

BEYOND ACCESS: Family Centered Care

There is growing recognition among health care providers of the importance of including a patient's family in medical decision-making in order to achieve desired health outcomes. Family centered care (FCC) is an approach to health care delivery that offers a new way of thinking about the relationships between families and health care providers. It views the family as an integral part of the healing process and promotes involvement of family members as equal partners in the design and delivery of patient care.

THE ISSUE

Advances in specialized health and social services designed to increase the quality of life and to support longer term survival of children with severe chronic illnesses traditionally have not reflected the family's central role in promoting the well-being of these children. FCC provides this missing element. As a new philosophy, FCC places the family, rather than the hospital and medical staff, at the center of the health care delivery system. It recognizes parents as the most knowledgeable and committed advocates for their children.

Simply focusing on the family does not imply that providers are practicing FCC. To promote a common understanding of what FCC entails, the Institute for Family Centered Care (IFCC) established the following eight elements to guide the development of services considered to be family centered:

- recognize the family as the constant in a child's life;
- share unbiased, complete information with parents in an ongoing, supportive manner;
- recognize family strengths and differences in coping;
- encourage and facilitate parent-to-parent support;
- facilitate parent/professional collaboration at all levels of care;
- assure that delivery systems are flexible, accessible, and responsive to families;
- implement appropriate policies and programs that support families; and
- incorporate the developmental needs of children and their families into delivery systems.

The US Maternal and Child Health Bureau, within the US Department of Health and Human Services (US DHHS) has broadened the application of FCC as a standard of care not just for chronically ill children, but for all children. The concept, in fact, can be applied further to people of all ages whose families are involved in their care. FCC is particularly relevant for elderly persons and physically or mentally dependent adults. While more programming

needs to be done in the area of FCC and the elderly, leaders representing hospitals, managed care, and academia have expressed strong support for FCC to be implemented in nursing homes, long-term care, and assisted-living facilities.

GROWING INTEREST IN FAMILY CENTERED CARE

Since February 1996, there have been 5 national conferences and leadership forums promoting FCC among health providers. These meetings were sponsored by a variety of groups concerned with child and family health care issues including the federal government (the Child Care Bureau of the US DHHS); national professional organizations (the American College of Health Care Executives and the Association of American Medical Colleges); non-profit organizations (Family Re-Union 7); and foundations (Nathan Cummings Foundation).

Family centered care has also been promoted through hospital and community-based programs. For example, the IFCC has recognized eight hospitals throughout the US and Canada as "family friendly" for their work in promoting FCC. These institutions have implemented family resource centers, parent liaisons, family faculty programs, patient/family advisory groups, family peer education and support groups, and/or family advisory councils. These programs have also involved families in other aspects of hospital operations ranging from faculty/staff education to facility design.

Community-based groups have also emerged as national leaders in promoting FCC. For example, Project D.O.C.C. (Delivery of Chronic Care) prepares families of children with chronic illnesses and disabilities to teach physicians who care for such children. This program, begun at the North Shore University Hospital in New York, is now at twelve sites and has trained over 200 parents across the country. Kids Connected is a national organization that provides support and networking opportunities for children with a parent with cancer. Care Autism Now (CAN) provides a support network for parents with autistic children, develops models for caring for these children's complex needs, and disseminates information to researchers studying autism. Family Voices, a national organization serving families of children with special health care needs, promotes the dissemination of information designed for families on issues such as Medicaid, managed care, and family centered service delivery.

FOUNDATION INVOLVEMENT IN FAMILY CENTERED CARE

Family centered care has been furthered, in part, by support from foundations. Given the interest among grant-makers in supporting children, families, and the improvement of health care delivery, as well as the relevance of FCC to the elderly and other populations, there are a number of opportunities for foundations to consider this approach in their programming.

The *Nathan Cummings Foundation* has played a leading role in promoting FCC. It sponsored a one-day meeting on FCC in June 1996. In addition to providing grants to the IFCC for programs to promote FCC in hospitals serving mothers, newborns and young children, the Foundation has funded the American College of Healthcare Executives (ACHCE) for the development of a training program for ACHCE members. In proceedings from the June 1996 meeting on FCC, the Foundation identified three general ways in which foundations can help facilitate incorporation of the FCC model across and within institutions. These include:

- *supporting research* on the links between FCC and improvements in child health and on the impact of family-centered teaching practices at health professions schools;
- *supporting innovative programs* such as training programs for both lay people and professionals, community- or hospital-based programs that incorporate the FCC approach (especially in managed care or other large systems), peer-exchange programs for families interested in establishing their own parent resource centers or peer-to-peer networks, and programs that partner professionals and families in promoting FCC; and
- *supporting special projects* that promote FCC such as leadership forums and conferences, educational materials development and media campaigns, and website development and technological resource assistance.

Other foundations supporting FCC include:

- *A.L. Mailman Foundation* – provided a grant to the IFCC for the development of written and audiovisual materials for use by hospitals and other health facilities to design and establish patient and family resource centers;
 - *Arthur K. Watson Charitable Trust and Josiah Macy, Jr. Foundation* – provide funding for initiatives to incorporate FCC principles in physician education and to raise awareness of FCC innovations nationwide;
 - *Hilda B. and Maurice L. Rothschild Foundation* – funds initiatives in Chicago that apply FCC principles to the care of the elderly;
 - *John Connelly Foundation* – provided capital support for the development, construction and staffing of a 4,000 square foot family resource center at the Children's Hospital of Philadelphia;
 - *The Robert Wood Johnson Foundation* – funded programs in New Hampshire and Michigan to implement FCC service delivery in hospitals and managed care settings; and
 - *The United Hospital Fund* – funded Project D.O.C.C. to implement FCC in hospitals throughout New York City.
- Additionally, a number of foundations supported the June 1998 Family Re-Union 7: Families and Health Conference, which convened leaders in FCC to promote both FCC practice and the research to document the impact of FCC on health outcomes and costs. Among them were the *Allina, Annie E. Casey, Benton, Robert Wood Johnson, and Xerox Foundations, as well as the Baruch Family Fund and the Julie and Peter Cummings Philanthropic Fund.*

RESOURCES

COMMUNITY PROGRAMS

Institute for Family Centered Care

301/652-0281

Project D.O.C.C.

516/773-8747

Kids Konected

949/380-4334

Parents Helping Parents

408/727-5775

HOSPITAL PROGRAMS

Family Advisory Council

Blank Children's Hospital

512/241-6726

Family Resource Center

Children's Hospital of Philadelphia

610/695-4660

Blum Patient and Family Resource Center

Dana Farber Cancer Institute

617/632-3459

Family Resource Center

Vanderbilt Children's Hospital

615/322-0111

PUBLICATIONS/REPORTS

Meeting Notes and Synthesis

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www.ncf.org

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