

The Primacy of Trust: Part II

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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 the "Straight Talk" column. Furthermore, who is better qualified to address this issue than someone who has "lived" the experience, and can reflect on it so eloquently from a few perspectives: as a person with AS, a father who has a son with AS, and a dedicated professional who has devoted his life's work to supporting others with ASD – Barry M. Prizant

In Part I, we considered many of the challenges faced by persons with ASD in developing trusting relationships with other people, as well as within everyday activities and environments in which they live, go to school and work. We will now consider positive steps that can be taken to facilitate the development of trust. But first, there is one overriding truth that will always make the process easier; that is, in order to develop trust, each partner, and not the individual with ASD, must first accept the obligation to change, and must make the greatest effort for developing trust. A 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.

This notion may seem confusing, harsh or even accusatory to those caregivers, educators or clinicians who see the problem solely within the person with ASD, and even for those are truly 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 their trust?"

However, to act on solely on this instinct, without understanding how difficult it is for most persons with ASD to develop trust, might result in ignoring and invalidating the gravity of what the ASD individual goes through every day and may have been through in his or her life.

We have to understand that depending more on their age and life experience than on where they fall on the spectrum, the life of an individual with ASD, at the very least, is marred by varying amounts of misunderstandings, and at worst, repeated traumatic experiences, for the primary challenges in ASD are centered around communication—two or more worlds trying to understand one another. And the cumulative incidents where the ASD individual's intentions were good, yet were interpreted negatively, may have serious consequences over the long term. With a history of cumulative stress, and negative or even traumatic emotional memories due to 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, misinterpretations and sensory stress there are 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. Dare we say it, given the human condition's limited capacity for frustration and stress, it may be *wise* for persons with ASD **not** to trust others or to trust being out in the world until they have sufficient reason to feel safe and to do so, no matter how well-intentioned or understanding partners may be.

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 being "heard". A complicating factor for many people with ASD is that how they communicate may be idiosyncratic, and sometimes "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) 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 them, 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, and allow that person to have some degree of control. In contrast, persistent imposition of control on another inhibits the development of a trusting relationship. Depending on 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 validates that the person “has a voice” and is heard and respected. These principles may be applied even for those most challenged in communication, through the 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 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.

4. **Be dependable, reliable and clear** - As noted earlier, part of the disability experienced by people with ASD is 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 reduce confusion felt by many people with ASD by trying to be more consistent in our use of language, how we express emotions, and explain rules and expectations. By being clear and consistent, and by using visual information when appropriate, we become more dependable and will be seen as reliable, and therefore, worthy of trust.
5. **Be respectful in our language and behavior** - Too often, it is assumed that people with ASD are unaware, or are not sensitive to another person's attitude about 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 ASD individuals, whom too often we 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, and even asking if it is okay to provide support when appropriate (e.g., Can I help?). We have to remember that no matter how helpful we are trying to be, if we *sell* the message through an imposing or coercive manner; the individual will not likely respond in the manner we wish.

7. **Celebrate successes** - Too often, we observe an excessive preoccupation with what is challenging, therefore what is going wrong. The excessive use of the word “No”, and other corrective language directed towards persons with ASD is a symptom of this problem. No person can trust others 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 are building trust, not only with people with ASD, but with family members. 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 in activities and everyday environments**
– 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 we should “smooth over all the bumps in life”, as we must 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 of 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. This can begin with a simple act of reflection: pretend you’re that individual ASD, and ask yourself, “Why *should* I trust?”