Autism Parenting Magazine

Issue 73

Help Your Child Socialize Using Video Self-Modeling

Are Girls on the Spectrum Not Being Diagnosed?

Why You Need to Support Your ASD Child in Physical Education

Improving the Future for Young People with Autism

AMAZING WAYS TO SUPPORT AUTISM

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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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Editor's Letter

I received a touching note the other day from a woman who confessed to becoming teary as she turned the pages of *Autism Parenting Magazine*. More than 20 years ago, she explained, she had to travel to conferences all over the country to navigate the autism journey with her son. The woman shared how grateful she is that young parents today have access to so many amazing resources and support. The autism community has grown immensely.

The woman's note made me smile as I considered the evolution over the past few decades for families affected by autism spectrum disorder (ASD). While the road may seem long and arduous a lot of the time, there has been positive change. It's rewarding to receive emails from families excited to share their stories, advice, and triumphs. While we don't have all the answers, we have a strong community diligently working on the future for people with autism.

As I was assigning articles for this issue, it occurred to me how expansive our autism village has become. This month alone we have articles written by doctors, behavioral analysts, autism specialists, a financial planner, a motivational speaker, an autism advocate, a shiatsu and acupuncture practitioner, several devoted parents, as well as the teenage sibling of a young man with autism. The level of commitment to helping families is inspirational.

For example, we have a couple of articles in this issue that focus on new ways to teach social skills and provide social opportunities for people with autism. Melissa M. Root, PhD, president and founder of Root Success Solutions™ LLC, has provided us with the piece *Easy Ways To Help Your Child Socialize Using Video Self-Modeling*. A certified school psychologist and international presenter on Video Self-Modeling, Melissa's advice on simple ways you can teach social skills using video is invaluable. The examples she provides can be easily tailored to meet your child's specific needs.

Kids can also work on acquiring social skills while mastering other tasks, such as participating in physical education. California State University faculty member Josephine Blagrave, PhD, and Dr. Rebecca Lytle, professor of kinesiology at California State University, coauthored the piece *Why You Need to Support Your ASD Child in Physical Education*. In their article, they highlight ways kids with autism can acquire much-needed skills through activity to help provide self-regulation and social opportunities and attain a healthy lifestyle.

Ensuring safety can take more thought, consideration, and perhaps some in-depth teaching when it comes to a loved one on the spectrum. Rethink's Executive Director of Family and Clinical Services Angela Nelson, MS, BCBA, has provided us with a three-step approach to help prevent accidents or dangerous situations from occurring. Take a look at her piece *Special Needs and Safety: Ways to Keep Kids Protected* as Angela says it's never too late to begin or reassess your strategy for preventing accidents or dangerous situations from occurring.

It's so fulfilling to learn about people who work relentlessly to make affirmative change. First, we want to introduce you to Dr. Barbie Zimmerman-Bier who has been named Autism Warrior for the month. Frustrated by the limited employment opportunities in the autism community, Barbie developed top jobs for people on the spectrum through Popcorn for the People, a social enterprise of the nonprofit 501(C)3 Let's Work for Good. Take a look at the article *Mom Creates Amazing Job Opportunities for People with Autism* to learn how this mother and chief of developmental pediatrics at Metropolitan Hospital in NYC created a safe and nurturing employment opportunity for people with autism.

We recently learned about a positive partnership developed in Michigan where individuals with special needs live side-by-side with similarly aged students attending either Western Seminary or Hope College. This dorm consists of pods where three students and one person with challenges live together as roommates. Each person has their own room and shares common areas like a kitchen, laundry room, deck, and TV room. Not only are people with special needs given an opportunity to gain independence, but seminarians can become better equipped personally and professionally to serve people with special needs and their families as future pastors. If you're looking for positive changes we see on the horizon, take a look at Jane E. Finn's, EdD, news article *The Best Way to Serve People with Special Needs: Live with Them.*

We are also grateful for the families who graciously and honestly share their autism journeys with us through personal narratives. For inspiration this month, take a take a look at Taryn Plendl's piece *A Loving Mother Shares: The Blessings of Autism* as she encourages parents to always look for the blessings in their lives. Equally poignant is *Ten Best Things About Raising a Kid With Autism Today* by Jane Stein, the mother of a 20-year-old son with high-functioning autism. Her love and commitment to her child shine through.

Let's continue to strengthen our autism communities by reaching out to one another and offering much-needed understanding and support. It makes a difference.

Amy KD Tobik
Editor-in-Chief

Easy Ways To Help Your Child Socialize Using Video Self-Modeling

By Melissa M. ROOT, PhD

Is saying hello or waving "hi" hard for your child to do?

Does your child ask you questions about something you shared with him/her?

Will your child ask another child to play?

These may be some of the challenges your child with autism faces every day, and they impact the ability to make friends. Thankfully, there is an effective technique you can use with your child to help him/her learn these social skills and more. It is called Video Self-Modeling (VSM) and has almost 50 years of research behind it. What's the best part? You can do it yourself with your smartphone or tablet.

This article is the first in a series that focuses on ways to use Video Self-Modeling to help your child with different challenges common to children with autism. It provides examples of how to create VSM videos to help your child with social problems. The examples are general but can be easily tailored to meet your child's specific needs.

What is Video Self-Modeling?

VSM uses videos of your child to show him/her exactly what to do in certain situations. The videos are short—about 30 seconds to two minutes long—and they only show your child performing the skill correctly. All mistakes, errors, and old habits are removed from the video through careful recording or simple editing.

In the case of learning social skills, your child will learn to socialize by watching himself/herself on video performing specific social skills correctly. Below are some examples of how to create a VSM video to improve social skills, but you can adapt these to match your child's specific needs.

How do I use Video Self-Modeling to teach social skills to my child?

Let's use the three questions at the start of this article as examples of how to create VSM videos for your child focusing on social skills.

VSM example for saying hello or waving "hi."

If saying hello or greeting others with a gesture like waving is not part of your child's skill set, you can teach him/her how to do it with a 30-second VSM video. Here's how:

1. Tell your child you're going to make a short movie and that he/she will be the star.
2. Explain the video will help him/her say hi to people or wave to people, which will help make friends.
3. Using your smartphone or tablet, record your child waving or saying hi. He/she likely won't do this on his/her own, so you will need to prompt by either showing how to do it ("Watch Mommy say, 'Hi Patrick,' and then you say, 'Hi Patrick,'" or, "Watch Mommy wave – now you wave") or by gently using your hand to help wave. Be careful not to show your hand in the video.
4. Using the same smartphone or tablet, record other people saying or waving hi to your child.
5. Edit the video to show your child waving or saying hi to several people. It can be the same footage of your child repeated over and over with different people placed in between each repeat. This can easily be accomplished using free editing software such as iMovie or KineMaster.
6. Insert an image of your child smiling or looking happy at the beginning and end of your VSM video.
7. At the start of your video, say something like, "This is Mary saying hi to her friends when she sees them," or, "This is Mary waving hello to her friends when she sees them."
8. During editing, remove any errors or images of you telling your child what to do so it only shows him/her saying/waving hi to people who respond back.
9. Show the final 30-second video to your child every one to two days and praise him/her every time he/she greets another person in real life ("Great job waving hi to your friend Colin, Mary").
10. Once your child is consistently saying/waving hi to others, you can show the video one to two times per week for two weeks or just stop showing it altogether. There are no specific rules about when to stop showing the video, although your child will likely tire of watching the same video too often. If he/she becomes tired of watching the same video but still needs the instruction, create another video for the same behavior.

VSM example for asking follow-up questions

If your child has a hard time asking follow-up questions in a conversation, create a VSM video showing him/her doing it with several other people. If you are already teaching your child how to do this, you can show exactly what you're teaching in the video. For example, if you're teaching your child to find something in common with what the other person said or to ask a W question such as "Where did you go next?" or "What made you go there?" or "Who went with you?" you can show your child using those skills in the video. Here's how to make your video:

1. Tell your child you're going to make a short movie and he/she will be the star.
2. Explain the video will help him/her have a conversation with people, which will help make friends.
3. Develop a script that shows the types of responses you'd like your child using in conversations. For instance, the script might have person one saying, "I went to Italy on vacation last week," and your child responding, "What made you choose Italy?" The script

should have a few back-and-forth conversations. Let your child practice the script until he/she is comfortable with what to say. Be certain your child is facing the other speaker.

4. Using your smartphone or tablet, record your child and someone else performing the script as naturally as possible. You may need a few takes to get it right. You may want to include back-and-forth conversations between your child and several different people for variety's sake.

5. Edit the video to show your child responding to several conversation starters without errors. This can easily be accomplished using free editing software such as iMovie or KineMaster.

6. Insert an image of your child smiling or looking happy at the beginning and end of your VSM video.

7. At the start of your video, say something like, "This is Donna asking follow-up questions to people in a conversation."

8. Show the final video to your child every one to two days and praise him/her every time he/she responds to another person with a follow-up question in real life ("Great job asking Caroline what made her want to go to Italy, Donna").

9. Once the child is consistently asking appropriate follow-up questions in a conversation, you can show the video one to two times per week for two weeks or just stop showing it altogether. There are no hard-and-fast rules about when to stop showing the video. If your child tires of watching the same video but still needs the instruction, create another video with new footage for the same behavior.

VSM example for asking a child to play

Some children with autism want to play with other children but are not sure how to. You can create a video showing your child exactly what to say. Here's how:

1. Tell your child you're going to make a short movie and that he/she will be the star.

2. Explain that the video will help him/her ask other children to play, which will help with having fun with friends.

3. You will need other children to participate in this video, so ask your child's classmates, neighbors, siblings, or cousins to help you make the video.

4. Put out toys, paper and crayons, playdough, etc. Prompt your child to say, "Do you want to play ________ with me?" and prompt the other child to happily say, "Yes," or, "Sure." Using your smartphone or tablet, record them having that exchange and then record them playing with that toy. Repeat this several times with different toys or activities such as tag or hide and seek.

5. Edit the video to show each exchange and subsequent play without errors. The final video will thus show your child asking the friend to play with playdough, the friend saying sure, and then them playing with it. The video should then show the same sequence related to playing tag, etc. This can easily be accomplished using free editing software such as iMovie or KineMaster.

6. Insert an image of your child smiling or looking happy at the beginning and end of your VSM video.
7. At the start of your video, say something like, "This is Samson asking his friend Andrew to play."
8. Show the final video to your child every one to two days and praise him/her every time he/she asks another child to play ("Great job asking Andrew to play hopscotch with you, Samson").
9. Once the child is consistently asking friends to play with him/her, you can show the video one to two times per week for two weeks or just stop showing it altogether. There are no strict rules about when to stop showing the video. If your child no longer likes the first video but still needs the instruction, create another video with new footage with a different friend.

Remember, you can adapt these examples to meet the specific needs of your child. You can also recommend to your child's school system that they use Video Self-Modeling to teach your child in school. It is an effective tool for special education teachers, physical therapists, occupational therapists, speech-language pathologists, school psychologists, and counselors.

The possible uses of VSM are nearly endless. The next article in this series will focus on using VSM to teach your child to eat a variety of foods. Until then, happy recording!

Melissa M. Root, PhD, is president and founder of Root Success Solutions™ LLC and a certified school psychologist in Connecticut. Dr. Root is a coauthor of Picture Perfect: Video Self-Modeling for Behavior Change, available from Pacific Northwest Publishing and through her website. Dr. Root offers a professional certificate in Video Self-Modeling and trains families and professionals on how to use the technique. She presents internationally on Video Self-Modeling as an effective tool for positive behavior change.

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Special Needs and Safety: WAYS TO KEEP KIDS PROTECTED

By Angela NELSON, MS, BCBA

We've all heard of "baby-proofing," wearing a helmet, looking "both ways," or even putting a gate around the pool. These actions are pretty common and aren't usually too difficult.

When it comes to ensuring the safety of our children with special needs or disabilities, these can take more thought, consideration, and perhaps some in-depth teaching. We have seen the unfortunate stories and events that have necessitated actions such as Kevin and Avonte's Law, and parents of children with special needs are committed to keeping their loved ones safe. It's never too late to begin or reassess your strategy for preventing accidents or dangerous situations from occurring. Here's a three-step approach that's worth considering:

1. Planning

One trick to ensuring your child's safety is to make a plan. Think, "What are the unique concerns or dangers for MY child?" Every child is different and so too are the supports needed to protect each child. Keep in mind that the plan will need to be revised periodically as your child ages. Some children are at risk for wandering from their homes and are unable to communicate with safety officials. Others may be highly verbal but impulsive and prone to taking risks, which presents a completely different set of worries for parents. Here are a few considerations for planning (see www.cdc.gov/ncbddd/disabilityandsafety/child-safety.html).

