

2000 Utah Child Health Survey

Children With Special Health Care Needs

Office of Public Health Assessment
Center for Health Data

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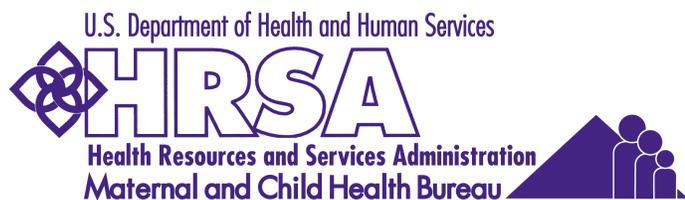
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Introduction

This report is intended to provide an overview of the information collected in the 2000 Utah Child Health Survey. The survey was designed to address the important health issues among Utah children, including health insurance coverage, special health care needs, and patterns of health care delivery and utilization. Two overview reports have been produced, one that provides information on a sample representative of all Utah children, and this report, that provides information on the subgroup of children with special health care needs. A report on insurance coverage for children, and one taking a more in-depth look at children with special health care needs are also planned for publication.

This report presents a Summary of Findings, followed by seven sections that provide demographic breakouts and age/sex graphs for selected questionnaire items. Although we would have liked to provide race and ethnicity breakouts, the sample sizes in most race categories were not large enough to provide reliable estimates. We were, however, able to provide Hispanic ethnicity estimates with reasonable precision for most survey variables. The Highlights and Reference Tables section is organized in the following sections:

- Health Status and Risk Factors
- Health Insurance Coverage
- Problems with Access to Care
- Medical Home
- Satisfaction with Care
- Utilization of Services
- Family Support Services

A Technical Notes appendix provides detailed information on the survey methodology, and other appendices provide survey respondent characteristics, open-ended responses, and the survey questionnaire.

The data were collected by telephone by Pegus Research, Inc., in Salt Lake City, Utah, between November 11, 1999 and February 10, 2000. Interviews were conducted with the adult who was most knowledgeable about the health of the children in the household. In 97% of the interviews, this person was the child's parent, most often the mother. The response rate for the survey was 53%, with an upper-bound rate of 61%. A total of 18,488 phone numbers were called, of which, 4,814 were eligible Utah households (households with children age 0-18 living there) and 13,674 were not working phone numbers or non-eligible households.

The survey sample consisted of 2,536 Utah households with children, 5,979 total children, and 753 individual children with special health care needs. Children who had already turned 18 were originally included in the survey sample so that analyses of health insurance status could include all children who were eligible for Medicaid and the Children's Health Insurance Program (CHIP). For the purposes of the two overview reports, only children age 0 through 17 were included ($n = 5,749$). It was believed that this, more standard, age range would be more useful for purposes of reporting child health status information and comparing with other data sources. A report on health insurance status is planned by the Office of Public Health Assessment, and will include analyses of those children who had already turned 18.

The estimate for the prevalence of special health care needs in this report is based on all 5,749 children age 0-17 in the surveyed households. The screening questionnaire used to identify children with special health care needs was adapted from the October 1999 draft of the Foundation for Accountability (FACCT) Living With Illness questionnaire. According to this questionnaire, a child was considered to have special health care needs if he or she had any of the following conditions that had lasted or were expected to last for at least 12 months:

1. Prescription medications
2. Needs more services (medical, educational, mental health) than most children
3. Restricted activity
4. Physical/speech/other therapy
5. Mental health treatment
6. Durable medical equipment / special equipment
7. Life-threatening allergies
8. Special diet
9. Individualized Educational Plan, Early Intervention, Special Education classes
10. Learning or behavioral difficulties

After the screening questions were asked about all children in the household, all remaining survey questions were asked about *up to three* children with special health care needs per household (n = 696 for age 0-17).

	Age 0-17	Age 18	Total: Age 0-18
Asked CSHCN screening questionnaire only	22	1	23
Asked entire questionnaire	696	34	730
Total identified in screening questionnaire	718	35	753

The data presented in this report have been weighted to represent all non-institutionalized Utah children living in households with telephones on the following characteristics: age, sex, Hispanic status, and geographic distribution of children currently living in Utah. Population projections for the year 2000 were produced by the Governor’s Office of Planning and Budget (published January 2000). A more detailed description of the methodology may be found in the Technical Notes section of this report.



Summary of Findings

Prevalence of Children With Special Health Care Needs

- Results of the draft Foundation For Accountability (FACCT, Portland, OR) Living With Illness questionnaire indicate that 12.6% (almost 90,000) of Utah children have a chronic illness or condition that requires special health care. The most common conditions among these Utah children were behavioral conditions such as attention deficit, hyperactivity disorder (35% of CSHCN had a behavioral condition), and asthma or respiratory conditions (19.3%).
- The prevalence of special health care needs increased with the child's age. This is because problems develop as a child gets older, and also because many problems, although present, are not detected until a child matures.
- The CSHCN prevalence of 12.6% is relatively low; reports of the prevalence rate in other areas of the country range from 16% to 19%. Utahns are healthier in many aspects, and while a prevalence rate of 12.6% seemed within the range of possibilities, it was low enough to warrant investigation of possible methodology factors that may have caused the survey to produce an artificially low rate. Several factors were ruled out. However, it was observed that the Utah CSHCN rates were lower primarily in the younger age groups. This suggests that, 1) Utah children have fewer of the problems that affect younger children, or 2) compared with children in other places, children in Utah are less likely to be identified as being CSHCN while they are young.

