Children With Special Health Care Needs: Results of a National Survey

H. Barry Waldman, DDS, MPH, PhD Steven P. Perlman, DDS, MScD

ABSTRACT

The purpose of this review of the 2001 National Survey of Children with Special Health Care Needs (SHCN) was to offer an overview of these youngsters from the perspective of parents. Survey findings include: (1) Nearly 13% (9.4 million) of US children were reported to have SHCN, with the highest prevalence rates among children living in poverty and among Native American children. (2) Dental care was the most commonly reported needed service that was not received. (3) Despite the availability of public forms of insurance, compared to children with private insurance, low-income SHCN children are 2 to 3 times more unlikely to obtain needed health services. (4) SHCN children have a significant impact on family time requirements, economics, and employment patterns. The challenge is to use this information to improve services for SHCN children. (J Dent Child 2006;73:57-62)

KEYWORDS: CHILDREN WITH SPECIAL NEEDS, DEMOGRAPHICS, HEALTH INSURANCE, ACCESS TO CARE, NATIONAL SURVEY

The *2001 National Survey of Children with Special Health Care Needs* paints a positive picture of access to care for this child population.[1] It was reported, however, that 5% of children with special health care needs (SHCN) were reported to have had no health insurance at the time of the survey, 18% were not receiving all the services they needed, and 11% did not have a personal doctor or nurse.[1] (Unless otherwise specified, all data for this presentation were drawn from the extend report of the national survey. Note: all numbers and percentages in this presentation have been rounded.)

In addition, it was reported by family members that, among SHCN children:

1. 23% are usually or always affected in their activities by their condition.
2. 12% were uninsured at some point during the year prior to the survey.
3. The coverage for one third who are insured did not meet their needs because of inadequate access to benefits or providers, or unreasonable charges.
4. 30% of their parents had to cut back on work or stop working to care for their children.
5. 9% live in families with a need for respite care, 7% need genetic counseling, and 13% need family counseling to help deal with the stresses involved in having a SHCN child.

RELATED STUDIES

Reports from the National Health Interview Survey series carried out by the National Center for Health Statistics present statistics on selected health measures for children by an extended variety of demographic characteristics (eg, age, gender, race, ethnicity, family structure and income, health insurance). These reports also present information on the usual place of medical care, last contact with health professionals, and the number and proportion of children with learning disabilities and attention deficit disorder. The National Health Interview Survey does not provide a review for all SHCN children, nor does it provide data by specific state or for the District of Columbia.

Results from the latest of these reports indicate that, in 2003, 3.7 million children aged 2 to 17 years (6%) had unmet dental needs because their families could not afford dental care. Nineteen percent of uninsured children had unmet dental needs, compared with 3% of children with private health insurance and 7% of children with Medicaid. Non-Hispanic Caucasian children were more likely to have

---

Dr. Waldman is Distinguished Teaching Professor, Department of General Dentistry, School of Dental Medicine, SUNY at Stony Brook, NY; Dr. Perlman is Global Clinical Director, Special Olympics, Special Smiles, Associate Clinical Professor of Pediatric Dentistry, The Boston University Goldman School of Dental Medicine, Boston, Mass, and is a pediatric dentist in private practice, Lynn, Mass.
Correspond with Dr. Waldman at hwaldman@notes.cc.sunysb.edu

had a dental contact in the past 6 months (63%) than non-Hispanic African American children (48%) or Hispanic children (47%).

Hispanic children were almost twice as likely as non-Hispanic Caucasian children to have had no dental contact for more than 2 years.[2] While these are overall national data, they do provide a basis for comparative reference to the oral health care need findings from the study of SHCN children.

SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Parents and/or guardians of almost 39,000 SHCN children (0 to 17 years old) were interviewed via telephone by the National Center for Health Statistics (NCHS) between October 2000 and April 2002. The survey used a random digit dial methodology developed by the NCHS. A total of 373,000 children in all 50 states and the District of Columbia were screened to identify a sample of SHCN children. A parent or legal guardian most knowledgeable about the child completed the screening questionnaire. If the child met the screener criteria, the parent completed an additional battery of survey questions. The entire questionnaire took an average of 30 minutes to complete. The response rate for completion of the SHCN interview was 61%, ranging from 53% in New Jersey to 72% in Montana.[1,3]

The national survey data are subject to the usual variables associated with sample surveys. Small differences between survey estimates may be due to random survey error and not true differences among children or across states. The margin of error for the national prevalence estimates is 0.2%.[1] (For national estimates, the margin of error for health and health care for all SHCN children is 1.1%. For state prevalence estimates, the maximum margin of error is 1.4%.) Despite the limitations of telephone interviews, the intensive effort of this national survey does provide detailed broad data for a population about which information is commonly unavailable.

