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Access to the Medical Home: Results of the National Survey of Children With Special Health Care Needs

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ABSTRACT. *Objective.* The purpose of this article is to report the findings of the National Survey of Children With Special Health Care Needs regarding parent perceptions of the extent to which children with special health care needs (CSHCN) have access to a medical home.

Methods. Five criteria, selected to reflect the characteristics of a medical home as defined by the American Academy of Pediatrics (AAP) policy statement on the medical home, were analyzed to describe the extent to which CSHCN receive care characteristic of the medical home concept. These criteria included having 1) a usual place for sick/well care, 2) a personal doctor or nurse, 3) no difficulty in obtaining needed referrals, 4) needed care coordination, and 5) family-centered care received. Items from the Survey were selected and clustered to characterize each of the 5 components. Criteria for each item were established with the requirement that the criteria must be met for all items in a component to receive credit for the component.

Results. Results of the survey indicate that 1) approximately half of CSHCN receive care that meets all 5 components established for medical home; 2) most CSHCN have a usual source of care and a personal doctor or nurse, but other components of the medical home, especially elements of care coordination and family-centered care, are lacking; 3) access to a medical home is significantly affected by race/ethnicity, poverty, and the limitations imposed on daily activity by the child's special health care need; and 4) parents of children who do have a medical home report significantly less delayed or forgone care, significantly fewer unmet health care needs, and significantly fewer unmet needs for family support services. The 5 components described represent major characteristics of the comprehensive care model recommended for all children by the AAP.

Conclusions. The findings suggest that although some components of the medical home concept have been achieved for most CSHCN, the comprehensive care model described by the AAP policy statement on the medical home is not yet in place for a significant number of CSHCN and their families. *Pediatrics* 2004;113:1485-1492; children with special health care needs, chil-

dren, chronic illness, access, medical home, quality of health care.

ABBREVIATIONS. CSHCN, children with special health care needs; MCHB, Maternal and Child Health Bureau; AAP, American Academy of Pediatrics.

The National Survey of Children With Special Health Care Needs represents an unprecedented opportunity to establish uniform prevalence estimates for children with special health care needs (CSHCN) and to gather essential information on how this population of children and families fares in the current health care environment. A major component of the survey addresses the medical home. This article presents the findings of the survey related to medical home using the measurement and monitoring framework established by the US Maternal and Child Health Bureau (MCHB).

During the past decade, significant effort has been made at the federal and state levels to expand health care coverage for all children, including those with special health care needs. The State Children's Health Insurance Program and other federal- and state-led efforts have created unprecedented opportunities for outreach and enrollment to ensure that children have access to the care that they need to be healthy and ready to learn.

Insurance alone is not enough. CSHCN require more than the routine physician visit to become and stay healthy. They need a convenient, reliable source for comprehensive care where families are welcomed and encouraged to be involved in their child's care and where comprehensive services are provided and coordinated.¹ However, according to data from the 1994 National Health Interview Survey, 5.6% of CSHCN nationwide were without a usual place to go when they were sick or needed advice about health care, and a significantly larger number of these children received health care that was difficult to access and inadequate to address their complex needs.² Evidence suggests that children with and/or at risk for developmental or behavioral delay may be significantly less likely to receive comprehensive services than children who do not have special needs.³

The medical home concept, which encompasses the characteristics of pediatric care that have long been considered essential for all children, is currently receiving widespread national attention as a mechanism for ensuring quality in health care for children

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and families. The American Academy of Pediatrics (AAP) characterizes the medical home as “not a building, house, or hospital, but rather an approach to providing continuous and comprehensive primary pediatric care from infancy through young adulthood, with availability 24 hours a day, 7 days a week, from a pediatrician or physician whom families trust.”⁴ As such, the medical home concept is not so much a new idea as a strong reiteration and affirmation of comprehensive health care endorsed for all children. Families, child health professionals, and health plans have endorsed the concept of medical home as a standard of care, but much remains to be established to operationalize and ensure implementation of all aspects of the medical home.

