

Families' Recommendations for Improving Services for Children With Chronic Conditions

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Background: Little research has been done on services and programs for children with chronic conditions and their families from the perspective of family caregivers from diverse cultural backgrounds.

Objective: To identify recommendations that urban caregiving families from 3 major ethnocultural backgrounds have for improving the care of children with chronic conditions (ie, chronic illnesses and disabilities involving physical health impairments).

Design: Qualitative, community-based study.

Setting: General community.

Participants: The volunteer convenience sample included 21 African American, 20 Hispanic, and 22 European American families from 2 midwestern cities who care for school-aged children with chronic conditions.

Methods: In-home semistructured interviews were conducted with each child's family caregivers. Content analytic techniques were used to identify and classify 275 recommendations from 63 families.

Results: Families focused on the following 4 topics: (1) improving the quality of health care services; (2) decreasing barriers to services and programs; (3) improving the training that health care professionals, families, and the public receive about chronic conditions and their management; and (4) improving the quality and availability of community-based services. Families from all 3 ethnic groups had similar recommendations for improving services and programs; however, several African American and Hispanic families also suggested making information more culturally relevant and resources more accessible to families from diverse cultural backgrounds.

Conclusions: The findings indicate that further work needs to be done to deliver care that is, indeed, family centered and culturally sensitive. Families' recommendations provide information that health care professionals and policymakers can use to transform rhetoric about family-centered care into action.

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Editor's Note: This study represents a massive undertaking, and the most striking finding is that not much is new, except perhaps that personalized care is more desired than culturally specific care. That's probably true of all interactions with persons of different ethnic and cultural backgrounds.

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THE PURPOSE of this study is to identify recommendations that African American, Hispanic, and European American family caregivers have for improving services and programs for school-aged children with chronic conditions and their families. Although the principles of family-centered, culturally competent care have been well documented in the literature, few studies have investigated how services should be delivered from the family's point of view. Inherent in the philosophy of family-

centered care is involving families in the development and evaluation of services and programs. Thus, our goal is to improve the quality of care that children and their families receive by informing clinicians and policymakers about families' recommendations.

Within the past decade, significant strides have been made in articulating the philosophy and elements of family-centered care. In 1987, Surgeon General C. Everett Koop called for a national agenda with a commitment to family-centered, community-based, coordinated care and proposed a plan for improving access to care and the quality of life for children with special needs.¹ This

This article is also available on our Web site: www.ama-assn.org/peds.

PARTICIPANTS AND METHODS

This community-based research project on childhood chronic conditions was developed in collaboration with families, community leaders, and health care professionals using a participatory action research model.⁸ Leaders from community organizations that serve children and families were actively involved in the design, recruitment, and implementation of this project. For example, community leaders helped identify and invite families to participate in the project. Because the literature indicates that families from minority backgrounds often have difficulty accessing medical services⁹ and that families from different ethnocultural backgrounds frequently use both traditional medical and alternative health care services,¹⁰ we recruited families through informal community networks rather than the conventional method of recruiting through medical institutions.

RECRUITMENT

A snowball sampling technique was used to identify African American, Hispanic, and European American families who care for school-aged children with chronic physical health impairments, such as asthma, cerebral palsy, diabetes, and spina bifida. A noncategorical approach was used to recruit children with a variety of chronic conditions from diverse socioeconomic backgrounds. The noncategorical approach identifies and classifies children with chronic health conditions by common features of the condition (eg, type of impairment, degree of visibility, prognosis) rather than by the particular medical diagnosis.^{11,12} This method is based on the premise that most children with chronic conditions and their families have similar experiences and encounter similar problems, regardless of the specific diagnosis. A chronic condition was defined as an ongoing physical health condition that has a biological, anatomical, or physiological basis that has long-term sequelae.¹³ Since this study focused on children with physical health impairments, children with cognitive impairments who did not have physical health impairments (eg, autism, learning disability) were excluded from the study. The number of children with a particular type of diagnosis was limited to 4 per ethnic group to ensure a broad representation of different types of chronic conditions.

