

2000 Utah Child Health Survey: Children with Special Health Care Needs

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Acknowledgments

The *2000 Child Health Survey* was designed and conducted under the direction of the 2000 Child Health Survey Work Group, consisting of the following members:

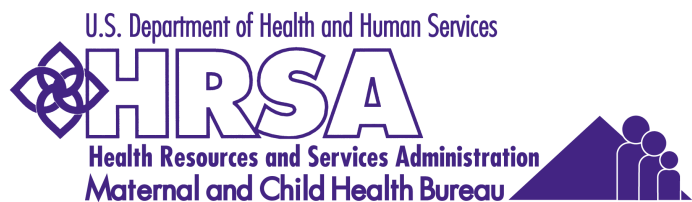
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- State Systems Development Initiative (SSDI) Grant from the Health Resources and Services Administration (HRSA)
- The Preventive Services Block Grant from the Centers for Disease Control and Prevention (CDC)
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2000 Utah Child Health Survey

Children With Special Health Care Needs

Office of Public Health Assessment
Center for Health Data

April 2001

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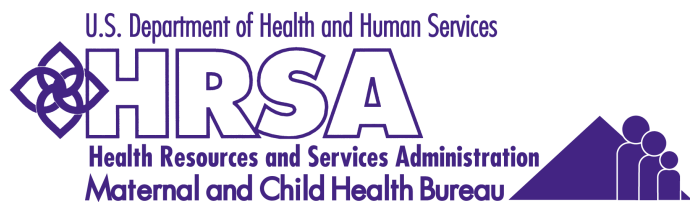
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Introduction

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%).

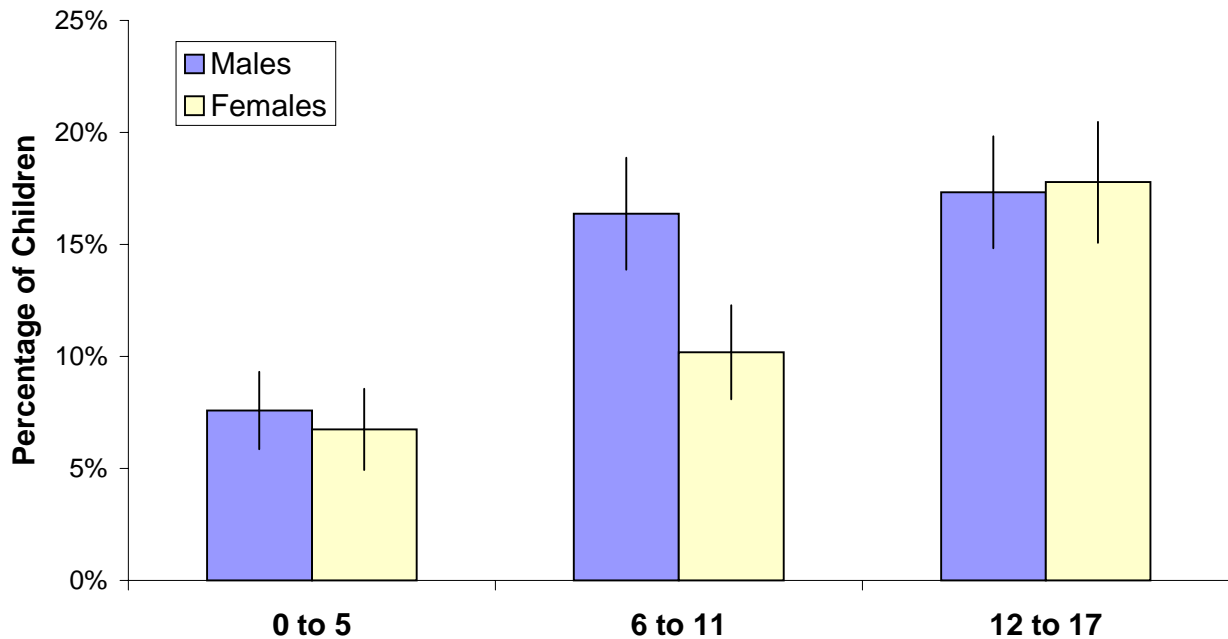
Auxiliary Services

- 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.

Health Status and Risk Factors



Percentage of Children Who Were Reported to Have Special Health Care Needs* by Age and Sex, Utah Children Age 0-17, 2000



*CSHCN definition: This survey used a draft version of the foundation for accountability (FACCT, Portland, OR) living with illness instrument to identify children living with chronic conditions

- Children With Special Health Care Needs were identified using a questionnaire that 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 physical 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 Education Plan, Early Intervention, Special Education classes
 10. Learning or behavioral difficulties
- Results of the Utah draft Foundation For Accountability (FACCT, Portland, OR) Living With Illness questionnaire indicate that 12.6% (almost 90,000) of Utah children have a chronic disability, illness, or condition that requires special health care beyond that of children generally (for a more detailed description of Utah's CSHCN rate, please refer to Appendix D, p. 107).
- The most common conditions among these Utah children were behavioral conditions, such as attention deficit hyperactivity disorder, and asthma or respiratory conditions.
- 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.

Children With Special Health Care Needs (CSHCN): Percentage of Children Who Were Reported to Have Special Health Care Needs (Question 1-4A) by Selected Demographic Characteristics, Utah Children Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates of Children Who Were Reported to Have Special Health Care Needs | | |
|---|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children Who Were CSHCN ² | Number of Children ^{1,3} | Percentage Distribution of Children Who Were CSHCN by Category |
| Special Health Care Need Child (CSHCN) | | | | | |
| CSHCN | 12.6% | 88,600 | | | |
| NOT CSHCN | 87.4% | 614,900 | | | |
| Total, All Children 0-17 | 100.0% | 703,500 | | | |
| Sex | | | | | |
| Males | 51.3% | 361,100 | 13.7% ± 1.4% | 49,400 | 55.7% |
| Females | 48.7% | 342,300 | 11.5% ± 1.3% | 39,300 | 44.3% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 36.8% | 258,700 | 7.2% ± 1.3% | 18,500 | 21.2% |
| 6 to 11 | 32.2% | 226,300 | 13.4% ± 1.7% | 30,400 | 34.8% |
| 12 to 17 | 31.1% | 218,500 | 17.6% ± 1.9% | 38,400 | 44.0% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 18.9% | 132,900 | 7.6% ± 1.7% | 10,100 | 11.6% |
| Male, 6 to 11 | 16.5% | 116,300 | 16.4% ± 2.5% | 19,000 | 21.8% |
| Male, 12 to 17 | 15.9% | 112,000 | 17.3% ± 2.5% | 19,400 | 22.3% |
| Female, 0 to 5 | 17.9% | 125,900 | 6.8% ± 1.8% | 8,500 | 9.8% |
| Female, 6 to 11 | 15.6% | 110,000 | 10.2% ± 2.1% | 11,200 | 12.9% |
| Female, 12 to 17 | 15.1% | 106,500 | 17.8% ± 2.7% | 18,900 | 21.7% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 93.5% | 657,800 | 13.1% ± 1.1% | 85,000 | 95.9% |
| No | 6.5% | 45,700 | 7.9% ± 3.0% | 3,600 | 4.1% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.0% | 63,300 | 13.7% ± 4.0% | 8,700 | 9.7% |
| No | 91.0% | 640,200 | 12.7% ± 1.1% | 81,100 | 90.3% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |
| Poverty | | | | | |
| 0-100% | 8.6% | 60,500 | 15.5% ± 4.6% | 9,400 | 10.5% |
| 101-200% | 28.6% | 201,200 | 12.3% ± 2.2% | 24,700 | 27.6% |
| 201-300% | 29.1% | 204,700 | 11.1% ± 1.9% | 22,800 | 25.4% |
| Over 300% | 33.8% | 237,800 | 13.8% ± 1.9% | 32,700 | 36.5% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |
| County of Residence | | | | | |
| Urban | 76.8% | 540,200 | 13.1% ± 1.2% | 70,700 | 78.7% |
| Rural | 23.2% | 163,300 | 11.7% ± 2.1% | 19,100 | 21.3% |
| Total, All Children 0-17 | 100.0% | 703,500 | 12.6% ± 1.0% | 88,600 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

*CSHCN definition: This survey used a draft version of the foundation for accountability (FACCT, Portland, OR) living with illness instrument to identify children living with chronic conditions

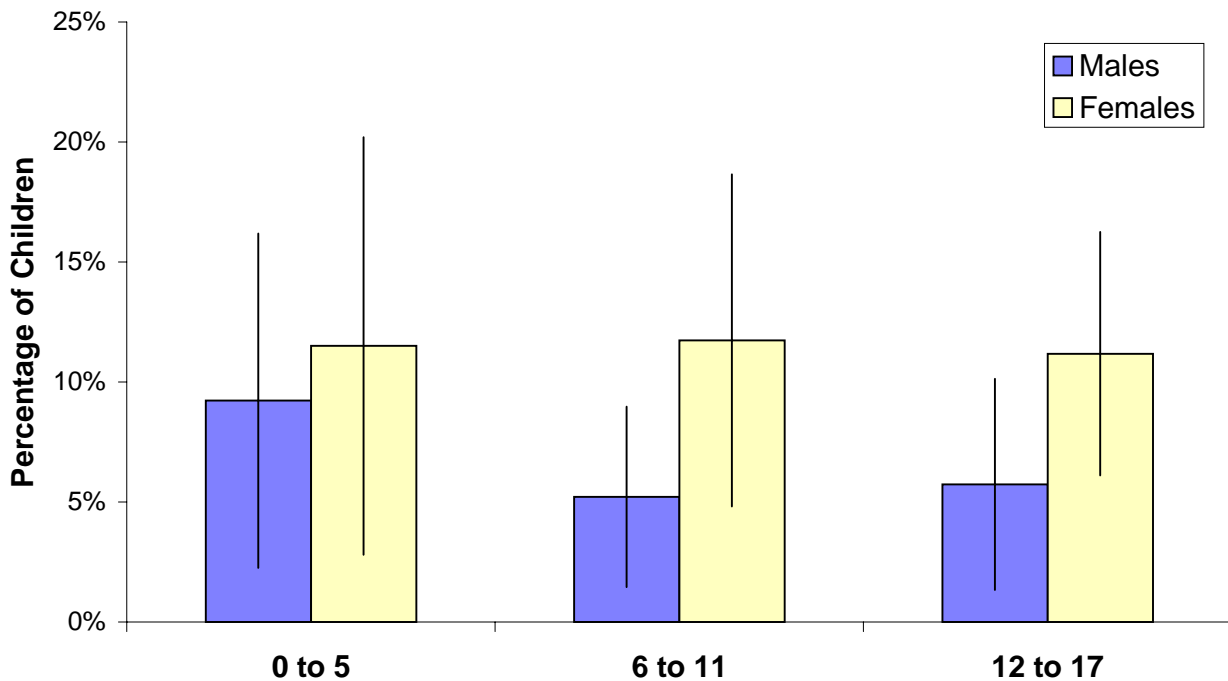
Condition or Diagnosis (Questions 5A and 5B):
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Responses | Weighted Size ¹ | Survey Percentage Distribution ¹ | 95% Confidence Interval | Estimated Number of Children ¹ |
|---|----------------------------|---|-------------------------|---|
| Behavioral | 253 | 35.2% | ± 4.0% | 31,000 |
| Asthma/Respiratory | 140 | 19.5% | ± 3.4% | 17,100 |
| Allergy | 82 | 11.4% | ± 2.6% | 10,100 |
| Syndromes | 35 | 4.9% | ± 1.8% | 4,300 |
| Speech | 24 | 3.2% | ± 1.3% | 3,000 |
| Neurologic | 25 | 3.4% | ± 1.4% | 3,100 |
| Orthopedic | 21 | 3.2% | ± 1.3% | 2,600 |
| Dermalgic | 20 | 2.9% | ± 1.4% | 2,500 |
| Nutritional/Metabolic | 21 | 3.0% | ± 1.5% | 2,600 |
| Diabetes | 15 | 2.1% | ± 1.0% | 1,800 |
| Gastro-intestinal | 14 | 2.0% | ± 1.0% | 1,800 |
| Hearing Loss | 16 | 2.2% | ± 1.2% | 2,000 |
| Cardiac | 14 | 1.9% | ± 1.0% | 1,700 |
| Developmental Disability/Mental Retardation | 7 | 1.0% | ± 0.7% | 800 |
| Vision | 7 | 1.0% | ± 0.7% | 900 |
| Arthritis | 7 | 1.0% | ± 0.7% | 900 |
| Chronic Otitis Media | 7 | 0.9% | ± 0.8% | 900 |
| Gynecological | 4 | 0.5% | ± 0.5% | 400 |
| Traumatic Brain Injury | 4 | 0.6% | ± 0.6% | 500 |
| Oral Facial Anomaly | 3 | 0.4% | ± 0.5% | 400 |
| Prematurity | 2 | 0.3% | ± 0.4% | 300 |
| Other | 17 | 2.3% | ± 1.2% | 2,000 |
| Not Specified | 15 | 2.2% | ± 1.1% | 1,900 |
| TOTAL | 718 | 100.0% | | 88,600 |

¹ Figures in these columns sum to greater than 100% because respondents were allowed to choose multiple categories.

- The prevalence of children with special health care needs measured in other U.S. locations has tended to be higher, closer to 16%. Investigation of potential methodological artifacts that may be responsible for the Utah Child Health Survey's lower observed rate 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 (see Appendix D for additional detail).

Percentage of Children Who Were Reported in Fair or Poor Health by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- Overall, 8.5% of children with special health care needs (CSHCN) were reported in “fair” or “poor” health. This is significantly higher than the 1.8%¹ reported by parents of Utah children in general.
- Fair/poor health status was more common among children in the youngest age group (age 0-5, 10.3%, difference not significant), and is significantly more common among girls (11.4%¹).
- Hispanic children (15.1%) and children in poverty (17.4%) were also more likely to have been reported in fair/poor health, though the difference was not statistically significant.

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

General Health Status: Percentage of Children Who Were Reported in Fair or Poor Health (Question B1)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children in Fair/Poor Health | | |
|----------------------------------|------------------------------|---------------------------------|---|------------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children in Fair/Poor Health ² | Number of Children ^{1, 3} | Percentage Distribution of Children in Fair/Poor Health by Category |
| General Health Status | | | | | |
| Excellent/Very Good | 68.0% | 60,200 | | | |
| Good | 23.5% | 20,800 | | | |
| Fair/Poor | 8.5% | 7,500 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 6.2% ± 2.7% | 3,000 | 40.0% |
| Females | 44.6% | 39,500 | 11.4% ± 3.8% | 4,500 | 60.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 10.3% ± 5.4% | 1,800 | 23.7% |
| 6 to 11 | 35.2% | 31,200 | 7.7% ± 3.6% | 2,400 | 31.6% |
| 12 to 17 | 45.1% | 40,000 | 8.5% ± 3.4% | 3,400 | 44.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 9.2% ± 7.0% | 900 | 12.2% |
| Male, 6 to 11 | 22.4% | 19,900 | 5.2% ± 3.8% | 1,000 | 13.5% |
| Male, 12 to 17 | 22.5% | 19,900 | 5.7% ± 4.4% | 1,100 | 14.9% |
| Female, 0 to 5 | 9.1% | 8,100 | 11.5% ± 8.7% | 900 | 12.2% |
| Female, 6 to 11 | 12.8% | 11,300 | 11.7% ± 6.9% | 1,300 | 17.6% |
| Female, 12 to 17 | 22.6% | 20,000 | 11.2% ± 5.1% | 2,200 | 29.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 8.0% ± 2.3% | 6,800 | 90.7% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 15.1% ± 11.4% | 1,300 | 17.3% |
| No | 90.3% | 80,000 | 7.8% ± 2.2% | 6,200 | 82.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 17.4% ± 12.4% | 1,700 | 23.3% |
| 101-200% | 28.8% | 25,500 | 7.6% ± 4.6% | 1,900 | 26.0% |
| 201-300% | 25.4% | 22,500 | 7.8% ± 4.4% | 1,800 | 24.7% |
| Over 300% | 35.0% | 31,000 | 6.1% ± 3.3% | 1,900 | 26.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 8.4% ± 2.5% | 5,900 | 77.6% |
| Rural | 21.0% | 18,600 | 9.0% ± 5.3% | 1,700 | 22.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 8.5% ± 2.3% | 7,500 | 100.0% |

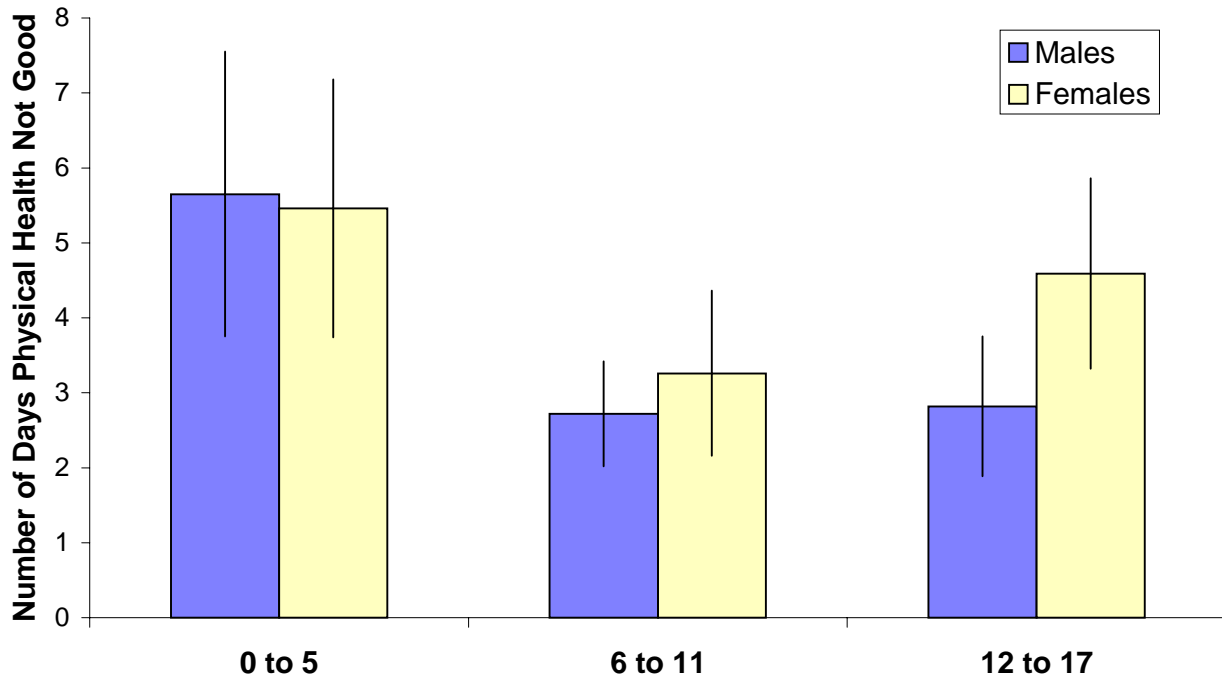
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Average Number of Days During Past 30 Days Child's Physical Health Was Not Good by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- Fifty-nine percent of children with special health care needs (CSHCN) had one or more days out of the previous 30 when their physical health was “not good” (including illness and injury). On average, CSHCN experienced 3.8 sick days in the previous month. This is significantly higher than the 2.3 sick days reported for children in the general Utah population.¹
- Girls, on the average, had one more sick day than boys (4.4 vs. 3.3 days¹). Children age 0-5 had almost two more sick days than the overall average (5.6 days¹).
- The number of reported sick days was inversely related to income. Children in the below-poverty group had 4.4 sick days, whereas those in households with incomes above 300% of the federal poverty level had only 3.2 days, on average. Although the means of these groups appear different, the difference is not statistically significant.

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

**Physical Health Status: Average Number of Days During Past 30 Days
Child's Physical Health Was Not Good (Question B2)**

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Number for Days Physical Health Not Good. | | |
|--|------------------------------|---------------------------------|--|------------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Average Number of Days Physical Health Not Good ² | Number of Sick Days ^{1,3} | Percentage Distribution of No. of Days Physical Health Was Not Good by Category |
| Days Physical Health⁴ Not Good | | | | | |
| 0 Days | 41.1% | 36,400 | | | |
| 1 to 6 Days | 41.5% | 36,800 | | | |
| 7 to 12 Days | 8.8% | 7,800 | | | |
| 13 to 18 Days | 3.9% | 3,500 | | | |
| 19 to 24 Days | 0.8% | 700 | | | |
| 25 to 30 Days | 3.9% | 3,500 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 3.3 ± 0.6 | 162,000 | 48.5% |
| Females | 44.6% | 39,500 | 4.4 ± 0.8 | 172,200 | 51.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 5.6 ± 1.3 | 96,700 | 28.8% |
| 6 to 11 | 35.2% | 31,200 | 2.9 ± 0.6 | 91,400 | 27.2% |
| 12 to 17 | 45.1% | 40,000 | 3.7 ± 0.8 | 148,000 | 44.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 5.7 ± 1.9 | 52,500 | 15.6% |
| Male, 6 to 11 | 22.4% | 19,900 | 2.7 ± 0.7 | 54,100 | 16.1% |
| Male, 12 to 17 | 22.5% | 19,900 | 2.8 ± 0.9 | 56,100 | 16.7% |
| Female, 0 to 5 | 9.1% | 8,100 | 5.5 ± 1.7 | 44,200 | 13.2% |
| Female, 6 to 11 | 12.8% | 11,300 | 3.3 ± 1.1 | 36,800 | 11.0% |
| Female, 12 to 17 | 22.6% | 20,000 | 4.6 ± 1.3 | 91,800 | 27.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 3.8 ± 0.5 | 323,900 | 96.7% |
| No | 4.1% | 3,600 | 3.4 ± 2.3 | 12,100 | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 4.5 ± 2.1 | 38,600 | 11.5% |
| No | 90.3% | 80,000 | 3.7 ± 0.5 | 296,000 | 88.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 4.4 ± 1.9 | 42,200 | 12.9% |
| 101-200% | 28.8% | 25,500 | 4.0 ± 1.2 | 101,000 | 30.9% |
| 201-300% | 25.4% | 22,500 | 3.8 ± 1.0 | 85,700 | 26.2% |
| Over 300% | 35.0% | 31,000 | 3.2 ± 0.8 | 98,000 | 30.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 3.8 ± 0.6 | 266,700 | 79.7% |
| Rural | 21.0% | 18,600 | 3.7 ± 1.1 | 68,100 | 20.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.8 ± 0.5 | 334,900 | 100.0% |

1 Rounded to the nearest 100 persons or days.

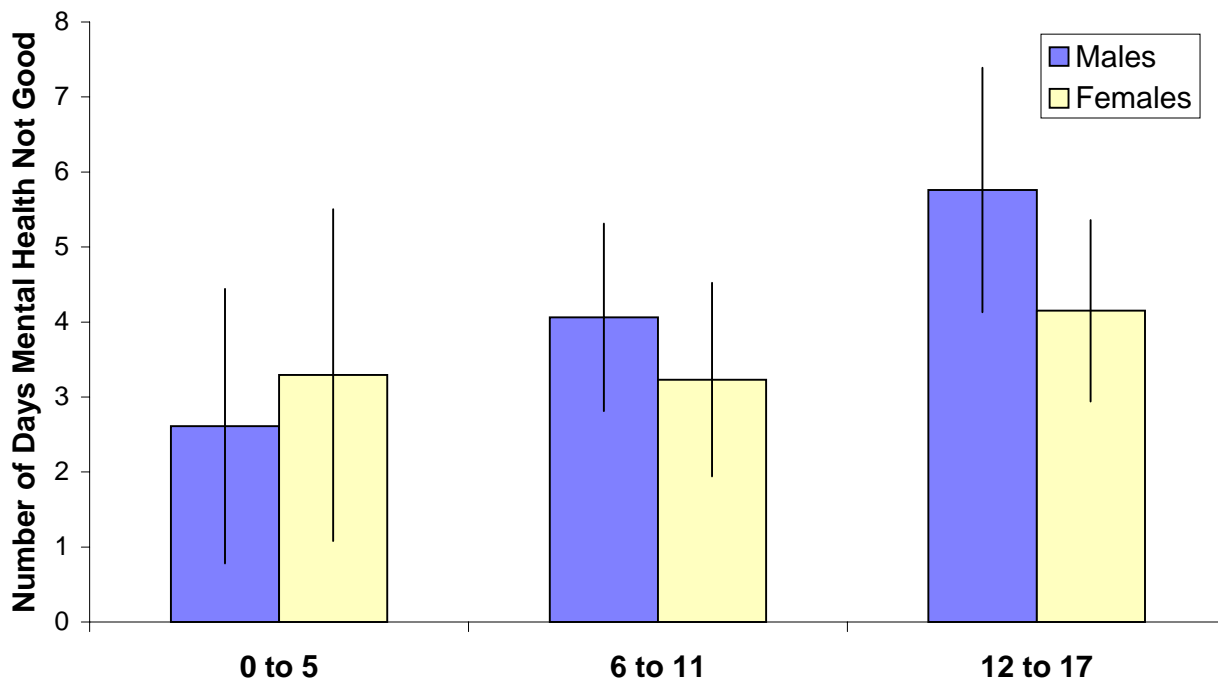
2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

4 Physical health includes "illness and injury."

*** Sample size insufficient to produce population estimates

**Average Number of Days During Past 30 Days Child's
Mental Health Was Not Good by Age and Sex, Utah
Children With Special Health Care Needs, Age 0-17, 2000**



- Approximately 42% of children with special health care needs (CSHCN) were reported to have one or more days out of the previous 30 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. This is statistically higher than the 1.5 poor mental health days reported for children in the general Utah population.¹
- More poor mental health days were reported for boys (4.5 days), children age 12-17 (5.0 days), Hispanic children (6.0 days), and children in households with incomes below the federal poverty level (8.6 days¹).

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

**Mental Health Status: Average Number of Days During Past 30 Days,
Child's Mental Health Was Not Good (Question B3)**

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Days Mental Health Not Good | | |
|--|------------------------------|---------------------------------|---|------------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | of Days Mental Health Not Good ² | Number of Sick Days ^{1,3} | Percentage Distribution of No. of Days Mental Health Not Good by Category |
| Days Mental Health⁴ Not Good | | | | | |
| 0 Day | 57.8% | 51,200 | | | |
| 1 to 6 Days | 23.6% | 20,900 | | | |
| 7 to 12 Days | 6.3% | 5,600 | | | |
| 13 to 18 Days | 3.7% | 3,200 | | | |
| 19 to 24 Days | 2.2% | 2,000 | | | |
| 25 to 30 Days | 6.4% | 5,700 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 4.5 ± 1.0 | 221,900 | 60.1% |
| Females | 44.6% | 39,500 | 3.7 ± 0.8 | 147,300 | 39.9% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 2.9 ± 1.6 | 50,800 | 13.9% |
| 6 to 11 | 35.2% | 31,200 | 3.8 ± 0.9 | 117,000 | 31.9% |
| 12 to 17 | 45.1% | 40,000 | 5.0 ± 1.1 | 198,400 | 54.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 2.6 ± 1.8 | 24,300 | 6.6% |
| Male, 6 to 11 | 22.4% | 19,900 | 4.1 ± 1.3 | 80,800 | 22.1% |
| Male, 12 to 17 | 22.5% | 19,900 | 5.8 ± 1.6 | 114,600 | 31.3% |
| Female, 0 to 5 | 9.1% | 8,100 | 3.3 ± 2.2 | 26,600 | 7.3% |
| Female, 6 to 11 | 12.8% | 11,300 | 3.2 ± 1.3 | 36,500 | 10.0% |
| Female, 12 to 17 | 22.6% | 20,000 | 4.2 ± 1.2 | 83,000 | 22.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 4.1 ± 0.7 | 344,300 | 93.4% |
| No | 4.1% | 3,600 | 6.3 ± 4.3 | 22,600 | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 6.0 ± 3.0 | 51,900 | 14.1% |
| No | 90.3% | 80,000 | 4.0 ± 0.7 | 316,800 | 85.9% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 8.6 ± 3.7 | 81,400 | 21.2% |
| 101-200% | 28.8% | 25,500 | 4.8 ± 1.5 | 122,100 | 31.8% |
| 201-300% | 25.4% | 22,500 | 3.1 ± 1.1 | 70,400 | 18.3% |
| Over 300% | 35.0% | 31,000 | 3.6 ± 1.0 | 110,400 | 28.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 4.4 ± 0.8 | 308,000 | 83.3% |
| Rural | 21.0% | 18,600 | 3.3 ± 1.2 | 61,600 | 16.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.2 ± 0.7 | 368,600 | 100.0% |

1 Rounded to the nearest 100 persons or days.

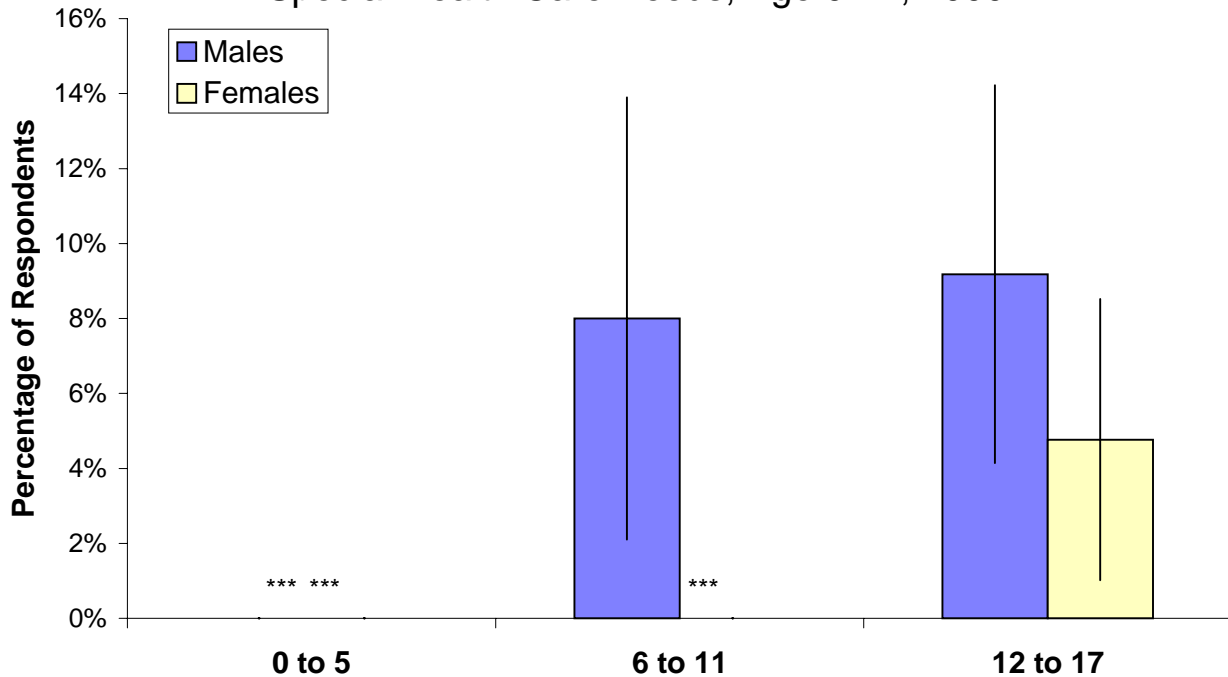
2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

4 Mental health includes "stress, depression, and problems with emotions."

*** Sample size insufficient to produce population estimates

Percentage of Respondents Who Reported Having Difficult Relationship With Child by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- While most parents of children with special health care needs (72.9%) reported that they had a close relationship with their child(ren), 6.5% reported that their relationship was difficult.
- Parents were more likely to report having a difficult relationship with boys (7.8%) and older children (7.1%)
- Parents in households from 101% to 200% of poverty were also more likely to report having a difficult relationship with their child (9.1%). For households with incomes below the poverty level, the sample size was not sufficient to produce population estimates.

