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Understanding and Developing Communication Skills

Empowering Voices: The Importance of Self-Advocacy and Effective Communication for Autistic Individuals

By Gina-Marie Moravcik, MA, CCC-SLP
Speech Language Pathologist
Sunrise Speech and Language Services

Self-advocacy is a critical skill requiring communication for individuals on the autism spectrum, enabling them to express their needs, rights, and preferences effectively. It plays a significant role in their personal and academic lives, particularly as they transition into adulthood and face new challenges. This article explores the importance of self-advocacy and effective communication, drawing insights from the research conducted by Siva Priya Santhanama and Kaitlyn Wilson, as well as Stephen M. Shore's work on self-advocacy.

Self-advocacy refers to the ability to speak up for oneself and make informed decisions regarding one's life. This can involve articulating one's needs and the use of partial or full disclosure in social situations, educational environments, and healthcare settings. According to Shore (2018), self-advocacy is not just about speaking for oneself but also about understanding one's rights and responsibilities. This understanding empowers individuals to take control of their lives and advocate for necessary accommodations in college or work settings.

Effective communication is a cornerstone of self-advocacy. Autistic individuals may face unique challenges in communication due to differences in social interaction and processing of verbal and nonverbal information. However, developing effective communication skills can significantly enhance their ability to advocate for themselves. This includes verbal communication, non-verbal cues, and written expression (Santhanama & Wilson, 2020).

While transition goals begin at the age of 14 for students with Individualized Education Plans (IEPs), not all students actively discuss their strengths and weaknesses or understand how, when, and what to disclose to others for social or academic purposes. Yet, they are expected to be able to do so upon graduation from high school. In addition, those students may not have access to neurodivergent mentors who speak positively about their differences and can share strategies that have contributed to their accomplishments and self-esteem. Self-advocacy skills need to be emphasized and actively targeted in high school to prepare students for life in college or the workplace.

Universities often have an onsite Speech and Language Center, which can and should be utilized by neurodivergent students to continue to support their social, academic and self-advocacy needs. Speech Language Pathologists should be accessed as social and advocacy coaches in both academic and workplace settings to assist in

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How to Best Determine if an Autistic Individual is Using an Effective Communication System

By Maryanne Robertson, MS, CCC-SLP
Speech Paths, LLC
and Dr. Todd Harris, PhD
Devereux Advanced Behavioral Health

Clear and effective communication is one of the most significant challenges autistic individuals encounter. As with many other characteristics of autism, the communication abilities of autistic individuals present across a wide spectrum. While many individuals understand and use spoken language, they may encounter difficulties using language effectively in certain situations, particularly social situations. For others, the comprehension and use of spoken words may be significantly impacted by autism. Nearly 30% of autistic individuals will not develop spoken words or will develop only a small vocabulary of expressive words that are not sufficient to meet their communication needs (Holland, 2023). To enable individuals who are considered to be minimally verbal or nonverbal learners with a communication modality other than speech, an augmentative or alternative communication system (AAC system) is typically introduced.

AAC refers to an area of clinical practice that supplements or compensates for impairments in speech-language production and/or comprehension and falls under the broader umbrella of assistive technology or the use of any equipment, tools, or strategies to improve functional daily living in individuals with disabilities or limitations (American Speech Language Hearing Association, n.d.). These supplemental systems can include *unaided* systems, such as sign language or gestures, in which no external tools are needed, or *aided* systems in which external tools or materials are used. Aided systems range from light tech systems, which may use printed picture symbols or objects, to mid-tech systems, which can include switches or simple voice output systems, to high-tech voice output devices such as tablets. These systems are considered *augmentative* when used to supplement existing speech or *alternative* when used in place of speech that is absent or non-functional (Elsahar et al., 2019).

For non-verbal and minimally verbal autistic individuals, establishing an effective functional communication system should be an immediate priority in improving outcomes. Often, challenging behaviors arise in autistic individuals in the absence of an effective communication system. Learning to communicate in an effective way can be life-changing for these individuals and their families.

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Autism Spectrum News Receive Prestigous "Leader in Adult Autism Award"

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"We applaud Autism Spectrum News' efforts to showcase diverse and varied experiences from Autistic adults and their commitment to featuring articles written by Autistic contributors.

Autism Spectrum News exemplifies leadership in journalism that is vital to advancing acceptance for the Autism community."

- **Christopher Banks, President and CEO**
  Autism Society of America

It's Never Too Late to Communicate: Increasing Communication Access for Adults with Intellectual Disabilities and Autism

By Laura Nagy, MS, CCC-SLP
Speech-Language Pathologist
Melmark

Darius using his AAC device to communicate with staff

An estimated 5 million people in the United States are living with complex communication needs (CCN) (Beukelman & Light, 2020). This estimate includes people across all age groups and disability types who experience difficulties meeting their communication needs using only verbal speech. Alternative and augmentative communication (AAC) methods offer a way to communicate for people who do not use verbal speech or who have significant limitations on their speech. AAC may be appropriate for people of any age when they have the opportunity and support needed to learn.

In typically developing individuals, language acquisition begins around 6 months and continues developing through early adolescence. If a child does not use functional speech by age 5, they are considered nonverbal or minimally verbal (Tager-Flusberg & Kasari, 2013). Historically, it was believed that if language skills did not develop prior to age 5, a person would be unable to gain this skill later in life. However, with the growing availability of alternative communication methods, learning to communicate does not have to be limited to young children and may be possible well into adulthood.

Many nonverbal and minimally verbal adults rely on non-symbolic communication, such as eye gaze, gestures, facial expressions, and body language, to meet their communication needs. While these methods are effective in some circumstances, non-symbolic communication significantly limits the type and variety of messages an individual can communicate. AAC increases access to symbolic communication, which consists of spoken and written language, signed languages, and picture symbols. With increased access to symbolic communication via AAC, non-verbal and minimally verbal individuals can expand their communication abilities to include more complex and abstract messages.

Why Was My Adult-Child Never Offered AAC Before?

Children with CCN have access to speech-language pathology (SLP) services up to age 21, as schools must provide a Free and Appropriate Public Education (FAPE) (Office for Civil Rights, 2010). However, access to SLP services in public schools and AAC treatment is relatively recent, with the passage of the Individuals with Disabilities Education Act (IDEA) in 1975 and the introduction of AAC as a viable treatment option in 1981 (U.S. Department of Education, 2024; Calculator & Delaney, 1986; Gorenflo & Gorenflo, 1991; Shane & Cohen, 1981).

Given this history, adults 43 or older, likely never had access to the services necessary to meet their complex communication needs. Even today, individuals leaving the public education system may not have received adequate AAC support, as knowledge of when to implement AAC and how to provide effective treatment continues to be limited (Assistive Technology Industry Association, 2011, as cited in Brittlebank & Sowers, 2024).

Although many adults with CCN may not have received AAC intervention as children, increasing meaningful communication is still possible and valuable as an adult. Melmark is a multi-disciplinary disability services agency at the forefront of supporting life-long communication opportunities for adults with disabilities. With the introduction of adult speech therapy services in 2018, 45 of Melmark's 70 non-verbal/minimally verbal adult residential clients have gained access to functional symbolic communication through AAC. In other words, these individuals are able to use picture symbols on a device to communicate their wants, needs, and thoughts, greatly expanding their ability to effectively express themselves to others. The following case studies discuss two individuals at Melmark whose communication journeys demonstrate the value of AAC in adulthood and highlight steps and considerations when pursuing AAC for adults.

Who Could Benefit from AAC?

Even without access to verbal speech or AAC, people with CCN are often able to communicate some of their needs using non-symbolic communication, such as eye gaze, vocalizations, body movements, and physical manipulation of a person or object. AAC offers access to symbolic communication through methods other than verbal speech, which greatly expands the type and clarity of communication available to the individual. AAC is typically recommended for people who are nonspeaking, but it may also benefit people who have limited verbal output, and people with low speech intelligibility. Melmark clients Will and Darius demonstrate contrasting profiles of individuals who may benefit from AAC.

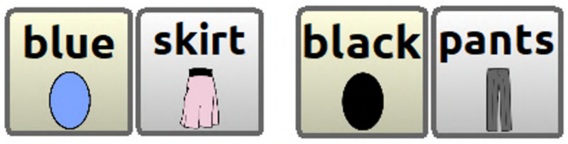
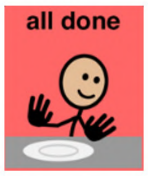
<u>Will</u> - Will is a nonspeaking 57-year-old man with severe intellectual disability and spastic quadriplegic cerebral palsy. He is a highly social individual who spent the majority of his life relying on non-symbolic communication. When unable to effectively express himself, Will engaged in challenging behaviors, such as disruption and aggression, in an attempt to meet his needs. Will was 51 when he first trialed AAC to support his communication.

<u>Darius</u> - Darius is a 38-year-old man with moderate intellectual disability, spastic diplegia with left hemiparesis, and optic neuropathy. He can communicate through vocal/verbal means, but his speech is highly unintelligible to unfamiliar listeners or in an unknown communicative context. Darius may attempt to repair communication breakdown when prompted, but most often he will change the subject or stop talking altogether. At age 32, Darius trialed articulation therapy to improve intelligibility, but he had limited success due to the severity of his deficits. He began utilizing a speech-generating device (SGD) to support his communication at age 37.

When determining who may benefit from AAC in adulthood, it may help to move away from asking, "Can this individual communicate anything?" and toward, "Can this individual communicate everything?" To narrow this broad question, consider whether an individual can engage in new environments, with new people, using the six primary functions or reasons why we communicate:

- To request - ask for what you want or need
- To protest – express dislike, disinterest, or discomfort
- To comment – identify people, things, and experiences in our environment
- To ask questions – gain information about specific topics
- To socialize – engage in greetings, gain attention, and build social closeness
- To share information – discuss your thoughts, opinions, ideas, and feelings

Examples of ways to model during daily routines:

Verbally you say:	Using the AAC system you select:
I'm hungry. I'm ready to eat dinner.	 I want to eat my meal
I see you looking at the ball. It looks like you want to play ball.	 play ball
It's time to get dressed. Do you want to wear the blue skirt or the black pants?	 blue skirt black pants
Hello! It's good to see you today	 hello
When you're ready to be all done, you can let me know.	 all done

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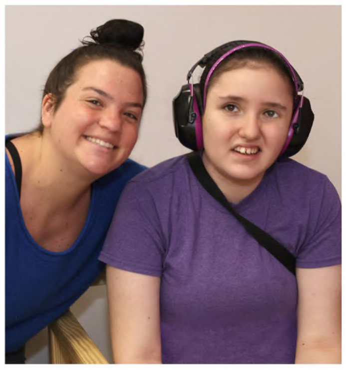

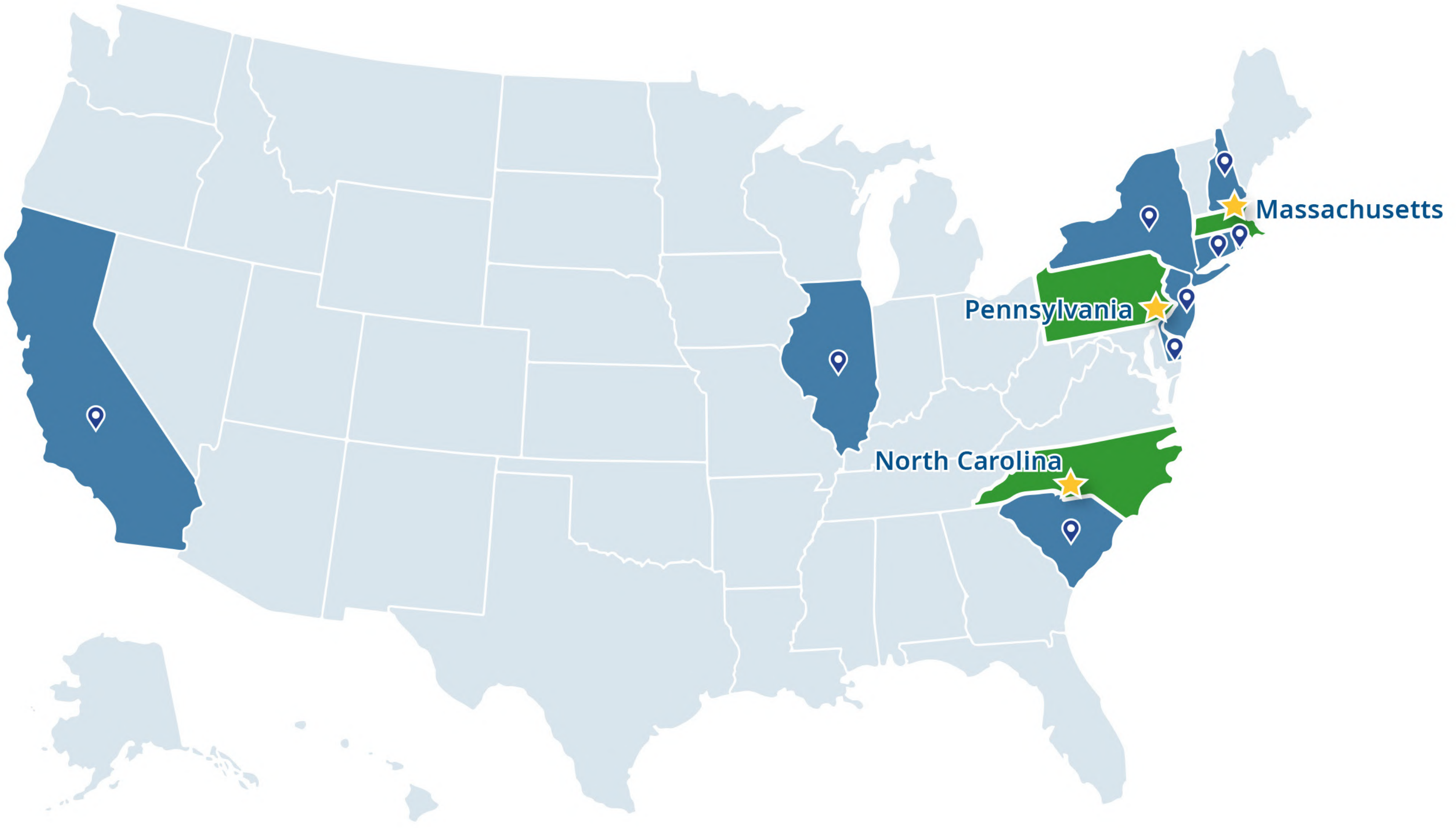

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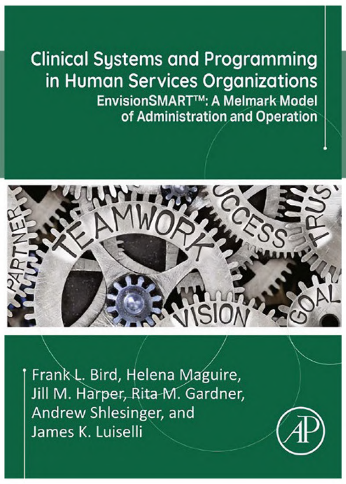

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More Than Words: Empowering the Voices of People with Autism

By Michelle Bynoe
Residential Manager
Living Resources

Living Resources, a Capital Region agency where I proudly work, serves about 1900 people with autism or other disabilities and life-challenging conditions. As I pen this piece during the holiday season, I am reminded of one of the most rewarding and instructive moments I experienced at one of the agency homes I manage.

The moment provided a lesson about the power of communication. But here's the thing: not a word was spoken.

This is what happened: A few years back, during Christmas, residents and staff together decorated our home's living room. It was transformed into a winter wonderland, with lights and ornaments on the tree, garlands across the walls, and other holiday decor placed all around. Everything was just so beautiful, warm, and comforting.

One subsequent evening, I sat on the living room sofa admiring our handiwork when a resident made herself comfortable, laying down in front of me on the rug with pillows all around her.

We were both sharing a cherished moment, appreciating the glow of the room and the magic of Christmas, family and community all wrapped in one. It was a gift, and neither of us wanted to be in another place. In our silence, we communicated everything.

Living Resources Residential Manager Michelle Bynoe in a kitchen with a person she supports

Thinking back, that moment summed up the wonder and power of communication: it often isn't spoken. It is almost always much more than words.

Still, the wonder and power of communication is not without its challenges. In working with people with autism, that communication always needs to be "heard."

There is a myriad of ways we all communicate through both verbal and non-verbal means -- and that's especially true of autistic people. So, being on the other end of a verbal or non-verbal cue and "listening" to understand what is being communicated is fundamental to my job.

How people with autism communicate can differ immensely. For one thing, like all of us, some people with autism are extroverts, and some are introverts. For extroverts who may have little difficulty verbalizing, we must listen intently. For the less verbal introverts, we need to actively observe and be even more studious about picking up on non-verbal cues.

By the way, there is a horrible misconception that those who don't verbalize do not understand what you are saying or requesting. There is a huge difference between speaking and understanding. Many people who don't verbalize understand you just fine. They just can't verbalize their thoughts adequately.

Another thing to keep in mind with communication with autistic people is that there is frequently a delay in processing. It is imperative to be patient and allow them to think and answer. If their social skills are delayed, you might think they are not listening or ignoring you, but they do hear you, and they will respond when they are ready and able.

Finally, it is crucially important to be open to people to give them the confidence they need to express themselves. If people don't trust you, if they don't feel comfortable bringing their thoughts to you, or feel they will not be heard, they will not attempt to communicate.

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The Autism Society of America Awards Desiree Kameka Galloway the 2024 Daniel Jordan Fiddle Foundation Leader in Adult Autism Award

By Staff Writer
Autism Spectrum News

The Autism Society of America is pleased to announce that Desiree Kameka Galloway will be honored with The Daniel Jordan Fiddle Foundation *Leader in Adult Autism Award* for 2024. This award celebrates individuals and initiatives that allow Autistic adults to live fully.

The Daniel Jordan Fiddle Foundation *Leader in Adult Autism Award* aims to inspire the Autism community and society by recognizing autistic adults, professionals, and businesses that focus on the diverse adult community in meaningful ways, highlighting strengths, talents, and abilities. "As a leading expert in neuro-inclusive housing, Desiree is an inspirational leader in an area of vital impact for all adults seeking to attain suitable housing options as a matter of human rights," stated Linda Walder, Founder and CEO of The Daniel Jordan Fiddle Foundation.

Ms. Galloway has demonstrated exceptional leadership and dedication to creating neuro-inclusive communities. With extensive experience visiting over 120 residential programs and leading a network of over 250 organizations, she has become a key advocate for supportive housing and service models that foster meaningful inclusion for individuals with neurodiversities. As the founder of Neuro-Inclusive Housing Solutions, LLC, she advances this vision through market analysis, advocacy, coalition-building, and consulting with housing developers nationwide.

"Desiree's work is instrumental in preventing displacement and homelessness among Autistic individuals, paving the way for more inclusive communities," shared Christopher Banks, President and CEO of the Autism Society of America.

When learning about her award recognition, Ms. Galloway said, "The Autism Society, being the oldest grassroots Autism organization in our nation, has led the charge to improve the lives of Autistic adults for decades. I continue to be inspired by the leaders and important work of The Daniel Jordan Fiddle Foundation Endowment Funds at universities across the country- truly the best of the best. Thank you for this prestigious award and for your unwavering dedication to the Autism community."

Autism Society of America

The Autism Society's mission is to create connections, empowering everyone in the Autism community with the resources needed to live fully. As the nation's oldest leading grassroots Autism organization, the Autism Society and its approximately ~70 local affiliates serve over half a million members of the Autism community each year. It envisions a world where everyone in the Autism community is connected to the support they need when they need it – including education, advocacy efforts, and supports and services throughout the lifespan. For more information, visit the Autism Society at AutismSociety.org, Facebook, Instagram or X.

The Daniel Jordan Fiddle Foundation

The Daniel Jordan Fiddle Foundation was the first not-for-profit and only all-volunteer-run organization in the United

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2024 Daniel Jordan Fiddle Foundation Leader in Adult Autism Award Winner

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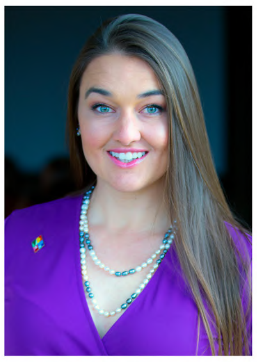

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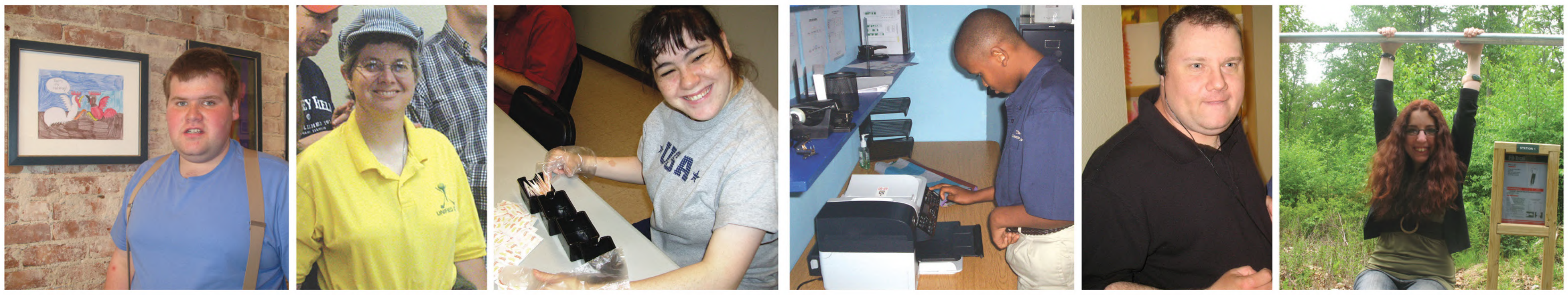

“Nothing About Us Without Us” Leaves Voices Out

Dr. Doreen Samelson speaks at Catalight’s EYI conference in Walnut Creek, California, in March, 2024.

By Doreen Samelson, EdD, MSCP
Chief Clinical Officer
Catalight

In the autistic community, we often hear the phrase “nothing about us without us.”

On its surface, that seems like the ethical standard that those of us who are not autistic should commit to. It feels respectful for non-autistic clinicians, educators, and researchers like me to take our lead from autistic people. And bringing autistic advocates to the table is doable, as there are plenty who have the willingness and ability to lead. In fact, not doing so seems ableist.

That said, if we look beneath it all, strictly adhering to “nothing about us without us” may not be in the best interest of all those on the wide-ranging autism spectrum and those who care for them. In fact, if we’re talking about empowering the voices of the entirety of the community, outside advocacy is necessary for those who require round-the-clock support and significant care. If we paint everyone within this heterogeneous population with a broad brush, we’re leaving those with the most needs behind.

I am a physically disabled person and a wheelchair user. I identify as disabled and usually use identity first language. I travel and speak at conferences and have had the opportunity to advocate for many issues related to wheelchair users like me. So, what does this phrase, “nothing about us without us,” mean for me and the physically disabled community?

Before I can answer that question, there are some other important questions I need to ask: Do I really represent the broad, varied experiences and needs of the diverse population of physically disabled people? Do I represent quadriplegics? Should I place myself in a position to speak for someone who needs 24-hour assistance to do physical activities like eating, dressing, or toileting when I can manage these personal tasks on my own? Can I speak for someone with a fast progressive disease like amyotrophic lateral sclerosis (ALS) when my own condition is very slowly progressive?

I follow a number of people on social media with ALS who refer to themselves as “ALS Warriors.” While I rarely think about a cure for myself, many ALS Warriors think about a cure every day. The truth is my disabled experience is as different from someone with ALS as the experience of an autistic person with a PhD is to someone with autism and severe/profound intellectual disability.

For me, “nothing about us without us” is specific to people whose disability experience is close to mine.

I rarely hear this perspective from autistic advocates either at the conferences I go to or in the articles I read. What I hear is articulate, educated autistic advocates like the medical student I listened to at a conference last year suggest that they speak for the autistic population. Some even going so far as to say parents of autistic children “can’t speak” for their autistic children because they themselves aren’t autistic.

This begs the question for autism researchers and clinicians like me, ‘Who does the phrase “nothing about us without us” refer to when considering the needs of significantly disabled autistic people?’ If the data about severe autism is correct, almost one-third of the autistic population falls into the category of profound autism. It is beyond the cognitive abilities of individuals in this group, whose severe disability includes minimal language, to understand the phrase “nothing about us without us.”

As a disabled person and advocate, I think I must ensure that I am not speaking for people whose disability experience is very different from mine. Similarly, autistic people who are able to communicate and understand the phrase “nothing about us without us” shouldn’t speak for autistic people for whom this phrase is meaningless. Instead, I propose that for severely disabled autistic people, we broaden the phrase “nothing about us without us” to include parents. This will not happen unless autistic advocates recognize that they cannot speak for the entire autistic population and acknowledge that parents should be included in “nothing about us without us.”

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Enhancing Communication Skills in the Workplace: Strategies for Autistic Employees and Employers

By Ben VanHook, BA
Community Support Coordinator
Organization for Autism Research

Communication in the workplace is a vital key to increasing employee engagement and allowing new perspectives and voices to be heard. Once a work environment exists where all members of staff feel comfortable communicating, you are likely to see greater innovation, growth, and more effective teams (Indeed Editorial Team, 2024).

However, common neurotypical communication patterns involving abstract concepts and idioms are often challenging for autistic people to decipher. Autistic individuals communicate and process information differently from neurotypical people (Rudy, 2023).

Some communication differences observed can include but are not limited to:

- Processing delays
- Interpreting phrases literally
- Office etiquette
- Challenges with self-advocacy

As communication styles vastly differ between individuals, it is essential for employees to effectively advocate for their needs and for employers to be open and understanding of these varying requests to be successful in the workplace. Employers and employees must collaborate to identify the most effective ways to work together.

Inclusive Training for Staff

A significant first step towards enhancing communication in the workplace is to create a more inclusive workplace through staff education. At many companies, the lack of inclusive training and knowledge regarding autism can leave supervisors, managers, and colleagues ill-equipped to support their autistic colleagues. This education gap perpetuates disinformation, stereotypes, biases, and stigma around autism.

Inclusive workplace training practices can help teach staff about autism and essential concepts such as:

- Everyone has different needs
- Ask, don't assume
- Respect boundaries

Accommodations

The accommodations process is crucial for supporting autistic employees (JAN). As such, one of the most important aspects of the accommodation process is the interactive communication between employee and employer.

Not every employee will have the same needs, making this conversation critical for employers to understand how best to provide individually tailored support to meet each employee's needs. A good starting point for the employer and employee is to enter this conversation with an open mind and a blank slate. This allows for a thoughtful and productive discussion where both parties can learn how to coexist and operate efficiently while ensuring the needs of the individual and company are met simultaneously.

Some examples of reasonable accommodations might include:

- One-on-one meetings

see Workplace on page 43

Active Listening and Multimodal Communication: Strategies for Understanding and Supporting Unique Needs

**By Eve McCoog, LCSW,
Nishi Kadakia, MAP, BCBA,
Liane Elton, MS, RBT,
and Howard Savin, PhD
First Children Services**

You're going through your workday, and suddenly, the bottom of your foot starts to ache. You stop, untie your shoe, and take it off to see what's happening. Relief washes over you when your supervisor appears because help has arrived! You start to peel your sock back to show them where you're hurt, and—your supervisor tells you to put your shoe back on. What? No! You need help! You want to tell them what you need but can't find the words. When you don't put your shoe back on, they put your shoe back on themselves. You try several times, only to end up with them tying your shoe again.

The hurt turns to pain over the day, but you endure it. "Maybe I can make it until I go home," you think to yourself, but then your supervisor places an urgent project on your desk. You can't take it anymore! You cry. You scream. You rip off your shoe, throw it across the room, and push away your supervisor when they try to put your sock back on. Your coworkers stare. Then, your supervisor finally sees the blister on your heel.