The same recruitment procedures were used to recruit families from 2 large metropolitan areas in the Midwest—Minneapolis–St Paul, Minn, and Chicago, Ill. Approximately 100 community leaders at each site were informed about the study and invited to tell families about the project. Interested community leaders received packets of information about the project that they distributed to families. An incentive of \$25 per family

was offered for participation. Family caregivers then contacted a project coordinator who informed them about the project in more detail and conducted a telephone screening interview. A limitation of this recruitment strategy is that the actual number of families who were informed about the project is unknown. Families were recruited from a variety of community organizations including (1) organizations that serve school-aged children, such as the Young Men's Christian Association, Young Women's Christian Association, and Boys' and Girls' Clubs; (2) community park and recreation centers; (3) community programs that serve ethnic groups; (4) religious organizations; and (5) parent advocacy and parent support groups.

Of the 67 family caregivers who contacted the project coordinators, 63 met the following inclusion criteria: (1) the child had a chronic illness or disability with a physical health impairment; (2) the child was between 5 and 12 years of age; and (3) the child was living at home at the time of the family interview. Two of the families were excluded because their children were too young, and 2 others because their children had cognitive impairments without any physical health impairments.

Institutional review board approvals of the study were obtained before its initiation. Informed written consent was obtained from family caregivers prior to their participation in the interview.

PARTICIPANT CHARACTERISTICS

This community-based sample included 63 families who have school-aged children (age, 5-12 years) with a variety of chronic physical health impairments. Twenty-one of the families identified themselves as African American, 20 as Hispanic, and 22 as European American. Thirty families were recruited from the Minneapolis–St Paul metropolitan area and 33 from Chicago. Families from each ethnic background were equally represented at each site. Total family incomes ranged from less than \$10 000 to more than \$100 000 per year, with a median family income of \$25 380. Approximately one fourth of the families also received need-based assistance, such as Aid to Families With Dependent Children, food stamps, or both, and one third of the families received Medicaid benefits. More than one third of the children ($n = 22$) received Supplemental Security Income for Disabled Children. (See **Table 1** for further background information.) Because of the community-based nature of the recruitment, education and income were not equally distributed throughout the ethnic groups in this sample. However, the lower median income and educational attainment of the Hispanic and African American groups reflect socioeconomic patterns reported by the US Bureau of the Census.¹⁴

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call to action was based on 8 elements of family-centered care articulated by the Association for the Care of Children's Health,² which included (1) recognizing that the family is the constant in the child's life; (2) facilitating parent-professional collaboration in all aspects of health care; (3) informing the family about the child's care in an appropriate and supportive manner; (4) implementing appropriate policies and programs that meet the

needs of families; (5) recognizing family strengths and respecting different methods of coping; (6) understanding and incorporating the developmental needs of children and their families into health care delivery systems; (7) encouraging and facilitating parent-to-parent support; and (8) assuring that the design of health care delivery systems is feasible, accessible, and responsive to family needs. In 1990, the National Center for Fam-

A wide variety of chronic conditions were represented in this sample. **Table 2** lists the primary medical diagnoses for the children in this sample. Most of the children (60%) had more than 1 chronic condition (eg, asthma and diabetes, seizure disorder and Down syndrome). In addition to physical health impairments, parents reported that 13 of these children also had some type of cognitive impairment (eg, developmental delay or mild mental retardation).

The children ranged in age from 5 to 12 years (median age, 6 years 5 months; mean age, 7 years 6 months). The children in the sample had been living with their chronic conditions for at least 1 year (range, 1-12 years). The children were almost equally divided between the sexes (31 boys and 32 girls). Fifty-six of the children were born in the United States, 3 in Mexico, 2 in Puerto Rico, 1 in Honduras, and 1 in Bolivia.

The age range of family caregivers was 19 to 52 years (mean \pm SD, 35 \pm 6.4 years). The educational level of family caregivers ranged from less than seventh grade to graduate or professional degrees. Twenty-one percent of the male caregivers (n = 8) and 16% (n = 10) of the female caregivers had less than a high school degree; all except 2 of these caregivers had been educated outside the United States. Although Hispanic caregivers were represented in each of the other educational groups, a higher proportion of Hispanic family caregivers had less than a high school education. Ten percent of the male caregivers (n = 4) and 25% of the female caregivers (n = 15) had a high school diploma, and 25% of the male caregivers (n = 10) and 37% of the female caregivers (n = 23) had some vocational-technical education or college education. Forty-four percent of the male caregivers (n = 17) and 21% of the female caregivers (n = 13) had completed a college education. Approximately half of the female caregivers (n = 33) were employed outside the home.

