AMERICAN ACADEMY OF PEDIATRICS
Committee on Hospital Care

INSTITUTE FOR FAMILY-CENTERED CARE

POLICY STATEMENT

Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of All Children

Family-Centered Care and the Pediatrician's Role

ABSTRACT. Drawing on several decades of work with families, pediatricians, other health care professionals, and policy makers, the American Academy of Pediatrics provides a definition of family-centered care. In pediatrics, family-centered care is based on the understanding that the family is the child's primary source of strength and support. Further, this approach to care recognizes that the perspectives and information provided by families, children, and young adults are important in clinical decision making. This policy statement outlines the core principles of family-centered care, summarizes the recent literature linking family-centered care to improved health outcomes, and lists various other benefits to be expected when engaging in family-centered pediatric practice. The statement concludes with specific recommendations for how pediatricians can integrate family-centered care in hospitals, clinics, and community settings as well as in more broad systems of care.

ABBREVIATION. AAP, American Academy of Pediatrics.

INTRODUCTION

Family-centered care is an approach to health care that shapes health care policies, programs, facility design, and day-to-day interactions among patients, families, physicians, and other health care professionals. Health care professionals who practice family-centered care recognize the vital role that families play in ensuring the health and well-being of children* and family members of all ages. These practitioners acknowledge that emotional, social, and developmental support are integral components of health care. They respect each child and family's innate strengths and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Family-centered approaches lead to better health outcomes and wiser allocation of resources as well as greater patient and family satisfaction.

Family-centered care in pediatrics is based on the understanding that the family is the child's primary source of strength and support and that the child's and family's perspectives and information are important in clinical decision making. Family-centered practitioners are keenly aware that health care experiences can enhance parents' confidence in their roles and, over time, increase the competence of children and young adults to take responsibility for their own health care, particularly in anticipation of the transition to adult service systems.

"During the past decade, family advocates have promoted family-centered care, 'the philosophies, principles and practices that put the family at the heart or center of services; the family is the driving force.' "[1] This is in harmony with but different from *family pediatrics [family-oriented care]* as outlined in the report of the American Academy of Pediatrics (AAP) Task Force on the Family, which ". . . extends the responsibilities of the pediatrician to include screening, assessment, and referral of parents for physical, emotional, or social problems or health risk behaviors that can adversely affect the health and emotional or social well-being of their child."[1] This policy statement specifically defines the expectations of family-centered care.

HISTORY OF FAMILY-CENTERED CARE

Family-centered care emerged as an important concept in health care the second half of the 20th century, at a time of increasing awareness of the importance of meeting the psychosocial and developmental needs of children and of the role of families in promoting the health and well-being of their children.[2–12] Family-centered care has long been a characteristic of an effective medical home.[13] Much of the early work focused on hospitals; for example, as research emerged about the effects of separating hospitalized children from their families, many institutions adopted policies that welcomed family members to be with their child around the clock and also encouraged their presence during medical procedures. Family-centered care was given additional impetus by consumer-led movements of the 1960s and 1970s and by professionals in education, health, and child development. Federal legislation

*In accordance with the policies of the American Academy of Pediatrics, references to "child" and "children" in this document include infants, children, adolescents, and young adults up to age 21.

of the late 1980s and 1990s,† much of it targeted at children with special needs, provided additional validation of the importance of family-centered principles.

Today, momentum for family-centered care continues to build. It is supported by a growing body of research and by prestigious organizations, such as the Institute of Medicine, which in its 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century*, emphasized the need to ensure the involvement of patients in their own health care decisions, to better inform patients of treatment options, and to improve patients' and families' access to information.[14] All these recommendations are intrinsic to family-centered practice. The AAP has incorporated some of the principles of family-centered care into its policy statements "The Medical Home,"[13] "The Pediatrician's Role in Family Support Programs,"[15] and "Child Life Services."[16] *Guidelines for Perinatal Care*,[17] a manual jointly published by the AAP and the American College of Obstetricians and Gynecologists, also supports the practice of family-centered care.