How could the supervisor not see that something was clearly wrong with their employee? In the same way, we sometimes don't see it when working with our kids. Our hearts break when we realize one of our clients is hurt, but It's not easy to reduce our client's distress and perform effectively as ABA professionals when encountering what we perceive as challenging behaviors. Let's be fair to ourselves—it's human to become frustrated and even angry when things are thrown or we get hit. What is also important to acknowledge is that our clients are just as frustrated, and it is often because they have little or no effective way to express their needs. We can see this in how functional communication training (FCT) reduces these behaviors (Cooper et al., 2020). However, we also need to train ourselves to be effective listeners so we can close the communication gap and ensure that those we serve can be heard no matter their level of skill.

Communication encompasses several different purposes for our students. This ranges from expressing emotions to asking for what they want or need and sharing information. Our students need effective communication skills to function well in their classrooms and other school environments. Special needs students come with special challenges in effective communication. They rely on their adults to help them both learn functional communication skills and try to do all the things without the benefit of effective communication. These students depend on their adults to not only teach the skills for improved communication but also to translate and interpret for them when their attempts at clear communication fail. Several skills and strategies have been proven to help learners achieve the goals of teaching and interpreting. The most important skill is actively listening. Active listening may seem easy, but it requires practice, focus, attention, and intention to do well. Five steps constitute good active listening: 1) paying attention, 2) showing you are listening, 3) providing feedback, 4) deferring judgment, and 5) responding appropriately. Steps 1 and 2,

see Multimodal on page 31

Social Communications: An Essential but Often Overlooked Skill for Autistics

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

Autism has been described, and sometimes defined, as a disorder of communication. This is certainly the case for nonverbal autistics and others who are completely unable to communicate, but it is just as true for those who are articulate and able to express themselves verbally. For them, autism is often, if not usually, a deficit (sometimes serious) in social communication. For many, if not most level 1 autistics of at least average intelligence, who are able to read, write, and otherwise communicate verbally, this deficiency is often not recognized and, as such, never addressed. This does not help the affected autistic since social communications are about the most important form that humans engage in, and the lack of skill in which can be detrimental to the life of an individual.

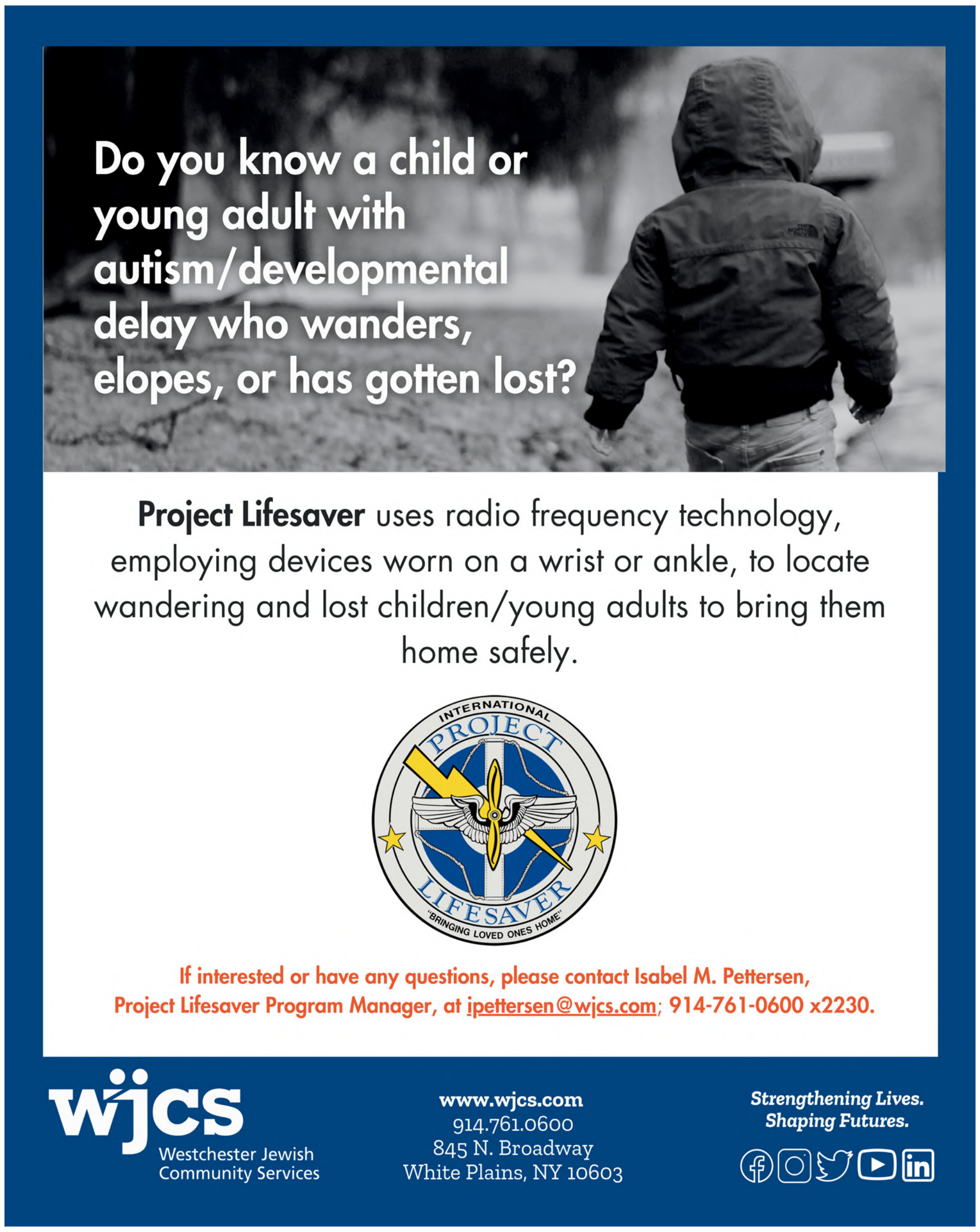
Teaching Social Communication Skills

Social communication skills, like other skills, need to be learned. This happens through personal experience (sometimes painful) and by explicit instruction, as in a school setting. During much of my life, I believed that the educational system ignored this issue and regarded it as something to be "picked up" in the course of one's life. For many years, I was very angry about this and felt that my schools had completely failed me in this regard. At least, so I thought.

Later in life, however, I was occasionally told that reading a lot of fiction was of great value in learning to understand others and interact with people. I had always been a slow reader and, like many autistics, read almost entirely non-fiction with only the occasional (of course) science fiction or techno-thriller. I also learned, not long after my diagnosis in late 2000, that autistics often had difficulty with discussions, after reading a story, about what the characters might be thinking or feeling – this was attributed to deficits in theory of mind. Upon reading this, I immediately recalled having had this exact difficulty. I also remembered that when the thoughts and feelings of characters were explicitly stated in a story, I was able to follow, even though it wasn't particularly easy for me to do so. Later, when these were not articulated but instead became part of the subtext (something that I was completely incapable of discerning), I had absolutely no idea how to make such a determination; to this day, I wonder how I ever got through those classes in school!

This all means that at least this one method of teaching social communication was being used in schools, but because I was completely oblivious to such, it was of no use to me whatsoever. Being a twice-exceptional student, though, I had always received high scores on standardized tests of reading comprehension – usually two to three years above grade level. As it happens, these consist of passages that are always non-fiction and questions about such that almost always concern something explicitly stated in the text and rarely, if ever, in the subtext. Is it any wonder that I did so well on these? Clearly, these tests can measure literal understanding of written material but not much else. I subsequently learned that high reading scores are not uncommon among autistic students, who typically process language very literally. When presented with anything that

see Essential Skill on page 31



Improving Health Care Communication for Autistic Teens

By Heidi Hillman PhD, BCBA-D, LMHC
Eastern Washington University

Effective communication is essential in health care for accurate diagnoses, quality patient care, and positive outcomes (Ratna, 2019). However, communication barriers can significantly impact the health care experience, particularly for individuals with autism spectrum disorder (ASD) (Saqr et al., 2018). Autistic adolescents encounter unique challenges due to differences in communication styles that may not align with typical expectations (Araujo, Mophosho, & Moonsamy, 2022; Nicolaidis et al., 2015). ASD is a neurodevelopmental condition characterized by variations in communication, social interaction, and behavior. The communication abilities of autistic individuals vary widely, ranging from nonverbal to highly advanced language skills. Even those with advanced language may struggle with the social nuances of communication, such as interpreting tone, body language, or indirect speech.

Many autistic teens find health care environments challenging; the unfamiliar environments and complex interactions can increase stress and impede effective communication. This article aims to identify barriers faced by autistic individuals in health care contexts and explore how health care providers can adapt their communication approaches to better support autistic patients.

Interviews

Six autistic individuals ages 15 -17 and eight parents of autistic teens were interviewed to explore communication barriers experienced during doctor appointments. The autistic individuals provided first-person accounts of their communication experiences with medical providers, whereas parents shared insights into their teen's communication challenges and the effects of these challenges on health care experiences. The interviews focused on two primary questions: What communication barriers do you experience when dealing with your doctor(s)? What specific changes in communication methods would help decrease these barriers?

Interviewing Autistic Teens

An analysis of the interviews revealed three general communication barriers the teens reported during medical appointments: difficulty with abstract language, feeling pressured to respond quickly, and physical touch during examinations. The barriers are further explained below.

Barrier 1. Abstract or Ambiguous Language: Several autistic teens expressed difficulty in understanding abstract language or metaphorical expressions that doctors often use. Words or phrases like "We'll take a look" or "How have you been feeling lately?" were perceived as unclear or even confusing, which sometimes led them to give inaccurate responses.

Teen's comment: "I don't always understand what the doctor is asking because they use expressions I'm not familiar with. I wish they would speak more directly."

Barrier 2. Pressure to Respond: All six teens reported that the pressure to respond quickly and accurately often led to increased anxiety, impairing their ability to communicate clearly. Many felt rushed during appointments, leading to incomplete communication of symptoms or concerns.

Teen's comment: *"Doctors expect me to answer quickly, but I need time to think about what they're asking. When they rush me, I can't give a good answer. Or they keep asking questions while I am answering their previous question. I then get frustrated."*

see Health Care on page 29

Autistic Lived Experience: To Be Disabled Is to Be Strong!

By Sam Farmer
Neurodiversity Community Self-Advocate, Writer, Author, and Public Speaker

Not everything is as it seems on the surface. Many things can be looked at in more ways than one. Much of what comprises a person is hidden from plain sight, though it is nonetheless very real and often of great power. Human strength is a prime example.

When I attended a 2-week tennis academy during Spring break of my sophomore year of high school in 1986, my build was anything but muscular. In fact, I was so thin that if somebody looked at me with my shirt off, they would likely notice a portion of my sternum sticking out in the middle of my chest. There was simply not enough there to cover it up.

I spoke particularly slowly and with anything but an authoritative tone. I took things in stride due to my relatively laid-back attitude. It was not like me to take control of situations or assert my needs, having not yet come to an understanding of the importance of self-advocacy. My quirky, idiosyncratic behaviors often rubbed people the wrong way.

All told, my physique and my unidentified autistic, learning-disabled attributes rendered me a prime target. And a few of the people with whom I shared a dormitory suite pounced. Not to the point of physical injury, thankfully, though it still was not what I would call a joyride.

The only memory I have about these bullies was having tennis balls thrown at me, too fast to catch or to deflect with my racket, giving them a reason to mock my inability to do so. In this scenario, longer reaction times, a primary challenge associated with my learning disability, came to the fore. During a tennis match, reaction time was never an issue for me because balls were always headed my way from the other end of the court. Conversely, the tennis academy bullies did what they did from only a few feet away, in the living room inside our suite.

I will never know what their agenda actually was in treating me this way, but if it was to try to force me out of the suite or the academy altogether, they outright failed. I had no desire to go anywhere in spite of what I was up against. Those suitemates who didn't bully me, among them a fellow tennis teammate and friend in my high school class with whom I traveled to the academy, were kind, decent, likable people on whom I chose to focus my attention.

And that was the key to it all: prioritizing the right people and what really mattered while steering clear of the wrong people and the toxicity they brought with them.

Soon after this incident, my mother called me to check-in. When I explained to her what had happened, she asked me if I wanted to head home early, understandably thinking that the bullying may have been too much for me to take. I told her that I was going to stay, to which she replied, in so many words, "ok," then left it at that. This was a truly wonderful moment, indicative of the fact that she was never overprotective of me and was always willing to meet me where I was, regardless of what she may have been thinking deep down.

Nobody was going to sidetrack me from pursuing my goal at the academy: to up my game ahead of the upcoming high school tennis season. Nobody was going to impose their will on me with any success. I remained laser-focused on what I had to do and returned home ready to roll.

The tennis academy bullies had no idea who they were dealing with, at least not at first. My secret weapon lived inside of me, always there when I needed it. Unbreakable inner strength! It made me a force to be reckoned with, which may have dawned

see Bullying on page 39

Navigating Mental Health and Life Transitions for Autistic Youth

By Abraham Abdulrazzak, DO,
and Samuel Jackson, MD
SUNY Downstate Health
Sciences University

Meet Josh, a 19-year-old autistic young adult who recently graduated from high school. Josh thrived in the small, structured environment of his school, where individualized support helped him focus on his interests and manage his daily routine. However, the transition to college overwhelmed him with a new set of challenges: large class sizes, unstructured time between courses, and increased social expectations from peers. Not knowing who to talk to, Josh struggled with feelings of anxiety and depression. He started to isolate himself more, and his grades began to drop. He started to doubt his ability to succeed in college.

Life transitions, particularly from adolescence to adulthood, can be a challenging experience for anyone, but for autistic individuals, these periods of change are marked by unique stressors that can directly impact quality of life. (Lee & Shivers, 2019). Autism Spectrum Disorder (ASD) has been characterized by persistent challenges with social communication, restricted interests, and repetitive behavior (APA, 2013). While ASD is typically thought of as primarily a social and communication disorder, it frequently involves significant mental health challenges. Research has shown that autistic individuals face higher rates of co-occurring psychiatric conditions, including anxiety and depression, which often become heightened during times of transition (Lever & Geurts, 2016). While autistic youth may have effectively managed co-occurring psychiatric conditions in highly structured environments like high school, the added stressors of transitions, such as graduating, starting college, or entering the workforce, can worsen psychiatric conditions, leading to behaviors that disrupt their lives and interfere with achieving personal goals.

The Transition to Adulthood: A Unique Set of Stressors

A child turning 18 is expected to assume newfound responsibility overnight. The transition from adolescence to adulthood is often marked with a period of increased responsibility, which could include managing healthcare decisions and finances, pursuing post-secondary education or joining the workforce, and navigating interpersonal and intimate relationships. Structured support becomes limited as these young adults move away from high school to settings that demand increasingly more independence, e.g., college, workforce, or independent living. This becomes a period for youths to seek autonomy and assert their independence.

For transition-aged autistic youth, navigating social relationships can take on new forms. Autistic young adults report perceived challenges with understanding social norms, forming meaningful connections, and managing the complexities of interpersonal or intimate relationships. These difficulties can be further compounded by increasing social expectations during this period, such as collaborating in an academic or work setting. Without adequate support, individuals might feel a sense of isolation and frustration, in turn exacerbating any co-occurring mental issues.

The Importance of Transitional Healthcare Services

Ensuring that these individuals receive the necessary support while maintaining their autonomy becomes imperative.

see Mental Health on page 34

Yes, We Can Socialize

By Robert Schmus, MSW, LCSW
Mental Health Therapist
and Autistic Self-Advocate

Throughout my life as an autistic person, I have been fortunate to have experienced great moments where I have been able to socialize with others and gain long-lasting friendships. There were also times when, due to my misunderstanding of certain social situations and the anxiety that comes with it, this has been very difficult for me and has even led me to feel lonely. Such feelings of loneliness are not uncommon in our community. This loneliness has even led to dire results for our community. The truth of the matter is that we autistics can be social creatures if we are able to socialize on our terms.

Each and every autistic person is different when it comes to how much socialization they want in their life. There are a good number of us who want to thrive socially in our lives. We want to gain such experiences and know that it will be fulfilling for us to be able to feel such an enriching experience. With that said, it must be noted that we socialize differently from our neurotypical peers.

In fact, fellow autistic writer Pete Wharmby wrote in his book *Untypical* to give pointers to keep in mind when it comes to how we socialize. Some autistics might not be consistent in their interactions with others (Wharmby, 2022). This doesn't mean that the autistic person doesn't value a relationship. Friendship is greatly valued, and that friendship works differently for us. There are some of us who rather interact online rather than in person (Wharmby, 2022). This doesn't mean that the autistic person doesn't want to meet up with someone. The autistic person might feel less stressed by interacting online. There are also some of us who might mentally tire out at an event for too long and might leave early (Wharmby, 2022). This doesn't mean that they are not enjoying the company or having a good time. In fact, they might have an amazing time. It could just be the case that the autistic person might be drained from too much social interaction and would need to recharge.

Like I stated before, much of this differs with each autistic individual. However, of all the tips Wharmby makes, I relate to the last one the most. There have been many times when I have gone to social events with friends and enjoyed myself. I would love every minute of it and even become the life of the party. The beau of the ball, if you can say that. However, there are times when I would need to leave early because I might get sensory overload. Nevertheless, I still have a good time and go to more in the future. I just need to recharge my batteries, that's all.

Many practices have been used to help autistics with socialization. However, one of the methods that have, in a way, been forced upon autistics is the use of masking. Masking, also known as camouflaging, is when an autistic person hides their autistic characteristics in order to assimilate into neurotypical society. This would be used to help them in social situations, such as finding friends and obtaining employment. In theory, this was seen as a way to help autistic individuals socialize. However, it has done more harm than good.

Masking prevents autistics from truly being themselves. They are told to deny the characteristics that make each of them unique. For instance, there are those who have to hide certain interests because neurotypicals might see them as "weird." Because of this, autistics would mimic how neurotypicals talk, act, and behave, trying to hide how they really feel so that they can act "normal."

see Socialization on page 43

Cooking Up Communication: A Recipe for Using AI to Support AAC with Modeling Scripts

By Lauren Tucker, EdD,
and Kristy Hynes, PhD, BCBA-D
Southern Connecticut State University

Augmentative and Alternative Communication (AAC) plays an important role in empowering individuals with autism and other complex communication needs to engage meaningfully in their communities. Essential to AAC adoption is the evidence-based practice of modeling, wherein communication partners demonstrate the effective use of AAC systems during everyday activities. Communication partners pair their verbal speech with the symbols or representations on the device or support. Recent advances in artificial intelligence (AI) offer new opportunities to enhance AAC modeling through tools like ChatGPT, Claude, Poe, and more. Although the use of AI to develop modeling scripts can be a significant support, there are crucial ingredients to the recipe.

Passed Down from Generations: The Research Base

Modeling is widely recognized as a cornerstone of AAC intervention. By demonstrating the use of core vocabulary—words that make up the majority of daily communication—in real-world contexts, communication partners create meaningful learning opportunities. The research underscores the efficacy of modeling in AAC. Sennott, Light, and McNaughton (2016) found significant gains in vocabulary acquisition, syntax, and pragmatics through AAC modeling interventions. Similarly, Biggs, Carter, and Gilson (2019) emphasize the importance of training natural communication partners, such as parents and educators, in modeling techniques. Senner et al. (2019) demonstrated that parent training in partner-augmented input significantly improved both parent and child engagement with AAC systems. Although many studies have demonstrated the value of modeling, it is not consistently implemented in school settings for a myriad of reasons. One reason is that staff do not have specific scripts to model unique activities, and without specific modeling scripts, staff are unsure how or what to model.

Main Ingredient: Aided Language Stimulation (ALS)

Aided Language Stimulation (ALS) is an evidence-based strategy around AAC modeling. This approach is essential for effective implementation because it demonstrates how AAC can be used functionally in natural contexts, allowing AAC users to see and learn language in action. ALS enhances language development by providing consistent exposure to core vocabulary and demonstrating appropriate use, thereby bridging the gap between receptive and expressive communication skills (Sennott et al., 2016). Including ALS in the prompting recipe is a key ingredient for success!

AI as the Rising Agent

Language-generating AI tools, like ChatGPT, have the potential to transform how professionals approach script development. The systematic review by Hopcan et al. (2023) on AI in special education highlights the potential of AI-driven tools to enhance learning and communication for students with disabilities. It emphasizes the value of adaptive technologies in

see Cooking Up on page 33

The Autistic Guide to Small Talk

By Rachel Guttentag
Autistic Self-Advocate

Small talk is often declared the bane of existence to those on the spectrum everywhere. An inane social ritual where you're expected to exchange obvious facts about the weather and be happier for it. But small talk is your foot in the door for communication. If you're trying to branch out more socially, you're not getting very far without it. It's an essential step in getting to know people, one that (generally) can't be skipped.

I'm not going to pretend to be some small talk expert. I'm sure some could break down the social expectations and purpose of small talk into an exact science.

But I have realized, through talking with others on the spectrum, that I've acquired a decent understanding of small talk. With this article, I hope some of the insights I've gained can help others as well.

To prevent this from becoming a jumble of thoughts, I've attempted to add some organization to my tips. I'll be listing them out in broad categories.

These tips should apply whether you're trying to make a new friend or just exchanging pleasantries with the cashier.

What Is It With the Weather?

Small talk provides easy common ground to start a conversation. This is especially valuable for strangers who know nothing about each other. Unless you have the magical power of mind reading, you have no idea what some random person on the street might be interested in talking about. But you can find something in common in any situation; just look at your shared surroundings.

This is why weather is the small talk go-to. As banal of a topic as it is, there is no denying that all of us are aware of it and affected by it. Even if you spend the entire day indoors, that doesn't mean conditions outside are irrelevant to you. If you do need to go outside later, it's good to be warned if the next biblical flood is coming or if it's hot enough to fry an egg on the sidewalk.

I often use the weather as a conversation starter with others when I don't know what else to talk about. If nothing else, it can give me time to think of how to get a conversational ball rolling. Plus, sometimes I just want to complain about something, and the weather can often be a worthy candidate. Which brings me to…

Find Something to Complain About Together

People love to complain. There is something so cathartic about sharing our grievances with a sympathetic ear. Being that sympathetic ear is your conversational in.

When striking up a conversation this way, don't get too personal with your woes. You should try to bond over a mutually shared inconvenience (like bad weather!). Offering someone space to gripe together can be an instant conversation starter. If you're stuck in line at airport security, maybe you can at least be stuck in line together.

Start the conversation with a statement about how much the current situation sucks, though keep it light. Maybe throw in a little anecdote about the last time you were in such a situation, or make a joke if that's your thing. If the other person is receptive to being chatted up, the conversation can flow from there.

And once you have someone's willing ear, maybe you can eventually move on to…

Find a Topic You Both Want to Talk About

When looking for a topic of conversation, your first thought may go to your

see Small Talk on page 25

Exploring the Overlooked Connections: Sensory Processing Impairments and Communication Challenges in Autism Spectrum Disorders

By Annie Kent, MA
#ActuallyAutistic Mental Health Systemic Advocate, Educator, and Freelance Writer

(Note: "Aspie" is my preferred term for people on the Autism Spectrum)

Effective communication is the foundation of strong relationships and personal growth. Sensory and emotional processing disorders affect children on the Autism Spectrum and may persist into adulthood, affecting all aspects of one's life.

Aspies are characterized by social awkwardness, attributable to differences in how we process sensory stimuli and emotions, which in turn affect our ability to communicate effectively. It's important to understand the *why* of communication barriers in order to reduce Autism stigma, which itself is influenced by "public and professional understanding of autism in combination with interpretation of visible autistic traits" (Turnock et al., 2022).

Key Factors Affecting Autistic Social Communication

Alexithymia: Alexithymia is characterized by difficulties identifying and describing one's own emotions. Loosely translating to "*no words for emotion,*" it's estimated to affect 1 in 10 people. Alexithymia is not a condition recognized by the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Rather, it's a secondary diagnosis in mental health and neurocognitive/developmental conditions such as Depression, Autism, and ADHD. Not every Autistic person has Alexithymia, but estimates across research studies suggest it occurs at a rate of approximately 50 to 60 percent (Neff, n.d.).

Because Alexithymia affects how one recognizes and distinguishes between different emotions and bodily sensations, those affected may "come across as being out of touch or apathetic. In a relationship, the person may appear incapable of empathy" (Cherney, 2020).

"People who live with alexithymia are less likely to infer or sense the emotions of others, so unless you state your feelings explicitly, your partner might seem to ignore them" (Lovering, 2022).

Rejection Sensitive Dysphoria (RSD): RSD is an experience of severe emotional pain due to feelings of failure or real or perceived rejection. It is not a diagnosis either. Instead, it's a type of social anxiety that leads to people feeling overwhelmed by intense emotions such as anger, shame, hurt, and sadness.

RSD is probably caused by brain structure differences that affect how rejection-related emotions and behaviors are regulated, resulting in more intense emotional reactions.

"Psychologist William W. Dodson explains, "' *Rejection sensitivity is like having an emotional sunburn—every touch or comment feels more painful and overwhelming*.' This analogy highlights how minor comments or actions can be perceived as threats by those who are rejection sensitive" (Sanders, 2024).

Negative Thought Patterns and Beliefs

Rejection sensitivity leads to a negative interpretation of often innocuous social

see Connections on page 30

The Autistic Special Interest as a Form of Communication

By Daniel Crofts, MA
Arc GLOW

"What is with his *obsession* with dinosaurs?!?"

"She just won't shut up about Disney movies!"

"If these kids would spend half as much time studying as they do playing with Pokémon cards, they'd be a lot better off."

Such are the responses that tend to greet special interests among the autistic population — interests that, in the eyes of neurotypical observers, more often than not rise to the level of obsessions. But I want to join Prizant (2015) and a mother of an autistic child he quotes in giving these special interests a name more consistent with fairness: "'*enthusiasms*'" (p. 54).

Whatever the terminology, the readiness with which people on the spectrum share their enthusiasms only tends to worsen society's perception of them. Society tends to see such readiness in terms of autistic blindness to other people's perspectives.

But first things first. What has any of this to do with communication?

When speaking of autism spectrum disorders, it is helpful to widen the scope of one's inquiry beyond verbal communication. In autism, language often (though not invariably) lacks the nuance and richness needed on which to build a relationship.

Regardless, people on the spectrum are still human. Deficits in verbal communication exist alongside the human need for relationship, outreach, and some kind of mutual rapport. That said, what if it is precisely in the realm of enthusiasms that meaningful, fruitful communication happens?

There is research to support this notion. Laber-Warren (2021) offers the following observation:

> [R]esearch conducted over the past 15 years is revealing that special interests are valuable to people on the spectrum. In addition to occasionally launching a career, they reliably build self-confidence and help people cope with emotions. Studies also suggest they can help autistic children gain social skills and learn (para. 6).

Later in the article, she cites a study that shows this playing out:

> Winter-Messiers and her colleagues found that talking about special interests reduced other autism traits. For example, children fidgeted less, made more eye contact, and their speech shifted from vague comments to complex, vocabulary-rich statements. Many of the young people were also better able to initiate conversation and organize their thoughts. "We found it across every single major area of deficit," Winter-Messiers says. "It was incredible" (Laber-Warren, 2021, para. 15).

But it is not just a matter of taking an enthusiasm and drawing communication out of it. I would suggest that on the part of the autistic person, the communication is already there. To be sure, it requires refinement and development, but enthusiasms form a language all their own deserving of attention.

Setting aside the differences between verbal and nonverbal communication, let us note something that they have in common. Words, like other forms of communication, are symbols — that is, materials that point beyond themselves.

I think looking at the origin of the word "symbol" can be of help to us. "Symbol" derives from the Greek word "symbolon," which refers to a common practice in Greco-Roman antiquity. People would receive one-half of an object — a vase, for example — and then a correspondent, when sending a message, would include the other half with that message. If the two halves fit, the recipient could be sure the message did, in fact, come from the purported sender. It was a matter of recognition.

see Special Interest on page 40

Bridging the Gap: Mastering Workplace Communication for Autistic Young Adults

By Kellye McIntyre, MSW
Director of Vocational Services
Lifeworks for Autism

Effective communication is essential for workplace success. For autistic young adults seeking employment, understanding and adapting unique communication styles can help create more successful outcomes.