PROCEDURE

In-depth interviews were conducted with the 63 families who were participating in the Cross-cultural Meanings of Childhood Chronic Illness and Disability research project. Spanish and English versions of the interview protocol were developed, reviewed by the advisory boards, and then tested with 2 pilot families. Revisions in wording were made to clarify ambiguous terminology and ensure the cultural relevance of items. The semistructured interview guide included open-ended questions about the family's cultural background, the impact of the child's chronic condition on the family, and the family's recommendations for improving services and programs. This article focuses on the qualitative analysis of collective family responses to the following question: If you were designing programs or services to help families with children like yours, what do you think should be included?

Interviewers representing the 3 ethnocultural groups were recruited and trained by 1 of the investigators (C.K.) who used the same training methods at both sites. Interviewers had ethnocultural backgrounds similar to the families they interviewed. Families had a choice of English-speaking or Spanish-speaking interviewers, and 17 interviews were conducted in Spanish.

Interviews were conducted in home settings with the child's family caregivers. All of the family caregivers older than 16 years were invited to participate in the interview. The majority of interviews included 2 parents (n = 38). Eighteen of the interviews were conducted with mothers alone (16 of these mothers were from single-parent households and 2 were from dual-parent households). Six of the interviews were conducted with mothers and other family members (eg, the child's grandmother, aunt, uncle, the child's adult sibling, or a friend of the mother who was defined as a family member). One of the interviews was conducted with the child's grandparents who had custody of the child with the chronic condition and 2 of the child's aunts. The number of family caregivers who participated in the family interviews ranged from 1 to 4. Family interviews were audiotaped and then transcribed verbatim.

ANALYSIS

The primary goal of the analysis was to identify the range and types of recommendations that family caregivers described during in-depth family interviews. Content analytic strategies¹⁵ were used to identify and categorize families' recommendations for improving services and programs.

The family as a whole was the unit of analysis in this study. Thus, if a mother and a father in the same family made the same recommendation, it was only counted once. First, verbatim transcripts of family interviews were read in their entirety to gain an understanding of the context of the interviews. Then, the principal investigator reviewed each transcript on a line-by-line basis and marked each recommendation. Next, a summary list of 275 recommendations was compiled from the 63 interviews and entered into a computer data file. The principal investigator developed a coding scheme for categorizing these recommendations by theme and topic area. A codebook was developed, and 53 thematic coding categories were organized into 4 topic areas: (1) health care recommendations, (2) decreasing barriers to services and programs, (3) training recommendations, and (4) community-based recommendations. The thematic coding categories are listed as specific recommendations in **Table 3** through **Table 6**. Using the codebook, 2 coders independently categorized the 275 recommendations into 53 themes. Interrater agreement was 97%.

ily-Centered Care³ added an element that specifically addressed cultural sensitivity by recommending that health care professionals honor the racial, ethnic, cultural, and socioeconomic diversity of families. In 1996, Garwick and Millar⁴ adapted these guidelines to fit the adolescent stage of development and identified strategies for promoting resilience in adolescents with chronic conditions and their families. Currently, refer-

ences to family-centered, culturally competent care are commonly found in articles related to children with special health care needs.

Although the philosophy and principles of family-centered care are frequently cited in the literature, less is known about the extent to which these principles are enacted in practice. Relatively little attention has been paid to the skills, supports, and resources that health care

Table 1. Family Demographics*

Family Demographic Characteristics	No. (%)
Family composition	
1 Parent	24 (38)
2 Parents	38 (60)
Grandparents as parents	1 (2)
Primary language	
English	44 (70)
Spanish	17 (27)
English and Spanish	2 (3)
Additional benefits	
AFDC	15 (24)
Medicaid	21 (33)
Food stamps	17 (27)
SSI	22 (35)
Child support	8 (13)
Other income	7 (11)
Household size	
Range	2-9
Median	5

*For these families, the median total annual income was \$25 380, with a range of less than \$10 000 to more than \$100 000 per year. AFDC indicates Aid to Families With Dependent Children; SSI, social security income.

Table 2. Types of Chronic Conditions by Primary Diagnosis

Primary Diagnosis	No.
Arthritis	1
Asthma	10
Biliary atresia	1
Blood dyscrasia	1
Cerebral palsy	8
Congenital heart disease	1
Congenital hypothyroidism	1
Deafness	3
Diabetes insipidus	1
Diabetes mellitus	7
Genetic disorder	1
Hydrocephalus	2
Kidney problems	3
Neuromuscular problems	1
Seizure disorder	8
Short-bowel syndrome	1
Spastic quadriplegia	3
Spina bifida	6
Stroke	1
Tuberous sclerosis	1
Turner syndrome	2
Total	63

professionals need to implement family-centered care.⁵ Given the length of time family-centered principles have been espoused, our interest is in assessing the relevance of these principles to caregiving families from diverse cultural backgrounds.

