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

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

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

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

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

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

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

There’s no doubt about it—change is hard. Whether you’ve moved, been promoted at work, or even entered a promising relationship, new beginnings can generate stress. For some people, especially those diagnosed with autism spectrum disorder (ASD), new life chapters can create high levels of anxiety. This is particularly true when it comes to transitioning from the calm days of summer to the often-hectic school year. Different faces, routines, sights, sounds…the expectation to prosper in a changed environment can be overwhelming for kids with autism.

Knowing this is an immense challenge for many, we connect with doctors, teachers, autism experts, and parents for guidance on ways to make positive transitions. Whether your child is headed to daycare, primary, middle/high school, or college, this is definitely an issue you will want to read!

First, we reached out to Marisa Goudy, BCBA, of the National Speech/Language Therapy Center for some simple strategies to help kids with autism make the vital transition back to school. Take a look at her piece Successful Transitioning: The Back to School Blues, as Marisa lays out an approach you and your child can use to help prepare for the week leading up to school, the nerve-wracking night before, and the momentous first day.

Another way to help the academic year go more smoothly is to make solid connections with your child’s school. Angela Conrad, a former special education teacher turned autism mom, has provided us with her sage advice on ways both parents and teachers can come together to help children on the spectrum. In her piece A New Autism Perspective: The Other Side of the Table, Angela reiterates the importance of being patient, understanding, and respectful in order reach long-term goals.

For many people with autism, the very thought of exams can create high levels of anxiety. If your child experiences this type of stress, take a look at Ways to Prepare for Exams in the New School Year with Autism, provided by Kirsty Maher, BA, PGDip, SEN. Kirsty, who has Asperger’s syndrome, offers excellent advice on exam preparation and concessions, and she shares the importance of providing your child with reassurance.

The ability to secure healthy relationships is another key concern for many children with autism. A survey conducted by a charity in 2015 revealed 80 percent of respondents over the age of 16 reported to have been bullied by someone they thought was a friend. Social situations are often confusing for people with autism, making it difficult to know who to trust sometimes. Please take a look at Catherine Sarginson’s piece Ways to Help Someone With Special Needs Spot a Fake Friendship, as the Head of Learning Support at Sedbergh School, Cumbria, England, provides questions you can ask as a conversation prompt to establish whether a child or young person with autism is at risk for mate crime. This is a relatively new term used to describe when people gain friendship and trust with the aim to mistreat.

We tend to focus on kids when we talk about heading back to school. But what about parents and caregivers? It’s not just students who experience trepidation and worry. Please take a look at Bussing My Son to The World, as James Guttman shares his very personal experience placing his nonverbal son with autism on the school bus and his warm advice for other parents when handling the big day.

We also have an enlightening piece written by Colleen Hittle, the mother of a recent college graduate, who shares information she wished she had known when her son with Asperger’s syndrome went away to college.

This month, we are thrilled to introduce a new regular column called Autism Warrior, which has been formed to celebrate people in the autism community who work tirelessly to pave the way for autism awareness and acceptance. We chose Ernie Els as our first warrior, the professional golfer whose son with autism inspired the establishment of the Els for Autism Foundation and the Els Center of Excellence. Take a look at the piece Professional Golfer a Game Changer for Autism Community, as Ernie shares his inspiration and goals.

This issue touches on so many interesting topics, from ways music intervention can support social interaction to steps you can take to encourage personal thought and verbal sharing with your child with autism. If you’re in search of fresh therapies, we have an article on the benefits of service dogs and a personal narrative written by a mother who has successfully used art therapy with her young boy with autism.

We would like to thank all of the families who participated in our first cover photo contest. Congratulations to Natalya Smith whose 16-year old son, Isaiah Noah Williams, is featured this month on our cover. We recently learned more about Isaiah’s miraculous journey from his mother, as he was born at 23 weeks and weighed in at only 1 pound 1.5 ounces. He lost his right eye from too much oxygen, which detached his retina and required surgery. Isaiah is visually impaired and nonverbal, but he understands everything and is very independent. He was diagnosed with autism at age four. Natalya will receive all of our back issues, worth $239!

We also want to congratulate three additional families whose photos were so charming we requested to use them throughout this issue. Be sure to look for Asher Hufton (5), Jason Cooper (6), and Chalom Lee Pittman III (9). If you missed our contest, be sure to be on the lookout for our next one!

Wishing you happiness as summer ends and a peaceful transition to your next journey.

Kind regards,

Amy KD Tobik
Editor-in-Chief

Disclaimer:
Autism Parenting Magazine tries its best to deliver honest, unbiased reviews, resources, and advice, but please note that due to the variety of capabilities of people on the spectrum, these are recommendations and not guaranteed by Autism Parenting Magazine or its writers. Medical information, including but not limited to, text, graphics, images and other material contained with Autism Parenting Magazine is for informational purposes only. Always seek the advice of your physician with any questions you may have regarding treatment.
Heading back to school means your child needs to be awake and ready to go early in the morning and then spend all day in an environment with more people, lights, and sounds than he/she may like. This may be followed by after school activities—and we haven’t even mentioned the amount of schoolwork piled on.

Does your child need some help making these important transitions? Let’s take a look at some strategies you and your child can use to help prepare for the week leading up to school, the night before the first day, the first morning, and your child’s arrival at school to help him/her transition with ease.

The Week Leading Up to School

Before school starts, it is helpful for your child to be introduced (or re-introduced) to familiar people he/she will be seeing (e.g., teachers, peers, etc.). Some schools allow a teacher to meet you and your child in the comfort of your own home, so they can get to know one another. Some schools will let your child meet the teacher in the classroom before school starts, so he/she can explore the space. Sometimes a teacher is able to suggest families who would be open to connecting before school starts, so your child can get to know classmates. Ideas for play dates include: going to the playground, getting ice cream, going to local activities (e.g., museums, fairs, etc.). These
initial play dates can serve as the stepping-stone for continued play dates throughout the year, which is a great way to expand social relationships outside of the classroom.

**The Night Before the First Day of School**

One of the most important strategies is to create a schedule and stick to it as much as possible. A potential schedule could include:

- Dinner: 6:30 pm
- Playtime and prepare school bag/lunch: 7:00 pm
- Bath: 7:30 pm
- Story: 8:00 pm
- Lights out: 8:30 pm

Having the same bedtime every night is the most important part of the schedule, as sleep is important for everyone (including kids). It’s a good idea to get the backpack ready the night before, so everything is organized. You can have your child prepare for school in different ways depending on his/her age (e.g., picking out clothes, making lunch, etc.). If your child brings a lunch to school, you can allow him/her to help pick some of the food going into the lunchbox (such as a favorite snack), so your child has something yummy to look forward to at lunch!

**The First School Morning**

The morning before school can be a hectic time, so having the backpack already prepared is one less thing to do. If your child doesn’t eat breakfast at school, one important thing you want to make time for is breakfast at home. Being hungry can impact a child’s ability to focus, so it’s important to head to school with a full stomach, ready to learn! After breakfast, you may have to wait for the bus, which can be hard for some kids. Plan a quick activity to do with your child (e.g., playing “I Spy” while looking out the window, singing songs, etc.), so there is something for your child to do if he/she has a difficult time waiting.

**At School**

Time for school! If you take your child to school, saying goodbye can sometimes be a challenge. While telling your child goodbye for the day, be sure to say when you will see each other next, such as, “I’ll see you after school today.” Having a clear expectation is helpful for all of us. For the younger kiddos, leaving when they are engaged in an activity (e.g., playing with trains) can be helpful, because they can be distracted by something they enjoy. When you are leaving, it is best to leave the area rather than stand outside the door/window where your child can see you. Saying goodbye and still being visible can confuse a child, even though you aren’t directly with him/her. While it can be hard to see your child get upset, the teacher is well prepared and can help him/her start the day.

Do you want to know how your child’s day was? Tell your child’s teacher one or two things that are most important for you to know about (e.g., meltdowns, communication, eating, play, etc.). This way, you can obtain the information you need.

Marisa Goudy is a Board Certified Behavior Analyst (BCBA) with National Speech/Language Therapy Center. She directs the behavior programs in their Washington, DC, location. For more information, or to contact National Speech directly and view the Behavior BluePrints blog, visit their sites:

- Website
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Can we help children and adolescents with autism make sense of the world?

Recruitment is now open for the aViation study – a clinical study that will ask if an investigational medicine can improve the social communication and interaction skills of children and adolescents who:

- Have autism spectrum disorder (ASD)
- Are 5-to-17 years old
- Are ‘high-functioning’ (for this study, that means an IQ of at least 70)

If you’d like to know more, please contact us via our website or ask your family physician about the aViation study.
theaViationstudy.com
This is the work of Oliver, who is a 26-year-old music student from Brighton in the UK.

Interesting lyrics, but nothing too usual, you may say. And under ordinary circumstances, you would be right. However, Oliver is autistic and echo laic. So these lyrics take you on a more significant thought trail, one that allows you a window into the world of a young man who is unable to vocally express himself in fluid speech. He is, however, more than able to express himself through song.

The significance of putting a melody to these words frees up his cognitive ability and reaches through his autistic mind, allowing perfect speech to emerge through song lyrics. This, in itself, is a little miracle, and for Oliver, one can only imagine the freedom and sheer joy of this flow. It’s like letting in the sunshine from tightly drawn curtains.

The first time Oliver and I were in the studio recording his songs, we were playing back the vocal track on its own to get a mix level, and Olli’s face lit up. He beamed like the Cheshire Cat from Alice in Wonderland. It took me several minutes to work out why he was having such a positive reaction, as most people cringe when they hear themselves singing back through professional speakers. Olli, on the other hand, seemed to be in rapture. Eyes closed and face pointed toward the speakers, he was listening to himself singing. He heard the essence of himself, his voice, unhindered and flowing like a river. He was in tune, in time, and in control of his expressions, and I marveled at what that might feel like after 26 years. An undiscovered part of him suddenly burst forth, singing his thoughts and feelings in a song.
With echolalia, Olli can only repeat what others around him say, sometimes answering ‘yes’ and ‘no’ questions as well. However, with a simple melody, he was able to transform his unique thoughts into song, making the impossible possible.

Would it be perhaps like seeing a giant image of yourself on the screen for the first time?

With echolalia, Olli can only repeat what others around him say, sometimes answering ‘yes’ and ‘no’ questions as well. However, with a simple melody, he was able to transform his unique thoughts into song, making the impossible possible. It was humbling to witness, and so our musical partnership took on a more symbolic meaning. This wasn’t about playing music with an autistic student: our work together was about co-creating his music and giving him a voice.

I have worked with Olli for nearly two years now, and we spend 45-50 minutes each week improvising. I follow his lead and create a musical structure for him to express himself through what I call melodic words. Melodic words are sometimes in English, French, or Slovak (his exceptional SEN support worker Peter Juhas is from Slovakia), and sometimes the words are not in any language. However, they are still creations that serve to show how he is willing to participate and formulate a flow. We traverse subjects that many people with autism enjoy—like machines and animals—and we roam around in the world of possibilities as his sense of humor explores every corner of life from his unique perspective. Songs are about ride-on lawnmowers, eating pizza in the Spanish mountains, black panthers, etc. Most recently, Olli was able to express his observations on feelings, which, again, is unusual. As the words took a melodic shape, they fell freely from his lips. Perhaps the most touching song about Olli’s ability to see and understand a relationship between him and another is “I Can See When You’re Not Happy.”

Our sessions began in a spacious music studio, with him setting up the microphone through the mixer while I faced away from him at the piano. I observed how he was standing or walking around, and I listened for his low verbalizations (usually, but not always, in F) then I musicalized his offerings and found a chordal pattern to act as a boat under him, carrying him off. Olli is also a good drummer and was able to sing and play at the same time. Musical idioms that Olli seems to enjoy are klezma, blues, and tribal drumming, and I wonder if it’s the quick rhythmic patterns of these styles that awaken and pique his musicality. He is very responsive and takes the lead with his melodies once we have established a loose structure of 8-16 bars.