Being on the autism spectrum doesn't mean that you can't have a meaningful and productive employment experience. In my role helping prepare and place autistic young adults in various businesses and industries, I've seen employers realize that these individuals are a welcome addition to their workplace. Autistic young adults form a dedicated workforce known for their dependability, punctuality, and earnestness. They can excel at all types of roles.

While part of my focus is working with employers to develop their autism-readiness skills and aiding in the transition of incorporating a diverse workforce, I also work individually with participants in a vocational program to prepare for successful and meaningful employment. Here are some practical tips to ensure successful communication as you prepare for employment and once you've landed the job.

Ronnie Ward from the Bowling Green Police Department meets LifeWorks 2024 graduate Noah Thomas for a mock interview to practice interview skills and help Noah become more comfortable sharing about himself and the type of work he likes to do.

Job Shadowing

An effective strategy for becoming employment-ready is to participate in a job shadowing program, where you can experience a role and understand communication expectations. For example, one young person that we worked with thrived during a job-shadow opportunity at a local conference center as a laundry attendant. The position was single-focus and task-oriented. However, because of the nature of the work, another participant found the role more challenging because of the multiple conversations occurring with other staff in the room. She found a better fit while job shadowing a lobby attendant, engaging in one-on-one conversations with guests while managing specific lobby tasks. For both participants, this hands-on experience was a crucial part of understanding the communication styles each role required and where they were better suited.

Mock Interviews

Participating in a mock interview is a valuable tool in preparing for job interviews and workplace interactions. Mock interviews to hone your skills and learn to be comfortable sharing about yourself and the types of work you like to do. Look for local community centers, autism support organizations, or vocational development services that offer mock interview sessions. Alternatively, you can ask friends, family, or professionals in your network to practice interviews with you. We have developed a system for facilitating these interview sessions, complete with templates, guiding questions, and a process for

see Lifeworks on page 24

Can Being Denied Augmentative and Alternative Communication (AAC) Cause Lifelong Trauma?

By Ren Koloni, MA
Program Associate
CommunicationFIRST

Complex trauma happens when someone feels they are trapped and alone in continuing threatening or unsafe circumstances, like child abuse, war, or racism (World Health Organization, 2019). In situations where a person experiences threats every day, changes occur to the part of the nervous system that recognizes danger. Instead of only switching on when there is an actual threat, it is switched on all the time, even if the person is safe (Bremner, 2006; Porges, 2009). This is called traumatic stress, and it can lead to many physical and mental health problems, including complex post-traumatic stress disorder, or C-PTSD (Herman, 1992a, 1992b; van der Kolk et al., 1996; Streeck-Fisher & van der Kolk, 2000; van der Kolk, 2014; SAMHSA, 2014).

For autistic people who are nonspeaking or have intermittent, unreliable, or insufficient speech, being denied access to augmentative and alternative communication (AAC) tools and supports that work for them results in a kind of complex trauma in and of itself. **Without effective communication, a person cannot express themselves, make decisions about their own life, connect with others, or be a part of their community.** In addition, a person with an expressive communication disability is likely more susceptible to experiencing additional forms of trauma, such as abuse and violence (Bryen et al., 2009; Shapiro, 2018; Baladerian et al., 2013). They may experience more interventions that effectively punish them for being disabled (Lovett, 1996; Sandoval-Norton & Shkedy, 2019; Shkedy et al., 2019; Harvey, 2012); more isolation, seclusion, and restraint (National Disability Rights Network, 2009); and greater serious and preventable health events (Stransky et al., 2018; Morris, 2022). This trauma is compounded by the fact that these events may not be recognized, reported, or addressed by others (Blanco et al., 2020). **People who have been denied access to AAC need to be understood and should be assumed to have experienced multiple kinds of trauma multiple times for some, most, or all of their lives.**

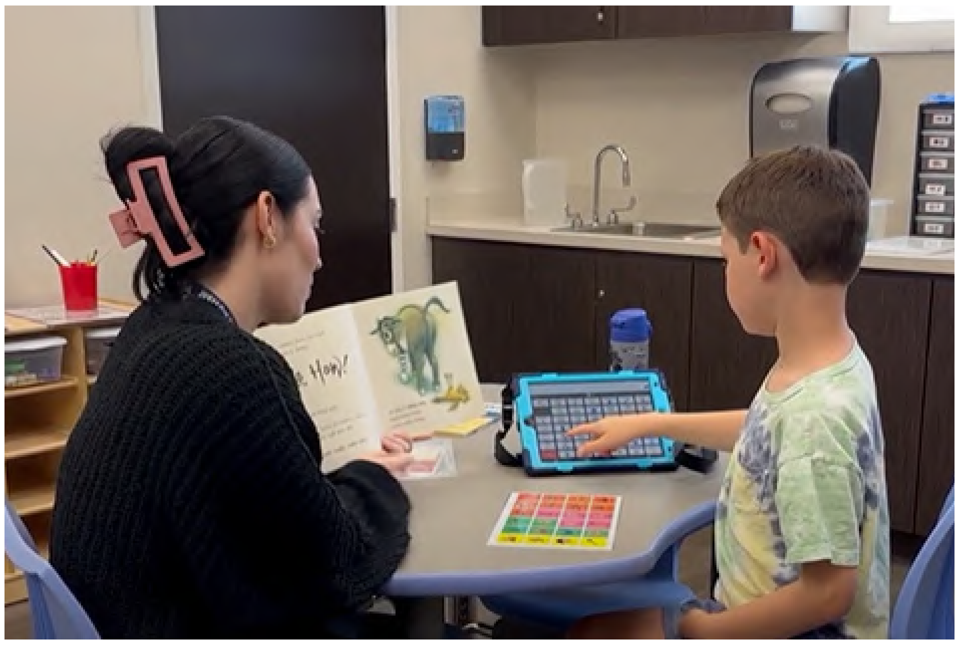
Understanding that a person has experienced trauma is crucial to beginning the healing process. However, in the case of people who need AAC to be heard and understood, this recognition may be even more important and urgent given the current lack of societal understanding of this dynamic. Each day, millions of disabled people, autistic and non-autistic alike, are subjected to coercive, dehumanizing treatment in an attempt to change their "challenging behaviors" (see, e.g., Lovett, 1996; Harvey, 2012).[1] Yet these "behaviors" may not be inherent to their disability or possible to change with behavior plans. They may be manifestations of trauma.[2]

There are five dimensions of complex post-traumatic stress disorder: re-experiencing, avoidance, hypervigilance and difficulty with emotions, persistent negative feelings about the self, and persistent problems with relationships (World Health Organization, 2019). These dimensions remain the same regardless of disability, but the trauma that nonspeaking and sometimes-speaking people endure is

see Denied AAC on page 32

Beyond Words: Overcoming Barriers to Augmentative and Alternative Communication (AAC) for Autistic Individuals

By Amanda Lopez, MS, CCC-SLP,
and Victoria Giannone, MA, CCC-SLP
Els for Autism Foundation®



In recent years, numerous professionals working in the autism and special education fields have launched small businesses, using the materials they have crafted, drinkware for personal use, and other wearable accessories. It's likely you'll see professionals from all different disciplines wearing t-shirts with fun, catchy expressions or inspiring phrases like "communication looks different for everyone" or "your words matter." How are we honoring those messages?

Imagine struggling to express your thoughts and needs every day, unable to rely on spoken words to connect with those around you. For many individuals with autism, this is a reality, making communication a daily challenge that impacts their independence and well-being. Augmentative and Alternative Communication (AAC) offers a lifeline, but for AAC to be truly effective, the barriers to its implementation must be addressed.

As speech-language pathologists working with autistic individuals, we strive to provide an exceptional level of care and consideration for everyone's overall well-being, which is largely dependent on effective communication development. Another important factor is fostering independence and ensuring the individuals we support can communicate effectively for all purposes daily. Often, the individuals we serve cannot rely solely on spoken language alone to meet all their communication needs. Professionals have seen the value of AAC as tools to support communication development for individuals who benefit from utilizing alternative communication modalities.

AAC is not solely for individuals who do not use spoken language. It's a valuable tool for anyone who experiences challenges communicating their wants and needs independently in everyday situations. While AAC may not be inherently intuitive and can present challenges, systematic instruction has proven effective for individuals with autism and complex communication needs.

Barriers to AAC implementation can include various forms of social, physical, and environmental challenges. In a study conducted by Yau, Choo, Tan, Monson, and Bovell (2024), some common barriers include:

1. Stakeholder knowledge: lack of AAC knowledge

2. Stakeholder attitude and stigma: negative attitudes towards AAC use or implementation

3. Resources: financial funds and time demands

4. AAC user engagement: willingness to use AAC

5. Device fit and features: lack of customization to meet the needs of the AAC user.

Authors reference "stakeholders" as parents/caregivers, educators, and clinicians supporting AAC users. For the purpose of the article, we will refer to these individuals as communication partners.

Upon review of the study and clinical

see Beyond Words on page 23

Project ImPACT: Empowering Parents with Evidence-Based Strategies for Early Autism Intervention

By Alexis Bancroft, PhD,
E. Emilie Weiner, MA, BCBA,
and Cynthia Martin, PsyD
Child Mind Institute

The prevalence of autism has increased dramatically over the last 20 years, with current estimates at 1 in 36 children having a diagnosis or special education classification of autism (CDC, 2023; ADDM surveillance network, 2023). The American Academy of Pediatrics (AAP) recommends that all children be screened for autism at their 18-and 24-month well-child visits, and the availability of screening (e.g., M-CHAT) and diagnostic tools (e.g., ADOS-2) has allowed for the accurate diagnosis of autism in children as young as 12 months. Concurrently, it is universally agreed that intervention should begin as early as possible to maximize developmental benefits for autistic children (National Institute of Child Health and Development, 2017; National Academy of Sciences, 2002). We know that the period between birth and age 4 is a time of rapid development where key milestones are acquired during biologically pre-determined windows. Developmental theory suggests that mastery of early skills is necessary as a foundation for subsequent skill acquisition (Bornstein, Hahn, & Haynes, 2010; Masten & Cicchetti, 2010). Further, parents have a unique opportunity to guide and support their child's early development; however, most parents are not naturally familiar with how to facilitate communication, social, adaptive behavior, and play skill development in young children with autism.

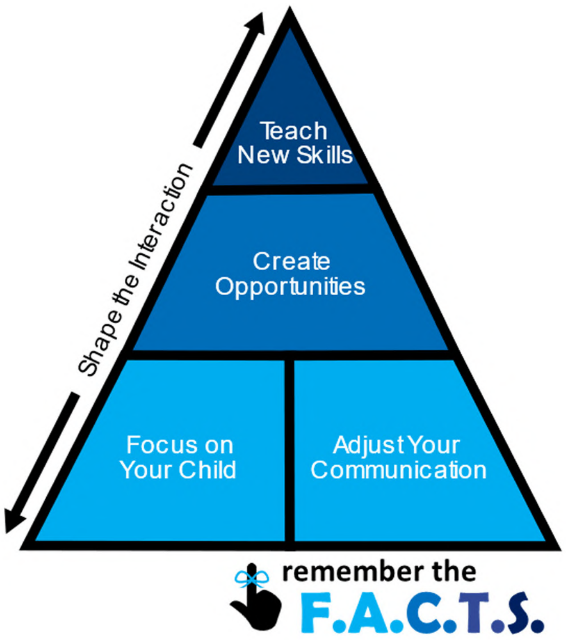


Figure 1. Project ImPACT F.A.C.T.S Pyramid

History of Naturalistic Developmental Behavioral Interventions (NDBIs)

Most of the current studies (i.e., in the last 10 years) on intervention approaches for young children with autism or social communication delays are based on behavioral interventions that utilize more naturalistic approaches of Applied Behavioral Analysis (ABA). Naturalistic approaches, such as the Early Start Denver Model, Project ImPACT, and JASPER, have shown efficacy (Dawson et al., 2010; Kasari et al., 2008; Ingersoll et al., 2017) as well as effectiveness (Sandbank et al., 2020; Tiede & Walton, 2019) in targeting and improving skills specific to children under age 3 (and up to age 8) with autism. Naturalistic interventions utilize the principles of behavior (e.g., reinforcement, shaping, modeling, etc.) and developmental sciences, which consider the foundational, prerequisite skills needed to acquire new skills and learn from one's environment. In this way, the intervention target skills are selected using established developmental sequences and naturalistic teaching (e.g., teaching skills in the natural environment and within the context of natural routines).

As of 2015 (Schreibman et al., 2015), these interventions are now collectively referred to as Naturalistic Developmental Behavioral Interventions (NDBIs). To be classified as an NDBI, the intervention must be based on principles of Applied Behavioral Analysis (ABA) and implemented within a naturalistic, developmentally based framework. Concurrently, it requires a manualized curriculum, a structured

see Project ImPACT on page 27

Painful Conversations: Unconscious Neurodiversity Bias in Higher Education

By Michael John Carley
Facilitator, New York University
Connections ASD Program

NOTE: This article is an adaptation of a lecture given at Northeastern University on August 9, 2024. For the full, hour-long video of the presentation, please click here. A shorter version was co-hosted by Vanderbilt University and UCONN on December 13.

The author, Michael John Carley, as a Hampshire College undergrad with the artist (and college-best bud), Johan Westenburg.

When I was researching my last book (The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum...and Beyond!), one of the biggest discoveries lay in the power of “painful conversations.” Painful conversations, I discovered, save relationships, and they keep us out of relationships we should not be in. But 99% of the time, we avoid them because...they’re painful. And so, often, nothing changes in the relationship. We don’t progress.

Respectful study after study tells us that neurodivergent university students face major obstacles in their search for a happy, healthy college experience—and one that also leads to solid preparation for that outside world. Whether it’s executive functioning challenges towards homework, a partially due to an inadequate social life, a lack of self-advocacy skills, or yes—even *conscious* bias...we spectrumfolk face proportionately greater obstacles herein than our neurotypical peers.

But while neurodiversity higher education professionals are more than comfortable challenging conscious bias? The *unconscious* stuff, not so much. That’s par for the course with most of us, perhaps. But universities, the supposed pinnacles of wisdom, can be surprisingly ignorant, if not proudly ableist.

To start, *how* could higher education professionals possibly have biases towards neurodiversity? Not only are colleges supposed to represent the height of learning, but the majority of college specialists herein are actually VERY progressive in other areas. Not a lot of disability accommodations pros are “Trumpers.” Compared to other professions, college professors and research professionals are rarely racist or transphobic, and a higher percentage are themselves LGBTQ. But when it comes to neurodiversity—if not all of disability—an examination of their actions reveals a shocking tolerance of and comfort with organizations who demonstrate a firm belief that our neurodiverse lives are not worth as much as yours.

Let’s start with a brutally obvious example (I know, I know...) - chapters of the much-maligned autism research organization, Autism Speaks, that exist on college campuses.

For those *not* “in the know” about this organization, they offended people with autism to degrees unseen by any other organization. But unlike their fellow bigoted autism organizations (and there were a LOT), Autism Speaks was different because they were an absolute machine in recruiting celebrities and churning out successful fundraisers and publicity. This 2009 video they made is a great starting point to show their attitudes towards our value (but feel free to email me for hours of aghast reading). But because university

see Neurodiversity Bias on page 36

The Problem with Calling Neurominorities “Neurodiverse”

By Bernard Grant
Writer

Using the word “neurodiverse” to refer to individual people spreads neurodiversity lite (Neumeier, 2018), an appropriative, performative paradigm that upends the neurodiversity paradigm. Everyone follows paradigms, though many of us don’t know which paradigms we follow. This can become a problem when we rely on paradigms that harm ourselves and those around us.

When it comes to the intertwined realities of disability and neurodivergence, most people default to the medical model of disability. The medical model isn’t completely harmful, as it lengthens and saves lives by diagnosing and treating illnesses. However, the medical model marginalizes neurominorities (cognitive minorities) because it frames innate neurodivergences as illnesses – “disorders” and conditions – and neurominorities as inherently broken.

Under the social model of disability, disability lies not solely within a person’s bodymind but within barriers within their environment: disability is a mismatch between a person’s bodymind and their environment. These barriers not only include physical and sensory barriers but also attitudinal barriers, such as the neuronormative, ableist attitudes that pervade society.

Neurodiversity lite is the medical model in disguise; it performs neuroinclusion, and sounds like people talking about “neurodiversities,” “neurodiverse conditions,” and referring to individual people as “neurodiverse.” This type of language may sound harmless, a simple matter of personal choice, but the opposite is true. The problem with the word neurodiverse lies not in its existence but in how neuronormative people use it: to refer to neurodivergent people, neurominorities. Calling a person neurodiverse is not only grammatically incorrect; it carries the pathology paradigm.

To pathologize someone is to determine that they are abnormal in some way, though “normal” people have never existed. Neurominorities have, historically and presently, been medicalized due to the pathology paradigm that pervades the Western world. According to Dr. Nick Walker, a neuroqueer academic and researcher, and professor of psychology at California Institute of Integral Studies, the pathology paradigm is defined by two assumptions: (1) there is only one healthy way for human minds to function (neurotypical) and (2) if your neurological functioning diverges from neurotypicality, then there’s something wrong with you (Walker, 2021). Under the pathology paradigm, there is something wrong with neurodivergent minds. Which means there is something wrong with the pathology paradigm.

In her book of essays, Neuroqueer Heresies, Walker notes that framing neurological minority groups in terms of pathology (as “disorders”) amounts to a cultural value judgment, not unlike drapetomania, a so-called psychological “disorder” that supposedly caused those enslaved in America to flee their enslavers – as if a person should appreciate slavery. Only in a capitalist-racist society would medical professionals construct a “disorder” like this. Similarly, queerness remained pathologized in the DSM as a mental “disorder” until 1987. Only in a heteronormative, queerphobic society would medical professionals construct a “disorder” like this. Only in a neuronormative, ableist society would someone create a so-called autism spectrum “disorder.”

This is often what neurodiversity lite sounds like: “Neurodiversity is the idea that neurological disorders like autism, ADHD, and dyslexia are normal neurological variations.” This kind of thinking that there is such a thing as a “disordered”

see Neurominorities on page 38

Empowering Families Online: Reducing Barriers Through A Virtual, Group ESDM-based Caregiver Coaching Program

By Hanna Kent, BS,
Dan Magin, MA,
Krista Drapalik, MA,
Erica Davis, LMSW,
Melissa Rinaldi, PhD,
and Kristin Christodulu, PhD
Center for Autism and Related Disabilities at the University at Albany

Autistic children often experience difficulties with language and communication development (Tager-Flushberg et al., 2005). Early intervention (EI) is an integral and highly efficacious tool to target and promote optimal development in this population (Zwaigenbaum et al., 2015). By targeting specific developmental needs at an early stage, EI offers an opportunity to build foundational skills that set the stage for long-term success. A commonly utilized form of EI is naturalistic developmental behavioral interventions (NDBI) (Tiede & Walton., 2019). NDBIs use behavioral strategies to teach skills in a developmentally appropriate sequence (Schreibman et al., 2015), and substantial evidence suggests these interventions promote language development in autistic children (Crank et al., 2021). NDBIs serve as a reliable and effective intervention for addressing the language development challenges often faced by these children.

The Early Start Denver Model (ESDM; Rodgers et al., 2012) is an evidence-based NDBI that integrates behavioral and developmental principles to enhance social communication skills in autistic toddlers. The efficacy of ESDM is well-documented in traditional one-on-one, in-person settings, with research consistently highlighting significant improvements in children's cognitive and language development (Fuller et al., 2020). However, limited research focuses on the intervention's effectiveness when delivered via a virtual, group-based modality. Due to the sudden halting of in-person services during the COVID-19 pandemic, the University at Albany's Center for Autism and Related Disabilities (CARD) adapted the ESDM program to be delivered in a virtual group setting for caregivers of autistic children.

This virtual group program was designed to follow a 12-week caregiver coaching group format. The program focused on providing caregivers with knowledge and tools to support their child's communication and social development through ESDM-related topics such as imitating, following their child's lead, engaging in social routines, supporting joint attention skills, and scaffolding their child's play levels. In order to adapt to the virtual group-based setting, two main modifications were made. Caregivers were given 20-minute pre-recorded didactic videos weekly, which outlined the session topic, to watch prior to group. The videos then served as the basis for the 60-minute virtual sessions led by a program leader. These sessions provided caregivers an opportunity to review module strategies and brainstorm in-home applications for use with their children. Additionally, by implementing a train-the-trainer model, the program aimed to empower caregivers with the confidence and skills to apply evidence-based strategies at home, effectively increasing intervention hours for their child. By incorporating both virtual and group-based modifications, the program sought to address gaps in service availability.

see Empowering Familes on page 41

Neurodiverse Couples: When One Partner Comes Out as Trans

By Leslie A. Sickels, LCSW
Clinical Social Worker

When partners begin neurodiverse couples therapy, they bring a myriad of topics into the session. As a therapist specializing in gender and sexuality, I often hear couples discussing challenges related to intimacy and sex. However, what happens when one partner realizes they do not fully identify with their sex assigned at birth? This article will explore the process of identifying gender differences, integrating those new gender roles and identities into the relationship, and ways this may impact intimacy and sexuality. In a time when gender non-conformity is highly publicized and criticized, we will focus specifically on gender-affirming approaches and the range of emotions and experiences that may come up throughout this process for both the trans individual and their partner.

Identifying Gender Identity

Many individuals do not have the ability nor insight to pause and truly consider who they are internally (*gender*) and instead live life as the *sex* they were ascribed at birth. For individuals whose gender is not congruent with their birth sex, this is not a choice but rather a deeper understanding and awareness of who they truly are. In order to speak about the diversity of gender experience, this article will use the words "transgender" and "gender diverse" to describe individuals who identify as transgender, gender non-binary, gender nonconforming, gender questioning/curious, etc. Gender is a nuanced construct that needs to be thoroughly explored for each individual. Everyone uses different language to describe their unique gendered experience. When working with someone who is gender diverse, it is most appropriate to utilize the language they use to define their own identity. Only they know who they are and how to describe their gender.

When someone with Autism Spectrum Disorder (ASD) is also gender nonconforming, they may have felt "othered" in multiple domains of their life. While this is not everyone's experience, in my clinical practice, I often see individuals diagnosed with ASD who then recognize there is still something different about their life experience. Research shows that individuals who are gender diverse have higher rates of autism than a cisgender or individuals whose birth sex and gender identity are congruent counterparts (Warrier et al., 2020). Kallitsounaki and Williams (2022) conducted a meta-analysis that found the prevalence of autism within the gender-diverse community was as high as 11%. While research on ASD and gender has nearly doubled in the last two years, there needs to be ongoing research on their co-occurrence and potential social and cultural implications. (Kallitsounaki and Williams, 2022).

For clinicians, inquiring about gender and pronouns is not only useful but also best practice. Clinicians ask a variety of questions on intake paperwork and should incorporate questions regarding an individual's gender and sexual identity. This demonstrates awareness and understanding, and it begins to set up a safe, supportive therapeutic space to have these conversations during sessions. It communicates in writing that this topic will be addressed therapeutically. Research has shown that suicidality in transgender populations is significantly higher than in cisgender individuals (Bränström et al., 2022). In addition, we know that autistic individuals have higher rates of suicidality. In 2021, South et al. "report adjusted incidence rate ratios (aIRRs) more than 3 times higher among individuals with autism for both suicide attempts and deaths, with significantly

see Neurodiverse Couples on page 37

Voices from China: Psychology Students Reflect on Autism Awareness and Advocacy

**By Monica E. Carr, PhD, Hyde, J., Hu, Y., Liu, Z., Hua, X., Zheng, W., Ren, S., Li, Y., Yang, Y., Long, X., Tang, A., Xia, S.
Wenzhou-Kean University**

Wenzhou-Kean University is one of three Sino-US universities, with Kean University being the only public university that has a campus in China (Stern, 2024). The mission of this alliance is to foster cooperation and encourage people, especially youth, to get to know each other better (Zhang, 2024). President Xi Jinping (2024) described these education exchanges as a “project for the future” for the development of China-US ties (Zhang, 2024).

In late September 2024, we hosted a guest lecture for Psychology Major students at Wenzhou-Kean University. Undergraduate psychology students from all year levels listened to our guest speaker, who joined us in the lecture theatre via Zoom from his home in the United Kingdom. Jack Hyde is a British actor, model, and motivational speaker who has lived most of his life in Singapore. Jack joined us after his trip to the Toronto NoHo International Film Festival in September 2024, having been nominated for Best Actor in the Short Film “My Shards.”

Monica Carr, PhD, with Undergraduate Psychology students at Wenzhou-Kean University, fostering cross-cultural learning and understanding in China.

Jack gave the students an insight into the preparation and work that he did when he acted in the role of Jadon, a young man with Schizophrenia. In addition, Jack explained to the students that he has Asperger’s syndrome. Jack gave the students a view into his world, in which he successfully navigated many challenges, graduated from LaSalle College of the Arts in Singapore, and rose to become a top young British actor who has already received numerous accolades for his professional performances.

“I’m so incredibly thankful to the university for not only giving me a platform to share my story but also to help spread the word about Asperger’s, Schizophrenia, and all forms of mental health,” said Jack. “Mental health is not a joke, and it should be taken seriously. I am so grateful for the positive response that I have received from the students,” he continued. “Not only do I want to inspire people in the same profession as me but, at the same time, and the main reason why I wanted to do this lecture, is to inspire those outside of it. A psychologist is definitely a tough job that requires a lot of patience, and I wish the students all the best in both that field and future!” said Jack.

Interacting with people on the autism spectrum in China is significantly different from in the United States. Pang and colleagues (2018) reported that only about 300 hospitals in China diagnose ASD, unlike in the US, where thousands of hospitals and clinics can conduct assessments and make a formal diagnosis. Social stigma and misunderstandings about autism abound. Recent research has indicated that only 9% of parents in China seek professional help upon noticing their child’s atypical early behaviors (Sun et al., 2015).

Accordingly, the chance for the students to listen to an individual like Jack was a rare and unique opportunity. Students were not bully anyone,” said Zhiyi.

see China on page 38

Nina: A Nonspeaker Who Found Her Voice

**By Debra Brause, PsyD
Clinical Psychologist**

Trapped in her inner world for 16 years, unable to speak, Nina Meehan describes how it felt: “It was torture…I suffered in silence for my entire life. I have always been locked inside, but no one could hear me.” Nina communicates these feelings by spelling them out, using a method called spelling to communicate (S2C), which enables her to share her story.

Meehan is an autistic nonspeaker who grew up with her parents and two sisters in Fairfield, Connecticut. After multiple doctors told Meehan’s mother, Raquel, that Meehan lacked the cognitive ability to communicate, Raquel lost hope that she would ever be able to connect with her daughter. Raquel laments how the physicians’ messaging detached her emotionally and spiritually from her child. Among the general public and within the medical community, too, there is a common misconception that autistic nonspeakers do not have cognitive ability. This persistent fallacy can lead nonspeakers to lose hope, as well as lose access to an appropriate education that can unlock their deep potential.

Nina Meehan using a Spelling to Communicate (S2C) letterboard

Within disability circles, “presuming competence” is an essential mindset. When people are assumed not to understand or be able to learn, our educational and medical systems create barriers that deprive them of dignity and respect. Throughout history, the dominant majority has suppressed the voices of marginalized communities. Individuals who are led to believe that they are cognitively impaired lose faith in the systems designed to support them. When we assume that those without a voice are not verbal, we demean their capability and fail to uncover the intelligence they hold inside. Not only did Meehan know English, but likely due to exposure to her grandmother’s native language, one day, Meehan spelled in Spanish, “I’m bilingual. I know how to speak Spanish, too.”

Due to apraxia, a motor movement disorder, many autistic people cannot demonstrate what they understand. Apraxia is a disconnection between the brain and the body, and autistic people often struggle to get their bodies to do what their minds intend. Nonspeakers cannot show their verbal acuity without the motor skills to convey their intelligence.

When Meehan was younger, she would point at pictures on an iPad, a form of augmentative and alternative communication (AAC) that provides options for one-word prompts. The trouble with many AAC devices is that they are limited to icons and don’t represent natural speech. The devices rely on limited choices that can perpetuate motor loops (getting stuck on one icon or word) that may not reflect what the person really wants to say.