A few studies have documented the needs of families who care for children with chronic conditions. For example, Horner et al⁶ conducted a statewide assessment with 164 parents of children with chronic health impairments living in Kansas and found that parents identified a broad range of needs, including the need for information about the child's condition and support ser-

Table 3. Health Care Recommendations

Recommendation	No.
Service delivery recommendations	
Improve accessibility and availability of health care services	27
Develop centralized information and referral sources for families and clinicians	9
Provide a case manager, if needed, to access and coordinate resources and services	9
Centralize services for children with chronic conditions	5
Provide comprehensive care to meet the needs of the whole child	4
Provide appropriate referrals and improve access to qualified, knowledgeable clinicians	3
Improve methods of treatment for children with chronic conditions	3
Coordinate services and resources more effectively	3
Include families in planning services and staffing programs	3
Ensure quality of services	3
Provide patient and family advocates	3
Total	72
Family-centered care recommendations	
Provide services and programs that meet the child and family's particular needs	9
Improve communication and working relationships between clinicians and families	5
Provide flexible, family-oriented services and programs	4
Assess family strengths and resources when planning care	3
Total	21

vices, parent-to-parent support, family caregiving, financial assistance, appropriate educational opportunities, and recreational opportunities for the child. Diehl et al⁷ conducted focus group interviews with 80 parents of children with complex medical needs and found that parents emphasized the need for information about the child's condition and how to care for the child. Participants also appreciated health care professionals who valued parents' expertise and expressed frustration when inappropriate treatments and unnecessary hospitalizations occurred as a result of poor collaboration or communication between families and professionals. These findings indicate that families have a broad range of needs and appreciate health care professionals who are sensitive to these needs; however, little is known about the influence of culture on families' identification of needs, since data were not collected from ethnically diverse families. This exploratory study fills a gap in the literature by identifying the recommendations that families from 3 major ethnocultural backgrounds have for improving services and programs for children with chronic conditions and their families. Given the lack of research on this topic, a qualitative research design was selected.

RESULTS

Since no unique themes were identified by ethnic group or site, families' recommendations will be summarized by topic area. Specific recommendations are summarized in Tables 3 through 6. The frequencies listed in these tables indicate the number of families who spontaneously emphasized particular issues in response to the open-ended question about recommendations during the

Table 4. Recommendations for Decreasing Barriers to Services and Programs

Recommendation	No.
Funding-related recommendations	
Provide financial resources, if needed, to cover services and programs	16
Expand insurance coverage to cover costs of treatment	11
Provide needed equipment in home, school, and community settings	4
Make camps for children with special needs financially accessible	3
Simplify reimbursement procedures for families	2
Provide insurance coverage at a reasonable rate	2
Coordinate funding streams	2
Total	40
Transportation-related recommendations	
Provide transportation if needed (eg, to hospitals, clinics, support groups)	6
Provide accessible transportation	1
Total	7

Table 5. Training Recommendations

Recommendation	No.
Training health care professionals	
Train health care professionals how to be more supportive and sensitive to family's needs	9
Train more health care professionals who are knowledgeable about childhood chronic conditions	6
Provide more continuing education opportunities for health care professionals	2
Involve parents of children with chronic conditions in training physicians	1
Total	18
Educating families	
Provide more educational resources and programs for families in different formats	16
Keep the family informed about the child's condition and how to care for the child	11
Improve access and availability of information about chronic conditions and resources	10
Target information to fit the family's needs and child's status	4
Teach a broad range of coping skills to family members	4
Provide resources in different languages and use family-friendly language	3
Train families how to work with professionals and negotiate systems of care	2
Include children and families from different cultural backgrounds in resource materials	1
Total	51
Educating the public	
Educate the public about chronic conditions	3
Sensitize the public to the special needs of children with chronic conditions	2
Total	5

family interview. These frequencies likely underestimate the number of families who would have endorsed particular recommendations if they had responded to specific closed-ended questions instead of an open-ended question.

