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#### Dear Readers,

s it really time to count down the final days of summer? Just when we finally got into the swing of the summer holiday how, we ask, can it possibly be time to switch gears again? While it may seem a little early to think about school, the sooner your family prepares for the transition, the smoother it will be. With some schools starting back as early as July and August, we decided it would be most beneficial to feature an early back-to-school issue. We also plan to include education-centered articles in next month's issue as there is always so much information to cover.

First, we are delighted this month to be able to offer the advice of Esther Hess, Ph.D., Executive Director of the Center for the Developing Mind. In her article, Starting the School Year Off Right: Tips for a Smooth Transition for Your ASD Child, the developmental psychologist provides practical ways to prepare your autistic child for a smooth transition back into the classroom. From guidance on social stories and role playing to the need for Individualized Education Plan (IEP) meetings and communication plans, readers will learn new ways to prepare for that first day back. Being equipped is key to reducing stress levels.

Unfortunately, for many children on the spectrum, heading back to school triggers high levels of angst and uncertainty. Be sure to read Certified Autism Specialist and licensed Christian Counselor Stephanie C. Holmes' piece called, *The ABCs of Back to School for ASD Children: Anxiety, Bullying, Confusion...* as she provides thoughtful guidance on how to prepare your autistic child several weeks before the first day of school to avoid unnecessary stressors.

Sometimes our children need a little extra help relieving anxiety. That's why it was a pleasure to be introduced to award-winning entrepreneur Lisa Fraser this month and learn about her product known as the Snug Vest. Take a look at our article called *Putting the Squeeze on Sensory Processing Disorders* to learn how her innovative invention works to relieve anxiety by regulating the sensory system when it is over stimulated from environmental input and overload.

Many of us can relate to those stressful and perhaps tumultuous teen years when we had to transition to middle school. Typically, middle school includes new teachers, demanding schedules, and possibly, a sudden shift in friendships. That's why we are thrilled to share advice on helping your ASD child make this transition from Lisa Timms, Creator/Director of The Timms Social Skills Program. Be sure to check out *Helping your ASD Teen Survive the Middle School Transition* and learn helpful tips on guiding your teen through the ups and downs of friendships.









As I have mentioned in the past, in addition to featuring premium advice monthly from certified autism specialists, developmental psychologists and therapists, we like to highlight personal advice from our readers. These are the moms, dads, siblings and even grandparents of children on the spectrum who deal with life's daily challenges and can offer special insight. This month, for example, we have the pleasure of hearing from college student Siri Smith who expresses in *Sibling Love* how fortunate she feels to have a brother with autism as the experience has shaped her into the kind of person she is today.

We also hear from mother of four children, Jamie Thomas, who explains how she had almost given up on attending church out of fear one of her two autistic children might disrupt the service. In her narrative, *Making My Fears His*, Jamie explains how she once became so focused on what could go wrong during an outing, she ended up projecting her own fears and anxiety onto her child. Jamie later comes to the conclusion she may actually be the one holding herself back from the joy of the church service because of her own fears.

Diana Fernandez, mother of an autistic 10-year-old, reveals a very personal story in her piece called *Embracing Autism: Forgiving Those Who Judge*. Openly chastised in a grocery store during her daughter's breakdown, Diana shares how she was able to educate strangers on the challenges of autism and change the way people react to something they don't fully understand. Her solution is inspirational.

Wishing our readers a happy final weeks of summer and an anxiety-free start to a new school year.

With Regards,

**Amy KD Tobik** *Editor-in-Chief* 

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**Autism Food Club** 

## Helping your ASD Teen

### **Survive the Middle School Transition**

By Lisa TIMMS

Do you remember going into middle school? You may have been excited to start but once you got there everything seemed different. Teachers expected more, friends formed new alliances and left you behind, and you may have felt lost. Transitioning into middle school is hard for any teen but particularly difficult for teens on the spectrum.



verything begins to change at this time in a teen's life. Teens tend to become more independent at this time and start separating from their families. They think they know it all. At the same time, friends that they've had for years may no longer want to hang out with them because they are trying to get into the "in" crowd. Puberty heightens emotions and only exasperates the situation for the teen feeling left out and they don't want to go running to their parents with their problems. What can a parent do to help their teen through this transition?

The first and foremost thing to help your teen is to let them know you are still there for them even though they may not be as open with you as they once were. Try to set some time aside at least weekly that is quality time for you and your teen. Talk about anything they want to talk about. If you ask questions and your teen isn't reciprocating in the conversation, go to a topic that you know they enjoy talking about. If you get them chatting about something of interest they may feel more comfortable opening up to you about other things.

If a teen has lost a friend upon entering middle school remind them that a true friend wouldn't abandon them just to fit in with others. A true friend could be trusted. A true friend wouldn't try to get them into trouble. A true friend would be there for them no matter what. A true friend would listen. Ask your teen what they would do if their new crowd didn't like one of their old friends. Would they turn their back on them or would they honor the tried and true friendship. This of course isn't going to instantly make your teen feel better but it will give them something to think about.

If your teen's friends change, take the time to get to know the new friends. Pay attention to who your teen is hanging out with and what activities they are participating in. Stay involved with your teen's life. Always make sure you know where they are going, who they are going with and when they expect to be home. Keep a list of new and old friends phone numbers so you can easily check on your teen if you think there may be something awry. Keep a close eye on changes in behavior and attitude.

Stay in touch with the school. Keep in contact with teachers and the school counselor even if there seem to be no issues. Always attend parent/teacher meet-



ings and parent nights. This is your "in" to find out if anything is going on in school that your teen may not be telling you.

This may turn into one of the most difficult times for your teen, but on the bright side, as old friends fall to the wayside, they will form new friendships and alliances that could last a lifetime.

Lisa Timms, MS Special Education
Creator/Director The Timms Social Skills Program
www.SocialSkillsForSuccess.org
www.facebook.com/TSSP.LTimms
https://www.linkedin.com/groups/Skills-SuccessSpecial-Needs-Students-6789237/about
https://twitter.com/tsspltimms

Lisa Timms has a Master of Science Degree from the University of Scranton. She is the author of "60 Social Situations and Discussion Starters" published



by Jessica Kingsley Publishers. You can find her book online at <a href="http://www.jkp.com/catalogue/book/9781849058629">http://www.jkp.com/catalogue/book/9781849058629</a>. She is also the creator of The Timms Social Skills Program. A live, fun, interactive, peer-to-peer online social skills program which is offered nationally for students ages 6-18+ with Autism, Aspergers, ADHD and/or related disabilities or atypical students who may be struggling with their problem solving and/or social skills.





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## Making Making His

By Jamie THOMAS

Saturday my husband sort of slipped into our conversation that he would be going to church on Sunday. He would be speaking about his Wounded Warrior retreat he went on the weekend before and he also wanted to check out the church. He also asked if I would join. I sort of haphazardly replied with a sure and carried on with our conversation.

hurch — a word that hadn't been a huge part of my vocabulary since graduating from a Catholic High School in '98. It popped up a few times after my first two children were born but nothing ever came to fruition on it and I sort of let it just go. In 2014 I moved to what is affectionately known as the Bible Belt or West Texas. About 90% of my friends attend church but after the birth of H. I really stopped even trying to think that Sunday service was going to happen. I also started to feel conflicted on what I wanted to do so I just let the whole topic drop completely.

When we got our autism and sensory diagnosis two years ago, I decided to try and keep it simple. My friends around me all offered to open their church homes to my family, but honestly, the thought of schlepping my special needs child to a church service was about as much fun as walking across hot coals barefoot. I already had it set in my mind this would end poorly. He would freak out in the nursery so they would kick him out. I would try to keep us with him during the service and, if he became disruptive, I would deal with the angry eyes of all those in the congregation. None of these outcomes sounded remotely appealing to me, so I politely declined offers and said that church would just be something we might not do for a long while.

Sunday morning comes and honestly I am trying to talk myself out of this. H. has never been to church and I don't know any of these people, and while yes, it's the house of God and they shouldn't judge, I sort of felt that the judging would come harsher because this is a place of worship and my child could wreck this for them. I literally tuned the morning out because I was trying to mentally prepare myself for this new endeavor. Normally I would prep H. for a new situation. I selfishly prepped myself instead and forgot about the important factor in all of this. To this point I don't even think I had made mention of what



we would be doing. Maybe looking back I didn't prep him because I had no idea what the church setting would be like.

We pulled up to the church and I sort of stalled. I wasn't ready myself to walk through this unfamiliar territory. I suddenly became hyperfocused on H.. I did what I could to slow down time. I walked in the door clutching H. close. I am trying to protect him. From what, I have no idea, because it's church and seriously who is going to hurt him? Chris walks in and takes a seat. I am far from ready to take that step myself so I opt to wait out in the hall. H. is growing anxious or maybe it's me. I see a nursery, however the lights are off and I don't want to barge in. I draw in a deep breath and walk through the doors. The setup is ideal. There are no typical pews, they are folding chairs. Chris introduces me to a friend of his who set him up to go on the retreat. His wife had worked at the hospital that we have taken H. to and she has actually encountered him before. We took our seats and gave H. his trucks and some sensory items. He lay down on the floor and started to scoot back under the seats. This is what he does in new situations. At this point as long as he wasn't distracting anyone or taking his clothes off I am good with it.

I started using H. as my security blanket. He wanted to sit in our lap so I took out his brush and started brushing his arms. He is relaxing but I just can't. I know there were so many articles and stories shared from my autism friends and support groups I just never felt the need to read them because I never figured I would be here to need them. At this point I am winging it. I am racing with thought and suddenly I look down and see he is crashed out in my arms. I breathe. I let out a sigh of relief that suddenly I know he won't bother anyone and everyone here can enjoy the sermon without the possible distraction of my child. The biggest fear was H. being such a disruption in a place we had never been and that first impression not being the one we wanted. He slept; he slept a good 75% of the service. I was good with that, far better than I had given him credit for.

I feel bad that I didn't even give my full attention to the sermon given. Honestly, I couldn't recall anything minus maybe a few announcements and them calling the children to take them to their class. I feel horrible I haven't given either one of us credit. I am so focused on "the what could go wrongs" or the "hope they don't happens" that I lost sight of the rea-

son I was there. I was there to share in the experience that my husband had when he went on the retreat a week ago. I was so wrapped up in my fears that I was deflecting. I didn't see my child for whom he could have been during that service I was so anxious I was so busy preventing things I didn't let him experience the situation for what it could have been for him. Minus the trip to the small nursery to keep him quiet, it went very well. That nursery, however, made me feel insecure all over again. It was unoccupied. The children were either sitting in the service or old enough to go enjoy the children's class. There was one other child in there but her mom was preoccupied in ensuring the horses that were tied up outside stayed put. I didn't take into consideration they might not have had a worker for the nursery. I saw it as a sign, some stupid sign that I read too far into.

As they served communion, I gathered up H.'s things we brought to the room and had him sit with me. I believe at this point Chris had caught on and was a bit more insistent on holding H.. I could sense he wanted me to participate. I am not there yet. H. maybe I am not. After all I am still so busy projecting my fears my anxiety onto my child that I can't see past that he might have actually handled a huge routine change, AND new place with minimal interruption. I am not giving him enough credit. He deserves it. I have to stop being so reluctant to try new things with him for fear of it not going the way it should. I can't keep sheltering him and using my fears of being judged and or rejected to keep him from experiencing hurt. He is growing and changing. All the tools we have been given to help him are working. I just need to let them prove their work instead of dealing with the possible failure. However, I need to stop making my fears his fears.

Jamie Thomas was born in Garland, TX and currently resides in Abilene with her husband of five years, Chris, and her four children Sean (15) Hannah (13) Ella Grace (10) and Hunter (4). Her two young-



est children are on the autism spectrum and are higher functioning. She is working on her Bachelors from Western Governs University in Special Education and currently is a Special Education Aide in the autism classroom at Cooper High School. Her passion is children.

