

STRAIGHT TALK

About *Autism*

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Treatment Options and Parent Choice: An Individualized Approach to Intervention

Choices about educational and treatment approaches may be among the most important, yet anxiety-arousing decisions made by parents of children with autism. A few decades ago, the limited amount of information and number of choices available for supporting children with autism were sources of great frustration for parents. Today, the myriad educational and treatment approaches, and claims of success associated with some of them—most often made by those most invested in those approaches—are sources of overwhelming confusion for many parents.

Today, especially in the United States, parents are deluged with an overwhelming amount of information about treatments, both biomedical and educational. Given the competitive nature and commercialism of our culture, we have come to expect the “selling” of approaches; however, unlike buying a new brand of toothpaste, the choices that parents make have significant long-term consequences for both the child and the family.

This month’s *Straight Talk* column is the first part of a three-part series that will examine issues related to treatment options and parent choice. In this series, we will explore the concept of parent choice and family-centered philosophy and practice, and we will critically review current practices in educational and treatment approaches for children with ASD from those perspectives. To begin with some “straight talk”, it is my experience that many practices that predominate in the field of education and treatment for autism are inconsistent with,

and in fact, often violate principles of family-centered practice, now considered the “gold standard” of practice for children with developmental disabilities (including autism) and their families. Most current approaches focus on the child, to the exclusion of family support and collaboration. In some cases, when parents are more directly involved in services, they may receive training (i.e., parent training) on how to “handle” their child. In contrast, it is within family-centered practice that parents are best supported in making informed decisions about educational and treatment options.

“In Order for Professionals to Grow, Parents Must Water Them”

I first heard this quote almost two decades ago. At the time, it resonated with me as I had been trained in family-centered intervention during an advanced postdoctoral fellowship at the University of North Carolina-Chapel Hill, an internationally recognized center for family-centered research and practice for families with children with disabilities. What this quote said to me was: 1) We can learn a great deal by listening to and collaborating with families; and 2) An “expert” model followed by most professionals in the field of child disabilities was passé. Research has demonstrated that when parents are “told” what is best for their child, and “prescriptions” are written for families to follow, many parents do not develop the knowledge to advocate for their child in a productive manner; may not develop an understanding of their child’s disability; may not develop the skills to play an active role in supporting their child’s development over time; and may feel disenfranchised from the educational or treatment process. While in the short term, some parents may feel relieved to follow professionals’ advice faithfully, especially when that advice is found to be helpful, there are many shortcomings to an expert model.

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Some problems may be apparent immediately, as when parents' beliefs about their child are not consistent with that of the professional, putting parents in the quandary of "do we follow our 'gut', or do we comply with what professionals tell us to do". Other problems with an expert model may appear over time, when it becomes clear that the priorities espoused by a professional for a child are inconsistent with the priorities, hopes, and dreams that parents have for their child. In some cases, when treatment programs based on priorities selected by professionals are not successful, the "expert" may blame parents for the lack of success due to insufficient carry-over at home. In contrast, when parents are supported as collaborators, there is a sense of community and team-work, as well as shared ownership of both progress and challenges.

The "Landscape" of Educational and Treatment Approaches

Educational approaches and treatment options vary greatly along a variety of dimensions (Prizant & Wetherby, 2005). Examples of these dimensions may include, but are not limited to: attitudes about, and approaches to address problem behavior; whether learning contexts for a child should focus on training skills in isolated situations versus natural activities; the amount of inclusive learning experiences; the use of visual supports and augmentative communication; the focus on compliance training versus spontaneous initiated communication; teaching academic readiness skills versus functional living skills; and most relevant to this discussion, the degree of collaboration with parents in both assessment and educational programming decisions. Programmatic decision-making along these dimensions is too often dominated by professionals. Furthermore, when made by professionals, decisions may not be consistent with the cultural values of parents, or with their priorities and hopes for their child. For example, many parents greatly value relationships and social connections for their child. It is not uncommon for parents to be concerned about the potential for their child to develop friendships and caring relationships with others, even as early as when they first receive their child's diagnosis. However, while some approaches place a high priority on the development of social relationships in educational programming, others do not share this priority, despite the fact that research demonstrates that this should be an area of high priority. Many parents want their child to be able to make choices, express opinions, and for

older individuals, play a more active role in determining choices in their lives. Notwithstanding, some approaches provide few opportunities for an individual to develop these skills, especially when compliance training is a stated priority.