Health Status and Risk Factors

- Overall, 9% of children with special health care needs (CSHCN) were reported in “fair” or “poor” health. Fair/poor health status was more common among children in the youngest age group (age 0-5, 10.3%), and among girls (12.1%). Hispanic children (14.9%) and children in poverty (18.9%) were also more likely to have been reported in fair/poor health.
- Fifty-nine percent of CSHCN had one or more days out of the last 30 when their physical health was “not good” (including illness and injury). On average, CSHCN experienced 3.9 sick days in the last month.
- Approximately 42% of CSHCN were reported to have one or more days in which their mental health was “not good” (including stress, depression, and problems with emotions). On average, CSHCN experienced 4.2 poor mental health days in the last month.

Health Insurance Coverage

- Children with special health care needs were more likely than other children to be covered by some type of health insurance; 4.1% of CSHCN were uninsured, compared with 6.5%, overall. The most common reasons given for the child lacking health insurance coverage were “could not afford premium” and “lost Medicaid/CHIP eligibility.”
- CSHCN who were more likely to be without health insurance coverage included children age 6 to 11 (7.2%) and children living in households with incomes below the federal poverty level (20.1%). Almost all uninsured children living below 200% of the federal poverty level are eligible for Medicaid or the Children's Health Insurance Program (CHIP).
- Only 31.1% of parents rated their health insurance plan as “excellent” at covering all the health care costs associated with their child with special health care needs. While most (66.6%) indicated that their annual out-of-pocket costs were less than \$500, 1.9% (1700 families) reported annual expenses of \$5,000 or more.

Problems With Access to Health Care

- The survey asked parents about various reasons they may have delayed or had problems getting medical, dental, or other types of health care. The most common reason for having a problem with access to care was “could not afford services,” cited by 20.9% of parents. Parents of older children and those with lower incomes were more likely to report that cost had prevented or delayed services for their child.
- Almost 18% of CSHCN had problems getting medical care, 15.1% of CSHCN had problems getting dental care, and 7.3% had problems getting mental health care.

Medical Home

- Only 3.2% of parents reported that their child had no usual provider or place for acute medical care. Because of the small percentage, many of the estimates were not published (the confidence intervals in these cases were larger than the estimates). The estimates that are available indicate that children in households with incomes below the federal poverty level are almost four times as likely to lack a primary care provider.
- Children with special health care needs often have more than one health care provider. In order for appropriate medical care to be delivered, it is often necessary for a child’s provider to understand all the health care services that the child is receiving. Almost three-quarters of parents of children with special health care needs reported that their providers had a thorough understanding of all their child’s health care services.
- Having access to a child’s medical records facilitates effective coordination of care: 77.3% of parents reported that their doctor always had access to all their child’s medical records.

Satisfaction With Care

- Almost all (96.9%) parents reported that they were satisfied or very satisfied with the health care received by their child or children. There was very little variation in the rate across various demographic subgroups.
- Some children with special health care needs receive services from several different providers. Some parents (14.8%) rated services coordination as fair or poor.
- Parents reported that doctors had spoken with the family about the child’s future adult life plans in 58.9% of the cases.
- 29.8% said that the providers did not usually speak with them in a way they could understand.
- Most parents (93.5%) reported that they were “satisfied” or “very satisfied” with their ability to get the information they needed to make decisions about their child’s health care needs.
- Most parents (82.8%) reported that medical and other staff always treated them and their child with courtesy and respect.
- Most parents who responded to the Child Health Survey, regardless of their race or ethnic background, reported that their doctor always showed respect for their customs, beliefs and language (93.4%).

Utilization of Services

- We asked parents how long it had been since their child’s most recent well-child visit and compared this information with the child’s age to ascertain whether the child was late for his or her well-child visit. 77.7% of children with special health care needs in the Child Health Survey had received a well-child visit on time.
- Among children with special health care needs who were age 1 or older, 85% had had a dental visit in the past 12 months. Only 52.9% of children in the youngest age group (age 1 to 5) had had a dental visit in the last year. There was a marked gradient for dental visits along the poverty continuum, with annual dental visits for only 73.6% of children in households whose incomes were below poverty level, and for 92.4% of children in households with the highest incomes.

- At the time of the survey, parents reported that 43.4% of children with special health care needs visited a specialist or specialty clinic, such as an orthopedist, neurologist, or a specialty clinic. Younger children were somewhat more likely to visit (52.1% of the 0 to 5 age group), and children in households with incomes below poverty level were less likely to visit (36.4%).

Auxiliary Services

- Of the parents in the Child Health Survey, 42.3% were satisfied with the opportunities they have had to talk with other CSHCN families, 8.1% were dissatisfied, and 49.6% reported that they had had no opportunity to do so.
- Family Voices is a parent-to-parent information and support service for families of children with special health care needs. 18.3% of parents of children with special health care needs had received information or support from organizations such as this. Parents of younger CSHCN were somewhat more likely to have used this service.
- Parents indicated that, on average, their child was unsupervised for only about 40 minutes each day. Families caring for CSHCN need support and respite care services.