STRAIGHT TALK
About Autism

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

The Primacy of Trust

Part one of a two-part article

In recent years, the issue of *trust* has emerged as a significant personal theme in my understanding and supporting children and older individuals with ASD. Sometimes, its significance reveals itself in subtle ways, while at other times and under different circumstances, the importance of trust surfaces in a bold and dramatic manner that cannot be overlooked. The primacy of trust in parent-professional relationships served as the basic premise of my August, 2008 *ASQ* "Straight Talk" column. My interest in the subject gradually evolved over the course of numerous school consultations in which I observed the damage caused by mistrust in parent-professional relationships. In that article, I argued that when there is a foundation of trust, parents and professionals can work collaboratively even through difficult and potentially contentious situations. Without the foundation of trust, however, true collaboration does not occur and, under such conditions, things can go terribly wrong, resulting in significant stress for both parents and professionals. In this article I examine an expanded view of trust and its profound implications not only for individuals with autism and their ability to cope in a confusing world, but also for informing professional practice.

Recently, in my consulting practice, I have been profoundly struck by the importance of trust as a key element in developing positive relationships with people with ASD of all abilities and ages. It was when I began to reflect on my own relationships with persons with ASD, as well as view other teaching and therapeutic relationships through the "window of trust", that the issue took on greater primacy as a critical factor in quality of life enhancement and how that relates to our interaction patterns and intervention practices.

In any one week these days, I spend most of my time in classrooms with students with ASD, and the staff who support their development. As a part of these consultations, parents often join the team to discuss how their child is doing; the necessary supports that need to be in place to insure continued progress; or the need to develop new strategies to address challenges that arise. As part of this process, I now consciously attempt to observe everyday encounters and teaching interactions between staff and students through the window of trust. That is, are we as professionals, caregivers, and parents trust*worthy*—worthy of trust by those whom we serve? In attempting to answer this question, I often find myself asking: What are the practices that result in trustworthiness, and ultimately, trusting relationships?

The Primacy and Significance of Trust

It must be an enormous task for individuals with ASD to develop trust in people, in everyday activities, and in living environments, given the everyday challenges that they face. For example, the importance of trust from the point of view of the person with ASD was driven home to me recently. Just the other day, a middle school student whom I was meeting for the first time shared with me his honest and frankly-stated feelings about school. As part of a school consultation, I was asked to observe him in his middle school because he was reportedly having greater difficulty in school and at home, becoming more disengaged and "shut down". With his permission following the observation, we met in a private room for a discussion. After I explained why I was visiting, he told me that he felt sleepy all the time, and very sad. I asked him why he felt sad, and he said the subjects at school, except for science, focused

on his weaknesses, and not on what he was good at or interested in. When I asked him if there was anybody he could trust at school, he quickly responded, "not a chance". He then added somberly that he felt that other kids hated him, but that there was one he could trust who was nice to him and would never pick on him. I then asked, "What does it take for you to trust someone?, to which he replied, "Trust takes a year of knowing someone and at least four visits over my house, or a combination of four visits at my house and the other person's house". Clearly, familiarity and shared positive experiences were essential for this young man to have a sense of trust in others. I then asked him why trust was important to him. He responded, "Trust is important because you could tell other people about your problems and you do not have to be on your guard all the time."

This recent experience, and many others, have convinced me that as with parent-professional relationships, a trusting relationship between a person with ASD and his or her partners in school, and indeed in life, may be the most significant factor for successful coping in a world that may be perceived as confusing and overwhelming. Trusting relationships may ultimately contribute to tremendous progress and growth in the face of the inevitable challenges of having an ASD. This belief has also been validated by persons with ASD, whom I have shared time with and learned from in recent years.

Learning about Trust from People with ASD

Over the past year, I have had the wonderful opportunity to get to know Michael John Carley, a unique and gifted individual with Asperger's syndrome, and the father of a young boy with AS. Michael is the founder and Executive Director of GRASP, the premiere international organization focusing on advocacy and support for adolescents and adults on the autism spectrum, and the author of *Asperger's Syndrome: From the Inside Out*. Michael reflects on and talks about trust from different perspectives, and our discussions and his writings have informed me and resonated with my recent "obsession" with trust from the perspective of a person with ASD who is also a parent. What I have learned from Michael has validated many of

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my assumptions that have emerged from my own personal experiences.