- If your child has challenges with mobility, vision, hearing, or sensory, think about the physical environment. Are there ramps and handrails available for your child to easily navigate? Is your home free of hanging cords, tripping hazards, or small objects that may be put into your child's mouth? Do you have smoke alarms with vibration and light signals that can alert danger? Put yourself in your child's shoes and from that lens, look at your house for red flags. This also applies to when you're at someone *else's* house.
- If your child has challenges making decisions or being impulsive, similarly to above, take a tour of your house with your child in mind, and remove or lock up any hazardous items. Would those scissors in your desk be better kept in a locked cabinet? Review safety instructions with your child and provide examples/scenarios, especially if he or she has a difficult time deciding whether situations or people may be safe or dangerous. Reinforce and highlight the "safe" choices your child makes on a regular basis.
- If your child has challenges speaking and understanding, think about alternate ways for your child to convey danger (e.g., a whistle, pictures). Practicing and modeling (more on this below) can provide different ways of teaching safe versus dangerous situations. Since wandering is also a concern for many parents, consider securing your home, having your child wear an ID bracelet, teaching your child to swim, installing alarms for doors and windows, and rearranging furniture to a safer layout (away from windows).

2. Teaching

A big part of carrying out a safety plan will include teaching your child *how* to be safe. Some children are receptive to simple explanations while others may benefit from more creative or systematic methods. Using visuals is a common and simple strategy used by many parents. For example, taking a picture of each step involved in safely crossing the street broken down into several components can help a child who needs to be taught more than simply to observe others. Other parents use social stories, or stories written about the children who are learning new skills (e.g., *My Safe Bike Riding Story*). Parents will use their children's names as the main character and incorporate rules and guidance into a fun and engaging picture story. Video modeling is another strategy, also rooted in research, where parents film themselves or siblings performing a skill or scenario (e.g., what to do if a stranger approaches them) and the children can watch as many times as needed.

You also can't underestimate the use of good ol' practice! Some children require repetition, and it pays to be patient in these circumstances. Having a child practice how to turn on the faucet and test with one finger, for example, may take 20 tries to get it right but it's worth it to have peace of mind that your child can independently wash his or her hands without getting burned.

> **"A big part of carrying out a safety plan will include teaching your child how to be safe. Some children are receptive to simple explanations while others may benefit from more creative or systematic methods. Using visuals is a common and simple strategy used by many parents."**

Of course, we can't forget the hundreds of lessons and visuals within the Rethink program that parents can use to teach their children new skills to keep them safe.

3. Sharing

The third part of your safety strategy can include connecting with others who support and interact with your child. Close family and those who care for your child regularly should be well aware of the potential dangers your child may face and how to proactively avoid them. Occasional babysitters may have no idea what is considered a hazard for your child. Connecting with teachers to brainstorm ways to keep your child safe at school is crucial. Also, while law enforcement and emergency responders have increased their understanding of special needs over recent years, it may benefit your child to connect with such agencies, and explain your child's characteristics and share contact information just in case there is a need to interact with them in the future.

As we're now thinking about safety and our children, I encourage you to assess your current strategy. Make a plan, focus on what skills your child needs to learn to prevent accidents or injuries, and share with others. Being proactive and thinking ahead could turn out to be lifesavers.

Angela Nelson, MS, BCBA, is Rethink's executive director of family and clinical services and has been with Rethink since 2011. She currently supports parents utilizing Rethink through their employee benefits program from their employers. Angela leads a team of skilled clinicians in conducting parent consultation, which includes supporting families as they sharpen their teaching skills in their own homes and providing tips along the way. She provides educational content for Rethink and collaborates on the advancements of the Rethink platform. Angela also conducts supervision for candidates pursuing their board certification in Applied Behavior Analysis (ABA).

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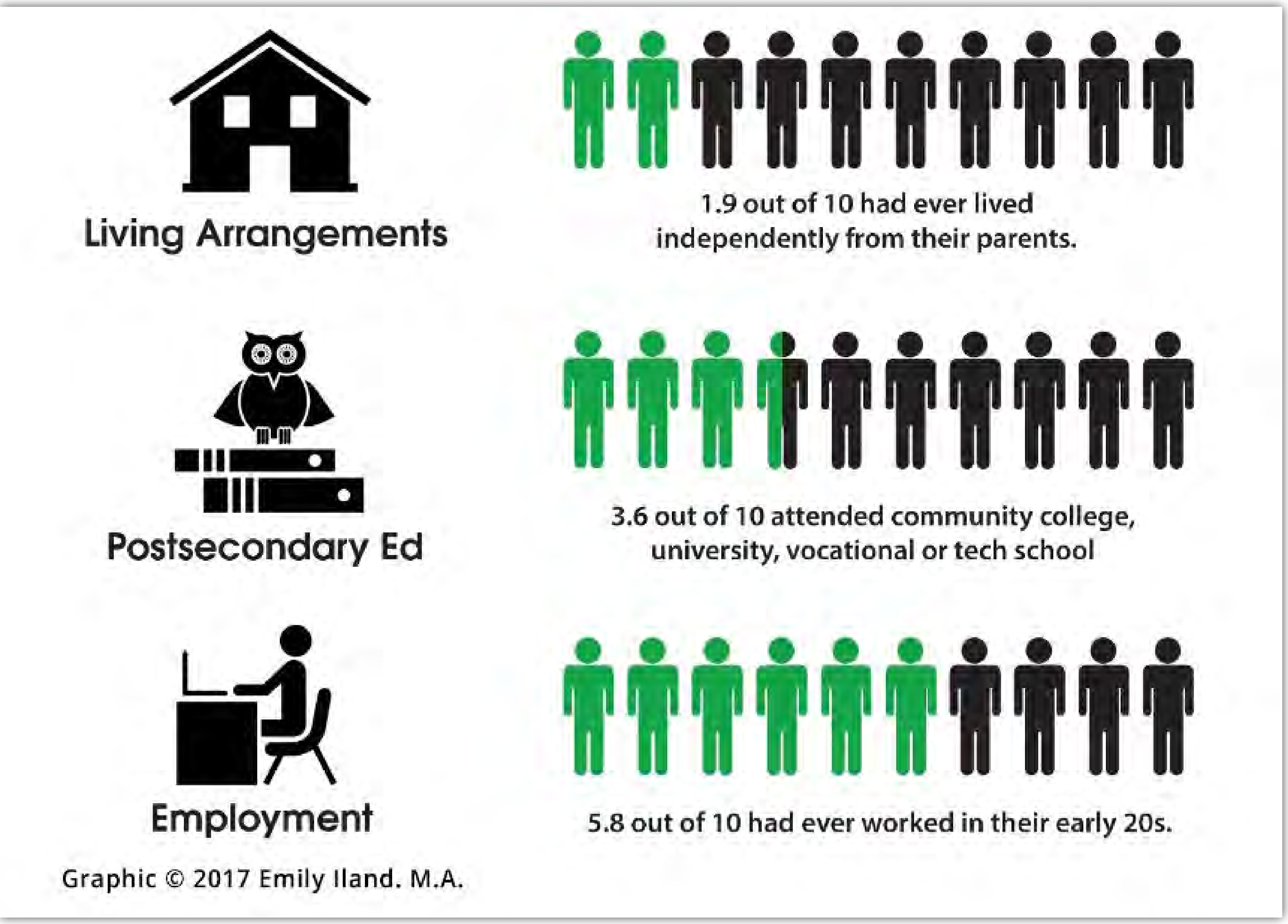
Improving the Future for Young People with Autism

By Emily ILAND, MA

Almost all parents, including those who are actively involved in their children's special education plans, feel unprepared to navigate the transition from high school to adult life. This article highlights important findings about outcomes for adults with autism spectrum disorder (ASD) from several new studies. (Warning: You may not like what you read.) The discussion continues with specific things you can do to improve your child's chances of becoming a successful adult.

How do adults on the autism spectrum do once they leave high school? Until very recently, there wasn't enough information to answer that question! Fortunately, the [A.J. Drexel Autism Institute]() recently analyzed data about the lives of individuals on the spectrum in their early 20s. They published their findings in the [National Autism Indicators Report (2015)](), available on their website.

Unfortunately, the outcomes are not good. For example, in the area of independent living, only about 20 percent of young adults in the study had ever lived independently from their parents. Just under 40 percent went on to pursue some education after high



school, whether it was a community college, vocational school, or a university. Only about 60 percent had ever worked by the time they were in their early 20s. Of those who worked, the majority were part-time workers earning minimum wage or less.

These are just some of the disappointing outcomes identified in the report. This is not what we parents envision when we picture the future of our children! The data leads to an obvious conclusion: our current system of transition services is not working. If we want to improve adult outcomes, we need to change how we plan and deliver transition services for students across the spectrum.

This conclusion is echoed by a study by Taylor and Seltzer (2011) that focused on 66 young adults with autism who had recently left high school. The finding showed very low rates of employment for all the study participants, but those with ASD and *no* intellectual disability were *three times more likely* to have *no* daytime activities (work or education) than those with ASD *and* intellectual disability. In other words, high-functioning individuals with average or above-average intelligence actually fared WORSE as adults than individuals on the spectrum who also have intellectual disability. The researchers concluded, "Our findings suggest that the current service system may be inadequate to accommodate the needs of youths with ASD who do not have intellectual disabilities during the transition to adulthood." Problematic!

Now let's focus on four ways you can improve the transition process and potentially positively impact adult outcomes.

1. Get off the tracks!

Earning a diploma can be a good thing, but the "diploma track" can be a bad thing. Why? Students on the diploma track are "exited" from high school and special education once they've earned enough credits to graduate, usually around age 18. The right to a free, appropriate public education (FAPE) ends.

The problem is that the diploma track can limit a student's access to needed transition services and supports. Students on the diploma track focus almost exclusively on academic skills. They rarely receive sufficient transition services or have enough time to develop important life skills. This situation can be a real disadvantage, undermining efforts to help them reach their potentials and their dreams.

One way around this problem is to create a "blended track," individualized to the needs of your child. A blended track includes academic courses *plus* meaningful opportunities to develop the skills needed for a successful adult life. (More details are offered in Tips 2 and 4). Blended track services may be delivered on a high school campus, at a district-sponsored transition program, or even at a community college.

Just a heads up: there may be some resistance about creating a blended track. First, your child may not like the idea, especially if he/she *under*-estimates what it takes to be a successful adult and *over*estimates his/her own skill sets. He/She may be determined to take his diploma and get out of high school. Making a clear link between the blended track and your child's own lifetime goals may help with a buy-in for the idea!

The school system might also resist the notion since very few schools offer blended tracks for diploma-bound students. We have already discussed that doing things the way they have always been done is not working. Especially if people need convincing that it is time to do things differently, research data can be used to make a case for creating an individualized and appropriate plan or blended track.

2. Provide meaningful opportunities to develop the skills needed for a successful adult life

IDEA Law (2004) defines transition services as "a coordinated set of activities for a child with a disability that is designed to be a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation."

That mandate could not be more clear! Students across the spectrum, including those on the diploma track, are likely to need help developing skills to develop academic and functional skills for all their adult roles: student, employee, friend, and neighbor. The key is being sure that all needs of the child are assessed and addressed. That way, meaningful learning and skill-building activities can be carried out, along with any other needed services to enhance the adult's success in post-school activities.

Research indicates that students with ASD are more likely to have success as adults, particularly in the area of employment, when their transition plan includes some very specific activities. These practices are known as "predictors" because of the strong association between the activities and adult success. Implementing these practices can help prepare students with disabilities to be successful in their lives after high school (NTACT, 2016, Southward & Kyzar, 2017). Here are some points to keep in mind:

- Two of the most important predictors of employment are *teaching employment skills* and *paid work experience during high school*. Be sure that these very do-able activities are part of your child's plan!
- Simply including *a transition goal for work* and/or *a transition goal for higher education* are also predictors of success. Keep your eye on the prize!
- Instruction in *independent living skills* is a powerful predictor of adult success. For this reason, it should be part of the plan for *every* student.

3. Be actively involved

Hopefully, you are part of an exceptional school district with excellent transition planning and services. However, if that is not the case, you'll need to take a leadership role to ensure that your student gets individualized, appropriate transition services. In other words, don't leave it up to the school or district to do things "the usual way."

In fact, *parental involvement* in transition planning is another predictor of success. You have the opportunity to share your vision of your child's future success and give direction to the plan to realize it. A related predictor is *high parental expectations*. Southward & Kyzar (2017) report that a parental expectation of paid, competitive employment predicts success in the workplace. Telling the team that you want to aim high for your child can result in a lot of hard work to move in that direction. In contrast, having low expectations can be a self-fulfilling prophecy.

Be sure to share your parental concerns about preparing your child for the demands of adult life with the special education team. Autism-specific needs like social skills, behavior, communication, executive function, and emotional self-regulation can be addressed and incorporated into transition activities.

4. Focus on youth development

The National Collaborative on Workforce and Disability (NCWD/YOUTH) has also done an extensive literature review to connect specific transition activities and adult outcomes. Their five *Guideposts (available at no cost on their website)* can help families, institutions, and youth with disabilities improve the transition process.

One of the *Guideposts* is called "Youth Development and Leadership," a process NCWD/YOUTH defines as, "Youth acquire the skills, behaviors, and attitudes that enable them to learn and grow in self-knowledge, social interaction, and physical and emotional health." Clearly physical, emotional, and social wellness are central to a healthy adult life.

