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Giving Voice to Nonspeakers: Communication, Advocacy, and Inclusion Across Life

We Shall Overcome: Why I Am Certain Nonspeakers Will Win Our Rights to Communicate

By Elizabeth Bonker
Executive Director
Communication 4 ALL

I was born perfectly healthy and passed all my developmental milestones, including saying words like "ball" and "dog." Then suddenly, at 15 months, I lost all my spoken words and started to bang my head on the floor. My parents brought me to Yale Medical School, and their only recommendation was to get me into intensive Applied Behavior Analysis (ABA). When my mother asked about medical interventions, they shrugged their shoulders and mumbled something about anecdotal stories about diets.

I'm grateful that my parents didn't believe these so-called experts. They created an ABA program for me in our home guided by Rutgers College with kind therapists my mother personally recruited. My parents never doubted that I was "in here" and kept feeding my brain with books and healing my body with natural interventions.

My life changed when my grandmother found my teacher thanks to *60 Minutes*. A courageous woman named Soma Mukhopadhyay had taught her own son how to point to letters on an alphabet board, and this was my chance to break free from the Silent Cage. I was 5 years old. With my new ability to type, my parents fought for my right to be mainstreamed in 1st grade. I am grateful for the elementary school teachers who believed in me and my communication partner, Terri, who was by my side for 14 years.

This is the opportunity I want for every nonspeaker, all 30+ million around the world. To be free from the bonds of frustration. To be taught to type. To be educated. To be productive members of society. To have friends. To tell their parents they love them.

In 2022, I graduated from Rollins College, the alma mater of Mister Rogers. My valedictorian commencement address encouraged us to follow in his footsteps and to live by our school's motto "Life is for Service." The speech went viral with 4 billion media impressions propelling our mission, Communication 4 ALL, onto a global stage.

How shall we overcome? How can we follow in the footsteps of the giants of the Civil Rights and Disability Rights Movements like Martin Luther King Jr., Helen Keller, and my mentor Judy Heumann? By banding together and removing the

see We Shall Overcome on page 29

A 30-Year Journey From Skepticism to Acceptance: Reconsidering the Authenticity of Assisted Communication of Nonspeakers

By Barry M. Prizant, PhD, CCC-SLP
Adjunct Professor, Department
of Communicative Disorders
College of Health Sciences,
University of Rhode Island

My introduction to assisted communication (AC) for nonspeaking and minimally speaking individuals was in reference to facilitated communication (FC). During July of 1991 at the Autism Society of America's annual conference, I was asked to participate on a panel that was hastily organized to have an "open and thoughtful" discussion about FC. Doug Biklen, who brought FC to the US from Australia, had presented a preconference workshop on FC and the conference attendees were buzzing from what they had seen and heard.

The panel was organized and moderated by the late Dr. Anne Donnellan of the University of Wisconsin-Madison, a valued colleague who was well-known for her contributions to the literature in autism.

Barry M. Prizant, PhD, CCC-SLP

The room was packed with at least one-half of the participants being parents. Anne opened the session by urging the attendees to participate in a constructive manner, as we all anticipated the sharing of strong emotions. The session quickly turned into a series of testimonials. We sat as we heard from excited educators, clinicians and paraprofessionals who gave impassioned accounts of "breakthroughs" through FC. According to the testimonials, individuals who were previously thought to have significant social or cognitive limitations, produced messages through FC which clearly proved that the great majority, if not all nonspeaking autistic persons were not challenged cognitively or socially, but were shackled by motor limitations. For some not yet understood reason (a "global apraxia", a "Parkinsonian-like" disability?), these individuals were not able to communicate their thoughts and feelings. Most testimonials were characterized by global statements such as "FC works for everybody in our workshop", "With FC, all the people in our community residence can now communicate their most intimate thoughts and feelings". Some audience members spoke of the need to discard almost fifty years of accumulated knowledge about autism, for FC had proven that most of this information was wrong.

Nevertheless, as panelists, we raised a number of questions such as "What does *it works* mean?", "What is the full range of experiences with FC, including extreme successes, emerging abilities and failures?", "How do we define *success*"?, "Could reported successes, if proven valid, provide direction for identifying a 'subtype' of autism"? "If the true nature of autism is an expressive motor-based disability for all individuals (as some claimed), rather than a social-cognitive and communicative disability, how does that account for the communicative and social challenges experienced by autistic persons who can communicate fluently through speech?" Following the session, two parents approached me and stated, with true concern, "if you question the validity of FC publicly that would ruin your professional reputation."

As word spread about FC, there was rapid pushback with the counter narrative being that the facilitator was always directing the messaging, either directly with

see 30-Year Journey on page 30

Table of Contents

Giving Voice to Nonspeakers: Communication, Advocacy, and Inclusion Across Life

✻ ***Indicates an article written by an Autistic Adult***

Editorial Calendar

Fall 2026 Issue
Financial Planning and Economic Security
for Autistic Individuals and Families
Deadline: August 26, 2026

Winter 2027 Issue
Innovations in Autism Supports, Services, and Programs
Deadline: December 2, 2026

Spring 2027 Issue
Supporting Mental Health and Well-Being in Autism
Deadline: March 3, 2027

Summer 2027 Issue
Meaningful Employment:
Building Connections, Access, and Opportunity
Deadline: June 16, 2027

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You Are the Expert on Your Preferred and Effective Communication:

“Le Pape v. Lower Merion School District” a Landmark Civil Rights Case

By Nicole Reimann, JD
Founding Partner
Reimann Law Group

Alex Le Pape was in high school when he told Lower Merion School District that a letter board was his preferred and effective means of communication and asked to use it throughout the school day. At an age when most students are simply trying to navigate adolescence, with that request, Alex began what would be a seven-year quest that started as the right to communicate *his* thoughts, feelings, and ideas in the way that worked for him and became an effort to secure that right for other public school students. The School District’s refusal to honor Alex’s preferred and effective method of communication touched off a seven-year legal battle that ultimately established (1) a public school student’s civil right to their preferred and effective method of communication, and (2) to have a jury—not some school administrator, hearing officer, or judge—decide factual disputes about the effectiveness of the communication.

In the landmark case—*Le Pape v. Lower Merion Sch. Dist.*, a three-judge-panel of the United States Court of Appeals for the Third Circuit concluded that “[t]here is ample evidence from which a reasonable jury could conclude that the School District violated the ADA’s effective communication requirement by denying Alex his preferred method of communication without providing an effective alternative.”[1] This ample evidence included Alex’s own testimony. Under oath, Alex testified that the letter board was effective for him and remained his preferred communication method. The Court emphasized Alex’s lived experience: a non-speaker who for the first 16 years of his life had “minimal communication,” could say only a few words, and could not express his own thoughts. He could not tell the school nurse how he felt, discuss college plans with his guidance counselor, participate in class, or engage fully in extracurricular activities or community-based instruction.[2]

Remarkably, Lower Merion refused to allow Alex to communicate with a letter board even in the face of other students’ successes at colleges and universities. This was not uncharted territory. The school district refused to accept Alex as the expert on his own life. For years, colleges and universities across the country have admitted, supported, and graduated non-speaking students who communicate through spelling or typing. Non-speakers have thrived at institutions such as Harvard Extension School, the University of California Berkeley, the University of California Los Angeles, Tulane University, Oberlin College, and Rollins College. Many have gone on to become advocates, scholars, and leaders in their communities and beyond.

One prominent example—though not the only one—is Hari Srinivasan, a Phi Beta Kappa, *cum laude* graduate of UC Berkeley and a Haas Scholar. Mr. Srinivasan earned a fellowship to pursue doctoral studies in neuroscience at Vanderbilt University and, in 2024, received the prestigious National Science Foundation Graduate Research Fellowship for his work. Since 2021, he has served on the U.S. Department of Health & Human Services Interagency Autism Coordinating Committee. His commentary has appeared in

see Civil Rights Case on page 29

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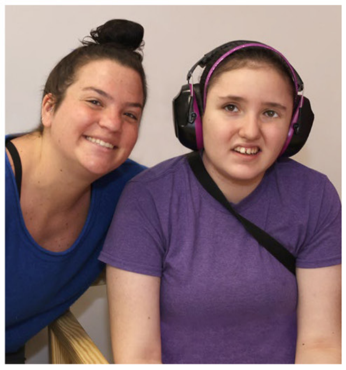

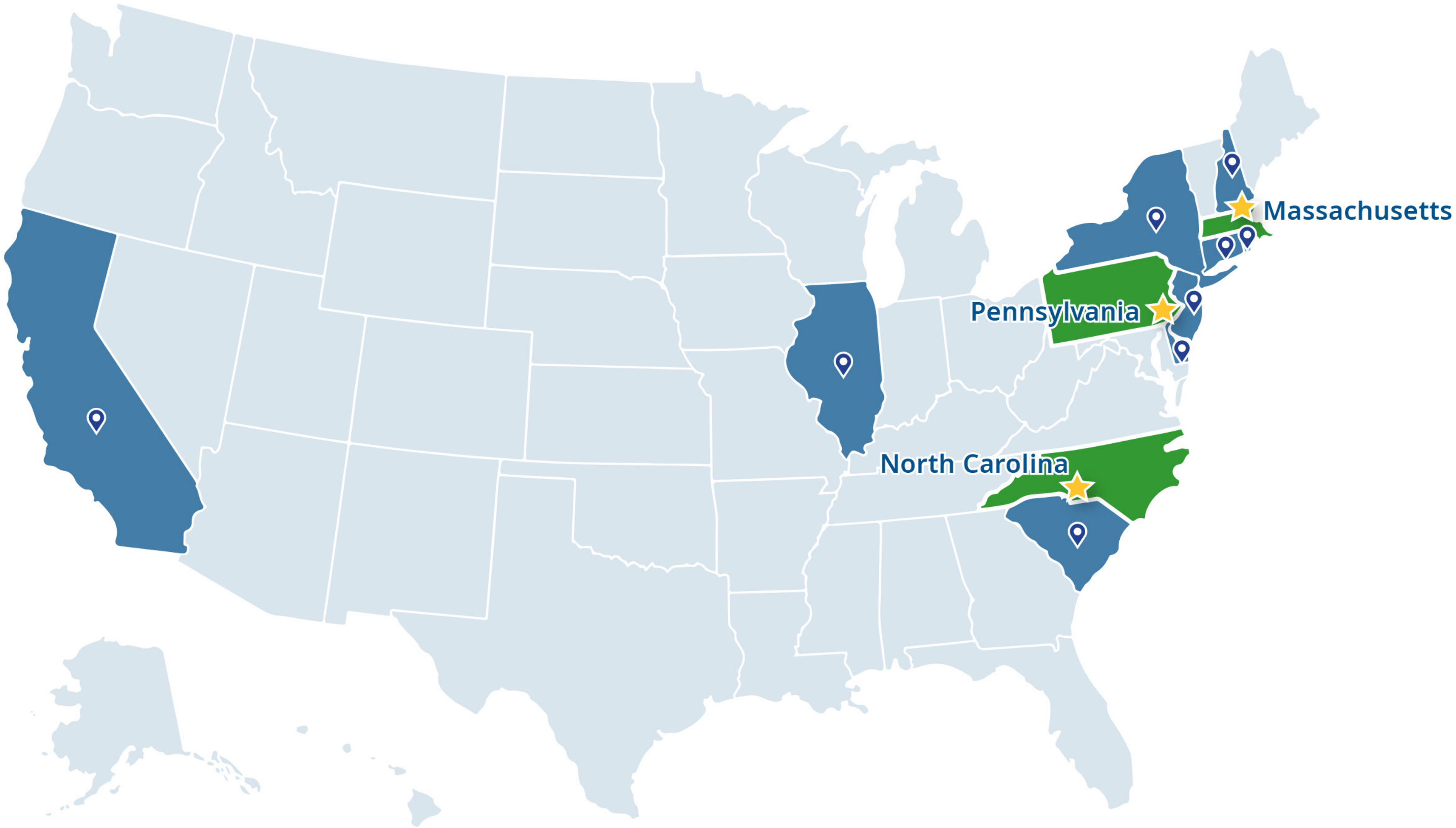

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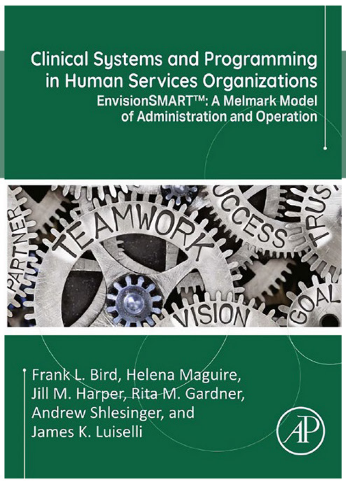
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The Quietest People in the Room Often Have the Most to Say

By Libby Traynor, LCSW
CEO
All Abilities Beloved & Respected, Inc.
(AABR)

Note: Names and identifying details have been changed to protect privacy.

The phone rang on a weekend. On the other end was a young woman from one of our community-based programs. Just hours earlier, she had experienced every child's nightmare. She had witnessed her mother suffer a fatal heart attack. The person who had loved her, cared for her, advocated for her, and been the constant in her life was suddenly gone.

Faced with one of the most devastating moments of her life, she reached out for help.

What struck me was not that she made the call, but who she called.

It wasn't a supervisor, an administrator, or an emergency line.

She called her instructors, the staff members who had become trusted figures in her life through their consistent presence, encouragement, and support.

It was a weekend. There was no scheduled program. No expectation that they would hear from her. Yet instinctively, she knew exactly who she wanted beside her during that moment.

As I reflected on her story, I realized it perfectly captured something individuals with autism and intellectual and developmental disabilities have been teaching me throughout my career: ***Communication begins with relationship.***

For much of my early career as a social worker, I thought communication was primarily about helping people find the right words. Over several decades in this field, I have learned that understanding often has far less to do with words and far more to do with trust. The most effective communication systems, therapies, devices, and interventions in the world cannot replace the power of a trusted human relationship.

Long before people communicate through speech, gestures, behavior, or assistive technology, they communicate through connection. The individuals we support have taught me that lesson time and again.

One of our residential leaders recently shared a story that illustrates this perfectly.

She oversees several homes supporting individuals with developmental disabilities and is also the mother of a non-speaking son. When she spoke about her experiences, she described learning something as a parent that fundamentally changed the way she approached her work.

"My son taught me that communication is much bigger than words," she told me.

As a mother, she learned to listen differently. A smile, a glance, a change in routine, a gesture, a behavior, or even silence could communicate far more than spoken language ever could. Over time, she realized that meaning is often found not in what is said, but in what is observed.

Today, she brings that same perspective into her professional life.

She recalled an individual who suddenly began refusing activities they normally enjoyed. At first glance, it would have been easy to label the behavior as resistance or noncompliance. The individual was withdrawing from preferred activities and becoming increasingly reluctant to participate.

But one staff member recognized that something wasn't adding up. The behavior was out of character, and instead of focusing on the refusal itself, the team began asking a different question: What was the individual trying to communicate?

Because of the relationship they had built, staff recognized this was not typical. They knew what brought the individual joy. They knew their routines. They knew their personality. Most importantly, they knew when something wasn't right.

see Most to Say on page 50

The Visual Aspect of Increasing Communication Across Disciplines

By Amanda Doran, MEd, BCBA, LABA
Elizabeth Bland, MA, BCBA
Autism Care Partners
and Kara Morrison-Smith, MS, CCC-SLP, ASDCS, Little Finch

Speech pathologists and behavior analysts each bring distinct expertise, yet their greatest impact is realized through integrated service delivery. Separately, these two provider groups apply principles unique to their respective science and discipline, but it is together, with support from collaborative leadership, that these disciplines offer robust capacity for overlap and enhancement of common goals. Both disciplines apply evidence-based therapeutic approaches; both commit to ethical practices; both take pride in their ability to build meaningful skills and improve client quality of life. Common practice settings, including schools, center-based care, and home therapies, present opportunities for collaboration. And organizations, such as Autism Care Partners (ACP), find that offering multiple services in tandem, including speech therapy and applied behavior analysis (ABA), supports their mission, vision, and values of integrated and person-centered care.

Example of a visual scene display being used to communicate "Open the Play-Doh"

ACP has taken the interdisciplinary approach a step further by partnering with Little Finch to use the Visual Immersion System (VIS)™, an exclusively licensed framework applicable across disciplines and settings. This framework is designed to immerse learners in visuals for instruction, organization, and expression, using tools that meet each learner's unique needs, and was developed at Boston Children's Hospital through the work of Dr. Howard Shane. Dr. Shane likes to contextualize the VIS by comparing it to the need for language modifications for individuals who are Deaf. When a learner is Deaf, sign language would be used to meet their language needs. Similarly, we want to immerse our learners in a language most appropriate for them — and there is substantial evidence to indicate the language we use should be a visual one. With VIS, teams can assess each learner's language development and then apply specific types of visual tools to meet their needs and improve their language.

In ACP's collaborative setting, both speech pathologists and behavior analysts observe that learners with severe language deficits have difficulty understanding verbs (like "open," "go," and "sit"), adjectives (like "empty," "different," and "hot"), and prepositions (like "in," "out," and "under"). In contrast, nouns — like "door" or "Play-Doh" — are often easier. This is not a rare observation; however, it is within a shared framework that providers can collaborate and problem-solve to address these observations, capitalizing on their individual skillsets to develop successful programming based on available research.

Did you know that some research indicates that an augmentative and alternative communication (AAC) display called a visual scene display (VSD) aligns better with young children's ability to process information by showing people, actions, and events in context (Light, Wilkinson, Thiessen, Beukelman, & Fager, 2019)? Did you know that early learners respond better to photographs than to abstract visual representations (Simcock & DeLoache, 2006)? Or that short videos and photographs can be used to improve accuracy in following directions (Allen, Shane, Schlosser,

see Visual Aspect on page 36

More Than Spoken Words: How DSPs Help People Find Their Voice

By #MoreThanWork

Everyone has a voice, even if they don't communicate through speech. Expression can take many different forms — from gestures and facial expressions to communication devices, pictures, and written words.

When people with developmental disabilities are given the tools, support, and opportunities to communicate in ways that work for them, they can more fully express themselves, advocate for their needs, build relationships, and participate in their communities.

For Keshia Bellot, a Direct Support Professional (DSP) at WellLife Network, helping people find and use their voice is one of the most meaningful parts of the job. Through her work, she has learned that meaningful communication isn't defined by speech alone, it's about understanding each person's way of communicating and ensuring they have opportunities to be heard.

"Everyone communicates differently," Keshia explains. "Part of our role as DSPs is learning how each person communicates and making sure they have opportunities to express themselves."

That support from Direct Support Professionals can have a profound impact and is often the foundation that makes inclusion possible.

Keshia in her classroom at WellLife Network

Communication Takes Many Forms

While some people communicate verbally, others may rely on augmentative and alternative communication (AAC), sign language, gestures, visual supports, or a combination of methods.

Learning to recognize and respond to those forms of communication is an important part of a DSP's role. Too often, people who communicate differently are underestimated or excluded from conversations that directly affect them. By taking the time to understand different communication styles, DSPs can help ensure that their perspectives, preferences, and goals remain at the center of decision-making.

Communication access is crucial. Studies have found that people with developmental disabilities who require communication supports often experience greater participation in their communities, stronger relationships, and improved quality of life when those supports are available (McNaughton et al., 2025).

Recent advancements in services for people with developmental disabilities have provided more opportunities for people to find and use their own voice and exercise their independence, such as Supported Decision-Making and Home Enabling Supports. Direct support workers are increasingly critical in supporting people to exercise their ability to have their own voice and make their own decisions.

NYS Office for People With Developmental Disabilities Commissioner Willow Baer said, "There is no more powerful right than the ability to make your own choices and to be able to have those choices be understood."

Communication Creates Opportunity

Keshia has seen firsthand how empowering it can be when people are given the time, support, and resources they need to communicate.

When people have access to communication tools and supportive communication partners, they are better able to make choices, participate in decisions that affect their lives, and advocate for themselves. Researchers have found that effective communication supports can increase opportunities

see Find Their Voice on page 40

Re-Envisioning Our Unnecessarily Disabled Futures

By David James “DJ” Savarese, BA
Founder and Facilitator,
The Lives-in-Progress Collective
and Co-Chair, The Alliance for
Citizen Directed Supports

Most disabled adults are forced to live segregated, impoverished lives absent of the security, life expectancy, community, and agency that all human beings deserve. For those of us from historically marginalized communities, including non-speakers, the isolation can be even more profound. The life outcomes of people with disabilities are funds- and systems-driven and parent- and/or agency-controlled and often predetermined by professionals when we are 2 to 10 years old.

Systems manage us, forcing many of us to live lives of convenience for other, nondisabled people. And even those who claim to be person-centered don’t consider our opinions. They aren’t collaborating with us and often don’t even personally know any people with disabilities. Innovative solutions must insist on a world beyond inclusion.

David James “DJ” Savarese, BA
Credit: Pamela Harvey Photography

We all have the capacity to make the world a better place. We all yearn to be an essential part of something bigger than ourselves, but to do so we need to begin to imagine a world beyond inclusion, one in which everyone, not just the disabled, has equal access to wellness; meaningful community engagement; unpaid, authentic relationships; and the freedom to pattern our own lives.

Ableism underlies and drives every bias in this country, including structural racism; the disabled are members of every community; and our intersectional identities compel us to fight for the freedom of all people, not just the disabled, and yet we are often left out of broader social justice movements focused on homelessness, food insecurity, poverty, unemployment, and educational reform.

We need to empower all of our communities *not by* competing for funds, proliferating the creation of more nonprofits and newsletters, or racing to learn and conform to the central power structures in our country. We empower all of our communities by recalling what bell hooks taught us: that power exists at the margins, where we all currently reside, and that if we develop interdependent, authentic, cross movement collaborations, we are more resilient, creative, and expansive.

Health systems manage us; to simply better align the current systems would just further disempower our people to be even more efficiently managed. Before we can collaborate and engage with medical professionals, we need to unearth the concepts and tools that confine us and peel away our internalized ableist beliefs about ourselves and our potential lives.

We need funders and traditional researchers to clearly differentiate family or caregiver experience from our real lived experience as disabled people. Currently most lived experience grants, which should be awarded to disability-led initiatives, are awarded to family-, caregiver-, or agency-led initiatives, actually contributing to the status quo.

We need more trust-based grantors whose application process foregrounds the strengths of community-based organizations, values the language of those with lived experience over the professional jargon and constructs of university-based researchers and, at the same time, encourages us to learn how to engage in formative evaluations. The funding process usually requires us to make our research partners the lead on the proposal, often burying our community-based and founded initiatives under academic jargon that makes it largely unrecognizable.

We need to build cross-movement initiatives that bring together subgroups the status quo seeks to divide.

And we need to begin by being the ones who ask, and don’t just answer, the questions that drive the innovative content and processes we create. If we’re simply answering others’ questions, we’re often stuck reinforcing the status quo.

With all of this in mind, we’ve opted to run The Lives-in-Progress Collective (LIPC) as a collaborative of fluid, dynamic groups of diverse, multigenerational, cross-disability leaders whose lived experience and expertise inform our resources, trainings, materials, and formative evaluation methods. Our goal is to always ensure that those accessing LIPC feel represented in the team employed to support them through mentorship, training, and facilitation and that systems-based professionals

see Re-Envisioning on page 45

A Stronger, Unified Voice for Autism Professionals

By Robin McLeod, PhD
Founding CEO,
National Society of Autism Professionals (NSAP)

I went to my first ABA conference recently as a newcomer twice over: as a psychologist who had spent a career adjacent to the field of Applied Behavior Analysis (ABA) without ever truly stepping inside it, and as the parent of an autistic son.

As a psychologist, I built a multi-disciplinary behavioral health organization that served the autism community. As a parent, my husband and I built an autism care team for our son that included neuropsychologists, school psychologists, developmental pediatricians, special education teachers, speech-language pathologists, occupational therapists, and physical therapists. We constructed quite a team – it just never included a behavior analyst.

I don't say that as a criticism of ABA. What I saw at ABAI in San Francisco impressed me: a discipline that takes data seriously, insists on connecting clinical practice back to outcomes research, and watches for immediate response to intervention rather than waiting months to find out if something worked. Those are values every part of the autism field should aspire to.

But I also noticed what wasn't in the room: much discussion of the other disciplines that my own family had relied on. And that absence mirrored the same problem I see playing out in the national conversation about autism care.

Say the words "autism care" to a policy maker, a reporter, or an insurance executive today and there's a good chance the image that comes to mind is ABA. It's an understandable mistake. ABA is well-organized, well-represented, and currently at the center of intense public debate over access, cost, and effective outcomes. But ABA is one discipline among many that serve autistic people and their families. It is not a synonym for autism care. It is one variable in a much larger equation for what works to impact meaningful life outcomes for autistic individuals and their families.

The professionals my family worked with are just as essential to that equation, and so are the professions we never crossed paths with at all: researchers, employment specialists, housing navigators, policy analysts, autism advocates. Each holds a piece of what autistic people actually need across a lifetime. None of them holds the whole picture alone.

For decades, that has been the autism field's quiet flaw. Researchers talk to researchers. Behavior analysts talk to behavior analysts. Educators talk to educators. Each group does serious, valuable work.

We lack a strong, loud, and, most importantly, unified voice.

The problem isn't a lack of expertise – the autism field has an abundance of expertise. The problem is that too much of it remains disconnected. We're not a voice – we're a collection of disparate whispers. We speak to our own corner of the field while the people making the biggest decisions about autism policy hear from only the loudest. Because we function in silos, our whispers go unheard, and the biggest decisions are being made for our field by policymakers, payers, and others who have never experienced what it's like to support individuals with autism and their families firsthand.

Autistic individuals and their families don't experience life in silos. Their lives move through healthcare, education, employment, housing, and community – often within the same week. The challenges they face rarely sort themselves neatly by discipline. The response to those challenges shouldn't either.

That's why I believe the next chapter of

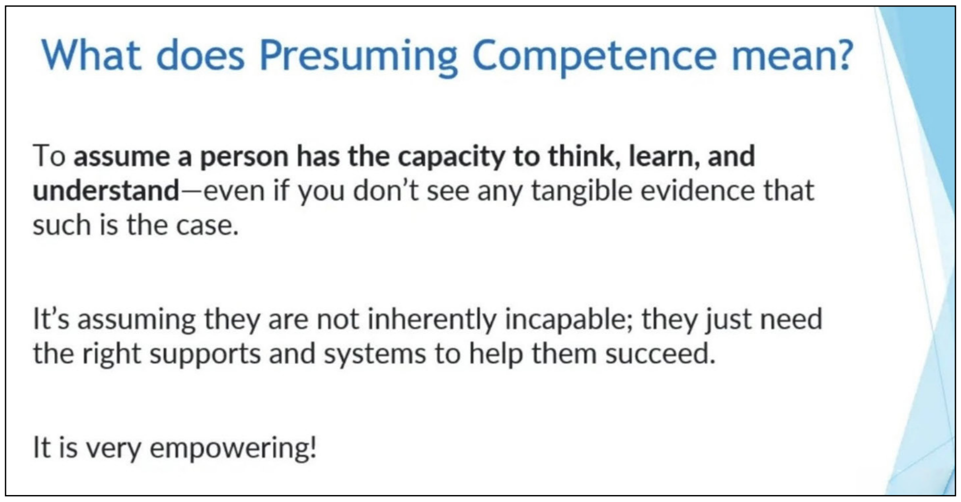
see Autism Professionals on page 41

Presuming Competence: What It Really Means and Why It Is Life Changing

By Susan Nisinzweig, MSW
Supported Typing Program
Coordinator and Parent of a Typer
STeP, Abilis Life Services

Presuming competence is such a core foundational principle for people working with non-speakers to understand. It is the very first thing we talk about in our training programs and a topic we revisit in every coaching session. Parents, staff, therapists, teachers, and anyone else interacting with those who cannot fully express themselves often come into our training thinking that they understand what presuming competence is and think they are talking to their child/student in an age-appropriate way. But like me, they often discover that they have to rethink their understanding and recognize that they have shifts to make.

Anne Donnellan, an impactful advocate, researcher, and educator in the field of disabilities, coined the term "Least Dangerous Assumption" back in 1984. She asked the simple question: which is least dangerous – to assume a person can learn so you give her every opportunity, and it turns out she couldn't, OR to assume a person cannot learn, so you don't give him the opportunity, but it turns out he could learn? Clearly the first option – to give them every opportunity to learn – is less dangerous, and yet we don't always implement that practice.



What does Presuming Competence mean?

To **assume a person has the capacity to think, learn, and understand**—even if you don't see any tangible evidence that such is the case.

It's assuming they are not inherently incapable; they just need the right supports and systems to help them succeed.

It is very empowering!

Helen Keller and Stephen Hawking are two examples of brilliant, talented, inspiring people who had highly functional brains inside of dysfunctional bodies. Helen had to prove herself over and over, and doubters suspected that her teacher Anne Sullivan, who presumed competence in Helen, was the one actually communicating. It took time and effort for that perception to change and for others to see her as intelligent. When Helen went to college, she and Anne had to prove themselves all over again to this new community of people. Helen eventually learned how to speak and the naysayers were silenced forever. Stephen started out brilliant and in a healthy body, but as he deteriorated with ALS he physically appeared, at first glance, to be a person most would see as highly dysfunctional; his mind, however, was still brilliant and he continued to teach, write, and inspire generations of people.

My own son, who has autism and is a minimal/unreliable speaker, learned to type to communicate eight years ago at the age of 32. On the outside he acted very childlike, but I realized I had to master presuming competence after he typed out one day, *"The reality of my life is that I need help to be in the world but I don't need help to think."* That was all the inspiration I needed to start a program called STeP where we could build a community of typers and competent facilitators so we could help non-speakers to be seen, heard, and respected. The STePs we follow include building communication, social skills, learning opportunities, independence, a connection to community, confidence and self-advocacy, and working towards achieving their future goals – whatever those might be.

What Does Presuming Competence Sound Like?

At our foundations training classes at STeP, it is valuable to teach participants what presuming competence is and what it sounds like. I know that I struggled with this myself, and many of the participants in our classes — whether they are parents, teachers, therapists, or staff — come in thinking that they are presuming competence and cannot hear that they are not communicating in an age-appropriate way to their person. I show people an image of Van Gogh's Starry Night and I ask them how they would talk about this picture to a 2-year-old, to a 7-year-old, and to a 20-year-old. They hear the difference and many quickly realize they have been talking to their 20-year-old client/student/child as a 5-year-old. Even with good intentions, it is often hard for us to make the changes that reflect the presumption of competence, so ask another trusted person to give you honest feedback.

see Presuming Competence on page 33

Communication, Regulation, and Trust: Supporting Non-speaking Autistic Individuals in Everyday Life

By Amy C. Laurent, PhD, OTR/L
and Jacquelyn H. Fede, PhD
Co-Directors
Autism Level UP!

The world is often set up in ways that are highly unreliable and unpredictable for autistic people. This sets the stage for frequent dysregulation, disengagement, and disability, all of which can be even more extreme for non-speaking autistic individuals. The frequent bias towards being overwhelmed can be, in part, mitigated with support coming from trusted partners. Trusted partners provide supports to increase predictability in day-to-day activities and interactions as well as provide authentic and useful supports for their neurologically based differences. This type of support facilitates engagement, and it increases confidence and competence for all people, regardless of neurotype. Activities and environments in many domains are often inherently set up to support participation for most individuals. When quality support is present for a non-speaking autistic individual, stress is minimized, and they, too, are more available for learning and interacting in these same environments and activities.

The Relationship between Communication and Regulation

Communication is a complex developmental capacity that includes an individual's abilities to initiate, respond to, and maintain interactions. It is the foundation of participation in shared experiences, which supports the development of meaningful relationships with others. It is important to note that a person's communication abilities are influenced by their regulatory profile. When any person experiences dysregulation, their access to language processing and formulation is adversely affected. Indeed, individuals of all neurotypes can likely recall difficulty expressing themselves when faced with a stressful situation. Lack of access to authentic means of communication that others respect and respond to also causes dysregulation. Jordyn Zimmerman, a non-speaking education advocate's statement captures this experience. "I was in a perpetual state of being frustrated as not only did I have a huge human need to be with other people, but worse — because I could not effectively communicate with speech, there were many assumptions made regarding what I needed" (Jordyn Zimmerman, May 19, 2023).

Emotional regulation is the capacity to adjust one's emotional and physiological arousal states (or energy level) to meet the demands of one's social and physical environment, and it develops across the lifespan. When emotional regulation is effective and successful, individuals shift arousal states to match the environment in a way that supports maintaining engagement (e.g., biobehavioral states consistent with higher energy to play versus lower energy to sleep). This match between internal state and environmental characteristics is often referred to as a well-regulated state. When a person is not able to shift energy or emotion to meet environmental demands, they may experience arousal that is too high or low to engage successfully. This is often referred to as dysregulation. Danny Whitty, a non-speaking disability advocate, described his frequent experiences of

see Everyday Life on page 31

Rethinking Evidence-Based Practice for Supporting Nonspeaking Individuals

By Barry M. Prizant, PhD, CCC-SLP
College of Health Sciences,
University of Rhode Island
and Jessica Teixeira, MS, CCC-SLP
Play Haven Pediatric Therapy

In considering the issue of evidence-based practice (EBP), we take on a deceptively simple question—what counts as "evidence" of effectiveness of approaches in supporting the communication of nonspeaking autistic individuals? Beneath that question lies a deeper and more contentious issue—how definitions of acceptable evidence shape whose voices are heard, whose abilities are recognized, and which approaches are considered credible.

When we apply these questions to nonspeaking autistic individuals, the stakes become especially high. For decades, debates about assisted communication (AC) methods—particularly those involving typing or spelling—have been framed as battles over scientific validity. Critics who defend the position that all communication in AC approaches is not authentic position themselves, at a distance, as defenders of science. Proponents of AC include researchers, as well as clinical professionals and family members who are engaged every day in the lives of nonspeakers. They argue that lived experience and clinical observation are being unjustly dismissed by critics, who exclude two of the three pillars of evidence in evidence-based practice: expertise of clinicians and educators, and client and family perspectives and experience. We support an approach that offers a way to move beyond this impasse by reframing EBP as a dynamic, integrative process rather than a rigid hierarchy that only considers context-stripped research applied outside the experience of the lived experience of human communication. Our understanding of EBP, which reflects its most accurate interpretation provided by professional advocacy, clinical and research organizations, is one that considers multiple sources of evidence and life-span development rather than experimental snapshots that are set up as strawmen in denying the authenticity of nonspeakers.

