

AUTISM DIGEST

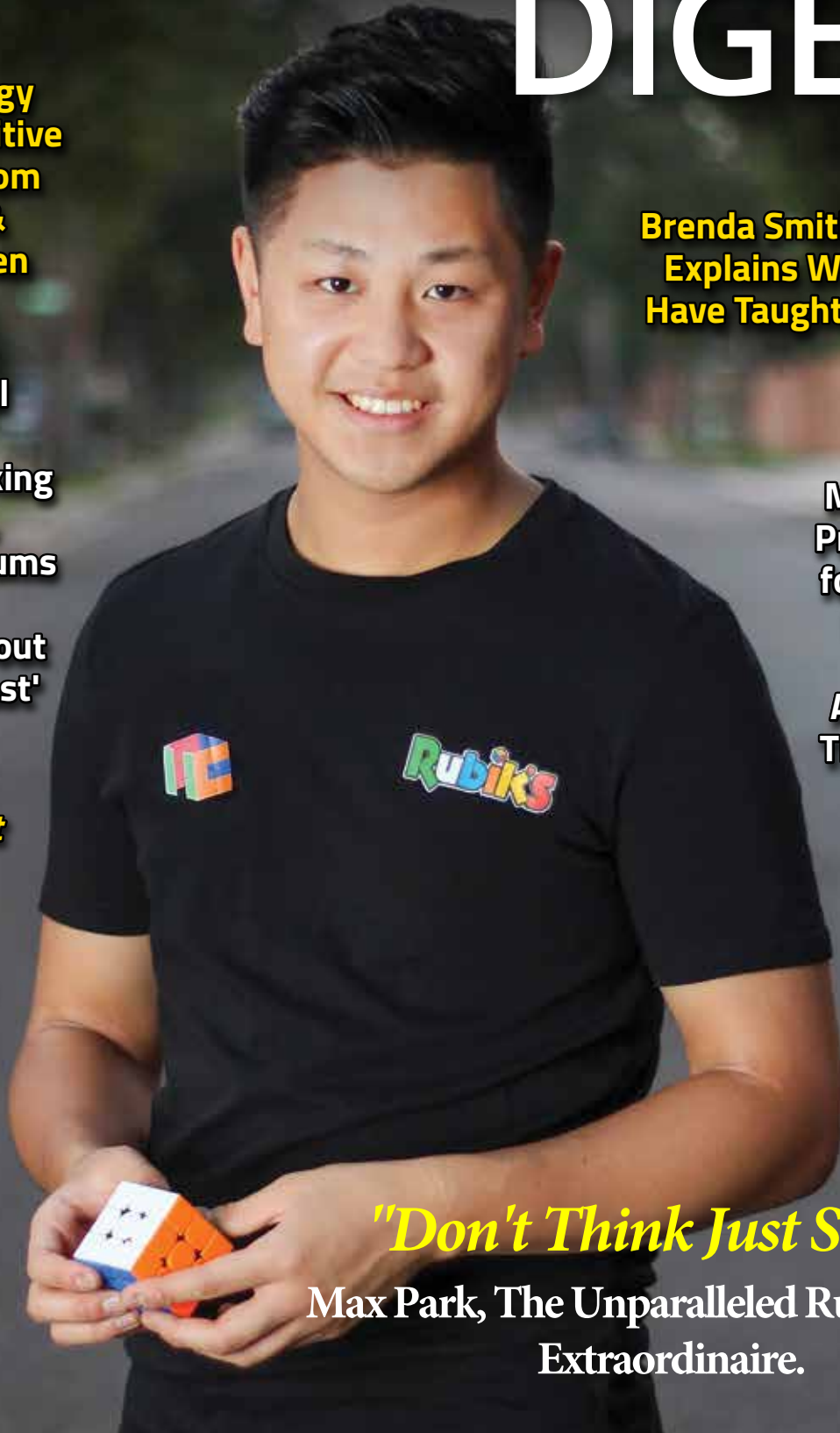
**VAST Technology
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**Daily Parental
Dilemmas:
Positively Speaking
to Your Kids,
Managing Tantrums
in Public &
What-to-Do About
'Leaving the Nest'**

**Autism Digest
Focuses on
the Impact
of the New
Category of
'Profound
Autism'**

**Brenda Smith Myles, Ph.D.
Explains What Autistics
Have Taught Her & Others**

**How You
Must Create
Predictability
for Autistics'
Brains So
They Can
Accomplish
Their Unique
Abilities**



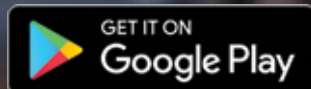
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contents

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The *Autism Digest* magazine was founded 23 years ago by a U.S. book company, Future Horizons, as the first magazine internationally solely focused on autism. Over the years, the magazine has incorporated sensory issues (SPD) in every issue, because it is a critical component of autism. The magazine addresses all issues involving autism, from birth to adulthood, from education to jobs, focusing on all components, so parents, teachers, professionals and anyone who is autistic can live and support those with special needs.

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On The Cover

Max Park is an exceptional talent in the world of speedcubing, celebrated for his remarkable achievements and unwavering commitment to perfection. His unique perspective as an individual on the autism spectrum adds depth to his incredible journey. With unyielding tenacity and unparalleled dedication, Max has shattered numerous world records in Rubik's Cube events, captivating audiences worldwide. His extraordinary ability to solve complex puzzles with lightning speed showcases his innate talent and relentless pursuit of excellence. Max's achievements serve as an inspiration to aspiring speedcubers everywhere, demonstrating that with dedication, practice, and an unwavering focus, one can reach unimaginable heights in their chosen field.



Lyn Dunsavage Young

Lyn Young, editor of *Autism Digest*, has worked in the field of autism for almost twenty years and has decades of writing, editing, and publishing magazines, newspapers, and the first author of five co-authored books on art, history, and revitalization of cities and small towns.



Temple Grandin

Temple is an internationally-respected specialist in designing livestock handling systems. She is also the most famous person with autism in the world today. She is the subject of the Emmy Award-winning HBO biopic *Temple Grandin*. She frequently writes and speaks on the subject of autism, sharing her personal experiences.



Jan Starr Campito, M.S., M.Phil.

Jan is a life/college/career coach specializing in neurodiverse clients. She is the author of the book *Supportive Parenting: Becoming an Advocate for Your Child with Special Needs* and recently published a book chapter on moving towards adulthood in *A Spectrum of Solutions for Clients with Autism*.



Krisshonda Odufuwa, M.Ed., BCBA., LBA., SLP-Assistant

Krisshonda Odufuwa is board-certified behavior analyst, speech-language pathologist assistant, autism expert, speaker, and writer. She has 10 years of experience walking hand-in-hand with families through autism.



Carol Kranowitz, MA

www.carolkranowitz.com

Carol's *Out-of-Sync Child* books help parents, teachers and therapists understand Sensory Processing Disorder. An OT-wannabe and former preschool teacher, she continues writing and speaking about SPD.



Elizabeth Irish, MLS

Elizabeth is a health sciences librarian, specializing in education and consumer health information. She is a frequent contributor to *AD* as well as having published and presented in the library field.



Brenda Smith Myles, Ph.D.

Brenda Smith Myles Ph.D., formerly a professor in the Department of Special Education at the University of Kansas, is the recipient of the Autism Society of America's Outstanding Professional Award, the Princeton Fellowship Award, The Global and Regional Asperger Syndrome (GRASP) Divine Neurotypical Award, American Academy of Pediatrics Autism Champion, and two-time recipient of the Council for Exceptional Children Burton Blatt Humanitarian Award



Dear Readers,

We're delighted to bring you another edition of *Autism Digest*, your trusted source for understanding and navigating the diverse spectrum of autism experiences. Our focus remains committed to delivering authentic, community-sourced perspectives that offer clear and insightful views into autism.

In this edition, we shine a light on the often misunderstood label of "profound autism." Experience the powerful stories of non-speaking young adults on the spectrum, sharing their unique insights on education access and how this label shapes their experiences. Their testimonies highlight the need for inclusive understanding and equal opportunities for all on the spectrum.

In our spotlight feature, we celebrate the achievements of Max Park, a speed-cubing sensation and proud autistic individual. Max's journey perfectly encapsulates our guiding theme: "Given the right resources, autistic individuals are unstoppable." His story challenges the *status quo*, illustrating the untapped potential inherent in everyone.

We are ecstatic to announce that noted autism researcher, Brenda Smith Myles, will be joining *Autism Digest*. She will be offering invaluable takeaways from her experiences with autistic individuals. She brings to light their unique perspectives, shared empathy, and impressive ability to adapt. Her insights reinforce the idea that with the right support and understanding, the potential of individuals on the spectrum is boundless.

In the same vein, Carol Kranowitz highlights that children with SPD engage as much as they are able in routine activities. The need to appreciate, recognize, and work in harmony with their

adaptive behavior is crucial. Meanwhile, Temple Grandin provides indispensable advice on teaching autistic individuals about money management, a vital skill for fostering independence.

Jan Starr Campito enlightens us on the nuanced dynamics of cognitive and emotional inertia in her article "Stuck." Additionally, Krisshonda Odufuwa offers practical tips for parents navigating autism, addressing public tantrums and the vital role of self-care. Her message carries a reassuring undertone of optimism, reminding parents they are part of a supportive community.

In this issue, our exceptional authors once more navigate these complex topics with respect, depth, and understanding. Their shared insights offer invaluable guidance to parents, educators, caregivers, and anyone touched by autism.

