



Assessing and Ensuring a Comprehensive System of Services for Children With Special Health Care Needs: A Public Health Approach

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The US Department of Health and Human Services called for comprehensive systems of services for children with special health care needs in its *Healthy People 2000* and *2010* health care objectives for the nation.

We report on the proportion of children with special health care needs receiving care in high-quality systems of services measured by attainment of 6 essential system elements, or quality indicators, generated from a survey of 40 723 families of children with special health care needs in 2005 and 2006.

Only 17.7% of children with special health care needs received services in a high-quality service system that met all 6 quality indicators in 2005–2006. Therefore, much more work lies ahead to meet the national *Healthy People* objective for these children. (*Am J Public Health.* 2011;101:224–231. doi:10.2105/AJPH.2009.177915)

PROGRAMS ADDRESSING THE unique needs of children, particularly those at increased risk for or with special health care needs, have long been a component of the public health system. The Federal Children's Bureau, established in 1912, was the first government program to serve

children with severe chronic conditions—then referred to as crippled children. That program was eventually transferred to the Maternal and Child Health Bureau (MCHB) of the US Public Health Service in 1969. Today, Children with Special Health Care Needs (CSHCN) programs, supported through Title V of the Social Security Act, exist in every state, territory, and the District of Columbia.¹

Building on a foundation of initiatives by the US Surgeon General,^{2,3} Congress used the 1989 Omnibus Budget Reconciliation Act to direct state and federal Title V public health agencies to

provide and promote family-centered, community-based, coordinated care . . . and facilitate the development of community-based systems of services . . . for children with special health care needs and their families.⁴

Subsequently, the federal government called for comprehensive systems of services for children with special health care needs in its *Healthy People 2000* and *Healthy People 2010* health care objectives for the nation.^{5,6}

At the federal level, the definition of children with special health care needs was significantly broadened beyond “crippled children” in 1998 to include those children

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 amount beyond that required for children generally.^{7(p138)}

During 2005 to 2006, 13.9% (10.2 million) of US children younger than 18 years were estimated to have a special health care need.⁸ This represents an increase in prevalence from the 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN), which produced an estimate of 12.8%. Children with special health care needs are a heterogeneous population with a wide range of diagnoses and functional limitations. Their common denominator is an elevated need for services. Those service needs often must be met in multiple settings by a variety of professionals and service agencies.⁸ Because children with special health care needs often require complex and long-term health services; consume a disproportionate share of health care dollars spent on children⁹; are vulnerable to access, cost, quality, and coverage weaknesses in the health care system^{10–12}; experience disparities in accessing care^{13,14}; and constitute a sizeable minority of children,⁸ it is important that public health agencies assess, monitor, and develop policies to protect and

promote the well-being of this population of children and youths.

Increasingly, Title V CSHCN programs have moved away from providing direct services to children with special health care needs toward a public health infrastructure-building approach to ensure a seamless system of services and access to care for children with special health care needs and their families. To provide direction and accountability, MCHB worked with state Title V agencies, families, and other stakeholders to develop and promulgate 6 key system building blocks, referred to as core outcomes or quality indicators, to describe what families should be able to expect from the service system: (1) family partnership in decision-making and satisfaction with care, (2) receipt of care through a medical home, (3) adequate health insurance, (4) early and continuous screening and surveillance, (5) services that are organized for ease of use, and (6) effective transition planning for adult health care. Together, these quality indicators represent the essential elements needed for high-quality systems of services.^{15,16} Defining a high-quality system as one that meets all 6 quality indicators sets a high bar in that meeting all criteria requires that children receive care



that is adequately financed, organized for easy use, and provided in a family-centered, coordinated fashion.

The 6 quality indicators are intended to complement the 3 core public health functions of (1) assessment of public health problems and needs, (2) policy development to address these issues, and (3) assurance of access to quality programs and services.¹⁷ Public health programs utilize these functions and associated essential health services as tools to promote the quality indicators for CSHCN. Because states and communities differ significantly in regard to the challenges they face in achieving these quality indicators, they differ significantly in how they approach improvement.