For more than a decade, the MCHB has played a major role in the development and promotion of the medical home concept for CSHCN and their families. Beginning in 1988, *A National Goal: Building Service Delivery Systems for Children With Special Health Care Needs and Their Families* laid the groundwork for legislative changes in 1989 (Omnibus Budget Reconciliation Act of 1989), which established the authority of the MCHB to facilitate systems of care for CSHCN and their families.⁵ In 1992, the need to increase the number of states with systems of care for CSHCN became a national health objective and was included in the Healthy People 2010 objectives.⁶ Healthy People 2010 and the MCHB describe the system of care as one in which:

- Families and providers work together as partners at all levels of decision making
- Children have access to ongoing comprehensive health care through a medical home
- Children and families have adequate sources of financing for the services that they require
- Children are screened early and continuously for special health care needs and receive the early intervention services that they require
- Community services are organized so that families can use them easily
- Youths receive the services and support necessary to transition to adult health care, work, and independence

Not only is the medical home included as a component in the national goal to ensure that all states and territories have systems of services for CSHCN (Objective 16-23), but also a goal has been added to the goals for 2010 that specifically addresses the need to ensure that all CSHCN have access to a medical home (Objective 16-22). Moreover, several federal programs, including the Maternal and Child Health Block Grant and the Head Start Program, have established the medical home as a required program-reporting component.

At the community level, physicians and other primary care providers must be available and equipped with the skills and resources to provide the comprehensive health care that children require. The Future of Pediatric Education II, which established recommendations pertinent to the provision of optimal pediatric care, identified the medical home as 1 of 5 key principles in the provision of pediatric care and

recommended that all children receive primary care services through a consistent medical home.⁷

The AAP recently published the “Medical Home Policy Statement.”⁴ The medical home concept described in that statement includes 39 elements that can be summed up as care that is medical home accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective. These characteristics reflect the consensus of professionals and families on how health care for children should be characterized. Although little empirical research has examined the direct and overall effects of a medical home on child health outcomes, some research does exist to support several characteristics associated with the medical home in general.⁸

METHODS

Components of the Medical Home Concept

In this article we have operationalized the medical home concept using the National Survey of Children With Special Health Care Needs. This operationalization includes 5 major components: 1) having a usual place for sick/well care, 2) having a personal doctor or nurse, 3) experiencing no difficulty in obtaining needed referrals, 4) receipt of needed care coordination, and 5) presence of family-centered care. Items from the survey were selected and clustered to characterize each of the 5 components. To the extent possible, items were selected to best reflect the multiple characteristics of medical home described in the AAP policy statement.

Usual Source of Care

Having a usual place to go for sick- and well-child care represents the core element of the medical home concept because it is associated with continuity in the health care that children receive. For the general population, continuity is associated with improved levels of satisfaction, as well as use of necessary preventive and ambulatory care, decreased hospital and emergency department use, and lower costs.⁸⁻¹¹ For children specifically, continuity of care is associated with increased use of preventive and well-child services and improved health outcomes.¹⁰ In fact, having a usual source of care may be the most influential factor in determining whether a child will actually see a physician for routine and sick care. Although CSHCN often receive excellent specialty care, evidence suggests that routine health care often is overlooked, and some basic primary care for CSHCN can be missing.¹²

Personal Doctor or Nurse

Research suggests that the consistency and stability of the doctor-patient relationship is an important determinant of patient satisfaction and access to care. Having a personal doctor or nurse is also a precondition to continuity of care. Children who have a personal doctor or nurse are significantly more likely to receive comprehensive care than children without a personal doctor or nurse.^{3,13} Having a consistent relationship with a primary care provider may help to address minority patient mistrust of health care systems and providers, particularly when the relationship is with a health care professional who is able to bridge cultural and linguistic gaps.³

Referrals for Specialty Care

A medical home facilitates efficient and easy access to specialty care when needed. In turn, access to specialty care is an important aspect of the broader concept of comprehensive care. Coordinated and timely access to specialty care is especially important for CSHCN, who often require greater and more frequent access to multiple specialty services than typically developing children,^{14,15} yet families of CSHCN consistently report difficulty in obtaining and coordinating needed referrals.¹⁶ Delayed recognition of need, denied or delayed referral, lack of coordination, and failure to communicate information are issues often cited as barriers to appropriate specialty care. Although most CSHCN receive most of their care from their primary care physician,¹⁷ the medical home

must ensure that, when necessary, referrals are made appropriately and in a timely manner and ultimately integrated into a well-coordinated treatment plan for the child and family.