Table 6. Community-based Recommendations

Recommendation	No.
Support system recommendations	
Develop a variety of types of support groups	10
Provide child and family counseling if needed	9
Increase availability of recreational and community-based activities	8
Provide more parent-to-parent support in a variety of settings	4
Provide opportunities for family-to-family support	4
Make support groups and activities more accessible	3
Ensure quality of support provided in support groups	2
Provide opportunities for youth to meet adults with chronic conditions	1
Total	41
School-related recommendations	
Inform school personnel about chronic conditions and their management	6
Make appropriate accommodations for children with special needs	3
Integrate health care services into school settings	2
Provide choice of schools for children with special needs	1
Total	12
Child care recommendations	
Provide child care so parents can attend support groups and other appointments	3
Improve availability of affordable child care for children with special needs	3
Train child care workers to provide competent care	2
Total	8

HEALTH CARE RECOMMENDATIONS

Participants had numerous recommendations for improving the quality of health care for children with chronic conditions (Table 3). The majority of these recommendations focused on improving the accessibility and availability of health care services. For example, family caregivers suggested that services be provided at more convenient times and locations. Participants also recommended decreasing the time families wait for appointments, developing more information hotlines for families, and providing more health care services in the community (eg, physical therapy and occupational therapy in school and child care settings). Another dominant theme was the need to develop centralized information and referral networks for families and health care professionals. Participants frequently talked about problems related to fragmented care and suggested that services be centralized and coordinated.

Participants also had a number of family-focused recommendations for improving care. A primary recommendation was that services and programs need to fit the child and family's particular needs. To accomplish this goal, they suggested that health care professionals assess family strengths and resources and design services and programs that are flexible and family oriented. To improve the delivery of care, caregivers recommended that communication barriers and working relationships between health care professionals and families be improved.

RECOMMENDATIONS FOR DECREASING BARRIERS TO SERVICES AND PROGRAMS

Based in large part on their personal experiences, family caregivers made numerous suggestions for decreasing financial and transportation barriers (Table 4). Financial barriers were identified by families from lower, middle, and upper income groups. Most of the financial barriers were related to difficulties encountered in accessing services; others were tied to difficulties with insurance companies and time-consuming reimbursement procedures. The financial barriers that participants identified reflect the broad range of costs involved in caring for a child with physical health impairments. Financial barriers can also limit or prohibit the child from receiving particular treatments (eg, transplant surgery, homeopathy), needed equipment, or participating in special programs for children with chronic conditions, such as diabetes or asthma camp. Participants had a variety of policy-related recommendations for decreasing access problems, such as funding the child rather than the program, unifying nonprofit funding streams, and implementing a national health care plan.

Transportation barriers were primarily related to economic issues. Participants without cars emphasized the importance of providing transportation as needed for hospital and clinic visits, as well as support group activities.

TRAINING RECOMMENDATIONS

According to families, information about caring for children with chronic conditions needs to be targeted to children and their families, health and education health care professionals, as well as the general public (Table 5). Participants also identified the need to increase the public and health care professionals' awareness of the needs of children with chronic conditions and their families. For example, one parent stated, "The community should be more educated regarding asthma . . . then the community would be more supportive."

Family caregivers who had encountered poorly prepared health care professionals particularly stressed the importance of providing state-of-the-art information and consultation to health care professionals in practice.

In addition to being knowledgeable about chronic conditions and their management, families emphasized that health care professionals need to know how to be supportive and sensitive to family needs. To meet that goal, one family suggested that parents of children with chronic conditions be actively involved in training physicians. Others suggested that health care professionals need specific interpersonal skills training.

Most of the family education recommendations focused on improving the quantity, quality, and availability of information for children and their families. Participants underscored the importance of keeping the family informed about the child's condition and care. In addition to information about the condition itself, they noted that families also need to know how to cope with the demands of the condition, access resources, and negotiate systems of care. Family caregivers had numerous suggestions for improving the accessibility of information

for families through different formats (eg, pamphlets, videos, computer programs, learning packets) and settings, including hospitals, clinics, schools, and community centers. Some participants also stressed that children and families from diverse cultural backgrounds be included in resource materials. For example, one mother talked about how helpful it would be to have African American children portrayed in videos and pamphlets about asthma. She pointed out that children need role models and that teaching materials should include children from diverse cultural backgrounds. Several Spanish-speaking parents talked about the importance of having teaching materials available in other languages and interpreters available in health care settings. While family caregivers emphasized the need to develop a broad range of resources for families, they also highlighted the need for health care professionals to target information to the particular needs of the child and family.