TOOLS FOR MONITORING SERVICE SYSTEMS

Working with state Title V CSHCN programs, families, and other stakeholders, MCHB developed a monitoring strategy for assessing progress toward attaining the 6 quality indicators and the systems goal using the NS-CSHCN, a large-scale telephone-based survey of parents of children with special health care needs with independently drawn samples for all 50 states and the District of Columbia.^{18,19} The NS-CSHCN was created in 2000 to establish prevalence estimates and assess and monitor the health status of children with special health care needs. It was first conducted in 2001 and repeated in 2005–2006. A third iteration, the 2009–2010 edition, is currently in the field.

The survey questionnaire includes items on health and functional status, need and receipt of health care services, and measures of the impact of children's health conditions on the family. In addition, questionnaire items designed to measure success in meeting the 6 quality indicators were incorporated into each edition of the survey. The survey provides state-level estimates of prevalence of special health care needs and other health status and health care indicators, thus enabling state CSHCN programs to monitor progress and plan for achieving the quality indicators. In contrast, most public health initiatives for children do not have a state-based survey component conducted on a periodic basis.

A baseline assessment of each quality indicator was conducted with the 2001 NS-CSHCN.²⁰ This article provides a current assessment using the 2005–2006 NS-CSHCN. Another assessment will be available in 2012 with data from the 2009–2010 NS-CSHCN. This monitoring strategy is unique in that it is based entirely on the experiences and perceptions of families of children with special health care needs. Hence, it represents a family-based, or consumer-based, approach to monitoring important national public health goals.

The quality indicators have evolved over time on the basis of ongoing input from stakeholders. As a result, several of the quality indicators and their respective measurement strategies changed between the 2001 and the 2005–2006 surveys. Although these changes improved measurement of the health care experiences of

children with special health care needs and their families, they also created methodological issues that limit comparisons over time. This article presents results from the 2005–2006 NS-CSHCN on the proportion of children for whom each quality indicator is met as well as the proportion for whom all 6 quality indicators and, hence, a system of services, are in place. Variation among states for each of the quality indicators is also provided.⁸ The methodology for estimating the proportion of children with special health care needs for whom the quality indicators are met is described in the appendix (available as a supplement to the online version of this article at <http://www.ajph.org>). The quality indicators and their components are shown in Table 1.

PROPORTION OF SYSTEMS MEETING QUALITY STANDARDS

We describe each of the CSHCN quality indicators, how the indicator was operationalized in the 2005–2006 NS-CSHCN, and the proportion of children for whom the quality indicator was met.

Quality Indicator 1: Decision-Making and Satisfaction

This quality indicator focuses on the important role of the family in sharing decision-making in regards to their children's health. The outcome was operationalized in the 2005–2006 NS-CSHCN by using the 2 components presented in Table 1. An estimated 87.7% of children with special health care needs had doctors and nurses who usually or always made the

family feel like a partner in the child's care, and 59.8% of parents were very satisfied with the services their child received. The criteria for both components together and, thus, for quality indicator 1 were met for 57.1% of the children with special health care needs during 2005–2006. State success rates for this indicator ranged from 46.6% to 65.7% (data not shown). State-level results are available at <http://www.childhealthdata.org>.

Quality Indicator 2: Medical Home

This quality indicator was operationalized by 5 components. First, 92.9% of children with special health care needs had a usual source of preventive care and sick care. Second, 93.5% of children with special health care needs had a personal doctor or nurse. Third, 78.9% of children with special health care needs needing a referral for health care services had no problem receiving it. Fourth, 59.2% of children with special health care needs received effective care coordination when needed. Fifth, 65.8% of children with special health care needs with at least 1 doctor visit in the preceding year received family-centered care. An estimated 47.1% of children with special health care needs nationally had all 5 components of the medical home quality indicator met during 2005–2006. State success rates for this indicator ranged from 36.9% to 57.4%.