Youth development is an essential *prequel* to transition, preparing students to take part in the process. IDEA 2004 explains that transition services are to be "based on the individual child's needs, taking into account the child's strengths, preferences, and interests." Developing skills such as self-awareness, self-determination, and self-advocacy can enable your child to find his/her voice, share his/her strengths, preferences, and interests, and actively give direction to a life plan.

Unfortunately, personal development is often overlooked during transition. This can be particularly problematic for youth with developmental disabilities like autism who are likely to need significant support to grow in these areas. The new book, *Come to Life! Your Guide to Self-Discovery* may be a useful tool for this process. Whatever resources you use, be sure to focus on youth development, so your child is more prepared for the next chapter in his or her life!

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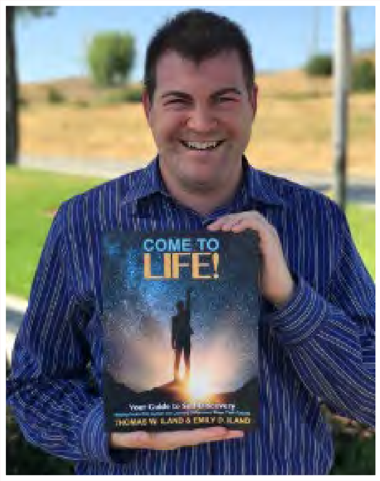

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Emily Iland, MA, is an award-winning author, film-maker, educator, researcher, and leader in the autism field. Emily just helped her son Tom, who has autism, realize his dream of becoming a published author. Their new book Come to Life! Your Guide to Self-Discovery, is an ideal prequel to transition, helping parents and teens discover answers to the critical questions that drive transition.

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Living With Autism:

THE LONG JOURNEY TO A PEACEFUL HEART

By Janie DIXON

Life is wonderful, then bam! You have been chosen—you have a child with special needs. Now begins the whirlwind of emotions, pain, sorrow, heartache, fear, and the feeling of helplessness—each one serving as a necessary component in the long process of acceptance, healing, and moving on.

It's amazing how you instantly feel you are all alone in the world. One's thought might be that it is impossible anyone would or could understand the turmoil that has infiltrated your mind, your existence. Oh, if only kids came with manuals to guide us through the difficult decisions. In many instances, everything you learned and experienced with your typical offspring seems to be null and void.

There are three check-in stations on this new journey.

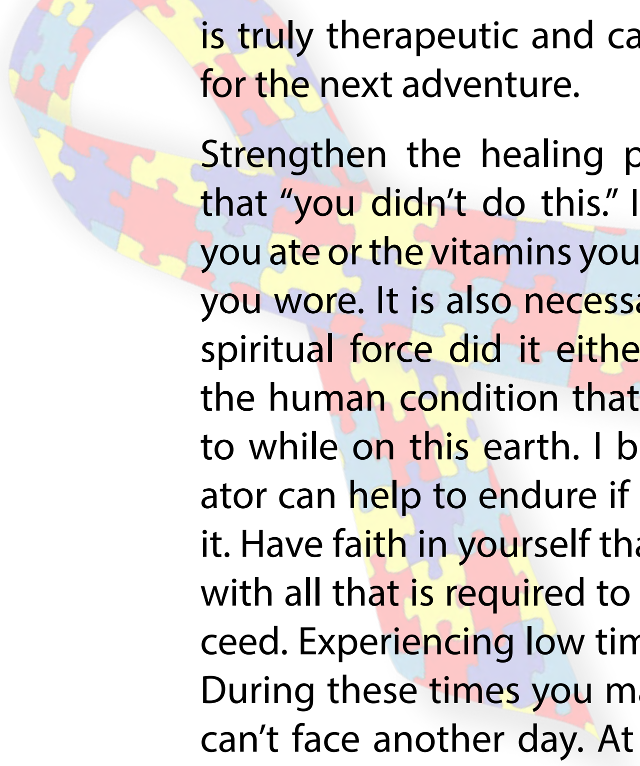
1. ACCEPTANCE

A difficult endeavor yes; however, healing can begin once acceptance is in place. Please do not waste weeks, months, or even years thinking that it will go away. It will not happen, and the longer you linger in this gray zone, the more hopeless and depressed you can become. Should this happen, you are of no help to the loved one who needs you so desperately. Regardless of the reason your child is the way he or she is, that child is yours.

Ecclesiastes 3:1 states, "To everything there is a season and a time to every purpose under the heavens." I believe that our special children have concrete purposes and they are of more value to this world than anyone can imagine. I believe they are the windows to knowledge and key components in the birth of human kindness. Their innocence and unconditional love erase much of what is wrong in this world. Once you have reached acceptance, you can move on to healing.

2. HEALING

Do not try to achieve this alone. Find a support group or another family or friend who shares what you are going through or is experiencing a similar situation. You will be amazed how communicating everyday events and hardships with someone else can bring you the inner strength you may need to get through a day. One example: taking your special needs child to the dentist. Not a big deal for the typical parent and child to take on, but for you, it can turn into a very stressful, heart-tugging,



and energy-draining event. Having the option to turn to someone who actually understands is truly therapeutic and can help prepare you for the next adventure.

Strengthen the healing process by realizing that "you didn't do this." It wasn't something you ate or the vitamins you missed or the shoes you wore. It is also necessary to know that no spiritual force did it either. It was a result of the human condition that we are all exposed to while on this earth. I believe that our Creator can help to endure if we seek and accept it. Have faith in yourself that you are equipped with all that is required to help your child succeed. Experiencing low times can be frequent. During these times you may feel that you just can't face another day. At this time, ask yourself, "Who other than myself would I want to take care of my child?" I'm willing to bet that you cannot come up with any other caregiver because no one else would know, love, or accept your child as you do.

I, for one, believe that everything happens for a reason and something good generally will follow the not so desirable. While it may seem impossible to understand why or what good could come from an individual's challenges, consider these precious people are here teaching us patience and humility and are placing before us immeasurable displays of love that will enrich so many lives.

3. MOVING ON

This could be the most difficult because it is now time for everyday decision-making and a deep look into the future. Like most, you are probably considering entering your child in an early intervention center or school setting to give him/her a head start on the new journey. Affording your child with the earliest possible start can prove most beneficial. However, I feel there is nothing more nurturing than sufficient time in a loving home to instill a feeling of safety and well-being. Take into consideration that your child will be in the new environment for many years to come.

Unfortunately, there is no preparation for the day when you leave your child in the hands of basically strangers. Count on it to be one of the hardest days of your life. However, all bad days pass. File it in your mental strength builder folder.

In a previous paragraph, I touched on how the passing of time is credited with healing. The passing of time will also greatly reduce separation anxiety between you and your child. Once you have located the establishment your child will attend, by all means, research it fully. Plan a tour and visit the teaching staff and support staff, and ask about the special services offered. You have the right and obligation to do this for your child. Quality professional employees will not find this offensive, and if anyone does, then keep in mind you are doing your part to the best of your ability. Remember that piece of mind is priceless.

Here are some helpful points to guide you through the process:

- Do all you can do at home to get your child ready for this new adventure. It is your job as a parent to ensure your child is prepared in as many ways as possible, such as being toilet trained, able to use utensils and possess some self-help skills. If your child is capable of performing these tasks or shows potential toward mastering them, it is important to strive for this success in the home setting.
- In the case that it is necessary for such skills to be practiced in the daycare setting, it is crucial that all parties work together to achieve them. What is done at home must be carried out in the daycare setting as well.
- Realize that in some cases there are individuals who will never be able to do for themselves. This should not compromise good quality, professional care.
- Good hygiene is a kindness that is appreciated by students and staff. Accomplishing this at home saves time and will promote a more successful day.
- There may not be a cure, but there is help for those who seek it. Together, you and the outside provider can work toward suitable goals for your child to accomplish.
- Once goals are set in place, it is very important that all parties' parents, teachers, and

caregivers work together as a team. Failure to do so may bring forth unwanted results.

There will always be many ups and downs in the daily life of a person with special needs. One must try to remember that:

- Life is full of possibilities.
- Failures go hand in hand with successes.
- There will be good days as well as not so good days.
- Always keep a "can do" attitude, but try to stay realistic about the fact that while some things will become a reality, some may not.
- Embrace all of the help that is available because more effort trumps less.
- Draw strength from those who care.
- We were placed on this earth to unite in love, grow in brotherhood, practice compassion, and care for each other as if we are all family because, in truth, we are.

I have traveled this special journey for more than 25 years. It is a process that I never dreamed I would have to experience. Life is never predictable, never easy, but success is obtainable on a daily basis with perseverance, dedication, the strength of family, and faith in our abilities as parents. All perceived failures become valuable lessons. All successes yield victorious peace.

Janie Dixon lives in the state of Delaware with her two daughters, ages 31 and 35 years, and son Adam who was born in 1989. He was diagnosed with autism in 1993. He is verbal and moderately self-reliant. Now 28 years old, Adam has held a kitchen steward position for six years. Hard work and dedication from family and available help services afforded him his happy existence.

Are Girls on the Spectrum Not Being Diagnosed?

By Stephanie C. HOLMES, MA, BCCC

The Centers for Disease Control (CDC) reports as of 2015 that autism spectrum disorder (ASD)/Asperger's syndrome (AS) affects one out of 68 children in the United States. Previously, it was thought that ASD was diagnosed in boys to girls 10:1. Statistics report a slight shift in diagnosis that results in one out of 42 boys and one out of 189 girls, which is a 5:1 ratio. However, it is believed by many experts that girls are being missed, that there is more "pink" on the spectrum than first realized.

Why is it important to realize the subtleties and find more "pink" on the spectrum? Various studies show that females are either undiagnosed completely, misdiagnosed, or diagnosed much later in life. As a clinician and mother of a female on the spectrum, I am concerned about the bullying, dating violence, anorexia, anxiety, or depression that may be masking the ASD/AS in the spectrum female. I want to help educators, parents, and clinicians take a second glance at the spectrum. There are far more females on the spectrum than once realized, and I am grateful that research and studies are increasing about the subtleties found in males and females on the spectrum.

Last year while presenting a seminar, I showed a video interview with my daughter who is on the spec-

> **“Females on the spectrum may appear to be more competent socially, but they are really hiding the great effort and difficulty for them about being social. Females are also more likely to break down or meltdown later in private.”**

trum, without identifying she was my daughter. At the end of the presentation, a clinical psychologist inquired if the diagnosis for the young lady in the video was accurate and said, “If that girl is on the spectrum we are missing them because she did not present like someone on the spectrum.” As a mother of a female on the spectrum, I can attest few clinicians understood differences in male and female presentation of the spectrum.

The author of *Six-Word Lessons on Female Asperger Syndrome,* Tracey Cohen, was diagnosed with AS at the age of 39 and wrote her book about her experience, in her words, “to help prevent others from much of the hardships and pitfalls” she experienced living life undiagnosed. Tracey further explained that she always knew she was different from the other girls, but she did not know why. She began a new teaching job with a family who had a child on the spectrum, and while attending a conference to better understand ASD/AS sat in disbelief as she heard the speaker describe ASD/AS. She realized what was being presented was describing her and her experiences. After speaking to the presenter after the presentation, he encouraged her to speak with a professional, and this led to her diagnosis journey at age 30. Along this journey, she found clinicians were not always aware of nuances of symptoms and presentation of autism by gender, and she was 39 when she and her mother flew to Oregon to seek a professional who specialized in diagnosing women on the spectrum. I asked Tracey, according to her research and personal journey, why did she think females were being missed?

Tracey reflected back on her life in our interview and said that she had many struggles and was often treated differently by others or referred to as being incompetent. She said, “Females on the spectrum tend to internalize a great deal, so any ‘symptom’ or off-putting behaviors are less obtrusive than their male counterparts on the spectrum. They tend to have fewer behaviors seen as ‘red flags’ or behaviors are dismissed by professionals or parents as immaturity, shyness, or being naïve. Females on the spectrum may appear to be more competent socially, but they are really hiding the great effort and difficulty for them about being social. Females are also more likely to break down or meltdown later in private.”

As our discussion continued, Tracey and I discussed how diagnostic descriptions of symptom manifestation measure and assessment were normed on males, but Tracey emphasized, “When it comes to females, it is all about the nuances and subtleties.” For example, the symptom of “special or restrictive interests” is not about how “normal” the interest is, but how the child interacts/plays with toys, etc. Tracey explained that she had dolls like other girls her age, but she did not play with them or create a dialogue with them in what clinicians refer to as “social play.” Tracey said she preferred to line them up, and she played with her dolls differently than peers might have interacted with their dolls. When it comes to special interests, professionals may not be asking the right questions as to what the special or restrictive interests may be if they are relying on stereotypical interests such as ceiling fans, collections, or modes of transportation as categories of interests.

