

AUTISM SPECTRUM NEWS

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Siblings and Autism

Guidelines for Parents on Addressing the Needs of Siblings

By Marci Wheeler, MSW
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There is little doubt that those of us raised with siblings have been influenced by that relationship. Living with a brother or sister with an autism spectrum disorder adds more significant and unique experiences to that relationship. Throughout numerous accounts of parents and siblings of children with disabilities it becomes very clear; when a child in the family has a disability, it affects the whole family. Also clear is that families and each member can be both strengthened and stressed from this situation. It is the degree of these conflicting effects that seem to vary from family to family and person to person. There are some factors that have been found to help strengthen families and minimize the stressors. This brief article is meant to arm you with important information and practical suggestions for helping and supporting siblings.



Though limited research has been done, a child's response to growing up with a brother or sister with a disability is influenced by many factors such as age, temper-

ament, personality, birth order, gender, parental attitudes and modeling, and informal and formal supports and resources available. Certainly, parents have little control

over many of these factors. However, parents do have charge of their attitudes and the examples they set. Research by Debra Lobato found that siblings describing their own experiences consistently mentioned their parents' reactions, acceptance and adjustment as the most significant influence on their experience of having a brother or sister with a disability (Lobato, 1990).

It is also important to note from Lobato's research that a mother's mental and physical health is probably the most important factor in predicting sibling adjustment regardless of the presence of disability in the family (Lobato, 1990). Positive outcomes that siblings frequently mention are learning patience, tolerance, and compassion and opportunities to handle difficult situations. These opportunities also taught them confidence for handling other difficult challenges. Research by Susan McHale and colleagues found that siblings without disabilities viewed their relationship with their brother or sister with autism as

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Adult Sibling Support

By Amy Halm, MSW, LCSW
Sibling Leadership Network

Siblings often have the longest-lasting relationships of their lives with each other. With this lifelong connection, siblings have a great opportunity to support each other. In families where a person has a disability, the roles that siblings play may be different – not only in childhood and adolescence, but also in adulthood. With these different roles, there are also different needs. As parents age and are less able to provide support to their child with a disability, siblings' roles will increase, and siblings often anticipate taking on a greater support role in the future. Although siblings expect to be involved in future roles, many families are not engaging in future planning and siblings are often not included in conversations about the future (Burke, Arnold, & Owen, 2018). Additionally, siblings have not traditionally been involved with peer support opportunities so as they enter adulthood, they often find that they



Amy Halm, MSW, LCSW

are searching for opportunities to connect with other siblings that they can turn to for collaboration and information.

The needs of siblings of people with disabilities are complex, varied, and change

over time. Two common areas of need for adult siblings include: information about future planning and peer support. These are two of the areas that adult siblings often talk about the most when they connect with the Sibling Leadership Network (Arnold, Heller, Kramer, 2012; Halm & Arnold, 2017). [The Sibling Leadership Network \(SLN\)](http://www.siblingleadership.org) is a national nonprofit whose mission is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and promote the issues important to them. Find out more about the SLN at www.siblingleadership.org.

Future Planning

The term "sandwich generation" is often used to refer to adults with aging parents who are juggling care for their parents and raising their own children. Siblings of people with disabilities often refer to themselves as being part of the "Club Sandwich Generation" (similar to a large club sandwich with many layers) because they have an extra layer of providing care for a

sibling with disabilities which often compounds their caregiving roles (Hodapp, Sanderson, Meskis, & Casale, 2017). Through adulthood there are increasing questions about living arrangements, career transitions, finances, and caregiving roles. Siblings need time and space to discuss and process these conversations both within their family and possibly with other people outside the family.

Adult siblings often have questions and concerns that they have been considering over their lifetime. These questions typically revolve around wondering what will happen to their own life and the lives of their siblings when their parents are no longer present or unable to care for their siblings. Siblings might be wondering: "Will my sibling live with me?" and "Will I become my sibling's primary caregiver?" Of course, there aren't universal answers to these questions. Families are well-served to have ongoing conversations about future planning that involve parents, children, siblings and extended family members. It

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Supporting Siblings is a Family Affair: Thoughts From an Insider to Help Guide the Conversation for Best Outcomes

By Suzanne Muench, MSS, LCSW, and
Mary Jane Weiss, PhD, BCBA-D, LABA
Melmark

The impact of having a child with a disability extends far beyond that individual and impacts the parents and siblings over the course of the family's lifetime (Harris & Glasberg, 2003; Powell & Ogle, 1985). Developmental disabilities are certainly not universal in how they impact the family, it is universal in that it does have an impact (Feiges & Weiss, 2004; Harper et al., 2016).

Many parents worry about the effects on siblings, both while they are growing up and when they become adults. They often worry that they are neglected, because of the energy that is allocated to the child with a disability. They may also worry that they feel burdened by the need to support their sibling with a disability, especially after the parents are less able to do so (Harris & Glasberg, 2003).

Indeed, the literature tells us that siblings are affected, and that there are challenges that are common (Meyer et al., 2011; Moyson & Roeyers, 2011; Tanaka et al., 2011). Many siblings experience a wide range of emotions and worry about their sibling and their family (Feiges & Weiss, 2004; Ferraioli & Harris, 2009). However, siblings are insulated by many factors that help with adjustment and adaptation. For example, fostering a sense of fairness is important. In addition, creating a safe space for siblings to express the range of emotions they may feel is essential, and is associated with fewer negative effects and higher levels of coping. Families that can discuss fears about the future and who plan effectively for the future adapt better over time.

While parents concern themselves with the negative impact, it is also true that siblings of individuals with disabilities experience positive effects as well. For example, siblings tend to be more positive, tolerant, and understanding than others. Frequently, they express a sense of mission about making the world a better place and about helping those who are disadvantaged. Many siblings of individuals with autism also report that the disability provided a central focus and a glue for the family, that it helped the family appreciate the positives in life, and that it provided perspective on what is important.

In the excerpt below, the Director of Admissions at Melmark provides insight into the experience of a sibling. Her story illustrates these findings in a personal way that may help families to understand the impact and to plan for the future.

From Suzanne Muench:
My Personal Experience

Working with individuals with disabilities was a job I never planned on having. Growing up, I had had enough of being the sibling of a special needs brother and did not want anything to do with it as a career. I went to college to be a social worker, specializing in juvenile delinquency. Little



Suzanne with her father and brother John

did I know that years later, I would end up not only working in the field, but finding it to be the most rewarding work I would ever do.

My brother John, eight years older than me and born with Down syndrome, was the focal point of our family. He was adorable and stubborn in every way, and demanded a lot of my parents' attention, as did my other brother, who had learning differences. I was the youngest, and most eager to help out with John. I happily attended and participated in many of John's therapy sessions hoping to increase the likelihood that I would get attention. I loved feeling exceptionally smart, as I was able to do much of the work they were asking him to do, and it bolstered my confidence along the way. However, because I took a liking to this, it soon became an expectation that I would be involved in many aspects of John's life and care that I was not always keen on. I was to include him in activities with my friends, be a best buddy in his sports activities, and do it all with an attitude of gratitude that I could do "normal" things that he could not. My mother assumed that I would always be there to take care of my brother, and in the absence of information, I simply agreed, knowing that caring for my brother for the rest of my life was just the hand I had been dealt.

As I got older, I realized what a huge undertaking this would be. I began to imagine the impact this would have on the choices I made as a young adult, the relationships I would have, and how I planned a future for myself. I felt very concerned about this as my parents' health began to decline over the years, but there were never opportunities, or open minds, to discuss alternatives to a plan that was just inherently understood. It would be my responsibility to care for John once my parents were not able to. This was daunting and overwhelming as a young adult with little experience caring for myself, much less someone with John's needs. There was no expectation that I was entitled to a life of my own, and this

I was fortunate to be working in this field, and would be able to use my knowledge and resources to navigate through the confusing system of services to advocate for additional support for my father and brother.

Advice for Parents with Younger Children

As an adult sibling having gone through this with my parents, I would like to offer the following thoughts to consider for parents with younger children:

1. Offer children choices about participating, or not, in therapy and home sessions.

2. Give kids access to age appropriate information about their sibling's disability. In the absence of information, a child can unnecessarily create erroneous narratives and worry about what will happen to them, their siblings, and their family. These feelings can impact how they perceive their role in the family, and can help them develop coping skills.

3. Regardless of the child's insistence on caring for their sibling "forever," let them know that you and your family have a plan for future care needs. Let them know that you appreciate and welcome their involvement in developing the plan, but that it will not be their sole responsibility. This is especially important while children are still young and the thought of having to care for a sibling long term could influence their decisions about where to go to college, what careers they choose, how they establish their own families, etc. Siblings may be very reluctant to tell parents that they do not want to take on this responsibility, or that their life choices are being made with these things in mind. Remind siblings that they are entitled to their own lives, and that an identity that is separate from being the sibling of someone with special needs. Let them know that this does not mean they

see Family Affair on page 29



Suzanne and her brother John

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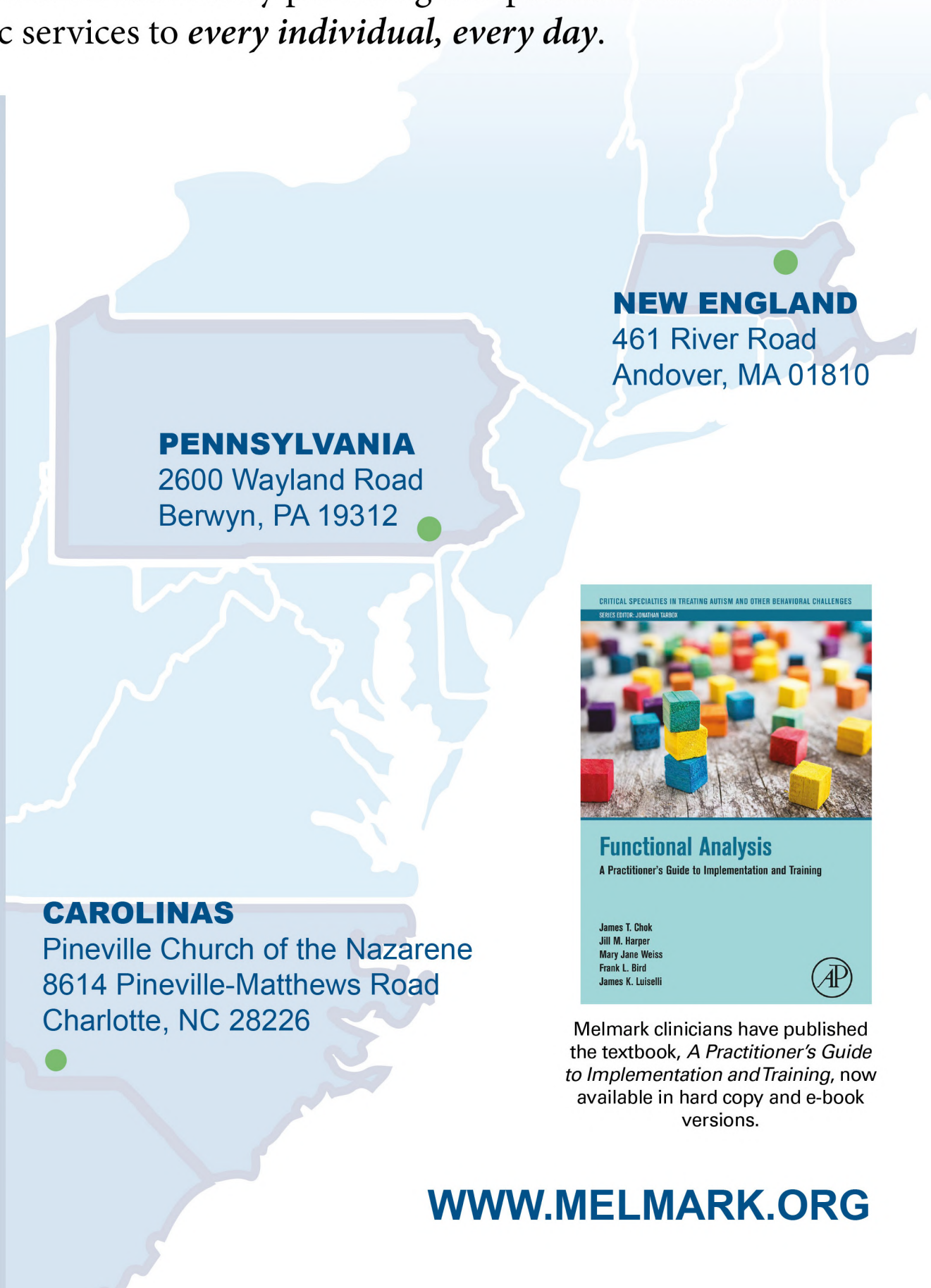
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Carrie working on her lesson plans with her teacher, Anna Eisenberger, M.Ed., at Melmark Pennsylvania



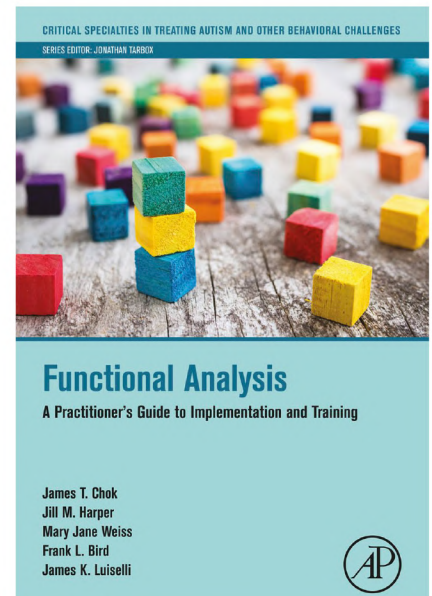
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Autism Spectrum Disorders in the Home: How to Thrive as a Family Unit

By Sheila Simchon, LSP, LCSW and
Samantha Curiale-Feinman, MEd, TSHH
New Frontiers Executive Function Coaching

Various research studies have shown that early intervention for children with autism spectrum disorders (ASD) is important for providing the tools and strategies needed for long term success in areas such as education, career, and life in general (McEachin, Smith, & Lovaas, 1993). It is important to note that most attention up to this point has been given to the effectiveness of treatments directed solely towards the individuals diagnosed with ASD specifically. However, understanding the complexity of ASD and its implications on the family unit, it is just as important to call attention towards interventions that support the family and its functioning as a whole (Estes, Swain, & MacDuffie, 2019).

Living with an individual diagnosed with autism can require that one readjusts their expectations of the family unit, both in terms of general day-to-day activities, as well as special events and occasions. Families raising an individual with ASD can sometimes find themselves isolated from others, feeling overwhelmed and/or tired, exhibiting high levels of stress, or feeling a sense of worry or embarrassment by how others may perceive their child's behavior in a social setting (Begum & Mamin, 2019). Supporting the child's development of social and communication skills, finding support to get any challenging behaviors exhibited under control, AND providing support for caregivers and siblings has the potential to make life run more smoothly for everyone in the family. Through open interviews from various parents, caregivers, siblings and professionals, we have collected the following recommendations on best practices on how to help the family unit as a whole flourish.

Appreciating Neurodiversity

Families have identified that, first and foremost, in order to set the stage for a healthy family dynamic, there should be a focus on creating and celebrating a neurodiverse household. Letting go of assumptions of how people "should" be, focusing on strengths, setting realistic expectations, and honoring the differences that each family member brings to the table are all key factors necessary for practicing gratitude



Sheila Simchon, LSP, LCSW

of the family unit as a whole. It is also important to identify each family member's needs and learn the language of how they communicate when their environment or experience is too overwhelming, whether they be the individual diagnosed with ASD or one of their loved ones. This can help the whole family unit communicate more effectively and be more prepared to deescalate frustrating and stressful situations.

Supporting Learning Opportunities

Caregivers and siblings note that it is important to provide explicit social skills support and practice to their loved ones with autism, as well as behavioral therapy to decrease maladaptive behaviors and encourage more positive and productive ones. This can help individuals with ASD to learn the social norms in various social situations, thus making it easier to participate in gatherings and events as a whole family. On the other hand, it is just as important to provide education to the family as a whole. Education is key and each and every family member should be invited and involved in the learning process. Learning about topics such as self-stimulatory behaviors, sensory differences, the root of maladaptive behaviors, and comorbidity considerations can be essential to success and should be looked at as an integrative family process. Having a solid foundational knowledge of autism and how to effectively encourage learning creates opportunities for the whole family to develop and understand the importance of structure and routine to encourage suc-



Samantha Curiale-Feinman, MEd, TSHH

cess. Knowledge truly is power for families affected by ASD.

Access Resources

There are many reputable resources available to provide various levels of support to families. Seek out both individual supports and support groups as appropriate. Individual support is appropriate when the individual with ASD or family member can benefit from self-exploration, the development of self-awareness and one's own boundaries, and personal issues surrounding a diagnosis, treatment, or the processing of such. There are also support groups for individuals diagnosed with ASD specifically, or groups for their parents and/or siblings that can also benefit the family as a whole. Support groups can assist in validating the issues being faced by the family, while allowing for a venue to brainstorm solutions with others that can understand and relate to your point of view. Research groups in your community that provide these types of supports and encourage participation of family members. It can assist in developing a better understanding of the diagnosis and open one up to what other types of resources and services are available. Support groups help to provide a sense of unity to families that many times feel like they are alone in the process.

Further, family members should be encouraged to ask for help directly when they need it. You can request advice from trusted sources, including professionals in the field, such as your pediatrician or therapist, or those that are part of your family or friends circle.

Practice Family Mindfulness and Well-Being

As a family, do not be too hard on yourselves or each other. Remember you might have moments of sadness when things do not go the way that you expected them to go. Remind each other that this is okay and that you are a team working *together*, not against each other. In times of distress, self-care can be very powerful, and it is important to remind each other of the importance of taking care of your own personal health and the health of each other. Plan and participate in structured family wellness activities, such as yoga class, art or music therapy, outdoor exercise, meditation, cooking activity, or other therapeutic and/or recreational activities. Such activities not only continue the development of social communication skills in an organic context, but also allow for the family to work as a team and enjoy time together.

All families face challenges in some capacity, and families living with an individual with autism may at times feel overwhelmed by the challenges they are facing. Always remembering that all families struggle at times can provide some peace of mind. Reframing back to why family is important – love, support, traditions and values – can reframe the experience. Remembering that family members are there to learn from each other, help one another and be there for each other through the good and difficult times can remind us what an incredible influence we can be for one another.

Sheila Simchon, LSP, LCSW, Coordinator, and Samantha Curiale-Feinman, MEd, TSHH, Director, New Frontiers Executive Function Coaching (www.nfil.net), can be reached at info@nfil.net or (646) 558-0085.

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My First Employment Experience Working for Autism Spectrum News

By Vincent Dante-Maniglia

I graduated from Marist College in May of 2018. While I was on hiatus as I enjoyed free time for the summer, I was thinking about getting a job, but I needed help with planning my next steps. When January came, I started out at [Shrub Oak International School](#), where I would receive help with career advice and guidance for the future living as an adult on the autism spectrum.

I met with transition coordinators Candice Baugh and Katie McDermott to plan for the inevitable necessity of a job. I discussed with them what I am interested in, what I am good at and what I wanted to learn. I shared that I had previously interned at the media center at Marist College, where my task was organizing and labeling video files for the center to make available for clients. I also majored in Media Studies and Production with a minor in Games and Emerging Media.

After completing an assessment of my skills and interests, my transition coordinators connected me to an opportunity to work for Mental Health News Education, publisher of [Autism Spectrum News](#) and [Behavioral Health News](#). I agreed that this would be a good match for me because it was similar to the work I had done for my college internship. I was also interested in getting more experience in a job in the media field.

The publisher, David Minot, interviewed me over the phone to evaluate my potential as an intern. The interview went very well as I was prepared for it. Mr. Minot and I felt like the role would be a good fit. I signed the internship agreement and, from April 2019 to August 2019, I worked 10 hours per week for this position.

Internship and Consulting Work

My good work ethic and previous experiences were beneficial for my perfor-



David Minot, publisher of Autism Spectrum News, with Vincent Dante-Maniglia and transition coordinator Katie McDermott

mance in this new role. My work involved creating Word documents from articles in a Publisher file and then I had to transfer the text in those Word documents to the website online using WordPress. My work was critical for bringing their database online for use on their newly designed websites.