Quality Indicator 3: Adequate Health Insurance

Quality indicator 3 was operationalized by using 5 components



TABLE 1—Percentage of Children With Special Health Care Needs (CSHCN) With Criteria for the Quality Indicators and Their Components Met: United States, 2005–2006

| Quality Indicators and Their Components | Valid No. | Not Ascertained, No. | % (SE) |
|--|-----------|----------------------|-------------|
| Quality indicator 1: family partnership in decision-making and satisfaction with care | | | |
| Doctors usually or always make the family feel like a partner ^a | 38 825 | 90 | 87.7 (0.29) |
| Family is very satisfied with services received | 39 734 | 989 | 59.8 (0.42) |
| CSHCN with quality indicator 1 met | 39 664 | 1059 | 57.4 (0.43) |
| Quality indicator 2: receipt of care through a medical home | | | |
| Child has a usual source of care | 40 551 | 172 | 92.9 (0.23) |
| Child has a usual source for sick care | 40 614 | 109 | 94.3 (0.21) |
| Child has a usual source for preventive care | 40 626 | 97 | 97.1 (0.16) |
| Child has a personal doctor or nurse | 40 658 | 65 | 93.5 (0.22) |
| Child has no problems obtaining referrals when needed ^b | 13 358 | 264 | 78.9 (0.64) |
| Child receives effective care coordination ^c | 30 971 | 890 | 59.2 (0.48) |
| Family is very satisfied with doctors' communication with each other ^{c,d} | 26 706 | 274 | 63.8 (0.51) |
| Family is very satisfied with doctors' communication with other programs ^c | 11 077 | 462 | 52.1 (0.82) |
| Family usually or always gets sufficient help coordinating care if needed ^c | 17 803 | 301 | 67.4 (0.60) |
| Child receives family-centered care ^a | 38 242 | 673 | 65.8 (0.42) |
| Doctors usually or always spend enough time ^a | 38 765 | 150 | 78.7 (0.37) |
| Doctors usually or always listen carefully ^a | 38 809 | 106 | 88.8 (0.28) |
| Doctors are usually or always sensitive to values and customs ^a | 38 555 | 360 | 88.9 (0.28) |
| Doctors usually or always provide needed information ^a | 38 773 | 142 | 83.1 (0.32) |
| Doctors usually or always make the family feel like a partner ^a | 38 825 | 90 | 87.7 (0.29) |
| An interpreter is usually or always available when needed ^{a,e} | 420 | 1 | 56.3 (4.35) |
| CSHCN with quality indicator 2 met | 38 886 | 1837 | 47.1 (0.43) |
| Quality indicator 3: adequate private or public insurance to pay for needed services | | | |
| Child had public or private insurance at time of interview | 40 634 | 89 | 96.5 (0.15) |
| Child had no gaps in coverage during the year before the interview | 40 563 | 160 | 91.2 (0.24) |
| Insurance usually or always meets the child's needs ^f | 39 007 | 279 | 87.3 (0.30) |
| Costs not covered by insurance are usually or always reasonable ^f | 38 839 | 447 | 71.9 (0.39) |
| Insurance usually or always permits child to see needed providers ^f | 39 032 | 254 | 90.7 (0.27) |
| CSHCN with quality indicator 3 met | 40 042 | 681 | 62.0 (0.42) |
| Quality indicator 4: early and continuous screening and surveillance | | | |
| Child has received routine preventive medical care in past year | 40 583 | 140 | 77.1 (0.35) |
| Child has received routine preventive dental care in past year ^g | 40 144 | 112 | 78.5 (0.36) |
| CSHCN with quality indicator 4 met | 40 491 | 232 | 63.8 (0.41) |
| Quality indicator 5: community-based services organized for ease of use | | | |
| Child's family has experienced no difficulties using services | 40 344 | 379 | 89.1 (0.26) |
| CSHCN with quality indicator 5 met | 40 344 | 379 | 89.1 (0.26) |
| Quality indicator 6: effective transition planning for adult health care | | | |
| Child receives anticipatory guidance in the transition to adulthood ^h | 14 414 | 1214 | 38.2 (0.69) |
| Doctors have discussed shift to adult provider, if necessary ^h | 4 585 | 524 | 41.9 (1.21) |
| Doctors have discussed future health care needs, if necessary ^h | 13 171 | 507 | 62.4 (0.73) |
| Doctors have discussed future insurance needs, if necessary ^h | 11 162 | 371 | 34.1 (0.77) |

Continued



TABLE 1—Continued

| | | | |
|--|--------|------|-------------|
| Child has usually or always been encouraged to take responsibility for his or her health care needs ^h | 18 062 | 136 | 78.0 (0.56) |
| CSHCN with quality indicator 6 met ^b | 16 889 | 1309 | 41.2 (0.65) |
| CSHCN with age-relevant systems goal met | 36 176 | 4547 | 17.7 (0.33) |

Notes. Valid no. indicates unweighted sample size with non-missing data. Not ascertained includes children for whom a response was refused or was not known by the respondent.