But why is it essential for someone to know if they are on the spectrum if they appear to be functioning “normally” or did not require a 504 or Individualized Education Program (IEP) in school? I have heard people suggest that a diagnosis is a disservice to older teens or adults. I have had parents tell me that their child was diagnosed, but they chose not to tell their child for fear of them “not living up to their true potential” if they knew about their diagnosis. I am very passionate about anyone who has a learning difference or social interaction difference knowing what the proper diagnosis is to help them achieve their full potential and not to be mislabeled. I asked Tracey her thoughts on diagnosis, and if parents should tell their children they are on the spectrum. Tracey responded, "Knowing your child has the diagnosis and not sharing, in my opinion, is very harmful to them and not only harmful it is indirectly communicating shame as if having autism is something to be ashamed about." She also shared that telling the child earlier in age-appropriate communication will give them knowledge, and knowledge is power. Tracey and I both understand and share that the autism spectrum is not a mental illness—it is about neurodiversity, and it is part of the identity of who that person is. Keeping this diagnosis from someone is a disservice to helping them learn about self.

Females on the spectrum in their teens or young adult lives may be misdiagnosed with bipolar disorder, generalized anxiety disorder, or untreated eating disorders. Tracey discusses so much more in her book, which is very informative about the differences in males and females and shares much more of her journey. Tracey encourages adults who may think they could be on the spectrum to seek professional diagnoses because, in her words, this would be "validation, knowledge, and understanding for themselves as well as to those they may be in a relationship with."

Tracey Cohen, a lifelong competitive runner, freelance writer, returned Peace Corps Volunteer, was diagnosed with Asperger's syndrome as an adult. Sharing her struggles and discoveries, she aims to empower others to learn, accept, and find peace in our complex, neurotypical dominated world in her book, Six-Word Lessons on Female Asperger Syndrome.

Stephanie C. Holmes, MA, BCCC, is a Christian counselor with the board of examiners for Georgia Christian Counselors and Therapists as well as a Certified Autism Specialist. Stephanie's career path changed when her eldest daughter was diagnosed with Asperger's in 2004, and her story can be found in Confessions of a Christian Counselor: How Infertility and Autism Grew My Faith. She is the founder and sole counselor with Autism Spectrum Resources for Marriage & Family, LLC.

The Radiant Smile That Changed Our Lives

By Ellie FADDEN

Earlier this week, my husband Andy and I sat around the kitchen counter, eating dinner, delving into the details of our day as usual. Leo, enjoying a rare night off from therapy, switched focus between playing with his beloved Toy Story figures and gathering his fill of tickles and scratches from us when needed.

We recounted our outing to the fair over the weekend, discussing how well Leo had done, despite not having fully recovered from a cold. And we talked about how nice it was to see the interaction between Leo and his cousins who were also there that day.

“It will be fun and interesting to see where their lives will take them all as they get older,” I commented, while almost immediately feeling that oh-so-familiar knot in the pit of my stomach as I stared pensively at my boy, wondering too what life had in store for him.

“It’s hard sometimes,” I said softly, perhaps more so to myself than to Andy sitting across from me.

“Life is so ambiguous,” I continued, “with so many questions that have yet to be answered for Leo.”

Andy’s gaze slowly turned towards our boy, his concerned expression gently giving way to one filled with peaceful certainty.

“It always amazes me,” he began, “how even today there is still so much negativity surrounding autism...”

“One of the best things about Leo,” he remarked, “is how genuine he is. When he’s happy, he lets you know. When he’s upset, he lets you know. His emotions are pure, and there is no pretense. The sad part is that people will say that this is abnormal. When really, this is how more people should be…”

I listened, as Andy went on, his words giving me strength with each passing syllable.

“Somewhere along the way, someone said Leo is going to be different. We’re going to wire him differently...Not everyone will understand him, but that’s okay. And even if he only touches these two people’s lives, he will have made a difference. Of course, there will be frustrating times ahead. But we will never allow it to affect his quality of life. And if this boy, who faces constant challenges, can wake up smiling every day, he's going to be okay."

Tears quietly streaming down my face, I allowed my husband's beautiful message to seep in.

It is difficult to evade the worries of tomorrow, and the months, and years that follow. But what we can control is making sure that Leo will always be cared for and loved wholly and unconditionally.

And when I close my eyes and imagine a grown-up version of my sweet boy, the future, while many parts unclear, presents one constant, vivid, and unwavering certainty…

That radiant smile existing always and his beautiful soul touching our lives and so many others along the way.

Ellie Fadden is a wife, mom, and blogger who writes about the ups, the downs, and everything in between of life with her extraordinary son, Leo, who is on the autism spectrum.

Website: lifewithleoweb.wordpress.com
Facebook: https://www.facebook.com/mylifewithleo

How to Handle Bullying at School As the Parent of a Special Needs Child

By Bret COLSON

Growing up can be a challenge even under the best of circumstances. But when you are the parent of a child with special needs bullied because he or she is different, the ability to cope and resolve this type of situation can be upsetting. While there is no single or easy solution, there are several steps you can take to make things better for your child in the short- and long-terms.

First, you need to know that according to the letter of the law, bullying when directed at a child because of his or her challenges at school can constitute a hostile environment and can be construed as disability harassment. Under Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act of 1990, the school must take steps to address and correct the harassment, or they will be in violation of one or more civil rights laws enforced by the Department of Education and the Department of Justice.

Here are some steps to follow if you suspect your special needs child is being bullied at school:

1. Stay calm and talk to your child

If you find out your child with special needs is being bullied, resist your initial urge to become angry, lash out, and seek immediate and harsh punishment against the guilty parties. While this may be a short-term solution that will fulfill your desire to protect your child, it could close doors and make it more difficult to find a permanent solution.

Instead, you should support your child by talking to him/her. Get as much information as possible about what has happened and be sensitive to any signs of bullying. Many times, a child with special needs may not even be aware or realize they are being bullied. Follow up by reassuring the child that he/she is not at fault. Do not encourage the child to fight back, since this will only escalate matters.

2. Begin a dialogue with the school

As soon as you suspect your child may be a victim of bullying, immediately contact your child's teacher to get additional details about what he or she sees and to help resolve the problem. Many times, this will be enough to correct the situation.

However, if bullying extends beyond the classroom, or if the teacher does not respond appropriately, put your concerns in writing to the school's principal. At this point, you may also want to copy district officials as well. Make sure also to start keeping records of all conversations and written communications from this point forward.

Unless you know the other child's parents well, it is probably best to not contact them on your own. Instead, let the school mediate the situation on your behalf. Just as you may tend to become emotional on your child's behalf, so too will other parents come to their own children's defenses.

3. Get additional help

If you do not get the support you need, or the school does not take reasonable or appropriate steps to end the bullying of your child, the school may be violating federal, state, and local laws. You can contact a civil rights attorney, or you have the option of contacting the following agencies to get additional help:

The U.S. Office of Education, Office for Civil Rights (800) 421-3481

The U.S. Department of Education, Office of Special Education Programs (202) 245-7468

The U.S. Department of Justice, Civil Rights Division 1-877-292-3804

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.

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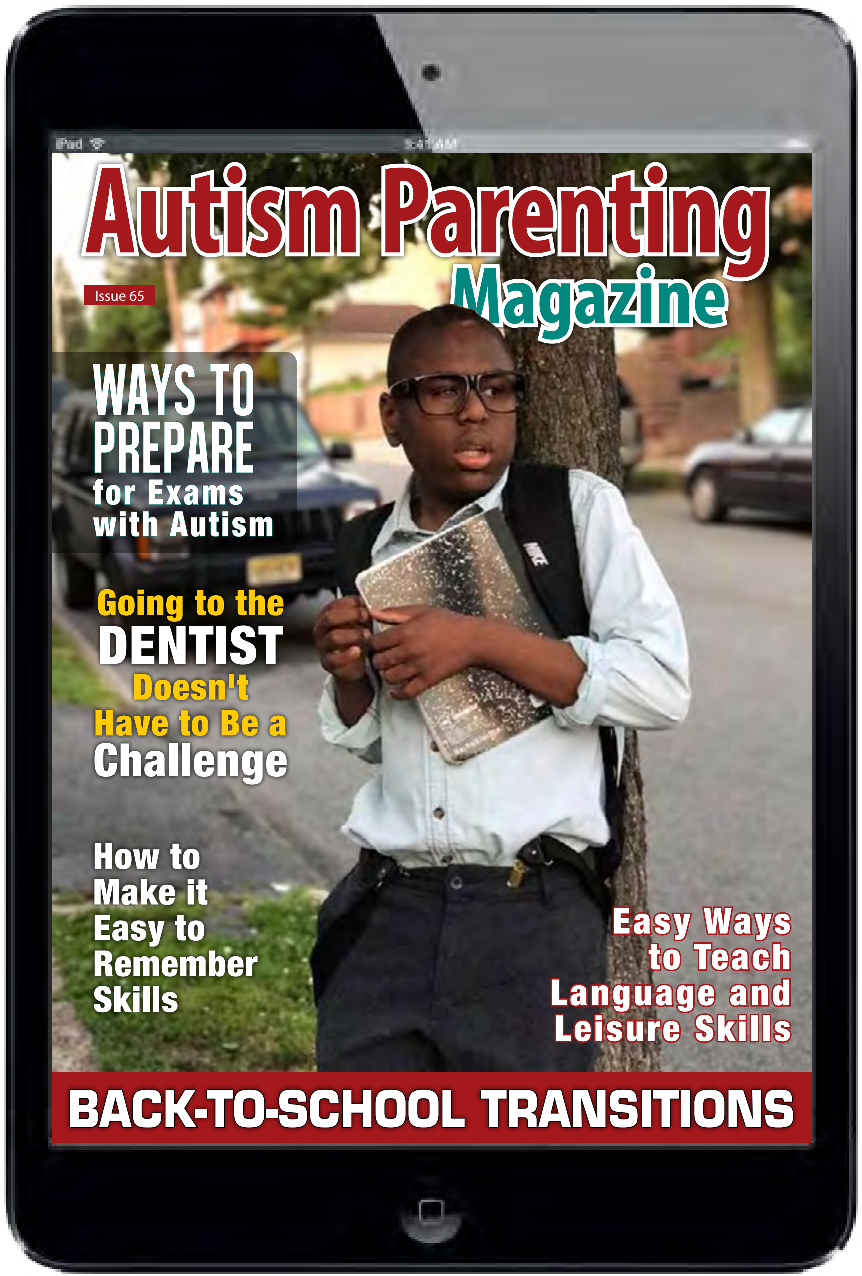

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The Need to Understand Irregular Sensory Regulation

By Tal BADEHI

Ian, one of my regular patients, usually starts his shiatsu session with significant delay. He walks slowly and often stands for minutes, weaving his body, before going through every door. Before we get to the room where the shiatsu sessions are held, several minutes have typically passed. The shiatsu mat is ready on the floor with a blanket on top of it, and Ian stands next to it, refusing to lie down. Like many people with autism spectrum disorder (ASD) and complex needs, Ian has sensory difficulties that make participation in the sessions difficult for him.*

Understanding sensory regulation

People with autism often experience irregular sensory regulation requiring substantial attention. Our sensory organs are continually receiving stimulations from the environment. It is the nervous system's job to regulate the senses and distinguish between the relevant stimuli and those which are irrelevant to us at any specific moment. Without the regulating function of the nervous system, we would not be able to concentrate or adequately emotionally or physically function. Functions such as sleep, speech, balance, movement, and more are affected by irregular sensory regulation. Many people with autism are often affected by irregular sensory regulation, and we must keep that in mind whenever we communicate with them.

Which senses should I focus on?

In addition to the five "common" senses (sight, hearing, smell, touch, and taste) I recommend taking into account the less recognized senses: balance, proprioception (feeling the location of the body organs and limbs), pain, hunger, tiredness, temperature, spatial sense, and more.

People with autism might experience different stimulations in excess or deficiency, which may cause them to avoid specific stimuli or to seek particularly strong ones. For example, some people with autism cannot stand loud noises, preferring calm, while others feel the need to rock or throw themselves against walls. Often, a person with autism can experience a combination of excess and deficiency in different senses.

---

* Not his real name

Finding new ways to manage autism

"Ian, do you want the blanket or not?"

Ian smiles as he looks at the blanket and after some time answers, "No blanket."

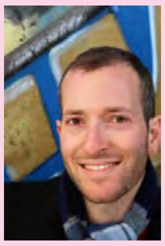
I remove the blanket and Ian, smiling, lies down on the mat. The shiatsu session can begin.

When taking into account the various possibilities of irregular sensory regulation, and through trial and error, it is possible to discover creative solutions to encourage people with autism to take part in various activities.

In Ian's case, I understood something in the shiatsu mat bothered him, and through some thought and exploration, learned the problem was either the color or the texture of the blanket I used to cover the mat. Sometimes Ian refused to lie down if I removed the blanket ahead of the treatment, and I had to realize that occasionally Ian wanted to have the blanket on, and I should give him an opportunity to make a decision each time. That realization was a significant step forward for me in working with Ian, as he seemed to enjoy making his choices each time.

I would like to point out that the prolonged time Ian required to answer my questions and to pass through doors can also be the result of irregular sensory regulation. The ability to execute a thought, through action or words, requires the combined activation of several systems (emotion, speech motor particles, decision making, choosing appropriate words, calculations of probable outcomes, and more). Passing through a door is stepping from one space to another, which requires quick processing of many sensory stimulations and accustomization to a different environment.