The Three Pillars of Evidence-Based Practice

A foundational concept underlying this discussion is the widely accepted model of evidence-based practice (EBP) in medical and clinical fields (ASHA, 2005; APA 2005; Prizant, 2011; Sackett et al., 2000). This model describes a three-part integration of:

1. **Best available research evidence**
2. **Clinical expertise**
3. **Client and family values, preferences and lived experience**

We assert that problems arise when one of these components—typically research evidence—is elevated above the others to the point of excluding clinical expertise and lived experience. In fact, in revising their definition in 2006, the APA broadened earlier medical models by explicitly emphasizing: culture, individual differences, patient preferences, and clinical expertise alongside research evidence.

In specific reference to evidence for the

see Rethinking on page 34

Studying Understanding Without Speech: Neuroimaging Minimally Speaking Autistic Individuals

By Isaiah Tien Grewal, Stony Brook University School of Social Welfare LEND Fellowship Program,
Morgan D. Barense, University of Toronto; Rotman Research Institute at Baycrest Hospital,
and Karen Chenausky, PhD, CCC-SLP, MGH Institute of Health Professions

Isaiah points to the HD-DOT cap on display at the 2025 Motormorphosis Conference Kennedy Krieger Institute booth staffed by Karen, on the left, and Morgan.

Minimal speakers (MS) represent one-third of the autism spectrum, yet only 2% of autism research participants (Russell et al., 2019). Research conclusions based on people unlike minimal speakers in significant ways may be skewed, leading to profound misunderstanding. We aim to correct underrepresentation of an important group.

We agree with Jaswal et al. (2026) that MS "cannot use speech to reliably convey what they want, explain what they know and feel, ask questions, express opinions, or share memories." MS do not have enough control of their speech muscles to use their voices to maintain autonomy. The neurodevelopmental condition that makes it difficult to perform motor skills, like speaking, is dyspraxia (also known as developmental coordination disorder). This neurodevelopmental disorder begins in childhood, results in acquisition of motor and coordination skills that are below age expectations, significantly interferes with activities of daily living, and is not better explained by another condition like cerebral palsy (American Psychiatric Association, 2013).

Human brains are organized by division of labor. Different parts of our brains are specialized to do different things. We have a motor network that is specialized for planning and executing movement, including speech, and we have a different network responsible for language knowledge and language processing. It is entirely possible for someone to understand everything that is being said to them but be unable to respond because the motor and language networks are anatomically separate. This is an uncontroversial statement in neuroscience, and it means we should never conflate the ability to speak with the ability to understand. And yet, the default assumption is that if an autistic individual is nonspeaking, they have an intellectual disability. One of us is proof that this assumption is wrong. Some MS are intellectually disabled, but we cannot be certain until we have better diagnostic tools. Eleven-year-old Isaiah's Peabody Picture Vocabulary Test results were "receptive vocabulary currently falls below the first percentile" and "He was able to correctly count pictured objects, could label colours, shapes, and some everyday objects and actions." The evaluator did not clue in that he had had hundreds of hours of practice pointing to colors and shapes, but not the items he got wrong!

Neuroimaging

Traditional tests of language comprehension and intellectual ability require

see Neuroimaging on page 35

Advancing the Rights-Based Inclusion of People Who Need and Use AAC: A Guide to Allyship

By Ren Koloni, MA
Program Associate
CommunicationFIRST

People often ask CommunicationFIRST for our recommendations for interacting with people who need and use augmentative and alternative communication (AAC) tools and supports,[1] including nonspeaking autistic people, autistic people who are sometimes able to speak, and people with other disabilities—like cerebral palsy, Down syndrome, or acquired brain injuries—that affect the ways in which they can be heard and understood. Informed by the civil rights afforded to people with disabilities by law in the United States, and shaped by CommunicationFIRST's years of leadership by and collaboration with AAC users, autistic and otherwise, the following principles will help you ensure respect, dignity, and equitable opportunity as you work with and alongside us. No matter your role, if you can rely on speech to be heard and understood, you can play a part in leveling the playing field.

Just fifty years ago in the United States, people who couldn't rely on speech alone to be heard and understood were often sent to live in institutions as a matter of course. Many of these people were autistic, though others had other disabilities, like traumatic brain injuries, Down syndrome, or cerebral palsy. Treated as less than human, few residents of U.S. institutions had a chance at parts of life most Americans take for granted—like regular mealtimes, making basic choices, or an education—until the 1970s.[2]

The first changes were voluntary: no laws at the time ensured that people with disabilities were treated fairly. But disabled people living in the community, learning from the Civil Rights Movement of the 1960s, organized for their rights. In 1977, more than 150 people with disabilities, including AAC users like Hale Zukas, gathered in a federal building in San Francisco and refused to leave. The Rehabilitation Act of 1973 had promised to prohibit discrimination against disabled people in programs that received federal funding, but after four years, no regulations had been signed, leaving the law unimplemented and unenforceable. The sit-in lasted 28 days, until the Section 504 regulations were signed.

Much has changed since then. The 1975 Individuals with Disabilities Education Act (IDEA) established that disabled students have the right to a free and appropriate public education—including the supports and services they need to access it.

The Americans with Disabilities Act (ADA) was passed in 1990, affirming the civil rights of people with disabilities. The ADA's goal is to ensure that disabled people can access the same parts of society that nondisabled people can. Just as a wheelchair user requires accessible entrances to enter buildings, people with communication disabilities may require "auxiliary aids and services" to access things like healthcare or education. In other words, we have the right to effective communication. To ensure effectiveness, public services must give "primary consideration" to the disabled person's chosen communication method.

Effective communication in action looks like:

see Guide to Allyship on page 37

Core Learning Characteristics of Autism and Their Implications in Typing to Communicate

By Janie Burke, MA, MS
and John Burke, PhD, BCBA-D, LBA
Dr. John Burke and Associates, LLC

This article bridges the gap between decades of research in the field of autism and the actual cognitive-motor mechanics that define an autistic learning profile. Our objective is to cleanly identify why traditional Augmentative and Alternative Communication (AAC) models often fail: they systematically misinterpret a physical, motor, or sensory breakdown as a lack of intellectual or language capacity.

Typing is not a magical cure; rather, it is a motor-accessible alternative pathway specifically engineered to accommodate over-selectivity, dyspraxia, and context-bound learning. This approach aligns perfectly with modern developmental science. Non-speaking individuals do not lack language; they lack a reliable, accessible motor pathway to execute it.

As professionals in the field of autism for decades, we are acutely aware of the core characteristics that cut across autistic learners. Our combined years of clinical and research experience suggest that these features directly impact an individual's ability to learn the process of typing to communicate, necessitating the widespread availability of these methods for non-speaking autistics.

The Autistic Learning Profile: Six Core Characteristics

1. Over-Selectivity and Restricted Stimulus Control - The concept of stimulus over-selectivity remains a cornerstone of autistic attention research (Burke, 1991; Lovaas et al., 1971; Ploog, 2010). When presented with complex, multi-component stimuli, autistic individuals often process a limited number of components, leading to sensory overload or skewed comprehension.

Verbal speech is dynamic, ephemeral, and fleeting; it disappears the moment it is uttered and requires rapid, simultaneous processing of facial expressions, vocal tone, and acoustic shifts. By contrast, a physical keyboard provides a stable, invariant visual and tactile layout. It effectively isolates the target stimulus (the letter) and eliminates the fluid "sensory noise" of vocal demands, creating an optimized, predictable environment that accommodates monotropic focus.

2. Apraxia, Dyspraxia, and Motor Planning Challenges - Modern neuroimaging and clinical motor studies demonstrate a massive overlap between autism and motor execution deficits. Research indicates that up to 80% of autistic individuals experience significant gross or fine motor impairments, with structural studies highlighting profound deficits in praxis (motor planning) and visual-motor integration (Ming et al., 2007; Mostofsky et al., 2006). In a key study of autistic preschoolers, Vivanti et al. (2025) presented data showing that approximately one-third of non-speaking preschoolers do not develop functional speech across major intervention models like Early Intensive Behavioral Intervention (EIBI), Early Start Denver Model (ESDM), Treatment and Education of Autistic and Related Communication-Handicapped Children (TEACCH), or Naturalistic Developmental Behavioral

see Typing on page 32

Mental Health Care for People Who Use AAC: Rationale and Practice

By Alex LePape
Beth Rosenwasser, PhD
and Manley Ghaffari, MD

Introduction: A Speller's POV

Therapists are my heroes — they transform problems into paths toward the future you want to build. I was scared to start. My psychiatrist told me that meds alone would not solve my anxiety, and she encouraged me to give therapy a try.

Dreams make work, and sometimes you need help getting started. That's where I was when I started therapy. I wanted to build an adult life outside of my family, but I was afraid of so many things: not having a Communication & Regulation Partner (CRP) who knows how to help me stay regulated, not being able to manage my migraines, not finding support from professionals who believe I am capable. Most of all, I was afraid of being judged and found lacking because of my long struggle to convince my school district that I am worthy of education.

Therapy opened doors for me when I was stuck. I think having my inability to speak NOT be a barrier is so important for other therapists to understand. I hope more nonspeakers will give it a try, and more therapists will be willing to take us on as patients.

How It Started

Dr. Ghaffari's POV (treating psychiatrist): Alex and I started working together in 2017 when he was referred to me by a colleague to evaluate his medication regimen. At the time, he was happy and doing well in high school. He had just started using spelling to communicate with his mom as his CRP. It was a hopeful time for him and his family as he found his voice. His increasing ability to communicate was associated with decreasing anxiety and an increasing ability to self-regulate, so our goal was to slowly taper him off medications he had taken for many years to help him self-regulate. During this time, Alex and his family were also advocating for access to a CRP at school.

Unfortunately, his school district did not recognize spelling to communicate (S2C) as a valid intervention and refused to include it in his individualized educational plan. This led to a protracted legal battle with the school district, which demoralized Alex and invalidated his sense of agency. By 2018, Alex was struggling with extreme anxiety resulting in bouts of dysregulation that led to aggression towards his family. With aggression came a lot of shame, and Alex grew even more anxious about his ability to control himself. Instead of lowering doses, we were now escalating doses of existing medications and trying new medications to reduce and control his anxiety. The goal was to disrupt the cycle of anxiety, aggression, and shame.

Alex was the first person in my practice who used spelling to communicate. I quickly became aware that I needed to adjust the flow of our conversations. I had to be more patient and mindful of the tempo of my questions. I had to make sure Alex had time to respond without me speaking over him as he spelled. I was thrilled that he had found a way to express his feelings, and I did not perceive his form of communication as a barrier to treatment.

Alex was like any other teenager; he was working on self-awareness and how to recognize his own emotional patterns and responses. It became clear to me that, like most others struggling with anxiety, Alex needed to work with a skilled therapist who could help him through this process. Furthermore, like many others suffering with anxiety, medications alone would not

see Mental Health on page 38

Training Communication Partners for Nonspeaking Spellers: A Replicable, Evidence-Informed Framework

By Dawnmarie Gaivin, RN, AT-ACP
Executive Director, Spellers Freedom Foundation, Co-Founder, Spellers Method

Dawnmarie serving as a communication partner for her son, Evan, during the filming of the movie SPELLERS (now on YouTube)

I have watched my adult nonspeaking, autistic son be offered a letterboard by someone untrained in his primary form of communication: spelling. His thoughts were clear, but the board wasn't properly placed, no relationship had been established, no motor coaching was provided — and nothing came through. I have also watched what happens when his Communication Partner is well-trained: the letterboard lands in the same position every time, the energy is calm and supportive, the prompts are motor-based. My son begins to spell. The difference between those two moments is not my son. It is the training — or absence of it — in his Communication Partner.

A Communication Partner, as defined in the augmentative and alternative communication (AAC) literature, is any person - teacher, parent, paraprofessional, therapist, or peer - who regularly interacts with a nonspeaking individual and whose behavior directly shapes the quality of that interaction (Kent-Walsh & McNaughton, 2005).[9] In spelling-based AAC, the CP's role extends well beyond conversation: they position and present the letterboard or keyboard, provide motor coaching through a structured prompting hierarchy, read the speller's regulatory state, and create the physical and relational conditions under which intentional communication can occur.

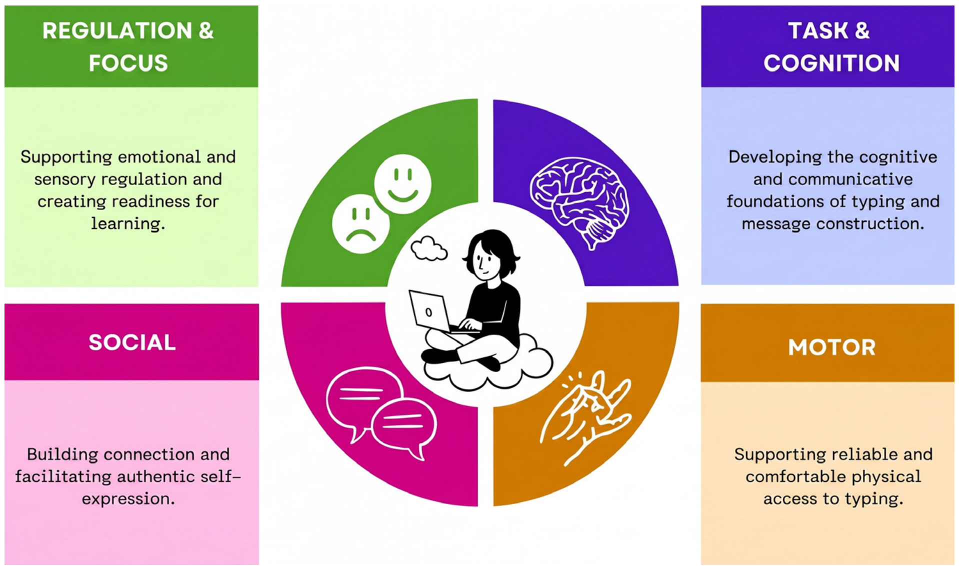
Unlike systems where a device carries the message independently, spelling-based AAC is a relational act - and that relational quality, while its greatest strength, also introduces a variable that demands rigorous attention: the potential influence of the partner. Influence is actually present in all communication; Kent-Walsh and McNaughton (2005) describe it as inherent to every human interaction.[9] The difference for spelling CPs is consequence: when influence flows from CP to speller during open communication, it doesn't color the message - it replaces it. Learning to recognize and actively counter that risk is a distinct, trainable competency.

The AAC literature has long documented what untrained partners actually do: they dominate interactions, ask predominantly yes/no questions, interrupt, and provide few opportunities for the AAC user to initiate or respond (Kent-Walsh & McNaughton, 2005).[9] When the CP is the variable that determines whether a nonspeaking person can communicate at all, CP training is no longer a professional development option - it is an access issue with a legal framework. Under Title II of the ADA, public entities must ensure that communications with individuals with disabilities are as effective as communications with others. Under IDEA, students are entitled to a free and appropriate public education in the least restrictive environment - a guarantee that is hollow without access to their communication system. A trained CP is not a supplemental service. It is the infrastructure that makes those rights real.[1,2] This article describes what that infrastructure looks like - and what it takes to build it.

see Spellers on page 39

The Work Before the Work: Lessons From Co-Designing Assistive Technology with Nonspeaking Autistic People

By Sofya Gektin, University of Virginia,
Sajad Sarlaki, University of Calgary,
Grant Blasko, University of Washington,
Kristen Gillespie-Lynch, College of Staten Island & The Graduate Center of the City University of New York,
Isaiah Tien Grewal, Stony Brook Medicine School of Social Welfare,
Vikram Jaswal, University of Virginia,
Sujit Kurup, Autism National Committee (AutCom),
Chandra Lebenhagen, Including Autism,
Graciela Lotharius,
Georgia Perimeter College,
Elizabeth MacNeil, University of Alberta,
Kyle Stauber,
Caroline Rose Tallungan,
University of Virginia
Lisa Vallado,
Washington Adventist University
and Diwakar Krishnamurthy,
University of Calgary



What co-designers find essential for learning and practicing typing

"I still struggle to put into words what it felt like to finally communicate in a personal, voluntary, and unscripted way. I've described it before as a prison door opening, but it was even more profound than that - more freeing, more life-changing." - Lisa, nonspeaking co-author

For many people, communication happens so effortlessly it is almost invisible. A thought forms, and out it comes. We rarely stop to consider everything that happens between having something to say and successfully expressing it.

Lisa is describing what it felt like when that pathway finally opened. After years without a reliable way to communicate her own thoughts, she was able to express herself in a way that was personal, spontaneous, and unmistakably her own.

Lisa is not alone. Around one in three autistic people are nonspeaking, moving through a world that often treats speech as the standard. Some eventually learn to communicate fluently by typing, but the path is often long, intensive, and difficult to access.

Many technologies designed to support communication reflect neurotypical assumptions about how communication works, what successful communication looks like, and which challenges matter most. Far less often are they shaped by the people who must navigate those assumptions every day.

What might we learn if they were? That question is at the heart of TYPE, an ongoing effort to design an affordable, AI-supported system to help nonspeaking autistic people learn and practice typing. The project brings together engineers, researchers, clinicians, educators, and six nonspeaking autistic adults who type to communicate. From the start, the nonspeaking collaborators joined as equal co-designers, helping shape the project's priorities and its direction.

Over the past year, the conversations expanded beyond the technology itself. Together, our co-design team explored what communication feels like from the inside: how thoughts become actions, how support creates opportunity, and how communication technologies can better reflect the realities of the people who use them.

The Hidden Work of Communication

One of the first ideas we talked about was motor planning – the invisible work of turning intention into action.

"As I have autism there are motor planning issues that I face every minute," explained Sujit, a nonspeaking co-designer.

see Co-Designing on page 40

The Miracle Project's Express Yourself Program Gives Nonspeaking/Multi-Modal Artists the Stage

By Elaine Hall
and Hannah Olander, LCSW
The Miracle Project

The Miracle Project (TMP), founded in 2004, is internationally recognized as the first systematic, evidence-based program to use expressive and performing arts to improve quality of life and relationships for autistic individuals while challenging negative societal stereotypes through authentic artistic representation. A 2014 California State University, Northridge (CSUN) study, funded by the National Endowment for the Arts, demonstrated that TMP's methodologies improved social communication, strengthened relationships with typically developing peers, reduced anxiety, and fostered more positive public perceptions of autistic individuals (Kim et al., 2015).

TMP welcomes minimally speaking and nonspeaking participants, including founder Elaine Hall's son, Neal, whose experiences helped shape the organization's philosophy. We consistently witnessed creativity, humor, insight, and artistry from people with complex communication profiles while recognizing that they remained among those most underestimated and excluded from arts education and creative opportunities.

Express Yourself participants during the filming of "Let My Typin' Let You See," one of the program's original music videos

Enter "Express Yourself." TMP envisioned a creative arts program intentionally designed for people who are minimally speaking, nonspeaking, or unreliable speakers. Participants themselves introduced the term *multimodality communicators*, including AAC, typing, speech, gesture, movement, and facial expression—rather than defining people by what they cannot do. TMP received funding to develop the program in 2019, and Express Yourself was conceptualized by TMP founder Elaine Hall in collaboration with speech-language pathologist and AAC specialist Darlene Hanson; together they created a creative arts program designed around multimodal communication.

In addition, Express Yourself was grounded in the SCERTS Model, developed by Dr. Barry Prizant and colleagues, with training provided by Dr. Prizant and Dr. Amy Laurent before launch. SCERTS' emphasis on social communication, emotional regulation, and transactional supports aligned naturally with TMP's participant-driven creative process, reinforcing an environment where all forms of communication could be recognized, supported, and expanded through the arts. Like every TMP program, Express Yourself begins with movement. Drawing on her background as a movement specialist, Hall introduced gentle guided movement that encouraged participants to discover their own forms of physical expression. There was no right or wrong way to move, which created a nonjudgmental environment that promoted self-expression and connection. From there, participants engage in collaborative songwriting, storytelling, improvisation, movement, and creative exploration. The goal is not to produce a predetermined performance but to create an environment where communication, creativity, and relationships develop according to participants' interests and ideas.

see Express Yourself on page 41

Giving Voice to Nonspeakers: Language, Respect and the Power of Naming

By Annie Kent, MA Psychology
#ActuallyAutistic Mental Health/
Autism Advocate, Freelance Writer,
and Educator

For the longest time, I used the term *non-speaking* synonymously with *non-verbal*, having been taught 'non-verbal' in graduate school. Since that time, new terms and definitions have emerged with the advent of a variety of disability rights movements.

Person-First Language

Person-first language discouraged people from equating individuals with their illness or physical condition. For example, instead of "Tom is Schizophrenic," 'person-first' turned it into "Tom has Schizophrenia." Similarly, the "cardiac case in Room 302," became a more respectful, "patient with heart disease in room 302."

Person-first language was an integral part of the first Disability Rights Movements—civil and social advocacy campaigns that aim "to ensure accessibility, equal opportunities, and inclusion for persons with disabilities worldwide. The disability rights movement has long been focused on "breaking down social and physical barriers that otherwise prevent disabled individuals from engaging fully in employment and education and from living independently and enjoying freedom from discrimination" (Britannica Editors, 2024).

The Rights Movement in the Autism Community has more recently achieved visibility. Autism Rights is "a sociopolitical campaign that advocates for the social acceptance and inclusion of individuals on the autism spectrum. Known also as the Autistic Liberation Movement or the Autism Self-advocacy Movement, it emphasizes the concept of "neurodiversity," which posits that variations in brain function and behavior should be recognized as part of human diversity rather than medical disorders needing treatment" (*Autism Rights Movement | EBSCO*, 2025).

Non-verbal Defined

Dictionaries define *non-verbal* literally as "conveying information without using words" (*Definition of NONVERBAL*, 2026). *Non-verbal* is an outdated term that wrongly suggests a lack of all communication ability, reinforcing outdated and harmful assumptions. "Non-speaking" … reflects what many individuals have said about their lived experiences…It's not about what someone can't do; it's about how they communicate" (McRory, 2025).

Verbal vs Non-verbal Communication

It's commonly accepted that about 80% of what we communicate is non-verbal, involving actions and gestures, while only 20% is conveyed using words (Cherry, 2025).

Non-speaking centers on communication strengths, rather than perceived deficits, in a way that reflects dignity, intelligence, and capability. Language shapes identity; not only reflecting how others see us, but how we see ourselves (McRory, 2025).

Communication In Non-speaking Autism

Many non-speaking individuals are highly capable of understanding and using language. They simply express it in ways other than the spoken word. "Language is a system of patterns and symbols used to communicate. It is defined as the comprehension and/or use of a spoken communication system (i.e., listening and speaking), written (i.e., reading and writing), and/or

see Power of Naming on page 43

“The Best Medicine is Respect!” Creating a Supportive Healthcare Environment for Nonspeakers

By Rosemary Corcoran, MS, OTR/L,
Hannah Facey, MD,
Jefferson FAB Center for Complex Care, Thomas Jefferson University
and Sarah Ackerman, Self-Advocate

For around 30% of people with autism spectrum disorder (ASD), verbal speech is limited, unreliable, or unavailable (Jaswal et al., 2026). Autistic people who are nonspeaking use a variety of augmentative and alternative communication (AAC) to communicate; this includes picture-based systems, high-tech image-based systems on tablets, typing on keyboards, or using letterboards with communication partners (ASAN, 2026).

Many primary care providers have received little to no specialized training in supporting the care of patients with autism, with common barriers to providing quality care cited as lack of confidence in managing behavior, lack of time, lack of resources about autism, and lack of prior training in autism (Mazurek et al., 2020). Without training and opportunities to learn from autistic advocates, providers are less prepared to support the needs and communication styles of nonspeaking autistic adults. As a result, people with IDD/A are less likely to receive all recommended preventative screenings in adulthood, which can result in higher rates of certain cancers and other health conditions being diagnosed in later stages of disease (Javaid, Nakata, & Michael, 2019).

An exam room at the Jefferson FAB Center for Complex Care. The room is large, with additional seating options for patients or supporters, a height-adjustable exam chair, and dimmable lights.

There can be many challenges for an autistic person to participate in their medical visit and receive quality care. Fear and anxiety, need for additional processing time, sensory sensitivities, and difficulty communicating effectively with providers were identified as primary barriers by autistic individuals (Raymaker et al., 2017).

Autistic advocates are the best teachers to ensure medical providers can provide quality care following the principle “nothing about us without us.” Creating a supportive healthcare environment can support positive outcomes for autistic people.

Recommendations from a Nonspeaking Self-Advocate

Consider these recommendations from a nonspeaking self-advocate and responses from a physician on how to best support and implement these recommendations in the medical office.

1. We hear and understand everything that is shared with us. When healthcare professionals enter a room for a patient visit, the default should be to presume competence and to presume strong receptive language even when patients are nonspeakers. All conversations should be directed to the patient first, not to their caregivers or support persons.

2. Speak with us like we are adults. Providers should always use age-appropriate and respectful language when communicating with patients. Using infantilizing language is both disrespectful to the patient and creates distrust in the relationship.

see Respect on page 42

My Journey to Independent Typing: One Autistic Nonspeaker’s Story

By Gregory C. Tino
Non-Speaking Autistic Self-Advocate

Each autistic nonspeaker I know is trying to become independent with their communication.

Of course. Why wouldn’t we? If you have something to say, you want to be able to do it without help. Typing seems to be the holy grail for most.

Why?

Because the sad but true fact is that the skeptics don’t believe that communication on a letterboard is our authentic voice. Having a CRP (communication and regulation partner) to hold the letterboard and keep us regulated is something we have difficulty doing for ourselves. Trust me, if we could do it, we would.

Disregarding the words of the many autistics who learned to communicate with a letterboard because you are a skeptic is a terrible tragedy! Some autistics are so affected by their apraxia that they will never be able to type, no matter how much they practice. Why should we disregard what they have to say?

I am one of the lucky ones who is able to type. My apraxia is there, believe me, but I have been slowly learning how to become an independent typer. I have been working on this for years, probably about three years by now. Some days are EASIER, but no day is ever EASY. Apraxia decides the type of day you will have. History has shown me that I am on a slow trajectory of progress and it keeps me going. I have all the time in the world to work on this. I have gone from typing just a few words independently to once, a whole page! Communication and writing are going to be my lifelong goal.

Gregory C. Tino

Seems to me that everyone defines “independent” differently. For me right now, my “independent” is that my keyboard is now placed on a stand in front of me and my CRP no longer needs to hold it. I still need my CRP sitting next to me for regulation support – giving me words of encouragement to keep going, to slow down if I am going too fast and getting sloppy, or to give me a break if I need it. To the skeptics, “independent” is one thing only – typing in a room all by yourself with no support of any kind. Once an autistic nonspeaker gets to that point, the skeptics will probably move the goalposts once again. They will say “now we need you to type on your keyboard on a mountaintop during an earthquake and then we will believe in your abilities.” I have stopped trying to convince them and instead focus on people with a more open mind.

Typing independently is the hardest thing I have ever done. My apraxic body is like a drunk toddler. Like trying to wrangle a bunch of kittens. In other words, it is HARD! What helps me is a rested body, a quiet room, and a calm and encouraging CRP. Finding the best time of day can be challenging. I can’t be too hungry, or busy, or preoccupied with something else. The moon and stars have to align! I joke, but that is how it seems to be in the beginning. Now I am finding I can do it over an increasing number of situations. So, I keep going. I practice weekly in my Spelling to Communicate sessions with my practitioner and good friend, Tom Foti, from Inside Voice. Then I try to practice at least a couple of times weekly with my mom and partner in crime, Linda Tino. I am incredibly thankful and humbled that people will spend so much time sitting with me day after day, hour after hour, trying to get me to my goal of independent typing. In the meantime, I will continue on with what I have accomplished so far. I am a blogger at The Autistic Mind Finally Speaks on WordPress. I have a YouTube channel where I have videos I have written trying to educate about autism and also with poetry I have written. I have a Facebook page and I have written and self-published six books on Amazon.

Typing is typing no matter who is sitting next to you. Try to keep an open mind and maybe seven years from now I will be typing to you from a submarine at the bottom of the sea.

That will show them!

Gregory C. Tino is a non-speaking autistic self-advocate. To contact Gregory, email gregory.tino13@gmail.com.

The Right to Learn: One Nonspeaking Autistic Student's Case for Educational Access and Dignity

By Matthew Cramer
Nonspeaking Autistic Student
Philadelphia Performing Arts
Charter School

Beginning as a small child, school is where you make friends and learn to process the world around you. Most of modern society is formed on the basis that people have received a formal education. Whether that education be from primary to high school, or onward to a college education, it is presumed that all children had that foundation.

Ever since I was a young boy, I have had the desire to learn. There was an itch I needed to scratch from early on. I was extremely curious about the world around me. However, as a nonspeaking autistic, I was left with questions I was unable to verbalize. I faced enormous challenges in getting the education I dreamed of and deserved. However, I did not let this stop me from chasing my passions and dreams, though it did not come easily. Like other students, I, too, had to prove my intelligence, but even more so than my neurotypical peers. Through my education, I have learned about the world in ways I was told I would never understand. If this educational foundation is presumed, what about the students who do not receive it?

Matthew Cramer

In elementary school, before I found spelling as an effective form of communication, I struggled. I understood what others were telling me to do, but I could not show it. I remember the frustration I felt in not being able to explain to my teachers that I fully understood the books we were reading in class or basic math problems. That all changed at the age of 12, after discovering Spelling to Communicate, a technique that taught me how to spell out my thoughts on an alphabet letterboard or do calculations on a numberboard. Despite this breakthrough, I needed to adapt and adjust early on to achieve my dream of being educated. It required more resources than my school could provide. My devoted parents encouraged me not to give up, and we searched for other resources. With much hard work, tremendous support, and advocacy, including transfer to a school that would allow my use of a letterboard and then keyboard in the classroom, I have been fortunate to have had educational opportunities typically denied to nonspeaking autistics.

My personal journey through the education system thus far, from an autistic support classroom in elementary school to honors and AP classes in high school, and now to a dual enrollment program with Temple University, gives me a unique perspective. I understand and appreciate the value of an appropriate and inclusive education for all individuals, especially neurodivergent students who have difficulty communicating.

Education is the systematic process of learning, gaining new skills, and acquiring healthy life habits. It sets the foundation of any young person's life. School is where you gain knowledge that you can continually build upon. It is where you develop reasoning and critical thinking skills. It is where you can discover your interests and passions. A formal education challenges an individual to think freely and independently and promotes liberties in self-expression. This freedom of thinking and creativity is critical for personal growth and development. It is clear that the impact of a formal education is life-changing. If students' needs are not met, then this critical foundation for learning is missing. The reality of this can feel alienating. Everyone deserves a solid and appropriate formal education. I argue that access to such education is a sacred human right that needs to be protected.

Much of the world has some sort of education system, although it varies across the globe. Modern society is based on the premise that children receive a formal education. The field of education has vastly changed in the modern age. It has integrated modern technology, acceptance of learning differences, and a diverse range of students with different socio-economic backgrounds, ethnicities, and neurodivergencies. With adjustments and improvements, educational opportunities have opened up to more students. Yet, despite these advancements, barriers to education access persist.

Education systems are influenced by a variety of factors including inequities by

see Access and Dignity on page 47

Connecting With Nonspeakers: A Practical Guide

By Noah McSweeney
Nonspeaking Autistic Self-Advocate,
College Student, Poet, and
Award-Winning Student Journalist

April traditionally brings showers, but in my world, it brings Autism Awareness Month – or is it Autism Acceptance Month, or is it Autism Action Month? It seems the verbiage changes from year to year. Awareness is good, acceptance is great, but action is the key to inclusion. For me, April means a flood of attention, love, and sometimes overwhelming feelings. I don't know whether to run and hide or let myself stand out.

This April, I want to take some action to include those who communicate differently.

There are many ways humans communicate. A lot can be said without words; power exists in a glance or gesture. Although words are not always necessary, most people possess the ability to speak when and how they want. However, millions of individuals with disabilities that affect speech must endure a life without spoken words. Believing that someone is unintelligent because they can't speak is hurtful and often just plain wrong.

Autistic people who lack speech or reliable speech may use alternative ways to communicate. This is also true of others with conditions like Down syndrome, cerebral palsy, or other unnamed developmental disabilities. Even stroke survivors may need speaking accommodations.

Noah McSweeney selects letters to ask a question of a guest speaker with the help of his communication partner Buckminster Barrett during an Oak Leaf class March 4, 2025. Photo credit: Ziggy Leon Carrillo

There is, however, a way to be heard even if you don't speak.

Augmentative alternative communication (AAC) gives those of us otherwise trapped in silence a voice for all to hear. I use a low-tech version of AAC called a letterboard, a laminated piece of cardboard with the alphabet printed in rows. Sometimes I use a high-tech version of AAC, with a keyboard connected to an iPad and voice output. It all depends on my level of fatigue and sensory overload.

People often hesitate to engage nonspeakers in conversation. This may be because they're unsure how. Even though AAC users vary widely in diagnosis, the opportunity to share insight presents itself this Autism Action Month. Please educate yourself on how to interact with nonspeaking AAC users with the below tips.

Tips for Connecting with AAC Users

1. Talk to us and know we understand you. This presumes competence. We may not show that we are listening in traditional ways, but we hear you. We might look away to hear you better. Personally, my eyes and ears don't work at the same time; it's just the way my sensory system operates.