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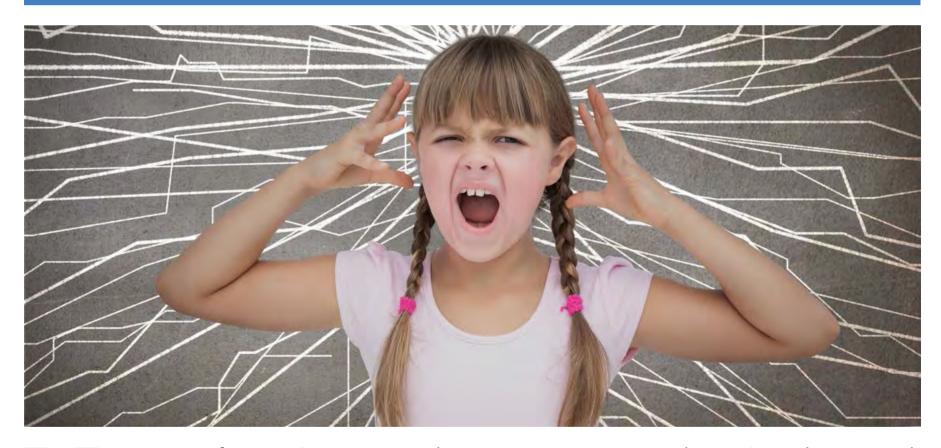


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## The ABCs of Back to School for ASD Children: Anxiety, Bullying, Confusion...

By Stephanie C. HOLMES, MA, BCCC, Certified Autism Specialist

Oh the wonders of a new school year. Back-to-school shopping, meeting a new teacher, a new colorful classroom welcoming students, new faces, sounds of hundreds of children returning to school, the sights, the sounds, the new routine — all things most neuro-typical children handle with stride but often overwhelm our spectrum children.



ost parents of Autism Spectrum Disorder (ASD) children usually have their IEP or 504 in place for the coming school year, but there are many nuances to school that an IEP or 504 simply cannot cover to prepare an ASD student for all the potential challenges of a new school year.

With almost 12 years of "new school year" experiences with my own ASD student, I have learned to live by a famous Zig Ziglar quote, "Expect the best. Prepare for the worst. Capitalize on what comes." The key word is prepare. There are many unknowns and uncertainties as you and your ASD student approach the school year. It is hopeful, but not guaranteed, that during the IEP/504 process there was good dialogue with the team and a good match was made between teacher and student. I have found teachers that are very firm, but fair and compassionate, are often the perfect choice for my student. It is important for the ASD child to trust the teacher and feel liked or respected by the teacher. Not all teachers are open to this, but when the school would contact me about my child's teacher, we would try to set up a time to meet the teacher one-on-one without the

entire class present. I would bring my daughter's favorite book or treat to share with the teacher and try to build a positive experience before the start of the school year. I wanted the teacher to see the side of my child I often see when not encumbered by the stressors of the classroom.

Two other huge aspects of being prepared, include the playground and the classroom setting itself. While meeting the teacher, I would survey where the teacher was thinking of seating my student and help troubleshoot or brainstorm if this was indeed the seat that should be chosen for preferential seating. Often times educators assume the preferential seat should be by the teacher desk or the front row, but this may differ from child to child based on their sensory issues or if the child was like mine and prone to dart from the classroom. After a seat was chosen, I would request my child's seat stay the same throughout the year. Moving to a new desk and a changing classroom is not necessarily fun for the ASD student.

Having issues with gross motor skills, I would usually bring my child to the school a few weeks early if we were allowed to play on the playground equipment. This would help her with familiarity and rebuild her skills so that if she made it past the social barriers of playground play, she would be able to feel confident and safe on the equipment on itself.

I also learned that not every school will provide the teacher with the IEP/504 right away at the beginning of the school year, and this is not fault of the teacher. The next step was to provide a short email to the teacher the first day of school reminding her of my child's needs with bullet points as key points in the IEP. Most teachers find this helpful if short and sweet if prepared without demanding or condescending language. I want to provide a foundation of teamwork based on mutual goals of my child's success in her classroom.

Prevention is also a key ingredient to academic success. In knowing your child and what situations or objects or settings tend to set the child off into melt-down mode can important. Prevention can start with back-to-school shopping. If the child has sensory issues, making sure every item of clothing from under garments to socks and shoes and outwear are something the child will be comfortable in at school. I had to give up the idea of cute and accessorized back-to-school outfits. Within the guidelines of the dress

code for each school, it is far more important for the clothes not to be an issue. Back-to-school supplies are also crucial. If the school has rules about every student having the exact school supplies, work with the teacher to see if some accommodations can be made so that the child's sensory issues are addressed with the tools he or she will be using every day. If the child hates cutting assignments, maybe it is the metal scissors that are problematic and finding some soft rubberized handles is the perfect solution. Another part of prevention is strategizing the back-up plan for non-routine days. Assembly days, picture days, field trips, field days, special speakers, or substitute teachers can all throw a monkey wrench into the perfect plan. These days take special preparation to plan for possible melt-down scenarios.

You have probably heard the saying, "If you have met one child with ASD, you have simply met one child with ASD." ASD is a broad spectrum wherein no two children are the same. Each symptom of ASD is a spectrum and each ASD is unique in how they fall on various aspects of the spectrum. It is impossible to be prepared for each possible potential challenge of a new school, but with some preparation, prevention, and provisions you can enter the school year perhaps a little better and stronger each year. As my ASD student is approaching her senior year in high school, we have learned to be flexible and take each new year as a new challenge with the ultimate goal being to optimize success however we can. These ideas are aimed at elementary school years. With each transition to middle school, high school, college, there are far more adaptations to be made. Reach out to your state's autism society and seek out additional helps or resources they may have on their website for ideas about back-to-school readiness for your state.

Stephanie C. Holmes, MA, CAS is a board certified Christian Counselor who practices in Atlanta, GA. Her book, Confessions of a Christian Counselor: How Autism Grew my Faith, outlines her personal journey as a mother



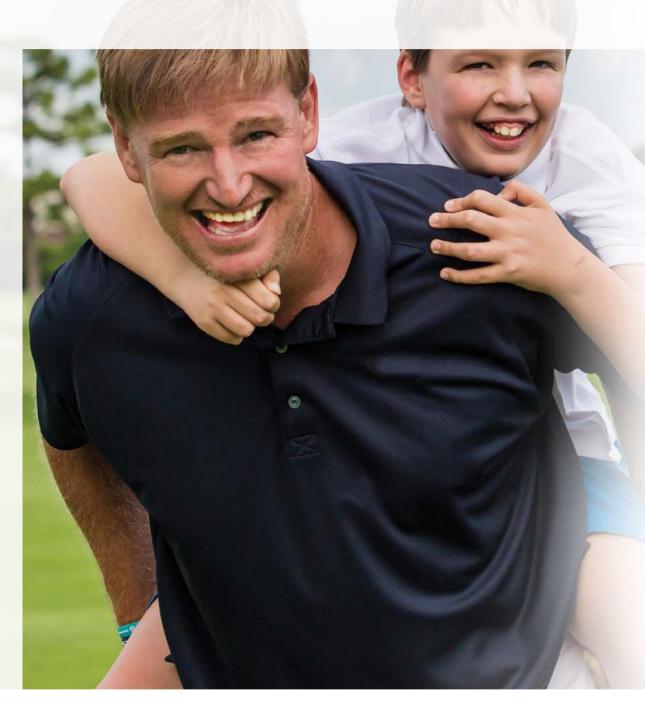
of a spectrum child, will be published fall of 2015. You can look up other articles and blogs about ASD and marriage and family issues at <a href="https://www.counselorstephanieholmes.com">www.counselorstephanieholmes.com</a>.

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Floridian National Golf Club	FL	5/19/15
Royal Montreal Golf Club	QC	5/25/15
Congressional Country Club	MD	6/01/15
Duke University Golf Club	NC	6/15/15
Rich Harvest Farms	IL	6/22/15
Hawktree Golf Club	ND	6/29/15
Baltusrol Golf Club	NJ	7/13/15
TPC Jasna Polana	NJ	7/27/15
Scarboro Golf & Country Club	ON	7/27/15
The Country Club at Castle Pines	CO	8/03/15
Hoakalei Country Club	HI	8/06/15
Chambers Bay	WA	8/10/15
Atlanta Athletic Club	GA	8/17/15
TPC Boston	MA	8/24/15
Hazeltine National Golf Club	MN	8/24/15
Glencoe Golf & Country Club	AB	8/31/15
University of Texas Golf Club	TX	8/31/15
Silver Creek Valley Country Club	CA	9/03/15
Edmonton Country Club	AB	9/14/15
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## MAINSTREAM OR SPECIAL NEEDS: Selecting The Best School For Your Autistic Child

By Linda MASTROIANNI

Finding the right school for your child with autism is no easy task. Depending on your child's needs, there will be multiple factors to take into consideration. Perhaps your child is non-verbal or has severe behavior issues such as hitting, biting or pinching and requires a great deal of support. Maybe your child is high-functioning but has difficulty with social skills or has sensory issues that make it difficult to sit down in class. There are myriad factors to consider before making this decision.



he first major point to consider is whether or not your child should attend mainstream school or a school for children with special needs. Each one is designed and structured differently.

As the parent, you know your child best. You understand his/her capabilities as well as challenges.

You know what works best with your child and what approaches are successful when engaging him/her in activities. These are extremely important factors that will guide you when making your decision.

My son went to an all-inclusive school from kindergarten to grade 6. When I was visiting the different schools trying to make my final decision, it was very important for me and for my son that I find a school that wouldn't dictate what was expected of him. I wanted the person working with my son to have a knowledgeable experience on the different types of behavioral issues that autism sometimes brings and understand that these behaviors are never seemingly out of the blue. And I most definitely wanted a school with an open line of communication with me. I wouldn't and couldn't settle for anything less.

The process of learning and growing wasn't just limited to academics. This had to include growth on a social level as well. It had to do with seeing his abilities and building on those skills; listening and respecting his voice even when he was silent; having him feel safe when things around him became overwhelming and understanding his behavior as a form of communication. So many different aspects came into play when making my final decision on the right school for him.

We were lucky we found one. Although, this doesn't mean we didn't have issues and problems to deal with. Year after year I had to fight to ensure my son had enough hours allotted to him for support. It was absolutely ridiculous to have to constantly fight for what was rightfully his. The growing pains never seemed to disappear but as a parent that advocates for their child, this is what we do.

It was when my son was in 6th grade that another major decision was before us. Which high school will he attend? I quickly realized that our options of sending him to a mainstream high school with support would be impossible. There wasn't any high school that had the right resources for him, not to mention the risk factor of being bullied in a school where the population was three times that of his grade school.

Our road took another turn and we were now looking at schools for children with special needs.

Personally, this was difficult for me because, at the time, I whole-heartedly believed that inclusion into a mainstream school for my autistic son was not only



the best option but, in my mind, the only option. I believed that if I kept him out of mainstream schooling it would be like working in reverse for him. It would not be working in a positive, forward motion for him. If I want him to integrate into society as an adult then the integration must begin as a child at school, with his peers, his teachers and the first real community that he will experience outside of the family unit. I truly believed that a school for special needs couldn't provide him with such integration.

I had many concerns when my son started his first day at his new school. It was a very small school, less than 70 kids, all with special needs. I worried that he would regress. I watched him carefully. One day turned into the next and the next and soon enough I began to notice something. I noticed that he was never sad about going to school. He was always happy and ready to go. Although he wasn't able to tell me what he did during the day, the communication journal that the teacher provided told me how his day went. On occasion I would spend the day in his class and observe. What I saw overwhelmed me. He was coming out of his shell. He was engaging more with his classmates and his teacher. Here, in this school, with all these children having different abilities, some verbal some not, there was no difference.

It was this school, the school that I mistakenly believed wouldn't be capable of teaching him about integrating in society, that taught him how to ride a

The growing pains never seemed to disappear but as a parent that advocates for their child, this is what we do.

### I once believed that mainstream school was the best and only option for my son. Today things are different and he is thriving at his school with a group of kids that all have special needs ...

bus, and how to bake cookies that he later delivered to the nursing home with his classmates and played board games with them. It was this school that was and still is teaching him life skills.

Having experienced a regular mainstream school with support and a school for special needs I can say this with certainty, every child is different and what works for one child never means or guarantees it will work for another. A school for special needs may be beneficial for some but not all. Same is true for a mainstream school.