Parent/Child Relationship: Percentage of Respondents Who Reported Having Difficult Relationship With Child (Questions B4 and B4A-B4B) by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Respondents Having Difficult Relationship With Child | | |
|----------------------------------|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage Having Difficult Relationship ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Having Difficult Relationship by Category |
| Parent/Child Relationship | | | | | |
| Close | 72.9% | 64,600 | | | |
| Average | 20.6% | 18,300 | | | |
| Difficult | 6.5% | 5,700 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 7.8% ± 3.4% | 3,800 | 66.7% |
| Females | 44.6% | 39,500 | 4.8% ± 2.9% | 1,900 | 33.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | *** ± *** | *** | *** |
| 6 to 11 | 35.2% | 31,200 | 7.0% ± 4.3% | 2,200 | 38.6% |
| 12 to 17 | 45.1% | 40,000 | 7.1% ± 3.2% | 2,800 | 49.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | *** ± *** | *** | *** |
| Male, 6 to 11 | 22.4% | 19,900 | 8.0% ± 5.9% | 1,600 | 28.1% |
| Male, 12 to 17 | 22.5% | 19,900 | 9.2% ± 5.0% | 1,800 | 31.6% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | *** ± *** | *** | *** |
| Female, 12 to 17 | 22.6% | 20,000 | 4.8% ± 3.8% | 1,000 | 17.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 6.8% ± 2.4% | 5,700 | 100.0% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 6.6% ± 2.4% | 5,300 | 93.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 9.1% ± 6.0% | 2,300 | 40.4% |
| 201-300% | 25.4% | 22,500 | 3.5% ± 3.5% | 800 | 14.0% |
| Over 300% | 35.0% | 31,000 | 5.6% ± 3.6% | 1,700 | 29.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 7.4% ± 2.8% | 5,200 | 91.2% |
| Rural | 21.0% | 18,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 6.5% ± 2.3% | 5,700 | 100.0% |

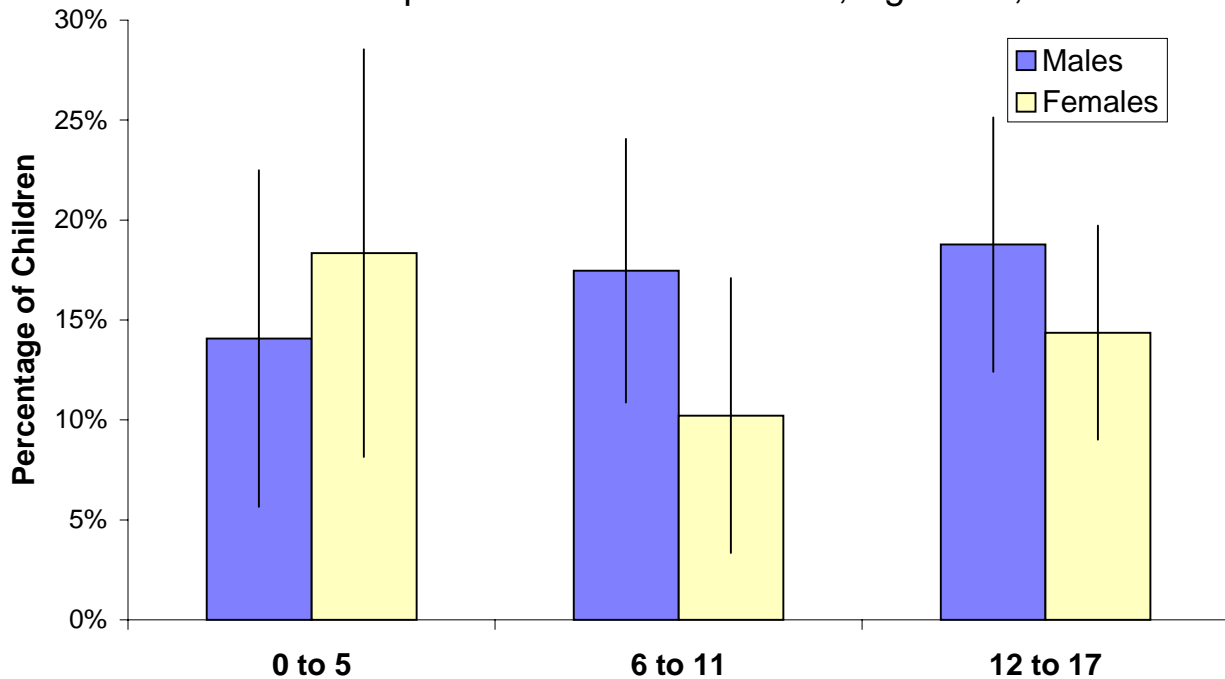
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of Children Who Spent More Than Three Hours per Day on TV/Computer Games by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- The number of hours spent watching TV or playing computer games is intended to indicate sedentary lifestyle. Overall, 15.8% of children with special health care needs were reported to spend more than three hours per day in front of their TV or computer.
- Children most likely to spend more than three hours included boys (17.4%), Hispanic children (22.9%), and children in households with incomes from 201% to 300% of the federal poverty level (17.8%).

Sedentary Lifestyle: Percentage of Children Who Spent More Than 3 Hours per Day on TV/Computer Games (Question G1)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children Who Spent More Than 3 Hrs on TV/Computer Games | | |
|-----------------------------------|------------------------------|---------------------------------|--|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children Who Spent More Than 3 Hours On TV/Computer Games ² | Number of Children ^{1,3} | Percentage Distribution of Children Who Spent Time On TV/Computer Games by Category |
| Hours on TV/Computer Games | | | | | |
| More Than 3 Hours | 15.8% | 14,000 | | | |
| Less Than or Equal To 3 Hours | 84.2% | 74,600 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 17.4% ± 4.2% | 8,500 | 60.7% |
| Females | 44.6% | 39,500 | 13.9% ± 4.0% | 5,500 | 39.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 16.0% ± 7.0% | 2,800 | 20.0% |
| 6 to 11 | 35.2% | 31,200 | 14.7% ± 5.0% | 4,600 | 32.9% |
| 12 to 17 | 45.1% | 40,000 | 16.6% ± 4.4% | 6,600 | 47.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 14.1% ± 8.4% | 1,300 | 9.2% |
| Male, 6 to 11 | 22.4% | 19,900 | 17.5% ± 6.6% | 3,500 | 24.8% |
| Male, 12 to 17 | 22.5% | 19,900 | 18.8% ± 6.4% | 3,700 | 26.2% |
| Female, 0 to 5 | 9.1% | 8,100 | 18.4% ± 10.2% | 1,500 | 10.6% |
| Female, 6 to 11 | 12.8% | 11,300 | 10.2% ± 6.9% | 1,200 | 8.5% |
| Female, 12 to 17 | 22.6% | 20,000 | 14.4% ± 5.4% | 2,900 | 20.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 16.0% ± 3.2% | 13,600 | 97.1% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 22.9% ± 12.4% | 2,000 | 14.2% |
| No | 90.3% | 80,000 | 15.1% ± 3.2% | 12,100 | 85.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 16.6% ± 11.0% | 1,600 | 11.8% |
| 101-200% | 28.8% | 25,500 | 13.4% ± 6.4% | 3,400 | 25.0% |
| 201-300% | 25.4% | 22,500 | 17.8% ± 6.7% | 4,000 | 29.4% |
| Over 300% | 35.0% | 31,000 | 14.7% ± 5.4% | 4,600 | 33.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 15.9% ± 3.5% | 11,100 | 79.3% |
| Rural | 21.0% | 18,600 | 15.5% ± 6.6% | 2,900 | 20.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 15.8% ± 3.1% | 14,000 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

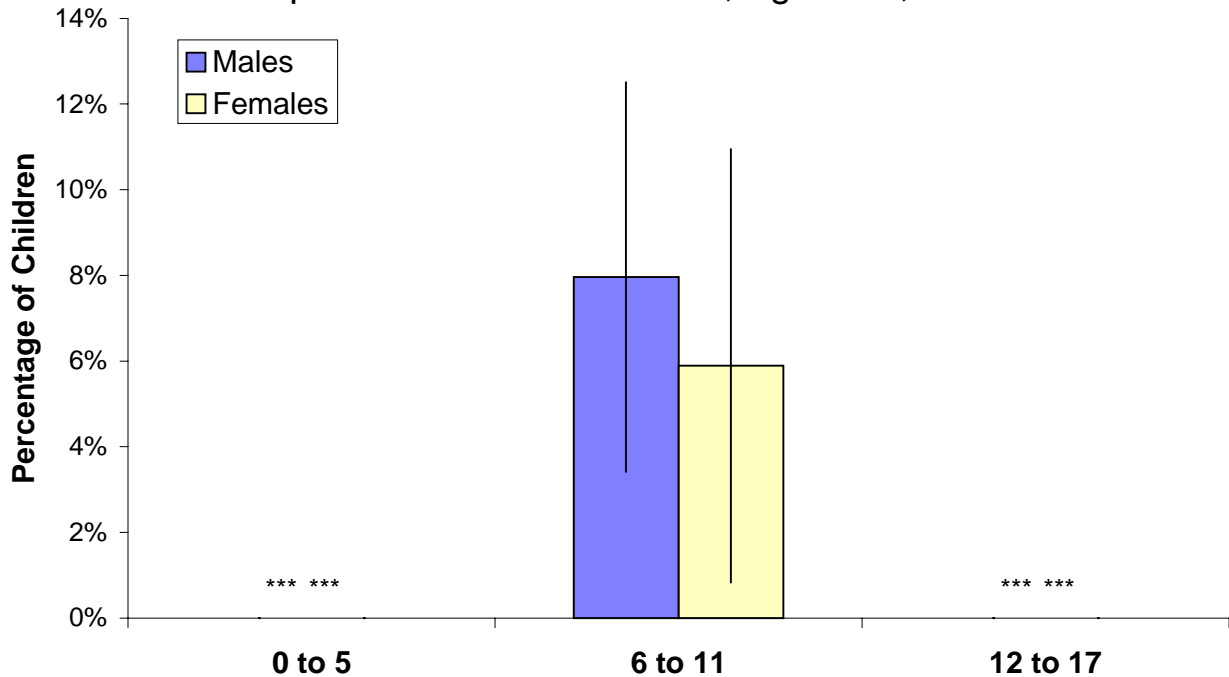
3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Health Insurance Coverage



Percentage of Children Who Were Without Health Insurance Coverage by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- Children with special health care needs were more likely than other children to be covered by some type of health insurance; 4.1% of children with special health care needs (CSHCN) were uninsured, compared with 6.5% overall.¹
- 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%¹). Almost all uninsured children living below 200% of the federal poverty level are eligible for Medicaid or CHIP (Children’s Health Insurance Program). The most common reasons given for the child lacking health insurance coverage were “could not afford premium” and “lost Medicaid/CHIP eligibility”.

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

Insurance Status: Percentage of Children

Who Were Without Health Insurance Coverage (Questions F2 and F3)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children Who Were Without Health Insurance | | |
|----------------------------|------------------------------|---------------------------------|---|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children Who Were Without Health Insurance ² | Number of Children ^{1,3} | Percentage Distribution of Children Who Were Without Health Insurance by Category |
| Insurance Status | | | | | |
| Insured | 96.0% | 85,000 | | | |
| Not Insured | 4.1% | 3,600 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 4.6% ± 2.4% | 2,300 | 63.9% |
| Females | 44.6% | 39,500 | 3.4% ± 2.1% | 1,300 | 36.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.1% ± 1.6% | 3,600 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 3.2% ± 3.1% | 600 | 16.7% |
| 6 to 11 | 35.2% | 31,200 | 7.2% ± 3.6% | 2,200 | 61.1% |
| 12 to 17 | 45.1% | 40,000 | 2.1% ± 1.7% | 800 | 22.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.1% ± 1.6% | 3,600 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | *** ± *** | *** | *** |
| Male, 6 to 11 | 22.4% | 19,900 | 8.0% ± 4.6% | 1,600 | 44.4% |
| Male, 12 to 17 | 22.5% | 19,900 | *** ± *** | *** | *** |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 5.9% ± 5.1% | 700 | 19.4% |
| Female, 12 to 17 | 22.6% | 20,000 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.1% ± 1.6% | 3,600 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 6.0% ± 5.9% | 500 | 13.9% |
| No | 90.3% | 80,000 | 3.8% ± 1.7% | 3,100 | 86.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.1% ± 1.6% | 3,600 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 20.1% ± 11.8% | 1,900 | 52.8% |
| 101-200% | 28.8% | 25,500 | 5.9% ± 4.1% | 1,500 | 41.7% |
| 201-300% | 25.4% | 22,500 | *** ± *** | *** | *** |
| Over 300% | 35.0% | 31,000 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.1% ± 1.6% | 3,600 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 3.6% ± 1.7% | 2,500 | 69.4% |
| Rural | 21.0% | 18,600 | 5.7% ± 4.3% | 1,100 | 30.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 4.1% ± 1.6% | 3,600 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Reasons for Lack of Health Insurance: Percentage of Children to Whom Each Reason Applied (Questions F7-F13):

Utah Children With Special Health Care Needs (CSHCN), Age 0-17, Who Were Without Health Insurance, 2000.

| Reasons | Survey Estimates | |
|---|--------------------------------------|---------------------------------|
| | Percentage Distribution ¹ | Number of Children ² |
| Employer Offers No Insurance | 18.8% | 700 |
| Lost or Changed Job | 27.0% | 1,000 |
| Part Time Employment | 15.0% | 500 |
| Could Not Afford Premium | 47.2% | 1,700 |
| Child's Good health | 4.7% | 200 |
| Insurance Refused To Cover | 7.3% | 300 |
| Lost Medicaid/CHIP Eligibility | 33.5% | 1,200 |
| Total, CSHCN Children 0-17 Without Health Insurance | 100.0% | 3,600 |

1 Percentages sum to greater than 100% because respondents were allowed to choose multiple categories.

2 Rounded to the nearest 100 persons.

Rating Insurance on Covering CSHCN Child Cost: Percentage of Respondents by Their Rating of Health Insurance on Covering Health Care Cost (Question F5) Utah Children With Special Health Care Needs Who Had Health Insurance (CSHCN) Age 0-17, 2000.

| Subgroup | Survey Estimates | |
|---|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Rating Insurance on Covering CSHCN Child Cost: | | |
| Poor | 7.1% | 6,000 |
| Fair | 11.1% | 9,500 |
| Good | 23.4% | 19,900 |
| Very Good | 26.9% | 22,900 |
| Excellent | 31.5% | 26,700 |
| Total, CSHCN Children 0-17 Who Had Health Insurance | 100.0% | 85,000 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

**Extra Cost for CSHCN Child: Extra Cost of Caring
for CSHCN Child in the Last 12 Months (Question F16)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|----------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Extra Cost for CSHCN Child | | |
| Less than \$500 | 66.9% | 59,200 |
| \$500 - \$1,000 | 15.7% | 13,900 |
| \$1,000 - \$3,000 | 12.8% | 11,400 |
| \$3,000 - \$5,000 | 2.6% | 2,300 |
| \$5,000+ | 2.0% | 1,700 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

**Health Insurance: Percentage of Children Who Were Without
Health Insurance Any Time During Past 12 Months (Question F4):
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|----------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Health Insurance | | |
| No Health Insurance | 8.1% | 7,200 |
| With Health Insurance | 91.9% | 81,400 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

**Received SSI: Percentage of Children Who Received
Supplemental Security Income (SSI) (Question F17)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|----------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Received SSI | | |
| Yes | 5.3% | 4,700 |
| No | 94.7% | 83,900 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

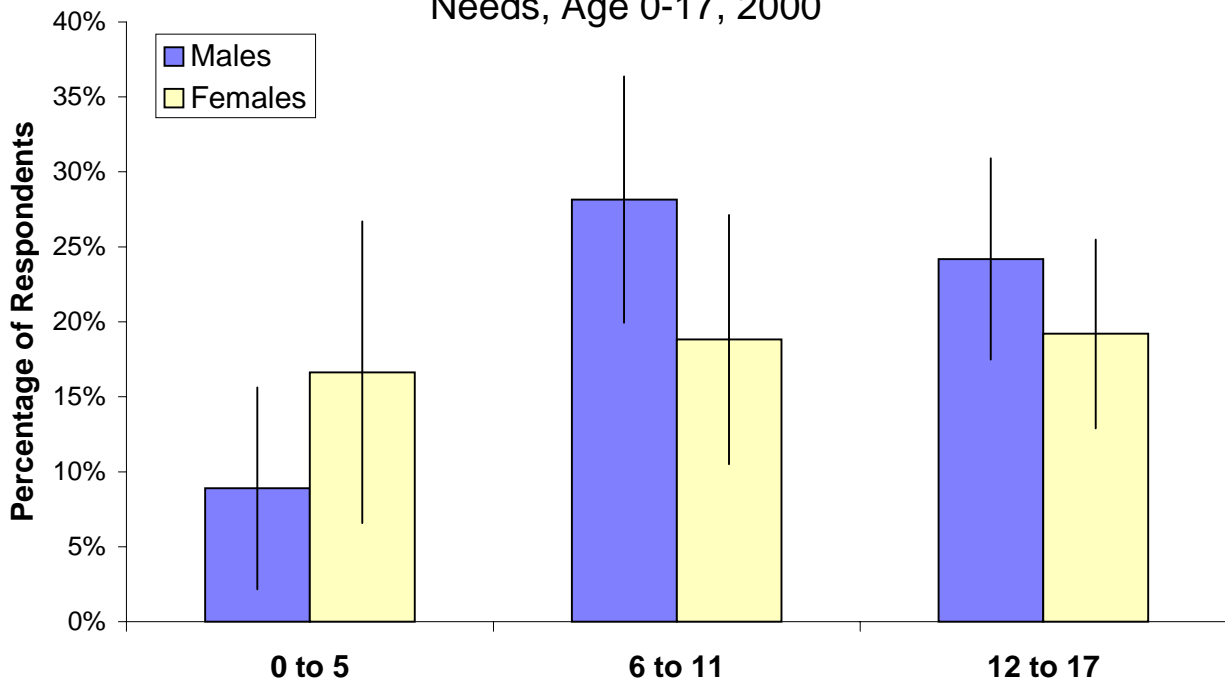
1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

Problems With Access to Health Care



Percentage of Respondents Who Could Not Afford Medical, Dental, Eye Care, Mental Health Care, or Other Services by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- 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 21.0% of parents. This is significantly higher than the 14.9% reported for children in Utah’s general population. 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 children with special health care needs (CSHCN) had problems getting medical care. The most commonly cited reason was “could not get an appointment in a reasonable amount of time”.
- 15.1% of CSHCN had problems getting dental care, and 7.3% had problems getting mental health care.
- When asked about prescription medicines, 7.0% of parents said they could not get prescription medicine for their child because of the cost.

Could Not Afford Services: Percentage of Respondents Who Could Not Afford Medical, Dental, Eye Care, Mental Health Care or Other Services (Questions E3 and E3A)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Respondents Who Could Not Afford Services | | |
|----------------------------------|------------------------------|---------------------------------|---|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of Respondents Who Could Not Afford Services ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Who Could Not Afford Services by Category |
| Could Not Afford Services | | | | | |
| Access Problem | 21.0% | 18,600 | | | |
| No Problem | 79.0% | 70,000 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 22.9% ± 4.9% | 11,300 | 60.8% |
| Females | 44.6% | 39,500 | 18.6% ± 4.4% | 7,300 | 39.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 12.4% ± 5.9% | 2,200 | 11.8% |
| 6 to 11 | 35.2% | 31,200 | 24.6% ± 6.3% | 7,700 | 41.4% |
| 12 to 17 | 45.1% | 40,000 | 21.7% ± 4.7% | 8,700 | 46.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 8.9% ± 6.7% | 800 | 4.3% |
| Male, 6 to 11 | 22.4% | 19,900 | 28.2% ± 8.2% | 5,600 | 30.4% |
| Male, 12 to 17 | 22.5% | 19,900 | 24.2% ± 6.7% | 4,800 | 26.1% |
| Female, 0 to 5 | 9.1% | 8,100 | 16.6% ± 10.1% | 1,300 | 7.1% |
| Female, 6 to 11 | 12.8% | 11,300 | 18.8% ± 8.3% | 2,100 | 11.4% |
| Female, 12 to 17 | 22.6% | 20,000 | 19.2% ± 6.3% | 3,800 | 20.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 18.8% ± 3.5% | 16,000 | 86.0% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 25.5% ± 14.8% | 2,200 | 11.8% |
| No | 90.3% | 80,000 | 20.5% ± 3.6% | 16,400 | 88.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 38.2% ± 16.2% | 3,600 | 17.6% |
| 101-200% | 28.8% | 25,500 | 34.5% ± 8.5% | 8,800 | 42.9% |
| 201-300% | 25.4% | 22,500 | 25.4% ± 7.8% | 5,700 | 27.8% |
| Over 300% | 35.0% | 31,000 | 7.8% ± 3.7% | 2,400 | 11.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 19.9% ± 3.9% | 13,900 | 74.7% |
| Rural | 21.0% | 18,600 | 25.2% ± 8.5% | 4,700 | 25.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 21.0% ± 3.5% | 18,600 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Problems With Access to *Medical* Care: In Last 12 Months, Had Problems or Delayed Getting Medical Care (Questions E1 and E1A)

Utah Children With Special Health Care Needs (CSHCN) and Children in General Population, Age 0-17, 2000.

| | CSHCN Survey Estimates** | | Survey Estimates** for Children in Utah's General Population | |
|---|--------------------------|---------------------------------|--|---------------------------------|
| | Percentage Distribution | Number of Children ¹ | Percentage Distribution | Number of Children ¹ |
| Problems With Access to Medical Care | | | | |
| Provider Would Not Take Insurance | 3.2% | 2,800 | 2.0% | 14,100 |
| Could Not Find Services in My Area | 5.0% | 4,400 | 2.5% | 17,600 |
| Could Not Afford Services | 6.5% | 5,800 | 3.8% | 26,700 |
| Services Not Covered By My Insurance | 6.8% | 6,000 | 3.8% | 26,700 |
| Could Not Get Referral for Care | 2.7% | 2,400 | 1.5% | 10,600 |
| Could Not Get Timely Appointment | 7.4% | 6,600 | 5.0% | 35,200 |
| Problems Getting Medical Care, Any Reason | 17.9% | 15,900 | 12.1% | 85,100 |
| No Problems With Access to Medical Care | 82.1% | 72,700 | 87.9% | 618,400 |
| Total, All CSHCN Children 0-17 | 100.0% | 88,600 | 100.0% | 703,500 |

Problems With Access to *Dental* Care: In Last 12 Months, Had Problems or Delayed Getting Dental Care (Questions E2 and E2A)

Utah Children With Special Health Care Needs (CSHCN) and Children in General Population, Age 0-17, 2000.

| | CSHCN Survey Estimates** | | Survey Estimates** for Children in Utah's General Population | |
|---|--------------------------|---------------------------------|--|---------------------------------|
| | Percentage Distribution | Number of Children ¹ | Percentage Distribution | Number of Children ¹ |
| Problems With Access to Dental Care | | | | |
| Provider Would Not Take Insurance | 4.8% | 4,300 | 3.3% | 23,200 |
| Could Not Find Services in My Area | 2.0% | 1,800 | 2.1% | 14,800 |
| Could Not Afford Services | 9.7% | 8,600 | 8.5% | 59,800 |
| Services Not Covered By My Insurance | 9.5% | 8,400 | 7.7% | 54,200 |
| Could Not Get Referral for Care | 1.0% | 900 | 0.5% | 3,500 |
| Could Not Get Timely Appointment | 2.3% | 2,000 | 1.9% | 13,400 |
| Problems Getting Medical Care, Any Reason | 15.1% | 13,400 | 13.6% | 95,700 |
| No Problems With Access to Medical Care | 84.9% | 75,200 | 86.4% | 607,800 |
| Total, All CSHCN Children 0-17 | 100.0% | 88,600 | 100.0% | 703,500 |

Problems With Access to *Eye* Doctor: In Last 12 Months, Had Problems or Delayed Getting Eye Care (Questions E3 and E3A)

Utah Children With Special Health Care Needs (CSHCN) and Children in General Population, Age 0-17, 2000.

| | CSHCN Survey Estimates** | | Survey Estimates** for Children in Utah's General Population | |
|---|--------------------------|---------------------------------|--|---------------------------------|
| | Percentage Distribution | Number of Children ¹ | Percentage Distribution | Number of Children ¹ |
| Problems With Access to Eye Doctor | | | | |
| Provider Would Not Take Insurance | 0.3% | 300 | 0.2% | 1,400 |
| Could Not Find Services in My Area | 0.5% | 400 | 0.3% | 2,100 |
| Could Not Afford Services | 0.3% | 300 | 0.6% | 4,200 |
| Services Not Covered By My Insurance | 0.8% | 700 | 0.4% | 2,800 |
| Could Not Get Referral for Care | *** | *** | *** | *** |
| Could Not Get Timely Appointment | 0.5% | 400 | 0.3% | 2,100 |
| Problems Getting Medical Care, Any Reason | 1.5% | 1,300 | 1.1% | 7,700 |
| No Problems With Access to Medical Care | 98.5% | 87,300 | 98.9% | 695,800 |
| Total, All CSHCN Children 0-17 | 100.0% | 88,600 | 100.0% | 703,500 |

Problems With Access to *Mental* Health Care: In Last 12 Months, Had Problems or Delayed Getting Mental Health Care (Questions E4 and E4A)

Utah Children With Special Health Care Needs (CSHCN) and Children in General Population, Age 0-17, 2000.

| | CSHCN Survey Estimates** | | Survey Estimates** for Children in Utah's General Population | |
|--|--------------------------|---------------------------------|--|---------------------------------|
| | Percentage Distribution | Number of Children ¹ | Percentage Distribution | Number of Children ¹ |
| Problems With Access to Mental Health Care | | | | |
| Provider Would Not Take Insurance | 2.4% | 2,100 | 0.3% | 2,100 |
| Could Not Find Services in My Area | 98.5% | 87,300 | 0.6% | 4,200 |
| Could Not Afford Services | 2.9% | 2,600 | 0.7% | 4,900 |
| Services Not Covered By My Insurance | 3.6% | 3,200 | 0.8% | 5,600 |
| Could Not Get Referral for Care | 1.2% | 1,100 | 0.3% | 2,100 |
| Could Not Get Timely Appointment | 2.6% | 2,300 | 0.5% | 3,500 |
| Problems Getting Medical Care, Any Reason | 7.3% | 6,500 | 1.6% | 11,300 |
| <u>No</u> Problems With Access to Medical Care | 92.7% | 82,100 | 98.4% | 692,200 |
| Total, All CSHCN Children 0-17 | 100.0% | 88,600 | 100.0% | 703,500 |

Problems With Access to *Other* Type of Care: In Last 12 Months, Had Problems or Delayed Getting Other Type of Care* (Questions E5 and E5A)

Utah Children With Special Health Care Needs (CSHCN) and Children in General Population, Age 0-17, 2000.

| | CSHCN Survey Estimates** | | Survey Estimates** for Children in Utah's General Population | |
|--|--------------------------|---------------------------------|--|---------------------------------|
| | Percentage Distribution | Number of Children ¹ | Percentage Distribution | Number of Children ¹ |
| Problems With Access to Other Care | | | | |
| Provider Would Not Take Insurance | 0.8% | 710 | 0.3% | 2,100 |
| Could Not Find Services in My Area | 0.7% | 620 | 0.3% | 2,100 |
| Could Not Afford Services | 1.9% | 1,680 | 0.8% | 5,600 |
| Services Not Covered By My Insurance | 2.1% | 1,860 | 0.7% | 4,900 |
| Could Not Get Referral for Care | 0.7% | 620 | 0.3% | 2,100 |
| Could Not Get Timely Appointment | 0.4% | 350 | 0.3% | 2,100 |
| Problems Getting Medical Care, Any Reason | 4.4% | 3,900 | 1.7% | 12,000 |
| <u>No</u> Problems With Access to Medical Care | 95.6% | 84,700 | 98.3% | 691,500 |
| Total, All CSHCN Children 0-17 | 100.0% | 88,600 | 100.0% | 703,500 |

¹ Rounded to the nearest 100 or 10 persons.

* Some respondents to this question indicated that they had problems getting multiple types of care.

** Figures in these columns sum to greater than 100% because respondents were allowed to choose multiple categories.

*** Sample size insufficient to produce population estimates

In most cases, the types of care mentioned were "medical and dental" care.

**Could Not Afford Prescription Medicine: Percentage of Respondents Who Did Not Get Prescription Medicine Because of Cost, Last 12 Months (Question E7)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | CSHCN Survey Estimates | | Survey Estimates for Children in Utah's General Population | |
|--|-------------------------|---------------------------------|--|---------------------------------|
| | Percentage Distribution | Number of Children ¹ | Percentage Distribution | Number of Children ¹ |
| Could Not Afford Prescription Medicine | | | | |
| Could Not Afford | 7.0% | 6,200 | 3.4% | 24,100 |
| Could Afford | 93.0% | 82,400 | 96.6% | 679,400 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 100.0% | 703,500 |

¹ Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

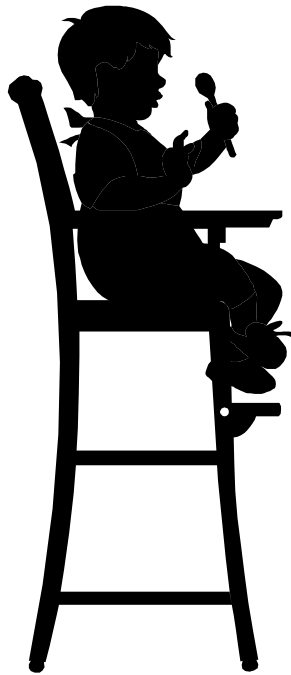
**Timely Care for CSHCN Child: When Your Child Needs Care Right Away for Illness, How Often Are You Able to Get the Care You Want? (Question E8)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|-----------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Timely Care for CSHCN Child | | |
| Never | 0.3% | 300 |
| Sometimes | 5.6% | 5,000 |
| Usually | 18.9% | 16,700 |
| Always | 75.2% | 66,600 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

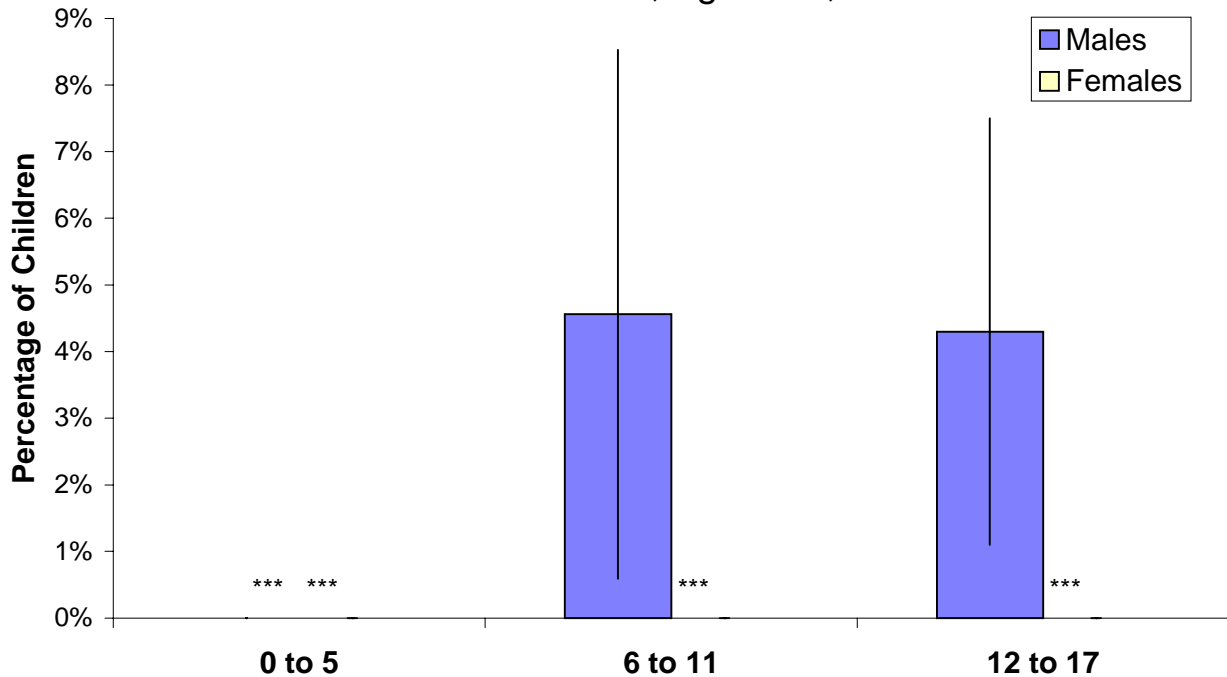
¹ Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

Medical Home



Percentage of Children Who Did Not Have a Provider/Place for Acute Care by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- Only 3.0% of parents of children with special health care needs reported that their child had no usual provider or place for acute medical care. This is significantly lower than the 6.9% reported for children in Utah’s general population.¹
- 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.