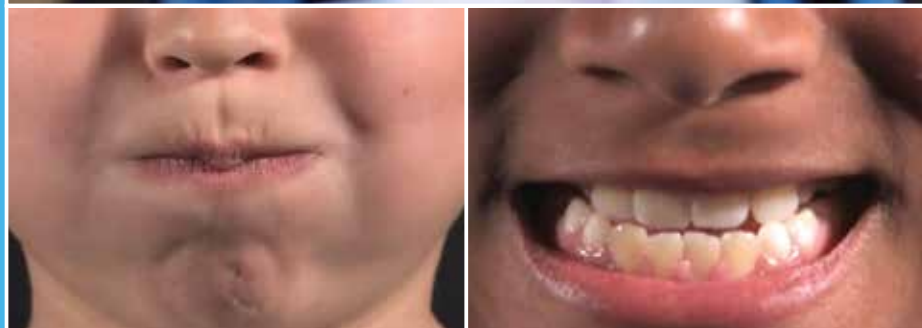
As we share this thoughtfully curated issue, we remain passionate about promoting narratives that foster empathy, encourage inclusivity, and challenge existing misconceptions. We trust in the power of these stories to broaden understanding and shift perspectives. We're excited for you to join us on this enlightening journey. ■



Lois Jean Brady & Matthew Guggemos, Publishers

HARNESSING TECHNOLOGY FOR SPEECH THERAPY:

Therapy Study Offers Hope and Insights for Parents of Autistic and Non-Verbal Children



Recent technological advancements, such as mobile devices and iPads, have introduced a groundbreaking therapeutic technique called Video-Assisted Speech Technology (VAST). This innovative approach combines video modeling, music therapy, and literacy to facilitate the development of spoken language skills in non-verbal students.

VAST is a very simple method of using a video of a close-up model of the mouth and speaking simultaneously with it. This article explores the effectiveness of VAST and its potential to revolutionize speech therapy for individuals with autism and motor speech programming disorders.

Preliminary research indicates that combining VAST with mobile technology enhances attention to motor planning information for speech.

Initial pilot studies have shown that students engage with VAST videos by mimicking lip movements and responding to the models. Within weeks, previously non-verbal students have started attempting words and showing improvements in generalizing skills during daily communication.

Video modeling has proven to be a rapid and highly effective method for teaching and generalizing new behaviors. By presenting visual models of desired actions, video modeling enhances learning and comprehension for individuals on the autism spectrum. Also, VAST incorporates visual language and literacy to improve reading and spelling

"Initial pilot studies have shown that students engage with VAST videos by mimicking lip movements and responding to the models. Within weeks, previously non-verbal students have started attempting words and showing improvements in generalizing skills during daily communication."

abilities for individuals with speaking and writing difficulties. Visual processing of information facilitates understanding, preventing mislabeling and ensuring functional word usage.

As an innovative tool, VAST is a groundbreaking therapy that combines video modeling, written words, and auditory cues. It assists individuals with autism and motor speech programming disorders, such as apraxia, in acquiring vocabulary, phrases, and sentences.

This approach is particularly effective for individuals with strong visual skills, which significantly contributes to speech development.

iTherapy conducted a small-scale study that demonstrated the effectiveness of the VAST platform in enhancing functional speech and attention among autistic non-speaking participants. The research team measured and analyzed key metrics such as articulation accuracy, and Mean Length of Utterance (MLU). The participants demonstrated positive social skill improvements, showing heightened attentiveness and increased responses to social cues – such as increased eye gaze focused on parents and caregivers as they spoke.

Follow-up assessments conducted after

the study's conclusion revealed sustained progress among participants. Therapists reported no regressions in functionality and observed the generalization of skills learned during the study. While some metrics showed modest improvements, larger sample sizes and longer study durations are needed to fully understand the technology's impact.

Video-Assisted Speech Technology (VAST) is an empowering approach for teaching spoken language to non-verbal students. By leveraging video modeling, literacy, and auditory cues, VAST provides unprecedented support for vocabulary development and communication skills. Ongoing research and pilot studies have shown promising results, including increased attention and speech attempts.

VAST has the potential to transform speech therapy and improve the quality of life for individuals with autism and motor speech programming disorders.

What Parents Can Do Today:

- VAST is very affordable and available on the Apple App Store and Boom Learning
- Parents can video their own mouths pronouncing words and short phrases
- Parents can zoom-in on a video to highlight the mouth movements

For more information on the VAST technique and research findings check out <https://www.vastspeech.com/>

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THE WAY I SEE IT by Temple Grandin, PhD



Autistics Need to **UNDERSTAND MONEY**

I have been getting more and more questions about how to help children and young adults to understand money. Fortunately, when I was a child, I was taught about the value of money in elementary school. I was given fifty cents a week for allowance.

In the 1950's, I could buy quite a lot with it. There were choices. I could get either five Superman comics or ten candy bars. If I wanted a 69-cent toy plane with a propeller, I had to save for two weeks. Mother never bought the above items; they were "allowance items."

One of my favorite toys was a table hockey game with players that were moved with sliding rods. The game provided lots of opportunities to have fun

playing with another child. One day, I saw a hockey game in the window of the local toy store, which cost \$21. I calculated that buying that game would be almost a year's worth of my allowances. To understand money, I had to relate different amounts of money to real things.

In today's world, five dollars would buy a meal at McDonalds, and \$100 may buy a nice shirt and a pair of pants. A hardback book may cost \$25.

To understand huge amounts of money -- such as millions or billions of dollars -- I now relate it to real large things. The Denver Airport cost five billion dollars. When I read about government spending for different programs, I will ask myself, "Is that program worth two Denver Airports' worth of money?"

Understanding Money in a Cashless World

Having coins and paper money make decisions less abstract. Today, a child also has to learn that the debit card does not keep working forever. Many banks have debit card accounts for children. When the child goes shopping, s/he should look at the statement both before and after they buy something.

Another method to learn the value of money is calculating the hours a parent has to work at a job to buy different things. For example, at the gas station, the parent should tell the child the number of hours you have to work at your job to fill up the car with gas. When bags of groceries are brought home, tell your child the number of hours you had to work to pay for them. It makes it easier to connect the amounts of money to real things, because, when you talk about it, the child can understand that bags of groceries or any other purchased things related to money. ■

Temple is an internationally-respected specialist in designing livestock handling systems. She is also the most famous person with autism in the world today. She is the subject of the Emmy Award-winning HBO biopic *Temple Grandin*. She frequently writes and speaks on the subject of autism, sharing her personal experiences.





"I'M ALLERGIC TO APPLES" AND OTHER EXCUSES: NONSENSICAL OR INTELLIGENT?

By Carol Stock Kranowitz, MA



Margaret is an exceptionally tidy child. On the preschool playground, she stands aside and mopes while her classmates make mudpies and dig ditches in the sandbox. When her teacher invites her to participate, Margaret cries, "I can't get my Sunday shoes dirty!"

Margaret has tactile over-responsivity. For her, messy play has no allure. She happily complies when her parents remind her on Sundays to keep her dressy shoes clean. Margaret figures it out: If she wears them on school days too, her grownups will be pleased that she doesn't get them muddy, right? Margaret is brilliant!

Kindly, her teacher mentions to Margaret's mother that sneakers or boots would help Margaret participate in outdoor activities.

Mother sighs, "She won't wear sneakers. She insists on wearing Mary Janes and frilly socks every day. It makes no sense to us, but what can we do about it?"

Her teacher and mother discuss the problem and evolve a plan. Her mother begins offering stickers to bribe Margaret to wear sneakers or boots on Mondays ... and then Wednesdays ... and then every school day. Her teacher introduces classroom art activities using sparkly colored sand, hoping Margaret is enticed to touch it. Step by step, she gets into messy play and has fun with new friends, together digging a muddy hole "almost all the way to China!"

Every Sunday, Wednesday, Friday ... children like Margaret with Sensory Processing Differences (SPD) must use their energy

and wits to get their sensory needs met, to get along at home, to socialize at school, and to get through the day without upsetting everyone. Their behavior may seem to indicate immaturity, poor manners, inattention, or lagging developmental skills; however, if we can understand what they are communicating through their behavior, we can recognize and marvel at their intelligence and ingenuity.

First-grader Chip, another child with tactile over-responsivity, wears his tee shirts inside out, risking his father's wrath but "saving his skin." Is Chip a defiant, uncooperative slob who hasn't the sense to put his clothes on right -- or is he a thoughtful boy



who has come up with an intelligent plan to avoid the tee-shirt's irritating seams and tag?

When Chip's parents understand the underlying reason for his unusual way of dressing, they find seamless clothes on-line. Chip's wardrobe and family life become much more comfortable.

No tee shirt for Liam! Another lad with tactile issues, Liam wears a button-down shirt to school. His hands never leave his pockets. Charming and verbally precocious, he informs his teacher, "Playdough is childish. I prefer reading books."

Liam would have his teacher believe that he's way too mature to play with sticky materials. But five-year-olds need to manipulate things to learn about them. Does Liam's "I'm-too-old-for-this-baby-stuff" excuse make sense? Or is the excuse his intelligent way to avoid something he can't bear to touch?

His teacher 'gets' Liam. She provides disposable gloves to protect his over-sensitive hands, and he begins to dabble in the finger paint and playdough activities that his peers relish.

Jasmine's tactile issues are in her mouth. She is a picky eater who prefers smooth food. She avoids school snacks by saying, "Mommy told me not to eat pretzels." Really?

Chris, another selective eater, says, "I'm allergic to apples." Really? These intelligent children have learned that they can avoid eating crunchy foods by making socially acceptable excuses, which their teacher cannot dispute. These children's oral sensitivities are getting in their way.

Occupational therapy and speech-and-language therapy help them improve their tactile and proprioceptive processing.

Eventually, they become more adventurous eaters.

