



Function Junction: Behavior Matters November 2022 Research Recap

It's time to Embrace "Profound Autism" by **Alison Singer**
President, Autism Science Foundation

Last month there was an opinion piece in Spectrum News (one of our favorite sources for current research) that discusses the need for the term "profound autism" to be considered when diagnosing individuals, rather than autism spectrum disorder (ASD). The notion that more than 50% of people with autism fall into this category was one reason the author, Dr. Singer, believes this is necessary. Another reason is her and her family's personal journey having a daughter with profound autism. She wrote about her daughter and the many behaviors that cause her to have less favorable adult outcomes than those who receive much more attention in some circles, especially those with high functioning autism.

Dr. Singer talked about her daughter, Jodie, who has profound autism and the day-to-day challenges of life on the profound end of the autism spectrum, a reality that is largely invisible to mainstream society. Jodie is minimally verbal and suffers from painful self-injurious behaviors, intellectual disability, aggression, anxiety, sleeplessness, and seizures. Her frequent aggressive outbursts make it hard to involve her in community activities. Although she is often content and enjoys working on a farm, those who witness her pulling her own hair or headbutting the wall find it difficult to watch during those episodes. In addition, it is unpleasant understanding that she will require 24-hour care and supervision for the rest of her life.

Dr. Singer stated her conviction that we need to divide the diagnosis of "autism spectrum disorder" and add a new diagnosis of "profound autism" to better serve this vulnerable and underserved population. Families like Dr. Singer's have advocated for this distinction for quite some time, stating their belief that the

breadth of the autism spectrum has become unwieldy, and the phrase “autism spectrum disorder” has become such a “big tent” term that the people under that tent often have little in common with one another. Autism can mean genius or an IQ below 30. Autism can mean highly verbal or nonverbal. It can mean graduating from Harvard Law School or ‘exiting’ high school with a certificate of attendance. If we are going to be able to personalize our approach to care we need terminology and language that are specific and meaningful, rather than terminology that lumps everyone together. The neurodiversity community’s success at drawing attention to its issues has led many without deep experience with autism to conclude that those issues are representative of everyone. To the broader public, the word “autism” now only describes the more verbal, traditionally skilled, visible end of the spectrum — because people who meet those criteria are able to have a voice, attend conferences, represent themselves at policymaking meetings and appear in the media. The result is that autistic people with severe intellectual disability and the most challenging behaviors have become invisible and been left behind.

We found this article so interesting because we work with children who fall into this category often, and as the author stated their needs are much different and much more profound than autistic people seen in the mainstream. We are excited at the prospect of having Dr. Singer on the podcast!