I did this for about a semester's length of time. Because of my experience interning at my college's media center, I already knew how to complete my tasks. Since I was no stranger to the organization of articles, I knew how to approach this work methodically and with patience. It became a repetition that I found myself comfortable with.

If I were to analyze my strengths during this internship, they would include: my organized view of how to proceed about selecting each article, and my attention to detail for noticing if the author or organization categories in WordPress were miss-

ing specific results. From my experience, I learned about responsibility and the importance of keeping up with the expectations from others. I always kept a consistent pace with my workload, stayed focused on the task, and I gained more experience working with archives and articles. I was also exposed to a wealth of information as I had access to read any article of my choosing! They contained so much knowledge about issues regarding people on the autism spectrum, as well as emotional issues and the opioid epidemic within some communities. This gave me more awareness about how people deal with these types of subjects in the world.

In one semester I was able to work with over 900 articles for [Autism Spectrum News](#). After completing the internship, I was fortunate to be offered a contracted position with Mental Health News Education doing similar work but now for the

company's other publication, [Behavioral Health News](#). Altogether, I processed almost 2,000 articles between both websites. In addition to being a great work experience for me, I am proud to have made a very positive impact on the autism, mental health and substance use disorder communities by assisting in giving them a library of content they can now access easily and for free.

Working for a paycheck is time-consuming but worth it, and I have been learning to spend money carefully. I look forward to when I have a steady income so I can purchase whatever I desire without restriction.

Advice for Other Young Adults with Autism

My advice for other young adults on the spectrum entering into their first employment experience is to make sure you know what the job is about and what might be expected of you before you apply to a job. A great way to prepare for the interview is by role-playing. This type of preparation can help you feel less nervous and more secure. Also, experience matters and practice makes perfect.

My first job experience was a good opportunity to work in a familiar field and earn a paycheck for my efforts. I hope to get another paying job after this, preferably in game design with graphic design and animation. I would like to be a game designer because I think it would be fun to create games the way I want them to be and, in a way, bring my imagination to life. I am so grateful for the opportunity that David Minot and Mental Health News Education have provided to me. I was lucky to have this opportunity and I will always remember my first job - the experience will go a long way!

For more information, please contact David Minot, publisher of [Autism Spectrum News](#), at dminot@mhnews.org.

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The Siblings of Autism

By Carrie Cariello
Mother and Advocate

About a million years ago, a kind doctor told me the best thing we could do for Jack was to give him siblings. A lot of people ask me how we decided to have more kids once we knew something was up with him. I wish I had a more sophisticated answer to give, but the truth is, we just didn't know what the heck we were doing. We had no plan.

People wonder if we worried about having another child with autism. To be honest, we found out Jack was on the spectrum - originally diagnosed with [Pervasive Developmental Disorder, Not Otherwise Specified](#) - and we learned we were pregnant with our fourth child exactly one day later.

So, yes and no. It definitely crossed our minds that another child could have the same symptoms he did, but we didn't spend a lot of time discussing or dwelling on it. Partly this was because we had three boys under the age of three, and there wasn't a whole lot of time to discuss anything. And partly this was because we thought Jack would outgrow his symptoms and turn into a regular, sunny boy who played catch in the backyard and told jokes at the dinner table maybe, if we were really lucky (fingers crossed!) made the honor roll at school every once in a while. We were so



Brothers Charlie, Jack, and Joey Cariello

precious; I can barely stand us.

But I will say this: the doctor was right. Deliberate or not, poor planning or simply naiveté, growing up alongside three boys and a girl has been very, very good for Jack. He eats what they eat, when they eat. He takes a bath at bath time, he goes to bed when they go to bed - in a room he shares with his three brothers and a puppy. He wears itchy khaki pants and a button-down

shirt on holidays because our family dresses up on holidays. He says a prayer before dinner because our family begins the evening meal with a few moments of quiet.

Let me tell you, Jack is boss-ey with a Capital B. If he had the chance, this boy would control what we have for lunch every day, what we watch on TV, and which movie theater we go to see Zootopia. But as one of five kids, he cannot run the show.

He cannot be in charge all the time. It's more than that, though.

When Henry was about a year old, he had this giant Mickey Mouse doll. The thing stood at least two feet tall, and when you pressed the middle of his hand, he would shuffle and sing and laugh a high-pitched Mickey-laugh. Jack *hated* that doll. He was probably about four years old at the time, and he would run shrieking from the room whenever it started to sing. One night after dinner, we found him trying to tape Mickey's mouth closed.

See, we can't give him a perfect, quiet world. We can only help him learn to live where it's loud and unpredictable; where Mickey sings and bedtime comes at 8:00 and your dad wants to go to a different movie theater because he has a gift card. With three brother and one sister, they make sure of it.

Oh, it's not as pretty as you might think. They pester him. They drag him off the couch and out of the house and into the yard when they need an extra body for games of tag, hide-and-seek, manhunt. They repeat his name until he answers. "Jack, Jack, I am talking to you. Answer me." They force him to share. "No! You chose the last song, now it's my turn." They push him and pull him and talk to him and love him.

And I learned long ago not to get too involved - to let them fight their battles and

see *The Siblings* on [page 18](#)

Siblings: Common Concerns and Effective Support Strategies

By Emily Holl, MFA, LMSW
Director
Sibling Support Project

Like parents of individuals with Autism Spectrum Disorders (ASD), siblings experience unique concerns and opportunities. The sibling relationship can easily exceed six decades, and siblings face these issues for even longer than parents. Historically, siblings have had few opportunities to receive information and support. Parents have access to professionals and each other. Siblings are often overshadowed at home and overlooked by service providers. Recognizing some common sibling concerns and engaging a few simple strategies can support the well-being of siblings and the entire family.

Information Needs

Siblings, like parents, need information about the disability (Meyer & Vadasy, 2008, p. 37). Very young siblings need to know they didn't cause and can't catch ASD. School age kids need language to explain their sibling's ASD to themselves and to others. Having a name for the thing that makes your brother or sister "different" can be very helpful.

Teen siblings worry about the future



Emily Holl, MFA, LMSW

care of their brothers and sisters, and what role they will play. Adolescents need to know that future plans are being made and should be part of planning conversations. Adult siblings often support their brothers and sisters later in life, an overwhelming situation for many. Adult sibs need help navigating the service system and opportunities to connect with other siblings to share information and support.

"Question for sibs of those with severe autism," one sibling recently wrote on [SibNet](#), our online group for adult siblings

of people with disabilities. "What sort of living situation have you found for them and is it working? My parents are struggling more than my heart can take! Being a new mom, newly single, and the only other sib, I'm feeling helpless and beyond overwhelmed" (SibNet, 2020).

Ongoing communication in age-appropriate language enables siblings to understand, come to terms with, and support their sib's autism. Conversations with parents and professionals are key. We encourage parents to check in frequently with kids regarding their understanding of their sib's autism and services. We urge professionals to set aside time to address siblings' questions and concerns.

Isolation/Loss

Siblings experience isolation from family members, peers and the greater community (Meyer & Vadasy, 2008, p. 20). Sibs may feel the loss of a "normal" sibling relationship, and isolation from parents, whose attention is largely focused on their ASD sibling. Many struggle silently with mental health and safety concerns.

"My brother has autism and gets extremely violent," shared a sister in our [SibTeen](#) group for adolescents. "I've been having so much anxiety since school is coming up. Since the routine is about to change, meltdowns are about to happen.

I've had nightmares about him and everything. I wish I had a way to bond with him but I'm anxious whenever I try to. I'm not sure what to do" (SibTeen, 2016).

Providing siblings with opportunities to connect with each other is an important way to help them understand they are not alone. "I have a younger sister who has autism. She is very low functioning, non-verbal and lives in a group home," shared a sister on [SibNet](#). "For my entire life I've longed to connect with others in a similar situation. This feels like a start. I'm in tears looking through some of the posts. You guys get it" (SibNet, 2020).

Resentment

When family life seems to revolve around one person, resentment is a natural response. Often, a family's financial, social, and emotional resources are heavily invested in the child with autism. Siblings often resent receiving less parental time and attention, and how a disability can limit family outings, vacations, and activities (Meyer & Vadasy, 2008, p. 25).

Siblings can resent unequal expectations for behavior and chores, and often have a clear sense of which behaviors and limitations can be attributed to the diagnosis. "My older brother has autism, and I have

see *Support Strategies* on [page 34](#)

Siblings Realize They're Not Alone: AHRC NYC Sibshops Unveil Common Challenges

By Lynn Uhlfelder Berman
AHRC New York City

Lori Jacobs recalled a conversation with her younger son Seth, whose brother Ian has high-functioning autism and mood disorders. "Seth said, 'Promise me I won't have to take care of him when I grow up. And please, promise me you have a plan for him,'" Lori said.

This wasn't the type of conversation she imagined having with then 13-year-old Seth. "He worries about his brother," she added. "He loves, adores and respects Ian."

Growing Up Quickly

Seth, now 14, is a member of [AHRC New York City's Sibshops](#), a therapeutic recreation workshop for siblings of a brother or sister with autism or other developmental disabilities. He joined at age 5. Annette Spallino, Coordinator for [AHRC New York City's Sibshops](#) and Social Work Supervisor with the agency's Family and Clinic Services, has seen siblings grow up quickly. While neurotypical siblings' experiences vary widely, this is one of many challenges they share.

"Some (like Seth) are scared that they may have to take care of their sibling," Spallino said. "I tell them that this is not something they have to be concerned about now. 'What you have to do now is be a kid. What you have control over is what you can do now.'"

Like many of the 5- to 14-year-olds in Sibshops, Seth is extremely mature, bright, and articulate. "He's a young boy beyond his years," Spallino added.

Early Adopter of Sibling Programs

AHRC NYC began one of the first sibling programs in the country in the 1980's. In the late 80's and 1990's, AHRC NYC sponsored several sibling conferences where siblings from the tri-state area gathered to talk about what it was like to grow up with a sister or brother with developmental disabilities and the shared issues they faced. Today, AHRC NYC continues to run sibling programming in the form of Sibshops for younger siblings. Several siblings are also members of the AHRC NYC Board of Directors where they advocate for people with disabilities and share their perspective with the Board.

The sibling relationship is likely to last longer than any other. Siblings welcome professional and peer support in Sibshops' non-judgmental environment.

Support for All Family Members

"Families need comprehensive early intervention that includes support for sibling interactions,"¹ says Helen Tager-Flusberg, a Boston University autism researcher on language development. "Siblings with and without ASD need strategies to relate to each other - to help themselves and the functioning of the family as a whole."

Parents are more willing to discuss what's going on in their lives, Spallino



Seth Jacobs, 14, and his brother Ian, 20, who has high functioning autism. Seth has been a member of AHRC New York City's Sibshop since he was 5.

said. "They want to see themselves as a family unit, not as damaged goods. There's a lot more support for the individual with autism and the family thanks to advocacy which is really helpful to parents," she added.

Veronica Sterling, a Bronx mother of two sons with autism and a neurotypical daughter, agrees. "We need support and our kids need support."

Not Alone

"Our Sibshops help them to understand and not feel alone," Spallino said. "The kids often feel they're the only ones with this problem - they're very 'me' focused. It's eye-opening for them to see 15 other kids in the same boat. And they know you can say whatever you want here."

Jocelyn Sterling, 10, joined AHRC NYC's Sibshops at age 6. "It's not easy to have a sibling with autism," she said. "You have to understand they're different from you." Her brothers, Noah, 14, and Jayce, 3, are on the spectrum.

"I was really nervous about going," she said. "I thought there was only one special need (autism), but I learned there are different special needs. I feel more comfortable talking about my brothers with others because my friends don't understand autism."

Understanding Your Sibling

One of the top challenges facing siblings spans the youngest and teen Sibshop members. "Understanding why my sibling does what he or she does is difficult," Spallino said. "What is really wrong with him/her and why is it always 24/7 the United State of Johnny or Jane?"

This logically leads to feelings of jealousy. Sibshop members don't understand why their parents pay so much attention to

their sibling with autism. They see a double standard cause the sibling gets more attention when he/she has a behavior problem and requires special services, yet if they misbehave, they may be punished.

Sharing a Strong Bond

Despite this, strong bonds evolve. A Tel Aviv University and University of Haifa study found that [relationships between children and their siblings](#) with intellectual disabilities are more positive than those between typically developing siblings.² The research examines the relationships of typically developing children with siblings with and without intellectual disabilities through artwork and questionnaires. It was conducted by Prof. Anta Zaidman-Zait of the Department of School Counseling and Special Education at TAU's Constantiner School of Education and Dr. Dafna Regev and Miri Yechezkiely of the University of Haifa's Graduate School of Creative Art Therapies. The study was recently published in *Research in Developmental Disabilities*.

Virtual Sibshops to Start in Fall

With the Covid-19 pandemic, AHRC NYC was unable to host Sibshops since the spring. Siblings also missed out on an annual weekend at AHRC NYC's Camp

Anne. "I can only imagine how much worse it can be with everyone at home," Spallino said, adding that going to school would provide a welcome break for neurotypical siblings. "School helps them to normalize. It's very hard when these kids are home in a virtual classroom and their sibling is home not cooperating. That can be very distracting."

Sibshops across the nation are going virtual. AHRC NYC's Sibshops will begin in September on Saturdays, Spallino said. "We may be able to reach a wider audience by going virtual," she added. Among the activities planned for AHRC NYC's Sibshops are:

- asking participants to find a personal item in their home and what makes it so special
- describing your feeling about being home during the pandemic by coloring in this picture of a heart
- finding something in your home that makes you think of your sibling, aka "Zoom Around the Room"

Ian and Seth

In many ways, Seth and Ian Jacobs' re-

see [Sibshops on page 21](#)

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Autism Through a Different Lens: A Sibling's Perspective

By Amy Kelly, MBA, MNM
National Director of Family Engagement
Devereux Advanced Behavioral Health

In my profession, I often write articles from a parent's perspective about having an 18-year-old daughter (Annie) with severe autism, and intellectual and developmental disabilities. My overarching goal with these stories is to provide compassion, understanding and hope to families, caregivers and professionals who may be in a similar situation.

For more than 15 years, I've made it my mission to understand Annie's diagnosis and provide her with a secure, happy and fulfilling future. Learning how to advocate not only for Annie but for all individuals with autism has aided in this mission. Becoming educated on the topic of autism also has been somewhat cathartic, as it allows me to feel as though I'm doing something to help Annie.

For Annie and countless others living with cognitive differences, there is no known cause, cure, predictable therapy or treatment regime guaranteed to ensure maximum impact. These truths can be extremely overwhelming for any parent or individual. These truths, however, also can be eye-opening.

My 19-year-old son, Danny, shared an essay about his personal journey with his sister – from a sibling's perspective. It was



Danny with his sister Annie

similar to my own journey, yet uniquely different, and it could not go unseen (I did get his permission to reprint!):

A Sibling's Perspective

"Haircut."

"Yes, Annie, you will have a haircut on Tuesday."

"Haircut."

"Yes, Annie, I know."

"Haircut ... Haircut."

Now, imagine this conversation continuing for four hours straight, while working on a crucial school assignment. All my life, I have lived with my sister, Annie, who has autism. Autism is a developmental disorder that affects the social interactions and communication of an individual. She means the

world to me and is one of my biggest inspirations. Although I feel this way, the rest of society doesn't always understand her in the way I do. Her disorder isn't apparent in how she looks, but it is in how she acts. She struggles to communicate and gets very frustrated.

I am a firm believer that something positive comes out of every situation. Annie's autism has served as a catalyst to change my own outlook on life. She has changed me as a person, shaped who I am, and has instilled three core values I hold above all else.

- The first value is **patience**. Every time I get frustrated with Annie, I imagine the struggle she undergoes every day that is infinitely harder than what I am going through. Annie has anxiety, in addition to autism, so she often repeats the same phrases, such as getting a haircut, over and over again because she needs to have a set schedule she follows every day. From this, I have learned to be patient with others and become less frustrated in the real world.
- The second value is **perseverance in helping others**. I am committed to helping my community and helping make people aware of individuals like Annie. This led me to volunteer in my community with organizations that help

see *Perspective on page 34*

What Happens When One Twin Has Autism

By Marguerite Elisofon, BA
Author, Writer and Autism Consultant

When my twins were born prematurely on December 26th, 1990, nobody talked about autism. There was no internet and autism support groups did not yet exist. Caring for two premature babies was overwhelming enough, but the dawning recognition that our daughter Samantha was not developing at anything like the same rate as her twin brother was both terrifying and heartbreaking.

When we learned that Samantha had pervasive developmental delays, later recognized as a form of autism, it seemed like a doomsday diagnosis. But we were fortunate to discover our daughter's challenges very early, thanks to the differences between her and her neurotypical twin brother. Matthew spoke early, asked questions and acted hungry to engage with the world. In contrast, Samantha spoke much later, rocked, stared into space, failed to answer to her name and seemed mostly disconnected from the world.

Although parents aren't supposed to compare their children, it was impossible not to notice the glaring differences between our twins' behavior. When premature babies reach developmental milestones and "catch up" to full-term babies, parents are thrilled and relieved. However, for us, watching Matthew grow and explore the



Matt and Samantha Elisofon

world was bittersweet because we also saw Samantha fall further and further behind.

When our daughter was only 8 months old, we were already reaching out to experts for help, much sooner than if she didn't have a neurotypical twin brother. Four months after beginning our autism journey, we finally got an appointment to see the renowned child psychiatrist Dr. Stanley Greenspan. Greenspan convinced us that early intervention was essential for our daughter's success. In addition to recommending speech, occupational and play

therapy (floor time), Dr. Greenspan believed that Samantha would benefit greatly from having a neurotypical brother as a role model.

Sadly, it was almost impossible for Matt to interact successfully with his twin sister, although he tried his absolute best. When he initiated play with Samantha in the bathtub by splashing her, she cried instead of splashing back. Simple conversation between the twins was close to impossible because our son was so far ahead verbally. One short-lived success occurred when Samantha decided she wanted her brother's penis and chased him around the house while Matt teased her, waving a towel like a matador with a charging bull.

Although Matt and Samantha started together in the same pre-school, it became clear by the second year that our daughter was struggling. She couldn't follow simple directions and put her coat in her cubby. Matt tried to help her with these tasks to prevent her from melting down, but that just made Samantha angrier. From the moment we brought our daughter home from the hospital, she wanted to act independently and hated people helping her.

Lying on her stomach in her crib, Samantha was too weak to turn her head - even though she turned purple trying. Worried that she might suffocate, I gently nudged her face the extra few inches sideways. Samantha immediately struggled to turn her head in the opposite direction, crying in fury. Without yet hearing the words, I

still knew she was saying: "I want to do it myself." That would become her battle cry throughout her childhood, as well as a source of embarrassment and frustration to her brother.

In addition, Samantha became increasingly envious of Matt's ability to dress himself and accomplish age-appropriate tasks independently. Despite lacking the motor skills to put on her clothes, Samantha lashed out at her brother and anyone else who tried to help her. It took three people to gently wrestle her into her clothing and get her to the school bus on time. Half the time, she would rip off her clothes in frustration and we'd have to start again.

At age 5, Samantha started at The Parkside School for language impaired children while Matt continued in mainstream schools. Her meltdowns embarrassed him, and each of them needed to grow and develop at their own pace. After school, I would take Samantha to a variety of therapy sessions, while Matt went on play dates with the babysitter.