Caroline Mazza is a physical therapist who has been working with neurodivergent clients for over 20 years. She has a customized brain-based approach and has worked with Meehan for the past few years. Mazza created a treatment plan for Meehan that addresses her posture, ocular-motor skills, and balance. Core strength, motor planning, and nervous system regulation are all necessary to spell one’s thoughts using the letterboard.

As motor skills improve, the goal is to progress to independent typing. Meehan, now 18, has been practicing her spelling for the last two years with the support of her family and the professionals around her, and she takes typing lessons three times a week. In Meehan’s words, “Through spelling, I can participate in my own life and

see Nonspeaker on page 41

Parent-Led Strategies to Support Communication in Children with Autism Spectrum Disorder

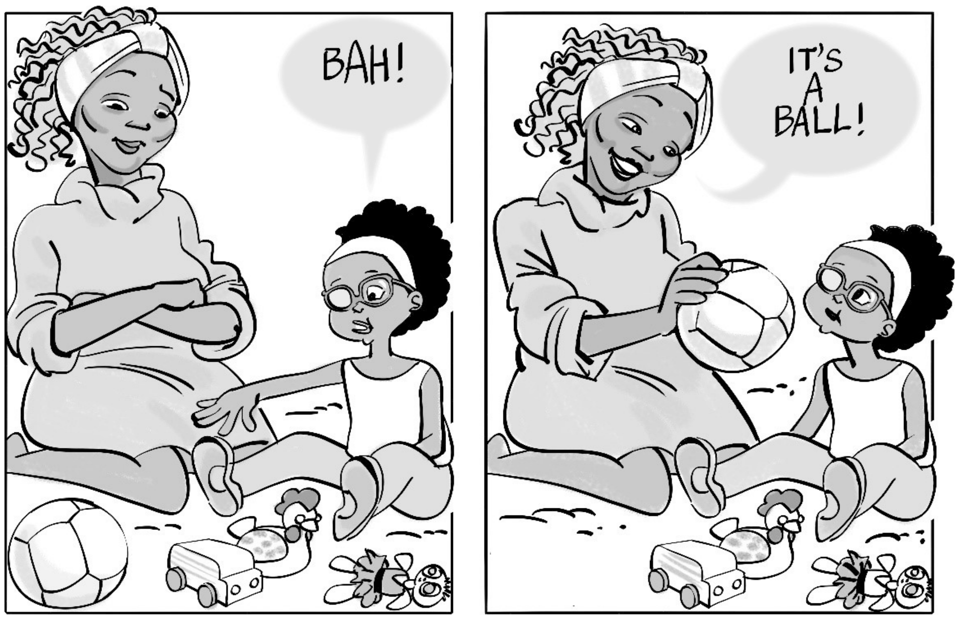
By Marta Chmielowicz
Content Manager
Autism Speaks

When Mukri Yilma noticed her son Kibur's use of words and gestures starting to fade at 22 months, she knew something was wrong. Suddenly, he was not waving "hi" or pointing at airplanes anymore, and he stopped using words that had been part of his vocabulary.

Concerned, Mukri took Kibur to his pediatrician, where a screening found that he was at high risk for autism. A developmental pediatrician confirmed Kibur's autism diagnosis—and Mukri's search for early intervention services began.

"Going into the pediatrician, I already suspected that he was on the autism spectrum," says Mukri. "I couldn't really face my emotions at the time because I felt like if I lingered in my own emotions, I wouldn't be successful in getting him what he needed. But my thinking was so wrong because these things don't just go away—they come back much bigger if you don't deal with them right away."

Soon after Kibur's diagnosis, Mukri signed up for the World Health Organization's Caregiver Skills Training (CST) program, supported by Autism Speaks. Run by the Ethiopian Eritrean Special Needs Community (EESNC), a local organization serving Ethiopian families in Maryland, the program was a turning point for her family.



"Respond and expand" is a core Caregiver Skills Training strategy to improve communication skills.

What is Caregiver Skills Training (CST)?

CST is an evidence-based, parent-mediated intervention designed for parents and caregivers of children with developmental disorders, including autism, between the ages of 2 and 9 (World Health Organization, 2022). Delivered in 12 sessions, including nine group training sessions and three home visits, the program teaches caregivers how to use everyday play and home routines as opportunities to build their child's communication, engagement, positive behavior, and daily living skills, all at no cost to families (World Health Organization, 2022; Salomone et al., 2019).

Research shows that the strategies taught in CST help children with developmental delays build critical communication and emotional regulation skills while also increasing caregiver confidence and self-efficacy and reducing stress (Seng et al., 2022; Sengupta et al., 2023; Salomone et al., 2022a, 2022b; Tekola et al., 2019).

"CST taught me the best way possible to help my child grow," says Mukri. "I learned how to play with him, how to manage his challenging behaviors, and how to manage my own emotions. I started seeing the best of him when my husband and I changed our strategies. I think this program is very important because it closes the gap between now and when you get services. If services are interrupted, you still have some knowledge to do what you need to do to support your child."

Today, Mukri is a CST trainer and an advocate for other parents walking the same path. Here are some of the practical strategies she learned through CST and how they impacted her family.

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Beyond Words from page 19

observations made in our history of practice, these challenges in implementation outlined are commensurate with attitudes noted by those charged with supporting AAC users. To support AAC users, we must first look at supporting their communication partners. This starts by shifting the attitudes and enhancing knowledge surrounding AAC, which can be done through methodical training across communication partners. Communication Partner training is key in supporting AAC learners in developing and generalizing acquired skills. That said, it is important to recognize that there is a learning curve when implementing AAC, and therefore, individuals in need do not become proficient AAC users overnight. The goal of a speech-language pathologist when training a novice team is to foster a growth mindset and to encourage teams to presume potential (Zangari, 2020).

With a focus on the communication development of individuals with autism, particularly those with complex communication needs, we have advocated for priority access to personalized and reliable AAC systems. In our personal practice, we have collaborated with third-party companies to assist families in assessing insurance coverage for personal communication devices. On a broader scale, we continue to advocate for a greater emphasis on allocating funds to ensure access to AAC. Research has shown that parents often must prioritize their child's other needs, which can limit the funds available to access adequate communication support, such as AAC (Yau et al., 2024).

Amanda Lopez, MS, CCC-SLP

Victoria Giannone, MA, CCC-SLP

To justify the need for AAC, data is vital to accompany requests for the technology and support needed. By analyzing the usage of AAC, such as tracking the number of communication opportunities provided, we can further assess any additional areas where support is needed and further develop a personalized treatment plan (Zangari, 2013). Suitable feature matching is also vital in the overall success of AAC use. Systematic trialing of varied communication supports (e.g., no tech, low tech, mid tech, and high tech AAC) creates a personal connection, enhancing motivation and overall engagement with the system. Greater customization fosters the development of an AAC system that accommodates the individual user's preferences, ultimately enhancing their quality of life.

A common obstacle to AAC implementation that is highlighted throughout this discussion is a lack of knowledge and understanding among stakeholders, including parents, educators, and clinicians. Many people hold misconceptions about AAC, believing it is only for individuals with severe disabilities. By providing comprehensive training and education, we can dispel these myths and promote a more positive attitude towards AAC.

Furthermore, it's crucial to advocate for increased funding and resources to support AAC access and training. Providing access to a personalized AAC system, working collaboratively to support communication partners, and monitoring skills are vital in developing the primary areas of communication competence in AAC. The concept of "presuming potential," or assuming all individuals can benefit from direct services and support and, as a result, further develop skills, encourages a shift in mindset that the AAC user has acquired all skills to be a competent communicator. This shift supports the systematic development of AAC user skills.

Amanda Lopez, MS, CCC-SLP, and Victoria Giannone, MA, CCC-SLP, ASDCS, are Speech-Language Pathologists at the Els for Autism Foundation®.

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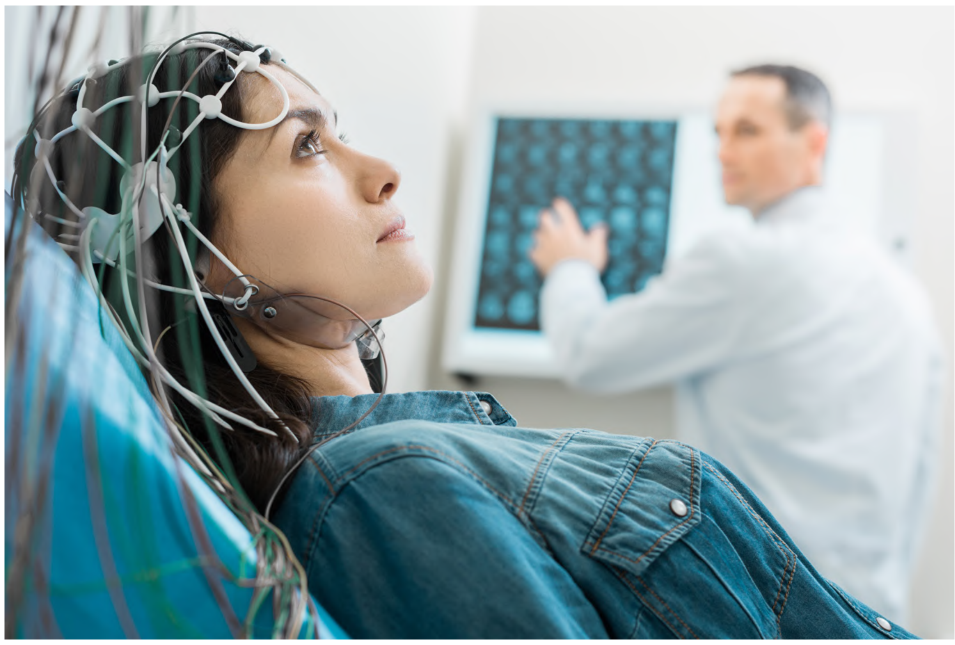
A Key Brain Difference Linked to Autism is Found for the First Time in Living People

By Isabella Backman
Associate Editor-Writer
Yale School of Medicine

For decades, researchers have relied on animal models and post-mortem subjects to help unlock the key to certain social and communication differences that are hallmarks of autism. Now, a new study has uncovered a molecular difference in the brains of autistic people that is linked to the central features associated with the condition. It is the first time that synaptic density has been measured in living people with autism.



Using positron emission tomography (PET) scans, researchers found that the brains of autistic adults have fewer synapses—crucial junctions where nerve cells send signals to and from each other or other types of cells—than the brains of neurotypical people. Furthermore, the research team found that the fewer synapses an individual had, the more autistic features they exhibited. The team published their findings in Molecular Psychiatry on October 4.

"As simple as our findings sound, this is something that has eluded our field for the past 80 years," says James McPartland, PhD, Harris Professor in the Yale Child Study Center and the study's principal investigator. "And this is truly remarkable—because it's very unusual to see correlations between brain differences and behavior this strong in a condition as complex and heterogenous as autism."

There are several different theories about brain differences in autistic individuals, and atypical connectivity has been at the root of a number of these hypotheses. This has made synapses a prime area to investigate. "Synapses are the way neurons communicate," says Adam Naples, PhD, assistant professor in the Child Study Center and co-investigator on the study. "They're the fundamental mechanism for how information moves around the brain and is computed."

Previous studies have measured synaptic connectivity in indirect ways, such as through animal models or post-mortem studies. "It's like trying to figure out what something is by looking at the shadow it casts on the wall," says McPartland. But the introduction of a new element in the PET scanning protocol permitted McPartland and his team to see connectivity directly—in living human beings—for the very first time.

Pet Scans Reveal Fewer Synapses in Autistic Brains

Before the study, all of the subjects participated in a clinician interview. Given the complexity of autism, clinicians used the Autism Diagnostic Observation Schedule (ADOS)—the gold standard for diagnosing autism—to evaluate participants for the condition. Participants also filled out self-report questionnaires about their own experiences living with autism, such as difficulty with social interactions or sensory issues. The researchers ruled out any potential subjects with medical conditions or neuropsychiatric disabilities that could influence the study's findings. In total, 12 autistic adults and 20 neurotypical adults participated in the research.

Then, each participant underwent a brain scan using both magnetic resonance imaging (MRI) and PET technology. The MRI scan allowed researchers to visualize each

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getting volunteers in the mix without the need for extensive training.

Inform Your Employer

Individuals on the autism spectrum tend to be very literal in their communication. It's important to let your employer know this so they can also communicate with very specific instructions to avoid misunderstandings. For example, an employer who asks, "Do you want to run this report for me?" might receive a very direct "no." But "Please run this report for me" is a clear and specific request. This approach reduces ambiguity and ensures clear expectations.

Additionally, let your employer know that information from you may sometimes come out differently than someone who is neurotypical. Encourage the employer not to make assumptions about their meaning and to check with you if they are unsure about what you meant. You can also share published guides on how to communicate with you more effectively.

Addressing Sensory Issues

Sensory issues are common among autistic individuals. If you require accommodation, don't hesitate to ask for support. The Americans with Disabilities Act ensures that workers who require an accommodation have equal access in the workplace. There may be a local program in your community that can help provide funding for accommodations. For instance, in my community, the Office of Vocational Rehabilitation has been able to provide funding for noise-canceling headphones as assistive technology in the workplace.

Clarify Preferences

Talk with your employer about their communication preferences and agree ahead of time on how to proceed. For example, discuss the best way to receive instructions (in writing or over the phone), when the best time to communicate with you is (when you first get to work or after your break), and more. Ask them to be very specific with their request. For instance, instead of saying, "Could you get this done when you have a moment?" ask them to be more specific by saying, "Please complete this by 3 p.m."

Workplace Etiquette

Some workplace environments encourage small talk before meetings, asking about weekends, etc. Others don't. Ask your employer to share workplace-specific etiquette with you. This information will provide clarity about expectations.

Practicing Nonverbal Cues

Nonverbal communication, such as eye contact, body language, and facial expressions, can enhance your interactions with colleagues. But it takes practice. Try role-playing with friends or family so you can get more comfortable with these types of interactions. Join a social skills group with others who also want to learn nonverbal communication. It is important to recognize nonverbal cues without feeling the pressure to conform to social expectations. Masking can be stressful and exhausting, which may not lead to successful outcomes.

Seek Consistent Feedback

Regular check-ins and feedback sessions with your employer to clarify expectations and expected progress will provide valuable insights into your communication skills and areas for growth. Be open to the feedback and suggestions. Accepting feedback also takes practice. This is another skill you can practice with friends and loved ones. Becoming defensive or frustrated when employers give constructive feedback does not make a good impression.

Use Written Communication

Written communication can help clarify messages and reduce misunderstandings. Ask your employer to provide written instructions when possible so you can refer back to the information as needed. This could be as simple as what time to be at work and when you can break for lunch to get more specific instructions on how to proceed on a certain project. The more specific and precise the instruction is, the easier it will be to understand and follow.

Understand Social Norms

Learning to make small talk, understanding conversational cues nonverbal cues, and recognizing when others are ready to end a conversation can enhance social interactions at work. Practice this with your peers. Volunteering in the community is a great way to practice and build confidence in social interactions.

While employers who create a supportive environment that allows autistic individuals to succeed is crucial, utilizing these practical steps will enhance communication in the workplace. With the proper strategies and support, you can thrive in a career and contribute meaningfully to the organization.

Kellye McIntyre, MSW, is the Director of Vocational Services for Lifeworks for Autism, a living and learning community for autistic young adults as they transition to independent living and employment in Bowling Green, Kentucky.

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Overcoming Barriers in Math Education and Assessment for Autistic Children

By Ailton Barcelos da Costa, PhD,
Alessandra D. M. Picharillo, PhD,
and Nassim Chamel Elias, PhD
Federal University of São Carlos, Brazil

In the 21st century, there is no disagreement that math teaching is considered important for all students, including those with disabilities or Autism Spectrum Disorder (ASD), so that their access and success contribute to the development of skills necessary for an independent life. Good performance in the discipline of math has a significant impact on academic and work opportunities (Bouck et al., 2021).

However, the academic research on math teaching and evidence-based interventions for people with ASD still has important gaps and is very limited (Tonizzi & Usai, 2023). These gaps may be due to the idea that individuals with ASD have extraordinary math skills, but their good performance in math assessments seems to be mainly anecdotal. That is, only a limited number of them have excellent performance in this discipline, and math difficulties seem to be more common among these students than among their peers with typical development (Tonizzi & Usai, 2023).

ASD is characterized by high heterogeneity due to the different levels of intellectual and linguistic abilities and the presence of comorbidities (Zeidan et al., 2022). Such students may face barriers that affect their learning abilities, such as not having developed executive function, which includes working memory, inhibitory control, and cognitive flexibility (Demetriou et al., 2018).

Another significant barrier is related to communication. When a child with ASD does not develop language skills, understanding instructions and responding to school demands, which are mostly based on verbal instructions, will interfere with the development of math skills. This includes number sequence formation, calculation skills, fact retrieval, and problem-solving involving words. Additionally, difficulties may arise in generalizing properties and procedures, as well as recognizing multiple strategies for solving a problem (Cox et al., 2021).

Rottmann et al. (2020) state that it is essential for mathematical content to be taught effectively in early childhood. Learning pre-arithmetic skills (major/minor, plus/less, large/small, first/last, before/after) builds a solid foundation of repertoires that will be used in the development of new concepts in the subsequent years. Neglecting the teaching of this set of content can create gaps that will worsen as students progress through school. According to these authors, to make math teaching effective, it is necessary to prioritize the assessment of learners' repertoires.

An assessment model of the math repertoire is proposed by Costa et al. (2017), who evaluated the mathematical skills of children with Down syndrome and typical development in pre-arithmetic (relations of greater, lesser, equality, addition, and subtraction), counting and measuring, numerical sequence production skills, and recognition of geometric figures, using the Protocol for Registration and Evaluation of Mathematical Skills (PRAHM). The PRAHM has 34 questions.

After its publication, the PRAHM was used to assess the repertoire of 35 children aged 6 to 12 years with ASD in recent years,

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special interest. You could talk about it all day! But when you're with a stranger or a casual acquittance, you don't know if your inclination to nerd out will be met warmly or have them sneakily trying to check the time. To the wrong audience, an infodump makes the conversation one-sided.

Finding something you and your conversation partner both find interesting is important. My go-to subject when trying to find common ground is travel. I love talking about places I've been, and most people usually have a passing interest in hearing me out.

You can also take context clues about a person's interests from what they're carrying or wearing. If you're lucky, you'll find your conversation starter there.

Even if common ground is hard to find, there may be some life experiences you broadly share: tackling a big project at school/work, planning a big family gathering, preparing for a big trip, and many other common life events. A tip I picked up long ago was that you can create a feeling of depth and closeness in a conversation by sharing personal stories. It can be helpful to have a few anecdotes stored in your back pocket for such occasions.

But, when in doubt during small talk, you can always turn to this next tip…

Ask People About Themselves

Carrying a conversation is hard, but asking people to tell you about themselves is always an option!

This is also a good way to learn about the common interests and experiences you might share with a person. As I've pointed out, this is the real key to preventing small talk from becoming an impossible slog.

Rachel Guttentag

Even if the worst comes to pass, and you find yourself chatting with someone you can't seem to find a single thing in common with, getting them to talk about themselves (something many people love to do) is the real lifesaver. In any small talk situation, it takes two to tango. Ask them about their job or their plans for the day. Whatever you ask, make sure it's something they can answer easily. Even if you don't find their answer interesting, it will at least keep the conversation going.

Of course, if your conversation partner is polite, they'll ask you about yourself in turn. That's when it's important to remember that there are certain boundaries to what's considered acceptable in small talk…

What Is "Too Personal"?

In this article, I've recommended not getting "too personal." Yet, at the same time, I advocate the importance of drawing on your own experiences to form a connection during a conversation. So, then, what's the deal? Should you share personal stuff about yourself or not?

This is the thing about small talk most of us on the spectrum get hung up on. It's another one of those frustratingly vague social norms that others seem to understand intuitively.

I would say the best rule of thumb for this is to avoid focusing on the negative. When sharing about yourself, it's good to stick to positive details. Fun vacations, plans with friends, a new outfit you bought, or anything that makes you feel happier talking about it. Conversely, anything that makes you upset, even when thinking about it, should be steered clear. Things like negative experiences at work, fights with loved ones, or any bad news in general.

When someone shares something positive, we generally know the reaction they want: congratulations of some kind. But when it comes to sharing something negative, different people want different responses. Some want to hear things will be ok, others want empathy or sympathy, and still others want advice. It's impossible to tell what a stranger wants. It can feel like other people "just know the rules" when it comes to social interactions, but no one likes navigating an uncertain situation blind. That's a feeling most of us on the spectrum can understand. When you start venting to a stranger, you force them into that difficult situation.

My tip about shared complaining is an exception to this, but only because the shared experience prevents it from being one-sided.

There's also one more thing I'd like you to keep in mind…

Nothing Works 100%

Don't mistake this article for an infallible how-to guide for small talk. I don't want to present it that way. I'm not drawing from anything other than my own experiences and what others I've talked to have told me.

But even if I could cite a million papers that proved every tip I gave in this article was backed by undeniable scientific rigor… it still wouldn't be an infallible how-to guide.

One of the most frustrating things about social interactions is that you can follow all the "rules" and still mess things up.

When attempting to do more small talk, you have to accept that some of your attempts will fall flat. A joke won't land, your words won't interest someone, or that person may just refuse to engage with you. It's hard not to take these things personally. I don't even succeed at not taking it personally. Yet, one of the biggest secrets to getting more comfortable approaching others is learning to shrug off failure.

Go out and chat with strangers more. Try to meet new people and maybe make some friends. Small talk can be your starting point, but where the conversation goes… well, that can be up to luck.

Still, the more you try, the better your chances will be.

Rachel Guttentag is an Autistic Self-Advocate and can be reached at ryerguttentag@gmail.com.

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developing these skills and to help neurotypicals understand and embrace the communication styles of their neurodivergent peers, creating a welcoming environment.

Santhanama and Wilson's (2020) research highlights several perceived challenges faced by autistic college students in self-advocacy. These challenges include:

1. **Social Anxiety**: Many autistic individuals experience social anxiety, which can hinder their ability to speak up in group settings or confront authority figures.

2. **Misunderstanding of Rights**: A lack of awareness regarding their rights can prevent autistic individuals from advocating effectively.

3. **Communication Barriers**: Difficulties in expressing thoughts and feelings can lead to frustration and misunderstandings, making it hard to advocate for their needs and feel socially connected to their peers and campus community.

4. **Fear of Judgment**: Concerns about being judged or misunderstood by peers and educators can further inhibit self-advocacy efforts.

Despite these challenges, Santhanama and Wilson (2020) found that many autistic students are eager to engage in self-advocacy. Engagement levels vary, with some students actively seeking opportunities to express their needs and others feeling overwhelmed. Their study emphasizes the importance of supportive environments and allies that encourage self-advocacy. It also supports the need for self-advocacy training to be more developed during the high school years so that they may not feel as overwhelmed in secondary settings.

Self-advocacy fosters personal empowerment. When autistic individuals learn to express their needs and preferences, they gain confidence in their abilities. This empowerment is crucial for their mental health and overall well-being. According to Shore (2018), self-advocacy can lead to increased independence and improved life satisfaction. Effective self-advocacy is also linked to academic success. Autistic students who can articulate their needs are more likely to receive necessary accommodations, such as extended time on tests or modified assignments. Santhanama and Wilson's (2020) research indicates that students who engage in self-advocacy are more likely to report positive academic experiences. Self-advocacy also plays a vital role in building and maintaining social relationships. By effectively communicating their needs and boundaries, autistic individuals can foster healthier relationships with peers and mentors. This communication can help mitigate misunderstandings and promote inclusivity.

Gina-Marie Moravcik, MA, CCC-SLP

Strategies for Developing Self-Advocacy Skills

Educating autistic individuals about their rights and the importance of self-advocacy is essential. Embracing neurodiversity and learning about one's particular learning style, communication preferences, and needs should happen prior to graduating high school. Workshops, seminars, and community-based peer support groups can also provide valuable information on how to advocate for oneself in various settings, shared experiences, and helpful strategies.

Role-playing scenarios can help autistic individuals practice self-advocacy skills in a safe environment with a mentor or socialization coach. This practice can include situations like asking for help in class, setting up meetings with their professors, requesting accommodations, or navigating social interactions. For example, self-advocacy may look like letting peers that you sit with at lunch know that you need some downtime but would like to join them later, e.g., "I'm going to sit outside for a minute to decompress from all of this work, but would like to join you for lunch." Normalizing self-care through communication is something everyone can relate to. In fact, a peer may even say, "Same, can I join you." Such exercises can build confidence and reduce anxiety. Having access to a neurodivergent mentor who has already experienced similar situations may provide added support.

Support from educators and peers is crucial in fostering self-advocacy. Educators can create inclusive environments that encourage open communication and respect for individual needs. An example of this would be a professor inviting students with varied learning styles to alert them to their needs as part of their discussion of the class syllabus, which typically happens during the first class meeting. Scheduled meetings or "check-ins" with students prior to midterms are also a way to invite students to share their successes and hurdles, offer executive functioning support, and continually guide students toward success.

Technology can be a powerful tool for enhancing communication and self-advocacy. Augmentative and alternative communication (AAC) devices, apps for note-taking and summarizing key points, and online platforms can facilitate expression and connection. Technology can and should be used both receptively and expressively to aid comprehension of material across settings. Shore (2018) advocates for incorporating technology into self-advocacy training to help individuals articulate their needs more effectively.

Family plays a pivotal role in the development of self-advocacy skills. Encouraging open dialogue within the family can help autistic individuals feel more comfortable expressing their needs. Families can also model effective communication and self-advocacy behaviors by speaking positively about diagnoses strengths and positively praising the act of asking for help when needed.

Self-advocacy and effective communication are essential skills for autistic individuals, impacting their personal, academic, and social lives. Despite the challenges they may face, fostering these skills can lead to greater empowerment, independence, and success. By understanding the importance of self-advocacy and implementing supportive strategies, we can create a more inclusive society that values the voices of autistic individuals.

As we continue to advocate for the rights of autistic individuals, it is necessary to recognize the significance of self-advocacy and effective communication in their journey. Empowering autistic individuals to speak up for themselves is not just beneficial for them; it enriches our communities and promotes understanding and acceptance for all.

Gina-Marie Moravcik, MA, CCC-SLP, is a neurodivergent SLP and ADHDer who owns and operates Sunrise Speech and Language Services. For more information, visit sunriseslpsvcs.net.

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participant's brain anatomy in great detail. Before the PET scan, researchers injected a novel radiotracer known as 11C-UCB-J, which was developed with the Yale PET Center and enabled them to measure synaptic density in the brain.

The researchers found that autistic people had 17% lower synaptic density across the whole brain compared to neurotypical individuals. Furthermore, they found that lower synaptic density was significantly correlated to the number of social-communication differences, such as reduced eye contact, repetitive behaviors, and difficulty understanding social cues, in these individuals. In other words, the fewer synapses a person had, the greater number of autistic traits they showed.

Understanding Autism Mechanisms Could Help With Diagnosis and Support

A major limiting factor in clinicians' ability to understand and offer support for autistic people, says McPartland, is the lack of a mechanistic understanding of the condition. "Today's diagnostic criteria [which predate this new study] involve descriptions of behavior that are broad and pretty vague," he explains. "We could be so much more effective in figuring out whether and what supports are needed if we could aid our clinical decisions with an understanding of the biology of autism."

Isabella Backman

Investigating the underlying mechanisms of autism could also help researchers better define subgroups within the condition. "We historically had the hubris to think we could create subgroups without this understanding," McPartland says. The Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), which was published in 1994, divided autistic spectrum disorders (ASD) into Asperger's syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), and autistic disorder. "Then, in the DSM-5, we had to swallow our pride and throw these categories away because they weren't working."

Today, the DSM-5 defaults to one broad, non-specific category of ASD. McPartland hopes his work will help pave the way for parsing autism into better defined subgroups, which will, in turn, help clinicians better understand the wide range of features autistic individuals may present with.