I also believe that all-inclusive schools can be successful and very beneficial, not only to the child with autism but to all the students. Sensitizing children to other children with special needs is the beginning of establishing a society that is aware, accepting and understanding of all forms of diversity.

Here are five points I believe are required in order for an all-inclusive school for autistic children to succeed:

- 1. Have enough support staff to support the special needs students in the class. It's not rocket science and it shouldn't be too difficult to figure out but somehow this is a recurring problem in most, if not all schools.
- 2. Have qualified and experienced individuals knowledgeable and capable of assisting an autistic child with academic learning. I'm not saying that all aide/educators must have a master's or doctorate degree but to have at least the right certification and prior experience as a bare minimum.
- 3. Access to specialized resources such as trained behavioral technicians, speech therapists, occupational therapists, psychologists, etc. This is especially true when dealing with specific issues, for example severe behavioral issues and access to the right resources in a timely fashion is critical.

- 4. The ability to modify or adapt the autistic child's curriculum (IEP) to fit his/her abilities and most importantly make it logical, comprehensible and easy to implement. If any part of the IEP is unclear and difficult to decipher, then that means that it will be impossible to implement.
- 5. An open line of communication with the parents and the school. This is extremely important for the well being of the child as well as the parents. Establishing a professional and positive relationship with the school is critical to all involved especially for the academic success of the child.

Today, my son is in a school for special needs and as I sit here going over his IEP I am extremely grateful for all the progress he has made. I look back and see how far in our journey we have travelled. Looking ahead, I can only imagine how glorious it can be. I am thankful for everything.

I once believed that mainstream school was the best and only option for my son. Today things are different and he is thriving at his school with a group of kids that all have special needs and of course different abilities.

Whether you decide on a school for special needs or a mainstream school, always remember that in order for a child with autism to learn, thrive and reach their full potential, the proper resources and support must be put in place to ensure that they too receive the education that they rightfully deserve.

Linda Mastroianni, founder of www.SpeakingAutism.ca , is a certified life coach providing consulting services on many issues such as special education, life skills, transition into the work-



place, aging out of the school system, employment programs and much more. She is also a contributor for Huffington Post Canada.



### 9th Asia Pacific Conference of Speech, Language and Hearing 2015

Date: Oct. 9-11, 2015 (Friday - Sunday) Location: Yihe Hotel, Guangzhou, China

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#### Keynote Speakers

#### **Autism**

Prof. Patricia Prelock, PhD, CCC-SLP

#### **Swallowing**

Prof. Michael Groher, PhD, CCC-SLP

**Aural Rehab** 

Prof. Nancy Tye-Murray, PhD

#### **Aphasia**

Prof. Linda Worrall, PhD

#### Honorary Speaker **Bilingualism** Prof. Lilly Cheng

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Submission Deadline is July 31, 2015 Abstract should be submitted to: abstract\_apcslh2015@yahoo.com with the submission filled form download at http://en.rehabcongress.com

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- I. Areas of Interest in Speech-Language Pathology (SLP)
- 1. Academic and Clinical Education in SLP
- 2. Augmentative and Alternative Communication (AAC)3. Autism-Spectrum Disorders (ASD)
- 4. Children and Adult Speech Disorders (e.g., stuttering, articulation, cleft palate) 5. Children and Adult Language Disorders
- 6. Multi-/Bilingual Issues on Clinical Services
- 7. Motor Speech Disorders (e.g., dysarthria, AOS)
- 8. Neurologic Language Disorders (e.g., aphasia, TBI, RHD) 9. Aging and Communication Disorders Related with Dementia
- 10. Swallowing and Dysphagia
- 12. Others
- II. Areas of Interest in Audiology & Hearing Sciences
- 1. Academic and Clinical Education in Audiology
- 2. Amplification and Technology
- 3. Hearing Device Technology: Cochlear Implant, Brainstem Implant, Middle-Ear Implant, BAHAand others
- 4. Aural Rehabilitation
- 5. Diagnosis and Intervention of Hearing Disorders6. Vestibular and Balance Assessment and Treatment

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## **Embracing Autism:**Forgiving Those Who Judge

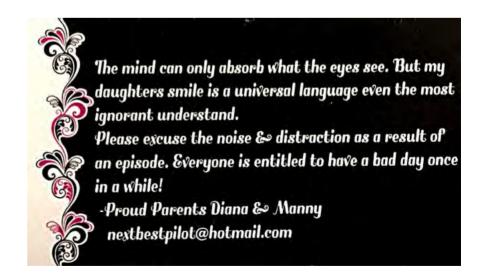
By Diana FERNANDEZ

How many times did I think twice about going out in public with my autistic daughter? It was a constant thought up until I made the decision to embrace autism. It wasn't a matter of feeling embarrassed, scared, or incompetent.

ut rather, because I knew that others would judge without really knowing and understanding the reason for the Public Display of an Autism Breakdown (PDAB). Now I have learned what most antecedents trigger a breakdown, but before I would attribute it to the time of the month, a full moon, or simply bad luck. When I began the journey of reading about the subject at hand, made the effort to attend conferences to initiate a broader network of friends alike, and meet parents with similar adversities, it was then that I had my moment of realization that autism is not a disability, it's a way of life! My daughter Emma was allowing me to understand and shed a light on the ability to view the world in a beautiful perspective.

Interaction, socialization, and facilitating Emma's interests have been a priority. She has an unwavering talent for dance, singing, and music. She will commit herself to any child that she is comfortable approaching and is the kindest and most loving person I know. This journey has not been easy. I'm perfectly OK with this and look forward to what lies ahead. The confidence I have gained with taking her out in public was a direct reflection of an approach that not only assisted me with being able to handle any PDAB, but made others observing it more aware and educated of what was transpiring right before their eyes.

A few years ago I was at a grocery store collecting items for dinner. Emma was helping me with the grocery list. We had to enter the store a certain way and go up and down every aisle. Dinner trips were scheduled in two-hour increments every time we went. This particular day I somehow managed to skip the produce section which we normally hit right before we headed to the register. I noticed that I was not hearing Emma recite the grocery list, so I stopped and looked back and there she was on the floor crying. I set the cart aside and quickly dropped to her level and tried to settle her down. She was loud, she was throwing what she could get her hands on and she had now managed to get the crowd's attention. I quickly started to move any items around her out of her way and someone managed to alert the store



"

Don't let your lack of judgment cloud your mind, learn from it! Share with a friend and help educate the world. manager who came to the area about 10 minutes after the PDAB commenced.

Every PDAB is incident-driven and this particular breakdown I knew would be best if I made sure the area was safe for Emma and let it ride its course. During the back-end of the PDAB, a couple with two kids approached me and made the comment that I was a horrible mother that was ignoring my daughter and just letting her cry and purposely causing a scene. The kids then said she looks stupid on the floor

and is acting like a baby. I reached in my pocket and took out a business card. I gave the adults each one to read and keep. The mother immediately ripped it while the father walked away with the kids. She continued to taunt me and accuse me of unbelievable things, but I continued to focus on my priority which was my daughter. Emma then stood up and came running to me and gave me a hug. She asked me why I had not gone to the "salad" section. I quickly apologized for skipping the section and asked her to help me pick out the vegetables because she was the best at doing that. We both silently cried and wiped each other's cheeks. As we were collecting our last vegetable item, the family that had previously judged what was going on approached us with an apology. I vividly recall the mother looking down at Emma and telling her, "You have an amazing mom and you cutie pie are an amazing girl." The couple's little girl hugged Emma while the little boy gave her a high-five. Both parents shook my hand and repeatedly apologized for what they had done. Now you are all probably wondering what caused this change of heart. Remember how I pulled out two business cards, well this is what the business card reads:

"You are receiving this card from my # 1 advocate. I may be intellectually challenged, but my parents' LOVE serves a greater purpose. I have been taught to forgive uneducated individuals and bullies. Don't let your lack of judgment cloud your mind, learn from it! Share with a friend and help educate the world.

The mind can only absorb what the eyes see. But my daughter's smile is a universal language even the most ignorant understand. Please excuse the noise and distraction as a result of an episode. Everyone is entitled to have a bad day once in a while!"

I leave you with this thought: The love and influence a parent has over a situation is far greater than what

#### Say Hi to Emma

You are receiving this card from my #1 advocates. I may be intellectually challenged, but my parents LOVE serves a greater purpose. I have been taught to forgive uneducated individuals and bullies. Don't let your lack of judgment cloud your mind, learn from it! Share with a friend and help educate the

world. - DINNY

we give ourselves credit for. You and only you as a parent of a child on the spectrum know what is best for your child. Don't let anyone influence it in a negative way. My daughter knows without a doubt how much I love her and what I will do for her. The mere fact that she tells me "Mommy, you are my hero" gives me the strength and confidence that all I do is and will continue to be a direct reflection of the love I have for the love of my life...my amazing and beautiful daughter Emma!

I hope this story is not only an inspiration, but motivation that everything you do for your children will pay off.

Diana Fernandez is the mother of a beautiful autistic daughter named Emma. She is originally from Los Angeles, CA but moved to San Diego in July of 2013. Emma suffered two brain hemorrhages as a result of severe meconium aspiration and was born with bilateral clubfeet and a premature hip. She spent the first month of



her life in the NICU with doctors not expecting her to live nor walk because of the extreme feet deformation but several surgeries have changed her life. When it was discovered brain hemorrhages affected her frontal lobe, Emma was immediately enrolled with the Regional Center. Today, she is a healthy 10-year-old involved with dance and is part of the Special Olympics Aquatic Team in San Diego. She receives ABA Therapy several times a week to include a Saturday Generalized Program which allows her to interact with the community with her friends and continue her road to independency. Emma enjoy trips to the zoo, park, beach, libraries and will take on any adventure as a family.



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## Putting the Squeeze on Sensory Processing Disorders

By Amy KD TOBIK

Industrial Designer Lisa Fraser never imagined she would one day become an award-winning and celebrated entrepreneur. "It was never in my plans – it sort of just happened," said the 28-year-old from Vancouver.

"I wanted to alleviate discomfort and develop a tool that could help children with autism function better in their daily lives. I didn't think I was going to be the one to bring my ideas and designs to market, but I felt it was my duty to do so after developing the Snug Vest™," Fraser said.

While studying industrial design at Emily Carr University of Art and Design, Fraser ingeniously developed a discreet and sporty vest that can be inflated to evenly-distribute pressure thereby creating a relaxing and calming effect for people with sensory processing disorders. The Snug Vest works to relieve anxiety by regulating the sensory system when it is overstimulated from environmental input and overload. The vest features handy pockets for comfort as well as a hood to help block out overwhelming distractions such as light. For those people who are still growing, the Snug Vest is adjustable in length and width using special Velcro adjustments.

"I worked with children with autism as a classroom aide for several years while I was studying medical product design at university because I realized my creativity could have a huge impact on the lives of many by developing medical advances," Fraser said.

Fraser said she first began creating her product in 2009, building prototypes to give to autistic children she worked with for their feedback (with parental and national ethics board's consent/approval). It took four years of continuous research and the development to get to market. More than 200 prototypes were built and tested. "I sought out and implemented continuous feedback from children with autism and their parents, teams of occupational therapists,



behavioral therapists, pediatric medical doctors, and caretakers that work for health authorities, in school boards, and in private practice," Fraser said. "We are still making improvements to the product, taking all feedback into consideration and are working on new technologies to assist individuals with autism."

### GETTING TO KNOW LISA FRASER, INVENTOR

#### What inspired you to develop the Snug Vest? How is it different from a weighted vest?

One day, I saw a therapist putting a weighted vest and lap-pad on a child I worked with while I was a classroom volunteer. I understood first-hand that firm hugs and pressure had a very calming and relaxing effect, but for some reason I intuitively felt that using weight to provide pressure was not very safe or effective, and limiting to natural movement and mobility. I became more interested in the matter and discovered that pressure was a type of therapy called 'deep pressure therapy' or 'deep touch pressure' used widely among occupational therapists. I researched other pressure products and still was unhappy. I then came up with the concept of using air instead of weight to provide a squeezing-hugging sensation. With air, you can get the exact amount of pressure the person needs, and the person wearing it can independently control it themselves if there's a pump. Air ultimately allows a person to take control of regulating his or her own sensory system.