For purposes of the survey, SHCN children were defined (using the definition of the US Maternal and Child Health Bureau) 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]

NUMBERS AND DISTRIBUTION

There are about 9.4 million SHCN children (13% of children under age 18 in the United States). The prevalence increases with age, from just under 8% for children 0 to 5 years old, to almost 16% for 12 to 17 year olds. The higher prevalence of SHCN among older children is likely attributed to conditions that are not diagnosed or do not develop until later in childhood. Among boys, 15% have SHCN, compared to 11% of girls. The prevalence of SHCN does not vary substantially among income groups. The prevalence, however, does vary by race and ethnicity. It is highest among multiracial and Native American/Alaska Native children and lowest among Hispanic and non-Hispanic Asian children (Table 1).

Table 1. Reported Prevalence of Children With Special Health Care Needs by Race/Ethnicity: 2001[1]

Non-Hispanic Caucasian	14
Non-Hispanic African American	13
Native American/Alaska(n) Native	17
Native Hawaiian/Pacific Islander	10
Mixed race	15
Hispanic	9
Total population	13

On a state-by-state basis, the overall number of SHCN children is a function of the jurisdiction general population; ranging from an estimated 16,000 SHCN children in the District of Columbia and Wyoming to 723,000 in Texas to 970,000 in California. In terms of percentages:

1. The proportion of SHCN children ranges from 10% in California to 17% in West Virginia.
2. The proportion of SHCN children with unmet service needs ranges from 11% in Nebraska and South Dakota to 20% or more in 13 states (Alaska, Arkansas, California, Florida, Louisiana, Mississippi, Montana, New Mexico, Nevada, Oklahoma, Oregon, Texas, Washington) to 26% in the District of Columbia (Table 2).

RELATIONSHIP TO POVERTY

Although the prevalence of SHCN children does not vary substantially among income groups: "Among children with (SHCN) living in poverty, 40% need emotional, behavioral, or developmental services, compared to 23% of (children with) SHCN in the highest-income families."[1]

The prevalence of limitation in activities also varies by income for SHCN children; 28% of poor SHCN children have activity limitations, compared to 17% of SHCN children in high-income families. By contrast, while the use of prescription drug medication is one of the more prevalent health care services, the need is reported to be greatest among SHCN children in higher-income families than among those in lower incomes. (The study report provides no explanation for this finding. One possibility may be the more frequent contact with health practitioners by SHCN children in higher-income families.)

The proportion of children living in families with poverty level incomes is not uniformly distributed throughout the country. While the national poverty rate for children was 17%, the proportion of children living in poverty ranged from 10% or less in Connecticut, Minnesota, and New Hampshire to approximately 25% in Louisiana, Mississippi, New Mexico, and the District of Columbia.[4]

In addition, the proportion of children living in poverty was greater in rural areas (a national average of 20%); ranging from less than 10% in Connecticut, Massachusetts, and

Table 2. Reported Number and Percent of Children With Special Health Care Needs (SHCN) and Percent With Any Unmet Service Need by State: 2001[1]

	No. of SHCN children	% of children with SHCN	% of SHCN children with unmet needs
Alabama	153	14	19
Missouri	216	15	16
Alaska	21	11	20
Montana	27	12	22
Arizona	153	11	19
Nebraska	57	13	11
Arkansas	97	14	23
Nevada	59	11	21
California	970	10	23
New Hampshire	47	15	14
Colorado	130	11	18
New Jersey	267	13	17
Connecticut	119	14	12
New Mexico	57	11	24
Delaware	30	15	18
New York	558	12	12
Dist. Col.	16	14	26
North Carolina	281	14	14
Florida	488	13	24
North Dakota	20	12	13
Georgia	282	13	19
Ohio	403	14	14
Hawaii	32	11	16
Oklahoma	130	15	22
Idaho	43	12	18
Oregon	113	13	23
Illinois	379	12	17
Pennsylvania	379	13	16
Indiana	225	14	12
Rhode Island	35	14	13
Iowa	90	12	19
South Carolina	34	13	15
Kansas	106	15	19
South Dakota	23	13	15
Kentucky	156	16	15
Tennessee	199	14	16
Louisiana	193	16	20
Texas	723	12	23
Maine	46	15	15
Utah	80	11	19
Maryland	209	15	16
Vermont	23	15	14
Massachusetts	222	15	12
Virginia	270	15	12
Michigan	361	14	15
Washington	211	14	20
Minnesota	161	13	14
West Virginia	66	17	14
Mississippi	100	13	22
Wisconsin	184	13	12
Wyoming	16	12	15
US total	9.4 million	13%	18%

Table 3. Most Commonly Reported Services Needed and Not Obtained by Children With Special Health Care Needs: 2001[1]