In an, as yet, unpublished manuscript Michael shared with me, he made a statement that, for me, was "earth-moving". In referring to the range of experience of people with ASD, Michael stated:

(Some people with ASD)… are without families, without jobs, without services, without homes, without cognitive understanding of why their sensory assaults are painful, why their stomachs hurt, or why someone they trusted is restraining them … I recently came to the conclusion that the opposite of anxiety isn't calm, it's trust: The ability to ward off the feelings of impending misfortune, betrayal, or personal slight, and believe that everything really will be OK. Too often for so many others, that sense of being unheard and misunderstood—that very well-informed track record of non-spectrum people getting you wrong—leaves the option of trust at a relative distance … determined more, to our surprise, by the lives people have lived, rather than where they fall on the spectrum.*

*Carley, M.J. *Cures, Vaccines, Research, and the Promise of Alarmist Rhetoric: Autism Politics 101*. Unpublished Manuscript

Michael's insight clearly places much of the burden of enhancing trust on "non-spectrum" people, as we are so responsible for shaping the lives lived for most persons on the spectrum.

In an interview on "60 Minutes", Daniel Tammet, another person with ASD, and author of *Born on a Blue Day*, was asked why he was so "obsessed" with numbers and letters when he was a young boy. He explained that numbers and letters were always reliable friends and could be depended on and trusted, whereas people were hard to makes sense of and changed all the time. In discussing his childhood in *Born on a Blue Day*, Tammet described how as a child, he sought out settings and became immersed in activities that helped him to stay well-regulated emotionally, and avoided those that caused dysregulation, because many people and settings were not predictable on a sensory or social basis.

Some will say that these are the musings of only "high-functioning" persons with ASD who cannot speak for the full range of people on the spectrum; however, a case could easily be made that more challenged people with ASD are at equal, or even greater risk for having "trust challenges" due to more significant problems in communication, social understanding, and/or sensory processing. A focus on trust may even help us reframe a basic core symptom of ASD. In 1943, Leo Kanner cited *insistence on preservation of sameness* as an essential criterion for diagnosing ASD. Couldn't this "characteristic", as well as the more recent DSM IV-TR criterion of *restricted repetitive and stereotyped patterns of behavior, interests, and activities* be understood as coping strategies, and as attempts by people with ASD to make the world more reliable and trustworthy? I do believe so!

Why Are People with ASD at Risk for Not Developing Trust ?

As noted above, many of the common challenges associated with ASD may contribute to a lack of trust in people as well as in everyday activities and experiences. Sensory sensitivities and intrusions may result in a state of hypercaution and hypervigilance as protective mechanisms. Difficulty reading other people's intentions and nonverbal behavior, and problems interpreting non-literal use of language such as sarcasm and cynicism may also be barriers to trust. How is it possible to feel comfortable and safe in a world that is so unpredictable and ever-changing, especially if your neurological "hard-wiring" leads to a bias in interpreting information and sensory experiences more in blacks and whites than in shades of gray? And, as noted by Michael, how can one trust others if he or she does not feel "heard" and therefore not validated and respected by others?

Even the simple inconsistencies in life may pose a great challenge. Recently, I visited an 11-year-old for whom I have consulted on a quarterly basis over a number of years. The first school visit typically occurred in early October; however, due to scheduling problems, I was not able to visit until November of this past school year. After noticing the student's increased reticence and anxiety during the first hour of my November visit, I asked him how he felt about

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my visiting him. He immediately blurted out, "Why are you first coming in November this year when you always have come in October?!" To him, I clearly appeared to be undependable, and yet I was unaware that he was so concerned about which months I visited.

Conclusion

In this discussion, I have argued that the development of trust in people and in the world is a major challenge for most people with ASD. Furthermore, this difficulty may provide insight into some of the frequently-cited characteristics of people with ASD. Under this basic premise, parents and practitioners must accept the obligation to consciously engage in efforts to support trusting relationships, and engender trust in the world for people with ASD. In part two of this article, which will appear in the November issue of *ASQ*, I will explore strategies and approaches to fulfill this obligation.

Author's Note: My heartfelt thanks to Michael John Carley, a person who fosters an ever-deepening sense of trust with each of our encounters. And as always, my sincere gratitude to all the people with ASD and their families from whom I learn so much each week.

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**.

