

STRAIGHT TALK

About **Autism**

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Respect Begins with Language

Part two of a two-part article

In part one of this article, I considered the impact that language has on our perceptions of individuals with ASD, with specific reference to the language of problem behavior. In part two, I will address other general categories of language in Autism Culture. I will then recommend steps that we can take to develop a more helpful and respectful language culture.

The Language of Uncooperative Behavior

At times, people with ASD may indicate a reluctance or lack of willingness to go along with “our agenda”. When this occurs, we make a value judgment and use the most common term in Autism Culture to refer to this reluctance: *noncompliance*. Some educational approaches even include *increasing* or *training compliance* or *reducing noncompliance* as major goal areas. There are significant problems with the use of the term *noncompliance*, especially when it is used broadly and cited as an “explanation” as to why the person is not cooperating.

A major problem with the term is the implication that if a person is noncompliant, he or she is simply “choosing” to be so, and that our job as practitioners and parents is simply to make him or her COMPLY! About 10 years ago, I recall going to a talk given by a major researcher/consultant who began by stating that autism is “resistance to learning,” and therefore, this resistance needs to be “broken” through “compliance training.” Such a belief system leads us down the slippery slope of issues related to control, often resulting in procedures to control people with ASD. This cultural value is reflected in terminology such as maintaining “instructional control;” bringing a child’s behavior under “stimulus control;”

or statements such as “We can’t let him/her have control.” However, people with ASD are complex individuals facing complex neurologically-based challenges, and such a reductionist approach is not only rarely helpful, but also contradictory to values such as *building self-determination*, *shared control*, and *increasing independence*, concepts that underlie the most contemporary, *quality-of-life-focused* approaches for persons with ASD and other disabilities. Furthermore, individuals with ASD tell us that they find approaches that focus on controlling them extremely disrespectful.

As with the term *noncompliance*, when the description of behavior is used as the explanation for the behavior, it gives us permission NOT to ask WHY the behavior is occurring.

Before considering WHY a person may be referred to as *noncompliant*, we need to acknowledge that once the term is used as an “explanation” regarding why a person resists or avoids, as in—*He’s just being noncompliant*—it gives us permission *not* to ask WHY a particular behavior may be occurring. Indeed, use of the term *noncompliant* clearly implies that this is an act of conscious choice on the part of the person with ASD. A similar popular term is that of, *escape-motivated behavior*, which results in goals that aim to “reduce escape-motivated behavior.” As with the term *noncompliance*, when the description of behavior is used as the explanation

for the behavior, it gives us permission NOT to ask WHY the behavior is occurring.

In fact, there are many reasons why a person may not comply, or attempts to escape from a situation or from demands. These may include confusion about what is being requested, or they may be related to sensory issues, fatigue, boredom, fear or anxiety, or arousal states that interfere with participation (e.g., hyper- or hypoarousal). Under these circumstances, a person may also be deemed *manipulative* in his or her presumed “willful” attempts to avoid activities, tasks, or demands that, in actuality, are stressful or painful due to the underlying, previously-cited factors that cause distress. Instead of labeling the person as *noncompliant*, we should try to understand the perspective of the person with ASD to determine the reasons behind the “uncooperative” behavior. This type of thinking enables us to make appropriate modifications or provide appropriate supports to ensure success. However, when we interpret so-called “noncompliant” or “manipulative” behavior as a “control” issue, we look no farther than the judgment conferred for explanations. For example, for those individuals who have a “low arousal” bias and, by definition, have less energy and are challenged with respect to remaining engaged and alert, if we view them as “lazy” or “stubborn” (two terms often encountered in Autism Culture), we will not understand the need to support a higher state of alertness by, for example, providing more movement opportunities or using motivating topics and activities to support engagement.

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Additional Terminology Reflective of Autism Culture

The term *self-stimulatory behavior* (or *self-stims*, for short) has an interesting history in Autism Culture. This term was used to refer to behaviors that appeared to be an attempt to increase sensory stimulation, sometimes used as an effort to “shut out” or reduce input from the social world. Initially, self-stimulatory behavior was thought of as volitional, undesirable, problematic, and definitive of being “autistic.” Research in the 1960s and 1970s centered on extinguishing or eliminating self-stims. In fact, many checklists of autistic behavior were largely “populated” by self-stims such as rocking, flapping, finger-flicking, spinning, and so forth. Circular reasoning prevailed: “Why does he stim? Because he has autism.” and

then, “Why is she diagnosed with autism? Because she stims.” The reasoning that followed was that if such behavior could be eliminated, we would be directly reducing the autism, because such behavior was, in part, definitive of autism. Although some practitioners still retain this belief, the field is clearly shifting to an understanding that behavior referred to as self-stimulatory may serve different purposes, not the least of which is the person’s attempt to self-regulate or cope by using sensory-motor means to increase or shut out stimulation, or to engage in activity that calms the neurological system. Such understanding has come from recent research, as well as from first-person accounts from people with ASD. As an aside, we all “self-stim,” but we hide it better or find more conventional/acceptable ways to engage in it (e.g., twirl fingers in our hair, tap our feet lightly, squeeze our hands, stroke our faces, and so forth).