^aThis component was ascertained only for CSHCN with 1 or more doctor visits during the previous year.

^bThis component was ascertained only for CSHCN who needed a referral during the previous year to see a doctor or receive a service.

^cCare coordination was ascertained for CSHCN who used more than 1 type of health care service during the previous year. Specific types of health care services included routine preventive care; specialty care; preventive dental care; other dental care; prescription medicine; physical, occupational, or speech therapy; mental health care; substance abuse treatment; home health care; eyeglasses or vision care; hearing aids or hearing care; mobility aids; communication aids; medical supplies; durable medical equipment; early intervention services; and special educational services.

^dCommunication with other health care professionals is reported only for CSHCN who used specialty care; physical, occupational, or speech therapy; mental health care; substance abuse treatment; or home health care during the previous year.

^eAvailability of interpreters was ascertained only for CSHCN living in homes where the primary language spoken was not English and who needed an interpreter during the previous year.

^fAdequacy of insurance was ascertained only for CSHCN with insurance at the time of the interview.

^gPreventive dental care is reported only for CSHCN aged 1 year or older at the time of the survey.

^hThe transition quality indicator was ascertained for CSHCN aged 12 years or older at the time of the survey. Need for anticipatory guidance was assumed if a discussion occurred or the parent indicated that a discussion would have been helpful.

addressing presence and continuity of coverage, comprehensiveness of coverage, adequacy of financial protection, and provider choice. During 2005–2006, 96.5% of children with special health care needs had coverage at the time of the interview and 91.2% had no gaps in coverage during the preceding year. Among insured children with special health care needs, 87.3% had insurance that usually or always covered needed services. For 71.9%, the costs not covered by insurance were usually or always reasonable. Finally, 90.7% of insured children with special health care needs had insurance that usually or always permitted access to needed service providers. Overall, 62.0% of children with special health care needs had all components met of the quality indicator on health insurance. State rates of success for this indicator ranged from 53.5% to 73.5%.

Quality Indicator 4: Screening and Surveillance

For 2005–2006, this quality indicator was operationalized by 2 components: having at least 1 preventive medical visit and at least 1 preventive dental examination during the previous year. During 2005–2006, 77.1% of children with special health care needs had at least 1 preventive medical visit during the previous year, and 78.5% of those aged 12 months or older had at least 1 preventive dental examination during the previous year. Together, 63.8% of children had this quality indicator met. State achievement rates for this indicator ranged from 50.3% to 79.9%.

Quality Indicator 5: Ease of Use

This quality indicator was operationalized by using a single item: whether the family experienced no difficulties in using the health-related community-based

services the child needed. On the basis of this measurement, 89.1% of children with special health care needs had the quality indicator met in 2005–2006. State success rates for this indicator ranged from 82.6% to 94.3%.

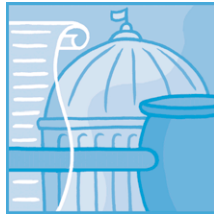
Quality Indicator 6: Effective Transition Planning

Because most transition issues occur as youths approach adulthood, the reference population for this quality indicator was restricted to children with special health care needs aged 12 to 17 years in 2005–2006. This quality indicator was operationalized by using 2 components. An estimated 38.2% of children with special health care needs in this age group received appropriate guidance and support in health aspects of adult transition. Additionally, 78.0% of teens received encouragement to take responsibility for self care. Together, an estimated 41.2% of adolescents

aged 12 to 17 years experienced a fully met transition quality indicator in 2005–2006. State rates of achievement on this indicator ranged from 24.0% to 54.4%.

HIGH-QUALITY SYSTEMS

As indicated above, the 6 quality indicators were originated as building blocks for a system of care. That is, when successfully met, each quality indicator provides an essential piece of a high-quality system of care. A proxy indicator of the proportion of children with special health care needs receiving care in such a system can be calculated based on the proportion receiving care consistent with all quality indicators appropriate for their age group (5 outcomes for children with special health care needs aged 0 to 11 years, 6 outcomes for those aged 12 to 17 years). During 2005–2006, 17.7% of children with special health care needs received



care consistent with all quality indicators and could be considered as receiving care in a high-quality system.

