wanted to play first shooter games on the computer. When my son tried to get him interested in Minecraft he chose to play the laptop instead. On the other side of the room. Good, I thought. Maybe they were finally drifting apart. But the thing about my son's brain is that it works really well to connect facts and ideas, but it's terrible at reading people. He had no idea they weren't playing together. To him, nothing had changed.

At pick-up time his mom asked me how my son liked middle school. Asked me how his grades were. She told me that her son was finally getting As. She asked if I wanted to know how she kept him motivated, focused. “He and his dad have this deal,” she said, “for every A he brings home, he gets one more piece of an AK47.” She smiled. She seemed to be pleased with the arrangement. Her son was an A student, and she got to give him what he wanted: A semi-automatic weapon. An assault rifle. Designed for combat.

What would a 12-year-old boy do with it? What would anyone do? What image did she hold in her mind when she saw her son using it? Because in my mind, I saw him standing on a tower over a crowd of people. I saw him walking into a school cafeteria. I saw him point that gun at all the people who called him weird or poor or told him he smelled like dirt.

I looked at his mother with fresh eyes. She had the same yellowed skin as her son. She wore the same tired jeans. I wondered when they had last bathed. Or hugged. I wondered how the inside of their house felt when no one was looking. Was there love in that house alongside the neglect? Was there abuse?

My sister thought that maybe he kept his shoes and clothes on because he felt like he always had to be ready to run.

I hadn't thought of that. We sat there in silence for a few minutes, my sister and I, later. After they left.

“Is this how mass shooters are made?” I asked her.

“Maybe,” she said. “Maybe this is exactly how they're made.”

*Dacia Price lives in Seattle WA with her two boys and their dog, rabbits, and sometimes chickens. When she's not writing she can usually be found on a mountain peak or in a vineyard. Her short stories and creative nonfiction can be read in Pacifica Literary Review, Toasted Cheese, and Storm Cellar.*

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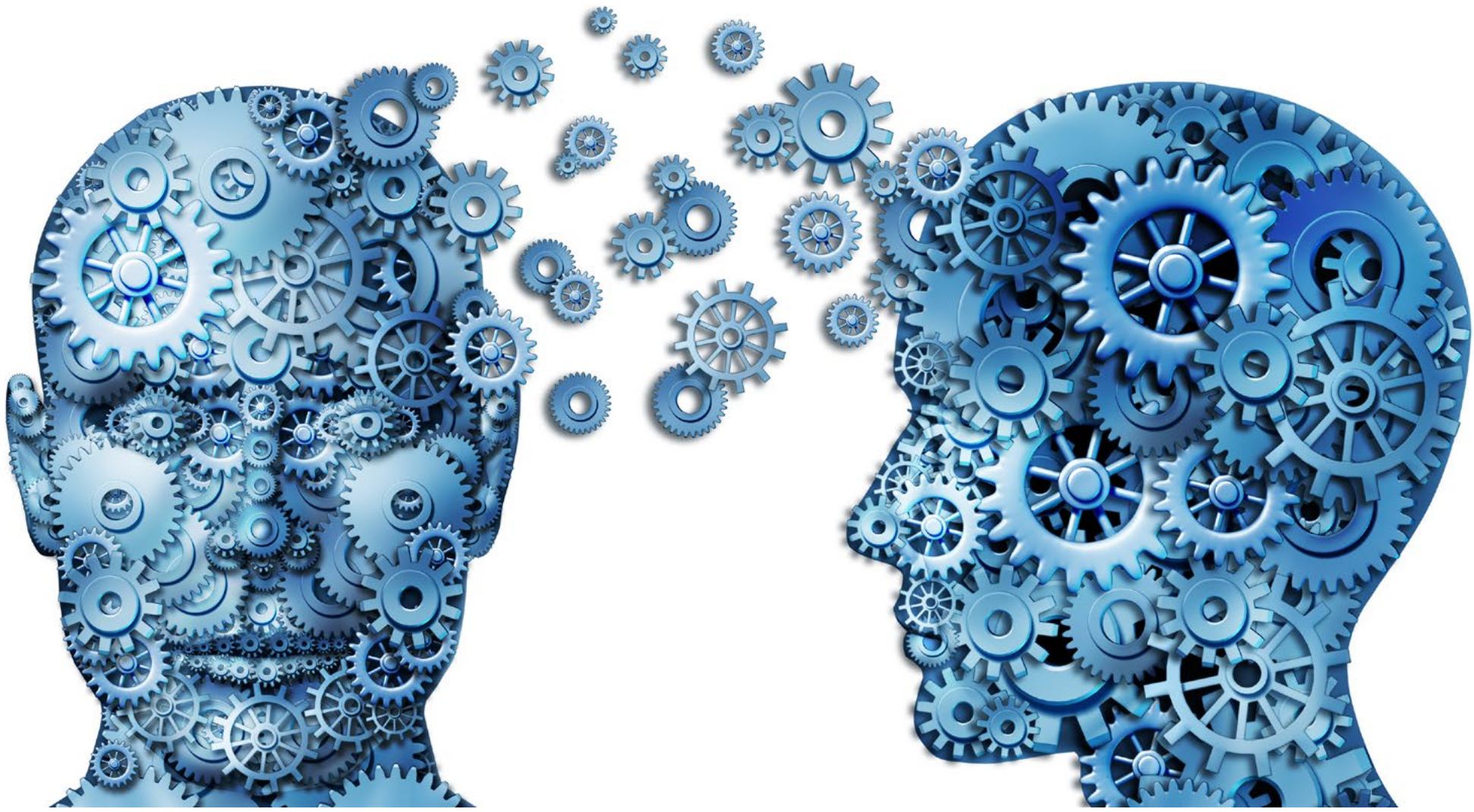
# The Most Important Things I Learned From My Child's Therapists

By Diana ROMEO



My son is 16 years old and is on the autism spectrum. He started speech therapy at age three and applied behavior analysis (ABA) at the age of four. He's had occupational and music therapies and been to social skills groups led by therapists. A whole lot of therapy! Some of the therapies have been at school, some in the community, and a lot have been in our home. I've liked some therapists more than others, and I've found some more competent than others. I've learned something from all of them. Here are five really important things that I've found helpful.

## 1. Behavior is communication

This point is huge. If your child is nonverbal, slightly verbal, or just has trouble expressing needs and wants, behavior is a *very* big clue. I've been at this game for a while and sometimes in the middle of life I just forget this. We were at the beach recently, and my son kept going over to the shower and drinking from it (you know, the one with the sign saying it's not safe to drink the water). After repeatedly telling him not to do that I realized he was thirsty (duh). It may not always be that clear-

cut. If your child keeps running away from you, consider the possibility that he/she is running towards something. There is often a reason behind the behavior if you stop to try and consider it from the child's perspective. Ask yourself what motive your child could have that they can't express.