It is necessary to search for creative solutions for people with autism to make them more involved in various activities and allow them more freedom of choice. Neurotypical people might take this freedom for granted, but it is not necessarily the case for people with complex needs.



Tal Badehi is a shiatsu and acupuncture practitioner based in London. He has worked with people with autism and 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.

Dear Younger Self…

A Mother's Letter of Love

By Kim McCAFFERTY

This is the letter I would write to myself if I were an old lady telling my younger self that everything would be okay, even after both boys were diagnosed with autism.

Dear Younger Self,

Hi, hon. I want you to know I see how exhausted you are. You just got your five-year-old with severe autism settled into your district's kindergarten program, and what a long five years it's been with him, even with all the progress he's made. I know you thought you were home free with your youngest boy, the one who made all his milestones on time and has been babbling up a storm, the one who your pediatrician says is "fine" when you make your anxious inquiries. I know you went on a much-deserved vacation and came back to a sick toddler who's stopped speaking, has a rash all over his body, and has lost the light in his eyes. I know you're thinking that Justin showed signs of autism as early as six months, and this baby didn't until this week. I know you know what the doctor is going to say when you take him in for that appointment, the myriad phone calls you're going to have to make, the Early Intervention Program (EIP) you'll have to create for him. I know how much work this will be for you, once again.

I know you're wondering how the hell both of your kids could have two different kinds of autism.

It must seem impossible to you, how you're going to manage, how you could possibly create a life where you meet the needs of both your boys. After all, Justin is still potty-training (so much fun!), still "learning" how to sleep through the night, and still refusing to eat anything other than a carb on most occasions. There's still his meltdowns to deal with, your need to create plans B, C, and D whenever you take him anywhere.

There's still the enormous amount of time he needs you, and the depth of that need.

You comfort yourself with the fact that your oldest will be out of the house for seven hours a day so you can focus on your youngest's needs, and believe me, that time will save you. Despite your exhaustion, you will be able to manage the 11 different people traips-

> **“I know you are mourning quietly in your few moments of solitude because that’s all the time you get. I know this experience with Zach is so different than what happened with Justin, because somehow around the time your oldest was learning to sit up, you knew he was different, and sensed his difference would be challenging. I know this gave you time to ease into his diagnosis.”**

ing through your house for the next 15 months. (you should have been a party planner—your attention to detail from being a teacher will come in handy). You will be grateful that at least this time you live in a state where there is actually an Early Intervention Program that doesn’t expect you to do it all yourself (sorry, Virginia), and these practitioners will truly help your child. You will spend more time with them than your own husband.

And a bonus: two of them will become good friends.

I know you are mourning quietly in your few moments of solitude because that’s all the time you get. I know this experience with Zach is so different than what happened with Justin, because somehow around the time your oldest was learning to sit up, you knew he was different, and sensed his difference would be challenging. I know this gave you time to ease into his diagnosis.

This time you went away and came home to a different child, one who seems to have most of the joy sucked out of him. You wonder if you’ll even see that spark again. You wonder if he’ll ever say “mama” again.

You wonder if he’ll ever be happy.

I want you to know that I see the strain, the way your husband believes your little one will “come back,” and how you just can’t allow your heart to embrace that idea because the alternative is too painful. I see how your heart will love them both no matter what, but how much you wanted at least one to live an independent life, and how that dream may now be shattered. I see you both mourning the now and the later, acknowledging that you will have to wait and see what happens. I see that is perhaps the most difficult part for you, planner that you are.

I see you desperately wish someone would just end your misery and tell you how it all turns out.

I can’t tell you the ending; I can’t even tell you the middle. But I can tell you that you will make it through those early years, the ones where your entire existence is therapy, chores, and the anxiety that takes up permanent residence in the recesses of your brain and claims your sleep. I can tell you that your attention to detail, your refusal to cut corners, and the decisions you make regarding school placements, diets, and therapists will pay off.

I can tell you that your eldest child will one day not only sleep through the night almost every night but will joyously welcome slumber.

I can tell you your eldest child who hated the car and going anywhere for more than 32 minutes will now revel in your excursions and bring you his sneakers in a plea to go out.

I can tell you this same child now eats lettuce and broccoli with gusto (and yes, you wanted a medal).

I can tell you your youngest will not only speak in full sentences again but will keep you running to Google to answer the vast amount of questions your old brain no longer has the answers to.

I can tell you your youngest will have friends and will enjoy a wide array of activities both in and out of school.

I can tell you a few years from now you will have no doubts about his ability to lead an independent life and to look out for his brother when you’re gone.

I can tell you both boys will regain their happy, joyous souls.

I can tell you that you will once again sleep (albeit it's "old lady sleep").

I can tell you your daily life will still have its struggles, but the struggles will be mostly outweighed by joy. I can tell you your life will always be shades of gray, some mourning of what could have been, some acceptance, and always some celebration of what is and what will be.

I can tell you that you will have a happy family, the dream you held onto all those years you struggled to create one. It will look different than you expected. There will be challenges you could not have foreseen.

I can tell you your profound love for them both will make a difference.

I will tell you, a happy family it will be.

And for you, it will be okay.

Kimberlee Rutan McCafferty is the mother of two sons on the autism spectrum. Her writing, featured in Exceptional Parent Magazine, Autism Parenting Magazine, the Patch network, and on her blog Autism Mommy-Therapist, is grounded in her experiences as an educator, a stay-at-home mom/therapist, and an advocate. She is also the author of a memoir entitled Raising Autism: Surviving the Early Years. She has authored and produced a play about mothers of children with autism and serves on the Family Partners Program at Children's Hospital of Philadelphia, which is part of the Autism Speaks-supported Autism Treatment Network.

Blog: autismmommytherapist.wordpress.com/me-and-my-blog

Finding New Ways to Help Manage Meltdowns

By Jane COOPER

My uncle was a butcher. As a child, I vividly remember my parents saying, "Don't touch the knives, Uncle Phil has sharpened them!" With the sentence still ringing in the air, I was "hot-footing" it over to the knife drawer to check just how sharp they were, another cut finger being the predictable result.

Knives, in general, are sharp, but butcher's knives take sharpness to a different level. Let's put it this way: in the film *The Bodyguard,* Kevin Costner throws a silk scarf into the air. It then floats gently down onto the glistening blade of a sword, which slices it effortlessly in half. That sword was probably sharpened by my Uncle Phil.

There is another vital skill that a butcher has to learn however that might surprise you, and it is this: When the knife drops, DON'T try to catch it!

This is a far more difficult lesson than it sounds. Reaching out to catch something that is falling is instinctive: before we have even thought about it, we have done it. My uncle suffered many injuries, including one which almost completely severed his thumb, before he learned this crucial lesson.

So, what does this have to do with managing meltdowns?

My daughter Megan, now 20 years old, has severe autism. Sometimes the world becomes too much for her, and she suffers a meltdown. She will flap her hands, make a loud noise, scream, hit herself, bang her head, pull her hair, kick herself, pinch herself, throw herself on the floor, or lash out at other people—sometimes all at the same time.

Seeing my child going through this is painful, and, like any caring parent, I want to fix it, to make it better.

My instinct was always to rush over to my daughter, shouting, "Megan, Megan, please don't do that! Megan! What is it, Megan? What's the matter?" I would try to comfort her by putting my arms around her, only to be pushed away and for the meltdown to continue. It made my stomach turn over to see her hurt herself so much, and when it was over, I was mopping up another nose-bleed, trying to bathe a bite injury, or looking at yet another bruise on my daughter's pretty little face. It would make me feel sad—it would make me feel a failure as a parent.

I thought things would be like this forever until one day, out of the blue, the cavalry arrived. Okay, she wasn't on horseback, she wasn't wearing the uniform, and she seemed to have left her sword in the car, but Claire Bell from our local Child and Adolescent Mental Health Service (CAMHS) rode to our rescue all the same. Megan's self-harming had become so severe

> **People with autism may experience textures very differently too; their clothes, for example, may feel like sandpaper against their skin. In the same way, they may have extreme experiences of tastes and smells, which can be utterly overwhelming.**

that our need for help had finally been recognized and Claire had come to observe us as a family, give us advice, and support us in supporting Megan.

During one of her visits, while Claire and I were chatting at one end of the room, Megan had one of her meltdowns. Sitting in her favorite armchair by the window in our living room looking at a book, she suddenly began flapping her arms, making a loud noise, screaming, and biting her finger. My stomach turned over, and as I went to comfort her as usual, Claire said quietly, "Hang on, wait here a minute."

The meltdown continued, and I became even more anxious.

"I feel awful not going over and…" I began

"Try turning the television off," suggested Claire before I could finish.

"The television?" I questioned.

"Yes."

Having no idea why I was doing it, or what good it would do, I walked over to the TV set next to Megan, pressed the button on the top, and walked back to Claire.

The meltdown continued. "What are we doing?" I asked. "Why aren't we helping?"

"We are helping," she replied. "Try turning the main light off."

I flicked the switch. We waited. It took a little while, but gradually, the flapping slowed, the screaming and biting stopped, and apart from being red in the face and sweating, Megan returned to normal. I was confused.

"But we didn't do anything," I said.

"We did," she replied.

Claire explained that people with autism can become overwhelmed by their environment and this, as well as things like changes in routine or sheer frustration, can trigger meltdowns.

I was puzzled, but intrigued and also relieved that this now meant that there was something I could do (or rather, not do) as a parent to help my daughter. I started to do some research of my own and discovered that people with autism can be oversensitive or under-sensitive to the sights, sounds, tastes, textures, and smells around them.

For example, instead of seeing "a room," someone with autism may see a chair, a TV, a curtain, another curtain, a pattern on a carpet, another pattern, another pattern, another pattern, another pattern, a picture, another picture, another picture, a light, another light, and so on.

Similarly, whereas many of us are naturally able to "block out" the other noise in a room when we are holding a conversation with someone, an individual with autism may not be able to and will hear the other person speaking, the television, the six other conversations that are happening, the person tapping a pencil in the corner, the cars going past on the road outside, etc.

People with autism may experience textures very differently too; their clothes, for example, may feel like sandpaper against their skin. In the same way, they may have extreme experiences of tastes and smells, which can be utterly overwhelming.

By going over to comfort Megan with my usual "Megan, Megan…" I wasn't helping; I was just adding to the multitude of noises in the environment. By trying to put my arms around her to comfort her, I was giving her yet another sensation with which to cope. I was adding to the stimuli which had triggered her reaction. Switching off the television, turning off the lights, and so on helped to take some of this stimuli away.

Now, when Megan experiences a meltdown, instead of dashing over and adding to the situation, I look for ways to reduce the stimulation around her. Sometimes this means turning off the television or the radio. Other times it means turning off the lights. On one occasion in the car, the only thing I could think of was to turn off the air-conditioning. It worked instantly.

Of course, I am always where I can see Megan, making sure she is okay, ready to intervene if I need to, such as holding a cushion in front of her when she goes to bang her head. I keep her safe, but I have learned not to "wade in" as I used to. I am close to her, but I give her the space and time she needs to recover.

It was a hard lesson to learn. Like the desire to catch a falling object, our instincts are to catch our children when they "fall" and to "fix it," to make it better, to "do the right thing."

It has taken a while but, like the butcher with his knife, I have learned that "doing the right thing" is not always the right thing to do.

Jane Cooper is a mum living-and-working in Derbyshire, England. Her daughter Megan, aged 20, has severe autism. Having given up a successful career in training and development to care for Megan, Jane went on to raise over £1 million to build a specialist therapy pool at her daughter's school in Chesterfield. Since 2003, Jane has been a volunteer campaigner for Changing Places facilities. She is also the cofounder of a registered charity, Accessible Derbyshire, along with fellow cofounder Gillian Scotford, herself a mum to three boys, two of whom are disabled. Most recently, the pair established Access For All UK: an access consultancy which provides access auditing, training, and business support services to organizations throughout the U.K.

Access For All UK
Website: www.accessforalluk.com

Accessible Derbyshire: *www.accessiblederbyshire.org*
Email: info@accessiblederbyshire.org

Simple Ways to Prepare Your Child with ASD for Air Travel

By Martina RIEPEN

We all need holidays at least once a year. Traveling by plane is pretty exciting for many of us, but for children with autism spectrum disorder (ASD), air travel can be particularly stressful.

Here are eight tips to help make traveling by plane an easier, more positive experience for the whole family:

1. If it is the very first flight for your child, choose a short journey. It is essential to limit the flight time; do not choose a flight that is longer than three or four hours. A small trip can give your child an opportunity to get acquainted with the process.

2. It's important you prepare your child and practice the possible situations step by step. For best results, consider starting two to three

weeks before the flight. Hopefully, this will make your child feel much more secure during the trip. Start, for example, by reading a few books aloud to learn everything about planes and airports. If possible, visit an airport just to give your child a chance to experience some of the sights and sounds. Social stories are also effective tools, providing more personalized information.