CORE PRINCIPLES OF FAMILY-CENTERED CARE

Family-centered care is grounded in collaboration among patients, families, physicians, nurses, and other professionals for the planning, delivery, and evaluation of health care as well as in the education of health care professionals. These collaborative relationships are guided by the following principles:

1. Respecting each child and his or her family
2. Honoring racial, ethnic, cultural, and socioeconomic diversity and its effect on the family's experience and perception of care
3. Recognizing and building on the strengths of each child and family, even in difficult and challenging situations
4. Supporting and facilitating choice for the child and family about approaches to care and support
5. Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family
6. Sharing honest and unbiased information with families on an ongoing basis and in ways they find useful and affirming
7. Providing and/or ensuring formal and informal support (eg, family-to-family support) for the child and parent(s) and/or guardian(s) during pregnancy, childbirth, infancy, childhood, adolescence, and young adulthood
8. Collaborating with families at all levels of health care, in the care of the individual child and in professional education, policy making, and program development
9. Empowering each child and family to discover their own strengths, build confidence, and make choices and decisions about their health

†Among the legislation advancing the practice of family-centered are such statutes as: Public Law 99-457, Education of the Handicapped Act Amendments of 1986, Part H—Early Intervention Programs for Handicapped Infants and Toddlers; Maternal and Child Health block grant amendments contained in the Omnibus Budget Reconciliation Act of 1989 (Public Law 101-239); Individuals With Disabilities Education Act of 1990 (Public Law 101-476); the Developmental Disabilities Assistance and Bill of Rights Act of 1990 (Public Law 101-496); Mental Health Amendments of 1990 (Public Law 101-639); and Families of Children With Disabilities Support Act of 1994 (Public Law 103-382).

OUTCOMES OF FAMILY-CENTERED CARE: BRIEF SUMMARY OF RECENT LITERATURE

Family-centered care can improve patient and family outcomes, increase patient and family satisfaction, build on child and family strengths, increase professional satisfaction, decrease health care costs, and lead to more effective use of health care resources, as shown in the following examples from the literature.

Patient and Family Outcomes

- Family presence during health care procedures decreases anxiety for the child and the parents. Research indicates that when parents are prepared, they do not prolong the procedure or make the provider more anxious.[18–21]
- Children whose mothers were involved in their post-tonsillectomy care recovered faster and were discharged earlier than were children whose mothers did not participate in their care.[22]
- A series of quality improvement studies found that children who had undergone surgery cried less, were less restless, and required less medication when their parents were present and assisted in pain assessment and management.[23]
- Children and parents who received care from child life specialists[16] did significantly better than did control children and parents on measures of emotional distress, coping during procedures, and adjustment during hospitalization, the posthospital period, and recovery, including recovery from surgery.[24]
- A multisite evaluation of the efficacy of parent-to-parent support found that one-to-one support increased parents' confidence and problem-solving capacity. Interviewees noted that this type of support could not be provided through any other means.[25,26]
- Family-to-family support can have beneficial effects on the mental health status of mothers of children with chronic illness.[27]
- Since 1993, family-centered care has been a strategic priority at a children's hospital in Georgia. Families participated in design planning for the new hospital, and they have been involved in program planning, staff education, and other key hospital committees and task forces. In recent years, this children's hospital has consistently received among the highest patient and family satisfaction scores in a nationwide survey of comparable pediatric facilities.[28]
- In a federally funded medical home project using a quality improvement model, families served by 13 community-based pediatric practices in New Hampshire and Vermont are collaborating with pediatricians and office staff to enhance the prac-

tices' capacity to provide care to children with special needs and to be more responsive to the priorities and needs of these children and their families. These practices have permanently integrated family input into decisions about their processes of care and have demonstrated a 34% improvement on a standardized measure of medical home implementation.[29]

Staff Satisfaction

- Staff members at a children's hospital in Pennsylvania who participate in education programs with families as teachers believe these experiences to be highly valuable.[30]
- A Vermont program has shown that a family faculty program, combined with home visits, produces positive changes in medical students' perceptions of children and adolescents with cognitive disabilities.[31]
- When family-centered care is the cornerstone of culture in a pediatric emergency department, staff members have more positive feelings about their work than do staff members in an emergency department that does not emphasize emotional support. This may lead to improved job performance, less staff turnover, and a decrease in costs.[32]
- Coordination of prenatal care in a manner consistent with family-centered principles for pregnant women at risk of poor birth outcomes at a medical center in Wisconsin resulted in more prenatal visits, decreased rates of tobacco and alcohol use during pregnancy, higher infant birth weights and gestational ages, and fewer neonatal intensive care unit days. All these factors decrease health care costs and the need for additional services.[33]
- After redesigning their transitional care center in a way supportive of families, creating 24-hour open visiting for families, and making a commitment to information sharing, a children's hospital in Ohio experienced a 30% to 50% decrease in the infants' length of hospital stay. Other outcomes included fewer rehospitalizations, decreased use of the emergency department, greater parent satisfaction, and a decrease in maternal anxiety.[34]
- In Connecticut, a family support service for children with human immunodeficiency virus infection hired family support workers whose backgrounds and life experience were similar to those of families served by the program. This approach resulted in decreases in human immunodeficiency virus-related hospital stays, missed clinic appointments, and foster care placements.[35]
- King County, Washington, has a children's managed care program based on a family-participation service model. Families decide for themselves how dollars are spent for their children with special mental health needs as long as the services are developed by a collaborative team created by the family. In the 5 years since the program's inception, the proportion of children living in community homes instead of institutions has increased from 24% to 91%; the number of children attending community schools has grown from 48% to 95%; and the average cost of care per child or family per month has decreased from approximately $6000 to $4100.[36–38]
- The risk-management literature indicates that patients and families are significantly less likely to initiate lawsuits, even when mistakes have been made, if there is open and effective communication and there are trusting relationships between the practitioner and patient and family. Communication problems that can lead to malpractice, by contrast, include failing to understand patients' or families' perspectives, delivering information poorly, devaluing patient or family views, and provider unavailability.[39,40]
- Ongoing research for family-centered care, especially in community-based practices, is needed.