## 2. Ask, "How do you feel?"

Ask it often. Maybe, in the beginning, you won't get an answer. It's so important for children with autism to be able to express feelings that this should be practiced continuously. If you don't get an answer, provide two or three options for the child. If you know the answer (maybe your child is screaming, and it's lunchtime), then prompt the answer, "Mom, I'm hungry." Maybe when you ask you will get a nonverbal answer (sorry if an iPad is thrown at you, but you'll know the child wants the iPad). Checking in regarding feelings can help reduce frustration on everyone's part.

## 3. Idle hands are the devil's playground

Many kids on the spectrum need structure. They need schedules, and they need to know what's coming next. This is often hard to provide at home, especially for kids who don't have a lot of interests. I had a hard time keeping my son busy, particularly because he didn't/couldn't do many things on his own. One therapist suggested I provide chores for him. I wasn't sure what he would be able to do on his own in the house. It turns out this was one of the best suggestions I ever received. In the beginning, we made up chores just to keep him busy. We took all of his socks out of his drawers and brought them into the living room. He put them away one by one. We took all of the cans off the pantry's shelves, and he had to replace them. This developed over the years into skills he can use productively around the house and possibly transfer to a job one day.

## 4. Independence is key

No matter what you see in your child's future—an independent living situation, a group home, a full-time job, or vocational training—you want your child to be as independent as he/she is capable of being. Don't do something for your child that he/she is capable of doing for himself/herself. If your child can say "milk," make him/her say it before you provide it. If your child can sign "milk," make him/her sign it. Don't give it to the child without the request. You may know your child wants it, but someone else may not. If your child can put his/her clothes in the hamper, don't do it for him/her. This can be a springboard to other independent skills, such as putting away dishes or taking responsibility for his/her own belongings.

## 5. Presume competence

I remember a friend's reaction watching my son unloading the dishwasher. "Wow! How'd you teach him to do that?" I was a little offended, but I opted to educate rather than show my disappointment. I said, "He's capable of a lot more than you'd think. He just has to be taught little by little." Other people will underestimate your child often. Be willing to try things. Break them into steps. Provide visuals in the form of pictures or words. Be there for support. If it doesn't work today, try again tomorrow, next week, or next year. Timing is everything.

As parents of special needs kids, we have learned no two kids have the same needs. Everything on this list can be altered to your child. Do things according to his/her capability with the hope of stretching that capability little by little. We have to go at the child's pace, not ours. A step forward is a step forward.

*Diana Romeo is a full-time stay-at-home mom of two kids, a 14-year-old neurotypical girl who is equal parts sweet and sassy, and a very sweet 16-year-old boy who has autism. She has a degree in business management and has worked in human resources. She enjoys reading, writing, cooking, walking, and yoga. She has been published in Autism Parenting Magazine and Exceptional Parent Magazine.*

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# A New and Improved Approach to SOCIAL SKILLS

By Debra MOORE, PhD

**Kids with autism spectrum disorder (ASD) usually struggle socially and often find the teen years especially difficult. Anxiety and depression can emerge or worsen, along with senses of helplessness, worthlessness, and loneliness.**

Mental health professionals often refer these teens to social skills groups. These groups teach lessons about how to "appropriately" interact in a neurotypical (NT) world.

I've led these groups myself, and have found them useful. But I also noticed the teens really just wanted to talk to each other—to have a safe place where they weren't judged and where they could hear echoes of their own experiences in others. They rarely showed much enthusiasm for the actual "lessons"—and hardly ever practiced them at home.

I recently met a woman who is experimenting with a new model of social skill groups, and I'm excited by her approach. Catherine Robertson is the mom of two teens, a neurotypical daughter Sophie, and a son, Walter, who is on the autism spectrum. She is not a mental health professional. Her family lives in Washington, DC, and she calls her program "DC Peers." We chatted about what she calls her "experiment."

**Dr. Moore (DM):** How did DC Peers get started?

**Catherine Robinson (CR):** The idea came from my wish for a place my son could "hang out" with kids his age—somewhere he was not only welcome but where he was excited to go. Somewhere "cool." I wanted a place that felt natural and part of the community—not a doctor's office or clinic. And I wanted him to have someone his age who would be willing to be honest with him, and kind of coach him socially.

My first idea was simple (I thought!): just have a mentoring group. I'd find socially adept kids to mentor kids like mine and teach them the ways of the world.

Because kids in high school no longer want advice from their parents.

**DM:** I think all parents want this for their kids—a safe place for them to be themselves and have fun. I love your idea of getting peers involved.

I always thought this was the way to go. Mentoring is vital but doesn't require a professional. It just takes someone who cares and has some knowledge of autism. Sometimes we make it more complicated than it has to be.

**CR:** Exactly. In fact, I tried twice before to get something going. I had neurotypical kids excited about being peer mentors. But Walter's school administration wouldn't get on board because of liability concerns. It was so frustrating!

“I got a nonprofit status so that I could give student volunteers “community service hours.” In DC, kids need 100 hours of volunteer service to graduate, so this seemed like a natural fit. And this is important: I give both the “typical” and the autistic teens community hours—because they are building awareness of neurodiversity together. It motivates all of them to think of this as a service to the community.”

So I decided to start my own program based on volunteers and with no bureaucracy. And I wanted it to be free. Right now, too often the only kids who get access to social skills support are those whose parents have resources unless they're lucky enough to be in a really good school district!

I got a nonprofit status so that I could give student volunteers “community service hours.” In DC, kids need 100 hours of volunteer service to graduate, so this seemed like a natural fit. And this is important: I give both the “typical” and the autistic teens community hours—because they are building awareness of neurodiversity together. It motivates all of them to think of this as a service to the community.

**DM:** Sounds like a great plan. How did you structure it?

**CR:** Right—I needed to figure out how it would actually work! One of the things I wanted to avoid was having the volunteers just “be nice” to the spectrum kids. My daughter (and cofounder) Sophie calls this the “Best Buddies” problem. I wanted to see real learning and genuine understanding develop.

At the time, Walter was doing a program developed at UCLA called PEERS (Program for the Education and Enrichment of Relational Skills). I liked the way it broke down basic social situations into sets of rules and steps. But I thought if Walter could practice these situations in a safe environment with more skilled peers, he would benefit even more. If, for example, he was learning to join group conversations, he could try it a few times, make mistakes, and get supportive feedback and suggestions from these peers.

