Steps Toward Inclusion for Those Without Words

By Vanessa Lista, SPT

Billy is lost in himself and unable to communicate with the world around him. His life first notably began to change when he was two. He could no longer verbalize his thoughts, socialize with other children, or tolerate sensory disturbances. Billy was then diagnosed with Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS). As his lifelong caregiver, I have witnessed the many challenges he has faced throughout his life. Due to Billy's inability to communicate, I always make sure he is heard and understood by being an advocate for him.

A Different Perspective

Growing up with Billy provided me with a different perspective of the world. Although I have no specific memory of learning what autism formally was, I do remember advocating for him from a young age. My friends, both current and from our childhood, have come to understand Billy's diagnosis and have become his supporters as well. They have learned how to include, understand, and communicate with him. Whether it was defending him on the playground from other children, being patient while he tried to ask for help, or helping him complete a task, they were always willing to care for and support him. Despite our education system's efforts to teach about individuals

living with disabilities, Diversity, Equity, and Inclusion (DEI)-related discussions fail to emphasize the importance of advocacy. If we, as caregivers, family, friends, or even strangers, don't advocate for individuals with communicative disorders, how else will they be heard?

Steps Toward Advocacy and Inclusion

1. AWARENESS

People living with disabilities can teach us much about kindness, empathy, respect, and patience. I truly believe that connecting with Billy, as well as receiving love from him—given in his own way—has greatly impacted the way those around him interact with others. Awareness and understanding of the barriers that come with these disabilities create a more accepting community overall, especially because not all disabilities are visible to the eye. If we were able to incorporate effective education about disabilities into early childhood, we might be able to promote and grow a culture of inclusion that will enhance the lives of us all. However, awareness is only the first step toward this goal.

NARRATIVE REFLECTION STEPS TPWARD INCLUSION

2. COMMUNICATION

Collectively, we can promote inclusion for all in our communities by learning ways to communicate with those with disabilities, placing emphasis on people-first language. Some ways of communicating with these individuals may include learning sign language, or how to use Picture Exchange Cards (PECS) that help these individuals communicate their requests or thoughts through images. This reminds us that people with disabilities are more than their diagnosis and should be respected for all of who they are.

3. HUMANITIES EDUCATION

Additionally, we can highlight the fact that individuals with disabilities are human beings who share similar interests with able-bodied individuals and thus should not be limited by their disability. Ideally, incorporating these practices regularly in early education will reduce any hesitation to approach individuals with disabilities and will encourage inclusion with their peers.

While early education about disabilities can teach children about inclusion on the playground, continued education into adulthood can help provide comfortable environments for individuals with disabilities in healthcare and in their communities.

Moreover, being around individuals with disabilities both clinically and non-clinically can improve the way medical professionals create their plans of care by considering the variety of obstacles that people with disabilities may face in accessing and utilizing health systems.

As a caregiver for someone who has a communicative disorder, transitioning into the medical field has taught me the importance of treating all patients without bias due to a disability, visible or not, and with compassion.

A foundation of respect creates motivation to prioritize improvements in patients' quality of life throughout their treatment. These principles should be carried out not only in our homes and within our professions, but in our communities to lead by example and promote inclusivity in all environments.

4. PROMOTION OF AUTONOMY

Through my previous work as an Applied Behavior Analyst (ABA) and caregiver, I have learned the value of patient autonomy. By placing focus on what the patient wants while keeping therapeutic goals in mind, the patient is more likely to engage with treatment interventions. Personally, I find patient autonomy in treatment to be of utmost importance as it reminds the patient that their opinions matter and that they are being heard. Although working on specific skills during treatment is important, it comes second to promoting quality of life and independence.

Additionally, creating a treatment plan that includes activities that are interesting to the patient can increase their participation and collaboration. This is especially true of individuals who may not be able to understand why they need therapy services. Approaching every case individually is beneficial to both the patient and the provider as it will create better patient outcomes and increase the quality of life for the individual receiving services.

Involvement Breeds Understanding

Billy inspired me to become a physical therapist and to be active in the autism community. With my background as a caregiver and ABA therapist, I provide a unique perspective within the physical therapy profession because of my intimate involvement with the autism community. Understanding disabilities is beneficial to a physical therapist as it provides a better perspective and an empathetic dimension to patient care.

Ultimately, as physical therapists, it is important to use our education to promote function, reduce pain, and improve quality of life by empowering patients with disabilities to do the things they love, all while feeling heard and respected.

About the Author/s



Vanessa Lista, SPT is from Schwenksville, Pennsylvania. She is enrolled as a second-year Physical Therapy student at Neumann University in Aston, Pennsylvania. She currently is a full-time caregiver and a former ABA therapist. Her goal is to incorporate her passion for kinesiology with her personal and professional experience in the special needs population. In her free time, she enjoys spending time outdoors with her dog Cora, volunteering for organizations such as the Special Olympics, and traveling with her partner Eric.