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

No Usual Place for Acute Care: Percentage of Children Who Did Not Have a Provider/Place for Acute Care (Questions C1A and C2) by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children With No Provider/Place for Acute Care | | |
|--------------------------------------|------------------------------|---------------------------------|---|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children With No Provider/Place for Acute Care | Number of Children ^{1,3} | Percentage Distribution of Children With No Provider/Place for Acute Care by Category |
| No Usual Place for Acute Care | | | | | |
| Doctors Office | 69.5% | 61,600 | | | |
| Pvt/Hosp Clinc | 19.5% | 17,300 | | | |
| Hospital ER | *** | *** | | | |
| Urgent Care | 1.6% | 1,400 | | | |
| Clinic | 4.7% | 4,100 | | | |
| Military/V.A. | *** | *** | | | |
| Other Place | 0.7% | 594 | | | |
| No Provdrr/Plice | 3.0% | 2,676 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 3.9% ± 2.4% | 1,900 | 70.4% |
| Females | 44.6% | 39,500 | 2.0% ± 1.6% | 800 | 29.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | *** ± *** | *** | *** |
| 6 to 11 | 35.2% | 31,200 | 3.2% ± 2.5% | 1,000 | 37.0% |
| 12 to 17 | 45.1% | 40,000 | 3.1% ± 1.9% | 1,200 | 44.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | *** ± *** | *** | *** |
| Male, 6 to 11 | 22.4% | 19,900 | 4.6% ± 4.0% | 900 | 33.3% |
| Male, 12 to 17 | 22.5% | 19,900 | 4.3% ± 3.2% | 900 | 33.3% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | *** ± *** | *** | *** |
| Female, 12 to 17 | 22.6% | 20,000 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 2.3% ± 1.4% | 2,000 | 74.1% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 2.5% ± 1.3% | 2,000 | 74.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 12.8% ± 11.0% | 1,200 | 44.4% |
| 101-200% | 28.8% | 25,500 | 3.5% ± 3.1% | 900 | 33.3% |
| 201-300% | 25.4% | 22,500 | *** ± *** | *** | *** |
| Over 300% | 35.0% | 31,000 | 1.9% ± 1.9% | 600 | 22.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 2.4% ± 1.4% | 1,700 | 63.0% |
| Rural | 21.0% | 18,600 | 5.3% ± 4.8% | 1,000 | 37.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 3.0% ± 1.5% | 2,700 | 100.0% |

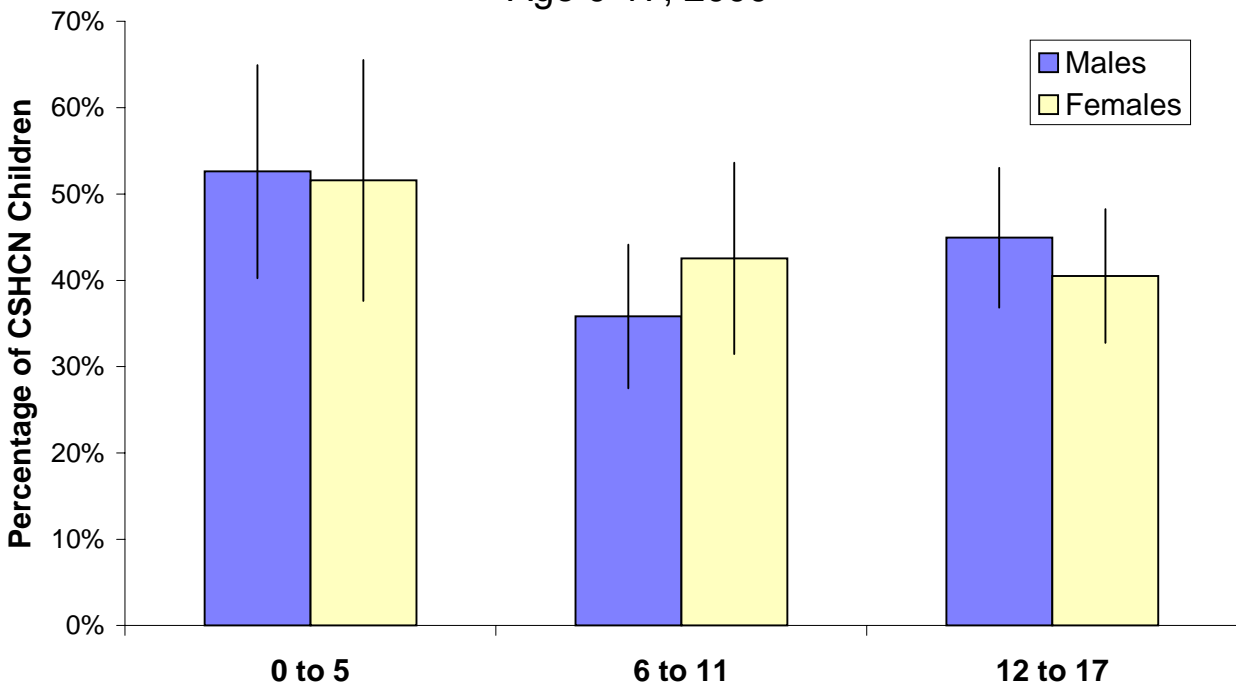
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of CSHCN Children Who Visited Specialist or Specialty Clinics for Special Health Care Need by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- Because of the complicated needs of a child, children with special health care needs often require the services of one or more health care providers, often a specialty provider or specialty clinic. These services need to be coordinated through a medical home.
- At the time of the survey, parents reported that 43.0% of CSHCN visited a specialist, such as an orthopedist, neurologist, etc., or 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 (35.2%).

**Visited Specialist: Percentage of CSHCN Children Who Visited
Specialist or Speciality Clinics For Special Health Care Need (Question C9)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Utah CSHCN Who Visited Specialists | | |
|---|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of CSHCN Who Visited Specialists ² | Number of Children ^{1,3} | Percentage Distribution of CSHCN Who Visited Specialists by Category |
| Visited Specialist or Specialty Clinic | | | | | |
| Visted | 43.0% | 38,100 | | | |
| Not Visted | 57.0% | 50,500 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 42.8% ± 5.4% | 21,000 | 55.3% |
| Females | 44.6% | 39,500 | 43.2% ± 5.9% | 17,000 | 44.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 52.1% ± 9.5% | 9,100 | 23.8% |
| 6 to 11 | 35.2% | 31,200 | 38.4% ± 6.8% | 12,000 | 31.4% |
| 12 to 17 | 45.1% | 40,000 | 42.7% ± 5.7% | 17,100 | 44.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 52.6% ± 12.4% | 4,900 | 12.9% |
| Male, 6 to 11 | 22.4% | 19,900 | 35.8% ± 8.3% | 7,100 | 18.7% |
| Male, 12 to 17 | 22.5% | 19,900 | 44.9% ± 8.1% | 8,900 | 23.4% |
| Female, 0 to 5 | 9.1% | 8,100 | 51.6% ± 14.0% | 4,200 | 11.1% |
| Female, 6 to 11 | 12.8% | 11,300 | 42.5% ± 11.1% | 4,800 | 12.6% |
| Female, 12 to 17 | 22.6% | 20,000 | 40.5% ± 7.8% | 8,100 | 21.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 43.5% ± 4.2% | 36,900 | 96.9% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 40.9% ± 14.7% | 3,500 | 9.2% |
| No | 90.3% | 80,000 | 43.2% ± 4.2% | 34,500 | 90.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 35.2% ± 15.1% | 3,300 | 8.5% |
| 101-200% | 28.8% | 25,500 | 42.2% ± 8.5% | 10,800 | 27.8% |
| 201-300% | 25.4% | 22,500 | 44.0% ± 9.3% | 9,900 | 25.5% |
| Over 300% | 35.0% | 31,000 | 47.8% ± 6.8% | 14,800 | 38.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 42.2% ± 4.6% | 29,500 | 77.6% |
| Rural | 21.0% | 18,600 | 45.8% ± 9.0% | 8,500 | 22.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.0% ± 4.1% | 38,100 | 100.0% |

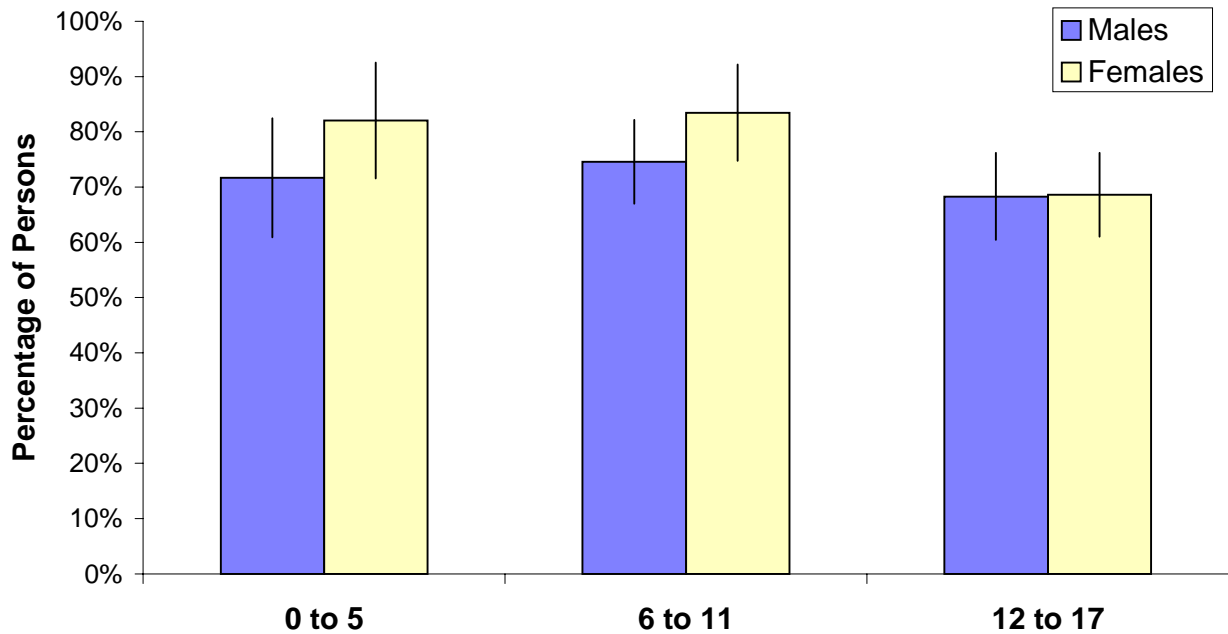
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of Persons Who Reported Their Doctor Always Had a Thorough Understanding of All Child's Health Care Services by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- Children with special health care needs (CSHCN) 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 CSHCN reported that their providers had a thorough understanding of all their child's health care services.

Coordination of Care: Percentage of Persons Who Reported Their Doctor Always Had a Thorough Understanding of All Child's Health Care Services (Question C5) by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children Whose Doctor Always Had Understanding of the Services | | |
|----------------------------------|------------------------------|---------------------------------|---|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children Whose Doctor Always Had Understanding of the Services ² | Number of Children ^{1,3} | Percentage Distribution of Children Whose Doctor Had Understanding of All the Services by Category |
| Coordination of Care | | | | | |
| Always | 73.3% | 64,900 | | | |
| Frequently | 16.8% | 14,900 | | | |
| Sometimes | 7.9% | 7,000 | | | |
| Rarely | 1.6% | 1,400 | | | |
| Never | *** | *** | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 71.4% ± 5.0% | 35,100 | 54.1% |
| Females | 44.6% | 39,500 | 75.5% ± 5.2% | 29,800 | 45.9% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 76.4% ± 7.8% | 13,300 | 20.5% |
| 6 to 11 | 35.2% | 31,200 | 78.0% ± 5.8% | 24,300 | 37.4% |
| 12 to 17 | 45.1% | 40,000 | 68.5% ± 5.8% | 27,400 | 42.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 71.7% ± 10.8% | 6,700 | 10.3% |
| Male, 6 to 11 | 22.4% | 19,900 | 74.6% ± 7.6% | 14,800 | 22.8% |
| Male, 12 to 17 | 22.5% | 19,900 | 68.3% ± 7.9% | 13,600 | 21.0% |
| Female, 0 to 5 | 9.1% | 8,100 | 82.1% ± 10.5% | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 83.5% ± 8.7% | 9,400 | 14.5% |
| Female, 12 to 17 | 22.6% | 20,000 | 68.6% ± 7.6% | 13,700 | 21.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 72.8% ± 3.9% | 61,900 | 95.4% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 73.4% ± 3.9% | 58,700 | 100.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 71.8% ± 8.2% | 18,300 | 28.2% |
| 201-300% | 25.4% | 22,500 | 69.7% ± 8.8% | 15,700 | 24.2% |
| Over 300% | 35.0% | 31,000 | 74.5% ± 6.6% | 23,100 | 35.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 72.4% ± 4.3% | 50,700 | 78.0% |
| Rural | 21.0% | 18,600 | 76.7% ± 8.3% | 14,300 | 22.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 73.3% ± 3.8% | 64,900 | 100.0% |

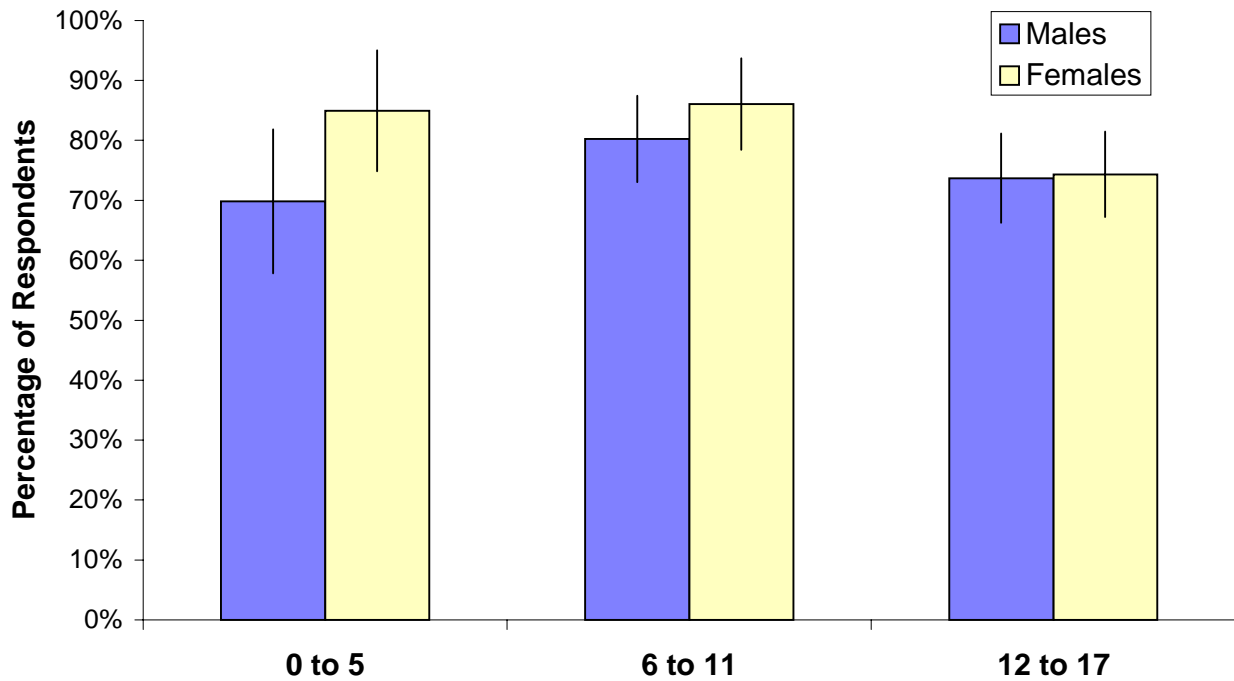
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of Persons Who Reported Doctor Always Had Access to All Medical Records by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- Having access to a child’s medical records facilitates effective coordination of care and potentially reduces duplication of services. 77.5% of parents reported that their doctor always had access to all their child’s medical records.

Doctors Access to Records: Percentage of Persons

Who Reported Doctor Always Had Access to All Medical Records (Question C4)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Respondents Whose Doctor Always Had Access To Records | | |
|----------------------------------|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage Whose Doctor Always Had Access To Records ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Whose Doctor Always Had Access to Records by Category |
| Doctors Access to Records | | | | | |
| Always | 77.5% | 68,600 | | | |
| Frequently | 13.2% | 11,700 | | | |
| Sometimes | 5.5% | 4,900 | | | |
| Rarely | 2.6% | 2,300 | | | |
| Never | 1.2% | 1,000 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 75.6% ± 5.0% | 37,100 | 54.1% |
| Females | 44.6% | 39,500 | 79.8% ± 4.9% | 31,500 | 45.9% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 76.6% ± 8.4% | 13,300 | 19.4% |
| 6 to 11 | 35.2% | 31,200 | 82.5% ± 5.5% | 25,700 | 37.5% |
| 12 to 17 | 45.1% | 40,000 | 74.0% ± 5.3% | 29,600 | 43.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 69.8% ± 12.0% | 6,500 | 9.5% |
| Male, 6 to 11 | 22.4% | 19,900 | 80.2% ± 7.2% | 16,000 | 23.3% |
| Male, 12 to 17 | 22.5% | 19,900 | 73.7% ± 7.4% | 14,700 | 21.4% |
| Female, 0 to 5 | 9.1% | 8,100 | 84.9% ± 10.1% | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 86.1% ± 7.7% | 9,700 | 14.1% |
| Female, 12 to 17 | 22.6% | 20,000 | 74.3% ± 7.1% | 14,900 | 21.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 78.0% ± 3.8% | 66,300 | 96.6% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 77.3% ± 3.9% | 61,800 | 100.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 77.3% ± 7.8% | 19,700 | 28.7% |
| 201-300% | 25.4% | 22,500 | 70.8% ± 9.0% | 15,900 | 23.2% |
| Over 300% | 35.0% | 31,000 | 80.5% ± 6.1% | 25,000 | 36.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 76.8% ± 4.2% | 53,800 | 78.3% |
| Rural | 21.0% | 18,600 | 80.0% ± 8.1% | 14,900 | 21.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 77.5% ± 3.7% | 68,600 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

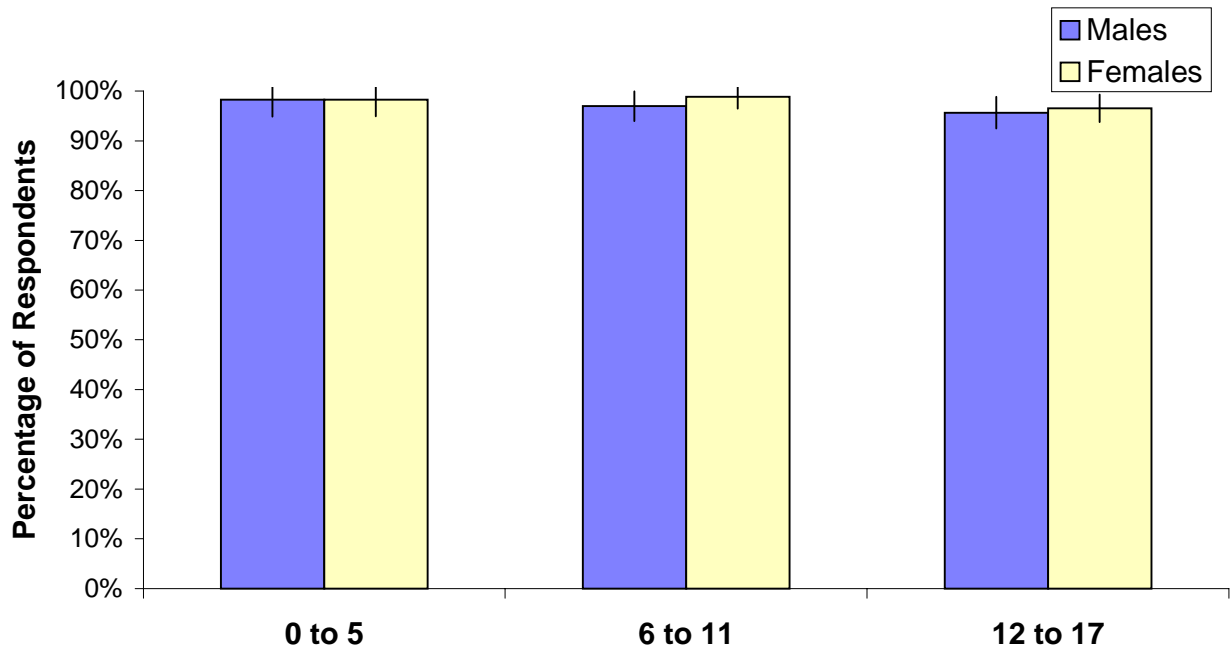
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*** Sample size insufficient to produce population estimates

Satisfaction With Care



Percentage of Respondents Who Were Satisfied* With the Health Care Received by Their Child by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



* Includes "Satisfied" and "Very Satisfied" responses.

- Almost all (97%) 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 sub-groups.

Satisfaction With Health Care: Percentage of Respondents Who Were Satisfied* With the Health Care for Their Child (Question C18)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Respondents Satisfied* With Health Care | | |
|--------------------------------------|------------------------------|---------------------------------|---|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage Satisfied With Health Care ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Satisfied With Health Care by Category |
| Satisfaction With Health Care | | | | | |
| Satisfied | 97.0% | 85,900 | | | |
| Dissatisfied | 3.0% | 2,700 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 96.6% ± 1.9% | 47,400 | 55.2% |
| Females | 44.6% | 39,500 | 97.5% ± 1.7% | 38,500 | 44.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 98.3% ± 2.4% | 17,100 | 19.9% |
| 6 to 11 | 35.2% | 31,200 | 97.6% ± 2.1% | 30,500 | 35.5% |
| 12 to 17 | 45.1% | 40,000 | 96.1% ± 2.1% | 38,400 | 44.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 98.2% ± 3.4% | 9,100 | 10.6% |
| Male, 6 to 11 | 22.4% | 19,900 | 96.9% ± 3.0% | 19,300 | 22.5% |
| Male, 12 to 17 | 22.5% | 19,900 | 95.6% ± 3.2% | 19,000 | 22.1% |
| Female, 0 to 5 | 9.1% | 8,100 | 98.3% ± 3.3% | 8,000 | 9.3% |
| Female, 6 to 11 | 12.8% | 11,300 | 98.8% ± 2.3% | 11,200 | 13.0% |
| Female, 12 to 17 | 22.6% | 20,000 | 96.5% ± 2.7% | 19,300 | 22.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 97.4% ± 1.2% | 82,800 | 96.3% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 96.8% ± 4.5% | 8,300 | 9.7% |
| No | 90.3% | 80,000 | 97.0% ± 1.4% | 77,600 | 90.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 96.4% ± 4.9% | 9,200 | 10.7% |
| 101-200% | 28.8% | 25,500 | 97.0% ± 2.7% | 24,700 | 28.8% |
| 201-300% | 25.4% | 22,500 | 96.4% ± 3.1% | 21,700 | 25.3% |
| Over 300% | 35.0% | 31,000 | 97.6% ± 2.1% | 30,300 | 35.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 96.7% ± 1.6% | 67,700 | 78.7% |
| Rural | 21.0% | 18,600 | 98.3% ± 2.0% | 18,300 | 21.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 97.0% ± 1.3% | 86,000 | 100.0% |

1 Rounded to the nearest 100 persons.

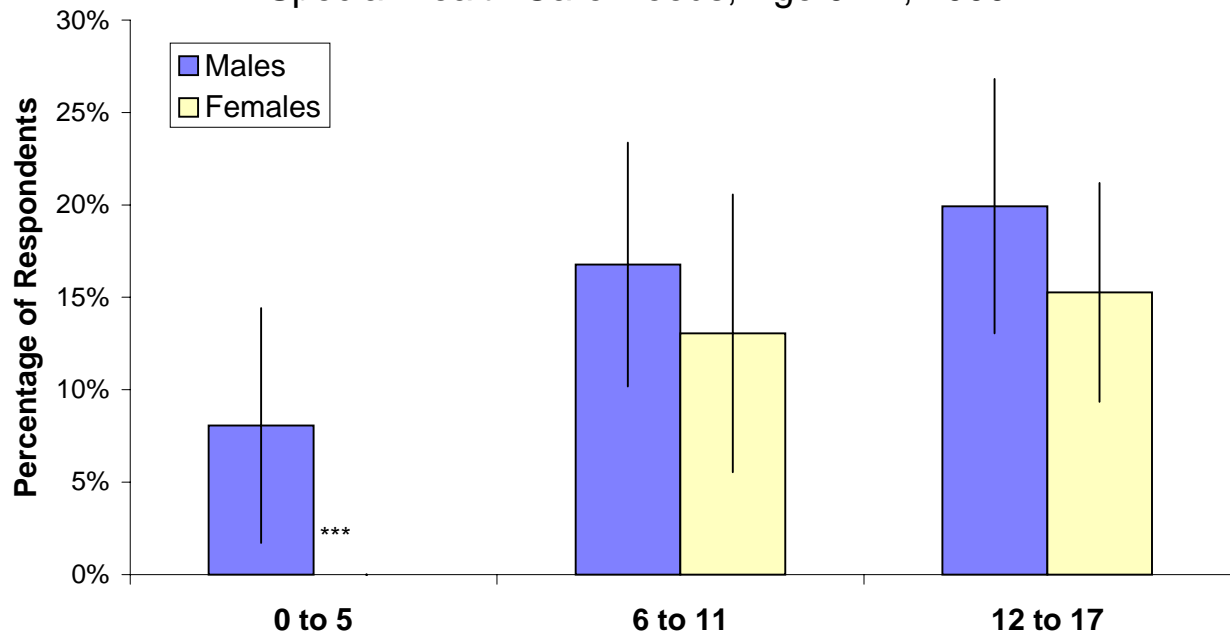
2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

* Includes "Satisfied" and "Very Satisfied" responses.

Percentage of Respondents Who Rated Services
Coordination Among Providers and Services for CSHCN
Child as Poor or Fair by Age and Sex, Utah Children With
Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- In order for health services to be of value to children with special health care needs and their families, services used to be coordinated among providers so that needs may be met in a family-centered, comprehensive, accessible, and non-duplicative manner.
- Some parents (14.8%) rated services coordination as fair or poor. These parents were asked why they gave this response. Their open-ended answers are in Appendix 3, item # C14B.
- Parents of older children, and especially boys, were more likely to rate services coordination as “fair” or “poor.”

**Rate Service Coordination: Percentage of Respondents Who Rated Services
Coordination Among Providers & Services for CSHCN Child as Poor or Fair (Question C14)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Respondents Who Rated Services Coordination as Fair or Poor | | |
|----------------------------------|------------------------------|------------------------------------|---|--------------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage Who Rated Services Coordination as Fair or Poor ² | Number of Children ^{1,3} | Percentage Distribution Who Rated Services Coordination as Fair or Poor by Category |
| Rate Service Coordination | | | | | |
| Excellent/Very Good | 59.7% | 52,900 | | | |
| Good | 25.5% | 22,600 | | | |
| Fair/Poor | 14.8% | 13,100 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 16.5% ± 4.1% | 8,100 | 61.4% |
| Females | 44.6% | 39,500 | 12.9% ± 4.2% | 5,100 | 38.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 7.2% ± 4.7% | 1,300 | 9.9% |
| 6 to 11 | 35.2% | 31,200 | 15.3% ± 5.0% | 4,800 | 36.6% |
| 12 to 17 | 45.1% | 40,000 | 17.6% ± 4.8% | 7,000 | 53.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 8.1% ± 6.4% | 700 | 5.3% |
| Male, 6 to 11 | 22.4% | 19,900 | 16.8% ± 6.6% | 3,300 | 25.2% |
| Male, 12 to 17 | 22.5% | 19,900 | 19.9% ± 6.9% | 4,000 | 30.5% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 13.1% ± 7.5% | 1,500 | 11.5% |
| Female, 12 to 17 | 22.6% | 20,000 | 15.3% ± 5.9% | 3,100 | 23.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 14.6% ± 3.2% | 12,400 | 94.7% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 15.9% ± 12.2% | 1,400 | 10.6% |
| No | 90.3% | 80,000 | 14.7% ± 3.2% | 11,800 | 89.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 12.2% ± 7.9% | 1,200 | 9.1% |
| 101-200% | 28.8% | 25,500 | 16.3% ± 6.3% | 4,200 | 31.8% |
| 201-300% | 25.4% | 22,500 | 15.6% ± 7.6% | 3,500 | 26.5% |
| Over 300% | 35.0% | 31,000 | 13.8% ± 5.4% | 4,300 | 32.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 14.3% ± 3.4% | 10,000 | 76.3% |
| Rural | 21.0% | 18,600 | 16.9% ± 7.6% | 3,100 | 23.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 14.8% ± 3.1% | 13,100 | 100.0% |

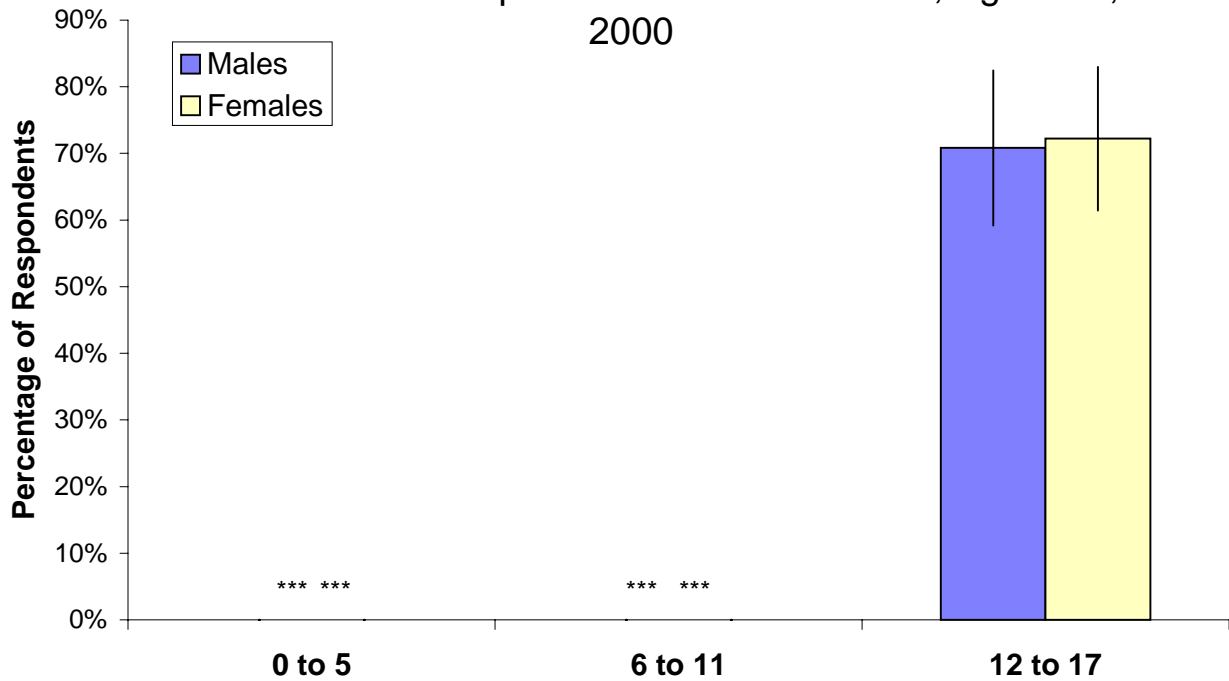
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of Respondents Who Understood Explanation Given by Specialist or Specialty Clinic by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- Despite a doctor’s best efforts, sometimes medical diagnoses, test results, and procedures are difficult for parents to understand. Although most parents said that providers usually spoke with them in a way they could understand, 30.1% said that the providers did not usually speak with them in a way they could understand.
- There was little variability in this finding across different demographic subgroups.

**Understood Doctors Explanation: Percentage of Respondents
Who Understood Explanation Given by Specialist or Specialty Clinic (Question C10)**
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimate for Utahns Who Understood Doctor's Explanation | | |
|--|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of Respondents Who Understood Doctor's Explanation ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Who Understood Doctor's Explanation by Category |
| Understood Doctors Explanation: | | | | | |
| Understood | 70.0% | 62,000 | | | |
| Not Understood | 30.1% | 26,600 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 67.7% ± 8.2% | 33,300 | 53.8% |
| Females | 44.6% | 39,500 | 72.5% ± 7.6% | 28,600 | 46.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 79.6% ± 10.8% | 13,900 | 22.7% |
| 6 to 11 | 35.2% | 31,200 | 60.3% ± 11.1% | 18,800 | 30.7% |
| 12 to 17 | 45.1% | 40,000 | 71.5% ± 8.2% | 28,600 | 46.7% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | *** ± *** | *** | *** |
| Male, 6 to 11 | 22.4% | 19,900 | *** ± *** | *** | *** |
| Male, 12 to 17 | 22.5% | 19,900 | 70.8% ± 11.7% | 14,100 | 22.7% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | *** ± *** | *** | *** |
| Female, 12 to 17 | 22.6% | 20,000 | 72.2% ± 10.8% | 14,400 | 23.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 70.1% ± 5.9% | 59,600 | 96.1% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 69.8% ± 6.0% | 55,800 | 90.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 68.5% ± 12.2% | 17,500 | 28.2% |
| 201-300% | 25.4% | 22,500 | 64.6% ± 13.9% | 14,500 | 23.4% |
| Over 300% | 35.0% | 31,000 | 71.2% ± 9.3% | 22,100 | 35.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 68.8% ± 6.9% | 48,200 | 77.9% |
| Rural | 21.0% | 18,600 | 73.6% ± 10.7% | 13,700 | 22.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 70.0% ± 5.9% | 62,000 | 100.0% |

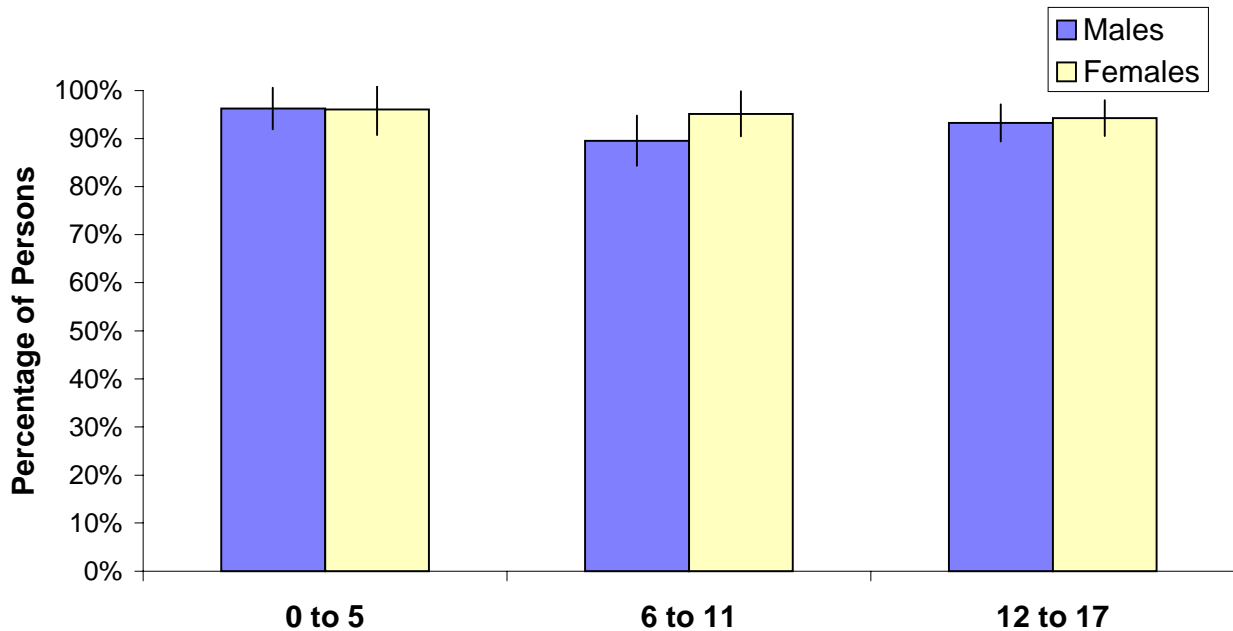
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of Persons Who Were Satisfied* With Their Ability to Get Needed Information From Their Medical Provider by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



* Includes "Satisfied" and "Very Satisfied" Responses

- Although physicians and other professionals provide medical care to children with special health care needs, it is the parents who must ultimately make the decisions about treatment. 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.
- There was little variability in this finding across different demographic subgroups.