Over the years, I kept hoping and encouraging our twins to bond. They were always affectionate toward each other, but otherwise avoided any extended interaction. Sadly, most of their interactions were negative. They were endlessly jealous of each other. Samantha envied her brother because everything that came easily to him was difficult for her: making friends,

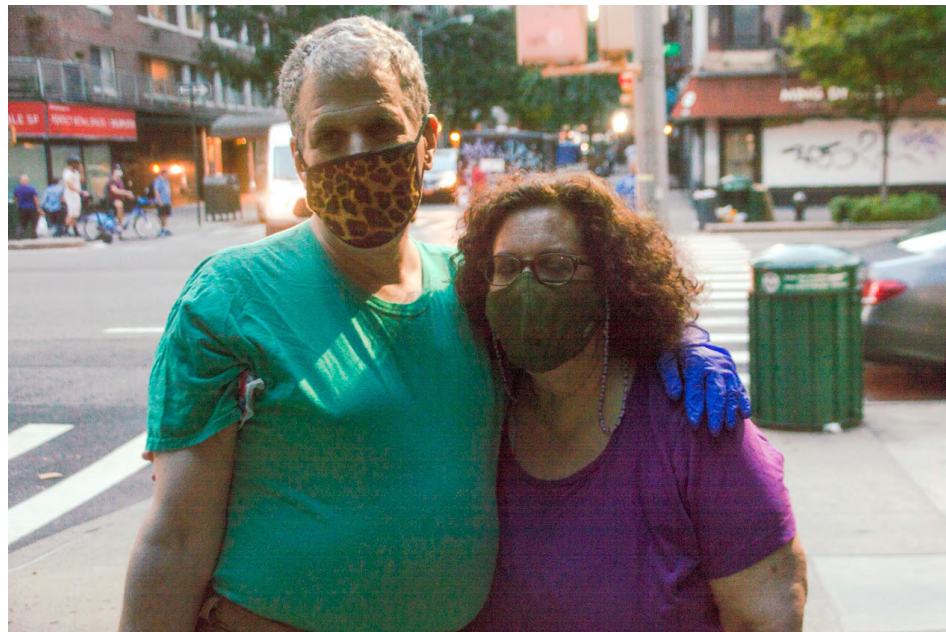
see *Twin on page 27*

Sheltering at Home with My Brother Douglas

By Gerri Zatlow
Director
Siblings for Significant Change

After the death of my mother I became my brother Douglas' legal guardian and sole relative who would advocate for, protect and welcome him every weekend and holiday. The only time he was not able to come to me was when there was an epic snowstorm preventing travel, when I was sick, injured and or had surgery. We established a routine which included the usual, a fair amount of what is called activities of daily living skills, helping Douglas with shaving and laundry.

I have always been my younger brother's protector, teacher, confidant, translator, speech assistant, direct support professional and above all, friend. This is the nature of our relationship. I am the older sister, he is the younger brother, he had and has a condition that makes it necessary for me to provide protection and support for him always. I desperately wanted a brother when I was a child and was very specific with my mother. I wanted a brother, not a sister. Since he was yearned for and happily arrived, playing that role was understood. I'd always expected to be the big sister, offering love and guidance, but expecting some reciprocity in return. Before Douglas was diagnosed with autism, I embraced



Gerri Zatlow with her brother Douglas

being the big sis and dreamed of what our lives would be later. After acquiring a label that was frightening in 1965, I came to understand that my responsibilities would be much greater for my baby brother.

I was groomed from the time that I understood Douglas would require protection and direction for his entire life. As an adolescent it was a subtle awareness that showed me what might be needed. Douglas is younger than me and as a baby and

toddler he seemed quite OK. To my parents, especially my mother who compared his milestones with mine, he was different. When diagnosed at age 5 with what was then called "Infantile Autism Childhood Schizophrenia," my mother's fears were realized. I was more afraid of his label.

As Douglas reached adolescence his behavior and peculiarities were obvious. Douglas was never going to be average, but he was loved without condition. Some-

how our family managed through struggles, my parents' divorce, and numerous challenges for us all. Disabilities in general, and autism in particular, can be hard on any marriage.

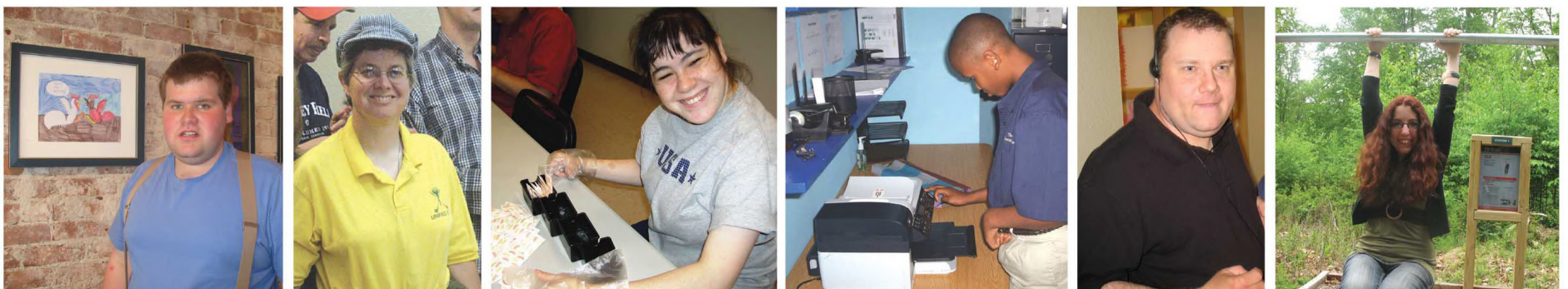
My mother's obsession to protect Douglas from a disinterested and uncaring world culminated in the creation of an agency to serve adults with autism. I was co-opted into joining the endeavor when my whirlwind of a mom realized she couldn't do it all by herself. My sibling persona was satisfied in this arena. I could see to it that people like my brother were cared for and happy.

On March 7, 2020 my brother came home for a weekend visit as usual. Since there were tidbits on the news that talked about a need at some point to perhaps clean or even close places, the thought never crossed my mind that it would happen. I spoke to staff at Douglas' day program and group home and was told that the day program would not be open on Monday or Tuesday so that a thorough deep cleaning of the facility could take place. We decided that I would take Douglas back to his residence on Tuesday, and he would get an extra day and night with me.

On Monday an email showed up in my mailbox that basically said "Nobody Out/ Nobody IN," dictating the recommendations of OPWDD (The New York State

see *Sheltering on page 25*

This is what success looks like...



This is what an adult living with autism looks like!

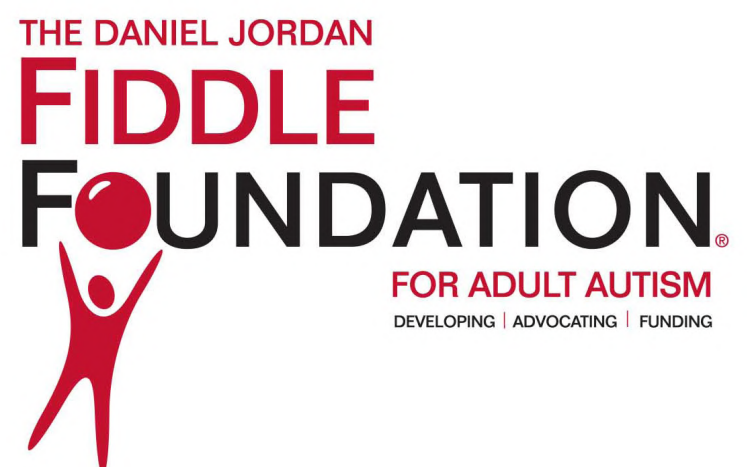
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Talking to Siblings About ASD

By Julie M. Wolf, PhD
Yale Child Study Center

Siblings of children with Autism Spectrum Disorder (ASD) have unique needs and may have a range of feelings, both positive and negative, about their experience with their brother or sister with ASD. They may be reluctant to share these feelings with parents due to feelings of guilt (Opperman & Alant, 2003) or concern that they will get in trouble for sharing them. However, open communication among family members has been associated with more positive adjustment for siblings (Howlin 1988; Lobato & Kao, 2002), and therefore it is very important for families to keep the lines of communication open.

There are a number of ways that parents can create an environment that encourages open communication among family members. One simple strategy is to make sure that autism is mentioned from time to time in the household. In this way, siblings will know that it is not a forbidden topic and as a result, they may be more open to sharing their own thoughts and feelings. However, it is equally important that parents initiate conversations to check in with their children. In doing so, parents should be prepared for children to share their entire range of feelings, even ones that parents may not feel are rational or valid. As difficult as it



Julie M. Wolf, PhD

can be, it is important for parents to remain neutral and give their children the opportunity to express themselves. Parents should offer support and ask their children if there is anything they as parents could do to help with any negative feelings. Parents might end the conversation by praising their children for sharing their feelings. Creating an atmosphere in which children feel heard and supported will increase the likelihood that they will share their feelings again in the future.

It is also perfectly appropriate and beneficial for parents to share their own feelings, within appropriate limits. Children sense their parents' feelings, and without communication, they may make their own inferences about their parents' emotions that may be far from the truth, or they may erroneously believe that their parent is angry or upset about something they did. That being said, parents should be thoughtful about how they convey their feelings and not overburden their children with the full intensity of their own emotions.

One critical area of communication is to ensure that siblings have accurate information about their brother or sister's diagnosis. Although their understanding matures over the course of development, research has suggested that siblings of children with ASD show delayed understanding of ASD (Glasberg, 2000). The reason for this delay is unknown, but one possible explanation is that adults in their lives assume that they are knowledgeable due to their personal experience and are thus less likely to talk to them about autism. However, when children are not provided adequate information about a diagnosis, they may invent their own explanations which may be more frightening or stressful to them than the truth (Lobato, 1993).

When it comes to sharing factual information about autism, most children will not be able to absorb large amounts of information in one sitting, so parents should focus

on sharing small amounts of information at a time or just answering the specific question their child asked. Information should also be repeated over time, as children will absorb the information differently over the course of development. The way in which information is best shared will change over the course of development as children mature in their ability to process information.

For young children, language should be kept simple, and information should be tied to a specific behavior. For example, a parent might say, "Your sister is upset because she does not like the bright lights." Young children may hold erroneous beliefs about autism (Glasberg, 2000); for example, some young children may believe that autism is contagious. Parents should always correct any false beliefs their children hold. Another strategy that can be beneficial for young children is to create a book explaining autism. Children can be involved in helping to create the book and illustrate / color its pages.

Adolescents are capable of more complex thinking and should be provided as much information as they desire. At this age, siblings may be interested in reading books or articles about autism. While their thinking and reasoning abilities have advanced, emotional development is still ongoing, and adolescence has been found to be a time of more intense and less stable

see *Talking on page 33*

How a Sibling Connection Inspired Advocacy and a Career

By Nicholas Lombardi
The Arc Westchester

When I was nine years old, I became an advocate. We were out in public and a woman chastised my mom for being unable to control my younger brother, Joey. My blood started to boil and I was outraged by this woman's lack of empathy. However, my mom handled the situation with poise and grace, focusing less on the reprimand and more on helping my brother calm down. As the woman walked away, I thought to myself, "If only she knew Joey, and knew about autism, maybe she would have treated him differently."

But it's often difficult to know when someone is on the spectrum, which is why I was compelled to create something tangible to help spread awareness. And so I designed a pin that said: "I'm not misbehaving, I have autism. Please be understanding." This pin became a symbol of empowerment for my brother, and eventually expanded out to the greater autism community. We partnered with Autism Speaks to sell this pin on their platform and went on to raise tens of thousands of dollars for autism research. This became a defining moment in my life and one that encouraged me to pursue a career in education and advocacy for those with special needs.

I was two years old when my brother Joey was born. I could not have been hap-



Nicholas Lombardi

pier to assume the role of older brother. Of course, for so many kids, the sibling bond is complex. But for siblings of individuals with autism, like myself, that bond can be even more complex, changing and evolving over time. In the book *Autism Spectrum Disorders: Identification, Education and Treatment*, Dianne Berkell Zager explains, "Living closely and intensively with a sibling with a disability can be both rewarding and stressful" (2004). To me,

that sentence defines this sibling connection perfectly.

My brother is non-verbal and was formally diagnosed with Autism Spectrum Disorder (ASD) at the age of twenty-two months old. As you can imagine, my four-year-old brain didn't quite understand what that meant. I remember my parents sitting me down and explaining that while our dynamic would be different, we were still a strong family unit. And they were certainly right. It was not always easy, and I often compared my relationship with Joey to those of my friends and their siblings. But I learned to accept Joey for exactly who he was. And we developed our own type of amazing special bond. Whether it's cheering on the Yankees together or holding hands during the Radio City Christmas Spectacular, Joey and I have developed a close relationship built around trust and unconditional love.

But perhaps one of my greatest joys as a brother has been watching Joey progress against all odds. He was the type of baby who escaped from his crib and couldn't stay in one place for very long. When he started formal schooling and speech therapy, we began to see small improvements in his communication skills and behavior.

As the number of children diagnosed with ASD increases and as they grow up, there is a greater focus on adult issues. And while there has been a decent amount of research into the effects of ASD on siblings during childhood, there has not been as

much focus on what happens when they become teens and adults (Foden, 2008). This research would have a huge impact on the lives of autism families and could hopefully inspire more siblings to get more involved in advocacy efforts at a young age.

Below are just a few examples of the innumerable ways that having a brother with autism has impacted my life, from my career choices to the ways in which I interact with the community on an everyday basis.

Inspiring a Career

I knew that the ASD community and this type of environment would always be a part of my life, I just didn't know how. When I was in college, I changed my major a few times, and at one point I thought I would become a special education teacher. I then found marketing and communications, fell in love with it and ended up finding a perfect blend of these two passions at The Arc Westchester. I was able to marry my love of marketing and my deep connection with this special needs community.

Throughout the COVID-19 pandemic, I faced an interesting situation in my career. I was working from home with my brother; who's routine was interrupted by sheltering in place. At the same time, I was helping my organization come up with new ways to innovate and expand their services virtually.

see *Connection on page 34*

Preparing Children with ASD for New Siblings

By Devon Ritenour, MEd, BCBA,
Jennifer Rosenblum, MS, BCBA,
and Samantha Smith, MS Ed, BCBA
Exceptional Learning, LLC

Introducing a new baby is a wonderful, joyous time for a family. When preparing children with Autism Spectrum Disorder (ASD) for a new sibling, your approach may need to begin long before the new baby arrives. According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), individuals with ASD may demonstrate inflexible adherence to routines, poorly integrated communication, and adverse responses to specific sounds (American Psychiatric Association, 2013). In general, a new baby is accompanied by unpredictability, frequent, loud noises, inconsistent schedules, among other new challenges. Establishing protocols and teaching new skills to your children prior to a baby's arrival may be essential in facilitating the transition for a growing family. Here we will briefly introduce a variety of strategies to teach these skills that may be beneficial to add to daily routines.

The first drastic change for your child will be the new noises associated with a baby, such as crying, cooing, etc. Effective preparation for baby noises, most markedly crying, for individuals with sensitivities can allow for fewer challenging reactions.



Systematic desensitization, or shaping, where the individual is reinforced for tolerating successive approximations of increased duration or intensity of a baby crying is one way to assist in the preparation. This procedure may include the individual being reinforced for listening to a video of a baby crying for systematically increased durations and volumes. Upon meeting a predetermined criterion (e.g., listening for five minutes, at volume three, across ten days), the individual would be expected

to listen for a progressively increased duration and/or volume until they were able to listen at the final duration or volume. As an alternative or supplemental strategy, individuals may benefit from embedding the sound into positive, playful activities or use noise-canceling headphones. It is important to pair the use of noise canceling headphones with the functional communication response in which the individual is taught to recognize the need for the headphones and either requests or retrieves

them independently.

Another skill to apply desensitization strategies to is tolerating diverted attention from a parent or caregiver. A new baby, while already having other children, requires a great deal of multi-tasking. However, there are going to be times when you will need to solely focus on the new baby. Teaching your child to tolerate not being in your vicinity or accessing your attention for a period of time while they occupy themselves will be an extremely helpful skill. Ways to begin this process are similar to exposing the child to new noises. First begin with brief periods of time that you cannot attend to them (e.g., 5-10 seconds). Once the child is able to tolerate the diverted attention and engage with other items or people, slowly begin to increase the amount of time. As with any procedure, promoting communication is the key to success.

As indicated above, when teaching a child to request for noise canceling headphones, teaching the request to access this item can effectively decrease the likelihood of challenging behavior. Functional communication training (FCT) to teach communication responses has been shown, repeatedly, to effectively prevent or reduce challenging behaviors (Tiger et al., 2008). FCT can be taught using a variety of modalities including but not limited to

see *Preparing on page 28*

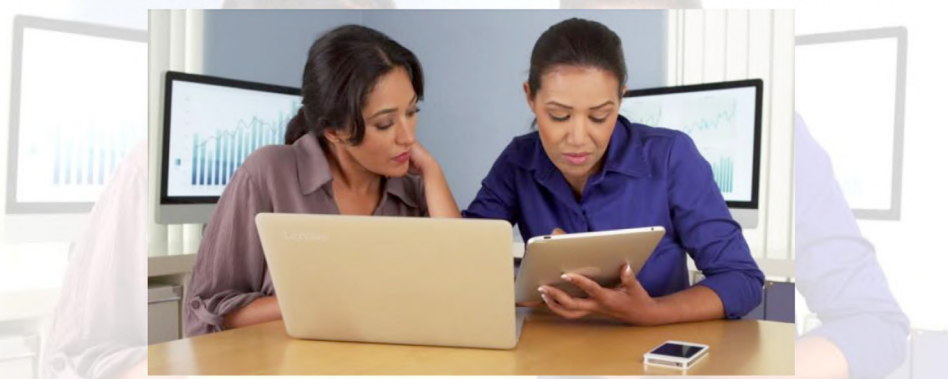
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Using Siblings as Peer Models During Telehealth Sessions

By Kelly Stafford, MS, BCBA, LBA
and Maria Gilmour, PhD, BCBA-D, LBA
Wynne Solutions, LLC

In the past few years, the use of telehealth services in the field of Applied Behavior Analysis (ABA) has grown substantially. Due to health concerns related to COVID-19 and social distancing recommendations, ABA providers now use telehealth more than ever to deliver services remotely. Telehealth allows practitioners to continue providing treatment to individuals and their families while following social distancing guidelines.

There are many benefits to providing behavior analytic based services using telehealth. Not only can practitioners provide evidence-based interventions to individuals living in rural areas, but these services can be delivered in a more cost-effective way (Ingersoll & Berger, 2015). Other benefits noted by clinicians include quicker generalization of skills and the extension of behavioral education to family members and caregivers.

Research has shown the positive effects of using neurotypical peers to model appropriate behaviors across skills for individuals with Autism Spectrum Disorder (ASD). Jones & Schwartz (2004) suggest that siblings could potentially make ideal peer models due to shared social histories and the ability to model skills within the home.



Kelly Stafford, MS, BCBA, LBA

For many children with ASD, the first peer relationship is with a sibling. Neurotypical siblings can help parents manage behaviors of neurodiverse siblings and model social behaviors as well as functional skills (Angell et al., 2012). Using siblings in social skills interventions for children with ASD has proven successful. In one study, researchers taught neurotypical siblings ways to socially engage their siblings with



Maria Gilmour, PhD, BCBA-D, LBA

ASD. These lessons included such things as establishing eye contact, initiating conversations, turn-taking, and offering help. The neurotypical siblings were able to effectively use these skills with their sibling with ASD and results showed increases in social interaction as well as joint attention, despite this skill not having been targeted (Tsao & Odem, 2006). Utilizing siblings to model appropriate behaviors is com-

mon practice in behavior analytic-based sessions. Sibling involvement during telehealth sessions should also be considered common practice.

In our experience since the world pandemic, we have included siblings during telehealth sessions more now than ever before. Siblings can be utilized in telehealth sessions similarly to how they can be utilized during in person behavior analytic-based sessions. Using siblings during telehealth sessions has been helpful in teaching a variety of social interaction skills. For instance, we have a neurotypical sibling serve as a communication partner for Picture Exchange Communication System (PECS) for their sibling with ASD. This sibling is also used as a model in gross motor imitation and following 1-step directions. As a result, we have witnessed quick and positive responses and interactions between siblings. We have also seen that access to certain siblings can serve as reinforcement during sessions.

Additionally, we have had success with involving neurotypical siblings in a program for teaching their sibling with ASD to accept *no*. The sibling with ASD was taught to respond to a nonverbal cue (thumbs up for *yes* and thumbs down for *no*) when approaching parents and siblings. If given a thumbs up, the sibling knew that the parent or sibling was available to interact at that

see *Peer Models* on page 28

Under Pressure: Support for Siblings of Individuals with ASD

By Alison Kolber-Jamieson, EdS
School Psychologist

As a school-based mental health professional and a sister of a person with autism spectrum disorder (ASD), the sibling perspective on family-centered care is not just important to me, but necessary in order to give comprehensive and competent care to the families who look to communities and schools for help. Sibling relationships are especially unique in that they are typically the longest lasting of most human relationships. Therefore, siblings require unique services.