Coordinated Care

Care coordination may be the element that most distinguishes medical home from a traditional pediatric practice. Coordinating and monitoring services for CSHCN, indeed all children, are integral aspects of comprehensive care. Activities such as risk screening, assessment, planning care, service coordination, transition planning, and monitoring and reassessment are commonly considered necessary for care coordination. Studies suggest that patients with coordinated care are more likely to follow through on referrals.¹² However, although most pediatricians indicate that someone in the practice serves as the primary coordinator of medical care, far fewer practices routinely schedule extra time for CSHCN to discuss results of visits to specialists, communicate with the child's school, or meet with discharge planning teams to assist in the child's transition back to the community after hospitalization.¹⁸ Although professionals and families alike believe that care coordination is a core element of the medical home, this element is often lacking because of issues of time and reimbursement.⁴

Family-Centered Care

Family-centered care is an essential element of health care for all children. It provides the context within which health and health-related services are provided to the child and the family. It means that families are respected and listened to and receive appropriate information necessary to share in decision making on behalf of their child. Because families are the ultimate coordinators of their child's care and must often navigate complex systems to obtain needed services, promoting family-professional partnership is a necessary component of the health care provided to CSHCN. Existing research suggests that care that is coordinated, comprehensive, accessible, and family centered is associated with parents' perceptions of better access to care and more respectful care.¹⁹ However, for many families, these partnerships do not exist.³ Although most pediatricians report that they involve families in decision making, make an effort to understand their needs, and get to know families, far fewer report actually engaging in specific activities such as translating materials, using interpreters, and obtaining feedback from families regarding the care and services provided by the practice.¹⁸

The National Survey of Children With Special Health Care Needs

Although a legislative agenda and national health objectives promoting systems of care for CSHCN have been in place since at least 1989, there has been, until now, no systematic strategy for determining the extent to which these systems exist. The National Survey of Children With Special Health Care Needs was developed and launched over a 3-year period beginning in 1999.²⁰ The survey, a partnership between the federal MCHB and the National Center for Health Statistics, represents the first-ever measure of CSHCN using a common definition and tool providing national and state prevalence estimates. The survey was designed to

- Establish national and state prevalence estimates for CSHCN younger than 18 years with existing special health care needs, using the MCHB definition that CSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or an amount beyond that required by children generally.²¹
- Determine the impact and status of the system of health care for CSHCN and their families at the national and state levels as baseline estimates for federal and state performance measures, Title V needs-assessment activities, and reporting on Healthy People 2010 national health objectives.

The survey, a random-digit-dialing telephone survey, uses the sampling frame of the National Immunization Survey and the State and Local Area Integrated Telephone Survey mechanism developed by the National Center for Health Statistics. The State and Local Area Integrated Telephone Survey mechanism provides a ready sample and economizes on the cost of selecting and

screening households by allowing all households that were contacted for the National Immunization Survey to become potentially eligible for the National Survey of Children With Special Health Care Needs. The survey screened >373 000 children for special health care needs and identified 38 866 CSHCN interviews to identify and conduct interviews with a minimum of 750 CSHCN per state.

The survey interview consists of 3 parts: 1) identifying CSHCN using the CSHCN screener developed by the Foundation for Accountability; 2) gathering demographic information; and 3) obtaining information on aspects of health care for CSHCN in the areas of health and functional status, access to care, care coordination, satisfaction with care, health insurance coverage, adequacy of health care coverage, and impact on family. The respondent is the parent or legal guardian who is most knowledgeable about the health care of the children in the household.

RESULTS

The overall prevalence of CSHCN in 2001 is 12.8% nationally. Among CSHCN, 52.6% had access to a medical home using the 5 criteria listed above. To be considered as having a medical home, all 5 criteria had to be met.

Although only 52.6% of CSHCN were reported as receiving health care that met all 5 medical home criteria, most met at least 1 of the 5 criteria. Table 1 shows the frequency of each of the 5 medical home criteria for the entire population of CSHCN surveyed by race/ethnicity, age, gender, poverty status, and degree of adverse impact on the child's activity level.

Usual Source of Care

According to the survey, 90.5% of CSHCN had a usual source of care. Children who used the emergency department (0.67%) were not considered to have a usual source of care. The percentage of CSHCN who had a usual source of care decreased as poverty level increased, from 92.7% for nonpoor children (>400% of the federal poverty level) to 87.6% for poor children (<100% of the federal poverty level). Although 91.9% of non-Hispanic white children had a usual source of care, only 85.2% of Hispanic children and 88.0% of non-Hispanic black children had a usual source of care. Only 89.4% of children whose special health care need had a significant adverse impact on the child's activity level had a usual source of care, as opposed to 91.3% of children whose special health care need was reported as having no impact.