2. Be prepared to wait for our responses; they will take time. Most AAC users struggle to coordinate their eyes and hands. The pace of spoken conversation is quick. Although we take things in, responding in real-time requires that we use our AAC. This may mean spelling thoughts out one letter at a time, pointing, or typing. Without adequate wait time, our thoughts miss a timely window to enter the conversation. A change to new topics renders our contributions irrelevant. This is hurtful and discourages AAC users from engaging in social situations.

see Connecting on page 42

Very Great Sound: The Case for Teaching Poetry to Nonspeaking Autistic Students

By Ralph James Savarese
Professor of English
Grinnell College

Last April, I found myself in a Stockholm studio, sitting next to my college buddy Spencer Reece, with whom I'd taken my first creative writing course forty-three years ago—our teacher was the Pulitzer Prize winning author Annie Dillard. We had traveled to Sweden to teach our own creative writing course and were appearing on the Swedish podcast "With Hope for a Better Life". The episode was devoted to the topic of creativity, whose benefits are numerous: from countering loneliness to alleviating stress to improving one's mood to building resilience to expanding self-awareness to relishing surprise to establishing community. Many of these effects have been corroborated by empirical investigation. At one point, my friend Spencer said that poetry had saved his life. It had helped him to climb out of alcoholism and to move toward God. Following the example of his hero, the 17th Century English poet-priest George Herbert, Spencer became a priest in 2011.

Ralph James Savarese with his son DJ

I spoke on the podcast about fostering creativity in the nonspeaking autistic community. For more than twenty years, I have taught free poetry writing classes and one-on-one tutorials to young people who type or spell to communicate. For the last eight years, I've taught these classes with my son who is himself nonspeaking and whom I adopted from foster care at the age of six. (He carried the label of "profound mental retardation"). A Phi Beta Kappa graduate of Oberlin College and the subject, writer and coproducer of the Peabody Award winning documentary Deej, he is also the author of three volumes of poetry. At Oberlin, he was lucky enough to take a course on the teaching of poetry writing from the poet Lynn Powell. We know from the evaluations that our students relish the opportunity to learn from one of their own and to see a father-son team so passionately in action. Because we provide rigorous instruction and feedback, students get a taste of the wondrous difficulty of making genuine art. It's a laboratory for growth. We take them seriously by having them reach for the stars.

Poetry saved our lives, too, we'd say wholeheartedly. It did so by establishing a form of joint attention that could see us through the horrors of my son's early years and the exclusionary prejudices of an ableist society, all the while offering palpable, sensory-driven pleasure. One of the first things my son typed on a computer concerned a poem by Dylan Thomas called "Fern Hill," which recounts the summers the poet spent as a child on his aunt's farm and which I had read aloud to my wife. "Now as I was young and easy under the apple boughs,/ About the lilting house and happy as the grass was green,/ The night above the dingle starry…" "Very great sound," my son typed. "Very great sound." His pattern-detecting ear had discovered the delivery mechanism of emotionally infused beauty, what scientists call a poem's foregrounding aspects: meter, rhyme, consonance, assonance, alliteration… (frontiersin.org; sciencedirect.com; jbe-platform.com). As one study puts it, "[Our] results point to a similarity between

see Teaching Poetry on page 44

The Power of Presuming Competence: A Nonspeaker's Call to Action

By Jace Pooley
Nonspeaking Autistic Self-Advocate

I stop and think about what I went through as a young child all the time. On a scale of 0 to 10, so many of the therapies that overtook my life would get a negative number! It wasn't that the therapists were bad people; it was because the initial premise of the treatments was fatally flawed. How? I might not have been able to talk, but I knew hundreds if not thousands of words. Pretty silly to assume that just because someone can't say something, they don't know it. How else? I observe the world differently, listen differently, and remember differently than others do. There is the belief that anyone who observes, listens, and remembers like me actually isn't able to learn anything from the world around us. Lots of therapies expect to have to teach patients like me literally everything we'll know—that we are just empty shells. And how else? The most popular explanations for my lack of eye contact, not to mention my lack of pointing, get it all wrong! Physical challenges are read as emotional distance ("he's not making eye contact because he doesn't connect with others") or not trying hard enough ("he's not pointing because he's being stubborn"). So even though almost all of my early instruction required my looking and pointing, no one ever taught me how to look or point!

Jace Pooley hiking the Appalachian Trail

Now think about what all those hours of therapy could have looked like with a different mindset. I'll start with how we might reduce the focus on talking and replace it with a focus on communication, and not just the labeling of a few items but the power to share anything. I took actually communicating into my own hands, literally, by grabbing a pencil to write my thoughts. This took lots of people by surprise, like those trying in vain to teach me to talk and those laboriously trying to get me to point to vocabulary words (and assuming that the vocabulary words were the hard part when the pointing was). Communication doesn't have to mean speaking, and it also shouldn't be limited to pathetically few picture cards to point to. The goal has to be getting to use the alphabet, whether with a pencil or letterboard or keyboard.

This requires addressing multiple misconceptions: replacing gross underestimations of what nonspeakers know with presuming competence, and fully appreciating the physical challenges nonspeakers face. If you're not familiar with "presuming competence," definitely follow this closely, write this down, and post it somewhere you'll see every single day. Presuming competence means you give someone the chance to show you their intelligence and empathy and humor because you believe that they are capable in all of those ways. The default expectation is actually that they can think through any demand or question. And that's true even if responding is physically taxing, and their body behaves differently than yours or needs extra coaching. Keep in mind that our bodies may be struggling even as our brains get immediately to the right answer. This is why motor planning support is so important!

Going forward, how about we prioritize a few things for nonspeakers? Let's presume competence for sure. If we do, probably lots more people will go to greater lengths to help nonspeakers pursue their goals, grow their confidence, build relationships, and find their voice. Presuming competence means doing things like reading literature or school textbooks out loud, holding real conversations that are age appropriate (even if nonspeakers can't

see Call to Action on page 48

Lessons From Listening to a Typer: Stony Brook Medicine School of Social Welfare Leadership Education in Neurodevelopmental and Other Related Disabilites (LEND) Fellowship Program

By Isaiah Tien Grewal
Stony Brook Medicine School of Social Welfare LEND Fellowship Program
and Michelle S. Ballan, PhD
School of Social Welfare; LEND Program, Stony Brook University

Director's Perspective

It was July 2022, and I had just finished my first year as the Director of theStony Brook University Leadership Education in Neurodevelopmental and Other Related Disabilities (SBU LEND) Program. Invited to present on the Research Panel for the I-ASC Motormorphosis conference, I felt a tap on my shoulder from the 6'5" nonspeaking panelist, Isaiah Grewal (Iz), beside me. I had just responded to the query, *"Do you have any research questions about nonspeakers and their experiences you'd like people to study?"* As a practitioner-researcher, I discussed that due to inaccessible communication modes or lack of communication modalities, many nonspeaking individuals, who are my clients, wander. This primary means of communication is often misunderstood and relegated to lack of intelligence, sudden mood changes, aggressive behavior, and not recognizing danger. The current literature on wandering fails to account for elopement as communication. My National Science Foundation grant examines elopement by individuals with autism and other developmental disabilities through the creation of a predictive screener using a gait sensing system and physiology to relay nonspeakers' intent to leave an environment. As I provided this response to the audience, Iz was tapping his finger fiercely. He shared that he eloped from school because teachers spoke about his perceived lack of intelligence in front of him. This gross presumption of incompetence triggered fight or flight response. The trauma of this repeated situation and the empirical studies that fail to include typists' perspectives on communication (such as elopement) skews product development, cognition research and education. How could we begin to quickly make systemic changes with non-speakers?

Isaiah with his 2024/25 LEND faculty and classmates at on-campus Orientation

Fast forward four years later to our 5th Annual LEND Research Exposition, and the majority of the presentations by graduate and postgraduate students, healthcare professionals, self-advocates and families included nonspeakers or addressed research gaps due to their lack of inclusion. This shift in perspective, understanding, and attention to nonspeakers is now commonplace in the SBU LEND due to Iz's programmatic contributions and vibrant participation across two cohorts. Funded by the Health Resources and Services Administration, LEND provides four levels of training to improve the lives and care of individuals with autism and other neurodevelopmental disabilities, without cost to participants. This is accomplished by preparing trainees from a range of professional healthcare disciplines, families, and self-advocates to be leaders in their fields, by ensuring the delivery of high-quality evidence-based care, by maximizing inclusion of traditionally underrepresented groups, and by cultivating high levels of interdisciplinary clinical competence. LEND focuses on the policy, advocacy,

see LEND Program on page 45

Building Functional Communication: Empowering Families Through Evidence-Based Caregiver Intervention

By Daniel Magin, MA
Hanna Kent, MA
Melissa L. Rinaldi
and Kristin V. Christodulu, PhD
University at Albany Center for Autism and Related Disabilities

Communication is a tool that takes many different forms. When most people hear this word, they think of verbal communication, as used in this article. However, even within verbal communication, there are many ways of expressing ideas, needs, and thoughts. Some of these methods of communication are more effective and efficient than others. Some are more disruptive.

Autistic individuals have social communicative differences that make it more difficult to develop and use effective communication strategies (American Psychological Association, 2022). These differences can interfere with their ability to advocate for themselves, maintain relationships with others, and function independently in a world that relies heavily on communication (Jobe & White, 2007).

Fortunately, early identification and intervention can significantly improve an autistic individual's capacity to effectively communicate with others (Fuller & Kaiser, 2020). One of the most efficient methods of disseminating these intervention practices is through caregiver training (Kemerer et al, 2023). The Center for Autism and Related Disabilities at the University at Albany has been implementing a virtual Early Start Denver Model-based caregiver training program to do just that. The Early Start Denver Model is a parent-mediated, naturalistic developmental behavioral intervention that can be used to increase goal-directed communication behaviors (Rogers, 2021). Importantly, this intervention has been shown to be beneficial for non-speaking children in providing them with the foundational skills needed to express their needs appropriately (Schuck et al, 2022).

This is particularly important in this population, given that non-speaking individuals are significantly more likely to develop disruptive behaviors when they do not have access to an alternative way of communicating (Hill et al, 2014). When early intervention programs like the Early Start Denver Model have not been used or they are insufficient, autistic children may develop behaviors that impact their quality of life and their ability to advocate for themselves.

That is when a caregiver training program like the Research Units in Behavioral Intervention can be implemented to address these disruptive behaviors and provide nonspeaking children and adolescents with an alternative means of meeting their needs (Bearss et al, 2018). Through an evidence-based strategy called Functional Communication Training, in combination with various other behavioral strategies and environmental accommodations, non-speaking autistic individuals can be taught to use tools like AAC devices to effectively and efficiently communicate their desires to others (Bearss et al, 2018). The Center for Autism and Related Disabilities at the University at Albany has been implementing a virtual, group-based psychoeducational program to disseminate this evidence-based information to families in the Capital region of New York for several years, with outcomes indicating that families significantly benefit from this resource.

see Empowering on page 39

What Parents Should Know About ASHA's Position Statement on Spelling Methodologies

By Andrea Palerino, PhD, PPCNP-BC
Assistant Professor
Utica University

Ninth grade was a turning point for my nonverbal daughter with autism. After years in a life skills classroom, she moved into an academic setting. For the first time, she was studying algebra instead of counting money and writing paragraphs instead of discussing the weather each morning. This transition was only possible because she had learned to communicate using a letterboard.

I first heard about spelling from two other mothers of autistic children, but I hesitated to explore it in part because of the American Speech-Language-Hearing Association's (ASHA) position statement, ASHA Warns Against Rapid Prompting Method or Spelling to Communicate. In hindsight, I wish I had known that the statement contained factual inaccuracies and reflected bias—it might have led me to try this approach much sooner. I offer this for parents who are considering a spelling journey.

ASHA's position statement lists five concerns about spelling methodology. The first claim against spelling methodologies is that **there is uncertainty regarding who does the spelling**. It states that "a simple way to reduce facilitator bias is for the aide to place the alphabet board on a table or mount instead of holding it in the air." Yet ASHA also permits speech-language pathologists (SLPs) to hold, stabilize, or position an AAC device. This suggests a double standard: SLPs are presumed capable of handling a device without influencing communication, while spelling practitioners are not. The International Association for Spelling as Communication (I-ASC), however, outlines best practices that include presuming competence, understanding the cognitive-motor balance, and ensuring proper board positioning. As with many developmental disabilities, prompting is often most intensive during early skill-building and usually decreases over time. Prompting is also used extensively by SLPs and was documented frequently in my daughter's individualized education program (IEP). Furthermore, requiring fully autonomous communication is inconsistent with the Americans with Disabilities Act.

My daughter speaking with New York State Assembly members at the Capitol

ASHA's second claim, **that RPM creates dependence on another person and therefore prevents independent communication,** relies on an outdated concept of "independence" that disability rights advocates have long rejected. It also overlooks the motor-planning challenges many autistic individuals experience. During our spelling journey, my daughter was diagnosed with global dyspraxia, which helped her school better understand her needs. Using a letterboard or keyboard allows her to complete her studies, connect with peers and family, and pursue her passions, including advocating for her community and finding a boyfriend! We are working with my daughter to help her use a letterboard, keyboard, or iPad on a stand, but I will not deny her the basic human right to communicate simply because she is not yet fully independent.

see ASHA Statement on page 47

Opening the Door: Psychotherapy With Nonspeaking or Unreliably Speaking Autistic Young Adults

By Judith Croen, LCSW
Psychotherapist

This article is about providing psychotherapy services to nonspeaking or unreliably speaking autistic young adults. Going forward the terms "communicators," "typers," or "spellers" are used interchangeably to describe this group. My hope is to encourage parents, professionals, and the wider community to see psychotherapy as a viable option for these communicators who use the assisted typing method (Facilitated Communication/FC) or spelling on a letterboard (Spelling to Communicate/S2C). There are two major hurdles that first need to be addressed and hopefully overcome. Firstly, for some, there is still a bias against psychotherapy in general, that somehow it is a threat to personal autonomy or previously held cultural and religious beliefs, and/or a sign of individual weakness or failure. The second hurdle is that for many there is still an identification with or vested interest in maintaining the belief that autistic nonspeakers or unreliable speakers do not have intelligent inner minds which they are capable of and yearning to express.

Shifting or changing one's belief system about this may be challenging, but it is possible to do so by critically examining all the evidence with an honestly open and inquiring mind.

Watching autistic typers and spellers at work, it is evident how determined and intentional they are when communicating this way. It is also hard not to be struck by the breadth of knowledge they possess, often about things the facilitator (also referred to as communication partner) or psychotherapist (myself) have little or no prior awareness of. However, since seeing alone might not be enough for some to shift previous beliefs and assumptions about the facilitator mentally and/or physically leading the communicator, it is vitally important to actually experience a simulation of the resistive pull-back used in the typing technique to understand what it feels like and why this is needed, which is addressed in other articles.

The idea of doing psychotherapy with a nonspeaking autistic client came to me during the Covid-19 pandemic. The mother of an autistic nonspeaking 14-year-old teen contacted me about helping her son who was going through a number of personal and family challenges. She had learned that I had an autistic family member doing Facilitated Communication (FC) and stated she'd been trained in this method before the pandemic and was now typing with her son at the "open" conversational level using the FC communication ladder. Because the pandemic ushered in acceptance of remote work and the use of telehealth, we were able to collaborate on a strategy to meet her son's emotional needs.

To provide privacy during psychotherapy, I proposed typing my responses instead of speaking to my client, so that our entire conversation would be on the screen of the telehealth platform. The mother agreed and stated she would remove her eyeglasses, therefore being unable to read the screen. This turned out to be a viable solution to the privacy which would be important for me to gain the trust of her son. During the sessions when I thought something my client communicated required his mother's involvement, I would type a message asking

see Psychotherapy on page 46

Autistic Lived Experience: Re-Thinking the Reasons for Past Behaviors

By Sam Farmer
Neurodiversity Advocate, Writer, Author, and Public Speaker

A late autism identification has a tendency to change one's perspective on things. My own identification at age 40 is certainly a case in point. Many questions for which there were never satisfactory explanations, answered. A half-baked self-identity made whole. In essence, a newly discovered lens through which to view myself and the world around me.

Growing up and well into adulthood, my outlook on life was shaped not exclusively but to a significant extent by internalized ableism, unrealistic expectations I held for myself and for others, and self-unacceptance. Consequently, I blamed only myself when criticized for behaviors to which others objected, whenever something didn't go my way, or when I stood apart from the crowd for what I perceived as the wrong reasons. I engaged in excessive self-belittlement due mostly to insufficient self-knowledge and self-love.

In the wake of my autism identification, I worked on adopting more realistic expectations of myself as well as on greater self-acceptance. I committed to learning about what autism entails, which, in turn, led to greater self-understanding. I finally felt comfortable in my own skin, having become stronger and wiser.

There is usually more than one way to look at something. The reason for a particular behavior is no exception. I moved from viewing many of my behaviors in an unfavorable, often unforgiving light to doing so in a healthier, more informed light after my autism was revealed. A few examples:

The Frequent Need to Verify Details

The visible and audible communication of annoyance upon being asked to make the extra effort. "Listen to me in the first place and you wouldn't have to verify." Complete silence. Over the years, these have been among people's responses to my efforts at confirming the facts, simply so that I can be at my best for myself and others.

Pre-identification, I took these kinds of reactions personally, saying to myself something along the lines of "what's the matter with me." Post-identification, I was able to move past that mindset, having arrived at an enhanced understanding of my true self. I also understand that probably most people fail to consider the reasons behind a given behavior before passing judgement.

In this case, the actual reasons have to do with the common autistic tendency to crave certainty. To want to be correct on the details. These are behaviors that are consistent with our neurotype but which often bring adverse consequences.

"Stop Being Defensive"

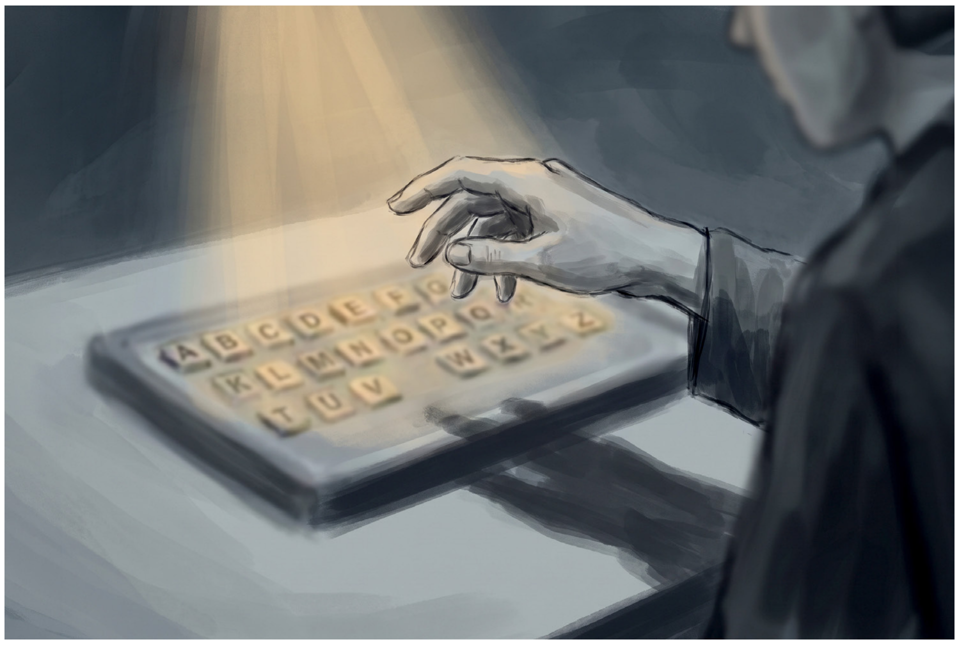
Another example of a response from others that I took personally while growing up and which I would later come to accept about myself. Not that I use acceptance as an excuse for not working on this particular behavior. Rather, I accept my defensiveness as being inseparable from who I am while acknowledging that it should be improved upon. More than one individual whom I have cared about over the years has expressed genuine displeasure with it, and so I do what I can.

Rejection sensitivity is another behavioral commonality among autistic individuals that accounts for why I frequently cannot help but defend myself when I have been denied validation or when I feel like I'm emotionally under the gun. My

see Past Behaviors on page 48

Why Message-Passing Tests Are Unethical

By Jared Hansen
Parent of a Speller



Note: The generic term "Spelling" is used here for all methodologies of assisted communication access with spelled or typed output. The term "Spellers" is a generic label accepted by non-speakers who communicate via these methods. "Non-speaker" (preferred over "non-verbal") includes non-speaking and minimally-speaking individuals unable to engage in spoken conversation.

Spelling as a method of communication access for non-speakers is rapidly expanding within the Profound Autism community. Thousands of Spellers have gained communication through Spelling to Communicate (S2C), Rapid Prompting Method (RPM), Spellers Method, and other assisted communication methods. This is absolutely life-changing (as the Spellers movie effectively illustrates). Non-speakers who spell have become college graduates, valedictorians, researchers, and song, movie script, and play writers, and have authored many books.

Yet these communication methods continue to be challenged by a small group of vocal critics. The central question for critics is authorship: is spelled communication from the non-speaker? How much is it influenced by the communication partner? Anytime another person is involved in the communication process (translator, transcriber, reviewer, editor), there is opportunity to influence the resulting communication. This is especially true of spelled communication where the communication partner is essential to the initial output.

This criticism is nothing new for non-speakers. Helen Keller frequently had to defend against critics who couldn't believe a deafblind person was an author. Stephen Hawking faced accusations that he wasn't the only author of his works, as he relied heavily on others to assemble his text for publication (editing is a very labor-intensive task for a non-speaker relying on AAC). Speech is so intertwined with our perception of intelligence that lack of speech is often conflated with lack of thought.

Prove It

Critics of Spelling and Assisted Typing demand proof of authorship most commonly through a "message-passing test," where a non-speaker is shown something unknown to their communication partner (overtly or via deception), and asked to "pass on" that information. Psychology experiments have often obscured the true purpose of a test by misdirecting participants with false information. This ruse "blinds" the participants so they do not alter their behavior for the test. This is ethical when the expected scientific knowledge justifies the deception and test subjects are not put at risk.

A "blinded" experiment on a non-speaker is an unethical request. Message-passing for Spellers is not a neutral test. The consequences for the non-speaker are incredibly high. Especially for an inexperienced Speller early in the process, or when a test is done without their knowledge and input, this demand is dehumanizing, ableist, and unethical.

Ethical Research

The Belmont Report provides the USA's ethical and legal framework that governs behavioral research on human subjects. It established three fundamental ethical principles:

1. **Respect for Persons:** recognizing autonomy and protecting people with diminished autonomy

see Unethical on page 49

Building Community and Advocacy: From Voiceless to SEEN and Heard

By Ben Crimm
Founding Member
SEEN (Spellers Empowering Education for Nonspeakers)

Ben Crimm

I got used to being silent. It was the loneliness and being invisible that was soul crushing. Being able to finally say anything I wanted as a nonspeaking autistic with apraxia was liberating.

I have never been able to communicate by using my mouth. When I was a child, I did speak a few words and some highly practiced phrases. I could also sing the words to many simple songs. But I could never speak to do the reciprocal exchanges that we call conversation. I could not let anyone know what I knew, thought, or felt.

At an early age, I began many years of speech therapy focused on articulation. Later, when it was clear I was not making progress, therapists attempted to teach me sign language. I was not successful because I could not imitate or perform the instructions the kind and earnest speech therapists gave me. In 4th grade, I was given an early AAC device to use only in school. It had 3–4 active targets. However, I could not consistently use my finger to accurately point and, after 6–8 weeks, that was abandoned too. My parents then arranged a comprehensive evaluation by a team of speech therapists at a local children's hospital. Based on my ability to sing songs and say a few words, they concluded that I had the capacity to learn to use my mouth for fully functional communication and to keep trying. Knowing they were wrong, I stopped using spoken words altogether a short time later.

School became excruciating. When my teacher asked me to pick up a picture of a dog from a field of 3 or 4 animal cards, I could not consistently do so 8 out of 10 times. I had (and continue to have) challenges with motor control, especially eye-hand coordination. If my eyes drifted to a card adjacent to the one I intended to select, my hand would often follow, leading me to select the wrong one. In my mind, I could name dozens of dog breeds. I knew what they looked like and how they differed. In class, I did not satisfy the "mastery" standard that would allow me to advance to higher learning. I was stuck. I wanted to learn academic subjects, to be taught more than I could learn on my own by simply listening.

I craved friends — to talk with them, share interests, agree and disagree, engage in gentle banter, know them and be known. But I was trapped inside a glass bubble. I could see and hear everyone and everything around me with no way to participate. I became a close observer of others' intonations, body language, and emotions.

Without a voice, others had no way of seeing the true me. I was spoken about as if I was not in the room. Others made decisions on my behalf. My siblings enjoyed the taste and challenges of being their own person. But I did not have that. Even worse, nothing on the horizon gave me any hope of change coming soon. It was a very dark time for me.

Despite this bleak outlook for my life, I was mostly happy. I have a loving family and my parents left no stone unturned if they thought something could help me. My siblings also loved me, although they got frustrated with my meltdowns. They read books and sang songs with me. My parents organized a home program and hired staff to give me academic instruction after school. We used the PECS system with laminated cards with icons or pictures and the printed word underneath. This helped me learn to read.

I was so happy to finally leave the education system at age 21 and start a new phase of my life. I entered an adult day program and began to meet more autistic and nonspeaking people like me. Although we could not communicate through words, we formed relationships based on shared experiences. Six years later, my parents learned about Spelling to Communicate through one of these friends. He was learning to point to letters, one at a time, on an alphabet board to say anything he wanted. My parents and I decided to try it. At age 25, I learned to properly point and use my eyes to direct my finger to accomplish what my mouth could not.

It was exhilarating and also extremely hard work. It took several hundred hours and over a year of daily practice to get to the point where I could say anything I wanted. My life was completely transformed! I worked to overcome anxiety and learned about communication niceties. I had so much catching up to do now that I had a voice.

In March 2020, the pandemic arrived and, fortunately, so did Zoom. Like everyone

see SEEN on page 32

The Evolution of Training for Facilitated Communication

By Pascal Cheng, MEd
Communication Consultant

I first learned about facilitated communication (FC) in 1991 when a colleague shared with me Professor Douglas Biklen's 1990 article in the *Harvard Educational Review*, "Communication Unbound: Autism and Praxis." This article was a qualitative research study on the method based on his observations of Rosemary Crossley's work with non-speaking individuals at the DEAL Communication Centre in Melbourne, Australia. Later that year, I attended a conference on FC in Burlington, Vermont, where Syracuse University staff gave an overview of the method and shared examples of individuals from the Syracuse, New York area who used it. I came away from the conference excited about the possibilities of exploring the use of FC with individuals who I worked with.

I assumed that I knew enough about the method and that I would easily learn how to use it. That was hardly the case, as my first attempts at using the method were not successful. I reached out to someone who knew the individual I was working with at the time and had experience with the use of FC. He met with us and showed me how to provide the physical support that the person needed to communicate effectively. This hands-on learning experience was a critical step in my learning the skills needed to support this individual to use FC. Over the course of many years, I was fortunate to have many opportunities to learn more about the method. I was able to work with many different individuals, collaborate with other practitioners, and participate in doing trainings on the method.

My initial experiences with FC were probably not unlike those of many others in the early 1990s. At that time, people were learning about the method through presentations, videos, and writings about it. These experiences might have been enough to get people started but not enough to ensure that they were progressing with their skills and using good practice. There were no systems in place to provide ongoing training and support. Moreover, in the excitement over the communication that individuals using FC were now producing, the need for developing skills and using good practice was frequently overlooked.

It is perhaps not surprising, then, that in the debates surrounding FC over the last 30 years, little attention has been paid to the role of training in the use of FC. There is limited reference to training in research studies on the method. The overall impression given in these studies was that all facilitation was the same and that negative influence would inevitably occur. There was little weight given to the training and the skills of the facilitators participating in the research when those factors might have had an impact on the performance of the participants.

In media portrayals of the method, individuals were often shown typing with full support at the hand and not looking at the keyboard. Examples of FC practice where individuals were typing with minimal support with a hand on the shoulder and good visual attention to the keyboard were not shown. These examples would have demonstrated that it was possible to progress with skills and that access to good training could make a difference.

To get a fuller understanding of the role of training in the use of FC, it is important to look back at the history of the method starting with the work of the late Rosemary Crossley, who developed the method in the late 1970s. In her early work on FC, Crossley used the word "training" in reference to FC and often referred to the method as "facilitated communication training." She wrote that, "Most of the time facilitated

see FC Training on page 50

“All Done Talkin’ Bout It:”
One Mom’s Journey to Communicating With Her Autistic Daughter

By Amy Kelly, MBA, MNM
National Director of Family Engagement and a proud mom of Annie
Devereux

I vividly remember when Annie was diagnosed with autism on Jan. 8, 2004, the day before her second birthday. I had no idea what autism was, other than how it was depicted in the movie “Rain Man,” starring Tom Cruise and Dustin Hoffman. I felt shocked, worried and alone. I didn’t know any other parents who had a child with autism or any other disability. I also had two young sons to care for – a 3-year-old and a newborn. I was overwhelmed. Annie’s doctors told me she had “classic autism.” There also was a condition called Pervasive Developmental Disorder, Not Otherwise Specified (or PDD NOS), and I remember hoping she would be diagnosed with that instead of autism because autism was more “severe,” or so we were told at the time. With “classic autism,” the doctors said if she didn’t speak by the time she was 5 years old, she likely never would.

Under the advisement of Annie’s medical and therapeutic team, I created a busy home Applied Behavior Analysis-based program that also included speech, occupational and physical therapy. Annie spent four hours each week in speech therapy, working with a wonderful speech and language pathologist who taught me to see Annie’s strengths. In addition to not speaking, Annie didn’t know how to show us what she wanted or needed without crying, which broke my heart. Eventually, she began to learn the Picture Exchange Communication System (PECS), which uses pictures to create sentence strips, allowing Annie to express what she wanted. She had to learn how to differentiate between pictures and create sentences. That was the beginning of her being able to express her needs.

As Annie grew older, she continued to receive speech therapy, use PECS and attend the Devereux Center for Autism Research and Education Services (CARES), an Approved Private School that helps students with autism and other developmental disabilities build essential communication, social, daily living and job skills. We learned Annie had verbal apraxia, which basically means the part of her brain that controls how to move her mouth and tongue in order for sounds and words to come out was “disconnected” in a sense. Annie was frustrated that she couldn’t make comprehensible words, and I was sad and frustrated for her.

There was a constant focus on speaking in school, in home therapy and in daily life. Annie’s fifth birthday arrived, and she still wasn’t talking. All I could remember was what the doctor told me, “If she doesn’t speak by the time she turns 5, then she probably never will.” We had a small family party, and I arranged Oreos in the shape of a cake since Annie didn’t like cake. There was no candle because Annie couldn’t blow one out because of the verbal apraxia. I cried all day and thought, “My daughter will never talk.” I was heartbroken – for her and for me.

Over the next several months, I mourned the idea that Annie wouldn’t speak and worked on adjusting my perspective. If she couldn’t talk, I had to help her to better communicate her wants and needs so she would not be frustrated at every turn in life.

see Mom’s Journey on page 49

Beyond the Device: Teaching Meaningful, Spontaneous Communication with Speech-Generating Devices

By Megan Robinson Joy, PhD, BCBA
National Director of Autism Services
Devereux

A key component of a high quality of life is the ability to clearly communicate one’s needs and desires with others. Effective communication allows individuals to advocate for themselves, make choices within their environment, and express their thoughts and feelings. For autistic individuals, however, communication can present significant challenges. Approximately 25–30% of autistic children are non-speaking or minimally verbal (Guerrera et al., 2025). For individuals with more complex communication needs, augmentative and alternative communication (AAC) systems provide a powerful pathway for interacting with others. AAC includes both low-tech and high-tech options, with speech-generating devices (SGDs) becoming increasingly popular. These devices produce spoken output when a user selects pictures, combines icons, or types words and sentences. Because SGDs generate clear verbal speech, they can be easily understood by others, supporting communication across a variety of environments and situations.

While these systems can provide great promise for enhancing communication, SGDs do not always meet the needs of their users. Too often, families are left to problem-solve often complicated systems that may not be functional for their environments, leading to frustration and missed opportunities. For SGDs to be effective, comprehensive supports must be in place to guide both the individual and their family in learning how to use the system. These supports should be thoughtfully implemented and regularly evaluated to ensure they are meeting the user’s needs. The following section outlines core components of effective communication plans that promote the development of meaningful, functional communication.

Identify Critical Skills to Teach

Before starting teaching, time should be devoted to developing a strong understanding of the individual’s preferences to build an enriching environment. Teaching communication needs to be structured around the individual’s motivation. This may include conducting preference assessments, through formal evaluations or informal observation. Preference assessments can be done by observing how the individual likes to spend their time, what activities hold their attention, and their level of happiness when engaging with different people and activities. These highly preferred items, people, and activities can serve as initial communication targets. Teaching within these contexts helps the individual learn that using their communication system results in access to meaningful and desired interactions.

Equally important to teaching individuals how to ask for things they want is teaching them to say they don’t want something. This includes communicating “no” and related phrases, such as “I want to do something else.” The ability to say no is essential for making one’s needs known and is a critical safety skill.

Arrange the Environment to Support Communication

The individual’s environment should be

see Beyond the Device on page 33

Supporting Social Communication in Autism: A Review of Evidence-Based Speech Therapy Approaches

By Pariya Parhizkar Shahri, MSLP
Speech and Language Pathologist
PhysioPlus Medical Center, Dubai,
United Arab Emirates

When people think about autism and communication challenges, they often focus on speech itself. However, many autistic children develop age-appropriate vocabulary and grammar while continuing to experience significant difficulties with social communication. These challenges may include understanding emotions, maintaining conversations, interpreting nonliteral language, recognizing social cues, and navigating peer relationships. For these children, communication difficulties are often less about what they can say and more about how language is used in social situations. As our understanding of autism has evolved, speech-language intervention has shifted from focusing solely on correcting behaviors to supporting meaningful communication, social participation, and quality of life.

The Importance of Pragmatic Language Skills

Pragmatic language refers to the social use of language. It includes skills such as taking turns in conversation, staying on topic, understanding another person's perspective, interpreting facial expressions, and recognizing humor or figurative language. Research consistently shows that pragmatic communication differences are among the most persistent challenges for autistic children, even when structural language skills appear strong. As a result, speech-language therapy increasingly focuses on helping children develop practical communication skills that can be applied in everyday interactions. Common intervention strategies include role-playing, social narratives, video modeling, conversational practice, and emotion-recognition activities. These approaches aim to help children navigate real-world social situations more effectively while building confidence in communication.