Lovell and Wetherell (2016) examined the psychophysiological impact of children with ASD on siblings. Their results indicated higher levels of depression symptoms in children who had siblings on the autism spectrum when compared to children who had siblings not on the autism spectrum. Data indicated that siblings' depressive symptoms were related to the behavior problems of their sibling, as well as social support, or lack thereof, received through the school or at home. Additional challenges for siblings include lowered self-esteem (Emerson & Giallo, 2014), increased risk of internalized behavioral problems (Meyer, Ingersoll, & Hambrick, 2011), and a heightened sensitivity to typical family stressors (Emerson & Giallo, 2014; Meyer, Ingersoll, & Hambrick, 2011).



Alison Kolber-Jamieson, EdS

For this project, I sought to find what social and emotional needs are most pressing to school-age siblings of individuals with ASD, as well as what services were provided to them. I interviewed nine participants with the intent to gather individual experiences of growing up with a sibling with ASD, social and emotional experiences due to the participant's sibling's diagnosis, and what was - or would have been - helpful.

Pressure to Perform

Many participants described feelings of

anxiousness over a presumed responsibility to be "unproblematic" or "perfect." This included pressure to perform well in school and extracurricular activities while still being available to help at home. They also reported feeling sadness and grief over missed or sacrificed opportunities due to family obligations.

"I want to be the one that is there with him all the time and watching over him because I know of issues in the past where things have happened to him and he hasn't been able to communicate to us. And then I'm terrified... What if there are some things going on and he can't tell me?"

"I do put a lot of pressure on myself to succeed academically. I don't know if that's a product or not of [my brother] not being able to succeed in this one way. I wonder if that's a reason why I put a lot of pressure on myself."

Systems of Support

One of the most universal findings was participants' desire to have a support system of others who "get it," such as a support group or Sibshop. Many talked about the feelings of isolation that come with having a sibling with autism and felt that they could not talk to their friends about home life, as some situations are difficult to explain to those who have not experienced it. At the same time, participants

felt they could not discuss their feelings at home, because they did not want to cause feelings of guilt in other family members.

"I wish I had somebody older to talk to when I was younger... Not my parents. Somebody who understood my brother's situation and understood what it was like to be a sibling and told me it was okay to feel the way I felt."

"I googled once, because I was curious, 'autism family resources' and the stuff that popped up was all for parents, not the whole family. It would be nice to be included more in the services."

"Normal Kids"

Though there are many difficult experiences that come with having a sibling with ASD, there are many positive elements as well. All the participants described their siblings as their favorite person and reported feeling uncomfortable when others assumed that their life is extraordinarily difficult. Situations that would appear strange or difficult to those who do not live with an individual on the spectrum - siblings may take in stride as a part of their everyday life. Though some situations may be challenging, no meaningful relationship is without challenges.

see *Pressure* on page 30

How to Best Support Siblings of Individuals with ASD

By Amy B. McCoy, MS Ed
Children's Author and Disability Educator
Little Big Sister Books, LLC

Typically developing siblings of individuals with autism spectrum disorders (ASD) have a unique set of needs that often go overlooked and unnoticed. These needs are generally social and emotional in nature and can affect siblings at any age during their lifespan. When one family member has a disability, it affects the whole family because family members may feel isolated from others or different because of the impact of the disability (Burke, 2004)

Main Causes of Sibling Difficulties

Lack of communication and information

- Many siblings are not given the name or definition of their sibling's disability. When siblings have a limited understanding of their sibling's condition, this lack of information may lead to distortion and confusion (Kahn & Lewis, 1988). Some may wonder if they caused their sibling's autism or if it is contagious. As they get older, they may wonder if they will become responsible for their sibling's care after their parents are no longer able to care for his or her needs. Having an open line of communication between parents, siblings and other family members about autism alleviates this struggle. Siblings need more information about autism not only for their own understanding, but also to make it easier for them to explain to others why their brother or sister with ASD behaves differently (Abrams, 2009).

Lack of Support - Siblings may feel isolated and unaware that they are not the only one who has a sibling with ASD. Many siblings feel disconnected from their peers because peers can't understand the complexity of their relationship with their sibling who has ASD. Social support specifically for siblings may play an important role in the healthy and adaptive adjustment of siblings (Kaminsky & Dewey, 2002). Support groups for siblings help to counter feelings of isolation by enabling siblings to identify that others are dealing with similar circumstances (Abrams, 2009).

Feelings of Resentment, Embarrassment and Frustration - Some siblings have reported feelings of resentment because of the extra parental attention given to their sibling with autism (Benderix & Sivberg, 2007). From the moment of an ASD diagnosis, (and often before), parents are propelled into a world of therapies, special education meetings, medical appointments



Amy B. McCoy, MS Ed

and other time-consuming elements of the ASD experience. While every family is different, it is inevitable that parents' time, energy and attention becomes focused disproportionately on their child with ASD. Some siblings feel embarrassed by their sibling's behavior and as a result do not invite friends over to their homes (Abrams, 2009). Many siblings have reported feelings of frustration and even grief over the loss of a typical sibling relationship. They may also experience frustration over witnessing or being a target of aggressive behaviors by their sibling with ASD.

Supporting the Unique Needs of Super Siblings – Tips for Families

Honest, Age Appropriate and Ongoing Communication - Keep the conversation about autism open and ongoing, as the siblings' need for information and the extent of details will change as he/she matures. Providing age appropriate explanations for what autism is can help siblings understand and manage their perceptions about why their sibling with ASD receives extra attention and support (Harris and Glasberg 2003). It is important that the sibling can share his or her feelings, both positive and negative with parents or others (Benderix & Sivberg, 2007). If the child is not comfortable sharing thoughts and feelings verbally, use of a two-way journal, where parent and child alternate written entries may be helpful. Reading children's books that include characters with ASD together may spark an open, honest, ongoing conversation about ASD.

Support Groups – You Are Not Alone

- One well documented program for supporting siblings is [Sibshops](#). Siblings who

attend Sibshops show an increase in positive feelings about their brother or sister with a disability and acquire useful coping strategies (Johnson & Sandall 2005). If there are not any support group opportunities in your area, connect with other families through your child's school or through special needs recreational sport programs. Locate babysitters or caretakers who are siblings of individuals with ASD so your younger child has access to a role model who is living in this situation.

One-on-One Time, Making Socializing Possible, Acknowledging Strong Emotions

- To counter the feelings of resentment caused by extra parental attention focused on the child with ASD, parents can schedule one-on-one time with their typically developing child(ren). Just 20 minutes per day of undivided attention engaging in your child's choice of activity makes a meaningful difference.

To make socializing possible, arrange for a caretaker to bring your child with ASD out for a few hours so your other child can invite a friend over. If that is not possible, the caretaker can stay in your home while you take your typical child out with a friend to the park, a movie, a restaurant or any location that is appealing to your child.

When siblings are able to express their strong feelings (of frustration, anger, sadness or any other feelings related to their sibling with ASD) parents can acknowledge these feelings without judgment. "I noticed you are feeling angry about your brother," is a response that allows the expression of strong feelings. Identifying and allowing the strong feelings helps siblings to process their emotions and feel understood.

Summary

Siblings of individuals with ASD have specific and unique needs. Keeping communication open, honest and ongoing is a key component when supporting siblings. Providing siblings with opportunities to meet other siblings of individuals with ASD is beneficial in order to decrease feel-

ings of isolation. Planning one on one time with our typically developing children and arranging creative ways for them to socialize comfortably with peers are two approaches that parents can take to support these specific needs. Acknowledging and allowing siblings to express strong emotions helps them to process their emotions and feel better supported.

Amy B. McCoy is a former elementary school teacher and current children's book author. She writes the *Little Big Sister* book series which focuses on autism awareness, told from a sibling's point of view. She is a visiting author to elementary schools spreading autism awareness and understanding. For more information please visit www.littlebigsisiterbook.com.

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Guidelines from page 1

positive when: 1) they had an understanding of the siblings disability; 2) they had well developed coping abilities; and 3) they experienced positive responses from parents and peers toward the sibling with autism (McHale et al., 1986).

There are negative experiences of having a sibling with an autism spectrum dis-

order that should be acknowledged and addressed. Anxiety, anger, jealousy, embarrassment, loss, and loneliness are all emotions that children will likely experience. Because of the nature of autism spectrum disorders there are barriers to the sibling bond that can cause additional stress as a result; communication and play can be difficult between siblings when one has an autism spectrum disorder. Often the sibling

without the disability is asked to assume or may on their own feel obligated to assume the role of caretaker. It is best to be proactive in addressing these issues. Siblings are members of the family that need information, reassurance and coping strategies just as parents do.

Each family is unique. There are various family structures such as single parents, multi-generational households, and

households with other significant stressors including more than one member with a disability. Each family has its own beliefs, values, and needs. Regardless of family circumstances, the suggestions for parents discussed here should be viewed as supportive strategies that can be considered to assist siblings in coping with having a

see [Guidelines on page 35](#)

Programming for Multiple Siblings with ASD: Tips to Promote Family Success

By Tori Massimo, MPA, MAEd, BCBA, Lynn Roba, MEd, BCBA, LBS-PA, Kristen Daneker, MS, BCBA, LBS-PA, and Jennifer Croner, MSEd, BCBA
Exceptional Learning, LLC

Current data suggest that if a family has one child with Autism Spectrum Disorder (ASD), the chance their second child will also have that diagnosis is 2-18% (Autism Speaks, 2020). If the family has two or more children with ASD, the risk their next child will also have ASD increases to 30% (The Australian Parenting Website, 2020). With each child, it is important to discuss any concerns regarding his or her development with your developmental pediatrician. Monitoring developmental milestones for younger siblings can be key to an early diagnosis. Early red flags to look for include a lack of joint attention, imitation, simple pretend play, and interest in peers (Barton & Harn, 2014). Early diagnosis is key to accessing early intervention and quality programming.

Individualizing a program for a child with an ASD diagnosis can be difficult at times, but programming for multiple siblings with ASD within the same household presents its own unique challenge. Quality program-



ming should include goals to address cognitive, behavioral, communication, functional living, play, and social skills. Programs that effectively address each of these areas will allow children to be successful in both typical settings and novel environments. These programs are derived from a variety of assessments that include the Assessment of Basic Language and Learning Skills (ABLLS), Assessment of Functional Living

Skills (AFLS), Essential for Living (EFL), Promoting Emergence of Advanced Knowledge (PEAK), Verbal Behavior Milestones Assessment and Placement Program (VB-MAPP), and Functional Behavior Assessments (FBAs). The assessment that your child's clinician chooses to use is based on their current skill set, treatment goals, and clinician training. Therefore, it is possible that one assessment will be used to devel-

op programming for your older child and a separate assessment will be used to develop your younger child's program!

While programming should be individualized for each child, families will have greater success implementing programs if there is some consistency across their children's programs. For example, families can develop a schedule to structure their day, and during some blocks of time the siblings may be prompted to engage in a group activity and at other times each child completes an independent activity. The activities included on the schedule will vary depending on your children's current skill level and treatment plan goals, or a group activity can be adapted accordingly. As an example, when playing Candy Land one child may simply be prompted to pick a card or move their piece while a second child may be asked to name the square color or count the number of spaces he moves. Increasing replacement behaviors throughout the day, such as independence with functional skills and communication, can help to decrease challenging behaviors and make these everyday activities easier to manage.

Focusing on similar social skills to target to increase appropriate interactions between

see *Programming on page 23*



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The Siblings from page 10

ask their questions and play their games. This, to me, is his progress. And it's even more than that.

In our house, if it's your birthday, you get to pick a restaurant for dinner. And one of the kids always picks the Japanese hibachi restaurant in town. Jack hates Japanese hibachi. Sure, he'll eat some chicken teriyaki, he just prefers it not be accompanied by a flaming onion volcano or people throwing food at his face.

I get it, I do. That big gong and all the fire and sake-soaked people shouting from the table next to us jangles my nerves too, and I'm not exactly on medication for anxiety. But it's a birthday, and we have to respect the wishes of the birthday child. Yet we also must respect Jack and his autism and the fact that loud, unexpected noises make him a nervous wreck. So, if we go to Japanese hibachi, he can bring headphones in for music, and if he needs to duck under the table for a few minutes, that's fine too.

Whether it's school, church, or dinner in a crowded restaurant, it can feel like we are jamming a square Jack into a round hole. But at home, our pegboard has no circles or squares. There is just a Jack-shape. We are constantly balancing our familial seesaw; we tip this way and slide that way un-

til we stop at a perfect standstill - until we find a quiet harmony. "I will make room for autism. I will make room for you, my brother."

Jack is *regressing* lately. I don't mean he's losing language (although there's been a bit of that, too) but his behavior is sliding backwards. He can't cope in situations that used to cause him no stress. He is impulsive. His right-and-wrong reasoning is off; skewed.

And oh, the deregulation. Do you know, I never incorporated this word into my own vernacular until about a year ago? Sure, I've bandied around *tantrum* and the ubiquitous *he threw a fit today*, but deregulation is a whole new level. It's like a tantrum is the candle on a birthday cake, but deregulation is a blowtorch. Sure, both can burn the house down if you're not careful, but deregulation melts everything in its path.

There are moments when he appears nearly incoherent - as though his brain is running at a marathon pace and the rest of him cannot keep up. It is scary, like watching a stranger inhabit our home. I don't know where he is. I don't know how to reach him. And then, just as fast as it began, it is over, and he is back.

And I wonder what it's like for them - for Joey, Charlie, Rose, and Henry - to see their brother disappear altogether and laugh maniacally at a joke no one told and

twitch his fingers and scream and startle when someone bangs the cabinet door too loudly. I wonder what it's like when I stop them mid-sentence, finger raised, and say, "Please, let me just handle Jack for a second." Or when we all have to listen to him argue for over an hour about why the *other* movie theater is better than the gift-card movie theater. I worry.

I worry when I - and it shames me to say this - lash out after one of his meltdowns because my patience is as thin as rice paper and I am brittle. Or when Jack's starting to rev up and I'm trying to calm him, and I catch 10-year-old *Charlie's* face out of the corner of my eye - pale and serious.

I see 13-year old Joey put his hand gently on his younger brother's shoulder at the bus stop to keep him from jumping and stimming right into the street. And I worry less.

I listen when Charlie calls his older-brother across the yard, "Jack! One more time! Let's play one more round of tag!" And I worry less.

I hear Henry lean over during our hibachi dinner and whisper, "Jack. It's almost over. They're almost done singing." And I worry less.

I stand at my kitchen counter the morning after Easter, tired and annoyed because I'd just stepped on a sticky jellybean, and I watch my daughter tap her brother on the

arm. "Jackie," she says, with her special nickname for him. "Jackie, look at me. Look. I made you this." She holds up a long braid she's made with the yarn from her new crocheting kit. "I made you this stress braid. You can pull it as hard as you can whenever you feel yourself getting mad. It will help you." I look at her earnest face and I watch him slowly take the braid from her hand and turn it over in his own. I watch him pull it - once, twice - to test its strength, before he tucks it into his pocket. And I worry less.

To Joey, Charlie, Rose, Henry, and every other brother and sister who lives alongside the spectrum disorder every single day, I wish you a happy forever autism awareness month.

May your world be filled with singing Mickey's, flaming onions, and long, colorful strands of unbreakable yarn.

And in the middle of the chaos autism often wreaks - in the center of the storm when your voice seems lost and your needs unmet - I hope you know that you, too, are very, very loved.

"What Color Is Monday?" is available on Amazon.com and BarnesandNoble.com. You can also follow Carrie on her weekly blog: www.CarrieCariello.com and Facebook.com/WhatColorIsMonday.

AUTISM SPECTRUM NEWS DESK

Marco Damiani, CEO of AHRC New York City, to Receive NCE Lifetime Achievement Award

By Dylan Watton
AHRC New York City

Marco Damiani, CEO of AHRC New York City, has been announced as the recipient of *The Arc's* 2020 NCE Outstanding Lifetime Achievement Award. This prestigious national honor recognizes an individual whose lifelong work has significantly contributed to the mission, core values, and positions of The Arc and salutes extraordinary service and outstanding dedication to people with intellectual and developmental disabilities (I/DD).

There are few more deserving leaders in our field than Marco. His commitment to promoting social justice for people with disabilities began more than 40 years ago as a Direct Support Professional at FECS, which included supporting people living at Willowbrook. In a recent meeting with AHRC NYC employees, Marco said that he can still vividly recall details of the experience of working at the infamous state-run facility and that his time there cemented his resolve to improve the lives of people with I/DD.

Marco later worked for **OPWDD** and then to the non-profit sector, including Executive Vice President positions at YAI Network and Cerebral Palsy Associations of New York City. He was the CEO of Metro



Marco R. Damiani, CEO, AHRC New York City

Community Health Centers prior to assuming the same role at AHRC NYC. He has overseen numerous important initiatives since his arrival, including our continued preparedness for the expansion of managed care, establishing New York Disability Advocates, emphasizing technological advancements, and policies encouraging open, honest, direct, constructive, and positive communication internally and ex-

ternally. His leadership since the onset of the pandemic has provided stability to the organization while it faces unprecedented challenges.

"Many thanks to the National Conference of Executives of The Arc of the United States for this recognition," Marco said. "It's been a long, winding and wonderful trip, with more road to cover. Inspired by many colleagues, families and peo-

ple with disabilities over the years, I've come to realize that what we do together, enables supports and opportunities wherever possible, is extremely important. But it's why we do it, to achieve social justice for people with disabilities, that's the ultimate goal."

In addition to his executive leadership positions, Marco was previously Chair of the Manhattan Developmental Disabilities Council and Chairman of the Alliance for Integrated Care of New York. He is also an appointee to the NYU College of Dentistry Dean's Strategic Advisory Council and is a recipient of the Kriser Medal, the College's highest honor. Most recently, Marco was appointed to Mayor Bill De Blasio's Sector Advisory Council on Public Health and Healthcare, which will provide a critical voice for people with I/DD and their support systems as New York City seeks to become more equitable following the COVID-19 crisis.

On behalf of our entire organization, congratulations Marco on this award celebrating your career. We look forward to continuing to support your mission to provide equality and social justice for everyone.

Dylan Watton is the Communications Coordinator at AHRC New York City. For more information, please visit www.ahrcnyc.org.

The Sibling Project at the Mental Health Association in Orange County, NY

By Jessica Markman
Mental Health Association
in Orange County, Inc.

Over the past twenty five years, Mental Health Association in Orange County, Inc. has had the pleasure of hosting The Siblings Project; a group for siblings of children with developmental disabilities. The participants, otherwise known as the "Super Siblings," meet monthly on Saturday mornings to partake in meaningful activities and experiences throughout Orange County, NY. Before COVID-19, this group met for a multitude of different activities such as arts and crafts, mini golf, arcades/escape rooms, holiday parties and more. Since the pandemic, the group continued meeting via Zoom;

playing games like trivia and Pictionary together. In August of 2020, the group was able to meet in person for the first time in months. The Super Siblings were thrilled to see each other again, and although we all had to maintain a distance, we were all able to play some outdoor games and go on a nature scavenger hunt together at Thomas Bull Memorial Park. Watching those kids playing together after months of isolation really warmed my heart, and it made me hopeful that the best is yet to come.

Although these activities are recreational, a clinical approach is added to ensure the Super Siblings get to share their personal experiences. An integral part of our group would be our Special Education teacher, Jacqueline Murray, who facilitates along with staff and adds that clinical approach to each gathering. Both Jacki

and staff create a safe space for those who attend to express themselves. It is understood that each sibling's emotions and feelings are entirely valid, which is the foundation on which this group was built on. Not only is this a safe space for the Super Siblings to express their anger, sadness, embarrassed feelings, or confusion, but they are surrounded by others who go through the same or similar life situations. It's a wonderful opportunity for those who participate to make lifelong friends who understand them on a different level than other may.