#### How would you explain the benefits of deep pressure therapy?

Deep pressure therapy has a very calming, relaxing effect and on many that soothes anxiety rapidly. It activates the proprioceptive nervous system and regulates the sensory system when overwhelmed or overstimulated from environmental input. As cortisol – a major biomarker of stress – decreases, problem behaviors can mitigate such as self-injury, tantrums, and meltdowns. Other effects include improved spatial body awareness, and an increase in focus and attention. It really depends on the individual as effects vary greatly.

#### What is the science behind Snug Vest?

Snug Vest has been tested clinically by university researchers who found a significant interaction between treatment and time point in salivary cortisol (stress) and found more concentration with Snug Vest during tabletop activities. Snug Vest uses patent-pending technology to keep the product safe so that it provides very firm pressure, but will never 'over-squeeze.' It uses radio frequency welding and tested features that provide an even pressure distribution and ventilation.

#### Which features make Snug Vest therapeutic?

It's the pressure itself that the vest provides when inflated. Pressure is evenly-distributed throughout the torso but does not place pressure on the stomach or chest for safety. Pressure is controlled and varied by the user to the exact amount they need. The optional hood, high collar, and pockets can help provide a further sense of comfort, and the fabrics are comfortable with no inside tags.



## Who benefits most from deep pressure therapy? an effective treatment for? Can people of all ages benefit from the Snug Vest?

All kiddos, teens and adults with autism should give it a try because when it works, it really works! I can't say who would benefit most, as each individual is so different and it really is a 'trial and error' kind of thing (as most things are!) That is why we offer a 60-day money back guarantee, because we know that not everyone does respond to deep pressure. We get 8% of our vests returned because of 'no effect' or simply, the child refuses to put it on or even look at it. Snug Vest sizes range from fitting a three-year-old up to a large adult, and all sizes adjust 6" around the waist and 3" in height to accommodate growth and last for years. We feel that no one should be stuck with something that does not work for him or her. Unlike medication, there are no harmful side effects and we know that over 70% of our customers who ordered a Snug Vest two years ago still benefit and use their Snug Vest on a regular basis.

#### What has the response been like toward your product?

We have had overwhelming demand and positive response from individuals, health professionals, autism thought leaders, and parents alike. We have multiple distributors, worldwide customers, and partnerships with established autism organizations. Everyone who receives their Snug Vest says that the quality of the product is so much better than ever anticipated, and the results for many have been a life saver, some testimonials bringing us tears of extreme joy! Every success story is momentum that makes the hard path of entrepreneurship well worth the journey.

#### Could you share one of your favorite success stories?

There are so many to choose from! Danny stands out for me as he was the first teen to ever receive a Snug Vest. Danny lives in California and found out I was developing an inflatable vest in the early stages, so he and his father would Skype me to provide me with feedback throughout the product development process. Danny's dad would give him pressure (firm hugs) every morning before he went to school to get rid of the stress that causes his bad behavioral events. His dad would tell him to stay calm at school, but they both knew that the morning ritual was a temporary solution and Danny had no way of

administering pressure to himself when he needed it. Once he wore a tight women's leather jacket to school and was made fun of. Danny's dad said, "The pressure I provide him rapidly changes his personality from aggressive to calm." Once Danny got his Snug Vest, his dad said, "The results are phenomenal. It calms him down, it comforts him. It's very fast-acting. He pumps it up and he feels good. And unlike medication, it doesn't have any side effects. Its wearable therapy." Danny's focus and grades improved at school and even Danny's sister commented that their first family dinner out with Snug Vest was the best ever, because of Danny's amazing behavior at the restaurant. He wore his Snug Vest inflated when we got into the car, when we walked into the restaurant, and for the first 10 minutes or so until he adapted well to the new environment. "The transitions are always chaotic for us, but not with the Snug Vest." We've been in contact with the family since, and are so happy that Danny is still benefiting from his Snug Vest today.

All readers can receive a special Snug Vest discount valid until September 15<sup>th</sup>, 2015. Use coupon code AutismParenting when going through the checkout at <u>www.snugvest.com</u>. Lisa Fraser also hosts a webinar series called 'Inside the Spectrum – Interviews with Autism Thought Leaders.' She interviews autism experts to help parents access free educational information. To sign-up, visit <u>www.insidethespectrum.org</u>.

#### RECENT AWARDS

2015: Ready to Rocket Award, Life Science category

2014: Red Dot Design Award, Product Design, Life Science category for Snug Vest Product

2014: BC Business, Top 30 under 30

2014: International Medical Design Excellence Awards, Finalist

2013: BC Creative Achievement Award for Applied Art & Design

2012: International Design Excellence Award (IDEA) from IDSA (Industrial Design Association of America) Gold Concept Award

2012: International Design Excellence Award (IDEA) from IDSA (Industrial Design Association of America) Silver Award

2011: International Spark Design Award Concept Winner - Spark! (ranking above Gold)

2011: Core 77 & Autism Connects Design Challenge Community Award (by Autism Speaks)

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## STARTING THE SCHOOL YEAR OFF RIGHT: Tips for a Smooth Transition for Your ASD Child

By Esther B. HESS, Ph.D.

Sara is really worried. Her son Joshua is six years old and has a moderate form of autism. "He's never done well with transitions and last semester the start of the new school year was a disaster. He would tantrum in class nearly every day, crying and shouting and making it impossible for his teacher to handle him. We didn't recover until Thanksgiving!"

ids get derailed for all kinds of reasons; fatigue, hunger, illness, etc. But when you have a child with autism, that derailment, the underlying neurological differences that are potentially responsible for the delays in your child's development, can make the beginning of the school year seem like an almost impossible task.

Autism, which can be characterized by differences in reciprocal social interactions, communication and behaviors, is currently the most common developmental disorder in this country according to the Centers for Disease Control and Prevention, and impacts one out of every 150 children. Experts suspect that there will be 4 million Americans coping with autism within the next 10 years. With this rising number,

schools are rapidly striving to implement programs, resources, and support tools for families and children dealing with autism. To help provide autistic children with added support, parents can utilize these core tips to more effectively improve their child's transition into the new school year.

#### **Countdown to Transition Preparation; Social Stories, Role Playing and Calendars**

Start a month ahead with a scheduled bedtime and wakeup routine. Keep the schedule of events exacting — getting up, eating, dressing, brushing hair and teeth, etc.. See how much the child can do without a prompt but, if needed, have a picture schedule or written visual schedule posted on the refrigerator or bathroom mirror.



In order to make back-to-school run smoothly, read age-appropriate books about going to school to help your child know what to expect or help your child make their own story with the creation of a personalized social story. Social stories are unique in that they can identify a concern and develop a story that supports a desired outcome, also allowing differing perspectives to be addressed.

To begin your social story, try and get a picture of the school, teacher and classroom setting and make a social story about school. The more information your child has about his new teacher, the easier the transition will be. In the context of writing your child's social story, let him/her know that their thoughts are perfectly normal. If your child is unable to express emotions, simply tell him/her that whatever he/she is thinking and feeling is valid and that you are there to help.

Here are a few suggestions to add to your child's social story:

Vacation is so much fun. I really enjoy going to

School begins on \_\_\_\_\_

I am going into \_\_\_\_\_ grade.

My teacher knows all about me and I can't wait to meet her. Her name is \_\_\_\_\_.

I might know some friends in my class but I will also make new friends.

It's good to go to school because I get to learn and play/hang out with my friends.

Never use school as a threat or a means to change or challenge a child's behavior. If you can, meet the teacher before the school year begins. Make sure that you walk through the building locating the classrooms, bathrooms, and lunch room and recess areas. For older children and teens, practice the route they will take as they go from class to class and spend time helping them figure out locker combinations in a timely fashion.

Role-playing is another way for the child to use visual depiction to ease into the new school year. Depending on your child's developmental age, prepare for school experiences by using puppets or by role-playing some enjoyable school activities. Playing "school" is a great way to help your child under-

stand how school works and what will go on while he/she is there.

To help reduce anxiety and create predictability, consider creating another kind of visual aid, in this case, a back-to-school calendar. Create a countdown to school with each day numbered as to the days left until the new semester starts. Begin your child's day by going to the calendar and marking off the last day. Continue the activity by counting how many days are left until school begins.

#### **Find Out About Available Programs**

Whether a child with autism is in elementary, middle, or high school, the first step to fostering support outside of the home is with parents meeting with teachers and school administration. The earlier parents can meet with school, the more tailored the program can be made for your child.

When meeting with the staff, find out how much experience the teachers have with autistic students. This is an opportunity for parents to seek out answers to all relevant questions that will impact their child's upcoming academic year.

It's equally important for parents to honestly share with their child's teacher any behavioral concerns or issues that they are aware of so that the teacher can be better prepared with appropriate strategies to service the needs of the child. If your child is a visual learner (as many children with autism are) you may want to suggest that the teacher create a visual schedule on the board and/or at the child's desk that creates visual cueing, point by point, to help the student break down and understand the sequential order of events in class. Likewise, if your child becomes overloaded easily, suggest that the teacher make an accommodation by creating a 'safe space' corner in the classroom. This area might include a bean bag, something special to hold (akin to a transitional object/and or sensory tool to soothe) and a timer so that children know when they need to return to the rhythm of the regular class. If there are district budgetary constraints, parents might want to consider offering to buy these items and bring them into class for everyone's benefit.

Parents should also keep in mind that they have the right to ask questions and request administrative intervention if they are concerned with the actions or behaviors of their child's teacher. Always start by

respectfully approaching the teacher with your concerns. If this approach proves ineffective, then parents should always reserve the right to advocate for their child by speaking to the principal or resource specialist at school.

#### **Individualized Education Plan (IEP) Meetings**

If your child has an individualized education plan, please be aware of when those goals will expire. If the IEP is scheduled to expire sometime in the first months of school, then you need to contact the special education department of the school to schedule an IEP meeting as soon as the staff comes back from summer break. If your child has had significant changes in the past 12 months then you should start to think about the new goals that you would like to place into your child's IEP program.

#### **Establish a Communication Plan**

When meeting with teachers, parents should set up a clear and agreeable communication plan. Students with developmental delays like autism can often exhibit unexpected outbursts or tantrums and parent and teachers must be able to quickly contact one another in case of an urgent need or emergency. Parents need to have a respectful and trusting relationship with their child's teacher. If a teacher observes some form of behavior or expresses a concern, parents need to remind themselves not to take this feedback personally.

In addition, considering that many autistic students struggle with organizational issues, teachers and parents can set up a dialogue where the parents are informed of all assignments and upcoming academic requirements. A positive pattern of communication may include asking the teacher to email the parent each day with a quick summary of homework and upcoming quizzes or test. Or, if the child needs less support, then an alternative plan could involve the parent calling or emailing the teacher when a concern arises.

#### Maintain and Monitor a Routine with the Child

Each day, a parent can review homework assignments with their child in a specific order to maintain routine and predictability. If a child needs less one-on-one support, then a parent can establish a routine where and when a child should complete their

homework each day. Start the homework at the same time every day. The earlier the child gets started, the better. Have the work area organized and free from distractions. The supplies should be color-coded and in a set place. The kitchen table of a desk might not be a comfortable work area for a child with autism. He/she might do better sitting on a soft cushion bean bag with a lap desk. Have an exact order, always using picture cues and a visual timer (with or without an alarm depending on your child's auditory processing sensitivities) to show the expected work time.

In regards to homework, think about your child's sensory needs and ask yourself the following questions:

- ✓ Is the lighting too bright?
- ✓ Are there noise distractions or will music help?
- ✓ Does my child need deep pressure input, such as a weighted blanket or vest?

Consider a physical activity before settling down to do work and remember to include sensory breaks, like a crunchy snack, as a way to help a child tolerate the homework load.

Create daily checklists that can include tasks like putting completed homework in the correct class folders, make sure materials for the next day are in the child's back pack, etc..

Be aware that sometimes the amount of homework a teacher assigns may not be appropriate for your child. Consider asking for a shortened work load written in on the child's IEP plan, especially if the assignment keeps repeating the same concept over and over. Be aware of problems with muscle tone such as weak hand muscles. Your child might need adaptations such as a parent's help with the writing or being able to key the work into a computer.