We have worked especially on endings in recent sessions, and Olli is now able to read musical cues, such as slowing down, that signal the end of a song. Quite often, we are able to finish a song together at a musically natural point. Olli always takes time to process after a song, standing still and looking like he is quietly contemplating his creation. He may then rock back and forth and vocalize in his familiar low hum—perhaps waiting for the next song to set him free.
Olli is now playing with other young people at college and enjoys singing covers from his favorite bands, REM, and Oasis. His gentle and good nature makes him a popular bandmate, coupled with his dedication to the music.

He is a musical being, and being musical seems to bring him closer to his soul.

Dominique Levack is a music specialist in Brighton, England. She studied at Nordoff Robbins in London and works with various clients with mixed pathologies, including dementia, autism, and Down syndrome. She enjoys using music interventions and singing to connect and create, and she was presented with The John Lennon Songwriting Award by the PRS in her early career. Through music, Dominique helps to allow clients to express themselves and realize their musical potentials, especially when other means of communication isn’t always possible.

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A New Autism Perspective: The Other Side of the Table

By Angela CONRAD

I’ve been on both sides of the table. I’ve been the professional telling you what your child can and cannot do. I’ve reviewed Individualized Education Programs (IEPs) and have felt the hurt from parents when they review the results. I have watched parents sit in IEP meetings, crying as professionals discussed their children. My heart has ached for you, and I have cried with you. However, I am now the parent hearing the words that hurt so much. I am now in the shoes that I once witnessed. Even though I have had a lot of sympathy for my student’s parents over the years, it just doesn’t even come close to experiencing the anguish myself.

As a special education teacher, I thought I had a good understanding of special needs in general. I recall sitting in my college courses, learning about all of the mild to severe disabilities, wondering what else I needed to know. I learned more and more each year from my amazing students in my classroom. What I didn’t know at the time was that I actually knew very little. Teaching children with special needs and raising them are two totally different journeys in life. I now have had the pleasure of experiencing both.

If there is anything that I can pass along to all of the special education teachers and therapists, it would be to listen to your parents. They may not have a degree in their child’s disability, but they know more than any professional could ever begin to imagine. You don’t know the level of exhaustion your parents endure daily. You can’t even begin to imagine the heartache they experience daily watching their child struggle in a world that most definitely does not cater to special needs. The loneliness and isolation the parents feel daily is unimaginable. With that said, please be empathetic in your meetings with the parents. It is not easy listening to what you have to say about their child—I know that all too well. Think about their perspective, and have compassion. Each and every child has some spectacular talent. It is your job to find it and make sure you praise that tal-
ent to the moon and back with the family. If you can’t do that, you will never know the kind of difference you could be capable of making in the special needs world.

Now, to the parents sitting on the other side of the table: respect your child’s teacher and therapist. Be actively involved in your child’s education and therapy. Work with the professionals, and help them understand your child. No one knows your child better than you, so your involvement is crucial for your child. Ask questions, and do your best to understand everything you can. Most importantly, educate them. They may have a degree in your child’s specialty, but that is just a small step toward understanding and knowing the unique disability that your child has. Be your child’s advocate, educate others, and make them aware.

I know it is not easy sitting on your side of the table. I know. I sit there now, too. I never thought I would find myself on that side of the table when I was teaching. I am here to say the parents’ side of the table is the hardest. If both sides keep an open mind and work with each other, then amazing things can happen for the child in need.

So, thank you to everyone who sits at the table. In the end, we are all in it together in order to better the life of the child with special needs, and that simply can’t be done without both sides.

Angela Conrad is a former special education teacher turned autism mom. She is the mother to two boys who have autism. She is a published author of the book Two Brothers One Journey: The Loving, Courageous Struggles of an Autism Mom. You can follow Angela on social media.
My 24-year-old son, Sean, was diagnosed with Asperger’s syndrome at eight years old. He graduated with a degree in informatics from Indiana University in Bloomington, IN, in 2017. Sean is a voracious reader, writer, and standup comic whose greatest pleasure is correcting his mother’s use of the English language. Now that Sean has successfully completed his degree, I thought it would be helpful to other families to share some of the important things I wish I had known as a parent when he first headed off to college:

1. Sean’s reason for going to college was to actually LEARN, not to earn a degree, socialize, or date. Sean attended IU for six years and never attended a college football game, basketball game, or ‘barn dance.’ Sean graduated without regrets, on his terms, on his schedule.

2. He would not self-report about class work, grades, work, or academic progress toward graduation accurately—not because he didn’t care, but because his reason for attending college was to LEARN, not to get an ‘A’ (see #1 above). Sean rarely remembered to check his grades at all and was astonished to learn he had made the Dean’s List. Oh, and then he FORGOT he had made the Dean’s List. I doubt he knew his overall GPA or even cared.

3. I needed to be on a first name basis with his academic advisor. You and your child will need to get a release signed with the university so you can access academic records and add/drop options. That way, you can be included on the
pathway to graduation. Thank you, Melody, for making us aware of the critical dates and for showing us the options available to Sean, so I could continue to advocate (from afar) on his behalf.

4. My son’s living situation was a key success factor. Living alone was NOT AN OPTION. Not all introverts should have single dorm rooms on the third floor with little to no contact with the outside world.

5. Your child will surprise you with the things he/she figures out without your help: doing laundry, paying bills, depositing checks using the ‘app,’ ordering pizza without ever greeting a delivery person, and getting a haircut. However, refilling prescriptions on time will ALWAYS be a challenge. Set up a mail order service to avoid medication interruptions.

6. Your child may lose most of his interest in Nintendo, Wii, Xbox, Pokémon, or Yu-Gi-Oh! cards. Most, not all.

7. Accountability partners are critical. These can take the form of friends, roommates, counselors, and therapists. These amazing people made sure Sean went to class, kept his commitments for meetings and appointments, took his medication, and cleared his voicemail to make room for new phone messages. The relationships that evolved naturally were the most powerful (such as his peers), but a weekly therapist visit reinforced conversations between us as parent and child. See #3 above, related to mutual release of confidential information.

8. Never underestimate the value of a mundane, hourly wage job. After six months working at a grocery meat counter (originally self-reported as the ‘deli’…see #2 above), Sean confessed that he was surprised to find that he was able to “get out of his head” long enough to complete low-level job tasks. These work successes on his own terms proved to be far more valuable than anything I could have orchestrated.

9. My child did not want to wear the cap and gown and walk across the stage. It turns out you can have a remarkable graduation celebration without baking in the hot sun in a polyester cap and gown with thousands of people you don’t know. Don’t force your definition of ‘success’ on him…it’s his life, not yours.

Colleen Hittle is a mom to five children. The oldest, Sean, was diagnosed with Asperger’s at the age of eight. Sean recently graduated with a degree in Informatics from Indiana University after a six-year journey of successes, failures, self-discovery, gained independence, and parental imperfections.
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Let's go back to a moment when your child shared a story that was not his/her own and was disconnected from that present situation. Give yourself the luxury of a short daydream. First, focus on your child’s adorable, precious face. Next, fill in the scene that you just imagined. Include your shared words or story and the scripted story your child launched.

Now, let’s examine the reasons why a child with autism spectrum disorder (ASD) scripts others’ stories.

Many of you who are raising a child with autism have experienced this moment. You attempt to have a connected conversation, or perhaps just a word or a phrase. You feel the moment slip away as your child shares a favorite movie script or a phrase instead of connecting to you. “Feel” is the key word in this scenario. You may “feel” puzzled by the sudden shift in attention, determined by your desire to draw out a connected response and/or frustrated by your unclear plan on how to make this happen.

As a speech and language pathologist with 40 years of experience, my passionate mission is to share some proven tips and strategies that can help make this connection a reality. When I share this message at my office, I usually receive blank stares from parents, as they often have trouble envisioning this. Then, we get to work. Slowly, I can see that faraway look replaced with a look of empowerment, a look that says, “I got this! I have a plan I can use to help create more and more connected conversations!”
I will tell you now that empowered look in parents’ eyes is my greatest professional reward!

Scripting can begin to fade away with a first step toward creating an original thought. The easiest way is by giving your child choices in all situations. In that moment of choice, magic happens! Your child owns that decision. He/She has to connect that choice to a real thought picture in his/her mind. Remember, we think in pictures, not words. These inner thought pictures become our outward expression in the form of words.

An important message at this juncture is to give your child time to think. We all need time to showcase our best work; your child is no different.

**Step 1:** Always give choices in all situations. And give your child time to make a choice: “Do you want grapes or apple slices?”

**Step 2:** Know that a choice becomes a thought picture, which transforms into the expression of original words. Your child thinks about the two images and anchors one more firmly in his/her mind as the stronger, personal image.

Next, always know that we talk about what we do. This is the essence of all conversations. Your child owns that thought picture in his/her head, so it’s time to interact with it. Move the story forward with a suggestion of what can happen. Here’s another magic moment. Lead in phrases are: “How about…,” “Maybe…,” “I wonder….” Again, your child needs to choose one of your suggestions, and now, a little interactive movie appears on his/her mental landscape. Always remember your child thinks it, owns it, and says it!

**Step 3:** Make a suggestion of what to do with the choice that’s been made. Give time to your child to choose a suggestion to move forward: “How about putting some grapes in a bowl?”

**Step 4:** Watch your child’s action story unfold. Be the narrator who puts the story into words: “Wow, you picked grapes and put some in your favorite bowl!”

Over time, by using these four steps/strategies, your child may begin to make more personal choices and interact more with the results of these choices. You will also see your child’s personal narrative begin as a natural consequence of his/her internal thought organization. You will now begin to interact with his/her story with natural comments. The beauty of a real conversation is born!

Now, just continue the process of personal thought by offering an open-ended phrase: “Let’s see…what you can do next.”

**Step 5:** Choices, and your child’s interactions with them, will start happening on their own. Keep the story going by sharing, “Let’s see…what you can do next.” This is a great opening line for a meaningful conversation! A significant process takes hold as your child moves through multiple, sequenced actions. A full-length movie happens in the mind, and stories get longer. We all love that!

**Step 6:** Always know you can be the narrator until your child naturally assumes the role for himself/herself.

Hello real conversations, goodbye scripting! You can systematically move your child toward personal thought and real, verbal sharing using these simple steps. You have a plan, and your child has his/her own story to tell—no need to retell a stored movie conversation from an outside source.

Enjoy the journey, and cherish the conversations. This is the stuff life is made of!

Beth Ann Shanks, a speech/language pathologist, has established a style of therapy that sees the promise of success in every child. Today, Beth Ann is the owner and CEO of Speech Academy LLC. Her cutting-edge approaches and innovations have been infused into her clinic. She helps to educate parents on how to make simple changes in their language as they engage their child with language-processing challenges, including those with autism spectrum disorder (ASD). As a result, family conversations are developed and continue to flourish. Her parent-coaching master class video series, Uttering Joy, is here to light up the dreams of all of the children and parents who come to its virtual doorway. Beth Ann’s Uttering Joy allows visions of success to become a reality.
follow us
Prior to learning he had autism, Lucas was already the baby of the house. He was always in our sight, and, like most babies, received the bulk of the attention. As we began to find out about his special needs, that mindset carried over, and I was always very concerned with keeping him safe.

No matter what we did or where we went, I always worried about how he would be. No parent wants their kid to be upset, but when you have a child who can’t communicate easily, it puts a difficult twist on things. In the early years, I found myself always trying to guess ahead of time what he might want or need. That was my job, and I was happy to do it. I couldn’t imagine things any other way.

That was a different time, though. Now he would be embarking on his academic adventure, and the only way to get him there was through a school bus. Although it came directly to our door, the thought of letting him go was still difficult.

I pictured the first day long before it happened. As is usually the case, our imagined perception of how things will go never matches reality. Thankfully so, because the scene in my head was straight out of a Lifetime movie. Tears. Closing doors. My outstretched hand. “Noooooo! Not without my son!”

Worry doesn’t make time stop, though, and when the day finally arrived, I braced myself for the sure-to-be-awful exchange. The moment of truth was upon us. This is how it went:

Bus pulls up.

“Hi Lucas. Let’s get on the bus to school. Say good-bye.”

Sound of footsteps, closed doors.

Bus drives away.

Vroom. I stood there for a few seconds, unsure if the bus would be making a return so we could play out our catastrophic Lifetime movie. After weeks of stomach-turning worry, that couldn’t be it. Could it?