It is still unclear whether autistic people are born with fewer synapses or if this difference occurs as a result of living with autism. But, PET scans could one day potentially help clinicians anticipate a child's prognosis and enable the care team to administer appropriate interventions earlier. "This is the dream — to be able to give biologic confirmation to patients and their families," says David Matuskey, MD, associate professor of radiology and biomedical imaging and the study's first author. "That would change everything."

Future Studies Aim to Maximize Quality-Of-Life for Autistic People

In future studies, the team is investigating the use of nonradioactive approaches that are less expensive than PET scans for directly studying the autistic brain. They are also interested in measuring synapses in adolescent brains to better understand how this may evolve as an individual ages. Finally, the team plans to explore how their findings relate to other outcomes associated with autism. For instance, autistic individuals are at a higher risk of mental health issues such as depression or anxiety than neurotypical people. "This is something that's really important for us to investigate to serve our overarching goal, which is to get information that can maximize the quality of life for autistic people," says McPartland.

Isabella Backman is Associate Editor-Writer at Yale School of Medicine.

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Alexis Bancroft, PhD

E. Emilie Weiner, MA, BCBA

Cynthia Martin, PsyD

approach for data collection (pre/post-treatment and during treatment to guide clinical decision-making), and an assessment methodology for therapist fidelity. Meta-analyses on NDBI interventions indicate positive treatment effects on improving social engagement and cognitive development in young children with autism (Tiede & Walton, 2019; Crank et al., 2021; Dawson et al., 2010; Drew et al., 2002; Kasari et al., 2018; Sandbank et al., 2020). Smaller effects are noted in increasing communication and play skills and overall reduction in autism symptoms (Tiede & Walton, 2019; Ingersoll et al., 2017; Wetherby & Woods, 2006).

Involving Parents in Intervention Programs

Though individually administered NDBI programs yield substantial gains in young children's development when delivered with intensity (Dawson et al., 2010 & Rogers et al., 2019), they remain difficult for many to access due to resource constraints. As a result, there has been an increased appreciation and need for interventions which leverage parents and caregivers. The American Academy of Pediatrics (Zwaigenbaum et al., 2015) strongly recommends Early Intervention for the treatment of autism, including the combination of developmental and behavioral approaches, beginning as early as possible, which also incorporates family and/or caregiver involvement. Teaching parents the skills to promote their child's development during everyday interactions effectively promotes parents from caretakers to primary mediators and catalysts for change (Nevill et al., 2018). Approaching intervention through parent mediation has significant benefits. This transactional model results in the behavior of the child and caregiver being reciprocally influenced by each other over time. This interaction-based model strengthens the parent-child relationship and enhances parental responsiveness, efficacy, and empowerment (Green et al., 2010; Siller et al., 2013; Sone et al., 2021; Watson et al., 2017; Bryson et al., 2007; Tomeny et al., 2020; Russell & Ingersoll 2021), while simultaneously reducing parental stress (Estes et al., 2014). Parent-mediated interventions also increase the number of learning opportunities for a child. Though many individually administered interventions include a parent training component, at least one randomized control trial has suggested parent-mediated, hands-on training was superior to a parent-only psychoeducational intervention (Kasari et al., 2015), which further supports the need and relevance of a parent-mediated approach, especially during the early learning years.

Using Project ImPACT to Promote Parental Involvement

Project ImPACT (Ingersoll & Dvortcsak, 2019) is an evidence-based, parent-mediated NDBI intervention program that focuses on **I**mproving **P**arents **A**s **C**ommunication **T**eachers to build children's social engagement, communication, imitation, and play skills (Barber, 2020; Schreibman, 2015 & Ingersoll, 2017). Project ImPACT is designed for children aged 1 to 8 who present with social communication delays and current language levels up to about four years of age. The intervention is delivered to caregiver-child dyads over multiple sessions. It has been shown to be effective in single-case designs (Ingersoll et al., 2017; Ingersoll & Wainer, 2013) and group designs (Stahmer et al., 2019; Yoder et al., 2020). Early efficacy has also been established for use in telehealth (Hao et al., 2021) as well as when administered within a group setting (Sengupta et al., 2020). Current research is being conducted on using Project ImPACT within the community (Brian et al., 2022; Pellecchia et al., in press).

Project ImPACT begins with a collaborative goal-setting session between the clinician and caregiver to set realistic short-term and long-term goals in the target domains of social engagement, communication, imitation, and play. The subsequent sessions move through the Project ImPACT F.A.C.T.S. Pyramid (Figure 1), which stands for **F**ocus on Your Child, **A**djust Your Communication, **C**reate Opportunities, **T**each New Skills, and **S**hape the Interaction. Project ImPACT incorporates behavioral teaching and parent-child relationship-building activities through interactive and direct teaching methodologies (Ingersoll & Dvortcsak, 2010; Ingersoll & Dvortcsak, 2019). Each new skill presented builds on skills targeted in prior sessions, allowing for continued practice of previously mastered strategies. During sessions, parents have opportunities to observe the clinician modeling each strategy and then receive feedback from the clinician as they interact with their child. More specifically, there are seven interactive teaching techniques (following a child's lead, imitation, animation, modeling and expanding communication, playful obstruction, balanced turns, and communicative temptations), which are designed to increase a child's engagement and spontaneous communication. Direct techniques include prompting and reinforcement (Ingersoll & Dvortcsak, 2010; Ingersoll & Dvortcsak, 2019).

During the initial sessions, the concept of *focus on your child* is introduced, which places emphasis on building a positive relationship between the child and caregiver. This is achieved by teaching a caregiver to *follow your child's lead* and *imitate your child's behavior*. By doing so, there is an increased likelihood of social engagement, longer duration of parent-child interactions, and opportunities for vocalizations and language. Once these skills are mastered, parents are coached on how to *adjust* their *communication* by *using animation* and *modeling and expanding communication*. Using animation facilitates social attention, helps children understand nonverbal communication, and encourages initiation. Frost, Russell, and Ingersoll (2021) also found that when using qualitative content analysis, animation was associated with parent reports of social engagement and child enjoyment. *Modeling and expanding communication* provides ongoing opportunities for a child to increase receptive language skills while also learning new communication skills. *Creating new opportunities* involves using a set of strategies to gain a child's attention before teaching new skills or to help the child initiate during an interaction. This is accomplished through *communicative temptations*, *playful obstruction, and balanced turns*. *Teaching new skills* involves prompting and reinforcement to promote more complex communication or play. Lastly, *shaping the interaction* teaches caregivers to adjust their behavior by moving up and down the strategy pyramid (Figure 1) based on how a child is responding (e.g., increasing caregiver attunement and responsiveness).

Overall, NDBIs are effective interventions that can drastically change the outcomes for younger learners who have an autism diagnosis. Project ImPACT specifically is an effective parent-mediated intervention which can be used in a wide variety of settings and scales, including clinic, home, and community settings, to help build young children's social communication, social engagement, play, and imitation skills. It utilizes naturalistic approaches and builds parents' skills and self-efficacy in engaging with their children with social communication delays.

NDBI Programming in the Autism Center at the Child Mind Institute

At the Child Mind Institute's Autism Center, we provide a comprehensive range of NDBI services for young children with autism and their caregivers. Our team of developmental specialists – including psychologists, speech-language pathologists, and Board-Certified Behavior Analysts (BCBAs) – creates personalized intervention plans for each child and collaborates closely with home- and school-based providers. For more information, please visit childmind.org or email us at autismprograms@childmind.org.

Alexis Bancroft, PhD, is a licensed psychologist; E. Emilie Weiner, MA, BCBA, is a board-certified behavior analyst; and Cynthia Martin, PsyD, is a clinical psychologist and senior director of the Autism Center at the Child Mind Institute.

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See full list of references here.

Autism Award from page 9

States to focus on adult Autism and has been blazing trails since 2002. They create paths leading to fulfilling and potential-driven lives. Their model programs, resources, public policy, and awareness initiatives are person-centered and derive from the needs and hopes of the diverse population of adults diagnosed with Autism and their families. The Daniel Jordan Fiddle Foundation's visionary leadership in establishing the first and only adult Autism focused endowment funds located at Arizona State University and The Medical University of South Carolina College of Health Professions assures a global focus on cutting-edge program development, research, family support, vital resources and public policy for decades to come. The Daniel Jordan Fiddle Foundation Leader in Adult Autism Award is presented annually by the Autism Society of America to recognize and inspire the world by honoring exemplary individuals and endeavors that highlight the strengths and potential of all individuals with Autism to live their best lives.

***Never Too Late** from page 6*

How Do You Choose an AAC System?

AAC is an umbrella term used to describe many different alternative communication methods. AAC is commonly subdivided into high-tech and low-tech categories. Low-tech AAC includes systems such as single-message voice output buttons, the picture exchange communication system (PECS), and picture point boards. High-tech AAC refers most commonly to speech-generating devices (SGDs), which utilize a digital display and produce a multitude of auditory messages. We will return to our case studies for examples of the AAC trial and selection process.

Will - In 2018, Will began using the Picture Exchange Communication System (PECS) – a low-tech system in which an individual gives a picture of an object to a communication partner to make a request. Initially, PECS served this client's communication needs, as he established his understanding of symbolic communication. However, due to limited mobility, he could only communicate with people in his immediate area. Additionally, icons became lost or damaged overtime, limiting what he could communicate to what icons were available. Will showed an increase in challenging behaviors when he could not request or gain staff attention effectively using PECS, indicating the need to consider other AAC options.

In March 2023, Will began trialing a speech-generating device (SGD). The SGD provided auditory output, allowing Will to communicate with people at a greater distance. It also increased his access to vocabulary, as his communication layout could easily expand as his skills grew. During the trial period, Will demonstrated consistent interest in using the device, and he quickly began to independently activate icons on the screen to make requests. He also demonstrated skills in operating the device, independently illuminating the screen, and using arrows and folders to navigate to different vocabulary pages. After this successful trial, Will received his own SGD in April 2023.

Darius - In February 2023, Darius began trialing a high-tech SGD to support his verbal communication when communication breakdowns occurred. Due to his significant visual impairment and motor deficits, this client initially demonstrated difficulty navigating the flat touch-screen surface of his SGD. However, his use of the device improved with changes to the graphic display to enhance visibility, and the implementation of a keyguard – a customized plastic screen overlay – to support fine motor access. Darius' SLP and PT team also worked together to position the device on the client's wheelchair, allowing for improved visual and motoric access on the go.

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There are pros and cons to using any AAC system. Low tech systems are easily transported and typically low-cost, offering an accessible entry point for many first time AAC users. However, they are limited in the amount of vocabulary available, and they do not offer or have very limited auditory output. High-tech systems offer flexibility in the size of the communication layout, the amount of vocabulary available, and the ease of editing and updating as communication skills change. However, these devices are often costly and require some technological knowledge to edit and operate. Selecting the right AAC system is a highly individualized process that requires trialing different systems to determine physical accessibility, the ability to meet the client's current and future communication needs, as well as client and family preferences. When possible, it is beneficial to collaborate with an interprofessional team to select and implement an appropriate AAC device. Team members may include:

- Speech-Language Pathologists (SLPs)
- Occupational Therapists (OTs)
- Physical Therapists (PTs)
- Behavior Analysts (BCBAs)
- Residential and/or Day Program managers

How Does AAC Support Communication Skills?

Gaining access to an AAC system is only part of the equation when working to improve communication for adults with CCN. It is also essential to teach individuals how to use the device and effective methods of communicating. After selecting an AAC system for an individual, developing the skills to use the system requires continuous exposure and education. The methods for teaching an AAC system are two-fold: individualized direct treatment sessions and incidental learning in the natural environment. Individual treatment sessions target specific skills to support the user with their device and communication development. The skill areas focused on in treatment follow the communicative competencies outlined by Janice Light (1989; Light & McNaughton, 2014), specifically:

Linguistic Competence: language skills such as vocabulary and grammar

- *Examples*: requesting, labeling, building multi-word sentences

Operational Competence: technical skills related to the AAC system

- *Examples*: navigating folders/pages, activating and clearing the message bar, navigating the environment with an AAC system

Social Competence: skills for social engagement using AAC

- *Examples*: taking conversational turns, appropriately entering/exiting a conversation, topic maintenance

Strategic Competence: compensatory skills for repairing communication breakdown

- *Examples:* repeating a message, gaining the conversational floor (e.g., "please, wait for my message")

Psychosocial Competence: skills related to motivation to communicate and self-confidence

- *Examples*: persistent communication if misunderstood, developing device ownership

During individual treatment, the communication partner contrives learning opportunities to allow for repeated practice with the targeted skills. For example, the communication partner may set up a "requesting session," during which they offer a variety of choices for the AAC user to request for in quick succession. During such a session, the AAC user practices the vocabulary for making requests, the operational steps to access each of the vocabulary terms, and the social timing of when it is appropriate to make a new request.

Contrived treatment sessions offer opportunities for massed practice, which supports new skill acquisition. However, AAC users also benefit from natural environment teaching, in the form of modeling, to generalize new skills and support continual learning. Modeling consists of the communication partner using the AAC system to express their own message during daily routines, conversations, and activities.

Through modeling different messages, the communication partner demonstrates the location of new vocabulary, different types of communication (e.g., commenting, labeling, social engagement), and how to navigate the AAC system. If you are unsure where to begin, some guidelines for effective modeling include:

- Use your own words – you speak through the AAC system
- No response required – the AAC user does not have to say anything back to learn from the interaction
- Lower the pressure – make statements rather than asking questions and give plenty of wait time for a response
- Engage naturally – use activities in the environment and your daily routine to start conversations
- Making mistakes is OK – even your mistakes provide valuable information about how to look for words and ways to navigate the AAC system.

At the end of the day, the only wrong way to model is by not modeling at all. Through offering frequent communication examples and adequate time to learn, you can support your adult child in improving their communication abilities. When given the necessary support, communication improvement is possible even in adulthood. Consider the outcomes of our two case studies:

Will - After 1 year with an SGD, Will has demonstrated incredible communication gains. He is capable of requesting preferred items and activities across a variety of categories, including foods, drinks, toys, and locations. He also uses functional communication responses (FCRs) to gain access to attention, leave an area, and express that he is finished with an activity. These FCRs have significantly decreased this client's reliance on challenging behaviors to meet his needs. Lastly, given Will's social nature, he has thrived with access to social language, which allows him to greet others, introduce himself, and identify the names and pictures of people he interacts with. Over the past year, this client has experienced age-related changes to his mobility, but his SGD has changed with him, allowing him to continue to access communication. He now uses a walker bag to safely carry the device with him, and he began using a keyguard to support his fine motor skills. During his most recent individual support plan meeting (ISP), this client demonstrated his love of his communication device, showing it off to his family and team and requesting attention from everyone in the room. At the end of the meeting, Will's mother said "I wasn't sure when you suggested the device. I am so pleasantly surprised that he has learned so much."

Darius - After receiving his own SGD in March 2023, Darius developed a clear love for and ownership of his device. He is responsible for taking the device with him, and if it is not within his view, he will say "my iPad" to get help finding it. Darius can utilize his device to clarify his message when his verbal speech is not understood. He has also benefited from increased access to social and phrase-based communication. Darius enjoys exploring the names of friends and staff members, and he has been practicing using social phrases, such as "see you later alligator," to build diversity in his verbal repertoire. Darius continues to use his verbal speech, but his SGD has increased the clarity with which he can express his thoughts and feelings.

Summary

Adults with complex communication needs can improve communication skills when given access to and instruction in AAC. Any adult who is unable to effectively communicate their wants, needs, and thoughts using verbal speech may be a candidate for an AAC system. When choosing an appropriate AAC system, you must consider the individual's communication needs, their physical access, and for what system they demonstrate a preference. Once you have selected an AAC system, a combination of direct skill instruction and communication modeling are essential to support communication development and generalization of device use across settings and communication partners.

Readers can continue to expand their AAC knowledge or gain support during the AAC journey using the following resources.

Education and Support Resources

- AbleNet: AAC Resources (Augmentative and Alternative Communication Resources)

*see **Never Too Late** on page 29*

***Health Care** from page 14*

Barrier 3. Physical Examinations. Four of the six autistic teens mentioned that physical touch during examinations was a significant barrier for them. They shared that they often feel uncomfortable or even distressed by the physical contact, which doctors do not always explain adequately beforehand. This can cause anxiety that makes it difficult to focus on the conversation or express needs.

Teen's comment: *"I don't like being touched, especially by people I don't know well. It makes it hard to pay attention when they're asking questions at the same time."*

Interviewing Parents

An analysis of parent interviews revealed three general themes impacting autistic teens during medical appointments: sensory sensitivities, verbal expression and processing delays, and a general lack of autism awareness among healthcare providers. Below is a more in-depth look at the themes.

Theme 1. Sensory Sensitivity. Parents emphasized that sensory sensitivities—such as discomfort with bright lights, loud noises, and strong smells—often prevented their teens from communicating effectively during medical appointments. Even though medical environments are rarely designed with sensory sensitivities in mind, many autistic individuals are unable to focus on communication when overwhelmed by sensory stimuli, which can result in shutdowns or even refusal to attend appointments.

Parent Comment: *"My son can't handle the fluorescent lights and constant noise in the doctor's office. By the time he sits down with the doctor, he's too overwhelmed to communicate anything."*

Theme 2. Processing Delays. Parents noted that autistic teens usually need extra time to process questions and respond, which is often not allowed in fast-paced health care settings. This can lead to frustration for both the patient and provider and may result in incomplete or misunderstood information being conveyed.

Heidi Hillman PhD, BCBA-D, LMHC

Parent Comment: *"Doctors often seem impatient, especially when my daughter needs extra time to process the question and respond. She sometimes shuts down and doesn't answer at all."*

Parent Comment: *"One time, I requested extra time for our appointment. We received an extra 15 minutes, but the doctor then billed us an extra $300!"*

Theme 3. Lack of Understanding. Many parents felt that health care providers lacked awareness about autism-specific communication needs. Some described instances where medical providers interpreted their teen's behavior as rudeness or defiance rather than a response to stress or sensory overload.

Parent Comment: "We've *had doctors tell us my son is 'uncooperative' when he just doesn't understand the questions or feels too anxious to respond."*

Recommendations for Improving Communication

When autistic individuals and parents were asked about their recommendations to help health care providers minimize communication barriers, five recommendations emerged.

1. **Use Literal Language.** Health care providers should use direct, literal language, avoiding idioms, metaphors, or overly abstract questions. Statements like, "Let's examine your throat to make sure there's no infection" instead of "Let's take a look" were suggested to minimize confusion.

2. **Extra Time for Processing.** Providers should allow autistic patients additional time to process questions and formulate responses. This can alleviate the anxiety associated with rushed interactions and help ensure that patients provide accurate information.

3. **Sensory-Friendly Accommodations.** To address sensory sensitivities, medical facilities can implement simple adjustments, such as (a) reducing lighting intensity or allowing the use of sunglasses; (b) providing noise-canceling headphones or quiet spaces; (c) allowing the patient to bring familiar sensory items, such as fidget toys or weighted blankets, to appointments.

4. **Increased Trainings.** Health care professionals would benefit from training that highlights autism-specific needs, such as learning de-escalation techniques for managing anxiety, understanding sensory accommodations, and practicing patience with processing delays.

5. **Develop Communication Plans.** A communication plan tailored to each autistic patient's preferences could be a valuable tool. This plan might include preferred language style, specific sensory triggers, and other individual needs, allowing providers to engage with the patient in a consistent, accommodating manner across appointments.

Conclusion

Autistic individuals face numerous communication barriers in health care settings, ranging from sensory overload and the use of abstract language to the need for more time during interactions. Based on interview insights, these challenges underscore the need for more accommodating and autism-informed healthcare environments. By using patient-centered communication methods—such as literal language, extra processing time, and sensory accommodations—health care providers can significantly reduce barriers and enhance the overall patient experience. With further research and continued professional training, health care providers can better meet the needs of autistic teens, promoting trust and improving health outcomes for this population.

Heidi Hillman, PhD, BCBA-D, LMHC, is an autistic researcher and professor at Eastern Washington University. For more information, please contact Heidi Hillman at hhillman@ewu.edu.

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- ASHA: American Speech & Hearing Association: AAC (Augmentative and Alternative Communication)
- AssistiveWare: Strategies for AAC use at Home
- Easterseals: Caregiver Resources and Groups
- ISAAC: International Society for AAC (International Society of Augmentative and Alternative Communication)
- USSAC: US Society for AAC (U S Society for Augmentative and Alternative Communication)
- NWACS: AAC in Adults with IDD (Augmentative and Alternative Communication in Adults with Intellectual and Developmental Disabilities)
- NWACS: Blog posts related to AAC for Adults with IDD (Augmentative and Alternative Communication for Adults with Intellectual and Developmental Disabilities)
- PRC: Caregiver Resources
- SPD: AAC for Caregivers Training & Manual (Augmentative and Alternative Communication for Caregivers Training and Manual)
- AAC for Caregivers PDF

Laura Nagy, MS, CCC-SLP is a Speech-Language Pathologist at Melmark. This article has been republished with permission from the Association for Science in Autism Treatment. The original source can be viewed here.

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cues, heightening anxiety and stress. Fear of rejection may then lead to behaviors that provoke rejection, such as withdrawing from social interactions or becoming overly defensive.

“Cognitive-behavioral theories suggest that negative thought patterns and beliefs about oneself and others contribute to this heightened sensitivity. For instance, thoughts like “I’m *not good enough*” or “*People will reject me*” exacerbate the fear of rejection” (Sanders, 2024).

Dr. Tasha Oswald writes, “Most teens and adults with high-functioning autism fear rejection... When conflict arises, it can be extremely upsetting… The instinct might be to avoid conflict…[but] avoiding conflict can mean avoiding deep, meaningful relationships” (Oswald, 2021).

Feelings of rejection often lead to shame. Shame invokes the fight-or-flight response, which may entail “becoming defensive, explaining or defending your actions, or arguing with others. A flight response may include withdrawing, self-isolating, walking out or running away, not talking… [and] avoiding eye contact.”

But neither fight nor flight will “eliminate the conflict [or] the root of the issues you’re having in that relationship. Furthermore, it may hurt the person you’re in conflict with. It can cause them to feel…invalidated or ignored. And [they]…may lash out at you to protect themselves, which causes further conflict” (Oswald, 2021).

C. N. Ginapp et al. conducted focus groups to learn how ADHD teens [a Neurodivergent condition closely related to ASD] perceived ‘typical’ ADHD symptoms. High among their concerns were Alexithymia and Rejection Sensitivity.

Alexithymia: “I can’t really verbalize what it is that I’m feeling, which frustrates me even more because I can’t put the words to what I’m feeling … If I don’t know what’s wrong with me, then why in the world am I upset?...[S]ometimes I don’t even know what I feel.”

RSD: “It’s literal pain for me…in my chest... I’ll sit and think about it for a… long time and nit-pick it and replay it over and over again to the point where people are like, a lot of time has gone by, it’s not that big of a deal, let it go, and I’m still sitting there pondering everything I could have done” (Ginapp, 2023).

Being unable to perceive one’s own - or other’s - emotions has a profound impact on mental health, behavior, and relationships.

The prevailing belief is that RSD may be a consequence of differences in brain structure. Structural differences affect how the brain regulates rejection-related emotions and behaviors, making the emotions much more intense.

According to author Olivia Sanders, “People with rejection sensitivity may frequently misinterpret neutral or ambiguous social cues as negative, leading to increased anxiety and stress. This can create a vicious cycle where the fear of rejection leads to behaviors that inadvertently provoke rejection, such as withdrawing from social interactions or becoming overly defensive.

“Understanding rejection sensitivity requires recognizing the underlying cognitive and emotional processes. Cognitive-behavioral theories suggest that negative thought patterns and beliefs about oneself and others contribute to this heightened sensitivity. For instance, thoughts like “I’m *not good enough*” or “*People will reject me*” can exacerbate the fear of rejection” (Sanders, 2024).

Annie Kent, MA

Rejection and Shame

How do Alexithymia and RSD affect communication in important relationships? Dr. Tasha Oswald writes,

“While a fight or flight response may temporarily make you feel better, “Most teens and adults with high-functioning autism fear rejection and will do what they can to avoid it... When conflict arises…it triggers feelings of rejection and shame. The instinct might be to avoid conflict… Avoiding conflict can mean avoiding deep, meaningful relationships.”

“A fight response may entail becoming defensive, explaining or defending your actions, or arguing with others. A flight response may include withdrawing, self-isolating, walking out or running away, not talking, looking at your phone/computer/tablet, [and] avoiding eye contact” (Oswald, 2021).

It doesn’t eliminate the conflict and the root of the issues you’re having in that relationship. Furthermore, it may hurt the person you’re in conflict with. It can cause them to feel…invalidated or ignored. And… that’s a very painful feeling. It may also cause them to lash out at you to protect themselves, which causes further conflict.

“Over time, the cycle of conflict continues until it escalates, and the relationship or friendship usually ends or gets stuck… as dissatisfying…lacking intimacy, safety, and trust.”

Non-Adaptive Emotion Regulation and Intense Emotional Pain

Alexithymia is essentially non-adaptive emotional regulation, while Rejection Sensitivity may be viewed as behavioral manifestations of intense emotional pain. Those with RSD are “vigilant in observing and monitoring the moods and behaviors of others and are overly sensitive to interpersonal problems” (Morin, 2019).

Different Presentations

RSD doesn’t present the same way in all Autistic/Neurodivergent people. And its causes differ. “Possible causes include childhood experiences like critical parents and bullying, along with biological factors and genetics” (Morin, 2023).

In her Blog, *Neurodivergent Insights*, author Megan Anna Neff points out, “Our minds, by their very nature, are wired to pick up even the faintest hints of rejection, which perpetually fuels our quest for these cues in our surroundings. Regrettably, this constant vigilance can reinforce our belief that rejection is an ever-present force in our lives” (Neff, n.d.).

No Research Literature?

I was surprised by how difficult it was to find any literature examining potential links between Rejection Sensitivity and Alexithymia. Emotional dysregulation itself has been the subject of extensive research, but the keywords autism, Alexithymia, and Rejection Sensitivity – in any combination – led to nothing. *Why?* A link between these processes seems probable.

Final Thoughts

Some researchers have suggested that affected people may “go through life not realizing they have RSD. This can lead to intense and unnecessary suffering without the language to communicate their needs. The intense feelings of rejection, shame, and devastation from RSD can be overwhelming and debilitating for daily life, work, and relationships…Learning how to manage and cope with these intense emotional reactions becomes essential for living a fulfilling life” (Lee, 2024).

“Autism doesn’t come with an instruction guide. It comes with a family who will never give up.”

- Kerry Magro (*80 Autism Quotes to Inspire and Educate*, 2023)

Annie Kent, MA, spent two decades working in public sector disability, mental health, and infectious diseases advocacy and education. Diagnosed with three closely related categories of neurodiversity, a lack of awareness and understanding led to autistic burn-out and retirement from the field. She remains an active advocate, learning and engaging remotely with several Autism organizations and forums, including Autism Northwest. For more information, visit her website, www.aspiefemmepress.ca, or email Annie at ajollymo@lakeheadu.ca.

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involved subtext, however, particularly concerning the thoughts, feelings, or motivations of characters, their interactions, or their behavior in social settings, I had no idea what was happening.

Reading good fiction, which includes much of the great literature that is studied in schools as well as that which people read simply for pleasure, provides a form of exposure to different kinds of people and situations (social and otherwise) that one may never have personally experienced but might encounter in the future. This, in turn can prepare the reader for the day when such does happen by providing an abstract form of "script." For me, as for many other autistics, this largely implicit means of instruction in social communication was of no value whatsoever; it was simply too advanced for my level. As a result, I got little benefit from this form of education; not to mention that the science fiction stories that I sometimes did read were hardly known for realistic character development!

Even for younger autistics, this can present a challenge. There is no shortage of children's stories, going back (at least) to Aesop's fables, which teach a moral message; these usually do so in a manner explicit enough to more likely be understood by younger autistics. Unfortunately, such is not the case for stories that involve the thoughts and feelings of others, let alone how people are expected to behave towards and interact with each other. Once again, the need for teaching social communication skills remains unmet.