Another Autism Culture word we use to refer to individuals with ASD is that of *obsessive*. This stems from their tendency to be highly focused on particular topics or areas of interest, often referred to as *obsessive interests*. To be clear, I am not referring to extreme patterns of obsessive—compulsive behavior known as *obsessive-compulsive disorder* that involves non-adaptive patterns of behavior that may interfere significantly with activities of daily living. When the term *obsessive* is used to describe an individual, it is most often used with a negative connotation suggesting that “obsessions” need to be reduced or eliminated. Another related term is *perseverative*, used when an individual does the same thing over and over

again. For example, children may love to play with Thomas the Tank Engine trains for hours on end, and older individuals may become preoccupied with game shows on TV, historical facts, or other topics or activities. Thankfully, there has been some progress in moving away from this unidimensional and judgmental description of behavior. Some individuals with ASD now ask us to use the term *deep interests* rather than *obsessions* to describe behavior in more neutral terms.

A few years ago, I heard Clara Claiborne Park, one of the parent pioneers in the field of autism, speak at a conference. She was asked about her daughter’s (Jessy Park) obsessions. Her response was to the point: “Obsessions? We’ve always thought of them as enthusiasms.” She went on to explain

that whenever possible, Jessy's "obsessions" were used to support her social and artistic growth, and partially due to this attitude, Jessy is now a renowned artist, who happens to have autism.

Toward a More Respectful Language Culture

If it is true that the language we use shapes our attitudes and beliefs, underlies our actions, and communicates information to the general public about people with ASD, we should not take this issue lightly. The following are some suggestions to help practitioners and parents reflect on the language we use, and when necessary, make appropriate modifications.

- 1. Be aware of, and minimize use of terms that have become clichés, and are no longer precise or descriptive.** As noted, terms such as *self-stims*, *non-compliant behavior*, and aggressive behavior have been used so broadly and generally, that they have lost usefulness, and are often stigmatizing.
- 2. When terms are used to describe behavior that is considered problematic or challenging, try to recast the discussion in terms of the experience of the person with ASD.** This may require that we make an educated guess as to what the person is feeling or experiencing, but taking the perspective of the person with ASD can lead to more respectful and compassionate action.
- 3. Whenever possible, use terms that would be used to describe the experience of any person or child (with or without disabilities).** The goal here is to look through the window of human experience, rather than have the diagnosis of ASD limit our perceptions.
- 4. Be aware of the impact that language has on those less familiar with people with ASD, and how it shapes their perceptions in a manner that either increases understanding and compassion, or judges and stigmatizes the individual with ASD.**
- 5. Respectfully challenge the use of imprecise or disrespectful language that others use.** Use phrases such as, "*I prefer to refer to this as...*," or, "*To me, James appears anxious or afraid.*" At times, it may be necessary to be more direct by saying, "*I find the use of this term to be unhelpful – can we discuss this?*"
- 6. Ask parents about terminology that they use, or their comfort level with terms that are being used by others.** Parents often are most offended by disrespectful language,

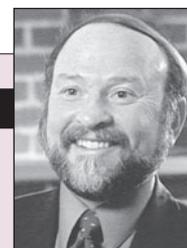
and trusting relationships depend, in part, on a shared-language, respectful culture.

- 7. For agencies or schools supporting people with ASD, develop a glossary of terms, with brief definitions, that supports a positive language culture.** Identify terms that are considered to be unhelpful and unacceptable for professional use within the school or agency, and in discussions with parents.
- 8. Whenever possible and appropriate, ask individuals with ASD about terms that are being used, and their feelings about such language.**

Conclusion

Our understanding of autism is evolving rapidly. Practitioners and parents are coming to have a greater understanding of patterns of behavior and why they occur. Notwithstanding, the language of Autism Culture remains highly judgmental, and in some cases, disrespectful of individuals with ASD. Awareness of this issue is increasing, and we have made some progress; however, it is time to put greater conscious effort into effecting change, and to sever old patterns. We can do this by reflecting on the language we use with our colleagues and with parents, so that we can begin to eliminate judgmental and less-than-respectful language. In this way, we may keep pace with the great innovations that are occurring in the research and science of ASD by creating a more respectful language of Autism Culture. 

BIO



Dr. Barry Prizant is the Director of Childhood Communication Services and an adjunct professor in the Center for the Study of Human Development, Brown University. Barry has more than 35 years of experience as a researcher and international consultant to children and adults with ASD. He has published more than 90 articles and chapters on childhood communication disorders and has given more than 500 seminars and workshops at national and international conferences. He also serves on the Editorial Boards of six scholarly journals. Barry is a co-author of the SCERTS Model (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006—www.SCERTS.com). In 2005, Barry received the Princeton University-Eden Foundation Career Award "for improving the quality of life for individuals with autism". For further information about Barry's work, go to www.barryprizant.com, or contact Barry at Bprizant@aol.com.