Family-Centered Care

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SEVERAL RECENT REPORTS describe the important role medical homes play in ensuring favorable outcomes for children.1-4 Central to the success of a medical home is the practice of family-centered care (FCC). The purpose of this commentary is to describe the evolution of FCC, provide an updated definition of FCC, and discuss implications for practice, programs, and policy.

The development of the FCC definition presented here spans at least 2 decades, beginning in 1987 with Surgeon General Koop's call for "family-centered, community-based care for children with special health care needs and their families," a message that resonated with families and professionals alike.5 The family community, led by Family Voices, took the FCC message to heart and encouraged endorsement of the concept by health practitioner organizations, including the American Academy of Pediatrics and the American Academy of Family Physicians,6 other consumer organizations, including the Institute for Family Centered Care,7-9 and agencies within the Department of Health and Human Services and the Department of Education.10 Although early development of FCC focused on children with special health care needs, recent discussions have emphasized the importance of FCC for all children.

Throughout the long history of FCC, the federal Maternal and Child Health Bureau provided leadership in the development of the concept and ultimately its incorporation into the legislative authority for the Title V program. In 2004, it sponsored a series of meetings to refine the FCC concept. Over 30 individuals representing family and provider organizations, researchers, and policy makers participated in those meetings. After much discussion, a consensus emerged around the following updated definition:

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

This definition applies to all children and their families and all health care practitioners, including pediatrics, family physicians, nurses, social workers, and other allied health care professionals. At its core is the transformational idea that the provision of health care is a partnership in which families and practitioners work together for the child. As the child grows and is able to take on greater decision-making capabilities he/she assumes a partnership role. For this family-professional partnership to succeed, each member must respect the skills and expertise the other partners bring to the relationship; partners must fundamentally trust each other's actions and motivations; communication must be open, and decisions must be made together, with a willingness to negotiate as needed. The attributes of a successful family-professional partnership are further articulated in Figure 1.

Because the FCC concept is evolving, evidence concerning its effectiveness in improving outcomes for children is limited. Indeed, developing a sound evidence base for FCC is an important goal in its own right. However limited, the extant evidence, as summarized in the article by Kuhlthau and colleagues11 in this issue, supports the value of FCC in improving outcomes for children and families. Several studies demonstrate that FCC results in fewer hospitalizations,12-14 reduced hospital costs,13 improvements in medication use,15,16 reduced rates of unmet needs,17 and increased use of appropriate services.12,18 FCC interventions are associated with reduced symptoms,19 improved physical and mental health and functional status,13,20-25 and fewer missed school days17,26 for children with a number of chronic conditions, including asthma, diabetes, attention and behavior disorders, or traumatic brain injuries. Families who receive FCC report higher satisfaction,16,17,25,27,28 better communication,13,29 and greater ease accessing and using service systems.30

The preponderance of studies show that FCC is associated with improved access and satisfaction, more appropriate utilization of services, and improved health and functional status, as well as reductions in use of hospital care, suggesting potential cost savings for FCC, especially for children with significant health problems. The relationship between FCC and these outcomes is shown in Figure 2.

Fully embracing FCC can offer many rewards to practitioners, foremost being the greater satisfaction derived from knowing that the child's needs are better served when the family is a partner and is satisfied with care.
1. Acknowledges the family as the constant in a child’s life
2. Builds on family strengths
3. Supports the child in learning about and participating in his/her care and decision-making
4. Honors cultural diversity and family traditions
5. Recognizes the importance of community-based services
6. Promotes an individual and developmental approach
7. Encourages family-to-family and peer support
8. Supports youth as they transition to adulthood
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings
10. Celebrates successes

Figure 1. Attributes of family-centered care.

Figure 2. Context, process, and outcomes of family-centered care.

However, adopting FCC as a practice model is not without challenges. Changes in clinical training within health and other professional schools are needed to imbue new practitioners with the skills to deliver care in a family-centered fashion. Continuing education programs devoted to FCC are also needed for professionals already in practice. Financial incentives, perhaps using “pay for performance” to reward practitioners for provision of FCC, can help provide additional encouragement to practitioners desiring to adopt FCC-oriented practice styles.

Although FCC was initially developed around the needs of children and their families, the family-professional partnership at its core can benefit adults as well. This is especially true for adults with chronic conditions whose needs go beyond the patient. In this regard, we are encouraged by calls for universal FCC.31

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REFERENCES