Getting Information: Percentage of Persons Who Were Satisfied* With Their Ability to Get Needed Information From Their Medical Provider (Question C17)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Persons Who Were Satisfied With the Information | | |
|----------------------------------|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of Persons Who Were Satisfied With the Information ² | Number of Children ^{1,3} | Percentage Distribution of Persons Who Were Satisfied With the Information by Category |
| Getting Information | | | | | |
| Satisfied* | 93.5% | 82,800 | | | |
| Dissatisfied | 6.5% | 5,800 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 92.4% ± 2.8% | 45,300 | 54.7% |
| Females | 44.6% | 39,500 | 94.8% ± 2.6% | 37,500 | 45.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 96.2% ± 3.4% | 16,700 | 20.2% |
| 6 to 11 | 35.2% | 31,200 | 91.6% ± 3.8% | 28,600 | 34.5% |
| 12 to 17 | 45.1% | 40,000 | 93.7% ± 2.7% | 37,500 | 45.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 96.2% ± 4.4% | 8,900 | 10.8% |
| Male, 6 to 11 | 22.4% | 19,900 | 89.5% ± 5.2% | 17,800 | 21.5% |
| Male, 12 to 17 | 22.5% | 19,900 | 93.2% ± 3.9% | 18,600 | 22.5% |
| Female, 0 to 5 | 9.1% | 8,100 | 96.1% ± 5.4% | 7,800 | 9.4% |
| Female, 6 to 11 | 12.8% | 11,300 | 95.1% ± 4.7% | 10,700 | 13.0% |
| Female, 12 to 17 | 22.6% | 20,000 | 94.2% ± 3.7% | 18,800 | 22.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 93.8% ± 2.0% | 79,700 | 96.3% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | 94.3% ± 6.5% | 8,100 | 9.8% |
| No | 90.3% | 80,000 | 93.4% ± 2.1% | 74,700 | 90.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | 94.6% ± 5.9% | 9,000 | 10.9% |
| 101-200% | 28.8% | 25,500 | 91.1% ± 4.5% | 23,200 | 28.1% |
| 201-300% | 25.4% | 22,500 | 90.3% ± 5.7% | 20,300 | 24.6% |
| Over 300% | 35.0% | 31,000 | 97.0% ± 2.4% | 30,100 | 36.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 93.3% ± 2.3% | 65,300 | 78.9% |
| Rural | 21.0% | 18,600 | 94.0% ± 4.2% | 17,500 | 21.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.5% ± 2.0% | 82,800 | 100.0% |

1 Rounded to the nearest 100 persons.

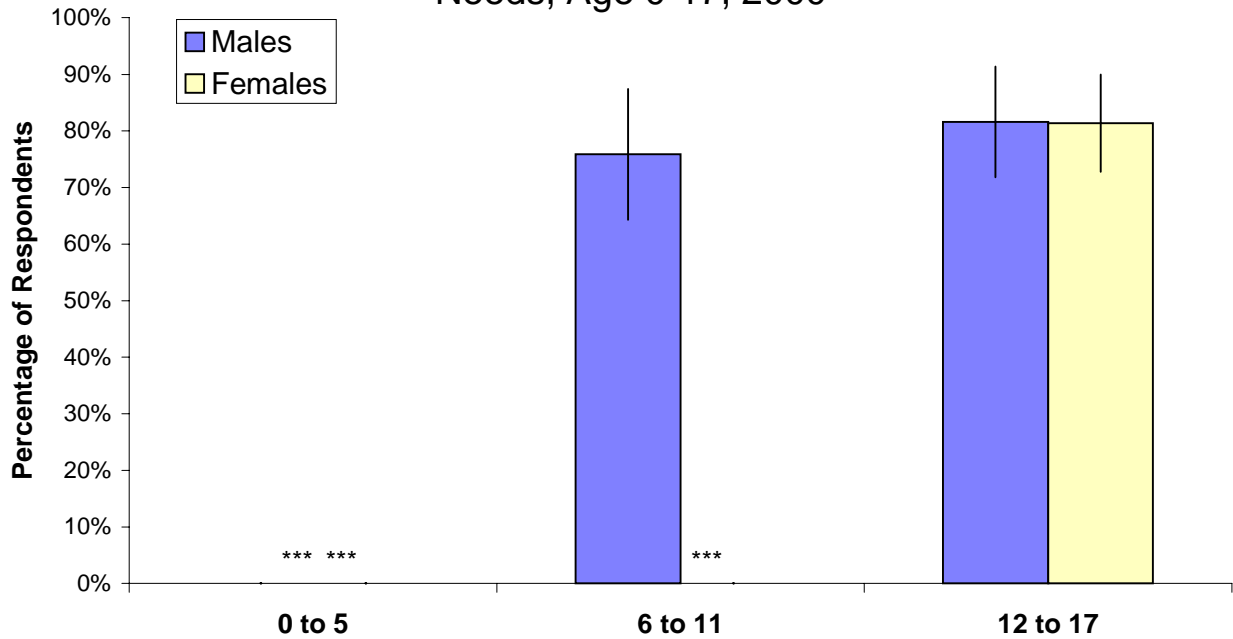
2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

* Includes "Satisfied" and "Very Satisfied" Responses

Percentage of Respondents Who Reported Medical and Other Staff Always Treat Them With Respect and Courtesy by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- Most parents (82.9%) reported that medical and other staff always treated them and their child with courtesy and respect. There was little variability in this finding across different demographic subgroups.

Treated With Respect & Courtesy: Percentage of Persons Who Reported Medical & Other Staff Always Treat Them With Respect & Courtesy (Question C15)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Persons Whose Medical & other Staff Always Treat Them With Respect & Courtesy | | |
|--|------------------------------|---------------------------------|--|-----------------------------------|--|
| | Percentage Distribution | Number of Children ¹ | Percentage of Persons Who Were Always Treated With Respect & Courtesy ² | Number of Children ^{1,3} | Percentage Distribution of Persons Who Were Always Treated With Respect & Courtesy by Category |
| Treated With Courtesy & Respect | | | | | |
| Never | *** | *** | | | |
| Sometimes | 2.5% | 2,200 | | | |
| Usually | 14.6% | 13,000 | | | |
| Always | 82.9% | 73,400 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 82.0% ± 6.3% | 40,300 | 54.9% |
| Females | 44.6% | 39,500 | 83.8% ± 6.1% | 33,100 | 45.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 90.6% ± 7.9% | *** | *** |
| 6 to 11 | 35.2% | 31,200 | 80.6% ± 8.2% | 25,100 | 34.2% |
| 12 to 17 | 45.1% | 40,000 | 81.5% ± 6.5% | 32,600 | 44.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | *** ± *** | *** | *** |
| Male, 6 to 11 | 22.4% | 19,900 | 75.9% ± 11.6% | 15,100 | 20.6% |
| Male, 12 to 17 | 22.5% | 19,900 | 81.6% ± 9.8% | 16,200 | 22.1% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | *** ± *** | *** | *** |
| Female, 12 to 17 | 22.6% | 20,000 | 81.4% ± 8.6% | 16,300 | 22.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 83.0% ± 4.5% | 70,500 | 96.0% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 82.9% ± 4.6% | 66,300 | 90.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 79.6% ± 10.9% | 20,300 | 27.7% |
| 201-300% | 25.4% | 22,500 | 80.4% ± 9.7% | 18,100 | 24.7% |
| Over 300% | 35.0% | 31,000 | 86.2% ± 7.0% | 26,700 | 36.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 82.6% ± 5.0% | 57,800 | 78.7% |
| Rural | 21.0% | 18,600 | 83.8% ± 9.7% | 15,600 | 21.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 82.9% ± 4.4% | 73,400 | 100.0% |

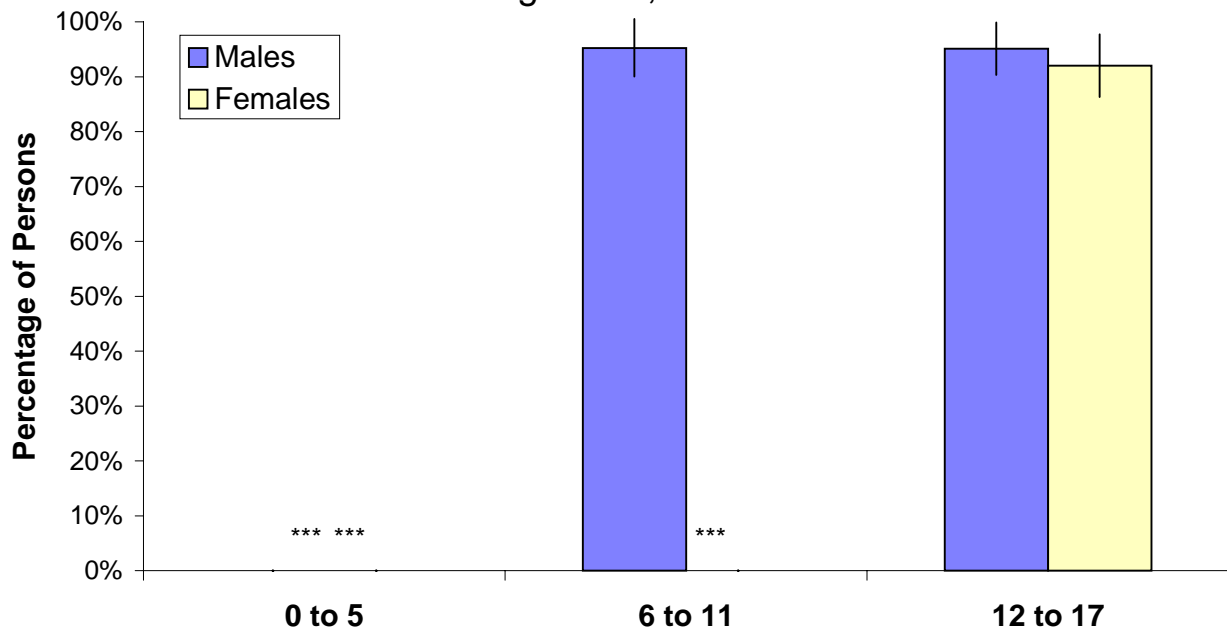
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Percentage of Persons Who Reported Doctor Always Had Respect for Their Customs, Beliefs, and Language by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- The medical systems in the U.S. are, by and large, systems created by and for the majority, white, “Anglo” culture. Persons from other cultural backgrounds often report that their encounters with the medical system demonstrate little respect for their culture. Most parents who responded to the Child Health Survey (93.9%) reported that their doctor always showed respect for their customs, beliefs and language.
- Note that among the children in the survey for whom race/ethnicity data were provided, 83.9% were White-only and non-Hispanic. Among the other 16.1% who were either Hispanic or non-White, the perception was equally positive.

**Doctor Respected Family's Customs: Percentage of Persons Who Reported
 Doctor Always Had Respect for Their Customs, Beliefs and Language (Question C6)
 by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Persons Whose Doctor Respected Their Beliefs/Customs | | |
|--|------------------------------|---------------------------------|---|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Persons Whose Doctor Respected Their Beliefs/Customs ² | Number of Children ^{1,3} | Percentage Distribution of Persons Whose Doctor Respected Their Beliefs/Customs by Category |
| Doctor Respected Family's Customs | | | | | |
| Always | 93.9% | 83,200 | | | |
| Frequently | 4.9% | 4,300 | | | |
| Sometimes | *** | *** | | | |
| Rarely | *** | *** | | | |
| Never | *** | *** | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 94.2% ± 3.4% | 46,200 | 55.5% |
| Females | 44.6% | 39,500 | 93.6% ± 3.9% | 37,000 | 44.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 88.7% ± 8.0% | 15,400 | 18.5% |
| 6 to 11 | 35.2% | 31,200 | 97.1% ± 3.2% | 30,300 | 36.5% |
| 12 to 17 | 45.1% | 40,000 | 93.4% ± 3.8% | 37,400 | 45.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | *** ± *** | *** | *** |
| Male, 6 to 11 | 22.4% | 19,900 | 95.3% ± 5.3% | 19,000 | 22.8% |
| Male, 12 to 17 | 22.5% | 19,900 | 95.1% ± 4.8% | 18,900 | 22.7% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | *** ± *** | *** | *** |
| Female, 12 to 17 | 22.6% | 20,000 | 92.0% ± 5.7% | 18,400 | 22.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 94.0% ± 2.6% | 79,900 | 96.0% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 93.7% ± 2.7% | 74,900 | 90.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 90.3% ± 7.0% | 23,000 | 27.6% |
| 201-300% | 25.4% | 22,500 | 91.6% ± 6.5% | 20,600 | 24.8% |
| Over 300% | 35.0% | 31,000 | 97.1% ± 3.2% | 30,100 | 36.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 95.6% ± 2.5% | 66,900 | 80.5% |
| Rural | 21.0% | 18,600 | 87.1% ± 8.0% | 16,200 | 19.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 93.9% ± 2.6% | 83,200 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

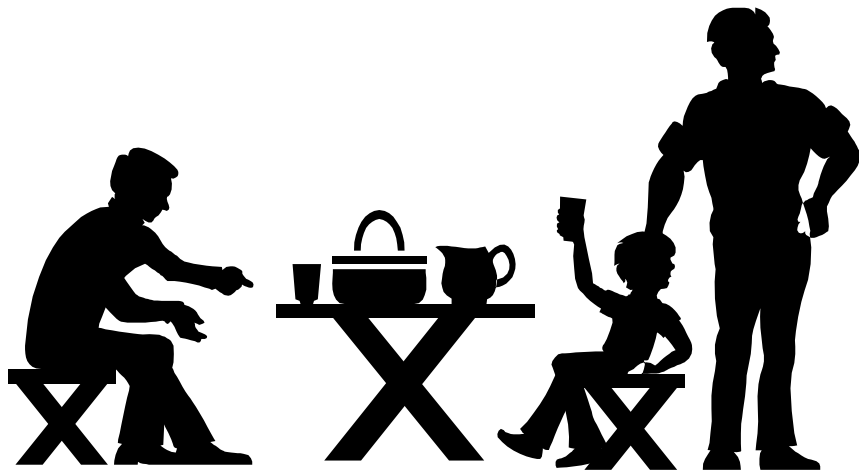
**Provider Discussed Adult Life Plan: Percentage of Respondents Who Reported That Doctor Discussed About CSHCN Child’s Future Life Plans (Question C12)
Utah Children With Special Health Care Needs (CSHCN) Age 14-17, 2000.**

| <u>Demographic Subgroup</u> | <u>Utah Population Distribution</u> | |
|-------------------------------------|-------------------------------------|---------------------------------------|
| | <u>Percentage Distribution</u> | <u>Number of Children¹</u> |
| Provider Discussed Adult Life Plan: | | |
| Discussed | 59.5% | 16,100 |
| Not Discussed | 40.6% | 11,000 |
| Total, CSHCN Children 14-17 | 100.0% | 27,100 |

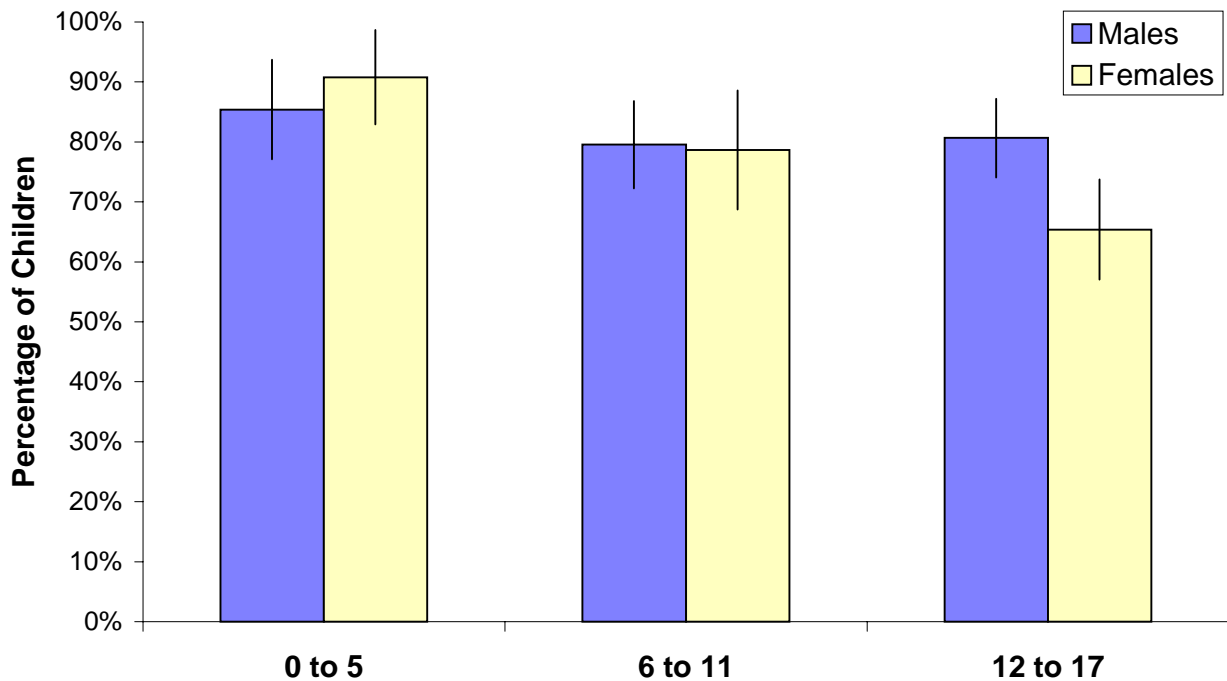
1 Rounded to the nearest 100 persons.

- Children with special health care needs must be able to expect appropriate health care, and employment with benefits and independence as they reach adulthood. It is the role for the health care provider to prepare the child and parents for successful transition.
- Parents reported that doctors had spoken with the family about the child’s future life plans in 59.5% of the cases.

Utilization of Services



Percentage of Children Who Received Routine Preventive (Well-Child) Medical Visits on Time by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- Clinical preventive services, or “well-child” visits, are recommended once a year for children age 10 and over, and more frequently for younger children (guidelines published by the National Center for Education in Maternal and Child Health, Arlington, VA). Well-child visits allow children to receive clinical services, such as assessment for developmental delays and immunizations, that they might otherwise not receive.
- 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. 78.0% of children with special health care needs in the Child Health Survey had received a well-child visit on time.
- Older children (age 12 to 17) were less likely to have received a well-child visit on time (73.1%), especially girls in this age group (65.4%¹), but the differences were not statistically significantly different.

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

Regular* Medical Checkup: Percentage of Children Who Received Routine Preventive (Well-Child) Medical Visits on Time (Questions D1 and D2) by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children Who Have Had Regular Medical Check-up | | |
|----------------------------------|------------------------------|---------------------------------|--|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children Who Have Had Regular Medical Checkup ² | Number of Children ^{1,3} | Percentage Distribution of Children Who Have Had Regular Medical Check-up by Category |
| Regular Medical Check-up | | | | | |
| Regular Medical Checkup | 78.0% | 69,100 | | | |
| No Regular Medical Check | 22.0% | 19,500 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 81.1% ± 4.4% | 39,800 | 57.7% |
| Females | 44.6% | 39,500 | 74.0% ± 5.7% | 29,200 | 42.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 87.8% ± 5.7% | 15,300 | 22.1% |
| 6 to 11 | 35.2% | 31,200 | 79.2% ± 6.1% | 24,700 | 35.7% |
| 12 to 17 | 45.1% | 40,000 | 73.1% ± 5.5% | 29,200 | 42.2% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 85.4% ± 8.3% | 7,900 | 11.4% |
| Male, 6 to 11 | 22.4% | 19,900 | 79.5% ± 7.3% | 15,800 | 22.9% |
| Male, 12 to 17 | 22.5% | 19,900 | 80.6% ± 6.6% | 16,000 | 23.2% |
| Female, 0 to 5 | 9.1% | 8,100 | 90.8% ± 7.9% | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 78.6% ± 9.9% | 8,900 | 12.9% |
| Female, 12 to 17 | 22.6% | 20,000 | 65.4% ± 8.4% | 13,100 | 19.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 77.3% ± 3.7% | 65,700 | 95.1% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 77.6% ± 3.7% | 62,100 | 100.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 77.8% ± 7.5% | 19,800 | 28.7% |
| 201-300% | 25.4% | 22,500 | 76.5% ± 7.8% | 17,200 | 24.9% |
| Over 300% | 35.0% | 31,000 | 75.8% ± 6.6% | 23,500 | 34.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 80.1% ± 3.8% | 56,000 | 81.2% |
| Rural | 21.0% | 18,600 | 69.9% ± 9.0% | 13,000 | 18.8% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 78.0% ± 3.6% | 69,100 | 100.0% |

1 Rounded to the nearest 100 persons.

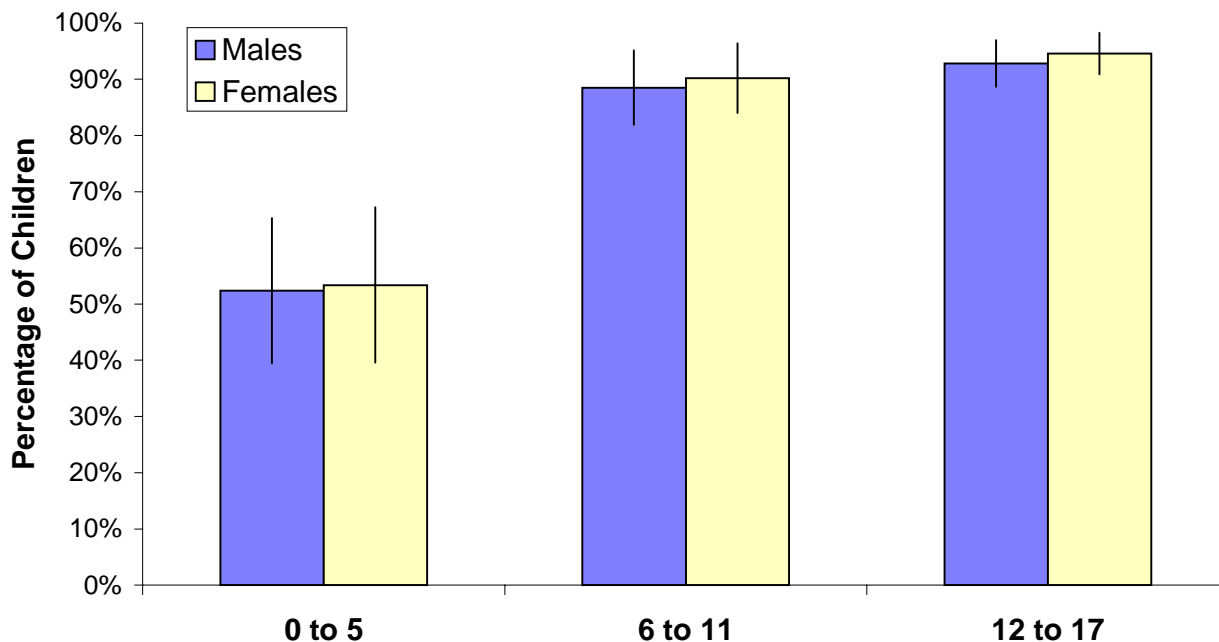
2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

*According to the clinical preventive services guidelines published by National Center for Education in Maternal and Child Health(Arlington, Virginia) , visits should occur at age 1 month, 2 months, 4 months, 6 months, 9 months, 1 year, 15 months, 18 months, 2 years, 3 years, 4 years, 5 years, 6 years, 8 years, and once each year between 10 years-18 years.

Percentage of Children Who Were Reported to Have Had a Routine Dental Exam in the Past 12 Months by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



- In order to ensure a future of oral health, regular dental visits should begin at about one year of age. The dentist will discuss bottle/breast feeding habits and make sure the child is receiving appropriate fluoride supplementation. Children assessed to be at risk for cavities may receive topical applications of fluoride varnish. At approximately six and twelve years of age, sealants will be applied to the chewing surfaces of the first and second permanent molars.
- 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%¹ 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%¹ of children in households with the highest incomes.

¹ Comparisons reported in the bulleted text that were found to be statistically significant have been marked with a “¹.” All other comparisons were not statistically significant, and should be interpreted with caution.

Regular* Dental Checkup: Percentage of Children Who Were Reported to Have Had a Routine Dental Exam in the Past 12 Months (Questions D4 and D4A)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 1-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for Children Who Have Had Regular Dental Checkup | | |
|----------------------------------|------------------------------|---------------------------------|--|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Children Who Had Regular Dental Checkup ² | Number of Children ^{1,3} | Percentage Distribution of Children Who Have Had Regular Dental Checkup by Category |
| Regular Dental Checkup | | | | | |
| Regular Dental Checkup | 85.0% | 71,500 | | | |
| No Regular Dental Checkup | 15.0% | 12,600 | | | |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | | | |
| Sex | | | | | |
| Males | 55.3% | 46,500 | 84.2% ± 4.4% | 39,100 | 54.7% |
| Females | 44.7% | 37,600 | 86.0% ± 4.2% | 32,400 | 45.3% |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |
| Age Group | | | | | |
| 1 to 5 | 18.3% | 15,300 | 52.9% ± 9.7% | 8,100 | 11.4% |
| 6 to 11 | 35.9% | 30,100 | 89.2% ± 5.0% | 26,800 | 37.7% |
| 12 to 17 | 45.9% | 38,600 | 93.7% ± 2.8% | 36,200 | 50.9% |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |
| Sex and Age | | | | | |
| Male, 1 to 5 | 9.6% | 8,100 | 52.4% ± 12.9% | 4,200 | 5.9% |
| Male, 6 to 11 | 22.8% | 19,200 | 88.5% ± 6.7% | 17,000 | 23.8% |
| Male, 12 to 17 | 22.9% | 19,300 | 92.8% ± 4.2% | 17,900 | 25.0% |
| Female, 1 to 5 | 8.7% | 7,300 | 53.4% ± 13.8% | *** | *** |
| Female, 6 to 11 | 13.0% | 11,000 | 90.2% ± 6.2% | 9,900 | 13.8% |
| Female, 12 to 17 | 23.0% | 19,400 | 94.6% ± 3.7% | 18,300 | 25.6% |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 95.9% | 80,700 | 85.3% ± 3.2% | 68,800 | 96.2% |
| No | 4.1% | 3,400 | *** ± *** | *** | *** |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,200 | *** ± *** | *** | *** |
| No | 90.3% | 75,900 | 85.5% ± 3.0% | 64,900 | 100.0% |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.5% | 8,900 | 73.6% ± 16.5% | 6,600 | 9.3% |
| 101-200% | 28.9% | 24,300 | 77.6% ± 6.8% | 18,900 | 26.8% |
| 201-300% | 25.2% | 21,200 | 83.1% ± 7.1% | 17,600 | 24.9% |
| Over 300% | 35.4% | 29,800 | 92.4% ± 4.0% | 27,500 | 39.0% |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |
| County of Residence | | | | | |
| Urban | 78.9% | 66,300 | 86.5% ± 3.2% | 57,300 | 80.1% |
| Rural | 21.1% | 17,800 | 80.0% ± 8.6% | 14,200 | 19.9% |
| Total, CSHCN Children 1-17 | 100.0% | 84,100 | 85.0% ± 3.2% | 71,500 | 100.0% |

1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

*Annual dental visits are recommended beginning at age 1.

**Assistance in Locating Services: Percentage of Respondents Who Got Assistance in Locating & Setting Up Services for CSHCN (Question C13A)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|---------------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Assistance in Locating Services | | |
| With Assistance | 36.9% | 32,600 |
| Without Assistance | 63.1% | 56,000 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

**Assistance in Locating Services: Percentage Distribution of Respondents by Source of Assistance in Locating and Setting Up Services (Question C1)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|----------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Who Assisted | | |
| Family Member | 15.0% | 13,200 |
| Doctor or Nurse | 54.0% | 47,900 |
| Svc Coord/Case Manager | 8.7% | 7,700 |
| Health Plan Manager | 1.9% | 1,700 |
| Community Screen Program | *** | *** |
| Social Service Worker | 2.1% | 1,800 |
| Therapist | 3.9% | 3,500 |
| Public Health Staff | *** | *** |
| School Staff | 6.1% | 5,400 |
| Religious Leader | *** | *** |
| Someone Else | 8.4% | 7,400 |
| None | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

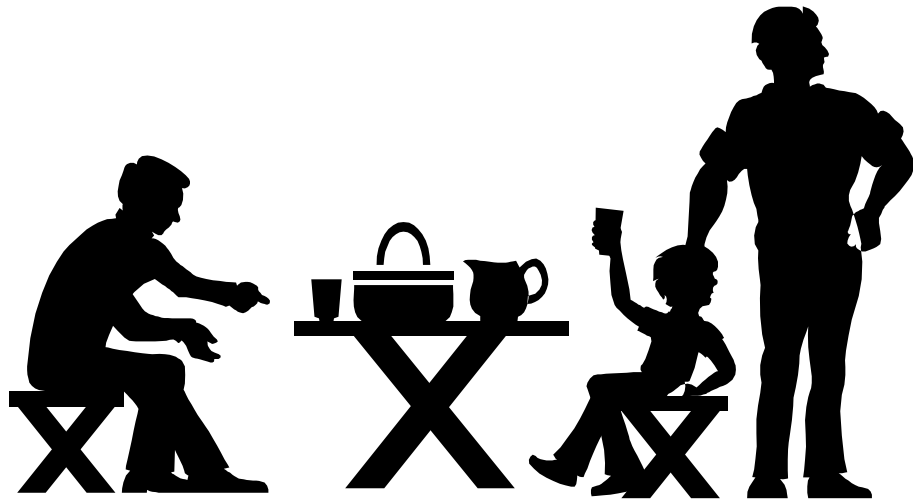
**Immunization: Place Where Most Recent
Immunization Services Were Received (Question D3)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Subgroup | Survey Estimates | |
|----------------------------|----------------------------|------------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Immunization | | |
| Public Clinic | 35.8% | 31,800 |
| Care-a-Van | 2.4% | 2,100 |
| Doctor's Office | 47.7% | 42,300 |
| Other Doctor | 6.7% | 6,000 |
| Somewhere Else | 7.0% | 6,200 |
| No Immunization | 0.3% | 300 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

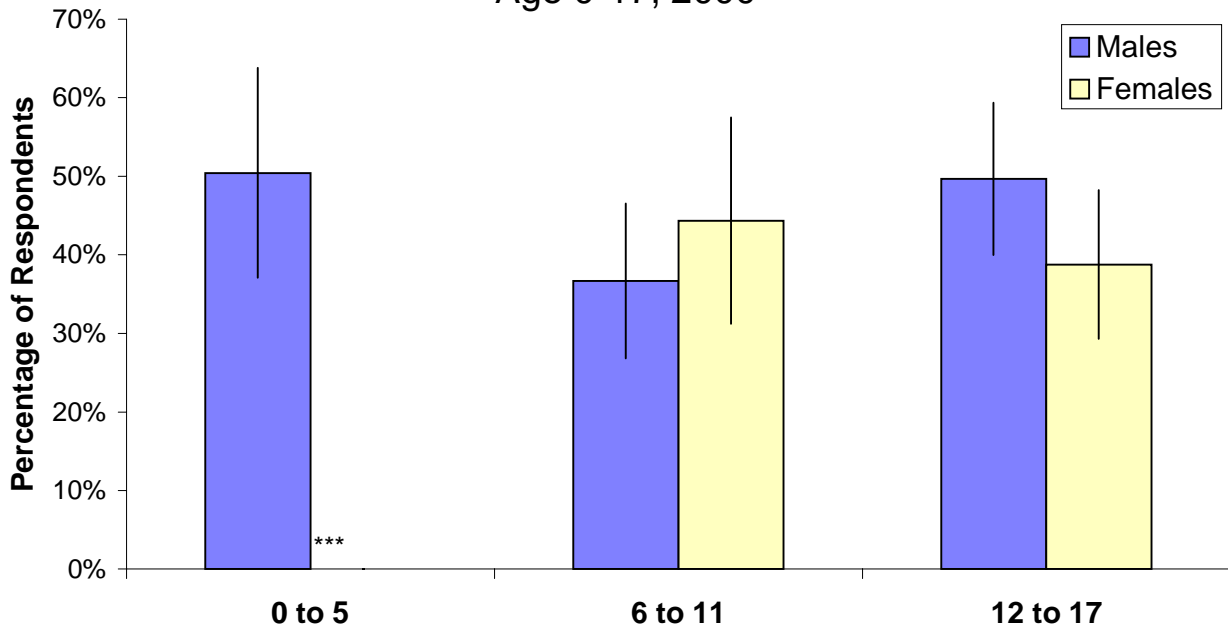
¹ Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

Family Support Services



Percentage of Respondents Who Were Satisfied* With Opportunities to Talk With Other CSHCN Families by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

* Includes "Satisfied" and "Very Satisfied" responses.