Currently, we are all experiencing overwhelming thoughts and feelings, but to a child or adult on the spectrum, this is exacerbating. Individuals with autism have difficulty with change to schedules, surprises, transitioning, and transcribing emotions; making home life hard on a

sibling. If you are a sibling, and you care for or live with a brother or sister with a developmental disability, please read this message: be kind to yourself. Give yourself more credit. You are doing everything you can to maintain this new "normal" for yourself and loved one. During these unprecedented times, it's difficult not to feel defeated. If you haven't heard this message today, please know that you're doing a great job, your sibling cares for you, and others care for you as well.

Jessica Markman is Developmental Disabilities Family Support Supervisor at the Mental Health Association in Orange County, Inc. If you have any questions regarding The Sibling Project, please contact myself, Jessica Markman: jmarkman@mhaorangeny.com or 845-342-2400 ext. 1253.

Tips for Communicating with Your Sibling on the Autism Spectrum

By Rachel Reich
Undergraduate Student, College of
Human Ecology at Cornell University

All sibling relationships can be challenging. Communicating with your sibling on the AS (Autism Spectrum) poses particular challenges for both of you. If you find yourself frustrated because you and your sibling are not communicating well, here are some tips that should help you both. The goal is to help both siblings feel heard, want to communicate, and know that they have the ability to make this happen.

Use Words Not Just Actions

You may be accustomed to communicating non-verbally, like with facial expressions, body language, inflection, behaviors, and/or omitting behaviors. To many, this may be an effective way to express your feelings, but for a loved one on the spectrum, much or all of these subtleties may be missed or misinterpreted. If you suspect your loved one is not “hearing” you, be sure to ask yourself if you explicitly stated what you wanted them to know (National Autistic Society).

Be Clear

Your loved one may not pick up on all



Rachel Reich

the meanings of people’s words to them. You may think that what you are saying is obvious, but they may not be receiving your meaning. Be as explicit as you can when talking to your AS loved one, especially when talking about emotions. For example, explain “I was angry this morning because _____.” Remember to stick with the literal. Avoid sarcasm, irony, figurative language, rhetorical questions, idioms, or exaggerations (National Autistic Society). For example, don’t say “Let your

hair down,” say “Take time to relax.” Clarify the meaning of the words you are using. When your sibling doesn’t understand the meaning of words you are using, let them know how you define these words. For example, you might explain something like, “When I say that may be ‘impractical,’ I mean it may not be possible because there is not enough time.”

Be Patient

If you ask a question, wait for their answer. They might need a little more time to absorb and process information before giving you their response (May Institute). If it seems like your sibling finds it hard to process what you are saying, slow down and simplify your speech. Additionally, be aware of the environment. It might be harder for your sibling to process information if it’s too noisy or crowded.

Be Sensitive

Your sibling on the AS might be accustomed to criticism for the way they communicate, which can leave them hurt, defensive, and/or desensitized due to repetition and perceived failure. You may appear judgmental or accusatory even if you aren’t trying to be. If you are asking them to communicate in a different way or challenging something they said, focus on making sure you let your sibling know

these are your feelings, and not an attack on your sibling’s flaws (Roberson). Importantly, encourage your sibling to say whatever is on their mind. For good communication to happen, your sibling needs to feel that they are in an environment where they feel safe, not judged, and where honesty is valued. Remind yourself that your sibling’s mind is physically and chemically different than that of a neurotypical person. Communication is not hard because either one of you is being “difficult” or “stubborn.” You have unique neurodiversities, and because of this, the way in which you speak with each other will be unique.

Support Your Sibling’s Communication Skills

So far in this article, you’ve read many ideas of things *you* can do. Your sibling may be working on (or open to working on) communication practices, too. Talk directly with your sibling about what these skill development areas are or could be, and make an agreement on how you can help. For example, if they are working on emotional regulation or two-way conversations, you may decide on a clear, concrete sentence you can say to them when you detect they are becoming dysregulated or entering a monologue pattern. By this predetermined prompt, they can identify their

see Communicating on page 31

Neurodiversity and Sibling Relationships

By Heidi Hillman PhD, BCBA-D
Eastern Washington University

Having a child with an autism spectrum disorder has a transformative effect on the entire family. Typically, when a child is diagnosed with autism, parents embark on a mission to find effective treatments and support systems. However, during treatment planning neurotypical siblings are often overlooked. Given the high prevalence of social deficits, many autism interventions focus on social interactions. However, few of these interventions focus on teaching neurotypical siblings how to interact with their autistic siblings (Conway & Meyer, 2008; Tsao, Davenport, & Schmiede, 2012). Yes, there are interventions that involve siblings (e.g., Tsao & Odom, 2006; Walton & Ingersoll, 2012), but the siblings are primarily utilized as peer trainers. I am not advocating for neurotypical siblings to be treatment implementers; I am advocating for strengthening the relationship between the neurotypical and autistic siblings. Supporting the entire family - including the sibling relationship - is important to fostering positive, life-long connections (Conway & Meyer, 2008).

Many autism interventions are based on the medical model, which views autistics as lacking “appropriate” behaviors, and



Heidi Hillman PhD, BCBA-D

needing treatment. An alternative framework that has arisen in the autism field is neurodiversity. Neurodiversity views there are many acceptable ways of acting - rather than one “normal” way - and that autism is the result of naturally occurring cognitive variations with distinctive strengths (Silberman, 2016). The autistic’s quirky behaviors are viewed as unique traits, leading to celebration - rather than elimination (Cascio, 2012).

What if instead of modifying the autis-

tic’s behaviors, we work with siblings on modifying their interactions? Behavioral therapists routinely shape behaviors of autistics, why not the other way around? In this article I propose using the neurodiversity concept as a guide in reshaping the long-held focus of “modifying” the autistic to helping neurotypical sibling understand their autistic siblings’ experience and the motivations behind their behaviors.

Siblings and Autism

Some siblings may not fully understand autism. Seeking out education regarding challenges and abilities of autistics may help neurotypical siblings understand the motivation behind their sibling’s behaviors. For example, behaviors that others may label as atypical - be it hand flapping, echolalia, wearing headphones, hiding under blankets to reduce stimuli, or jumping up and down when excited - are ways autistics communicate their emotions. Teaching neurotypical siblings that autistics communicate differently and have different ways of coping, it promotes increased acceptance of a diverse array of behaviors.

Social Supports

From my experience, neurotypical siblings feel many of the same emotions that parents of autistic children experience. Research shows that for neurotypical sib-

lings, social supports can be a protective factor against stress and anxiety (Tomeny, Rankin, Baker, Eldred, & Barry, 2019). Encouraging neurotypical siblings to connect with peers experiencing similar situations - such as support groups - may help them feel more comfortable expressing feelings they would otherwise not divulge. In addition, support groups may help reduce the siblings’ feelings of social isolation since many families with an autistic child avoid outings and social gatherings.

Play

An effective way to strengthen relationships is through play. Although it may be challenging for siblings to connect with their autistic siblings, encourage them to interact through activities both siblings can enjoy. For example, is there a game that both siblings enjoy? Or can the neurotypical sibling introduce their favorite video game to their autistic sibling? Due to its sensory properties and encouragement of imaginary play, having siblings play with slime or playdough together is another great option.

Respecting Routines

Children with autism are rule governed; they take directions and turn them into

see Neurodiversity on page 30

The Critical Need for Tracing Individual Trajectories After an Early Diagnosis of Autism

By Cynthia Martin, PsyD,
Bethany Vibert, PsyD,
and Adriana Di Martino, MD
Autism Center at the Child Mind Institute

Autism Spectrum Disorder (here forward referred to as autism) is more commonly recognized at early ages (Zwaigenbaum, Bauman, Choueiri, et al., 2015). This has led to increased access to early intervention and special educational supports, which in turn provide opportunities to better long-term outcomes (Zwaigenbaum, Bauman, Choueiri, et al., 2015; Dawson et al., 2010; Lovas, 1987). Given the early onset and long-term nature of autism, its presentation changes over time and throughout the course of life. Thus, tracking each individual's development over time is as critical as early diagnosis. Tracking over time includes not only frequent objective monitoring within the area targeted by a specific current intervention - as required in evidence-based approaches - but also regular comprehensive follow-up using neurodevelopmental and psychological assessments. Building from initial diagnostic observations, these follow-up assessments allow for development of longitudinal trajectories that, in turn, can inform intervention programs. Although



Cynthia Martin, PsyD

to date, there is not a single schedule for follow-up assessments that fits all, here, we discuss the evidence supporting the need for regular follow-up in the preschool years, following an early diagnosis.

Early Childhood:

A Time of Change and Opportunities

The first five years of life are a time of



Bethany A. Vibert, PsyD

significant change in all children and are a critical and sensitive window for opportunities in autism. This developmental period is characterized by dynamic progress in multiple domains of functioning ranging from motor and sensory processing to language and social cognition. In this context, particularly prior to age 36 months, core symptoms of autism begin to unfold (Kim et al., 2018; Wetherby et al., 2004; Stone



Adriana Di Martino, MD

et al., 2000; Coonrod & Stone, 2004). Several studies following the same children throughout early childhood (e.g. Kim et al., 2018) and into adulthood (e.g., Lord et al., 2012), have revealed that the trajectory of core autism symptoms varies tremendously across children, ranging from minimal to large improvements and vary in rate of

see *Trajectories on page 26*

Sibshops from page 11

relationship isn't that different from other siblings. During a recent weekend away with his father, Seth decided to ping Ian's phone nonstop, simply to get on his brother's nerves. After a while his mother called his father to tell him to knock it off.

"When Ian got diagnosed at 16, it was almost a relief," Lori Jacobs said. "We could put a name on and a reason for things that had been challenging to our family. I told Seth, 'this is why Ian insists on playing one game with you over and over again or talk only about Star Wars.'"

Seth, who like other younger siblings took on the role of older brother at a young age, already had been aware of Ian's challenges. Over the years, he has learned to read Ian's moods. His mother explained that sometimes you can say something to Ian that's perfectly acceptable, but it was not acceptable to say the same thing a week later.

"When I was younger, I would have no clue what would set him off," Seth said. "The biggest challenge now is that his mood can change pretty fast."

The two enjoy playing video games. Seth is particularly proud of the first time he defeated Ian in chess on a giant board at a hotel in the Catskills. And then there was a recent morning when Seth was sleeping and Ian began poking him nonstop. After he stopped, Ian started in again. "Ian's

pretty cool to be around," Seth said.

"They are each other's closest friend," Lori said.

More Support for Siblings

"Sibling support has exploded," Spallino said. With more community inclusion, society sees individuals with autism and other developmental disabilities in schools, restaurants and anyplace people without disabilities gather. "The world is more open and there are opportunities to identify as a sibling," Spallino said.

Lynn Uhlfelder Berman does Public/Media Relations for AHRC New York City. For more information about AHRC New York City's Sibshops or to register, call 212-780-2592 or email annette.spallino@ahrcnyc.org.

Footnotes

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Maintaining Connection with Siblings with ASD in Young Adulthood

By Amanda Austin, BA,
Daniela Silva, MS, BCBA,
Caitlin Chambers, MEd, BCBA
and Kate Fiske, PhD, BCBA-D
Douglass Developmental Disabilities
Center at Rutgers University

Sibling relationships are some of the longest that people will have in their lifetime, and these relationships can significantly influence sibling development (McHale, Updegraff, & Whiteman, 2012). While each sibling relationship is different, they are commonly characterized by shared experiences and intimacy (Dunn, 2002). The sibling connection can be particularly unique and complex when one or more of the siblings is diagnosed with autism spectrum disorder (ASD).

When asked to reflect on their childhood relationships with their siblings with ASD, adult siblings—like siblings of neurotypical individuals—report both positive and negative feelings, though the context for these feelings can be quite different from that of neurotypical sibling relationships. Negative feelings toward a brother or sister with ASD are often associated with the impact of autism on their lives, such as sadness or frustration about limited reciprocity in the relationship, or a sense of loss of a typical sibling relationship (Tozer, Atkin, & Wenham, 2013). However, siblings also report great admiration for their siblings and less competition in their relationships (Kaminsky & Dewey, 2001), as well as feeling protective of their siblings (Tozer et al., 2013).

All sibling relationships can change across the lifespan. Sibling relationships in adulthood become more voluntary as each sibling grows independent of their families by pursuing higher education or beginning careers, or even by starting their own families. For siblings of individuals with ASD, these milestones can be especially monumental. Many adult siblings report that, as children or adolescents, they assumed more responsibility, care, and support for their brother or sister than did siblings who did not have a brother or sister on the spectrum (Bigby, 1997). Shifting away from this role may give young adult siblings the opportunity to develop an identity separate from their family. However, siblings may also experience stress and concern about their family's well-being and future. It is common for young adults to consider the type of role they will assume in the lives of their siblings with ASD once their parents become too old to care for them (Bowey & McGlaughlin, 2007). Some young adult siblings feel a desire or sense of obligation to remain in close proximity to their family and be involved in the care of their sibling even after moving out and starting college or a career (Atkin & Tozer, 2014; Tozer et al., 2013), but they may struggle to balance this connection with new roles and responsibilities. Similarly, siblings who are physically distanced may work to maintain their connection with their brother or sister across the miles.

As young adult siblings live more independently from each other, it often becomes more difficult to connect. Even if



Amanda Austin, BA

siblings remain in close proximity, fostering and maintaining social connection with the sibling(s) with ASD can be a challenge. As deficits in social communication are a core symptom of ASD (American Psychiatric Association, 2013), siblings may struggle to understand the other's approach to social interaction. This challenge is especially pronounced when the sibling with ASD is unable to communicate using speech (Travers, Carlton, & Carter, 2020). Identifying ways to connect with a sibling with ASD despite living separately is paramount to maintaining the desired relationship. The following are some ways that young adults can maintain social connections with their sibling(s) with ASD:

Evaluate Current Knowledge About ASD and One's Sibling with ASD

ASD looks different in every individual. It can be beneficial for a sibling to identify what they already know about their sibling with ASD and whether anything is still unclear. Siblings who are more knowledgeable about ASD report having more positive relationships with their siblings with ASD (Roeyers & Mycke, 1995). Some resources that may provide helpful information are the sibling's treatment provider, informational websites, a caregiver, or siblings themselves. Sibling support groups have also been shown to improve siblings' knowledge about ASD as well as foster positive interactions among siblings (e.g., Evans, Jones, & Mansell, 2001). One can find in-person support groups through websites (e.g., [Autism Sibling Support Meetup](#)) or obtain support virtually (e.g., Facebook Groups, [MyAutismTeam](#)).

Join Them in Activities They Love

Siblings of individuals with ASD typically spend less time with their brother or sister than do siblings of individuals with Down syndrome or neurotypical siblings (Knott, Lewis, & Williams, 1995). Engaging in activities with a sibling with ASD enjoys can be a great way to spend time together, especially if they do not prefer or are unable to converse. Many siblings report watching television together as a way to connect (Travers et al., 2020); other activities may include playing video games,



Daniela Silva, MS, BCBA

spending time outside, or introducing the sibling to a new hobby they might enjoy. For siblings who can go into the community, commonly reported activities include shopping at the mall, going to concerts, and spending time with each other's friends (Travers et al., 2020).

Use Technology to Connect

As siblings age, it can be more difficult to spend time together in person, as adults may live independently and/or have busy schedules. Technology can be a helpful way to maintain connections from a distance. Many siblings report talking with their siblings with ASD on the phone (Travers et al., 2020); however, for those with siblings who do not use speech to communicate, texting, emailing, or video may be more feasible methods of communication. These modalities may also be more comfortable or preferred for siblings who do use speech. Individuals who communicate with other family members through these means can see if their siblings with ASD can join the conversation, even if only for a few minutes. Some technology platforms may also allow siblings to join in activities together remotely, such as by playing video games together on an internet server or watching a favorite movie together using a streaming service's "watch party" feature.

Regardless of family dynamics and circumstances, social connectedness among siblings when one or more siblings has autism is unique and challenging, especially with the new freedom that accompanies young adulthood. Each sibling relationship is unique, and the extent to which these recommendations may apply will vary across families. Studies have found that siblings who spend more time together report more positive relationships (Travers et al., 2020), and positive social relationships are often associated with increased psychological functioning and well-being (Seligman, 2018). Building and maintaining these relationships may be challenging at times but can provide many benefits for both neurotypical siblings and their siblings with ASD.

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see Connection on page 29

Lies, Damned Lies, and Statistics: The Tyranny of Typicality

By Karl Wittig, PE
Aspies For Social Success (AFSS)

There is an old saying, often attributed to Mark Twain but apparently of unknown origin, that there are three kinds of lies: lies, damned lies, and statistics. The problem with the latter, as I have always seen it, is that it seeks to find norms in populations within which there can be considerable diversity. These in turn are often used to establish policies that tend to most greatly benefit individuals who are closest to those norms. Such policies can either evolve naturally or else be actively implemented by governments, organizations, or other agencies. In either case, they will ideally (if not always) result in “the greatest good for the greatest number” (the fundamental principle of utilitarian philosophy) or, as interpreted by Mr. Spock in Star Trek II, “the needs of the many outweigh the needs of the few.”

This is well and good for those who are close to the norm or, at least, not too far from it. But what about the “outliers” (to use the statistical term), who are so distant from the bulk of the population that they are actually discarded as data points in many statistical analyses? As a person on the autism spectrum, this is of great concern to me. Autistics are often characterized as “atypical” – there is even a popular



Karl Wittig, P.E.

television series by that name about the lives of young autistics, not to mention Jesse A. Saperstein’s hilarious memoir about growing up on the spectrum. Essentially, autistics as a group are often seen as “peculiar,” “eccentric,” “odd,” and “strange,” not to mention a variety of less-flattering and even derogatory terms. In short, we are usually identified by our differences or, to put it in statistical terms, our deviations from the norm.

This is rarely if ever done for any other demographic, whether racial, ethnic, religious, gender, sexual, or even other disabilities. As far as I can tell, it only happens with the autism community. Apparently, some of our differences are so pronounced that they are conspicuous to many parts of society, even when not particularly severe. Matters are further complicated by the fact that, even as there is far more commonality among autistics themselves than with the general population, significant deviations exist between ourselves in many categories – there are very good reasons why the common saying that “if you’ve met one person on the spectrum, you’ve met one person on the spectrum” is so popular among autistics.

The Disadvantages of Being Atypical

All of this can have adverse consequences for many of us on the spectrum. Many (if not most) autistics have unpleasant, and even painful, memories of being marginalized because of personal peculiarities, and often were victims of (sometimes horrible) bullying. They also experience a lifetime of not fitting into communities that they presumably belong to, if not outright being marginalized or even ostracized.

In the school environment, our different (and varied) learning styles often result in academic difficulties, on top of which many autistics also have co-morbid learn-

ing disabilities. Even twice-exceptional students like myself sometimes found school very unpleasant because our unusual and specialized interests did not conform to the standard curriculum (this was certainly the case with me). For all these reasons, the advent of individual education plans (IEPs) has been of tremendous benefit to autistic students. Additionally, our social skills deficits make it difficult for us to become socialized with the general school population. The result of all this is that our differences make us stand out more conspicuously among more typical classmates than just about any other category of students.

The work environment, however, is probably the most problematic for many autistics. Unemployment figures for autistics have always been alarmingly high and are often said to be higher than they are for other disability communities. I personally consider those numbers to be in error because there are quite a few successfully employed autistics who simply were never identified, let alone diagnosed (another failure of statistics!). Nevertheless, far too many autistics have difficulty finding and keeping jobs. In most cases, this has everything to do with not interviewing well, interpersonal issues with bosses and co-workers, inappropriate behaviors, or running afoul of workplace culture and politics, and little to do with incompetence,

see *Typicality* on page 33

Programming from page 18

siblings can also be helpful. Appropriate sibling interactions may not occur naturally between siblings with ASD and are therefore an area of concern families want to prioritize immediately. As socialization deficits are a core feature of ASD, social interactions between siblings often have to initially be facilitated by one or two adults. These adult interventions, such as modeling and prompting, can be faded as the siblings become more independent.

When programming, we often look at the end result or long-term goal, but it is important to remember that long-term goals are generally met after a series of small victories. So, celebrate the small victories your child achieves and do not be afraid to ask for help! Here are seven tips and coping strategies families can use when programming for multiple children with an ASD diagnosis.