Family-Centered Practice and Parent Choice

Clearly, parent choice about treatment options is one of the most important aspects of family-centered practice. Although there are many definitions for family-centered practice, I would like to offer my own:

Family-centered practice has at its primary goal, empowering families with the knowledge and skills to make the best choices for their child and for the family. In family-centered practice, professionals collaborate with families in decision-making about specific goals and objectives, as well as educational/treatment approaches. Parents are respected as experts regarding their child, and professionals consider each family's unique strengths and needs, as well as its cultural and religious values.

Research and practice has clearly indicated that there are multiple benefits when professionals collaborate with parents in family-centered practice. These include:

- 1. Parents gain a greater sense of control**—A significant stressor on parents and families is the feeling that events are not within their control. Uncertainty about a child's future, and even how the child will act and react to everyday challenges on a day-to-day basis, create a high degree of anxiety for many parents. Family-centered practice helps parents to be focused on collaborative problem-solving and future directions, with the support of professionals. For parents less knowledgeable about treatment options, professionals should support and inform them about various approaches and strategies as part of this process.
- 2. Individual differences in children and families are respected**—We now live in a country of incredible racial, ethnic, religious, and socioeconomic diversity. As noted, such diversity is reflected in the values and belief systems of parents, which greatly impact practices for raising children; the degree of trust that parents are willing to place in professionals and service delivery systems; and the hopes and dreams that parents have for their children. In family-centered practice, the focus is not primarily on the techniques used, or even the specific curricula developed for children with autism. Goals

and programmatic priorities emanate from family priorities, and the individual strengths and needs of each child.

3. Priorities and goals for treatment and educational programming are shared

—When parents and professionals are “on the same page”, there is great potential for promoting a high level of intensity of services (I define *intensity* by the degree of coordination achieved among professionals and family members, not by the number of hours of service provided for a child). However, when parents are asked to agree to priorities and goals chosen by professionals—often based on pre-prescribed curricula—it is likely that parents may not be fully invested in, or value those priorities and goals. I have observed numerous situations where professionals determine what the highest priorities will be (e.g., toilet training, eye contact, compliance), when the particular priorities chosen are not shared by the parents. This type of situation may hinder the development of a collaborative, trusting relationship between parents and professionals.

4. A long-term perspective is taken so that parents can develop the skills and strategies to face future challenges

—For most children, the family is the most enduring influence on their development and quality of life. Given that autism is a life-long disability for the great majority of individuals, most families will continue to be faced with a seemingly endless list of decisions and problems to solve. With the support and guidance of professionals following family-centered practice, parents will come to see themselves as the primary voices that must be heard in decision-making. An important aspect in such decision-making is parental knowledge of their child and their “gut” reactions as to how to best support their child. An expert model can preclude this process from developing. Professionals typically are brief visitors on each family’s journey. When services are provided according to an “expert-as-decision-maker” model, parents are left unprepared to make important decisions. In family-centered practice parental competence in decision-making is fostered over time.

A few years ago, I became involved with a family when the parents decided to change the treatment approach that had been followed for the previous two to three years with their five-year-old daughter. They felt their child was developing significant anxiety as a result of the treatment approach being used. In discussing their experience, the parents asked me my opinion about an intervention that was prescribed for what they called their child’s “happy dance”, which involved

moving a few steps backwards and forwards on tiptoes while flicking her fingers in front of her eyes. The parents were very clear that the “happy dance” happened mostly during transitions between activities, and when she was bored. Although it happened only briefly (15-30 seconds or so), the therapy plan prescribed by the supervisor involved telling their daughter in a stern voice, “sit down, quiet hands, sit on hands”. The parents, however, viewed the “happy dance” as a brief “break” the child was taking, and they did not have any concerns about this, even though the behavior appeared unconventional. After I got to know this youngster, it was clear that the parents’ perspective was correct. The danger in this scenario was that parents were told not to trust their intuitions about their child, and had they continued to work with professionals who were so adamant about imposing their “expertise”, it was highly likely that this child’s anxiety would have worsened.

In conclusion, current approaches for children with autism are limited when viewed from the perspective of family-centered practice. In part two of this series, we will explore how principles of family-centered practice may be violated when professionals are prescriptive in making recommendations to parents, and in part three, we will consider recommended practices for supporting parent choice about treatment options within the larger framework of family-centered practice. 

Reference

Prizant, B.M., & Wetherby, A. M. (2005). Critical considerations in enhancing communication abilities for persons with autism spectrum disorders. In F. Volkmar, A. Klin & Paul, R. (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd Edition). NY: John Wiley & Sons.

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