Watching Walter try PEERS, I realized that curriculum could be the structure for my mentors. So in the fall of 2016, I traveled to LA and became a Certified Provider.

**DM:** Kudos to UCLA for allowing you to adapt their program and make it your own. So once you returned to DC, what was next?

**CR:** Then I started recruiting teens with autism for my pilot program. I held a meeting for interested parents, and all but one, whose child was too young, signed their kids up!

Then my daughter pulled together a focus group so we could see what would convince a neurotypical high school student to volunteer. We wanted feedback on the idea, but instead of giving me feedback, they all just signed up!

Without even trying, we ended up with twice as many kids as I had envisioned, 50 percent on the spectrum and 50 percent neurotypical.

**DM:** How excited you must have been! But you were also wading into uncharted territory; that must have been a bit daunting.

**CR**: As I told all the parents and the kids from the beginning, what we were doing would be an experiment. That approach seemed appealing; we were all working together to build something.

We scheduled our first meetings to run for five months and called it a “club.” We sometimes used the PEERS lessons and sometimes expanded on them.

For example, once we took a long time talking about a difficult situation that had come up for one of the members. We brainstormed how to handle it, which the participant found to be a big relief.

**DM:** I think jointly solving a real-life issue in real time is what bonds people. Did the kids start to develop relationships with each other?

**CR:** Well we followed the PEERS rule preventing contact outside the group, but the group developed real comfort with each other. We offered a few optional social activities with no agenda other than to have fun. We had a trivia night and a picnic in a local park. Almost everyone came, and it was clear the kids had come to like and trust each other.

By our fifth month, the kids were all very comfortable with each other. Some were set to graduate from high school, but all of them still in school wanted to come back after the summer and do the group again. So I had to come up with a new curriculum for "Club Peers 2!"

**DM:** That says a lot. What did you come up with for the second year?

**CR:** I realized one critical goal I hadn't met: helping the kids learn to coach each other based on knowledge I shared with them.

I had hesitated to ask NT kids to actually advise the autistic kids because I'd set up the group as one where everyone was on the same level. The idea was that we all struggle with social skills. That's true on one level, but not entirely honest.

That summer my daughter and I attended a seminar on neurodiversity. We resolved to improve Club Peers using what we learned, and that meant not glossing over differences, but *actually talking about them explicitly.*

The second year we held two trainings before the club restarted. One was for the neurotypical teens to help them understand the neurology of autism. I wanted them to have insight into the source of the behaviors and social blindness they would see.

Then we held another training for the teens with autism. I wanted them to understand the "typical" brain. I wanted them to know the neurological reasons that other teens find socializing so easy and fun. In each training, I explained how brains are wired differently and how each kind has unique strengths. I taught them about how certain parts of the brain impact things like eye contact. This resonated with them and proved very popular.

I also really wanted to them see the bigger picture—that because these "typical" teens are in the majority, our culture has said "neurodivergent" kids should learn "typical" behavior. But that is an enormous task, and we are putting the burden all on them. Imagine how much easier, and less anxious, the lives of the autistic would be if their communities understood them?

**DM:** That is what I really love about your approach. I sense you treated all the kids with respect and trusted that they would be able to understand and appreciate information that, in my opinion, therapists often do not explicitly share with their clients.

**CR:** Well, the kids have certainly responded with enthusiasm, and they keep coming back, wanting more. And parents are noticing more confidence and the willingness to try some new things.

**DM:** I wonder if you could give a couple of specific examples of group experiences that stand out for you.

**CR:** Well, last year as the group got more comfortable together, we laughed a lot, which made practicing social skills more fun. We got to the point where everyone was okay trying awkward things (like joining group conversations, or telling jokes) and getting feedback from the whole group, which was exactly what I'd hoped for. I'll never forget the expression on one girl's face when she was trying to pretend she found my joke funny.

**"The kids have certainly responded with enthusiasm, and they keep coming back, wanting more. And parents are noticing more confidence and the willingness to try some new things."**

**“I think a possible difference between groups run by parents vs. professionals is that parents have developed more tolerance. I’ve seen professionals get kind of freaked out by behavior that doesn’t really faze me.”**

Another moment was at one of our trainings when a young autism advocate who is working with us this year (Joel Carver) was trying to help our typical volunteers understand autism better. He asked for a neurotypical volunteer and handed her a chair. While she held it, he described how it feels to have a passion that you really, really want to talk about and can’t. And that pressure to talk about it stays with you all day—all through class, after school, and throughout most social situations. You hold that chair the whole time, and it gets heavier and heavier. The only time you get to put it down is when you can finally talk about what you love.

After what we had learned about how the neurotypical brain gets pleasure from socializing in a way that many autistic brains don’t, someone in the group said that hey, maybe for neurotypicals, *socializing is that chair!* We all agreed we need to figure out what our “chair” is.

**DM:** I have two last questions. One is what you would tell other parents who have teens resistant to getting together with other kids. The other is what has been the most powerful to you personally in doing these meetings.

**CR:** To your first question, I, too, struggle knowing how much and when to push. I think the best approach is to help them feel safe to reach outside their comfort zones, little by little. One mom said to me she was afraid her son would leave after five minutes or start to scream. I told her that was fine if he did, and in fact, Walter had done that, and that this was a group where we all knew why that might happen.

I think a possible difference between groups run by parents vs. professionals is that parents have developed more tolerance. I’ve seen professionals get kind of freaked out by behavior that doesn’t really faze me. I sometimes think, “What exactly were you expecting? This is the problem we are here to push through.”

To answer your second question, I’ve learned that both groups of kids love discussing their lives with other kids and widening their perspectives. It’s been powerful to see all the kids—both neurotypical and autistic—understand themselves and each other better. I want to foster talk about autism as a difference—and a really interesting one—not just a disability. We’ve done that in our meetings.

I really do think that most people who encounter an autistic person want to understand and help. And I think teaching neurotypicals about autism is the best possible way to help people with autism.

It’s a work in progress, and the kids and families are willing to go along for the ride, so I’ll keep experimenting and learning!