Not tactile but auditory over-responsivity affects Drew. Drew can't tolerate the metallic sound of triangles, tambourines, and twanging guitar strings. When his class goes to the community room for music and movement activities, he wears earmuffs and presses his hands over them to block the painful sounds. Is Drew being rude -- or is his behavior communicating, "My ears hurt, and you grown-ups aren't helping, so I've come up with my own semi-satisfactory solution"? Smart boy!

The answer for Drew is noise-canceling headphones, found on the Internet. Environmental sounds are filtered out, making his life more peaceful.

Let's remember that when it comes to playing and participating in ordinarily fun activities, children with SPD would if they could.

Let's strive to understand the underlying rationales for their novel excuses or unusual actions. Let's recognize, applaud, and work with their sensible and truly intelligent behavior. ■



Carol Stock Kranowitz is the author of the "Sync" series, including *The Out-of-Sync Child, 3rd edition*, and *Growing an In-Sync Child* (with Joye Newman.) Visit her websites: www.out-of-sync-child.com and www.insyncchild.com to learn more.



LABELS ARE FOR JARS, NOT PEOPLE!

By Lois Jean Brady and Matthew Guggemos



Express Yourself Troup members - Otto Lana, Bella Santoyo, Justice Killebrew, Emma Cladis, Neal Katz, and Willian Del Rosario - are striking a pose for their original single, 'Let My Typin' Let You See.' This distinctive music video was created by and features non-speaking actors and multimodal communicators from the Express Yourself program (https://www.youtube.com/watch?v=EyG_WqC_eRA).

For years, children who exhibited limited verbal abilities or were nonverbal were frequently assigned IQ scores in the range of 50 to 65. This categorization was a result of limited understanding and knowledge surrounding these children, especially if they had the term "autistic" attached to them.

As a result of both their limited verbal abilities and the gross assumption the children had exceedingly low IQs, they were placed in "special programs." In such cases, the communication barriers hindered the assessment process, so educators and professionals lacked the necessary information to accurately categorize these children.

As a result, the children were often assigned lower IQ scores year after year, contributing to a cycle of limited expectations and restricted opportunities for growth and support.

In a recent report "(The Prevalence and Characteristics of Children with Profound Autism, 15 Sites, United States, 2000-2016," published in the peer-reviewed scientific journal *Public Health*

Reports) and the Centers for Disease Control and Prevention (CDC) **revealed for the first time that 26.7 percent of individuals with autism spectrum disorder have been categorized as having 'profound autism.'**

This distinction reflects a growing awareness of the unique challenges faced by individuals with profound autism, highlighting the need for tailored support.

The Significance of Profound Autism: 'Profound autism' refers to individuals who are nonverbal, minimally verbal, or have an IQ below 50. It serves as a descriptor for the severity and complexity of their condition, differentiating them from individuals with milder forms of autism. These individuals often encounter communication barriers, self-care limitations, and a higher prevalence of self-injurious behaviors and medical conditions.

Challenging Expectations and the Rosenthal Effect: Expectations play a crucial role in shaping outcomes for individuals with profound autism. The Rosenthal effect, also known as the 'Pygmalion Effect' is a psychological phenomenon that states that when people

are given high expectations, they tend to perform better, while when they are given low expectations, they tend to perform worse.

When individuals are believed to possess greater potential and abilities, they tend to exhibit heightened confidence and motivation, leading to improved performance. Conversely, when individuals face low expectations or negative labels, their self-confidence and motivation may diminish, resulting in poorer performance.

The Rosenthal effect emphasizes the importance of fostering positive expectations and providing support that empowers individuals to achieve their full potential.

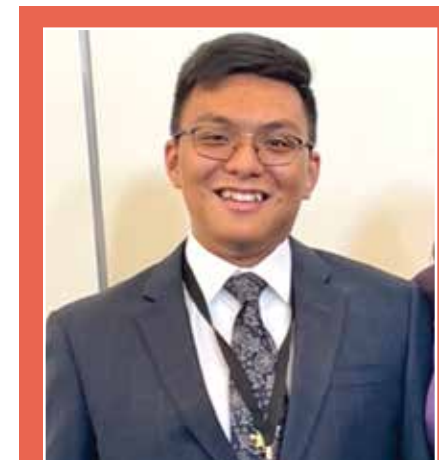
Labeling individuals with profound autism may inadvertently shape their self-perception and impact the support they receive. Therefore, it is not only essential to challenge limiting beliefs, it's important to foster high expectations for growth and development.

Educational Implications: Expectations within the educational setting can significantly influence the experiences and achievements of students with

profound autism. Lower expectations based on IQ levels may result in a reduced focus on providing appropriate educational opportunities and support.

To break this cycle, it is crucial to view each student as an individual with unique abilities and strengths, offering tailored interventions and promoting inclusive practices.

Three young adults (below) have much to say about the new "profound autism" diagnosis:



William Del Rosario

I am a 23-year-old non-speaking adult learner with autism. I type to communicate and am currently working toward earning my high school diploma one letter at a time. While my communication and learning differences do not define me, they have been used against me when determining the support services that I have received.

I have historically been viewed as being capable of learning only the most basic skills with limited interests. My years in public education were spent in a segregated classroom for students with severe autism.

There is often an assumption made that if you are non-speaking, you are also non-thinking, so managing behaviors will give you the best future. What educators failed to see was that the behaviors they were seeing came from my frustration of not having access to communication or grade level academics.

Even into my adult years, there were educators who offered me picture books such as *The Hungry Caterpillar* to read.

My parents bought me an iPad and a communication app and paid for communication training to learn how to support me at home. Access to an iPad at school took time to get approved. Even with this accommodation, the experts had few expectations for me, and it was difficult getting staff support trained on my communication modality.

As a person who requires communication support, I am sometimes viewed as less. My requests for support have been met with testing requirements to prove that I am worthy of services.

Imagine having to take an intelligence test first every time you asked for help or, in some cases, even the most basic human rights? These tests do not allow for me to have a communication support person, which greatly limits my ability to respond.

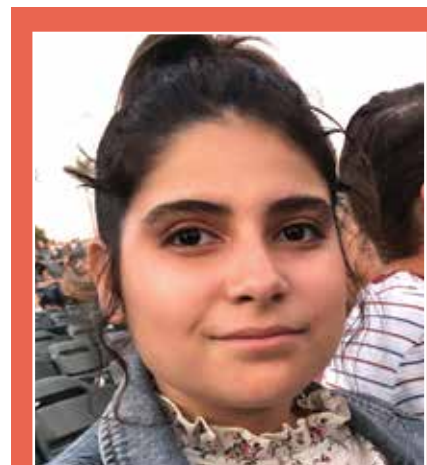
For example, I was recently asked to have a psychologist's evaluation to receive Department of Rehabilitation (DOR) services. They didn't want to let me have a communication partner for the testing, but they said that my mom could be outside the door. My case manager said that I would have access to my communication because I would have my iPad with me. I wonder if they would test a deaf person while their interpreter stands outside the door and tell the person that they still have access to their communication because their hands are with them?

Without this access to communication, the expectations are lower.

Thinking about the word 'profound' and what in the context of autism it has been known to mean, there is often an associated capacity. This article focuses on limitations fired by the imagined futures they believe can be determined by age 8 or 9. What type of life does this set anyone up for? Of course, the best

possible outcome might be achieving fundamental life skills, if that is the only expectation taught or learned from early childhood.

Given adequate support in an inclusive environment that sets the expectation to learn, access communication, and find purpose to a life lived with autonomy should be the lifelong learning goal. **Everyone deserves dignity of care, not a box they get placed in.** What if we had a metamorphosis of thought and changed our mindset to being one that sees the possibilities?



Isabella Santoyo

Hello, my name is Bella. I am a 21-year-old autistic self-advocate who just completed high school requirements to earn a diploma. I should note that I happen to fall under your 'Profound Autism' definition as I am non-speaking.

Your definition of 'profound autism' is not helpful nor correct, **as the inability to speak does not equate with mental retardation.** If my truth is not enough, a simple view of the Communication First website, where you can see non-speaking autistics communicating, should be enough to dispel this myth. <https://communicationfirst.org/thoughts-from-an-autistic-aac-user-after-the-april-2022-meeting-of-the-interagency-autism-coordinating-committee/>

Continued on page 14

"Labels are for jars, not people."

When I was in my early elementary years, educational administrators wanted to label me as intellectually disabled. My parents' response to this was the exact opposite of what you would suppose; instead, they demanded that I be given access to the general education curriculum.

I sense that you do not presume competence in non-speaking individuals like myself. I am impacted by my autism, but I also am able to communicate and direct my own life. I am not unique. I want to live a happy and fulfilling life without limitations. I may need support to do these things but that does not make me less human.

I believe that to better serve the autistic community, you must do away with further fracturing of autism into harmful categories.

It is no wonder that autistic non-speakers struggle with communication as educators have no expertise in Augmentative Alternative Communication (AAC). This is problematic.

I do believe access to communication support for non-speakers is paramount. Communication is a basic human right.

Once a non-speaking autistic is able to access communication, you would find that lack of intelligence does not exist.

Other needs -- such as sensory and motor differences -- can impact one's ability to provide their own self-care. Needing personal care support does not imply mental deficiency. Look at Stephen Hawking.

Discrimination is a reality we autistics face by going against the norm. Just last year I was the victim of being labeled as profoundly impaired by the administration of my previous school. This was in retaliation to requesting needed support

to access my academic curriculum. The first thing I was mandated to complete was a behaviorist-created assessment which essentially focused on my motor skills. The result of said assessment indicated that I would unlikely benefit from an academic school program.

This determination and later unjust withdrawal of said school greatly affected my self-esteem and mental health. I was extremely depressed, thinking I would never get my chance at an education.