Dr. Esther Hess is a developmental psychologist and executive director of Center for the Developing Mind, a multidisciplinary treatment facility that supports children, adolescents and their families with developmental and/or regulatory disorders in West Los Angeles. You can contact Dr. Hess through her website: <a href="www.centerforthedevelopingmind.com">www.centerforthedevelopingmind.com</a>.

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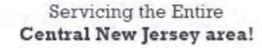


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## Encouraging ASD Children to Develop Whole Selves

by Beth KUKLINSKI

Fourteen years ago I became a mother to a boy and girl set of twins. Two short years after that my son Jon, began losing language and was soon diagnosed with autism.

aybe some of you can relate to the whirl-wind that begins when you hear that your precious and beloved child has an exceptional need. I describe it being pulled out with the tide, rolled and tossed by the ocean, and then if you stop struggling, you find yourself underwater in a new and mysterious world with skills more amazing than you dreamed and that you never knew you possessed...such as breathing underwater. It isn't easy.

I live an unusual life now. After years of interventions and fighting for services, fighting for understanding, fighting against the world as it was, we walked away. Literally, we walked away. In the short version I struggled to find a charter school that would accept my son due to his bathroom accidents. He attend-

ed private school with an aide for a year while I went to grad school and worked full time. He went to a public school for four days. He began pulling his hair out and screaming not to go. I watched boys tease and bully him while I was a few feet away. I felt helpless. So did he. So I told the teacher we were leaving. "You can't do that," she said. "Watch me," I replied and we walked out of that school, that life, forever.

I dreamed of opening a school. I think I always had, but got caught up in worrying about how life looked and the approval of others. A new fuel filled me; I was so tired of fighting against things that were, and I began to fight for the way I wanted things to be instead. After three challenging years, Jordan Lake School of the Arts, opened its doors. We are going on our fourth year now. The kids have grown and changed. Jon's words are still coming back and he smiles — the satisfaction of knowing what it is like to belong, to have friends, and to be part of a school. I have remembered why I love teaching and I feel passionate about it again. We hike every morning at school, do academic work, and have arts all afternoon. The kids just finished performing *Rats!*, a play based on the Pied Piper.

I guess what I want people to know about special kids is that they do change your life. They turn it upside down and inside out and shake it every which way. It doesn't look or feel the same-and therein lies the gift. I used to dream of the status quo, now

I shoot for the stars. I used to feel the need to be normal and I now I know the beauty of being myself. My son and the unique kids with autism who are my students have taught me that. I don't want to spend time with anyone else. I feel more alive and live with more purpose that I ever had in my picture perfect "normal" life. To those of you reading this who have just received a diagnosis for your child, you may not believe me now. Mark my words. You will be grateful one day, if you can relax and trust this was all completely intended, that you are made for this experience and that the





growing and learning strengths you never knew you had, is the point! Your child is your teacher and you are theirs. It is a symbiotic and heavenly thing and you both deserve to enjoy the experience regardless of how far behind society is in understanding unique individuals. Don't buy into the lack of what is, see where the world needs to change and be the one to bring it along. You can do it, or you wouldn't have been picked for the job. And trust me, the people who you meet who "get it" are worth a thousand of those who don't. Your child has given you a chance to remember what it means to be free from caring what others think and to see the beauty of things the way they are.

I hope I can inspire you to see the beauty of what is and the opportunity that is woven into a one of a kind package...that perfect and special child that has brightened your life. There is something in you that is going to grow and blossom because of this experience. You are one of the lucky ones. Enjoy the gift.

Five lessons learned opening an inclusive school:

- 1. Students arrive with the ability to teach you of your own strengths and weaknesses. Welcome the lesson.
- Remain true to your mission in life and work
   — a purposeful life is a powerful one. Stay on course.
- 3. Believe. My son whispered to me in one of my periods of doubt in my dream of a school, "You have to believe it, Mommy." He was right.
- 4. Not everyone believes in inclusion. They may have material success, but their lives with never be as rich as those who do.

5. Everyone says they will move mountains for their child. Some really will. Hold these people close because they are bound to change the world.

### About Jordan Lake School of the Arts (JLSA)

Jordan Lake School of the Arts is a small inclusive private school community in Apex, North Carolina. They offer a top-quality liberal arts program with a focus on nature and arts. All students benefit from small class size, an art-based education, and hands on activities in a beautiful stress-free setting. The school fosters independence, self-confidence, and academic and social achievement. With a multi-faceted approach to instruction children learn with their whole selves. Experiential opportunities promote learning, connection to peers and inspire students to explore the world they live in.



Photos by Shira Rose

Beth Kuklinski is a graduate of North Carolina State University with a Bachelor's in Education, graduate coursework in Special Education, and is completing a Master's in English with a specialization in multi-cultural and transnational literature. Beth is the founder of Jordan Lake School of the Arts: an arts and nature based pilot program inclusive to children with autism and was a radio host of Breathing Underwater: Stories of Autism airing on WCOM and nationally podcast on AutismRadio. She is working on her first book about progressive education.

To contact Beth use the contact form at <u>www.jor-danlakesa.com</u> or call (919)387-9440

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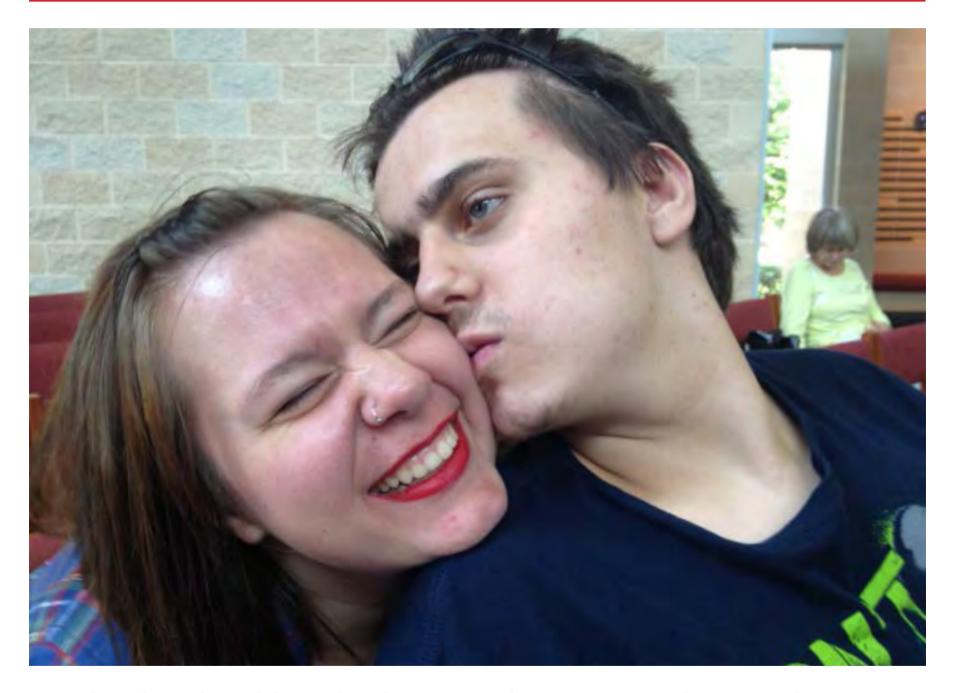
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## Siding Love

By Siri SMITH

I still remember when my parents told me my brother was autistic. I was five years old and I didn't understand what autism was at all. I just remember they told me about his diagnosis and they had a negative, upset tone in their voice.



hy is this such a sad thing, I thought to myself. He's still my little brother.

Ever since I could speak, I was asking for a little brother, and nothing was going to make me not love the little brother that I got.

Not to say that growing up with a younger autistic brother wasn't difficult for me.

When I was young, I always wanted to go to Disneyland. All of my friends in elementary school had gone already, and I felt like I was the only one left to go to Disneyland. It wasn't until I was 12 did we finally go as a whole family. But looking back on it, I am glad we went so late in my life so I can still vividly remember it. I was also lucky to even have had the chance to go at all.

It was also frustrating for me at times that my little brother got more attention than I did. I never did think it was unfair, I always understood that he had a major disadvantage being autistic and non-verbal, but I sometimes felt like no one would care that I was in the room or not.

But even though I sometimes felt a tiny ounce of jealousy in that regard, there was nothing that would stop me from standing up for my brother.

I knew a fair amount of older siblings who would get embarrassed by their younger, autistic sibling. There was one girl I knew whose autistic sister was getting picked on in the locker room of the local pool. The girl went in, saw her sister curled up on the bench in tears, and all she could do was blush and walk back out of the locker room.

I still remember being at a community event, and the boys that verbally bullied me in middle school were verbally bullying my brother. My dad walked in and told them off, and I heard about it not long after that. I don't get angry often, but this infuriated me. I get most infuriated by people who make fun of, or even give my brother an evil look.

This harsh judgment has also been helpful with boyfriends and friends. I judge all of my new good friends and significant others based on how they treat my brother.

Having an autistic brother creates a different kind of sibling relationship, but it also is quite similar to any regular one. I feel incredibly lucky to have my little brother in my life, and I would not be the hard-headed, smart, selfless person I am today if it wasn't for him.

Siri Smith is originally from North Bend, Washington. She is currently living in Seattle, where she is studying creative writing at Seattle University. She hopes to utilize her love for reading and writing, her nurturing personality (which she has gained



because of her brother), and adoration for quality education to become a high school language arts teacher at a Waldorf school. Siri also hopes to someday write a memoir about her experience growing up with a younger autistic brother.



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## A Mom's Reflection: Lessons from Jacob

By Allison HILL

For years now, my husband and I have been working rigorously to help our youngest child, Jacob, gain functional speech and make connections with us. Jacob is five and has been diagnosed with autism. I realized something was going on with Jacob at a very early age.



e wasn't gazing at us, imitating our facial gestures or looking at himself in the mirror. After an early diagnosis at 14 months, we began behavioral therapy. Through therapy, Jacob has made tremendous gains in preschool

skills. He also has some functional speech and, occasionally, even engages with us. However, during the majority of his free time, Jacob enjoys running in circles, climbing and flipping off the furniture, spinning wheels, lining up toys, opening and shutting

doors, and mimicking sounds of his favorite clicking objects. His brother and sister find it difficult to play with Jacob or understand that we must always make special arrangements when going places to ensure Jacob's safety.

Nevertheless, our family has found tremendous hope and encouragement despite the challenges of autism. We learned early on that Jacob would respond to us in amazing ways through music. When we experience difficulty calming Jacob down, we simply play music on the computer. In an instant, almost as if he is hypnotized, he stops what he is doing and runs over to us to listen. As the music plays, he climbs into our arms, snuggles up, and makes us move him back and forth to the music. Often, music is the main source of bonding between Jacob and his big sister. She sits close to him and turns on her iTunes and he nestles in next to her to listen. Amazingly, he even attempts to sing entire songs with words that he has never vocalized before.

Some time ago, we decided to try to teach Jacob to say, "I love you," by singing him a song every morning that repeated the phrase over and over. When I would forget, his big brother or sister would always be sure to remind me that we needed to sing the "I love you" song to Jacob. One night, as my husband was tucking him into bed, Jacob repeated, "I love you." Those moments are so special to us. We know that Jacob wants to connect with us, but sometimes we have to understand that he must connect in his own unique way. Jacob's way happens to be through music.

Every week, Jacob seems to fall in love with a new song. These songs usually aren't typical preschool songs, either. It makes us giggle when our family is in public and Jacob suddenly decides to belt out the most random lyric to a song. Most recently, he has been singing "How Can It Be" by Lauren Daigle. While we were sitting in an alterations shop one day, Jacob used his deepest singing voice to shout out the first line, "I am guilty!" three times in a row. All of the people in the shop turned and looked at me awkwardly. I couldn't help laughing out loud and thanking God in that moment for those precious words. To those people, it was a very peculiar thing for a little guy to be shouting in public. However, to me, every single word is a blessing because I simply don't know when he will speak again.

