

National Survey of Children with Special Health Care Needs: Wisconsin-Specific Data

Elizabeth Oftedahl, BA; Ruth Benedict, OTR, DrPH; Murray L. Katcher, MD, PhD

ABSTRACT

Background: The National Center for Health Statistics developed and conducted (2000-2002) the National Survey of Children with Special Health Care Needs (CSHCN), a module of the State and Local Area Integrated Telephone Survey (SLAITS).

Objective: The purpose of this paper is to present the Wisconsin-specific data derived from analysis of the national survey and to make a comparison with the United States as a whole.

Results: In Wisconsin, approximately one fifth (21%) of households have CSHCN, and 13.4% of children have a special health care need; US comparison data are 20% and 12.8%, respectively. When examined by type of special need, Wisconsin shows slightly higher proportions of CSHCN in all categories, when compared with US data, with the exception of limitation in activity. Families in Wisconsin with CSHCN are more likely to report being involved with medical decision making and satisfied with services they receive (67%); having a medical home (57%); having adequate insurance; easy use of community-based service systems (81%); and receiving services to make transition to adult life (7.5%).

Conclusion: Though Wisconsin has a slightly higher proportion of CSHCN than the United States as a whole, a greater proportion of Wisconsin families re-

ceive important services. These measurements allow us to strive for further improvement through coordination of services in the private health care delivery sector with public health programs.

INTRODUCTION

The federal Maternal and Child Health Bureau defines children with special health care needs (CSHCN) as “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 amount beyond that required by children generally.”¹

The 1994-1995 Disability Supplement to the National Health Interview Survey, for the first time, provided population-based data on the special health care needs of non-institutionalized US children.² From these data, it was estimated that 18% of US children have a special health care need. However, there are limitations to this survey, including the lack of state-level information and the fact that it was fielded prior to the adoption of the above definition of CSHCN.³ The National Survey of CSHCN was developed to begin to answer questions regarding how many children meet the definition of CSHCN, where they reside, the nature of their health and functional status, the types of services they use, and whether children and their families feel their needs are being met.

METHODS

To obtain responses in SLAITS from 750 CSHCN in each state, 196,888 households with children were screened, 373,055 children were screened for special health care needs, and 38,866 CSHCN interviews were completed.⁴ In Wisconsin, 3642 households with children were screened, 6948 children were screened for special health care needs, and 750 CSHCN interviews were completed.

Ms Oftedahl is the epidemiologist for the Children with Special Health Care Needs (CSHCN) program, Bureau of Community Health Promotion (BCHP), Division of Public Health (DPH), Wisconsin Department of Health and Family Services (DHFS). Dr Benedict is assistant professor, Occupational Therapy Program, Department of Kinesiology, University of Wisconsin. Doctor Katcher is chief medical officer, BCHP, DPH, DHFS; and Clinical Professor of Pediatrics, University of Wisconsin Medical School and the Medical College of Wisconsin. Please address correspondence to Murray L. Katcher, MD, PhD, Wisconsin Division of Public Health, 1 W Wilson St, Room 233, Madison, WI 53701-2659; phone 608.266.5818; fax 608.266.8925; e-mail katchml@dhfs.state.wi.us.

Children were identified as having a special health care need by using the Children with Special Health Care Needs Screener[®] developed by the Foundation for Accountability.⁵ If a parent responds affirmatively to at least 1 of the 5 screening questions and also responds affirmatively to the follow-up questions attached to each of the 5 screening questions, then the child is considered to have a special health care need.

The 5 screening questions are

1. Does your child currently need or use medicine prescribed by a doctor (other than vitamins)?
2. Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age?
3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
4. Does your child need or get special therapy, such as physical, occupational, or speech therapy?
5. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or gets treatment or counseling?

If parents answer any of the above questions affirmatively, they are then asked the follow-up questions:

- a. Is this because of any medical, behavioral, or other health condition?
- b. Is this a condition that has lasted or is expected to last for at least 12 months?