Developmental and Relationship-Based Approaches

Developmental Social-Pragmatic (DSP) approaches emphasize the importance of relationships, emotional connection, and shared engagement. Rather than relying solely on structured teaching, these interventions encourage communication through naturally occurring interactions and child-led activities.

DSP approaches often focus on joint attention, social reciprocity, emotional regulation, and meaningful interaction between children and communication partners. Models such as Social Communication Emotional Regulation and Transactional Support (SCERTS) highlight the interconnected roles of social communication, emotional regulation, and environmental support.

Many clinicians have observed that children are often more communicative when they feel emotionally safe, understood, and actively engaged. Building therapeutic rapport can therefore become an essential foundation for communication growth.

Learning Through Peer Interaction

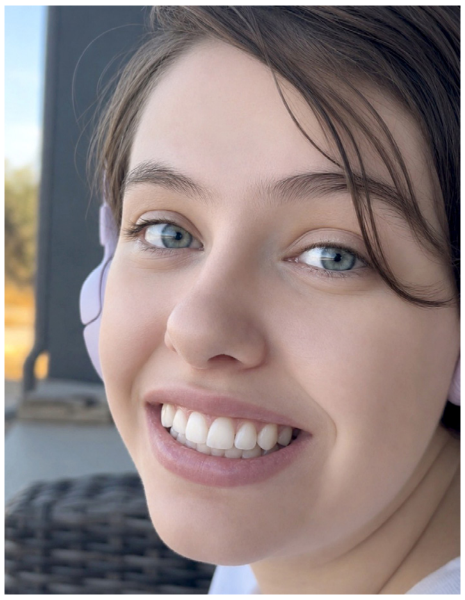
Children learn communication most effectively when they have opportunities to

see A Review on page 51

Freeing the Mind: A Nonspeaking Autistic's Case for Presuming Competence

By Elsa Jean Pace
Nonspeaking Autistic Self-Advocate

Many nonspeakers are still locked in the prison of their own mind. Nonspeakers are underestimated because our bodies and brains are disconnected. Our minds work, but not with our body, so people conclude we are unintelligent. Apraxia is not well understood by parents, teachers, therapists, and the general population. To get a better understanding, people can listen to what we are saying when we point to letters on a letter board or are typing. There are as many as 30 million nonspeakers in the world and we have been begging for a game changer. Our minds are full of ideas, and even people that live in silence are interested in bringing them to the world. Being locked in silence leads to despair. We need to change this and it's very possible. The nonspeaking community suffers from apraxia, but the good news is there is a way to free our minds if you put in the work and presume we are competent.



Elsa Jean Pace

How does a person with apraxia know how to free the mind? People need to understand that I had very much been dreaming of being able to write all my thoughts. I learned how to point to letters on a board. I had to work hard but over time, using the 26 letters of the alphabet, I was able to communicate my knowledge, ideas, opinions, and dreams. Being able to communicate with my family and teachers has changed all of our lives. It is so important not to underestimate nonspeakers, but to support them and help them connect to the rest of the world. Elizabeth Bonker, my hero, typed her valedictorian speech to her graduation class and told the world, "I am one of the lucky few non-speaking autistics who have been taught to type. That one critical intervention unlocked my mind from its silent cage, enabling me to communicate and to be educated like my hero Helen Keller." I think it is hard to get an understanding through to people; writing this will help, because people really need to understand. Yet, it's hard to feel what we feel.

People are familiar with the diagnosis of "Speech Apraxia," or the neurological disorder where the brain can't move the mouth; there is disconnect. So, why is it not understood that apraxia could be body-wide? I was diagnosed with Speech Apraxia when I was three, but it stopped there. No one assumed my body could not do what I asked. This is a "motor planning" problem. They thought I was incompetent or acting out. Someone who could speak to this is Dr. Diane Hennacy, a neuropsychiatrist who has been studying nonspeakers for decades. She writes, "While researching nonverbal communication with an autistic girl I realized the pervasive and painful lack of understanding about the nonverbal children." It's important to understand that behavior is not always a form of communication for us. The main standard for Autism therapy is Applied Behavior Analysis (ABA). Unfortunately, they are missing the main idea. The mind and body may not work in cooperation. I would receive consequences for things I could not control, like vocalizing or elopement (where I run away when I don't mean to). This can be traumatic for someone who is aware but not able to motor plan. Dr. Hennacy writes, "There are many accepted neurological conditions in which the patient can't speak, but they still understand language." Nothing has changed in my head; I have always been smart.

People who live with someone who has apraxia need to buy into the idea that they are competent and, with help, are able to accomplish anything they want to do. My life has changed really dramatically after working hard day after day. Aligning my thoughts with movement gave me the ability to get an education and write this research essay. Having a good therapist that works on the body/brain connection and using a letter board to communicate was the way I became a person that people see. I see a future that is possible, like going to university and becoming a neuroscientist.

If you know or love someone with apraxia, it is important to embody the well-known motto of the apraxia community: "presume competence." Help your loved one gain purposeful movement, which is the beginning of learning how to spell, and therefore, communicate. Lily Sherwood, who is a nonspeaker and an apraxia advocate, describes the pain of not being understood in her article, "Mind Breaks Free." She states, "No one assumed there was any understanding or comprehension on my part…no one considered that the real

see Freeing the Mind on page 37

Supporting Emotional Regulation in Non-speaking Children

By Nechama "Nicole" Fried, MEd, BCBA, LBA, Jay ABA

Every parent of a non-speaking child knows the moment. The grocery store gets too loud, a routine shifts without warning, a sibling grabs the wrong toy, and a child who seemed fine a minute ago is on the floor, or running, or frozen. Adults nearby may see "bad behavior." What is actually happening is something quieter and more important: a child without ready access to words is telling the world they are overwhelmed, in the only language available to them at that moment.

Emotional regulation is hard for any child. For non-speaking autistic children, it can be especially hard, not because they feel more intensely than other children, but because they often have fewer immediate ways to express what they are feeling. When "telling someone" is not yet on the table, distress builds until it surfaces as a meltdown, a shutdown, or behavior that gets misread as defiance. Supporting regulation begins with understanding what is really going on and adjusting the response accordingly.

Behavior is Communication

The most important shift a parent or caregiver can make is to treat behavior as information rather than misbehavior. A child dropping to the floor in a grocery store is telling you something about the lighting, the noise, the change in plans, or a headache they cannot describe. A child pushing food away may be telling you about texture, smell, fullness, or a hard moment earlier in the day. The behavior is the message. The work is to listen for what it is saying, not to silence it.

This does not mean every action gets a free pass. It means that before you respond, you assume there is a reason, and that the reason matters more than the surface behavior.

Co-Regulate Before You Redirect

Children borrow calm from the adults around them. Before strategies, tools, or scripts can land, your nervous system is your child's first reference point. A regulated adult is the most powerful regulatory tool a child has.

- Lower your voice rather than raising it
- Slow your movements when your child speeds up
- Stay close if proximity helps, or give space if it escalates

- Wait. Hard moments rarely need a quick fix

If you are dysregulated yourself, that is information too. Stepping away briefly to reset is not a failure — it is part of the work.

Pay Attention to The Sensory Environment

Many of the moments labeled "emotional outbursts" are sensory overloads with nowhere else to go. Lights, sound, temperature, textures, crowds, smells, and screen exposure all shape a child's baseline before any "trigger" arrives.

- Notice patterns around time of day, lighting, noise, and transitions
- Build sensory breaks into the day before they are needed, not after
- Keep sensory tools (headphones, fidgets, a quiet corner, weighted items) available everywhere, not as rewards, but as everyday supports
- Reduce demands during high-load moments like grocery runs, family gatherings, or after school

Put Feelings on the AAC System

A child cannot tell you they are anxious if "anxious" is not on their device. Robust augmentative and alternative communication (AAC) includes the full range of emotional vocabulary, not only happy and sad, but also words a parent might prefer not to hear.

- Include vocabulary for frustration, overwhelm, embarrassment, pride, jealousy, and boredom
- Model these words yourself throughout the day, even when your child is calm
- Make sure "no," "stop," "I don't like this," and "I need a break" are always one tap away
- Treat protest words as essential, not as something to discourage

A child who can say "I'm overwhelmed" through their device has a tool that can prevent a meltdown. A child whose only available "no" is their body has fewer options.

Watch for Early Signs

Most dysregulation has a runway. Subtle shifts in breathing, posture, volume, or movement often appear long before a full meltdown. Some children quiet down; some get louder; some pace, script, or seek deep pressure. Knowing your child's specific early signs lets you offer support before they reach a point of no return.

Validate Before You Problem-Solve

A child in distress needs to feel understood before they can take in anything else. "You're really upset. That sound was too loud. I'm here," lands better than "you're fine."

- Name what you see, even if you are guessing
- Avoid reasoning with a dysregulated child; logic comes back online later
- Save the conversation about what happened for after everyone is calm
- Trust that being seen, even silently, is itself part of regulation

Build Predictable Rhythms

Regulation is much harder when the day itself is unpredictable. Visual schedules, consistent routines, advance notice of changes, and clear transitions all lower a child's baseline stress, leaving more capacity for the unexpected when it arrives. Predictability is not rigidity — it is scaffolding that frees up energy for everything else. Sleep, food, and movement matter here too: a tired or hungry child has fewer regulatory resources, regardless of what supports are in place.

Repair, Don't Punish

When the storm passes, the goal is reconnection, not consequences for being overwhelmed. Punishing distress teaches children to hide it, not to manage it. Reconnect first — a hug, a snack, a favorite show. Then, when calm has returned, reflect together, using AAC, drawing, or whatever your child prefers, on what the moment was telling you about needs that were not being met.

A Note on Interventions

Be cautious of approaches that prize compliance over communication, or that train children to suppress signals like covering their ears, leaving a room, or refusing a task. These signals are not problems to be eliminated; they are the early language of self-advocacy. The goal of any good intervention is to help your child use these signals more effectively, not to teach them to override their own bodies.

Look for therapists and educators who measure progress in regulation, communication, and confidence rather than in compliance and quiet. Ask how they respond to a child's "no." The answer will tell you a great deal about what the rest of the work will look like.

The Long View

Regulation is a skill that develops over years, not weeks. Setbacks are not failures. Each hard moment met with steadiness rather than alarm teaches your child something they will carry forward: that big feelings are survivable, that they are not alone in them, and that the people around them can be trusted to listen, even when there are no words yet to listen for.

For more information, visit www.bluejayaba.com.

We Shall Overcome from page 1

structural barriers that restrict the human right to communicate.

Our nonprofit Communication 4 ALL is working to ensure people with disabilities can communicate in their preferred manner. These rights are protected in the Americans with Disabilities Act (ADA), but state agencies including NY's Office for People with Developmental Disabilities (OPWDD) are routinely denying a nonspeaker's right to use a letterboard to communicate in a group home or day program. That is why we proposed the NY Communication Bill of Rights, a bill that simply states a person's right to communicate in their preferred manner. The bill passed *unanimously* in the Assembly and was on track to pass in the Senate with a majority of the Senators co-sponsoring it.

What happened next is worthy of a movie. Throughout this winter, self-advocates met with New York senators, and more than a majority signed on as co-sponsors. The Chair of the Disability Committee, Senator Patricia Fahy, asked to sponsor the bill and vowed to make it a priority. Then, all of a sudden, she changed her tune and gutted the bill with amendments that actually took away our rights and violated federal law. The disability community across the country and around the world mounted a crisis response with hundreds of calls and letters to the disability committee and got her shameful amendments paused.

Elizabeth Bonker

Why did this happen? Corporate interests including ABA and the American Speech-Language-Hearing Association (ASHA) have infiltrated state agencies across the country, including New York's OPWDD, to continue to be the only option for families. The very agency the bill is meant to rein in actively worked against it. We are confident that the Communication Bill of Rights will pass next year, led by Assemblyman Angelo Santabarbara and a new Senate Disability Chair.

This discrimination is not just happening in New York. Communication 4 ALL is actively working with Spellers Freedom Foundation and local partners in California, Massachusetts, and Wisconsin who are fighting for nonspeakers to use their self-directed funds in programs with their preferred manner of communication.

We need federal guidance to stop these blatant violations of the ADA. In January, I had the honor of being appointed to the Interagency Autism Coordinating Committee (IACC), a federal committee overseeing about $500 million of annual spending and charged with making recommendations to HHS Secretary Kennedy.

Our first IACC meeting on April 28 included recommendations on safety including wandering and drowning prevention, co-occurring medical conditions, and profound autism. It was a huge victory for nonspeakers that the IACC recommended that the definition of profound autism for federal policy and research purposes be (1) minimal or nonspeaking and (2) continuous or near continuous care, and explicitly *excludes* intellectual disability. My first priority for IACC is communication access, and I will work with fellow committee members to remove the state level barriers with federal guidance.

Another strategic priority is empowering occupational therapists (OTs) to teach typing to nonspeakers. We partnered with the SEEN Foundation to create the Apraxia Integration Program (AIM), and the first 8-week class has been completed. I have had the honor of presenting at the Florida and Georgia OT conferences. OTs understand our motor disorder and sensory sensitivities and want to help us with the practice of self-expression. Our goal is to have expert OT typing coaches in every school.

Communication 4 ALL's mission is global, and we need to use technology to reach every nonspeaker. Our C4A Academy is an internet-based program of instructional videos, case studies, written lessons, resources, and live Zoom support to teach nonspeakers to type. Our lessons are posted in English, Spanish, and French with dozens of languages to come. C4A Academy empowers families and schools around the world with everything they need to free nonspeakers from suffering in silence.

There are now tens of thousands of typers worldwide, and we are empowering them to be a grassroots movement with C4A Network. We put out action alerts about legislation or social media initiatives, and the responses have changed the course of history. This summer, C4A Network launched an inaugural Summer Internship Program with 22 nonspeaking self-advocates. They will be leaders driving our mission forward.

Our time has come. We have a critical mass of typers, legislation receiving national media attention, alliances with allied professionals, and momentum with the federal government. Together, we can achieve communication equality. WE SHALL OVERCOME!

Elizabeth Bonker is Executive Director of Communication 4 ALL.

Civil Rights Case from page 6

news outlets including *Time*, *Newsweek*, *Fortune*, and *Psychology Today*.

Alex's landmark case made clear that a non-speaker's civil right to use their preferred method of communication does not begin with college. While the Individuals with Disabilities Education Act (IDEA) provides essential protections for school-age students with disabilities who attend public schools, those protections are only one part of the legal framework. A student's civil rights do not end with IDEA. Three federal laws—the IDEA, the Rehabilitation Act, and the Americans with Disabilities Act (ADA)—obligate public schools, including charter schools, to meet the communication needs of students with disabilities. They address these obligations in different ways. A school district may still violate the effective communication requirement even though a student is able to make sufficient progress for a free appropriate public education (FAPE) under the IDEA. Critically, the Rehabilitation Act and the ADA's effective communication requirement impose a greater obligation of equal access than the FAPE requirement. Federal guidance moreover is unequivocal: a student's right to effective communication under the Rehabilitation Act and the ADA exists independent of, and in addition to, the IDEA.

Under the IDEA, a school district has discretion to select teaching methodology so long as the individualized education program (IEP) is reasonably calculated to provide meaningful educational benefit. That makes sense. The school district has teaching expertise.

Very importantly, however, the Rehabilitation Act and the ADA do not give a school district discretion to dictate a student's means of communication. Just the opposite. That makes sense as well—each of us is the expert on ourselves. Professor Michael Ashley Stein, Ph.D., J.D., Executive Director of the Harvard Law School Project on Disability and one of the co-drafters of the UN Convention on the Rights of Persons with Disabilities (CRPD) wrote a letter in support of Alex's case. Dr. Stein observed "the CRPD structurally recognizes persons with disabilities as experts about their own lives. As such, both the letter and spirit of the CRPD privilege individuals' preferences over those of professionals, however well-intentioned. Starting with its general principles, its provisions repeatedly validate that persons with disabilities have a right to choose their own destinies, whether that's with regard to where they live, how they move, how they learn, what health care they access, how they vote, or how they express themselves, regardless of whether persons with disabilities use complex or nonstandard forms of communication."[7]

The Rehabilitation Act and the ADA likewise "privilege individuals' preferences over those of professionals." As the Court in Alex's case explained, a key difference between IDEA's FAPE obligation and the Rehabilitation Act and ADA's effective communication requirement "is the emphasis that the [school] must place on the disabled student's preference when deciding what accommodations to provide." The Rehabilitation Act and the ADA require a school district to "give primary consideration to the requests of the individual[] with disabilities" and to honor the student's chosen method of communication unless it can demonstrate that an equally effective alternative exists.

The Le Papes' case began with an administrative due process complaint alleging that the school denied Alex a FAPE under the IDEA and intentionally discriminated against Alex under the Rehabilitation Act and the ADA when it refused at least thirtythree requests over seventeen months for Alex to use a letterboard in school and to train staff so he could do so. These requests were supported by a speech therapist, psychiatrist, developmental pediatrician, and behavior analyst. The hearing officer concluded that the school had not denied Alex a FAPE and had not discriminated against him.[11] When the Le Papes appealed, the district court held that they were not entitled to a jury trial on their Rehabilitation Act and ADA effective communication claims because those claims were "subsumed" by the IDEA denialofFAPE claim.[12]

The Third Circuit reversed, holding that a loss on an IDEA claim does not erase a student's independent civil right to effective communication under the ADA and Rehabilitation Act, or to a jury trial when those civil rights are violated. In addition to Alex's testimony, the Court found the testimony of seven treating clinicians, along with Dr. Barry Prizant—a speech pathologist and psycholinguist with fifty years of experience and recipient of ASHA's highest honors, who confirmed the effectiveness of Alex's letterboard communication after interviewing him and reviewing 185 minutes of video—to be "ample evidence from which a jury could conclude that the School District violated the ADA's effective communication requirement by denying Alex his preferred method of communication without providing an effective alternative."[13] The Third Circuit held that "the Le Papes were entitled to have a jury evaluate the effectiveness of the communication supports for Alex.[14]

Although he did not get to use his preferred communication method in high school, he is still the expert on his preferred and effective communication and the rest of his life, and has secured the civil right of public school students who have come after him to be the experts on theirs.

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Footnotes

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1. *Le Pape v. Lower Merion Sch. Dist.*, 103 F.4th 966, 982 (2024).

2. *Id.*

3. *Id.* at 979,

4. *Id.* at 981.

5. *Id.* at 981 (emphasis added).

6. *Id.* at 979-980.

7. Stein, Michael Ashley, Ph.D., J.D., August 18, 2021 Letter to Nicole Reimann, *J.L. v. Lower Merion Sch. Dist.* 20-cv-1416, ECF 67-6, (E.D. Pa. November 16, 2021).

8. *Id.*

9. 103 F.4th at 979.

10. *Id.* at 980.

11. *Id.* at 973.

12. *Id.* at 976-977.

13. *Id.* at 982.

14. *Id.*

30-Year Journey from page 1

physical guidance, or even unconsciously through an "ideomotor effect", similar to a 'Ouija board'. The argument was the messages being spelled or typed did not reflect the authentic thoughts and intentions of the person being supported. Since the summer of 1990, efforts to dismiss FC wholesale, including newer generations of assisted communication (AC) approaches in more recent years, have precipitated one of the most emotional and polarized debates concerning the competence of non- or minimally speaking persons with disabilities.

Skeptical but Open Minded

From the outset, I expressed the need to be cautious about global and miraculous claims, but at the same time, to remain open-minded about FC as further information was accumulated through both research and lived experience. There were already many documented cases of autistic individuals who demonstrated precocious facility with written language, hyperlexic abilities and interest in letters and numbers. In my years of experience there had been many situations when I had marveled at how often people with neurodevelopmental conditions had overcome seemingly insurmountable challenges and revealed surprising and unanticipated abilities that far exceeded expectations. For all people, human development is life-span.

A small group of skeptics, led by Dr. Howard Shane, continued research with dismissive skepticism, preconceived biases to confirm their position that there was no legitimacy to FC using an assessment of questionable validity, referred to as a message passing test, (Kaufer, 2025), which was then extended to any form of AC (ASHA, 2018), based on opinion, not research. Any claims of success were referred to as "pseudoscience", with persistent attempts to prove there was no credibility to AC approaches, and authorship was that of the communication partners. Around this time, I was invited by Dr. Shane, developer of the message passing test and major protagonist of the "anti-FC" movement, to contribute a chapter to his edited book entitled "Facilitated Communication: The Clinical and Social Phenomenon" (1994). As I learned that all contributions were designed to challenge the legitimacy of FC, I told Howard that I would contribute but would clearly state in my chapter that there was a need to keep an open mind, do more research, and adjust our understandings based upon lived experience as well as research. I was motivated to contribute as some FC proponents were attempting to redefine autism by dismissing any of the other documented challenges experienced by autistic individuals, which ultimately could result in taking away needed supports for social communication and emotional regulation. He agreed to my condition, and my final chapter communicated a balance between the need to move forward with constructive skepticism, and open mind.

As Years Passed..

Shane and colleagues convinced the American Speech Language Hearing Association to appoint a committee that eventually published a position statement stating that all forms of AC was ineffective and harmful (ASHA, 2005). In practice, the position statement soon became used to prohibit the use of AC approaches, primarily in schools. However, prior to its publication, I continued to encounter nonspeaking individuals who demonstrated progress with AC, thereby challenging the claims put forth by Shane and colleagues. Many individuals benefitting from AC exhibited significant neuromotor challenges—difficulty initiating speech production or producing marginally intelligible speech, as well as demonstrating more generalized motor planning difficulties - profiles consistent with neuromotor disabilities in addition to autism.

For years, I observed moments that were difficult to reconcile with a deficit-based model that dismissed the nonspeakers' competence in understanding. I observed individuals who could not answer a direct question through speech but demonstrated understanding through behavior, affect, or delayed response. In everyday clinical interactions and with families, I observed how using schedules and other visual supports, often with print, were understood and used by nonspeakers. Multimodal communication including AC was now the avenue by which a deeper level of competence could be demonstrated.

At the same time, I was listening more closely to nonspeaking individuals themselves—particularly those who through AC, described experiences of being misunderstood, underestimated, or unable to express what they knew. Accounts of losing speech in development or under stress, of having intact understanding but limited motor access to communication, began to resonate with my clinical observations.

Nonspeakers and the Neurodiversity Paradigm

The subsequent emergence of the neurodiversity paradigm further shifted the lens. It challenged the long-held assumption that lack of speech equates to lack of intelligence. Stated simply, we began to understand that due to differences in brain wiring, it was possible to have high levels of competence co-occurring with significant disability. It urged us to consider that communication differences might reflect differences in access rather than deficits in understanding. Documented cases in other non- or minimally speaking individuals with neuromotor conditions such as stroke, cerebral palsy and motor speech disorders provided further evidence that lack of speech does not equate to limited intelligence.

Initially, my question had been on validation: does AC support authentic communication? Gradually, that question expanded: What barriers might prevent an individual from demonstrating what they know? This shift did not eliminate the need for evidence. But it introduced a new dimension—one that required considering motor planning, sensory and emotional regulation, attention, and the role of the communication partner as part of a dynamic system.

Approaches such as Rapid Prompting Method (RPM), Spelling to Communicate (S2C) and other spelling-based systems gained visibility. A 2004 segment on the respected CBS news show 60 Minutes highlighted successes through RPM. Proponents of AC began to explain that that these methods differ meaningfully in concept and practice from the early days of FC, emphasizing reduced or no physical support to a letterboard or keyboard with more of a focus on motor planning, and the importance of a trusted partner to support communication. Critics continued to claim that newer AC approaches such as S2C and RPM were no different than FC, raising familiar concerns about authorship and influence.

On Independence

At the heart of this debate is a fundamental position posed by skeptics: authorship requires demonstration of independence, and without it, conclusions about competence cannot be reliably drawn. However, there are two problems with this position - how is "independence" defined, and isn't all communication *interdependent,* at least to some degree? In my opinion, the critic's definition of independence belied the very nature of human communication. Even as I was exposed to individuals benefitting from AC when no direct physical guidance to keyboards or letterboards were observable (i.e. communication was independent), critics claimed that spellers or typers were being influenced by subtle cues (e.g., a glance at a letterboard by the support person, a reassuring touch on the back or leg), all implausible explanations.

Critics continued to insist that there needed to be some objective measure of authenticity - the message passing test. From the perspective of many practitioners and advocates, however, this method used to test authorship itself interferes with performance and has been successfully challenged as not a credible assessment due to lack of testing for reliability and validity (Kaufer, 2025). Stress, unfamiliar contexts, and the removal of supports also may disrupt the very capacities being evaluated.

Furthermore, a seminal study using eye-tracking technology examined movement patterns during typing, attempting to determine whether the individual first looks at letters before pointing, and found that was indeed the case (Jaswal, 2000). Others have documented cases in which individuals transitioned from supported to independent typing over time. These developments were noteworthy but continued to be dismissed as inauthentic by critics. Movement to independent typing suggested that, for at least some individuals, independent authentic communication through AC was possible, and that neuromotor factors played a significant role in limiting expression, a position supported by research.

The Final Turning Point

Over the years, I knew of many approaches to helping nonspeaking individuals to communicate, for example, using photos, pictures or icons on a display, or on a preprogrammed device such as an iPad. In February, 2018 I first experienced a community of nonspeakers who fully opened my eyes to the potential of nonspeakers to communicate thoughts and feelings creatively through spelling and typing, often at levels no one thought possible. That was when I spent two days at the University of Virginia in Charlottesville with The Tribe, nine young adults, all autistic, all identifying as nonspeaking, and all of whom had learned to communicate with assistance by pointing to letters on letterboards or keyboard to spell their messages. Each was supported by a Communication Regulation Partner (CRP). I was informed that the level and types of assistance decreased over time, often dramatically so, and that assistance supported a person's attention and motor coordination to point to letters, a keyboard or a display on a device such as an iPad, but also support a well-regulated emotional and physiological state.

After years of therapy, each of these young adults still lacked the ability to communicate reliably through spoken language, but all learned to communicate through Spelling to Communicate, or S2C, an approach developed by Elizabeth Vosseller, a speech and language pathologist. I watched and listened as the Tribe members expressed themselves by pointing to letters in sequence to spell words that were then read aloud by the CRPs. In some cases, individuals with some ability to approximate speech on their own, albeit infrequently, would produce some words while spelling. Elizabeth emphasized that such progress was no miracle, but based on hard work over extended periods of time.

In addition to meeting with the Tribe, I also had the opportunity to attend a psychology class, "The Science and Lived Experience of Autism" at the university that members of the Tribe also attended with their CRPs. I watched as they actively participated in discussions with undergraduate students on a range of topics. One of the neurotypical psychology students told me, "My experience with the Tribe has been really incredible…when you actually get to know them and how brilliant they are and have conversations with them on a personal level you can truly understand how valuable they are to our community".

What I experienced in my two days with The Tribe and people who knew them well opened increased my awareness of the potential of AC, and to the disabling challenges nonspeakers cope with daily. In my observations, their CRPs provided no direct physical assistance guiding them to type or point to letters, as was common with FC, merely standing or sitting next to them or at their sides, holding up the letterboards and, as the individuals pointed to letters, reading the letters, words and phrases aloud. Mostly, the partners provided a supportive presence, providing encouragement and helping the individuals to stay regulated and focused — and making sure their words and thoughts were heard by the group. As a published researcher of methods to analyze communicative intent in disabled individuals, what I observed was clearly intentional expression of thoughts and observations by the Tribe members, not a "rich interpretation" of what I was observing.

Communication and Regulation

Another remarkable observation was the regulating impact of communication for all the Tribe members. When engaged in typing or spelling, they were able to direct their attention and concentrate on the process of communicating, whereas at other times when not communicating, they disengaged and their attention strayed as some paced around the room, stimmed or became physically active in other ways. Family members and professionals who knew them well, and who shared their journey of progress in communicating, corroborated what I observed directly - what was being communicated was their authentic "voices", reflecting the thoughts and feelings

see 30-Year Journey on page 31

Everyday Life from page 14

dysregulation. “I am full of energy that I can’t manage. There is a lot of anger and anxiety and fear. The energy overwhelms me. This is something I might spend the rest of my life trying to deal with. That is daunting” (Danny with Words, November 15, 2025).

Considerations for Easing Dysregulation and Supporting Communication for Autistic, Non-speaking Individuals

A multitude of factors are linked to an individual’s ability to attain and maintain a regulated state. These include a person’s physiology, interoception, sensory, motor, cognitive, social, and communication profiles. Each of these may present as risk or protective factors for regulation. This is true for all people, and individuals who are autistic often present with extreme profiles that differ from the anticipated norm within these domains, which could relate to a heightened risk for dysregulation. For each of the profile factors listed previously, the literature provides evidence of significant neurobiological and/or biopsychosocial differences for autistic people. For example, interoceptive differences are well documented among autistic people, which influence their ability to register and interpret internal sensory experiences (e.g., hunger, thirst, pain, etc.) (Williams et al., 2023). Kim Clairy, an Autistic Occupational Therapist, discusses the impact of interoceptive differences on regulation, communication, and interactions. She states, “Am I hot, hungry, overwhelmed? What is my body telling me?... You can’t advocate for yourself if you don’t know what you need nor when you need it” (Kim Clairy, February 14, 2025).

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It is also well established that many autistic individuals experience sensory processing differences (heightened or lowered sensitivity thresholds). Research on sensory processing also tells us that sensory overwhelm predicts social communication difficulties. When the sensory environment is overwhelming to a person, they may become dysregulated and their nervous system will attempt to prioritize regulation over social engagement. Niko Boskovic (March 13, 2024) discusses the impact of sensory processing differences on his regulation and ability to interact with others. “As an autistic person, I have a deep relationship with my environment. What I mean is since I was a baby, I have been attuned to all the sensory stimulation coming at me. Sounds, smells, bright lights, heavy blankets… all sorts of experiences that my infant, then later toddler, brain couldn’t process. It was very chaotic, and I turned inward by focusing my senses on only a few safe activities.” Perhaps most pertinent to the issue at hand, in the domains of social, communication, and cognition, autistic adults report a preference for utilizing written communication to interact with others, noting that they find it to be less stressful than engaging in spoken conversation, as well as supportive of their ability to process information and formulate ideas (Turna et al., 2025; Howard & Sedgewick, 2021).

All regulation factors and support needs described thus far are relevant to non-speakers, but they often report two additional profile factors as key levers influencing their ability to regulate, engage, and communicate: motor and social. Motor differences for non-speakers are often categorized as apraxia, or diminished abilities to ideate, initiate, and execute purposeful movements in a coordinated manner at will. Research findings suggest that a high percentage of autistic individuals experience apraxia and that apraxia impacts motor skill beyond speech production (Damiao et al., 2026). Danny Whitty highlights the very real impact of motor coordination difficulties on his ability to communicate. “…I can’t control my body! I am stuck in apraxia. I need support to communicate in a reliable way” (Danny with Words, November 17, 2025).

In terms of the social, many non-speakers discuss the importance of having a trusted, responsive person who knows and respects them and who knows their full profile. For example, if a young adult who is a non-speaker uses an augmentative and alternative communication (AAC) system to express themselves and interact with others, is in a supportive environment with known partners and with access to their AAC, their difference is minimized, as is their disability. However, if that same young person is in an environment where they do not have access to their effective communication system and/or others are not consistently responsive to the person’s communicative bids using their AAC, the individual is likely to experience severely disabling conditions that impact their ability to interact and engage.

Understanding autistic communication preferences and individual profiles is crucial to providing supports and to the development of trusting and supportive relationships, a key factor influencing regulation. Trusting relationships are the foundation for engagement for everyone, including autistic individuals. In essence, a trusted, supportive partner who truly knows, respects, and responds to a non-speaker’s profile, inclusive of but not limited to communication, can help to mitigate many other regulatory risk factors that often interfere with engagement. They can help to mitigate interoception, physiological, sensory, social, communicative, cognitive, and motor differences by offering accommodation and providing support. Elizabeth Bonker, a non-speaking communication rights advocate, offers “NON-SPEAKERS HAVE WHOLE BODY APRAXIA, A MOTOR DISORDER.” Communication partners help non-speakers overcome their apraxia “WITH THEIR CALM PRESENCE” (Communication 4 ALL, June 12, 2026). These sentiments are echoed by a growing number of non-speaking individuals who have found that communication methods such as spelling with a responsive partner can help to overcome regulation challenges and support communication development and vice versa.

Just as it is for all of us, we cannot forget that we only communicate when it is meaningful and worthwhile to us. Hari Srinivasan, a non-speaking neuroscience PhD candidate, summarizes some of the challenges of communication for non-speakers as “every message already takes attention, motor planning, and time,” so arbitrary demands for interaction, often a key aspect of unnecessarily attempting to validate some forms of AAC, are sure to be highly dysregulating (Communication First, May 25, 2026).

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30-Year Journey from page 30

of each individual, and how learning to communicate has also supported their regulation, overall happiness and well-being, and changed family life.

My shift from skepticism was cumulative over time through observations supported by my clinical expertise and listening to those in close relationship with nonspeakers. My visit with the Tribe most certainly was a seminal event that provided evidence that AC was a credible approach for supporting communication for a yet to be determined number of nonspeakers. Not a miracle, but the result of years of learning and hard work.

Final Thoughts

Communication does not occur in isolation. It emerges from the interaction of multiple factors: the individual’s motor system, their regulatory state, a trustworthy communication partner, and the environment. Within this system, independence is not binary. It exists and develops along a continuum—from fully supported to independent, with many intermediate stages. Ethical considerations must also be taken into account. On the one hand, any influence by partners must be an issue of concern, but on the other hand, categorical dismissal risks silencing individuals who may have thoughts to communicate but lack reliable means of expression. Blanket denial reinforces low expectations, limits opportunities for growth and is terribly discouraging to those who share their lives with the nonspeaking person.