Personal Doctor or Nurse

Although most CSHCN were reported to have a personal doctor or nurse, 11.0% did not. Having a personal doctor or nurse varied significantly by race/ethnicity, poverty status, and degree of adverse impact that the special health care need had on the child's activity. As with usual source of care, having a personal doctor or nurse decreased as poverty increased, with 82.1% of poor children having a personal doctor or nurse, compared with 91.1% of nonpoor children. A total of 90.4% of non-Hispanic white children were reported as having a personal doctor or nurse compared with only 86.0% of non-Hispanic black children, 86.8% of Hispanic children, and 85.8% of non-Hispanic children of other race and ethnic backgrounds. Only 86.8% of children whose

TABLE 1. Frequency of the 5 Medical Home Criteria for the Entire Population of CSHCN Surveyed*

	Had a Usual Source of Care		Had a Personal Doctor/Nurse		Had No Problem Obtaining Referrals When Needed		Received Effective Care Coordination When Needed		Received Family-Centered Care	
	%	SE	%	SE	%	SE	%	SE	%	SE
Overall percentage	90.5	0.3	89.0	0.3	78.1	0.6	39.8	1.5	66.8	0.5
Race/ethnicity										
Non-Hispanic white	91.9†	0.3	90.4†	0.3	80.1†	0.6	38.5	1.6	71.4†	0.5
Non-Hispanic black	88.0	0.8	86.0	1.0	76.2†	1.8	47.8	4.5	57.7	1.4
Hispanic	85.2	1.2	86.8	1.1	68.9†	2.2	38.9	5.1	53.2	1.7
Non-Hispanic other	90.3	1.3	85.8	2.2	74.6†	2.8	39.6	8.3	61.2	2.4
Age, y										
0–5	90.7	0.6	89.5	0.7	80.3	1.2	44.2	3.1	68.5†	1.1
6–11	90.6	0.4	89.5	0.5	77.7	0.9	40.9	2.5	68.6	0.7
12–17	90.3	0.4	88.4	0.6	77.2	0.9	35.9	2.5	64.5	0.8
Gender										
Male	90.2	0.4	88.9	0.4	77.5	0.7	40.9	2.0	66.3	0.6
Female	90.9	0.4	89.3	0.5	78.9	0.9	37.9	2.2	67.6	0.8
Poverty status										
<100%	87.6†	0.8	82.1†	1.2	66.7†	2.1	39.4	3.7	50.2†	1.4
100%–199%	88.7	0.7	86.9	0.9	74.4	1.4	39.8	3.9	62.5	1.1
200%–399%	92.0	0.4	91.8	0.4	81.1	0.9	37.3	2.5	70.3	0.8
≥400%	92.7	0.5	91.9	0.5	81.8	1.0	42.2	2.7	74.7	0.9
Impact on activity										
Never affects activities	91.3†	0.4	90.4†	0.4	87.0†	0.8	54.1†	3.0	75.8†	0.7
Sometimes affects activities	90.3	0.4	89.2†	0.5	76.8†	0.9	42.9	2.3	64.5	0.8
Affects activities usually/ always or a great deal	89.4	0.7	86.8†	0.9	69.5†	1.3	32.5	2.5	54.8	1.2

* Significant findings are highlighted in bold.

† $P < .001$.‡ $.001 \leq P \leq .005$.

special health care needs were reported as having a significant adverse impact on the child's activities had a personal doctor or nurse, as opposed to 90.4% of children whose special health care needs had no such impact.

Difficulty Getting Needed Referrals for Specialty Care

Overall, 78.1% of CSHCN were reported as having no difficulty getting needed referrals for specialty care. Difficulty increased by poverty status, race/ethnicity, and degree of adverse impact on the child's activity level. Only 66.7% of poor children had no difficulty receiving needed referrals, as opposed to 81.8% of nonpoor children. Only 68.9% of Hispanic children, 76.2% of non-Hispanic black children, and 74.6% of non-Hispanic children of other racial and ethnic backgrounds were reported as having no difficulty getting needed referrals, as opposed to 80.1% of non-Hispanic white children. Children whose special health care needs had a significant adverse impact on activities of daily living were more than twice as likely to be reported as having difficulty getting needed referrals (30.5%) than children who experienced no adverse impact (13.0%).