3. Investigate whether your airport offers special programs for children with autism. For example, the Philadelphia International Airport works together with autism professionals, ensuring that children with autism become more familiar with traveling. They offer access to the airport to let your child see everything in advance, such as the check-in and the security gate.

4. Talk to your child about what will happen—creating a dialogue with your child will aid the process.

5. In the case of more than one child, agree with your partner who is responsible for which child during the flight. Discuss the particular incidents that could happen (tantrums, boredom, hunger, etc.) and agree how to calm the child or ways to help him/her sleep. Be prepared.

6. Talk to the airline too. Make sure that you find someone willing to listen and accommodate your family's needs, as not everyone understands autism. Also, try to find out if the flight crew offers varied programs between the meals. I recommend taking various toys with you as well as some entertainment (favorite music), a camera, little gifts (packaged in wrapping paper and appropriate to the particular age of your child), and treats. All of this is very helpful for your child's distraction and relaxation. Here a little trick: One week before the flight, let a few of the favorite toys disappear and magically let the toys come back out of your luggage during the flight.

7. Ask the airline about what will be available to eat and to drink ahead of time. Be sure to mention food issues or allergies. This way, you can decide if it would be better to bring snacks.

8. Be sure to plan your arrival and transfer times carefully, so your child doesn't become too tired. Staying well-rested will make a big difference.

Wishing you all the best during your next journey.

Martina Riepen was born in Germany and has been living since 2009 in the UK. She is a dedicated teacher in London, teaching English and German. On a daily basis, she works with students on the autism spectrum and with students who struggle with sensory processing disorder, social anxiety, and learning difficulties. You can follow her blog autism-in-the-classroom.simplesite.com or just visit her autism group "Autism Spectrum Radio" on Facebook she created about four years ago. Here Martina informs the world about autism news. In her free time, she plays the cello.

Why You Need to Support Your ASD Child in Physical Education

By Josephine BLAGRAVE, PhD, and Rebecca LYTLE, PhD

Children with autism spectrum disorder (ASD) move a lot—as a parent, family member, or loved one of someone with ASD you can probably attest to that. There can be constant movement in an ASD household: circles, spinning, running in the yard or the house, jumping off of couches (or bookcases, or coffee tables…I'm not judging, trust me). With all that movement, it is easy to think that your child with ASD is good at moving.

But stop to ask yourself this: Does my child have the skills needed to move *meaningfully*?

This meaningful movement can be as simple as walking from point A to B without bumping into everything in his/her path or walking without tripping over a penny on the ground. Meaningful movement can also be as complex as climbing on the jungle gym with peers at recess, playing kickball in physical education class, or participating in a dance performance. When you start to think about movement as more complex, what does that look like for your child?

Some of you may have a child on the spectrum who participates in a variety of meaningful activities and engages with peers through movement in age-appropriate ways—that's wonderful! There are others of you reading this who may be thinking about physical movement in a new way and considering that, though your child is a "mover," he/she might not move in a way that facilitates development or social interaction. If so, this article may be helpful for you!

Why Movement is Important

Though delays in motor skills are not part of the diagnostic criteria, there is a large body of research that suggests there are underlying motor deficits for individuals with ASD across the lifespan. These deficits are seen in the gross motor (large body movements such as running, hopping, jumping, and skipping) and object control skills (ability to manipulate objects to complete a motor task—for example, striking a ball off a batting tee, or catching a lightly tossed ball from a few feet). Individuals with ASD also show lower levels of engagement in game play, less participation in sports, and higher obesity rates than their peers.

This might not seem like an issue at first glance—maybe you don't care if your child can catch a playground ball, and maybe he/she is not interested in playing a team sport. There are a lot of other skills that might be priorities for you to teach your child, such as language, social skills, behavior, and joint attention. However, research has shown that physical activity improves positive behaviors and decreases negative behaviors. (Table 1)

Also consider all the time your child may have spent in early intervention services, some of which were delivered in a highly structured and sedentary setting, while peers without disabilities were practicing their movement skills through play and exploration of their environments in highly unstructured environments. They were learning how to move their bodies and be comfortable in their own skin in their yards, on the playground, and in the park. Our children on the spectrum are not getting the same amount of motor practice as their peers through natural play-based settings.

Benefits of Physical Activity for Individuals with Autism

Table 1

Physical Activity can DECREASE	Physical Activity can INCREASE
Stereotypic behavior	Social interaction
Aggression	Attention span/time on task
Off-task behavior	Health and fitness
Elopement	Positive behaviors
Stress	

(Lang, Koegel, Ashbaugh, Regester, Ence, & Smith, 2010)

A lack of basic motor skills can make it impossible for a child to enter a game of four square or tetherball on the playground. Even a simple game of tag may be difficult if the child has not learned spatial awareness and how to change directions or to move away from a tagger. Thus, this child becomes excluded from all the social activities that occur on the playground, after school, and in the park. Having the motor skills to participate in activities with peers creates opportunities to make friends, develop social skills, and learn to problem solve with others.

The Case for Physical Education

Physical education is included as part of the "well rounded" education under the Every Student Succeeds Act (ESSA) with other core subjects such as science, art, and history. Though it is identified as a core subject, it is often overlooked when parents are considering the education of their children. This can often be due to the fact that many people had bad physical education experiences as children and remember being picked last, hit by dodgeballs, or forced to exercise as punishment. However, most of us can also remember a bad math teacher or a bad English teacher. Such experiences turn us away from participating in that activity. On the contrary, not much beats quality physical education for joy, engagement, social interaction, participation, health, wellness, and future quality of life. The Society for Health and Physical Education (SHAPE) has wonderful information on what should be taught at every grade level and what makes a physically literate individual (https://www.shapeamerica.org). In fact, the national guidelines require 150 minutes per week in elementary programs and 225 minutes in middle and secondary programs (SHAPE, 2010).

If meaningful and task-directed movements are challenging, and motor skills may be an underlying deficit, it would be easy to think that children on the spectrum hate physical education and activity. As parents and researchers in physical education and ASD, we had fallen into that thought process until we asked the question directly to people with ASD. These were their responses regarding physical activity:

> *"I'm excited for days [referring to adapted physical education]…I mean I wish I could do it two days." —11-year-old male with ASD*

> *"It makes me exhausted but happy." —10-year-old male with ASD*

> *"One good thing I could say is that sometimes the games can be pretty fun. Because like, you know you can really do some fun stuff." —12-year-old female with ASD*

> *"It makes me feel heavy. Heavy is a good feeling." —10-year-old male with ASD*

These sentiments have been echoed in many teens and young adults who we've asked about their feelings on physical activity. They wanted more time in PE to learn skills and wished they had to play with their peers at recess in games.

What is Adapted Physical Education?

Physical education is a federally mandated component of special education services for your child and must be modified, if needed, to be appropriate for your child. If a child is unable to or has challenges participating in the physical education curriculum at his or her school, adapted physical education (APE) services may be appropriate to help the child gain access through individualized development of gross motor skills, fundamental movement patterns, group games, and sports, as defined in the Individuals with Disabilities Education Act (IDEA).

Suggestions for Supporting A Child with ASD in Physical Education

Hopefully, by this point, you have been convinced of the importance of physical education services. We have identified why physical education is important to your child with ASD. Now, here are ways you can promote and support your child with ASD in physical education!

- Help make movement fun but play low-stakes games and activities that build skills.
- Focus on games that require cooperation rather than competition.
- Integrate a child's interest into play for added motivation such as chasing dinosaurs, or jumping off equipment as if into a lake to encourage pretend play.
- Communicate with your physical education (PE) or adapted physical education (APE) teacher to find out what activities are being taught ahead of time and help pre-teach those skills to your child.
- Educate yourself on the minute requirements for physical education in your state and find out if your child is getting the required amount of time.
- Ask where and how your child is receiving the required minutes: in general PE, adapted PE, or a combination.
- Talk to your child's physical education teacher and find out what curriculum and standards are being used in their program.
- Observe your child's school playground to see what games and activities children are playing. You can then teach these games or ask about the school supporting the learning of these games through APE or support on the playground.
- Advocate for your child, but also teach your child to advocate for him/herself—help your child communicate needs so he/she can actively engage with peers in the PE setting.

Conclusion

Moving and being physically active are important to promoting a healthy lifestyle. Helping build skills for your child with ASD by supporting meaningful movement experiences, educating yourself on the physical education requirements that your child should be receiving, and then advocating for those resources will help your child become physically literate. He/She can then use those skills throughout a lifetime to access social opportunities, help provide self-regulation, and live a healthy and active lifestyle.

Resources:

Adapted Physical Education National Standards http://www.apens.org/whatisape.html National Center on Health, Physical Activity and Disability: Building Healthy and Inclusive Communities http://www.nchpad.org/

Society of Health and Physical Educators (SHAPE) http://www.shapeamerica.org/

Support REAL Teachers http://www.supportrealteachers.org/

Physical Education for Students with Disabilities http://www.wrightslaw.com/info/pe.index.htm

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Ways Using a BEHAVIORAL JOURNAL Can Help With MELTDOWNS

By Tiffany LIU

My brother has autism, and as his sister, I've learned a lot about how to deal with meltdowns over the years. As my brother has gotten taller and stronger, his meltdowns have also gotten increasingly intense. Before, I used to try to shout over the noise to try to get him to stop, prevent him from hitting himself or beg him to tell me why he was upset. Over the years, as I've read various books about autism, talked to his counselors and therapists, and engaged in a lot of trial-and-error, I've figured out a method that works well for my brother. Generally, I believe that the best way to help loved ones with autism is to really listen to them and dig deeper into the root cause of a meltdown, instead of treating it like a violent outburst that you have to "cure" or "fix" right away. Here is a recent example:

About a week ago, after my brother returned home from transition school, he was extremely agitated and jumpy, seemingly for no reason. Because he has autism, he couldn't articulate to the family why the frequency of his meltdowns had suddenly increased. To figure out the real reason for his meltdowns, I kept a daily behavioral journal: I tracked his diet and sleeping cycles, observed where and when he would have meltdowns throughout the week, and noted his topics of conversation and tics. After a week, I noticed that he woke up about half an hour before he usually did, had a meltdown about ten minutes before his school bus came to pick him up, and frequently asked questions about bullying incidents from years ago. From these observations in my journal, I concluded that he had a conflict with a classmate on the school bus, and with his teachers' help, discovered that a classmate had been knocking over his books on the bus on the way to school.

Of course, autism is a spectrum disorder, and what works for my brother may not apply to others with autism. Meltdowns are complicated—of course, I wish I could intervene and hold down my brother's arms so that he doesn't hurt himself physically, but I also must keep in mind that his repetitive behaviors during a meltdown are ways to calm himself down and process an overload of sensory information. So my best advice is really to observe and listen to your loved one and don't be afraid of trying a new method of dealing with meltdowns, such as a behavioral journal!

Tiffany Liu is a high school senior and the sibling of a young man with autism. She is passionate about breaking the silence and stigma of autism through writing, scientific research, dance, and community advocacy.

A Loving Mother Shares: THE BLESSINGS OF AUTISM

By Taryn PLENDL

***Blessings?* Most people would not use that word when they think of autism. I probably wouldn't have either until I had a child on the spectrum, but it is true.**

When my daughter was a toddler, I was always so impressed by how smart she was. She could line things up by colors and shapes better than any of her peers. She could memorize huge portions of dialogue in movies at only three and four years old. She could also meltdown like no other. Gifted? Expressive? Yes, and yes. Different? YES.

Different isn't bad. It isn't wrong. Society makes us feel like we should conform and fit in. I disagree. As a mom of a child on the spectrum, I want what every parent wants. I want my child to be happy, liked, successful, and independent. It just looks a little different than it might with her neurotypical peers. Not less, just different.

I remember when my daughter was in second grade and came home from school one day. She told me that her best friend told her they weren't friends anymore. There were no tears or sadness, just a statement. I asked her what they were doing when she said that. She explained that she took her friends swing because she wanted to swing. That was when her friend said this. I asked my daughter what she said to her after she told her that. She popped a fruit snack into her mouth and chewed. Then she turned and said, "I told her, 'Yes we are, remember?'" Cut and dry. In her mind they were friends, and she just figured her friend forgot.

This is one of those *blessings* I mentioned. Why? Because most children would be hurt and emotional in this situation. My child is "Black and White." This made it easier to make things like the swing incident a learning opportunity. She learned when it was appropriate to apologize in a very practical way. She didn't want to hurt people's feelings, and over the years she was able to "learn" social cues to know when she may have made a mistake.

Lying. Don't be jealous, but my child doesn't lie. Most of the time it is another one of those *blessings*! At the same time, it can also be a curse. As a parent of a child on the autism spectrum, you need to have strong self-esteem. You will need it for the times when family, friends, and even strangers feel the need to give you unsolicited advice on how to "fix" your child. You will need it when people stare at you as your child melts down because the lights or sounds in the store are too much. But, the main reason you will need solid self-esteem is when your child is brutally honest with you. Nothing is sacred. I've been ratted out publicly for passing gas. I've been told I must be putting too much food in my body because my butt is getting bigger, and I have had my child look at me in complete disgust as I don a pair of pantyhose, finishing it with the comment, "I don't think those fit you." By the way, pantyhose are the devil. All in all, this is a blessing because I know I will always get a truthful answer from her. I will also always know when her little sister is doing something wrong. She unknowingly rats her out all the time! See it now? Parenting win! *Blessings*!

