American Academy of Pediatrics
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POLICY STATEMENT

# Patient- and 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 patient- and family-centered care. In pediatrics, patient- and 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 essential components of high-quality clinical decision-making, and that patients and family are integral partners with the health care team. This policy statement outlines the core principles of patient- and family-centered care, summarizes some of the recent literature linking patient- and family-centered care to improved health outcomes, and lists various other benefits to be expected when engaging in patient- and family-centered pediatric practice. The statement concludes with specific recommendations for how pediatricians can integrate patient- and family-centered care in hospitals, clinics, and community settings, and in broader systems of care, as well. *Pediatrics* 2012;129:394–404

COMMITTEE ON HOSPITAL CARE and INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

**KEY WORD**
patient care

**ABBREVIATIONS**
AAP—American Academy of Pediatrics
IHI—Institute for Healthcare Improvement
IOM—Institute of Medicine
NICHQ—National Institute for Children's Healthcare Quality



## INTRODUCTION

Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and providers that recognizes the importance of the family* in the patient's life. When patient- and family-centered care is practiced it shapes health care policies, programs, facility design, evaluation of health care, and day-to-day interactions among patients, families, physicians, and other health care professionals. Health care professionals who practice patient- and family-centered care recognize the vital role that

*Family is broadly defined. The following serves as an example of such a definition: "We all come from families. Families are big, small, extended, nuclear, multigenerational, with one parent, two parents and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence one another. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations." (New Mexico's Memorial Task Force on Children and Families and the Coalition for Children, 1990)

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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 cultural values and view the health care experience as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Patient- and family-centered approaches lead to better health outcomes and wiser allocation of resources as well as to greater patient and family satisfaction. It should be noted that the term "family-centered care," is replaced with the term "patient- and family-centered care," to more explicitly capture the importance of engaging the family and the patient in a developmentally supportive manner as essential members of the health care team. Patient- and 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. Practitioners of patient- and family-centered care are keenly aware that positive health care experiences in provider/family partnerships 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 American Academy of Pediatrics (AAP) Task Force on 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 patient- and family-centered care.

## CORE PRINCIPLES OF PATIENT- AND FAMILY-CENTERED CARE

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

1. Listening to and respecting each child and his or her family. Honoring racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporating them in accordance with patient and family preference into the planning and delivery of health care.
2. 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 and facilitating choice for the child and family about approaches to care.[2]
3. Sharing complete, honest, and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming, so that they may effectively participate in care and decision-making to the level they choose. Health information for children and families should be available in the range of cultural and linguistic diversity in the community and take into account health literacy. In hospitals, conducting physician rounds in the patients' rooms with nursing staff and family present can enhance the exchange of information and encourage the involvement of the family in decision-making.[3–6]
4. Providing and/or ensuring formal and informal support (eg, peer-to-peer support) for the child and family during each phase of the child's life. Such support is provided so that Health Insurance Portability and Accountability Act and other relevant ethical and legal guidelines are followed.
5. Collaborating with patients and families at all levels of health care: in the delivery of care to the individual child; in professional education, policy making, program development, implementation, and evaluation; and in health care facility design. As part of this collaboration, patients and families can serve as members of child or family advisory councils, committees, and task forces dealing, for example, with operational issues in health care facilities; as collaborators in improving patient safety; as participants in quality-improvement initiatives; and as leaders or coleaders of peer-support programs.[7,8] In the area of medical research, patients and families should have voices 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.[9]
6. Recognizing and building on the strengths of individual children and families and empowering them to discover their own strengths, build confidence, and participate in making

†In accordance with the policies of the AAP, references to "child" and "children" in this document includes infants, children, adolescents, and young adults up to age 21.

choices and decisions about their health care.[7,10–12]

A self-assessment tool is available for families to evaluate whether the care they are receiving fits into the realm of family-centered care and also can be used by pediatricians to evaluate the care they deliver.[13]