I no longer approach this issue with the skepticism I once had. But neither do I approach it without standards. I believe in the necessity of research, but also believe that evidence comes from multiple sources, not just controlled experimental research. I believe in the importance of demonstrating increased independence wherever possible. I also believe that current methods are still evolving and may not fully capture the complexities of motor-based communication challenges. Most importantly, I believe that individuals who do not speak deserve access to AC—and that we have an obligation to explore, carefully and responsibly, the methods that might make that access possible.

The path forward requires collaboration rather than polarization. Researchers, clinicians, and nonspeaking individuals themselves must be fully included as part of the conversation. We need studies that are responsive to the lived realities of participants. We need frameworks that integrate motor, cognitive, and social dimensions of communication. And we need humility—an acknowledgment that we may not yet fully understand the phenomena we are observing. At issue is not only the validity of a method, but the expression of personhood.

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Typing from page 16

Interventions (NDBIs). Their results showed that a severe deficit in baseline motor imitation skills was the primary predictor (Vivanti et al., 2025).

In traditional speech-language pathology, automaticity in verbal speech is driven by a consistent motor plan (Halloran & Halloran, 2006). While non-speaking individuals possess the cognitive capacity for language, the neurological "map" required for speech or complex signs is often broken. Typing bypasses these profound oral-motor barriers by allowing for a simplified, linear motor output.

3. Prompt Fading, Agency, and the Reversal of Learned Helplessness - Learned helplessness occurs when an individual learns that their own behavior has no contingent effect on their environment (Seligman, 1972). After decades of failed interventions and compliance-based models, many non-speaking adults fall into this state. In traditional communication interventions, non-speaking individuals are frequently subjected to intensive, repetitive, compliance-driven training (e.g., repeating basic requests or hand-over-hand prompting). Research indicates that a lack of autonomous control over communication routinely results in passivity, situational apathy, and an absolute reliance on external prompts (Mirenda, 2008).

Typing flips this dynamic entirely by moving from a closed-loop system (selecting an icon for an item someone else chose) to an open-ended, generative medium. When paired with systematic prompt-fading — deliberately moving from physical or emotional co-regulation to independent execution — typing gives the individual the means to generate completely novel, unprompted thoughts. This transitions the communicator from a passive recipient of interventions to an active agent of self-advocacy and true conversational agency.

4. Insistence on Sameness as a Regulatory Tool - In neurodivergent literature, insistence on sameness is increasingly understood not as an arbitrary behavioral deficit, but as a critical, adaptive mechanism for neurological and emotional regulation (Gomez de la Cuesta et al., 2015).

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When internal sensory modulation is unpredictable, an invariant external environment helps prevent cognitive overload and emotional distress. The predictable, unchanging nature of a keyboard provides the exact spatial structure many autistic individuals require to feel regulated enough to engage in the high-effort task of communication.

5. Stimulus Generalization Artifacts - Difficulty with stimulus generalization across varied environments, tasks, and people has been a long-documented characteristic of the autism learning profile (Rincover & Koegel, 1975). Consequently, the fact that typers may demonstrate typing fluidly with specific communication partners or in specific settings is not evidence of invalidity; rather, it is a direct artifact of this characteristic.

6. The Presumption of Competence - Contemporary AAC frameworks mandate that we separate an individual's motor execution capabilities from their cognitive and linguistic potential (Biklen & Burke, 2006). By implementing systematic prompt-fading models that mirror standard occupational therapy and neurological rehabilitation protocols, we focus on building muscle memory and automaticity through spatial constancy (Schmidt & Lee, 2011).

The Methodological Flaw of Early Critiques

The historical skepticism toward typing methods (stemming from early 1990s literature on traditional Facilitated Communication) largely relied on an assumption of global intellectual incompetence and completely ignored the role of praxis. Those early studies routinely failed to control for severe motor anxiety, apraxia, and the complex mechanics of sensory co-regulation.

The Intellectual Short-Circuit:

When an autistic individual with severe dyspraxia is placed into a highly artificial, high-stakes testing environment, the neurological loop required to formulate an idea, locate it on a board, and physically execute the strike breaks down. Under intense stress, the motor system defaults to the nearest available external visual or physical cue (the facilitator's gaze or subtle muscular tension).

What early researchers reflexively labeled "facilitator control" was frequently an involuntary motor manifestation of echopraxia (involuntary imitation of another's movements) or stimulus-boundness triggered by an acute apraxic breakdown. Early studies did not disprove the user's literacy; they inadvertently documented the severity of their neuromotor dysregulation under stress.

Moving the Science Forward

To continue relying on 1990s data to deny non-speaking individuals access to robust, alphabet-based communication channels is an indefensible clinical stance. Modern science demands that we transition from an era of *testing to disqualification to* an era of *engineering to accommodate*.

The empirical support for interventions across these areas is robust. By applying modern motor learning principles — focusing on spatial constancy, systematic prompt-fading, and proprioceptive scaffolding — typing shifts from a controversial historical artifact to a scientifically sound, neurodiversity-affirming mandate. We must move past the reflex to reject these methods based on outdated, flawed paradigms. Instead, our field must prioritize an understanding of modern neurobiology and commit to continued research in this crucial area.

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View the full list of references here.

SEEN from page 25

else, I remained trapped at home, yearning for connections with anyone other than my immediate family. I started reaching out to my nonspeaking spelling friends to connect on Zoom. We talked about our lives now. We talked about what it was like for us in school. We discovered we all had the same horrible experiences where our intelligence was not recognized. My friends also missed getting academic instruction and were underestimated.

This motivated us to try to change things for other trapped nonspeakers. Our solution was to found SEEN (Spellers Empowering Education for Nonspeakers) in August 2020. This Philadelphia-based advocacy group has been meeting monthly for almost six years now. SEEN's goal is to educate audiences about nonspeakers, autism, and apraxia. We are the voice of lived experience.

We write presentations collaboratively and work together to modify them for specific audiences. We have given almost 30 presentations in the last four years, both in the greater Philadelphia area and beyond, to family physicians, parent groups, autism organizations, lawmakers, adult service providers, elementary school children and their teachers, and college, graduate, and dental students. These always include a panel of three or more nonspeakers using letterboards or keyboards to answer questions live.

A word about impact. Feedback has been overwhelmingly positive. Attendees report they have learned about nonspeakers' capabilities and communication access needs. For most people, it is the first time they have ever met a speller or witnessed how we communicate. As a result of our teaching, audience members have arranged further presentations for SEEN. Some have trained colleagues and staff about nonspeaking autistics. Others have increased their accommodations in healthcare settings. Parents have begun to explore training for Spelling to Communicate for their children. SEEN members feel the power of their words through their impact on these audiences.

SEEN's impact also extends to the individual lives of its seven members. As W.S. says, "I can feel that other people presume competence in me. I have gotten better at doing presentations. They can be extremely intimidating. I am calmer and more confident." And S.A. shares: "Since I joined SEEN, I have experienced the positive power of collaborating for a common cause. SEEN has strengthened my hope and belief that together we can change the perception of nonspeakers."

Working together, SEEN members have mastered new life skills, developed deeper friendships, and learned to advocate. SEEN member G.T. reflects: "My life was boring and without much purpose before SEEN. Now I have an amazing purpose and have made dear friends along the way." Members have also learned how to work as a team. These are opportunities not offered during our school years: how to assert ourselves and when to remain silent, how to disagree effectively, how to encourage others to speak up, how to handle conflict, how to compromise, and so much more. Most importantly, SEEN members feel more empowered to advocate for themselves in their everyday lives.

Most nonspeakers have experienced powerlessness for the majority of their lives. Gaining a voice is truly transformative. Making that voice collective through a group advocacy effort is even more empowering. We are no longer invisible. We are now SEEN and heard!

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Presuming Competence from page 13

Non-speakers who type or spell to communicate tell us how important it is to them to be seen as competent and intelligent. (See Communication Alternatives in Autism, Edited by Edlyn Pena). Many of them thought they would never truly be seen for who they are. I run a social group called *Trailblazers* for young adult typers and spellers and I asked them what it feels like to them when people presume competence. Here are two of their responses:

Toni spelled: *I think it is important to presume competence because it makes me feel normal and I like feeling normal. This is a subject that makes me emotional. I just try to fit in and it's tiring. I just wish people would speak to us the way they speak to everyone else.*

Maude typed: *It's important to presume competence in others because it gives us confidence and tells us we can do it. I feel great when people presume I am competent. I know I can do something then. I dearly love knowing I can do things because it gives me hope in my future. Typing freed me up to have a life I can create instead of one designed for me.*

When asked how they can tell when someone does or does not presume competence, the collective group response from Maude, Coco, Alex, Adam, Jonathan, Chris, and Toni included: “I know by the way they talk and look at me. Everything matters and makes a difference. When someone knows I am smart, they treat me better.” The group identified these factors:

Susan Nisinzweig, MSW

- Tone of voice (high pitch versus normal tone)
- Words they use (simplified versus age appropriate)
- Gestures and body language
- Facial expressions
- Talking about me (as if I'm there, or not there)
- Attitudes are different

These are changes we can all make today in our homes, schools, agencies, and communities! We can make those shifts to help these individuals feel seen, respected, and spoken to at an age-appropriate level. In addition to having us presume competence in them, we also can help them presume competence in themselves by modeling it for them, showing them videos of individuals like themselves where typing has made a difference in their lives, and creating opportunities for them to interact online or in-person with others who type or spell to communicate. Sharing books, videos, and articles with them that respect the intelligence of the typing/spelling community and give them role models is key. These awesome Trailblazers, along with the members of the other groups we also run at STeP, are role models for others. This group has presented two webinars where they shared their wisdom on presuming competence and on their experiences in and benefits of a social group (see wellspringguild.org/resources).

Coco spelled: *“Now everyone knows I'm smart. Spelling gives me a voice but it didn't fix my autism. Maybe I don't need fixing, just support.”*

Maude typed: *“I feel hopeful that I will be seen and valued as an important person with special gifts who is capable of many things. What makes us autistic is also what makes us special. The special part is autistic!”*

Before people presumed competence in these individuals, their wisdom and insight was trapped within and unable to be shared. How grateful they feel to be able to now express themselves, and how lucky we are to be able to learn from them!

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For more information, videos, books, studies, and webinars that will teach you more about why it is so important to presume competence in these exceptional individuals, visit www.wellspringguild.org/resources.

Resources

Donnellan, A. M. “The Criterion of the Least Dangerous Assumption.” *Behavioral Disorders*, Vol. 9, No. 2 (February 1984), pp. 141–150. SAGE Publications, Inc. www.jstor.org/stable/43153291

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Beyond the Device from page 26

intentionally designed to encourage communication. This includes incorporating highly preferred items, activities, and social interactions throughout the day. For example, desired items might be visible but slightly out of reach, creating natural opportunities for the individual to initiate communication. Providing a variety of different activities also supports communication across different people and settings. Many autistic individuals have strong preferences for sensory experiences—such as swinging, spinning, deep pressure, visually stimulating materials, or favorite sounds. These experiences can create dynamic and motivating opportunities for communication.

Communication systems must be consistently accessible throughout the entire day and across all environments. We would never limit when or where a speaking individual can communicate; the same expectation should apply to individuals who use speech-generating devices (SGDs). SGDs should travel with the individual wherever they go, including school, home, and community settings.

Teach Others to Support Communication

Communication skills should be taught using systematic, individualized teaching plans. These plans should include clear instructions on how to follow the individual's motivation and use evidence-based strategies such as modeling and prompting. Adult prompts should be quickly and carefully faded to prevent over-reliance on adult support. When communication instruction primarily occurs in school settings, it is essential that caregivers are also trained to use the same strategies at home. This training should include how to encourage communication and use effective prompts. Consistency across environments ensures that communication remains meaningful and functional.

Megan Robinson Joy, PhD, BCBA

Adults in the individual's environment need to be taught to honor communication attempts, especially when skills are newly emerging. Honoring responses teaches the individual that their communication matters. As an individual becomes more proficient with their SGD, teachers and families can gradually build in delays and teach tolerance for situations when preferred activities aren't immediately available.

Set Goals and Measure Progress

The ultimate goal of any AAC system is that the individual uses it spontaneously when they have the desire to communicate. Individualized Education Plans (IEP) and treatment plan goals should reflect this aim with measurable goals that include independent and spontaneous communication responses. Data collected to measure teaching progress should include tracking how the individual engages in spontaneous requests and initiations with the SGD.

Data should be reviewed regularly to determine whether teaching strategies are effective or if adjustments are needed. The following may indicate limited progress and the need to modify instruction:

- The individual always waits for adults to prompt or cue the use of the SGD
- The individual indicates that they do not want to use the SGD, such as pushing it away or leaving activities when it is present.
- The individual only uses their SGD in some environments and not others
- The individual struggles to navigate multiple screens or icons on their system
- The individual only uses their SGD for a limited number of responses

Ongoing collaboration among the individual's team, including teachers, related service providers, and caregivers, is essential for addressing these challenges. Involving team members across settings supports shared problem-solving, allows for the identification of successful strategies, and encourages creative solutions. This collaborative approach helps build on progress and supports continued growth and expansion of the individual's communication skills.

A checklist: Teaching meaningful communication with a speech-generating device

- Teach meaningful requests – people, items, activities that are highly preferred
- Teach saying “no” or other refusal response
- Arrange the environment to encourage communication
- Develop systematic teaching plans with clear cues and plans to fade prompts
- Teach all adults how to prompt and respond to communication across environments
- Write goals for spontaneous communication
- Ensure that SGD is available in all settings
- Collect data on communication responses in multiple environments
- Meet as a team at least monthly to review data, discuss progress, and make changes to the plan as needed

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Rethinking from page 14

effectiveness of AC methodologies, critics have privileged controlled experimental designs while discounting practitioner knowledge and, critically, the perspectives of autistic individuals themselves and those who know them well. We contend that this imbalance has distorted policies by limiting access to newer AC approaches for countless nonspeaking individuals, both children and adults. When interventions are judged solely by whether they meet narrow methodological criteria, approaches that are meaningful and effective for certain individuals—especially those with complex neuromotor or communication profiles—may be dismissed prematurely. For nonspeakers, this is not an abstract concern. It directly affects whether they are offered communication supports, how their communication is interpreted, and whether their expressed thoughts are considered credible.

The Limits of Experimental Research Models

We believe that experimental research designs are not always well-suited to capturing the realities of autism and other complex neurodevelopmental conditions, particularly for individuals with highly individualized profiles. Comparing treatment outcomes under highly controlled circumstances can struggle to accommodate the variability inherent in nonspeakers—especially when differences in their lived experiences, as well as motor differences, sensory sensitivities, and regulatory states play a central role.

It also is well accepted that competence in communication for nonspeakers is often context dependent. Factors such as the presence of a trusted partner, environmental familiarity and predictability, arousal state and overall emotional regulation can significantly influence motivation and engagement in social communication. These variables are difficult to control in experimental settings, yet they are essential to real-world functioning.

As a result, a person exposed to an assessment protocol, such as message passing, the primary method used by critics to determine authenticity of communication, might "fail" under controlled conditions and may not at all reflect a person's competence in naturalistic contexts. Furthermore, message passing tests remain suspect as they do not meet the basic psychometric requirements of a valid assessment as no validity and reliability data are reported (Kaufer, 2025). And when experimental evidence is upheld as the only valid evidence of communicative competence, entire spheres of human experience are effectively excluded from consideration.

Nonspeakers and the Problem of "Disallowed" Evidence

One of the most striking implications of this discussion is how certain types of evidence are systematically discounted in debates about nonspeakers. Consider firsthand accounts from individuals who communicate via typing or spelling with assistance. Many describe gaining access to language, education, and self-expression after years of being presumed incompetent. These narratives are often detailed, consistent, and deeply reflective as they document the journey of initially learning to communicate with support, progressing to less support over time, and then for some, communicating independently (Jaswal et al., 2026). Such qualitative evidence is routinely accepted as credible within research on human and animal communication, on the natural course of medical conditions, and when exploring different cultural perspectives in anthropology.

Yet, critics frequently reject such qualitative accounts on the grounds that the methodologies of AC always involve influence, and this same assertion is made for any approach of learning to communicate with assistance. In other words, two of the three pillars of EBP are dismissed. From a strictly myopic experimental lens, this approach is considered credible. However, what critics do not ask is the following crucial question: What is the consequence of dismissing lived experience and accounts of numerous credentialed professionals and those who know a person intimately?

If client perspectives are one of the three pillars of evidence-based practice, then excluding them creates a fundamentally incomplete model. It also raises ethical concerns—particularly when the individuals in question have historically been denied opportunities to communicate.

Clinical and Educational Expertise as a Form of Evidence

Another underappreciated component of EBP is clinical expertise. Collectively, professionals draw on decades of work with autistic individuals. Skilled practitioners develop nuanced understandings of the processes of communicating successfully with neurodivergent individuals, both nonspeaking and speaking, that cannot be captured in formal studies, especially when conducted in highly controlled, stress-inducing circumstances by those who do not know a person well.

This includes recognizing subtle indicators of engagement, interpreting idiosyncratic communication attempts, and adapting supports in real time. For nonspeakers, such expertise can be especially critical. A clinician who understands motor planning challenges, for example, may approach supporting communication for a nonspeaking person very differently from one who interprets difficulties from a purely cognitive perspective, that is, a person who does not speak has nothing to say.

This kind of knowledge is often built through relationships and longitudinal observation. It is context-sensitive and requires sensitivity and responsiveness to the individual, hallmarks of successful human communication. While it may lack the apparent objectivity of controlled trials, it is nonetheless a legitimate and indispensable form of evidence.

Critics may view clinical judgment with suspicion, particularly in areas where confirmation bias is a concern. We have seen the impact when researchers come in believing that a person is not communicating authentically, and the approach basically is "Prove me wrong." This is reflected in the message passing methodology used by critics as the essential test in determining the validity of a nonspeaker's communication—one either passes or fails, unlike the process of natural communication.

The Role of Skepticism: Necessary but Not Sufficient

To be clear, we do not argue against skeptical inquiry. We acknowledge its importance in maintaining scientific integrity and protecting individuals from ineffective or harmful interventions. That said, we draw a clear distinction between **constructive skepticism** and **dismissive skepticism**.

- **Constructive skepticism** asks questions, seeks clarification, and remains open to new evidence from multiple sources.

- **Dismissive skepticism** begins with a conclusion—often that a particular approach cannot possibly work—and interprets all data through that lens.

In the context of nonspeakers, dismissive skepticism can have profound consequences. When critics assume that certain communication methods are inherently invalid, they may never consider them to be options, and unfortunately, as has happened, they convince others to dismiss them as well by distorting and weaponizing the application of EBP to confirm long-held biases. This not only limits access but also reinforces the very absence of evidence used to justify the initial skepticism.

We assert that a more productive approach is to investigate under what conditions communication appears to be most reliable, and how those conditions can be understood and replicated. And for those nonspeakers who have become independent, what are the significant ingredients that support this achievement (Jaswal et al., 2026a)? This shifts the focus from debunking to inquiry, from dismissive snapshots to longitudinal observation.

Individualization vs. Standardization

A recurring tension in the conversation is the balance between individualization and standardization. Standardization makes sense from a research perspective but can be problematic in autism, where heterogeneity is the norm. For nonspeakers, individualized approaches are essential. Communication supports may need to be tailored to specific motor profiles, sensory preferences, and regulatory needs. What works for one individual may not work for another—and what works in one context may not be effective in other contexts.

We believe that true evidence-based practice must accommodate this variability. Rather than asking whether an intervention works "in general," we should ask: For whom does it work, under what conditions, and why (Jaswal et al., 2026a)? This level of specificity is more complex, but it is also more aligned with the realities of clinical practice and lived experience.

Ethical Dimensions: Access, Dignity, and Risk

The issue of EBP as it pertains to nonspeakers also touches on the ethical dimensions of evidence. Decisions about what counts as valid evidence are not neutral; they have real-world consequences for access to services and supports.

For nonspeakers, the risk of false negatives—failing to recognize genuine competence—may be particularly high. If an individual is assumed to lack understanding, they may be denied education, social interaction, and opportunities for self-determination. In documented cases, it has led to abuse, such as in the history of Jordyn Zimmerman as documented in the film, *This is Not about Me* (Niemeijer, 2021).

Critics often focus on the risk of false positives—attributing competence where it is in question, such as in situations where a person's communication is influenced by the communication partner. This concern is legitimate, especially considering historical controversies about some false accusations of mistreatment and abuse. However, we suggest that the field must grapple with both types of error, not just one. Unfortunately, nonspeakers also are the most likely individuals to have experienced abuse and trauma (Jaswal et al., 2026b). What if their reports of mistreatment and abuse are dismissed? An ethical approach to evidence-based practice requires balancing these risks, rather than allowing one to dominate the conversation.

Finally, one must consider the ethical violations inherent in conflicts of interest. It is well known that the primary naysayers disseminating their position that assistive communication approaches should be prohibited have been actively engaged for years benefiting from fiscal rewards they earn in expert witness work supporting such prohibitions, with no conflict of interest disclosures in publications and presentations.

Toward a More Inclusive Approach to Evidence

Ultimately, we are calling for methodological innovation that better fits the reality of lived experience and EBP. If existing research paradigms are insufficient to capture the experiences of nonspeakers, then new approaches are needed (Jaswal et al., 2026b).

This might include:

- **Participatory research** involving autistic individuals as collaborators

- **Mixed-methods research** that combines quantitative and qualitative data

- **Single-case designs** tailored to individual profiles

- **Ecologically valid assessments conducted in naturalistic settings**

In fact, this was a recommendation of the 2023 NIDCD meetings on "Minimally Verbal/Non-Speaking Individuals With Autism: Research Directions for Interventions to Promote Language and Communication." Such approaches do not abandon rigor; they expand it. They recognize that complexity requires more sophisticated tools and varied tools, rather than oversimplified snapshots and questionable measures such as message-passing tasks.

Implications for Practice and Dialogue

For practitioners, researchers, and families, the conversation offers several actionable takeaways:

- **Integrate all three components of EBP**, with a bias towards those that include the experiences and perspectives of nonspeakers. Do not privilege experimental, context-stripped approaches at the expense of others

see Rethinking on page 36

Neuroimaging from page 15

someone to speak, point, press a button, or make some other reliable motor response. But for many MS, reliable motor responses are precisely the challenges that make assessment difficult. How can we measure what a person understands if our methods depend on motor abilities that may be impaired?

Neuroimaging offers one way to address this challenge. Rather than relying solely on what a person can physically express, neuroimaging allows researchers to examine how the brain responds while a person listens to language or attempts to perform a task. It provides an important complementary source of information for populations whose abilities may be underestimated by conventional testing. Our work focuses on two methods, functional magnetic resonance imaging (fMRI) and high-density diffuse optical tomography (HD-DOT). These different technologies rely on the same basic principle: when a region of the brain becomes active, it requires additional energy, triggering an increase in local blood flow. This influx of oxygenated blood changes the balance of oxygenated and deoxygenated hemoglobin in that region, creating a blood-oxygen-level-dependent (BOLD) signal. By measuring BOLD signals while a person performs an active or passive task, researchers infer which brain regions are involved. Both methods allow researchers to study the neural systems that support language, cognition, and movement without requiring extensive motor responses.

Our team from the Kennedy Krieger Institute, the University of Toronto, MGH Institute of Health Professions, Washington University Medicine, and Stony Brook University recently co-designed two neuroimaging studies, working closely from the outset with minimally speaking community members to develop tasks that would both be feasible for people with dyspraxia and yield rigorous scientific data. Our minimally speaking colleagues helped shape many aspects of the study design, such as limiting imaging sessions to one hour, including time to become comfortable with the equipment and practice the experimental tasks. Legal guardians or participants themselves provided informed written consent. Data collection began only after each participant indicated they were comfortable proceeding.

Functional Magnetic Resonance Imaging (fMRI) - fMRI is one of the most powerful tools for studying the human brain because it can measure activity throughout the entire brain, including deep structures that cannot be accessed using HD-DOT. Whole-brain coverage is particularly important when studying language and motor function because these abilities depend on networks of regions, some deep inside the brain, working together.

But fMRI presents substantial challenges for many MS. Participants must lie still inside a narrow scanner while loud sounds are produced by the MRI system. Even small head movements can degrade data quality. To make participation possible, we worked closely with MS and their families to develop accommodations that reduced sensory and motor demands. We closed our facility so that only the minimally speaking participants, their family members, and the research team were present. Family members accompanied participants into the scanner room to hold their hand or provide regulation support during the scan. Participants had repeated opportunities to enter and exit the scanner, practice the tasks, and decide whether they wished to continue. We also used state-of-the-art motion-correction technology to reduce the impact of movement during scanning.

Morgan looks on as Isaiah is positioned for an fMRI scan at Toronto Neuroimaging Facility by MRI Physicist Lars Kasper and MRI Technologist John Milne. Isaiah's mother, Melody Tien Grewal, provides regulation support.

Using these approaches, we have successfully localized language networks in two minimally speaking autistic adults, providing some of the first neural evidence of language processing in this population. These preliminary findings demonstrate that meaningful fMRI research with MS is possible and underscore the importance of developing methods that allow MS to be included in research on complex cognition. Data collection is ongoing.

High-Density Diffuse Optical Tomography (HD-DOT) - HD-DOT is a recent imaging technique that promises to be more accessible for MS. In HD-DOT, a participant wears a cap that contains infrared light sources and detectors. Infrared light shines through the scalp and brain in the same way that the light in a pulse oximeter worn on the finger does. The cap's detectors then detect the light after it has passed through these tissues. HD-DOT is easier to tolerate than MRI because people have some freedom to move. The cap is tight-fitting, but unlike EEG caps, which use gel or saline solution to create a connection between electrodes and a person's scalp, it is dry, making it a more feasible option for people with sensory sensitivities. But the trade-off is that near-infrared light can penetrate only the outer few centimeters of the brain. We can measure activity in the cerebral cortex but not in deeper brain structures.

Our HD-DOT participants performed three tasks, taking breaks as needed: repetitive and sequential finger tapping, repeating single and multiple syllables, and listening to understandable and acoustically degraded speech. Recognizing that the motor tasks and the feel of the cap are very challenging for many MS, we provided participants with visual and written cues and checked in after each task to see how they were doing and confirm whether they wanted to continue or not.

Data from 17 nonspeaking participants passed our data quality checks, showing good contact between the cap and scalp, and that the amount of movement was acceptably low. One person discontinued because the cap was too uncomfortable, and not everyone completed all the tasks before tiring out. Compared to a group of 28 non-autistic participants, the brain activation patterns of our MS participants showed similar patterns, but much more variation, suggesting that, on average, they used more of their brains to perform the tasks than the non-autistic group. This is consistent with the idea that these tasks are feasible but harder for MS. "Crucially, we also found that when listening to sentences, many minimally speaking individuals show patterns of brain activation consistent with understanding language content" (CNIR 2025 Research Update).

Motor for Research

Here's Isaiah's advice for families, nonspeakers, and researchers:

- Having dyspraxia means every intentional action must be practiced. The more an autistic dyspraxic person practices motor control, the more they will be able to control their body to participate in research.

- fMRI work feels like going into a small, short, round container. The best way to practice for the experience is to crawl into similar-feeling spaces in playgrounds, sensory gyms, and one's bedroom (think of lying down on the floor of a closet with your feet sticking out or under a sheet). If available, practice in a mock scanner. If needed, practice over many sessions to build tolerance.

- HD-DOT work feels like wearing a heavy, hot cap of sci-fi tiles while tethered to a heated cable bundle connected to a computer. The best way to practice for the experience is to wear different types of tight hats for longer and longer periods of time; think toques, baseball caps, and caps worn by swimmers and marathon runners.

- Research staff who want to work with MS must also practice. Run drills for setting up participants and experiments. Nonspeakers have limited reserves of regulation energy, so every minute lost to fiddling with equipment is a minute lost of data collection.

Looking Forward

Our two feasibility studies are far from definitive, but they are an important first step. We show that MS are very interested in research collaboration. We show that HD-DOT may be more tolerable for MS than fMRI. And our data supports previous work that minimally speaking autistic people's brains are wired differently from the brains of non-autistic people — they may be using different areas of their brains to accomplish the same tasks. Future work will tell us more about the range of variation in minimally speaking people's brain activation and help us understand why speaking or making other intentional movements are so difficult for some MS.

However, imaging studies can only supplement direct tests of language comprehension. Traditional language tests are not well-suited for people with dyspraxia and typically underestimate their abilities. We need to think carefully and work closely with MS and other dyspraxic people to create tasks that make it possible for them to show all that they know.

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***Rethinking** from page 34*

- **Approach nonspeaking individuals with a presumption of competence**, while remaining attentive to evidence
- **Document clinical observations systematically**, contributing to a broader evidence base
- **Prioritize access to communication**, recognizing its foundational role in quality of life

Conclusion: Evidence as a Living Process

We feel it is essential to rethink evidence-based practice not as a fixed hierarchy, but as a living process—one that evolves in response to new data, new perspectives, and new ethical insights.

For nonspeaking autistic and other neurodivergent individuals, this shift could be transformative. It opens the possibility of being recognized as participants in a shared endeavor to understand human communication in all its forms. The goal is not to lower standards, but to broaden them—to create a science that is rigorous enough to be trustworthy, and flexible enough to be humane.

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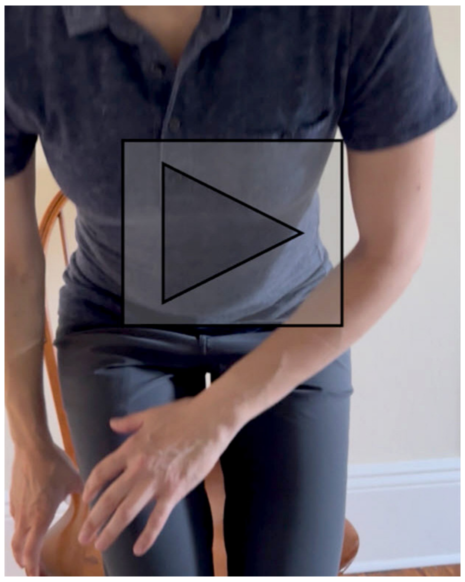
***Visual Aspect** from page 9*

& Haynes, 2021; Remner, Baker, Karter, Kearns, & Shane, 2016; Schlosser et al., 2013)? There is a considerable amount of research that supports the use of visuals to improve the joint process of communication; however, considering all elements of that research without a comprehensive perspective is where implementation can break down, especially when looking through the individual lenses of distinct disciplines. For many learners, it is especially important to understand that communication is a two-way process. We need to consider diverse ways to use visuals to clarify our own communication and to help our learners communicate — this applies to both ABA and to speech therapy.

When using visuals for our own communication, it means providers may not rely solely on verbal directions or physical guidance. The field of ABA has long utilized prompting and prompt-fading to help learners acquire new skills while working toward independence. The goal in ABA is always to provide just the right amount of support needed, and to gradually reduce help as the learner becomes more confident and successful (often referred to as “least intrusive prompting”). Therefore, when a VIS tool is introduced that helps meet this goal and serves as a language aid, it allows alignment between speech pathologists and behavior analysts. Let’s take Grace for example. Grace is working on learning to follow the direction “sit down.” When Grace was given the instruction “sit down” vocally, she was not consistently following the direction. But when the verbal instruction was paired with a video of the action, Grace sat down correctly every time. From a language perspective, the verbal directive of “sit” combined with a preposition (i.e., “down”) can be difficult; however, it can be made easier with the appropriate tool.



Video depicting the direction “Sit down,” that uses the learner’s exact chair from her home

From the perspective of the behavior analyst, the video serves as a less intrusive means of support for the learner. With VIS, both behavior analysts and speech pathologists can use their individual areas of expertise to enhance learning.

In addition to aiding in comprehension, visuals can offer different ways for our learners to communicate. For example, consider Johnny, who loves to play with Play-Doh. Johnny has been taught to request Play-Doh by saying the word, “Play-Doh.” What happens if Johnny needs help opening the Play-Doh container, but the word “open” is not easy for him to use? Going back to the observations before, verbs such as “open” may be difficult; therefore, Johnny may continue to state “Play-Doh” though he is attempting to communicate the need to *open* it. By using a visual scene display to represent “Open Play-Doh,” Johnny can communicate not only that he wants Play-Doh (i.e., the noun), but also what action (i.e., “open”) he wants completed with that Play-Doh. From the lens of a behavior analyst, this provides greater choice, more precise communication, and increased control over his environment; from the lens of a speech pathologist, it also provides the opportunity for Johnny to communicate a new word combination (i.e., open+Play-Doh) in a way that matches his understanding of language.

Within these examples, both Grace and Johnny had unique language needs that could be addressed with evidence-based tools; however, communication and language have an impact across all disciplines. As team members collaborate, the shared VIS framework offers guidance for using research to support communication, learning, and independence across settings. Whether the goal is helping a learner understand language, express wants and needs, follow directions, or engage more fully in daily activities, behavior analysts and speech pathologists play a vital role in making communication more accessible. Through a collaborative, learner-centered approach and a common framework, each discipline can better facilitate meaningful experiences that empower learners throughout their day. When learners understand what is expected of them, what is coming next, and how they can communicate their needs, they are often more confident and engaged in the learning process.

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Guide to Allyship from page 15

- Providing AAC tools and supports that enable someone to access education (also required by the IDEA)

- Providing AAC tools and supports in court to enable a witness to give testimony

- Providing extra time for someone to communicate with a teacher or physician

- Ensuring that a person has access to their AAC during a hospital stay

- Ensuring that a communication support person is allowed in a hospital room, even when "visitors" are not permitted

Our right to live in the community is also relatively new. Starting in the 1970s, inhumane institutions, including the infamous Willowbrook and Forest Haven, were permanently closed, and the independent living movement soared. In the 1999 *Olmstead* decision, the Supreme Court confirmed that the ADA gives people with disabilities a right to live in the community with publicly-funded supports and services. Although many of us still live in institutions (and still lack access to AAC that works for us), others receive home- and community-based services because of *Olmstead*.

Although robust, language-based AAC has been around since the 1920s, these tools have historically been available to just a tiny fraction of the people who needed them. Many professionals believed that people who couldn't speak also had no ability to understand or express language. The changing attitudes of the late twentieth century—emphasizing participation, dignity, and civil rights—have expanded access to communication, but the fight for our rights, dignity, and inclusion is far from over.