If a parent answers affirmatively to at least 1 of the 5 screener questions AND answers affirmatively to both (a) and (b) as follow-up to the same question, the child is counted as having a special health care need.

RESULTS

Nationally, 20% of households with children were identified as having at least 1 child with a special health care need; in Wisconsin, the figure was 21%. Among children nationally, 12.8% were identified as having a special health care need; in Wisconsin, the figure was 13.4%. The percent of CSHCN by age group is represented in Figure 1.

When compared to the CSHCN in the United States, Wisconsin has a smaller percent in the birth-5 years category, but a significantly larger percent in the 6-11 year group. Of the 750 Wisconsin children interviewed, 367 (49%) answered affirmatively to 1 of the 5 screener questions, 183 (24%) to 2, 116 (15%) to 3, 57 (8%) to 4, and 27 (4%) answered affirmatively to all 5 screener questions. Figure 2 shows the percent of CSHCN by type of special need as determined by the screener. Wisconsin and national data are fairly similar

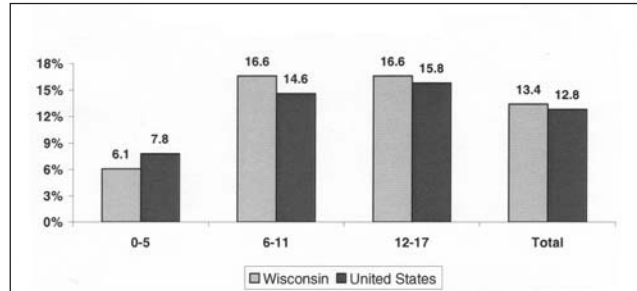


Figure 1. Children with special health care needs by age range in years (%).

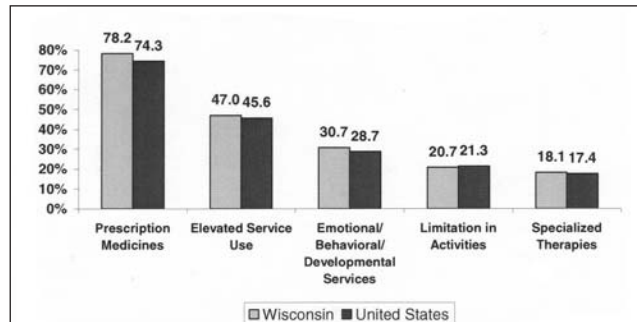


Figure 2. Proportion of children with special health care needs by type of special need (%).

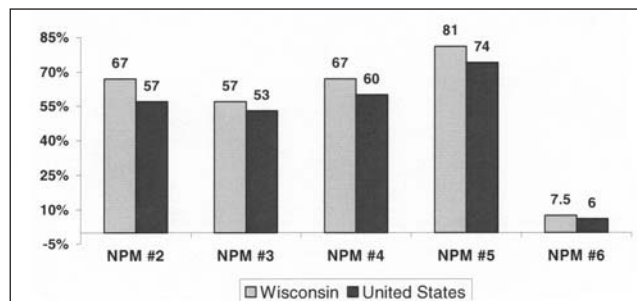


Figure 1. National performance measures (NPM) derived from the SLAITS children with special health care needs survey (%).

except for the larger proportion of Wisconsin CSHCN who take prescription medicines.

The federal MCHB required states to use the SLAITS data beginning in 2003 as part of their 2004 Title V Maternal and Child Health Block Grant annual reapplication. The data were used to assess progress towards meeting National Performance Measures (NPM) 2-6 (see Sidebar). Figure 3 shows the national and Wisconsin percentages for the 5 NPM. Wisconsin performed slightly better on all of the measures than the nation as a whole. However, for NPM #6 the MCHB ruled that, due to the small number of observations, the data did not meet the National Center for Health Statistics standards for reliability; therefore the national

Sidebar. National Performance Measures Derived from SLAITS CSHCN Survey Data

Performance Measure #2. The percent of children with special health care needs age 0 to 18 years whose families partner in decision making at all levels and are satisfied with the services they receive.