BENEFITS OF FAMILY-CENTERED CARE FOR PEDIATRICIANS

Given the documented benefits, pediatricians who practice family-centered care can expect to experience the following benefits:

- A stronger alliance with the family in promoting each child's health and development
- Improved clinical decision making on the basis of better information and collaborative processes
- Improved follow-through when the plan of care is developed collaboratively with families
- Greater understanding of the family's strengths and caregiving capacities
- More efficient and effective use of professional time and health care resources (eg, more care managed at home, decrease in unnecessary hospitalizations and emergency department visits, more effective use of preventive care)
- Improved communication among members of the health care team
- A more competitive position in the health care marketplace
- An enhanced learning environment for future pediatricians and other professionals in training
- A practice environment that enhances professional satisfaction
- Greater child and family satisfaction with their health care

RECOMMENDATIONS

1. Pediatricians should actively consider how they can ensure that the core concepts of family-centered care are incorporated into all aspects of their professional practice.
2. Pediatricians should unequivocally convey respect for parents' or guardians' unique insight into and understanding of their child's behavior and needs, should actively seek out their observations, and should appropriately incorporate family preferences into the care plan. Decisions on a patient's plan of care should be made only after such consultation has been made. In hospitals, conducting attending physician rounds (ie, patient presentations and rounds discussions) in the patients' rooms with the family present should be standard practice. This will facilitate the exchange of information between the family

and other members of the child's health care team and encourage the involvement of the family in the decisions that are commonly made during rounds. In teaching hospitals in particular, a lasting impression will be made on students and house staff when they are encouraged in this process by their attending physician.

3. Working with families in decision making and information sharing in all practice settings should always take into account the older child's and young adult's capacity for independent decision making and right to privacy and confidentiality.
4. Parents and guardians should be offered the option to be present with their child during medical procedures and offered support before, during, and after the procedure.
5. Pediatricians should promote the active participation of all children in the management and direction of their own health care, beginning at an early age and continuing into adult health care.
6. In collaboration with families and other health care professionals, pediatricians should examine systems of care, individual interactions with patients and families, and patient flow and should modify these as needed to improve the patient's and family's experience of care.
7. In every health care encounter, pediatricians should share information with children and families in ways that are useful and affirming. They should also ensure that there are systems in place that facilitate children and families' access to consumer health information and support.
8. Pediatricians should encourage and facilitate family-to-family support and networking, particularly with families of similar cultural and linguistic backgrounds or families who have children with the same type of medical condition.
9. In hiring staff, developing job descriptions, and designing performance-appraisal processes, pediatricians should make explicit the expectation of collaboration with patients and families and other family-centered behaviors.
10. Pediatricians should create a variety of ways for children and families to serve as advisors—as members of child or family advisory councils, committees, and task forces dealing with operational issues in hospitals, clinics, and office-based practices; as participants in quality improvement initiatives; as educators of staff and professionals in training; and as leaders or coleaders of peer support programs.
11. Health care institutions should design their facilities to promote the philosophy of family-centered care. Pediatricians should advocate for opportunities for children and families to participate in design planning for renovation or construction of hospitals, clinics, and office-based practices.
12. Education and training in family-centered care should be provided to all trainees, students, and residents as well as staff members.
13. Ongoing research on outcomes and implementation of family-centered care in all venues of care, including community-based pediatrics, is needed.
14. Families should be invited to collaborate in pediatric research programs. They should have a voice at all levels in shaping the research agenda, in determining how children and families participate in research, and in deciding how research findings will be shared with children and families.
15. Health care payment systems should examine their policies to ensure that appropriate reimbursement is provided for family-centered services.

Note: Excerpts of this policy statement have been reprinted from Rationale for Family-Centered Care *with permission from the Institute for Family-Centered Care, 2002.*

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