*Debra Moore, PhD, is a psychologist who, prior to retirement from active practice, worked extensively with children, teens, and adults on the autism spectrum. She coauthored The Loving Push: How Parents and Professionals Can Help Spectrum Kids Become Successful Adults (2016) with Dr. Temple Grandin. She contributed two chapters (one coauthored with Dr. Temple Grandin) to The Nine Degrees of Autism (2015) and wrote the chapter Internet and Gaming Addiction in Youth on the Autism Spectrum: A Particularly Vulnerable Population in Internet Addiction in Children and Adolescents: Risk Factors, Assessment, and Treatment (2017). She also facilitates the groups “Autism Spectrum Across the Lifespan,” and “Autism Spectrum HELPING HANDS Mentors” on LinkedIn.com.*

ASD MARKETPLACE

# Top Tricycle a Sweet Ride for People with Special Needs


**Product:** Nuvotrike 20-inch tricycle.

Great for individuals with the desire to ride a bicycle but unable to balance on a traditional bicycle. Currently used by individuals of many ability levels.

Introducing the Nuvotrike, which has a patented design with a spring suspension to potentially absorb joint stress when transitioning over different surfaces.

This simple design eliminates a chain and the weight of the larger trikes on the market. The ability to fold combined with a weight of just under 50 pounds allows transport of the Nuvotrike in SUVs, minivans, and larger sedans.

It is currently being used in schools for children with special needs in their physical therapy settings.

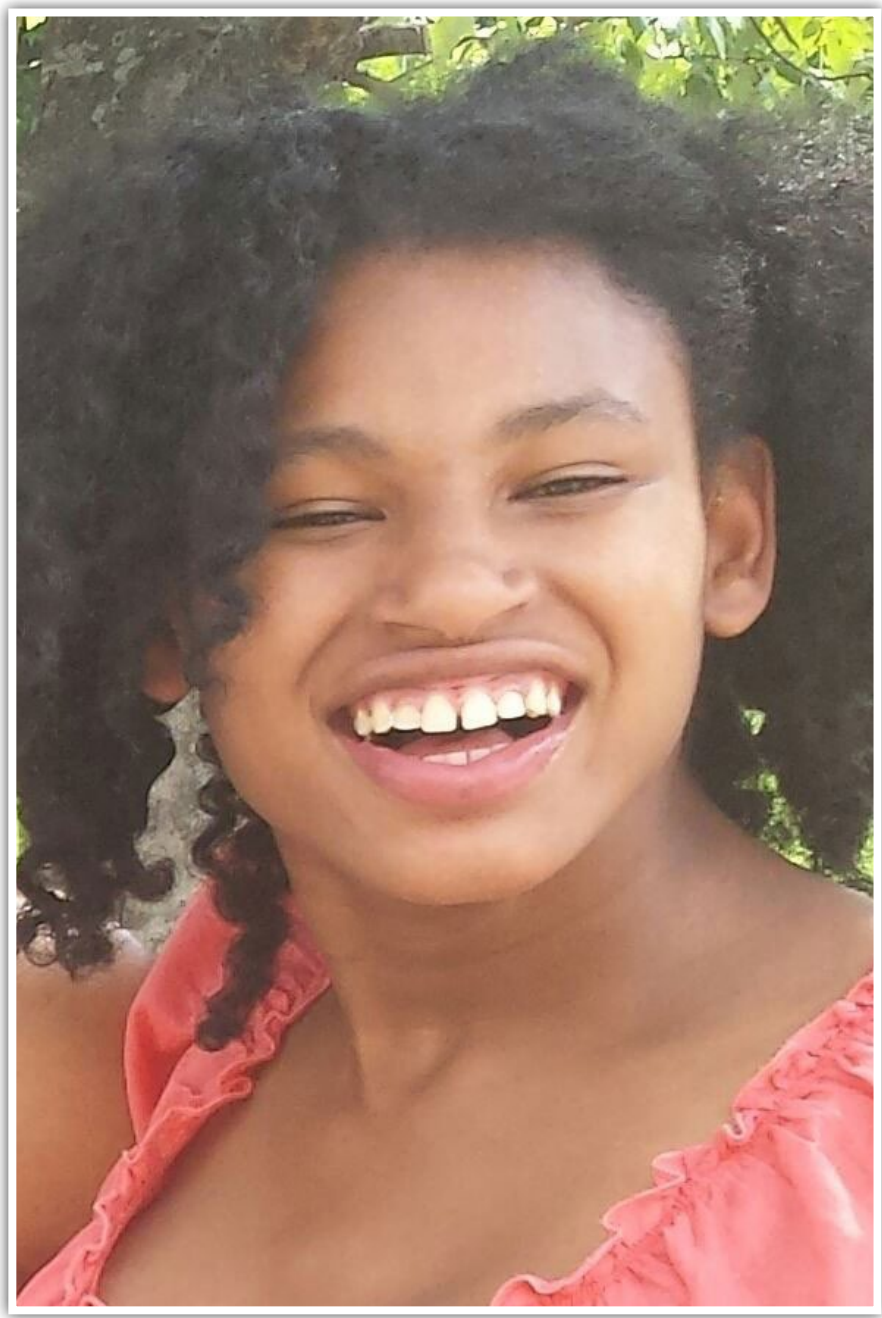
**Mission:** It is our mission to provide a low-cost tricycle for individuals of many ability levels currently unable to balance on a bicycle, as the parents of these individuals have a large financial burden with daily living expenses in raising their children with special needs.

The Nuvotrike is available on our website at www.nuvotrike.com or by calling 347-620-1234. Please contact us today if you are interested in this new product.

Hot Off the Press!

# Family and Community Inspires Special Needs Woman to Reach for the Stars

Nothing will keep Kyleigh LaRavann Dirton from achieving her dreams. Born with meningitis, Kyleigh was diagnosed with autism spectrum disorder (ASD), developmental delays, cerebral palsy, and seizure disorders as a young girl. Her parents were told by doctors that her chances of walking, talking, or having any type of "normal" life was slim. But they didn't know Kyleigh. And they didn't know she would have a team of people ready to help shape her.



When Kyleigh was a toddler, her father, Chris, worked every day on her language skills by getting her to repeat words, allowing her to learn to communicate. Her family enrolled her in physical and occupational therapies which have allowed her to function well with assistance. It wasn't long before Kyleigh had a dream: to become a professional model.

At 24 years old, Kyleigh lives with her family who supports her aspirations. Her dad keeps her laughing every day and affectionately calls her his "Little Princess," while Kyleigh spends time with her mother, Tawana, working on her modeling skills. She aspires to become a print model and appear as an extra in movies. Kyleigh says her goal is to become a Victoria Secret model, meet celebrities, and be on the Ellen DeGeneres Show.

Kyleigh has always been excited about participating in special events and meeting new people—especially those that helped her increase her physical and verbal skills. At Woodmont High School in Greenville, SC, she had some wonderful peer tutors and an awesome high school teacher, Mr. Maddux. He taught Kyleigh social skills, developmental skills, and life skills for seven years. They remain friends today.