STRAIGHT TALK
About Autism

Barry M. Prizant, Ph.D., CCC-SLP
and Michael John Carley

The Primacy of Trust

Part two of a two-part article

First author's note: For part two of this article, I am grateful and honored that Michael John Carley has agreed to contribute as a co-author in addressing this crucial issue. As noted in part one, Michael's writings and ideas about the importance of developing trust with persons with ASD are insightful and thought-provoking, and were a major factor in my decision to focus on this topic for my "Straight Talk" column. Furthermore, who is better qualified to address this issue than someone who has "lived" the experience, and can reflect on it eloquently from a variety of perspectives: as a person with Asperger syndrome (AS); a father who has a son with AS; and a dedicated professional who has devoted his life's work to supporting others on the autism spectrum.

– **Barry M. Prizant**

Part one of this article addressed many of the challenges faced by persons with ASD in developing trusting relationships with other people within everyday activities and environments in which they live, go to school, and work. In this article we consider positive steps that can be taken to facilitate the development of trust. We begin with one overriding truth that will make this process easier: *In order to develop trust, it is the partner without ASD who not only must first accept the obligation to change, but also must make the greatest effort toward developing trust.* The person with ASD will change most certainly *after* trust has been earned – anxiety lessened, and acceptance appreciated—but the greatest burden for change that will result in trust lies with partners without ASD.

This notion may seem confusing, harsh, or even unfair to those caregivers, educators, and clinicians who view relationship problems as resting primarily or solely within the person with ASD, even though these individuals may be kind, experienced, and/or well-intentioned. Partners may subconsciously think: "Shouldn't my good intentions; my willingness to do anything for this person; and/or my hard work and expertise automatically earn me his or her trust?" The answer to this question is no, because to act solely on this instinct is to both ignore and invalidate – albeit unintentionally – the struggles that individuals with ASD have in developing trust in a world that is not always understanding of their needs.

Consider that the life of an individual with ASD, at the very least, is marred by varying amounts of misunderstandings and breakdowns in communication, and at worst, repeated confusing and challenging experiences that may result in chronic stress. The cumulative incidents in which the individual's intentions were either not understood, or worse, interpreted negatively, may have serious consequences over the long term. With a history of difficulties in communication, and for some persons, stressful or even traumatic emotional memories of being ignored, misunderstood or even invalidated as a person, the casualty is trust; trust that other people "get" them and respect them, and trust that the world is a safe place. And the more misunderstanding and stress there is over the years, the less an individual has faith in other people and the world. For many individuals, mounting disappointment and anxiety can become so great that to risk further disappointment (by trusting again) may seem just too threatening. Given that human beings have a limited capacity for frustration and stress, it may be *wise* for persons with ASD **not** to trust others, and to be guarded in everyday activities, no matter how well-intentioned or understanding partners may be.

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may engage in socially undesirable behaviors due to the stress and anxiety they are feeling. By asking ourselves, "What must this person be feeling now?", and "What can I do to lessen stress?", we are more likely to behave in a supportive and empathic manner that enhances trust. This requires that we understand a person's expression of dysregulation as a need for support and not simply as "bad" behavior that must be managed.

Strategies for Developing Trust

Given these challenges, what can partners do to foster trusting relationships with persons with ASD?

1. **Acknowledge communicative attempts** – One of the core elements that supports a trusting relationship is the feeling that others "hear" you; however, this is complicated by the fact that many people with ASD use idiosyncratic communication and are thus "difficult to read". It is crucial that all partners strive to listen, acknowledge, and whenever possible, respond to nonverbal and verbal communicative attempts. Be aware that some behavior management strategies such as "planned ignoring" when a person is stressed, or refusing to respond to communicative behavior (e.g., gestures, echolalia) in order to hold out for more complex communication, may interfere with efforts to foster a sense of trust, especially when an individual is clearly attempting to communicate intentions and feelings. Be patient too: If at first you don't understand the person, keep trying until you either figure it out, or feel that your frustration is starting to have a negative impact on the interaction.

2. **Practice *shared control*** – One way of building trust is to help another express his or her opinion, thus allowing that person to have some degree of control. In contrast, persistent imposition of control on another inhibits the development of a trusting relationship. Depending upon a person's ability and age, we should strive to build self-determination by offering control. For example, by offering choices; honoring protests and refusals when appropriate; and involving persons with ASD in planning schedules, activities, and so forth, we validate that the person "has a voice" and is heard and respected. These principles may be applied even for those who are the most challenged in communication, through nonverbal communication and the use of augmentative and alternative communication systems. As one famous YouTube video states: One autistic person's "meltdown" can simply be the equivalent of a neurotypical person "putting their foot down."