## HISTORY OF PATIENT- AND FAMILY-CENTERED CARE

Patient- and family-centered care emerged as an important concept in health care during 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.[14–24] 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. The Maternal and Child Health Bureau of the Health Resources and Service Administration played an active role in furthering the involvement of families and the support of family issues and service needs. Federal legislation 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.[7,10] Family-centered care has long been a characteristic of an effective medical home.[25] Family Voices, founded in 1992, advocates for family-centered, community-based services for children with special health care needs.[26] Building on the work begun in the previous decade, the Institute for Family-Centered Care (now the Institute for Patient- and Family-Centered Care) was also founded in 1992 to foster the development of partnerships among patients, families, and health care professionals and to provide leadership for advancing the practice of family-centered care in all settings.[7,10]

Patient- and family-centered care is supported by a growing body of research and by prestigious organizations, such as the Institute of Medicine (IOM), 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.[27] It specifies 6 domains for improving patient safety, one of which is patient centeredness. The IOM's recommendations are intrinsic to patient- and family-centered practice. In 2006, the Institute for Family-Centered Care and the Institute for Healthcare Improvement (IHI) brought together leadership organizations and patient and family advisors to advance the practice of patient- and family-centered care and ensure that there are sustained, effective partnerships with patients and families in all aspects of the health care system.[7,8]

The AAP has incorporated many of the principles of patient- and family-centered care into several policy statements and manuals.[25,28–37] In 2006, the AAP Board of Directors approved a Parent Advisory Group pilot program under the Section on Home Care.[38] Members of the Parent Advisory Group all share a special interest in patient- and family-centered care, have personal experience with children with special health care needs, and serve as advisors and leaders for patient- and family-centered pediatric care within their own communities and at the national level.

The IHI, founded in 1991, is an independent organization founded to improve health care throughout the world. Among its core values is patient and family centeredness.[39] The National Institute for Children's Healthcare Quality (NICHQ) was launched as an IHI program in 1999. The NICHQ is dedicated to improving the quality of health care provided to children. One component of its 4-part improvement agenda is promoting evidence-based patient- and family-centered care for children with chronic conditions. A strong focus of the NICHQ is the participation of family advisors.[40]

The value of patient- and family-centered care in health care quality is recognized by the American Hospital Association–McKesson Quest for Quality Prize, which raises awareness of patient- and family-centered care and rewards successful efforts to develop and promote improvements in the safety and quality of care.[41] As a result of improved outcomes when patient- and family-centered care is delivered in hospitals, the American Hospital Association partnered with the Institute for Patient- and Family-Centered Care to produce and distribute a toolkit, Strategies for Leadership: Patient- and Family-Centered Care, to the chief executive officer of every hospital in the United States to assist administration and medical leadership in advancing patient- and family-centered practice and to complement other

‡Among the legislation advancing the practice of family-centered care are such statutes as: the Education of the Handicapped Act Amendments of 1986 (Public Law 99-457), 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).

efforts to improve patient safety and the quality of patient care.[8,42–44]

The National Patient Safety Foundation, with patients and families serving on its Board of Directors and on a Patient and Family Committee of the Board, is working to ensure that all health care organizations meaningfully involve patients and families in enhancing patient safety and redesigning health care systems and processes.[45] The Joint Commission, likewise, promotes patient- and family-centered care in their efforts to improve patient safety practices.[46]

The National Survey of Children with Special Health Care Needs in 2005 to 2006 demonstrated that, although most families of children with special health care needs feel they are partners in the care of their child, approximately one-third do not, particularly families with incomes below the poverty level, families without health care insurance, and Hispanic or black families.[47]

## OUTCOMES OF PATIENT- AND FAMILY-CENTERED CARE: BRIEF SUMMARY OF RECENT LITERATURE

Patient- and family-centered care can improve patient and family outcomes, improve the patient's and family's experience, 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

High-quality, patient- and family-centered primary care is associated with a significant reduction in nonurgent emergency department visits in children.[48] 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.[49–53] Children whose mothers were involved in their posttonsillectomy care recovered faster and were discharged earlier than were children whose mothers did not participate in their care.[12]

