

# STRAIGHT TALK

## About *Autism*

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## Parent-Professional Relationships: It's a Matter of Trust

**A**fter three decades of supporting individuals with autism and their families, I've come to the firm conclusion that a trusting relationship between parents and professionals may be the most important factor in helping families navigate through the often stormy seas of raising a child with ASD. There is one simple rule: *Trust must be earned; it is not bestowed lightly.*

### The Trust - Mistrust "See Saw"

In my career, I've had the opportunity to observe education and healthcare professionals interacting with parents in schools, hospitals and university clinics, in activities ranging from diagnostic evaluations and informal encounters, to meetings of all shapes and sizes from the preschool years through the transition to adult services. I've listened in disbelief to the "war stories" shared by parents about the additional stress they've experienced due to the behavior of professionals. Many "problems" I am asked to address in school consultations are directly or indirectly grounded in less-than-harmonious parent-professional relationships. Also, I continue to be perplexed, as well as amazed, at how things can go so right in some situations and so wrong in others—*right*, when time spent together

engenders trust and builds positive and collaborative relationships; *wrong*, when encounters create mistrust, suspicion, and even anger (typically for the parents, but sometimes for professionals as well). Such polarization probably occurs because autism is a passionate affair—full of strong emotions for all involved, which may result in professionals and parents directing emotional energy in either positive ways, or in ways that interfere with the development of trust.

I've observed how often well-intentioned and caring administrators, educators, and therapists stumble through the complex and intricate process of attempting to support parents. Frankly, I've been appalled by how other professionals allow their own judgmental attitudes, egos, and insecurities to dictate how they interact with parents. (I also experienced this first hand as a parent, when a decade ago, my then 18 month old son was diagnosed with a potentially serious medical condition, which was eventually surgically corrected. The insensitivity of some medical professionals, and their lack of training in supporting parents was inexcusable, and it was a saving grace when we finally found a professional who knew how to listen and address our

concerns.) On the other hand, I've also seen how some parents misdirect their anger by targeting professionals who have done little or nothing deserving of such extreme reactions.

When things go right, parents are more willing to trust in the people and in the processes that are in place to support their child. Under such circumstances, there is a growing sense of mutual respect, collaboration, and a willingness to move forward as partners in the journey. Achievements and progress are celebrated, and the burdens and stresses of the difficult times are shared. Sadly, very few educators and therapists receive any comprehensive training in supporting parents from a "family-centered" perspective, especially in school settings. Professionals may erroneously believe that being a "nice person", or having good intentions is all you need to work well with families, even those under great stress; however, without expertise in family support, when things go wrong, the consequences may include wasted time, energy, and resources, resulting in parents feeling that many professionals are simply not that helpful. Unfortunately, there may be even graver consequences. Parents may feel that school-based and other

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professionals are not qualified to provide the services that their child needs. This may occur even when a school district has quality services, if the parents' initial encounters with school staff did not create a foundation for trust.

Clearly, the process of developing relationships and building trust rarely occurs with a few brief encounters. Establishing trust with parents is a delicate and intricate process, and demands far more than good intentions on the part of school personnel. The same may be said for professionals developing a sense of trust in parents, even though there is an imbalance, since professionals are most often in a position of power and knowledge, whereas parents are often in uncharted territory. Despite these challenges there are clear steps that can be taken to build and maintain trust.

The following discussion is based on personal experience, and is informed by Stephen Covey's discussion of types of personal and professional qualities that engender trust in his seminal book, *The Speed of Trust*. These include the qualities of *character* and *competence*. Here, we are referring primarily to the qualities of professionals and paraprofessionals; however, these sources of trust are relevant to parents and larger systems, as well. We may think of the following as a checklist of qualities we should all strive for in developing trusting relationships.

### Character and Competence Traits that Build Trust

- 1. Talk Straight**—Most parents want to receive information clearly, directly, and with sensitivity, even if it involves a “difficult” conversation. The amount of information provided must be calibrated to parental understanding and emotional state, so that parents are able to process what is being said. We must understand that professional jargon, such as *developmental delay* may have different meanings for professionals (*disability*) than for parents (*He'll catch up.*). Vague information, or “sugar-coating” a child's difficulties is not helpful. Professionals need to be clear and descriptive, and when appropriate, they need to be honest by saying, “*I just don't know*”. There is so much we are all learning together.
- 2. Practice Active Listening Skills**—Parents want and need to be heard, and there are very few people who know the child as well as the parents. Trust flourishes when professionals acknowledge the parents' expertise about their child and demonstrate a willingness to listen to their concerns and constructive criticism. Paying full attention and providing opportunities for open communication build positive relationships. A defensive attitude that communicates, *we know it all* or an impatient demeanor that indicates, *I do not have time to listen* is insulting to parents. Active

listening also involves suspending the impulse to attempt to “fix” all problems raised by parents. We must learn to distinguish between when parents just want to be heard, in contrast to their wanting tangible suggestions.