Here is what you are missing: motor differences don't make people incompetent or less than. Speech is a motor issue.

A label of profound autism would not help me or my non-speaking autistic peers. We need communication services -- not behavior-based interventions. We need inclusive schooling -- not separate or segregated schools.

We want to live happy and fulfilling lives doing what we choose to do, not be prescribed functional living skills as our life goal.

If we need support to access any of the above, then so be it.

Your thinking and proposed help would not advance the quality of life of the individual in need. I fear that non-speaking autistics would be more intensely segregated and isolated should you succeed in adding a new classification.

Please do your due diligence and learn from the very community you wish to help.

Isabella Santoyo resides in Long Beach, California. She is a limited speaking autistic who recently earned her high school diploma. At age 10 she was introduced to text based AAC that changed the trajectory of her life. She believes that all students deserve access to a quality education despite their differences.



Otto Lana

Labels are for jars, not people.

I just had a new thought to share...

We're in a risky zone when we distinguish between 'high functioning' and 'low functioning' autism, inevitably serving someone an insult. I confess: I'm no fan of the term 'disorder', but the word 'profound' sets me on edge. It's a cloaking term that seems to separate and segregate autistic individuals.

The language within some articles about autism can be divisive and downright offensive.

"The needs of these children are at risk of being neglected because they are radically different from those who are less affected".

RADICALLY DIFFERENT?!! Let me interject a reality check: their needs are not being met because their needs are not being identified properly. How can support be put in place if needs are not known. I've always wondered, how does one measure the IQ of a child who has no or limited speech, restricted fine motor skills, anxiety, or PTSD?

Let me explain why this interests me. Last week, I was scheduled by a federal agency for a cognitive evaluation by a third-party contractor, whom we'll call Dr. O. He was operating in a small room, in a chiropractor's office, half an hour from my home. The lack of identification -- no business card or certificate -- meant I couldn't verify his qualifications. Since

this was not his own office, it was devoid of any professional identifiers.

When he asked me my name, I couldn't respond verbally due to my apraxia. As I sought assistance from my mom, Dr. O said no support or aid of any kind was allowed, as the evaluation had to be fully independent.

Next, he handed me a worksheet of assorted questions, from fill-in-the-blanks to elementary math problems, and he asked me to complete it with a pencil. Given my limited fine motor skills, this was a tall order. Unable to answer through spoken word or written text, I was given zeros across the board.

The reason I question this testing approach as ineffective and inaccurate is because I had just completed an honors calculus course in high school and had received an award from the San Diego Writers and Editors Guild for my poetry writing. They even announced a perpetual award, the "Otto Lana Award" was to recognize young poets exemplifying dedication and creativity. Does that sound like a zero IQ to you? Yes, it's true I need assistance with daily activities, but this is due to motor skills, not cognitive ones.

"And we can predict who they will be... by age 8 or 9! "WHAT?!! Who among us is the same as when we were 8 or 9, seriously. What adult resembles who they were at 8 or 9? What 40-year-old resembles who he was at 18 or 19 for that matter? This is a not very shrouded attempt to parse us out and ultimately deny us services, because we won't fall into the category of those who can learn and who will benefit from higher education or other such services. When I was six, I was given an IQ test and was deemed intellectually disabled, so I was then transferred from a mainstream classroom to a segregated special day class.

Consequently, I was removed from a diploma track, and my academic curriculum was replaced with stacking blocks and wooden puzzles. Only when a school psychologist allowed me to be re-

evaluated using my communication device was I "discovered" to be 'gifted' - another unnecessary label. My academic life took a 180-degree turn then. Now, I am a high school senior and will graduate in 2024.

I hope more voices like mine are heard before they make this terrible category a reality.

It is about support and access to a robust system of communication. Without an accurate exchange of information, needs cannot be identified, let alone met.

Otto Lana is a high school senior living in San Diego. He is a poet, film maker, actor, lyricist, and self-advocate. He won the Harry Servidio Memorial Leadership Award for his work in advocacy and inclusion. He also won the first inaugural Heumann-Armstrong Award for Excellence in overcoming ableism in academia. He is an entrepreneur, designing and selling waterproof letterboards and apparel on his website www.ottosmottos.com

Conclusion: The recognition of profound autism as a distinct subset within the autism spectrum highlights the unique challenges faced by individuals with severe communication and intellectual impairments.

It is essential to approach the use of the term "profound autism" cautiously, considering its potential impact on expectations and the Rosenthal effect. By fostering high expectations, challenging limiting beliefs, and providing tailored support, we can create a more inclusive society that promotes the growth and development of individuals with profound autism.

Through collaborative efforts, awareness, and research, we can break down barriers and create opportunities for individuals with profound autism to thrive. Let us strive for a future where every individual, regardless of their IQ level, is valued, supported, and given the opportunity to reach their fullest potential within a compassionate and inclusive society. ■



Lois Jean Brady has over 30 years of experience as a practicing Speech-Language Pathologist. She's a Certified Autism Specialist

(CAS), and she also holds certification in Assistive Technology and in computerbased interventions. Career accomplishments include Winner of two Autism Speaks App Hack-a-thons, a Benjamin Franklin Award for *Apps for Autism* and an Ursula Award for the *Autism TodayTV*. In addition to *Apps for Autism*, she has co-authored *Speech in Action* and *Speak, Move, Play and Learn with Children on the Autism Spectrum*. Lois gives international presentations to both family members and fellow professionals at conventions and seminars on autism and technology.



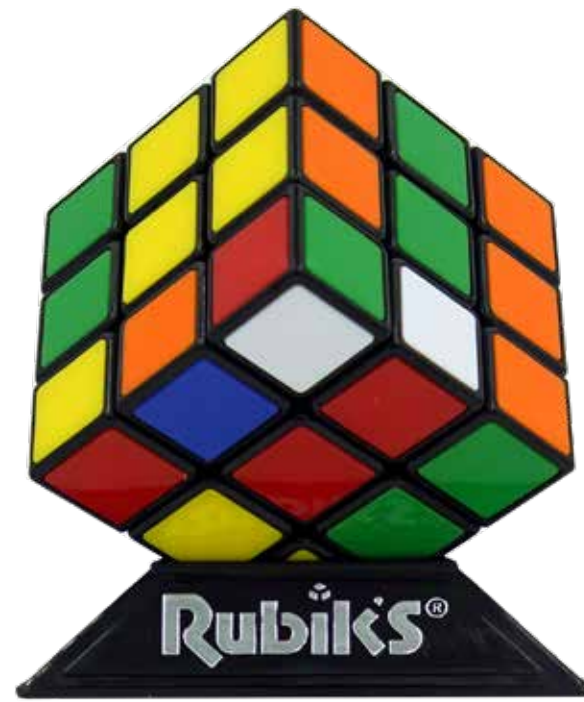
Matthew Guggemos is a speech-language pathologist, certified autism specialist, drummer, researcher, and publisher of *Autism*

Digest. As the co-owner of iTherapy, a Speech Pathology Corporation, Matthew supervises numerous clinicians who provide services for insurance companies, state-funded early intervention programs, school districts, and private clients. Along with Lois Brady, Matthew also owns iTherapy, LLC, which creates educational technology that has been funded by the National Science Foundation, the National Institutes of Health, Epic Games, Microsoft, Snap, and NewSchools Venture Fund. Matthew is the winner of Mensa's Intellectual Benefits to Society Award for his design contributions to InnerVoice, iTherapy's flagship product.

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**Don't
Think.
Just Solve.**



MAX PARK

The Unparalleled Rubik's Cube Extraordinaire

By
Lois Jean Brady

*Max Park with a win at
Red Bull Rubik's World Cup
Championship in 2021.*

One name stands out above the rest when it comes to solving Rubik's cubes: Max Park. Park has broken records and established his reputation as a true Rubik's Cube master thanks to his exceptional abilities, unyielding tenacity, and commitment to perfection.

Recently, he achieved an extraordinary feat by breaking the Guinness World Record for the Rubik's Cube. *Autism Digest* delves into Park's remarkable journey, his relentless pursuit of greatness, and the impact he has had on the Rubik's Cube community.

At the age of 10, Max Park received the Rubik's Cube as a therapy for his fine motor skill deficit, which ignited his passion for the puzzle. He had no idea that this toy, which appeared innocent, would spark a passion that would change the course of his life. Park became fascinated by the challenge, immersing himself in the complexities and methods of solving Rubik's Cubes.

Diagnosed with moderate-to-severe autism spectrum disorder, Park's journey was not without obstacles. He faced unique challenges in his pursuit of mastering the Rubik's Cube. With each setback, he embraced the opportunity to learn and grow, ultimately using the puzzle as a tool for self-improvement and personal development.

In 2017, Max Park made headlines by breaking the world record for the fastest time in solving a 3x3x3 Rubik's Cube, clocking in at an astonishing 4.69 seconds, Park not only showcased his lightning-fast speed but also his exceptional problem-solving abilities. His record-breaking achievement sent shockwaves through the Rubik's Cube community and established him as a force to be reckoned with. JUST LAST MONTH Max broke the world record in just 3.134 SECONDS crushing the previous record of 3.47 held by Yusheng Du since 2018.

Max Park's prowess was not limited to



Max Park: A Living Legend in the World Cube Association, Defying Limits and Inspiring Generations of 'Cubers.'

the standard 3x3x3 Rubik's Cube. He soon set his sights on other categories and dimensions, conquering larger cubes and even venturing into blindfolded solving. Park's ability to visualize and execute complex algorithms with precision allowed him to break records in various Rubik's Cube categories, demonstrating his versatility and skill.

