

STRAIGHT TALK

About *Autism*

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Join Us on the Journey

What Parents Want and Need from Service Providers

Author's Note: Despite four decades of experience, I know that I could never presume to be able to speak for parents, as I have never had the requisite experience of raising a child with ASD. In this "Straight Talk" column, I am sharing what parents have asked me to share when asked the question, "*What do you want, and need from service providers?*" I have put these thoughts in the form of a letter to service providers from a parent.

A Parent's Letter to Service Providers

As a parent, let me begin by saying that I am so grateful that you have chosen a profession that enables you to help other people overcome challenges and reach their greatest potential. Too few people dedicate their life's work to such a noble purpose. I do know that you do not do this for financial rewards, and that you are faced with challenges that often supersede those of educators and other professionals who work with typically developing children. That said, I am grateful for the opportunity to share my thoughts with you regarding what will make our journey as parents easier, and yours as the professionals we rely on, more successful. These thoughts will address what I, as a parent, want and need, 1) that is helpful for my child and, 2) that is helpful for me.

What I Want and Need for my Child

- 1. Use a collaborative, team approach.** The complexity of my child's challenges requires expertise from a variety of disciplines. A team approach will provide the strong foundation of support and informed decision-making that my child needs. And, it will guard against any one professional wielding a disproportionate amount of power.
- 2. Speak about, and act respectfully towards my child.** When he has difficulties, don't assume that he is capable of controlling his behavior, or that he is being *intentionally* manipulative or noncompliant. Rather, know that his challenges are neurologically-based, and that to *assume* "he knows better," is to "blame" him for his disability.
- 3. Do not speak about my child to others in a disparaging manner, nor speak to others in his presence as though he is not there.** The former can poison the minds of those who have the right to form their own opinions, and the latter is demeaning to him.
- 4. Provide appropriate levels of support to help my child succeed.** Appropriate levels of support go a long way towards building his confidence, competence, self-esteem, and motivation.
- 5. Have high expectations for my child!** Yes, I understand that we must be realistic, but my child is more successful when there are positive expectations with appropriate supports.
- 6. Think "outside of the box" and be flexible and open to creative ideas.** Too often, I have observed that "tried and true" approaches used with my child (such as an ill-conceived behavior plan) may seem logical, but may not work. Be open to creative and intuitive suggestions from me and from other team members. And if you need to bend the school rules a bit, (e.g., by allowing my child to chew gum if it helps him to stay focused), I will support you.
- 7. Demonstrate loyalty to my child.** Please let me know through your actions that providing the best services for my child is your top priority. I know that you may be under constraints in your work situation, but when you show loyalty

to my child by advocating for him, I will be motivated to go the “extra mile” to support you in your efforts.

8. Discover and use my child’s strengths and interests.

My child should not be defined by his diagnostic label. He is a youngster who also has interests and relative strengths. Let’s work together to best understand how we can nurture his strengths to improve his quality of life. Furthermore, do not put a ceiling on his potential by focusing on what he can’t do. All people are “a work in progress,” and despite discouraging predictions, there have been many success stories.

9. Don’t waste his time! Always ask yourself the question: *Is what I am working on making a meaningful difference in his life?*

Activities that will help him to develop meaningful relationships and become an active learner and engaged participant in daily life will serve him well.

10. Please like, appreciate, and have fun with my child.

Although it may not always be apparent, he knows when he is respected and liked by others. That’s when he does best, and even shines! He has so much to give back, but to allow him to do so may require that we adjust our attitudes and change our behavior toward him.

**Always ask yourself the question:
*Is what I am working on
making a meaningful
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What I Want and Need as a Parent

- 1. Respect me and understand that I am human, certainly not perfect, and trying very hard to do my best.**
- 2. Do not judge me—try to understand my perspective and experience as best you can so that you can see where I am coming from.** Raising any child is a highly emotional affair, and when that child is at the mercy of neurological differences that create many challenges, it spills over to the whole family and family life. At times, I may seem overly concerned, overly involved, and relentlessly persistent, but in most cases, I am simply a parent trying to do the best that I can for my child.

Make sure to share the good news and successes, no matter how small or inconsequential they may seem.

3. Understand that I may not be an expert on autism or on child development, but I am an expert on my child.

I am “on call” 24/7, and am ultimately responsible for my child’s well-being. I see my child at his best, and when he is most challenged. I observe his interests and his passions, and what is most tedious and boring for him. I observe his developing relationships with other children, and his frustration and confusion in trying to make sense of the social and sensory world. Please respect me for my expertise and see me as a resource so that you can get to know my child.

4. Let me know that my voice is being heard, even when I share information and suggestions with you that you may disagree with.

Although I may come across, or you may see me as *just a mom* or *just a dad*, please treat me as my child’s MOTHER or FATHER—the collaborative partner on my child’s team that the law affords me. At times, I will need educational support in the form of suggestions or strategies, but at other times, I may just want to talk about difficulties or successes as my way of seeking emotional support.

5. Be honest. I know when you are saying one thing, and thinking another, or when you are “sugarcoating” information even if you feel it is for my benefit. Open communication supports collaboration and trust. At times we may need to agree to disagree, but if we both have the well-being of my child in mind, we can come up with positive solutions. *You will not hurt my feelings if ultimately my child will derive benefit.*

6. Say I don’t know when you don’t, but help me to find the answers to my questions when you can.

7. Make sure to share the good news and successes, no matter how small or inconsequential they may seem.

We live the challenges every day, but the good news and reports of progress keep us moving forward; help us to cope with the challenges; keep hope alive; and allow us to celebrate together.

8. Ask me about my priorities for my child and family.

I will be more invested in following up on your suggestions if we collaborate to reach shared goals. Please also understand that I may question priorities and goals that you have set for my child, so help me to understand why you feel they may be important.

But please do not prescribe or dictate to me, especially if I do not fully agree with your position, as we must learn to make good decisions together.

9. Go the extra mile! Show interest and concern for my other children and my family. If possible, get to know me and my family outside of the school context. Any and all efforts to contribute positively to our family life will be appreciated beyond words.

10. Be humble and understand your place in our lives.

Many wonderful people have helped us in the past, and will help us in the future. Join us in our journey, but understand where we have been and what we have experienced. That will go a long way towards giving you the perspective you need to help make our journey as successful as possible.

Thanks for all you do! 🏡

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Three of these parents have published highly acclaimed books that are “must reads:”

Now I See the Moon by Elaine Hall

Dancing with Max by Emily Colson

The First Year: ASD: An Essential Guide for the Newly Diagnosed Child by Nancy Wiseman

Could it Be Autism? by Nancy Wiseman

BIO



Dr. Barry Prizant has more than 40 years experience as a clinical scholar, researcher and international consultant to children and adults with ASD and their families. He is an Adjunct Professor, Brown University, and Director of Childhood Communication Services, a private practice. Barry is co-author of *The SCERTS Model: A comprehensive educational approach for children with ASD* (Prizant, Wetherby, Rubin, Laurent & Rydell, 2006) and the assessment instruments, CSBS, and CSBS-DP (Wetherby & Prizant, 1993, 2002). He has published more than 100 articles and chapters and has presented more than 700 seminars and keynote addresses in the US and internationally. Barry developed and co-facilitates an annual weekend retreat for parents of children with ASD, and is the recipient of the 2005 Princeton University-Eden Foundation Career Award for “improving the quality of life for individuals with autism.” For further information, go to www.barryprizant.com, or contact Barry at Bprizant@gmail.com.