It was. In fact, three years later, it still is. To this day, he’s never had an issue with the bus. It turns out I was the one who had the real problem. Lucas could handle it. In fact, he could handle lots of things. I just wasn’t aware of them because I had spent so much time trying to play protector to a boy who was far less fragile than I realized.
That doesn’t change the fact I’m still here to protect him. Ever since the first day, I’ve made it a habit to stand by the window until the bus drives off. Through rain, snow, sleet, and hail, I’ve waited patiently—sometimes for minutes on end—while he takes a seat and looks through the window. I also wave incessantly.

The excitement of looking through the window usually trumps any wave back. Most days, it doesn’t even matter that I’m standing there. He never looks my way as he settles into his seat, but I keep going anyway. He’s my little guy. Autism spectrum or not, I always want my child to know that I’m there to protect him. With my daughter, I can simply say, “I’m always here to protect you.” With Lucas, it’s not as straightforward. My goofy, grinning dad-face in that window every morning is my way of telling him. Of course, he probably already knows that, but it doesn’t matter.

Truth be told, it’s not really about him. It’s about me. Lucas is fine. He’s been fine from the start. It’s about learning that I don’t always need to physically be there. I don’t have to beat myself up about sending him on the bus, because he can handle it. If he can’t, there is the matron or the driver there to help. It’s about learning I can let go and trust others will have my son’s best interests at heart. While that’s not true in every instance, it’s been true up until now. It’s given me a sense of relief that sending him out into the world isn’t as impossible as I imagined at the start.

I still stand there until the bus rolls away. I still jump at the chance to run and get him if he needs me. The difference now is I know he most likely won’t. If he does, though, I’ll be there waving and ready.

James Guttman has been writing for 15 years and introduced his blog earlier this year. James writes about parenting both of his children (one nonverbal and one non-stop verbal), self-reflection, and all that comes with fatherhood. His mix of humor and honesty aim to normalize the way people view raising a child with special needs and show that parents are all basically the same, regardless of the children they’re raising.

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The number of children receiving an autism diagnosis is on the rise. And 70 percent of these children are being educated in mainstream schools. This means that schools have had to adapt and introduce new measures to ensure everyone’s needs are met. The introduction of the Special Educational Needs and Disabilities Code of Practice in 2014 in the UK placed an emphasis on the ‘inclusion’ of children with special educational needs. But what does this inclusion actually look like? With 1 in 100 people in the UK being diagnosed with autism, it’s heartening to see Islington schools catering to the needs of their students with autism and embracing their unique strengths.

At its core, inclusion should be mutually beneficial and work for every child. Recently, Sesame Street welcomed its first autistic Muppet character, Julia. In a clip that has been widely shared, Julia’s friend Abby...
From mealtime supervisors, to teaching assistants, to classroom teachers, to senior leadership teams, everyone is working to create more autism-friendly schools throughout the country. They attend after-school training, create specialized and tailored plans, and regularly work with specialist consultants, who guide them in creating the structure that children with autism need to feel a part of the class.

A fantastic example of providing structure for children with autism who may struggle with free play is the creation of Zoned Playgrounds. These are playgrounds divided into different activity zones, including ballgames, a Lego table, a drawing area, or simply a chatting area. A child with autism can then be supported to choose an arranged activity, rather than having to devise one. More organically, some Key Stage 2 classes have chosen novels with autistic protagonists, such as *The Spaghetti Detectives* and *The London Eye Mystery*, as their class readers. This includes everyone. The class learns more about autism, and autistic children can read about someone just like them.

School staff also work hard to adapt the school environment to suit the needs of their students with autism. They allow children to leave the classroom during the noisiest times of day (e.g. tidy up time), to avoid noisy hand-dryers and use paper towels instead, to go to lunch 10 minutes before everyone else to avoid the noisy crowds, or to sit on a chair instead of on the ground during Carpet Time and fidget with a fiddle toy.

Another highly-effective way of highlighting autism as a ‘hidden disability’ is through a planned series of Autism Peer Awareness (APA) sessions. In fact, research has shown that children are more understanding and accepting of their peers with disabilities when they are equipped with knowledge about those disabilities and have some personal experiences with them (Lindsay and Edwards, 2013).

Autism Peer Awareness lesson plans can include the following topics:

- How we are all different
- Visible and hidden disabilities
- Learning to use Makaton and the Picture Exchange Communication System (PECS)
- Reading a case-study or a book about a similar-aged student with autism
- Celebrating the strengths of people with autism
- Highlighting well-known people with autism
- Visiting a special school for children with autism
- Presenting a whole-school assembly about autism

Jan Greenman, author and mother of a son named Luke Dicker with autism, has said that at school, ‘One person can make all the difference.’ Indeed, there are individuals throughout the UK quietly working to improve the lives of their students with autism. They
ensure students have access to a visual schedule, make photo schedules ahead of class trips to ensure that everything is safely predictable, prepare math and literacy boxes full of extra visual resources, and run social skills groups and weekly Reflection Sessions for teenagers with autism to help them make sense of their school week.

Great strides are being made in our schools every day. Children with autism are no longer expected to simply fit in. Teachers are making sure they are as much a part of school life and culture as every other child. Let’s celebrate the giant leaps being made in inclusion and the hardworking school staff who make them happen.

Claire Droney works as a specialist teacher for autism in the Bridge School Outreach Team. The Bridge Outreach team supports children and young people with autism in mainstream primary and secondary schools throughout Islington, as well as providing training sessions and resources for school staff. Claire holds a Masters degree in Education and a Post-Graduate Diploma in Special Educational Teaching from University College Cork. Previously, Claire worked as a classroom teacher for seven years in a special school for children with autism, and for three years as a class teacher in a special school for children with mild and moderate learning difficulties. She has written about special educational needs for publications including the Irish Examiner, the Islington Gazette, and Impact, the journal of the Chartered College of Teaching.

For further information on autism awareness and autism resources, please contact Bridge School.

Website

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Aiko & Egor: Animation 4 Autism is a tablet and smartphone app designed for children with autism to easily learn and engage with their families.

- To download, search “Aiko & Egor” on the iTunes Store for your Apple device and the Google Play Store for your Android device.
- Visit www.aikoandegor.org to learn more about the app, watch animated videos, and sign up for our e-newsletter.

The app is developed by See Beneath, a San Diego-based nonprofit co-founded by autism experts with years of experience in autism research and intervention.
Ways to Prepare for Exams in the New School Year with Autism

Exams can be particularly difficult for children with autism spectrum disorder (ASD). As a teacher with autism, I completely understand. Different timetables, different rooms…and that’s before you even think about worrying about doing well. So, how can parents help?

1. Preparation

Many children with ASD struggle if they are not in their routine.

It’s therefore really important to make sure that children know when their exams will be and what to expect. Luckily for parents, the exam dates are usually available on the school calendar at the start of the school year. This means you have time to think about how best to support your child. For some children, a quick chat with a teacher the week before is all they need.

However, other children will need several weeks of preparation with visual timetables and social stories to help them understand what will happen and when. They may need to see the exam hall and sit at a desk and chair so that any sensory difficulties can be spotted early.

2. Revision/Studying

Does your child know how to revise/study?

We take it for granted, but it is one of those skills that will need to be explained specifically to children with autism. Unlike other children, they usually struggle to generalize skills, and so although they may have practiced ways to learn things in class, there is no guarantee they will make the link that the same skills can be used to revise.

So what is revision? Reading over notes until you remember them?

While this may be one way, it should not be the only way used to revise. Children with autism often find it easier to understand information when it’s presented in different ways, such as pictures alongside text, and listening to recordings.

So, how can this help your child?

Look at the information your child may have been given to learn. How it is presented? It is in lines and lines of text? Does it have any pictures? Is it colorful? Is the writing broken up into clear sections?

Your child may find it easier to revise if the information is clearly laid out in sections, with pictures and colors to break the words up. Pictures give children a
way to help recall information, and using certain colors can aid the memory. They can do this themselves with some plain paper and colored pens. Creating the notes is good revision, and then it's presented in a much clearer way for when they come to revise.

As a child, these methods definitely helped me. I struggled to revise long pieces of writing, even though I loved to read! One thing I didn’t struggle to remember was anything that was put on the wall in classrooms. I can still recall a range of classroom posters that were on the walls in school, mainly because they had pictures on them and the points were laid out clearly.

Another way to revise is to make it a game. Even teenagers would rather play a game than read notes, and who can blame them? Luckily, today’s teens with autism have access to a wide range of technology that can help them. From mobile apps to specialized revision websites, there are many different ways to learn information. It’s about finding what is appropriate for your child. Ask the school if it uses any apps in classes, and encourage your child to use the same technology at home, too.

3. Anxiety

This is a big one.

Most pupils get anxious about exams, but if you have autism, then things are even more difficult.

Most children will be concerned about what the questions will be, but pupils with autism can worry about a whole lot more!

First, let’s think about where the exam will take place. For a formal exam, such as a General Certificate of Secondary Education (GCSE), pupils will usually be taken out of their normal classrooms and placed in a large room with rows of desks. There will usually be an entire year group placed in this room to take the exam, and pupils are usually in alphabetical order.

I can’t imagine a more challenging place to do such an important test.

Not only are you surrounded by far more pupils than normal, but you are also sitting at a single desk that creaks and rattles! If you are unlucky enough to be sat in the middle of a row, then there may be people surrounding you on all sides.

Every desk is creaking and groaning through lack of use, there are chairs squeaking and dragging on the floor, and it feels like you can hear every cough and sneeze taking place around you. And don’t even get me started on the squeaky doors that the staff come in and out of. No matter how quietly they try to sneak in, believe me, they’ve probably already distracted the children with autism—if not others!

Some rooms are well lit, some are not. Some rooms are warm, others aren’t. Some rooms are freezing in the winter when mock exams are taken and then baking in the summer heat when the actual exams roll around.

Heat can then lead to other issues, as 100+ pupils in one room for two hours in the summer will start to sweat. If you are particularly sensitive to smells, it may become almost impossible to concentrate.

So, what’s the answer?

4. Exam Concessions

Here in the UK, it is possible to apply for pupils to be considered for ‘exam concessions’ if they have special educational needs. Some pupils with low reading capabilities can be considered for a reader in all subjects except English. Other pupils may need the question paper enlarged due to vision difficulties.

For those with autism, one of the main concessions is a smaller exam room. They still complete the exam at the same time as everyone else, but they are in a smaller, more familiar room. They may not be alone, as there may be several pupils who need a smaller room.
space. But a room with 10 students is far more preferable than a large room with 100+. Often, these alternative rooms are classrooms set up for an exam, which means they may have larger desks that pupils are used to working on. Overall, the environment is much more familiar and, therefore, less stressful at a time when pupils need to stay calm.

If you think that this would help your child, you should speak to the Special Educational Needs Coordinator (SENCO) at your child’s school, as they arrange the concessions.

**5. Exam Day**

On the day itself, it’s important to stay as close to the routine as possible. The main aim should be to cause the least amount of stress as possible. Make sure your child arrives to school on time and with everything he/she needs.

If you have a teenager, you may think he/she is old enough to manage bringing all needed school supplies without you having to double-check.

On the one hand, I agree. As children with autism grow older, it’s important they gradually take on more responsibility in looking after themselves. If they don’t, they may never learn. They are unlikely to ‘pick up’ these things without being clearly taught them, and they will need parents to help them with new responsibilities at first. Eventually, however, they will become more independent.

But on that exam day, when your child needs to have a pen that works or a compass, then make sure he/she has it. You’ll feel calmer knowing your child definitely has everything that’s needed. It could also prevent a full-on meltdown if something has been forgotten. Remember, if it’s an external exam like the GCSE and your child has a meltdown minutes before because he/she has forgotten a pencil case, then the child will not be given another time to complete it or a delay. Instead, he/she will likely be ushered into the exam room and given the paper. It is very unlikely that your child will put forth his/her best effort if still recovering from the after-effects of a meltdown.

**6. Reassurance**

While this is last on my list, I still think it is extremely important. Many children and teenagers with autism have very low self-esteem and confidence.