COMMUNITY-BASED RECOMMENDATIONS

Community-based recommendations focused on (1) increasing the availability and quality of family support, (2) improving the quality of care provided for children with chronic conditions in school settings, and (3) improving the quality and access to child care for these children (Table 6). Participants placed the most emphasis on improving support systems for children and their families. The need for informal, as well as formal, sources of support was evident in their recommendations. Support groups were identified as a major source of informal support, while child and family counseling was an important source of formal support.

Increasing the availability of different types of support, as well as the accessibility and quality of support groups, was a major theme in the family interviews. Family caregivers recommended that various types of support groups need to be available for children with chronic conditions, and for parents, siblings, and extended family members of those children. They also suggested that different types of informal support (eg, parent-to-parent, family-to-family, group, and community support) should be available and accessible to families in a variety of settings. For example, recreational and community-based activities need to be affordable and accommodate for the child's special needs. Support groups should be offered at times and places that family caregivers can attend. A few caregivers, who had negative experiences in support groups, highlighted the importance of ensuring the quality of support provided. However, most caregivers who participated in support groups had positive experiences and highly recommended that support group opportunities be offered to other families.

With regard to school settings, participants focused on the need to better inform school personnel about children with special health care needs. They also discussed the importance of making appropriate accommodations and improving how children with special needs are included in school settings.

Child care recommendations focused on providing child care so parents can attend support groups and the child's medical appointments, improving the availability of child care for children with special health care needs, and training child care workers to provide competent care. A few parents recommended that health care services be integrated into school and child care settings.

COMMENT

Surprisingly, there were no distinctive differences in families' recommendations based on ethnicity alone. Participants stressed the importance of individualizing care rather than providing culturally specific care for particular ethnic groups. This may be because the interview guide focused on understanding the individual family's perspective; families were not asked to represent the viewpoints of their ethnic group. More important, the demands of the child's chronic condition overwhelmed issues of culture in families' stories. The recommendations that families emphasized are consistent with family needs that have been identified in the literature in the past decade. The stability in the content of the recommendations suggests that there is little variation in families' basic needs. However, the social context for providing services and programs has changed. Thus, policymakers need to consider how to implement these recommendations given changes in US demographic patterns, funding, and service delivery systems.

The common denominator in families' discussions about recommendations was improving the care that children with chronic conditions receive. Participants had numerous specific suggestions for improving services for children in home, school, health care, and community settings that are applicable to children with a variety of chronic conditions. An overarching theme was that services need to be designed and targeted to fit the family's particular needs.

Although family caregivers from African American, Hispanic, and European American backgrounds emphasized similar themes, several African American and Hispanic caregivers added suggestions for improving the cultural relevance of services and programs to families. Most of the culturally specific recommendations were associated with improving the information that children and families receive by including children from diverse cultural backgrounds in teaching materials, providing resources in various languages, and disseminating information in communities of color. Notably absent from the family interviews were recommendations that health care professionals need to know information about particular ethnic groups or provide separate support services for specific ethnic or racial groups. Instead, participants from all 3 ethnic groups focused on individualizing care to meet the particular needs of child and family, which is an effective strategy for providing culturally competent care, considering the many variations that exist within and between cultural groups.¹⁶

Given the complex nature of caring for children with chronic conditions and the need for family caregivers to interact with health care, educational, and government-

tal agencies, it is not surprising that caregivers from different cultural backgrounds placed more emphasis on changing systems of care and reducing a broad range of barriers to accessing services and programs than on how health care professionals could be more sensitive to the child and family's particular ethnocultural background. Family caregivers' recommendations suggest that providing culturally competent care includes informing the family about aspects of the medical culture (eg, how health care professionals understand chronic conditions and their management, how to access resources and services, who provides services, what rules and regulations cover how services are delivered) that influence the child's care. With this information, families can access the care they need more effectively.

Including families in the planning and delivery of services and programs was a theme that cut across the different types of recommendations. For example, participants recommended that youth with disabilities and family caregivers be actively involved in planning services and programs in health care and community settings, providing support to other families who have children with chronic conditions, and training health care professionals. Although including persons with disabilities and family caregivers from diverse cultural backgrounds in the training of health care professionals and planning and delivery of services was not a commonly stated recommendation, this strategy is a pivotal one for ensuring that services and programs are both family centered and culturally competent.

