

STRAIGHT TALK About *Autism*

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High- and Low-Functioning Autism *A False (Harmful?) Dichotomy*

In the autism culture, it is common to find references to functioning levels; hence, use of the terms *high functioning* and *low functioning*, or *more able* and *less able*. Although these terms are typically used qualitatively for the purpose of characterizing the range of abilities across different people, they have regrettably morphed into pseudo-diagnostic categories even though there are no formal diagnostic criteria to which they correspond. To be more specific, one of these terms, *HFA* (*high-functioning autism*) is often used as a categorical term in the treatment and research literature despite the fact that there is not a consistent and commonly-accepted definition.

Functioning-level qualifiers have been applied to subgroups, as well. For example, the term, *mild autism* has been used in reference to the current diagnostic subcategories of Asperger's Disorder and PDD-NOS (both of which are likely to go the way of the dinosaur if the proposed DSM V criteria hold up). The polar opposite of mild autism in ASD lingo is *severe autism*. Both of these terms suffer from the same lack of precision and unidimensionality as the high- low-functioning designations.

Even the sub-category of *Autistic Disorder* is sometimes used as if it refers to the most severe form of autism, likely due to the greater number of symptoms required for diagnosis in the current edition of the Diagnostic and Statistical Manual. Interestingly, Autistic Disorder is the diagnostic category that Temple Grandin believes best characterizes her form of autism—hardly a profile of severe limitations or low-functioning abilities! Ros Blackburn, another adult with a diagnosis of Autistic Disorder, has stated, “I am the lowest functioning high-functioning person with autism you're ever likely to meet.” Ros goes on to talk about how her high verbal and intellectual abilities mask many of her significant challenges, and further, that it is these challenges that have led to high levels of anxiety

and even panic reactions. Because of this, when she travels she does so with a companion. Furthermore, according to Ros, if she is pressured to engage in tasks that involve the execution of manual, sequenced fine motor movements, such as when using utensils for food preparation, her anxiety and dysregulation can escalate very quickly, negatively impacting her functional abilities. At such times, she may appear “low functioning” due to her level of stress and inability to carry out what may appear to be a simple task.

What Is Meant by the Terms *High* and *Low*?

In my experience, the abilities that result in the judgment of a person being characterized as high or low functioning are either cognitive abilities, verbal-linguistic abilities, or some combination of the two. While such abilities are correlated in development, the correlation is far from a perfect one. That is, one may have very low verbal abilities (especially in spoken language) with co-occurring high areas of cognitive skill. Or, one may appear to have relatively high levels of verbal abilities with significant cognitive challenges. These inconsistencies are often observed in ASD, as it is not uncommon for individuals to demonstrate uneven profiles of abilities. Moreover, some individuals experience additional challenges such as motor speech disorders that can limit the development of intelligible speech even though cognitive abilities are considerably higher.

It is beyond the scope of this discussion to address the complex issue of what falls under the category of intelligence; how intellectual abilities are measured; and how in Western culture we value two dimensions of intelligence disproportionately (i.e., linguistic intelligence and mathematical-logical intelligence), and place less value on other forms of intelligence such as spatial, musical, or bodily-kinesthetic intelligence,

as first elucidated in the seminal work on multiple intelligences by Howard Gardner in 1983. In general, academic success is determined primarily by linguistic and mathematical-logical intelligence, and as noted, these are the two dimensions that underlie impressions as to whether a person with ASD is characterized as high functioning or low functioning. The same can be said for the qualifiers severe and mild, although when these terms are used with persons with autism, two additional issues appear to be determinants of severity: 1) the degree of social interest/motivation and engagement, and 2) the presence of challenging or problematic behavior. Specifically, the more a person is socially engaged and demonstrates less problem behavior, the milder the autism is considered to be. Likewise, autism is considered to be more severe when there is less social engagement and higher degrees of challenging behavior.

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take into account the “whole child.” Parents of children described as high functioning are quick to point out that despite the presence of high-level abilities, their child continues

to experience major challenges that must be understood, rather than minimized or dismissed. These parents often express resentment about being told how “lucky” they are to have a high-functioning child, as such pronouncements are dismissive regarding the level of support their child requires and the challenges the family faces in obtaining those supports.

2. ASD impacts a person in multifaceted ways which vary greatly in specific symptomatology and severity from one person to the next. Areas that may be impacted include communication, language, sensory processing, motor, cognitive, and social-emotional abilities. How then is it possible to use unidimensional, dichotomous functioning-level terms such as *high* or *low* to accurately describe a person? A few brief examples will suffice:

- Thirty-month-old Eric is capable of doing puzzles at a level very few typically-developing four-year-olds are able to reach. However Eric does not yet speak and communicates primarily through gestures. Is Eric low or high functioning?
- Eight-year-old Amanda is fully included in school in her fourth grade class, and is doing grade-level work; however, she needs periodic support from an aide to help her transition successfully throughout the day. Without such support, she may become extremely anxious and bolt out of the classroom and even out of the school. Is Amanda low or high functioning?
- Fifteen-year-old José is not capable of speaking, but communicates with a speech-generating device. He is partially included in high school classes with a modified curriculum, but spends at least half of his day in special learning environments in the school. He loves to greet others and to stay with his friends on the playground, and he is an emotionally well-regulated, well-liked, and engaging young man. Is José low or high functioning?
- Thirty-five-year-old Thomas holds two advanced degrees, in mathematics and physics, from a nationally recognized university. Although he was the leading candidate for his new university position, he very quickly demonstrated extreme difficulties in managing the social

The Multifaceted Problems in Using Unidimensional Terms

From early in my career, and for reasons not always clear to me, hearing the terms high-functioning and low-functioning autism has been off-putting to me. Perhaps because I have been a career-long student of child and human development, I am fully aware of how overly simplistic such characterizations are; that is, people are complex and cannot be reduced to such simple stereotypes. The response of parents with whom I have worked has also contributed to my discomfort with such terminology, as many have responded with great sadness or even anger when these terms have been applied to their children. Over the years, I have observed how terribly inaccurate, misleading, and even disrespectful these terms have been when applied to many of the children and adults that I have known well. As a result, for most of my career, I have avoided using these terms in my publications, workshops, and presentations.

What follows are some of the reasons why I believe that use of the terms *high functioning* and *low functioning* is unwise:

1. I have an overarching concern that these terms are imprecise and, as such, may be misleading or potentially harmful. This happens at both ends of the low-high dichotomy. As noted, parents have legitimate concerns regarding the use of these terms. For example, when the term low functioning is used, many parents feel that it creates a limited, piecemeal view of their child’s abilities and potential that does not

requirements of teaching a class, and would often lecture while averting his gaze from the students seated in the class. His academic advisees expressed concerns that as an advisor, Thomas is not a good listener, does not help them to problem solve, and is inflexible. In less-structured social situations, Thomas demonstrates a high degree of social anxiety (pacing and only talking about his interests). Is Thomas low or high functioning?

3. Designations such as high functioning and low functioning tend to unfairly “cast in concrete” a person’s ability level. This is especially true when such labels are used early-on, since once applied, they tend to “stick.” However, it is widely known that children who appear less able at young ages often improve significantly over time. Furthermore, temporary states such as those involving high stress and/or challenging behavior can be characterized as “permanent” when a label is conferred. To summarize, when a person is identified as either high or low functioning, it can be construed as predictive of future behavior, with little consideration given either to the trajectory of development and how that might change over time, or to the positive effects of remediation on anxiety, challenging behavior, and other temporary states.
4. The terms high functioning and low functioning appear to put the onus on the individual with ASD. However, what may make individuals appear more or less able may have to do with the environments in which they live, attend school, or work; their interactions with other people; whether they are motivated to engage in particular activities; and whether the type and level of teaching needed and the necessary supports are in place.

Concluding Comments

I have yet to be convinced that use of the terms high functioning and low functioning play any useful role in our descriptions of people with autism, and in fact, as discussed in this article, such terminology can and does cause problems. I do believe that there are alternative ways, when necessary, to refer to ability levels of people with ASD.

One alternative approach is to refer to levels of support needed for a person to actively participate and learn. Individuals that are more challenged in general, or under certain circumstances, require greater support. Those who are less challenged need less support. This approach is also consistent with the notion that challenges can be overcome with appropriate levels of support.

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Another complementary approach is to refer to developmental levels that specify the range of a person’s abilities in a particular developmental domain. For example, in our educational model, The SCERTS Model (Prizant et al, 2006), we organize our curriculum according to three developmental levels: *Social Partner*, or person who communicates primarily through presymbolic means such as gestures and vocalizations; *Language Partner*, or one who communicates through early and less sophisticated symbolic means (speech, pictures, picture symbols, signs); and *Conversational Partner*, or one who communicates by combining symbols to express more complex meanings in interpersonal exchanges. We do not refer to functioning levels as low or high, but instead talk about abilities in social communication and emotional regulation from a developmental standpoint.

For all of the reasons discussed in this article, it is my hope that we can eliminate antiquated and misleading ways to refer to persons with ASD, given the great progress we continue to make toward more person-centered and respectful ways of supporting these individuals and their families. 🏡

BIO

Dr. Barry Prizant has more than 40 years experience as a clinical scholar, researcher and international consultant to children and adults with ASD and their families. He



is an Adjunct Professor, Brown University, and Director of Childhood Communication Services, a private practice. Barry is co-author of *The SCERTS Model: A comprehensive educational approach for children with ASD* (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006) and the assessment instruments, CSBS, and CSBS-DP (Wetherby & Prizant, 1993, 2002). He has published more than 100 articles and chapters and has presented more than 700 seminars and keynote addresses in the US and internationally. Barry developed and co-facilitates an annual weekend retreat for parents of children with ASD, and is the recipient of the 2005 Princeton University-Eden Foundation Career Award for “improving the quality of life for individuals with autism.” For further information, go to www.barryprizant.com, or contact Barry at Bprizant@gmail.com.