It is so easy to focus on the deficits with autism, but, when that is all we see, we miss out on the wonderfully unique and oftentimes comical experiences that bring us so much joy and hope. Finding silly and fun ways for our family to teach Jacob has not only helped him. Our entire family has now grown closer together and become much more compassionate to others. Having a child with special needs has encouraged my husband and me to be very intentional about giving thanks for each milestone that all of our children meet, even when that milestone is a new phrase shouted in a somewhat embarrassing way.

Allison Hill, author of Jacob's Special Power (Black Rose Writing, 2014), is an autism advocate who is passionate about encouraging acceptance for individuals with special needs. She writes a blog at <a href="https://www.jacobsjourneythroughautism.blogspot.com">www.jacobsjourneythroughautism.blogspot.com</a>



that is inspired by her youngest son, Jacob, who is diagnosed with autism. Allison graduated from Ball State University with a Master's Degree in Special Education. She resides in Houston, TX, with her husband and three amazing children.

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Autism is what our children have, autism is not who they are. Writing and recording this Autism Song-



"I'll Never Give Up On You" was such a positive experience. The picture of this little boy with his angelic face, is my son. He was diagnosed with autism at age 3. He is now a wonderful young adult. Different. Yet, equally important! Keep raising awareness.

The Best to You and Yours on this uncommon journey, George

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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 autistic children.

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.

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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.

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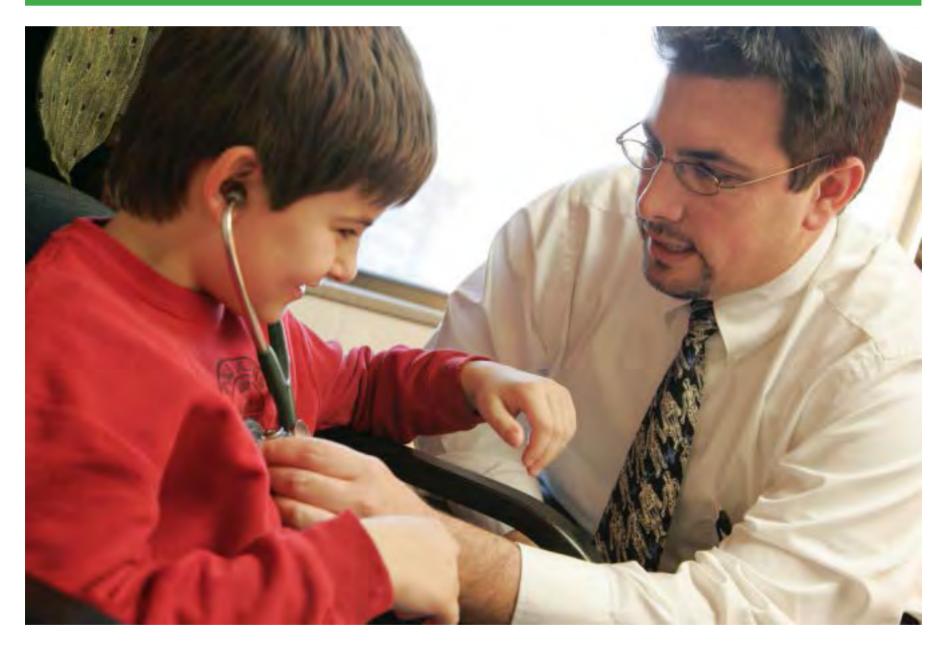
editor@autismparentingmagazine.com.



### Treating Genetic **Mutations in Autism**

Dr. Jared M. SKOWRON, Biomedical Autism Expert

Genetic testing is the biggest medical advancement of the early 21st century. Our understanding of how genes play a role in brain function is advancing every year. While many children receive negative genetic tests for Fragile X syndrome, there are thousands upon thousands of genetic tests available. If you think you've exhausted genetic testing for your child, think again!



ne of the top five genetic mutations that we inherit is called MTHFR. This gene is abnormal and poorly functioning in approximately 50% of the US population. It is the most important gene for the production and formation of

chemicals in the brain, such as serotonin, melatonin, and dopamine.

Why do these chemicals matter? Because these are the chemicals of emotion. The chemicals of happiness, the chemicals of sleep, the chemicals of language, as well as healthy sensory and motor function. MTHFR genetic mutations cause deficiencies in serotonin, melatonin, and dopamine. This leads to anxiety, quick temper, poor sleep, and worsens sensory and processing function.

Let's review how this works. You are what you eat. The brain creates these essential chemicals out of our proteins and vitamins. The vitamins that we get from our food need to be converted through a process called 'methylation.' Technically, this is an addition of a carbon atom, but think of an assembly line of a car. You take the frame, add the doors, lights, wheels, etc, and then you've completed production. Folic acid is converted into a methylated form called 5-MTHF also known as methyl-folate. Similarly, some of you may already be giving your children methyl-B12 shots.

This activated folic acid, 5-MTHF, is used by the brain to create the chemicals serotonin, melatonin, and dopamine. Follow the path. If the inherited gene (MTHFR) isn't working, the folic acid isn't being converted to 5-MTHF, and the brain chemicals aren't being created, and the symptoms present. Therefore, MTHFR gene mutations worsen anxiety, temper, sleep, learning and behavioral conditions. A 2013 meta-analysis of multiple research studies confirmed that children with autism have a higher likelihood of having inherited this gene mutation than neurotypical controls.<sup>1</sup>

Luckily, there's a treatment! While many genetic mutations are untreatable, MTHFR mutations are 100%

1 <u>Pu D</u>, <u>Shen Y</u>, <u>Wu J</u>. Association between MTHFR gene polymorphisms and the risk of autism spectrum disorders: a meta-analysis. Autism<u>Res.</u> 2013 Oct;6(5):384-92. doi: 10.1002/aur.1300.

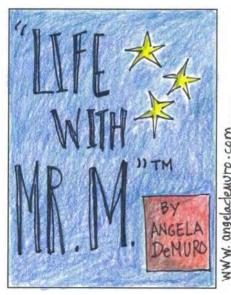
treatable. Similarly to the methyl-B12, 5-MTHF is available as a supplement. Simply put, if the body can't methylate folic acid to create serotonin, melatonin, and dopamine, you can give the supplement 5-MTHF to create serotonin, melatonin, and dopamine.

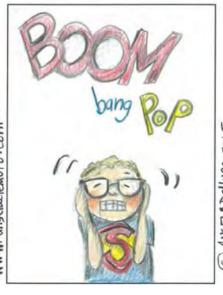
What should you expect? First, 5-MTHF has no taste, which is helpful considering most children on the spectrum are picky eaters and can taste a supplement hidden in apple sauce or yogurt from a mile away. Secondly, when serotonin, melatonin, and dopamine increase from 5-MTHF supplementation, you should expect more language, more development, less anxiety, better transitions, more sleep, and even better comments from teachers and therapists.

The world of genetics is expanding. We understand there's more genetics than just 'Fragile X syndrome.' Consider advanced genetic testing, consult your physician. If you are going to take biomedical supplements, take the activated forms, such as methyl-B12, 5-MTHF, and P5P (activated B6). Keep searching for a better answer.

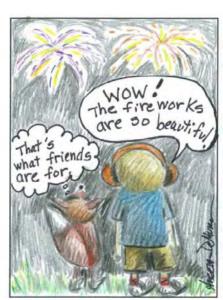
Dr. Jared M. Skowron is the Amazon best-selling author of 100 Natural Remedies for Your Child. Expert in biomedical interventions for children on the autism spectrum, he is on the Advisory Board of Autism Hope Alliance, Editorial Board of Natural Practitioner magazine, and sponsor of Generation Rescue. He lectures internationally on autism and is striving to unleash the full potential of all children and families.

### life with MR. M. by Angela DeMuro



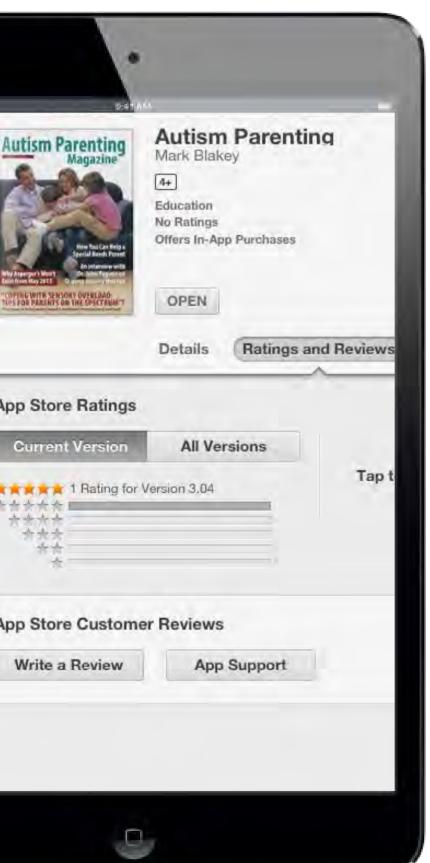






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### Overcoming the Bully Challenge

we, as parents, can't help but be a little anxious about the challenges the upcoming year may have in store for our children. Among the list of concerns, bullying is definitely at the top.

So what do you, as a parent, do when your child is being bullied?

Check out this episode from Dr. G's "Aspie Show!" as he talks with Barbara Coloroso, author of *The Bully, the Bullied, and the Bystander*.



https://www.youtube.com/watch?v=y s-uJhSbW8

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### **UPCOMING WEBINAR INFO:**

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Join Dr. Tracy Barcott for a free webinar on early detection, assessment, and diagnosis of autism spectrum disorders in young children. The webinar will include areas of concern that may be early warning signs of a possible autism spectrum disorder, such as developmental milestones and social-emotional behavior. Dr. Barcott will also discuss what measures should be included in an assessment to evaluate a young child for an autism spectrum disorder. The webinar will be particularly useful for mental health and

healthcare providers who work with young children and may be able to screen children and alert families to the possibility of an autism spectrum disorder. We look forward to you joining us for this free Webinar on Wednesday, July 15<sup>th</sup> at 7PM.

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### 4 Tips for Connecting with Your ASD Child: Breaking Through the Bubble

By Kristen WRIGHT

"What would happen if the autism gene was eliminated from the gene pool? You would have a bunch of people standing around in a cave, chatting and socializing and not getting anything done." - Temple Grandin

ypical infants and toddlers are very social beings. If you are the parent of a child with autism, you know that's not the case for your child. The Centers for Disease Control and Prevention (CDC) describes social issues as one of the most common symptoms of autism spectrum disorder. Many young children on the autism spectrum spend their days in a little "bubble" of their own little world, content to be alone.

It's the contentment part that tricks us as parents. We get busy, so it's easy to let our children sit for hours, fixating on a favorite toy, game, or video. In fact, I have many fond memories of extremely content babies who could be entertained for hours by a ceiling fan. At nine months that might be OK, at nine years old, not so much. What seems like a blessing in tod-dlerhood can turn into a nightmare for a young boy or girl who is struggling in a social world.

One of the first actions I took as a parent with newly-diagnosed children on the spectrum was to make a purposeful habit of breaking through the bubble of their little world. It may not seem like much, but it has been key to their social development.

So how do you do it? How do you grab a child's attention when he is busy spinning his favorite car on its top (because that's how my son always played with cars)? Here are some tips:



- 1. Find a gateway into his world. Can you play alongside him with the same toy? Imitate what he is doing and see if he responds. If he resists that, is there some favorite activity like tickles, chase, or bubbles that he can't resist?
- 2. Catch his eyes. Eye contact is one of the big social struggles for kids on the spectrum. It is important to start teaching eye contact as a skill at a young age. Grab that toy and bring it to your face. Ask him if he wants it back, but don't give it until he gives you eye contact. Be sure to reward and reinforce good eye contact.

- 3. Get some communication going. Sure, he may be nonverbal, but that doesn't mean he can't communicate. Play a game your child enjoys, but don't give him the part he likes until he communicates in some way that he wants you to do something. For starters, that might be tugging on your hand. As he makes progress, up the ante and make him give you eye contact or make whatever words/sounds he can. Continue to stretch him.
- 4. Be persistent. Your child may not like your constant interruption of his "me time," but don't give up. A little down time is OK, but hours of it will make his social progress much more difficult.