Performance Measure #3. The percent of children with special health care needs age 0 to 18 who receive coordinated, ongoing, comprehensive care within a medical home.

Performance Measure #4. The percent of children with special health care needs age 0 to 18 whose families have adequate private and/or public insurance to pay for the services they need.

Performance Measure #5. The percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily.

Performance Measure #6. The percentage of youth with special health care needs who received the services necessary to make transition to all aspects of adult life.

data were used. Wisconsin was not the only state that had a problem with this measure. Only Maine's data were determined to meet the standards for reliability.⁶

DISCUSSION

The SLAITS data provide the foundation to better understand the population of CSHCN. States now have some idea of how many CSHCN they have, and some idea of whether their needs are being met. The data are most reliable in areas where all 750 respondents answered the question; however, for age subgroups and for severely disabling conditions, where only a small number of respondents contributed to the results, the data may be less reliable. For example, the reason NPM #6 is unreliable is because only 110 of the 750 CSHCN responded to the question, and only 7 of them said that they were receiving services necessary to make transitions to adult life. Many families likely did not respond because the CSHCN were too young for the question to be applicable.

The MCHB plans to administer the SLAITS survey periodically. The data from the first survey period will then be compared to the data from the subsequent surveys, which will likely provide more robust state and national estimates on performance measures, increase confidence in the results, and may be used to establish trends.

Other considerations in using data from a family survey include the fact that the survey is limited to those families with a phone, and some families may refuse to take the opportunity to respond when an interviewer calls by phone. It is possible that families with

very needy children will be even less likely to discuss their child and family on the telephone; thus the survey may be weighted towards children who have less extreme needs. One way to address this issue may be to collect supplementary information locally.

CONCLUSION

The SLAITS results presented here provide us with a better understanding of the Wisconsin CSHCN population. The CSHCN program at the Wisconsin Division of Public Health is using these data, in conjunction with local public health departments, to forge strong partnerships with health care delivery systems and professional organizations, such as the Wisconsin Chapter of the American Academy of Pediatrics and the Wisconsin Academy of Family Physicians. We now have 5 regional centers for CSHCN—1 in each of Wisconsin's Division of Public Health regions. These centers provide information, referral and follow up, parent-to-parent support, and community-based service coordination.

From the family point of view, physicians seem to be providing medical home services in Wisconsin. Through the Medical Home Learning Collaborative we are attempting to find improved ways to translate the concepts of medical home to primary care practitioners. (See article elsewhere in this issue.)

With regard to transitions to adulthood for CSHCN, practitioners can listen carefully to the needs of the youth and his/her family beginning in early adolescence. If necessary the physician should begin to make plans to transfer care to a provider who cares for adults. Our public health programs are currently focusing on developing youth input through a youth advisory council.

REFERENCES

1. Maternal and Child Health Bureau, Rockville, Maryland 20857. Available at: <http://mchb.hrsa.gov/about/default.htm>. Accessed September 9, 2004.
2. Newacheck PW, Strickland B, Shonkoff JP, et al. An epidemiological profile of children with special health care needs. *Pediatrics*. 1998;102:117-123.
3. Van Dyck PC, McPherson M, Strickland BB, et al. The national survey of children with special health care needs. *Ambulatory Pediatrics*. 2002;2:29-37.
4. National Center for Health Statistics, Division for Health Interview Statistics, Hyattsville, MD. Available at: www.cdc.gov/nchs/about/major/slaits/cshcn.htm. Accessed September 9, 2004.
5. Foundation for Accountability. Portland, OR.
6. Maternal and Child Health Title V Block Grant Application, 2004. Technical notes, page 40. Wisconsin Department of Health and Family Services, Division of Public Health, Bureau of Family and Community Health, Madison, WI.