Needed health service	%
Dental care	8
Mental health care	5
Specialist care	4
PT/OT/Speech therapy	3
Preventive care	2
Eyeglasses/Vision care	2
Prescription medication	1

Table 4. Reported Proportion of Health Services Needed But Not Obtained by Income: 2001[1]

Income level	1 service needed (%)	2 or more services needed (%)
0-99% FPL*	19	13
100-199% FPL	16	10
200-399% FPL	10	4
400% FPL	6	2

**** FPL=federal poverty level. In 2001, the FPL was $11,610 for a family of 2, $14,630 for a family of 3, and $17,650 for a family of 4.[1]***

Table 5. Reported Proportion of Health Services Needed But Not Obtained by Insurance Type: 2001[1]

Insurance type	1 service needed (%)	2 or more services needed (%)
Private only	9	3
Public only	17	9
Public and private	15	7
Uninsured	19	27

Table 6. Report Percent of Children With Special Health Care Needs Requiring Specific Health Services: 2001[1]

Needed health service	%
Prescription medicine	88
Dental care	78
Preventive care	74
Specialist care	51
Eyeglasses/Vision care	36
Mental health care	25
Medical supplies	25
PT/OT/Speech therapy	24
Hearing aids or care	6
Home health care	5
Mobility aids	4
Communication aids	2
Substance abuse treatment	2

New Hampshire to 30% or more in Arizona, Louisiana, Mississippi and New Mexico.[5]

SERVICES NEEDED

DENTAL CARE

"The service most commonly reported as needed but not received was dental care: More than 8% of SHCN children needed but did not obtain this service." (Table 3)[1]

The reality is that low-income SHCN children (in both urban and rural areas?) and uninsured children are more likely not able to obtain needed services (Table 4; The *2001 National Survey of Children with Special Health Care Needs* report does not categorize children by urban and rural area groupings). For example, among SHCN children in low-income families, nearly one third reported at least one service needed, but not received—the most common being dental care (16% of poor children).[1] As previously noted, the National Health Interview Survey for 2003 reported that, nationally, 6% of all children had unmet dental needs because their families could not afford needed dental care.[2]

In most instances, for low-income children, public forms of insurance (eg, Medicaid and the State Child Health Insurance Program) provide the needed coverage for health services. The reality, however, is that—compared to children with private health insurance coverage—the proportion of SHCN children, who need one or more services and are covered by public forms of health insurance are 2 to 3 times more likely to be unable to obtain the needed health service. Only children with no insurance are less likely to receive needed care (Table 5).

Among uninsured SHCN children, nearly half report not receiving needed services, "…with 29% lacking needed dental care…"[1] By comparison, the service that privately insured SHCN children are most likely to lack is dental care; 5% needed but did not obtain this service.

Parents indicated that, other than prescription medicines, the health service needed in the past year by the most SHCN children was dental care (78% of SHCN children; Table 6).

FAMILY SUPPORT SERVICES

Family support services include family counseling (mental health care for other family members), respite care (having someone else care for the child so parents or other family members can take a break), and genetic counseling for advice on inherited conditions related to the child. Family counseling is the support service most commonly mentioned as being needed by families of SHCN children. While the overall proportion of families unable to obtain needed counseling services was small (5% of families), families of low-income and uninsured children were most likely to report an inability to receive services.

USUAL SOURCE OF CARE WHEN SICK

The proportion (between 6% and 8%) of SHCN children with no usual source of sick care did not vary substantially by family income. Only 58% of poor children, however, turn to a doctor's office as a usual source of care, compared to 82% of higher-income children. Compared to SHCN children in higher-income families, SHCN children living in poverty were more than 4 times as likely to rely on emergency rooms as their usual source of care.

IMPACT ON FAMILIES

FINANCIAL BURDEN

Over 40% of uninsured SHCN children live in families that reported a financial problem, compared to 24% of those with public coverage and 17% of those with private insurance. While SHCN children from low-income families have lower out-of-pocket costs, these children are more than twice as likely as children from higher-income families to have conditions that result in financial problems.

TIME SPENT PROVIDING CARE

Many families devote substantial amounts of time to the care of their SHCN children. In addition to administering medication and therapies, maintaining equipment, and providing transportation to appointments, families also spend time arranging and coordinating care for their child by making appointments, ensuring that providers are exchanging information, and following up on their child's health care needs. Thirteen percent of these families spend 11 hours a week or more on these tasks.

EMPLOYMENT

The parents of almost 17% of SHCN children reported that they reduced their employment, and the parents of another 13% reported that they stopped working because of their children's needs. Children in lower-income families are more likely to have parents who have given up their jobs than children in higher-income families (26% vs 7%).