Every therapy and experience has helped Kaleigh to develop and gain the skills she needed to grow. For example, she was vice president of the Impact Club,

**“Kyleigh was already popular in high school, but her win changed her life in such a positive way. It showed her she could accomplish anything she set her mind to with the support and love of family and friends. She loved and appreciated all of her peer tutors and her high school friends.”**

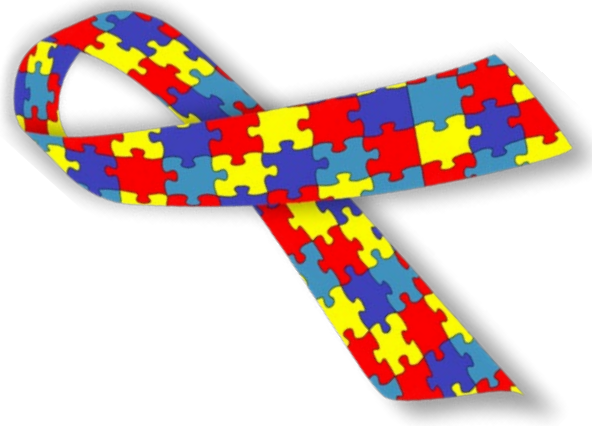
an activists group that supports positive activities for special needs individuals, which allowed her to do community service and increase her social skills. She joined a cheerleader squad called the Greenville Starz, which helped her with her ability to follow direction while developing her communication and physical skills. And Kyleigh competed and won Gold and Bronze medals with Special Olympics of SC many times.

One particular event that helped shaped and inspire Kaleigh was her high school prom that she attended with her special needs class. Imagine her surprise when she heard her name announced and was crowned Woodmont High School Prom Queen 2015, not just for special needs, but for the entire student body.

Kyleigh was already popular in high school, but her win changed her life in such a positive way. It showed her she could accomplish anything she set her mind to with the support and love of family and friends. She loved and appreciated all of her peer tutors and her high school friends. They were very loving and attentive to Kyleigh’s needs and over the years, have taken her to dinner, bowling, and skating, which has increased her verbal communication and activity in the community.

Family support has also influenced Kyleigh, from her amazing grandparents, aunts, and uncles to her enthusiastic cousins who fills her life with special memories, love, and joy. Close to her heart is her 21-year-old brother Cameron who is studying to become a physical therapist. Cameron is a huge supporter of his sister and is always uplifting Kyleigh to follow her dreams and shoot for the stars.

Kyleigh is currently in an active daycare program for special needs young adults. She is working on photo shoots and developing composition cards to distribute to casting agents with the help of her mother. Kyleigh and her family are very grateful to have had such amazing people in her life.



# Iris

By Paula TIMPSON, MA

*Iris dances through Art*
*Her beautiful Maine Coon cat by her side*
*inspiring her to create*
*beautiful*
*Monet-like paintings*
*The autistic have such*
*creative potential*
*we can see if we look*
*with new eyes*
*Iris in the UK*
*silent butterfly she is*
*a dream of goodness and*
*light*

*Paula Timpson, MA. special education, is the mum of a 10-year-old boy who is her forever muse. A published poetess, her poetry books, including In Praise of Autistic Children, can be found on Amazon.*

Websites: http://paulaspoetryworld.blogspot.com & http://paulaspoems.blogspot.com

# On The Spectrum Poem

By Jerrice J. BAPTISTE

I rub his head in my lap, saying, *"It's okay Dean. It's okay."*
He shuts his ears with his palms.
A world of high pitch voices, humming of air conditioning, and a song,
*"Good morning. How are you?"* trapped in his mind.
I lull his head in my lap.
We rock back and forth, and repeat together in harmony, *"It's okay Dean. It's okay."*
The morning circle breaks. I pick up eight name tags, ABAB pattern of circles and squares, clouds and sun.


*Jerrice J. Baptiste is a poet, author, and educator who has been published in The Crucible; So Spoke The Earth: Anthology of Women Writers of Haitian Descent, Inc; African Voices Magazine, Chronogram; Shambhala Times; Hudson Valley Riverine Anthology; Events Quarterly; Human Journey Magazine. Her poetry in Haitian Creole and collaborative songwriting is featured on the Grammy Award-winning album, Many Hands: Family Music for Haiti, released by Spare the Rock Records LLC. Jerrice is the author of eight books. She resides in the Hudson Valley, NY.*

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# ASPIE DATING: 10 Things to Keep in Mind When Looking for Love

By Alan DD

Dating can be filled with stress and insecurity, but what happens when you add to this the fact that your date has Asperger's syndrome? What should you do and what should you not do? How can you make things work? Here are 10 points to keep in mind when falling in love with one of us Aspies:

## 1. We prefer to listen

Anyone who knows the basic signs of Asperger's syndrome will understand this. We're not that interested in talking, but we can handle listening to other people, learning their opinions, or just sharing our thoughts now and then. And sometimes it takes less of our energy to do it.

## 2. There is a right way get us talking

It's better to directly ask when you want an opinion from us. We're not best friends with indirect comments or sarcasm, although we can learn depending on the person. And be careful when touching on a topic we are interested in: we will talk and talk, and will love it if you share the same interest!

## 3. Our social needs tend to change

Who says we don't go to parties, movies, restaurants, and so on? Yes, we may not be fans of going out every single weekend, but some days are okay. Keep in mind that we may prefer to spend a day at home, watching a TV series or listening to music. We may also like going to the library or a museum, somewhere with minimal noise. Now, if your Aspie is a Metalhead, things will be a little confusing from time to time, but they will stay interesting!

## 4. Be upfront about gifts

When there's something you really love and would like to be given it as a present, it's better if you share the information. We do have ideas and do try to guess what our significant other might like, but if there's a detail you know you will love, say it. We won't have to worry about the endless "is this right?" drama.

## 5. Hugs? Kisses? We want a relationship first

We prefer to keep a distance when there's not a solid connection yet, similar to the old days when you had to get to know someone first. You won't get a kiss on the first date, but maybe on the third or the fourth. We're romantics in that sense, and there are not many of us left!

## 6. Don't overwhelm us with new friends

Please don't say, "I'll just introduce you to my family/friends," and bring about five people. We'll be terrified. Think about going one by one, or two by two, giving us enough time to process new people, and do it with enough time between each group. The next time we are at a social event, we'll go with the flow and will thank you for it!

