STRAIGHT TALK
About **Autism**

Barry M. Prizant, Ph.D., CCC-SLP

Respect Begins with Language

Part one of a two-part article

My interest in language first began with the study of foreign languages and then evolved into an interest in normal and atypical language development. At this time, I also began to work as a counselor in summer camps for children and adults with disabilities. It was there that I became acutely sensitive to the "language culture" of autism / disabilities, a sensitivity that deepened as I became immersed in the study of both typical and atypical communication and language development—particularly in relationship to individuals with autism—in college and later in my Ph.D. program.

In part one of this two-part article, I will address the issue of what I have come to call the "Language of Autism Culture" by critically considering the language we use when referring to significantly challenging or problematic behavior. In part two of this article, to be published in the Fall 2010 issue of *ASQ,* I will address the language of behavior that is considered uncooperative, as well as the miscellaneous terminology that refers to other characteristics of people with ASD and to their family members, as well. I will then recommend actions that we need to take to make the language culture of ASD one that is descriptive rather than judgmental, helpful, and ultimately more respectful.

The Psycholinguistics Revolution

In 1970 my interest in language took me to an exciting new field that merged the study of language development with cognitive psychology, the study of thought, memory, and information processing. Developmental psycholinguistics emerged in the late 1960s in response to non-developmental behavioral accounts of language development espoused by B. F. Skinner, the American behavioral psychologist best known

for his animal conditioning research, followed by attempts to apply his theories of learning to human verbal behavior. In short order, a decade of research in psycholinguistics refuted and dismantled Skinner's theory of verbal behavior by demonstrating that language learning and development could not be explained by processes of operant conditioning, and that language and thought were inextricably related. I was fortunate enough to have been immersed in this true revolution in American psychology.

A subsequent explosion of research in developmental psycholinguistics helped to document stages of language development in children, and their relationship to cognitive development. Continuing research revealed the complex relationships among social, language, communication, and emotional development in children, both with and without disabilities. This line of inquiry continues to have a major impact on our understanding of ASD, since difficulties in joint attention, theory of mind, and social thinking are all grounded in the psycholinguistics revolution of the 1960s and 1970s. Another major contribution of psycholinguistics—and one that is very much at the heart of this article— is its explanation of how language shapes our thoughts and perceptions, and vice-versa.

Language Use in Autism Culture

When I began my initial research on echolalia for my Ph.D. dissertation in the early 1970s, I was exposed to definitions of immediate and delayed echolalia that included terminology such as *psychotic speech*, *meaningless parroting*, and *verbal aggression*, each of which conveyed a not-so-subtle negative attitude toward echoic speech. These attitudes, based upon unexamined

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assumptions about echolalia, gave way to intervention efforts aimed at extinguishing echolalia through behavioral procedures such as mild physical punishment and verbal reprimands (e.g., "No silly talk" or "Don't echo!"). My Ph.D. dissertation was an effort to explore the credibility of such attitudes and assumptions about echolalia. It involved a year-long videotaped longitudinal study of four children who used echolalia. The results of this research refuted these beliefs and assumptions by demonstrating that immediate echolalia was most often not only used functionally by these children, but also served as a strategy that supported, rather than interfered with language development. In addition, I found similar patterns of functional use for delayed echolalia, even finding documentation of the same processes—referred to as a *gestalt pattern of language acquisition*—in some typically developing children.

Negative terms used to describe echolalia are but one example of how the language of autism culture has developed or borrowed terms that have become part of the vernacular. While some of these terms are descriptive and benign, others are judgmental, disrespectful, and even harmful. Terms such as *non-compliance, extinguish, self-stims, manipulative,* and *aggressive,* are now a part of the "autism dialect". This trend in language use became so striking, that in 1983, I referred to it as the "deficit checklist approach" to understanding autism. Even with the progress we have made in understanding ASD, this judgmental and negatively-toned use of language continues. What is more disturbing is that practitioners and parents rarely acknowledge the impact that such language has on our perceptions, values, and indeed, on our behavior. Interestingly, we rarely, if ever, use these terms in reference to children who do not have a label of ASD!

The language of autism culture has also impacted public perceptions as conveyed through the media, as well as colored everyday casual discussions among those who know little about people with ASD. For example, the classic phrase *child in his own world* has perpetuated the inaccurate perception that individuals with ASD have no interest in connecting with others.

The need to scrutinize our use of language is not simply an issue of being politically correct (PC). It is also about our need to become more self-aware of how the use of vague, poorly defined, and judgmental language affects our attitudes and behavior. For example, a very recent and ongoing debate in the mainstream media concerns use of the "R" word as a derogatory label in contemporary culture; that is, referring to a person as *retarded* as an attempt to be condescending or put him or her down. Such terms reveal the user's perceptions of people with disabilities as lesser beings than people without intellectual disabilities.

Thankfully, over the past one or two decades, there has been slow improvement in addressing the language we use. For example, "people first language" (e.g., child with autism vs. autistic child) has become the preferred syntax when speaking about individuals with disabilities, and is now even required in some professional journals. To be clear, I am not a zealot about "people first language", and see it as a personal choice; however, I have chosen to use this style in my consulting and workshops as a means of demonstrating respect for individuals with disabilities.