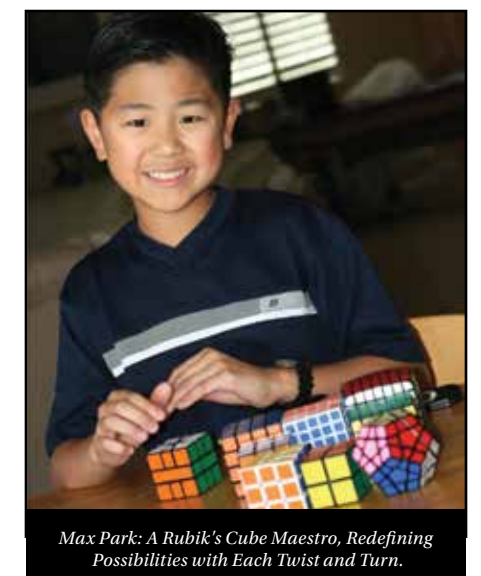
Park's incredible journey has inspired countless Rubik's Cube enthusiasts and aspiring 'speedcubers' around the world. His achievements have shattered perceived limitations and showcased the boundless potential within each individual. Park's story resonates with people from all walks of life, reminding them that dedication, perseverance, and a love for what they do can lead to remarkable accomplishments.

Max Park's quest for excellence is far from over. He continues to push the boundaries of Rubik's Cube solving, constantly refining his techniques, and seeking new challenges. Park's insatiable hunger for improvement drives him to innovate and redefine what is possible in the realm of Rubik's Cube solving.

While Max Park's achievements are awe-inspiring, his impact extends beyond the Rubik's Cube. As a prominent figure in the autism community, he serves as an inspiration for individuals on the

autism spectrum, showcasing the unique strengths and abilities that they possess. Park's success story stands as a testament to the power of determination, resilience, and embracing one's differences.

Max Park's extraordinary journey of breaking the Guinness World Record for the Rubik's Cube showcases the limitless potential of individuals within the spectrum of neurodiversity. His story transcends the boundaries of mere puzzle-solving, offering us profound insights into determination, resilience, and the power of embracing our unique strengths. As we celebrate Max Park's achievements, let us be inspired to rewrite our own narratives. ■



Max Park: A Rubik's Cube Maestro, Redefining Possibilities with Each Twist and Turn.

POSITIVELY SPEAKING



By
Elizabeth Irish, MLS

Now, don't take this the wrong way, but some days it's hard to have a positive attitude, isn't it? It could be an unexpected phone call from school, a meltdown, mounds of paperwork, or just one more bump in the road that makes us sound like Eeyore's more depressed cousin.

For me, those tough days seem to happen when there's an important planning meeting on the calendar. Preparing for my son CJ's Committee on Special Education (CSE) meetings comes to mind. For those of you who haven't experienced a CSE meeting yet, I'll let you in on a secret. A good CSE meeting is one where you've met in advance with your child's teachers and service providers so there are no surprises during the actual meeting. In CJ's case, the planning meetings always went like this:

"You know, we like CJ. He's bright, has a good sense of humor, and such a good

heart." Funny, I can always hear a *but* coming. "But we're not going to focus on those qualities. Just remember, no matter what we say, we know he's a good kid with so much potential."

Therein lies the first catch.

In order to get services, you have to meet the requirements. 'Bright,' 'charming,' and 'kind' aren't qualities that are on that list. You have to hear the worst first, which makes you feel like, compared to your child, Dennis the Menace is an Eagle Scout.

The second catch is even more sobering. During these times, kids often hear the negative coming out of our mouths. We sometimes forget that little ears are listening. This thought struck home to me when CJ was seven at his first neurology appointment. Here were the adults, discussing the implications

of this little boy's newly diagnosed Tourette Syndrome as if he wasn't in the room. No big deal, right?

On the way home, we heard a small voice behind us quietly ask, "Am I dying?"

Ouch. None of us took the opportunity to actually explain Tourette's to *him*. We didn't think he was listening.

I wish I could say that didn't happen often, but it happened more than it should have. The notes sent home from school that emphasized his daily struggles far outweighed the notes that celebrated his victories. Why? It's not that the positives went unrecognized, but they were often left unspoken. Rather, time was spent addressing behaviors that needed to be improved.

Think about it though: when we

"Let's not become so fixated on the challenges that we lose sight of our kids' positives."

focus mainly on areas in need of improvement, how does that make the person feel?

What if we take a moment to reflect on and acknowledge their best qualities as well?

Two recent studies have explored what positive character traits parents associate with their child on the spectrum.^{1,2} Regardless of the age - child, adolescent, or young adult - both studies found that parents used words such as 'kind,' 'humorous,' 'playful,' 'affectionate,' 'sociable,' 'creative,' and 'intelligent' when describing their child.

It wasn't just positive personality characteristics that were identified. Parents mentioned their children's strengths, including technological, artistic, and musical abilities. These are real-life, potentially employable skills. Parents also noted their children's work ethic, perseverance, independence, and desire to succeed. Combine the two, and we may be on to something!

However, to have an impact, compliments need to be more than mere lip service. Kids need to

experience success. One example is strengths-based programming that builds on an individual's special interests, like technology. Parents' perceptions of these programs are that they positively impact their adolescents' self-confidence, well-being, and relationships.³

I see this play out in CJ's Life Plan meetings with his care management organization. As he is a young adult now, these meetings revolve around his strengths, his concerns, and his self-identified goals to help him find meaningful employment and develop life skills. This makes the focus more tailored to CJ's individual wants and needs. His team's attitude is always positive. Not surprisingly, at the end of these meetings, CJ's smiling. He even seems, dare I say, motivated and excited for what's to come.

I'm not trying to sound like Pollyanna. I'm really not. Challenges absolutely have to be addressed. But, CJ, like many of us, responds better to positive input. Too much negativity destroys self-confidence, squelches motivation, and

is downright discouraging for anyone, parent or child.

Let's not become so fixated on the challenges that we lose sight of our kids' positives. Never forget, no matter how old they are, they are listening. ■



Elizabeth Irish, M.L.S., A.H.I.P., is a health sciences librarian specializing in education and consumer health information.

She is a distinguished member of the Medical Library Association's Academy of Health Information Professionals and has earned their Level 2 Consumer Health Information Specialization certificate. She is a frequent contributor to *Autism Digest*. As an associate college professor, her works also appear in information science and medical publications. She may be contacted at irishelizabeth@gmail.com.

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HELP! THEY'RE STUCK!



By Jan Starr Campito, M.S., M.Phil.

When I monitor various forums for parents of young adult autistics, I see a frequent cry for help: *"My kid is unmotivated, does nothing except electronics, is isolated, is depressed. They don't leave the house; there is no structure to their day. They seem stuck! I'm frustrated and scared. What can I do?"*

The parental concerns and fears are palpable. They have tried everything they know to try, and it often results in power struggles, fights, avoidance, and everyone feeling worse with no end in sight. Sadly, this is not uncommon in times of major life transitions.

The situation is made worse by common societal views of what *should* happen after our kids turn 18. Remember

those accusations of helicopter parenting you faced when they were little? Well, the grown-up version of that is the accusation that we're making life too comfortable. We are the reason our young adults won't leave the nest.

Or... perhaps they can't?

In his collaborative problem-solving model, Dr. Ross Greene's mantra is "Kids do better when they can."¹ His professional experience is that what we outsiders see as troubling behaviors are actually manifestations of unsolved problems that overwhelm our young adults. It's why the parental tug-of-war over moving forward doesn't work! The parents are on one side of the rope, the kids on the other, and an unattractive, muddy mess lies in the middle awaiting the loser.

So, what are some alternatives?

Conversations with my coaching clients inevitably reveal that they are "stuck" for good reason. They bear so many scars from past academic, social, or emotional struggles, it is hard for them to see their own beauty, their strengths, their accomplishments, and their potential.

Over time, many have lost confidence in themselves. They are tired of comparisons to others, using standards by which they often appear "less than." And they often have a long history of feeling trapped in situations over which they had minimal control.

For example, "Mary's" failed attempt at college prevented her from trying anything new. "José" eventually found his way, but nothing had prepared him for life post-college. "Ellen's" short-lived job experience was filled with

unclear expectations and constant overwhelming stress. "Glyn" was stuck because their primary resource was their parents, and this seemed less appropriate or sustainable as an adult.*

There is also a harsh reality at play here. We have all heard about "the autism cliff" where supports and services are scarce or difficult to access once an individual on the spectrum ages out of school.² Yet we expect our young autistics to forge their way into this unfamiliar adult world anyway. It's a daunting task! No wonder many of our folks freeze. They are not saying "no" to life. They are saying "no" to the overwhelm and the fear of the unknown.

Whether in my role as parent or in

my role as coach, I find that the way forward is based on understanding and compassion. Instead of assuming that I need to tell them what they should do, I begin a dialogue to uncover their thoughts. They are experts on what does *not* work for them! But discovering what *does* work may be more challenging, for them and for me. Typical brain development continues until the mid-to-late 20's, and many individuals experience lifelong executive functioning challenges due to their autism.³ So, I need to pull back, listen, and help them explore alternatives that perhaps neither of us had looked at before.

By constructing a positive vision

together, or even a small piece of one, we can move into collaborative problem solving that respects their wants, their choices, their emerging vision, and their pacing. After all, there is not just one way of thriving in the adult world. And if we are honest with ourselves, there truly aren't easy answers to 'adulting' for any of us.