- It is often extremely helpful for parents of children with special health care needs (CSHCN) to be able to talk with other parents in a similar situation. Not only does this type of communication offer the parents an opportunity to share information about services and health care systems, but it allows them to give and receive much-needed social support.
- Of the parents in the Child Health Survey, 43.3% were satisfied with the opportunities they have had to talk with other CSHCN families, 8.3% were dissatisfied, and 48.4% reported that they had had no opportunity to do so.

Satisfaction With Communication: Percentage of Respondents Who Were Satisfied* With Opportunities to Talk With Other CSHCN Families (Question C19)
by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Respondents Who Were Satisfied | | |
|--|------------------------------|---------------------------------|--|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Respondents Who Were Satisfied ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Who Were Satisfied by Category |
| Satisfaction With Opportunities | | | | | |
| Satisfied | 43.3% | 38,400 | | | |
| Dissatisfied | 8.3% | 7,300 | | | |
| No Opportunity | 48.4% | 42,900 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 44.9% ± 6.2% | 22,000 | 57.4% |
| Females | 44.6% | 39,500 | 41.4% ± 6.9% | 16,300 | 42.6% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 47.4% ± 10.1% | 8,200 | 21.5% |
| 6 to 11 | 35.2% | 31,200 | 39.5% ± 7.9% | 12,300 | 32.2% |
| 12 to 17 | 45.1% | 40,000 | 44.3% ± 6.8% | 17,700 | 46.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 50.4% ± 13.4% | 4,700 | 12.2% |
| Male, 6 to 11 | 22.4% | 19,900 | 36.7% ± 9.9% | 7,300 | 19.0% |
| Male, 12 to 17 | 22.5% | 19,900 | 49.7% ± 9.7% | 9,900 | 25.8% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 44.3% ± 13.1% | 5,000 | 13.0% |
| Female, 12 to 17 | 22.6% | 20,000 | 38.8% ± 9.5% | 7,800 | 20.3% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 43.7% ± 4.7% | 37,200 | 96.9% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 43.6% ± 4.8% | 34,900 | 90.9% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 33.3% ± 9.2% | 8,500 | 22.1% |
| 201-300% | 25.4% | 22,500 | 45.0% ± 9.5% | 10,100 | 26.3% |
| Over 300% | 35.0% | 31,000 | 46.5% ± 8.3% | 14,400 | 37.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 42.0% ± 5.2% | 29,400 | 76.6% |
| Rural | 21.0% | 18,600 | 48.2% ± 9.8% | 9,000 | 23.4% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 43.3% ± 4.6% | 38,400 | 100.0% |

1 Rounded to the nearest 100 persons.

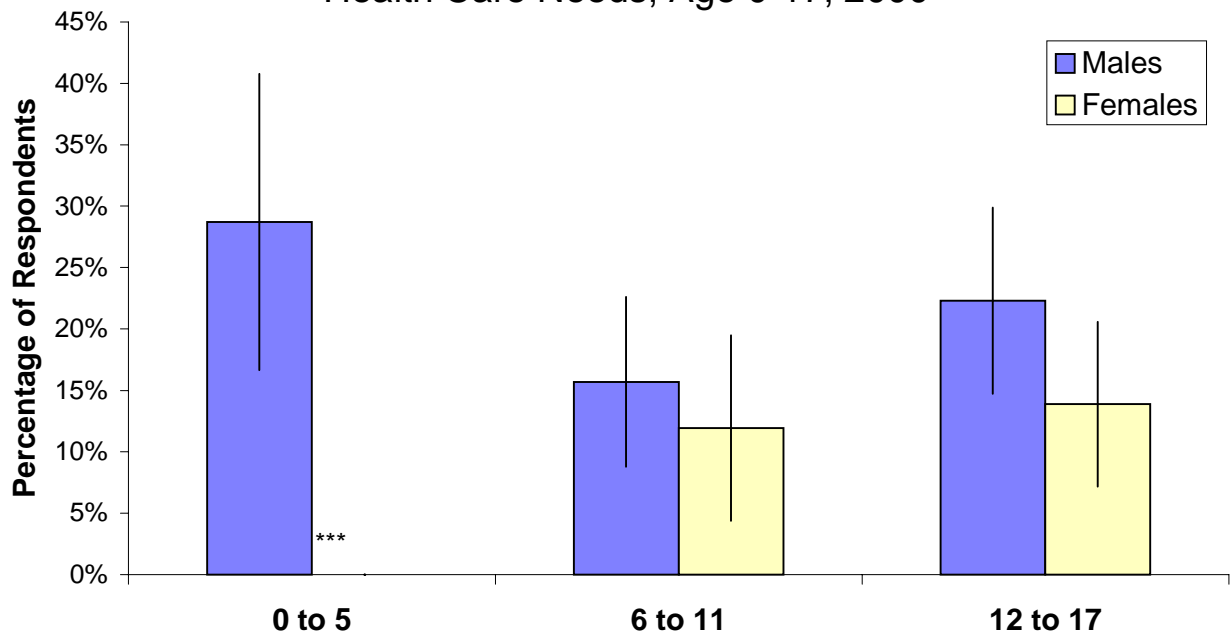
2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

* Includes "Satisfied" and "Very Satisfied" responses.

Percentage of Respondents Who Received Information or Support From Family Voices and Other Parents' Organizations by Age and Sex, Utah Children With Special Health Care Needs, Age 0-17, 2000



*** Sample size insufficient to produce population estimates

- Family Voices is a parent-to-parent information and support service for families of children with special health care needs. 18.0% of parents of children with special health care needs (CSHCN) had received information or support from organizations such as this. Parents of younger CSHCN were somewhat more likely to have used this service.

Parent Support Groups: Percentage of Respondents Who Received Information or Support From Family Voices and Other Parents' Organizations (Question C20)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Respondents Who Were Supported | | |
|----------------------------------|------------------------------|---------------------------------|---|-----------------------------------|---|
| | Percentage Distribution | Number of Children ¹ | Percentage of Respondents Supported by Family Voices/Other Parent's Orgs ² | Number of Children ^{1,3} | Percentage Distribution of Respondents Supported by Family Voices/Other Parents' Orgs by Category |
| Parent Support Groups | | | | | |
| Yes | 18.0% | 16,000 | | | |
| No | 82.0% | 72,600 | | | |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | | | |
| Sex | | | | | |
| Males | 55.5% | 49,100 | 21.1% ± 4.8% | 10,400 | 65.0% |
| Females | 44.6% | 39,500 | 14.2% ± 4.7% | 5,600 | 35.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |
| Age Group | | | | | |
| 0 to 5 | 19.7% | 17,400 | 24.0% ± 8.5% | 4,200 | 26.4% |
| 6 to 11 | 35.2% | 31,200 | 14.3% ± 5.2% | 4,400 | 27.7% |
| 12 to 17 | 45.1% | 40,000 | 18.2% ± 5.1% | 7,300 | 45.9% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |
| Sex and Age | | | | | |
| Male, 0 to 5 | 10.5% | 9,300 | 28.7% ± 12.1% | 2,700 | 16.9% |
| Male, 6 to 11 | 22.4% | 19,900 | 15.7% ± 6.9% | 3,100 | 19.4% |
| Male, 12 to 17 | 22.5% | 19,900 | 22.3% ± 7.6% | 4,400 | 27.5% |
| Female, 0 to 5 | 9.1% | 8,100 | *** ± *** | *** | *** |
| Female, 6 to 11 | 12.8% | 11,300 | 11.9% ± 7.5% | 1,300 | 8.1% |
| Female, 12 to 17 | 22.6% | 20,000 | 13.9% ± 6.7% | 2,800 | 17.5% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 96.0% | 85,000 | 18.6% ± 3.5% | 15,800 | 98.8% |
| No | 4.1% | 3,600 | *** ± *** | *** | *** |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.7% | 8,600 | *** ± *** | *** | *** |
| No | 90.3% | 80,000 | 18.6% ± 3.6% | 14,900 | 93.1% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.7% | 9,500 | *** ± *** | *** | *** |
| 101-200% | 28.8% | 25,500 | 17.5% ± 7.0% | 4,400 | 27.5% |
| 201-300% | 25.4% | 22,500 | 19.9% ± 7.7% | 4,500 | 28.1% |
| Over 300% | 35.0% | 31,000 | 18.1% ± 6.0% | 5,600 | 35.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |
| County of Residence | | | | | |
| Urban | 79.0% | 70,000 | 19.4% ± 4.0% | 13,600 | 85.0% |
| Rural | 21.0% | 18,600 | 12.8% ± 6.1% | 2,400 | 15.0% |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 | 18.0% ± 3.4% | 16,000 | 100.0% |

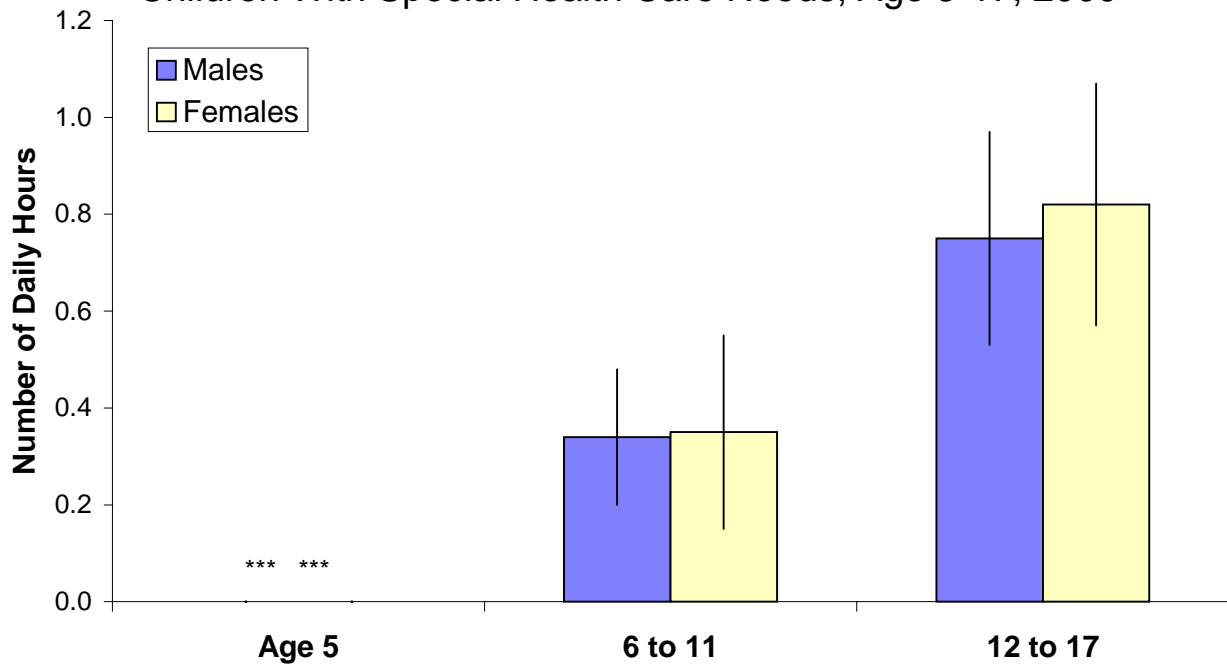
1 Rounded to the nearest 100 persons.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Average Number of Daily Hours, by Age and Sex, That the Child Was Not Supervised on a Typical School Day, Utah Children With Special Health Care Needs, Age 5-17, 2000



*** Sample size insufficient to produce population estimates

- It is difficult to make a general rule about the age at which children are mature enough to be safe when left without adult supervision. Conventional wisdom is that by age 12 most children are able to care for themselves for limited amounts of time. Among children with special health care needs (CSHCN), however, this age may vary considerably.
- Parents were asked to tell us how many hours, on a typical school day, their child was not supervised by an adult or older child who was responsible for the child's well-being. Parents of CSHCN indicated that, on average, their child could be left unsupervised for only about 40 minutes each day. There is a critical need for support and respite care services for families caring for CSHCN.

Weekday Supervision: Average Number of Daily Hours That the Child Was Not Supervised on a Typical School Day (Question G2)

by Selected Demographic Characteristics, Utah Children With Special Health Care Needs (CSHCN) Age 5-17, 2000.

| Demographic Subgroup | Utah Population Distribution | | Survey Estimates for No. of Hours Children Were Unsupervised | | |
|----------------------------------|------------------------------|---------------------------------|--|--|---|
| | Percentage Distribution | Number of Children ¹ | Average Number of Hrs. Child Was Unsupervised ² | Total # Daily Child Hours ^{1,3} | Percentage Distribution of Unsupervised Hours by Category |
| Weekday Supervision | | | | | |
| 0 Hours | 70.7% | 51,500 | | | |
| 1 to 2 Hours | 22.9% | 16,700 | | | |
| 3 to 4 Hours | 5.3% | 3,800 | | | |
| 5 to 6 Hours | 0.3% | 200 | | | |
| 7 to 8 Hours | 0.6% | 400 | | | |
| 9+ Hours | 0.2% | 100 | | | |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | | | |
| Sex | | | | | |
| Males | 55.7% | 40,600 | 0.5 ± 0.1 | 21,500 | 52.3% |
| Females | 44.3% | 32,200 | 0.6 ± 0.2 | 19,600 | 47.7% |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |
| Age Group | | | | | |
| Age 5 | 5.6% | 4,100 | *** ± *** | *** | *** |
| 6 to 11 | 41.4% | 30,100 | 0.4 ± 0.1 | 10,500 | 25.3% |
| 12 to 17 | 53.0% | 38,600 | 0.8 ± 0.2 | 30,100 | 72.5% |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |
| Sex and Age | | | | | |
| Male, Age 5 | 2.9% | 2,100 | *** ± *** | *** | *** |
| Male, 6 to 11 | 26.4% | 19,200 | 0.3 ± 0.1 | 6,500 | 15.7% |
| Male, 12 to 17 | 26.4% | 19,200 | 0.8 ± 0.2 | 14,400 | 34.7% |
| Female, Age 5 | 2.6% | 1,900 | *** ± *** | *** | *** |
| Female, 6 to 11 | 15.1% | 11,000 | 0.4 ± 0.2 | 3,900 | 9.4% |
| Female, 12 to 17 | 26.6% | 19,300 | 0.8 ± 0.3 | 15,800 | 38.1% |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |
| Health Insurance Coverage | | | | | |
| Yes | 95.8% | 69,700 | 0.6 ± 0.1 | 40,400 | 97.3% |
| No | 4.2% | 3,100 | *** ± *** | *** | *** |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |
| Hispanic | | | | | |
| Yes | 9.9% | 7,200 | 0.6 ± 0.4 | 4,000 | 9.7% |
| No | 90.1% | 65,600 | 0.6 ± 0.1 | 37,400 | 90.3% |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |
| Poverty | | | | | |
| 0-100% | 10.1% | 7,400 | 0.7 ± 0.5 | 4,800 | 10.9% |
| 101-200% | 28.6% | 20,800 | 0.5 ± 0.2 | 10,200 | 23.1% |
| 201-300% | 23.5% | 17,100 | 0.7 ± 0.3 | 12,300 | 27.9% |
| Over 300% | 37.9% | 27,600 | 0.6 ± 0.2 | 16,800 | 38.1% |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |
| County of Residence | | | | | |
| Urban | 78.7% | 57,300 | 0.6 ± 0.1 | 33,800 | 82.0% |
| Rural | 21.3% | 15,500 | 0.5 ± 0.2 | 7,400 | 18.0% |
| Total, CSHCN Children 5-17 | 100.0% | 72,800 | 0.6 ± 0.1 | 41,500 | 100.0% |

1 Rounded to the nearest 100 persons or hours.

2 Plus or minus 95% confidence interval

3 Figures in these columns may not sum to the total because of missing values on the grouping variables.

*** Sample size insufficient to produce population estimates

Quality of Child Care Services: Rating of Child Care Services Other Than Medical for CSHCN (Question E9)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Subgroup | Survey Estimates | |
|--------------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Quality of Child Care Services | | |
| Poor | 4.8% | 4,200 |
| Fair | 5.3% | 4,700 |
| Good | 11.5% | 10,200 |
| Very Good | 6.9% | 6,100 |
| Excellent | 14.2% | 12,600 |
| Do Not Use It | 57.3% | 50,780 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

Respite Care Services: Rating of Respite Care* Services for CSHCN (Question E11)
Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Subgroup | Survey Estimates | |
|----------------------------|-------------------------|---------------------------------|
| | Percentage Distribution | Number of Children ¹ |
| Respite Care Services | | |
| Poor | 1.6% | 1,400 |
| Fair | 1.1% | 1,000 |
| Good | 3.2% | 2,800 |
| Very Good | 2.7% | 2,400 |
| Excellent | 4.5% | 4,000 |
| Do Not Use It | 86.8% | 76,931 |
| Total, CSHCN Children 0-17 | 100.0% | 88,600 |

1 Rounded to the nearest 100 persons.

*** Sample size insufficient to produce population estimates

*Respite care is short-term, temporary care provided to children with special needs in order that their families can take a break from the daily routine of caregiving.

Appendix A. Sample Characteristics



Sample Characteristics

Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Unweighted Child Health Survey Sample Distribution | |
|-----------------------------------|---|-----------------------|
| | Percentage Distribution ³ | Number of Children |
| CHILDREN'S CHARACTERISTICS | | |
| Age and Sex of Children | | |
| Male, 0 to 5 | 10.3% | 72 |
| Male ,6 to 11 | 21.3% | 148 |
| Male, 12 to 17 | 23.6% | 164 |
| Female, 0 to 5 | 8.2% | 57 |
| Female, 6 to 11 | 12.5% | 87 |
| Female, 12 to 17 | 24.1% | 168 |
| Missing | *** | 0 |
| Total, CSHCN Children 0-17 | 100% | 696 |
| Race/Ethnicity¹ | | |
| White | 94.6% | 652 |
| Black, African American | 3.9% | 27 |
| Asian | 1.9% | 13 |
| Indian or Alaskan Native | 2.2% | 15 |
| Pacific Islander | 1.2% | 8 |
| Other | 1.7% | 12 |
| Hispanic | 8.3% | 57 |
| Missing | *** | 6 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |
| Local Health District | | |
| Bear River | 6.0% | 42 |
| Central | 3.3% | 23 |
| Davis | 13.6% | 95 |
| Salt Lake | 34.8% | 242 |
| Southeastern | 3.2% | 22 |
| Southwest | 4.7% | 33 |
| Summit | 1.0% | 7 |
| Tooele | 2.7% | 19 |
| Tricounty | 2.3% | 16 |
| Utah | 16.8% | 117 |
| Wasatch | 0.3% | 2 |
| Weber-Morgan | 11.2% | 78 |
| Missing | *** | 0 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Sample Characteristics**(Continued from Previous Page)****Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Demographic Subgroup | Unweighted Child Health Survey Sample Distribution | |
|----------------------|---|-----------------------|
| | Percentage Distribution ³ | Number of Children |

HOUSEHOLD ECONOMIC CHARACTERISTICS**Income**

| | | |
|-------------------------|--------|-----|
| 5K | 1.2% | 6 |
| 5-10K | 2.6% | 13 |
| 10-15K | 3.3% | 16 |
| 15-20K | 3.9% | 19 |
| 20-25K | 5.9% | 29 |
| 25-30K | 5.7% | 28 |
| 30-35K | 8.1% | 40 |
| 35-40K | 9.2% | 45 |
| 40-45K | 10.0% | 49 |
| 45-50K | 6.9% | 34 |
| 50-55K | 5.1% | 25 |
| 55-60K | 4.7% | 23 |
| 60-65K | 4.5% | 22 |
| 65-70K | 5.7% | 28 |
| 70-75K | 5.1% | 25 |
| 75-80K | 3.5% | 17 |
| 80-85K | 2.9% | 14 |
| 85-90K | 0.8% | 4 |
| 90+K | 11.0% | 54 |
| Missing | *** | 94 |
| Total, CSHCN Households | 100.0% | 585 |

Poverty Status

| | | |
|-------------------------|--------|-----|
| 0-100% | 9.0% | 44 |
| 101-200% | 26.3% | 129 |
| 201-300% | 26.3% | 129 |
| Over 300% | 38.5% | 189 |
| Missing | *** | 94 |
| Total, CSHCN Households | 100.0% | 585 |

Sample Characteristics

(Continued from Previous Page)

Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Unweighted Child Health Survey Sample Distribution | |
|----------------------|---|-----------------------|
| | Percentage Distribution ³ | Number of Children |

RESPONDENT CHARACTERISTICS

Sex/Age

| | | |
|-------------------------|--------|-----|
| Male, 24 and Under | 0.2% | 1 |
| Male, 25-34 | 3.1% | 18 |
| Male, 35-44 | 7.4% | 43 |
| Male, 45 and Over | 3.8% | 22 |
| Female, 24 and Under | 2.6% | 15 |
| Female, 25-34 | 22.4% | 131 |
| Female, 35-44 | 40.2% | 235 |
| Female, 45 and Over | 20.5% | 120 |
| Missing | *** | 0 |
| Total, CSHCN Households | 100.0% | 585 |

Relationship to Child

| | | |
|----------------------------|--------|-----|
| Parent/Step | 95.9% | 663 |
| Grandparent | 1.7% | 12 |
| Aunt/Uncle | 0.4% | 3 |
| Brother/Sister | 0.1% | 1 |
| Other Relative | 0.9% | 6 |
| Legal Guardian | 0.7% | 5 |
| Foster Parent | 0.1% | 1 |
| Non-Relative | *** | *** |
| Missing | *** | 5 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Sample Characteristics**(Continued from Previous Page)****Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Demographic Subgroup | Unweighted Child Health Survey Sample Distribution | |
|----------------------|---|-----------------------|
| | Percentage Distribution ³ | Number of Children |

PRIMARY CAREGIVERS' CHARACTERISTICS**Sex/Age**

| | | |
|----------------------------|--------|-----|
| Male, 24 and Under | 0.0% | 0 |
| Male, 25-34 | 3.4% | 11 |
| Male, 35-44 | 2.8% | 10 |
| Male, 45 and Over | 3.4% | 12 |
| Female, 24 and Under | 4.6% | 15 |
| Female, 25-34 | 22.3% | 72 |
| Female, 35-44 | 39.3% | 133 |
| Female, 45 and Over | 24.1% | 85 |
| Missing | *** | 358 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Relationship to Child

| | | |
|----------------------------|--------|-----|
| Parent/Step Parent | 95.8% | 636 |
| Grandparent | 1.7% | 11 |
| Aunt/Uncle | 0.5% | 3 |
| Brother/Sister | 0.2% | 1 |
| Other Relative | 0.9% | 6 |
| Legal Guardian | 0.8% | 5 |
| Foster Parent | 0.3% | 2 |
| Non-Relative | *** | *** |
| Missing | *** | 32 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Education

| | | |
|----------------------------|--------|-----|
| Some High School | 4.4% | 29 |
| High School Grad/G.E.D. | 27.1% | 180 |
| Some College | 33.5% | 222 |
| Tech/Vocational Degree | 8.0% | 53 |
| College Grad | 18.6% | 123 |
| Post Grad Courses | 3.5% | 23 |
| Professional Degree | 5.0% | 33 |
| Missing | *** | 33 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Sample Characteristics**(Continued from Previous Page)****Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.**

| Demographic Subgroup | Unweighted Child Health Survey Sample Distribution | |
|----------------------|---|-----------------------|
| | Percentage Distribution ³ | Number of Children |

PRIMARY CAREGIVERS' CHARACTERISTICS**(Continued from Previous Page)****Marital Status**

| | | |
|----------------------------|--------|-----|
| Married | 83.9% | 556 |
| Divorced | 10.7% | 71 |
| Widowed | 1.2% | 8 |
| Separated | 2.6% | 17 |
| Never Married | 1.7% | 11 |
| Missing | *** | 33 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Employment Status

| | | |
|----------------------------|--------|-----|
| Full Time | 31.2% | 207 |
| Part Time | 18.5% | 123 |
| Stay at Home | 44.6% | 296 |
| Going to School | 2.1% | 14 |
| Unemployed | 1.1% | 7 |
| Retired | 0.6% | 4 |
| Disabled | 1.5% | 10 |
| Other | 0.5% | 3 |
| Missing | *** | 32 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Sample Characteristics

(Continued from Previous Page)

Utah Children With Special Health Care Needs (CSHCN) Age 0-17, 2000.

| Demographic Subgroup | Unweighted Child Health Survey Sample Distribution | |
|----------------------|---|-----------------------|
| | Percentage Distribution ³ | Number of Children |

HOUSEHOLD STRUCTURE²

Child With Working Parents

| | | |
|-----------------------------|--------|-----|
| Two Parents Working FT | 22.7% | 145 |
| One Parent FT One Parent PT | 17.5% | 112 |
| One Parent FT One Parent NW | 43.0% | 275 |
| Two Parents Working PT | 0.5% | 3 |
| One Parent PT One Parent NW | 1.6% | 10 |
| Two Parent NW | 3.6% | 23 |
| Single Parent FT | 7.4% | 47 |
| Single Parent PT | 1.7% | 11 |
| Single Parent NW | 2.0% | 13 |
| Missing | *** | 70 |
| Total, CSHCN Children 0-17 | 100.0% | 696 |

Child/Adult Ratio in Household

| | | |
|--------------------------|--------|-----|
| 1 Child/1 Adult | 2.5% | 17 |
| 1 Child/2 Adults | 9.5% | 66 |
| 1 Child/2+ Adults | 3.0% | 21 |
| 2 Children/1 Adult | 3.6% | 25 |
| 2 Children/2 Adults | 22.5% | 156 |
| 2 Children/2+ Adults | 5.3% | 37 |
| 3 Children/1 Adults | 1.7% | 12 |
| 3 Children/2 Adults | 18.9% | 131 |
| 3 Children/2+ Adults | 3.6% | 25 |
| 3+ Children/1 Adult | 1.7% | 12 |
| 3+ Children/2 Adults | 23.8% | 165 |
| 3+ Children/2+ Adults | 3.8% | 26 |
| Missing | *** | 3 |
| Total, All Children 0-17 | 100.0% | 696 |

1 Figures in these columns sum to greater than 100% because respondents were allowed to choose multiple categories.

2 FT=Full Time, PT=Part Time, NW=Not Working, "Single Parent" indicates children in single-parent household.

3 Percentages were calculated on valid responses only.

Appendix B.

Open-ended

Responses



Open-ended Responses to Question C13d: Reasons for Rating Assistance Received in Locating and Setting up Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|--------|----|---|
| Male | 4 | when ever I've gone its been hard. |
| Male | 11 | not a whole lot of contact except by mail |
| Male | 14 | because, um, prior to the last worker he had a lot of assistance, but with the new worker it has not been there for him like the other now has been. |
| Male | 14 | I don't know what choices I have with whom. |
| Female | 14 | The school is where her problems are and they don't have any helpful programs. |
| Female | 14 | They used to be good and now they're only fair. The health care insurance we had was really Good but then we had to switch and it's not as good as we used to have. |

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|------|----|--|
| Male | 3 | because they are not coordinated at all |
| Male | 3 | I think that there is not a very good communication system |
| Male | 4 | when we take him to the ear, nose and throat, the doctor at the regular clinic has no record of his visit with the specialist |
| Male | 4 | our insurance restricts us |
| Male | 4 | cause a lot of times they don't know what they are doing. |
| Male | 5 | they don't coordinate n the office in general |
| Male | 6 | Because there's not really any coordination between the two. The speech therapy doesn't send any information to [child's doctor] and the doctor didn't send any information to the clinic before we started. |
| Male | 6 | The are good about referring him, but their not good about following up. |
| Male | 8 | She doesn't think that the communication between the different providers are sufficient. |
| Male | 8 | don't think they communicate well with each other, they don't follow through with calling each other and reporting to each other. |
| Male | 8 | His condition has always been a emergency condition and use different doctors so it is hard because they don't have access to other doctor records |
| Male | 8 | because they don't know each other they don't do anything to each other. |
| Male | 9 | Most of the questions I want answered are not answered. There is no solution. No other options or a lot of options. |
| Male | 9 | They hurry you. Quick Diagnosis |
| Male | 9 | Basically the cost, and I feel that they could do more. I feel that he should have been to specialists |
| Male | 9 | there no communication between the speech therapist and the dr. |
| Male | 10 | same as other two sons. they are in different places |
| Male | 10 | Because we've been to doctors and they keep shifting us around, and they make wrong diagnoses. And not really informative. |
| Male | 10 | [Child] was seeing a psychologist and wasn't working well with family doctor |
| Male | 10 | because Primary Children's does not coordinate with any one, I had to beg. |
| Male | 10 | He felt like they were put on the back burner and he had to light a fire under their butts to get them to do something. |
| Male | 10 | it is the responsibility of the parent |
| Male | 11 | Because of the insurance and getting the referral and the lack of communication and a lack of effort from the staff |
| Male | 11 | Insurance company doesn't want to pay |
| Male | 11 | They don't tell you what you need to know. They don't take the time. |
| Male | 11 | the specialist deals with his disease and not his physician so there hasn't been much contact between the two. |
| Male | 12 | well neither place has access to the others records (one is medical and one is mental)...they could have if requested |
| Male | 12 | They are just too busy to follow up with information |

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

| | | |
|------|----|---|
| Male | 12 | lean towards school as much as to doctor |
| Male | 12 | we have tried three times and can't get the records over there and keep blaming each the other for losing them |
| Male | 12 | they don't communicate, his doctor does not know him so they don't know what to watch for |
| Male | 12 | because they do not really communicate together back and forth about what is going on with his physical and mental health |
| Male | 12 | if I want things coordinated I have to do it |
| Male | 12 | Because its seems that sometimes they do not have all the info |
| Male | 12 | some work together good, others don't |
| Male | 13 | They don't coordinate at all |
| Male | 13 | They don't talk |
| Male | 13 | Some times you have to go out of your way |
| Male | 14 | they are different places (or for mental health the other for physical) |
| Male | 14 | Well, because the doctor that we go to doesn't have hospital privileges because I have to get the records and take them to the hospital if there is a problem. |
| Male | 14 | we are fairly new in the area and he has only seen the doc at central Utah medical clinic once and that was when he got in an accident so they do not have his records yet |
| Male | 14 | They are not very coordinated. |
| Male | 14 | because sometimes like when you take them to just a regular doctor they have a different idea of what is going on so you get different diagnoses so I never know what to believe. |
| Male | 14 | I don't know, if it is just the military that made me think that or what. |
| Male | 14 | she would like to get him to see a physiatrist but insurance makes it hard |
| Male | 14 | Each doctor feels as if the others a quack, nobody want to work together |
| Male | 14 | well all of them work fairly well together, I just had problem working with the school, we've put him on home school now. |
| Male | 15 | IT IS HARD FOR THE COUNSELOR AT THE MIDDLE SCHOOL TO COMMUNICATE WITH THE DOCTOR, I HAVE TO BE THE MEDIATOR |
| Male | 15 | I got the runaround last time, one said I should call this person and the other said to call there and I want to know what to do to help him at home |
| Male | 15 | It's kind of unfair to say these schools are not good because he is all grown up now. |
| Male | 16 | I have to coordinate the services, so fair. |
| Male | 16 | I don't think that they communicate very well |
| Male | 16 | They really haven't coordinated them yet, they might but not yet |
| Male | 17 | well I don't think that the medical doctor has dealt worth the school |
| Male | 17 | because we moved and it was very hard and I tried to contact the public office and the treatment was not the best for him |
| Male | 17 | they don't even communicate at all |

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 2 she does not have a primary care provider so there is no one to coordinate with. We have tried to get one the provider that sees the rest of our kids won't see her because of her special needs. She...

Female 2 there was issue in terms of what our insurance would cover. A referral was not covered by the insurance, so we are stuck with the bill

Female 3 Because the promptness of the specialists Dr office

Female 6 She only has a primary care, dentist and ophthalmologist and there is not really a need for much communication

Female 6 No one knows how to treat her asthma. The health care providers argue among themselves.

Female 8 Her doctors just handle the medical part they don't have good communication.