One thing they need from their loved ones is reassurance. They want to know that, while you want them to do well, you will be happy with their best effort.

I was lucky in this respect. When I was little, my mum always told me, “All I want is for you to do your best. If you can come home and honestly tell me that you did your best, then that’s good enough for me.”

These words stuck with me, and I use them in my own classroom to encourage children to give it a go. I want every child to do well and to aim high, but not every child will get top grades. It is important your child knows if he/she gives his/her very best, then that’s the best that can be done.

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**Kirsty Maher, BA, PGDip, SEN, is a SEN teacher in the UK who also has Asperger’s syndrome and blogs about her experiences.**

**Blog**

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Children with autism spectrum disorder (ASD) benefit from direct instruction regarding leisure skills and the language that is embedded throughout these activities.

As students get older, this lack of leisure skills can cause them to feel isolated and to not have as many social opportunities as other children. When we incorporate these skills into daily family routines, our children can learn so much.

I have always targeted leisure skills in my work as a speech language pathologist. But one student in particular made me want to share this information with other families. I was working with a student on how to play a modified game of Connect 4. The student would
pick a game piece and insert it in the board. Getting four in a row was not the focus; it was more about taking turns and engaging in sustained cooperative play. I shared with the parent that we were working on this activity and outlined the exact way we were teaching the student to play the game. Around the holidays, the parent wrote me a note to tell me that this student received this game as a gift and was able to play it with his sister. Hooray—success!

The following steps may help to embed these activities into your family routines:

1. **Collaborate with the school team**
   Is your student working on increasing play or leisure skills in the school environment? If so, this is a good place to start. Ask the speech language pathologist, Board Certified Behavior Analyst (BCBA), or the intervention specialist about which games they are working on at school. If they are teaching something specific, ask them how they are working on the skill. Get the specifics and try to play it at home.

2. **Modified leisure activities to try at home**
   If the school team is not addressing these skills, look through the examples listed below and try a few with your child:

   - **Modified Musical Chairs**
     My students love this game! I set up the same amount of chairs that I have students. So, if we have three students, we have three chairs. We never take a chair away. I tell the students the rules: when the music is on, we walk, and when the music is off, we sit down. I play music that my students enjoy, and we play for 5-10 minutes. So fun!

   - **Modified Simon Says**
     This game is great for those bursts of 5-10 minutes where you have unstructured time. Let’s say you are in the airport waiting for your plane, or you are at the pharmacy and it is taking forever. Try this to fill up that space. The modification for this game is that it is always Simon says. “Simon says touch your toes,” “Simon says jump,” “Simon says run in place,” “Simon says shout hooray,” “Simon says march,” etc.……

   - **Modified Uno**
     Most students love to play Uno but can be confused by the special cards that are included in the deck. There are two ways to modify this game based on the level of your students. You could take out all of the
non-numbered cards (i.e., reverse, skip, draw two, wild) and have the students match the number or color of the card. If students would benefit from more modifications, you could put one card out of each color (red, green, blue, and yellow). The students pick a card and match it to the correct pile.

- **Modified Scrabble**
  My students were excited to learn how to play this game. We modified it by allowing students to create words anywhere on the game board. The words did not have to touch each other. This makes the game easier to manage for all students. I would have the students create a word and then use it in a grammatically-correct sentence.

- **The Store Game**
  This game allows students to use their language skills to come up with words. I write the entire alphabet up on the board, and we take turns coming up with a word that we could buy at the store that correlates with the letter you have. For example, “I went to the store and I bought apples,” “I went to the store and I bought bread,” etc. Students seem to love this game, and it is easy to play with a group. If a student has trouble thinking of a word on his/her turn, show a visual of an item he/she could say. If the student lands on ‘d’ and can’t think of anything, show a picture of a donut, and he/she could say “donut.”

Working on language and leisure can be engaging and fun for parents and children alike! Engaging in these modified activities with friends and family can allow our children to feel successful and happy!


Rosemarie Griffin is a speech language pathologist and Board Certified Behavior Analyst. She serves students in a public school setting and a private school setting. Rosemarie uses the science of applied behavior analysis to help her students improve their overall communication skills. Her goal is to help all students become more effective communicators and to help all professionals feel more comfortable with providing effective instruction for students with autism and other developmental disabilities. If you have questions about the content of this article, please feel free to contact her.
AUTISM EDUCATION
GAMES & WORKBOOKS
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- social interaction
- WH questions

"I predict that this game will be an integral part of my clinical practice for years to come!"

Claire Dumke, Psy.D. (Licensed Psychologist)
live at home with my two parents and two sisters, and not only have I had to cope with many issues and challenging situations, but so have they. I am lucky to have a large family that includes 17 cousins, 8 uncles, and 6 aunts, and they have helped me a lot throughout the years and have always given me somewhere to go when I am stressed or if things become a little heated at home. A number of my friends who have Asperger’s don’t have a large family like myself and don’t have that extra support that I have found invaluable. Even to this day, if I ever become stressed, I can always go to my Grandad’s or my uncle’s place or just give them a call. When I was younger, I was always on the phone with one of my uncles when I got stressed—which, back then, was quite frequent, maybe about once every two or three days.

When I was first told that I had Asperger’s, my dad told me others in the family had it as well, we were very fortunate, and it made us positively different from everyone else. My Grandad is very eccentric...
and has many Asperger’s syndrome traits. I have always got on really well with him, and I am just like him in many ways, such as the clothes I wear and the music I listen to. We often enjoy going shopping together and singing all of his old ‘50s rock and roll songs around the supermarket.

Some of the things that have really caused problems at home have been certain sensory issues, such as the ticking radiator that nobody else seems to notice but drives me crazy. I also have to have all of the labels taken out of my shirts, and my Grandma even has to fix my socks, as I can’t stand the seams. My sisters and I have never really got on, and this all started from when we were very young. For a lot of people with autism, it is probably easier to be an only child.

When I was at primary and secondary school, I used to bottle my stresses up until I got home, as I felt a lot more secure there. All of the stresses that I had from the day at school were all crammed up inside me like a bottle of cola. When I got home, one little incident that for most people would not have even been a bother would make me explode. That one small incident would make that final little thread of string inside of me snap, and I just could not think of anything else or see any way out of the anger. After about one hour, I would usually go to my room and just cry, as I did not want to get angry at my parents but saw no other way of dealing with my stresses. Two things that used to calm me down were chocolate and children’s television. I used to be more frustrated when I was hungry, and so chocolate just took that frustration out of me. I have always liked watching children’s television, and as soon as my mum put on a children’s program, I used to instantly feel relaxed. All of the stresses and worries would just go in an instance, and I would become glued to the television. It must have felt like magic to my parents.

A lot of people with Asperger’s syndrome struggle in social situations, but for me, this has been an area where I feel my Asperger’s has really helped. From a very early age, I really enjoyed talking to and being around adults. When I went into a restaurant, I would always insist I would have to eat off of the adult menu, as I was a very good eater and would try all sorts of weird and wonderful foods. When we used to go on holiday, I would always prefer going and looking around wool shops with my grandma than playing on the beach with my cousins, and I could always keep up with adult conversations even though, at the time, I would have only been around nine or ten years old.

My Uncle Tim has always been one person I could always—and still can—rely on to calm me down whenever I was stressed. Like many people with Asperger’s, I have a subject that I am obsessed with football. My uncle would always be taking me to football matches on the weekends up and down the country, and this was a huge stress reliever. If ever I
was stressed at school, I could always think about recent trips that I had had with him to different matches and ground or look forward to up-and-coming matches. I would always buy a program from each and every match I attended, and if ever I was feeling a little stressed or panicky during the school day, I would always have somewhere quiet I could go to have a read of my programs. My Grandad has also been someone who has had a huge part in my life. Every Friday evening, without fail, I would go after school and stay the night at his house, which again gave me something to look forward to. As I have become older and have started my own business creating promotional videos, I have started to stay at his house more often, some weeks spending more time at his house than at my own.

As I mentioned previously, living with Asperger’s has had its many challenges—not only for me but also for my family. My dad, for instance, put a lot of time into helping me get my statement (for special needs) and in fighting a lot of my battles at school. They included incidents such as teachers not understanding my Asperger’s, homework struggles, changes that were made to the school day, and many more. My Mum, on the other hand, felt the full force of my stresses and challenges and has been the one person who has always been there through most of them.

Now that I have become an adult, I have been able to cope better in stressful situations and find solutions that help me when I am feeling stressed. I have started my own little business creating promotional videos and have an ambition to become a TV presenter in sports or children’s TV, which are my two main passions. Being able to share my experiences with Asperger’s will hopefully help others, and I feel lucky and privileged to be able to do this.

Alex Manners is 20 years old and from the UK. He was diagnosed with Asperger’s syndrome when he was 10 years old and looks upon his Asperger’s as positive. It is something that brings out his colorful, quirky, and unique personality. He has an ambition to become a TV presenter and also has an aim to watch a match at all 92 English Football League Clubs.
In 2015, a UK autism charity conducted a survey which found that a high number of people had been subjected to mate crime; 80 percent of respondents over 16 years old reported that they had been bullied by someone they thought was their friend. As people with autism spectrum disorder (ASD) commonly face challenges making friendships, it can be hugely positive when relationships start, names of others are mentioned in conversation, and arrangements to socialize are made. Confusion about what friendship is and how it is formed, as well as a lack of understanding of social situations and appropriate interactions can make children and young people particularly vulnerable to unscrupulous ploys to engage with them and secure their trust. They are then susceptible to abuse including...
physical and verbal assault, intimidation, theft, and even coercion into committing crime. This places an obligation on educators and parents to take steps to help children and young people recognize and resist being drawn into abusive relationships.

Analyzing friendship and the particular dynamics of it is complex. It is a natural part of life to have favored company, uneven dynamics within relationships, and to face “give and take.” It is an element of friendship to make allowances for the aspects of a person’s character that we like less, to give the benefit of the doubt, and to do favors for one another.

It can also take time for the real agenda to become evident, which can mean the betrayal can be more devastating for the victim as they may not have realized they had been taken advantage of if they did not recognize the behavior as abuse.

On other occasions, if so eager for friendship, a person with autism may tolerate aggressive and unpleasant behavior from the outset if it means they are not alone. The company of an abusive person is still company.

So how can we support children and young people to distinguish genuine friendship from harmful relationships and negative influences?

We can ask 10 questions to serve as a conversation prompt to establish whether the child or young person is at risk of mate crime:

1. Do your friends sometimes make you upset?
2. Do your friends ever call you names that you don’t like?
3. Do your friends ever hurt you physically?
4. Do your friends ask you for money but don’t pay it back?
5. Do your friends take, use, or damage your belongings?
6. Do your friends use your phone, or ask you to use your phone to take photographs or send messages that you don’t want to send?
7. Do your friends bring other people to your home that you don’t know or didn’t invite?
8. Do your friends only want to meet you alone?
9. Do your friends encourage you to do things you know are against the law?
10. Do your friends pressure you to do things that make you feel bad?

Asking these questions or having to tell a child or young person that someone is using them is not a message that will be easy to deliver. It may be that they seek to justify the behavior if they are convinced the perpetrator is a friend and feel a sense of guilt at the prospect of reporting them. There may be added feelings of embarrassment and humiliation.

It is also important to add that people with autism can of course be perpetrators and not only the victims of mate crime, and they will need support to understand as well.

The shocking figures relating to the rise in mate crime compel us to take steps to safeguard against it without becoming cynical ourselves or instill mistrust. It is possible that genuine relationships can form and that people can befriend those on the autism spectrum without an agenda. Educators and parents can see these relationships as part of the social and emotional support that can be given to children and young people to empower them to distinguish real friendship from fake, and enjoy positive, healthy friendships with others.

Catherine “Kate” Sarginson has been a teacher for 16 years. She has a master’s degree in inclusive education and post graduate qualification “National Award in Special Educational Needs Coordination.” She is working towards an MPhil from the University of Manchester, focusing on training teachers and influencing best practices for pupils with various special educational needs. Kate has experience in specialist residential college for young adults with learning difficulties, mainstream high school, and, currently, independent boarding school. Her current role is head of learning support at Sedbergh School in Cumbria, England.
Mary Ann Napper’s twin brother, Johnny, was autistic at a time when autism spectrum disorder (ASD) was not understood and rarely diagnosed. Too often children with autism were institutionalized and not given a chance to experience life. While there have been some challenges over the years, Mary Ann and Johnny share a special bond and feel blessed to have one another. Their unique friendship is reflected in Mary Ann’s letter written to her brother.

