

Building Systems of Care: Findings From the National Survey of Children With Special Health Care Needs

AUTHORS: Michael D. Kogan, PhD,^a Bonnie B. Strickland, PhD,^a and Paul W. Newacheck, DrPH^b

^aUS Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Rockville, Maryland; and ^bUniversity of California, Philip R. Lee Institute for Health Policy Studies and Department of Pediatrics, San Francisco, California

KEY WORDS

children with special health care needs, national estimates, health services, health care utilization, disability

ABBREVIATIONS

CSHCN—children with special health care needs

NS-CSHCN—National Survey of Children With Special Health Care Needs

MCHB—Maternal and Child Health Bureau

The views in this article are those of the authors and not necessarily those of the Health Resources and Services Administration of the US Department of Health and Human Services.

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Address correspondence to Michael D. Kogan, PhD, Health Resources and Services Administration, Maternal and Child Health Bureau, 5600 Fishers Lane, Room 18-41, Rockville, MD 20857. E-mail: [mkogan@hrsa.gov](mailto:mkogon@hrsa.gov)

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Approximately 1 of every 7 children younger than 18 years in the United States, or ~10.2 million children, can be classified as having special health care needs.¹ Children with special health care needs (CSHCN) are defined as 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 by children generally.² Besides any limitations from their conditions, they are at greater risk for unmet health care needs,³ poorer dental health,⁴ and behavioral problems.⁵ Expenditures for their care are ~3 times higher than for other children, accounting for ~42% of all medical care costs for children.⁶

Until the 2001 National Survey of Children With Special Health Care Needs (NS-CSHCN), little was known about this population. The 2001 NS-CSHCN was the first large-scale study devoted to assessing the health and health care experiences of this population. This study was also one of the first surveys of children in which it was possible to derive state-level estimates.

This supplement to *Pediatrics* is dedicated to findings from the second national study of this population: the 2005–2006 NS-CSHCN. Both the 2001 and 2005–2006 NS-CSHCN were funded and directed by the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) and conducted by the Centers for Disease Control and Prevention's National Center for Health Statistics. The 2005–2006 NS-CSHCN was conducted from April 2005 to February 2007. This random-digit-dial telephone survey used the State and Local Area Integrated Telephone Survey platform to obtain approximately equal-sized samples of CSHCN from each state and the District of Columbia; therefore, the survey can provide both national and state estimates.

All of the children younger than 18 years ($N = 300\,910$) in 191\,640 households were screened for special health care needs. For purposes of the survey, CSHCN were identified by using the CSHCN screener and did not include the "at-risk component of the definition."⁷ On the basis of parents' answers to 5 stem questions and 2 follow-up questions, this screener classified children as CSHCN if they had a medical, behavioral, or other health condition that had lasted or was expected to last 12 months or longer and that had resulted in functional limitations, elevated needs for medical care, mental health, or education services or needs for specialized therapy or prescription medications. One child with special health care needs was randomly selected from households with CSHCN to be the target of the detailed interview. The total sample size for the study was 40\,723 CSHCN, with at least 750 in each state. A parent or guardian who knew about the child's health and health care was the respondent. Interviews were conducted in English, Spanish, and 4 Asian languages. The overall weighted response rate was

61.2%. Institutional review board approval for the study was obtained through the National Center for Health Statistics. (Some authors may have also needed to obtain institutional review board approval at their institutions. If so, that is noted in their articles.) Additional details about the survey methodology are available elsewhere.⁸

The survey was designed to serve a number of research purposes. First, the NS-CSHCN allows for the monitoring of an integrated set of 6 core objectives for CSHCN, designed by the MCHB, which forms the basis for measuring the performance of state Title V programs and are reflected in the nation's Healthy People 2010 goals.^{9–11} These objectives specify that:

- families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive;
- children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
- families of CSHCN have adequate private and/or public insurance to pay for the services they need;
- children are screened early and continuously for special health care needs;
- community-based services for children and youth with special health care needs are organized so that families can use them easily; and
- youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

Second, the survey can address broader issues such as the factors associated with the receipt of better quality, more comprehensive care, or whether the children's special health

care needs and their families' concerns are being addressed. As such, the survey contains sections on the children's health and functional status, access to care and unmet needs, care coordination, family-centered care, transition issues, and ease of service use, adequacy and type of health insurance, and impact of the child's conditions on the family. Moreover, the inclusion of geographic identifiers permits researchers to readily add state-level contextual data to the NS-CSHCN, providing a basis for multi-level modeling of population health and health care.