3. **Acknowledge emotional state, and support emotional regulation** – Being responsive and supportive when a person with ASD is most vulnerable also fosters trusting relationships. When emotionally dysregulated, many people with ASD

4. **Be dependable, reliable, and clear** – As noted earlier, part of the disability experienced by people with ASD is their confusion in "reading" other people, especially when our behavior may vary dramatically from one situation to the next. Although it is virtually impossible to "be the same person" under all circumstances, it is imperative that we take steps to reduce confusion by trying to be more consistent in our use of language and expression of emotions. We should also take the time to explain rules and expectations. By being clear and consistent, and by using visual information when appropriate, we become more dependable and will thus be seen as reliable, and therefore, worthy of trust.

5. **Be respectful in language and behavior** – Too often, it is assumed that people with ASD are unaware, or are not sensitive to another person's attitude regarding them. This is especially true for individuals who have more limited expressive communication skills. In contrast, partners who are respectful in their verbal and nonverbal behavior are more successful in developing trusting relationships. For example, partners should not talk about individuals in front of them in critical or disparaging ways as if they are not there. Including people with ASD in conversations in a respectful manner, through both verbal and nonverbal behavior, is trust-enhancing. Even with non-verbal individuals, whom we too often think of as unaware, we still don't know how much they are taking in. So why risk their emotional health when it is already challenged enough?

6. **Do not overly intrude by using excessive verbal and physical prompting** – Some individuals with ASD may need physical guidance and support. However, when support is provided in an imposing, controlling, and/or intrusive manner, either verbally or nonverbally, this may cause anxiety and defensiveness, especially for those with sensory sensitivities. Even "good" intentions, such as exclaiming "Good Job!" in a piercing voice, "encouraging eye contact" or "visually screening"

(putting one's hands on or next to a child's face to "block out distractions") may be experienced as stressful and aversive. It is important not to "force" compliance, as such attempts to do so may be perceived as a violation of trust. When it is appropriate, provide "graded support" and prepare a person by commenting on the support that will be provided, even asking if it is okay to provide support when appropriate (e.g., May I help?). We have to remember that no matter how helpful we are trying to be, if we try to *sell* the message through an imposing or coercive manner, the individual will likely not respond in the manner we wish.

7. **Celebrate successes** – Too often, we observe an excessive preoccupation with what is challenging; that is, what is going wrong. The excessive use of the word *no,* and other corrective language directed towards persons with ASD are symptoms of this problem. No person can trust those who are the source of *excessive* negative feedback. When we discuss and celebrate successes, and emphasize a person's strengths and abilities through clear and consistent verbal and nonverbal behavior, we are also supporting a person's self-esteem and building trust, not only with people with ASD, but with family members, as well. As one mother shared recently, "Teachers and professionals need to talk more about what is going right; even the little things. We know about the challenges – we live those 24/7".

8. **Anticipate what may be stressful, and make appropriate modifications and accommodations to lessen stress** – As noted, everyday activities or environments may be a source of great stress or confusion due to sensory sensitivities (loud sounds, smells, confusing or intense visual stimulation), too many transitions that occur too quickly, and other factors. When we anticipate what may be stressful, make appropriate modifications, and provide appropriate supports, we earn the trust of those who experience such vulnerabilities. This is not to say that we should smooth over all the "bumps" in life, as we must also help individuals develop coping strategies to deal with everyday stresses. However, as Ros Blackburn, a woman with ASD has stated, "Have high expectations for people with ASD, but with appropriate, and when necessary, high levels of support". In fact, when there is a foundation of trust, partners are better able to "raise the bar" and help individuals overcome challenges and take even greater risks.

Conclusion

We have come a long way since the days when the primary focus of supporting persons with ASD was in *shaping, changing,* and *reducing* behaviors. In the past, it was considered taboo to discuss "unobservable" social-emotional factors such as developing trust, or trying to understand the perspective and experience of people with ASD. Therefore, the importance of trusting relationships was dismissed or not even addressed. With our current experience of benefiting from the wisdom of people with ASD, and the reemergence of developmental interventions that embrace relationships and social and emotional development, *trust* may now take its rightful place as front and center in efforts to support people with ASD. For those of us who share time in our lives with persons with ASD, we can begin with a simple act of reflection: *Am I a person who employs the types of strategies and behaves in a manner that leads to a trusting relationship with the individual with ASD?*

BIOS

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**.

Michael John Carley is the Executive Director of GRASP, the largest organization in the world of adults diagnosed along the autism spectrum. He is also the author of the acclaimed book *Asperger's From the Inside-Out: A Supportive and Practical Guide for Anyone with Asperger's Syndrome* (Penguin/Perigee).