Care Coordination

Only 11.7% of parents of CSHCN indicated a need for professional care coordination. As might be expected, children whose special health care needs had a significant adverse impact on their activity levels represented the largest proportion of children who were reported as needing care coordination (24.8%). The measure of care coordination used in operationalizing the medical home concept is a composite of

multiple items including whether the child received care coordination when needed and, if so, whether communication among doctors, as well as communication between doctors and other programs, was perceived by the respondent as very good or excellent. When any of these conditions were not met, care coordination was considered to be inadequate for that child. Consequently, the child would be counted as being without a medical home. Overall, care coordination was adequate for only 39.8% of the 11.7% of children who were reported as needing care coordination. Thus, for this group of children, care coordination represents the element most lacking in the provision of medical homes for CSHCN. For 18.1% of these children, care coordination was not provided when needed. Among those who receive needed care coordination, communication among doctors was considered to be very good or excellent for only 54.4% of children, and communication between doctors and other programs was reported as very good or excellent by only 37.1% of parents.

Although not significant, a greater percentage of parents of non-Hispanic black children reported care coordination as adequate (42.2%) than parents of non-Hispanic white (38.5%), Hispanic (38.9%), and non-Hispanic families of "other" racial and ethnic backgrounds (39.6%). Likewise, a greater percentage of parents of nonpoor children reported adequate care coordination (42.2%) than parents of poor children (39.4%). Although children whose special health care needs had a significant adverse impact on their activity level represented the group most in need of professional care coordination, these children were significantly less likely to receive adequate

care coordination (32.5%) than children whose special health care need had no such impact (54.1%).

Family-Centered Care

Overall, 66.8% of parents of CSHCN reported that doctors provided all elements of family-centered care. The measure of family-centered care is a composite of multiple items, including the extent to which the doctor 1) usually or always listens carefully, 2) spends enough time with the child and the family, 3) is sensitive to the values/customs of the family, 4) provides needed information, and 5) makes the parent feel like a partner. If 1 or more of these characteristics are reported as “never” or “only sometimes” occurring, then family-centered care is not considered to be provided for that child. The extent to which doctors provided family-centered care decreased significantly as poverty level increased, with only 50.2% of poor children receiving family-centered care, as opposed to 74.7% of non-poor children. Parents of non-Hispanic black (57.7%), Hispanic (53.2%), and non-Hispanic children of other racial and ethnic backgrounds (61.2%) were significantly less likely to report that doctors provided family-centered care than parents of non-Hispanic white children (71.4%). Parents of children whose special health care needs had a significant adverse impact on the child’s activity level were significantly less likely (54.8%) to report receiving family-centered care than parents of children whose special health care needs had no impact (75.8%). It is interesting that significant differences among age groups occurred for this component, with a greater percentage of young children (0–5) receiving family-centered care than youths aged 12 to 17.

Who Has a Medical Home?

As noted previously, 52.6% of surveyed children had access to a medical home using the criteria dis-

TABLE 2. ORs for Demographic Characteristics by Status of Not Having a Medical Home*

	Unadjusted OR	Adjusted OR
Race/ethnicity		
Non-Hispanic white	1.0	1.0
Non-Hispanic black	1.7 (1.5–1.9)	1.4 (1.3–1.7)
Hispanic	1.9 (1.7–2.2)	1.5 (1.3–1.8)
Non-Hispanic other	1.6 (1.4–2.0)	1.4 (1.2–1.7)
Age, y		
0–5	0.9 (0.8–1.0)	0.9 (0.8–1.0)
6–11	0.9 (0.8–1.0)	0.9 (0.8–0.9)
12–17	1.0	1.0
Gender		
Male	1.1 (1.0–1.2)	1.1 (1.0–1.2)
Female	1.0	1.0
Poverty status		
<100%	2.4 (2.1–2.8)	1.8 (1.6–2.1)
100%–199%	1.6 (1.4–1.8)	1.3 (1.2–1.5)
200%–399%	1.2 (1.0–1.3)	1.1 (1.0–1.2)
≥400%	1.0	1.0
Impact on activity		
Never affects activities	1.0	1.0
Sometimes affects activities	1.7 (1.5–1.8)	1.5 (1.3–1.6)
Affects activities usually/ always or a great deal	2.7 (2.4–3.0)	2.4 (2.1–2.7)

OR indicates odds ratio.