Dear Johnny,

I realized you were different when I started school without you. That was in 1951, when you went to a special school called the “Spastic Centre.”

I asked our mother why you were different. She told me you were “mentally retarded” because your brain had been damaged at birth due to lack of oxygen. Since I was the first-born twin, I believed for many years that I was the cause of your damaged brain. Autism was not fully understood back then and there were no treatment programs for the condition.

Growing up with you had a significant impact on my life. Throughout our childhood I harbored a subconscious resentment for having a special needs twin, of being deprived of the unique moments twins enjoy, and of being expected to carry the responsibilities of caring for you.

Even today, families feel stigmatized by their autistic children’s behavior. Our family was no exception.

Our parents isolated us from the community and restricted our social activities to visits with extended family. I was embarrassed in public when you damaged property or violated personal spaces. People stared at us, disapproving your ritual and repetitive behaviors particularly when you rolled your head, rocked your body, flapped your hands, and banged your head while making a monotonous sing-song noise. Sometimes adults would say to our parents, “Can’t you control your child? He needs to be in an institution receiving proper care.”
I was teased at school because I had a brother who was different. I pretended to ignore cruel taunts but I felt so alone. I had no one to talk to who understood what it was like to live with a brother who had special needs. When I invited friends home to play, they came once but never returned. You didn't have friends. Other children frowned warily at you and stared. You couldn't comprehend or socialize with them because you missed their subtle facial expressions, eye contact, and body language. I didn't understand how to play with you either. Each time you arranged your toys in long lines, I tried to rearrange them, and you threw tantrums. So I walked away and left you to play alone.

In your early 20s, you were committed to a mental institution. Our parents could no longer cope with your aggressive outbursts and self-harm attempts. I was studying nursing in Sydney at that time and was expected to continue caring for you. It broke my heart to visit you in that asylum. It was a locked ward. The inmates either ran amok or were over sedated with tranquilizers. You used to enjoy a drive in my white Mini. I would buy chocolate Paddle Pops, your favorite treat, and we would sit in a park to eat them.

Growing up with you also had positive effects on me. You taught me to be patient, tolerant, and compassionate, even though I did not fully understand your condition. Caring for you taught me how to handle difficult situations in my life, particularly when we were out in public or when I needed to be aware of your misunderstood behaviors. Your quirky sense of humor, your love of trains, and your unconditional acceptance of those around you are traits that have warmed my heart. You taught me to be wary of judging others and to accept people at face value. You taught me to appreciate the simple things in life, like riding on trains and buses and blowing up balloons until they popped.

Today, you live a meaningful and full life in a group home where there is 24-hour supervision by a caring staff. You participate in structured activities, which include daily chores and meal preparations. You take part in the weekly grocery shopping and manage your own money to buy your train magazines and clothes. You enjoy outings with your fellow residents to local clubs and community activities. You have learned to survive in our world but still retain the richness of your own.

I realize now how blessed I am to have you in my life and how much richer my life is because of you.

In April 2017, we celebrated our 71st birthday. That special bond between us has been life-long.

Sending you warm smiles and lots of love,

From your sister,

Mary Ann

“Mary Ann’s book, Born to Fly, provides insights for families and health professionals directly connected to autism. It is also a great resource for readers simply seeking to better understand the condition. Her skillful writing paints a vivid picture of one boy’s journey and opens a window to the determination and resilience of the human spirit, especially when life’s challenges seem insurmountable.” -Christiana Star, psychologist

Born to Fly is inspired by a true story and can be purchased on Amazon or Mary Ann’s website.

Mary Ann Napper self-published her debut novella, Born to Fly, in 2014. Since then one of her short stories has been selected for publication in an anthology by Birdcatcher Books and a feature article in News.com.au. The author is frequently asked to be a guest speaker at community groups.

Website
Going to the Dentist Doesn’t Have to Be a Challenge with ASD

By Aditi SRIVASTAVA, MOT, PGC

Taking a child to the dentist can be a very stressful experience for both parents and children. For children with autism spectrum disorder (ASD) or other developmental disabilities who have difficulties with sensory stimuli, communication, and increased levels of anxiety, the stress is even greater. From the time spent in the waiting room combined with new sounds and smells, to close interaction with dentists and dental equipment, stress levels can reach an all-time high.

Anxiety may be caused by various elements such as the fear of unknown, sensory sensitivities, and communication difficulties. Children may display noncompliant, impulsive, and restless behaviors when they are unable to communicate their feelings of anxiety while meeting new people or going to public places due to sensitivity issues such as tactile defensiveness and auditory sensitiveness.

Here are the parents’ top concerns when taking their children with ASD to the dentist:

- Will the dentist visit be successful or upsetting?
- Will my child be affected by the different noises or odors?
- Will my child be able to communicate, if needed?
- Will my child experience high levels of anxiety?
- Will I be able to find dental specialists near me trained to serve children with special needs?

Here are some great ways to make your dental visit a success:

1. **Prepare your child for the dentist visit as early as possible**
   
   It will be best for the parent, the child, and the dentist to meet and develop a plan before the official visit. Inform the child about dental visits as early as possible, as waiting for the last minute can lead to extreme anxiety. Communicate and educate the child about the purpose of the visit to help reduce anxiety levels. Try using a visual support, such as a calendar, to explain date of the visit or days remaining until the check-up.

2. **Talk to the dentist about your child’s special needs**
   
   Tell the dentist as much as you can about your child’s sensory sensitivities, including behavioral strategies that have been successful in the past. If this is your child’s first visit to the dentist, it is always better to ask for help from staff.
pending on your child’s personal needs, here are some tips you can share with the dentist:

- Don’t approach or touch my child without informing him/her or asking permission.
- Be cognizant of my child’s intrapersonal space.
- Speak slowly as information processing takes time. Use simple and short sentences while communicating.
- Provide answers to all questions asked by my child as not getting answers can create anxiety and mental tension.
- Tell my child what you will be doing. Showing equipment to be used during the check-up can help my child calm down and stay relaxed.

3. **Consider sensory strategies**

Here are some great strategies for making your child’s dentist visit a successful one:

- Use headphones to block background sounds.
- Use music for distraction and as calming strategy.
- Ask whether the sounds in the room could be reduced.
- Have the child wear a weighted vest or carry a weighted bag.
- Bring a weighted blanket in the car to calm the child.
- Use TheraBand or resistive tubes to stretch the body after a check-up.
- Wobble cushion or wobble wedge can be added to a dental chair with dentist’s support if the child feels comfortable having it.
- Stress balls can help child to reduce stress and anxiety in different settings.

4. **Provide fidgets to reduce anxiety**

Fidgets are the best source to keep the child focused on a task. It helps reduce anxiety levels, and keeps the child calm and his/her mind diverted. Different fidgets can be used according to developmental age groups: key chains,
finger squeezers, giant nut and bolt, and Blue Tack can be used by teens or adolescents for challenging in-hand manipulation skills and fine motor control, whereas fleece bags, chewy bangle bracelets, and Play-Doh can be provided to young ones for play and engagement purpose.

5. **Try visual reminders**

Pictorial presentation is always helpful for an individual to understand the sequence of events and know what will come next. Visual reminders reduce stress, anxiety, and ambiguity. It helps a child stay organized and well informed. Visual schedules may be used to depict the steps involved in brushing one’s teeth and what steps are involved in completing a dental procedure.

6. **Keep up with oral hygiene**

Children should brush their teeth for two minutes, twice a day. It is essential to supervise children until they are seven or eight years old. It is important to choose toothpaste and mouthwashes with the amount of fluoride, which helps prevent tooth decay. The toothbrush should have a small head to ensure brushing around the back of the mouth easily.

7. **Try an electric toothbrush**

Electric toothbrushes are much easier to manipulate around the teeth and encourage the child to brush his/her teeth. They should be used by children who have oral hyposensitivity for awakening the oral sensory receptors. These toothbrushes help control drooling and provide massage and sweeping within the oral cavity.

8. **Sand timers are a good visual tool**

Sand timers and other timers are an excellent visual tool for teaching children how long to brush their teeth. They can encourage the child to brush regularly and develop dental hygiene habits early.

9. **Use a mirror to check on progress**

A mirror can help children and parents examine the teeth to ensure they have been cleaned well.

References:

- National Autistic Society, UK
- Autism Speaks Family Services Community Connections
- Sensory Integration Network, UK
- Oral Healthcare for the Dyspraxic Child (Anna Vaguhan)

Aditi Srivastava (MOT, PGC in Sensory Integration) is a London-based pediatric occupational therapist who has been working with children with special needs for five years. She has a master’s degree in pediatric occupational therapy and certification in sensory integration from Sensory Integration Network, United Kingdom. She has authored an information booklet on Dyspraxia for educating parents and promulgate Dyspraxia awareness at her workplace. Besides being a dynamic occupational therapist, she is also an author of the blog RISING HORIZONS, where diverse children-related subjects are discussed. She writes on significant sensory issues, sensory integration strategies, parenting tips, classroom suggestions, and anger management problems.
Ways a Service Dog Can Change Your Special Needs Child’s Life

By Annie TANASUGARN, PhDc, BCBA

Most people are pretty familiar with the saying, “A dog is a man’s best friend.” Dogs are animated, fiercely loyal, and guarded protectors. But their worth goes beyond just being a trusted companion. For many, these furry friends serve a significant purpose as therapy dogs in the treatment of social, behavioral, and cognitive delays common in children with autism spectrum disorder (ASD).

The use of therapy dogs is not a new concept. The earliest studies from the 1960s found benefits of dogs in helping severely withdrawn children. However, it was not until nearly three decades later that science was able to validate the utility of using dogs for therapy.

Today, therapy dogs proudly serve several purposes:

- Safety
- Social behavior
- Compliance
- Emotional regulation
- Physical assistance/motor development

As a parent with a child on the autism spectrum knows, many kids have a limited concept of personal safety, which often results in children eloping (bolting) into...
parking lots, crowded stores, or the street. Autism therapy dogs are specially trained to assist families with public safety concerns by tethering the child to the dog’s harness which helps minimize the chance of elopement. While therapy dogs are often used to help prevent elopement for children with autism or other developmental disabilities, dogs should be used to supplement, not replace, individualized safety programs for children with special needs.

Often, the family dog is a child’s first “best friend.” This occurrence extends to children with special needs who often build very close friendships with their canine buddies, helping foster social and communication skills in developmentally challenged children. Research suggests that children feel more secure and less anxious in social environments when therapy dogs are present, thus promoting a positive social experience.

Improvements in daily schedules and compliance with caregivers’ directives have been reported in children with autism who routinely use therapy dogs for transitions, chores, and low-preferred activities. Existing research supports the use of therapy dogs for gaining compliance in school activities and homework, assisting in community outings, and in supporting medical/dental check-ups.

Studies suggest the use of therapy dogs in lowering the frequency, intensity and duration of tantrums, as well as repetitive and self-stimulatory behaviors in children with autism by helping to regulate the physiological stress response to environmental triggers. Less maladaptive behaviors can indicate more opportunities for developing new, pro-social skills. #WIN-WIN.

Similarly, therapy dogs are often used for occupational therapy to help increase children’s fine and gross motor development by performing simple tasks such as brushing the dog’s hair, playing catch, or going for a therapeutic walk. Simply stated, therapy dogs can provide significant support to a child’s occupational therapy needs, helping to increase independence toward goal mastery.

Parents of a child with autism should remember a number of things when considering a therapy dog:

- Dogs should be matched to the family’s personalities and home environment.
- Therapy dogs should be matched to meet the child’s developmental needs.
- Families should be prepared to undertake service dog training.
- Use reputable agencies that specialize in service dogs for children with ASD/developmental disabilities.