## 7. Take the time to learn to get along

Relationships are also about the thorns in the roses and the dark clouds before the rainbow. Even if it's hard to do when you're angry, watch your mouth before speaking as we tend to take comments literally. If you're not getting anywhere in the discussion, take five, calm down, and then start again.

## 8. Let us have our routines

We have a schedule and routines to keep our mind in order and under control. There's a reason why we do things like that, and yes, "it's the way it has always been" is valid for us. Changing it can make us feel lost and uncomfortable. It's better just to ignore those things when you're still new to an Aspie.

## 9. Work stress can be hard

Who hasn't had one of *those* days in the office? For us, it can be even more stressful than you can imagine, so we may be uneasy at the end of the day. Don't be scared about it. On the other side, if we have an amazing day and love what we're working on, then you'll have a great time with us, maybe even a surprise! Who knows?

## 10. It's exciting to plan for the future together

So you went through the whole process, you both know each other as no one else does, the feelings are mutual. Maybe it's time to make it official! Aspies don't take surprises that well, so if you propose, expect us to be overwhelmed with emotion! If it's the Aspie who is proposing, then you'll see us more nervous than ever. Either way, we're impossibly cute!

*Alan D.D. is a writer, journalist, and blogger from Venezuela. After years of thinking he was just introvert and shy, he discovered he had Asperger's syndrome while doing what he loves the most: reading. Since then, he writes about the topic whenever he can, and when not immersed in a book of his or from his favorite authors, he can be found most likely at the movies or playing Heroes of the Storm.*

# INSPIRED DAD TRANSFORMS THE WAY SPECIAL NEEDS CHILDREN DEVELOP AND LEARN

**AUTISM WARRIOR:**
**Rupert Isaacson**
is founder and co-director of the Horse Boy Foundation.

Rupert Isaacson is founder and co-director of the Horse Boy Foundation which consists of two main programs:

- The Horse Boy Method, an equine therapy that addresses the nervous system and builds neuroplasticity for autism spectrum disorder (ASD), attention deficit disorder (ADD), and other related conditions.
- Movement Method, a kinetic learning program applicable for both home and classroom.

Both of these dynamic programs work with the brain and nervous system, getting long-term kinetic learning and brain training by doing movement-based activities that act on the learning receptors of the brain. The foundation now works in 20 countries and serves about 30,000 families per week, a number that is rising. It's neuroscience disguised as play and works for kids and adults alike. Rupert said autism is their specialty, but they work with all neurocognitive diagnoses including attention deficit hyperactivity disorder (ADD/ADHD), anxiety, depression, eating disorders, post-trau-

matic stress disorder (PTSD), and more. Schools are adopting their kinetic learning modules for neurotypical kids, too.

**LOCATION:** Headquarters is located in Austin, Texas, but satellite locations are located all over North America and Europe with new programs starting in South America and Southern Africa.

**ACCOMPLISHMENTS:** Rupert said their main achievement is that they are the only autism program that they know of led and mentored by people with autism. Because of this base, along with mentoring from Dr. Temple Grandin and others from the start, they achieved the results they wanted. Rupert said they reached out to several neuroscientists including those from the University of California and the Marie Curie Institute in Paris to better understand WHY the program was so successful. The consensus was they had figured out a way to make the body move that shuts off the cell danger response (stress) that impairs learning and which, in turn, switches on the cerebellum (motor and social skills), Purkinje cells (communication between the different parts of the brain), the vestibular system (balance and attention, i.e., long-term learning), and producing brain-derived neurotrophic factor (BDNF), which ups the IQ and engages the logic and reasoning centers of the brain.

Rupert added, "The fact that we got here by following what autistic people themselves told us to do, rather than imposing theories from the outside, is probably our greatest accomplishment."

**INSPIRATION:** Rupert said his son Rowan, diagnosed with severe autism in 2004, is his greatest inspiration. At 15 years old Rowan has a job, a life, and a whole world of his own creation and is the most empathetic, quiet, egoed, yet brilliant young man Rupert has ever met.

**GOALS:** To consign to the historical trashcan, where it belongs, the notion that anyone, let alone children, let alone children with autism, need to suffer to learn. The science just doesn't support it.

**ADVICE FOR FAMILIES AFFECTED BY AUTISM:** "Celebrate the gifts—the amazing memory, the ability to focus interest and intellect, the quiet ego that is so healing just to be around. Follow the child's interests and obsessions and design his or her world and learning around those. Spend hours a day in nature away from bad sensory triggers. Eliminate those home triggers (fluorescent lights, cleaning solvent smells, cigarette smoke, perfume, rooms that echo, and all the other well-documented negative triggers). Get a nice big quiet dog. Put a trampoline in the backyard and USE it. Go slide in the mud on rainy days and go to the pool on hot days. Regard autism as a set of gifts, not a problem to be fixed. Teach life skills but don't make someone feel bad about who they are. Consult with adults with autism and follow their advice. Learn the basic neuroscience of how the brain's learning centers work and apply them by taking our online Movement Method course."

Websites: kidsmustmove.com & horseboyfoundation.org

# An Exclusive Look at AUTISM with *Alana Mithcwell*

By Derrick HAYES

*Encouragement speaker Derrick Hayes gives an AUTISM interview by asking six questions through each letter in the word "autism" to give readers insightful perspectives from parents, experts, entrepreneurs, and other leaders in the field.*

*"It is the strength that I see in my son every day that has kept me going."*

Today's AUTISM Interview is with Alana Mithcwell, who is a 35- year-old medical esthetician and business owner, happily married to her college sweetheart and mother of two boys (one of whom has autism).

Ten years ago my husband and I started an e-commerce, *skincarebyalana.com*, retailing 300+ beauty brands. This experience combined with my passion for skincare, my drive and love for my family pushed me to start my amazing and innovative skincare line "Alana Mitchell" at *www.alanamitchell.com*.

### A is for Awareness - When and how did you first become aware that something was different?

My son was about 15 months old. I know this is considered very early, but my mother's intuition was telling me that my son should be making more of an emotional connection.

### U is for Unique - How has this experience been Unique to you and your child?

For me, I have learned the meaning of unconditional love. I have learned to fight and persevere for what I know is right for my son. We celebrate and cherish every accomplishment, big or small!

I never compare my child to another. When you compare and contrast, you will find yourself feeling prideful or depressed, neither of which is an ideal outcome.

My son was created for and has a unique purpose that only he and his unique mind can accomplish. This really struck me when he was four years old and we were driving in the car. He asked me what color the number seven was to me, to which I said I don't see colors in numbers. He proceeded to tell me what numbers had color—five was blue, six was green, seven was red and orange. I have taught him that his brain and outlook on things is extremely important and needed in our society. I found this saying about autism a while ago: "It takes a sprinkle of autism for advances in math, science, and the arts." I don't know who said it, but it's a message we as parents need to keep in mind as we raise the next generation.