Many of these tips came from my experience working with teachers in early childhood intervention programs. I always encourage parents to find whatever help and support they can for their young children on the spectrum. However, you may find yourself playing a waiting game with therapy appointment times or finding medical coverage for treatments, and these strategies are a great place to start. And you don't have to stop—my boys are nine years old, and we still enjoy a good tickle fest.



"Signs and Symptoms." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, 20 Mar. 2014. Web. 11 Feb. 2015.

Kristen Wright is a teacher, children's ministry director, and full-time mother of three, two of whom are twin boys with ASD. She lives in small town lowa with her very supportive husband, David and enjoys blogging in her spare time. You can check out her blog, "Raising Kids on the Spectrum", at <a href="http://">http://</a> raisingkidsonthespectrum.blogspot.com/.

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### Am I Covered?

### **State Takes the Confusion out of Autism Coverage**

"Am I Covered," a tool to help families determine whether their health insurance policy covers services under the Massachusetts Autism Insurance Law, has been launched by UMass Medical School's Autism Insurance Resource Center.

"The tool was conceived in response to lots of questions from the autism community on where to start with figuring out if their insurance is covered by the Massachusetts Autism Insurance Law," said Amy K. Weinstock, founding director of the resource center at UMass Medical School's <u>Eunice Kennedy Shriver Center</u> and the parent of a young adult on the autism spectrum. "Insurance is complex and confusing. This was a tool to help families as well as providers."

An Act Relative to Insurance Coverage for Autism (ARICA), also known as the Massachusetts Autism Insurance Law, requires health insurers in Massachusetts to provide coverage for the diagnosis and treatment of children and adults on the autism spectrum, which affects one in every 68 individuals. Insurance plans that aren't subject to Massachusetts law may not cover autism treatments. The tool, which was designed to be used by consumers and health care providers, is the only resource of its kind available only for Massachusetts residents.

The tool was developed by the technical team at INDEX, the Shriver Center's Disability Informatics Resource, with funding from the Massachusetts Department of Public Health. The INDEX team spent 18 months developing the tool and testing it with consumers and health care providers before it was released.

"The feedback from the consumers and providers who tested the tool has been universally positive," Weinstock said.

The major influencers for the site were providers and families in Massachusetts who experienced challenges with trying to find out if their insurance was subject to ARICA, said Derek Chaves, director of technology at INDEX.

"When a parent or caregiver receives news of a diagnosis it can be overwhelming. It is important that they understand that one of the first steps is to understand their insurance coverage and how the ARICA mandate applies. Parents and caregivers can use the 'Am I Covered' tool to streamline the first step of the process and go down a path that ultimately leads to the child receiving the care they need," Chaves said.

Massachusetts law only affects some types of health care policies. Users employing the tool can quickly identify whether their policy includes ARICA's mandated coverage. Plans that aren't subject to ARICA may cover some treatments, but not others. If autism treatments aren't covered by a family's insurance policy, they may be able to obtain additional coverage. Information about obtaining additional insurance coverage is outlined on the tool, and the resource center can provide additional information and technical assistance.

The Autism Insurance Resource Center at the Shriver Center, a unit within UMass Medical School's Commonwealth Medicine division, was founded in March 2011 after a state law was passed that requires private insurance coverage of medically necessary autism treatment.

In addition to assisting families and caregivers in accessing and using the right health insurance to meet the needs of children and adults on the autism spectrum, the resource center provides assistance to providers, employers and educators on a broad range of issues related to medical insurance for autism treatment.

For more information:

Am I Covered?: <a href="http://amicovered.disabilityinfo.org/">http://amicovered.disabilityinfo.org/</a>

Eunice Kennedy Shriver Center at UMass Medical School: <a href="http://shriver.umassmed.edu/">http://shriver.umassmed.edu/</a>

### What's New on the Bookshelf

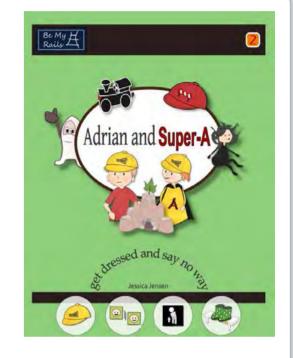
Here's a quick look at three recently-published books ranging from an illustrated story for young children on the spectrum to two highly-personal memoirs. Happy Summer reading!

### **Adrian and Super-A Get Dressed and Say No Way**

By Jessica Jensen

drian and Super-A Get Dressed and Say No Way is the second book out from Be My Rails Publishing in a series of books and workbooks for children with Autism Spectrum Disorder (ASD) and Attention-deficit/hyperactivity disorder (ADHD). Many children with autism, Asperger's syndrome, and ADHD have sensory issues, and getting dressed can prove to be a daily challenge both for them and their parents. Children with sensory issues are sure to find a book character they can identify with.

The book is based on the social stories technique and can be adjusted to the child's age or abilities. This makes it suitable for children between 4-10 years. Children will learn how a family can tackle different clothing problems together – from the itchy tags on clothing to dealing with the new winter boots, or just having to stand still.



To learn more:

Amazon (http://bit.ly/BuySuper-A)

The Autism & ADHD Kids Web Shop (<a href="http://bit.ly/SuperAWebshop">http://bit.ly/SuperAWebshop</a>)

http://bemyrails.com

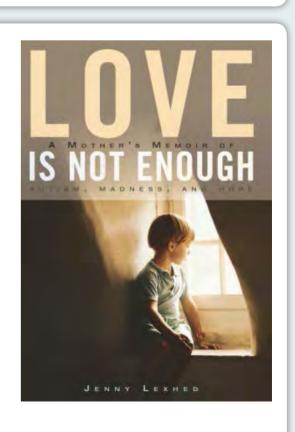
jessica.jensen@bemyrails.com

### **Love Is Not Enough**

### A Mother's Memoir Of Autism, Madness, And Hope

By Jenny Lexhed

When Jenny Lexhed and her husband have their first child, Lucas, they are living the dream. They're happily married, they've just bought a house, the company they built together from the ground up is starting to blossom. But with the arrival of their son, a feeling of anxiety slips into their life. What starts as a feeling becomes a conviction. Lucas is not like other children. Everything seems to indicate, and psychiatric evaluation concludes, that their son is severely autistic. Will he ever be able to communicate? Jenny vows to do whatever she can to help Lucas connect with his parents and others and live an independent life. Tossed between hope and despair, she begins a frantic effort to research the best among many competing therapies and find exactly the right treatment for her son. Her obsession takes her to the brink of exhaustion—and over, when she suffers a psychot-



ic breakdown and must be committed to a psychiatric clinic. There begins another journey, to find her balance and recover her strong, healthy life, before she can begin again to fight for her son.

To learn more: www.jennylexhed.com

### **Solitary Genius**

By Maureen Marshall

Solitary Genius is a story of intuition, love, and the power of true listening.

Paised in a boisterous family of 10, Mo was always searching for a sense of peace inside her mind. School was a struggle, and she often felt over-stimulated by her own brain. Marshall's deep sensitivity to other people's feelings and energies left her exhausted at the end of each day; yet, she was also bright, driven, and easily connected with others – especially anyone who was considered different.

After earning a degree in speech pathology, Marshall began teaching a small group of special needs children in a pilot educational program. Using a combination of empathy, her own "art form," and patient listening, she helped these gifted-yet-challenged students to become more communicative, more comfortable with others, and most importantly, more engaged in the world around them. *Solitary Genius* is Marshall's story of that transformative year.

Ideal for teachers, students, parents, teenagers, or anyone who has ever felt they didn't fit the mold, *Solitary Genius* opens readers up to experience a new understanding of themselves and others – to become more aware and empathetic as they move through an increasingly distracted world.

Solitary Genius doesn't explore the latest medical and psychological research or tackle theories about what causes autism, ADHD, learning disabilities, or other challenges. Instead, Marshall wrote this highly personal memoir to share her love for eight uniquely gifted children – and the success she achieved by patiently and intuitively meeting their needs. The book is also a resource to help people communicate more effectively in any situation.

Shifting between her small classroom and her own childhood experiences, Marshall's unassuming story demonstrates how listening can transform our lives. As she teaches from the heart, the children begin to blossom. Readers come to understand that everyone has different wiring – and compassion can be a powerful force for change. Ultimately, we all have special needs.

Inside everyone is a solitary genius, longing for love and true connection.

To learn more:

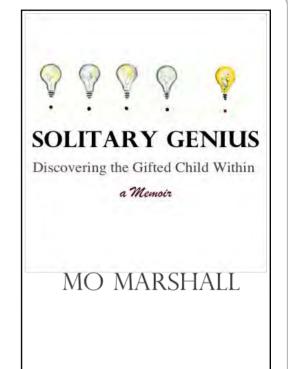
Amazon: <a href="http://amzn.com/B004Z1EFAG">http://amzn.com/B004Z1EFAG</a>

Website: momarshall.com

Twitter: twitter.com/themomarshall

Facebook: www.facebook.com/mo.marshall.artist

momarshall@yahoo.com



# What is the Best Way to Fund a Special Necks Trust?

By Ryan PLATT, MBA, ChFC, ChSNC

### **QUESTION:**

I have a Special Needs Trust for my son; however, I am not funding it at this time. I just have not been able to find the extra money in our budget to fund the special needs trust, especially after we save for our own retirement. What is the best way to fund a Special Needs Trust? — Sally

### **ANSWER:**

Congratulations on having a special needs trust for your son! Having this trust is critical in providing for your son's future.

Please know that you are not alone in your question. Many families come to us with the same concern. You are doing your very best paying the household bills, and saving some money for your own future retirement, but it does not seem that you can stretch the money any farther to begin saving for your son's future. You may not have to...yet.

There is no "best way" to fund a special needs trust; however, there are several factors you should consider.

- 1. First and foremost you need to know the amount your son will need to save. Without knowing the cost of your son's support needs (if your son is young, then you will need the help of a professional who works with families all over the age spectrum to educate you on the items your child will need, and then to assess the cost of those items) you will never know how much to save.
- 2. Once you understand the cost of your son's lifetime support needs, you then need to consider the amount government benefits will provide to help you in paying those costs. This is how we make the government a financial partner in your son's life.
- 3. Understand taxes This is an area where many mistakes are made. It is important to understand the tax structure of your special needs trust because it is different from your own. These differences will determine the assets that you want to use in funding your son's trust. The tax rules will also determine the type of assets you are using in saving for your own retirement. The reason for this is because the assets you use in saving for your retirement will most likely be transferred to the special needs trust after you die. If we transfer the "incorrect" asset to your son's special needs trust it could come with a tax sting of nearly 50% (2015 tax laws.)

By having a clear understanding of these three factors, you will be better able to determine what type of account to use in saving for your son's future needs, when you should begin saving, and how much you will need to save. You will want to be careful in not waiting too long to take action on saving for your son's future because time moves fast, and even a small amount each year will make a huge difference in providing for the life you want for your son.

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 what they call Unleash L.I.F.E.™- L.I.F.E. meaning Lasting Independence For Everyone™. This is accomplished with education, action, and support in the creation, implementation, and continued monitoring of a specifically designed lifelong and integrated plan for your family: parents, caregivers, your loved one with special needs and their siblings.

6000 Fairview Road, Suite 400 Charlotte, NC 28210 704-557-9637 www.aspecialneedsplan.com

## Uncovering the Mystery of Wandering and Developing an Effective Intervention

by Sarah KUPFERSCHMIDT, MA, BCBA

In October 2013, a 14-year-old boy by the name of Avonte Oquendo wandered away from his class and out of his school. The security cameras outside of his school captured him darting across the street until he was no longer visible. This is the last footage ever seen of him alive. After he had been missing for months, his mom was contacted by the police who let her know that they had found his remains. This is a parents' worst nightmare.

here are hundreds of cases of children with autism going missing because they have wandered or bolted in the media. In a study published in the Journal of Paediatrics in 2012, 49% of children with autism have wandered from a safe situation at least one time. Many of those children had close calls with traffic injuries and drowning. Avonte walked out of his school but it is even more common that children with autism are wandering out of the safety of their own homes. I recently heard about a parent that was moving the sofa every night to block the front door. This is where she slept every night because if her son tried to leave in the middle of the night, he would have to climb up and over her body and she would wake up and be able to keep him safe. Parents who are living with a child with autism who wanders or bolts face social, emotional and financial challenges that a parent who does not have a child with special needs cannot even fathom. Yet, many of the parents who have a child with autism who wanders report that the wandering is the most stressful challenge they have to contend with.

