

# STRAIGHT TALK

## About **Autism**

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

## Creating a Culture of Family-Centered Practice for the Autism Community

In this third and final part of my series on “Treatment Options and Parent Choice”, I will consider ways that professionals serving children with ASD and their families can adopt practices to move closer to the goal of becoming family-centered. I will begin by considering the essential elements of family-centered practice, the ultimate goal of which is that of empowering families with the knowledge and skills to make the best choices for their children and for the family unit, as a whole. When parents feel empowered, they feel more in control. In addition, parents also become more invested when they are respected as active collaborators in treatment and educational planning. Therefore, as a starting point, professionals must recognize the following truth: *Once you are in a relationship with a child, you are also in a relationship with the child’s family.* As with all relationships, there will be good times, as well as difficult and stressful times. Needless to say, successful relationships require a lot of hard work. When the life of a child is in the balance, however, there are no acceptable alternatives to failure. Embracing family-centered principles and practice is a major way to ensure success in the ongoing process of supporting a child’s development.

### Collaboration is the Key

An essential element of family-centered practice is collaboration in decision-making, which plays a significant role, since teamwork is the foundation for successful, comprehensive

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programming for a child. In my definition of family-centered practice, I noted that “parents are respected as experts about their child”. Does this mean that the final decisions about educational/treatment options lie solely with parents? The answer is not that simple. Parents are indeed experts, in the sense that they are intimately familiar with their child’s strengths and needs; the types of supports that allow the child to do his or her best; and the types of challenges that compromise their child’s abilities in everyday activities. However, team-based programmatic decision-making must also be guided by research (“science-based” or “evidence-based” practice), as well as years of cumulative experience, referred to as “wisdom-based practice”. Although parents know their child intimately, they likely do not have years of experience with a wide variety of individuals with ASD or with the variety of approaches or supports that may be available.

### Bumps in the Road

Inevitably, difficulties in parent-professional relationships due to differences of opinion may arise, especially when the philosophy and practice of agencies or individual professionals clash with the desires of parents. In family-centered practice, the challenge is for professionals and parents to proceed collaboratively, and when necessary, to deal directly with differences of opinion regarding treatment/educational programming in a mutually respectful manner.

In my experience, differences of opinion may have to do with:

1. the choice of different types of “named” treatment approaches, such as ABA vs. DIR-Floortime, vs. TEACCH and so forth, and also with the intensity of programming. When parents

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believe that one approach or level of intensity (e.g., hours of service) is best for their child, and agencies or professionals offer another approach; are eclectic in their orientation; or offer less intensity than that desired by parents, the stage is set for a divisive scenario.

2. the use of specific instructional procedures or therapeutic strategies. For example, I recently met some parents whose three-year-old had just begun a preschool program, and they had strong reservations about the staff's use of visual supports such as picture systems for expressive communication and visual schedules, since they were concerned that it would prevent the development of speech, despite having been provided with information from staff refuting this claim.
3. how to interpret, and therefore, how to address children's behavior, especially problem behaviors. For example, parents may interpret their child's problem behavior as resulting from confusion, boredom, or being overwhelmed; whereas professionals may interpret such behavior as manipulative, or non-compliant. The reverse may also be observed. Once again, with respectful discussion, careful observation, data collection, and "reframing" the way a child's behavior is understood, a consensus may be reached over time.

Educational and treatment practice must also be guided by legal standards, such as those for providing a free and appropriate education for children with disabilities. When determining the appropriateness of treatment and educational options, these standards must be addressed and considered along with input provided by professionals and parents. However, as noted in part two of this series, when strong opinions are stated about the effectiveness of a particular approach, one must carefully examine the evidence for those claims, especially when those making the claims have a significant investment in that particular approach.

### **Guidelines for Family-Centered Practice**

Given these complexities, how can parents and professionals proceed in a collaborative manner that meets the basic tenets of family-centered practice? How can such collaboration respect both parental priorities, as well as evidence-based and wisdom-based knowledge that underlie practices of professionals and agencies? Easier said than done; however, the following guidelines, based on research and years of experience, are offered:

1. **Build trust in parent-professional relationships.** This is the foundation for family-centered practice, since without trust

collaboration is either not possible, or extremely painstaking. This important issue, along with specific strategies for developing and maintaining trust, was discussed in detail in my August, 2008 article "Parent-Professional Relationships: It's a Matter of Trust". When trust in relationships is established over time, the guidelines that follow may be implemented with greater ease.