Puberty. Ugh. Most parents dread this milestone. I know I am dreading it with my younger daughter; however, my child on the spectrum breezed through this stage. How? She is a fact type of girl. I explained menstruation in a scientific way. "This is what happens; this is why this is what you need to do to take care of yourself." When it finally happened, she called me into the bathroom and told me with no embarrassment. I told her, "This is what we talked about. Do you need help with anything?" She said no, and five years later, there has never been an issue. *Blessings*!

I have had people say things to me like, "It must be so hard to have a child with special needs." It is usually accompanied by a sympathetic frown. My response is usually, "She is actually the easy one." By the way, remarks like this should be on the top of the list of things to NOT say to a parent of a child with special needs. Don't pity me. I don't pity myself. My children are different, unique, and amazing in their own rights. Not less.

These are only a few of *our blessings* of autism, and there really are so much more. Every small success in my child's life is on a completely different level than that of her peers. Small things can be huge in the life of someone with autism. Tying shoes, potty training, talking. Huge!

Parenting is no joke. It is hard, and most of the time we are learning as we go. It is no different with a child on the spectrum. I may seem like I have a good grasp on this, but the truth is, I have just failed and learned from it enough to get to this point, and just when I think I've got it, the issues change.

The main point I am trying to make is that the *blessings* are there. Focus on them. They can be few and far between, but they are so much bigger than everything else. In times when things can be so overwhelming, they are sometimes the only thing that keeps you sane.

As a parent of a child on the autism spectrum, I worry. I hurt for my child. I cry for her, and most of all, I fight for my child. The biggest *blessing*? Most of the time, she doesn't know any of that. All she sees is my love.

Find those blessings!

Taryn Plendl is a wife, a mom, and a USA Today bestselling author of romance. She lives in the Mid-Atlantic area with her husband and two beautiful daughters and a very energetic Standard Poodle. Although Taryn wears many hats on a day-to-day basis, she is most proud to call herself mom of an amazing teenage daughter, who is on the spectrum, and a very busy, neurotypical 12-year-old daughter who keeps her on her toes. While being a strong advocate for her children, as well as an eternal optimist, Taryn recognizes the need to decompress, and occasionally can be found hiding in the closet with a package of Oreos in order to have a minute alone.

Devoted Family Inspires Creativity in Autism Community

By Melissa O'SULLIVAN

When I started Autistic Hero Teeshirts, I was a stay-at-home mom with a brand new graphic design degree I wasn't sure I would ever figure out how to use. I had been taking care of my children and going to school, and other than a few internships was struggling to find myself as well as my children's next steps, especially for my son Jake, diagnosed with autism spectrum disorder (ASD).

Like many families affected by autism, we wondered about the future. Jake is a "classically aloof autistic." He has behavioral issues—mostly aggression, emotional, violent outbursts, and non-typical verbal processing skills that made being in district in a less restrictive environment impossible for Jake. He needed support all the time and often psychiatric interventions. We wondered as a family: Would Jake go to high school? Even more elusive, college? Or have a job?

I will tell the truth. I think at first Autistic Hero Teeshirts made Jake very uncomfortable. He did not like me looking at his drawings. He did not like socializing about it. He did not like people talking to him about it, but I felt something in my motherly instinct and heart that said it would be good for him. He would grow socially. As I had guessed and truly hoped, he has become *very proud* of Autistic Hero Teeshirts. He has grown into the business, and our efforts, and now loves it. We wanted to share that success.

At the start of the company, we set out to sell a product that everyone would like, not just the ASD community, allowing us to spread the word about the lack of job resources out there for people with autism. To further impact, we decided to donate $1 a shirt right off the top to autism causes.

The statistics are stacked against employment for people with autism. The unemployment and nonparticipation rate of employee-age people with autism in the workforce is 80-90 percent. It was hard to figure out what to tell my son, who is very smart, what could be next and what he was allowed to dream. Basically, I had no idea.

Then I discovered that Jake is a great doodler. I found notebooks in his room and shared them when I went to graphic design college with my classmates. He was only a child at the time, and it was just a motherly gesture, but there was something unusual for Jake, whose language processing was delayed and facial affect was not very animated. The drawings were not like that. They had clear expressions. They showed happiness and teamwork and silliness to a level that was very heartwarming. It was a little peek behind the curtain of my son's autism. I became inspired by these drawings, and as time went on, that inspiration formed the beginning of Autistic Hero Teeshirts.

In addition to getting a closer glimpse into Jake's emotions, Autistic Hero Teeshirts has helped teach Jake new career skills and give him a sense of the working world.

But one of the most gratifying ways that Autistic Hero Teeshirts has started to impact the autistic community is with our Artists Wanted Program. We have turned to the community via the Autistic Heroes Facebook page and encouraged ASD artists of any age to submit designs for consideration to be featured on an Autistic Hero Teeshirt as a "featured artist." The teeshirt is sold at live events and on the website with a small bio about each artist, their original artwork, and their photographs.

Jake and I write back to Artists Wanted submissions currently and share our thoughts about their works regardless of whether they are selected. We offer encouragement to keep being creative and show respect for and interest in each artist and their story.

We also post the artwork frequently on our Facebook page, which has become a supportive community where ASD artists can display their work and find a new income source. The posts are also a source of pride for the community in the same way that Jake has built up his confidence through the company. Our Facebook page has grown to nearly 5,000 followers and is growing.

Autistic Hero Teeshirts, which began as a means to empower Jake, has also become a way for him to pay it forward. Today, it is a positive force that can ignite the entrepreneurial spirit and inspire creativity in all members of the autism community.

Based in Ridgewood, New Jersey, Melissa O'Sullivan is a graphic designer who is working with her son Jake Soper, a junior at Ridgewood High School and a member of the autistic community, to create Autistic Hero Teeshirts. This clothing company turns drawings by Jake and those from members of the autistic community into wearable designs and gives back to autism charities of their choice. Melissa is a Parsons The New School of Design graduate and has a master's degree in vocational rehabilitation for the disabled from NYU.

Website: autistichero.com
Facebook: www.facebook.com/Autistichero

Ten Best Things About Raising a Kid With Autism Today

By Jane STEIN

As a mom of a terrific 20-year-old son on the high-functioning end of the autism spectrum, it has recently occurred to me that as a young mom of a newly-diagnosed kid, I would have appreciated reading about all the great things that were ahead of me as my son worked his way through puberty and young adulthood all in his own unique way. Yes, there will be challenges, yes, there will be dark days (and nights) and lots of advocating and LOTS of therapy. Having said all of that, this is what you have to look forward to:

1. Your child has a unique way of seeing the world, as you know. There is much he/she can teach you. Go where your child is and see if from his/her point of view. It's not wrong; it's just the way your child sees it. And it's interesting.

2. Your child will love certain things passionately. Enjoy those passions and use them to connect. They will rotate from year to year. Except for LEGOs—which he/she will ALWAYS love.

3. Your son or daughter has a pure heart—there is no guile, no manipulation, no scheming or lying—he/she simply doesn't have that gene! He/she isn't terribly concerned about what's appropriate to say at any given moment, so

“You will meet the most AMAZING group of people: doctors, psychologists, speech and occupational therapists, resource people at school, Applied Behavior Analysis (ABA) providers, and all kinds of special people who have devoted their lives to helping our kids. I’m always amazed by the kindness and support of this community. It’s a wonderful village, and you will be surrounded by goodness.”

the most amazing things will come out of his/her mouth. Often truly profound things.

4. Your child can memorize literally ANYTHING—if you put it to a catchy tune. Math, phone numbers, addresses, you name it. Come up with a ditty.

5. It’s possible (maybe even likely) that your child will continue to surpass your expectations as he/she gets older. Expect the best and let your child tell you if he/she can’t do it. You’re likely to be pleasantly surprised year after year in school. Unless the school is no good. Ugh.

6. Most kids on the spectrum are serious rule followers. You don’t have to worry about them actually breaking ANY kind of laws. They just wouldn’t do it. Phew—no midnight calls from jail.

7. Your child will often say the most hysterical things that will stay with you for years. Like when the Rabbi asked my son what his biggest fear was on the day of his Bar Mitzvah, and my son said that he would have to give the money back. Really.

8. You will meet the most AMAZING group of people: doctors, psychologists, speech and occupational therapists, resource people at school, Applied Behavior Analysis (ABA) providers, and all kinds of special people who have devoted their lives to helping our kids. I’m always amazed by the kindness and support of this community. It’s a wonderful village, and you will be surrounded by goodness.

9. Your kid has a gift. You will find it. He/She will be very very good at something. You just may not know what it is yet. It might be making incredible card houses. Keep an eye out. Music is very likely to be involved. See #4.

10. Your kid was born at the RIGHT time to have autism. The zeitgeist of this generation of kids in school is that autism is cool. Maybe it was *The Big Bang Theory*, or maybe Julia on Sesame Street —or the atypical kid on *Parenthood*, or countless other new characters. When we read *Just Elliot* to classrooms of first, second, and third graders, at the end when I ask, “Who knows what autism is?” generally the majority of the hands go up. And invariably, there’s the kid who is madly shaking his/her hand to be called on so he/she can proudly announce, “I have autism!”

There’s never been a better time to raise a kid on the spectrum.

Jane Stein is the proud mom of Elliot now a sophomore at Ringling College of Art and Design. She helped champion a children’s book called Just Elliot based on Elliot’s childhood experiences, which has just been published and is available on Amazon.

Website: www.justelliot.com
Facebook: www.facebook.com/justelliotbook/

An Exclusive Look at AUTISM with *Liza Krassner*

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.

Today's AUTISM interview is with Liza Krassner, who is the mother of a son with autism and serves on the board of directors for Regional Center of Orange County (RCOC). It is one of 21 private, nonprofit organizations contracted by the State of California's Department of Developmental Services to coordinate lifelong services and supports for the more than 20,000 individuals with developmental disabilities and their families in Orange County. The regional center is the first stop for those seeking to obtain local services and supports to help them live safely and with dignity in the community. To learn more about RCOC, visit the website at www.rcocdd.com.

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

I was a new parent, with no clue of what to look for symptomatically. It took an expert at my son's preschool to suggest that something was different about him and to recommend we go for a diagnosis. That, I think, points to the fact that there are lots of people who are aware of autism as a condition that exists, but far fewer who grasp how that plays out in real life with families.

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

A spectrum disorder brings a unique set of capabilities and challenges for both parent and child, and it's a life of constant discovery. I'm not sure how that differs from the typical because we haven't known anything different, but I can tell you this uniqueness requires enormous quantities of understanding and a boatload of patience!

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

It's so exciting to see the many tools and resources available for parents today that we could not have imagined when my son was first diagnosed. There are apps now for everything from language assistance (especially for those who are nonverbal), find-

> “I have always been a learner—someone who seeks out new learning experiences and absorbs new information. Living with autism spectrum disorder (ASD) has taught us how we do things differently and enjoy life as a family, inspiring us to try to learn even more and, importantly, to share what we know with others, in hopes that it will help them in their life’s journey.”

ing directions, building resumes, and lots more. From a services standpoint, it’s wonderful that organizations like Regional Center of Orange County (RCOC), which serves our family, are now understanding and working toward person-centered planning which holds great promise for improving the quality of life for people with autism. And in government, Achieving a Better Life Experience (ABLE) accounts are meeting a truly critical need for families to be able to set aside funds for their loved ones’ future needs, without disqualifying them for government benefits.

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

I have always been a learner—someone who seeks out new learning experiences and absorbs new information. Living with autism spectrum disorder (ASD) has taught us how we do things differently and enjoy life as a family, inspiring us to try to learn even more and, importantly, to share what we know with others, in hopes that it will help them in their life’s journey.

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

Absolutely! Probably all parents struggle, and our support needs change as our children grow and change. At this stage in my son’s life, we’re struggling with rigid behaviors and transition planning. When a child approaches adulthood, it’s a time of great change, but I know we’ll get through it.

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

The biggest key to success is to ask for the help you need. Raising a child with autism is overwhelming, but you are not alone. Seek out the services and supports your child needs, but also take advantage of family resource centers, parent support groups, and parent workshops that can help to enhance your coping skills and bolster your family emotionally when your child’s ASD seems overwhelming.

Derrick Hayes is a paraprofessional who works with students who have autism and is also known as the “enTIEtainer” when he tells stories through neckties to empower others to greatness. Please visit his website, email, or call him for more information.

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

> “The biggest key to success is to ask for the help you need. Raising a child with autism is overwhelming, but you are not alone.”

ASD MARKETPLACE

Innovative Potty Protector Keeps Things Clean

Product: The Potty Protector is a simple device that converts an ordinary toilet into a urinal. It keeps your toilet, floors, walls, and baseboards free from misses and overspray that leaves stains and creates odors in incredibly hard-to-reach places. It's more than a shield for your toilet—it's a time-saver for Mom! Say goodbye to urine stains and overspray on and around your toilet.