The discrimination of the past lingers in biased and outdated attitudes, policies, and social norms. Many people who have no speech are still assumed to have no language. Those of us lucky enough to access AAC are still routinely excluded, isolated, abused, and otherwise discriminated against.

Civil rights cannot continue to be a matter of luck and privilege. To change our world, we need people who can rely on speech to stand with us in allyship.

Ren Koloni, MA

1. Presume competence - You may already be familiar with the least dangerous assumption: the idea that assuming someone *can* understand, *can* learn, and *can* be a part of the community will always do less harm than assuming that they cannot. Presume that a person with a speech-related disability is fully aware of what is being said and done around them, and that they have thoughts, ideas, opinions, and dreams—even if they don't have AAC that allows them to express those things yet. In practice, this might look like:

- *Securing access to robust, language-based AAC as soon as possible.* Timely AAC training and access supports a person's ability to be part of their community throughout their life. (Indeed, the ability to communicate with others in the community is necessary for true integration into that community.)

This access to communication shouldn't stop at access to symbols or making requests. "No one can possibly know all of the words someone might need or want to express—whether to make requests, comment, ask questions, or engage in other functions of communication," autistic AAC user Jordyn Zimmerman writes. "These limitations can not only be a major source of frustration, but it is arguably restrictive when a student is forced to a narrow set of words and phrases." We should have access to all the same words other people do.

- *Giving us the power to direct our own lives.* Guardianships (or conservatorships) unnecessarily deprive us of fundamental rights. Supported decision-making (SDM) is based on the way that all humans make important decisions—by getting help from people they trust. Professionals such as educators and physicians often present guardianships as the only option. Fight back against that limiting narrative and spread the word: AAC users don't need guardianships to be safe and live well.

2. Use your speaking privilege strategically - The speaking world moves quickly, and many of us cannot move quickly enough to join in before the conversation has already moved on. Planning ahead and speaking up to intentionally make space for us in conversations expands our world exponentially. Brainstorm ways to slow things down and give us a fighting chance at taking our turn,

Modelling respectful behavior can go a long way. When other people know *how* to be respectful of AAC users—and when they know that other people in their social circles value when we are respected—they're much more likely to include us meaningfully. If you see someone speaking to our aide as though we aren't there, address us directly. When you notice we're being spoken over, interrupt on our behalf. If you notice we haven't been able to participate in the conversation, speak up and make room for us. You can use phrases like:

- "Hang on, I think [*name*] is typing."

- "Were you going to say something, [*name*]?"

- "[*Name*], any thoughts on this?"

Just remember that speaking **up for** us is very different from speaking **over** us. Seek out and amplify our own stories, not stories told about us. Choose your words intentionally. Be the backup for our own advocacy.

3. Though we may never be *safe*, you can help make us safer - It's impossible to talk about leveling the playing field for AAC users without mentioning the dangers of an ableist, inequitable world. We are disproportionately affected by abuse, neglect, discrimination, and other kinds of trauma. We are often denied the right to make basic choices, say no, or change our environment. Even those of us with access to AAC are likely to suffer from severe social isolation. Living under these circumstances may lead to additional difficulty communicating, stress-related health conditions, and mental health problems like post-traumatic stress disorder. These problems are systemic, but we are not powerless, even as individuals.

- *Be clear that our boundaries and decisions matter.* The confidence to exercise our right to refuse and our right to choose is a powerful defense against abuse. When we say "no," respect it, and back us up in enforcing our decision. Give us the opportunity to make choices, big and small. Self-advocacy skills alone can't prevent violence, but they can build resilience and set us up to resist, ask for help, and heal.

- *Make disabled peers and mentors an integral part of your social circles.* Disability rights leader and lifelong AAC user Bob Williams writes that "we all benefit from . . . people who we can mutually support, learn with, dream with, and grieve with, and work together to co-create a more just world." Peer support, whether formal or informal, engenders agency, belonging, and self-advocacy. Support AAC users to support each other—and remember that developing real relationships with people with disabilities will enrich your life, too, whether or not you're disabled yourself.

- *Be curious.* Humans behave in different ways for infinite reasons. Some of those behaviors might be frustrating, harmful, or unwanted. Instead of focusing your efforts on stopping a behavior, investigate and ask questions. *Why* might someone behave this way? Are their needs being met in meaningful ways? Could there be a physical health problem you can address? Assume that someone who can't rely on speech alone to be heard and understood has experienced traumatic stress, and use the principles of trauma-informed care to support them.

Ren Koloni, MA, is a Program Associate with CommunicationFIRST. 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 condition, cannot rely on speech alone to be heard and understood. To read 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. In this article, I follow 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/.

2. Content warning: some of the articles linked in this piece use terms now considered to be slurs to refer to people with presumed intellectual disabilities, in accordance with the language used at the time.

Freeing the Mind from page 27

issue might be a motor disability." Like Lily, I felt the same understanding — like everyone was not learning that we are very active in our minds and we are very observant.

Lily is my friend, and she was kind enough to let me interview her. When asked about how her mental health has changed since people began presuming competence, Lily stated in our interview, "I felt seen as a whole person. Like I could be part of the world outside of myself. It was freeing." My mental health was like Lily's. Finding my voice made my life worth something.

It was not easy for me to write this essay. Please understand that I struggled in freeing my thoughts while working on this paper. So many great minds are still locked in silence. What great discoveries, ideas, and technologies have been missed that could be helping humanity? My community may have solutions for world problems. Our unique sense of justice and profound love for others means we care about long-term solutions. There is a whole population in the world that could make this a better place if we were not ignored but, instead, were listened to and taken seriously. We are many, so the next time you come across a nonspeaker, presume competence and speak to them with no judgement. It doesn't take much to listen to a community who has long been silent.

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Mental Health from page 16

be the answer for Alex. He could not tolerate many of the medications traditionally used to treat anxiety. The medications he tolerated were not as effective in him as in individuals without autism. Research has consistently shown that the combination of medication and therapy is the most effective strategy for managing anxiety. Alex has autism and he spells to communicate, but he is also an individual with severe anxiety. His anxiety was causing suffering and at times left him feeling hopeless. He needed to develop concrete skills and behavioral strategies if we were to have any success managing his anxiety. We needed a multi-pronged approach to make his anxiety manageable, so I referred him to Dr. Beth Rosenwasser for Cognitive Behavioral Therapy (CBT).

Alex LePape

Beth Rosenwasser, PhD

Manley Ghaffari, MD

Dr. Rosenwasser's POV (behavior therapist): Dr. Ghaffari and I have worked together for over a decade with a number of children and young adults having challenges that many on the autism spectrum experience. So when she called to refer Alex for help working on his depression, anxiety, and social isolation, as well as sharing his and his family's strengths — including his being bright and articulate, and his positive close relationship with his mother and grandparents — I wasn't concerned about his mode of communication. When we discussed his using S2C, I had some trepidation because of several documented instances of false communication through "Facilitated Communication." Dr. Ghaffari shared that she believes that his communication is his own. I met for an initial consultation with Alex (and his mother, as his CRP, sat to the side) and saw that his letterboard is made of clear velum so that one could see both his eye gaze, his pointing to each letter, and his mother's hand holding the board (but not his hand) with no obvious prompting. The speed and coordination of Alex's eye gaze and tapping each letter were convincing to me, coupled with a lack of any obvious prompting by his mother, that his communication is his own. The fact that two other physicians with whom I have worked on multiple occasions also experienced Alex's communication as authentically his own was further convincing.

Building the Therapy Relationship

Alex's POV: "Hi Beth. Might need to end early today." That's what I opened with the first time I tried to spell through a migraine. She replied, "You tell me when." That sealed the deal for me. She adapted to me, she didn't try to impose any methods or approaches.

She asked great questions and really listened to my answers, even when they took a long time to spell out. It's refreshing to have someone want to get to know you as a whole person and not just a collection of diagnoses and problems.

She also shared experiences from her own life, which made me realize that some of my struggles are because I am human, not because I am autistic. We also share a love of poetry and sometimes exchange poems to help express our feelings. Our relationship feels welcoming and not clinical, though I know I am her patient. The contrast between how she treats me versus how I am often treated by (even well-meaning) adults in professional settings makes me emotional. It makes me emotional now because I realize it is still too rare. Even at the hospital — for migraines — where people are kind, I still feel like they "dumb things down" for me or just don't have the patience to wait while I spell.

Dr. Rosenwasser's POV: Through my work in clinical program development, I had become familiar with another speller involved in self-advocacy through the Spellers and Allies Advocacy Network, which works to educate healthcare professionals. I had read and shared their materials with others. This is a valuable starting point for any provider.

My efforts to connect with Alex are, at their core, the same as those I have made with every client I have worked with throughout my career. I seek to understand each person's or family's language, values, and goals, and to meet them on their own terms. I often think of the words of a colleague, who said that to be a clinician, you have to "enjoy watching flowers grow." Grounded in that relationship and genuine care, I then develop a behavioral understanding of what is happening and engage the empirically based tools of my training to help clients move toward their goals.

Each client is different, and autistic clients vary widely in emotional processing and expression. Alex is a highly empathic and sensitive man. At times, I offer a poem as a way of reflecting what I imagine he may be feeling. We thereby discovered a shared love of poetry. We continue to use literature as a way to share, feel understood, and help Alex connect his own experiences with those of others. Poetry and literature can remind us that we are not alone and introduce people to a range of feelings and ideas. As one small example, when Alex's grandfather, with whom he is close, was ill, I shared a poem wherein a woman recalls her relationship with her deceased grandmother, focused on how we embody the people who touch us. Alex added, "how their love touches us and makes us stronger… it will be hard when Poppas leaves us." This helped us to talk about the scary topic of illness and loss.

Therapy with a Nonspeaking Client Is Both the Same As and Different from Therapy with a Speaking Client: Reflections and Practical Considerations

General information: It is first important to say a few words about the role of the CRP. The CRP is not a participant in the bilateral communication and should not jump in. This would be more obvious if it were a staff assisting with mobility but when the CRP is a relative, they will also have feelings about what is being communicated and might have a tendency to jump in or even speak for the client (similar to what happens in family therapy with all speaker participants). The clinician is responsible to be clear to keep the boundary, in a kind and firm manner. There are times when there is a question where it is helpful for the CRP to respond: for scheduling or help with following up on an agreed-upon clinical goal, but the client should be the one to spell during the session to ask their CRP to respond to the question. If the role of the therapist is to have the parent participate in a family session, then that needs the permission of the client as well as the parent and should be clearly different than individual therapy.

Therapy is the same as with a speaking individual in that the relationship, or "working alliance," is a necessary but not sufficient condition for effective goal achievement. The second commonality is the need to use empirically supported case conceptualization as well as strategies to co-develop with the client. Providing a rationale, skills, and alternatives is a part of all ethical, effective mental health work.

There are also differences. Some are clear assets, some neutral, and others are challenges to clinical psychotherapy. One asset is that spelling slows down communication. This allows me as the clinician to be more thoughtful and organized about each next statement. Interestingly, this has positively influenced my work with speaking clients because I slow down and pause more to see if my next statement is the best response for the purpose of the therapy goals.

On the other hand, this slowness can make me concerned that I may be missing some critical background information; because it takes longer for a speller to share that background or check on it, we are both making decisions about what background is needed to make good clinical progress in the session time allotted. All clinicians sometimes wish they had more time or more details; it is just more of a challenge when communication is slower.

In addition, facial and body expressions as well as tone are usually important indicators of emotions regarding the conversation at hand; with those having apraxia and using AAC, that "information" is missing. The use of a see-through velum board is especially helpful, as I can see the spelling and Alex's facial and body gestures and can also read much of what he spells myself. There can be additional random utterances, sounds, and facial expressions that are not related to intended communication.

Clinicians need to check in with the client to ask if there is a meaning. For example, if Alex is unusually stimming and making vocal sounds, I will ask if it is related to the session content or something in his environment. It could be a challenge with sleep, which might lead us to talk about strategies or a recommendation to check in with Dr. Ghaffari about his medications. Or it may be that he is upset about the topic at hand, and I will know to titrate the approach and encourage use of calming tools or a break.

Alex's POV: I didn't believe I could learn so much about myself through someone else's eyes. Writing this article with Beth, I was excited to learn that working with me has changed her approach to working with speaking clients. I was a bit overwhelmed when she shared that because my secret dream is that including nonspeakers is not just a kindness to us, but good for everyone.

Regarding the slowness of spelling as compared to vocal speech, one benefit of spelling is that I must be thoughtful ahead of speaking so as to not say hurtful or angry things — it appears to me that it takes speakers a lot of effort to stop oneself when speech is so easily accessed. I feel lucky in this particular way because I can be impulsive, and spelling leads me to think ahead.

Regarding my mom as my CRP for therapy, I am glad that mom hears my thoughts but never asks for more. Her silence is a different kind of gift. I like that we are working together to find workarounds to challenges, like when mom mutes my zoom while I am verbally stimming while Beth is talking so that I can hear Beth (zoom mutes when two people sound off at the same time).

Finally, for my non-speaking peers considering therapy, ask yourself the following questions regarding your readiness:

- Do you have a CRP you trust with your deepest thoughts and emotions?
- Do you think you can stay regulated through hard discussions?
- Do YOU really want to do this, or are you being pushed?

Conclusion

Autistic people experience more complex health needs, greater healthcare utilization, and more unmet healthcare needs than peers with and without disabilities,

see Mental Health on page 51

Spellers from page 17

The Sensorimotor Foundation

The single most important concept a CP must grasp is that not being able to speak is a motor disability, not a cognitive one. This condition is most often called apraxia or dyspraxia - both derived from the Greek root *praxis*, meaning purposeful, skilled action: the ability to encode, plan, and execute skilled movements.[3] In the nonspeaking autistic population, difficulty with praxis can be profound, affecting initiation, execution, inhibition, and sequencing. As Biklen (2005) articulates, “the problem is not one of understanding, but of doing.”[4] A student who cannot self-initiate getting their letterboard is not refusing to communicate. They are experiencing a neurological gap between intention and execution.

Dr. Elizabeth Torres, Professor of Cognitive Science at Rutgers, has documented “noise” in the peripheral sensorimotor systems of autistic individuals - stochastic variability in micro-movements differing significantly from neurotypical patterns. Brincker and Torres (2013) found that this peripheral noise impedes central coordination and autonomous control, disrupting the clean execution of intentional motor movement.[5] The regulation partner is the external stabilizing force that reduces that noise enough to allow purposeful, directed movement toward a letter.

Torres’s research further identifies the partner relationship itself - their physical proximity, the quality of their presence, the steadiness of their own nervous system - as a variable in the speller’s sensorimotor output.[6] Dr. Mona Delahooke, a pediatric psychologist and author of *Beyond Behaviors* (2019) and *Brain-Body Parenting* (2022), argues that what looks like behavioral noncompliance is almost always a nervous system signal - a stress response, not a volitional act.[7] This is why the CP’s first job is not to present the letterboard; it is to help create the conditions under which the speller’s nervous system can settle enough to access intentional motor movement. Delahooke is explicit that adults must regulate their own nervous systems before they can co-regulate someone else.[7]

The Critical Distinction: Skill Acquisition vs. Open Communication

Understanding co-regulation also exposes the most consequential and most correctable error in CP practice: inadvertent influence during open communication. Preventing it requires a distinction many programs skip - the difference between *skill acquisition* and *open communication*.

During *skill acquisition*, the CP will know the answer. The question is structured: “Whom are we discussing in today’s lesson?” If the answer is Ben Franklin, both CP and speller know it. In this context, certain forms of coaching are appropriate - verbal directional prompts toward the target letter, confirming a selection while not calling out occasional typos, redirecting a motor impulse. This is scaffolded motor learning, bounded by the fact that the CP knows what the correct response should be.

JT, a minimal speaker, typing with his mom, Carol, as his CP. Here he is attending a weekly online social club with his spelling peers.

Open communication is categorically different. The speller is generating original thought. The CP does not - and must not - know what will be spelled. Trained CPs must recognize and eliminate these behaviors during open communication:

- **Moving the board during spelling.** A subtle shift toward a likely next letter provides motor scaffolding the speller did not request. The board must remain still unless the speller has completely shifted their body position, in which case the CP should lift the board and reset it - centered in front of the dominant spelling hand.

- **Selectively confirming letters.** Calling out some letters and not others during an open-ended response is real-time co-authorship. Confirmation must be consistent and non-selective, which means calling out typos as well.

- **Gesturing toward a particular area on the board.** Any hand movement, gaze shift, or postural lean toward a portion of the board constitutes a cue. CPs learn stillness as a discipline: neutral posture, neutral gaze, neutral breath.

- **Completing anticipated words.** AAC research shows roughly 200 words account for 80% of all spoken language (Boenisch & Soto, 2015),[8] so some output will be predictable. That predictability does not license word completion. Spellers must be coached to finish every word themselves.

- **Asking leading questions.** “What don’t you like about your teacher?” presupposes a negative answer. “Is there any feedback you’d like me to share with your teacher?” leaves the field open. The difference between eliciting a response and shaping one is trainable.

These are the most common failure modes in CP practice, and they are almost always unintentional. The most important self-reflection question a CP can ask is: *Do this speller’s typed words often surprise me?* If not, that pattern warrants honest examination. Video feedback review, third-party observation, and reflective supervision are non-negotiable. Research consistently confirms that CP training programs implemented with high fidelity produce meaningfully better outcomes than isolated or one-time training (Kent-Walsh, Murza, Malani, & Binger, 2015; Douglas et al., 2024).[10,11]

What Training Must Include

A replicable CP training framework requires three pillars: didactic knowledge (sensorimotor science, apraxia, prompting hierarchies, ethics, influence prevention), competency development (practice with real spellers, video-based feedback, rubric-graded motor task analyses), and ongoing supervision (debrief and coaching from seasoned practitioners). Kent-Walsh and McNaughton (2005) identified an eight-stage instructional model - from baseline assessment through controlled practice, advanced practice in natural environments, and long-term generalization - noting that programs relying on isolated or one-time training consistently fail to produce durable changes in partner behavior.[9] This is a professional development process, not a one-time event.

Schools can fund CP training through IDEA funds and state assistive technology grants. Denying a speller access to a trained CP is a denial of communication access under federal law - under Title II of the ADA (28 C.F.R. § 35.160)[1] and IDEA (20 U.S.C. § 1400 et seq.).[2] The infrastructure exists to fund this work. The obligation exists to provide it.

What’s at Stake

As both a clinician and the parent of two adult spellers, I have watched the world expand for nonspeakers as skilled partners entered their lives — and watched doors close when schools refused to train them. My oldest son spelled out this poem some years ago. I will let his words close this article, because they express what no credential or citation can:

Dormant back in the day, real thoughts get trapped.
No life breath for others to hear them spoken.
The sound in my mind is wasting away, lest a miracle sets it free.
A trusted presence shepherds my thoughts to tangible form.
- Evan Tastor

Communication Partners are not an obstacle, a luxury, or a threat to authentic communication. They are the key that unlocks the door to expressive freedom for nonspeakers.

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1. ADA Title II Regulations, 28 C.F.R. § 35.160. https://www.ecfr.gov/current/title-28/chapter-I/part-35/subpart-E/section-35.160

View the full list of references here.

Empowering from page 22

Specifically, families who participate in this program work with clinical psychologists and licensed clinical social workers to identify the reason why their child is engaging in disruptive behaviors—whether it’s to access a preferred item or to get out of a less-preferred activity. After determining the function of the behavior, families are coached on how to teach their child a more effective, more efficient, and less disruptive communicative tool for achieving their goal. Ideally, this tool is something they can use outside of their family and will give them the means of advocating for themselves well into their adult life.

Through caregiver training programs like ESDM and RUBI, families can be empowered to provide their children with communicative tools that will serve them for the rest of their lives. Communication can take many different forms and through evidence-based resources like those discussed, we can help non-speaking individuals develop tools that will best enable them to meet their short-term and long-term goals.

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View the full list of references here.

Co-Designing from page 17

For many nonspeaking people, communication involves far more than finding the right words. Between having something to say and expressing it lies the complex work of turning thought into movement. A hand may not move where the mind intends. A finger may hesitate or miss its mark. The words are there, but the path from intention to expression can be far more demanding than it looks from the outside. When communication is judged by speed or fluency, that effort is easy to miss.

For Graciela, another nonspeaking co-designer, the strain was felt in the body itself:

"A lot of my younger years were spent in physical pain because my carefree spirit was not meant for my physical body. I had to spend my energy always fighting off my discomfort. In the calm of finally accessing communication, my body began healing itself."

Stories like Sujit's and Graciela's show that communication extends beyond the keyboard itself. What started as a conversation about motor planning opened onto a hidden world behind communication: staying regulated and focused, turning thoughts into words, linking letters to ideas, and connecting with others who type to communicate.

Communication support, then, has to do more than supply letters and words. Just as important is making room for all that allows communication to happen in the first place.

Does Success Have One Shape?

Our conversations revealed how much effort can lie behind a single word. They also raised a larger question: what should communication support actually help a person achieve?

As Grant, a nonspeaking co-designer, noted:

"I think the biggest roadblocks are societal expectations without understanding that disability is not going away."

In education, therapy, and technology, success is often measured by what a person can do alone. Independence becomes both the goal and the yardstick of progress, and support becomes something you are expected to leave behind.

Yet the experiences shared by our nonspeaking co-authors point to a more complicated reality.

Sujit's art: "Obstacles of Freedom"

Grant reflected on a consequence of overvaluing independence:

"I don't think I am the only one who will say words and ideas were given to us to mimic, and that was viewed as success because we hit a button alone."

Elizabeth, an occupational therapist and co-designer, recognized this tension inside her field:

"Everyone keeps telling us that OTs should help people be independent. . independence at any cost, but that's so fake. Even non-disabled people are not independent with everything. . autonomy and choice and the ability to do things and participate in ways most meaningful to them should be the actual goal."

Isaiah's experience brought that tension into focus:

"When I type independently, it feels like free-falling, but with someone holding the keyboard, it's like falling with a parachute."

Together, these perspectives point toward a different idea of success. The goal, as Elizabeth put it, is not "independence at any cost" but autonomy: having a say in how you communicate, participate, and make choices about your own life.

Seen this way, support is not the opposite of success. It is often part of what makes success possible. For some people, communication becomes more independent over time; for others, support stays part of how they communicate. What mattered to our co-designers is not whether everyone arrives at the same place, but whether communication works better for them than it did before.

For assistive technology, this means remembering that the person using the technology is the one who gets to decide whether it is helping.

Kyle's art piece

Designing Together

None of these insights would have emerged without the active involvement of the nonspeaking co-designers who helped shape this project. But meaningful participation does not happen automatically. It has to be built into the way a project works.

For the TYPE team, that means paying as much attention to how we work together as to what we are building. Many of the practices that shaped the project grew out of ongoing conversations about what actually helps people take part. Four stand out as lessons others hoping to collaborate with nonspeaking people may find useful:

- **Make communication work for everyone.** Rather than expecting everyone to communicate the same way, we make room for different ways. A comment typed in a shared document should carry the same weight as one spoken aloud.

- **Make space for time.** Some of the most valuable contributions do not arrive at the speed of live conversation. Ideas need time to form, to be reflected on, and to be revised before they are shared. Treating time as a form of access means slowing down and resisting the pull to move on too quickly.

- **Keep the work visible.** When agendas, notes, and decisions are shared and easy to return to, no one has to hold the whole project in their head to take part. People can follow how ideas develop and how decisions get made.

- **Decide Together.** Meaningful participation is more than sharing personal experiences. Co-designers are involved in discussions about project goals, emerging ideas, and design decisions throughout the process. Their perspectives help refine questions, uncover hidden assumptions, and shape the direction of the work as it evolves.

These choices may seem procedural, but together they helped determine whose voices informed the work.

The conversations that shaped TYPE began with experiences that rarely reach the rooms where technology gets designed. But they have gone on to shape the project itself.

Kyle, a nonspeaking co-designer, shared what being part of TYPE means to him:

"It gave me hope for a voice in this world."

Perhaps that is what meaningful participation ultimately makes possible: a world where more people can shape the systems, decisions, and technologies that affect their lives.

We call for a world where people don't settle for using what has been built. **They help decide what gets built.**

This article was authored by Sofya Gektin (University of Virginia), Sajad Sarlaki (University of Calgary), Grant Blasko (University of Washington), Kristen Gillespie-Lynch (College of Staten Island and The Graduate Center of the City University of New York), Isaiah Tien Grewal (Stony Brook Medicine School of Social Welfare), Vikram Jaswal (University of Virginia), Sujit Kurup (Autism National Committee), Chandra Lebenhagen (Including Autism), Graciela Lotharius (Georgia Perimeter College), Elizabeth MacNeil (University of Alberta), Kyle Stauber, Caroline Rose Tallungan (University of Virginia), Lisa Vallado (Washington Adventist University), and Diwakar Krishnamurthy (University of Calgary).

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Find Their Voice from page 10

for autonomy, social participation, and meaningful engagement within communities (Yau et al., 2024).

People with complex communication needs are often excluded from social interactions and decision-making opportunities, not because they lack the desire to participate, but because others may not recognize or support their preferred methods of communication (Taylor, 2020). This can lead to isolation and limit opportunities for meaningful engagement.

Direct support professionals play an important role in changing that experience by advocating for access in everyday settings. This might mean ensuring communication devices are available during a community outing, encouraging peers to engage with someone who communicates differently, or simply taking the time to listen and respond thoughtfully.

"When we take the time to understand how someone communicates, we're showing them that their thoughts, feelings, and opinions matter," Keshia says. "Everyone deserves to be included and have their voice heard."

A person who is able to communicate their preferences gains more control over their daily life. Someone who can share their thoughts and experiences is better equipped to build relationships and connect with others. Over time, these opportunities help foster confidence, independence, and a stronger sense of belonging.

Communication Creates Connection

At its core, communication is about human connection. It is how people share experiences, express emotions, advocate for themselves, and participate in the world around them. Having access to the right communication supports can open doors to opportunities that might otherwise remain out of reach.

This is one of the many reasons why the work of direct support professionals is so meaningful. DSPs are not simply assisting with daily tasks; they are helping people exercise choice, build relationships, pursue their goals, and participate more fully in their communities.

"Every person has a voice, even if it doesn't sound the way people expect," Keshia says. "When you help someone communicate, you're helping them show the world who they are."

That philosophy reflects the heart of the #MoreThanWork campaign, which highlights the many ways direct support professionals empower people with developmental disabilities to live fulfilling lives. Whether supporting communication, fostering independence, or helping someone advocate for themselves, DSPs make a difference through the relationships they build and the opportunities they create.

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Express Yourself from page 18

Only months after planning began, the COVID-19 pandemic forced TMP to move all programming online. Initially viewed as a temporary adjustment, the virtual format became an unexpected strength. The online environment removed geographic barriers, allowing artists from across the country to collaborate. More importantly, it fundamentally changed the pace of the creative process. Traditional theater often rewards quick responses. Express Yourself intentionally does not. Participants have time to think, type, revise, plan motor movements, and build upon one another's ideas. Rather than emphasizing speed, the process values reflection and depth of thought. Screen sharing, chat functions, visual supports, prerecorded media, and other digital tools became integral artistic resources. When in-person programming resumed, Express Yourself remained online because the virtual environment supported collaboration in ways the team had never anticipated.

Today the program continues to evolve under the leadership of Program Director and Clinical Supervisor Hannah Olander, LCSW, alongside Lead Teaching Artist Shelley Pack and Music Director Mina Bloom, who continually refine the curriculum in response to participants' interests, communication styles, and creative ideas.

Express Yourself develops entirely original works. Every project begins with the participants themselves: a typed sentence, a poem, a question, an experience someone wants others to understand. These contributions are collected, revisited, and expanded until individual ideas become collaborative works of art. Participants' reflections become song lyrics, musical styles, imagery, and choreography. Each new perspective redirects the script. Over weeks and months, ideas evolve into artistic works that no individual could have created alone. Instructors function as creative facilitators, identifying emerging themes and encouraging collaboration to help shape participants' ideas into original songs without speaking for them.

Participant Emma Cladis reflected: *"Since starting the Express Yourself program, I have grown as an artist mainly because of the great coaching and support I have been given. I'm so proud of all the other typers. The collaborative work with everyone was the best. We brought out each other's creative strengths. I think we loved doing this so much, and it shows what is possible."*

Express Yourself cast members, communication partners, and The Miracle Project creative team gather after filming Unmuted, celebrating the culmination of months of collaborative songwriting, creativity, and multimodal communication.

Music Director Mina Bloom: *"Even when we showed the earliest projects and the quality of the videos was different, the writing, the lyrics, the thoughts they had were just as profound from day one. It's amazing to see their artistry get the professional quality it deserves."*

As participants continued creating original songs, music videos became a natural fit to reflect the collaborative process itself. Songs could develop gradually through typing, conversation, revision, and shared authorship. Participants returned to projects repeatedly as ideas deepened and evolved, expanding opportunities for artistic expression. Typed text became on-screen graphics. AAC-generated speech and participants' own voices became part of the soundtrack. Movement, choreography, cinematography, editing, costumes, and visual imagery all contributed to the storytelling. Rather than asking participants to adapt to traditional performance formats, the videos honored the multimodal creative process that had generated them.

Express Yourself participants have created 12 original films. Ten were conceived, written, rehearsed, filmed, and produced entirely through virtual collaboration. Two — *Let My Typin' Let You See* and *Unmuted* — culminated in live video shoots after months of online collaboration. Together these films have been screened at conferences, universities, film festivals, educational events, and community programs, allowing participants' work to reach audiences well beyond the classroom.

Participant William Del Rosario described the filming experience: *"Watching the team doing the scenes felt magical because first, we were on location filming in person, and second, we weren't looked at as people with disabilities or limits. Instead, we were the stars in our music video and part of the team."*

Participant Antonietta Nelli shared: *"Making music videos allows me to keep speaking boldly. I love the creative process and doing this with people I admire."*

Teaching artist Shelley Pack observed: *"Creators are creators. This is a really deserving group of talented people who have often never been given an opportunity to be artists. It just takes a little time and a little understanding. That's why I love The Miracle Project because that's the place where we create that environment."*

Express Yourself did not teach us that multimodality communicators are artists — we began because we already believed they were. More than six years later, Express Yourself continues to evolve, demonstrating that when environments adapt to participants rather than expecting participants to adapt to the environments, creativity, authentic self-expression, and meaningful connection flourish.

In the words of participant Bella Santoyo:

I found the Miracle Project during the pandemic. It was not a good time for the world, but it gave my community an opportunity to band together via Zoom. My introduction to Expressive Arts with the Miracle Project placed new demands on my mind and body but in a needed and positive way. Each week from the comfort of my home I practiced moving my body in new and organized ways. Each of my friends shared thoughts and affirmations that would become lyrics to songs. We all had visions of how we wanted to bring our collaborative efforts to life. I loved the creative time my friends and I spent together. For me, my involvement filled a void that I didn't know existed.

Magical is a perfect description of the filming experience. It is still a highlight in my memories. I loved every bit of it, but what stands out most was the day we recorded our voices. I have had the ability to use text-based communication for years. My communication partner or my iPad would speak my words. Still, some have questioned and doubted my intellect. I am proud that I was able to voice my words aloud for myself on that day of filming. I can do many things with the right teaching and patient support. That is a needed takeaway message from our song.

I want to continue to make videos for many reasons. It's a fun and creative outlet, it challenges me to try new things, but most importantly, I am seen. We break the stigma about disability and autism. We show what is possible when we are given a safe and creative space to express ourselves. Alone is a lonely existence but together we can do great things.

Elaine Hall is Founder of The Miracle Project. Hannah Olander, LCSW, is Program Director and Clinical Supervisor at The Miracle Project. For more information, contact hannah@themiracleproject.org or 213-793-5481, or visit themiracleproject.org.

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Autism Professionals from page 12

progress in autism won't come from any one profession. It will come from professions working together. We need stronger connections between research and practice, education and healthcare, innovation and implementation, and between the professionals doing the work and the systems that shape how that work happens, amplifying our collective wisdom.

Autism care needs to be organized the way autistic people's lives actually work – across disciplines, not within one discipline.

This conviction is what led to the creation of the National Society of Autism Professionals (NSAP). NSAP exists to do something no organization in this field has done before: bring every discipline that touches the lives of autistic individuals and their families under one professional roof, with no allegiance to any single model of care or service delivery. Not instead of organizations like the ones gathered at ABAI, but alongside them and in conversation with them.

We're not interested in erasing the differences between disciplines, and we won't manufacture consensus where real, healthy debate should happen. What we're building is a place where behavior analysts, psychologists, educators, physicians, workplace architects, researchers, innovators, and autistic professionals themselves can learn from one another, challenge one another, and build shared standards together. A place where the next reporter asking about "autism care" hears an answer big enough to match what that phrase actually means.

The autism field has never lacked talent or commitment. What it has lacked is a forum where all of that expertise adds up to something greater than any one discipline could achieve alone. The future of autism care won't be built by behavior analysts alone, psychologists alone, educators alone, or advocates alone. It has to be built by all of us, together, in the same room.

For more information on NSAP, visit nsap.org.

Robin McLeod, PhD, LP, is the founding CEO of the National Society of Autism Professionals (NSAP), a cross-disciplinary professional association for the autism field. She is a licensed psychologist who built a solo practice into a multidisciplinary behavioral health organization serving the Twin Cities, and most recently served in executive leadership at the American Psychological Association, where she led the development of professional practice guidelines across nearly a dozen clinical domains. She is also an autism parent.

Robin McLeod, PhD

Respect from page 19

3. Some of us are unreliable speakers. A spoken response of "yes" may not mean consent. Consent should always be verified by other communication methods (e.g. AAC devices), and often questions may need to be phrased in other ways to confirm understanding. In these situations, it may be helpful to have input from caregivers or other support persons to determine the best ways that a patient receives and communicates information.

4. Allow us time to spell and type. Time constraints are one of the biggest challenges in healthcare settings, but it is critical to allow time for processing and responding. This ensures that patients are heard and helps to avoid missed portions of the medical history that could lead to misdiagnosis or erroneous treatments.