2. **Level the playing field.** Family-centered practice requires that parents' voices be heard in decision-making. Parents are more likely to become equal partners in discussion when the initial focus is on developing a consensus about priority goals and objectives for a child, rather than focusing on different categories of treatment. This may be achieved in a number of ways:
  - a) Employ systematic observation of a child across different settings to determine a child's strengths and needs, and use this information to prioritize functional goals and objectives. For example, observations from home and school across a variety of activities help to develop a more complete portrait of a child.
  - b) Use detailed questionnaires or discussions with parents to determine their priorities for their child, and support families in developing their "vision" for their child.
  - c) Have a procedure for professionals and parents to discuss and eventually reach consensus on educational and therapeutic strategies to help a child reach goals and objectives across home and school settings (as well as in community settings, when appropriate)

These processes may be derived informally, or guided by more systematic procedures such as those that have been developed in The SCERTS Model® (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006)

3. **Compromise on the part of both parents and professionals may be necessary** when there are differences of opinion. Compromise allows for communication to continue and is one more way to build trust and mutual respect. Furthermore, there is more of an emphasis on the collective "we" rather than on the divisive "us vs. them". For example, I was recently involved in a situation in which parents requested that one-to-one therapy be used as the primary strategy in a school-based

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program predicated on a model of supported inclusion and socially-based programming for all students. After considerable discussion, it was agreed that priority goals and objectives were in the domains of communication and social abilities. This led to a discussion about how to achieve those goals and objectives, rather than one focused on types of treatment. Through this process, the parents came to understand that most social-communicative objectives—which all parties had agreed were priorities—were most effectively addressed in social situations during daily activities and routines, rather than in a discrete-trial format. That said, the professionals also respected the fact that since this child had received one-to-one therapy in home-based early intervention and had made progress on specific skills, the parents were most comfortable with that teaching format. Therefore, a program was developed that infused discrete-trial training for appropriate functional objectives into the larger portion of the child's school day which involved well-designed small-group and larger-group activities consistent with the social and inclusive philosophy of the program.

**4. Systems that serve children with ASD must be flexible** in addressing parental concerns. For example, an elementary school student with significant challenges was scheduled to transition to middle school within his school district for the next year. His parents, who had always worked collaboratively with school staff, raised serious concerns about the timing of this transition. Their son had made significant progress in his last scheduled year of elementary school, but due to his sensory and emotional regulatory challenges, they believed that the complexities of middle school (more transitions, new building, new staff, etc.) put his continued progress at great risk. Furthermore, with the significant trust the parents had in their son's current school team, they wanted the transition process to be planned carefully over one more year in elementary school. The team discussed these issues with the special education director, and a consensus was reached to allow the student to spend one more year in elementary school. This decision served to maintain, if not solidify and enhance the parents' trust in the school district, and allowed the elementary team to collaborate with his parents in designing a systematic transition plan based upon the needs of the child.

**5. Professionals should “go the extra mile” in providing supports to families.** For example, school personnel may

arrange for, provide, or participate in creative support activities such as:

- “parents night out” (to allow parents to shop, eat out, etc.) while staff provide activities for children with ASD after school hours;
- educational activities such as presentations by staff or discussion groups on topics selected by parents;
- ASD walks and other local ASD awareness activities, school picnics, sibling support activities, and so forth;

Additionally, professionals should be generous with their time and expertise in supporting families and in developing supports such as visuals for activities that may not be directly related to educational programming. Such activities may include visits to doctors and dentists, family vacations, community activities such as visits to churches, synagogues, restaurants, shopping, and so forth.

**6. School Systems should include parents in quality improvement activities.** Through regular meetings and feedback activities, administrators and “on-line” staff can obtain important information from parents that may be used to improve services and build family-centered practice. For example, a number of school districts I have worked with have initiated system-wide ASD Steering Committees to evaluate current practices and proactively recommend changes to better support children and families. In each of these cases, parents collaborated with professionals and administrators on these committees.

### **Agreeing to Disagree Respectfully**

At times, differences of opinion cannot be resolved through collaboration. If the ultimate goal is family empowerment through mutual respect, family-centered practice still provides guidelines when legitimate differences of opinion exist that cannot be resolved. To a great extent, the burden now falls on the shoulders of professionals to maintain a mutually respectful relationship, even when strong emotions may prevail. However, parents also shoulder this burden. As readers know, legal and procedural safeguards are in place for families and professionals to consider all opinions and evidence regarding educational and treatment programming for a child. When such decisions need to be made by third parties (e.g., advocates, mediators, and lawyers), it is still essential to strive for mutually respectful processes and outcomes as it is likely that, if the student remains in the particular system, the family and the school staff will be

moving forward on the same journey together for many years. To this end, it is essential for third parties to maintain open communication and mutual respect for all, as family-centered practice cannot exist in a divisive atmosphere.

## Conclusion

Family involvement and collaboration in a child's educational programming is one of the factors that has been found to lead to better outcomes for children with ASD. However, due to strong emotions, both positive and negative, and stress that are an inevitable part of the experience of raising and educating children with ASD, there is the great risk of such emotions interfering with successful collaboration. In this series, I have discussed how family-centered practice may be the strongest foundation for supporting parents in making the best choices for educating their child in collaboration with professionals. 

**Author's Note:** I wish to extend my deep gratitude to the countless parents and family members I have gotten to know over the years, especially the hundreds of parents who have participated in our annual parent weekend retreats over the past 14 years. These parents and family members have been my greatest source of learning about how professionals can be most effective in supporting families on their journey.

## Reference

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**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](http://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](http://www.barryprizant.com), or contact Barry at [Bprizant@aol.com](mailto:Bprizant@aol.com).