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.[54] Children and parents who received care from child life specialists[29] did significantly better than did control children and parents on measures of emotional distress, coping during procedures, and adjustment during hospitalization, posthospital adjustment, and recovery, including recovery from surgery.[55]

A multisite evaluation of the efficacy of parent-to-parent support found that 1-to-1 support increased parents' confidence and problem-solving capacity. Interviewees noted that this type of support could not be provided through any other means.[56,57] Family-to-family support can have beneficial effects on the mental health status of mothers of children with chronic illness.[58]

Since 1993, patient- and family-centered care has been a strategic priority at 1 children's hospital. 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.[59] And more recently, it has demonstrated decreased length of stay, reduced medical errors, and improved staff satisfaction.[60,61] This children's hospital is part of a larger academic medical center and health system, recognized nationally for its commitment to patient- and family-centered practice. This health system is among the most cost-efficient organizations in the University Health System Consortium database and, for the past 5 years, has reported a decrease in malpractice claims and litigation, whereas many other academic medical centers, as measured by the University Health System Consortium, have reported annual increases in these expenditures.[8,62]

A different children's hospital has also been integrating patient- and family-centered care throughout its hospital and outpatient facilities since the late 1990s. In 2001, in response to the IOM report, "To Err is Human,"[63] and its outcome data, this hospital implemented an ambitious plan to improve safety and quality. Critical to its efforts and its subsequent success in improving safety and quality, improvement teams have consistently involved families as active members.[64] Because of the hospital's excellence in quality, safety, and patient experience, it has been the recipient of many honors, including the Leapfrog Group Top Hospital Award, the American Hospital Association's McKesson Quest for Quality Prize, and the Picker Award for Excellence in the Advancement of Patient-Centered Care.

In a federally funded medical home project using a quality-improvement model, families served by 13 community-based pediatric practices are collaborating with pediatricians and office staff to enhance the practices' capacity to provide care to children with special health care 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.[65] A review of the emerging literature on medical homes reported that there are favorable outcomes associated with medical home including better health status, timeliness of care, family perception of family centeredness, and family functioning.[66] Clear communication between physicians, patients, and parents leads to improved satisfaction with acute inpatient pediatric and NICU care.[67] Patient and family satisfaction are linked to hospital safety and communication.[68]

Parents of infants who received more patient- and family-centered care while in the NICU and in discharge planning were more satisfied with the care they received, demonstrated increased competence and confidence in infant caregiving, and were more willing to seek help from health care providers.[69–72]

Use of a patient- and family-centered care map to identify opportunities for and implement patient- and family-centered practices resulted in significant improvement in growth parameters and earlier discharge of very low birth weight newborn infants.[73] This care map was designed for the NICU to promote family-centered care throughout daily interventions with infants and families to deliver care in a holistic fashion to meet the developmental, physical, and psychosocial needs of the infants and their families.

### Staff Satisfaction

Staff members at another children's hospital who participate in education programs with families as teachers believe that these experiences are highly valuable.[74] A different 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.[75]

When patient- and 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.[76]

### Cost-Effectiveness

Coordination of prenatal care in a manner consistent with patient- and family-centered principles for pregnant women at risk of poor birth outcomes at 1 medical center resulted in more prenatal visits, decreased rates of tobacco and alcohol use during pregnancy, higher infant birth weights and gestational ages, and fewer NICU days. All of these factors decrease health care costs and the need for additional services.[77]

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, another children's hospital 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.[78]

In 1 community program a family support service for children with HIV infection hired family support workers whose backgrounds and life experiences were similar to those of families served by that program. This approach resulted in decreases in HIV-related hospital stays, missed clinic appointments, and foster care placements.[79]

One county program has a children's managed-care plan 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 ~$6000 to $4100.[80–82]

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 the failure to understand patients' or families' perspectives, poor delivery of information, devaluation of patient or family views, and provider unavailability.[83–86]

The pediatrician who appropriately incorporates patient- and family-centered care concepts in patient encounters will, by necessity, spend additional time with the child and the supporting family. This time has value because it will eventually improve care and prevent unnecessary costs in the future. Consequently, payment for the time spent with a family should be adequate, and paid to the physician without undue administrative complexities.

