



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.

REFERENCE

Hughes MM, Shaw KA, DiRienzo M, Durkin MS, Esler A, Hall-Lande J, Wiggins L, Zahorodny W, Singer A, Maenner MJ. *The Prevalence and Characteristics of Children with Profound Autism*, 15 Sites, United States, 2000-2016. Public Health Rep. 2023 Apr 19;333549231163551. doi: 10.1177/00333549231163551. E-pub ahead of print. PMID: 37074176.