References:


Annie Tanasugarn is certified as a Behavior Analyst by the Behavior Analyst Certification Board. She holds an MS degree in clinical psychology and is completing the final steps of her doctorate degree. Annie comes with 15 years of clinical training in behavior management for both neurotypical and developmentally delayed children and specializes in autism spectrum disorders. Annie has been trained in multiple intervention techniques, which are integrated into her comprehensive one-to-one and parent training programs. Annie is the owner/CEO and operator of her online blog, The Autism Analyst, and additionally holds a private practice in helping empower children and families impacted by autism and behavioral problems.
Diagnosed with attention deficit hyperactivity disorder (ADHD), mood disorder, and high-functioning autism, my son has been getting behavioral therapy for the past four and a half years. He was recently finally released as the mobile therapist who helped him feel that he was on the right track. She felt that I had everything under control, and in many ways, I do. I am firm and consistent with punishment, but it doesn’t always work.

During the past four years, I have watched my son struggle. I have faced his meltdowns, faced physical abuse, and spent the summer locking myself in the bathroom where I proceeded to have my own meltdowns. But, in the course of those years, I have watched him greatly improve. I have watched him go from being a child who didn’t know how to socialize or interact to becoming a social butterfly. Though he has struggled with empathy, he now understands it. Sure, there are still issues here and there. There are still the angry meltdowns at times, and punishment doesn’t always work, but we work through it the best we can. There is still the invasion of personal space, and as much as we have worked on it, he still has trouble understanding facial expressions at times. Though we have come a long way with behavioral therapy, there is still the issue with medication.

Beneath my feet, my eight-year-old son darts back and forth. His ears are beet red and his cheeks are flushed, but still he runs. I try to get him to slow down but he won’t—he can’t. His church clothes are still lying on the bed where I placed them a half hour ago when I asked him to change. As I try to tackle him to get his clothes on, he fights me tooth and nail. As he gasps for breath, I try to calm him by using the breathing techniques his behavioral therapist showed me. I can hear his heart pounding and I can feel his little body shaking. It’s a terrifying feeling as I hold him close, praying that he calms down.

Finding Wonderful New Ways to Connect with Autism

By Destiny Eve PIFER
For the past four years, my son has visited a child psychiatrist. I have watched the doctors put him on six different medications during this time, hoping it would help him—from Focalin to Adderall to Abilify. The worst of three, Abilify, led to daily meltdowns that left me being punched in the gut, kicked in the shins, and bitten on the arms. I dealt with a child who would leave me in the store and lead me on a chase that left me in tears. Timeouts and punishment didn’t work. I was dealing with a green-eyed monster, and it was all thanks to a medication that was supposed to help him and not make him worse. Desperate for help, I reached out to the doctor who placed him back on the Adderall, but still I face a hyper child. With the medications wearing off so quickly, I am left dealing with a child bouncing off the walls. So where do you turn when medications aren’t working? Do you watch their diet? Do you turn to home remedies? These are the questions I continually asked myself until I found another method—art.

Having struggled with ADHD and high-functioning autism myself as a child, I found solace in art, which proved to be the exact therapy that I needed. Armed with canvas boards and paints, I sat my hyperactive son down and handed him a paintbrush. At first he studied it before dipping it into a dark blue color and stroking it across the canvas. When he giggled and aimed the brush at me threatening to flick paint, I immediately directed him back to the canvas and encouraged him to flick the paint there instead. Soon I saw an array of colors splattered across the canvas, and I was amazed. From that moment on my son became focused on art. He pleaded for sketchbooks and colored pencils—begged me for more canvas and paints. He had me watch as he used his fingers instead of the brushes, thus giving it a whole new look.

It’s been almost four months since we began art therapy and my son and I are still painting together. We are still creating works of art that are hung across the walls. Recently the local art association asked both of us to host our own art exhibit, and it is something that has motivated my son even more. Though there are still the occasional meltdowns when Mom-my says, “No, you can’t have that toy,” there are days when I sit and watch him express himself through painting and, recently, sculpting. Art therapy has proven to the be the exact method that I needed to keep my son calm, and though we have those moments of outbursts and not listening, we also have those bonding moments of self-expression that have made our relationship stronger than it’s ever been.

Destiny Eve Pifer is a journalist who currently writes for her hometown newspaper The Punxsutawney Spirit. She has her own monthly column called Mapping My Destiny, in which she writes about her adventures as a mother. Her work has appeared in numerous magazines and anthologies.

It’s been almost four months since we began art therapy and my son and I are still painting together. We are still creating works of art that are hung across the walls. Recently the local art association asked both of us to host our own art exhibit, and it is something that has motivated my son even more.
Amazing New Sound Reduction Earplugs Can Change Your Life

**Product:** Vibes Hi-Fidelity Earplugs protect individuals with sensory sensitivities from the discomfort of loud sounds while preserving the clarity of sound in their environment.

**Cost:** $23.99

For decades, foam earplugs and over ear headphones have been the standard for protecting individuals with autism spectrum disorder (ASD) and other sensory disorders from the discomfort they experience in loud environments. These types of hearing protections are designed to block sound and muffle sound, which severely inhibits the ability to hear and understand people talking, as well as the ability to hear what is happening in one’s environment. This can hinder social interaction and participation, and can often be a safety concern. Not to mention, these common hearing protection devices are often uncomfortable and brightly colored, which can draw unwanted attention in a variety of situations.

**Vibes Hi-Fidelity Earplugs**, recently featured on ABC’s Shark Tank, are a product new to the world of sensory relief, but one that allows individuals with sensory sensitivities to be comfortable in environments that would typically feel uncomfortably loud and over-stimulating, while still being able to hear everything around them, including human speech, with clarity. Originally designed for live music, Vibes use acoustic filters and a sound tube designed to mimic the inner ear canal to lower decibels by an average of 22dB without sacrificing sound quality. In short, Vibes lower the volume of the wearer’s environment to a more comfortable level, while still allowing them to hear clearly.

In reference to the adjustments that a family has to make to accommodate their child’s sensory sensitivities, one parent who purchased Vibes for his son who has autism and is sensitive to noise, reported that Vibes “reduce those adjustments, and my son and the rest of our family get to share events and experiences we have not been able to in the past.”

With three interchangeable sizes of soft silicone ear tips (S, M, L), Vibes are designed to comfortably fit all sizes of ears. Vibes’ clear-as-glass design makes them virtually invisible, permitting individuals with sensory sensitivities to be discreet about their use of hearing protection at school, movie theaters, grocery stores, crowded streets, doctor’s offices, shopping malls, etc. Each pair of Vibes Hi-Fidelity Earplugs also includes a convenient pocket-sized carrying case, the option to include an attachable cord to prevent the earplugs from getting lost (available on Amazon), as well as a donation to Hear the World Foundation, a global hearing health charity that provides hearing aids, hearing healthcare, and education to children and families around the world in need.

**Link:** Vibes Hi-Fidelity Earplugs are available online through [Vibes](http://www.vibes.com).
Introducing the World’s First All-in-One Speech Tablet for Symbol Communication

**Product:** Unlike anything else on the market, the [Indi speech tablet](https://www.tobiidynavox.com) from Tobii Dynavox is designed specifically for augmentative and alternative communication (AAC), and it is ideal for symbol-based communicators of all ages with speech and language disabilities, including individuals with autism spectrum disorder (ASD), Down syndrome, cerebral palsy, aphasia, and other intellectual disabilities.

**Cost:** $999

Introducing Indi, the world’s first all-in-one speech tablet for symbol-based communicators. It comes with Tobii Dynavox’s revolutionary Snap + Core First software pre-installed, empowering users to instantly take control and accelerate their communication journey. Indi was created specifically for AAC and comes with intuitive software, powerful speakers, and a Core Word framework to help users continuously build vocabulary and communication skills.

Snap + Core First software is designed to be intuitive and easy to start so you don’t have to spend hours on choosing the right software, setup, or getting the right content in place—it’s already done for you! At the heart of Snap is the Core First pageset, a research-based Core Word framework to help users continuously build vocabulary and communication skills. Core First is built on three pillars for communication success: growth, engagement, and literacy.

**Featured product highlights:**

- **Built for your world,** with an easy-to-hold, ergonomic design. It is ultra-portable and ready to go out-of-the-box.

- **Created to be heard,** with powerful, outward facing, built-in speakers providing clear speech, exceptionally loud output, and a wide range of authentic sounding voices.

- **Adapts to your access method,** with numerous compatible inputs, such as switch-scanning, head-mouse, touching with keyguards, etc.

- **Made for everyday interactions,** with capabilities that go beyond speech communication, like environmental control units (ECUs), infrared (IR), access to social media, email, and texting.

The Indi is available for direct purchase from Tobii Dynavox. You can purchase it online and receive it within days!

**Links:**

https://www.tobiidynavox.com
I’m the brother of 54-year-old Colin (or Codge, as he’s been known since a kid). He lived with my Mam, Marion Rose, from the day he was born in her bedroom until the day she sadly died a few years ago at the age of 81 in the same house in Leeds.

My mother cared for Colin (solo, since my dad died 21 years ago) and only went into care for short periods of respite as she got older. Codge was always bit of a handful, profoundly autistic, and a bit of a free spirit (“wild” as a kid, we used to say) who liked to do things his own way. Mam got on with it “head down and battle through,” like a lot of working class ladies had to do in those days.

Help gradually got better—attitudes changed as more people realized it was not a “handicap” to be born different and, with help, those born different could live fulfilling lives.

But Mam was always too proud to ask for too much help, brought up in an age when “charity” was distrusted and looking after your own was the thing you had to do. “I’ll look after him while I drop,” she used to say, and she did, like the old warhorse she was.

Colin is now living in sheltered housing in Leeds, or independent living, as they say. He seems happy and we are keeping our promise to Mam to make sure he gets the things he wants and needs.

I’ve written a poem based on the story Mam told me years ago about how the consultant diagnosed Codge as autistic in 1966. She said autism was blamed on the mother, or so it seemed in those days. The poem highlights the change in attitude toward people with autism since his diagnosis more than 50 years ago.
AUTISM ADVOCACY

AUTISM WARRIOR:
Ernie Els,
South African professional golfer, founder of the Els for Autism Foundation, along with Liezl Els and Marvin R. Shanken

LOCATION: Jupiter, Florida

ACCOMPLISHMENTS: Ernie Els has 70 professional career victories to his name, including four Major Championships, two World Golf Championships, and a record seven World Match Play titles. Off the golf course, he has received many awards for his charitable endeavors:

- Charlie Bartlett Award by the Golf Writers Association of America
- Jefferson Award, essentially a Nobel Prize for Public Service, for outstanding athlete in service
- Named one of the “Top Five Most Positive Athletes in the World” by the United Nations NGO Voting Academy
- Golf Foundation Spirit of Golf Award for his achievements as a player, for his contribution to golf and commitment to young people in golf and education
- Metropolitan Golf Writers Association (MGWA) Winnie Palmer Award for his foundation work on behalf of autism (The MGWA had previously conferred on Ernie its prestigious Gold Tee Award)
- Eighth recipient of the Denver-based Nicholson Award for “a lifetime commitment and dedication to the game of golf”
- Payne Stewart Award in 2015
- Inducted into the World Golf Hall of Fame—2011 Class

One of his accomplishments admired most by golf fans and parents alike is the establishment of the Els for Autism Foundation in 2009, along with his wife, Liezl Els and Marvin R. Shanken, chairman.

INSPIRATION: The Els’ son, Ben, was diagnosed with autism spectrum disorder (ASD) at five years old. In 2008, the family moved from their home base in London, England, to Jupiter, Fla. Overwhelmed at times by their son’s special needs, the couple conceived of a nurturing place to learn for those on the autism spectrum and provided six million dollars in seed money for the Els Center of Excellence. Fast forward to 2016, the foundation provided services for 3,647 individuals with ASD and their families from 13 countries, focusing on education, global outreach, therapy, research, recreation, and adult services.

ELS FOR AUTISM FOUNDATION’S GOALS:

- To provide high quality information, intervention, education, and support to local, state, national, and international families of diverse cultures
- To provide programs based on best practices and develop innovative interventions through investigative study and analysis
- To engage in research to further knowledge in the field of ASD
- To establish funding required to sustain the mission and program goals through grants, donations, and events

ERNEIE ELS’S ADVICE FOR FAMILIES AFFECTED BY AUTISM:
“Autism hits families hard and I’ll be working for the rest of my life to help others in the same situation. I hope you’ll share an interest and join me in building a better future for people with autism.”