Female 9 he could be more understanding of a child who doesn't get sick that much

Female 9 the only way they know is if I take them reports. She was born with a congenital health disorder and that is why she sees a specialist. Her orthopedic surgeon sees her for the growth problem also

Female 9 We have to fight with them to pay with the bills, and it seems like they don't care about her mental health as much as her physical.

Female 10 Her last visits have been for step and they just treated it. She never really had been to a specialist.

Female 10 I'm the one who has to do everything

Female 11 the services is really poor, but they are excellent on prescriptions.

Female 12 I don't think that her specialist and her pediatrician talk at all

Female 12 Some are not trying at all and some are trying too much

Female 13 they don't communicate well

Female 13 sometimes I think that they overlook the condition or just not give them what they need until it's really BAD

Female 13 Well I say that because I think that the doctor, her regular doctor focuses a lot on the depression and her specialist views her depression as related to her hypothyroidism so they prescribe different

Female 14 Health Providers have no clue what her problem is.

Female 14 I hate that about our medical system, we can only go to providers our insurance covers and it really affects the care we can get

Female 14 Most of the time they aren't "on the ball".

Female 15 I'm trying to find records of an eye exam for her school. My primary physician can't find the records.

Female 15 due to available DR's some poorly trained DR's, only one or two good ones, good one's must not get paid enough to come out here, they just don't seem to know what they are talking about, to get good c

Female 15 Referral problems

Female 15 One insurance company doesn't like to pay so I have to argue with them

Female 15 The regular doctor and the mental health provider don't really coordinate, although mental and physical health are related.

Female 16 because the communication isn't that good for me as a parent

Open-ended Responses to Question C14b: Reasons for Rating Coordination Among Different Providers and Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 16 Because in going to them and being referred to another doctor she is supposed to report back to the primary physician and she in not able to get hold of them (primary).

Female 16 when she had her stroke no doctor knew what the other doctor was doing and what was going on, and my insurance was against me going a specific special ist

Female 16 Because the doctors don't usually listen

Female 17 Well, I have to coordinate it they don't communicate with each other and communicate to me.

Female 17 There is no system set up for communication between businesses and most of the time they follow up on it. the overall health system working for her health is fair

Female 17 Lack of communication dr. not having sufficient time

Female 17 There has been trouble transferring files, they have lost a lot of records, There computers are always down and we can barely ever get the medication that we need when we need it.

Female 17 They don't put forth effort unless we push them.

Open-ended Responses to Question C17a: Cause of Dissatisfaction With Ability to Obtain Information Needed to Make Decisions About Meeting Child's Health Care Needs, Utah Children With Special Health Care Needs, Age 0-17, 2000.

SEX AGE RESPONSE

Male 1 She hasn't received any information from doctors about [child]'s allergies.

Male 1 the pediatricians in Utah rush through all the patients and are too busy

Male 4 the insurance restrictions of who we can see.

Male 7 They don't tell me what is wrong with him half of the time

Male 8 because I just feel like I haven't received any information and that they don't want to talk with me about him

Male 8 because there are not any clear cut answers

Male 8 dislike of the communication between each other

Male 8 having to use different providers all the time

Male 9 needs more time

Male 9 I just don't feel that everything is being done that could be done. Also the medical industry thinks of themselves more than their patients

Male 10 I feel frustrated because I have to give the information. Doctors that have the training could care less.

Male 10 Well, because I've found out more on my own than the doctors about what's going on him.

Male 10 because I feel that he isn't getting all the help he needs.

Male 11 Just for the fact that in a situation with behavioral problems they label the children

Male 11 They don't really treat her and her child like they even know them. They don't take the time to find out everything they need.

Male 11 the same reasons I gave for [child]

Male 11 They are too busy, it is almost mechanical, and there is not the human touch.

Male 12 one doc tells you one thing but one doctor knows more about it than that doctor

Male 12 conflicting answers

Male 12 well about the same things as the other things they give me a diagnosis but they don't really give any information to pursue it any further or know how to handle it.

Male 13 because of his medication she had to go back to the doctor to get the medication approved and he had to write a letter and so on, it became a pain

Male 14 because of the case worker, he hasn't had the help he had. he had allot of threats. such as if he didn't go and volunteer or go date. threatened that his son could be put in foster homes.

Male 14 I don't feel like I have really good access to the doctor, his problems have mostly cleared up on their own but if they hadn't I would have had a lot more problem

Male 14 she's not sure because there is been a few issues with the specialist that some of the medication is been bad. diet the give to him... the problem is the specialist

Male 15 Professionals requiring too much money for their services

Male 17 my biggest problem is it is difficult to get health insurance when self employed, when we go to clinic we go to clinic they schedule us for PA not dr. due to any health insurance. This is has been long

Open-ended Responses to Question C17a: Cause of Dissatisfaction With Ability to Obtain Information Needed to Make Decisions About Meeting Child's Health Care Needs, Utah Children With Special Health Care Needs, Age 0-17, 2000. (continued)

SEX AGE RESPONSE

| | | |
|--------|----|---|
| Male | 17 | Because I feel like I'm out in left field and I don't know what's going on. |
| Female | 3 | getting the paper work from the specialist clinic and I am not getting what I need from the insurance company |
| Female | 5 | sometimes I feel I don't get enough info. no written material and some suggestion on research. |
| Female | 7 | there is not a lot of info out there and there is not a specialist in this area for adhd , I have to travel to 110 miles to get treatment for that (1 way) once a month |
| Female | 7 | She feels like she is not understood (at the doctor). She feels like there is not enough communication and there needs to be more research into ADD. There has got to be a better way to test for ADD. |
| Female | 8 | I just feel where she's an older child, they just don't put enough time into them like they do the infants. |
| Female | 11 | insurance |
| Female | 12 | There is no cure for what [child] has and nobody knows how to help her |
| Female | 12 | they don't care |
| Female | 13 | Haven't been able to find a reason for her seizures. |
| Female | 13 | when she goes she goes to the doctor and he gives her medicine and she still hurts. |
| Female | 15 | They cant give me an exact name or reason for her learning disability. some doctor's say it is not from an accident that she had as a baby. Then I read in books that it is very likely. I'm getting |
| Female | 16 | The number of times that she has had strep and that her treatments aren't working. |
| Female | 16 | you get the runabout |
| Female | 16 | Because they always change their mind or lose the test results |
| Female | 17 | hard to get medical records |
| Female | 17 | everybody we go to has a different treatment plan and it gets very frustrating and we do not know who to believe in English, and I don't understand half the stuff they are doing. It seems like nobody cares about your health |

Open-ended Responses to Question C18a: Cause of Dissatisfaction With Health Care Child Received, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|--------|----|---|
| Male | 1 | They rush and don't follow up on things |
| Male | 8 | The same reasons |
| Male | 10 | I am satisfied with the pediatrician, but very dissatisfied with the mental health care [child] is receiving. |
| Male | 10 | I don't think they're informative enough with medications they're like lets try this, lets try that. When we have reactions to things they give him then they just pass it off and we'll try something else |
| Male | 11 | Same as before. |
| Male | 12 | not being able to get a provider in our area |
| Male | 12 | Well because I don't think that they are really giving all that he needs it is just kind of a hit and miss. |
| Male | 14 | There has been no follow through. |
| Male | 14 | With the pediatric she very happy but not with the specialist. |
| Male | 15 | I'm satisfied in some ways, but I can't receive some of the health care needed because of the expenses |
| Male | 17 | Because I don't know what's going on |
| Male | 17 | We keep getting reports from school that he needs help but know one can ever find a place to go. |
| Female | 3 | She went in for a fever and the doctor wouldn't prescribe any antibiotic |
| Female | 10 | The dentist is turning her down cause she doesn't have insurance |
| Female | 16 | Same reasons. |
| Female | 16 | because of the lack of communication |
| Female | 16 | She wasn't diagnosed that fast and it could have helped |
| Female | 16 | the doctors were great but the hospital staff was very uncommunicative |

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|------|----|---|
| Male | 1 | occupational therapists, home health, a nurse through TLC |
| Male | 3 | early intervention |
| Male | 3 | speech therapy |
| Male | 5 | mental health, as far as getting testing and stuff done |
| Male | 6 | Medical |
| Male | 7 | dental |
| Male | 8 | dental |
| Male | 8 | Mental services. |
| Male | 8 | tried to get him in a special school for problem child and there was a long waiting list |
| Male | 9 | Just with his learning I've had to fight for that all the way. |
| Male | 9 | optical |
| Male | 9 | for family counseling |
| Male | 9 | Behavioral |
| Male | 9 | medical and dental |
| Male | 9 | Dental |
| Male | 10 | mental health and behavioral. |
| Male | 10 | specialized mental health |
| Male | 10 | Educational |
| Male | 11 | dental |
| Male | 11 | dental. He's not covered |
| Male | 11 | mental health behavioral |
| Male | 11 | Educational, it was reading |
| Male | 11 | changing mental health programs |
| Male | 11 | services for ADD |
| Male | 11 | mental health services... no children's facility in the area and can't find one to help a child. [Child] has psychotic attacks and goes crazy and no one will help. my insurance won't keep covering it |
| Male | 12 | educational |
| Male | 12 | Educational |
| Male | 12 | psychiatric |
| Male | 12 | insurance coverage |
| Male | 12 | well we have a hard time getting the education throughout the school and it is really hard to convince the school those children with autism need differ of education. Mental health is also hard |
| Male | 12 | Braces, medical stuff, |
| Male | 12 | Educational |
| Male | 12 | mental health and medical |
| Male | 13 | behavioral health |

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

| | | |
|--------|----|--|
| Male | 13 | mental health behavioral |
| Male | 13 | educational |
| Male | 13 | Dental. |
| Male | 13 | SSI took a while to get. Getting him on Medicare was very difficult. |
| Male | 13 | His studying habits. She is trying to find out if he has a learning disability and it is difficult to get to see anyone. |
| Male | 14 | to be able to get the same counselor. Schools counselor, wasn't as good enough the first counselor he had a special relationship |
| Male | 14 | Counseling services |
| Male | 14 | sometimes I've wondered if maybe he should have counseling or maybe I need it |
| Male | 14 | Neurologists. |
| Male | 14 | well we tried to get mental health for him but it was not covered |
| Male | 14 | Medication management. |
| Male | 14 | the same that is above |
| Male | 14 | For his eyes/eye doctor |
| Male | 14 | physical and occupational therapy |
| Male | 14 | The mental services |
| Male | 15 | dental |
| Male | 15 | he was struggling in school, it was obvious to the teacher he was having problems but the school won't pay attention until they are 2 to 3 ears behind so you have to go out and get a tutor and pay a |
| Male | 15 | educational |
| Male | 16 | we don't have a lot of accessibility as far as pediatric gastrointestinologist (sic) was not available in our area. |
| Male | 16 | mental health, dental, and medical |
| Male | 16 | I felt he could of used a qualified counselor in his youth and couldn't find one, now he's in a youth group. |
| Male | 16 | It was a counselor that what provided by the county to see him at school. |
| Male | 16 | metal health |
| Male | 17 | dental even just getting him into school was a fight. |
| Male | 17 | dental, |
| Male | 17 | mental health |
| Male | 17 | educational services |
| Male | 17 | The medical for his knee |
| Male | 17 | We have to drive two hours into Salt Lake to get counseling services. |
| Male | 17 | Medical insurance. |
| Male | 17 | counselor |
| Male | 17 | mental health |
| Female | 1 | health care |

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 1 Specialist’s services.

Female 2 can’t find a primary care provider for her, well I probably could if I started calling around but I don’t think of it until she has a crisis

Female 2 respiratory pediatric care at primary children’s.

Female 3 they have been trying to apply for Medicaid and it’s been a joke. They give them a different thousand reasons why they can’t get it.

Female 4 Medical and dental have been hard to get because she doesn’t have insurance right now.

Female 5 dental services

Female 6 Preventive medical equipment for her asthma is hard to get.

Female 6 when she was diagnosed with her condition

Female 6 dental.

Female 7 treatment for ADHD

Female 7 Physical therapy and dental

Female 8 educational services , same frustrations that I have experienced with [child]

Female 8 Finding speech specialists that would take her problem.

Female 9 Medical and Dental are hard to get and because she doesn’t have either type of insurance.

Female 9 We’ve had trouble getting the insurance to cover mental health care costs.

Female 10 Medical services

Female 11 medical

Female 11 Dental

Female 12 extra help at school...educational, behavioral kind of stuff

Female 12 She is home schooled and that has been hard to get sometimes.

Female 12 medical

Female 13 Just to let her stay in the main stream education instead of going into a special class

Female 13 mental health , she had become suicidal and it took 6 weeks to get her into a place, I got the run around every time I called a place

Female 14 Resource services

Female 14 mental health and educational health.

Female 14 treatment for ADD, insurance only covers a few providers

Female 14 The school has been difficult to communicate with about her special needs.

Female 14 mental health and behavioral

Female 15 Help working with her disabilities. The schools are good. In the community, it is hard to find help for learning disabilities. Private schools don’t take students with learning disabilities.

Female 15 medical

Female 15 Educational

Open-ended Responses to Question E10a: “Has [child] needed any health, dental, educational, mental health, behavioral, or any other services that have been hard to get?,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 15 Dental. Insurance don't cover it

Female 15 Medical and dental have been hard to get because of the insurance situation.

Female 15 Rehab,

Female 15 mental health counseling

Female 15 the mental health again

Female 15 getting her counselor was very hard for us to get.

Female 15 medical and dental, uninsured

Female 15 Behavioral, trying to work with the schools.

Female 16 It was hard to get an appt for a neurologist.

Female 16 dental

Female 16 The mental health it has been hard

Female 16 physical therapy

Female 16 dental and mental

Female 16 mental services

Female 17 Behavioral services, yes, the counseling, lack of insurance coverage.

Female 17 if your child is having problems with drugs it hard to find help, especially for behavioral problems

Female 17 She needs some counseling, but I don't know how to and the price, cost is a big issue because as a foster child she has no o insurance, we pay out of pocket.

Female 17 Physical therapy, the insurance wouldn't cover it.

Open-ended Responses to Question E11a: Reasons for Rating Respite Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|--------|----|--|
| Male | 6 | If it's not family, I feel that I don't have anywhere to get help. I can't afford daycare. I have cancel appointments |
| Male | 9 | They promised to find a weekend retreat for him and it never came to pass. |
| Male | 9 | don't use respite care |
| Male | 9 | Because of I don't know of any available respite. |
| Male | 12 | because they were supposed to be there when you needed them and they weren't always there |
| Male | 12 | The way they count the hours is weird, especially when you have more than one child with health care needs, the program's good, there is not enough there to take what we really need. |
| Male | 14 | I have to compare with |
| Male | 14 | when I checked into it they told me flat out that he didn't qualify. |
| Female | 4 | same reason as for the other |
| Female | 6 | because I have no help and the state won't help |
| Female | 9 | I'm a single parent and it's harder to get the respite care. Sometimes I need to just leave because I can't deal with the girls. |
| Female | 17 | They are unavailable. |

Open-ended Responses to Question 9a: Reasons for Rating Child Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|------|----|---|
| Male | 0 | With him he can't be around other babies |
| Male | 0 | Because there isn't any and what is here is very expensive. |
| Male | 0 | I almost died with him, and IHC never had the same nurse with him and the child needed consistency. The child care didn't know how to take care when I was trying to get rest. |
| Male | 1 | too many kids too expensive |
| Male | 2 | it is hard to find a good day care |
| Male | 2 | I read in magazines about other states and Utah doesn't have as many services providing daycare in the work places. |
| Male | 3 | it's too expensive |
| Male | 4 | It is very expensive. |
| Male | 4 | most of the things offered are during the day when I work |
| Male | 5 | waiting list for a year and a half, not a lot of options for child care |
| Male | 5 | it's hard to find someone that will take him in because sometimes his behavior is less than positive |
| Male | 5 | because the prices are so unaffordable |
| Male | 6 | The state licensed providers in my area take too many kids and there are not enough providers. I feel better paying someone not qualified by the state and paying them more because they are better qua |
| Male | 7 | I don t feel there are any options out there |
| Male | 8 | not enough info |
| Male | 8 | don't trust anyone with my kids |
| Male | 8 | because in Utah they don't have that good of services |
| Male | 9 | Can't support the child care that is available. -Too expensive. |
| Male | 9 | there should me more care |
| Male | 9 | I have put him in so many and some I don't like and they teach him anything |
| Male | 9 | I am a single mother with five kids, and can't afford care, I have to feed them |
| Male | 9 | Because he's older and there's a lot of places that won't take him, because he's an older child and he's difficult. |
| Male | 10 | Due to the cost to put 3 children is too much |
| Male | 10 | I had left him so I could go to work, he left the pro- care and came home. and the workers didn't know he had left. |
| Male | 10 | same |
| Male | 11 | Because I don't trust anyone with my kids |
| Male | 11 | his behavioral needs he is very hard to be placed and he has to be supervised |
| Male | 11 | I have an odd schedule and he is in year around school, so it was kind of hard |
| Male | 12 | Because lot of times there may be places available but the people who give care are undesirable. |
| Male | 12 | doesn't coordinate with her |
| Male | 14 | because there is none for that age group |

Open-ended Responses to Question 9a: Reasons for Rating Child Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male 14 his pediatrician had normal hours but when they had an emergency the problem was always the specialist and sometimes he get there so late (the specialist), and sometimes they don't even show up

Male 15 Because Tooele is limited on their providers and services so I have to go into salt lake.

Male 16 Well because when he was younger they put him on the drugs (ADD) and when he developed the ticks and had to stop the drugs they sort of brushed it off and forgot us and we had to work through it ourselves

Male 17 I can't even find babysitters around here so I can take some of the other kids to the doctor

Female 1 the prices are pretty outrageous

Female 2 I guess I do work at home and try to find people to cover, I guess I live in a neighborhood full of stay at home moms that aren't interested. I live in a rural area and it would take about twenty min

Female 3 too many kids

Female 3 Once people find out about her condition they don't want to be responsible for her period. Or they want to charge me An arm and a leg for her.

Female 4 because they didn't look at the fact that she was pre-me they only went off financial records. They wouldn't even look at her because we made to much money. I finally found someone on the school board

Female 5 hard to find reliable care services and it was expensive.

Female 5 you have to be in a certain income line, will give it to you for a couple of months and then cut you off.

Female 6 Most of it goes back to the public schools. The schedules for kindergarten don't accommodate for a parent to work. The upper grades also have inconsistent scheduling.

Female 6 not much of anything to rely on

Female 6 Because I needed state assistance at try to go to school to try and better myself and I couldn't

Female 8 because we live out in the middle of nowhere and there are about 5 families that live in town so when one kid gets sick you can't find a babysitter

Female 9 It depends if she has outburst and I'm at work. Since she's been medicated it less difficult but she still as outburst while I'm at work.

Female 10 don't like child care

Female 11 Because there is not services for older children

Female 11 it is expensive

Female 12 the day cares won't take her at her age

Female 12 during the school year we don't need it. During the summer we can't get it.

Female 13 as a provider there are always people calling her and wanting it but she can't give it. And there aren't enough people licensed

Female 15 I've had past experiences with people caring for my children -I don't trust anyone with my children.

Female 16 hard to juggle time

Female 16 they certainly aren't open in the evenings

Open-ended Responses to Question 9a: Reasons for Rating Child Care Services as “Fair” or “Poor,” Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 17 There are no resources available, what I'd really like is some respite but there aren't any resources. I haven't been able to find any respite services for her.

Female 17 personal decision and that she needed a parent available sometime and because of my personal health. Conflict with my life and decision to have someone available at all time for the children if there were

Female 17 just have to be with [child]

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000.

SEX AGE RESPONSE

| | | |
|------|----|--|
| Male | 1 | they haven't covered some things. They had to purchase his nebulizer, and they didn't cover it all. They don't cover out of state visits as well as if you were in the provider network. |
| Male | 3 | because we use alternative medic and the insurance does not cover it |
| Male | 3 | one of A's problems is dental work the insurance won't cover |
| Male | 3 | developmental delay and speech therapy are not covered by my health insurance |
| Male | 4 | doesn't cover his special needs, like speech therapy |
| Male | 4 | the restrictions |
| Male | 4 | Because I think they should cover more |
| Male | 6 | Same reason as before |
| Male | 6 | Because co pay to see the dr. and prescriptions are not covered very well |
| Male | 7 | they could always be better |
| Male | 8 | because we pay so much money every year for insurance |
| Male | 8 | insurance doesn't want to pay |
| Male | 8 | they don't always want me to pick the one I want |
| Male | 9 | the psychiatrist won't see him |
| Male | 9 | Everything's good except the therapy and medication |
| Male | 9 | because they are not paying any bills |
| Male | 9 | it is new coverage and I have not used it yet but you have to pay a very large copay |
| Male | 9 | Because they had such a high deductible I have to pay to much |
| Male | 10 | They don't pay hardly anything for dental or optical |
| Male | 10 | Delay and lies |
| Male | 10 | it's stupid they don't cover preventive care, like check-ups, immunizations, and etc.. |
| Male | 10 | because they don't pay for any of the mental health, they only take a small percentage of the cost. |
| Male | 10 | copay went up and the cost my husband has to pay out every two weeks is kind of high, there is \$25 copay for medical care and the copay on prescriptions is \$25 |
| Male | 10 | there is just a lot of things that they do not want to pay for, and they are slow on what they do pay for |
| Male | 10 | since the governor opened it to Medicaid patients, the way were treated, and the coverage that we receive. |
| Male | 11 | they only pay about 80% |
| Male | 11 | in dispute, they don't want to pay , they don't seem to want to pay for meds, it may or may not be on their list, he needs a common med but it is not on the list |
| Male | 11 | because the deductible is \$1000 |
| Male | 11 | it don't cover glasses, immunizations, ER visits are 50 dollars and no dental |

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Male 11 They randomly pick stuff to not pay for. Sometimes they pay for services and sometimes they don't pay for those same services.

Male 11 they don't cover the behavioral and mental health issues that he has

Male 11 see response for [child]

Male 11 Prices keep going up

Male 11 Cigna you have to pre-approve, You have to go to a certain doctor, and they don't pay for even half.

Male 11 it's a debate between the doctors and the pre-authorization

Male 12 there are things that it doesn't cover and if you have a secondary insurance it doesn't cover it all anyway

Male 12 It is major medical and he hasn't had any major medical only little injuries so it hasn't been any good for him

Male 12 their coverage is too limited

Male 12 They are very expensive and they don't cover very much.

Male 12 they won't cover his hearing aids and he has a heart murmur and they don't cover either

Male 12 It costs a lot of money to get insurance for health and dental

Male 13 they do ok I just am not totally satisfied and I don't have access to expended mental health

Male 13 you get what you pay for on the managed care

Male 13 some do not cover because of asthma.

Male 14 It doesn't cover what he needs.

Male 14 well because they do not want to pay for anything anymore

Male 14 We are so far away from a military base and my husband is retiring and we don't know if we will be covered.

Male 14 Because of the mental health benefits.

Male 14 really slow

Male 14 Because they don't cover most of the things he needs like the mental health, there is a thousand dollar deductible on that, and eye things, we obviously need that.

Male 16 Delay in payment. Claiming they didn't get the claims.

Male 16 Same reasons as with D's.

Male 16 They don't provide dental, Change prescriptions

Male 16 poor deductibles

Male 16 Because of where we live we can't get it out here, everything we do is cash even though they are full covered.

Male 16 There is some thing that they don't cover fully.

Male 16 one is paying and one isn't

Male 16 they don't cover office visits

Male 16 because they just suck...

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

| | | |
|--------|----|--|
| Male | 17 | Due to getting mixed up on social security numbers (she is married to her ex-husband's brother). |
| Male | 17 | because health insurance is a catastrophe. 90% I'm the one who is responsible and has to pay |
| Male | 17 | some doctors don't want to accept medical card |
| Male | 17 | because they don't pay for provider I will take my child to |
| Male | 17 | The deductibles are quite high. I have quite a bit of out of pocket. |
| Male | 17 | they don't make exceptions with children that are critically ill |
| Male | 17 | they declined what the specialized had prescribed to him for his care |
| Male | 17 | just for his condition, mental health, they have very limited coverage |
| Female | 0 | there are still a lot of unknowns, so they don't know what is being paid for by the insurance |
| Female | 1 | we just had to fight with them to get them to do anything |
| Female | 1 | because she has to get a referral for everything and when everything that is required is done then they can still reject the claim and not pay the bill. |
| Female | 2 | doesn't cover enough |
| Female | 3 | the out of pocket deductible and it is very expensive for everything |
| Female | 3 | they have a huge deductible and even after they pay the deductible, the insurance company still does not pay the rest of the amount |
| Female | 3 | Keep changing her prescriptions and the need for referrals for her medicine and their really disorganized and process papers wrong |
| Female | 6 | they only pay a % and to see a specialist it gets pretty expensive |
| Female | 7 | on the mental health side they are not good plus the doc we go to is not on the panel so they only pay a little bit |
| Female | 7 | They have a high co-payment and premiums and it is expensive. |
| Female | 8 | It doesn't cover well child visits after one year and it only covers 80% of all other visits. |
| Female | 8 | Well the cost of insurance, what the premiums are and what they cover. |
| Female | 8 | I'm not really sure what her health care coverage, it has been difficult to work with her father to get that info |
| Female | 8 | Rates keep going up and more keeps getting shifted to us. |
| Female | 9 | I don't think it's great insurance, I don't think it's bad insurance. I don't know that there's any great insurance's out there. No. |
| Female | 9 | poor deductibles |
| Female | 9 | Because they cover, like I said before, they'll cover her physical fine, but when it comes to mental they'll only cover half. |
| Female | 10 | I have to pay 20% |
| Female | 10 | they have poor coverage and high deductibles |
| Female | 11 | they do cover a very good percentage of the care that I need |
| Female | 11 | restrictions |

Open-ended Responses to Question F5a: Reasons for Rating Their Health Insurance as “Fair” or “Poor” in Covering Health Care Costs for Their Child, Utah Children With Special Health Care Needs (CSHCN), Age 0-17, 2000. (continued)

SEX AGE RESPONSE

Female 12 That should be fair on “A” too. ‘Cause it doesn’t pay for preventive medicine.

Female 12 It’s a lot lower than most charge, you pay.

Female 12 because it is a private plan we have a high deductible so we end up paying for it all before we get to the deductible

Female 12 too expensive

Female 12 because they don’t care about the people they care about the money

Female 13 Again, they don’t pay for prescription, dental, or eye.

Female 13 we have had to call and talk with them about bills they have sent us before and every time they end up paying it after we talk with them

Female 13 there is some stuff that they don’t cover so you have to get creative to have her needs covered, like she needs a nutritionist that Medicaid won’t cover so you have to go to a health educator and p...

Female 14 I have to pay at least 20%

Female 14 because they won’t pay for a provider I want to use

Female 14 She needs therapy and the insurance company won’t cover it.

Female 15 We can only afford major medical. We aren’t covered for glasses, dental etc. With major, there are certain stipulations.

Female 15 Because of mental health clause

Female 15 for one they overcharge for the initial insurance, then what you have to co-pay and stuff

Female 15 don’t like it

Female 15 they don’t cover the alt. therapies that I use but when we go to the regular doctor they are fine.

Female 16 Bad policy coverage

Female 16 2000 deductible and it does not pay for prescriptions

Female 16 because they wouldn’t cover the cost for the birth control pill

Female 16 because we have had trouble with ins. companies because they try to raise our rates so that they do not have to cover [child] because of her medical condition

Female 16 They have exclusions for certain doctors and we have to fight for the things she needs.

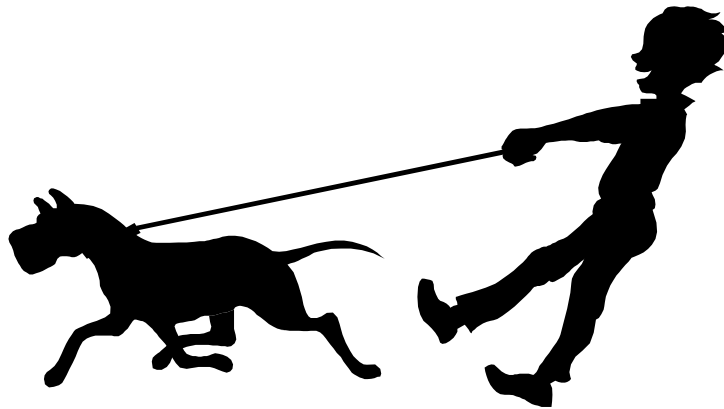
Female 17 our insurance Aetna and they make an agreement with the dr. that they get the coverage that we need at a discount but we pay a cobra of 10 and Aetna will pay the rest. the Dr are either unaware of how

Female 17 they refused a very important surgery that [child] needs to recover

Female 17 They really fight you , you have to jump through all your hoops to get their coverage and their prescription coverage has holes in it, and they’re really slow to pay.

Appendix C.

Technical Notes



General Technical Background to the 2000 Child Health Survey

Introduction

The purpose of this section is to provide the reader with a general methodological overview of the project. Persons interested in obtaining additional or more detailed information may contact:

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Sample Design

The 2000 Utah Child Health Survey was conducted between November 11, 1999 and February 10, 2000. The statistical estimates in this report are based on *2000 Utah Child Health Survey* data.

The sample was a **statewide random digit dial (RDD) sample** designed to be representative of all Utah children through age 18. It is best described as a weighted probability sample of approximately 2,536 households that cover the entire state.

A **single stage, non-clustered, equal probability of selection telephone calling design** was used to generate telephone numbers. This method begins by building a *comprehensive database* consisting of all possible residential telephone working blocks in Utah. Those telephone blocks or area code designations assigned for business use were excluded. Telephone numbers are arranged sequentially into groups of 100 by selecting all telephone numbers within an area code and prefix, plus the first and second digits of the suffix (e.g., 801-538-10XX represents a group that includes all 100 phone numbers between 801-538-1000 and 801-538-1099). Each group of 100 telephone numbers is classified as either high density (at least three residential listings) or low density (less than three listed residential phone numbers in the group). All low density groups are removed, and high density groups are retained. Telephone numbers are randomly selected from the high-density list. This sampling design ensures that both listed and unlisted phone numbers are included in the sample.

Once a household was contacted, the interviewer asked to speak with the adult (age 18 or older) in the household who knew the most about the health of all children in the household (most knowledgeable adult). This person was then asked to report on health topics for either all children in the household, one randomly-selected child in the household, or up to three children in the household with special health care needs, depending on the survey question.

Survey Data Collection

The Utah Department of Health contracted with Pegus Research, Incorporated to collect the survey data. Pegus programmed the telephone survey instrument into a **computer-assisted telephone interviewing (CATI) software program**, called Ci3. Interviews were conducted by trained interviewers in a supervised environment from a single site. Interviews were conducted in Spanish when appropriate.

Computer-assisted telephone interviewing was chosen as the method of data collection for several reasons. First, it yields higher response rates, thus resulting in a more representative sample and reducing the amount of bias resulting from non-response. Second, it helps reduce non-sampling error by standardizing the data collection process. Data-entry errors are reduced because interviewers are not allowed to enter non-valid codes. It was also efficient because it allowed interviewers to enter responses directly into a computer file.

The survey questionnaire consisted of three sections. Section 1 asked the respondent for information on *every child* in the household. It included questions on the age, sex, and first name or initial of each child living in the household. It also included the Foundation for Accountability (FACCT) Living With Illness draft questionnaire. The FACCT questionnaire is designed to identify Children with Special Health Care Needs. Although the questionnaire was not in its final version in time for the 2000 Utah Child Health Survey, we were able to use a near-final draft. The instrument included questions on ten health problems or conditions: 1) use of prescription medications, 2) needs more care than most children, 3) restricted activity, 4) physical/speech/other therapy, 5) mental health problems, 6) durable medical equipment/ special equipment, 7) life-threatening allergies, 8) special diet, 9) IEP (Individualized Education Plan, and special education), and 10) learning or behavioral difficulties. The child was considered to have special health care needs (SHCN) if any of these conditions were reported to have lasted, or were expected to last, for at least 12 months. Section 1 questions were asked of all children in the household (n=5,979).

For Section 2, the questions were asked about one randomly-selected (index) child in the household (n=2,536), plus up to two additional SHCN children (children with special health care needs, or CSHCN, n=730 additional children). Section 2 included questions on topics such as general health status, medical home, health insurance, health care utilization, problems with access to health care, and child activities and supervision. There were several questions that were asked only for SHCN children. The children with SHCN had known probabilities, and the sample was weighted to reflect the Utah population prior to data analysis.

Section 3 consisted of demographic questions about the household and the adult household members. The respondent was asked to report on such topics as the primary caregiver for the index child and the marital and employment status of adults in the household.

Response Rate

The interview process took place over a three-month period (from November 11, 1999 to February 10, 2000), and resulted in an estimated CASRO¹ response rate of 60.3%. If necessary, up to twelve telephone attempts were made to conduct the interview with each household.

¹ The Council of American Survey Research Organizations (CASRO) response rate formula apportions dispositions with unknown eligibility status (ring-no-answer and busy) to dispositions representing eligible respondents in the same proportion as exists among all calls of known status.

Weighting and Estimation Methods

Post-survey weighting adjustments were made so that the Child Health Survey findings could be more accurately generalized to Utah's population.