Tip 1: Follow a developmental pediatrician: Although your children may already receive early intervention or services through your local school district, a Developmental Pediatrician can provide additional resources. A Developmental Pediatrician may not only be the medical professional that diagnoses your children, but they can also play a critical role in comprehensive ongoing programming after your children are diagnosed. A Developmental Pediatrician is a great person for your Board Certified Behavior Analyst (BCBA) to collaborate with when it comes to all types of delays that can be associated with ASD, including language and communication delays, fine and gross motor impairments, challenging behaviors,

activities of daily living including feeding and toileting issues, etc. (Children’s Specialized Hospital, 2020).

Tip 2: Encourage ongoing collaboration amongst other professionals and trust the team members that are helping your children: When multiple team members have the chance to collaborate and co-treat children with ASD, the outcomes are better and keeps your child’s best interest at the forefront (Oommen et al., 2017). Collaboration enhances generalization across settings as team members are able to share resources and mastered targets.

Tip 3: Try not to compare your children’s programming and progress to others: Despite sharing common physical attributes, cognitive skills, adaptive skills, and personalities often vary from child to child. You may have multiple programs in place at once if you have more than one child with a diagnosis. Remember that programming can look very different for each of your children. Each child can achieve different milestones at different times.

Tip 4: Keep an open mind when trying an intervention more than once: Even though you may feel that you have tried everything to address an issue, keep an open mind, and try again. A different environment, or further developed pre-requisite skills, can help an intervention be more successful the second time around. Additionally, if a specific intervention or teaching strategy was not successful with one of your children, don’t immediately discount it for your other child – each child learns

differently, so it is important to let the team try it first.

Tip 5: Communicate early, communicate often: Do not wait to share thoughts or questions with your team members until they become concerns. You are the best advocate for your children and will be the person implementing interventions for most of the day – if an intervention does not work for your family, do not hesitate to speak up!

Tip 6: Trust the data and evidence-based practices: Make data-based decisions for your children. It can be challenging to see small changes day-to-day, so looking at graphs brings clarity to the successes your child has made. The professionals working with your children can help you collect and analyze data to ensure you are making a data-based decision and selecting evidence-based treatments (e.g., National Autism Center, 2015).

Tip 7: Put in the hard work early and consistently: We know having intensive therapy is hard work, but remember, children who receive early intensive therapy, defined as at least 25 hours per week, have better outcomes (Oommen et al., 2017). It is important to plan for discharge from the beginning, as our ultimate goal is to increase independence and fade services.

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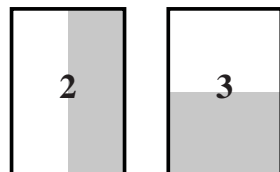
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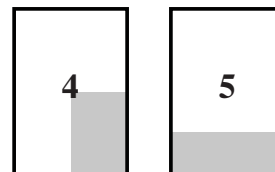
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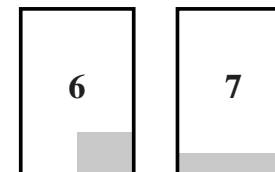
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What Happens When the Teacher Is on the Spectrum?

An Interview with a Pre-Service Teacher with ASD

By Christopher Bloh, PhD, BCBA-D
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With more and more people with ASD becoming adults, enrollment in higher education is also increasing for this population. Science, technology, engineering, and math majors are popular with students with ASD but what about education? An undergraduate education major with ASD was interviewed about his abilities, inabilities, and how they have affected and could affect his future career.

Autism spectrum disorder (ASD) currently includes the disorders formerly known as pervasive developmental disorder not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Asperger's (American Psychiatric Association, 2013). There previously existed independent diagnostic criteria for each of the aforementioned pervasive developmental disorders, generally grouped under the "autism umbrella." Asperger's criteria differed from PDD-NOS and PDD-NOS differed from autism, etc. (American Psychiatric Association, 1994). In other words, someone could receive a diagnosis for ASD today that may have been PDD-NOS before the change in diagnostic criteria. With the new diagnostic criteria



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ria established in 2013, these disabilities were consolidated under autism spectrum disorder.

Characteristics vary in ASD but include deficits in social communication, deficits in social interaction, stereotyped or repetitive movements, insistence on sameness, and highly restricted and fixated interests (American Psychiatric Association, 2013). While some behaviors are treatable

with proper educational and therapeutic supports, they will likely continue into adult life.

Over 500,000 children with ASD will be becoming adults in this decade (Buescher, Cidav, Knapp, & Mandell, 2014). Of that number, more than 200,000 will enroll in institutions of higher learning (National Center for Education Research, 2011) or approximately 15,000 students per year (Autism Speaks, 2017). Those students with ASD enrolling in colleges are more likely to choose science, technology, engineering, or mathematics (STEM) majors (Wei, Yu, Shattuck, McCracken, & Blackorby, 2013). With that large number enrolling in institutions of higher learning, do students with ASD pursue careers as teachers? While there are blogs from teachers with ASD (E, 2013; Wylam, 2018) there currently exist little data/information from those students training to be teachers.

Harry (name has been changed) is enrolled in an undergraduate teacher preparation with a dual major in special education and secondary (math) education. Because of his state's requirements at the time of his enrollment, all special education undergraduate majors were required to be dual majors in both special education and elementary or secondary education. He has a diagnosis of Asperger's and PDD-NOS and disclosed this to his peers and faculty. He completed his coursework, several

semesters in the field, and was preparing for his final semester of student teaching. Considering that Harry was one semester away from no longer receiving services, but providing them as a special education teacher, the interviewer sought his input to a few questions. The interviewer was a faculty member who had Harry for several classes, both face-to-face and online.

The following interview was conducted via phone on January 10, 2020:

What characteristics of ASD do you display or have been told that you display?

HARRY: There are a couple of definite ones but there are times when I talk with people and they are surprised that I don't display all the "stereotypical" ones. Throughout school, I have had difficulty with social skills but they improved drastically in 6th - 7th grade after several years of social skills instruction. Still, I had trouble working with people. It's difficult for me to understand because I believe I'm working well with others and, maybe, I'm not. My social skills deficits affected my academics. If I felt that I couldn't work with others, it was such a distraction academically.

I had a lot of difficulty having successful peer interactions and making friends. My

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Office for People With Developmental Disabilities) that agencies no longer allow consumers with their families to return to group homes. It also said that consumers IN residences would not be allowed to go outside to visit families, go on trips or in the community. This direction was to be for an indefinite period.

I always knew that someone would have to intervene on his behalf for his entire life. No problem. What was not prepared for was for Douglas to become a permanent resident. I was always glad to see him on weekends and holidays. Happy to spend vacation time together and when he was sick it was my job to keep him home with me until he was well. Since my mother's death 7 years ago, Douglas has had episodes where he needed treatment for 3 weeks at a time. I stayed with him in the hospital when he needed surgery and took him home with me to recuperate. These instances were finite, with a beginning, a middle and an end.

Douglas has been with me for 6 and a half months. In the beginning he was confused, asking me if he couldn't go back to the group home because he was bad. I told two of his favorite staff about this and both men called and assured Douglas he was missed, cared about and not banished because he was bad. They promised he'd come back soon and over the months he has been able to see them and other staff and consumers when they drive down to deliver his medication. We call his residence regularly and talk to consumers as well but at this point, I'm afraid Douglas

will not want to return or will have trouble adjusting once he is able to go back.

After being told to STAY HOME, we remained in the apartment 95% of the time. My brother is used to getting out going places, doing things. I used to complain that he was a mall rat because residents frequented several malls in the NY/NJ/CT tri-state area. He thrives on activities and even our weekends were spent going out to do things.

All this came to a screeching halt with orders to shelter at home. I kept the news on most of the day. The sirens of ambulances were a constant sound. Douglas covered his ears every time the sound reached us. I talked to Douglas about COVID-19 daily warning him that whenever we did go out, we were to wear a mask and gloves.

The first two trips to the grocery store in the building were a disaster. Douglas kept pulling his mask below his chin or above his nose and peeled off the gloves to do what he always does, remove any price stickers on an item. We looked peculiar no doubt. I walk with a crutch in my left hand, but my right fist held fast to his pants as all 6 feet plus of him gyrated and screamed. I yelled "no mask no shopping!" he screeched back "I don't care" before launching into his usual angry verbal tirade. People stare or try to avoid looking at us. The gaping of strangers used to mortify my mother, but as his sister it doesn't bother me in the same way; one of the benefits of being a sister, not a mother. We don't absorb that guilt in the same way. I wish I could stop it from happening, but I can't and am not responsible for his explosions.

After many attempts to go out and do

what we used to do with ease, there was an effort made to go to McDonald's. In defiance, Douglas ripped off his mask and hurled it on the street and we marched home sans burgers. At last this seemed to mark a turning point. Douglas no longer objected to wearing a mask or gloves. Of course, he has thrown away a few pretty masks that were mine as a gesture of disdain for my being a bossy sister, but this time I am fighting to keep him safe and prevent his getting sick. At least our trips outside are not all disasters.

For the first time in a very long time I am scared for Douglas and for me. While my mother's magnificent creation of a permanent place for people with autism could make a safe haven for him and others, it could neither predict nor stave off a once in a century pandemic.

Despite the duration of his time with me, I am grateful Douglas is home. Had he been at his residence when the lockdown went into effect and neither of us would have seen each other for months, we both would have been miserable. Having him in my domain gives me perhaps a false hope that I can keep him from becoming a statistic.

I have friends who have not been as lucky. A few have family members who came down with COVID-19 and suffered an array of consequences. For those who were unable to see their siblings or children for months it was torture. For those whose loving and vulnerable relatives had the virus it has been hell.

I have my share of sibling friends and have always turned to them for confirmation and support. It isn't that we talk about handicapping conditions and tribulations

with regularity. It's more that we seem to be members of the same fraternity, though we never pledged. There is a profound level of comfort we have with each other, able to gain solace from our camaraderie. We are also able to discuss our darkest fears for our parents and siblings. This is something you cannot often do with "outsiders" who have had no initiation into our world. Some professionals are in this field and will tell you that they got into service delivery *because* of their siblings.

This latest crisis is no different. I rely on certain men and women to talk through the issues that the Coronavirus presents. While one friend has a brother living in Douglas' group home, others have siblings who do not have autism. Their response is no different than mine when worrying about the future. As we are older and have watched our parents become ill and eventually pass away, we are filled with an overwhelming sense of responsibility. But this sense is diminished by an even stronger love for the brothers and sisters we were given.

I have been able to manage these stressful months with Douglas because I love him that much. There are no Direct Support Professionals to relieve me, no one to help with cooking, laundry or cleaning. As the sole source of recreation for the moment it is not out of need want to but because we are stuck at home together. As maddening as his rituals can be, as difficult as his behaviors may sometimes be, he is the brother I wanted and will love every day of my life.

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change. Studies of younger siblings at risk for autism have shown that while many toddlers meet full diagnostic criteria for autism at 18-24 months, others will not have a clear presentation until 30-36 months (Messinger et al., 2013; Chawarska et al., 2014; Ozonoff et al., 2015), and some will be recognized even later (Miodovnik et al., 2015).

Cognition, Language and Autistic Symptoms are Intertwined

Variable trajectories of autism symptoms are not independent from co-occurring changes in cognitive and language skills. Verbal and nonverbal reasoning paint the background against which all other skills develop. They, in turn, can impact the expression of core autism symptoms. The development of cognitive and language skills is paramount in the early years and have been shown to lead to better long-term prognosis (e.g., Simonoff et al., 2019), even with the persistence of autism symptoms. Thus, they need to be carefully monitored to identify specific areas of strengths and weaknesses that can serve either as supports or targets for interventions. Profound cognitive delays that extend past early childhood can require long-term comprehensive support plans.

Language skills are another important contributor to positive outcomes. Verbal skills change significantly over time and their trajectories vary across individuals ranging from reaching age-appropriate verbal fluency to remaining minimally verbal (Anderson et al., 2007). Nonverbal aspects of social communication and interaction are also important areas to monitor for intervention. For example, non-verbal communication skills, such as joint attention and spontaneous use of gestures are critical in further promoting language development (Murray et al., 2008; Bono, Daley, & Sigman, 2004; Mundy, Sigman, Kasari, 1990).

For children who develop verbal fluency, the expression of autism symptoms may change within the context of language development. For example, toddlers and preschoolers who transition from being non-verbal to phrase- or fluent- speech, may start showing atypical use of language, which can be transitory or persist. This may include frequent use of repetitive phrases, idiosyncratic speech, and scripting lines from books or movies. Follow-up assessments will determine the extent to which these atypical language patterns are either interfering with social communication or used to aid social interactions and inform treatment accordingly.

The Relevance of Behavioral Regulation

Behavioral regulation (i.e., the ability to control motor behavior, sustain attention and regulate emotions appropriately to a given context) broadly affects a child's functioning. Poor behavior regulation can challenge social functioning, may later affect academic achievement, or require placement in restrictive academic settings - regardless of intellectual and language capabilities (Sansosti & Sansosti, 2012). When autism symptoms co-occur with dysregulated behavior, it is important to identify the triggers early so they can be promptly targeted in behavioral interventions. Improvements (decreases) in hyperactive behaviors around 24 months of age to age 36 months, for example, have been

reported to characterize a group of individuals who, by young adulthood, have a very positive outcome with minimal-to-no symptoms of autism and greater adaptive functioning (Anderson et al., 2014). In this group, in addition to decreases in hyperactivity, the most significant early childhood characteristic was the magnitude of reductions in the severity of restricted repetitive behaviors (RRB) between 24- and 36-months age (Anderson et al., 2014). RRB is an umbrella term that captures both lower- and higher-order symptoms. The former includes symptoms such as atypical sensory processing and motor stereotypes, the latter includes symptoms such as excessive adherence to routines and restricted interest. The relative role of behavior regulation and RRB, particularly their interaction, on long-term outcomes remains to be fully understood, but is an important area of clinical focus in follow-up assessments and interventions for autism.

Guidelines for Assessment Battery

When reassessing developmental functioning and core autism symptoms, standardized testing is required. Some testing instruments provide greater utility in monitoring trajectory than others. Integrating gold-standard testing measures (i.e., measures that have been developed and validated based on robust and rigorous research), represent a common framework across providers and institutions, which can facilitate coordinated care. Standardized tests such as the Mullen Scales of Early Learning (MSEL; Mullen, 1995) and Differential Ability Scales, Second Edition (DAS-2; Elliot et al., 2007) quantifies a child's developmental functioning across verbal and nonverbal cognitive domains and have been used extensively in the research literature. The Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) to date is the gold-standard diagnostic instrument for autism. It is often used to track major changes over time. Standardized instruments that are more sensitive to subtle changes, specifically the Brief Observation of Social Communication Change (BOSCC), have been developed (Grzadzinski et al., 2016; Kim et al., 2019) and independent validation studies are underway (Kitzerow, et al., 2016). Moreover, assessments provided by clinician(s) not directly involved in the child's daily educational and treatment plan, may bypass potential biases and provide objective markers of change over time. Repeating follow-up neurodevelopmental and psychological assessments at least yearly, or more frequently if new concerns emerge, is recommended. Families can access these assessments through most autism specialty clinics and research programs.

As part of a study funded by the National Institute of Mental Health (NIMH; R01MH115363-03), the Child Mind Institute is currently offering autism diagnostic and yearly follow-up evaluations of behavioral and cognitive changes in toddlers and preschoolers with autism who are interested and eligible in participating in research.

Cynthia Martin, PsyD, and Bethany A. Vibert, PsyD, are clinical psychologists and Adriana Di Martino, MD, is Research Director at the Autism Center at the Child Mind Institute.

To learn more about the Autism Center at the Child Mind Institute, visit www.childmind.org/center/autism-center

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Twin from page 12

playing games and schoolwork. Matt was jealous of Samantha because she demanded so much of my attention. Samantha outdid her brother in one crucial area: she screamed louder and longer.

On the positive side, we did create love and family solidarity, although not what I imagine to be the normal, intimate bonding of twins. As a young child, Samantha always cheered for her brother at his sporting events. She laughed at his stand-up comedy when they became young adults. For his part, Matt attended and applauded every one of his twin sister's theater and singing performances, from the most awful production of *The Crucible* to Samantha's shining moments co-starring in the short and full-length feature film, *Keep the Change*. Despite all of their childhood rivalry and resentment, they never missed sharing each other's best moments. From birth to adulthood, they have enjoyed sharing



Marguerite Elisofon, BA

birthday celebrations - especially their B'nai Mitzvah at age 13. Their December birthday enabled us to enjoy many celebrations over Christmas holidays in tropical islands.

As a parent, it also brings me much joy that my two very-different children are both warm and affectionate with each other, as well as with their parents. Happily, Samantha defied the negative autistic stereotype of being aloof and allergic to touch. In spite of - or perhaps because of - her autism, our daughter has grown up to be a social butterfly. She loves to exchange hugs with friends and family. Luckily, my twins have a sense of humor (different from each other, of course) and enjoy laughing at their parents together. We love that!

At autism conferences over the years, I've always envied the siblings and twins with closer and more loving relationships. In these cases, the young man has always been autistic, and his sister (or twin) neurotypical. Typically, the young woman is her brother's advocate and protector.

But maybe it's not too late for my twins. As Matt and Samantha have matured, they have slowly grown closer, although they

still rarely converse. My twins are now 29, both in the movie business. Matt is a scriptwriter living in Los Angeles, and it's not a coincidence that he volunteers at [The Miracle Project](#), a theater group for young adults on the spectrum. Samantha is an actress and singer who lives with us in New York City.

My fantasy is that one day Matt will write a movie script that includes his sister. After so many years of watching my son cringe with embarrassment when we introduced Samantha as his twin sister, he is finally proud of her. When someone he knew in the film business who'd seen *Keep the Change* praised Samantha's performance, he remarked: "That's my TWIN sister!"

Marguerite Elisofon lives in New York City and blogs about disability issues for [The Never-Empty Nest](#) and [The Good Men Project](#). Her website is: www.MargueriteElisofon.com. Contact: mkelisofon@gmail.com Twitter: [MargueriteNEN](#)

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is important that the person with the disability be consulted about what role she or he wants their siblings to play. These should be continuing conversations that families have throughout life, with recognition that roles may evolve and change.

There are many obstacles to family future planning, including financial barriers and lack of available services (Burke, Arnold, & Owen, 2018). It can also be uncomfortable for family members to focus their conversations about the future because it requires an acknowledgement of mortality. Parents may worry that this is hard information for siblings to process, but siblings are often relieved to have an opportunity to talk, learn, and have input into the process.

Future Planning Resources

The Arc's Center for Future Planning provides a [Tip Sheet for Siblings: Getting the Future Planning Conversation Started](#). Additionally, they offer an online tool called [Build Your Plan](#) that allows family members to work through a future planning process collaboratively, think about various areas of planning, and create a written record.

[The Future is Now](#) is an evidence-based curriculum created by the University of Illinois at Chicago's Rehabilitation Research and Training Center on Developmental Disabilities that has been shown to have positive outcomes for families (Factor, DeBrine, Caldwell, Arnold, Kramer, Nelis, & Heller, 2010). It helps families start talking and planning for the future in a person-centered and family-centered manner. The curriculum is specifically designed to include people with disabilities as part of the process, along with siblings, parents, and anyone the person with disabilities wants to include. Organizations can purchase the curriculum and receive a train-the-trainer training so they can im-

plement "The Future is Now" with families they serve.

Peer Support

Parents of people with disabilities often find peer support early when they connect with other parents of children with disabilities. Health providers and educators help new parents make connections with other parents because they recognize that parent peers will provide information, friendship, support, and resources. However, those same opportunities for peer support are not as readily available for siblings. Thankfully, [The Sibling Support Project](#) created "Sibshops" to provide peer support groups where young siblings of people with disabilities to talk about their thoughts, feelings, and concerns in a recreational setting. As Sibshops grow and expand, siblings will increasingly have opportunities to connect at an earlier age.

Peer support is also promoted through the national Sibling Leadership Network where adult sibling can connect online and in person through events such as conferences, workshops, and seminars. It is a common occurrence to hear adult siblings come to an SLN meeting and share with emotion that it is the first time they are experiencing having a meaningful conversation with another sibling. This can be a powerful experience because they feel validated and realize they are not alone. They have lived for decades without actually having a connection with another sibling of a person with a disability! Peers can help siblings navigate family dynamics, provide resources, and offer insights about their current and future roles with their brothers and sisters with disabilities.