The 15 articles in this supplemental issue of *Pediatrics* were selected from among numerous worthy proposals that were submitted after a national solicitation. The call for proposals was disseminated through professional meetings and data-user Listservs. More than 60 proposals for articles were received and reviewed by the co-editors. The proposals were reviewed for originality, feasibility, variety (covering different survey content areas), geographic diversity (national, regional, and state-level analyses), use of innovative methods, and program, policy, and clinical relevance.

Certain themes emerged when looking at these articles as part of this supplemental issue. In many articles, it was apparent that those CSHCN were reported to be the most affected by their conditions; the most vulnerable, and the most in need of comprehensive, coordinated systems of care, were the least likely to receive such care. They were less likely to have a medical home (Singh et al¹²), less likely to receive transition services (Kane et al¹³), and less likely to receive preventive care (Kenney¹⁴). Their parents were less likely to report receiving family-centered care, less likely to be satisfied with their child's health care (Thompson et al¹⁵), and less likely to

receive genetic counseling (McGrath et al¹⁶). Yet, these families were more likely to pay a higher percentage of their income for the child's care (Parish et al¹⁷) and to have to cut back or stopped work (Okumura et al¹⁸). In a similar vein, parents who had adequate care coordination were less likely to report stopping or reducing work and higher out-of-pocket expenses (Turchi et al¹⁹). Other articles in this supplement examine demographic and socioeconomic correlates of special health care needs (Montes et al²⁰ and Bitsko et al²¹), high-risk demographic groups (Yu and Singh²²), and the health care environment for this population (Blumberg and Carle²³). Although the cross-sectional nature of the data set does not permit examination of the social determinants of special health care needs, Montes et al²⁰ and Bitsko et al²¹ take a step in that direction by identifying factors such as age, gender, race/ethnicity, and income that are associated with increased prevalence of select chronic conditions associated with special health care needs. In addition, certain groups, such as those in households in which English is not the primary language, were found to be at greater risk to lack access to a medical home and family-centered care (Yu and Singh²²). Blumberg and Carle²³ derived a composite variable for assessing the well-being of the child's health care environment, which may be useful for guiding clinicians' evaluations.

It is striking how many authors took advantage of the unique state- and national-level design to compare states or regions. The sophistication of the methods used is also noteworthy: More than half of the authors of the articles in this supplemental issue used multilevel modeling to merge the individual-level data from the survey with contextual-level data, such as state parity laws for mental health

care (Busch and Barry²⁴) or Part C eligibility policy for early intervention programs (McManus et al²⁵). A number of authors used Medicaid or State Children's Health Insurance Program eligibility levels and/or expenditures per child according to state. Without exception, these authors found that higher expenditures and eligibility levels at the state level were associated with benefits such as a greater likelihood of having a medical home (Singh et al¹²), preventive dental care (Kenney¹⁴), greater satisfaction with care (Thompson et al¹⁵), a lower uninsurance rate among State Children's Health Insurance Program participants (Yu and Dick²⁶), and less family burden (Parish et al¹⁷). These findings have clear implications for health care

reform and together suggest that expanding coverage to currently uninsured CSHCN will engender substantial improvements in access and quality of health care while reducing the risk of burdensome expenditures. More generally, almost all of the articles have useful policy implications and suggestions. Collectively, they are good examples of how data can be used to inform policy and practice.

Because the data were obtained from a cross-sectional survey based on parent interviews, there are certain limitations to the analyses presented in this supplement. Notably, families without telephones are underrepresented, although survey weights were adjusted accordingly. In addition, children who were homeless or living in

institutions or were migrants were not interviewed and, therefore, were not represented. As with any cross-sectional survey, there are limits on drawing causal inferences.

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