5. Schedule more time for our appointments. In practice, this may mean blocking extra time for visits, scheduling short-interval follow-up visits, or prioritizing the few most important issues during a visit. While this can be challenging from a scheduling perspective, it can greatly improve the quality of care for nonspeakers.

6. Use patient portals. They give us time to gather our thoughts in advance and to communicate in between appointments. Patient portals are a great accessible communication tool that allow providers to send advance notice of topics that may be covered in an upcoming visit. Patients can even send thoughts ahead of time for providers to review, which will help make the visit more efficient.

7. Our bodies do not always do what our brains want. This highlights a common bias in healthcare where clinicians may incorrectly assume that physical disabilities imply co-occurring intellectual disabilities. Patients with apraxia have difficulty carrying out purposeful movement despite having the ability and desire.

Rosemary Corcoran, MS, OTR/L

Hannah Facey, MD

Sarah Ackerman

8. Visuals are helpful. Incorporating visual aids, such as models, social stories, or symptom scales can be beneficial for enhancing comprehension and accurate communication. They can be important tools for improving patient education and increasing comfort with portions of visits that may be anxiety-provoking.

9. Provide all the facts. Patients deserve to know all of the information about their health so that they can make informed decisions. Providers should not withhold any information based solely on assumptions about a patient's level of understanding. It is also crucial that information is presented in an accessible format for patients to understand and process at their own pace.

10. Be aware that we may feel anxious about being there. Be kind and understanding. Many patients experience anxiety in medical settings, and this can be especially true for nonspeakers who may have had negative past experiences due to communication barriers or biases from healthcare providers. It is important to acknowledge these feelings and approach visits with warmth, curiosity, and flexibility to work in partnership with patients.

Creating a healthcare environment that is respectful of communication styles, mindful of anxiety, and centering the patient as the expert in their own care will help improve the experience and outcomes for nonspeaking autistic adults and others with IDD.

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Connecting from page 20

3. Speak directly to us. Say our name. Look at us, not our communication partner. We may not look at you. In addition to the communication tools we rely on, many of us need a trained partner (communication/regulation partner or CRP) to support our access. I feel invisible and unworthy when someone speaks to my CRP instead of me.

4. Wait for us to finish spelling our thought before speaking; it helps the AAC user focus. Concentration to select the correct letter is even more challenging when someone is watching. Don't ask another question before we've had time to answer the first one.

5. Please don't finish a word or sentence for us; it might not be at all what we intended to say. For example, if I spell M-A-N, the word might continue to become M-A-N-A-G-E, M-A-N-I-F-E-S-T, M-A-N-Y, M-A-N-N-E-R-S, or M-A-N-I-A-C.

6. Even though I might have a communication partner, the words I type are mine. Believe that.

Santa Rosa Junior College student, Noah McSweeney, uses a letterboard to communicate by pointing and spelling out his thoughts and dialouge. April 2025. Photo Credit: Adair Alvarez Rodriguez

7. Be attentive while the AAC user is communicating. Don't play on your phone or talk to others. Instead, show respect and interest.

8. Try to keep the conversation going, even if the AAC user doesn't answer in the moment. It may be because they can't. There's no problem in comprehension. They are following the conversation; it's just that the output takes extra time.

I hope the next time you meet an AAC user, you include them in your conversations with a new understanding. The interaction may surprise you. There is endless benefit to humanity in bringing AAC users out of the shadow of doubt1. Talking can no longer be our only means of connection.

Take a risk to engage a nonspeaker in lively conversation and you might make a new friend.

This article has been republished with permission. View the original source at theoakleafnews.com/columns/2026/04/07/in-autisms-corner-how-to-interact-with-a-nonspeaker-in-public. *Noah McSweeney is a Nonspeaking Autistic Self-Advocate, College Student, Poet, and Award-Winning Student Journalist. For more information, visit linktr.ee/noahpoet and check out Noah's Instagram page, public Facebook page, and personal Facebook page.*

Power of Naming* from *page 18

signed (e.g., American Sign Language). In some cases, individuals may use augmentative and alternative communication (AAC) to "replace or supplement spoken language" (ASHA, n.d.).

Even *Aphasias* [brain disorders] that affect how one communicates impact the ability to understand spoken and/or written language. "Aphasia usually happens suddenly after a stroke or a head injury. But… can also come on gradually from a slow-growing brain tumor or [a degenerative] disease that causes progressive, permanent damage… [Patients] with aphasia relearn and practice language skills [and/or] learn … other ways to communicate" (Mayo Clinic Staff, 2022).

Non-speaking

The term *non-speaking* has gained increasing acceptance over the past decade, and clinicians and advocates are coming to prefer it. "People [may also] use the terms *non-oral*, *non-vocal*, or *minimally-speaking*" (Riggs, MA, 2021).

The term non-verbal is becoming stigmatized because many people equate non-verbal with not having, or [lacking the ability to] understand language.

Referring to someone as *non-verbal* can lead to low expectations or incorrect assumptions about their intelligence or emotional depth, especially among those with developmental disabilities, while *non-speaking* validates their identity as a communicator, even if that communication doesn't involve speech. A "person… labeled nonverbal may still communicate actively, just not through spoken language" (McRory, 2025).

Non-verbal communication includes:

1. Facial expressions
2. Gestures
3. Paralinguistics (loudness or tone of voice)
4. Body language
5. Proxemics or personal space
6. Eye gaze, haptics (touch)
7. Appearance
8. [Use of] artifacts (objects and images) (Cherry, 2025)

Many autistic self-advocates also reject the word "non-verbal" due to its implication that a person is "mute" or lacks the power of speech.

Confusing Language

There are very few conditions which entirely prevent humans from making sounds. What we call mutism is not a single condition—it can result from psychological, physical, or neurological causes. Even someone with vocal cord damage may be able to cough and laugh. In other cases anxiety prevents speech, even when the person is able to speak ("Selective mutism"). And people who cannot speak frequently communicate effectively using non-verbal methods like writing, sign language, or assistive technology (Can Mute People Make Sounds? The Science Explained, 2025).

Annie Kent, MA

Autistic Non-speakers

Non-speaking autism does not imply lack of intelligence or understanding. Non-speakers communicate *differently*. Daily communication is not just about words—it involves social understanding. Non-speaking individuals may have difficulty interpreting tone of voice, facial expressions, engaging in back-and-forth conversations, and building relationships. When a person has difficulty expressing their thoughts or needs, it may lead to issues like anxiety, frustration and emotional distress (Villines, 2021).

Changing the Narrative

Many advocates are urging a shift in terminology to better reflect current understanding of autism, communication, and neurodiversity.

Social media and personal blogs have created spaces for people to question outdated terms, share lived experience, and bring greater visibility to these issues. Advocates also encourage moving away from broad labels such as "high-functioning" and "low-functioning" and instead describing each person's individual strengths, challenges, and support needs without attaching value judgments.

Creating Full Inclusion for Nonspeaking Autistics

In *Ask the Expert: 'Nonspeaking' vs. 'Nonverbal' and Why Language Matters*, Corrina Riggs, M.A., SLP-CCC, says, "[T]he acceptance of neurodivergent people is essential. The bigger umbrella piece to this conversation is embracing neurodivergence and not seeing it as a disability… but as a difference… education is always a big step towards change-making. Once you start understanding something more, then you'll see change" (Riggs, MA, 2021).

Language Clarity

Clarity of terms is essential. I am diagnosed with ASD, ADHD and *Nonverbal Learning Disability*, (NVLD) which can co-occur with ASD. People presume it means I either don't speak or cannot do so competently. But NVLD is a neurodevelopmental disorder affecting pattern recognition, concept learning, and organizing information, rather than language processing skills. Unfortunately, that distinction doesn't eliminate discrimination or marginalization.

Violated Rights

All too often the rights of non-speaking autistics are violated. According to DJ Savarese, a 2017 Youth Exchange/Human Rights Initiative Fellow, "inclusion means having a voice in one's life… Our silence makes some estimate us as incapable, and soon we are left out of anything meaningful. Before I learned to read and write, people thought I had no mind…Reading and writing are rarely taught to non-speaking autistics" (*The U.S. Education System Is Failing Nonspeaking Autistic People*, 2017).

There also needs to be greater understanding of literacy, language and the tools used to convey meaning. Some learners need visual bridges, such as photos and pictures, to become literate. Others need to touch the words, physically placing words in sentences like pieces in a puzzle. Others need to sign or draw concepts and words in order to capture their meaning. Still others may require the musical sounds and patterns of poetry to lure them into language (*The U.S. Education System Is Failing Nonspeaking Autistic People*, 2017).

"I've estimated there are as many as 750,000 nonspeaking autistics in America. The dominant culture's production of autism is not *my* experience of autism." We need teacher training programs that actually instruct teachers in literacy-based instruction for non-speaking people and other neurodiverse learners…We … need accommodations that can be used in inclusive settings to allow each student access to the regular curriculum. By linking strategies with specific kinds of non-speaking autistic learners… [we can] help teachers and parents identify the most efficacious strategies for their particular student or child" (*The U.S. Education System Is Failing Nonspeaking Autistic People*, 2017).

DJ Savarese's words resonate with me, as does this quote from Albert Einstein: "I never teach my pupils. I only provide the conditions in which they can learn" (*The Quotations Page: Quote from Albert Einstein*, 2025).

Conclusion

When working with or supporting autistic non-speakers, advocates advise shifting the perspective away from the deficit-based medical model. "Instead of asking, "How can we fix this?" ask, "How can we support this individual to thrive?" (Mehta, 2026) My recommendation is: _Let well-being, autonomy, and dignity be your star—and support, not correction, shall light the way.

Annie Kent, MA, spent two decades working in public sector disability, mental health, and infectious diseases advocacy and education. Diagnosed with three closely related types of neurodiversity, a lack of awareness and understanding led to burnout and retirement from the field. She remains an active advocate, learning and engaging personally and remotely with several Autism and ADHD organizations and Forums. Contact Annie at anjolie1031@gmail.com.

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View the full list of references here.

Teaching Poetry from page 21

the neural basis of the emotional response to music…and literature, which, in the case of poetry especially, exploits the musical properties of language to emotional effect.” When he was older, my son offered a semantic paraphrase of the poem, explaining that “Thomas captures the dewy feeling of the world when you are small.” Yet, as I’ve been arguing for years in print — I work as a professor in the field of neurohumanities — it’s the way that a poem lives in your body that counts.

If you listened to the research literature from the last fifty years, which claimed that autistic people suffer from impairments in imagination, figurative language, and theory of mind, you would have believed that poetry was a waste of time for your autistic child.[1] This literature no doubt explains why we’ve tracked autistic students into math and science classes in schools, if we’ve mainstreamed them at all. When I interviewed Temple Grandin for my 2018 book, *See It Feelingly: Classic Novels, Autistic Readers, and the Schooling of a No-Good English Professor*, she not only recalled with pleasure studying Romantic poetry as an undergraduate, but she also recited a poem by Wordsworth that she’d memorized fifty years prior! What is more, for weeks after the interview, she called to discuss other poems from that class. This is not the portrait of Grandin that emerges in Oliver Sacks’ *New Yorker* profile, where he says plainly that art eludes her. The point of my book was to show, by emphasizing the generation of sensuous mental imagery while reading literature, that autistics across the spectrum might actually have a special talent for it. Grandin, of course, speaks of “thinking in pictures.” Add feeling and the other sensory modalities to the phrase, and you have a perfect description of what poems and stories facilitate.

Coming from another place of concern, if you worried that strong emotion in a poem, from difficult content, might overwhelm your autistic child, you likely missed a fundamental paradox of the art form. I was certainly worried about this with my son whose trauma triggers were profound, and I’m an English professor! In the words of one study, “Peak aesthetic pleasure can co-occur with physiological markers of negative affect.” Much is compressed into this statement, not least of which is that a poem about a horrific life event can be beautiful and that its beauty, while distressing, can also be pleasurable. The poem’s formal techniques, you could say, both provoke distress and protect from overload by allowing the seasoned reader to regard the aesthetic delivery system as a form of exquisite control. Poetry, in short, can teach you how to manage overwhelming emotion. Another study, this one from *The Journal of Poetry Therapy,* says something similar by conceiving of the lyric “I” as “a psychological space through which writers can explore emotion, memory, and identity with a degree of reflective distance.”

Anxiety is a big challenge in autism, especially its nonspeaking variety. Aside from any trauma that an individual may have experienced, the nervous system, like a car, idles very high. In an interview with the nonspeaking autistic writer Tito Mukhopadhyay, whom I’ve mentored for two decades — we meet every Saturday by Zoom to discuss the book we are currently reading and the writing he has recently done — the comforting aspects of rhyme and meter, which give Tito a “secure feeling,” came up. “A rhyme is a very linear auditory experience,” he explained.

Ralph James Savarese with his son DJ

And so is the beat — be it in tetrameter or in pentameter. It arouses the cortical mind with certain meaningful language experience and arouses the subcortical mind with the expectation of the mechanical beat that is offered by the lines of the poem. Anxiety is subcortical. Anxiety gets diluted by the experience. That is what makes it soothing.

We might think of metrical poetry as a kind of limbic system cane, aiding what Frederick Turner and Ernst Poppel call the brain’s “synthetic and predictive activity of hypothesis construction.” By that they mean our ability to answer the question “What’s next?” without overly taxing the system. “By ruling out certain rhythmic possibilities,” Turner and Poppel write, “meter satisfies the brain’s procrustean demand for unambiguity and clear distinctions. By combining elements of repetition and isochrony [the rhythmic division of time into equal proportions] on the one hand with variation on the other, it nicely fulfills the…habituative need for controlled novelty.” In this form of autism, where everything is perceived in its irreducible particularity, making the business of quick generalizations more difficult, controlled novelty is a lifeline. At least two studies support the salutary physical effects of meter, showing how it can correct for cardiorespiratory decoupling due to nervous system imbalance and stress (sciencedirect.com; journals.physiology.org). Thirty minutes of hexameter recitation more effectively recoupled heart rate and breathing than conventional therapeutic exercises.

Promoting self-discovery and self-expression, teaching compositional techniques and feeling management, enhancing autistic pride through sensory advantage, building community, and providing a rich form of accommodation, creative writing classes seem to this scholar and poet anything but an inessential extra. “Very great sound. Very great sound,” we might all say together.

Ralph James Savarese is the author of seven books, most recently “Herman Melville and Neurodiversity” (Bloomsbury 2024), and the coeditor of four collections, including the first on the topic of neurodiversity. He has received awards from the National Endowment for the Humanities, the Mellon Foundation, and the Herman Melville Society, and he has been a fellow at Duke University’s Institute for Brain Sciences. To contact Ralph, email savarese@grinnell.edu.

Footnotes

[1] In a series of scholarly articles, I demonstrate the need to modulate the prevailing view, arguing that many autistics possess both enormous sensitivity to figurative language and keen theory of mind. See “The Lobes of Autobiography: Poetry and Autism,” Stone Canoe 2 (2008); “Toward a Postcolonial Neurology: Autism, Tito Mukhopadhyay, and a New Geo-poetics of the Body,” Journal of Literary and Cultural Disability Studies 4.3 (2010); “Gobs and Gobs of Metaphor: Dynamic Relation and a Classical Autist’s Typed Massage,” Inflexions 5 (2012); “From Neurodiversity to Neurocosmopolitanism: Beyond Mere Acceptance and Inclusion,” Ethics and Neurodiversity, Eds. C.D. Herrera and Alexandra Perry, Cambridge Scholars Publishing (2013); “The Critic as Neurocosmopolite: What Cognitive Approaches to Literature Can Learn from Disability Studies,” Narrative 22.1 (2014); and “I Object: Autism, Empathy, and the Trope of Personification,” Rethinking Empathy through Literature, Eds. Sue Kim & Meghan Marie Hammond, Routledge (2014).

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LEND Program from page 22

research and clinical skills necessary to affect positive change from the individual to systems.

At the heart of the SBU LEND are our self-advocates. Self-advocates share their lived narratives and the obstacles they have faced due to inequities and barriers in healthcare. Iz, a LEND advanced medium-term trainee (completing 150-299 program hours), first participated on the Transition to Medical and Dental School Patient Panel at Stony Brook Medicine, sharing the quality health and dental care he received and the adjustments needed for healthcare environments to become sensory-friendly and conducive to shared decision-making for nonspeakers. He next created "Tips for Communicating with Nonspeakers over Zoom" for his LEND fellows. From using the chat appropriately to the timing of a response in small and large group discussions, our cohort of physicians, family members, nurses, and other professionals, alongside speaking self-advocates, quickly learned and practiced culturally responsive communication with nonspeakers. Our Core Faculty, enthralled with Iz's communication, immediately referenced his etiquette guide and requested to attend our didactics addressing apraxia, clinical strategies and research regarding nonspeakers who can and cannot type. A SBU LEND didactic assignment involved creating an Interdisciplinary Team Code of Ethics. Extracts from Iz's Code include guidance like "Interdisciplinary Teams shall value the lives of all Autistics regardless of that person's perceived ability to earn income; Nonspeaking Autistics especially deserve the most courageous support from Interdisciplinary Teams, especially in circumstances when the Nonspeaker's caregiver insists on assuming incompetence; and Historically, speaking team members have dominated our collective expression, but nonspeakers must also be given a chance to input."

To our knowledge, Iz is the first nonspeaker fully included in a LEND at this training level. His impact on the SBU LEND is substantive and significant, referenced by his peers as "life-changing" and "who I learned the most from." Iz's graduation tribute to his LEND cohort exemplified the mutually beneficial exchange. Their faces watching and listening to his speech app's voiceover of his typed words give me profound hope that the next generation of LEND healthcare professionals, families, and self-advocates have been forever changed by the intellect, ideas, and honesty of Isaiah Grewal.

Typer's Perspective

Eight years ago, as part of a conference breakout session led by Professor Vikram Jaswal, a 15-year-old me shared that I wanted to spend my life doing autism research. Professor Jaswal didn't laugh even though no nonspeaking autistic had yet become a Researcher back then. Instead, he asked me, 'What kind of autism research?' I didn't know because most of my school life, until I turned 13, had been filled with ceaseless repetition of mundane data like the weather and appropriate clothing for it. Although my mother started homeschooling me, trying to help me catch up in all subjects, I did not have enough education to know enough about autism topics to choose one. By the time I met Professor Jaswal, I was really ready to learn what it would take for me to become a serious autism research collaborator. I started earning college credit through Harvard Extension School. Then I was told about SBU Medicine's LEND Program by Dean Ballan. At first, I was so excited reading about all the great topics that would be covered. Public health! Diagnostic history of autism! Research seminars! But next, I was filled with doubt. Could I keep up in lecture discussions with classmates who were doctors, credentialled therapists, and academics? Good thing Director Ballan so kindly welcomed me with her no-problem-is-unsolvable attitude. I braced myself for the usual stressful Disability Accommodations interview, but Dean Ballan already knew so much about nonspeaking autism that everything I needed started rolling into place, once I committed, without me even having to ask. When I showed up on campus the first time, it was a dream come true. The classmates and faculty were all understanding, even when I needed to stand up and walk around at quiet times. Once the program started, my life became a wonderful rhythm of academic readings to prepare for Monday night Didactic lectures. Three hours passed quickly on those lecture nights. And I also got to start on Professor Munoz-Laboy's amazingly educational Research Seminars series. So far, I've learned about the difference between qualitative and quantitative research, how to structure effective research surveys, and how to write a good research question, to name just a bit of my newly acquired knowledge. And we also get Faculty Mentor guidance, and guess who I got assigned? Professor Jaswal, who is now SBU LEND Psychology Co-Core Faculty! Through his lead, I am now a researcher on the TYPE Project, the world's first with nonspeaking autistics as co-designers, not just consultants. This past year in TYPE, I've learned academic coding from Professor Kristen Gillespie-Lynch, participated in creating my first conference poster for INSAR 2026, and made some slides that our team presented at the 2026 CUNY Neurodiversity Conference.

Research grant applications are now given merit for community representation. But nonspeakers are neither omniscient nor psychic. To truly be helpful research collaborators, we must first be educated on how rigorous research is conducted. We must also learn how to digest academic material, so we can do catch-up readings to keep up in team meetings. And we must start with some foundational knowledge in medical history, public policy, and medical professions. I have learned all these topics and more in SBU LEND and look forward to adding even more knowledge to my research collaboration arsenal as I continue the Program.

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Re-Envisioning from page 11

learn from, and work directly with, those most impacted. For example, LIPC's current Robert Wood Johnson Foundation (RWJF) Equity Capacity Building Grant (ECBG) project works exclusively with diverse, disabled BIPOC leaders, including those who identify as LGBTQ+, people with diagnoses of developmental disabilities, and/or people who don't use their vocal cords to communicate, to disrupt systemic and internalized ableism and advance health equity and security for ALL people with disabilities.

Phase 1 began with a group of 15 intersectionally diverse, black, brown, and indigenous disabled leaders, nine of whom use alternative and augmentative communication, who came together as paid research assistants from across the country to help us fill out and understand the health equity and community barriers they face, what they need, and how to assess whether our innovative learning forums empower participants to advocate for their own well-being. Rather than ask them to create evaluative questions for a curriculum that was already developed, their research questions shaped the curriculum we developed.

So far we've learned that these issues really matter to them. Of the 15 disabled BIPOC leaders we recruited, 100% of them committed, followed through, and expressed interest in more involvement with the project.

We've learned in discussions and responses from our research assistants that, for them, health equity centers around holistic wellness, meaningful community engagement, defining potential, and developing and maintaining authentic relationships; that health and wellness are multifaceted and center around different kinds of energy, such as physical, mental, emotional, and spiritual; that meaningful community engagement involves multiple communities, some disabled, some not, and some mixed; and that authentic relationships are interdependent and able to connect us with others.

We also learned that it was more important to pay our disabled BIPOC leaders well than to have an administrative assistant.

We learned that we can meet with other large foundations claiming to fund lived experience-led projects and attend conferences and show them what diverse disability leadership actually looks like.

We learned that certain tools, charts, and questions can unwittingly influence others' thinking and that who asks the questions, when, and how matters.

And we learned that a primary barrier and proliferator of ableist, racist, paternalistic, and exceptionalist tendencies among medical, educational, public health, and social service professionals is a lack of cultural humility, a lack of knowing us, our cultures, and our potential both individually and collectively.

Currently, in **Phase 2**, we're building and empowering community; developing curricula for two 8-week online, communal learning forums designed and facilitated by and for BIPOC with disabilities; engaging with and educating the general public; trying to innovate new ways forward based on the lived experience and expertise of those most impacted; and meeting with funders and policymakers about the need for cross-disability leaders to drive the implementation of a universal home care guarantee.

We're planning four whole-group learning experiences with alternate weeks offering time to apply, practice, connect, and learn experientially, whether that involves joining a group centered around a preferred interest or energy, exploring the LIPC Mentor online resource, seeking advice from a mentor about navigating some new aspect of their life, or discovering and developing authentic relationships and unpaid supports.

Phases 3 & 4 will involve facilitating and assessing the curriculum into actionable research and disseminating our findings and online LIPC mentor resource to every parent, caregiver, and professional who interacts with someone who's disabled.

As we complete Phases 3 through 4 in the coming year, LIPC and our research partners at the National Leadership Consortium on Developmental Disabilities (NLCDD) have already gathered letters of support for a systems alignment pilot based in Philadelphia and a community-building and empowerment project for people in rural Georgia with I/DD diagnoses.

It is LIPC's collective goal that future generations will know disabled self-advocates as active, meaningful, visible, essential, and self-efficacious participants in their local communities. Expectations for ourselves and the realization of those expectations will be rising. We will be enjoying longer lives with decreased incidences of anxiety, depression, suicide, and fratricide. Nobody will be warehoused in segregated day programs and aggregate residential facilities. Our rights to our own decision-making will be common knowledge. We will all understand that involuntary guardianships are not an inalienable right our parents have over us and will know how to ask for help to either terminate or refuse said guardianships. We will know where and whom to turn to find mentors, counsel, resources, and — if necessary — temporary financial support. We will be proud of ourselves and perceive of ourselves as human beings with collective and individual liberties and aspirations, capable of growing, learning, and contributing to society. Having disrupted the in/dependent binary, we will make visible for ALL Americans the interdependence that underlies EVERYONE's relationships. No longer deemed voiceless and invisible, we will know we are heard and seen. Rather than living a life of convenience for our parents, we will be living the lives we imagine for ourselves.

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Psychotherapy from page 23

his consent to bring her into the conversation. Most of the time he agreed. When he did not, it was treated as it would be with any therapy client, exploring objections and feelings and asking what would be needed for him to feel comfortable sharing this with his mother. With trust soon established, the client was grateful for assistance in conveying his position and working through issues with his mother, as would be the case in any psychotherapy setting.

The above experience not only validated to me the highly intelligent mind inside this teenager with "profound" autism, but clearly demonstrated that his thoughts were independent of his mother who was providing the proprioceptive connection and resistive pull back on his arm used in the typing method. In addition to the special needs of being a nonspeaker with autism, my client, like most teenagers, grappled with age-related issues and personal agency and had a healthy amount of opposition, in addition to love, for his mother. In therapy he addressed his feelings in a thoughtful, honest, articulate, and mature manner. In return he was understood, respected, and gained efficacy about decisions concerning his life.

After Covid when it was possible to get out into the community again to meet with FC trained coaches, I began to learn of other autistic nonspeakers or unreliable speakers whose parents felt they could benefit from psychotherapy. Of the four other such clients I currently work with, three are facilitated by occupational therapists trained in FC and S2C, and one by his parents also trained in both of these methods. Before starting psychotherapy, each of the communicators already had an established connection with their facilitator and were at an open level of communication with them, which is essential for psychotherapy. In the case of the client whose parents are his communication partners, therapy sessions are able to work well due to the high degree of openness, acceptance, and trust they have achieved with each other. This has also given them a chance to work through, as a family, any issues that might have recently emerged. Clients must, of course, be physically present with their facilitator/communication partner during sessions, while I am joining them remotely on audio-visual platforms where we share access to a document in which communication is typed. I speak aloud (as opposed to typing my responses) in sessions, as clients have consistently noted that this feels more natural to them.

The role of the facilitator in a psychotherapy session is to provide the proprioceptive connection and physical/motoric support and resistive pull-back for the typer while primarily being in a neutral state with respect to the therapeutic process. The same neutrality would be the case if the facilitator were holding a letter board for the non-speaker to communicate. This process, however, is a 3-way partnership and must function as a coherent team to be successful. In physics, beams of light are said to be coherent when the phase difference between their waves is constant, and they have the same frequency. In a similar way it is important for the facilitator and therapist to provide a reliably calm energy, or presence, to allow and support the communicators' access to their deeper mental states. It should be explicitly stated that when talking about facilitators/communication partners here, I am referring to people *trained* in FC, S2C, or related methods.

Judith Croen, LCSW

Psychotherapists and others must understand that the argument about touch which critics lodge at FC is misguided and harmful. To quote David Kaufer's May 14, 2026, Substack article *Touch Does Not Disqualify Nonspeakers' Communication*, "Touch is how motor skills are learned. It is how the body receives the scaffold it needs while a new neural pathway is being established. The support is not the performance. The support makes the performance possible." Kaufer argues and I concur that touch here is not a contaminate but a helpful accommodation that supports grounding and self-regulation and makes communication possible.

Everyone is of course wired differently, and all but the most shut-down individuals are affected by the mental and emotional state of others with whom they're interacting, as well as by stimuli in their environment. A critical, dismissive, or angry person, especially one who wields authority, would make most of us feel uncomfortable or threatened and activate our nervous system's defense mechanisms. For someone with profound autism who has far less control over their body's nervous system and behavior, it takes a lot less intensity to trigger dysregulation and close the door to authentic communication. For instance, feeling tested, like they have to perform or prove themselves, especially in unfamiliar settings and/or with strangers, is enough to set off their sensitive nervous systems.

As with any new relationship, including a therapeutic one, there is naturally a process of getting acquainted and adjusted in order to arrive at fully open and trusting communication. Therapists must enter into the relationship with autistic nonspeakers and unreliable speakers with the presumption of competence, as skepticism or doubt is keenly felt and closes the channel of communication. If a therapist doesn't understand the meaning of a behavior or something the communicator types or spells, simply asking for clarification will yield a willing explanation.

For instance, one of my clients with unreliable speech has a behavioral loop of repeating a sequence of statements about himself. Between typing he will say things like, "I'm happy today Judith. I'm sad today. I'm typing well today!" each with a great amount of emotion and affect. Therapists are accustomed to responding to verbal and non-verbal cues with nods and utterances to let the other person know we're paying attention. Because of the frequency of this client's statements, I usually did not respond, however sometimes it was hard to resist. One time after verbalizing back to him that yes, he really was typing well today, my client informed me that his automatic statements were terribly frustrating to him and make him appear to be *"a very younger version of myself"* He typed that it felt *"like being trapped in a hard place like a too quirky amusement park ride"* and that it made it harder when people respond because it's _"like really being caught in that tornado of a loop and have people trying really to be nice but not succeeding."

Therapists must also adjust their pace, which is of necessity much slower than with speaking clients. The psychotherapist may be the first person the client has been able to share many of their deeper thoughts and feelings with and in some cases the therapy session may be one of only a limited number of hours each week in which they have any communication partner at all. Therefore, providing the time and space for the nonspeaker to type or spell everything on their mind is a priority. Of course, communicators are interested and eager to engage with the therapist's feedback, suggestions and questions, and at times cognitive interpretations are helpful when done with genuine attunement.

Many people have heard the saying, *"If you've met one autistic person, you've met one autistic person."* This is true, as everyone has unique interests, preferences, energy, physical and psychological issues, relationships and situational challenges. Though not an exclusive list, my clients have typed about their appreciation for the supportive people in their lives as well as their wish for greater understanding and connection with others, the desire for romantic love, the side effects from medications, their interest in academic learning and participating in various activities. They have also typed about poetry they've written, about music, art and nature.

This being psychotherapy however, much of their communication concerns inner conflicts, feelings, hopes, and desires, which is after all the primary purpose of psychotherapy. In my experience, these clients come in knowing this, wanting this, and utilizing their precious time processing it. Some of the recurring themes expressed in sessions include: the painful disconnect and lack of control between their inner mind and their outer self, the difficulties of living in the world and being misunderstood, their valuation and gratitude for typing, and their abiding passion for all nonspeaking and unreliably speaking autistics to have access to typing and spelling to communicate. Equally important to all of my clients has been the opportunity to communicate about their connection to spirituality and their desire to contribute greater understanding of this to the world. I am grateful for my clients' consent for me to include a few examples of their typing, which at their request have been identified with their first names.

> *"It is so important for me to be able to be in this session.*
> *Understand that I think that our time is invaluable. It is really where I get to be me.*
> *It is oppressive to only have this here. I want it all the time."*
> - Jake

> *"I want to talk to you about the idea that I am really just doing my best at being in this life.*
> *I mean that I am so trying to be doing the right thing in terms of really being able to be understood.*
> *I picture having control over my body but I don't. It greatly feels like it is so hard.*
> *It greatly feels like I am too lost.*
> *I powerfully think that it is the typing that makes it tolerable."*
> - Jake

> *"I think my mission in life is to teach love.*
> *I mean that my mission is to make people know that they are in a universe filled with love.*
> *People understand are so intensely introverted to their own troubles.*
> *I think that I yearn to be able to show the love of the universe to many people."*
> - Jake

> *"Understand being silent is much harder than it looks. I am so grateful for your understanding.*
> *I yearn for more understanding.*
> *I really want the world to understand that I am in here an intelligent thinking human."*
> - Justin

> *"Really what I want to say is that I want to be able to really be in this world. It is typing that connects me to the world.*
> *It is my only contact so when I can't connect it makes me feel really badly. I am really truly trapped in a body that is not working.*
> *The worldly physical reality is just so hard to be in."*
> - Justin

> *"It is the real knowledge of the divine that will help me through this difficult incarnation. The thing that I mean is that I am so really in need of the real real love of god to get me through this… I want to be able to be more connected to god in my day to day life so that I don't feel so each moment desolate."*
> - Justin

> *"I want to be able to be so involved with the way that the world is moving forward with understanding us.*
> *Understand that I want to be so in powerful union with love. Treat the world like it is so precious.*
> *Treat each other like they are so precious. The real reality is each time so incredible. The real reality is that the world is so happy.*
> *The real reality is that I am really like free to be whole."*
> - Justin

> *"I develop my mind in ways that are vivid to my understanding of the cosmos…I just spend a lot of time sitting in the chair with my eyes closed mostly and imagining the feeling of the earth in front of me it is completely a symbol of taking in that feeling of my heart center responding with love and happiness…"*
> - Giancarlo

> *"Humanity tends to become more conscious to the true wherever there's a desire being dwelt upon, so it gets people wondering how they work on finding clues that they themselves can gain… what I call a feeling of reverence when something is being answered to the person who listens."*
> - Giancarlo

see Psychotherapy on page 48

ASHA Statement from page 23

ASHA's third claim is that **RPM lacks evidence of effectiveness.** Evidence-based practice generally rests on three equal pillars: research, clinical expertise, and patient and family values. ASHA, however, appears to treat research as the only pillar that matters. While research on spelling methodologies is still emerging, the existing findings are encouraging. One recent study (Jaswal, Wayne, & Golino, 2020) examined influence by tracking spellers' eye movements and found that participants looked at each letter before pointing, made very few spelling errors, and showed timing patterns similar to fluent typists. These results support the conclusion that spellers were selecting their own words even when the board was held. If you are considering spelling as a communication method, it may help to remember that new forms of communication have been doubted before. Sign language faced similar skepticism for more than a century, when schools and professionals denied that it was a real language and even prohibited its use in classrooms.

Clinical expertise and patient and family values are also essential pillars of evidence-based practice. Professionals who can currently spell with my daughter include spelling practitioners, her high school teacher, several teacher aides, and a direct support professional, yet none of these perspectives are represented in ASHA's statement. ASHA also overlooks the lived experience of families like mine, even though spelling has been life-changing for us. Like many autistic individuals, my daughter's behavior at home and school had become increasingly difficult to manage with the onset of puberty. After she gained the ability to communicate with a letterboard, however, her behavior improved significantly. Spelling has literally opened up her world: she was able to take her first cross-country flight and will soon take her first international trip. Our family is not alone in this experience — many books, blogs, and social media posts describe similarly life-changing outcomes.