The key to our young adults becoming unstuck is to be their ally, lending your strengths to help them feel safe enough to step back into the world, try again, and blossom. ■

**Client names and details have been changed to protect their identity.*

ADVICE FOR PARENTS (who sometimes get stuck too)

- **Bottom line, it is their life you are talking about. Listen to their voice.**
- **Be their ally, not a director.** Dialogue and collaboration are essential.
- **Problems and solutions are as varied as individuals.** Often the path forward lies in crafting something unique for your young adult's wants and needs.
- **Take baby, baby steps to build on success and to avoid shutdown from being overwhelmed.**
- **The best paths forward from "stuck" tend to be based on strengths and interests.**
- **Explore autistic voices as to what others have found works for them.**
- **Consider using the services of a mental health professional or a life coach to figure things out.**
- **Investigate applying for adult disability services.** These may provide funding and supports needed for greater adult independence.
- **Don't ever stop believing in your young adult's competence, their dreams, their future, and in the existence of a way forward that can work for them.**



Jan Starr Campito, M.S., M.Phil., is a life/college/career coach specializing in neurodiverse clients. She is the author of

the book *Supportive Parenting: Becoming an Advocate for Your Child with Special Needs*. She recently contributed a chapter on transitioning to adulthood, in the book *A Spectrum of Solutions for Clients with Autism* (edited by Rachel Bédard and Lorna Hecker). This is her fourth article for *Autism Digest*. To contact Jan or to learn more about her nationally available coaching services, visit <https://www.jancampito.com>.

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"No wonder many of our folks freeze. They are not saying "no" to life. They are saying "no" to the overwhelm and the fear of the unknown."



Managing TANTRUMS in Public: The Stares

By **Krisshonda Odufuwa, M.Ed., BCBA., LBA., SLP-Assistant**

in a public setting with your child by preparing to go before you go! This is a strategy that many parents forget, so be sure to inform your child and others of what to expect.

Rewards

While you are riding in the car, reward your child for simple and appropriate behaviors, like staying in his/her car seat, having an “inside voice,” or, even, commenting about your child’s keeping his feet from kicking the back of your seat. Keep it simple!

Social praise such as “I really like how you handled ____.” Or “I can’t wait to tell grandma how awesome you’ve been.” Or “Well, look at you! Are you enjoying looking out the window?” Social rewards are valuable in that they can potentially increase appropriate behaviors.

Your Mental Health

Parents, let’s not forget yourselves! Staying healthy, getting enough sleep, and taking time to get fresh air are vital in taking care of your children. When your physical, mental, and spiritual self are all functioning at its full capacity, you will have more patience, love, and compassion toward your child/children. If things become too difficult for you, seek help by reaching out to a family member or close friend. Consider further outreach by connecting a counselor in a safe environment to discuss your thoughts and feelings.

Take One Day at a Time

All children engage in tantrums. It’s not just your child. You’re not alone. There also are clinical, licensed, and certified professionals who can help you and your family if it becomes too difficult.

Grab a journal, do your research, and find the people who will do more than just stare at you. ■



Krisshonda Odufuwa is a wife, mother, board-certified behavior analyst, speech-language pathologist assistant,

autism expert, speaker, and writer. Krisshonda holds a bachelor’s degree in communication sciences and disorders and a master’s degree in special education with an emphasis on applied behavior analysis. With 10 years of experience walking hand-in-hand with families through autism, Krisshonda displays compassionate, relatable, realistic, and evidence-based strategies that are proven to improve the lives of families that love someone with autism. Blue Melo Connections on the following social media platforms: Instagram @bluemelobehaviorchange, Tik Tok @Bluemelobehaviorchange, Email: letsconnect@bluemelo.com

Whether you are a parent of one or six children or a parent of a child with autism, you surely are aware of the infamous stares that accompany tantrum behaviors in public.

As a parent, the shame, embarrassment, and guilt kicks in when your child has a tantrum in public, and then—suddenly -- you think “Why did I even come here?”

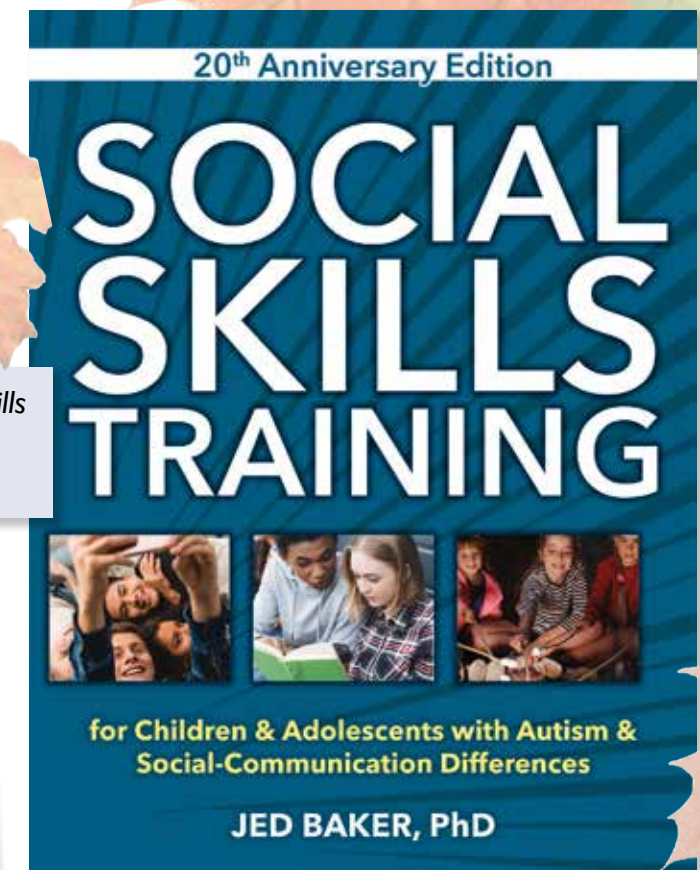
Take a deep breath. Get eye level with your little one and follow these easy steps to prepare you for a smoother outing with your family and/or friends when your child breaks down,.

Intentionality

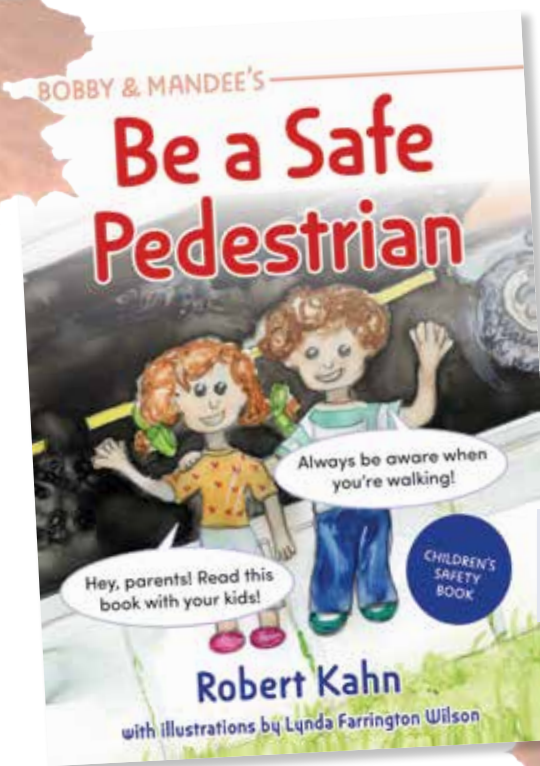
Parents, there is hope. First, be intentional by setting your child and family up for a successful community outing by Informing your them to the answers in the five “W’s”: where, why, who, what, and when. Where are you going? Why are you going there? Who will you see? What will you do there? And when will you return home?

You can conquer your fear of going out

Books for Back to School!



The classic book for learning social skills has a new 20th anniversary edition \$39.95



Keep kids safe \$11.95



A sweet picture book about a parent’s love for their child with autism \$17.95 (softcover) / \$24.95 (hardcover)

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What I Have Learned About Autism from Autistic People

By Brenda Smith Myles, PhD



Although I may have initially learned through journals and discussions with family members, almost everything that I know that is meaningful about autism has come directly from autistic people. I've observed. I've listened. I've asked questions, when appropriate. It is that straightforward.

What have autistic people taught me?

1. Autistic people are not broken.

Autistics have a neurology that responds in specific ways to the environment. Unique sensory experiences, learning style, and challenges in self-regulation are related to the autism neurology.

2. Theory of mind goes both ways.

We neuromajority² people have always thought - erroneously, I might add - that we had the corner on the theory of mind market. That is, we were convinced that the way we think and the way we interpret events, actions, and thoughts of others was absolutely correct. We thought that autistic people had it wrong. However, theory of mind goes both ways. We all have a theory of mind, and each theory can be as valid

as another. It is important that we understand each others' theory!

3. Autistic people have empathy. If cursing in an article were allowed, I might insert a colorful word or two here. Autistic people have empathy. I would further posit that many of the autistic people I know are very empathetic. In fact, I would describe some of my autistic friends as being overly empathetic. A "lack" of empathy often comes from a lack of understanding and having different life experiences. And we all want to understand each other. I have a friend with autism who broke her arm and did not experience much pain; when I broke her arm, she was surprised to hear that I was in severely hurt. Similarly, another autistic friend had "minor" surgery that left her in so much pain that she needed very strong medication. I had the same surgery several months before and experienced no pain. So, it can be difficult for neuromajority people to understand the autistic experience and vice versa. It has nothing to do with empathy. Autistic people can be tremendously empathetic.

4. Nothing is really obvious. I've spent some time talking about the importance of ensuring that autistic people understand the hidden curriculum - the unwritten rules and expectations that are often unclear to autistic people. I have (finally) realized that the items that fall under the hidden curriculum are often poorly worded, misleading, and sometimes a bit funny. An example can be found on an actual sign found in a community bathroom: "Toilet out of order, please use floor below." The sign really means to use the restroom located on the next floor/story down - but is that what the sign *really* says? Thank you, Judy Endow, for calling this to my attention.