Tools for Teaching Social Communication

On one occasion, while I was in high school, I came across a pile of discarded educational materials, which I quickly noticed dealt with social situations – these were clearly intended for a much lower academic level. I immediately picked up the entire lot, took it home, and voraciously devoured it that very afternoon. This was unusual for me because, as a slow reader, I rarely read anything so quickly, even when it dealt with my special interests. Clearly, I was nothing less than starving for this kind of information.

Unfortunately, the use of such paraphernalia as the above had been discontinued, given that they were discarded. The same is true for educational films used in earlier decades, some of which dealt with issues related to social communications. Once again, these fell out of favor and even became the subject of ridicule; in college, I once attended a dorm party at which some of these were shown as comedic entertainment! In any case, tools of this nature were eliminated in the schools and effectively replaced with nothing.

Karl Wittig, PE

For this reason, I was especially gratified when I learned (once again, shortly after my diagnosis) of a methodology called social stories, which depicted a variety of social situations in comic strip form. Remembering my above-described experience, I immediately recognized the value of this technique. When I was growing up, comics were greatly frowned upon, particularly for students of higher ability; even my own family strictly prohibited me from having them. It is ironic that such a tool might have been highly beneficial to me, even if I was attending a science school of very high standing at the time. Years of use attests to the fact that this method is an effective means of teaching social communication skills to a wide variety of autistic individuals.

All autistics need some form of simplified explicit instruction in social communication skills to be provided at appropriate grade levels, regardless of their age, intelligence, or academic ability. Whatever tools are available for this purpose, be they social stories or classes where fictional narratives involving social situations are discussed explicitly and extensively, must be deployed.

Social Communication Skills in the Workplace

As important as it is to develop social communications skills while in school, it is even more important to have them later in life, especially in the workplace. Unfortunately, this is one environment where not only are people expected to have these skills but is the most unforgiving of those who do not. As such, many work situations are generally not suitable for autistics; this is true of many positions that involve dealing with clients or customers and especially true of environments where workplace politics is a dominant part of the culture. As is usually the case, autistics thrive best in situations where they are evaluated and judged on the basis of their skills and talents in areas where they excel. The employer who is willing to accommodate such an individual will often be rewarded with an employee who does exceptionally good work in their area of ability.

Nevertheless, even in the most optimal work situations, it is desirable, if not essential, for autistics to be well-instructed in social communications as needed for their work environment. What is greatly needed are adult versions of the aforementioned tools that are used in school settings (or should be – certainly for autistics, but many non-autistic students would probably benefit from such as well); in particular, any material that deals with issues likely to be encountered in the workplace. The same methods that are used for younger individuals can be adapted for use with adults; once again, this applies to autistics regardless of age, educational attainment, or intelligence. Although some autistics have access to job coaches who can be of great help with this, and even employers who allow such coaching on their work premises, many autistics (perhaps the vast majority) do not. For them, anything that helps improve their skills in this essential area will be of immeasurable value.

My Own Experiences With Communications

For most of my life, communications have presented a variety of challenges. In school, especially in classes such as English and social studies, I always had substantial difficulty with topics that involved nonliteral or social communications. In particular, I could not write fictional stories beyond the most infantile level (and forget about poetry!). Essays, at least where analytical thinking was involved, were less difficult, and on the rare occasions when I was allowed to write about a special interest, I actually did quite well (hardly unexpected). I was able to pursue higher education largely because I attended an engineering college where these subjects were only minimally required.

Early in my career as an electronics engineer in research and development, I was often told, during performance evaluations, that my communication skills needed improvement (along with a few other areas that I later recognized were related to my autism). Over many years, they gradually improved; in particular, I often had to write engineering reports and patent disclosures (for submission to attorneys), which exclusively involved technical writing. Only in this manner was I able to improve my writing skills. With time, I came to recognize some of my bad writing habits: writing very long sentences, using superfluous words, and re-using the same word over and over, among others. I realized that, by going over anything that I wrote at least a few times, I could recognize and correct these, resulting in a higher quality of writing. Incidentally, that includes this very article!

As to spoken communications, I realized, at my job, that when a farewell lunch was given for a departing or retiring employee, and a number of speeches were given in their honor, I had a talent for giving the "funny" speech. In fact, I became so good at this that I was always asked to give such a presentation. This, in turn, prepared me well for giving technical presentations about my work and, eventually, for speaking at the many autism conferences where I talked about my life experiences as an undiagnosed autistic.

In conclusion, the whole area of social communications is one that, especially for undiagnosed autistics (which includes everyone on the spectrum past a certain age), has long, if not completely neglected, gotten far less attention than it deserves and that the autistic community needs.

Karl Wittig, PE, is Advisory Board Chair at Aspies For Social Success (AFSS). Karl may be contacted at kwittig@earthlink.net.

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paying attention and showing that you are listening, are part of the process of attunement, which Dr. Dan Siegel explains as the ability to hear, see, sense, interpret, and respond to another's verbal and nonverbal cues in a way that communicates being genuinely seen, felt, and understood. These steps require putting aside anything else competing for your attention, i.e., phones, T.V., books, paperwork, etc., turning toward the other person, even if making eye contact is not possible, and using noises and gestures at appropriate times to show interest, attempts at understanding, and encourage the speaker to continue. Step 3 attempts to understand what the other person is trying to communicate by repeating what you've heard, summarizing what you think was intended, and asking clarifying questions to give the other a chance to confirm or correct. This step requires step 4, deferring judgment, which is about putting aside any attempts to put a label on what you are hearing. Understanding and judging are incompatible behaviors. To truly grasp what another person is trying to say, you must be able to put aside one's own opinion or perspective. Thus, in step 5, the learner has the task of responding appropriately. If one has actively listened, the appropriate response will be one that is accurately connected to the intended message. Active listening is about making sure the person speaking feels understood by a listener. Almost nothing feels better than feeling understood. When a staff person accurately understands the needs and wishes of the student, the staff member can identify appropriate strategies to help the student meet their needs and reduce occurrences of inappropriate behaviors currently being used to meet needs or express frustration and disappointment.

Another important skill for effective communication is emotional literacy- being able to identify, label, and communicate one's emotions and the emotions of others. Typically, the role of therapists and other caring adults can help teach emotional literacy to students in several ways. Feelings face uses universal emotional expressions to connect emotions and their names and can be adapted to many contexts and activities. Children's books, shows, and movies provide ample examples of emotional expressions that can be identified and explained. Finally, adults can simply model labeling their own emotions and the child's emotions in daily communication. Adults can also encourage labeling emotions in debriefing sessions, expanding the child's reflection, review, and understanding of interpersonal situations. As emotional literacy skills develop, children are increasingly able to understand their needs, articulate wishes, and make better decisions for achieving their interpersonal goals. Teaching emotional literacy also provides the opportunity for the listener to elicit recognition responses from the talker's facial expression and body language, which suggests an accurate understanding has been grasped. This enables the child to develop relationships, improve problem-solving, and feel connected to their community.

As the field of ABA continues to develop, the concept of individualization has become a more common and important area of focus. There is a movement away from setting "cookie cutter" goals and towards identifying the learner's specific needs and wants, thereby formulating meaningful, valuable, and life-changing goals. Individualization has also started to evolve in teaching communication skills through multimodal communication. Multimodal communication is a method of teaching

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unique to them and their circumstances, and so are the ways that they might express that trauma (Lovett, 1996; Harvey, 2012; Macknight, 2014; Pitonyak, 2016; Blanco et al., 2022).

Re-Experiencing Trauma

A traumatized brain returns to the same experiences over and over again, attempting but unable to process them and move on. This results in potentially debilitating symptoms, including flashbacks, where a person's body and brain react as though a past threat is happening in the present; intrusive memories or emotions; intense nightmares; and re-enactments, conscious or unconscious ways of acting out the trauma again (Macknight, 2014; SAMHSA, 2014).

Unfortunately, these manifestations are often deeply internalized and can be difficult even for nondisabled people to understand or explain. Triggers—people, places, sensations, situations, memories, or feelings that remind a person of their trauma, causing distress and symptoms—may be obvious, or they might not, especially if the individual does not yet have access to AAC that works for them.

In the lives of nonspeaking and sometimes-speaking autistic people, the results of re-experiencing trauma may look like strong emotional reactions such as fear, panic, anger, or aggression; crying or curling up suddenly; rocking back and forth in distress; freezing up; self-injury, including self-injurious stimming like head-banging or biting; and re-enacting traumatic things that happened to them, which may look like risky behaviors, or like “bizarre” play or unusual behavior, sometimes mistaken for psychosis or agitation (chavisory, 2014; Pitonyak, 2016; Blanco et al., 2020). They may also become less able to communicate around specific people or in specific situations that remind them of previous traumatic experiences.

Avoidance

A survivor of trauma avoids triggers in order to avoid the distress and suffering that comes with them. In the lives of nonspeaking or sometimes-speaking people, this may be seen as “noncompliance,” elopement, or hiding (Blanco et al., 2020). Self-injurious or aggressive behavior may also be a strategy to keep triggers away from the person.

Hypervigilance and Difficulty With Emotions

A traumatized brain is always on the lookout for threats, no matter how safe the situation really is. This state of looking out takes a toll on the body, causing or worsening physical chronic health concerns like headaches, gastrointestinal problems, and chronic pain (Herman, 1992b; Streeck-Fisher & van der Kolk, 2000; SAMHSA, 2014). Hypervigilance, and the related issue of difficulty understanding and regulating one's own emotions, may appear as being jumpy, fearful, or easily set off; having a bad temper; lashing out or breaking down at seemingly minor problems; emotional numbness; and being unable to calm down after stressors, resulting in prolonged and frequent meltdowns and shutdowns (Herman, 1992b; Harvey, 2012; Macknight, 2014; Delahooke, 2019; Blanco et al., 2020).

Ren Koloni, MA

Persistent Beliefs About Oneself as Worthless, Helpless, or Powerless

These beliefs may include feelings of guilt, shame, and failure, as well as difficulties with maintaining a sense of self (Herman, 1992a, 1992b). The person may have persistent fears of being hurt, rejected, or abandoned, and perceived failures or rejections may be experienced intensely.

Persistent Difficulties With Relationships and Attachment

These difficulties may lead to abusive or unstable relationships, increased fear or anxiety in social situations, learned helplessness (accepting abuse; being unable to say “no”), lifelong social isolation, and difficulty trusting other people (Herman, 1992a, 1992b).

Struggling with such symptoms also leads to high rates of depression, anxiety, and suicidality in trauma survivors, which may contribute to problems like self-injury, feeding problems, social anxiety, agoraphobia, and more in nonspeaking and sometimes-speaking autistic people (Herman, 1992b; Pitonyak, 2016; Chong et al., 2024). Another common feature is dissociation, an experience of being separated from the world around you that can cause difficulty with sensory integration, self-awareness, and awareness of one's environment. It may be difficult for a person who is dissociating to connect to the world around them or notice things happening in their body (Macknight, 2014; Herman, 1992b).

Treating involuntary trauma responses as intentional, inconvenient, and unwanted does not extinguish those responses (Delahooke, 2016). Instead, it reinforces beliefs that the person cannot trust the people who claim to want to help them, that the person themself is bad or a problem, and that they are powerless to change the way people treat them. The trauma responses remain and may even intensify but become more and more internalized; the person becomes “compliant,” but at a terrible cost (Macknight, 2014).

No research to date has recognized the trauma that may come from being deprived of communication, despite the fact that the same things that characterize complex trauma—helplessness, loss of autonomy, loneliness, isolation, and recurrent perceived or real danger (Herman, 1992a; van der Kolk, 2014)—underlie the experience of being unable to rely on speech to be heard and understood in the absence of effective communication supports. The state of the science on trauma, communication disability, and “challenging behavior” must recognize the lived realities of autistic people who cannot rely on speech alone to be heard and understood. **Without recognizing the trauma that almost certainly results from being denied access to communication, millions will continue to suffer in silence.**

Family members, educators, paraprofessionals, direct support professionals, clinicians, and other allies must and will be an integral part of changing this dynamic. Strategies can include learning more about trauma and trauma-informed approaches to “challenging behavior” (Lovett, 1996; Harvey, 2014; Pitonyak, 2016),[3] presuming that every person has the basic human competence to understand and learn (LoStracco, 2017), fostering self-determination skills like saying no and how to set and respect boundaries (NJC, 2024), creating opportunities for meaningful choice, building genuine and trust-based relationships (Macknight, 2014; Pitonyak, 2016), and supporting people with speech-related disabilities to learn and use robust, language-based AAC as soon as possible.

Responding to trauma through anything other than trauma-responsive approaches and evidence-based trauma therapies[4] invariably harms, rather than helps, trauma survivors. For autistic survivors who cannot rely on speech, it also contributes to the lifelong violations of civil and human rights, such as access to education, access to effective healthcare, and the ability to live and participate meaningfully in the community. Paving the path to healing trauma from communication deprivation is long overdue.

In this article, the author follows the terminology guidelines adopted by CommunicationFIRST, an organization led by and for people who need and use AAC. See “The Words We Use” (2023) at https://communicationfirst.org/the-words-we-use/.

CommunicationFIRST is the only nonprofit organization dedicated to protecting and advancing the civil rights of the more than 5 million children and adults in the United States who, due to disability or other conditions, cannot rely on speech alone to be heard and understood. For a more in-depth version of this and other resources we have created, or to learn more about the organization, visit communicationfirst.org. The author can be reached at rkoloni@communicationfirst.org. All other communication can be addressed to info@communicationfirst.org.

Footnotes

1. Throughout this piece, the phrase “challenging behaviors” is written with quotation marks because, while it is a quick shortcut to describing a variety of problems that may be familiar to autistic people and those who work with us, it is ultimately an unnecessary, stigmatizing, and pathologizing judgment on a person who is struggling. It erases and dehumanizes the person behind the behaviors, denying the possibility that there may be valid and complex reasons behind their actions. Whenever possible, CommunicationFIRST chooses instead to describe the specific movements and actions that may be unexpected, inconvenient, or harmful to the individual or others (CommunicationFIRST, 2023).

2. Not all unusual, unexpected, or inconvenient behavior should be assumed to be related to trauma. “Challenging behaviors” may also be related to unknown medical problems (e.g., hitting one's ears to cope with the discomfort of a mild ear infection) (Kripke, 2016), attempts to communicate (e.g., repeatedly opening the fridge to ask for a snack) (Harvey, 2014), attempts to interact with one's own environment and exert agency (e.g., moving furniture to make a room more comfortable) (Lovett, 1996; Harvey, 2014), or even something that the individual can't control (e.g., compulsions, apraxia, or tics) (Harvey, 2014).

3. For more on the mechanisms and manifestations of trauma, see the work of Judith Herman and Bessel van der Kolk. For trauma and trauma-informed approaches to “challenging behavior” in the field of intellectual and developmental disabilities, see the work of Herb Lovett, David Pitonyak, Karyn Harvey, Dave Hingsburger, and Mona Delahooke.

4. These treatments may include dialectical behavior therapy (DBT), trauma-focused cognitive behavioral therapy (TF-CBT), or eye movement desensitization and reprocessing therapy (EMDR), all of which have been validated for people with intellectual and developmental disabilities (Macknight, 2014; Blanco et al., 2020; D'Amico & Hoover, 2021).

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personalizing learning and providing interactive experiences, aligning with the principles of AAC modeling. These tools enable the rapid generation of tailored-modeling scripts, freeing up time for clinicians and educators to focus on implementation. However, the quality of AI-generated scripts depends on the expertise of the human in the loop.

Prompting Recipe

To maximize effectiveness, professionals should:

1. **Identify Core Words:** Select words relevant to the activity, such as “stop,” “go,” “look,” or “help.”
2. **Describe the Activity Context:** Provide details about the setting and objectives, such as a painting class or a group ball game.
3. **Explicit Modeling Approach:** Include specific language in your prompt directing the AI tool to use aided language stimulation (ALS). This will ensure the modeling script is aligned with appropriate research practices
4. **Analyze and Adapt:** Be the human in the loop and edit the AI output to meet individual needs, ensuring alignment with evidence-based practices.

If this prompting recipe is followed, the script produced should provide guidance to support professionals in successfully modeling language, especially in more unstructured activities.

Example Prompt:
“You are a special education teacher working with students with complex communication needs using augmentative and alternative communication (AAC). Please develop a modeling script for a support professional to implement aided language simulation (ALS) during a cooking activity, making Enchurritos modeling the words “in,” “out,” “on, and “off.” Please be sure to indicate on the script when the individual should tap on the words on the device.”

Prompt Frame:
To assist in the use of AI in script generation, we have included a prompt frame with fill-in-the-blanks to develop a script based on specific activities and core words:

“You are a special education teacher working with students with complex communication needs using augmentative and alternative communication (AAC). Please develop a modeling script for a support professional to implement aided language simulation (ALS) during a______ activity modeling the words ______. Please be sure to indicate on the script when the individual should tap on the words on the device.”

Lauren Tucker, EdD

Kristy Hynes, PhD, BCBA-D

Where things can go wrong!
Prompting is integral to high-quality AI generation because if a vague prompt is utilized and the product is not audited, the result will be insufficient. As presented above, utilizing the prompting recipe will aid in an effective script. For example, when a prompt was added into ChatGPT that did not specify “using ALS,” the script that was produced instructed the communication partner to direct the student to repeat the word on their device after it was modeled. This pressure to respond is not recommended for effective modeling. Utilizing a structured prompt, like the frame above, ensures that AI-generated scripts align with evidence-based practices and the unique needs of AAC users.

Application to Recreational Activities: Cooking

Recreational activities offer rich opportunities for AAC modeling, promoting both social and communication skills. Consider a cooking class where the teacher is using an adapted recipe from The Accessible Chef to make Enchurritos where the core words to be modeled are “in,” “out,” “on,” and “off”:

- **Identify Core Words:** in, out, on, off
- **Describe the Activity Context:** Cooking the recipe Enchurritos from the Accessible Chef
- **Explicit Modeling Approach:** Using an aided language stimulation (ALS) model

Incorporating modeling strategies into naturalistic activities, such as family leisure, can lead to improved participation and expressive language outcomes (Senner et al., 2019) and foster creativity and engagement (Sennott et al., 2016). However, after the prompt is produced, reviewing your product is essential.

Human in the Loop: Assessing and Updating AI-Generated Scripts

While AI-generated scripts are invaluable, human expertise is crucial in assessing and refining them. The final step in our prompt recipe is “Analyze and Adapt.” In this step, professionals should be sure to:

1. **Align Scripts with Individual Goals:** Ensure the modeled words and activities align with the AAC user’s specific communication objectives.
2. **Monitor Effectiveness:** Use data collection templates to track engagement and vocabulary usage.
3. **Adjust Based on Feedback:** Modify scripts based on observed successes and challenges during implementation.

The systematic review by Hopcan et al. (2023) highlights the importance of teacher involvement in implementing AI tools effectively in special education. Personalized and adaptive approaches, as supported by AI, enhance learning outcomes and engagement.

The Final Course

Integrating AI tools into AAC modeling opens new avenues for customization and efficiency. By combining AI-driven script development with specific modeling approaches, like aided language stimulation (ALS), educators and clinicians can create meaningful communication opportunities during recreational and leisure activities. However, the role of the human in the loop remains indispensable. Professionals must ensure scripts are personalized, effective, and aligned with the unique needs of AAC users. As technology evolves, so too does the potential to empower individuals with AAC, fostering their communication, creativity, and social inclusion.

Lauren Tucker, EdD, is Associate Professor of Special Education, and Kristy Hynes, PhD, BCBA-D, is Assistant Professor of Special Education at Southern Connecticut State University. They can be reached by email at tuckerL7@southernct.edu and hynesk3@southernct.edu.

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and developing communication using a variety of methods, including the use of Augmentative and Alternative Communication Devices (AAC), Picture Exchange Communication System (PECS), Voice Output Communication Aids (VOCA), communication boards, spoken language, gestures or sign language

Typically, only one mode is utilized to teach the learner to communicate, which can be limiting. Some learners may struggle with the complexities of PECS, while others may want to use an AAC device for more than communicating. Multimodal communication can be used to teach the learner the same language in a variety of settings and with a variety of people. A learner can use PECS at home to travel to their caregivers but may find it better to use gestures at school. Another learner may have visual scanning deficiencies but may be able to imitate sign language or spoken language. With a variety of language tools, there is a higher rate of the learner reaching communication success.

Along with multimodal communication comes the acceptance of all attempts at communication, including approximations. If the learner travels to an individual and puts the PECS icon on the table instead of the listener’s hands, the learner is still communicating their need. If the learner states “cookie” instead of “I want cookie,” the listener can still determine what the learner is requesting.

However, what happens if a learner engages in maladaptive behaviors as communication, such as pushing a plate of food on the floor instead of stating “all done”? The behavior can be shaped! The clinician can accept the initial push and model verbally, stating “all done” or using sign language while removing the plate. The next time the learner goes to push the plate, the clinician can redirect the learner to use the modeled form of language until the learner responds independently.

By accepting all modes and approximations of communication, the learner’s frustration and stress can be reduced. This, in turn, can lead to reductions in behaviors, which are often caused by the inability to communicate wants and needs. One major end goal for clinicians is for learners to become happier and more independent. This all begins with teaching learners to communicate in a way that works best for them.

For more information about First Children Services, visit firstchildrenservices.com.

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Health Care Transition (HCT) services are vital for supporting autistic youth as they move from pediatric to adult health care. These services help maintain health insurance, promote independent health management, and improve outcomes like health care knowledge, vocational success, and overall quality of life.

While current federal law mandates that a transition plan be generated by the time the child is 16 years of age, typically earlier as determined by the Individualized Education Plan (IEP) team, there is no formal structure that exists in healthcare to do this. Research indicates that only 21% of autistic youth accessed transitional healthcare services during the transition to adulthood, and just 14% had discussions with their pediatrician about transferring care to an adult provider (Cheak-Zamora et al., 2013). This underutilization highlights a significant lack of access to transitional healthcare services for this population. Healthcare providers need to play a more proactive role in facilitating these transitions.

Primary care and child mental health providers should routinely address the challenges of transitioning into adulthood with autistic patients, including the process of transferring care to adult providers. Families should provide support and advocacy to ensure continuity of care, enabling autistic individuals to navigate these changes with appropriate support (Bennett et al., 2018).

Understanding Co-occurring Psychiatric Conditions in ASD

Autistic individuals experience psychiatric conditions at a significantly higher rate than individuals without ASD. Research has shown that more than 50% of autistic adults will have a reported psychiatric condition throughout their lifetime, which may include anxiety, depression, bipolar disorder, ADHD, and obsessive-compulsive disorder (Croen et al., 2015). As the challenging transition from youth to adulthood begins, these conditions often become exacerbated, hindering the development of independence.

Anxiety and depression are already highly prevalent among transition-aged youths, with the demands of adulthood often outpacing their coping mechanisms, leading to manifestations of behavioral and emotional difficulties (Schraeder & Reid, 2017; Backman et al., 2023). Transition-aged autistic youths are especially susceptible, have reported increased levels of stress during this time, and are found to be most susceptible to anxiety and depression during this period of life (Backman et al., 2023).

Suicidality is a particularly concerning issue among youth and autistic young adults, yet it is often overlooked. Research indicates that autistic individuals face an increased risk of suicidal ideation, largely linked to higher rates of co-occurring psychiatric conditions, particularly depression (O'Halloran et al., 2022).

Substance use has been historically understudied in autistic individuals. Recent literature has identified a higher prevalence of substance use disorders in autistic individuals, suggesting that substance use acts as a maladaptive coping mechanism for social impairments or "self-medication" for unmanaged psychiatric symptoms (Clarke et al., 2016; Butwicka et al., 2017).

Medical providers should provide frequent screening and professional mental health care during the transition to adulthood. Early identification of psychiatric concerns and timely interventions can ensure that autistic youth receive appropriate support through this challenging period.

Abraham Abdulrazzak, DO

His parents started to recognize red flags, changes in Josh's baseline behaviors, and his difficulty keeping up with his responsibilities. Out of concern for his well-being, his parents helped connect Josh with a mental health clinic. At the clinic, an interdisciplinary team consisting of physicians, psychologists, and social workers supported his transition. Together, with Josh's input, they developed a weekly schedule tailored to his needs, including dedicated times for studying, breaks, and self-care activities. A campus mentor provided guidance in navigating social and academic expectations, offering him a sense of stability and encouragement. Regular counseling sessions helped Josh develop strategic coping mechanisms to manage stress and anxiety. Additionally, ongoing support from a psychiatrist ensured his mental health was closely monitored, allowing adjustments to his care plan, including medications when needed.

Interventions for Mental Health Challenges in Transition-Aged Autistic Youth

Since the transition to adulthood is a particularly vulnerable time for autistic youth, regular mental health screening during this time can be critical to assess for depression, anxiety, suicidal ideation, substance use, or other co-occurring mental health issues. While some autistic individuals might have difficulty communicating or articulating their experiences or emotions, family members or caregivers may provide valuable context in understanding an individual's mental health needs.

Effective mental health care for transition-aged autistic youth begins with personalized, tailored support that addresses their specific needs and challenges. Early planning is essential. Families, schools, and other care providers need to work together and act as advocates to identify and secure experienced mental health providers.

When mental health concerns are identified, the most effective interventions integrate behavioral therapy, medication when appropriate, structured routines, and community-based support. These approaches address both mental health needs and the broader challenges of transitioning to adulthood.

Research into mental health inventions remains an ongoing effort, but current studies have suggested the benefit of SSRIs (i.e., escitalopram and sertraline, among others) to treat anxiety and depression in autistic adults. Therapeutic techniques have also been shown to be moderately effective at reducing anxiety and depression, specifically cognitive-behavioral therapy (CBT) and mindfulness-based stress reduction. Studies have shown that these approaches can be adapted to meet the individual need for autistic people (Sung et al., 2017).

Samuel Jackson, MD

While more research and clinical advancements are needed to improve strategies for preventing suicidality and addressing substance use, existing interventions offer meaningful improvements in quality of life. Notably, social skills intervention groups have shown a modest impact in reducing suicidality, highlighting their potential as part of a comprehensive approach (Schiltz et al., 2018). With the right support, transition-aged autistic youth can navigate this critical life stage successfully, enabling the youth to thrive as they enter adulthood.

Fundamentally, developing personalized care that incorporates a deep understanding of the specific challenges faced by transition-aged autistic youths becomes essential to improve mental health outcomes during this critical period. Considering the challenges of finding mental health providers, particularly those experienced with ASD, proactive planning and advocacy are essential to secure these resources and support systems early.

After connecting to care and receiving the right support, Josh began to thrive in college. He grew more confident in managing his coursework and balancing daily responsibilities, which led to significant improvements in his grades. Josh also became more socially engaged; he joined study groups and participated in social and interest-based campus events.

A long-time fan of animation, Josh was finally able to explore his passion without feeling overwhelmed. This newfound balance allowed him to connect with peers who shared similar interests, forming meaningful friendships. With the help of a structured routine, regular counseling sessions, and mentorship, Josh gained a stronger sense of control over his college experience and started to truly enjoy this new chapter of his life.

Key Takeaways

Raising awareness and expanding access to transitional healthcare services for autistic youth is a crucial step toward improving their mental health outcomes.

Primary care and child mental health providers should universally discuss the stressors of transitioning into adulthood with their autistic patients, including transferring care to adult providers.

Transition-age autistic youth should be universally screened for mental health conditions like anxiety and depression.

While more studies are needed to determine ideal treatments for this group, structured, personalized care plans, including psychotherapy, medications, financial, and social support help autistic people and co-occurring mental health conditions.

With adequate support, autistic youth can thrive as they transition to college or the workforce, gaining confidence, achieving their goals, and building a solid foundation for a successful adulthood.

Abraham Abdulrazzak, DO, is a Resident Psychiatrist at SUNY Downstate Health Sciences University and a Fellow with the Brooklyn LEND (Leadership Education in Neurodevelopmental Disabilities) program at SUNY Downstate. Samuel Jackson, MD, serves as the Clinical Director of Psychiatry at Erie Family Health and Co-Director of Public Psychiatry Education at SUNY Downstate Health Sciences University. For more information, email abraham.abdulrazzak@downstate.edu or samuel.wesley.jackson@gmail.com.