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The Language of "Challenging" or "Problem" Behavior

Let's consider some examples of language used in reference to so-called *challenging* or *problem* behavior. These terms were introduced as an admirable effort to be less judgmental of people with ASD and other disabilities and have come to replace old ways of referring to behavior as bad, as if all of such behavior is willful or intentionally directed towards others. That said, even use of the seemingly innocuous terms "challenging" or "problem" suggests a degree of fault on the part of the child. A much more appropriate and neutral way to describe the behavior would be to refer to the state of emotional dysregulation underlying the behavior. When a person is well-regulated emotionally, he or she is most available for learning and engaging with others, and has better control of his or her behavior. In contrast, the term "dysregulation" indicates that a person is in less control of his or her behavior and is less available for learning and engaging, along a continuum of mild to extreme dysregulation. Sources of dysregulation are many and varied, and may include physical discomfort or illness, communication and sensory challenges, fear, anxiety, confusion, inappropriate academic demands, sleep disorders, the behavior of others, and so forth. Describing behavior in reference to regulation and dysregulation is not only consistent with research into the typical causes of problem behavior, but is also far less judgmental than those terms that suggest volition on the part of the child.

For example, to whom is the behavior challenging or problematic? Most typically, these terms are used in reference to behavior that is judged to be problematic or challenging to other people who are with an individual with ASD. Aren't we as partners demonstrating limited perspective-taking (an attribution often directed toward people with ASD) when we don't consider the experience of the person that may be causing the behavior? I am not aware of any person who chooses to become, or enjoys being dysregulated emotionally!

Some of the more judgmental and emotionally arousing descriptors used when referring to behavior caused by dysregulation include *aggressive, negative, self-destructive,* or *violent.*

Such terms imply that the behavior is intentional, in the sense that the individual is making a choice to behave in a particular manner. Worse yet, these characterizations of behavior often become part of the student's permanent record. When this occurs, the student's "bad reputation" precedes him or her, coloring the judgment of teachers and clinicians before they even meet the student, and setting up a likely domino effect. Specifically, the language used in school records shapes perceptions and creates an expectation for negative behavior, which in turn influences the way in which school personnel interact with the student, and may even influence placement decisions. I often speak to school personnel who have read students' records before meeting them, who are not only surprised to learn that the person they later meet is very different than the records indicate, but also that his or her dysregulated behavior is more accurately described as reactive rather than intentional.

The word *aggressive* is emblematic of the problem of language use. Specifically, I have observed the term *aggressive* used both to describe individuals whose behavior is *intentional*, and to describe those whose behavior is *unintentional*. In the latter case, the individual may have become disruptive when dysregulated. In recent school consulting, I tracked instances in which the term *aggressive* was used to describe an individual when it was claimed that the person intentionally struck out at other people or attempted to harm them. Over a number of months, I observed numerous episodes of physical contact by individuals with ASD described as instances of aggression; however, more than 80% of the time I also observed that such instances followed physical contact that had been initiated by others, often well-intentioned teachers, therapists, or parents. An unexpected pat on the back or hand on the arm or shoulder to render support to the student, may be off-putting to individuals with ASD, especially for a person with tactile defensiveness (hypersensitivity to touch). Such physical contact may provoke an impulsive physical response that is interpreted as an unprovoked gesture intended to produce harm. When dysregulation and unintentional physical responses occur as reactions to such environmental events, responding to them as intentional aggressive acts does a disservice to the individual with autism.

Numerous examples of physically directed behavior resulting from dysregulation are commonly observed. In addition to unexpected physical contact, an individual may physically direct behavior towards others as a communicative act of protest or refusal when previous more acceptable acts of protest or refusal were not honored, or as an involuntary motor act when a person

is moving into a state of extreme dysregulation, such as flailing arms and legs and lunging or bolting during a "fight or flight" reaction. If the behavior is addressed from the point of *intention*, then none of these behaviors would quality as aggressive because they were not *intended* to harm another person. The problem is, of course, that the emotional loading of the term *aggressive* creates a circumstance in which partners become apprehensive or even fearful of such behavior, causing them to focus on the behavior itself rather than on the precipitants or triggers that cause it. A focus on the causes of dysregulation underlying the behavior would enable partners to look for ways to prevent or react to it in a more helpful way; while a focus on the behavior itself causes the partner to "blame" the individual with ASD for exhibiting behavior that is more related to his or her neurologically-based disability and underlying emotional dysregulation than any intention to harm others.

In summary, the language we use in referring to individuals with autism has a great impact on our perceptions; the perceptions of the public at-large; and the portrayals of individuals with ASD in the media. It is hoped that by scrutinizing the language we use in reference to the emotionally-loaded topic of problematic or challenging behavior, we may put a "nail" in the "coffin" of language that is too often disrespectful and indeed, inaccurate,

when referring to people with autism and their families. This is particularly important, since the language we use also influences our actions. In part two, I will consider other uses of language and will make recommendations towards the development of a less stigmatizing and more helpful culture of language use in ASD.

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**.