Furthermore, they are feeling powerless to handle it effectively because in many instances they have not received any professional guidance on how to deal with it in the best way.

Any discussion about autism and wandering must include GPS tracking devices and identifiable information. There are far too many cases where first responders are unable to locate a child as quickly as they might or they cannot determine where the child is from. If you are a parent of a child with autism who bolts or wanders or know someone who is, I urge you to look into GPS tracking devices and other ways of making your child easily identifiable. These can be customized to the unique sensory needs for your child. You could also consider whether or not your child would benefit from learning some important safety skills like what to do if they are lost. This is a complex skill so if your child is still learning how to follow simple instructions, or to identify community helpers you should start with those types of skills first. For more information on how to teach your

"

Government agencies and insurance companies are spending billions of dollars on treatment that is based on ABA for children with autism because they know that it works.

child what to do if they are lost or to find out if they have the prerequisite skills to learn that please check out our blog on that <u>here</u>.

Clinically-proven treatments like those that are based on Applied Behavior Analysis (ABA) are effective at improving the quality of life for children with autism and his/her family. A treatment that could help a child with autism who wanders or bolts that is based on ABA, would involve determining why the child is wandering. Different children wander for different reasons. Are they bolting to get access to something that they want (e.g., the park) or are they wandering to get away from something that they find terribly uncomfortable (e.g., a loud noise). Figuring out the why is a necessary part in developing an effective intervention. What I would do to help a family that has a child with autism who wanders to get something is very different from what I would do to help them if the child was doing it to get away from something. A Board Certified Behavior Analyst (BCBA) has a set of tools that allow them to identify why the wandering or bolting is happening which in turn will inform the selection of an intervention.

Once we have determined why the wandering or bolting is happening, then an intervention is selected that suits the unique strengths, areas of need and preferences of the child that wanders or bolts. The overall goal would be to empower a child with autism with skills that they can use to fulfill his/her needs instead of resorting to wandering or bolting. A treatment that is based on ABA would involve teaching the child with autism a better way to get that need met, that keeps them safe and considers their unique skills, and learning style. Finally, a necessary component to any treatment that is based on ABA is to track progress. Demonstrating whether or not the intervention is effective ensures that we are maximizing the child's learning potential and time.

There is an urgent need to support families who are dealing with a child with autism who wanders or bolts. Government agencies and insurance companies are spending billions of dollars on treatment that is based on ABA for children with autism because they know that it works. Unfortunately, despite these efforts, there continues to be huge waitlists and many families cannot afford it as they wait for services. In order to make ABA more affordable and accessible, we need to continue to inspire students to pursue graduate work in ABA and ensure that

there are enough academic institutions available to support the demand. Secondly, we need to leverage advances in technology to develop options that are more affordable and allow more families to access them because they are available anywhere, anytime. Finally, this is a call out to my fellow colleagues and other Behavior Analysts, traditionally we have done a poor job of marketing or disseminating the power that ABA can have in improving the quality of life for children with autism and their families. We need to do a better job of letting people know that ABA is a solution worth considering!

Parents should be able to go to sleep at night in their own bed and sleep, waking up feeling rested because they know that their child stayed safe in the middle of the night. Parents should be able to send their child to school every day, and expect that they will be coming home to them safely at the end of the day.

Sarah Kupferschmidt has her Masters in Psychology with a specialization in Applied Behavior Analysis (ABA) and is a Board Certified Behavior Analyst (BCBA) who has worked



with hundreds of children with autism and their families since 1999. She has clinically supervised and trained hundreds of staff on how to implement treatment strategies that are based on Applied Behavior Analysis (ABA), she conducts parent coaching and training in the form of workshops for families and teachers on a variety of topics (e.g., safety skills, toilet training, language development, using technology to teach, and challenging behavior) just to name a few. She is a Part-Time Professor and Co-Founder of Special Appucations, which is an mhealth company that develops solutions for children with special needs using ABA to inform the instructional design. Sarah has appeared on Hamilton Life, CP24, CHCH news, the Scott Thompson radio show, The Bill Kelly radio show and on A Voice for All on Rogers TV and Mom Talk Radio.

Email: sarah@specialappucations.com

Website: <u>specialappucations.com</u>

Facebook: Special Appucations

Blog:http://www.specialappucations.com/blog/



### **Reach Out**

We encourage you to send in your questions, comments, suggestions and concerns to <a href="mailto:questions@autismparentingmagazine.com">questions@autismparentingmagazine.com</a>. We will do our best to find you answers, resources, and improve the magazine to help all families with children on the autism spectrum. Please note that we may post your questions and edit them if needed. Please include a phone number in case we need clarification. We thank you for reaching out to us. We will do our best to provide helpful resources and the most current information.

### **Help: My Aspie Lacks Motivation**

Q

Hi, I am the parent of a 13-year-old boy with Asperger's syndrome. He was unable to cope with school so he now has a tutor come to the house each day for one hour. He is very withdrawn and this is worse when his tutor comes. How do I get him to engage with the tutor and what advice can you give me to motivate him to see the point of engaging? I've tried reward charts already and this didn't work. He's very stubborn when he doesn't want to do something. — Helen

A

Hi there,

Motivating teenagers can be so challenging! Here are a few tips on what you can do to build his motivation:

1. Build rapport between him and the tutor. I don't know if the tutor came over one day and just started drilling him with work, or if the tutor first took the time to get to know your son. But, building a relationship is key! In my line of work we train staff to "pair themselves with reinforcement" before placing demands on a child. Pairing looks like having fun. For your son maybe it's spending a day doing his favorite activities, or making his favorite food together, or talking about his preferred topics. What would be even better is once the tutor finds what interests your son, if he or she could bring over their own items that would interest him. For example: if your son loves video games perhaps the tutor can come

over with his or her collection and he can earn playing one after his session is over. Or if he loves cookies, perhaps the tutor can bring over some home-made treats. Think of "pairing" as associating oneself with highly preferred items, topics, activities, etc. Put yourself in his shoes...are you more likely to comply with a demand given by a friend or by a stranger? We adhere to instructions and participate more with those we have a relationship with. Build that rapport so he learns to like this person.

2. Ask him what the problem is. Sounds obvious, right? But have you really given him a chance to explain why he shuts down when the tutor comes? Maybe he's not confident and needs to be built up and shown how successful he can be. Maybe the tutor wears a perfume or cologne that drives him nuts and he can't stand it. Maybe the tutor reminds him of someone he doesn't like. Who knows what the reason could be, but some-

times there's a simple explanation. Encourage him to open up and validate his concerns.

- 3. Try the reward system again. For your son, an actual chart may not be necessary, depending on his likes and dislikes. I have had some teenagers who do well with charts and others who have told me it's for little kids and they don't want one. Regardless, you can still do a reward system.
  - a. Find what he is truly motivated by. This may be something he already gets or it may be an external reward you will incorporate into his daily routine. For example: If every day he gets to surf the Internet for an hour after the tutor comes, you can use that as the reward and make it contingent on participating with the tutor. "If you participate then you can have one hour on the Internet." This goes the opposite way too; if he does not participate, he does not get one hour on the Internet. Or, if nothing in his current day-to-day routine is very motivating for him, introduce something new. Maybe five days in a row of participating with the tutor earns him going out to dinner on Friday night. Or maybe he can earn a movie night. Whatever will pique his interest, make it contingent on engaging with the tutor and getting his work done.
  - b. Start small! We want him to be successful, so maybe for the first week or two of doing the reward system you ask him only to participate. Then once that is consistent you can change the expectation to include completing all his work. Or perhaps you start the token system on a Friday and let him earn his favorite restaurant for dinner if he does well that day in tutoring. Then the following week you can expect him to do well Thursday and Friday to earn dinner out. Then slowly increase to all five days to earn dinner out. Progression is key. We can't ask him to do too much at once. This will only frustrate him more.
  - c. Make sure the reward is SOLELY contingent on the tutoring behaviors. Unfortunately, I have worked with families who tell their kids "You will earn \_\_\_\_\_ if you \_\_\_\_\_."

    The child does exactly what they were sup-

posed to do, except later that day they do something the parent doesn't like (completely unrelated to the contingency), and the parent tells the child they will no longer earn the agreed upon reward. Stick to your word! If you tell him he will earn something for participating with the tutor, he needs to actually earn it when he participates. This agreement is separate of, and has nothing to do with, other behaviors. So let's say he does his work and engages with the tutor, but then later that day he refuses to clean his room. I would encourage you to STILL follow through with whatever he earned for doing well in tutoring. If you use what he earned from tutoring to punish a completely separate behavior it will not only frustrate him and make you a liar, but it will destroy the entire concept of the reward system. Keep it black and white and remember that what he earned was specifically for the tutoring behavior.

I hope these ideas are helpful for you and your son. Remember to communicate with him as well and try to understand what is holding him back. If being withdrawn is a persistent problem for him you may consider seeking additional help to work on this. Applied Behavior Analysis therapy can be an effective way to build relationship skills. Social skills groups and traditional psychotherapy are also other ways to assist in this area. We wish you all the best!

Angelina M. works as a Board Certified Behavior Analyst, specializing in assessing and treating children and adolescents with autism, down-syndrome, and other developmental delays. She began her career in



Applied Behavior Analysis in 2006, following her youngest brother's autism diagnosis, and has since worked with dozens of children and families. She also writes a blog about her experiences as both a professional and a big sister. Her brother, Dylan, remains her most powerful inspiration for helping others who face similar challenges.

Learn more about Angelina and her blog, **The Autism Onion**, at <u>www.theautismonion.com</u> or <u>www.facebook.com/theautismonion</u>

## Simple Yet Tasty Bolognese By Elouise RO



By Elouise ROBINSON, Autism Food Club

### Ingredients

- 500g / 1.21b beef mince
- · 1 large onion
- 1 large carrot peeled and grated
- · 1 red pepper deseeded and finely chopped
- · 1/2 cup red lentils
- 1 heaped tablespoon tomato puree
- · 1 can of tomato
- · 1 cup of water
- 200g / ¾ cup passata
- 1 beef stock pot/cube (ensure it's gluten free)
- · 1/2 teaspoon black pepper
- · 2 cloves of garlic, peeled and finely crushed
- ½ teaspoon dried oregano
- · 1 teaspoon of sugar or honey

### **METHOD:**

Pre heat oven to 160°C/325°F/Gas Mark 3.

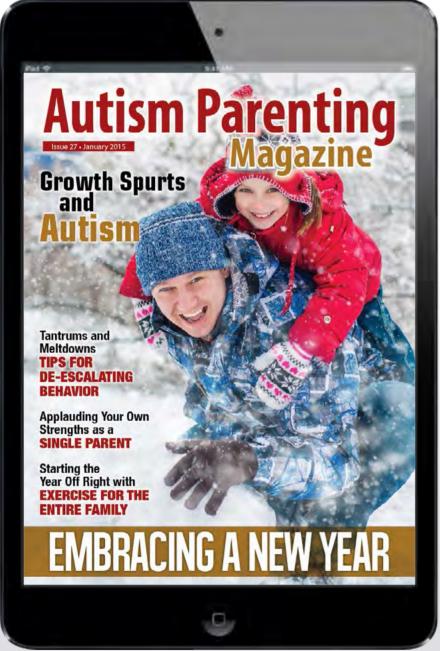
In an oven proof large pan, add the mince and brown, then drain off the fatty liquid. To the dry mince add the onions, tomato puree, and garlic and stir to distribute the tomato puree. Add all the rest of the ingredients and stir to combine. Place in the oven to cook for 3 hours.

Served with courgette spirals, made use either a spiralizer or a peeler, jacket potato or gluten free pasta.





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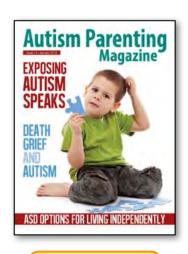
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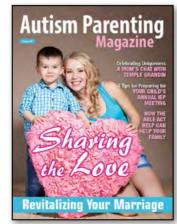
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