* Significant findings are highlighted in bold

cussed above. Not surprising, the extent to which all criteria were met for CSHCN varies by a number of demographic factors. Table 2 illustrates the extent to which CSHCN do not have access to a medical home by selected demographic factors. Adjusted odds ratios indicate that Hispanic, non-Hispanic black, and non-Hispanic children of other racial and ethnic backgrounds were significantly more likely not to have a medical home than non-Hispanic white children. Poor children were almost twice as likely not to have a medical home than nonpoor children. Children whose special health care needs had a significant adverse impact on their activity levels were more than twice as likely not to have a medical home as children whose special health care need had no such impact. Boys were somewhat less likely to have a medical home than girls. Age did not have a significant impact on the likelihood of having a medical home.

Impact of Having a Medical Home

Tables 3 and 4 illustrate the impact of having a medical home on the extent to which the child and the family experienced 1) delayed or forgone care, 2) unmet health care needs, 3) missed school days, and 4) unmet needs for family support services. Overall, 9.7% of CSHCN were reported as having delayed or forgone needed care during the past 12 months. As reflected in Table 3, a significantly greater percentage of children without a medical home were reported as having forgone or delayed care (13.9%) than children with a medical home (5.9%). Adjusted odds ratios (Table 4) indicate that children without a medical home are twice as likely to experience delayed or forgone care. Furthermore, poor children and children whose special health care need had a significant adverse impact on their activity level were significantly more likely to experience delayed or forgone care than nonpoor children and children whose special health care need had no significant impact on their activity levels.

More than 16.4% of CSHCN were reported to have unmet health care needs. A significantly greater percentage of children without a medical home (23.%) were reported as having an unmet health care need than children with a medical home (9.9%). Adjusted odds ratios (Table 4) indicated that children without a medical home are more than twice as likely to have unmet health care needs as children who have a medical home. As with delayed or forgone care, poor children and children whose special health care needs had a significant adverse impact on their activity levels were significantly more likely to have unmet health care needs than nonpoor children and children whose special health care needs had no significant adverse impact on their activity levels.

Overall, 49.4% of CSHCN missed 3 or more days of school in the last 12 months. Adjusted odds ratios (Table 4) indicated that having a medical home did not significantly decrease the likelihood of missing school as a result of illness. However, poor children and children whose special health care need had a significant adverse impact on their activity levels were more than 3 times more likely to miss 3 or more

TABLE 3. Impact of Having a Medical Home by Demographic Characteristics*

	Had Delayed/ Forgone Care		Had Unmet Health Care Need		Had 3+ Missed School Days Because of Illness		Had Unmet Need for Family Support Services	
	%	SE	%	SE	%	SE	%	SE
Total	9.7	0.3	16.4	0.4	49.4	0.2	5.1	0.2
Had Medical Home								
Yes	5.93†	0.4	9.93†	0.5	47.4†	0.7	2.22†	0.2
No	13.9	0.6	23.0	0.7	51.1	0.8	7.9	0.4
Race/ethnicity								
Non-Hispanic white	8.83†	0.3	14.2†	0.4	48.6†	0.6	4.6‡	0.2
Non-Hispanic black	10.2	1.0	21.3	1.2	45.1	1.6	5.9	0.8
Hispanic	13.7	1.2	21.9	1.4	49.8	1.8	5.8	0.7
Non-Hispanic other	12.0	2.1	21.1	2.3	49.7	2.5	7.2	1.4
Age, y								
0–5	8.26†	0.7	14.2†	0.9	54.0†	2.3	5.1	0.5
6–11	9.0	0.4	15.7	0.6	47.6	0.7	4.9	0.3
12–17	11.1	0.6	18.2	0.7	50.4	0.8	5.3	0.4
Gender								
Male	9.8	0.4	16.0	0.5	46.2†	0.7	5.3	0.3
Female	9.7	0.5	17.1	0.7	53.8	0.8	4.8	0.3
Poverty status								
<100%	16.14†	1.0	29.5†	1.4	58.5†	1.5	8.15†	0.7
100%–199%	16.3	1.0	25.0	1.1	54.9	1.2	6.8	0.6
200%–399%	8.0	0.5	13.7	0.6	47.7	0.9	5.2	0.4
≥400%	4.4	0.5	7.6	0.6	44.0	1.0	2.8	0.3
Impact on activity								
Never affects activities	5.0†	0.4	8.25†	0.5	36.5†	0.8	1.06†	0.1
Sometimes affects activities	11.1	0.5	17.4	0.6	57.2	0.8	4.7	0.4
Affects activities usually/ always or a great deal	16.0	0.9	29.6	1.1	58.7	1.2	13.2	0.7