5. Autistic people accommodate more than the neuromajority. We neuromajority folk talk about all of the accommodations that we make for autistic people, and we are proud of this fact. We talk about it a lot: we've reduced the number of problems; we've posted a visual schedule; we've lowered the television volume. Aren't we great neuromajority people for

doing this? We never stop to think about how much autistic people accommodate us. The world is not built for the autistic neurology. From the moment autistics get out of bed in the morning to the time they go back to bed at night, they are continuously adjusting to us. They accommodate for (a) how we present information (verbally vs visually); (b) how much loudness and light is in the classroom; (c) how we use nonliteral words to explain ideas and situations; and (d) so many, numerous unanticipated changes. Think about it. People with a different neurology (that can make life challenging) accommodate for the neuromajority all of the time - and they seek no accolades. Autistic people simply do it!



What have autistic people taught me? To be a better human being.

6. Autistic people have limitless potential (thank you to Lee Stickle who first used this term with me). Most innovations have occurred as a result of people who think differently or because of people who have inspired others to think differently. Unfortunately, most autistic people have not been provided the support to reach this potential. Whose fault is this? We in the neuromajority must shoulder the burden for this. That is, if we teach and support autistic people the way they need and deserve ... if we structure the environment in a way that is consistent with the autistic neurology -- think of the accomplishments that the world would experience.

What have autistic people taught me? To be a better human being. ■

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1 The term "neuromajority" is used throughout this article instead of the often-used term "neurotypical" as, I believe, there is nothing typical about people known as neurotypicals. There just seems to be more of them - hence the term "neuromajority". Thanks to Judy Endow for sharing this wisdom with me.



The Autism Digest is pleased to introduce in this issue Brenda Smith Myles, Ph.D., who has contributed two incredible pieces. Dr. Myles is one of two of the most prolific productive applied researchers in ASD in the world. Her expanded biography is printed at the end of her second piece "Prediction and the Autistic Brain."



PREDICTION AND THE AUTISTIC BRAIN

By Brenda Smith Myles, PhD

Imagine not being able to predict what is going to happen next. What would do you do? Most likely you would:

- Cling to the activities and events that are familiar to you;
- Decide not to willingly try new ventures;
- Experience anxiety and/or behavior challenges when you are *merely introduced to the possibility* to participate in new events or activities;
- Protest, refuse, or meltdown when forced to engage in a new activity or event;
- Feel overwhelmed by the possibility to actually have to change.

The Neuromajority¹ and the Autistic Neurology

How important is prediction in daily life? Research suggests that even **before** activities and events occur, people know or can largely estimate what is likely to happen. This is known as “external prediction.” People also estimate their chance of success even before they attempt an activity or event, which is called “internal prediction.” The ability to predict guides us toward tasks and problems we are likely to solve, and it steers us away from those that might be too difficult.

Peter Vermeulen writes in his book, *Autism and the Predictive Brain: Absolute Thinking in a Relative World* (2023) contending that “prediction is neurologically based.” He explains that the way people experience the world comes from within. Brains sense in advance what they will see, hear, touch, smell, taste and feel. In fact, the brain actually can create a model of what is expected.

The autistic neurology, however, does not know how to predict (Vermeulen, 2023).

Autistic people experience challenges in knowing what will happen next. Often, they cannot anticipate how they are to react; and many do not have a sense

How do we make the world more predictable? We start by understanding the importance of prediction in the autistic neurology. Then, we provide supports that create predictability.

that they will be successful. Indeed, they generally anticipate the opposite: confusion and failure.

Sinha et al. (2014) shares this quote about prediction, equating it to magic:

An essential component of a magical phenomenon is the lack of a discernible cause: An event that we are unable to predict happens “as if by magic.” Given how well-honed our predictive abilities are, magicians have to resort to clever contrivances to achieve their mystifying effects. However, if our predictive abilities were somehow to be compromised, then even mundane occurrences in the environment might appear magical. Although a brief magical performance is enjoyable, unrelenting immersion in it can be overwhelming. A magical world suggests lack of control and impairs one’s ability to take preparatory actions. (p. 15220)

Indeed, an inability to predict means that the autistic individual cannot prepare for upcoming events and activities, so he might feel as if he has no control over their environment. In the above, substitute the word “terror” for “magical” and we might begin to understand why autistic people cling to sameness, do not like change, and consider surprises as negative. It explains why many autistics experience meltdowns.

Samples of Interventions that Support Predictability

How do we make the world more predictable? We start by understanding the importance of prediction in the autistic neurology. Then, we provide supports that create predictability. The following briefly describes some of

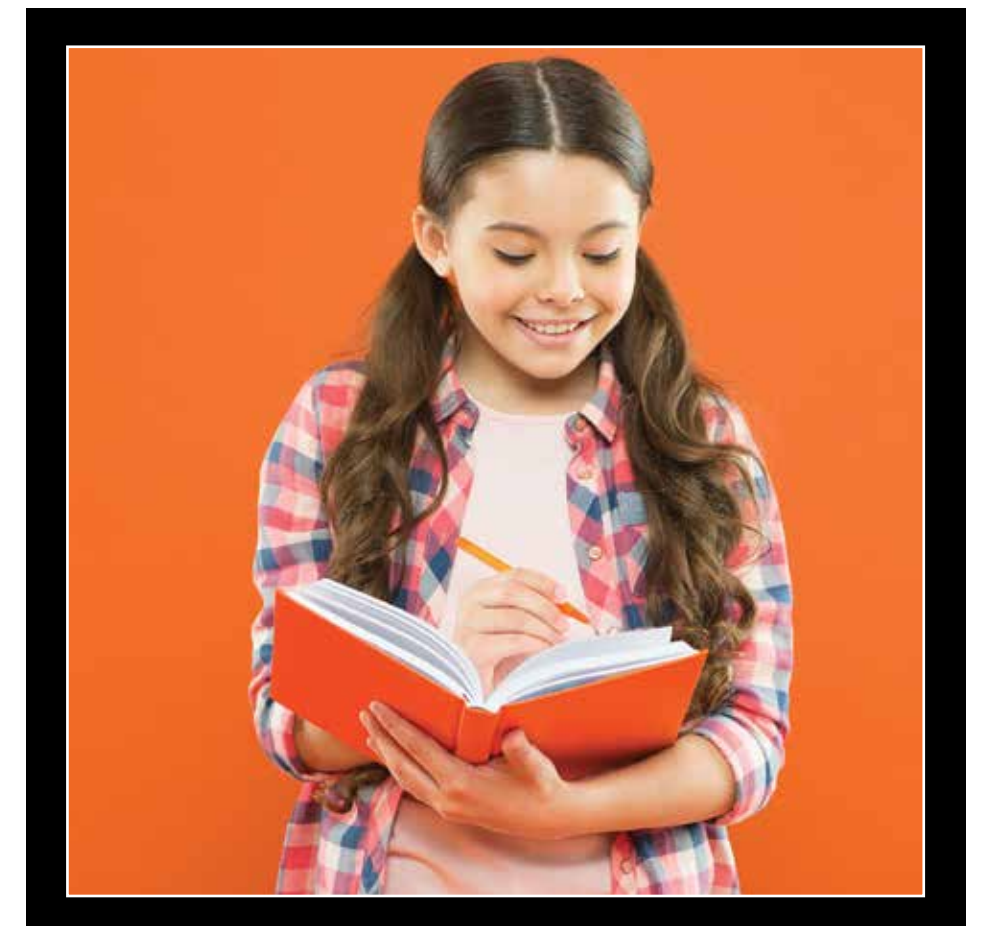
the supports that can make the world more predictable and how to teach predictability.

Visual Supports: The autistic brain learns and processes information best when it is visual. Hence, visual supports help create predictability in a manner that is consistent with the autistic neurology. Visual schedules, posted rules, routine cards, voice volume scale, problem solving charts, and visual boundaries’ markers each create predictability.

Priming: Priming is an intervention that introduces information or activities prior to their use. Almost every adult

primes themselves on a daily basis. Each time an individual looks at their planner, agenda or calendar the evening or morning before an activity, they are engaging in priming! Priming for autistic students includes reviewing the visual schedule as well as the actual materials that will be used in a lesson the day before or the morning before the activity. In some cases, priming may occur right before the activity, such as when a peer mentor overviews what will occur during the science experiment just prior to science class. It is most effective when it is built in as a part of the student’s routine.

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Priming should occur in an environment that is relaxing. The mood of the primer (the person doing the priming) should be patient and encouraging. The priming sessions should be short. Materials should merely be introduced; priming is *not* teaching, correcting, or testing. Priming is a relatively easy and time-efficient strategy that helps to create predictability while reducing stress and anxiety.

Social narratives: Social narratives are briefly written paragraphs that provide support and instruction for autistics by describing environments, social cues, the individual's perspective, and the actions of others; also, discussing potential responses to behavior, events and activities; while providing rationale and encouragement.

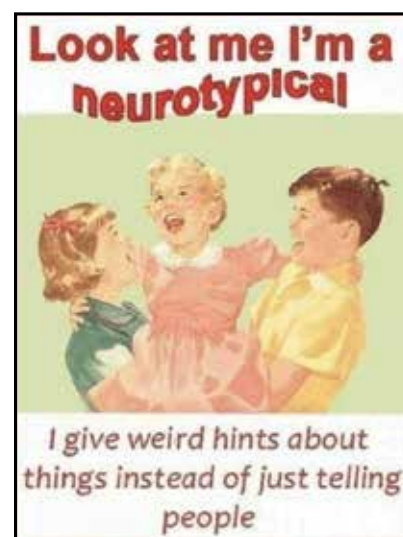
Written by educators or parents at the individual's instructional level, and often using pictures or photographs to confirm the content, social narratives can promote self-awareness, self-calming, and self-management as well

as predictability (Myles, Trautman, & Schelvan, 2013). Samples of social narratives include: (a) *Social Stories™* (Gray, 2016), (b) descriptive stories, (c) scripts, (d) the Power Card Strategy (Gagnon & Myles (2016), and (e) conversation starters.