OTHER DIFFICULTIES

The national survey addresses a series of further difficulties that impact families caring for their SHCN children, including difficulties in the coordination and quality of communication among doctors. Specifically:

1. Adequacy of information supplied by providers. Over 19% of SHCN children have providers who do not usually provide families with the information they need.[1]
2. Over 16% of SHCN children have providers who did not always spend enough time with their child; 12% do not listen carefully to parents.[1]

As always, there are factors beyond the scope of any particular study. Thus, despite the extensive coverage in the national survey report on the impact on families with a child(ren) with SHCN, there are potentially long-term and wide-ranging serious strains in family relations (between parents and among siblings; see a previous presentation in the *Journal of Dentistry for Children* for an extended review of the subject).[6]

CHALLENGE

The national survey of SHCN children provides both a national and local overview of the difficulties faced by families with SHCN children. The reality is that, increasingly, health providers will be called upon to provide the needed care for these children who reside in our communities and, in many instances, are members of families currently being treated in dental practices.

The impact of increasing numbers of SHCN children (and adults) on community dental practices is a reflection of the deinstitutionalization (mainstreaming and the establishment of community-oriented group residences) of former state institution residents (and individuals who in the past would have been placed in these facilities). Since the mid 1970s, there has been a 75% decrease nationally in the average number of state institution residents with intellectual and developmental disabilities.[7]

In the past, state institution residents received needed dental and medical services from government health employees. But many of the community residential facilities are too small in size to provide intramural services. As a consequence, the provision of health care increasingly has become the responsibility of health providers in our communities (see a previous presentation in the *Journal of Dentistry for Children* for an extended review of the subject).[8]

The results from the national survey offer insight into and explanations (from the parent's perspective) for many of the problems faced by practitioners dealing with and treating families and their SHCN children. Specifically, for SHCN children, it was reported that:

1. More than three quarters of the children needed dental care in the past year.
2. Dental care is the most commonly reported health service that is not received.
3. More than 10% of children were uninsured at some point during the past year. Almost 30% of the children without health insurance lacked needed dental care.
4. Almost 1 in 5 children were not receiving needed general health services.
5. Thirty percent of parents had to cut back on work or stop working to provide needed care.

An awareness of the particular problems faced by SHCN children, however, must be coupled with practitioners who are prepared to provide needed dental care for these children. In the past, most schools of dentistry and dental hygiene provided limited, if any, didactic and clinical opportunities to prepare graduates to provide care to SHCN individuals.[9,10] As a result of the authors' efforts initiated through the Special Olympics, the Commission on Dental Accreditation adopted new standards to ensure didactic and clinical opportunities to better prepare dental professionals for the care of persons with developmental, complex medical problems, significant physical limitations, and a vast array of other conditions considered under the rubric of "individuals with special needs." The standard states: "Graduates *must* (sic) be competent in assessing the treatment needs of patients with special needs." Implementation of this revised standard is required by January 1, 2006.[11]

Surely an appreciation of the results from the *2001 National Survey of Children with Special Health Care Needs* and the changes in the standards for accreditation of dental education programs can only improve the delivery of needed care.

REFERENCES

1. Department of Health and Human Services. *The National Survey of Children with Special Health Care Needs: Chartbook 2001*. Rockville, Md: Health Resources and Services Administration; 2004.
2. Dey AN, Bloom B. Summary health statistics for US children: National Health Interview Survey, 2003. National Center for Health Statistics. Vital Health Stat 2005;10(223):5-6.
3. Lotstein DS, McPherson M, Strickland B, Newacheck PW. Transition planning for youth with special health care needs: Results from the National Survey of Children with Special Health Needs. Pediatrics 2005;115:1562-1568.
4. Annie E. Casey Foundation. 2004 Kids Count Data Book. Baltimore, Md: Annie E. Casey Foundation; 2004.
5. Annie E. Casey Foundation. 2004 City and Rural Kids Count Data Book. Available at: www.aecf.org. Accessed January 26, 2005.
6. Waldman HB, Swerdloff M, Perlman SP. Understanding the siblings of children with mental retardation. J Dent Child 2000;67:345-349.
7. Prouty R, Coucouvanis K, Lakin KC. Fiscal year 2004 institution populations, movement, and expenditures by state with national comparisons in earlier years. Ment Retard 2005;43:149-151.
8. Waldman HB, Perlman SP. Deinstitutionalization of children with mental retardation: What of dental services? J Dent Child 2000;67:413-417.
9. Fenton SJ. People with disabilities need more than lip service. Spec Care Dent 1999;19:198-199.
10. Wolff AJ, Waldman HB, Milano M, Perlman SP. Dental students' experiences with and attitudes toward people with mental retardation. J Am Dent Assoc 2004;135:353-357.
11. Waldman HB, Fenton SJ, Perlman SP, Cinotti DA. Preparing dental graduates to provide care to individual with special needs. J Dent Educ 2005;69:249-254.