DISPARITIES IN RECEIPT OF HIGH-QUALITY CARE

Table 2 shows how rates of success vary across the quality indicators and the overall systems goal by demographic characteristics, socioeconomic status, and functional status. Significant patterns of effects were found for all variables except gender, which showed a significant association only for the transition quality indicator. The remaining results show a largely consistent pattern across the quality indicators, whereby success rates tended to be higher for non-Hispanic Whites, children in homes where the primary language was English, children in higher-income households, and children with lower levels of functional limitation. In contrast, children in traditionally disadvantaged groups (Blacks, Hispanics, those in low-income families, and those living in non-English-speaking households), and children experiencing more severe limitations in their activities were less likely to report receiving care consistent with the quality indicators. These same patterns also held for the overall systems goal of meeting all quality indicators appropriate for the child's age.

DISCUSSION

This article presents new findings on the degree to which children with special health care

needs are receiving high-quality care, as evidenced by the successful attainment of 6 quality indicators that together can be viewed as representing the essential elements of a system of care. The results presented here are unique in that they are derived from a consumer-based public health monitoring system generated from national survey data.

Success rates in attaining the quality indicators ranged from 41.2% (the quality indicator on transition to adult health care) to 89.1% (the quality indicator on ease in using services) in 2005–2006. For the other 4 quality indicators, success rates ranged from 47% to 64%. These results indicate that a foundation is in place for the nation to meet the 6 quality indicators. Nationally, the health care system is now at the halfway point or beyond for 4 of the 6 quality indicators and close to halfway on the other 2. These positive findings are tempered by the fact that approximately 1 in 6 children with special health care needs receives care consistent with all 6 quality indicators.

An area of concern, however, is the tremendous variation we discovered regarding the rates of success in attaining the quality indicators and systems goal for subgroups of the children with special health care needs population. The most socially disadvantaged and functionally affected children were least likely to have care that met the systems goal. A near twofold differential was found between non-Hispanic White children and Hispanic and

non-Hispanic Black children in meeting the systems goal; a near fourfold difference was found between children in English-speaking and non-English-speaking households; near threefold differences were present between children in high- and low-income households and between children with high and low degrees of functional limitation. These large differences are evidence that substantial disparities or inequities are present in the health care system serving children with special health care needs and corroborate findings from previous studies.^{8,10–14,20} The findings also suggest that racial, ethnic, and socioeconomic disparities may be larger for some system components, such as the medical home, than for others, such as organization of the service system for ease of use. Similarly, disparities by functional status are much greater for the transition quality indicator than they are for the screening quality indicator. Additional research directed at understanding the sources of these disparities could contribute to improved policies to ameliorate them.

Limitations

The monitoring system presented here is subject to limitations. The estimate of the proportion of children with special health care needs receiving their care in a high-quality system of services presented here is not measured directly but rather is derived indirectly based on success in attaining all 6 quality indicators. The assessment of whether the care received meets all of the criteria incorporated in the quality indicators is based on parent

reports. Although its consumer basis is a major strength of the monitoring approach, we recognize that consumers are not the only source of information on achieving the quality indicators. A truly comprehensive approach to measuring the degree to which children are receiving care in high-quality systems should incorporate the perspectives of other participants in the health care system. In addition, as indicated earlier these quality indicators are based on the consensus of nongovernmental stakeholders and the federal and state MCHB partnership through Title V of the Maternal and Child Health Block Grant. They have been refined and improved over the past decade, but further work continues to ensure the validity, reliability, and technical quality of each of the indicators.

All Title V CSHCN programs report annually on their progress toward meeting the CSHCN systems quality indicators and utilize these data in needs assessment activities to identify and address service gaps within the state. For example, many state public health agencies utilize these data to promote state policy and legislation and to mobilize community partnerships for the implementation of important public health goals such as the medical home concept. To ensure public access to the NS-CSHCN and other MCHB public health databases in an easy-to-use format, MCHB supports the Data Resource Center for Child and Adolescent Health (available at <http://www.childhealthdata.org>).