Hidden curriculum: Every environment has a hidden curriculum – the unwritten rules, expectations, assumptions, the do's or don'ts that are not spelled out but that everyone somehow knows (LaVoie 1994; Myles, Endow, & Mayfield, 2013). The hidden curriculum includes idioms, metaphors, slang, multiple meaning words, nonliteral phrases, pleasing behaviors, whom to interact with and whom to stay away from, behaviors that attract negative or positive attention and more. Understanding the hidden curriculum can make a huge difference in the lives of autistic people: it can help create predictability, facilitate success, reduce anxiety, and help develop friendships.

Many words, phrases, rules, and

guidelines used by the neuromajority are tricky and sometimes seem nonsensical to autistics. The neuromajority are definitely not literal. For many autistic people, hidden curriculum items are problematic – their meaning is not clear, and the curriculum is not taught, because they are assumed or expected knowledge. The following figures provide a brief insight into the hidden curriculum and why it is difficult for autistic people to understand.



Direct instruction is required. Teaching one hidden curriculum item per day can be life-changing for many autistics. Teaching the hidden curriculum is strongest when context (Vermeulen, 2012) and prediction (Vermeulen, 2023) are included in instruction.

For example, when teaching the hidden curriculum item, state that “Acceptable slang that may be used with your peers (e.g., dawg, phat) may not be acceptable when interacting with adults.” Ask learners (a) where and when this item may be true or false (context) and (b) what would happen if slang were used with a principal, police officer, college admissions officer, or human resources officer conducting an interview (prediction).

Summary

The autistic neurology thrives on predictability; yet the autistic doesn't know how to create or identify predictability. In short, the world was not constructed to be compatible with the autistic brain. Thus, it is incumbent on the neuromajority¹ to facilitate the introduction of predictability into the lives of autistic people. This can be done in myriad ways, including (a) visual supports, (b) priming, (c) social narratives, and (d) the hidden curriculum. Using these methods and others can help autistics reach their limitless potential (Lee Stickle, *Personal Communication*, 2015). ■



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- ¹ The term “neuromajority” is used throughout this article instead of the often-used term “neurotypical” as, I believe, there is nothing typical about people known as neurotypicals. There just seems to be more of them – hence the term “neuromajority”. Thanks to Judy Endow for sharing this wisdom with me.
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Helping Millions of Children Rather Than Thousands

By
MacKenzie
Freeman



Mike Jones shows a child how to operate the Pumper Car

Inspiration from his unusual childhood has allowed Mike Jones to fulfill his dream of helping children. Although life events changed his plan from pursuing medical school to become a pediatrician, this inventor's work has been dedicated to improving the lives and health of kids around the country.

Jones' family lived in an outfit car next to a Utah railroad yard where his father worked for Union Pacific. It was from this box car-like home that he watched with fascination as the railway crews rolled by pushing

and pulling a metal bar attached to the short flatbed handcars. He noticed that the workers' pumping action easily moved the handcars along the rails. Those images of the crews transporting maintenance materials throughout the railroad yard stuck with him.

Years later when his son's ride-on toy was stolen, Jones went to the store to find a replacement. He wasn't impressed with what was available and thought to himself, "I can make something better." That's when he remembered the handcars' capabilities — their strength, speed, and ease of movement.

From that eureka moment, Jones didn't just create a replacement toy for his son. He developed what became a patented drive mechanism that has turned into an innovative line of human-propelled mobility products. Their award-winning design offers a unique way to get around that's fun while also providing exercise, physical therapy, and even rehabilitation.

The Pumper Car Original, Kinder, and the new Uniflex are all durable, low-to-the-ground, and easy-to-operate ride-on devices. Almost all children, even those who can't ride a bike, are able to cruise around independently on a Pumper Car within a few minutes or less.

These devices are safe, too. They meet or exceed U.S. safety standards. Each model features a hand brake, zero pinch points, non-slip handles, and a mechanism that prevents the unit from rolling backwards.

Unlike other ride-on devices, the Pumper Car line of products requires

riders to use their arms and legs. This works the upper and lower body simultaneously; plus, it does a lot more.

The Central District Autism Program in Wahiawa, Hawaii conducted a pilot project using the Pumper Car on stereotypical behaviors, academic response, and social interactions of children with autism. Data from that study indicated that the children who used the Pumper Car increased their academic engagement after riding the Pumper Car and decreased problem behaviors.

Parents and teachers have found that Pumper Cars are an equalizer, as well. They notice that able bodied and special needs children enjoy riding the cars side by side. Some schools purchase the devices for their PE programs to provide all students the opportunity to participate in the same activity.

Bruce Davey, an Adapted PE teacher in Modesto, California's Sylvan Union School District, has incorporated the Pumper Cars in his curriculum for several years. He says, "These devices provide the best form of exercise (rowing) in a fun and engaging way. I've seen students get on the Pumper Car, and, as soon as they pull on the handle and push with their legs, they get smiles on their faces."

Davey's students have a wide range of disabilities. He indicates that they use the Pumper Cars, "...to address their specific needs. Some of these students are working on improving their strength and mobility, while other students are addressing their sensory needs and or spatial awareness. Moreover, the Pumper Cars can be easily used to measure and demonstrate improved fitness and motor coordination."

He gives an example of one child who is autistic and has cerebral palsy. Davey explains, "This 7-year-old boy uses a walker to help him walk long distances and walks bent over. After just a short time using the Pumper Car, the boy's posture improved, and he was walking more upright."

Recently Davey and his class test drove the Uniflex, the newest member added to the Pumper Car family. They found that it rides faster than the other two models, and they appreciated the Uniflex's adjustable seat. Davey sees this model as a game-changer in his program because one unit can accommodate every student in his class, no matter their age or height.

When Jones was asked to sum up his thoughts about his products and goals, he replied, "I didn't become a pediatrician, but I know the Pumper Cars can help just about every child — particularly those with special needs — to get the exercise they need and the fun they deserve. So, rather than helping a few thousand children as a doctor, I hope to help millions."

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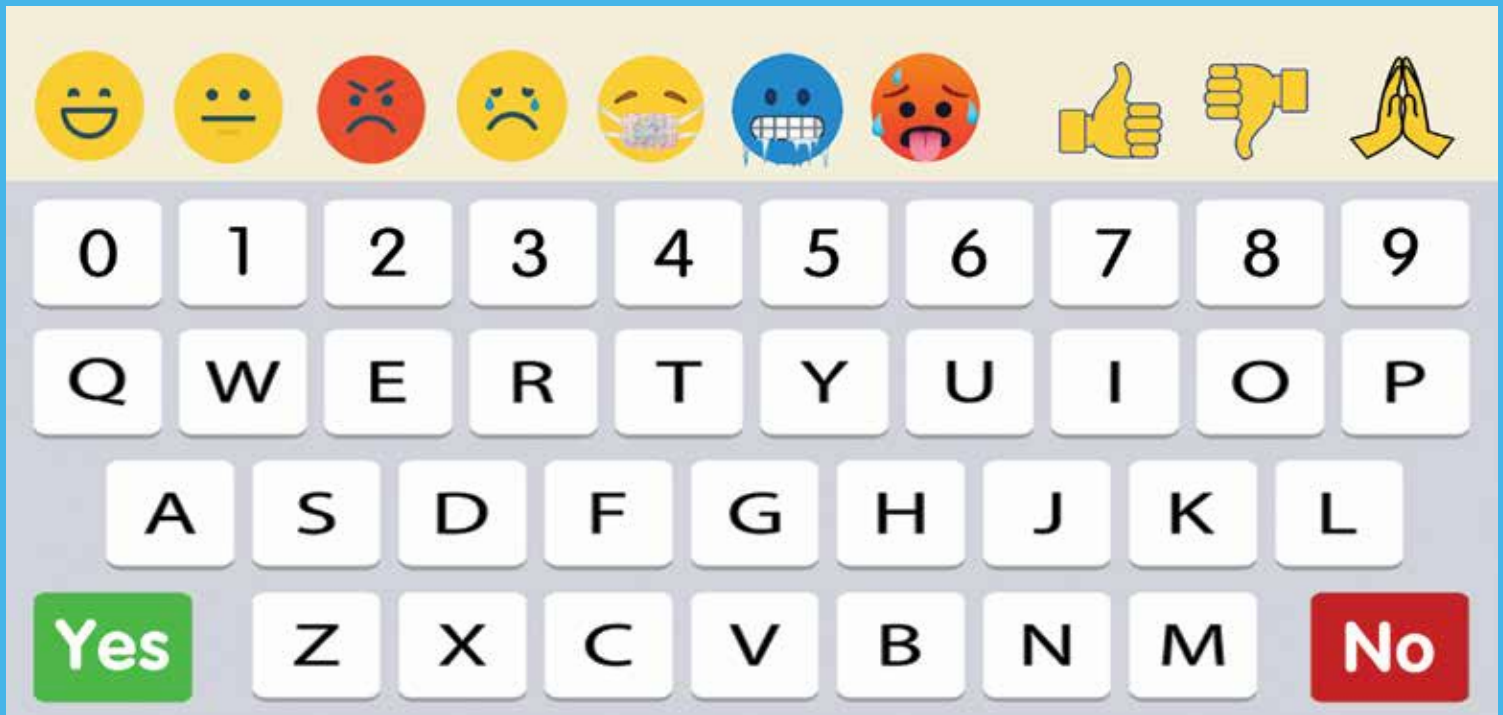
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