- 3. Demonstrate Respect and Be Nonjudgmental**—Respectful and non-judgmental language about a child and family go a long way toward developing trust. By referring to a child by his or her name, we emphasize that we see the child as an individual. When we use the words *he* or *she* excessively, or refer to a child as a member of a category (*That's what children with autism do.*), we are not communicating that we see the child as a unique person. Too frequently a child may be blamed for difficulties related to his or her disability when phrases such as *she's being manipulative*, or *he's so noncompliant* are used to explain behavior. Parents may also feel that they are being blamed. We can also communicate respect by referring to parents by their first names, or by Mr. or Mrs. \_\_\_\_\_, not simply *Mom* or *Dad*, which implies a hierarchy of status (*I'm the professional, and you're just the mom or dad.*). The parents of an adult child with ASD once shared, “On reflection, the professionals we have valued most over the past 18 years were those who never judged us as parents, but joined with us on our journey.”
- 4. Take Responsibility for, and Right Wrongs**—One of the most important trust-building behaviors is to admit when we have done something wrong; state that we regret it; and whenever possible, take actions to make things right. I have observed the healing power of both parents and professionals

taking responsibility for their mistakes, and righting wrongs. When it occurs in a public forum, such as at a meeting, it is even more powerful. When this does not occur and blame becomes the overriding message, it can be one of the most devastating blows to developing trust.

5. **Demonstrate Loyalty**—Professionals should always communicate loyalty to the child and his or her family. Unfortunately, some professionals are given the message by superiors that their loyalty must be to the agency or their supervisors. If professionals think of their role as *providing service*, and realize that's what we get paid to do, the child and the well-being of the family is more likely to be at the heart of their efforts. That said, one must "walk the walk" and not just "talk the talk". Unfortunately, in some cases, parents may be told not to trust professionals (especially school personnel), and may be coached to seek legal remedy early in the process of developing relationships, causing professionals to be forced into abandoning any potential loyalty to the family due to legal constraints. Under such circumstances, communication breaks down and the potential for trust is almost always lost.
6. **Deliver Results**—When progress is documented and shared with parents on a regular basis, it supports trust in a tangible manner, but only when it is both *meaningful* (in terms of the difference it makes in family life) and *valued* by the family. I have known situations where professionals highlight progress that *they* are excited about (the ability to learn academics, answer questions in a rote manner, and so forth), when parents are more focused on social communication, supporting a child's

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emotional regulation, and establishing relationships. Being on the same page with families about priorities for a child is an essential ingredient for trust.

7. **Acknowledge and Confront Reality**—We all know that, at times, things may not be going well for a child or family. Unless service providers acknowledge such difficulties, parents may feel that their concerns are being minimized. Even when uncomfortable issues are raised by parents (e.g., "James may be doing well at school, but he falls apart at home."), it is essential to join parents in their concerns, and solve problems together. Avoidance of challenges or concerns raised by parents violates trust, while acknowledgment and collaboration builds trust.
8. **Engage in Professional and Personal Growth Activities**—Professionals must demonstrate a willingness to grow and change, and communicate to parents how such efforts will have a positive impact on their services. Sharing information from such activities with parents also communicates our role as a resource, and our respect for parents as active learners. Following up on information that parents recommend for review also communicates respect for their knowledge and contributions.
9. **Clarify Expectations**—Trust is supported when expectations are clearly communicated—for example—expectations about the purpose of meetings, the role played by different professionals, and so forth. Trust is

supported when we ask parents what their expectations are, and how activities may be designed to meet them. This also pertains to the more formal policies and procedures of schools and other agencies. When parents are given clear information about program policies (e.g., transition planning), and have the opportunity to be actively involved in formulating policies (when appropriate), they may feel a degree of ownership rather than powerlessness. Additionally, parental perspectives may provide invaluable contributions to quality improvement. I now consult to a few public school districts that have undertaken system-wide reviews of services for children with ASD, and have included parents as active, contributing members of the steering committees.

10. **Practice Accountability and Keep Commitments**—Trust is supported when professionals are punctual and well organized, and when meetings are run in a manner that respects the voices of all participants. Any information that requires extra emotional or informational processing time (e.g., suggestions about changes in a child's program) is best shared prior to meetings, since unexpected "surprises" about emotionally-laden issues cause anxiety and create strong negative emotional memories resulting in a lack of trust. Clear systems of communication between parents and professionals, the development of

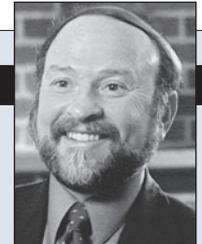
action plans, and specifying who is responsible for follow-through all contribute to trust.

### Concluding Comments

In a field that has become so preoccupied with choosing the so-called “right” treatment, softer issues such as developing trust with families are often lost. This is punctuated by the fact that most continuing education activities for professionals in ASD focus on educational or biomedical approaches to the virtual exclusion of training in family support. If, however, we understand that schools and other agencies are first and foremost systems of support, it puts the priority of trust in a very different light that then must become a “front burner” concern. 

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