## BENEFITS OF PATIENT- AND FAMILY-CENTERED CARE FOR PEDIATRICIANS

Given the documented benefits, pediatricians who practice patient- and family-centered care may experience the following benefits:

- A stronger alliance with the family in promoting each child's health and development.[87]
- Improved clinical decision-making based on 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, including the use of patient- and family-centered rounds.
- More efficient use of 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.[88]
- A practice environment that enhances professional satisfaction in both inpatient and outpatient practice.
- Greater child and family satisfaction with their health care.
- Improved patient safety from collaboration with informed and engaged patients and families.
- An opportunity to learn from families how care systems really work and not just how they are intended to work.
- A possible decrease in the number of legal claims, claim severity, and legal expenses.[62,85]

## RECOMMENDATIONS

1. As leaders of the child's medical home, pediatricians should ensure that true collaborative relationships with patients and families as defined in the core concepts of patient- and family-centered care are incorporated into all aspects of their professional practice.[89] The patient and family are integral members of the health care team. They should participate in the development of the health care plan and have ownership of it.
2. Pediatricians should unequivocally convey respect for families' unique insights 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.§
3. In hospitals, conducting attending physician rounds (ie, patient presentations and discussions) in the patients' rooms with nursing staff and the family present should be standard practice.[3–6]
4. Parents or 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. Families should be strongly encouraged to be present during hospitalization of their child, and pediatricians should advocate for improved employer recognition of the importance of family presence during a child's illness.
6. Pediatricians should share information with and promote the active participation of all children, including children with disabilities, if capable, in the management and direction of their own health care. The adolescent's and young adult's capacity for independent decision-making and right to privacy should be respected.
7. In collaboration with patients, families, and other health care professionals, pediatricians should modify systems of care, processes of care, and patient flow as needed to improve the patient's and family's experience of care.
8. Pediatricians should share medical information with children and families in ways that are useful and affirming. This information should be complete, honest, and unbiased.
9. Pediatricians should encourage and facilitate peer-to-peer support and networking, particularly with children and families of similar cultural and linguistic backgrounds or with the same type of medical condition.
10. Pediatricians should collaborate with patients and families and other health care providers to ensure a transition to good-quality, developmentally appropriate, patient- and family-centered adult health care services.
11. In developing job descriptions, hiring staff, and designing performance-appraisal processes, pediatricians should make explicit the expectation of collaboration with patients and families and other patient- and family-centered behaviors.
12. Pediatricians should create a variety of ways for children and families to serve as advisors for and leaders of office, clinic, hospital, institutional, and community organizations involved with pediatric health care.[7,8]

§It is the responsibility of the physician to make medical care decisions, but they should be made after such consultation has been made with the patient and the family. It is the patient's and family's responsibility to comply with the agreed upon medical care decisions. If there are major differences of opinion between physicians and families in the care of the child that cannot be resolved with consultation and further medical opinions, consultation with an ethics committee would be prudent. In rare and extreme circumstances, when the health and the life of the child is in jeopardy, appropriate legal action may need to be taken.

13. The design of health care facilities should promote the philosophy of patient- and family-centered care, such as including single-room care, family sleeping areas, and availability of kitchen and laundry areas and other areas supportive of families. Pediatricians should advocate for children and families to participate in design planning of health care facilities.[90–93]
14. Education and training in patient- and family-centered care should be provided to all trainees, students, and residents as well as staff members.
15. Patients and families should have a voice in shaping the research agenda, and they should be invited to collaborate in pediatric research programs. This should include determining how children and families participate in research and deciding how research findings will be shared with children and families.[9]
16. Pediatricians should advocate for and participate in research on outcomes and implementation of patient- and family-centered care in all venues of care.
17. Incorporating the patient- and family-centered care concepts described in this statement into patient encounters requires additional face-to-face and coordination time by pediatricians. This time has value and is an investment in improved care, leading to better outcomes and prevention of unnecessary costs in the future. Payment for time spent with the family should be appropriate and paid without undue administrative complexities.


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