TABLE 2—Proportion of Children With Special Health Care Needs (CSHCN) With Quality Indicators and Systems Goal Met by Selected Sociodemographic Factors: United States, 2005–2006

| | Quality Indicator 1: Family Partnership in Decision-Making and Satisfaction With Care (n = 39 664) | | Quality Indicator 2: Receipt of Care Through a Medical Home (n = 38 886) | | Quality Indicator 3: Adequate Private or Public Insurance (n = 40 042) | | Quality Indicator 4: Early and Continuous Screening and Surveillance (n = 40 491) | | Quality Indicator 5: Services Organized for Ease of Use (n = 40 344) | | Quality Indicator 6: Effective Transition Planning for Adult Health Care (n = 16 889) | | Systems Goal: All Quality Indicators Met (n = 36 176) | |
|--|--|----------------|--|----------------|--|----------------|--|----------------|---|----------------|---|----------------|--|----------------|
| | % (SE) | P ^a | % (SE) | P ^a | % (SE) | P ^a | % (SE) | P ^a | % (SE) | P ^a | % (SE) | P ^a | % (SE) | P ^a |
| Total | 57.4 (0.43) | .093 | 47.1 (0.43) | .179 | 62.0 (0.42) | .901 | 63.8 (0.41) | .209 | 89.1 (0.26) | .008 | 41.2 (0.65) | <.001 | 17.7 (0.33) | .399 |
| Gender | | | | | | | | | | | | | | |
| Male | 56.8 (0.56) | | 46.7 (0.57) | | 62.0 (0.55) | | 63.4 (0.54) | | 88.5 (0.34) | | 38.8 (0.86) | | 17.5 (0.44) | |
| Female | 58.3 (0.67) | | 47.8 (0.67) | | 61.9 (0.65) | | 64.4 (0.64) | | 90.0 (0.42) | | 44.4 (1.00) | | 18.0 (0.51) | |
| Age, y | | | | | | | | | | | | | | |
| 0-5 | 64.2 (0.97) | <.001 | 50.4 (0.99) | <.001 | 65.3 (0.93) | <.001 | 49.5 (0.98) | <.001 | 91.3 (0.58) | <.001 | NA | NA | 17.9 (0.72) | <.001 |
| 6-11 | 57.8 (0.70) | | 47.4 (0.70) | | 60.4 (0.69) | | 68.3 (0.64) | | 88.6 (0.43) | | NA | NA | 21.8 (0.59) | |
| 12-17 | 53.6 (0.65) | | 45.2 (0.65) | | 61.8 (0.63) | | 66.9 (0.60) | | 88.4 (0.41) | | 41.2 (0.65) | | 13.7 (0.47) | |
| Race/ethnicity | | | | | | | | | | | | | | |
| Hispanic | 46.4 (1.44) | <.001 | 32.2 (1.39) | <.001 | 54.2 (1.43) | <.001 | 55.5 (1.43) | <.001 | 84.1 (1.08) | <.001 | 26.3 (2.23) | <.001 | 11.3 (1.10) | <.001 |
| Non-Hispanic White | 61.0 (0.49) | | 52.8 (0.50) | | 63.8 (0.48) | | 67.2 (0.46) | | 89.9 (0.29) | | 46.5 (0.76) | | 20.2 (0.40) | |
| Non-Hispanic Black | 53.6 (1.19) | | 36.6 (1.16) | | 60.7 (1.18) | | 56.6 (1.18) | | 89.7 (0.73) | | 28.7 (1.71) | | 12.5 (0.79) | |
| All other non-Hispanic ^b | 52.9 (1.77) | | 44.3 (1.74) | | 63.4 (1.64) | | 63.4 (1.65) | | 89.2 (1.00) | | 38.6 (2.71) | | 18.3 (1.42) | |
| Primary language in home, all CSHCN | | | | | | | | | | | | | | |
| English | 58.5 (0.43) | <.001 | 48.3 (0.44) | <.001 | 62.7 (0.42) | <.001 | 64.7 (0.41) | <.001 | 89.5 (0.26) | <.001 | 42.2 (0.66) | <.001 | 18.3 (0.34) | <.001 |
| Not English | 34.6 (2.43) | | 20.5 (2.12) | | 45.4 (2.59) | | 44.3 (2.53) | | 80.5 (2.18) | | 12.1 (2.79) | | 4.1 (1.13) | |
| Primary language in home, Hispanic CSHCN only | | | | | | | | | | | | | | |
| Not English | 34.7 (2.48) | <.001 | 20.1 (2.14) | <.001 | 45.3 (2.63) | <.001 | 44.2 (2.58) | <.001 | 80.2 (2.23) | <.001 | 11.7 (2.80) | <.001 | 3.88 (1.15) | <.001 |
| English | 51.9 (1.75) | | 37.8 (1.74) | | 58.2 (1.70) | | 61.2 (1.67) | | 85.9 (1.20) | | 32.3 (2.83) | | 14.6 (1.48) | |
| Poverty status ^c | | | | | | | | | | | | | | |
| <100% of federal poverty level | 50.4 (1.10) | <.001 | 33.8 (1.08) | <.001 | 57.0 (1.10) | <.001 | 48.0 (1.09) | <.001 | 85.0 (0.78) | <.001 | 24.9 (1.55) | <.001 | 9.3 (0.67) | <.001 |
| 100%-199% of federal poverty level | 52.2 (1.00) | | 40.7 (1.00) | | 57.2 (0.99) | | 57.2 (0.98) | | 86.4 (0.70) | | 33.7 (1.59) | | 12.7 (0.71) | |
| 200%-399% of federal poverty level | 58.7 (0.78) | | 51.2 (0.79) | | 62.0 (0.75) | | 67.0 (0.72) | | 90.1 (0.44) | | 43.1 (1.18) | | 18.7 (0.59) | |
| ≥400% of federal poverty level | 64.8 (0.79) | | 56.4 (0.80) | | 69.6 (0.74) | | 77.5 (0.66) | | 91.9 (0.42) | | 53.9 (1.21) | | 26.0 (0.74) | |
| Impact on activities | | | | | | | | | | | | | | |
| Never affected | 69.9 (0.68) | <.001 | 60.3 (0.70) | <.001 | 70.3 (0.63) | <.001 | 66.7 (0.65) | <.001 | 96.4 (0.27) | <.001 | 52.2 (1.08) | <.001 | 25.2 (0.60) | <.001 |
| Somewhat/ moderately affected | 54.7 (0.69) | | 44.0 (0.69) | | 59.0 (0.68) | | 63.2 (0.66) | | 89.7 (0.42) | | 38.9 (1.02) | | 15.4 (0.51) | |
| Always/usually/a great deal affected | 42.4 (0.89) | | 31.2 (0.87) | | 53.6 (0.90) | | 60.4 (0.88) | | 76.8 (0.74) | | 29.0 (1.31) | | 9.5 (0.60) | |

