

## FEATURED ARTICLES

# Changing Perspectives on Autism: An Interview with Barry M. Prizant, Ph.D., CCC-SLP

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**TLAP:** Your bestselling book, *Uniquely Human: A Different Way of Seeing Autism*, is now published in 26 languages, was selected as the featured book on autism by the United Nations in 2017, and was ranked by Book Authority as #1 of the “100 best books on autism of all time.” Why has your book resonated so well with so many people around the world?

**PRIZANT:** First, I must say, it has been an incredible surprise, as well as joy to me, that so many have found the book helpful and relevant to their journeys. A very wide range of readers, or listeners of the audiobook, have let us know how *Uniquely Human* has positively impacted their families, has helped parents to see their kids or family members as whole human beings and complex individuals with many strengths and support needs. For some, they tell us it has deepened their understanding and acceptance of their own neurodivergence or autism, whether diagnosed or not yet diagnosed. Some have even shared that *Uniquely Human* has saved their lives as many stories I share are stories that provide a hopeful perspective. I’ve been told that the book is not simply about autism, or even “disability,” that it is about the human condition, and the challenges we all experience in life, and the hope that comes with trust and connection as we proceed on our unique journeys. In other words, readers apparently find that *Uniquely Human* touches upon so many universals of living in our complex world, regardless of your culture, ethnicity, race, family structure or neurotype. I am so grateful that so many have connected with *Uniquely Human* for so many different reasons.

**TLAP:** How has the understanding of autism changed over the past 30 years?

**PRIZANT:** I think the first major change is in the word “spectrum.” The whole category of autism has expanded in a number of ways. One of the reasons we are seeing so many late-diagnosed and self-diagnosed people is that there are many people who, either through their own masking, or just having a better ability to deal with some of the challenges of autism, will pass as not being autistic. We certainly see people who are more capable and whose language is much more sophisticated. Many people who are diagnosed on the spectrum and some self-diagnosed people live a fairly successful life with minimal support. In other cases, they are capable of making decisions about their support needs. I think that’s the first way that things have really changed: the spectrum is much broader, which in part explains why it seems that there are so many more autistic people.

Another way that it has changed is our understanding of autism in women. Traditionally it had been thought that the male



to female ratio was four or five to one. Now, many late-diagnosed and self-diagnosed people are women. I’m not aware of peer-reviewed research looking into this, but anecdotally, many people in the field are saying the ratio might be more like two to one, male to female, or even just one to one. That is another big change in terms of our understanding of autism.

As far as understanding the experience of autism, we have moved to seeing autism under this larger umbrella of neurodiversity and neurodivergence. It used to be thought that autism was a very distinct, separate category unto itself. Now there is much more discussion about the co-occurrence of autism and ADHD, bipolar disorder, anxiety disorders and other neurodevelopmental and mental health conditions.

The last thing I will say is that the self-advocate movement has dramatically changed our understanding of autism. For many years, Temple Grandin was the sole voice, and then Stephen Shore and John Elder Robison, and more and more people began to add their voices. Now it’s hundreds and thousands of autistic people across many cultures and countries writing books, giving lectures, really putting to rest a lot of the myths about autism. Our understanding has changed dramatically over the past 30 years because of the self-advocate movement.

**TLAP:** Where have you seen progress in how we understand and help individuals with autism?

**PRIZANT:** So much of what you are asking is a work in progress, and we are not where we want to be. But certainly, one of the issues is awareness. Last weekend I went to a show, “How to Dance in Ohio” on Broadway starring seven autistic people. It was an historical event. So progress has certainly been made in the visibility and awareness of autism but so much more is needed.

I think very significant progress has also been made because we no longer see autism as a tragedy, or as a condition that is going to result in a poor quality of life for the person with the diagnosis and for the family. We now understand with the right support and the right understanding of an individual, there is a much greater potential for a good quality of life now.

I’m also talking about autistic people who also might have intellectual disabilities. It is not just people who are more capable in terms of language proficiency, adaptive functioning, active problem-solving, and emotional regulation where we recognize this higher potential. I think we are really seeing the potential for improvement of quality of life for so many more people.

We need a much greater understanding of non-speakers. I think for too long it was thought that if a person is non-speak-

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ing, automatically they are considered significantly intellectually disabled. Or if a person has significant issues in staying well-regulated emotionally, resulting in what is called “challenging and problematic behaviors,” we do not just say, “Oh, that’s who that person is and will always be.”

With the right communication systems and the right support, many non-speaking people have demonstrated incredible abilities. It’s just amazing. We are talking about people who are high achieving individuals, such as Elizabeth Bonker, a valedictorian at her college and Hari Srinivasin, an award-winning cognitive neuroscience major at Vanderbilt. Likewise, Jordyn Zimmerman, who, up until her teen years, was thought of as severely intellectually disabled with massive “aggressive” problem behaviors. She now has a master’s degree in education and serves on national disability committees because she finally got the right support.

**TLAP:** As we look ahead, what are some concerns you have?

**PRIZANT:** I think the first concern is shared by many people, and that is the divisiveness in the world of autism. This divisiveness plays out in a lot of ways. One of the ways that has been most disturbing is the differences between parents who have children who are significantly challenged and need

significant levels of support, and who are very upset about self-advocates who speak about strengths and talk about how we can build quality of life. More specifically, there is a group of parents who say, “I don’t want those individuals who are very verbal, who could hold a job and live somewhat independently, to be the ones who describe autism to the public because that’s not my child, and that’s not what we experience 24/7.”

Another concern is commercialization, referred to in a recent book as the “autism industrial complex.” The unethical claims that are being made for financial gain, and that have been made for years, about the successes of some treatment models as opposed to others is just unbelievable. That commercialization and competition has led to business models where the basic goal is not to provide services and help people, but to make money. ▲

*Barry M. Prizant, Ph.D., CCC-SLP is the Director of Childhood Communication Services, maintains a private practice, and is an Adjunct Professor of Communicative Disorders at the University of Rhode Island. He has 50 years of experience as an international consultant and researcher. Barry’s recent book, Uniquely Human: A Different Way of Seeing Autism is a best-seller.*

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