

Family-Centered Care in Pediatric Practice: When and How?

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Article:

When a group of families and professionals sat down more than 10 years ago to summarize what leads to more effective care, it was an exciting but somewhat overwhelming task. However, since the articulation of the key elements of family-centered care in 1987,^{1,2} it has become clear that the most difficult challenge is to articulate how to make those principles of practice a reality. What types of interactions lead to the partnerships that are the critical cornerstones of family-centered care? How do we train professionals to develop collaborative skills? How do we support families to serve in advisory roles? How do we conduct research that documents the benefits of this approach? How do we create policies that support family-centered practice?

Since that time, there has been a growing number of families and professionals who have risen to these challenges. Advances have been made in medical training, and applications of this approach have been seen in adult health care, early intervention, children with mental health concerns, public policy, and research. The Adaptive Practice model detailed in the article by Feldman et al (see page 111) in this issue represents another important step toward the operationalization of the principles of family-centered care.

In their article, the authors quite accurately note that "physicians express confusion about when and how to provide family-centered health care." Physicians aren't the only ones who struggle with this! Many questions still remain as to "how" to put family-centered care into practice. Guidance can be found in the work on partnerships that has ensued since the beginning of the thrust toward family-centered care. Summarizing the business and help-giving literature, Dunst and Paget³ define partnership as "an association between a family and one or more professionals who function collaboratively using agreed upon roles in pursuit of a joint interest or common goal" (p.29). The Adaptive Practice model provides some guidance toward building the partnerships that are so essential to family-centered care. It also presents some key challenges and cautions.

Key to making this and other models of practice work, however, are three factors. First, there must be a fundamental commitment on the part of the provider to a helping style that truly embodies partnerships. Without this bone-deep commitment to partnership, to creating opportunities at every juncture for families to take the role they choose, and to providing them with the skills, information, and support to do so, no amount of training in the Adaptive Practice model will be effective. The Adaptive Practice model highlights a flexible leadership style—a continuum of decision-making. Much of what the authors describe is quite consistent with family-centered care. But we must be careful to point out that this model is effective only when there is this true, underlying commitment to building an effective partnership. Without it, some professionals will conclude that families do not want to or are not capable of being true

partners, or that partnership is possible only for *some* families. In these instances, we will be left with the old, ineffective, hierarchical model we sought to change. Conversely, as the authors note, collaborating does not mean an abdication of professional responsibility. The best outcomes come from the merger of what both families and professionals have to offer. The unique contribution of each partner is vitally important, for what is accomplished collaboratively is far greater than what can be accomplished separately. Thus, we must vigilantly guard against ineffective, unethical practices that masquerade as family-centered care.

This commitment to partnership colors the model's approach to interaction as well. Interactions between families and providers do vary as does the decision-making. However, without this underlying belief, it may be tempting to equate the amount of interaction between families and professionals with the degree of reciprocity inherent in those interactions. It is certainly easier to have an open and reciprocal interaction when there is more time. But again, if our goal in family-centered care is to develop and nurture empowering partnerships, then we must strive for an exchange of information even if the interaction is short. In partnerships, there are mutual contributions and agreed-upon roles and a desire to work together in pursuit of agreed-upon goals. Even if the interaction is short, this definition demands that the communication be reciprocal. Thus, we should broaden the definition of collaboration in the Adaptive Practice model to characterize all interactions between families and professionals and not just one style.

A second issue is the need to operationalize the specific skills that are necessary to develop partnerships. The model describes the different ways in which leadership can be shared. But without the prerequisite competencies, it will be difficult for professionals to respond to and support this type of flexible leadership. Some of the beliefs and behaviors that have been identified as critical for forging empowering partnerships include the following:

- A presumption of and respect for the inherent capabilities and strengths of families.
- A commitment to and valuing of diversity.
- An ability to communicate and share information in ways that are affirming and useful.
- An ability to treat others with dignity and respect.
- An ability to build on family strengths to enhance feelings of control and independence.
- An ability to provide assistance in ways that match family priorities.

There is an accumulating body of literature linking these and other behaviors to effective helping.³⁻⁵ Thus, if we can structure "how we behave in a way that shows a *presumption toward* adoption of partnership characteristics as a helping style" (p. 198),⁶ then we can begin to create a blueprint to follow for developing family-centered care practices.

Third, and most important, is the issue of family choice. The "Situational Leadership" described in the model may still result in "professionals in charge" if they are the ones who decide what the situation demands in the way of leadership and interaction. The authors quite accurately highlight that the cause of many of the conflicts between families and professionals is a mismatch between what families want in the style of leadership and interaction and what is provided. We know that help-giving is most effective if the help-giver offers aid and assistance that is congruent with the help-seeker's appraisal of his or her problem or need.⁶⁻⁷ What keeps this and other models of practice on the road Co family-centered care is *family choice*. In family-centered practices, 'Situational Leadership' really means "Family-Choice Leadership."

FUTURE DIRECTIONS

The Adaptive Practice model represents an important step forward in providing one mechanism for operationalizing family-centered care. With a commitment to partnering, adequate training in effective

helping skills, and respect for family choice, this model has much to offer. But practice models alone, no matter how compelling, cannot make the case for family-centered care. Health care decision-makers, providers, and third-party payers require evidence that family-centered care is effective. We already have evidence that family-centered practices are cost-effective (A. Talbert-May, unpublished master's thesis, 1995).^{8,9} These practices also result in benefits for families in terms of family empowerment, self-efficacy, satisfaction, and psychological health (G. Singer et al. unpublished manuscript, 1997)¹⁰⁻¹³ and for providers as well.¹⁴⁻¹⁶ But we need additional research in this area. A rigorous and systematic research agenda is needed in which all aspects are collaborative efforts between families and professionals. If we are practicing differently, then our outcome indicators and the manner in which we conduct the research must reflect the new way of operating. Thus, as former U.S. Surgeon General C. Everett Koop, noted, if the goal is "full participation of the family and community," then participation should be its own "outcome measure" (p. 10).⁴ Furthermore research must then inform public policy.

As part of a briefing paper developed for Vice President Al Gore in preparation for his seventh Family Reunion on Family and Health held in July 1998, the Institute for Family-Centered Care⁴ (7900 Wisconsin Avenue, Suite 405, Bethesda, MD 20814; <http://www.familycenteredcare.org>) identified the following recommendations which can be used as a "call to arms" as we continue to articulate what it means to be family-centered and chart new directions for practice, research, and public policy.

INSTITUTE FOR FAMILY-CENTERED CARE RECOMMENDATIONS FOR ADVANCING FAMILY-CENTERED CARE

- Ensure that patients and families participate in all areas of health policy and program development,
- Create a coalition of academic institutions, private foundations, corporations, and government agencies that have the resources and commitment to act as change agents for family-centered care.
- Develop comprehensive models of family-centered care that integrate family-centered principles in every aspect of operations.
- Promote research to strengthen the case for family-centered care, including quantitative, qualitative, and cost-benefit analyses.
- Promote the development of family-centered principles and teaching strategies into medical, nursing, and other health professions' curricula.
- Encourage professional associations and accreditation and standard-setting bodies to explore how they can support the implementation of family-centered care in their activities.
- Advocate for changes in fiscal and regulatory health policy at the state and national levels in ways that incorporate family-centered principles into health care planning, delivery, assessment, and financing, and enunciate those principles in enabling legislation.

CONCLUSION

While we continue on our journey toward articulating how family-centered care can be translated into practice, we are able to answer the other question of "when." The answer can be found in the accumulating body of literature on the benefits of making this fundamental shift toward a commitment to partnerships. The answer is **Always!**

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