^aχ² test of independence.
^bAll other includes non-Hispanic respondents identified as Asian, Alaska Native, American Indian, Native Hawaiian, Pacific Islander, or mixed race.
^cBased on the US Department of Health and Human Services poverty guidelines. For most households surveyed in 2005, 100% of poverty was defined as \$19 350 for a family of 4. For most households surveyed in 2006, 100% of poverty was defined as \$20 000 for a family of 4.



Clearly challenges remain. Ensuring the capacity, competency, and diversity of the workforce is a major challenge for ensuring a high-quality system of services for children with special health care needs. Addressing the substantial disparities presented here in the quality of care received by children with special health care needs is a daunting but necessary task. Public awareness, information, and education are needed to create informed consumers and other stakeholders. Existing demonstration programs must be evaluated for effectiveness and quality, and innovative research is needed to understand sources of disparities in access to systems of care and to determine the impact of high-quality systems of services on health outcomes for children with special health care needs and their families.

To address these public health challenges, MCHB endorses a strong public–private partnership and a concerted effort by federal and state programs serving children with special health care needs, their families, and their health care professionals. By incorporating the 6 quality indicators as annual performance measures for state Title V programs, a federal–state partnership has been created to achieve this goal. Partnerships have also been established with family organizations (e.g., Family Voices), the American Academy of Pediatrics, the March of Dimes, and other partners to support key elements of the goal. It is through these private–public partnerships that an effective community-based system of care for all

children with special health care needs is possible. The MCHB will continue to provide national leadership, direction, and resources, including demonstration grants to states, technical assistance through national resource centers for each of the quality indicators, public awareness activities, research opportunities, and continued monitoring activities through the NS-CSHCN and the *Healthy People* objectives for the nation.