### T is for Tools - What tools are there now that were not there at the beginning that could help other parents?

ABA (applied behavior analysis) at home is very helpful; when things can be smoother at home, everyone is happier.

### I is for Inspire - As a parent, when you look at your child or children, what inspires you?

Hope. I have so much hope!! I have seen it, and we have been a part of it. I love being able to look back

at a time when I thought things were hopeless, like when my son kept biting peers. I would think to myself, I can't wait for the day, and I will throw a party to celebrate when he stops biting his peers. That day has come. No more biting.

**S is for Support - Are there things you struggle with or have struggled with, and what types of support do you still need?**

I am too hard on myself, and I tend to blame myself for things. Thankfully my husband is always there to remind me I am the best mom and advocate for our son!

The support of other parents with children on the spectrum, especially moms—it's such good therapy to get together to share resources, laugh, and just vent when you are having a rough time.

**M is for Manage - What keys to success can you leave with parents so that they can better manage their day-to-day efforts?**

First of all, give yourself a lot of credit; you are doing a good job! Oh, sometimes the day-to-day can be so hard and taxing. But then again, don't compare your efforts or your child to others. Take things one day and one thing at a time. I look at our day-to-day efforts towards a long-term goal: when my son is 18 years old, he will be able to go off to college. So right now it's okay that he is behind in a school subject because we are working towards a different goal.

Also, you will be late for things. Just accept you can't do it all and be on time. Many times I have had to say to myself, "Well, you can be late and have him in a good place, or you can be on time and show up as a complete disaster. Make your choice, Alana. Is it worth the stress to be on time? No."

*Derrick Hayes is an author, motivational speaker, and paraprofessional with students with autism in the Muscogee County School District in Columbus, Georgia. For contact or booking information, please visit his website, email, or call him.*

*Website: www.derrickhayes.com*
*Email: info@derrickhayes.com*
*Call: (706) 615-1662*

# New Book Captures the Beautiful Spirit of Young People with Autism

*Faces of Promise: Looking Beyond Autism* is a collaboration between Dr. Richard Ehrlich, fine art photographer, and physician, and Dr. Barbara Firestone, president, CEO, and founder of The Help Group, one of the nation's largest, most innovative and comprehensive nonprofits serving children with autism spectrum disorder (ASD) and other special needs.

This inspiring, large-format, fine art photo essay book shares moving portraits of children on the autism spectrum paired with reflections from their parents and, in some cases, from the young people themselves.


Richard Ehrlich approached Barbara Firestone with an idea to promote the acceptance of children with autism through his photography. Underscored by the core belief that "Dignity, hope, opportunity, and love are the birthrights of all children," they set out to illustrate in photos and words the dignity and promise of the children. Their goal was to emphasize the importance of recognizing that these young people are not defined by a label; they are children first, and deserving of our respect and acceptance.

"This extraordinary volume is breathtaking in both sheer beauty and the power of its message. It brings us the fruit of a remarkable collaboration between Richard Ehrlich, who has a gift for capturing profound emotion in visual images, and Barbara Firestone, who has been a true champion of children with autism and their families. *Faces of Promise: Looking Beyond Autism* will move you and fill you with a deep appreciation for what is uniquely human in us all."

—Robert M. Bilder, PhD, ABPP-CN Tennenbaum Family Professor of Psychiatry & Biobehavioral Sciences and Psychology at UCLA

"*Faces of Promise* shines a much-needed light on the children and the families who meet the challenge of autism every day. Providing hope is key. Have a look, and prepare to be inspired."

—Gary Cole, Actor on *The Good Wife, Veep, Office Space*
Autism Advocate and Parent

*For more information:*
*Website: TheHelpGroup.org*
*Website: EhrlichPhotography.com*
*Amazon: www.amazon.com/Faces-Promise-Looking-Beyond-Autism/dp/151326088X*

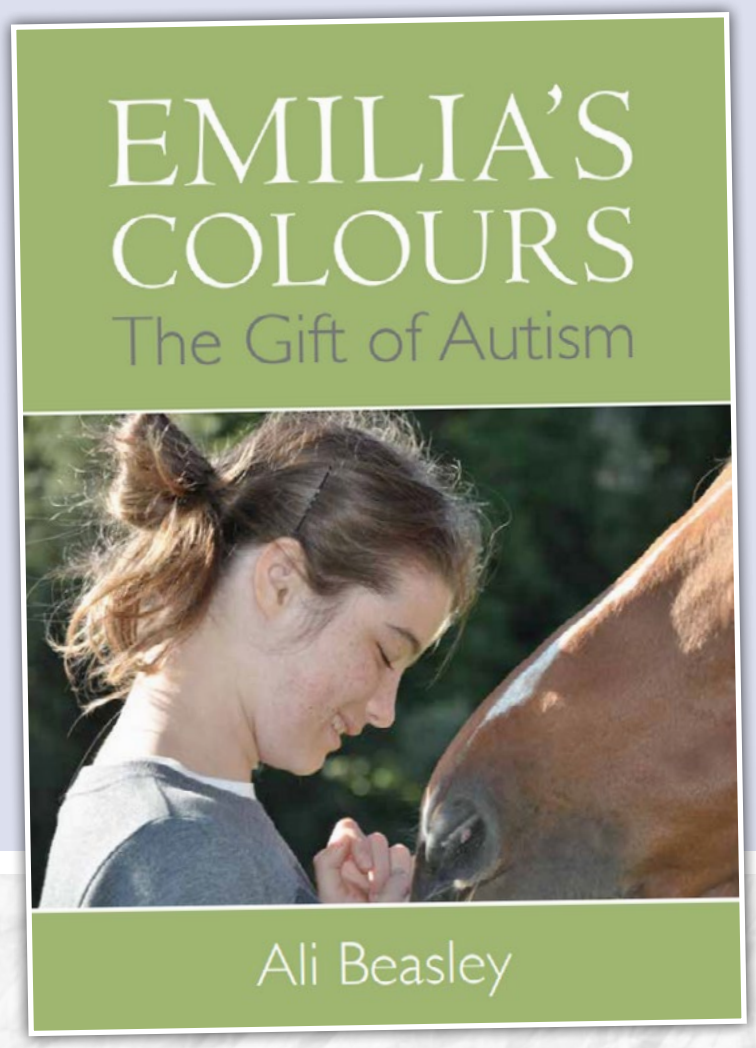
# Compassionate New Book Captures the Gift of Autism

Ali Beasley lives in Nelson, New Zealand, with her husband Keith and their two teenage children, George and Emilia.