Website
www.e4agolf.com
www.elsforautismglobalconf.org

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PROFESSIONAL GOLFER A GAME CHANGER FOR AUTISM COMMUNITY

www.e4agolf.com

www.elsforautismglobalconf.org

52 | Autism Parenting Magazine | Issue 65
As a mom, I can tell you that Damien’s behaviors could be scary and aggressive, and they scared and overwhelmed me. I thought if I did better, he would do better—but my family said it was because he didn’t have enough discipline. I couldn’t stand that I was allowing myself to feel anger for a four-year-old child because I was letting people fill my head with the lie that he could control it.

In March of 2016, we officially got the autism spectrum disorder (ASD) diagnosis. I broke down for 24 hours thinking I must have done something wrong (obviously, I know now I didn’t). I was just so angry that my baby was having to go through this, that he was trapped in his own world, and I didn’t have the key yet. After that 24-hour period crying and throwing a pity party, I stood up and started reading everything I could about kids on the spectrum, I got him specialists, and I figured out I was no longer angry anymore. I knew the problem, and I knew that I was going to be there right next to him however he needed me. Other people offered judgments still claiming we just needed to force him to do things, and they didn’t want to take him in public in case he had a bit of a sensory meltdown. I decided right then and there that if my family didn’t want to learn, that was fine because I would learn all I could. He even went to a special preschool and started kindergarten.

Until he turned three, I felt like everything we were going through was just what kids went through. Then Damien stopped talking, made repetitive movements, and we noticed him doing different things with textures and sounds. We know now he has sensory problems, but I am not going to lie, I felt so lost during that time. We went to doctor after doctor and were told that he would stop on his own, and when we finally got him the referral to the head autism center, we had to wait over a year to be seen.
in the fall. The transition was tough at first, but he was always ready to run to the bus in the morning. He has started acting like a big boy and I smile every time he proves wrong the many people who doubted him.

As most of you know, some of the things that stimulate kids on the spectrum can be tiring for us as parents. Damien watches the same parts of his movies over and over during Kindle time and has taken to banging noises because he likes the way the pressure feels on his arms. And the one thing that has this mommy a bit crazy is him shredding up every piece of paper or book he finds. I asked my husband if he was nesting, but he likes the sensation of shredding, and he likes to put different colors over the Kindle. We have started to get him to feel safe sleeping in his bed by using a bed tent. The only thing we have struggled with is potty training, but I see him making so many strides every day. For a minute, the idea of my kid having autism made me lash out at the people who made the comments, and now I just wish I could teach people tolerance and help them understand that just because a kiddo is on the spectrum doesn’t mean he’s not smart or can understand everything going on around him.

I’ve taken the philosophy that Damien had to let me into his world first before I could gently work on helping him in a non-ASD world. It has helped him wonders as he is very cuddly and always wants to lay in his tent with me, and we play with sensory toys that I found on Amazon. Really, I am the lucky one, because his smile wins me over. He now trusts me to come out of his world. He does not have sensory meltdowns in public; in fact, he loves to go out to dinner with people. He knows where his coat and backpack go after school, he asks with signs or uses the Picture Exchange Communication System (PECS) for things, and he can work electronics better than I can. Being an autism mom has taught me so much, especially that my son is a hero and he can do anything.

To other parents out there who are feeling alone and afraid of the diagnosis, I encourage you not to be. There is nothing wrong with mourning things you will miss that maybe your kid won’t do, but I promise you they can do so much more. I know that some families are unsupportive, but you know how to do right by your kid. I found autism less scary the more I read and asked questions. Behaviors can be hard, but they can get better. The hardest part I have dealt with is my son not talking except saying “my Momma.” I want to hear that little voice so much, and I believe in my heart it will happen one day. These kids have so much potential.

Don’t be afraid to venture into their world, even if you feel silly sitting in a ball pit because you are making a bond that lasts. The littles things that bring a smile to my lil’ man’s face amaze me. I have found mom support groups to be super helpful because the other moms understand what it can be like. I would just like to leave us all on this last note: The world better watch out because our ASD kids are going to take it by storm.

Andrea Taylor is 31 years old and is disabled from a chronic illness that left her needing a transplant. For now, she spends her life devoted to her son and raising awareness about autism. He is six years old and loves to cuddle with Mommy and wrestle with Daddy. They live in Columbia, Mo, and are currently considering doing an autism walk.
An Exclusive Look at AUTISM
with Anna Bullard

By Derrick HAYES

Today’s AUTISM Interview is with Anna Bullard who started her journey of advocacy for autism in 2007 when her middle daughter, Ava, was diagnosed with autism. She serves as the state policy chair of Georgia for Autism Speaks and won the 2014 national “Speak Out” award from Autism Speaks founders Bob and Suzanne Wright.

Anna was instrumental in the passage of Ava’s Law in Georgia, named for her daughter, requiring insurance coverage for autism. She served on the Autism Society of Georgia Board and the Board for Leadership and Disability for Georgia State University. Anna has started parent supports groups in multiple states and continues to advocate for services for children with autism throughout the country. She is currently working as the assistant vice president of Government, Business, and Community Relations for Chance Light Behavioral Health, Therapy, and Education.

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

When my daughter Ava was born, I started to see differences in her compared to her older sister. Ava didn’t sleep and cried most all day and night. When I tried to feed her, she wouldn’t open her mouth, she wouldn’t respond when I called her name, and she had no language skills. I felt like I didn’t know Ava, and Ava didn’t know me. It was during a birthday party for my oldest daughter when I determined something was definitely wrong. As soon as we started singing “Happy Birthday,” Ava started screaming and crying uncontrollably. This is when we started our journey of visiting doctor after doctor until we found a specialist who diagnosed Ava with autism.

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

Ava was my second child, so when she was born I thought I knew all the skills of parenting. I quickly discovered when you have a child with autism, everything you “think” you know is thrown out the window. Raising a child with autism was unique because I was dependent on therapists and others to help raise my child. It made me feel helpless. Because Ava responded differently, she and I had to learn to teach each other.
is for Tools - What tools are there now that were not there in the beginning that could help other parents?

When Ava was diagnosed with autism I thought someone would hand me a pamphlet that would provide guidance on where to seek therapy, how many hours of therapy she would need, etc. That didn’t happen because in 2006, that didn’t exist. When I inquired about programs for children with autism, I was told there were effective therapies, but they were too expensive and I wouldn’t find those programs in the state of Georgia. I was determined to help my daughter, so I attended a training session hosted by Early Autism Project. I think I was the only parent there. The room was full of teachers and speech therapists, but it sounded interesting so I stayed. At this training session, I learned about applied behavior analysis (ABA) therapy. I knew, based on my own research, that it was the most effective therapy for children with autism and typically not covered by insurances. At the time, Early Autism Project only provided home-based ABA therapy in Georgia and it was incredibly expensive because there was no insurance coverage. I didn’t care. We immediately started ABA therapy and I saw a dramatic difference in Ava. Early intervention helped Ava progress from a two-year-old who we were told would never speak or be in a regular classroom, to a successful eighth-grader who is thriving in a general education classroom and no longer requires intensive treatment. That is why I fought for Ava’s Law, which made Georgia the 41st state to mandate insurance for children with autism. Thanks to state mandates like Ava’s Law in Georgia and similar mandates in other states are so important because they provide children with coverage for life-changing autism therapy.

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

I struggle when parents who have a child with autism see the amazing progress Ava has made and they want the same outcome for their children. They want access to ABA therapy. I struggle with what I tell them because that treatment can cost $20-30K a year and most parents can’t do that without some kind of financial assistance. Children all over the country are being denied access to treatment. That is why Ava’s Law in Georgia and similar mandates in other states are so important because they provide children with coverage for life-changing autism therapy.

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

A strong support system is key when you have a child with autism. You need to surround yourself with people who believe in you and your child and the importance of the therapy. Raising a child with autism is difficult, but good friends and family can provide you with the encouragement you need to keep going. Society also puts a lot of pressure on parents to do everything at once. When children start therapy, you feel like you should be doing everything you can to help them. My suggestion is to try one thing at a time to help you determine what is going to work for you, your child, and your family. You can always add to things. Parents feel pressure to do everything and it just isn’t possible.

Every day I am inspired by Ava’s bravery and her tenacity to work hard. It requires such commitment for a child to participate in 30-40 hours of therapy a week. Children with autism have to work harder for everything. I watched Ava struggle to learn all the skills that come naturally for most children. However, Ava was committed to working hard because she knew ABA therapy was critical to her reaching her full potential. Her mature understanding of the power of therapy is the reason she now redirects her energy towards advocacy. She wants to ensure all children have access to ABA therapy. As I said, I am inspired by my daughter every single day.
When asked to name a therapy that will help the autism community, most people will say applied behavior analysis (ABA), occupational therapy (OT), or even speech therapy, but I am here to tell you there are additional therapies out there that can help. In this article, I will describe two specific therapies, their benefits, and what typical sessions might look like:

1. **Autistic Touch Therapy**

The first type of therapy that may help the autism community is called Autistic Touch Therapy. It is taught by Tina Allen who founded the organization Liddle Kidz who travels the world teaching people how to massage children of all ages and disability types. Autistic Touch Therapy is a type of massage where the therapist uses different objects that the child likes, such as a toy car, hairbrush, or even a hand puppet, to name a few, in the therapy session. The benefits include providing relaxation, stress reduction, and calming muscle spasms. It can also help a child become more accustomed to tactile stimulation and aids in body awareness. It is useful for a child who has difficulty sleeping, and needs help with sensory integration and regulating gastrointestinal tract (GI) issues.

When you perform Autistic Touch on a child, along with regular sensory integration, it will reduce inattentiveness, touch aversion, and withdrawal. A typical Autistic Touch Therapy session will last for approximately 30 minutes. In the first session, the therapist will get acquainted with the child along with the child’s family and then, in the next session, the therapist will begin the touch therapy. First, the therapist will make the child pick out the object that the child wants to use, and then the therapist will ask which part of the body he/she would like the object to be used on. Of course, the therapist always has a parent in the room during the sessions. Then, if the child is young,
the therapist will tell a story on what the object is doing, and then after that story, the therapist may ask the child to tell a story about that object. The good thing about Autistic Touch Therapy is that the therapist can conduct sessions in an office or at a client’s house. After the first touch therapy session with the child, the therapist might give the parents some information on the activities completed together so they can work with the child later, especially if the child isn’t sleeping well.

2. Tibetan Singing Bowls

Tibetan Singing Bowls are known to be the oldest and most natural form of healing to man. The bowls work through vibrations which have a calming effect on the nervous system and can travel deep into our body to penetrate the bones. We get a healing effect from the vibrations that a therapist could never get from his/her hands. Some of the benefits of the Tibetan Bowls are stress reduction through deep relaxation and endorphin release. They are said to liberate emotional traumas locked within the subconscious, activating self-healing mechanisms within the body, promote deeper sleep, and provide relief from headache, fatigue, insomnia, digestive disorders, joint or muscle aches, menstrual disorders, and emotional imbalances. A typical session for a child with autism lasts for about 30 minutes, and just like the autistic touch therapy, the therapist will get to know the child and his/her family first, and will let the child see the bowls and feel the vibration of them to see if he/she wants to participate. If that child wants a bowl session done, then the therapist would ask if he/she just wants to feel the vibration while the bowls are tapped or if he/she want the therapist to put the bowls on him/her. A bowl session can also be done along with Autistic Touch Therapy. Of course, parents will remain in the room for this therapy as well.

As you can see, these two therapies may benefit your child with autism along with an ABA, OT, and speech therapy session. A Tibetan Bowl session or an Autistic Touch Therapy session can be done before a child sees his/her regular therapist to help him/her calm. There are many different types of autistic therapies including the Son-Rise Program, horse therapy, music therapy, and even yoga, that will help an autistic child. If you want to learn more, feel free to contact me and I will try to explain in more detail. It is my mission and goal in life to help my community in any way that I can.