Cost: $24.95

The perfect tool for boys of all ages! Boys often miss their "marks" and leave overspray that you can't see.

The Potty Protector is a plastic shield that fits easily on your toilet to protect your porcelain and its surrounding areas (especially the back), leaving you with a fresh and clean surface every time you need to go. It fits every toilet size and shape and is easy to remove. It's made from polyethylene plastic with a slip agent that allows fluids to shed off without sticking, so when someone needs to "sit," simply lift it off by the handle and set it on the floor or in the tub. You will have a perfectly clean bowl and seat to sit on. Cleanup is a cinch too! Use a disinfectant wipe from time to time or just rinse it off in the tub or shower.

Cut down on cleaning, stop being embarrassed when guests use your restroom and eliminate odors that hang around and even penetrate into your bathroom floors! It even gives boys who struggle with confidence knowing they can go by themselves and not leave a mess, and especially gives Mom peace of mind. Whether you purchase it for yourself, family members, or clients, one thing's for sure: all potties will be protected!

The Potty Protector is the new, must-have device for any household or private facility with boys or men. Stop potty abuse by using this shield to stop the splashing and spraying of urine.

The Potty Protector is available online from The Potty Protector Website.

Light Up Hanging Hampers Are a Slam Dunk

Product: Store&SCORE™ LED Light Up Hanging Hampers

Cost: Free

A VERY SPECIAL OFFER FOR YOUR VERY SPECIAL CHILD: $14.99 on Amazon. However, FREE for your special one from Store&SCORE™

All children are special—and yours is extra special. This *Autism Parenting Magazine* ad is extra special too because we are not trying to sell you anything. Rather, we are giving you an early opportunity to see how much our patent-pending LED Light Up Hanging Hamper—which turns neatness into a game—might be able to improve your child's sense of timing, at NO cost to you.

Each Store & SCORE hanging hamper has a sports theme backboard (basketball, baseball, football, or soccer). When your child throws dirty laundry in the hamper, colorful LED's briefly light up to provide encouragement. If you are curious about whether your child might enjoy this product, and potentially might learn from it, get yours for FREE at Store-and-Score.com.

DISCLAIMERS: 1) Not for those children super-sensitive to light sources; 2) Supplies of Store & SCORE hampers are free to autism spectrum disorders (ASD) families as described on Store-and-Score.com. Quantities are currently limited to 10 hampers per month, so get yours soon. The more hampers purchased via Store-and-Score.com, the more hampers we can make available for free for children on the autism spectrum. So please tell your friends.

MOM CREATES AMAZING JOB OPPORTUNITIES FOR PEOPLE WITH AUTISM

AUTISM WARRIOR:
Meet
Dr. Barbie Zimmerman-Bier, who developed top jobs for people with autism as the executive director of Popcorn for the People, a social enterprise of the nonprofit 501(C)3 Let's Work for Good.

Dr. Barbie Zimmerman-Bier is the chief of developmental pediatrics at Metropolitan Hospital in New York City (NYC) and clinical associate professor at Robert Wood Johnson University Hospital. She is also the executive director of Popcorn for the People, a social enterprise of the nonprofit 501(C)3 Let's Work for Good.

The unemployment/underemployment rate in the autism community is 80 percent. Popcorn for the People trains and hires workers with autism to cook, package, and market gourmet flavored popcorn. They have workers ranging from 19 to 50 years of age, and for some, this is their first job. Many of their employees previously had difficulty maintaining steady employment. Popcorn for the People provides a caring, nurturing, safe environment.

LOCATION: The popcorn is produced at a popcorn processing center in East Brunswick, NJ, and has been sold in malls, festivals, ball games, and online at popcornforthepeople.com.

ACCOMPLISHMENTS: Popcorn for the People has developed a business that creates real, meaningful, and sustainable employment for the autism community. The business was trademarked by the US government and contracted to be the flavored popcorn for all Rutgers athletic events including Rutgers Big 10 Football and Basketball. This organization started with just Dr. Zimmerman-Bier's son, Samuel, and now you can see at least eight of their workers hawking popcorn at Rutgers football and even more running the three popcorn concession stands. All the popcorn they sell has been produced daily by two shifts of workers cooking and packaging popcorn at the processing center. The online store, popcornforthepeople.com, received a grant from Google and now ships throughout the US and Canada.

INSPIRATION: Barbie said she is inspired when her son comes home at 5:30 p.m. telling her about his long day at work. Not so long ago he was sleeping till noon, unemployed, and bored. Now, Barbie said, he is like every other working person. After getting a job at Popcorn for the People, he felt empowered and motivated knowing he is bringing smiles to people's faces when they try the popcorn.

GOALS: Barbie's goal is to standardize the operations of Popcorn for the People so their model can be reproduced in other cities, giving the opportunity to even more people around the country. She wants to raise awareness and change how society views people on the autism spectrum, but most importantly, secure jobs for the autism community.

ADVICE FOR FAMILIES AFFECTED BY AUTISM: "Never stop educating yourself! The field of autism is constantly changing. Many ideas that were once considered radical are now considered mainstream so keep learning. And don't get discouraged by bad moments. Remember it is not a sprint, it is a marathon."

Website: popcornforthepeople.com

Heartwarming Young Adult Novel Shares the Challenges and Rewards of Friendship

Trina, a puppy raiser for service dogs, believed this job would be the perfect way to have a dog. He would never grow old and die. But like all great ideas, this one has a flaw. She never expected getting attached. Her last week at the beach with her best friend, Sarah, is made more difficult when her dog, Sydney, makes a magical connection with a boy with autism. His older brother, Chase, takes an interest in Trina and causes Sarah to become jealous. It's hard enough to deal with losing Sydney, but now Trina may lose her best friend. And then she still has a daunting decision. Is she strong enough to train another dog?

Sheri S. Levy is an award-winning author for her Young Adult, Trina Ryan Novel Series: her debut novel, Seven Days to Goodbye, won in 2015, with the Dog Writers Association of America in the Special Interest category. On September 1, 2017, this novel won a Gold Medal with Readers Favorite. Her sequel, Starting Over, was nominated for a Maxwell Medallion with the DWAA in December 2017. Sheri taught special needs children for 16 years and uses her life experiences to write her stories. Sheri is an active member of SCBWI (Society of Children's Book Writers and Illustrators) and SIBA (Southern Independent Book Association).

Sheri enjoys doing school visits, teaching writing workshops, and tutoring students. Palmetto Animal Assisted Living Services (PAALS) helps Sheri with her research on writing about service dogs and how they change lives. Sheri, in turn, shares her book proceeds to help support PAALS.org.

Website: *www.sherislevy.com*
Facebook: *Sherislevyauthor*
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Hot Off the Press!

The Best Way to Serve People with Special Needs: Live with Them

By Jane E. FINN, EdD

Inclusion, or placing different ability levels together in the classrooms, has been a proven practice in education for years. Research has shown that this mixture has been good for everyone, including those with and without special needs.

The National Center for Education Statistics reports that 13 percent of public school students in the US have a documented disability. Autism, intellectual disabilities, developmental delays, and emotional disturbances account for five to nine percent of students in special education. This is a vast mass, and even with specific training, many teachers do not always feel fully equipped to serve these students well.

Church leaders are noticing that similar numbers of followers have disabilities, so this trend is emerging in the faith community as well. Although church leaders seek to be as welcoming and as inclusive as possible, people with special needs don't always find the support they want and need to engage deeply in this community.

People with special needs in schools and churches at times need advocates to help engage them and address the challenges they face in school and faith environments. The problem is that in both cases, the people who want to serve these populations don't always get the kind of one-on-one experiences that would help them prepare for this important work.

One model that has been radically changing this preparation is The Friendship House.

The Friendship House is a small residence dorm in Holland, Michigan, where individuals with special needs live side-by-side with similarly aged students attending either Western Seminary or Hope College. This dorm consists of pods where three students and one person with a challenge live together as roommates. Each of them has their own room and share common areas like a kitchen, laundry room, deck, and TV room.

By living here, the seminarians learn to be better equipped personally and professionally to serve people with special needs and their families as future pastors. Similarly, Hope College students, studying special education, psychology, or social work, use this hands-on experience to help prepare them for this future professional skill.

Through interviews with the student residents, my research has found that not only is this living model effective in preparing people for their future careers, but it also has immense personal benefits for all residents.

Through this qualitative research, it was revealed that after the first year of the program the student participants in this dorm felt immense joy in watching their roommates with challenges, whom they call "friends," improve their social skills, develop confidence, and become more independent as they bonded throughout the year.

The experience provided important benefits for the "friends" too. They had been living with their families until they moved into this dorm, and often their parents had performed simple tasks for them that, at times, they were capable of doing themselves. Since the "friends" now had to negotiate life on their own, their independence and self-determination skills began to blossom in this new environment. This included how to talk to their roommates appropriately, how to be considerate when living with busy university students, and how to find their own fun and entertainment in the community setting. To live at the Friendship House, the "friends" had to obtain either part-time or full-time jobs, find their own transportation to those jobs, and learn how to manage their own money, thus helping them develop important life skills.

There were, of course, challenges to this type of living. The non-disabled roommates sometimes ran into trouble balancing the roles of friend with the role of supervisor, but navigating that balance was essential for enabling the roommates with intellectual disabilities grow in their self-determination skills.

Despite the challenges, the majority of university students interviewed responded they would recommend this type of living arrangement to others who want to gain a better understanding of people with challenges and their families, as well as grow personally and professionally for their future careers. The roommates began to understand that their new "friends" were similar to them and experienced some of the same frustrations and joys that they did. This living situation made the students realize it is sometimes necessary to break down perceived ideas and barriers and ask questions to get to know a person—a lesson that is perhaps the most valuable of all in any walk of life.

Jane E. Finn, EdD, is a professor of education at Hope College in Holland, Michigan. She is recognized for her research in independent living for people with exceptionalities as well as transition practices for youth with disabilities. Dr. Finn has a background in education, administration, counseling, and special education. She has worked over 25 years in the field of education as a high school teacher, special education instructor, counselor, and professor.

How Do I Know How Much Money to Leave My Child With Autism?

By Ryan F. PLATT, MBA, ChFC, ChSNC

Question: *“We have three children, and only one of our children has autism. How do we know the amount of money we need to provide for each of our children?”*

It is very common to feel uneasy about determining the amount of money your child with autism may need for a lifetime of support, especially when you have other children that you want to treat fairly.

We call this conversation with the families we serve our “Fair and Equal Conversation.” Many parents understand that their children with autism will need more support during their lifetimes than their children without autism, and that support costs money. Because most families do not have endless supplies of money, this can cause some challenges. Parents fight the thought of their other children feeling slighted and holding resentment toward their siblings with a diagnosis, as well as towards the parents if their siblings are given all or almost all the parents’ assets. However, for most families, the facts are clear that children with autism will need more support and therefore more money to pay for that support than their other children.

The question is, “How much more?”

This question can only be answered by putting pen to paper and determining the true cost of a lifetime of support. Each individual's needs and therefore calculation will be different, but each calculation will lead to a definitive number that will allow you to answer your question.

You must consider the following items in your calculation:

1. **Reliance on Government benefits**
    a. **For which benefits does or will your child qualify?**
    b. **What do those benefits pay for? How much do they pay?**
    c. **Will they continue to pay for those items?**
    d. **How much reliance do you want on government benefits?**
    e. **How do you protect these assets so they are secure for your child's lifetime?**
2. **Define "lifestyle" of your child**
3. **Determine "cost" of that lifestyle**
4. **Choose an appropriate inflation rate**
5. **Complete a net present value calculation**

By following these steps, you will be able to find the amount of money your child with autism will need for his/her lifetime. With this number in hand, you can answer your question, "What percentage of your assets will you need to leave your child with autism?" Your answer may necessitate that you leave 70 percent of your assets to your child with autism and only 15 percent to each of your other children. Obviously, these percentages are not equal, but they may be fair because your other two children do not have the same lifetime support needs as your child with autism.

You will need to define "fair" for your family.

For more information on how to prepare for the future, be sure to contact a financial advisor who specializes in serving families with special needs. A Special Needs Plan is driven by their purpose of Leading Families to Independence through an on-going multi-generational plan. A Special Needs Plan is passionate about families moving confidently forward.

101 N. McDowell Street, Suite 120
Charlotte, NC 28204
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http://www.aspecialneedsplan.com

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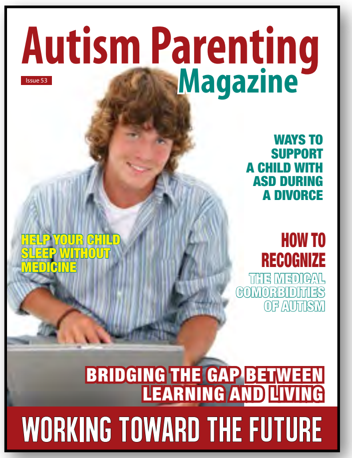

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