The post-survey weighting adjustments weighted the sample to be proportionately consistent with the CSHCN, age, sex, geographic, and Hispanic status distribution of the 2000 Utah population. The CSHCN population for 2000 was estimated by the number of CSHCN among all children in the survey (n=5979). Utah population projections by sex, age groups, and county of residence were provided by the Utah Governor's Office of Planning and Budget (GOPB) (the projections used were those compiled in 2000). Estimates of Utah's Hispanic population for 2000 were derived by calculating the average annual rate of increase of Hispanic persons for each county using data from 1990 to 1998 Bureau of the Census reports, and then projecting those increases to 2000 GOPB population counts.

The post-survey weighting variables adjusted for the following factors:

1. The total **number of children in the household**.
2. The proportion of **CSHCN**.
3. The proportion of **Hispanic persons** in each area.
4. The proportion of persons by **geographic area** (describe areas).
5. The **age and sex** distribution among Utah's population age 0-18.

Population count estimates. Once a percentage was calculated for a variable of interest (e.g., the percentage uninsured) using appropriately weighted survey data, a population count (N) to which the percentage applied was estimated. In some cases analyses referenced certain age or sex groups, Hispanic persons or combinations of Utah counties. These total population group counts were readily available from the sources described earlier. However, for other groups where population counts were largely unavailable (e.g., analyses that examined the distribution of CSHCN), the population counts were estimated. This was achieved by multiplying the appropriate 2000 population total for that group (from 2000 GOPB estimates) by a proportion obtained from a frequency distribution of survey data. For instance, to calculate a population count for CSHCN, the population of children age 0-17 from GOPB was multiplied by the percentage of CSHCN age 0-17 in the 2000 Utah Child Health Survey sample. Thus, any population count estimates not derived directly from existing age, sex, Hispanic status or county population estimates were derived from 2000 Child Health Survey data, and must be considered estimates.

Missing Values. Another consideration that affected the presentation of the population estimates in table format was the inclusion or exclusion of missing values ("don't know" and "refused to answer"). Population percentage estimates were calculated after removing the "don't know" and "refused to answer" responses from the denominator. This, in effect, assumed that persons who gave these answers were distributed identically on the variable of interest to those who gave a valid answer to that variable. For instance, among those who did not know whether they were insured, we assumed that 93.5% were insured and 6.5% were not insured — percentages identical to those found among the sample members who answered the question with a valid response.

Limitations and Other Special Considerations

Estimates developed from the sample may differ from the results of a complete census of all households in Utah due to two types of error, sampling and non-sampling error. Each type of error is present in estimates based on a survey sample. Good survey design and data collection techniques serve to minimize both sources of error.

Sampling error refers to random variation that occurs because only a subset of the entire population is sampled and used to estimate the finding in the entire population. It is often mis-termed “margin of error” in popular use. Sampling error is expressed as a *confidence interval*. The 95% confidence interval (calculated as 1.96 times the standard error of a statistic) indicates the range of values within which the statistic would fall 95% of the time if the researcher were to calculate the statistic (e.g., a percentage) from an infinite number of samples of size= n drawn from the same base population. It is typically expressed as the “plus or minus” term, as in the following example:

“The percentage of those polled who said they would vote for Al Gore was 52%, plus or minus 2%.”

Because CSHCN were oversampled, and then the sample was weighted to reflect the Utah population, the Child Health Survey sample was considered a complex survey sample design. Estimating the sampling error for a complex survey design requires special statistical techniques, derived from the standard error for each estimate. SUDAAN software (Research Triangle Institute) was chosen to estimate the standard errors of the survey estimates because it employs a statistical routine (Taylor-series expansion) that accounts for the complex survey design.

Graphs in this report include bars showing the estimated confidence interval around the survey estimate. In cases where the confidence interval was greater in magnitude than the estimate, the estimate was not given. Estimates were not presented where the sample denominators were less than $n=50$. Readers should note that we have always presented the confidence interval as though it were symmetric, that is, of equal value both above and below (plus and minus) the estimate. It is often the case, however, that a confidence interval will be non-symmetric. This occurs when the distribution is positively or negatively skewed, such as when a percentage is close to 0% or 100%. However, because the software program we use provides only symmetric confidence intervals, we were unable to provide the asymmetric estimates without considerable additional effort.

Non-sampling error also exists in survey estimates. Sources of non-sampling error include idiosyncratic interpretation of survey questions by respondents, variations in interviewer technique, household non-response to questions, coding errors, and so forth. No specific efforts were made to quantify the magnitude of non-sampling error.

Comparability with other surveys is an issue with all survey data. Differences in survey design, survey questions, estimation procedures, the socio-demographic and economic context, and changes in the structure and financing of the health care delivery system may all affect comparison between the 2000 Utah Child Health Survey and other surveys, including those conducted by the U.S. Bureau of the Census, the Behavioral Risk Factor Surveillance System surveys, and Utah Department of Health, Health Status Surveys.

Telephone surveys exclude certain population segments from the sampling frame, including persons in group living quarters (e.g., military barracks, nursing homes) and households without telephones. At the time of the 1990 Decennial Census, only four percent of Utah households were without telephone service. Typically, telephone surveys are biased because telephone households under-represent lower income and certain minority populations. In addition, studies have shown that non-telephone households tend to have lower rates of health care utilization (especially dental care), poorer health habits and health status, and lower rates of health insurance coverage (Thornberry and Massey, 1988).

Despite these overall disparities between telephone and non-telephone households, new survey research (Keeter, 1995) suggests that a similarity exists between data from non-telephone households and telephone households that experienced an interruption in service over the past 12 months. This similarity exists because many, if not most, households currently without telephones did have service in the recent past, and will have service again in the future. Therefore, telephone surveys to be more representative of non-phone households than had previously been thought.

Appendix D. Investigation of the Utah Child Health Survey CSHCN Rate





Investigation of the Utah C. H. S. CSHCN Rate

At the time that the 2000 Utah Child Health Survey was being designed, the Foundation for Accountability (FACCT) instrument for assessing children for special health care needs was also under development. At the time the 2000 Utah Child Health Survey went into the field, the most current draft version of the FACCT survey was obtained, and embedded in the Child Health Survey instrument.

The FACCT survey instrument has been administered on several occasions, in different states, and to different survey populations. On all of these occasions, the FACCT survey has produced estimates for the prevalence of Children With Special Health Care Needs (CSHCN) that are substantially higher than what was found in Utah. Utah's rate of CSHCN was estimated by the survey to be 12.6%, while others' estimates around the country ranged from 16% to 19%. With a 95% confidence interval for the Utah survey of only $\pm 1.0\%$, the differences don't seem to be explainable as survey sampling error. However, there are other methodological issues that could account for Utah's low rate, and Utah desires to explore these potential causes for the difference, and, hopefully, rule them out.

An examination of the low rate, and all potential causes for the lower survey estimate, was undertaken. The examination took the form of several discussions, meetings, phone conference calls, data analyses, and sharing of data in an attempt to ascertain gauge the validity of Utah's lower-than-expected observed rate.

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Mousumi Sarkar

DEFINITIONS:

CAHPS. Consumer Assessment of Health Plans Survey, a survey conducted with members of specific health plans to assess their satisfaction with various aspects of the plan.

Utah CHS2000. 2000 Utah Child Health Survey, a population-based telephone survey including 5,979 children, designed to be representative of all children living in Utah. To measure special health care needs among children, Utah adapted the October 1999 draft of the FACCT instrument. It looked at 10 conditions/behaviors:

1. Rx meds
2. Needs more care than most children
3. Restricted activity
4. Physical/speech/other therapy
5. Mental health problems
6. Durable medical equipment/special equipment
7. Life-threatening allergies
8. Special diet
9. IEP (Individualized Ed. Plan, Spec. Ed.)
10. Learning or behavioral difficulties

FACCT/LWI. (Living With Illness) instrument. The final version of the instrument that looks at 5 conditions/behaviors:

1. Rx meds
2. More care
3. Restricted activity
4. Physical/speech/other therapy
5. Mental health problems

FACCT Field Trial Survey. This survey was conducted in Oregon by the Foundation for Accountability (FACCT). We are using it as a comparison to explore reasons for our lower CSHCN rate.

VCU Survey. The Virginia Department of Health contracted with the Virginia Commonwealth University's Survey and Evaluation Research Laboratory to administer a telephone survey to a general population sample including 888 children in their state. Their questionnaire included a draft version of the FACCT questions that was very similar to the draft version administered as part of the 2000 Utah Child Health Survey. We are using it as a comparison to explore reasons for our lower CSHCN rate.

AT RISK vs. DURATION QUESTIONS. For each of the conditions/behaviors examined, there was a screener, or “at risk” question and one or two “duration” follow-up questions. The first question asks whether the condition currently applies to the child, the remaining question(s) ascertain whether the condition is chronic (has lasted or is expected to last 12 months).

CSHCN. A child in a surveyed household was defined as a Child with Special Health Care Needs (CSHCN) if, for any given condition or behavior, the survey respondent answered “yes” to BOTH the “at risk” and “duration” questions. For instance, if a child had an activity restriction (at risk) that had lasted or was expected to last for at least 12 months (duration), that child would be considered CSHCN. Alternatively, if the child had an activity restriction that was NOT expected to last a total of 12 months (e.g., broken arm in a cast) that child would not be categorized as a CSHCN.

HYPOTHESIZED REASONS FOR UTAH’S LOWER RATE:

1. Utah rate could be lower because of interviewers coding or respondents indicating “no” responses on the screener questions so they wouldn’t have to go through the follow-up questions.
2. Utah’s low rate could be due to the difference in question wording. The FACCT Utah Draft collapsed two follow-up questions, the FACCT/LWI broke them out.
3. Sampling frames are different. After a short time on the phone, it was discovered that the two survey samples were quite different. The age distribution of Utah kids may be more weighted toward the younger kids, and special health care needs are often not identified until a child is age two or older.
4. Utah has a lower rate of CSHCN.

Hypothesis 1: Poor interviewing techniques or respondent nea-saying.

If Pegus interviewers were opting out of the screener questions to save time, or if savvy parents were doing the same, we should have systematically fewer “yes” responses to the screener questions. There were two sources of data with which to compare our Utah survey results. FACCT had conducted a mail version of the FACCT Draft survey, and the Virginia Department of Health had conducted a general population telephone survey with a similar instrument. We compared the responses on the screener questions for most items in the FACCT Draft surveys (the three surveys were conducted at different points in the development of the questionnaire, so not all questions were administered across all three versions).

Table 1. Percentage of "Yes" Responses to the Screener Question

| ITEM | UTAH % | FACCT FIELD TRIAL % | VIRGINIA % |
|--|--------|---------------------|------------|
| Rx meds | 12.1 | 23.3 | 21 |
| Needs more care than most children | 6.0 | 10.0 | 7 |
| Restricted activity | 4.6 | 5.8 | 7 |
| Physical/speech/other therapy | 3.3 | 2.9 | 6 |
| Mental health treatment/counseling | 3.1 | 4.7 | 4 |
| Durable medical/special equipment | 2.1 | 4.9 | 3 |
| Life-threatening allergies | 3.3 | n/a | n/a |
| Special diet | 1.6 | 2.3 | 2 |
| IEP (Individualized Ed Plan, Spec Ed.) | 4.7 | 4.1 | 5 |
| Learning or behavioral difficulties | 4.8 | 8.5 | n/a |

From examining the Table 1, it is clear that for certain items (prescription medications and learning or behavioral difficulties) the Utah sample had fewer “yes” responses, but for other items Utah had similar or higher responses. There was no easily discernible pattern of “nea-saying” among the Utah respondents or the interviewers. The data do not support hypothesis #1.

This finding is interesting in light of the conventional wisdom that Utah is a state that uses medications such as antidepressants and Ritalin to a greater extent than other places.

Since Utah’s rate for use of prescription medications was so much lower than that found in the FACCT field trial (12.1% in Utah versus 23.3% in FACCT Field Trial), we wanted to look at the use of prescription medicines by age and health insurance. While it is true that the uninsured group had much lower rates of prescription medication use (7.0% for uninsured children versus 12.2% for children covered by health insurance), the proportion of children in Utah who were without health insurance was quite small (6.5%, overall), and the lower prescription medication use rates did not change the overall prescription use rate substantially (insured children only, 12.2%, all children, 12.1%, see Table 2).

Table 2. Percentage of Children Who Used Prescription Medications (Q2A) by Age Group and Insurance Status

| Age Group | Insured (n=2,332) | Not Insured (n=187) |
|-----------|-------------------|---------------------|
| Age 0-1 | 8.9 | 5.7 |
| Age 2-4 | 5.6 | 3.3 |
| Age 5-7 | 6.7 | 13.0 |
| Age 8-10 | 11.6 | 8.5 |
| Age 11-13 | 16.6 | 7.9 |
| Age 14-18 | 19.4 | 5.7 |
| All Ages | 12.2 | 7.0 |

Hypothesis 2: Difference in question wording/structure.

The FACCT Utah Draft collapsed two follow-up questions, the FACCT/LWI broke them out.

Utah follow-up question: “Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?”

FACCT Field Trial follow-up questions: “Is this because of ANY medical, behavioral, or other health condition?” “Is this a condition that has lasted or is expected to last 12 months or longer?”

Two sources of evidence speak against this hypothesis. First, if Utah’s lower CSHCN rate was due to the question structure, then we would have had similar rates on the screener questions, and differences in the follow-up questions. But it appears that we start out with different rates on the screener questions.

In addition, Debra Ried and Christina Bethell indicated that they have tested for effects of this methodological difference in their work, and the two question structures yielded very similar results. They indicated that the wording change would not make a difference in phone surveys. They have also tested the two- versus one-question follow up with behavior coding¹, and said that the one-question follow-up version held up well.

Hypothesis 3: Different sampling frames.

The Utah sample was a random sample of all children age 0 through 18 in the general population, whereas the FACCT Field Trial sample (and similar surveys that had been yielding the 18% estimates) was a CAHPS sample - all the children had health insurance, and had been enrolled in their current health insurance plan for at least 12 months. This alone should account for much of the difference in the two rate estimates, as CSHCNs are more likely to have health insurance. To test this hypothesis, we looked at the CSHCN rate among children in the 2000 Utah Child Health Survey who had been continuously insured for the past 12 months. Although these children were not necessarily on the same health plan during that time, they should be similar to the group in the CAHPS sample.

Had this hypothesis accounted for the difference, we would expect the Utah CSHCN rate among this group of children to increase to a level near 16%. Instead, the CSHCN rate among these children increased only modestly, so we continued to pursue the other hypotheses for the lower Utah estimate.

¹ Behavior coding is a process in which survey questions are pilot tested while a coder listens-in and codes for certain interviewer or respondent behaviors that would indicate a problem with the question. The coder would typically look for behaviors such as respondents asking for clarification, hesitating, giving irrelevant answers, interviewers needing to clarify a question, reread a question, etc.

Table 3. Percentage of Children in the Utah CHS2000 Who Were Considered CSHCN by Health Insurance Status

| | |
|----------------|---|
| | Index Kids With Health Insurance Throughout Last 12 Months(1) |
| All Index Kids | |
| 12.7% | 13.1% |

(1)Not necessarily the same health plan the entire 12 mos.

Hypothesis 4: Age distribution of Utah children.

The age distribution of Utah children may be more weighted toward the younger kids, and special health care needs are often not identified until a child is age two or older. Here is the age distribution of children in the CHS2000 survey compared with the age distribution of kids in Utah and kids in the U.S.

Table 4. Age Distribution of Utah Survey Subjects Compared With That of the Utah Population and FACCT Field Trial Subjects

| Age Group | CHS2000 Survey (1) | Utah Pop (2) | FACCT Field Trial (3) |
|-----------|--------------------|--------------|-----------------------|
| Age 0-1 | 14.1% | 16.5% | 4.0% |
| Age 2-4 | 19.8% | 23.0% | 26.5% |
| Age 5-7 | 24.6% | 20.9% | 24.2% |
| Age 8-10 | 21.3% | 20.4% | 23.7% |
| Age 11-13 | 20.2% | 19.2% | 21.5% |

(1) Weighted survey data, kids insured for at least 12 mo., (2) GOPB Jan 2000 projections for July 2000, (3) FACCT field trial sample (3 health plans: 2 commercial, 1 Medicaid)

Table 5. Age Distribution of Utah Survey Subjects Compared With That of the Virginia Children’s Health Access Survey

| Age Group | Utah CHS2000 Survey | Virginia Child Health Survey |
|-----------|---------------------|------------------------------|
| Age 0-5 | 33.3% | 31.1% |
| Age 6-9 | 20.9% | 23.5% |
| Age 10-14 | 25.7% | 24.7% |
| Age 15-18 | 20.0% | 20.7% |

Both surveys reported weighted survey data for all children, regardless of insurance

Table 6. Comparison of Age-Specific CSHCN Rates: Utah CHS2000 and FACCT Field Trial Surveys (% CSHCN in Each Age Group)

| Age Group | Utah Age-Specific CSHCN (1) | FACCT Field Trial (2) |
|-----------|-----------------------------|-----------------------|
| Age 0-1 | 5.2% | 3.7% |
| Age 2-4 | 8.1% | 11.9% |
| Age 5-7 | 8.6% | 18.6% |
| Age 8-10 | 14.7% | 20.9% |
| Age 11-13 | 19.5% | 19.2% |

(1) Weighted survey data, kids insured for at least 12 mo., (2) FACCT field trial sample (3) health plans: 2 commercial, 1 Medicaid

Table 7. Utah CSHCN Estimates Age-Adjusted to FACCT Field Trial Survey Standard Age Distribution

| Age Group | Utah Age-Specific CSHCN (1) | FACCT Field Trial Age Distribution | Utah Rate Age-Adjusted to FACCT Field Trial Survey |
|-----------|-----------------------------|------------------------------------|--|
| Age 0-1 | 5.2% | 4.0% | 0.0021 |
| Age 2-4 | 8.1% | 26.5% | 0.0215 |
| Age 5-7 | 8.6% | 24.2% | 0.0208 |
| Age 8-10 | 14.7% | 23.7% | 0.0348 |
| Age 11-13 | 19.5% | 21.5% | 0.0419 |

Utah Age-Adjusted Rate: 12.11%

(1) Includes only index kids who were insured at the time of the survey and at all times during the previous 12 months.

Table 8. Comparison of Age-Specific CSHCN Rates: Utah CHS2000 and VCU Surveys (% CSHCN in Each Age Group)

| Age Group | Utah Age-Specific CSHCN | Virginia Age-Specific CSHCN |
|-----------|-------------------------|-----------------------------|
| Age 0-5 | 7% | 12% |
| Age 6-9 | 12% | 18% |
| Age 10-14 | 17% | 26% |
| Age 15-18 | 17% | 24% |

Both surveys reported weighted survey data for all children, regardless of insurance

The prevalence of CSHCN increased substantially with age in the Utah sample. Table 4 shows the Utah survey sample contained more children aged 0-1 than the FACCT Field Trial sample, which could lower Utah's CSHCN rate. However, the proportion of children age five and under in the Utah survey was very similar to that in the Virginia survey (Table 5).

In comparing age-specific rates of CSHCN, the Utah survey identified fewer children as CSHCN in the 2 to 10 year age groups compared with the FACCT Field Trial. By the time the child is age 13, Utah appears to have "caught up" with the FACCT Field Trial sample rate (Table 6). We adjusted the Utah CSHCN rate to the FACCT Field Trial age distribution (Table 7) to see what effect the different age distribution would have on the Utah rate (i.e., what would the rate look like if the Utah survey age distribution was identical to the FACCT Field Trial age distribution?). After adjusting the Utah rate to the FACCT Field Trial age distribution, using only those children who were insured at the time of the survey and at all times during the previous 12 months, the Utah rate was 12.1%, still quite different from the FACCT Field Trial rate. Compared with age-specific rates from the Virginia Child Health Access Survey, Utah's rates appear to be lower for every age group.

CONCLUSIONS:

Although there was evidence to support the hypotheses for methodological and age distribution differences between Utah and other survey data, the differences were slight. It is unlikely that methodological or age distribution differences were responsible for Utah's lower CSHCN rate.

Examination of the age-specific rates did suggest that Utah rates may be lower in the younger age groups, but are almost identical to the FACCT Field Trial sample in the 11 to 13 year age group. This pattern of results suggests some possible explanations.

- (1) Utah has fewer CSHCN than other places
- (2) Younger children are less likely to be recognized by parents and identified by the health system as having a health problem. Children who have not been diagnosed with a special health care need will be less likely to be identified by the FACCT instrument as a CSHCN.
- (3) We could have fewer of the types of problems that affect young children, but the same amount of the types of problems that affect older children.

Compared with the Virginia survey data, however, the Utah survey sample yielded lower CSHCN rates in every age group, suggesting that Utah has lower CSHCN rates overall. Utah will continue to examine age-specific rates of various types of problems to attempt to address these questions further.

Appendix E. Survey Questionnaire



2000 Utah Child Health Survey
Utah Department of Health

QUESTION S1

Hello, this is _____ from PEGUS Research. I'm calling on behalf of the Utah Department of Health to talk with parents in Utah about their concerns for their children's health.

- [1] CONTINUE
- [2] ENTER A DISPOSITION
- [3] TO DO A SPANISH INTERVIEW

Logic Instructions (flow only):
IF (answer = 1) Skip to MICenter
if (answer = 2) CTRLEND

QUESTION S2

Your phone number was randomly generated by computer.

Is this ___-___?

- 1 Yes
- 2 No

Logic Instructions (flow only):
If (answer = 1) Skip to S2a
If (answer = 2) Skip to End1

QUESTION S3

Are there children or young persons under age 19 who live at this number?

- 1 Yes
- 2 No

Logic Instructions (flow only):
If (answer = 1) Skip to S4
if (answer = 2) Skip to End1

QUESTION S4

Thinking about ALL the adults in your household, who would know the MOST about the health of these children?

- 1 Person on phone
- 2 Someone else

Logic Instructions (flow only):
if (answer = 1) Skip to S6
If (answer = 2) Skip to S5

QUESTION S5

May I please speak with (him/her)?

- 1 Yes
- 2 No

Logic Instructions (flow only):
if (answer = 1) Skip to S1
If (answer = 1) Skip to End2

QUESTION END2

Is there a time that I could call back and speak with them?

- 1 Yes
- 2 No

Logic Instructions (flow only):
CTRLEND

QUESTION S6

Could you answer some questions for me?

- 1 Yes
- 2 No
- 3 They would like an explanation (PERSUADER)

Logic Instructions (flow only):

If (answer = 1) Skip to S7
If (answer = 2) Skip to End3
If (answer = 3) Skip to S6a

QUESTION END3

Is there another time that I could call back and talk with you?

- 1 Yes
- 2 No

Logic Instructions (flow only):
CTRLEND

QUESTION S6A

INTERVIEWER: READ ONLY IF NECESSARY

This is not a sales or promotional call. Results of this study are very important in helping to improve health care for children and teens in Utah. We need to speak with each selected household in order for the results to truly represent all children in Utah. We will never release your name or phone number without your permission, and the results will be presented as grouped information only. I'd be glad to arrange a time to call back when it is more convenient. Or, if you'd prefer, I can conduct the interview with you now.

INTERVIEWER: IF THEY ASK

The survey takes about 25 minutes to complete.

INTERVIEWER: TO VERIFY THIS SURVEY:

Call 538-9455 during business hours and ask for Dr. Lois Haggard at the Utah Department of Health. If you live outside Salt Lake County, call 1-888-222-2542 and ask to be transferred to Lois Haggard.

THE RESPONDENT MUST ASK TO BE TRANSFERRED TO LOIS HAGGARD!

- 1 Yes (continue with survey)
- 2 No (Refusal and terminate interview)

Logic Instructions (flow only):
if (ans = 1) Skip to S7
If (ans = 2) Skip to End1

QUESTION END1

Thank you for your time. Goodbye.

Press "1" to continue...

Logic Instructions (flow only):
CTRLEND

QUESTION S7

INTERVIEWER: THIS NEEDS TO BE READ TO EVERYONE

Thank you. I want to assure you that this survey is confidential and anonymous. I will not ask for your name or address, so there will be no way to identify you with your answers. No individual's answers will be released without their permission, and the survey results will be presented only after they are grouped together.

Your participation in this survey is completely voluntary. If at any time, you would like to skip a question or stop the interview, just let me know.

Press "1" to continue...

Logic Instructions (flow only):

QUESTION S8

I'd like to ask a few questions about all the children in your household, then I'll identify one child for the rest of the survey.

How many children, age 18 or younger, currently live in your household, including children who have already turned 18?

—>

Logic Instructions (flow only):
QAL Qalerror

QUESTION S9

Of these [N] children, could I please have the first name or initials of the oldest child?

PROMPT: I just need a way to refer to this child later in the survey.

Logic Instructions (flow only):

QUESTION S10

Is [NAME] a boy or a girl?

- 1 Boy
- 2 Girl

Logic Instructions (flow only):

QUESTION S11

And how old was [NAME] on [HIS/HER] last birthday?

—> years old

Less than 1 year = 0

Logic Instructions (flow only):

QUESTION Q1

Is [NAME] restricted or prevented in any way in [HIS/HER] ability to do the things most children of the same age can do?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q1a
If (answer = 2) Skipto Q2a
If (answer = 8) Skipto Q2a
If (answer = 9) Skipto Q2a

QUESTION Q1A

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q2A

Does [NAME] currently need or use any of the following:

MEDICINES PRESCRIBED BY A DOCTOR other than vitamins?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q2a1
If (answer = 2) Skipto Q2b
if (answer = 8) Skipto Q2b
If (answer = 9) Skipto Q2b

QUESTION Q2A1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q2B

Does [NAME] currently need or use MENTAL HEALTH TREATMENT OR COUNSELING?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q2b1
If (answer = 2) Skipto Q2c
if (answer = 8) Skipto Q2c
If (answer = 9) Skipto Q2c

QUESTION Q2B1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q2C

Does [NAME] currently need or use PHYSICAL, OCCUPATIONAL, OR SPEECH THERAPY?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q2c1
If (answer = 2) Skipto Q2d
if (answer = 8) Skipto Q2d
If (answer = 9) Skipto Q2d

QUESTION Q2C1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q2D

Does [NAME] currently need or use SPECIAL EQUIPMENT, for example: to help with moving, walking, talking, hearing, breathing, personal care, etc.?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (answer = 1) Skipto Q2d1
If (answer = 2) Skipto Q3a
if (answer = 8) Skipto Q3a
If (answer = 9) Skipto Q3a

QUESTION Q2D1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q3A

Does [NAME] currently have life threatening ALLERGIC REACTIONS?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q3a1
If (answer = 2) Skipto Q3b
if (answer = 8) Skipto Q3b
If (answer = 9) Skipto Q3b

QUESTION Q3A1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q3B

Does [NAME] currently have a SPECIAL DIET given by a doctor or other medical professional?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q3b1
If (answer = 2) Skipto Q3c
if (answer = 8) Skipto Q3c
If (answer = 9) Skipto Q3c

QUESTION Q3B1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q3C

Does [NAME] have a LEARNING OR BEHAVIORAL DIFFICULTY for which receives professional treatment or counseling?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q3c1
If (answer = 2) Skipto iffac3
if (answer = 8) Skipto iffac3
If (answer = 9) Skipto iffac3

QUESTION Q3C1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (S11.ROSTNUM < 3) Skipto Q3dx
if (S11.ROSTNUM < 14) Skipto Q3dy
If (S11.ROSTNUM <=18) Skipto Q3dz

QUESTION Q3DX

Does [NAME] have an IFSP, or is [HE/SHE] in an early intervention program?

INTERVIEWER: IFSP stands for Individualized Family Service Plan

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

NOTE: ALL MIDDLE AND HIGH-SCHOOL CHILDREN HAVE AN SEOP, STANDARDIZED EDUCATION AND OCCUPATIONAL PLAN. WE ARE NOT INTERESTED TO KNOW THIS.

Logic Instructions (flow only):

If (answer = 1) skipto Q3d1
if (answer = 2) skipto Q4
if (answer = 8) skipto Q4
if (answer = 9) skipto Q4

QUESTION Q3DY

Does [NAME] have an IEP, or is [HE/SHE] enrolled in a special education program?

INTERVIEWER: IEP stands for Individualized Education Plan

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

NOTE: ALL MIDDLE AND HIGH-SCHOOL CHILDREN HAVE AN SEOP, STANDARDIZED EDUCATION AND OCCUPATIONAL PLAN. WE ARE NOT INTERESTED TO KNOW THIS.

Logic Instructions (flow only):

If (answer = 1) skipto Q3d1
if (answer = 2) skipto Q4
if (answer = 8) skipto Q4
if (answer = 9) skipto Q4

QUESTION Q3DZ

Does [NAME] have an IEP, an IWRP, or is [HE/SHE] enrolled in a special education program?

INTERVIEWER: IEP stands for Individualized Education Plan. IWRP stand for Individualized Written Rehabilitation Plan

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

NOTE: ALL MIDDLE AND HIGH-SCHOOL CHILDREN HAVE AN SEOP, STANDARDIZED EDUCATION AND OCCUPATIONAL PLAN. WE ARE NOT INTERESTED TO KNOW THIS.

Logic Instructions (flow only):

If (answer = 1) skipto Q3d1
if (answer = 2) skipto Q4
if (answer = 8) skipto Q4
if (answer = 9) skipto Q4

QUESTION Q3D1

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION Q4

Does [NAME] NEED OR USE MORE medical care, mental health or educational services than usual or routine for most children of the same age?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q4a
If (answer = 2) Skipto iffacc4
if (answer = 8) Skipto iffacc4
if (answer = 9) Skipto iffacc4

QUESTION Q4A

Is this because of ANY medical, behavioral or other health condition lasting or expected to last for AT LEAST 12 months?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (Q1a.ROSTNUM = 1|Q2a1.ROSTNUM = 1|Q2b1.ROSTNUM = 1|Q2c1.ROSTNUM = 1|Q2d1.ROSTNUM = 1|Q3a1.ROSTNUM = 1|Q3b1.ROSTNUM = 1|Q3c1.ROSTNUM = 1|Q3d1.ROSTNUM = 1|Q4a.ROSTNUM = 1) Skipto CSHCN
Skipto Jump2

QUESTION CSHCN

Press "1" to continue...

Logic Instructions (flow only):

QUESTION Q5 (CSHCN)

Does [NAME] have a specific condition or diagnosis?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto Q5a
If (answer = 2) Skipto Q5b
If (answer = 8) Skipto Q5b
Skipto Jump2

QUESTION Q5A (CSHCN)

What is the condition or diagnosis?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION Q5AA (CSHCN)

INTERVIEWER ONLY:

Was the response to the last question NONE or DON'T KNOW?

- 1 Yes
- 2 No

Logic Instructions (flow only):

if (answer = 1) Skipto Q5b
If (answer = 2) Skipto Jump2

QUESTION Q5B (CSHCN)

Briefly describe [NAME]'s special needs.

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

If (S8 = 1) Skipto A2

QUESTION A1

Would you know the most about [NAME]'s health?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto A2
Skipto AWho

QUESTION AWHO

Is the person who knows the most about this child's health available?

- 1 Yes
- 2 No

Logic Instructions (flow only):

If (answer = 1) Skipto A1
If (answer = 2) Skipto AAsk

QUESTION AASK

Since the person who knows that most about this child's health is not available, let me ask you these questions and if you don't think that you can answer them, we can call back.

- 1 Yes
- 2 No

Logic Instructions (flow only):

if (answer = 1) Skipto A2
CTRLEND SAVE

QUESTION A2

What is your relationship to [NAME]?
(READ IF NECESSARY)

- Parent/Step parent
- Grandparent
- Aunt/Uncle
- Brother/Sister
- Other relative
- Legal guardian
- Foster parent
- Other non-relative
- Not sure/Don't know
- Refused

Logic Instructions (flow only):

If (ROSTNUM > 1) Skipto A4

QUESTION A3

INTERVIEWER, ENTER RESPONDENT'S SEX:

- 1 Male
- 2 Female
- 3 Don't know/Not sure

Logic Instructions (flow only):

If (NUMINT > 1 & Anna <> 1) Skipto A3a
Skipto A4

QUESTION A3A

I'd like to ask the main survey questions about [NAME] but because some of your other children have some special health care needs, I'd like to repeat some of those questions for them when we're done with [NAME], if that's alright with you.

INTERVIEWER: IF NECESSARY, READ TO RESPONDENT:

If the survey takes too long, we can stop when you need to and complete it at some other, more convenient time.

Press "1" to continue...

Logic Instructions (flow only):

QUESTION A4

People have many concerns for the health and well-being of their children. Of all the things that concern or worry you about [NAME] which one concern is most pressing for you at this time?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION B1

Would you say that in general [NAME]'s health is Excellent, Very Good, Good, Fair, or Poor?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION B2

Now thinking about [NAME]'s physical health, which includes physical illness and injury, for how many days during the past 30 days was [NAME]'s physical health NOT good?

—> number of days

Don't know/Not sure = 97
Refused = 99

Logic Instructions (flow only):

QUESTION B3

Now thinking about [NAME]'s mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was [NAME]'s mental health NOT good?

—> number of days

Don't know/Not sure = 97
Refused = 99

Logic Instructions (flow only):

QUESTION B4

Which of the following best describes your relationship with [NAME]? Would you say...