Meredith Siskron is from Shreveport, Louisiana where she is an autistic touch therapist, childcare specialist, certified children yoga instructor, a licensed massage therapist, water aerobics instructor, Tibetan Singing Bowl Sound Healer, and a children fitness instructor. She grew up knowing she had a learning disability. It wasn’t until she was into her mid to late 20s that she was finally diagnosed with a form of autism called PDD-NOS or Pervasive Developmental Disorder Not Otherwise Specified.

Facebook  
Twitter  
Tumblr  
Email

Resources:  
International Academy of Sound Healing at: iash.in/sound_therapy.html  
Autistic Touch Therapy Manual
**WHAT'S NEW ON THE BOOKSHELF?**

**Beautiful New Book Lends Support to Autism Siblings**

**What About Me?**

Having a sibling on the spectrum brings great joy. It also brings a flurry of emotions, challenges and questions. Written by a seven-year-old boy, *What About Me?* works through the day-to-day struggles and joys of being an autism sibling. Autism siblings can often feel left out or overlooked as their parents try to balance the needs of their autistic and neurotypical children.

The author and his mother shaped his sibling experiences and memories into a beautifully illustrated relatable story about the ups and downs of being an autism sibling. *What About Me?* is a must read for autism families that work every day through the realities of living in an autism household but always try to see the beauty in being an autism family.

This book discusses everything from having to tag along for multiple appointments to accepting that a brother or sister with autism may sometimes have different rules. The book has a positive message of acceptance and support, but is also very honest about the hard stuff. *What About Me?* is available on Amazon and perfect for autism siblings that need to hear that they are special and loved too.

_Brennan Farmer is seven years old and has a brother on the spectrum who is one year younger than him. He and his mother, Mandy Farmer, co-wrote *What About Me?* to let other autism siblings know they are not alone. Mandy has three children, seven and under. She is the founder of FromMotherhood.com and writes about autism, motherhood, and military family life._
New Book Encourages Friendship and Care for the Natural World

John, Robert and The Horseshoe Crab Book I & II

This new book promotes the values of friendship, collaboration, and care of the natural world.

This is a true story about two friends who came across a helpless horseshoe crab that was wedged inside the beam of a wooden fence. The two boys share their feelings about the situation. They communicate and work together to free the helpless animal. They show compassion for the horseshoe crab and free it from the fence. They each have done something out of the kindness of their own hearts.

After the horseshoe crab swims freely back into the bay, the two boys feel proud about what they have accomplished together. They feel good about themselves for giving this horseshoe crab a second chance at life. They have achieved something together that they may not have been able to do alone.

Available now on:
- Amazon
- eBay
- Xlibris
- Barnes and Noble

John Repp has loved to write and has had a unique and genuine way of expressing his feelings and putting them down on paper since he was 16 years old. He especially enjoys writing poems, short stories, lyrics, and songs. As John was growing up in a small suburban town on Long Island, he did not read much and as a result, did not develop his writing skills. It was only after he attended college and majored in 18th & 19th-century English literature that he was inspired to learn and grow as a writer, and his literary and writing skills improved dramatically. His appreciation for creative writing continues today and has become a very personal and gratifying hobby.
PinPoint Technologies, Inc. is a smartwatch start-up based out of Detroit, Michigan, that has made it a goal to help the autism community. It was founded by its chief operating officer, Quincy Hyatt, a Detroit native. Quincy, who has a sister with special needs, knows all too well what families affected by autism experience every day. Like some families affected by autism, Quincy and the Hyatt family endured many distressing incidents when his sister wandered way, sometimes for long periods of time.

After experiencing these episodes one too many times, Quincy developed his own solution. He set out to make sure that no other family went through the same thing.

In 2010, Quincy assembled a team and later secured patents for a wearable phone and GPS locating device that offers exclusive safety features. Given Quincy's experience and his connection with the autism community, the PinPoint team dedicated a significant amount of time and resources to develop a product that would be useful to the autism community.
Unlike other companies, PinPoint didn’t want to simply create a “tracking device.” PinPoint wanted to help members of the autism community keep their loved ones safe without it becoming burdensome to parents or children. While creating the PinPoint GPS-Phone SmartWatch, PinPoint kept one thing in mind: that everyone is equal whether they’re on the autism spectrum or not. Even though the PinPoint GPS-Phone SmartWatch is equipped with special features that are useful for the autism community, the device still has basic features that all families would find useful for their loved ones.

PinPoint understands the high level of concern that the autism community has when it comes to monitoring a person’s whereabouts. One thing that PinPoint learned from its research and conversations with members of the autism community is the importance of being able to locate the person wearing the device, and the PinPoint GPS-Phone SmartWatch communicates directly with satellites. The benefit of this feature means that the person monitoring the location from their smartphone doesn’t have to worry about being within range.

A popular question asked during the development of the device was, “What if the person wearing the watch doesn’t know how to make a phone call on a regular phone, let alone a smartwatch?” While developing the device, PinPoint took various scenarios into consideration including this one. For that reason, PinPoint added a feature by which the person monitoring the device through the smartphone app can command the watch to call his/her phone. After receiving the call from the watch, the person using the smartphone just has to answer like any other phone call. He/she will then be able to communicate with the individual wearing the device.

Since the development of this device, PinPoint Technologies has received outpouring support from individuals in the autism community. Quincy’s cousin, a special education teacher in West Virginia, praised the product as she believes that the device could be helpful to the autism community. The company is committed to helping raise awareness for autism and will also be active in the community and attend events to help promote the cause.

PinPoint Technologies continues to be dedicated to creating devices that allow families to stay connected to those they care about most. The PinPoint GPS-Phone SmartWatch comes equipped with many wonderful features, but what is most important is its usefulness and functionality. PinPoint Technologies understands caring for someone with special needs isn’t always an easy task and wants nothing more than to help make caring for a loved one with autism a bit easier.
HELP: How Can I Make it Easy For My Son to Remember Skills?

By Angelina M., MS, BCBA, MFTI

I’m struggling with my son remembering the things he has learned. I teach him one thing and he forgets. Any tips?
– Matsepo

Hey Matsepo!

What you’re experiencing is very common for people with developmental disabilities. Research shows that children with autism require significantly more learning opportunities to gain a new skill than other children. On top of that, children with autism often require more on-going training to maintain the skill. In other words, not only do our kiddos on the spectrum take longer to acquire new skills, they require more help to remember the skill. This applies to how they retain information, too.

The skill of remembering what you’ve been taught across long periods of time is called MAINTENANCE. Think of it like this: if you made a new meal one time, you probably wouldn’t remember how to make it again a month later without checking the recipe. But if you made the meal every other day for three weeks in a row, you will probably remember how to make it a month later. The more you practice, the better recall you have.

Here are some things you can do to help your son remember what he’s been taught:

1. Repetition: It’s key to create lots of opportunities for your son to use the information he’s
been taught. For example, if you taught him his brother’s name but he never has a reason to talk about his brother, he may not retain that information. But if you ask him throughout the day, “Who’s sitting over there on the couch?” or “Who has the book?” he will be forced to recall what his brother’s name is. Another example may be math facts. You can set up times throughout the day to practice his addition, such as every night before dinner or while in the bath.

2. **Generalization:** Practice the skills you teach your son across a variety of environments, with different people, and with different items. For example, if he knows how to wash his hands in the downstairs bathroom, make sure to also practice washing hands in the kitchen sink and master bathroom sink. Create a ton of opportunities for him to practice what he knows in a new setting. This can apply to almost anything: answering questions with different people, buttoning different shirts, tying various pairs of shoe laces, playing board games with different peers, etc.

For example, if you taught him how to write his name with a paper and pencil, try having him write it with markers, then paint, then on the iPad, or with chalk outside. Or with math facts, you can use flashcards, a dry erase board, a math app, and making them into a song! Find new and interesting ways to target the same skill.

I hope these ideas help! Keep in mind that your son will need extra practice to maintain the skills he has been taught. Be patient and have endurance. The more opportunities he has to use the skill, the more likely he is to remember it.

3. **Use prompts:** I like to create little hints to help my learners remember things. For example, I worked with a kiddo who had socialization goals to respond to peers’ comments during conversation. We taught him that he could reply, “Cool,” when a peer told him something interesting. We paired the word “cool” with the thumbs-up gesture so that from across the room I could signal him a thumbs-up and he would be reminded to say, “Cool,” to his friend during a conversation. With another kiddo, we created jingles to remember spelling words. On the day of the test I could just hum the tune and he remembered how to spell the word. Find little ways to remind your son of what he knows.

4. **Make it fun:** You can use different learning strategies to help your child remember things.

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. You can learn more about Angelina on her blog, The Autism Onion, or on Facebook.
At A Special Needs Plan, we advocate that as families look toward the future, they must consider the risk of government benefit support being reduced as the result of changes in federal and state coverage. Unfortunately, this risk may become a reality sooner than anticipated.

The proposed new Health Care Act combined with the proposed federal budget is drastically changing Medicaid and the manner in which services are provided. It is estimated that these changes will mean a cut to Medicaid funding by the federal government of $610 to $834 billion. The changes also institute a new way in which the funding is provided to the states, which many disability experts fear will drastically reduce benefits for individuals, placing much more financial burden on families for their loved ones’ support needs. The proposed budget not only affects Medicaid, but it also reduces funding to special education, the US Department of Labor’s Office of Disability Employment Policy, state developmental disabilities councils, autism programs, and medical research. (https://www.disabilityscoop.com/2017/05/23/trump-medicaid-disability-programs/23746/).

Based upon these impending changes to funding streams for those individuals with disabilities, including individuals with autism, it is becoming quite clear that each family must have their own plan with specific strategies that ensure a secure future. Fam-
Families must understand the economic landscape of their child’s entire life, knowledge of the adjusting government plans, and an individual strategy that provides for their child’s support needs regardless of government policy. This may feel like an overwhelming or daunting task, or many families feel they have simply started too late, but neither of those items are true.

Due to the complexities of this type of planning, families can start by taking a simple step: complete your child’s Letter of Intent.

A Letter of Intent is a document written about your child’s current needs (medical, therapy, education, employment, behavioral, daily routines, and structure), as well as your future goals for them. This document is an instruction manual for your child that will provide guidance to your child’s next caregiver if you are no longer able to care for them or if you pass away. (You can find a Letter of Intent at www.HowtoSecuretheFuture.com).

The second step is to find a special needs planning professional who can guide you in the process of this type of planning so that you do it correctly. Finding a specialized planning professional in this arena can be challenging because there are very few that focus their time specifically working with families like yours. We have included some tips below that can help:

- Ask organizations you trust for guidance.
- Reach out to other families for advice.
- Interview planning professionals:
  - Do they know the differences between Supplemental Security Income (SSI) and Social Security Disability Income (SSDI), as well as Medicaid vs. Medicare?
  - Do they know the qualification requirements of SSI and Medicaid?
  - What special needs planning certifications do they hold?
  - What continuing education do they complete in this area of planning? How often?
  - Can they explain the advantages, as well as the drawbacks, to an ABLE Account?
  - Can they describe the different types of special needs trusts and when each type is used?
  - Do they know how taxes work within a special needs trust?
  - Do they know what IEP means?
  - How are they involved in the special needs community (other than professionally)?
  - Will they share the planning process to use in creating a special needs plan?
  - Would they let you speak with two or three families they have helped in developing a special needs plan?
  - What is the professional’s business continuity plan, so that someone with your knowledge is still able to help if you are no longer here?

Your plan spans two generations, so it is critical you begin to build a team that can support your family today, as well as into the future.

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 of parents, caregivers, your loved one with special needs, and their siblings.

101 N. McDowell Street, Suite 120
Charlotte, NC 28204
704-326-7910
www.aspecialneedsplan.com

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A Chocolate Delight in a Matter of Minutes

Chocolate Mousse

Ingredients
250 grams / 1 cup coconut cream or thick part of tinned coconut milk, after it's been in the fridge
1 tablespoon honey
1 teaspoon of vanilla extract
1½ tablespoons cocoa powder

METHOD:
Whisk the coconut cream for a minute, add the rest of the ingredients, and whisk again. Place in small bowls such as ramekins and allow to chill for at least an hour.

Note: Though the ingredients can just be stirred together, the whisking just provides a lighter texture.