Resources for Sibling Support

The Sibling Leadership Network has [state chapters](#) in 27 states that hold regular

meetings with adult siblings.

There are also a number of online, interactive closed communities for siblings to connect with each other for information and peers support. Hosted by the Sibling Support Project, these groups serve as front-line resources for sibs, by sibs. Adult siblings can look on Facebook to request to be added to a group.

Sib20 for siblings in their 20s - www.facebook.com/groups/Sib20/

SibNet on Facebook for adult siblings of people with disabilities - www.facebook.com/groups/SibNet/

Amy Halm, MSW, LCSW, is Associate Director at the [Sibling Leadership Network](#).

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vocalizations, picture exchange, or Augmentative and Alternative Communication (AAC) devices. Different types of communication responses that can be taught using FCT in these scenarios could be requests for attention, alone time, special time with a specific person, to interact with the new baby, etc. It is important to ensure the response chosen to teach matches the function or reason the child is engaging in the challenging behavior in order for the intervention to effectively replace the problem behavior with communication.

Another major, initial disruption to the family will be sleep patterns. Sleep protocols to help individuals stay in their room when the baby cries at night may include the implementation of a bedtime routine, specific reinforcement for staying in their bedroom during disruptions, and scheduled awakenings. When implementing these strategies ahead of time, it may ease the need for intensive protocols once the baby arrives, relieve stress for parents and caregivers, and reduce the likelihood of challenges in the middle of the night when sleep deprivation may play a role in running the procedures with fidelity. As described by Mindell et al. (2006), scheduled awakenings require parents to wake their child at a specified interval prior to when

the child would normally wake throughout the night. Scheduled awakenings may be implemented around the baby's awakenings to preemptively prevent the child with ASD from leaving their bedroom; when starting these protocols, you can estimate, potentially on your previous children's awakening schedules or consult with a pediatrician on typical awakening times. In conjunction with scheduled awakenings, it would be beneficial to include specific reinforcement for staying in their room or even their bed and redirecting back to the designated space with minimal attention. Families may also consider setting rules or expectations related to overnight activities as appropriate.

Although the addition of a new baby may seem challenging and even scary at first when you have other children, especially those diagnosed with ASD, with effective preparation and dedication, you can have a successful transition. The strategies outlined here can promote the necessary skills prior to the new baby's arrival. However, once the baby does arrive, maintain and practice these skills and additional skills will most likely need to be introduced. Initially, particularly for children with autism who are anxious about changes in the environment, pairing positive interactions and fun activities with babies may be helpful. This might include practice visits with a

friend's or family member's new baby or even a baby doll in which the child is given some of their favorite snacks or toys contingent on appropriate interactions with the infant. When their own baby sibling comes home, this can be continued to help facilitate generalization. An evidence-based strategy known as Behavioral Skills Training (BST) which involves instructions, rehearsal, modeling, and feedback, has been effective in teaching a wide variety of skills across a variety of populations (Seiverling et al., 2009). In applying this methodology to practicing with a newborn, the child might be given short instructions on how to hold or touch the baby while a parent models the skill. The child would then practice the skill and would receive feedback including reinforcement for demonstrating the skills and corrections when making an error. A great way to include your child in a positive way with an infant is to incorporate them in their care, such as feeding, burping, playing, changing a diaper, etc. as appropriate for each individual child. If appropriate, you can apply the BST procedures described here to teach these skills. Overall, addressing challenges and skills needed to best prepare a child with ASD as well as their entire family for a new baby is crucial.

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time. If given a thumbs down, the sibling knew that the parent or sibling was not available to interact at that time. This program helped the sibling with ASD accept *no* while also providing siblings with ability to advocate for themselves and have a choice in whether they wanted to interact or play.

Telehealth sessions have provided opportunities to work with families who are traveling or on vacations, which can be stressful for individuals with ASD and oftentimes their parents and siblings as well. During a recent session with a family who was on vacation, our colleague could observe the client's siblings playing nearby and the therapist prompted the client to ask

what the sibling was playing. The sibling shared that he was writing scripts in order to record a video and then the therapist modeled how the client could ask to join the sibling. Following the lead of the therapist, the siblings joined activities, which led to the client and sibling writing scripts together, which in turn led to additional family members also joining in the imaginative screen writing session. In the end, the entire extended family participated in the activity and finished with an impromptu dance party!

Although we have observed success with utilizing siblings as peer models during telehealth sessions, more research is needed in this area. Given the growth of telehealth programming across the globe

during the pandemic, we look forward to clinicians amassing data on the most effective strategies with telehealth service and sibling involvement.

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Autism Spectrum News Editorial Calendar

Winter 2021 Issue:
“Supporting Children with Autism”
 Deadline: December 2, 2020

Spring 2021 Issue:
“Housing and Community Living”
 Deadline: March 4, 2021

Summer 2021 Issue:
“Autism and Employment”
 Deadline: June 3, 2021

Fall 2021 Issue:
“Challenging Behaviors and Autism”
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love their siblings any less. In families with multiple siblings, you may find that the neuro typical siblings may not have the same level of interest in their special needs siblings. Let them know that this is okay as well.

4. Be honest with children about the fact that having a child with special needs can potentially lead families to feel a wide variety of complicated feelings - including sadness and grief, and that it does mean life may be different from what was anticipated when a new child is expected. Families that can have healthy discussions about these multidimensional levels of feelings can influence how kids cope with these emotions long into adulthood, and increase the chances that the children will be more honest when they can be supported in sharing a wide range of feelings.

5. Specifically plan activities with other siblings that are exclusive of the child with special needs. These times will be invaluable for parents and children. These are great times to catch up on what is important in the lives of the other children, and help them develop identities outside of being the sibling of someone with special needs.

6. Consider a group for your child such as Sibshops (www.siblingsupport.org) where they can interact with others who are in similar situations. These are great ways for children to connect with others who share similar experiences, and where they can express their feelings in a safe and healthy environment - all while having a space that is their own.

Advice for Parents with Adult Children

For those parents who may have children with special needs that are getting older and moving into transitional or adult level services, here are a few things to consider:

1. Invite siblings to be involved in small caretaking roles such as short respites, attending meetings, and providing input into what their siblings like or do not like. If they do not want to attend in person, maybe they can offer suggestions ahead of time. For example, the sibling might have insight into what the other sibling might like or not like, especially if the sibling is not able to appropriately make their needs or wants known. If they do not want to participate at all, let them know that is okay, and that you would be open to hearing their feedback and suggestions, when and if they are ready.

**John and Suzanne**

2. Consider keeping a notebook with important information about the care needs of the sibling. This might include contact information for current service providers, the annual plan, pertinent medical information, etc. Having this information readily available for those left behind can be very useful in a stressful time.

3. Make sure your own will and financial affairs are in order, and share this information with your other children. These things are not easy to talk about, but they are even more difficult to deal with in the midst of grief. The time immediately after losing a loved one, especially a parent, can be disorienting for everyone, and having this information sorted out and available will make that process a bit easier on everyone.

4. Keep an open mind about future living arrangements for your child. While you may want to care for them at home forever, this may not be a reality. We know that what services and supports are available in an emergency situation are not the same as what can be available when a move to long term care is thoughtfully planned out. Additionally, availability of services, and funding for those services, can have lengthy waiting lists; therefore, the more proactive a family is about this planning, the better. Having families involved in these planning decisions early on, may also help the young adult with special needs to feel as if the transition is "okay" with the family. This, in turn, can give siblings further permission to naturally move on in their own lives, to be able to experience new things without feeling like they have this large responsibility looming over them. Consider these transitions to be similar to the experience of going off

to college or moving into their own apartment. If appropriate for your child, making these arrangements sooner, rather than later, can help assure that when the time comes that you are no longer available to manage their care, plans are in place. Involving siblings in these decisions can give them a better handle on what their role and responsibility might be, once you are no longer able to be involved. If appropriate, there are also legal options for siblings, such as becoming a legal guardian, or Power of Attorney.

About five years ago, while having a serious discussion with my father about placing my brother in a group home, he commented that he wished having a child with special needs came with a guidebook. One that would affirm that it was okay to be scared, nervous, excited, and proud of the child he raised, and assure him we would all be okay if he let him live under the care of someone else. It would also gently remind him that the decisions about what was best for his son was less about what he needed as a parent, and more about what was best for his son long term. The final years of dad's life while John was in a group home were some of the best years they both experienced together. Dad was able to see his son flourish and grow in his independence with his friends, and he learned to trust that caregivers could responsibly meet his son's needs-albeit not always in the same way he might. Last year, when dad became terminally ill, he shared that he was at peace knowing that John was cared for, and had siblings that would continue to watch over him, but would not bear the responsibility of meeting all of his care needs. As I moved through my own grief process of losing my father, the fact that John was in a well-established living situation afforded me the space I needed to provide self-care and cope in a healthier manner than I might otherwise have done, had I also had to take care of, and manage, John's care needs.

There were many difficult and heart-wrenching conversations along the way with my father, but as a sibling, I appreciated that my father was willing to have an open mind about different ideas. He thought carefully about each one, and how they would impact John, as well as the care he personally would ultimately need and require. He allowed me the opportunity to share my thoughts and feelings, as well as my knowledge of the field that contributed to his ultimately making the selfless choice to have John transition into a group home.

While I know that this is my experience as a sibling of someone with special needs, and I am only one voice in a sea of other

complex and varying situations, the common denominator remains the same. Families that can have open, honest, and timely conversations about many of these concerns as siblings grow and develop together, increase their chances of everyone having a better outcome than those that leave things to chance. I know that growing up as the little sister of a gregarious, and sometimes, mischievous boy, has helped shape me into the woman I am today. I would not have it any other way. Through sharing my experiences, I hope to offer families a few new ideas about how to plan for the future, while lending a voice to my fellow siblings out there learning to forge a path in their own dynamic lives.

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“When people find out, it’s weird because they think that I’m a really good person. They say, ‘Oh it’s so great that you’re such a good sister,’ even though they haven’t really seen me as a sister.”

“[My brother] is one of the funniest people I know, because he doesn’t have the best filter and it just ends up hilarious. He’s also super into music and I’ve learned so much from him. Getting to watch him talk about what he’s passionate about is really exciting to me.”

“Sometimes people hear the label and gasp and say, ‘Oh my goodness, that must have been such an experience.’ I’m not going to say that it wasn’t challenging, but I’m also not going to say we didn’t have a lot of fun growing up. We were normal kids for the most part. Normal kids that just had some different things to navigate than most families.”

Supporting Siblings

Siblings of children with ASD experience unique challenges that impact their everyday lives. Thus, there is a need for community and school-based mental health services for siblings of children with ASD. Many families are not aware that programs or professionals may be available to provide support and resources to the entire family and many professionals do not take the initiative or do not know how to begin to serve in such a role (Lovell & Wetherell, 2016).

These interviews showcase the complex and unique experience of having a sibling on the autism spectrum. According to the participants, community and school based-mental health services are crucial. Safe spaces to talk about difficult experiences and resources to educate one another about ASD would help normalize the social and emotional issues these individuals face. However, accessibility to established support groups is often affected by groups being too far for most families

to travel to or too poorly advertised to be easily searchable. Mental health professionals and community members have the opportunity and responsibility to increase accessibility of support for all who need it. School-based mental health professionals also have an important role, as they have access to the individuals with autism and their siblings each day. This provides a unique opportunity to provide support in a natural and consistent setting. Examples of this include school-wide education, after-school support programs, and one-on-one counseling.

All individuals want a sense of normalcy and understanding, and that includes folks on the spectrum and their families. Creating spaces of inclusivity, honesty, and positive support are crucial to the social and emotional health of individuals with autism, their siblings, and our community as a whole.

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You can access her full research paper here: https://etd.ohiolink.edu/pg_10?::NO:10:P10_ETD_SUBID:186724

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Neurodiversity from page 20

routines. Predictability of routines helps autistics reduce their stress level since they know the order of events in their daily schedule. Teaching neurotypical siblings that routines are beneficial, not restrictive behavior patterns, help them recognize the benefits of consistency - and not that their brother or sister is being rigid and difficult. For example, if the autistic child is following the “only one person in the bathroom at a time when brushing teeth” rule (thereby decreasing sibling shenanigans), and their sibling enters the bathroom only to be met with “Get out! I am brushing teeth!” - we educate the neurotypical sibling about respecting their sibling’s following of the one-person rule; rather than asking the autistic sibling to be more flexible.

Transitions

Autistics react more positively when given advanced notice before moving from one task to another. We can teach the neurotypical siblings how to provide effective transitions (e.g., I will play baseball with you for three more minutes and then I am stopping).

Precision

Autistic siblings teach family members to be precise in their responses. When an autistic child asks a sibling to play, and the sibling responds, “Ya, give me a few minutes,” to the autistic child that literally means a few minutes; not please go away

and leave me alone. We need to emphasize with neurotypical siblings that what they say is what they mean, and their brother/sister is eagerly waiting the few minutes to play.

Sensory Overload

Lastly, many autistics experience sensory overloads - otherwise known as the dreaded meltdown. An effective way for neurotypical siblings to navigate through a sensory overload is being calm and patient. Rather than the neurotypical sibling walking off or becoming upset, encourage siblings to be calm and not take the outbursts personally; try to understand why their autistic sibling is reacting this way and showing compassion rather than annoyance. For example, three kids are playing a game that involves a basketball and a basketball hoop. However, the game is not basketball, it is a game of who can put the ball in the hoop without getting tagged. A rule of the game, no blocking the hoop like in basketball. The older siblings block the younger sibling - who is autistic - who becomes upset. The younger sibling quickly becomes irritated, cries, and yells, “I am not playing anymore!” Rather than viewing this interaction as the little one being a jerk, realize that for him he is playing by the rules and it is the older siblings who are being jerks. Rather than saying “he is acting like a jerk” or “we need to teach him how to play more cooperatively,” we teach the neurotypical siblings to consider why the autistic sibling is experiencing a meltdown, sympathizing with how that may feel for him.

Parents

While parents of autistic children may become frustrated, tired, and experience stress, it is important for parents to realize neurotypical siblings often experience similar emotions. Hence, parents acknowledging the emotional toll each member of the family undergoes is important to the growth and development of all siblings. In addition, since parents spend large amounts of time caring for their autistic child, many neurotypical siblings crave dedicated time with their parents. It is important for parents to dedicate quality one-on-one time each week with their neurotypical children; where they are the center of attention and feel special.

Having a child with autism changes the family dynamics. Yes, it can be challenging but viewing an autistic child through the neurodiversity lens allows the family to see life from a strengths-based perspective. Additionally, neurotypical siblings may gain a profound appreciation for their autistic siblings. When you get frustrated with an autistics’ behavior, remember their way of learning and thinking is different from your own. An autistic sibling interacts with and views the world from a different lens than their other siblings; that is a strength not a limitation.

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peers viewed me with a stigma that I couldn't overcome even when my social skills improved during middle school. A lot of peers were not willing to talk with me because I was known as the "kid who would kick people to make friends." I was labeled with a stigma and it wasn't until college when I was able to make friends because my new peers didn't know my history. I don't think it was a change in my social skills from middle school to college but more that I had no known stigma to discourage others from socializing with me.

I've had fixations and focus on things that I like and can engage in them for long periods of time. I don't get bored with them. While I don't have huge issues with transitions, I usually prefer doing one thing for a long period of time, as opposed to doing something for 10-20 minutes and doing something else.

I did hum a lot. I would hum all the time to different music and thought that I was doing it in my head, but it was coming out a lot of the time. I think that I 'outgrew' that and haven't really done that since middle school. I have some 'tic' behaviors. I always feel that I need to adjust my hair and continue to do that. I've done a lot of finger biting in the past and would lick my lips all the time. Fortunately, I've stopped doing that because my lips became incredibly chapped. They were able to help me stop doing that when I was younger.

Who were "they" and how did they do it?

HARRY: I don't really remember. I still have some of my school documentation but was unable to locate that. It was a long time ago and there was a lot of paperwork.

I was diagnosed with PDD-NOS and Asperger's in the 2nd grade after I had a seizure. I was having seizures and the neurologist stated that I was OK but mentioned that I displayed ASD-related behaviors. So, he diagnosed and helped me for a long while.

Did you receive an IEP (Individualized Education Plan)?

HARRY: I received my IEP in the 2nd or 3rd grade. I had an IEP until the end of 8th grade when I got a Section 504 Plan and had that throughout high school.

Part of your teacher preparation program is that you are in classrooms teaching, which you did this past semester. Do the characteristics that you identified affect your teaching?

HARRY: I don't think about my social

skills while I'm teaching, but I may not be able to catch on to social cues in the classroom. I could be doing something and the students might be giving cues to which I am unable to respond. That happened in my recent placement but not as much with the students but with other teachers. It was not my cooperating (special education) teacher but other general education teachers with whom we were working. I had some miscommunications with them and they became frustrated with me. I didn't realize this until my cooperating teacher told me, which was very helpful. It worries me for my future and I need to find a way to let my future colleagues know that I may not successfully communicate what I really intend. I think I want to self-identify my disability to my future colleagues so they don't misinterpret my meanings. I'm aware of this.

Do you plan on identifying within-school and/or outside-of-school resources to help you accommodate your classroom?

HARRY: I've made a list throughout college of academic and disability supports, so I have resources for both my future students and me.

Do you plan to share your ASD diagnosis with your students? What do you hope to accomplish if you do?

HARRY: I'm not sure and would have to consider the pros and cons. I think if I told them, some may think of stereotypical ASD and am not sure how helpful that would be. I may tell them that they have to be explicit with their communication with me. Thinking about it, I'm leaning towards not disclosing my disability but sharing my communicative needs. With my colleagues, however, I will disclose my disability and beneficial accommodations.

Did you disclose to your university?

HARRY: Yes, and I was provided with the accommodations of extended test time and having a note taker.

Did the faculty support your needs related to your accommodations?

HARRY: Overall, very well, yes. There was only one professor that refused to provide extended test times. The university's disability-support office spoke with this professor, but s/he refused to provide that documented accommodation. I had to withdraw from the course.

What was the educational setting for your**most recent student teaching placement?**

HARRY: It was an ASD support classroom.

Knowing that your performance in the classroom was rated very well by your cooperating teacher, do you think that your performance would have been different in another special education setting based on your own abilities and disability?

HARRY: I believe that I did do a little better in an ASD setting because I naturally understood some of the students' needs. It may not have been as easy for the teacher, who did not have a diagnosis of ASD, to empathize. It might have given me a little bit of an advantage but don't think it would have been incredibly different in a different special education setting. I don't know for sure.

I've been in different special education settings (life skills) in the past and didn't feel as intuitive to the students' needs. However, I personally went through some of the same trials as the students I taught in my ASD classroom and was able to anticipate and help them achieve success. I think my diagnosis helped a little, but it wasn't the sole reason why I did well in my ASD placement.

What advice/recommendations would you have for students with ASD aspiring to be teachers?

HARRY: You need to be incredibly aware of your deficits. Social skills were my issue, not having difficulties in other areas. I know that I, sometimes, have trouble working with people. So, I really try to work on that and make others aware of my difficulties. It will depend in what area(s) the teaching candidate has difficulties. In general, they should be aware of where these struggles may be and where they could occur before any issues occur. For me, I try to improve these areas and try not to make the same mistakes again.

I think it's an interesting view having ASD and going into special education. I pursued this field purely because of the experiences that I had. It wasn't all bad, it wasn't all good, but it made me want to help people similar to me. I understand what they may have went through and it's been my motivation. There were times when people have understood and helped me and times when they didn't understand me and led to a lot more problems.

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behavior in the moment and implement their strategies. For example: "I am noticing that you have started to yell;" or "Right now is an example of you speaking for a long time without asking me any

questions."

For more information, email Rachel at rsr267@cornell.edu.