* Significant findings are highlighted in bold.

† $P < .001$.‡ $.001 < P > .05$.**TABLE 4.** Adjusted ORs for Impact of Medical Home by Demographic Characteristics*

	Had Delayed/ Forgone Care (OR [95% CI])	Had Unmet Health Care Need (OR [95% CI])	Had 3+ Missed School Days Due to Illness (OR [95% CI])	Had Unmet Need for Family Support Services (OR [95% CI])
Had medical home				
Yes	1.0	1.0	1.0	1.0
No	2.0 (1.7–2.4)	2.1 (1.8–2.4)	1.0 (0.9–1.1)	2.8 (2.1–3.6)
Race/ethnicity				
Non-Hispanic white	1.0	1.0	1.0	1.0
Non-Hispanic black	0.8 (0.6–1.0)	1.1 (0.9–1.3)	0.6 (0.5–0.7)	1.0 (0.7–1.4)
Hispanic	1.1 (0.8–1.4)	0.9 (0.7–1.2)	0.8 (0.6–0.9)	0.9 (0.6–1.2)
Non-Hispanic other	1.1 (0.8–1.6)	1.2 (0.9–1.5)	0.8 (0.6–1.0)	1.0 (0.6–1.5)
Age, y				
0–5	0.6 (0.5–0.8)	0.6 (0.5–0.8)	1.1 (0.9–1.4)	1.0 (0.7–1.3)
6–11	0.7 (0.6–0.8)	0.8 (0.7–0.9)	0.9 (0.8–1.0)	1.0 (0.8–1.2)
12–17	1.0	1.0	1.0	1.0
Gender				
Male	1.0 (0.9–1.2)	0.9 (0.8–1.0)	0.7 (0.6–0.8)	1.1 (0.9–1.3)
Female	1.0	1.0	1.0	1.0
Poverty status				
<100%	3.4 (2.6–4.5)	3.8 (3.0–4.7)	1.7 (1.4–2.0)	1.9 (1.3–2.6)
100%–199%	3.7 (2.8–4.9)	3.4 (2.7–4.2)	1.4 (1.3–1.7)	1.9 (1.3–2.6)
200%–399%	1.8 (1.4–2.3)	1.8 (1.5–2.2)	1.1 (1.0–1.2)	1.8 (1.3–2.4)
≥400%	1.0	1.0	1.0	1.0
Impact on activity				
Never affects activities	1.0	1.0	1.0	1.0
Sometimes affects activities	1.8 (1.5–2.2)	1.9 (1.6–2.2)	2.2 (2.0–2.5)	3.9 (2.8–5.4)
Affects activities usually/always or a great deal	2.6 (2.1–3.2)	3.4 (2.8–4.0)	2.4 (2.1–2.7)	10.1 (7.3–13.9)

OR indicates odds ratio; CI, confidence interval.

* Significant findings are highlighted in bold.

school days than nonpoor children and children whose special health care need had no significant adverse impact.

Only 5.1% of parents reported unmet needs for family support services. However, a significantly greater percentage of children without a medical

home were reported to have unmet needs in this area (7.9%) than children who had a medical home (2.2%). Adjusted odds ratios indicated that children without a medical home were almost 3 times more likely to have unmet needs for family support than children with a medical home. Poor children were almost twice as likely to have unmet needs for family support services, and children whose special health care need had a significant adverse impact on their activity levels were 10 times more likely to have unmet need for these services.