The breadth and scope of family caregivers' recommendations reflect the broad range of services needed by children with chronic conditions and their families. It is important to note that participants were recruited from 2 large urban areas in the Midwest. Distinct differences in recommendations were not found between participants who lived in the Minneapolis–St Paul metropolitan area and those who lived in Chicago. However, further studies are needed to determine whether family caregivers from different regions of the country and different types of urban, suburban, and rural locations emphasize similar recommendations. The recommendations data from this project have been used to develop items for the English and Spanish versions of the "What Do You Think?" survey (available from the authors), which will be used in future research and clinical work to systematically assess family caregivers' perceptions of the cultural relevance and quality of services and programs for children with chronic conditions.

Families' recommendations provide important clues for how health care professionals can provide family-centered care that is culturally competent. Instead of focusing on characteristics of ethnocultural groups, family caregivers recommended that health care professionals reduce barriers that hinder a family's access to needed services and fit services and programs to the particular family's needs. By listening and identifying the specific child's and family's needs, the health care professional can tailor intervention that fits within the context of the family and their cultural background.

African American, Hispanic, and European American participants emphasized that educators must train

health care professionals to be supportive and sensitive to the needs of children with chronic conditions and their families. For example, one Hispanic father underscored the importance of preparing physicians, nurses, and technicians to be sensitive to the human needs and feelings of patients and families. He expressed the belief that “if they have sensitivity, it does not matter if you are black or Hispanic or Chinese. . . . They would have the same feeling that we are human beings, so color would not be important.” Empathic interpersonal skills on the part of health care professionals can foster positive, collaborative relationships with family caregivers from diverse cultural backgrounds. Underlying the recommendations for training health care professionals to be more sensitive to the children’s and families’ needs was the value that family caregivers placed on being “heard.” As one African American mother stated, “You know this mother or father or whoever is with this child 24 hours a day knows more about this child than you will ever know. . . . You need to listen to what they are saying. And I think my experience was so frustrating because I did not feel like they were really listening.”

Although this mother thought that some health care professionals overlooked her opinions because of her race, she thought that they primarily did not listen to her because “parents are not listened to.” Participants from all 3 ethnic groups valued health care professionals who listened to their concerns. Active listening is not only an effective strategy for gathering data; it also conveys the health care professional’s respect for the family caregivers’ opinions and feelings.

Family caregivers’ recommendations for how care should be provided are clearly consistent with published family-centered care guidelines, yet their stories indicate significant gaps in the delivery of such care. In 1989, Brewer et al¹⁷ identified a number of barriers that pediatricians face in providing family-centered care, including (1) inadequate training in the long-term care of children with special needs, (2) fragmentation of care, (3) lack of knowledge concerning the comprehensive care of this population, (4) inadequate resources to help coordinate care, and (5) territorial issues inside and outside the medical system. Our findings indicate that families are still encountering these barriers.

The access and quality of information and services for children and families from diverse cultural backgrounds warrants further attention. Information needs to be available in a variety of languages, and children from diverse cultural backgrounds should be included in teaching materials. Health care professionals must discover better ways of informing families about services and programs and ensure that these services meet family needs. Actively including family caregivers from diverse cultural backgrounds in the planning, implementation, and evaluation of services and programs is one strategy that could increase the likelihood of meeting family needs. Moreover, family voices need to be heard and family contributions valued for care to be truly family centered. Our recommendation is that clinicians focus on the assessment of the particular child and family to understand how the cul-

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| <p>Target services to individual family needs</p> <p>Assess the needs and preferences of the child and his or her family</p> <p>Inform families and providers</p> <p>Listen to families</p> <p>Organize and coordinate services</p> <p>Respect the family’s cultural background and expertise</p> |
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An acronym summarizing strategies for providing family-centered care that is culturally sensitive.

tural context influences the child’s care. Cultural issues can be easily integrated into the family history section of the health history. In our clinical experience, open-ended questions about the family’s ethno-cultural background yield rich information, which informs intervention plans.

Based on families’ recommendations, we have developed an acronym (**Figure**) that summarizes strategies for providing family-centered care that is culturally sensitive.

CONCLUSION

The recommendations that participants emphasized substantiate the relevance of principles of family-centered care¹⁻³ to caregiving families from diverse cultural backgrounds. The challenge is to improve the ways in which such care is delivered.