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Communication from page 1

Assessment is the fundamental first step in understanding the individual’s communication abilities and needs. A thorough AAC assessment serves as a guide for choosing the best system; however, there is currently no prescriptive assessment available that can specifically define the best match between an AAC system and the individual user. According to Ganz (2014), “Given the variability in both the type of AAC interventions as well as the heterogeneity of skills and characteristics among individuals with ASD, it is difficult to establish that a particular type of AAC system will be effective for a given individual.” With this understanding, systems are proposed based on a feature-matching analysis in which the individual’s skills and needs are matched to the capabilities of the proposed systems. The SETT (Student Environments Tasks Tools) Framework is a model frequently used to assist teams in this decision-making process (SETT- Joy Zabala Site, n.d.). Trials are then conducted to gather objective data about the individual’s response to the proposed systems, and the most effective system is ultimately selected for the individual. The assessment process should not stop here, however. A system that was deemed to be a good fit for an individual during the initial evaluation process may not continue to be optimal if the individual progresses rapidly and his or her communication needs expand. Conversely, some individuals continue to use a selected system for long periods of time in the absence of real progress with no adaptions to instruction. Attention to ongoing assessment and decision-making is needed to ensure that an individual’s communication system is as effective as possible. The following parameters are essential for our teams to evaluate when determining if an individual with no or limited verbal abilities is using his or her communication system effectively. We have focused our examples on alternative communication systems. However, these parameters can be applied to individuals who use spoken language to varying degrees as well.

- **Independence** - The individual is able to use his or her communication system on his or her own, needing prompting or assistance only occasionally. An independent communicator can access his or her device, navigate to desired icons, and construct and deliver a message from start to finish without assistance. If the communication partner must regularly gesture to the device, gesture to icons, or model responses in order for the individual to deliver the message, the individual is demonstrating difficulties communicating independently.

Maryanne Robertson, MS, CCC-SLP

Dr. Todd Harris, PhD

- **Initiation** - The individual is typically able to spontaneously construct and deliver a message without prompting, questions, or other assistance. For example, an individual with solid initiation skills will gain the attention of a communication partner and activate a ‘help’ button on his or her device upon encountering difficulty. If the struggling individual activates the ‘help’ button only after a communication partner asks, “What do you need?” this individual is showing a deficit in initiation.

- **Accuracy** - the individual demonstrates an understanding of the communication system’s picture symbols or manual signs. An individual demonstrating accurate communication uses signs or symbols appropriate to the situation, or that match the desired item he or she is motivated to access. Individuals who ‘scroll’ through signs or immediately activate a certain icon on their devices, regardless of the context, may be having difficulty understanding the meaning of the symbols in their current system.

- **Intelligibility** - the individual is able to deliver a message that can be easily understood by a wide range of others across multiple settings. For example, a vocabulary of highly personalized manual signs might be understood only by familiar communication partners, not by the larger community. A voice output system might require multiple language capabilities for bilingual families.

- **Specificity** - the individual is able to deliver a message with necessary detail. That is, the individual can use the system to construct a request that communicates his or her specific preferences, such as requesting ‘chocolate milk’ or ‘apple juice’ rather than (or in addition to) a general request for ‘drink.’

- **Range** - the individual is able to use the system for multiple communicative purposes. Diverse communicative range can include the ability to request desired items or activities, indicate needs such as ‘bathroom ‘or ‘help,’ share information of personal importance, accept or reject items, and so on.

- **Efficiency** - from the moment an individual begins to construct a message, it takes no longer than 5-6 seconds to deliver.

- **Generalized** - the individual is able to use his or her communication system consistently across different settings, including home, school, work, and community, with different communication partners and in different situations.

In many cases, a combination of modalities may comprise an individual’s communication system. A single individual may verbalize ‘yes’ and ‘no,’ wave in response to greetings, and use a voice output system to make specific requests. The parameters described above can be used to guide teams in evaluating an individual’s strengths and needs with regard to the effectiveness of his or her current communication system. If data indicates significant deficits in any of the above parameters, the team should discuss adaptations to current instruction or possibly consider another approach to intervention.

It is important to remember that an AAC user’s communication needs can and will change over time as he or she develops new skills and encounters new challenges. Many individuals begin by using a less complex system as they develop foundational communication skills such as initiation, social approach, and understanding of picture symbols. Later, they may advance to more complex systems if the components of that system better meet their current communication needs. Some individuals may require the addition of AAC supports for a period of time in new or unfamiliar situations, and some individuals may gradually rely less on an AAC system if spoken language begins to emerge and becomes consistent. Whatever an autistic individual’s communication system may include, attention to ongoing assessment is critical to ensuring the most effective communication possible.

Maryanne Robertson, MS, CCC-SLP, is Private Practitioner and Consultant at Speech Paths, LLC. Dr. Todd Harris, PhD, is Executive Director of Autism Services at Devereux Advanced Behavioral Health. Questions or requests related to this article can be sent to Maryanne Robertson at maryanne@speechpaths.org.

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professionals were star-struck into wanting to go to their parties or be allowed into the “exciting world” of genetic autism research, on-campus Autism Speaks chapters stayed put.

And for those who *are* fully aware of this history, you may, depending on which side you’re on, either cheer me on or scoff. Scoffers will think: “*Michael John, again with the Autism Speaks criticisms...blah blah blah.*” Admittedly, Autism Speaks is a *really* easy target for people on my ideological side of the fence.

But if they’re such an easy target, why are they still allowed to exist (with or without “re-branding”)?

This article is *not* written to critique Autism Speaks. It’s written to critique higher education professionals *who are ok that Autism Speaks exists*.

There’s a blatant parallel that if any of us joined an organization that stated that (let’s say...) people of African descent were incapable of the same potential as whites...I think it would be justified that we’d lose every black friend we have. And if an organization represented that same view, then that organization wouldn’t just have been eliminated. They’d have been sued for hate crimes, and their employees and grant recipients were blacklisted from ever working in the field again. But the world can’t make that mental connection that autism might deserve the same human value. Why?

***

Think of the autistic college student who arrives on campus. Already, they, like their neurotypical peers, are impacted by partisan politics, COVID, remote learning, George Floyd, and maybe even “woke pressure.” You’re more challenged than most—You’re autistic, after all. But you’re also an autistic who was capable enough to become a college student, so you’re not likely to be ignorant of the ugly history that defines the history of autism in this country—the fights over “cure,” vaccines, or the lie and hurtful rhetoric of genetic autism research. Well, maybe your school doesn’t have an Autism Speaks chapter. But even if they did, you might be so sick of the politics and ignore it, uninterested because you just want a job and a boyfriend, so lonely that you are susceptible to the niceness of the pretty girl who belongs to that Autism Speaks chapter...but you didn’t escape the message. And probably you’re too socially anxious to mention it to people because, like many autistics, you’re terrified of confrontation, or you don’t want to lose the relationship because of the aforementioned loneliness. All of this will contribute to low self-esteem.

That’s the blatant example. Thankfully, university Autism Speaks chapters are now almost extinct. Less blatant but still very harmful and numerous are collegiate “social skills” programs, deficit-based words and attitudes (if not outright ableist thinking), and well-meaning but colonialist individuals in charge of our care. Colleges and universities still believe that “*Your way of doing things is bad. Our way of doing this is ‘appropriate.’*” This requires overall campus culture change, not just a tweak in personnel.

***

Oh, these are only from the first four pages of my Google search...

www.michaeljohncarley.com

Sometimes, it’s not even a neurodiversity program that contributes to low self-esteem. Is that autism *research program* on your campus? There was once a time when universities hysterically felt they weren’t complete without an autism research department. (I’m going to be very flippant here...) So they assembled clinical nobodies, promoted them as “leaders in the field” (but didn’t pay them that way), and most of these departments were dissembled or morphed into something else very quickly because the people they hired weren’t talented enough to get grants.

Even the newest Neurodiversity programs are often shamanist obligations. Near where I live, one respected New England college has posted an open position for the Executive Director of a new such center. However, the search firm’s position profile demands unreasonable excellence compared to the salary offered and, therefore, gives false optics toward whoever will be the inevitably disappointing hire. This job posting, like most, is also written in what I like to call “corporatespeak,” which, to a literal-minded person (such as many autistics like myself), is a language best described as “how to lie and get away with it.” Read for yourself...

“This center...is poised to become a national leader in neurodiversity, driving XXX College’s mission to create an inclusive, supportive, and dynamic learning environment for all students. XXX College has a long-standing history and reputation as a leader in supporting neurodivergent learners...XXX’s strong reputation for supporting students with learning differences...the College’s position as a leader in supporting neurodivergent learners.”

It’s a school with 2,000 students that has NO such “reputation” or “long-standing history in the field.” It doesn’t even mention a single disability on its DEI Initiatives page. I’m sure there are good, smart people working there. But leaders? Barf. This is just one microcosm of universities having fallen into a dependency on imagery and not transparency, which often renders the imagery fraudulent. Universities, often the powerful ones, sometimes choose to treat themselves as corporations, wherein executives call themselves “thought leaders” on their LinkedIn profiles (the Ivies, for instance, have notoriously humdrum neurodiversity programs and disability culture).

There are other examples of the unconscious harm that colleges enact on their spectrum students’ self-esteem. Drexel University publicly embraced the Medical Model of Disability; Rutger University’s autism support program exists in a multi-million dollar ABA program (ABA for college students???)...However, no one says anything despite the rarely noticed yet inarguable damage these programs subliminally do to their campus cultures. These situations are not the discussion topics on College Autism Network chats or AHEAD postings. And herein, we’re running away from our obligations to our communities.

As I’ve written about before, colleges have subliminal obstacles to inclusion for all their disabled students because of the way their disability accommodations departments are designed. I work for one, too. I get it. Our very system is there to treat the disabled student as a problem to be solved rather than a unique perspective to be shared and added to the broadly diverse university culture. Why should we need to obtain permission (i.e., accommodations) for what we need to learn? Extra time on tests? The ability to record lectures? Should we apply for accommodations allowing us to eat or go to the bathroom, too?

As many ASN readers saw play out in these pages, there was a 2022 article on college autism programs in the Chronicle of Higher Education that offended every autistic higher education pro in my circles, not to mention all of my students who read it. I wrote a response article using my column herein, stating that more autistics needed to be running higher education autism programs. No-brainer, right? Well, while it galvanized most, it received surprising resentment from powerful folks in the college autism program community. One individual with tremendous influence—well known to all—wrote me a stunningly dismissive email, talking down to me for criticizing Autism Speaks-influenced higher education professionals. “How dare I?” was the message because of “all the good work those people had done.”

In the context of “explanation and not justification,” I at least see that I am asking this person to have painful conversations with all their colonialist friends and that this might be a big ask of me to demand of this person. People have real relationships with these “villains” I critique. But what this person does not have, yet I do, is faith that their relationship will survive a painful conversation. I am still friends with Autism Speaks’ first-ever President, Mark Roithmayr. Why? We didn’t lie to each other, we had painful conversations, and we survived.

***

But even if we stopped the bigotry overnight, we cannot and will not move the needle on inclusion without the painful conversations about acknowledging past harm. Yet, no one practices restorative justice. We sweep the past transgressions under the rug, “don’t apologize,” “keep it ‘nice’” That’s the policy everywhere (and brudder, have I written a million times on the difference between “nice” and “good,” especially when “nice” is utilized to hide the fact that the person is anything but “good”). If people will not have these painful conversations yet are as nice as they come, then not only will they never further their cause, but they are categorically part of the problem and must be recognized as so.

Because what it comes down to is indeed that many of your categorical beliefs—Yes, even if you work in a college neurodiversity program—are that our lives are worth less. Not only do you not value our opinions of what you say about us...Do you all value us as human beings? Because when we see you hanging out and being friends with people who clearly don’t see us that way, you’re no ally. We may not confront you about this because, again, we’re terrified of confrontation, but we see it.

***

I’m lucky. I came from an upbringing (however risky) that taught me that no job is worth your soul. Later, I had higher education experiences that filled me with confidence and a work life that demanded a sense of ethics and a knowledge of restorative justice. These aren’t just vague, whimsical ideas about being nice. They’re core aspects of life that so few in the autism world seem to care about. They’re complicated and, like real diversity, they’re hard.

But I know something most of you don’t: When you do the right, humanist thing, you may get punished a little, and maybe you even lose a job. But you get rewarded much more (and you really can get another job). I know that what I say may seem like I am trying to sell you on a color no one’s ever seen. You’ll have to trust big time. My negative consequences for this presentation at Northeastern? A nervous boss (if she saw it), and people I don’t like, not liking me.

My positive consequences included an outpouring of respect and yet another post to add to my resume. In a new role (that replaces none of my others), I am now teaching a neurodiversity class at Northeastern’s new Neurodiversity Initiative—yes, the same school that hosted my lecture.

Do the right thing. Please?

***

As a youngster who’d lost his father in Vietnam, I was fascinated by the South African Truth Commissions. Don’t know about them? Look them up. After the fall of Apartheid, if you:

- had once been a (white) policeman, and you
- knew where the hidden bodies of blacks were, blacks that you or your colleagues had killed, and you
- testified in a public forum about where they were so that the families could achieve some closure via retrieval of the remains followed by proper burial and mourning

Then, you received full immunity from

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prosecution. No jail time. Lie about any detail under oath, and they throw the book at you, but...try to sit with that. What power! And also sit with how impossible it might feel to accomplish this here in the US.

But how hard would the following feel to say to colleagues who, let's say, use deficit-based language in their roles as college neurodiversity program professionals?

"I appreciate how polite you're trying to keep this conversation. But because I care about you, I can't let you ignore that somewhere inside them, our students are really hurt by your deficit-based words and thinking. It's not ok. I know you, and you're better than this."

How hard would it be for a university President to say the following?

"XXX University extends its heartfelt regrets and sadness to our autism community for once having hosted an active chapter of Autism Speaks. We want all of our community to know how aware we are of the damage that we might have done to the self-esteem—however subliminal—of our community's autistic administrators, staff, faculty, students, and their allies. We apologize with everything we have and will work with you all to achieve whatever restorative healing is necessary for full reconciliation."

And how hard would the following be for Autism Speaks?...

"We are so sorry. In our messaging and in our work, we did so much harm to the emotional health of families that trusted us, harm to the iconography of the very word "autism," and especially harm to individuals with autism. We honestly didn't know any better. In the early 2000s, when our founders initially consulted researchers, scientists promised us that a cure would be possible if we secured them with tens of millions of dollars. But 8-10 years later, when the promise of researchers was unraveling, and that maybe even we had been lied to...we arrogantly responded with denial. We made the decision not to apologize, we continued to spread lies about failed marriages, the potential of genetic research, the value of autistic lives... and we pretended not to hear their protesting voices, even though we knew they were right. Our very name is triggering trauma for so many, and therefore, we are finally folding. We will donate our resources and all remaining assets to humanist autism organizations and hope that somewhere in time, the world can forgive us."

Michael John Carley is the Facilitator of the "Connections" program at New York University for their worldwide autistic students, and he also has a private, Peer Mentoring practice. In the past, he was the Founder of GRASP, a school consultant, and the author of "Asperger's From the Inside-Out" (Penguin/Perigee 2008), "Unemployed on the Autism Spectrum," (Jessica Kingsley Publishers 2016), "The Book of Happy, Positive, and Confident Sex for Adults on the Autism Spectrum...and Beyond!," (Neurodiversity Press 2021, where he recently became the Editor-in-Chief), and dozens of published articles. His many other current posts include being the Neurodiversity and Leadership Advisor for the League School for Autism, and he is Core Faculty for both Northeastern University's School of Engineering, and Stony Brook University's LEND program. For more information on Michael John or to subscribe to his free newsletter, you can go to michaeljohncarley.com.

Michael John Carley

Neurodiverse from page 21

higher rates compared with the general population across all age ranges, beginning from age 10 years." This data suggests that individuals with both autism and gender differences are not just feeling "othered" but that these experiences can have an impact on their mental health, well-being, and life expectancy.

For clients, considering how one identifies gender identity and sexual interest allows for a deeper understanding of the self and can bring up helpful conversation topics for therapeutic work. As an example, if a neurodiverse couple is working on splitting up daily household tasks but have markedly different gender role expectations of housework, their perspectives will add another layer of complexity to this challenge. Many neurodiverse couples therapists will focus on the executive functioning of both partners and how to organize their schedules instead of on more deeply rooted thoughts and ideas about gender and gender roles that could impact one or both of their viewpoints.

Once a trans individual's internal identity is explored, the next step is discussing how they want to express or explore their gender. For some people, their gender can all come out at once. For others, it is a longer-term adjustment or self-discovery of who they are and how they want to live their lives. This may look like someone coming out as non-binary or gender non-confirming first and then later expressing a desire for more of a gendered transition. Others know exactly how they feel about their gender and want to move forward with living more authentically as soon as they make the disclosure. The concept of "transitioning" has a different meaning for each individual. For some people, it may mean changing the way they dress or the pronouns they use. For others, it could mean taking hormones or having gender-affirming surgical procedures. There is no "right" way to transition, and it is a deeply personal choice for each individual.

Understanding and Reframing Gender in the Relationship

Many people who are gender diverse may have felt different from their peers earlier in life before expressing their thoughts and feelings to family or a significant other. This can translate into an individual spending a period of time personally and/or therapeutically exploring their gender identity before the information is given to a partner. A spouse could receive information about gender diversity at the point that their partner is ready to transition or move forward with external gender changes. While cisgender partners may display a range of reactions, it often takes some amount of their own processing time to truly understand what this means for their partner, themselves, and the relationship. Many partners express feeling surprised or caught off guard by revelations of gender and need time to shift their paradigm. In addition to couples therapy, I typically encourage each partner to access additional support, individual therapy, groups, etc., to continue their own therapeutic work on understanding and incorporating this information.

Leslie A. Sickels, LCSW

Gender and Sexuality

When an individual comes out as gender diverse, they are still the same person. However, a fundamental part of their identity needs to be reframed and fully understood. Their public identity in the world may have shifted. What does this mean for their partner? Did they previously identify as straight and now identify as gay? Did their sexual orientation not change at all? Are they still attracted to their specific partner but not to others of that gender? The act of considering sexuality and identity within a relationship can be challenging but can also be gender-affirming to the trans individual, as their partner is seeing that their gender is different from what they originally understood it to be

When a partner's gender changes, their cisgender spouse often needs to consider their own internal sense of sexuality and attraction. Attraction comes in many different forms, from intellectual or emotional to sexual. For some individuals, sexuality can be on a spectrum. They can experience attraction to a wider range of attributes than they previously thought or knew about themselves. For others, attraction is limited and inflexible. The experience of internal feelings of connection and attraction is deeply personal, and only the individual in that experience can say exactly how they feel toward another person. Sometimes, partners are surprised by their flexibility in sexuality and feelings of desire for their partner post-transition, while others struggle to experience the same level of connection they previously had for their spouse.

If a neurotypical, cisgender woman is married to an autistic man who comes out as a woman, the neurotypical woman is no longer in a heteronormative presenting relationship. This does not mean her internal sense of self or sexuality changes, but the way she presents herself to the world will be as a woman married to a woman. Others may perceive her sexuality to be somewhere on the LGBTQ spectrum when that may or may not be reflective of her sexuality.

Conclusion

Gender and sexuality are complex constructs. Every person in the world has both a gender and a sexuality. Sometimes, it is very clear from early on, and for others, it shifts and changes throughout life. As therapists, it is our duty to address all parts of our clients, including their gendered and sexual identities. This work can be especially powerful and supportive for neurodivergent couples who are facing gender transitions within their long-term relationships. By exploring both partners internal senses of self, we allow couples to more fully understand one another and the emerging dynamics in their relationship. Gender-affirming neurodiverse couples therapy allows couples to work toward incorporating changes in gender and sexuality within the relationship framework or help couples have conversations about ending or shifting the dynamics in their partnership.

Leslie Sickels, LCSW works with neurodiverse couples and individuals on the autism spectrum in New York. For more information about Leslie's therapeutic work and neurodiverse couples therapy visit LeslieSickelsLCSW.com.

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***Neurominorities** from page 20*

mind and a "normal" mind opposes the neurodiversity paradigm, which sees all minds as natural and equal. Neurodiversity is, simply, the variety of all human minds; it's a deeper level of diversity that's been ignored for too long.

Under the neurodiversity paradigm, innate neurodivergences (non-neurotypical neurotypes) are not pathologies (or medical conditions) but are the natural way people see and experience the world. The neurodiversity paradigm doesn't determine which minds are valuable and which are not. Everyone has neurology, which determines your thinking and behavior, and there is no normal or abnormal neurology any more than there are normal or abnormal skin colors or sexual orientations. Or anything. The concept of "normal," like the concept of "race," will never exist and only serves to perpetuate harmful paradigms like racial/ist ideology (Mason, 2024) and neurodiversity lite that endanger underrepresented humans.

Neurodiversity is often incorrectly framed as an umbrella term for neurodivergences. However, the word neurodiversity is not synonymous with neurodivergence. Neurodiversity: examine the word, a shortened form of "neurological diversity." "Neuro" means "nerve" (the nervous system) and is short for "neurology," which determines your thinking and behavior. "Diversity" means "variety." The word "diverse" doesn't mean "minority" – it means "various." A single person cannot be diverse. So, a single person cannot be neurodiverse. "Diversity is a trait possessed by a group, not an individual," writes Walker. "And to talk of individuals as neurodiverse is to situate them as 'other' to the norm" (Walker, 2020).

Human diversity involves all humans, just as biodiversity involves all living organisms on Earth. Neurodiversity is part of biodiversity, and, like biodiversity, neurodiversity is not a social construct but a natural phenomenon. Neurodiversity is all human minds. Everyone thinks differently.

Listen closely to messages that use "neurodiverse" to describe individual people and "neurodiversities" to describe neurodivergences, and you'll hear the pathology paradigm, cloaked in neurodiversity lite: using the language of the neurodiversity paradigm and movement without understanding the true meanings of those terms. The term "neurodiverse" is often used to erase the terms "neurodivergent" and "neurominority," logical constructs created by neurominorities to highlight the injustice they face as a result of neuronormativity: the belief that neurotypicality is the only proper way to think and behave – and the behaviors and practices that go along with this thinking.

Bernard Grant

By saying that neurodiversity is only about neurodivergences (so-called "neurodiversities") neurodiversity lite (performative neurodiversity) excludes the neuromajority from the conversation, placing neurominorities in a separate box, segregating them, not unlike some "neurodiversity" hiring programs (GoingConcern, 2021). Neurodiversity lite has spawned an industry that looks like a pillar of the Autism Industrial Complex (AIC) (Broderick, 2021) – advanced by people who conflate neurodiversity with neurodivergence, (mis) using Autistic liberatory language to conceal harmful, neuronormative "therapies" like applied behavioral analysis (ABA). Such "therapies" attempt to condition the neurodivergence out of people, mostly young Autistic people who have little to no control over their lives. These compliance programs teach neurodivergent children to hate their core selves and to prize neurotypicality, often resulting in trauma. In identifying those who are responsible for spreading the pathology paradigm, Walker does not exclude Autistics:

> The psychiatric establishment that classifies Autism as a "disorder"; the "Autism charity" that calls Autism a "global health crisis"; Autism researchers who keep coming up with new theories of "causation"; […] anyone who speaks of Autism using medicalized language like "symptom," "treatment," or "epidemic"; the mother who thinks that the best way to help her Autistic child is to subject him to Behaviorist "interventions" intended to train him to act like a "normal" child; the "inspiring" Autistic celebrity who advises other Autistics that the secret to success is to try harder to conform to the social demands of non-Autistics […] (pp. 18-19)

Autists developed the neurodiversity movement and the neurodiversity paradigm, making neurodiversity lite a form of cultural appropriation, 21st-century colonialism. While your misuse of the term "neurodiverse" may be unintentional, as my use of the word "neurodiversities" once was, back when I didn't know any better, those who intentionally spread neurodiversity lite use the word "neurodiversity" as a pathologizing buzzword to erase the neurodiversity paradigm and profit from the appropriation of a necessary civil rights movement.

When used accurately, the word "neurodiverse" refers to a place that contains at least two people of different neurotypes. A household of neurotypical and Autistic family members would be a neurodiverse household, for example, whereas a household of purely neurotypical or purely Autistic people is not a neurodiverse household, as there is no neurological diversity in that home. These homes are neurologically homogenous (though neurominorities tend to multiply neurodivergent, so a household of Autists would likely be a neurodiverse household).

Despite what you may have heard, the neurodiversity movement is not about erasing disability. It's about refuting neuronormativity and the pathology paradigm; treating human minds the same way you'd treat any other form of human diversity, such as gender identity, religion, and skin color variances; focusing on the strengths of neurominorities while not disregarding neurodivergent disablement; refusing to see innate neurodivergences as pathological; helping to break down disabling barriers, including attitudinal barriers; and including the neuromajority (neurotypicals/neurotypicality) when talking about neurodiversity.

Promoting the neurodiversity paradigm sounds like talking about autism and other innate neurodivergences as neurotypes and cultural identities, like how you'd speak of queer identities. Promoting the neurodiversity paradigm also sounds like recognizing and accepting disability and neurodivergent cultures, including neurodivergences that are acquired rather than innate (traumatic brain injuries, post-traumatic stress), and emphasizing neurodivergent strengths without excluding the reality of our disabling barriers and need for support.

Keep in mind that the social model is intertwined with the neurodiversity paradigm, while the medical model is intertwined with the pathology paradigm. The neurodiversity paradigm exists to refute the pathology paradigm, which creates and maintains a hierarchy that dehumanizes neurominorities by prioritizing neurotypicality.

Whether knowingly or unknowingly, when you refer to neurominorities as "neurodiverse," and when you refer to our neurotypes as "disorders," you situate neurodivergent people as abnormal, pathological in some way, seen through a medicalized lens. Neurodiversity isn't mainstream; its appropriative paradigm is mainstream. Despite the reality that neurodiversity includes all human minds, society is still unsafe for neurominorities, and the neurodiversity movement is needed to bring all human minds together to dismantle neuronormativity and the pathology paradigm so that neurominorities can live (better lives).

Bernard Grant is a writer. Learn more at their website BernardGrant.com.

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***China** from page 22*

encouraged to write their reflections after the lecture, and this provided valuable insights into what they learned. "Psychology is a subject that help to understand and try to improve humans' mentality. What psychologists need to seriously solve is there are a lot of people who are suffering from discrimination because of different mental world they have. Psychologists are the pioneers in letting this world become more open and inclusive. Those (not only whose having autism spectrum) patients need our help in-depth, though they may have difficulties speaking out and showing the world that they matter. I would be proud to become a psychologist to help those in need," said Shan.

"This lecture contributes to my understanding of Psychology in ways of providing a personal experience in real life, which I think is an essential approach to learning psychology. Because psychology has a lot to do with real life, not only being limited to a single diagnosis but also covering many other mental disorders, such as anxiety and depression. In other words, we have multiple methods to learn psychology. Not only can we use DSM-5, a reliable reference to diagnose mental disorders by corresponding symptoms, but we also can engage with case studies to learn their own feelings as we did with Jack," said Yinyao.

"Through the lecture, I learned the importance of positive reinforcement in Applied Behavior Analysis for intervention therapy for individuals with Asperger's Syndrome and Autism. In ABA, positive reinforcement encourages the target behavior by providing a reward or positive feedback. In short, ABA is an effective intervention to help individuals with Asperger's Syndrome and Autism Spectrum Disorders improve adaptive behaviors through reinforcement and behavior modification techniques," said Yihan.

Students also provided their take-away messages that they would share with others who may have never met someone in their community who is on the autism spectrum.

"There are lots of people having Asperger's syndrome, but they are not diagnosed. Try to be good with people around you. Do not bully anyone," said Zhiyi.

*see **China** on page 42*

Bullying from page 14

on them once they noticed that I remained unfazed after they went in for the kill. That Spring back in 1986, my own inner strength manifested itself in more ways than one:

- The strength to persevere in the face of adversity.
- The strength to finish what I started, no matter who or what tried to get in my way.
- The strength to keep those who were trying to control me at bay.
- The strength that comes with the wisdom to see bullies for who they truly are.