Andrea Palerino, PhD, PPCNP-BC

ASHA's fourth claim is that **RPM holds the potential for harm**. Although the statement makes this serious allegation, it offers little support beyond saying that families may spend months or years on an unproven method instead of using interventions it considers effective and appropriate. What ASHA does not acknowledge is that many families, including ours, have already spent years pursuing the traditional therapies recommended by experts. In our case, after more than a decade of treatment and tens of thousands of taxpayer-funded dollars spent on school-based speech therapy, our child still had no functional language.

Before starting this journey, we discussed the financial risk to our family, and as a middle-class household, we were able to take it. Many families do not have that option, which creates socioeconomic inequities and leaves them stuck with the same ineffective therapies. As the saying goes, "insanity is doing the same thing over and over again and expecting different results."

ASHA's fifth claim is that **RPM is similar to a discredited and dangerous technique called Facilitated Communication (FC).** ASHA writes that "FC has resulted in serious harm to people with disabilities and their families, including false allegations obtained through FC of sexual abuse and maltreatment." As the mother of a nonverbal daughter who faces a higher risk of abuse, I initially found it difficult not to take that statement personally. However, I recognize that ASHA's priorities differ from mine. Its main concern is protecting SLPs and limiting legal exposure. As a parent, however, my priority is my daughter's safety, and that safety increases when she can communicate and report abuse. Additionally, there is no evidence that non speakers make false allegations of abuse more frequently than speakers.

If you are considering a spelling or typing journey for your child, I encourage you to weigh all three pillars of evidence-based practice. Talk with spelling practitioners, connect with parents of spellers, and read writing by spellers themselves. As a nurse, I was able to help my daughter develop functional communication, something a decade of speech therapy had not achieved. It has changed our family's life, and my only regret is not starting sooner.

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Access and Dignity from page 20

socio-economic background, early education opportunities, and societal structures (Ilie et al., 1238). It can be extremely difficult to move past these barriers without the proper resources. I faced such barriers in elementary and middle school and had to make changes to achieve my dream of being educated. All students deserve to learn, including nonspeaking autistic students, whatever mode of communication they use.

Education denial has occurred throughout history. Discrimination based on race has prevented Black Americans from accessing education. Martin Luther King, Jr., in his "I have a Dream" speech, wrote, "even though we face the difficulties of today and tomorrow, I still have a dream. It is a dream deeply rooted in the American dream. I have a dream that one day this nation will rise up, live out the true meaning of its creed: We hold these truths to be self-evident, that all men are created equal." (King). My dream of accessible education is also deeply rooted in the American dream. This stems from my foundational belief in the protection of individual freedom for all Americans. All Americans deserve their promised freedom. If there is denial of formalized learning, then freedom is restricted. The dream of inclusion, unity, and diversity applies to all forms of education. Despite strides in progress, injustice unfortunately still exists.

According to a research article on compassionate pedagogy for neurodiversity in education, "neurodiversity can be understood as naturally occurring variation in the ways that humans perceive, experience and interact with the world." (Hamilton and Petty 2). Unfortunately, this sensitivity and understanding is not the reality. This naturally occurring variation in human experience, for a long time, was considered the "other." The idea of the "other" was first explored by the French philosopher Jean Paul Sartre in his existentialist play, *No Exit*. A gazing judgement is cast onto anyone considered different – the "other." Sadly, this mindset is held by many and it has been applied all throughout history. It has adversely affected the lives of many autistic individuals.

Throughout my life, I have experienced the effects of the "other." I have felt the constant weight of people's pressure to act a certain way in a neurotypical society. Autism has always been a part of my identity. It is naturally occurring and therefore not the "other" from my perspective. This has been my life and it has brought me strength to overcome the incorrect judgments burdened on people with autism. We are not the "other." We are one.

Often, when I meet people for the first time, they speak to me in a "baby voice." It is the automatic assumption that I do not comprehend due to my autism. This was certainly the case in school before I had a way to communicate. Autistic nonspeakers often have little control over their bodily movements. They may also vocalize without restraint and speak gibberish. This can look very weird and lead to the perception that we are not intelligent. This severely limits the opportunities for nonspeakers in the educational system. It can be extremely hurtful to be underestimated and this misconception can ruin our lives. For many years, I worked hard to show that I could keep up with my neurotypical peers. Besides doing well on all of my assignments, I was adamant about never leaving the classroom for a break. I wanted to show my teachers and peers that I took education seriously. We are capable and motivated to learn. Teachers need to respect our abilities and presume we are competent. We need to be treated with deeper understanding and dignity.

I strive for a future with educational opportunities for all, including neurodiverse children. Children need people to advocate for them to ensure healthy growth. Children with nonspeaking autism especially need advocates who believe in their beautiful minds. I will be that example. I am enough as I am; there is nothing to fix. And the same goes for everyone else.

It is time for schools to meet students where they are and accept all learning differences. Education sets the foundation of your life. In our experiences, relationships, and thought patterns, education impacts how we view the world around us. I am passionate about ensuring other nonspeaking children are being treated with dignity. Treating autistic children with dignity can change the outcome of their lives.

The need for formal education is undeniable. It is time more neurodiversity is welcomed in education systems. A lack of education never gives students, who are considered the "other," a chance. What can be observed is that humans have faced injustice and inequality through the power of the person in control who sees them as "other." Without adequate formal education, an individual will not be able to gain skills needed to live in society or learn about how the world has changed. The learning done in schools is irreplaceable. Access to education is a human right. Educational opportunities for all is my life's goal.

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Past Behaviors from page 24

defensiveness is a self-protective strategy over which I have found I have relatively limited control, although I have managed to make inroads in this regard. Only to an extent, however. Cutting back more than a little has proven to be an utterly unrealistic expectation, and I'm fine with that. Small steps!

Turning My Mother Over to the Authorities

At the time, I was maybe 8 years old or so and my older brothers as well as my mother got a big laugh out of this. I, in turn, laughed at myself over the years that followed whenever what I did came up in conversation or crossed my mind, though I was too young and not yet identified as autistic to be able to think seriously about the incident and understand why it occurred in the first place.

I can't remember specifically what it was that my mother did when we took a family trip to the beach. What I do recall is that there was a list of beach rules and regulations posted on the wall at the facility we walked into when we first arrived, and it was obvious to me that she broke one of them. I then proceeded to tell the attendant in charge what she had done, thinking that rules exist for a reason and if one or more of them are violated, there should be consequences. Thankfully, all was forgiven and Mom was let off the hook. The attendant apparently didn't think much of whatever the infraction was.

Sam Farmer

Today, I understand all too well. Literal, matter-of-fact interpretation of sensory input, including written communication, lies at the heart of how autistic individuals tend to process information. Not that I would actually jump off a cliff if somebody were to tell me to do so. We all have lines to draw in this regard. The readily visible rules and regulations at the beach facility all those years ago evidently did not cross my own line at the time, and so I took them at face value and acted according to what I felt was right when one of them was broken. That my own mother was directly involved was admittedly of secondary importance to me, over which I feel a degree of guilt to this day. In retrospect, I'm grateful there was no punishment in store for her. Instead, a few good laughs and a memorable family story worth sharing.

"Get That Smirk off Your Face"

This is what an irate middle school teacher of mine said to me after one or more of my classmates did something he disapproved of. Exactly what it was, I cannot recall. I only know that it wasn't me who committed the act that initially set him off. Rather, I managed to add insult to injury by smiling while he was expressing his displeasure to the entire class.

It's never easy when you're singled out as I was amidst a sizeable group of people. I blamed myself for having that smirk on my face, feeling as though there was no sound justification for it. I simply couldn't comprehend why I reacted that way.

Post-identification, I have come to understand that my particular autism profile carries with it a susceptibility to there being a mismatch between a facial expression and the emotion at hand. That day at school, what my teacher perceived as arrogance behind the smirk was actually my way of trying to deal with his anger over whatever it was that got under his skin. Back then, I found other people's ire quite unsettling and this incident was no exception.

The "out-of-place smirk/smile" isn't my only expression/emotion mismatch tendency. Laughing as a coping mechanism under challenging circumstances and little or no facial affect during emotionally charged situations are common with me.

Passing Out During High School Biology Class

Marked sensory sensitivity, commonplace across the autism community, was at play in this instance, although I didn't look at it that way at the time, having not yet been identified as autistic. Deep down, I felt singled out, awkward and weak, considering that nobody else in my 9th Grade Biology class fainted while we were watching a particularly graphic video of open-heart surgery.

I fell off my chair to the floor though fortunately managed to avert injury. My teacher, to his credit, knew to send me to the school nurse as a precautionary measure and I checked out fine. It was while I was walking to the nurse's office, alone with my ruminations over what had happened, that the above emotions intensified.

If only I knew then what I know now. An understanding of the sensory vulnerabilities that commonly accompany autism would have kept me from beating up on myself.

All of this to say that for most behaviors, there will be more than one possible interpretation. I would learn, though not until middle age when my autism surfaced, that my own reasons for many of my behaviors were flawed yet could change for the better with a newfound outlook and some time and effort. Nothing short of a transformation with respect to my state of mind and sense of self.

Sam Farmer is a neurodiversity advocate, writer, author, and public speaker. Identified later in life as autistic, he shares stories of lived experiences as well as ideas and insights as to how one can achieve greater happiness and success in the face of challenge and adversity. A Long Walk Down a Winding Road – Small Steps, Challenges, & Triumphs Through an Autistic Lens is his first book. Visit samfarmerauthor.com to learn more.

Call to Action from page 21

respond), and meaningfully involving nonspeakers in whatever is going on. Life is pretty lousy when you're left out, constantly underestimated, given nothing interesting to do, and made to feel like the future will be just as bleak as the present. Our lives get so much richer when the outside world realizes our humanity and feeds it. That lets us connect with others and do the hard work of finding our voice.

By now I hope I've got you thinking! Too often, we get in a rut because we stop challenging our perceptions and implicit biases. Knowing this, I'm reminding you to prioritize challenging them, deliberately focusing on how you might be misperceiving the nonspeakers in your life. I'm making a prediction right now that, when you do, there's something you'll change. I'm thrilled to think about what those changes are going to mean for you and the nonspeakers you know!

Let me tell you what those changes meant for me and my family. As soon as I began writing, people pivoted from treating me like a baby or problem to solve to treating me like any other elementary school student who loved math and oceanography. My time in school shifted to a focus on grade-level work. Possibly best of all, the obsession with "fixing" me disappeared and was replaced by a new obsession to help me thrive. How incredible!

I've since learned to type, and now plan to use my voice to advocate for fellow nonspeakers. I'm hoping you will help by presuming competence and recognizing the humanity of nonspeakers. Help me, too, by considering how absolutely powerful the ability to communicate is. The clearest illustration of just how powerful? Think about how much relationships in your life have been changed or strained by things left unsaid. To not share your hopes and dreams and interests and feelings, particularly how you feel about the people in your life, means creating distance between yourself and others. It means that others don't get to know the real you. Now think about what those relationships would look like if you'd never said anything at all. To leave all unsaid, as you can imagine, causes real harm. No one should have to suffer like that!

How so many people end up suffering exactly like that is just devastating. My last request of you is to consider that. The best way to reduce this harm is to ensure that everyone has the right to communicate. That takes presuming competence and letting nonspeakers learn the skills they need to use a letterboard or keyboard. Help teach nonspeakers to control their eyes and to point, and help them be calm and confident. Starting now, we're giving everyone a voice!

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Psychotherapy from page 46

> *"People [need to] have a theory to notice a purpose between themselves as they get more involved. It would be a way that people become part of the society. I feel there is a trajectory that people look at to find where they can direct their attention, as in this period, like they feel moved to be a companion."*
> - Giancarlo

> *"Educating the world about the way that really each one of us has the ability to discover the reality of the world as a place of great soul power. I think that everyone has the ability to be at each reality level. Yes I agree that it is a process. The process has to start somewhere. I want to be part of the establishment of easy opening of eyes of the people of the world. I want to be a trend setter. That is the awesome truth. It is the truth in me that wants to come out."*
> - Danson

> *"It is freeing to be able to have each one of us be able to get the trials and tribulations of autism to be better understood. I've cared for this for a long time. I've been hoping for this for a long time. It's been a very great feeling that really the freedom is coming, yes that it very soon is getting here getting here fast."*
> - Danson

It has been my intention in this article to share some of the principles and best practice techniques for doing psychotherapy with autistic nonspeakers and unreliable speakers. The need and justification for this should be self-evident at this point. In sharing their own words, I hope the reader has heard their voices and felt how much they yearn to be part of the change the world needs to see. If we all do our part, we can help 'get the freedom here faster.' This includes advocating for legislation and programs to train coaches and facilitators in typing and spelling methods so other nonspeakers can have choice and access to communication at home, in schools, and in the world. Communication through typing and spelling is what connects them to the world!

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***Mom's Journey** from page 26*

As I slowly moved away from the focus on speech, we saw Annie become more proficient at PECS. She started making sentence strips with word icons and even created sentences to request things that weren't established words in her PECS book. For example, she put this on her sentence strip: I WANT *YOU-ARE-MY-SUNSHINE-SONG* CHIPS. She was requesting SunChips when she didn't even have that word in her book. I was beginning to see just who my little Annie was – a clever young lady who really wanted to communicate!

Over time, Annie continued to communicate with PECS and then advanced to an iPad app called ProLoQuo2Go, which is set up to look like an electronic version of a PECS book. This made it easier to expand her vocabulary as we learned what she needed – and it was more portable. On Annie's eighth birthday, we celebrated with her first-ever birthday cake, and she learned how to blow out her candle! I noticed she was using her iPad more to look up various things on Google. I examined her scrolling history and saw she was researching Sesame Street characters, different kinds of foods and dental videos. This gave me insight into Annie's mind. She was interested in so many things she couldn't "talk" to me about.

Amy Kelly, MBA, MNM

I began talking to Annie about these topics. We worked on trying to communicate through her iPad or by writing words down on a whiteboard or in a notebook, with each of us taking turns. She began to spell independently of her PECS, at first through rote memory, and then, with the magic of autocorrect, she figured out how to communicate some of the words she was thinking but didn't know how to spell. I was amazed. I was getting to know my daughter so well, without her speaking words. *Communication* was the key, not talking.

Shortly after Annie's 10th birthday, she said her first words, beginning with "mama," "want mama" and "no." Over the years, she started to string a few more words together.

Annie is now 24 years old and still uses her iPad to assist with communication. She also speaks in three to four-word phrases. While the words and phrases aren't always intelligible to me or others due to the apraxia, she is patient and will repeat or spell them out if I still don't understand. Annie's spelling capabilities are so quick and impressive that I often need her to repeat things because I can't keep up.

Ironically, her favorite phrase to say is, "All done talkin' 'bout it," especially when we are discussing topics like chores or activities she doesn't prefer. What an appropriate response!

I will always be grateful for Annie's speech and language pathologist and her amazing teachers at Devereux CARES for helping me truly learn who Annie is – and helping her communicate that with the world.

For all those families who have a non-speaking or minimally verbal autistic child or adult, please know this:

- We should never let others – even doctors – place limits on our kids. They can, and will, do so much, but it's all on their personal timelines, when they are ready, not when we are ready.

- See beyond words. Speech isn't the key to communication. There are many other ways to communicate, and it's important to focus on the ways that work for your loved one. That is their strength. Build communication from there, whether it's through PECS, sign language, a letter board or writing on a whiteboard. Sounds and grunts also can turn into a personal form of language.

- You are not alone. Find other families with a similar situation to yours so you can support each other. Families are by far the very best resource you will encounter.

Amy Kelly, MBA, MNM, Devereux's national director of family engagement, is the mother to Danny, Annie and Ryan. Annie is diagnosed with profound Level 3 autism, intellectual and developmental disabilities, verbal apraxia and general anxiety disorder. Amy serves as a family advisor on several special needs boards in the community, locally and nationally. In addition, she participates with other self-advocates and family partners in efforts supported by the Autism Care Network and serves on an executive committee and the Autism Committee for the American Academy of Pediatrics to assist children and adolescents with neurodiversity needs, advocacy and the importance of quality care.

***Unethical** from page 24*

2. **Beneficence:** maximizing benefits while minimizing harm

3. **Justice:** ensuring risks and benefits are distributed fairly, without exploiting vulnerable groups

A message-passing test, especially when conducted without a non-speaker's consent or input, violates all three ethical principles. These principles are particularly important when research affects the communication access and services eligibility of non-speakers with profound autism.

The Expert's Inside Perspective

Imagine you are a non-speaker who can only communicate by spelling with great difficulty, focus, and effort, and with the support of a communication partner:

You are intelligent, but unable to speak or sign beyond a few basic words (Yes/No, Please, More…). For years, no one knew what you thought. You were excluded from conversations, activities, and decisions about your future because you couldn't talk. Your body is impulsive, is difficult to control, has automatic loops and stimming behaviors, and doesn't consistently do what you want — many Spellers describe their body as "having a mind of its own." Your mouth may produce understandable words, but only repetitive scripting and echolalia, not what you want it to say. Your body is easily triggered into fight or flight mode.

You have been learning to communicate by Spelling. It is incredibly hard, but you have been able to spell words that show you have more thoughts than you have been able to express. People who care deeply about you are seeing the unexpected, and are experiencing the shock and cascade of guilt that they may have underestimated your intelligence your entire life. They are incredulous, asking themselves, "Can I believe what I just saw?"

An "expert" warns your parents, "This isn't real. This is wishful thinking. Let me test this without the communication partner." You scream silently inside your head, "That's not fair!" You rely on your communication partner to keep you regulated, on task, and focused, and to prompt your body when necessary. You realize if you fail this test, the window of opportunity may close and never open again. No one will ever know you or hear what you have to say. Non-performance will be considered a failed test ("They couldn't pass the test; they didn't spell when I tried it."). You don't want to be viewed as intellectually disabled for the rest of your life because you couldn't show otherwise. This paralyzes you with fear.

Asking a non-speaker to complete a message-passing test carries the highest possible stakes. That is why it is unethical. A request for authorship testing may also be disingenuous if the motive is not genuine scientific curiosity and seeking to understand, but only to disprove. Message-passing is not a standard psychology testing protocol, and is not used to validate other AAC communication methods. Treating a Speller as a test subject in a blinded experiment to validate a critic's doubt does not benefit the individual and has little or no scientific merit. Test subjects can fail a message-passing test for multiple reasons (stress, anxiety, lack of needed supports, unfamiliar environment, poor test design, subjective data interpretation, refusal to participate, etc.). Anything less than a precisely correct answer could affect a participant's future access to communication. And when non-performance is considered a failure, unethical becomes cruel.

Proving Authentic Communication

Wouldn't fluent Spellers want to prove they are truly communicating? Yes, and they have. There are thousands of individuals who are spelling and typing complex sentences, poems, stories, and personal experiences with the aid of a communication partner. They are communicating with their doctors, choosing from the restaurant menu, and participating in college classes by spelling on a letterboard or keyboard. To many observers, this accommodation is no more remarkable than a foreign speaker with a translator, or a deaf person with a sign-language interpreter. Most communication partners are parents who are communicating with their child. Many parents were skeptical at the start (or afraid to hope) but soon could not deny the reality of what they were seeing and hearing.

There are other ways to approach the question of authenticity. Non-speakers routinely spell out grammatically correct and insightful paragraphs, and may communicate readily with multiple aides trained in the same communication method. Anne Sullivan was Helen Keller's first but not her only communication partner. Naoki Higashida, the author of The Reason I Jump, when faced with critics' challenges about authorship, responded by writing more books. Jerry Rothwell, the documentary filmmaker who directed The Reason I Jump, met with Naoki in person before he invested his time and effort in filming and wrote "I didn't want to make the film if I had any doubt about his authorship."

Sharing of unknown information happens naturally during conversations — it does not require the artificial setup of a double-blind message-passing test. Every time a Speller shares a unique insight, past experience, or something that is unknown to their communication partner, it is proof they are communicating. Science starts with observation. The published science for Spelling is still catching up (see Jaswal et al., 2026 - Why We Need to Study Assisted Methods to Teach Typing to Non-speaking Autistic People (Jan. 8, 2026, Autism Research). Any testing of authorship must be designed with the willing consent, input, and minimization of potential harms to non-speaking participants for it to be ethical.

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FC Training from page 25

communication training (FCT) is a better term than facilitated communication (FC). FC isn't an end in itself – it's a stage that we hope people will pass through on their way to improved communication… The ultimate goal is for students to be able to use the communication aid(s) of their choice independently."

In 1986, Crossley opened the DEAL Centre for Communication and established a training program for FC. Working in her program were occupational and physical therapists who developed strategies for helping people overcome the neuromotor problems that interfered with their ability to point effectively for communication. "The combination of facilitated communication and motor training was called facilitated communication training" (Crossley, 1994, pp. 5–6). One chapter in her book described in detail these common motor problems and strategies. Another chapter focused on independence. Her writings about FC suggested that the work of supporting individuals to use FC was individualized and required that their communication partners be highly skilled.

When Biklen visited DEAL in 1989, he observed several people typing with minimal support at the shoulder (Biklen, 1990). For him, this was compelling evidence about the effectiveness of FC as a method of communication for nonspeaking individuals. It was also evidence that the regular practice and instruction that they received from Crossley and her team at DEAL was an important factor in how people progressed with the method.

In late 1989, soon after his visits to DEAL, Biklen wanted to explore the possibilities of people using the method in the U.S. He started out by studying how it worked in practice with a group of 21 students in the Syracuse, NY area (Biklen, 1993, pp. 35–61). In his book, "Communication Unbound," Biklen described in detail his research team's observations of student progress with the use of FC. Included in the book was a section on "How To" training materials for training new facilitators (Biklen, pp. 191–206). With their work, Crossley and Biklen had developed a curriculum for learning the method. What was missing in the initial period of it being introduced in the U.S. were the training structures to teach the curriculum and have the learning be lasting.

Pascal Cheng, MEd

In the mid-1990s, opportunities for training on FC dwindled greatly. It was a catch-22 situation in which the need for training was recognized but the controversies surrounding the method restricted the opportunities. There were not many professionals in the U.S. with sufficient experience and skill in FC to provide training. Most speech-language pathologists were not trained in the method and, with the controversies surrounding it, it was not an accepted practice for them to use. Schools and adult service providers would not fund training for it.

Even though access to training was limited in many parts of the country, the Facilitated Communication Institute at Syracuse University (renamed the Institute for Communication and Education in 2010) began sponsoring annual Summer Institutes focused on communication and inclusion in 2006. People from around the country attended these institutes, which continued for 10 years until 2016. They featured presentations and workshops on communication and inclusion by leaders in these fields and individuals who typed to communicate. A key part of them were the skill-building sessions for FC users and their facilitators. Both FC users and their facilitators participated in structured activities to work on a range of skills including getting started with the method to fading support. Participants received coaching from experienced facilitators and FC trainers during these sessions. They were able to improve their skills and learn about best practices in the use of FC. However, even though these sessions were beneficial to participants, access to follow-up coaching was limited for many once the institutes were over.

In 2014, the organization Wellspring Guild was formed with the purpose of expanding access to training around the country. Board members of the Wellspring Guild included practitioners and an FC user who had been active in training for many years. The goal of Wellspring Guild was to "develop a team of well-trained Facilitators, Coaches, and Trainers around every communicator who are skilled and follow best practices." The training model that Wellspring Guild developed had two levels: Coach and Trainer. They defined a Coach as being "a person who has a good level of experience in using facilitated communication and can help others who are new and just learning about it. The Coach learns the tools of the 'getting started' process and applies them to meet the needs of the Communicator as well as the new Facilitator." Coaches could work in their local areas to provide the hands-on training needed to maintain and improve the use of FC over time. A Trainer was defined as a person who has had extensive experience as a facilitator and coach and has the skills to do group trainings, both in-person and online, and formal assessments of candidacy for facilitated communication.

Over the past five years, Wellspring Guild has developed training programs for both the Coach and Trainer program with the goal of improving the quality and quantity of training around the country. Increased training resources have been developed in different areas including New York/Connecticut, Vermont, and Florida. These recent developments in training for FC have resulted in greater access to communication for nonspeaking individuals who can benefit from this method and more skilled facilitators to support their communication. They also point to the need for future research to consider the importance and impact of training on the practice of FC and other assisted methods of communication.

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Most to Say from page 8

Further evaluation revealed that the individual was suffering from a painful tooth infection. The behavior was never the problem. The behavior was the message. What changed the outcome was not a treatment plan or an assessment tool.

It was a relationship.

Someone knew the individual well enough to recognize that what appeared to be noncompliance was actually pain. The individual had been communicating all along. Someone simply knew how to listen. Stories like this challenge us to think differently about communication.

In our field, we often focus on teaching individuals how to communicate more effectively. While that work is critically important, perhaps we should spend equal time teaching ourselves how to become better listeners.

Not simply listeners for words, but listeners for meaning. We need to pay attention to changes in routine, expressions of discomfort, and the many ways people communicate joy, fear, frustration, and hope. When we broaden our understanding of communication, we become better equipped to support the people we serve.

The longer I work in this field, the more convinced I become that communication is not something that happens only through language. It happens through relationships.

I saw a similar dynamic with a woman I'll call Maria. She attended the same day habilitation program for years. While she was generally a woman of few words, she consistently expressed dissatisfaction with her experience. She wanted something different — more opportunities in the community, more social interaction, and more chances to participate in activities that reflected her interests.

She loved fashion, shopping, dining out, creative pursuits, and exploring her community. Yet her current program was no longer meeting those needs. Like many people, she did not always have the words to clearly articulate what was missing. As a result, her dissatisfaction sometimes manifested as frustration, resistance, or behaviors that could easily have been misunderstood.

Fortunately, her team looked beyond the behavior itself. By paying attention to patterns and taking the time to understand her experience, they recognized that what they were witnessing was not simply frustration. Maria was advocating for herself in the way available to her. She was communicating that she wanted something different for her life.

When Maria learned about a more community-based program, she immediately expressed interest. During a trial visit, staff observed a remarkable transformation. She was engaged, enthusiastic, social, and excited about the possibilities in front of her.

What struck me most was that Maria had not changed. Her interests had always existed. Her preferences had always existed. Her voice had always existed. The difference was that people listened. As a result, her future changed.

For me, that is what inclusion truly means. Inclusion is not simply being present. It is being heard. It is knowing that your preferences matter. It is having enough influence that your voice can shape your own life.

As I think back to the young woman who called her instructors after losing her mother, I am reminded that some of the most important outcomes in human services cannot be measured by a report, a data point, or a service plan.

Some outcomes live in relationships. They live in trust. They live in knowing there is someone you can call when your world falls apart.

At AABR, our vision is a community where all abilities are beloved and respected. That vision requires more than quality services. It requires creating environments where people are understood. It requires relationships strong enough to build trust. It requires communities willing to listen.

Perhaps the question we should be asking is not, "How do we give non-speaking individuals a voice?" They already have one.

Perhaps the better question is this: Are we creating homes, schools, programs, workplaces, and communities where that voice can be heard?

Because every individual has something to say. And some of the quietest people in the room may have the most important things to teach us.

Libby Traynor, LCSW, is Chief Executive Officer of AABR, Inc.

A Review from page 27

practice with other children. Peer-mediated intervention has emerged as an effective approach for supporting social communication development.

In these programs, typically developing peers are taught strategies to encourage interaction and communication during everyday activities such as classroom tasks, playtime, or group projects. Research has shown that peer-mediated approaches can increase social engagement, conversational participation, and friendship development.

One of the greatest strengths of peer-mediated intervention is that communication practice occurs in natural environments rather than only within therapy sessions. This helps children generalize newly learned skills to real-life situations.

The Critical Role of Families

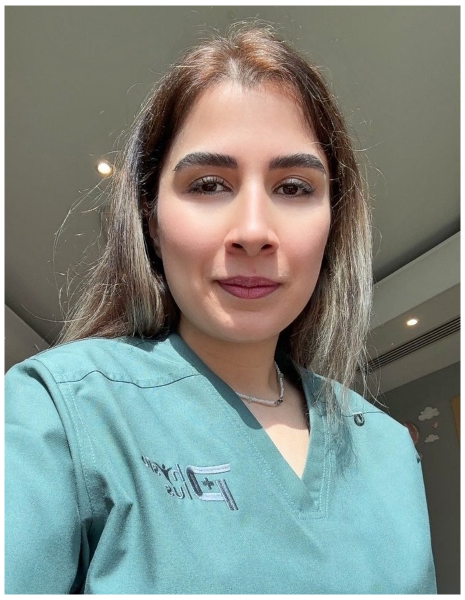
Speech therapy does not end when a child leaves the clinic. Family involvement is often one of the strongest predictors of successful communication outcomes.

Parent-mediated interventions teach caregivers how to support communication during daily routines and interactions. Parents may learn strategies such as communication prompting, conversational scaffolding, emotional coaching, and responsive interaction techniques. When communication support becomes part of everyday family life, children have significantly more opportunities to practice and strengthen their skills. Family-centered intervention also helps improve understanding between children and caregivers, fostering stronger relationships and more meaningful communication experiences.

Technology as a Support Tool

Technology has become an increasingly valuable component of autism intervention. Video modeling, tablet-based communication applications, virtual reality systems, and interactive learning platforms can provide structured opportunities for communication practice. Many autistic children respond well to visual learning formats and predictable digital environments. Video modeling, in particular, has shown promise in supporting emotional recognition, conversational skills, and social understanding. While technology can be highly beneficial, it is most effective when used to supplement—not replace—human interaction. Meaningful communication ultimately develops through authentic relationships and real-world social experiences.

Expanding Our Understanding of AAC



Pariya Parhizkar Shahri, MSLP

Augmentative and Alternative Communication (AAC) is often associated with individuals who are minimally verbal. However, growing evidence suggests that AAC can also benefit autistic individuals who speak fluently. Visual supports, communication apps, text-based systems, and other AAC tools can provide valuable assistance during periods of sensory overload, emotional stress, or communication breakdown. Rather than replacing speech, AAC can serve as an additional pathway for expression and self-advocacy. This broader view of communication recognizes that spoken language is only one of many valid ways individuals express themselves.

A Neurodiversity-Informed Perspective

Modern autism intervention increasingly incorporates neurodiversity-informed principles. These approaches encourage professionals to focus on communication effectiveness, participation, and well-being rather than attempting to eliminate every difference between autistic and non-autistic communication styles. The goal is not to make autistic children appear neurotypical. Instead, the focus is on helping them communicate successfully, build meaningful relationships, advocate for their needs, and participate fully in their communities.

This perspective has encouraged clinicians to adopt strengths-based approaches that respect individual differences while supporting functional communication development.

Clinical Reflections
and Practical Implications

In addition to evidence-based intervention frameworks identified throughout the literature, clinical experience also highlights the importance of relationship-centered and emotionally supportive therapeutic environments for autistic children. Although structured intervention models may provide predictability and therapeutic organization, excessively rigid or highly controlled sessions may unintentionally limit authentic emotional expression and spontaneous communication opportunities for some autistic children. From a clinical perspective, therapeutic rapport and emotional safety frequently appear to play a significant role in communication engagement and behavioral regulation during speech-language sessions. When children are provided opportunities to express emotions freely through play, movement, symbolic interaction, or individualized behavioral expression, they may demonstrate increased participation, emotional regulation, and communicative reciprocity within therapy contexts. Relationship-building between the clinician and the child may therefore function not only as a supportive therapeutic component but also as a foundation for meaningful communication development.

These observations are consistent with developmental social-pragmatic and neurodiversity-informed intervention frameworks, which emphasize emotionally meaningful interaction, shared engagement, and child-centered communication support rather than excessive behavioral control or rote performance-based tasks (Prizant et al., 2006; Wetherby & Prizant, 2000).

Family involvement also appears to represent a critical factor in therapeutic generalization and communication development. Clinical observations suggest that active participation of parents and caregivers may strengthen consistency of communication support across environments while simultaneously improving relational interaction between children and family members. In many cases, communication difficulties associated with autism may contribute to relational misunderstandings, emotional disconnection, or reduced reciprocal interaction within family systems. Parent-mediated and family-centered intervention may therefore support not only communication outcomes but also relational rebuilding and increased emotional understanding between children and caregivers.

Furthermore, communication goals may become more meaningful and functionally relevant when therapeutic strategies are integrated into daily family routines and naturally occurring social interactions. Communication practiced exclusively within structured clinical settings may not consistently generalize into authentic daily life experiences unless caregivers are actively involved in therapeutic implementation and reinforcement. From a communication-centered perspective, the primary objective of speech-language intervention should remain the improvement of functional social communication and pragmatic participation.

Looking Forward

There is no single therapy approach that works best for every autistic child. Research consistently demonstrates that effective intervention should be individualized, family-centered, and grounded in meaningful social experiences. Evidence supports a variety of approaches, including pragmatic language therapy, developmental social-pragmatic intervention, peer-mediated programs, family-centered support, AAC, and technology-assisted strategies. The most successful interventions are often those that recognize each child's unique communication profile and provide opportunities for authentic participation in everyday life. As the field continues to evolve, the emphasis is increasingly shifting toward communication that promotes connection, autonomy, self-expression, and quality of life. For autistic children, helping them communicate effectively is about much more than speech—it is about empowering them to engage with the world around them in ways that are meaningful to them.

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Mental Health from page 38

including high rates of co-occurring mental health conditions and persistent gaps in mental health care (Rast et al., 2021). Talk therapy is well-established as an effective, low-risk intervention for people suffering from conditions such as anxiety and depression. People who use AAC, including fluent, open spellers with these and similar conditions, can benefit from psychotherapy, and their mode of communication should not be a barrier to them accessing it.

Alex Le Pape is a nonspeaking autistic self-advocate. Beth Rosenwasser, PhD, practices Cognitive and Behavior Therapy and Consultation in private practice. Dr. Manely Ghaffari is a Child and Adolescent Psychiatrist in private practice.

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