Conclusions

Public health agencies, consumers, and other stakeholders are critical partners in planning and promoting policy to achieve the goal of a comprehensive system of services for children with special health care needs and their families. Because the NS-CSHCN provides state as well as national data, this survey is an important tool in providing public health agencies with a common definition of the broad population of children with special health care needs, data to guide state-wide needs assessment activities, a common measurement framework for comparing state progress to the nation, a strategy for monitoring the extent to which a system of services exists in the state, and a basis for implementing public health strategies to improve the system of services for children with special health care needs. Although this assessment documents a degree of success nationally in meeting the quality indicators and to a lesser extent the systems goal, continued and concerted efforts by government and private agencies, health care

professionals, and families are needed to ensure that children with special health care needs receive the high-quality care they need. As part of this effort, special attention should be given to eliminating disparities among subgroups of the population disadvantaged by minority racial or ethnic status, poverty, and functional limitations. ■

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Contributors

B.B. Strickland and P.W. Newacheck originated the study and coordinated all aspects of its implementation. P.C. van Dyck, M.D. Kogan, and C. Lauer helped to conceptualize and advise on the study. S.J. Blumberg and C.D. Bethell assisted with the study and completed the analyses. All authors helped to conceptualize ideas, interpret findings, and review drafts of the article.

Human Participant Protection

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State High-Risk Pools: An Update on the Minnesota Comprehensive Health Association

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State health insurance high-risk pools are a key component of the US health care system's safety net, because they provide health insurance to the "uninsurable."

In 2007, 34 states had individual high-risk pools, which covered more than 200,000 people at a total cost of \$1.8 billion.

We examine the experience of the largest and oldest pool in the nation, the Minnesota Comprehensive Health Association, to document key issues facing state high-risk pools in enrollment and financing. We also considered the role and future of high-risk pools in light of national health care finance reform. (*Am J Public Health.* 2011;101:231–237. doi:10.2105/AJPH.2009.185975)

STATE HIGH-RISK POOLS ARE an important component of the US health care system's safety net and will be needed as access expansions are phased in under national health care reform. In 2007, 34 states had individual high-risk pools providing health insurance coverage to 201,047 people at a total cost of \$1.8 billion.¹ High-risk pools have extended coverage to those with preexisting health conditions who do not have access to affordable employer-sponsored insurance, do not qualify for public assistance, and have not been able to secure affordable coverage in the individual market because of their health status. Plan eligibility requires individuals to demonstrate that they either have been denied coverage in the private market or were offered coverage with an excessively high premium. As of this writing, the 15 states without high-risk pools are Arizona, Delaware,

Georgia, Hawaii, Maine, Massachusetts, Michigan, Nevada, New Jersey, New York, Ohio, Pennsylvania, Rhode Island, Vermont, and Virginia.¹

The nation's current economic crisis amplifies the vulnerability of high-risk individuals. Increases in job loss, mortgage foreclosures, early retirement, and bankruptcies and decreases in individuals' financial assets have implications for the number of uninsured and the extent of their health care coverage needs. The current economic situation also has repercussions for states seeking to maintain existing safety net programs with decreasing general revenue dollars.

The recently passed Patient Protection and Affordable Care Act of 2010 (PL 111-148) established a temporary high-risk pool to supplement state efforts to provide coverage for individuals with preexisting medical conditions until 2014, when federal access

expansions will be fully implemented.² The temporary high-risk pool requires individuals to have a 6-month period of being uninsured before enrollment in the pool, which has subsidized premiums and limits annual cost sharing to \$5950 for an individual and \$11900 for a family in 2010.

We profiled one of the largest, oldest, and most expensive state high-risk pools in the nation, the Minnesota Comprehensive Health Association (MCHA, pronounced "M"-sha). We provide current information on enrollment, costs, and financing. We include a discussion of key policy issues that MCHA (and other state high-risk pools) are facing and conclude with a recommendation to develop a plan for those currently enrolled in state high-risk pools to transition into the new national model of health care access.

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