The kind of strength which disabled people everywhere possess which stems from having no choice but to navigate a world that was not built with us in mind. A world which we often find hostile, which tries to exert control over us by exploiting our vulnerability, the kind of vulnerability that comes with being different than most. Indeed, I did stand apart at this academy, behaviorally speaking, and clearly, I paid an unjust price for that. And yet, I was able to push through.

I would have fared better that Spring had these bullies shown less ableism and more acceptance. Regrettably, true acceptance on a societal scale and, more importantly, a sense of belonging remain elusive, largely because of stigma, as evidenced by my experience and those of countless other disabled individuals. Nonetheless, we find the strength to forge ahead as best we can.

Sam Farmer is an information technology consultant, neurodiversity community self-advocate, writer, author and public speaker. Identified later in life as autistic, he writes articles, records podcasts, and presents at libraries, conferences and for corporations and autism community organizations, sharing stories of lived experiences and his opinions on a variety of topics of relevance to the neurodiversity and disability communities. A Long Walk Down a Winding Road - Small Steps, Challenges, & Triumphs Through an Autistic Lens is his first book. To learn more, visit www.samfarmerauthor.com.

Sam Farmer

Parent-Led Strategies from page 23

Building Engagement Through Child-Led Play

Mukri initially struggled to connect with her son through play. Growing up in Ethiopia, play between children was common, while parents were more involved with their child's education. Through CST, she learned the importance of play in fostering her son's development.

"One of the most important lessons that I learned was about play," says Mukri. "I learned to declutter—to have an area just for me and my son to play—and to let him lead the play. I set aside time every day to engage with him one-on-one. It's not a lot of time, sometimes just 10 or 15 minutes, but spending that time together without any interruption is one of the most important lessons."

CST encourages caregivers to simplify their play area, offering just two or three activities and letting the child choose the one they prefer. For example, a parent might hold up a picture book in one hand and blocks in the other, observing which the child selects through their gaze, gestures, or words.

"CST focuses on helping parents to pay attention to what their child is interested in," says Pamela Dixon, Ph.D., director of clinical services and inclusion at Autism Speaks. "We call it 'look and listen.' They're taught to follow the child's gaze and to follow that as an area of play. The reason for that is people are more likely to spend time doing things that they like. The intention is to spend as much time as possible engaged with the child because we have research that shows joint engagement promotes language development."

Expanding Language Step-By-Step

Once a child is engaged in joint play, parents can help them build language skills by imitating their play while pairing language with the action.

"If the child is playing with blocks and tries to say the word 'block' but can only say 'b,' the parent builds on that and says 'block,'" explains Dr. Dixon. "If the child has more language and says 'train,' the adult would add another word - 'train go.' The idea is to imitate the child and expand on what the child is saying."

Dr. Dixon describes this as "respond and expand," a core CST strategy. Using gestures is also an important part of this process. If a child uses one word, a parent might use two and combine it with a gesture like a finger point or an open palm.

This method has been very effective in improving Kibur's communication skills. Murki says that when they first started CST, Kibur could only speak in one-word responses. She learned to gently build on his attempts by modeling slightly more advanced language.

"I learned to set a goal based on my child's level of communication. So, if he was using one word, our goal would be to use two words. If he said, 'water,' I'd respond with, 'drink water.' Over time, he learned to say full sentences," she explained.

Understanding the Communication Behind Behavior

CST also taught Mukri to reframe her understanding of meltdowns and other challenging behaviors. The program teaches that behavior is a type of communication, so understanding the cause of the behavior is critical to reducing it.

"You can do that by going back to the earliest skill we teach, which is 'look and listen,'" explains Dr. Dixon. "Pay attention to why the behavior is happening. It could be to get a need met, express discomfort, or communicate a want. By observing the child and paying attention to what they're looking at, you can get a sense of why that behavior is occurring and then match an intervention or a strategy with that behavior."

For example, if a child frequently has meltdowns in a certain aisle in the grocery store, it might be because they want something. With this knowledge in hand, parents can choose to avoid that aisle or give the child something to hold so that they have a distraction.

If the meltdown still occurs, the best thing to do is provide a calming presence—be quiet and let it pass. "Parents need to learn to regulate their own emotions first, as children mirror their caregivers' responses," says Dr. Dixon. "This soothing presence helps de-escalate situations."

One helpful tool that CST teaches for emotional regulation is imagining a "behavior thermometer" with three levels: cool, warm, and hot. When a child is cool, they are alert but not overstimulated. Warm means that they are beginning to become dysregulated, and hot is a full-blown tantrum or other challenging behavior. By observing their child's behavior when they are cool, caregivers can see the signs of an incoming meltdown and intervene.

"Sometimes, when Kibur is having a behavioral problem, I just want to pick him up and hold him because comforting him helps comfort me. But I've learned that actually makes things worse," says Mukri. "Now, when he is having a meltdown, the first thing I do is check in with myself and take a deep breath. Then, I try to understand what happened before that behavior. Over time, you become a mini parent scientist because you're collecting data on what's happening before the behavior, and you begin to see trends. Then, you can work with therapists to intervene."

The Impact of CST

The transformation Mukri and her son have experienced after participating in CST has been profound. Her son now speaks in full-length sentences, plays with his younger brother, engages with his family, and advocates for himself.

"I see so much progress in Kibur's communication skills, behavior, emotional regulation, and everything else. And I see changes in myself and my husband. We are much more understanding and aware of Kibur's needs, and we are setting aside time for self-care so we can be strong and healthy for our kids."

CST has also helped Mukri become a better advocate for Kibur. "Because we have this special time bonding, it helped me know his weaknesses and his strengths, and it gave me a voice during his IEP meetings and therapy evaluations. It propelled me to be a better advocate and, most importantly, a voice for my son."

Marta Chmielowicz leads science communications at Autism Speaks, working to advance the mission of the organization to create an inclusive world for all individuals with autism throughout their lifespan. For more information, email marta.chmielowicz@autismspeaks.org or visit autismspeaks.org.

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See the full references list here.

Voices from page 10

Parents and caregivers are the people who are there at 3 a.m. when a profoundly disabled, non-verbal autistic person is having a very bad night, is not sleeping, and has become aggressive. Unfortunately, in the push by some autistic advocates to speak for the entire autistic population, caregivers are being left out of "nothing about us without us."

My message is this: as disabled people, we should be careful about who we represent. In extremely heterogeneous populations like the autism community, we need to ask what "nothing about us without us" really means.

Doreen Samelson, EdD, MSCP, is the Chief Clinical Officer of Catalight, a non-profit that provides access to innovative, individualized care services, clinical research, and advocacy so people with developmental disabilities can choose their path to care. Samelson leads the organization's behavioral health research team, focusing on promoting families' overall well-being.

Special Interest from page 17

Recognition is a matter of correspondence. And though we are accustomed to thinking of this in terms of written communication between two parties, correspondence can also happen between one's inner and outer experience.

What sort of "inner" and "outer" do I have in mind? The general compatibility of self and others, as well as self and world, of course, forms part of the picture. But we need to go deeper. There is a certain ideal in both inner and outer, which we implicitly look at when seeking correspondence. That ideal is unity.

Unity is a sign of life. We see this in the way death is signified by its opposite: disintegration. Unity can signify safety in the sense of self-preservation. But it can also signify growth and outward movement, which point to a different kind of unity — namely, that of something undergoing development to become more itself, more in possession of its identity.

And here is where we come back to the phenomenon of autistic enthusiasm.

Loved ones and other concerned parties worry that when it comes to enthusiasms, people on the spectrum spend too much time and energy on things that do not matter. They should (so the logic goes) instead be paying attention to more important things and, indeed, to the people in their lives.

But I find myself reminded of something Matè (1999) says about attention within the context of a book on attention deficit hyperactivity disorder: "The origin of the word *attend* is the Latin *tendere*, 'to stretch.' *Attend* means to extend, to stretch toward" (p. 323).

Attention is about more than just listening to your teacher talk about the quadratic equation. It's about more than being able to repeat back to your mother the directions she gave you for cleaning your room. It is, at the bottom, about that correspondence between self and world, between the "in-here" and the "out-there," that all of us seek.

Daniel Crofts, MA

People on the autism spectrum can find the world to be an unwelcoming place. Sensory sensitivities impact their ability to move about in their environments with a sense of trust, and misunderstandings occasioned by social unawareness and alternative ways of thinking can make relationships, even with their family members, difficult to build. But when engaged in their enthusiasms, they find joy. In the objects of enthusiasm, autistic people feel "attended to" by outer reality — that is, they find that correspondence between self and world that tends to prove elusive under typical circumstances.

The fact that joy can be found in an enthusiasm takes us back to the concept of unity. Philosophers used to define joy in terms of repose in an object of delight. And repose, by the nature of the case, implies a gathering of oneself — in one's bodily position in the sense of being at rest and in one's inner life in the sense of gathering all one's faculties and attention into one focal point. It implies that one feels at home within oneself and in the world. Here, unity appears as a sense of self-integration within and unity in variety without.

And let's not forget the emotional appeal of an enthusiasm, since emotion can be a sign of movement beyond oneself.

Of course, an enthusiasm can go too far. It can, as some fear, become an impediment to the social and personal growth of someone on the spectrum. I would argue that this is where being able to share one's enthusiasms with others comes into play.

Consider an observation Lewis (1994) once made regarding the social aspect of personal enjoyment:

I think we delight in praising what we enjoy because the praise not merely expresses but completes the enjoyment. It is frustrating to have discovered a new author and not to be able to tell anyone how good he is; to come suddenly, at the turn of the road, upon some mountain valley of unexpected grandeur and then to have to keep silent because the people with you care for it no more than for a tin can in the ditch (p. 179).

This puts the autistic sharing of enthusiasms, with apparent disregard for the interest level of the other party, in perspective. For people on the spectrum, sharing an enthusiasm is not an instance of social obtuseness. On the contrary, it is a testament that for them, as much as for anyone, there is a social need manifested in the fact that the joy of an enthusiasm is incomplete without someone with whom to share it.

When people on the spectrum engage in their enthusiasms, they are saying to anyone who will listen: "This is where my voice is. This is what speaks to me. If I'm going to connect with the world and dive into the mess of social relations, my greatest chances of success lie in whatever paths lead from here, as from a safe base. Here, in the enthusiasm you call an 'obsession,' is the fire that will fuel my growth and enable me to do what you want me to do."

Listen carefully to enthusiasms. They speak louder than words.

Daniel Crofts is a 40-year-old man with Asperger Syndrome. He has an MA in English/Literature from the State University of New York College at Brockport and experience in freelance journalism, substance abuse prevention, online higher education, and service to children, youth, and adults with disabilities. He works as a direct support professional for Arc GLOW's IGNITE program, which provides a college experience to young adults with disabilities, and is also at work on a memoir about life on the autism spectrum. He may be contacted at danielcrofts31@yahoo.com.

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More Than Words from page 8

More Than Listening

When it comes to communicating with autistic people, nothing is more important than active listening and observing.

Still, it is just half the work.

How we communicate in response is the rest. Together, the two are the magic behind growth and independence.

But just like how differently people with autism communicate to us, how best to communicate back can vary immensely by person.

For example, a person in one of the houses I manage preferred to communicate with a certain staff member over another who had much more experience. We realized that the staff members had different communication styles, and the person preferred one style to another.

It really comes down to knowing the needs of the person and communicating and supporting each person in the way they respond best.

Communication tactics also need to be properly tailored to how each person listens and observes. Often, our communications need to be repeated in numerous ways for specific learnings to be understood and consistently used by someone. But, once learning is achieved, nothing is more rewarding.

When I have the privilege of witnessing such an accomplishment, I don't have to say a thing. The smile on my face silently says it all.

Michelle Bynoe

More Than We Know

So far, I have spoken about the power of communication in working with the people we serve, but the importance of communication in this field extends beyond that. It also extends to constant communication with our colleagues and peers so we can learn from one another.

When we professionals learn more than we already know, we are all better equipped to support the people we care for. For them to flourish and grow, so must we.

I am happy to report that such communication has been steadily increasing in recent years. I have been especially grateful for the increased focus on the professional development of direct service professionals (DSPs) like me.

More than ever, there are expanded offerings for training, micro-credentialing, and opportunities to network with our colleagues and share our experiences. That is already translating into better support for the populations we serve.

#MoreThanWork

The final piece of communication in our field is talking to people outside our profession who would be a great fit joining us in working with people with autism and other developmental disabilities. We need more of these people who are driven to help others, as there is a serious shortage of professionals in our field.

Earlier this year, a promising New York-based campaign called #MoreThanWork was launched to communicate with people working in other professions or who are ready to join the direct support workforce.

This recruitment campaign, which reaches out to people of every age and background, highlights the essential role DSPs play in helping others while promoting how rewarding and enriching a DSP career can be.

The #MoreThanWork campaign is already bringing new people into our profession, developing future leaders in our field, and, most importantly, improving the lives of the people we serve.

More Than Ready

I enter this new year full of hope and great expectation, with the tools of communication in my back pocket and the love of my residents squarely in my heart.

For the challenges and opportunities ahead, I am more than ready. This job means more to me than words can say.

Michelle Bynoe is Residential Manager at Living Resources. The agency's core purpose is to support and empower individuals with disabilities or other life-challenging conditions to live with dignity, independence, and happiness. Living Resources' services are individualized and offered in a variety of settings, from 60+ residential housing arrangements, site-based services, college programs, day opportunities, arts, community volunteering, supported employment, afterschool programs, and counseling services. Learn more about the agency at www.livingresources.org/.

Nonspeaker* from *page 22

Nina with her sisters, Paloma and Natalia

decisions. It feels like I am being reborn." She wants others to know that they can do this, too, with motor skill practice and the gift of neuroplasticity.

As Meehan's mother, Raquel, shares, "The depth of who she is is so moving. It's a different life now. It's reaffirmed my faith and kept my dreams alive…It's like meeting her for the first time." What surprised her most about Meehan is that she is a deep thinker and cares about "every single thing."

Meehan's older sister, Natalia, has been training in S2C and is a communication partner (CP) for Meehan. Natalia always knew that Meehan could read and understand, and it was painful to watch her sister's frustrations as they grew up. Now that Meehan can spell, it turns out that she and Natalia share a passion for helping people through healing modalities such as plants. "She had so much information about plants that I didn't know," says Natalia. Natalia and Meehan are building an apothecary for the sisters to run together, and they look forward to using herbs and plants to heal others.

Facilitated communication (FC) has been hotly debated in the disability world. Some studies have indicated the effectiveness of FC is attributable to facilitator bias. FC usually involves a communication partner physically supporting the child at the hand, wrist, arm, or shoulder while the child types or points to a letterboard. The concern amongst skeptics is that the facilitator is the one conveying their own thoughts. Rapid prompting method (RPM) and S2C, however, differ from FC in that the facilitators do not typically support the child's hand or arm and instead hold or move a letterboard.

Spelling to communicate teaches individuals with motor challenges the purposeful motor skills necessary to point to letters as a means of communication. The goal is to achieve synchrony between cognition and motor. Skilled and rigorously trained communication partners teach purposeful motor skills using a hierarchy of verbal and gestural prompts, never influencing the content of the speller's message. The 2023 documentary *Spellers* shows the process of S2C in action.

Her mother states that before S2C, no speech therapist had taken Meehan's motor abilities into account. This blind spot is frequently encountered, even though autistic individuals often rely on support to help with sensory, motor, attention, and self-regulatory needs.

The American Speech-Language-Hearing Association (ASHA), which certifies and sets the standards for speech and language pathologists, wrote a position statement in 2018 warning against the use of the RPM and S2C, claiming a lack of scientific validity. This is an emerging field, and having sufficient research means having the necessary interest from the public and funding from large institutions.

Regarding the efficacy and integrity of S2C, a recent study (Jaswal et al., 2020) used head-mounted eye-tracking to show communicative intent in their research subjects. The device measured how quickly and accurately the subjects looked at and then pointed to letters. "Our data suggest that participants actively generated their own text, fixating and pointing to letters they selected themselves."

United for Communication Choice, an organization made up of individuals with disabilities, their families, and allies, calls ASHA's position "flawed and dangerous." They consider access to preferred communication essential to "dignity, education, inclusion, independence, and self-determination." Gabriele Nicolet, speech therapist and family communication coach, says, "In ASHA's own language, evidence-based practice includes the inclusion of people's clinical and lived experiences. To deny someone's lived experience and call it a hoax is the opposite of what that organization stands for. It's abhorrent."

Recently, Meehan met another local speller named Wynston. They started hanging out, and Wynston asked her to be his Valentine. They are forming a deep and loving emotional connection. Through spelling, they can fully express their feelings for each other, and they hope that other spellers out there know that they can build meaningful relationships, too.

Meehan is on a mission to liberate nonspeakers from being silenced. She wants to create a school where spellers thrive. She is asking for neurotypicals to see what nonspeakers are capable of and give them the chance to have meaningful opportunities in society. She has created The Nina Foundation to educate the world about autism and raise awareness about autistic people's ability to comprehend the world around them. According to Meehan, "There is a revolution happening through unlocking the voices of all nonspeakers."

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Debra Brause, PsyD, has a private practice in Studio City, CA. She is the mother of a neurodivergent teen and specializes in working with parents raising neurodivergent children. Visit her website drdebrabrause.com.

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Empowering Families* from *page 21

Program effectiveness was measured by assessing parental stress, family empowerment, and overall family quality of life. These assessments were completed pre- and post-intervention. Parents also reported on the program's satisfaction and acceptability. As of yet, 20 caregivers have completed the program at CARD. Based on a recent analysis, the program demonstrated significant changes in parental stress, family empowerment, and family quality of life. Additionally, 100% of caregivers reported high satisfaction with the program and indicated that they would recommend the program to others. 72% of caregivers strongly agreed that they and/or their child benefited from the program and indicated that they felt more informed about important social/communication targets for their child's intervention.

These encouraging findings indicate that this virtual, group-based adaptation of an ESDM-based program is both effective and well-received by families. The results from this pilot program underscore the potential of virtual interventions to address the diverse needs of families, driving significant progress in both child development and overall family well-being.

This article was authored by Hanna Kent, B.S., Dan Magin, M.A., and Krista Drapalik, M.A., graduate assistants; Erica Davis, LMSW, training program coordinator; Melissa Rinaldi, Ph.D., clinical investigator; and Kristin Christodulu, Ph.D., director, at the Center for Autism and Related Disabilities at the University at Albany. For more information on programming and training opportunities at the Center for Autism and Related Disabilities at the University at Albany, please visit www.albany.edu/autism.

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***Math Education** from page 25*

including six females and 29 males (Costa et al., 2021; Picharillo & Postalli, 2021; Moura et al., 2023; Benitez et al., 2023; Vernini, 2023; Picharillo, 2024). Three of the 35 children could not respond to the PRAHM due to language barriers. Data from the other 32 children indicated an average of 69.2% correct responses (15 children presented at least 80.1% correct responses, and only nine of them presented less than 50% correct responses). The authors observed that there was no relation between age and performance, as children of different ages had the same performance. The poorer performances can be explained by language barriers caused by the instructions (Cox et al., 2021).

Protocols such as PRAHM are still rare in international literature regarding children with ASD but are fundamental to establishing the strengths and weaknesses of knowledge of basic mathematical skills. Furthermore, understanding the input repertoire is essential for the development of content planning and the choice of assertive strategies, leading to a successful teaching procedure.

Ailton B. Costa, PhD, is Postdoctoral in the Department of Psychology at The Federal University of São Carlos, Brazil. He has autism, ADHD, and giftedness, conducts research on teaching and assessing mathematics for people with visual impairments and people with autism. He can be reached at ailton.barcelos@ufscar.br, +55 16 3351-8357.

Alessandra D. M. Picharillo, PhD, is Postdoctoral Student in the Department of Psychology at The Federal University of São Carlos, Brazil. She is a scientist who conducts research on teaching and assessing mathematics for people with autism. She can be reached by email at alessandrapicharillo@estudante.ufscar.br, +55 16 3351-8357.

Nassim C. Elias, PhD, is Professor in the Department of Psychology at The Federal University of São Carlos, Brazil, who conducts research on autism and behavior analysis-related topics. He can be reached by email at nassim@ufscar.br, +55 16 3351-8357.

Ailton Barcelos da Costa, PhD

Alessandra D. M. Picharillo, PhD

Nassim Chamel Elias, PhD

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"First, it is important to recognize that people with autism are diverse and their experiences are unique. They may face challenges, but they also have the abilities and talents to enrich our communities. It's important to learn about autism spectrum disorder and challenge any misconceptions or stereotypes we may hold. Empathy needs to be translated into practical acceptance and support. We should take action in real life. Encouraging open dialogue and providing appropriate help can greatly improve the quality of life for people with autism. By increasing awareness and understanding, we can work towards a more inclusive society. The easiest way is to treat everyone with respect, even if they are different," said Xinyuan.

"Hey, have you heard of the Autism Spectrum? Maybe you've heard some stereotypes, like how they avoid communicating with people or possess super talents in certain areas. But let me tell you the truth: every person with Autism is unique. Don't put labels on them, use your heart to feel them. They may differ from us in some ways, but from inner, we're all the same! So, please, be open, empathetic, and patient to learn from their perspective, and then we can build a more inclusive environment where everyone is truly valued," said Wenhui.

"If I were to share a message with someone who's never met someone on the autism spectrum, it would be to not make assumptions. Autism varies a lot, so it's important to be patient and understanding since you never know exactly what someone might be going through," said Simeng.

"We should not discriminate against people with Autism. We also need to break the view that Asperger's syndrome is only bad. These people may have extraordinary intelligence and language ability, and a strong interest in something. We asked Jack if his Asperger's syndrome was a gift or a burden to him. Perhaps it is because of this experience that Jack's great achievements in the film industry, of course, cannot be separated from his own efforts. Finally, I will tell others that people with Asperger's syndrome do not lack emotion; they just express it differently from us, and they should be given more patience and understanding," said YiXun.

"Do not be afraid if you meet people with strange behavior in your daily life. Because they may be autistic people, they don't mean any harm, and they want to live like normal people. When we meet people with autism, we should treat them like normal people, and we should also actively provide them with suitable help," said Xingyu.

"Understanding and acceptance are key – everyone benefits from patience and open-mindedness. Encouraging meaningful interactions can ultimately foster connection and appreciation for people on the autism spectrum," said Aoyun.

Recent research into the prevalence of Autism in China has indicated similar rates as we see in Western countries, at around 1% (Sun et al., 2019). Through this guest lecture, and student's reflective writing, it is evident that the digital learning tools now available enable important conversations and deep learning experiences beyond traditional textbooks and classrooms. In our increasingly globally connected world, it is of great importance that students can learn from foreign experts and, in turn, share the knowledge they have developed with readers abroad. These student voices highlight the understanding and compassion of the new generation of psychology students in China. The lecture closed with a parting message from Jack to the students, "When you are interacting with someone on the autism spectrum, don't give up on them."

*see **China** on page 43*

Workplace from page 11

- Alternate means of training
- Providing agendas ahead of time
- Closed captioning and subtitles on videos
- Alt text to images

Communicating Needs

It can be intimidating for autistic people to share their needs with their employers. The stigma around autism, fear of judgment, and anxiety around potentially being bullied in the workplace can make disclosure a difficult experience. However, it is necessary for an organization to support them.

Some tips an employee can use when disclosing to employers include:

- Preparing a script and practicing alone or with friends and family
- Focus on abilities and skills
- Review the job description and be ready to discuss the essential functions of the role

Set Boundaries

An important aspect of communicating needs is also setting boundaries in the workplace. Healthy boundaries can lead to higher levels of productivity and workplace satisfaction; however, it can be difficult for autistic people to advocate for their needs (Indeed Editorial Team, 2024).

Ben VanHook, BA

Some important boundaries one can set include:

- Letting people know if you are uncomfortable with handshakes and physical contact
- Eating lunch by oneself
- Letting colleagues know your preferred method of communication
- Establishing the set hours you work
- Taking breaks if needed

Universal Design

When discussing accommodations, universal design is a common term one may hear. Universal design prioritizes accessibility and inclusion and seeks to create the most accommodating environment for all employees. Implementing universal design is a great way for employers to focus on equity and provide all employees with the individually tailored support they need to thrive (CAST).

Some examples of incorporating universal design into the workplace include:

- Providing multiple forms of communication, such as face-to-face meetings, virtual meetings, email, etc.
- Providing various forms of training for employees to include videos, hands-on activities, written and verbal instructions, and on-the-spot feedback.

Putting equity, accommodations, and accessibility at the forefront of workplace practices can help create an environment where everyone's needs can be heard.

The Hire Autism Program

There are many programs and resources available for employers and autistic individuals seeking to improve workplace inclusion. One such program from the Organization for Autism Research (OAR) is the Hire Autism program, whose mission is to improve employment opportunities for autistic individuals and help businesses create more inclusive workplaces.

Hire Autism has abundant resources for job seekers and employers. Ranging from information on how to write a stellar resume to ideas on how to become a more autism-friendly employer, the information available on the Hire Autism website can help job seekers and employers create more inclusive hiring practices and workplaces. A partnership with the Hire Autism program can help employers broaden their diversity, equity, and inclusion (DEI) strategy and take steps toward becoming a more neuroinclusive, autism-friendly employer. Interested in becoming an employer partner with Hire Autism? Learn more here!

Ben VanHook, BA, is Community Support Coordinator at Organization for Autism Research.

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- Indeed
- Indeed
- Verywell health
- Job Accommodations Network (JAN)
- CAST

Socialization from page 15

Some autistics could use masking when it comes to their difficulties. For example, an autistic who has great difficulty making eye contact would hide this issue so that he or she would not be seen as strange. This might be seen as a way to ease into a social environment, but the reality of it is that it could cause mental health issues, specifically anxiety.

Anxiety has been shown to be prevalent through masking. According to a British study in 2017, the autistic adults that were interviewed universally felt mentally, physically, and emotionally drained from masking, as well as having a great sense of loneliness (Hull et al., 2017).

This anxiety caused by masking has been shown to be prevalent in autistic women. It was reported that, due to autism in women being highly undiagnosed, the difficulties that many autistic women face are frequently mislabeled or misdiagnosed. This would force them to wear masks to fit in (Bargiela, 2016). Studies have also shown that masking amongst autistic women has a price, with many reporting feeling overwhelmed when hiding a certain characteristic, such as stimming because that stimming helps them with regulating emotions (Hull et al., 2017). Autistic women already have difficulties with being underrepresented; masking just makes it worse.

Robert Schmus, MSW, LCSW

Fortunately, there have been recent studies to help counteract this. The first is to have a neurodivergence-informed therapeutic approach. This means that clinicians working with autistic clients would see them where they are at and their strengths instead of trying to cure them of their autism (Allen et al., 2024). Self-advocates in the autism community have reported that such an environment is very beneficial (Allen et al., 2024). Clinicians can also help by letting autistic individuals with identifying triggers, creating a safe space for them, as well as practicing self-care. The latter of which would include sensory self-regulation and mindfulness.

It also shows how being part of a neurodivergent community can help with this. Many of these communities have been shown to be online and provide positive emotional responses towards autistic individuals. One study showed that, out of the 64 autistic individuals who took part in a survey regarding online autism communities, 45 reported giving social support, while 51 reported receiving social support (Ingouf, 2021). These aspects can help autistic individuals have confidence in themselves and, therefore, prevent masking.

The bottom line is that we autistics can socialize with others. Many of us have different ways to socialize, which is fine. We need to do it on our own terms and not mask ourselves in the process. We can reach a social goal as long as it is done our way.

Robert Schmus, MSW, LCSW is a Mental Health Therapist and Autistic Self-Advocate.

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Dr. Monica E. Carr is an A. Professor at Wenzhou Kean University, Wenzhou, Zhejiang Province, China, a Member of the Board of Directors, Genesis School for Special Education, Singapore, a Consulting Editor for Preventing School Failure, and an Editorial Board Member for Autism Spectrum News. For more information, please email mcarr.phd@gmail.com.

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