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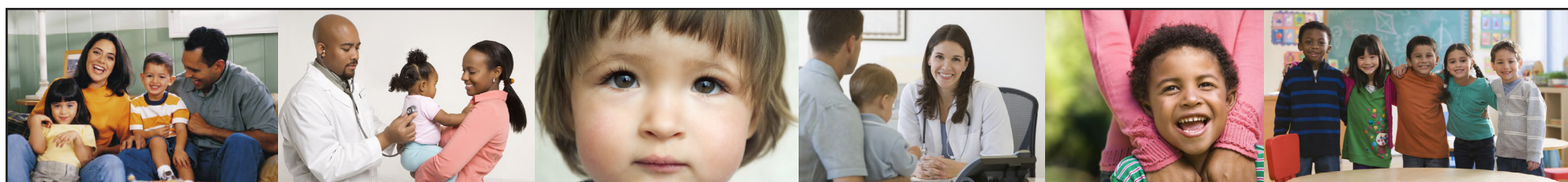
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Autism Spectrum News By The Numbers

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About Autism Spectrum News

Autism Spectrum News (ASN), published by the 501(c)(3) nonprofit organization Mental Health News Education, is a quarterly publication in print and online which premiered in the fall of 2008. ASN was developed to provide the autism community with a trusted source of evidence-based information and education, the latest in scientific research, clinical treatment best practices, family issues, advocacy and vital community resources.

ASN raises the level of the autism field by serving as a central repository of quality, practical information written by leading professionals in autism service delivery and research. The publication's content guides individuals, parents and service providers in the right direction from the very beginning, while taking efforts to avoid the promotion of unsafe and unproven interventions and treatment methods.

In keeping with the publication's evidence-based mission, ASN has an esteemed Editorial Board that will only accept articles and advertising offering science-based information and/or treatments that have been proven safe and effective for individuals with autism spectrum disorder.

ASN provides hope through education by collaborating with leading provider agencies and educational institutions across the US that are improving lives every day. The publication serves to unite and improve our evolving systems of care and advocate on behalf of individuals and their families to reduce the harmful effects of stigma in the community.

For more information contact David Minot, Publisher, at (978) 733-4481 or dminot@mhnews.org

Talking from page 14

emotional experiences (Bailen et al., 2018). Thus, parents should be aware that adolescents' emotional reactions to their siblings may not be at the same level as their cognitive capacity to understand autism. Increased openness, patience, and emotional support from parents may be indicated at this age. Adolescence may also be a time when siblings are beginning to consider their own future and their role in their sibling's adult life. Parents should respond to any questions pertaining to their future role, while being careful not to make any assumptions or communicate any pressure to assume a caretaking role. Many siblings do opt to care for their brother or sister with ASD in adulthood, but allowing them self-determination around this decision will promote more positive feelings regarding their caretaking role.

Finally, in young adulthood, parents and

siblings should continue to discuss caretaking decisions, and work toward finalizing these decisions as parents age. Adult siblings also benefit from increased access to information that is essential to planning for their sibling's future, including knowledge about financial arrangements, living arrangements, issues pertaining to legal guardianship, government benefits and other sources of aid, and therapeutic interventions and other supports that their sibling receives.

In summary, by adopting a family atmosphere of developmentally appropriate, open communication, parents will foster in siblings more positive feelings about their role as a sibling of someone with ASD, which will ultimately benefit all members of the family.

Julie Wolf, PhD is a Licensed Clinical Psychologist and Associate Professor of Clinical Child Psychology at the Yale

Child Study Center in New Haven, CT. The Yale Child Study Center offers clinical evaluation services and research into autism spectrum disorders. To learn more about our research, visit https://medicine.yale.edu/childstudy/research/clinical/autism_neurodevelopment/. To learn more about our clinical services, visit <https://medicine.yale.edu/lab/mcpartland/clinical/services/>. To request information about our sibling support services, visit <https://tinyurl.com/yalesibshops> or contact Dr. Wolf at julie.wolf@yale.edu.

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Typicality from page 23

negligence, insubordination, malfeasance, or any of the more common reasons for loss of employment. Once again, our difficulties in this area are anything but typical.

Even in daily life, our atypical differences frequently rear their ugly head. Most autistics have lived their entire lives with deficits in social skills and daily living skills, which are far less common in the general population. That this is the case is evidenced by the fact that such skills are rarely taught in schools (or anywhere else for that matter) to anyone without serious intellectual or other disabilities; they are seen as being so basic that people are literally expected to learn them on their own in the course of living their lives. Yet again,

deficits that are quite common in our community are considered so unusual that they are not even addressed.

Why Does All This Happen?

Since my diagnosis 20 years ago, I have wondered what it is about autism that makes those of us on the spectrum so atypical. It recently occurred to me that the high degree of normative behavior in the typical population is no accident but may be the result of active conformity on the part of most people. In other words, they can readily identify the prevalent or expected norms and adapt their behavior to satisfy them as much as possible; this constitutes a form of "self-correcting mechanism." Autistics, however, are far less able to do this.

Deficits in communications, particularly nonverbal communications, are quite common in autistics. As such, they are less able to recognize and sometimes even perceive how the vast majority of people in their surroundings behave. In more technical terms, the feedback mechanism that enables the above-mentioned adaptation is impaired in autistics, who consequently will have great difficulty conforming to the norms of their social environment.

All of this is further complicated by the impaired theory-of-mind that is so common among autistics. This means that, in addition to not being fully aware of what is typical and expected in their environment, they cannot appreciate how their non-normative behaviors are seen by or affect more typical peers. The additional fact that

their nonverbal communications are easily and often misinterpreted does not help matters either.

The upshot of all this is that, for autistics to be integrated into their communities, and into society as a whole, there will need to be much greater public understanding of the personal differences of autistics, not to mention improved tolerance of those differences. At the same time, autistics must be made to better appreciate the effects that some of their behaviors can have on others in their communities, and will need to be better educated in a variety of areas for which such education is rarely if at all available.

Karl Wittig, PE, is Advisory Board Chair for [Aspies For Social Success \(AFSS\)](http://AspiesForSocialSuccess.org). Karl may be contacted at kwittig@earthlink.net.

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Our mission is to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives.

**For more information, visit the website www.aane.org or contact the facilitators:
Bonnie Kaplan - Parenttalk@gmail.com | Judith Omidvaran - Judyomid@aol.com**

Socialization and Life Skills Group for Adults with an Asperger/Autism Spectrum Profile

This support group, Opening Doors, is now in partnership with the Asperger/Autism Network (AANE). This group is for adults who have an Asperger or similar autism spectrum profile. Learn, socialize and receive support from others who share common experiences. Focused on: Socialization, Mindfulness, Creativity, Self-Advocacy, Health and Well Being, Career Counseling, Relationships and Fun!

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Support Strategies from page 10

noticed that my parents treat him differently than they treat me, in a way that is unfair to me (i.e. discipline, helping us with our problems),” shared one SibTeen member. “Is it ok to think this is unfair, and should I ask my parents about it, or is this something I should try to just deal with” (Sibteen, 2017)?

Parents can support siblings by setting equal expectations to the greatest extent possible for all their children. Sharing an interest or activity - camping, sports, music, religion - can unify the family around something other than autism. Validating siblings’ feelings and acknowledging unfair circumstances helps siblings feel seen, heard, and supported. For busy parents, carving out even small windows of time with a sibling can go a long way. It can also be helpful to have a trusted adult relative or friend who a sibling can call upon for support.

Guilt

Siblings experience guilt for many reasons (Meyer & Vadasy, 2008, p. 13). Young siblings may feel guilty if they believe they

somehow caused or failed to “fix” their sib’s autism. Survivor’s guilt is common. Siblings experience guilt over natural, even healthy conflicts with their brothers and sisters with ASD. Reaching developmental milestones can also pose challenges, particularly for younger sibs who surpass their older brothers and sisters.

“It’s hard when you can do something like go to the mall by yourself with friends or get your driver’s license and because your sib has a disability he/she can’t,” shared one teen sibling (Meyer, 2005, p.100).

Siblings also feel guilty about something that many of us promote as a basic human right: self-determination. College students worry about returning home to help out. Adults feel guilty about pursuing their own careers, families, and happiness.

Providing siblings with accurate information and opportunities to talk about and validate their feelings can help manage guilt. What is worse than feeling guilty? Feeling guilty AND wrong for it.

Future Concerns

Siblings of all ages worry about the futures of their brothers, sisters, and selves.

Will they find a life partner who will accept a future caregiving role? What about children?

“One of the many things I’m struggling with is the idea of starting a family,” shared one SibNet member. “After growing up with my brother, I panic at the idea of having and raising a child with autism, while eventually caring for my adult brother. I feel such a horrible combination of sadness, anger, fear, anxiety, and heartbreak, and guilt about having these feelings at all” (SibNet, 2020).

Planning for the future of the person with ASD is an ongoing process that should begin early, be revisited often, and provide all family members with opportunities to discuss options and ideas. Families may not have all the answers, but talking together can provide great relief.

Silver Linings

Siblings play important roles in their families and experience many strengths and opportunities. Investing time, energy, and resources in siblings can benefit the entire family. We are grateful to all who acknowledge, validate and support sib-

lings, the family members who will have the longest lasting relationships with people with ASD.

The Sibling Support Project is a program of Kinderling, Washington’s largest and most comprehensive neurodevelopmental center. Reach us at www.siblingsupport.org, emilyholl@siblingsupport.org or 425-362-6421.

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families with autism because I understand the difficulties families undergo in adjusting to living with a child diagnosed with autism. I also began volunteering with local political candidates in my area because political decisions play a major role in how children with disabilities are treated. I want Annie, and others with disabilities, to be treated fairly and with care.

- The final and most important value is **kindness**. Interacting with Annie has taught me to be kind to others. There are a lot of people in society who do not understand Annie and tease people who have this disorder or differences.

As a result, I have learned to show, and treat others, with the respect I would want to see my sister treated. Without Annie in my life, I could have been just like those other people in society who do not understand. But she has allowed me to see people through a different lens and respect them for who they are as people. Every person should be kind, yet there are times when people are not kind to Annie, which disheartens me.

I care about Annie more than I care about anything else in the world. Not just because she is my sister, but because she created my compassionate personality. While I used to wish she didn’t have autism, I have used this to change the way

I interact with others. Annie’s influence spreads into every aspect of my life, and she has given me the inspiration to make an impact in the world around me.

Conclusion

As a mother, and as a professional in the behavioral healthcare field, this essay reminded me that siblings experience the same feelings and issues that caregivers and parents experience.

And to Danny: thank you for this wonderful essay about your sister. Annie is so lucky to have you and Ryan as her brothers. You make me so proud, and my heart so warm.

Amy Kelly, MBA, MNM, is the mother

to Danny, Annie and Ryan. Annie is diagnosed with moderate to severe autism, verbal apraxia, intellectual and developmental disabilities and general anxiety disorder. Amy is the National Director of Family Engagement for [Devereux Advanced Behavioral Health](http://www.devereux.org), one of the nation’s oldest and largest nonprofit providers of behavioral healthcare, and serves as a family representative on several special needs boards in the community, locally and nationally. In addition, she participates with other patients and families in efforts supported by the American Board of Pediatrics Foundation and the Autism Speaks Autism Treatment Network to address children with special needs and the importance of quality care.

Connection from page 14

Time and time again, we have seen that special services can sometimes cliff when individuals graduate from high school, but I define COVID-19 as a trap door for a lot of families. It was so sudden and abrupt. This pandemic showed us why organizations like ours are so vital to this community. Even when they couldn’t be there in person, or didn’t have all the answers, they were still there.

Impacting the World Around You

Studies have shown that siblings of people with autism report having less conflict in the sibling relationship, family resilience, and self-perceived competence. They have also been shown to have a more positive opinion of the sibling relationship (Green, 2013).

And I will attest that you feel a heightened sense of responsibility as a sibling of

an individual with ASD. My first-ever detention in school happened because I was reluctant to leave class during a fire drill because I wanted to find my brother and make sure he got out okay. Being Joey’s brother has also made me a very compassionate and understanding person. I always listen to others and try to understand where they’re coming from, because I know that everyone has a backstory.

Like most siblings of individuals with ASD, I have often wondered what life would be like if my brother didn’t have autism. But I’ve come to accept that this is who he is and it’s what makes him so special. We can’t change our siblings, but if we can educate the world around them, we might be able to have a profound impact on how the world views their differences and understands autism.

A Lifetime of Advocacy

From the moment my brother was first

diagnosed, my parents became autism advocates. They instilled this dedication in me and encouraged me to lead a life of education and compassion. I’ll never forget the first time my mom stood her ground when my brother started making a lot of noise in public. She didn’t apologize for his actions; she stayed calm and focused in helping him relax. And it was through her selfless actions that I was inspired to create the autism empowerment pin. To this day, I’m still blown away by the support we’ve received from these efforts, and I proudly carry out its ideals and mission every day. The pin itself is a constant reminder of how far we’ve come in society toward raising awareness around autism, its impacts on families across the globe, and the many ways that we can support individuals with autism achieve personal goals and independence. But we still have so far to go.

The Arc Westchester has been supporting families and individuals in Westchester County for over 75 years, and my work

here has really just begun.

Nicholas Lombardi is the Social Media and Marketing Manager of The Arc Westchester, the largest agency in Westchester County, NY, supporting individuals with developmental disabilities, including those on the autism spectrum, and their families. He has a Bachelor of Arts degree in Communications from Manhattanville College. For more information, visit ArcWestchester.org.

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brother or sister with an autism spectrum disorder.

Twelve Important Needs of Siblings and Tips to Address These Needs

1. Siblings need communication that is open, honest, developmentally appropriate, and ongoing. Parents may need to deal with their own thoughts and feelings before they can effectively share information with siblings. Children may show their stress through their withdrawal or through inappropriate behaviors. Parents should be alert to the need to initiate communication with their son/daughter. Siblings may be reluctant to ask questions due to not knowing what to ask or out of fear of hurting the parent. While doing research on siblings, Sandra Harris found that developmentally appropriate information could buffer the negative effects of a potentially stressful event (Harris, 1994).
2. Siblings need developmentally appropriate and ongoing information about their siblings' autism spectrum disorder. Anxiety is most frequently the result of lack of information. Without information about a sibling's disability, younger children may worry about catching the disability and/or if they caused it. The young child will only be able to understand specific traits that they can see like the fact that the sibling does not talk or likes to line up their toys. School aged children need to know if the autism will get worse, and what will happen to their brother or sister. Adolescents are anxious about the future responsibility and impact of the disability on their future family.
3. Siblings need parental attention that is consistent, individualized, and celebrates their uniqueness. Many families make a major effort to praise and reward the child with the disability for each step of progress. This same effort should be considered for the siblings even if an accomplishment is somewhat "expected." Self-esteem is tied to this positive recognition by parents. Remember to celebrate everyone's achievements as special.
4. Siblings need time with a parent that is specifically for them. Schedule special time with the sibling on a regular basis. Time with the sibling can be done in various ways such as a 10-minute activity before bed each night or a longer period of ½ hour to an hour 3-4 times a week. The important thing is to have some specific times with a parent that siblings can count on having just for them.
5. Siblings need to learn skills of interaction with their brother or sister with an autism spectrum disorder. Sandra Harris & Beth Glasberg (2003) offer guidelines for teaching siblings necessary play skills to interact successfully with

their brother or sister with an autism spectrum disorder. It is important to go slow and generously praise the sibling for his or her efforts. Toys and activities should be chosen that are age appropriate, hold both children's interest, and require interaction. The sibling needs to be taught to give instructions as well as prompts and praise to their brother or sister (Harris & Glasberg, 2012).

6. Siblings need to be able to have some choice about how involved they are with their brother or sister with an autism spectrum disorder. Be reasonable in your expectations of siblings. Most siblings are given responsibility for their brother or sister with a disability at one time or another. Show siblings you respect their need for private time and space away from the child with the disability. Make every effort to use respite services, community recreational programs, and other available supports so that you are not overly dependent on the sibling.
7. Siblings need to feel that they and their belongings are safe from their brother or sister with ASD. Some children with an autism spectrum disorder can be destructive and hard to redirect. They can also be quick to push, bite, or engage in other challenging behaviors with the sibling as a target. Siblings must be taught how to respond in these situations. Generally, this would include asking a parent for help in handling the situation. Parents should make every effort to allow siblings a safe space for important items and a safe retreat from their siblings' aggressive behaviors. Thomas Powell and Peggy Gallagher offer ideas on teaching basic behavior skills to siblings (Powell & Gallagher, 1993).
8. Siblings need to feel that their brother or sister is being treated as "normal" as possible. Explain differential treatment and expectations that apply to the child with a disability. As they mature, siblings can better understand and accept the modifications and allowances made for the brother or sister with a disability. For various reasons, parents sometimes do not expect their child with an autism spectrum disorder to have chores and other responsibilities around the house. Attempts should be made to make each child's responsibilities and privileges consistent and dependent on ability. Be careful not to underestimate the ability of the child with an autism spectrum disorder.
9. Siblings need time to work through their feelings with patience, understanding, and guidance from their parent(s) and or a professional, if appropriate. Listen and acknowledge that you hear what is being said. Validate the sibling's feelings both positive and negative as normal and acceptable. Repeat back what you have heard the sibling say and check for accuracy. Sharing your positive and negative emotions appropriately is also important. Remember parents are important models of behavior. Help

siblings learn ways to cope with and manage their emotions.

10. Siblings need opportunities to experience a "normal" family life and activities. If needed, draw on resources in the community both informal and formal. Some families are uncomfortable asking for help. For the sake of everyone in the family, it is important to find and use resources available such as respite care services and other community programs for persons with disabilities and their families. Most families would be overwhelmed without some breaks from the ongoing demands of caring for children with a disability. Siblings and parents need opportunities for activities where the focus of energy is not on the child with special needs.
11. Siblings need opportunities to feel that they are not alone and that others understand and share some of the same experiences. Parents should recognize the need for siblings to know that there are others who are growing up in similar family situations with a brother or sister with a disability. Opportunities to meet other siblings and/or read about other siblings are very valuable for most of these children. Some children might benefit from attending a sibling support group or a sibling event where they can talk about feelings and feel accepted by others who share a common understanding while also having opportunities for fun.
12. Siblings need to learn strategies for dealing with questions and comments from peers and others in the community. Parents should help prepare siblings for possible reactions from others toward their brother or sister with a disability. Make sure the sibling has facts about autism spectrum disorders. Discuss solutions to possible situations. They may even benefit from carrying their own information card about autism, for friends and situations in which they can hand out as needed.

Siblings have a unique bond with each other that is usually lifelong. Having a sibling with a disability influences this bond and will affect each sibling differently. The information presented here highlights some of the limited research and the most significant factors influencing a positive experience for siblings of a child with a disability. As a parent of a child with an autism spectrum disorder, you can directly influence and support positive relationships for siblings. Just as you have learned to be proactive for the sake of yourself and your child(ren) with an autism spectrum disorder, siblings need you to be proactive in helping them, too.

Marci Wheeler, MSW, is Social Work Specialist at the Indiana Resource Center for Autism at the Indiana Institute on Disability and Community at Indiana University, Indiana's Center for Excellence on Disabilities. For more information, visit www.iidc.indiana.edu/pages/irca.

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You may view the original article at www.iidc.indiana.edu/irca/articles/siblings-perspectives-some-guidelines-for-parents.html.

Resources

Books:

Feiges, L.S. & Weiss, M.J. (2004). *Sibling stories: Reflections of life with a brother or sister on the autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Company.

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Life as an Autism Sibling: A Guide for Teens. Retrieved 3/27/17 from www.researchautism.org/resources/life-as-an-autism-sibling-a-guide-for-teens/

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Sibling Support Project Website: www.siblingsupport.org/

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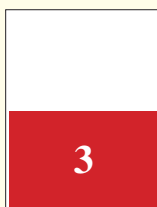
Fall 2021 Issue - September 2, 2021



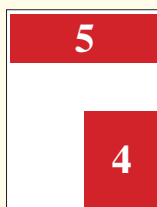
Full Page



Half Vertical



Half Horizontal



Quarter V & H



Eighth V & H

Ad Sizes - In Inches

	<u>Width</u>	<u>Height</u>
Full Page (1)	10.4	12.8
Half Vertical (2)	5.1	12.8
Half Horizontal (3)	10.4	6.4
Quarter Vertical (4)	5.1	6.4
Quarter Horizontal (5)	10.4	3.1
Eighth Vertical (6)	5.1	3.1
Eighth Horizontal (7)	10.4	1.5
Business Card (not shown)	5.1	1.5

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