Health care professionals and policymakers must renew their efforts to put the principles of family-centered care into action. Clearly, further work needs to be done to determine how to effectively train health care professionals to provide family-centered care that is culturally competent. Given the financial and time constraints that clinicians face in different practice settings, demonstration projects are needed to field-test and evaluate effective strategies for delivering family-centered care with limited resources. Meanwhile, we recommend that health care professionals listen carefully to family caregivers to gain an understanding of the impact of chronic conditions on families from diverse cultural backgrounds. Likewise, policymakers must listen to families to decrease the barriers (eg, financial, transportation, and service delivery system barriers) that preclude children with chronic conditions from receiving needed services.

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REFERENCES

1. Koop CE. *Surgeon General's Report: Children With Special Health Care Needs—Campaign 87—Commitment to Family-Centered, Coordinated Care for Children With Special Health Care Needs*. Washington, DC: US Dept of Health and Human Services; 1987.
2. National Center for Family-Centered Care. *What Is Family-Centered Care?* Bethesda, Md: Association for the Care of Children's Health; 1990. Brochure.
3. Shelton TL, Jeppson E, Johnson B. *Family Centered Care for Children With Special Health Care Needs*. Bethesda, Md: Association for the Care of Children's Health, 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814, 1987.
4. Garwick A, Millar H. *Promoting Resilience in Youth With Chronic Conditions and Their Families*. Washington, DC: Maternal and Child Health Bureau, Health Resources and Services Administration, US Public Health Service; 1996.
5. Barnsteiner JH, Gillis-Donovan J, Knox-Fischer C, McKindon DD. Defining and implementing a standard for therapeutic relationships. *J Holistic Nurs*. 1994;12:35-49.
6. Horner MM, Rawlins P, Giles, K. How parents of children with chronic conditions perceive their own needs. *Matern Child Nurs*. 1987;12:40-43.
7. Diehl SF, Moffit KA, Wade SM. Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings. *Child Health Care*. 1991;20:170-178.
8. Whyte WF. Advancing scientific knowledge through participatory action research. *Soc Forum*. 1989;4:367-385.
9. Newacheck PW, Stoddard JJ, McManus M. Ethnocultural variations in the prevalence and impact of childhood chronic conditions. *Pediatrics*. 1992;91:1031-1039.
10. Lupton D. *Medicine and Culture*. Thousand Oaks, Calif: Sage Publications; 1994.
11. Pless IB, Pinkerton P. *Chronic Childhood Disorder: Promoting Patterns of Adjustment*. London, England: Henry Kimpton; 1975.
12. Stein R, Jessop D. A noncategorical approach to chronic childhood illness. *Public Health Rep*. 1982;97:354-362.
13. Stein RE, Bauman LJ, Westbrook LE, Coupey SM, Ireys HT. Framework for identifying children who have chronic conditions: the case for a new definition. *J Pediatr*. 1993;122:342-347.
14. US Bureau of the Census. Mean earnings of workers 18 years old and over, by educational attainment, race, Hispanic origin, and sex: 1975 to 1995 (Table A-3). Current population survey. Available at: <http://www.census.gov/population/socdemo/education/tablea-03.txt>. Accessed March 11, 1998.
15. Weber RP. *Basic Content Analysis*. Beverly Hills, Calif: Sage Publications; 1985.
16. Cross T, Bazron B, Dennis K, Isaacs M. *Towards a Culturally Competent System of Care*. Vol 1. Washington, DC: Georgetown University Child Development Center, Center for Child Health and Mental Health Policy Technical Assistance Center; 1989.
17. Brewer EJ, McPherson M, Magrab PR, Hutchins VL. Family-centered, community-based coordinated care for children with special health care needs. *Pediatrics*. 1989;83:1055-1060.

Correction

Incorrect Author Affiliation and Block Quotation Notation Missing. In the article titled "Neonatal Circumcision: Randomized Trial of a Sucrose Pacifier for Pain Control" published in the March issue of the ARCHIVES (1998;152:279-284) an error occurred in Dr Ellman's affiliation. She should have been listed as being affiliated with the Department of Obstetrics and Gynecology and not as having an affiliation with the Department of Pediatrics. Another error occurred on page 279, left-hand column, with the quotation from the 1989 American Academy of Pediatrics Task Force, that begins on line 19. A block quotation should have been set for the words following "stated." The material that begins with the word "local" and ends with "circumcision."⁵ should all have been set as a block quotation. The journal apologizes for the error.