DISCUSSION

The results of this survey are consistent with results of previous studies that indicate that most CSHCN have a usual source of care and, to a somewhat lesser extent, a personal doctor or nurse. Considering that these elements represent basic elements of a medical home and that multiple studies have demonstrated the positive impact of these characteristics on various child health behaviors and outcomes, CSHCN seem to be relatively well off in this regard. For the 90% of CSHCN who have a usual source of care, that source of care was most often a doctor's office, a setting usually associated with the comprehensive care component of a medical home. That poor children and nonwhite children were far less likely to use a doctor's office as their usual source of care may reflect continuing lack of access as a result of insurance and other financial barriers. Some studies also suggest that sociocultural factors and preferences, independent of financial access, may play a role in determining where some children of racial and ethnic minority receive their routine health care.²²

Characteristics such as ease of obtaining referrals, care coordination, and family-centered care remain problematic for many CSHCN. These critical elements go beyond having a usual source of health care to the context and quality of care provided to CSHCN and their families. Even with a usual source of care and a personal doctor or nurse, these elements tend to be weak for many CSHCN.

As noted earlier, care coordination is a distinguishing feature of the medical home concept. Although there is no universally agreed-on definition, substantial consensus exists among families and health care professionals that care coordination is an essential component of the medical home.^{4,16,18} Not every CSHCN requires care coordination, as reflected by the current survey in which only a minority of CSHCN required this service from their medical home. In this survey, children whose needs were more complex required care coordination more often than those with less complex needs. Although not all CSHCN require care coordination, it is important to consider that families may tend to report as needed only those services that they have received in the past. For this reason, families may underreport the need for care coordination. In addition, because the scope of care coordination has not been defined clearly, some families may be receiving but may be unaware of care coordination services being provided, such as assistance in making appointments,

coordinating with medical specialties, and communicating with schools. As care coordination in the pediatric setting becomes more defined and operationalized at the practice level, better estimates should become available regarding the need, cost, and outcomes for this service for CSHCN.

Although most CSHCN have a usual source of care and a personal doctor or nurse, many do not receive care that is family centered. This finding is consistent with other studies that have suggested that pediatric health care for CSHCN may not fully support families in their role as primary caregiver for their children or take full advantage of the resources that families offer in optimizing the impact of the health care provided.^{3,16,18} Providing sufficient information, encouraging partnership, being sensitive to values and customs, spending enough time, and listening to the family's concerns are core elements of a medical home. Considering the increasing body of research that suggests a positive effect of family-centered care on health outcomes, pediatric health care may be missing an important opportunity to enhance child health outcomes.^{23,24}

The benefits of having a medical home are clearly reflected in this survey. Children with a medical home are approximately half as likely to experience delayed or forgone care, less than half as likely to have unmet health care needs, and less than a third as likely to have unmet needs for family support services than children without a medical home. As research continues to demonstrate the important child health outcomes attributable to a usual source of care, improved strategies for reaching all children must be developed and implemented effectively at the federal, state, and community levels.

This survey and others continue to reflect that disparities continue to exist for children in poverty and children of racial and ethnic minority. Significant is that the proportion of CSHCN who experienced characteristics of a medical home decreased as poverty increased. This was true for all measured components of medical home, including usual source of care, a personal doctor or nurse, getting needed referrals for specialty care, care coordination, and family-centered care.

Limitations

There are certain limitations to this analysis. First, although we believe that our operationalization of the medical home concept reflects the AAP conception, it was not possible to measure all 39 individual items using the National Survey of Children With Special Health Care Needs. Second, using parents to report on their perceptions of key components of the medical home is both a strength and a limitation. It provides the first attempt at a consumer-driven national measurement of the medical home concept. However, parents may not always be the best reporters for certain components of the medical home. In future work, it would be helpful to build in the perspective of other key players, especially health care providers, in measuring the extent to which CSHCN have medical homes. Finally, some CSHCN are excluded from or underrepresented in the sur-

vey, including those in institutions, the homeless, and those in migrant populations.

Overall, the survey of CSHCN indicates that despite very significant progress, we have not yet achieved this key component of the system of care defined more than a decade ago by *A National Goal: Building Service Delivery Systems for Children With Special Health Care Needs and Their Families*, OBRA '89, and the Healthy People 2010 objectives. Although most CSHCN have a usual source of care and a personal doctor or nurse, 10% do not, and almost half do not have access to the type of comprehensive health care necessary to promote optimal child outcomes. These findings reinforce the need to continue to expand federal, state, and community efforts to eliminate disparities in access to care and to implement strategies to ensure that all children have access to a medical home.

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