A diagnosis of autism spectrum disorder (ASD) when Emilia was seven had a profound impact on the whole family, which Ali explores in this honest, intimate work.

*Emilia's Colours* shares the highs and lows of living with a child with a major disability in words that are frank, touching, and ultimately hopeful.

From her initial feelings of shock and grief, Ali gradually learns to develop resilience as she comes to accept and even embrace her daughter's condition.




Through caring for Emilia, she discovers the importance of looking after herself as a parent, and restorative yoga becomes her "go-to" place for inner healing.

The book's opening chapters consider the many and varied challenges that Emilia faces, including stress, anxiety, anger and communication difficulties. Ali describes the hard reality for parents trying to cope with these challenges, which has an enormous impact on family relationships and activities, and childhood friendships.

She goes on to look at the ways she and Keith have learned to seek and find support on a parenting journey that began without a map—and at the gifts autism has provided them, by teaching values such as patience, gratitude, courage, compassion, and humor.

*Emilia's Colours* concludes with personal impressions by close family and friends of what Emilia means to them, and the effect she has had on their own lives.

Throughout the pages, heart-warming photographs capture Emilia in all her colors, together with the people who love and care for her most.

In writing her personal story, Ali hopes to support other parents who may be struggling to cope with the volatile, unpredictable nature of life with a child with autism.

She also aims to raise awareness and a better understanding of this "invisible" disability among those who may not have encountered autism first-hand.

*To purchase Emilia's Colours for NZD 23.95 ($16.74), go to www.alibeasley.com. Ali continues to write about Emilia through her blog on the website.*

# Finding the Special Needs Trust That's Right for Your Family

By Ryan F. PLATT, MBA, ChFC, ChSNC

***Question:*** *"My husband and I have been researching Special Needs Trusts, and we have realized there are multiple types. Would you mind describing the types of Special Needs Trusts that exist and the reasons for each?"*

***Answer:*** You are correct. Special Needs Trust is a broad term that can comprise various types of trusts. We will briefly explain the three main types:

## 1. D(4)a or Self-Settled Special Needs Trusts

This type of trust is used in situations when the individual with special needs receives money in his/her name, and that money must be removed from the estate (not owned by him/her), so he/she can continue to qualify for government benefit programs. This scenario can occur:

a. Due to an incorrectly designed will or beneficiary designation that lists the individual with special needs directly by name, which means he/she received a lump sum amount of money.

b. Due to a settlement from a lawsuit where the individual was provided a financial lump sum usually based upon some form of negligence that caused an injury to the individual.

c. If the individual with a disability was saving money and his/her savings exceeded the Medicaid Limit. To avoid a Medicaid Spend down, the individual could use one of these types of Special Needs Trusts.

By utilizing this type of Special Needs Trust, the individual can continue to benefit from this money, while still qualifying for government benefits. The drawback to this type of trust is at the end of the individual's life, any money remaining in the D(4)a trust is subject to a Medicaid payback, which could result in all the money in the trust being seized by Medicaid. However, if your child receives a large sum of money, this is many times the only option.

## 2. D(4)c or Pooled Special Needs Trust

A Pooled Special Needs Trust is typically run by a nonprofit organization that will manage the trust and be the trustee. "Pooled" means that

the organization pools the assets of all participants (beneficiaries/individuals with disabilities) into one "master trust" with separate "sub-trusts" or "sub-accounts" for each beneficiary. The advantage to this trust is that the pooling feature allows families with lower levels of assets to still have Special Needs Trust option for their children and have a qualified entity, such as the nonprofit, manage and provide for the needs of their loved ones.

A Pooled Trust does have similar rules regarding remaining money in an individual's "sub-trust" or "sub-account" when he/she dies, as the D(4)a trust. For most pooled trusts, when a beneficiary passes away, Medicaid is entitled to be reimbursed for expenses they paid on behalf of the beneficiary, and any remaining money is usually held by the charitable organization (each organization that runs pooled trusts will vary on the amount they hold onto when a beneficiary passes away).

Another important element to consider when deciding to use a Pooled Trust versus one of the other trust options is the mobility of your child with autism. If your child will be moving to another state, it could be problematic to begin a pooled trust in the state your child currently resides. Pooled Trusts can be state-specific, and if the pooled trust you choose is not national (meaning it accepts beneficiaries from all states), then if your child moves, the trust will most likely need to be moved to a new Pooled Trust in the state he/she resides.

## 3. Third Party Special Needs Trust

This trust cannot be funded with money from the individual with a disability. This type of trust can be funded by anyone other than your child with autism, which means parents, grandparents, siblings, aunts, uncles, etc. When money is placed in this trust, it is not considered your child's asset, which means your child will still qualify for government benefits such as Medicaid and Supplemental Security Income (SSI), but yet the trustee (the person who manages the trust) will use the money from this trust to benefit your child.

Families mainly choose this type of trust is because it has no Medicaid Reimbursement Provision at the end of your child's life. This means that if money remains in a correctly designed and managed Third Party Special Needs Trust at the end of your child's life, then the money will be directed to whomever you determined it would go, such as other children or grandchildren or a charity.

When considering the type of trust to choose for your child, you must consider your situation and consult with a professional. Please feel free to reach out and ask us questions.

*Ryan F. Platt, MBA, ChFC, ChSNC, completed his Special Care Planner Certification in 2005 at the American College in Bryn Mawr, PA, in which he received advanced training in estate and tax planning, Special Needs Trusts, government programs, and the emotional dynamics of working with people and families with special needs loved ones. In 2013, he went on to complete the Chartered Special Needs Consultant designation. A pioneer in his field, Ryan is one of only a few planners certified through Massachusetts Mutual Life Insurance Company (MassMutual) and the American College in Special Care Planning in Charlotte. He is the founder of A Special Needs Plan.*

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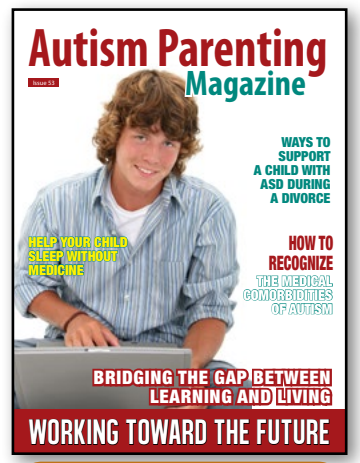


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