- 1 Close,
- 2 Average, or
- 3 Difficult?
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

If (ans = 1) Skipto B4a
If (ans = 3) Skipto B4b
Skipto C1

QUESTION B4A

Would you say fairly close or extremely close?

- 1 Fairly close
- 2 Extremely close
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

skipto C1

QUESTION B4B

Would you say fairly difficult or extremely difficult?

- 1 Fairly difficult
- 2 Extremely difficult
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

QUESTION C1

Is there a USUAL place that [NAME] goes when [HE/SHE] is sick OR you need advice about [HIS/HER] health?

- 1 Yes
- 2 There is no place
- 3 There is more than one place
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (ROSTNUM > 1) Skipto C1x
If (ans = 1) Skipto C1a
Skipto C2

QUESTION C1X

Does [NAME] see the same provider that [INDEX CHILD] sees when [HE/SHE] is sick OR you need advice about [HIS/HER] health?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

if (ans = 1) Skipto C4
If (C1.ROSTNUM > 1 & ans > 1) Skipto C2

QUESTION C1A

What kind of place is it ... ?

[READ ALL RESPONSES 1 THROUGH 7]

- A Doctor's office,
- A private clinic or hospital clinic,
- A Hospital Emergency Room,
- An Urgent care clinic, (E.G., INSTACARE)
- A Public clinic, community health center or health department clinic
- A Military or V.A. facility, or
- Some other place?
- Does not have a provider or place (DO NOT READ)
- Don't know (DO NOT READ)
- Refused (DO NOT READ)

Logic Instructions (flow only):

Skipto C3a

QUESTION C2

What kind of place does [NAME] go to most often

[READ ALL RESPONSES 1 THROUGH 7]

- A Doctor's office,
- A private clinic or hospital clinic,
- A Hospital Emergency Room,
- An Urgent care clinic, (E.G., INSTACARE)
- A Public clinic, community health center or health department clinic
- A Military or V.A. facility, or
- Some other place?
- Does not have a provider or place (DO NOT READ)
- Don't know (DO NOT READ)
- Refused (DO NOT READ)

Logic Instructions (flow only):

QUESTION C3A

Can you give me the name of this place?

- 1 Yes
- 2 No

Logic Instructions (flow only):

If (ans = 1) Skipto C3

Skipto JumpC8

QUESTION C3

What is the name of this place?

Logic Instructions (flow only):

If (CSHCN.KidNum = 1) Skipto C4

Skipto C5

QUESTION C4 (CSHCN)

When you take [NAME] to [DR'S OFFICE NAME] how often do the providers you see have access to ALL THE MEDICAL RECORDS, including specialist reports, to provide [HIS/HER] care? Would you say . . . (READ ALL RESPONSES)

- 1 Always
- 2 Frequently
- 3 Sometimes
- 4 Rarely
- 5 Never
- 8 Don't know
- 9 Refused

Logic Instructions (flow only):

QUESTION C5

When you take [NAME] to [DR'S OFFICE NAME] how often does the provider

have a thorough understanding of ALL the services [HE/SHE] is getting?

Would you say... (READ ALL RESPONSES)

- 1 Always
- 2 Frequently
- 3 Sometimes
- 4 Rarely
- 5 Never
- 8 Don't know
- 9 Refused

Logic Instructions (flow only):

If (C1x = 1) Skipto JumpC5

QUESTION C6

How often do the doctors or other health care providers at [DR'S OFFICE NAME]

respect your family's beliefs, customs, and language? (READ RESPONSES AS

NECESSARY)

- 1 Always
- 2 Frequently
- 3 Sometimes
- 4 Rarely
- 5 Never
- 8 Don't know
- 9 Refused

Logic Instructions (flow only):

if (ROSTNUM > 1) Skipto C8x

QUESTION C7

Is [DR'S OFFICE NAME] the same place [NAME] usually goes when [HE/SHE]

needs routine or preventive care, such as a physical examination or well child

check-up?

- 1 Yes
- 2 No
- 8 Refused
- 9 Don't know

Logic Instructions (flow only):

if (answer = 1) skipto JumpC1

skipto C8

QUESTION C8X

Does [NAME] see the same provider that [INDEX CHILD] sees when [HE/SHE]

needs routine or preventive care, such as a physical examination or well child

check-up?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

if (ans = 1) Skipto C9

QUESTION C8

What kind of place does [NAME] go to when [HE/SHE] needs routine or

preventive care, such as a physical examination or well child check-up?

[READ ALL RESPONSES 1 THROUGH 7]

- A Doctor's office,
- A private clinic or hospital clinic,
- A Hospital Emergency Room,
- An Urgent care clinic, (E.G., INSTACARE)
- A Public clinic, community health center or health department clinic
- A Military or V.A. facility, or
- Some other place?
- Does not have a provider or place (DO NOT READ)
- Does not go for routine preventive/well-baby care (DO NOT READ)
- Don't know (DO NOT READ)
- Refused (DO NOT READ)

Logic Instructions (flow only):
If (CSHCN.KidNum = 1) Skipto C9
Skipto JumpC2

QUESTION C9 (CSHCN)

Does [NAME] visit any specialists or specialty clinics for [HIS/HER] special health needs, such as orthopedists, neurologists, or Primary Children's Clinics?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
if (answer = 2) Skipto JumpC2

QUESTION C10 (CSHCN)

After going to the specialist or specialty clinic, does the provider at [DR'S OFFICE NAME] usually talk with you or [NAME] about what happened at the specialist visit in a way that you understand?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (CSHCN.KidNum = 1 & S11.KidNum > 13) Skipto C12
Skipto JumpC3

QUESTION C11 — there is no C11.

QUESTION C12 (CSHCN)

Do [NAME] 's health care providers communicate with [NAME] or you about plans for future adult life?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
IF (ROSTNUM > 1) Skipto C14
If (CSHCN.KidNum = 1) Skipto C13a
Skipto C15

QUESTION C13A (CSHCN)

Does anyone assist you in locating and setting up services for [NAME] and your family?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
if (ans = 1) skipto C13b
skipto C14

QUESTION C13B (CSHCN)

Who assists you the most in locating and setting up services?
[READ ALL RESPONSES 1 THROUGH 11]

- Family member,
- Doctor or nurse,
- Service coordinator or case manager,
- Health plan case manager,
- Community screening program,
- Social service worker,
- Therapist,
- Public Health staff,
- School staff,
- Religious leader, or
- Someone else? (specify)
- None; do it all myself (DO NOT READ)
- Don't know/Not sure (DO NOT READ)
- Refused (DO NOT READ)

Logic Instructions (flow only):
If (ans = 12) Skipto C14

QUESTION C13C (CSHCN)

How would you rate the assistance you receive in locating and setting up services? (READ)

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):
if (answer = 1) Skipto C13d
If (answer = 2) Skipto C13d
Skipto C14

QUESTION C13D (CSHCN)

Why did you give it this rating?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION C14 (CSHCN)

How would you rate the way [NAME] 's services are coordinated among the different providers and services that help [NAME] ? Would you say... (READ ALL RESPONSES)

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):
If (answer = 1) Skipto C14b
If (answer = 2) Skipto C14b
Skipto JumpC6

QUESTION C14B (CSHCN)

Why did you give it this rating?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):
if (ROSTNUM > 1) Skipto C17

QUESTION C15

In the last 12 months, when you have gone for medical care, how OFTEN did the medical and other staff treat you and your child with courtesy and respect? Would you say... (READ RESPONSES)

- 1 Never,
- 2 Sometimes,
- 3 Usually, or
- 4 Always?
- 5 NO VISITS IN THE LAST 12 MONTHS (DO NOT READ)
- 8 DON'T KNOW/NOT SURE (DO NOT READ)
- 9 REFUSED (DO NOT READ)

Logic Instructions (flow only):

QUESTION C17

How satisfied are you with getting the information you need to make decisions about meeting [NAME] 's healthcare needs? Would you say... (READ ALL RESPONSES)

- 1 Very satisfied
- 2 Satisfied
- 3 Dissatisfied
- 4 Very dissatisfied
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (answer = 3) Skipto C17a
If (answer = 4) Skipto C17a
Skipto JumpC4

QUESTION C17A

What caused you to feel dissatisfied?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):
If (CSHCN.KidNum = 1) Skipto C18
Skipto D1

QUESTION C18 (CSHCN)

Overall, how satisfied are you with the health care [NAME] receives? (READ RESPONSES IF NECESSARY)

- 1 Very satisfied
- 2 Satisfied
- 3 Dissatisfied
- 4 Very dissatisfied
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (answer = 3) Skipto C18a
If (answer = 4) Skipto C18a
Skipto JumpC7

QUESTION C18A

What caused you to feel dissatisfied?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):
if (FlagC = 1) Skipto D1

QUESTION C19 (CSHCN)

How satisfied are you with the opportunities you have had to talk with other families of children with special needs?

- 1 Very satisfied
- 2 Satisfied
- 3 Dissatisfied
- 4 Very dissatisfied
- 5 No opportunity
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION C20 (CSHCN)

Have you received any information or support from Family Voices or other parent organizations?

INTERVIEWER: Family Voices is a parent-to-parent information and support service for families of children with special health care needs.

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
if (answer = 2) Skipto C20a
Skipto D1

QUESTION C20A (CSHCN)

Would you like the phone number of Family Voices so you can contact them?

- 1 Yes (1-800-468-1160; In SLC call 272-1051)
- 2 No
- 8 Don't know/Not sure
- 9 Refused

INTERVIEWER: Family Voices is a parent-to-parent information and support service for families of child with special health care needs

Logic Instructions (flow only):

QUESTION D1

Has [NAME] ever had a regular check-up, that is, a well-child visit where the main purpose was a routine health check-up, and not a visit for an illness, injury, or condition?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto D2
Skipto D3

QUESTION D2

How many months or years has it been since [NAME] 's last regular check-up?

—> months (PLEASE ENTER IN MONTHS)

Not sure/Don't remember = 98
Refused = 99

1 year = 12 months
2 years = 24 months
3 years = 36 months
4 years = 48 months
5 years = 60 months
More than 5 years = 61 months

Logic Instructions (flow only):

QUESTION D3

The last time [NAME] had immunizations, did [HE/SHE] go to a public health department clinic, the Care-A-Van, to [DR'S OFFICE NAME] to some other doctor, or somewhere else?

- 1 Public health department clinic
- 2 Care-A-Van
- 3 [DR'S OFFICE NAME]
- 4 Other doctor
- 5 Somewhere else
- 6 My child has not received immunizations
- 8 Not sure/Don't remember
- 9 Refused

Logic Instructions (flow only):
If (S11.KidNum = 0) Skipto E1

QUESTION D4

Has [NAME] ever seen a dentist?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (answer = 1) Skipto D4a
Skipto E1

QUESTION D4A

How many months or years has it been since [NAME] 's last regular dental cleaning or check-up?

—> months (PLEASE ENTER IN MONTHS)

Not sure/Don't remember = 98
Refused = 99

1 year = 12 months
2 years = 24 months
3 years = 36 months
4 years = 48 months
5 years = 60 months
More than 5 years = 61 months

Logic Instructions (flow only):

QUESTION E1

The next few questions ask about some reasons parents might DELAY OR HAVE PROBLEMS getting MEDICAL, DENTAL, MENTAL HEALTH OR OTHER CARE for their child.

In the past 12 months, did you have problems or delay seeking care for [NAME] because the provider would not take your type of health insurance?

1 Yes
2 No
3 Child not covered by insurance
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):
if (answer = 1) Skipto E1a
Skipto E2

QUESTION E1A

The last time that this happened, was this a medical doctor, dentist, eye doctor, counselor or mental health provider, or some other type of provider who would not take your type of health insurance?

INTERVIEWER: If it happened more than once, just ask about the most recent time.

1 Medical doctor
2 Dentist
3 Eye doctor
4 Counselor/Mental health provider
5 Other provider (specify)
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):

QUESTION E2

Did you have problems or delay getting care for [NAME] because you could not find the services you needed in your area?

1 Yes
2 No
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):
if (answer = 1) Skipto E2a
Skipto E3

QUESTION E2A

Were the services [NAME] needed medical services? Dental services? Eye doctor, counselor or mental health provider, or some other type of services?

INTERVIEWER: If it happened more than once, just ask about the most recent time.

1 Medical doctor
2 Dentist
3 Eye doctor
4 Counselor/Mental health provider
5 Other provider (specify)
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):

QUESTION E3

Did you have problems or delay getting care for [NAME] because you could not afford the services?

1 Yes
2 No
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):
if (answer = 1) Skipto E3a
Skipto E4

QUESTION E3A

The last time that this happened, were the services you could not afford medical services? Dental services? Eye doctor, counselor or mental health provider, or some other type of services?

INTERVIEWER: If it happened more than once, just ask about the most recent time.

1 Medical doctor
2 Dentist
3 Eye doctor
4 Counselor/Mental health provider
5 Other provider (specify)
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):

QUESTION E4

Did you have problems or delay getting care for [NAME] because the service was not covered by your insurance?

1 Yes
2 No
3 Child not covered by insurance
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):
if (answer = 1) Skipto E4a
Skipto E5

QUESTION E4A

Were the services that were not covered medical services? Dental services? Eye doctor, counselor or mental health provider, or some other type of services?

INTERVIEWER: If it happened more than once, just ask about the most recent time.

1 Medical doctor
2 Dentist
3 Eye doctor
4 Counselor/Mental health provider
5 Other provider (specify)
8 Don't know/Not sure
9 Refused

Logic Instructions (flow only):

QUESTION E5

Did you have problems or delay getting care for [NAME] because you could not get a referral for the type of care that [HE/SHE] needed?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

if (answer = 1) Skipto E5a
Skipto E6

QUESTION E5A

Did [NAME] need a referral for medical services? Dental services? Eye doctor, counselor or mental health provider, or some other type of services?

INTERVIEWER: If it happened more than once, just ask about the most recent time.

- 1 Medical doctor
- 2 Dentist
- 3 Eye doctor
- 4 Counselor/Mental health provider
- 5 Other provider (specify)
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION E6

Did you have problems or delay getting care for [NAME] because you could not get an appointment in a reasonable amount of time?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

if (answer = 1) Skipto E6a
Skipto E7

QUESTION E6A

Did [NAME] need an appointment for medical services? Dental services? Eye doctor, counselor or mental health provider, or some other type of services?

INTERVIEWER: If it happened more than once, just ask about the most recent time.

- 1 Medical doctor
- 2 Dentist
- 3 Eye doctor
- 4 Counselor/Mental health provider
- 5 Other provider (specify)
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION E7

Was there a time during the last 12 months when [NAME] needed to use PRESCRIPTION MEDICINE, but could not because of the cost?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION E8 (CSHCN)

When [NAME] needs care right away for an illness, how often are you able to get the care you want? Would you say never, sometimes, usually, or always?

- 1 Never
- 2 Sometimes
- 3 Usually
- 4 Always
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (CSHCN.KidNum = 1) Skipto E9
Skipto F1

QUESTION E9 (CSHCN)

Now I'd like to talk with you about services other than medical care.

How would you rate the child care services available for [NAME] to allow you to work or attend school? Would you say excellent, very good, good, fair, or poor?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent
- 6 Don't use it
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto E9a
If (answer = 2) Skipto E9a
Skipto E10

QUESTION E9A (CSHCN)

Why did you give it this rating?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION E10 (CSHCN)

Has [NAME] needed any health, dental, educational, mental health, behavioral or any other services that have been hard to get?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto E10a
Skipto E11

QUESTION E10A (CSHCN)

Which services have been hard for you to get?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION E11 (CSHCN)

Respite care is short term, temporary care provided to children with special needs in order that their families can take a break from the daily routine of caregiving. How would you rate respite care services available for [NAME] ?

Would you say excellent, very good, good, fair, or poor?

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent
- 6 Don't use it
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (answer = 1) Skipto E11a
If (answer = 2) Skipto E11a
Skipto F1

QUESTION E11A (CSHCN)
Why did you give it this rating?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION F1

The next few questions ask about health insurance. By health insurance I mean private and employer plans, prepaid plans such as HMOs, and government plans, such as Medicaid. Does [NAME] have any kind of health care coverage?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If ((ROSTNUM > 1 & F1.SAMPKID = 1) & ans = 1) Skipto F2x
If (answer = 1) Skipto F2
If (answer = 2) Skipto F3
If (answer = 8) Skipto F3
If (answer = 9) Skipto F4

QUESTION F2X

Does [NAME] have the same type of health care coverage as [INDEX CHILD] ?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

if (ans = 1) Skipto F2x1
Skipto F2

QUESTION F2X1

So [NAME] has health insurance coverage through...

(lists all health plans for index child)

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (ans = 1) skipto F4

QUESTION F2

What type of health care coverage do you use to pay for [NAME] 's medical care?
Is it coverage through... (READ RESPONSES)

INTERVIEWERS: READ ALL RESPONSES 1 THROUGH 9 AND CHECK ALL THAT APPLY.

Probe: Is your child covered through any thing else?

Your employer,
Someone else's employer, (E.G., spouse's employer)
A plan that you or someone else buys on your own,
Medicaid,
Medicare,
Utah Children's Health Insurance Program, or CHIP,
The military, CHAMPUS, TriCare, or the VA,
The Indian Health Service, or
Some other source?
None, does not have health insurance (DO NOT READ)
Don't know/Not sure (DO NOT READ)
Refused (DO NOT READ)

Logic Instructions (flow only):

If (answer = 10) Skipto F3
If (answer = 11) Skipto F3
Skipto F4

QUESTION F3

There are some types of plans you may not have considered. Please tell me if you have any of the following: Coverage through: ...

INTERVIEWERS: READ ALL RESPONSES AND CHECK ALL THAT APPLY.

Probe: Is your child covered through any thing else?

Your employer,
Someone else's employer, (E.G., spouse's employer)
A plan that you or someone else buys on your own,
Medicaid,
Medicare,
Utah Children's Health Insurance Program, or CHIP,
The military, CHAMPUS, TriCare, or the VA,
The Indian Health Service, or
Some other source?
None, does not have health insurance (DO NOT READ)
Don't know/Not sure (DO NOT READ)
Refused (DO NOT READ)

Logic Instructions (flow only):

If (answer = 10) Skipto JumpF1

QUESTION F4

During the past 12 months, was there any time that [NAME] did not have any health insurance or coverage?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (CSHCN.KidNum = 1) Skipto F5
Skipto JumpF1

QUESTION F5 (CSHCN)

How would you rate your health insurance on covering [NAME] 's health care costs? (READ ALL RESPONSES)

- 1 Poor
- 2 Fair
- 3 Good
- 4 Very good
- 5 Excellent
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

If (answer = 1|answer = 2) Skipto F5a
Skipto JumpF3

QUESTION F5A (CSHCN)

Why is that? Why did you rate your health insurance as [FAIR/POOR] on covering [NAME]'s health care costs?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

if (ROSTNUM > 1) Skipto JumpF1

QUESTION F6

Does your health insurance allow you to see the PROVIDERS OF YOUR CHOICE, including pediatric specialists?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (F3.ROSTNUM = 10) Skipto F7
Skipto JumpF2

QUESTION F7

The next few questions ask about some of the reasons that children could be without health care coverage.

Is [NAME] not covered because your employer does not offer, or stopped offering health insurance coverage to its employees?

- 1 Yes
- 2 No
- 3 Not employed
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION F8

Is [NAME] not covered because you lost your job or changed employers?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION F9

Is [NAME] not covered because you are a part time or temporary employee?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION F10

Is [NAME] not covered because you could not afford to pay the premiums?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION F11

Is [NAME] not covered because [HE/SHE] is healthy and you decided it would be safe for [HIM/HER] to go without coverage?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION F12

Is [NAME] not covered because the insurance company refused to cover [HIM/HER] ?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto F12a
Skipto F13

QUESTION F12A

Did the insurance company refuse to cover [NAME] because of a (READ ALL RESPONSES)

- 1 Pre-existing condition
- 2 Exceeded lifetime benefits limits, or
- 3 Some other reason (specify)
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

QUESTION F13

Is [NAME] not covered because [HE/SHE] lost Medicaid or CHIP eligibility?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto F13a
Skipto F14

QUESTION F13A

Did [NAME] lose eligibility because... (READ ALL RESPONSES)

- 1 Your family income increased,
- 2 You went off welfare,
- 3 You did not complete paperwork to complete eligibility,
- 4 Your caseworker did not return my calls or requests,
- 5 You did not pay spenddown, or
- 6 For some other reason? (specify)
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

QUESTION F14

Was there any other reason that [NAME] was without health insurance coverage?

INTERVIEWER: RECORD VERBATIM (EXACT RESPONSE)

Logic Instructions (flow only):

QUESTION F15

About how long has it been since [NAME] had health care coverage? (READ ONLY IF NECESSARY)

- 1 Within the past 6 months (2 to 6 months ago)
- 2 Within the past year (6 to 12 months ago)
- 3 Within the past 2 years (1 to 2 years ago)
- 4 Within the past 5 years (2 to 5 years ago)
- 5 5 or more years ago
- 6 Never
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (CSHCN.KidNum = 1) Skipto F16
Skipto G1

QUESTION F16 (CSHCN)

Many families report higher costs for caring for a child with special health care needs. Extra costs include things like medical bills, transportation, special foods, clothing, or equipment. About how much extra did you spend out of your own pocket for the costs of caring for [NAME] in the last 12 months? (READ RESPONSES, IF NECESSARY)

- 1 Less than \$500
- 2 \$500 or more but less than \$1000
- 3 \$1000 or more but less than \$3000
- 4 \$3000 or more but less than \$5000
- 5 More than \$5000
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION F17 (CSHCN)

Does [NAME] currently receive Supplemental Security Income, known as SSI?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (S11.KidNum < 3) Skipto HIS

QUESTION G1

On an average week DAY, how many hours does [NAME] spend watching TV or playing computer games?

- 0 Does not watch TV or play computer games
- 1 1 hour or less per day
- 2 2 hours per day
- 3 3 hours per day
- 4 4 hours per day
- 5 Five or more hours per day
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

if (S11.KidNum < 5) Skipto HIS

QUESTION G2

Many parents work or have other commitments, which makes it hard to arrange for supervision for children at all times. On a typical school day, for how many hours is [NAME] unsupervised?

INTERVIEWER: Supervision means being in the company of an adult or older child who has responsibility for the child's well-being.

—> hours

Never unsupervised = 0
Eleven or more hours per day = 11
Don't know/Not sure = 98
Refused = 99

Logic Instructions (flow only):

QUESTION G3

During school breaks, for how many hours on a typical week day is [NAME] unsupervised?

INTERVIEWER: Supervision means being in the company of an adult or older child who has responsibility for the child's well-being.

—> hours

Never unsupervised = 0
Eleven or more hours per day = 11
Don't know/Not sure = 98
Refused = 99

Logic Instructions (flow only):

QUESTION HIS

The next few questions ask about family characteristics.

Is [NAME] Hispanic or Latino?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION RACE1

Which of the following applies to [NAME]? You may choose more than one. Do you consider [HIM/HER] to be White?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION RACE2

Do you consider [NAME] to be Black or African-American?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION RACE3

Asian?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION RACE4

American Indian or Alaskan Native?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION RACE5

Pacific Islander?

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION RACE6

Do you consider [NAME] to be any other race?

- 1 Yes (specify)
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION HNUM

The last few questions ask about characteristics of your household.

How many adults are there living or staying in your household, (INCLUDING YOURSELF?)

—> adults

Don't know/Not sure = 98
Refused = 99

Logic Instructions (flow only):

QUESTION HAGE

How old were you on your last birthday?

—> years old

Age 85 or older = 85

Don't know/Not sure = 98

Refused = 99

Logic Instructions (flow only):

QUESTION EDU

What is the highest year or grade of school you have completed?

- 1 Some high school or less
- 2 High school graduate or G.E.D.
- 3 Some college or vocational school
- 4 Technical or vocational school graduate or assoc. degree
- 5 College graduate (4 year college degree)
- 6 Some post-graduate courses
- 7 Post graduate/Professional degree (MA,MS,PHD,JD,MD ETC)
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION MAR

Are you currently... (READ RESPONSES)

INTERVIEWER: PROBE DON'T KNOW'S AND LIVING-AS-MARRIEDS:
What category do you think you fall into?

- 1 Married,
- 2 Divorced,
- 3 Widowed,
- 4 Separated, or
- 5 Never married?
- 8 Don't know (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

QUESTION EMP1

What were you doing MOST of last week... (READ RESPONSES)

- Employed full time,
- Employed part time,
- "Stay at home" parent
- Going to school or
- Something else?
- With a job, but not at work temporarily (Vacation, ill)(DO NOT READ)
- Unemployed, laid off, looking for work (DO NOT READ)
- Retired (DO NOT READ)
- Disabled/Unable to work (DO NOT READ)
- Don't know/Not sure (DO NOT READ)
- Refused (DO NOT READ)

Logic Instructions (flow only):

If (ans = 1) Skipto EMP4

If (ans = 2) Skipto EMP4

If (ans = 5) Skipto EMP2

If (ans = 6) Skipto EMP3

Skipto X1a

QUESTION EMP2

LAST WEEK were you PRIMARILY unemployed, retired, unable to work, or something else?

- 1 With a job, but not at work temporarily (vacation, ill)
- 2 Unemployed, laid off, looking for work
- 3 Retired
- 4 Disabled/Unable to work
- 5 Other
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto EMP3

Skipto X1a

QUESTION EMP3

Do you ordinarily work full or part time?

- 1 Full time
- 2 Part time
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION EMP4

About how many persons are employed by your employer?
(READ RESPONSES)

INTERVIEWER: "Employer" is the business that purchases health plans and provides employee benefits.

- 1 Less than 5,
- 2 5 to 9,
- 3 10 to 24,
- 4 25 to 50,
- 5 50 to 100, or
- 6 More than 100?
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

If (ans = 1) Skipto EMP5

if (ans = 2) Skipto EMP5

If (ans = 3) Skipto EMP5

Skipto X1a

QUESTION EMP5

Do you know the exact number?

—> number employed

Don't know/Not sure = 98

Refused = 99

Logic Instructions (flow only):

QUESTION X1A

Now I'd like to ask about the oldest adult in your household, other than you.
Is this person male or female?

- 1 Male
- 2 Female
- 9 Refused

Logic Instructions (flow only):

QUESTION X1B

What is [ADULT]'S relationship to [NAME] ?

- Parent/Step-parent of
- Grandparent of
- Aunt/Uncle of
- Brother/Sister of
- Other relative of
- Legal guardian of
- Foster parent of
- Other non-relative of
- Don't know/Not sure
- Refused

Logic Instructions (flow only):

QUESTION X1C

How old was this person on [HIS/HER] last birthday?

—> years old

Age 85 or older = 85
Don't know/Not sure = 98
Refused = 99

Logic Instructions (flow only):
If (X1b.ROSTNUM = 1|X1b.ROSTNUM = 6) Skipto X1d
Skipto JumpX

QUESTION X1D

What is the highest year or grade of school [HE/SHE] has completed?

- 1 Some high school or less
- 2 High school graduate or G.E.D.
- 3 Some college or vocational school
- 4 Technical or vocational school graduate or assoc. degree
- 5 College graduate (4 year college degree)
- 6 Some post-graduate courses
- 7 Post graduate/Professional degree (MA,MS,PHD,JD,MD ETC)
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION X1E

Is [HE/SHE] currently... (READ RESPONSES)

INTERVIEWER: PROBE DON'T KNOW'S AND LIVING-AS-MARRIEDS:
What category do you think they fall into?

- 1 Married,
- 2 Divorced,
- 3 Widowed,
- 4 Separated, or
- 5 Never married?
- 8 Don't know (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

QUESTION X1F

What was [HE/SHE] doing MOST of last week... (READ RESPONSES)

- Employed full time,
Employed part time,
"Stay at home" parent
Going to school or
Something else?
With a job, but not at work temporarily (Vacation, ill)(DO NOT READ)
Unemployed, laid off, looking for work (DO NOT READ)
Retired (DO NOT READ)
Disabled/Unable to work (DO NOT READ)
Don't know/Not sure (DO NOT READ)
Refused (DO NOT READ)

Logic Instructions (flow only):

If (ans = 1) Skipto X1i
If (ans = 2) Skipto X1i
If (ans = 5) Skipto X1g
If (ans = 6) Skipto X1h
Skipto JumpX

QUESTION X1G

LAST WEEK was [HE/SHE] PRIMARILY unemployed, retired, unable to work, or something else?

- 1 With a job, but not at work temporarily (Vacation, ill)
- 2 Unemployed, laid off, looking for work
- 3 Retired
- 4 Disabled/Unable to work
- 5 Other
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto X1h
Skipto JumpX

QUESTION X1H

Does [HE/SHE] ordinarily work full or part time?

- 1 Full time
- 2 Part time
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION X1I

About how many persons are employed by [HIS/HER] employer? (READ RESPONSES)

- 1 Less than 5,
- 2 5 to 9,
- 3 10 to 24,
- 4 25 to 50,
- 5 50 to 100, or
- 6 More than 100?
- 8 Don't know/Not sure (DO NOT READ)
- 9 Refused (DO NOT READ)

Logic Instructions (flow only):

If (ans = 1) Skipto X1j
if (ans = 2) Skipto X1j
If (ans = 3) Skipto X1j
Skipto JumpX

QUESTION X1J

Do you know the exact number?

—> number employed

Don't know/Not sure = 98
Refused = 99

Logic Instructions (flow only):

If (HNUM = 1) Skipto INC

REPEAT QUESTIONS X1A TO X1J FOR EVERY ADULT IN THE HOUSEHOLD

QUESTION CARE

Thinking about all the adults in your household, who provides most of the daily care for [NAME] ?

Respondent
(lists age and sex of all other adult household members)...

Don't know/Not sure
Refused

Logic Instructions (flow only):

QUESTION INC

Was the TOTAL combined family income from ALL WAGE EARNERS during the past 12 months less than thirty thousand dollars, between thirty and sixty thousand, or over sixty thousand? Include money from all sources, not just wages and salaries . . . and before taxes and other deductions.

- 1 Less than \$30,000
- 2 Between \$30,000 and \$60,000
- 3 More than \$60,000
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (ans = 1) skipto INC1
If (ans = 2) Skipto INC2
If (ans = 3) Skipto INC3
If (ans = 8) Skipto ZIPC
If (ans = 9) Skipto ZIPC

QUESTION INC1

I am going to mention several income categories. When I mention the category that describes your total household income in the past 12 months, please stop me.

- 1 Less than 5 thousand
- 2 Between 5 and 10 thousand
- 3 Between 10 and 15 thousand
- 4 Between 15 and 20 thousand
- 5 Between 20 and 25 thousand
- 6 Between 25 and 30 thousand
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
Skipto SIZ1

QUESTION INC2

I am going to mention several income categories. When I mention the category that describes your total family income in the past 12 months, please stop me.

- 1 Between 30 and 35 thousand
- 2 Between 35 and 40 thousand
- 3 Between 40 and 45 thousand
- 4 Between 45 and 50 thousand
- 5 Between 50 and 55 thousand
- 6 Between 55 and 60 thousand
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
Skipto SIZ1

QUESTION INC3

I am going to mention several income categories. When I mention the category that describes your total family income in the past 12 months, please stop me.

- 1 Between 60 and 65 thousand
- 2 Between 65 and 70 thousand
- 3 Between 70 and 75 thousand
- 4 Between 75 and 80 thousand
- 5 Between 80 and 85 thousand
- 6 Between 85 and 90 thousand
- 7 Over 90 thousand
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

QUESTION SIZ1

Are there some household members who do not rely on this income for support?

- 1 No, income used to support all household members
- 2 Yes, income used to support only some household members
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):
If (answer = 2) Skipto SIZ2
Skipto ZIPC

QUESTION SIZ2

How many household members rely on this income for support?

—> household members

Don't know/Not sure = 98
Refused = 99

Logic Instructions (flow only):

QUESTION ZIPC

What is your ZIP code?

—>84

Don't know/Not sure = 998
Refused = 999

Logic Instructions (flow only):

QUESTION CNTY

In which county do you live?

| | |
|-----------|---------------------|
| Beaver | Rich |
| Box Elder | Salt Lake |
| Cache | San Juan |
| Carbon | Sanpete |
| Daggett | Sevier |
| Davis | Summit |
| Duchesne | Tooele |
| Emery | Uintah |
| Garfield | Utah |
| Grand | Wasatch |
| Iron | Washington |
| Juab | Wayne |
| Kane | Weber |
| Millard | Don't know/Not sure |
| Morgan | Refused |
| Piute | |

Logic Instructions (flow only):

QUESTION AGAN

Occasionally, other researchers in Utah need to locate people with certain health conditions or demographic characteristics for their research, for instance parents of children with special health care needs. Would it be alright for us to make your phone number available to researchers at the Department of Health or Utah Universities so they may ASK YOU to participate in their research?

INTERVIEWER: PROBE: You are not agreeing to participate. You may decline if you like once they ask you to participate.

- 1 Yes
- 2 No
- 8 Don't know/Not sure
- 9 Refused

Logic Instructions (flow only):

If (answer = 1) Skipto CbCk
Skipto Tyend

QUESTION CBCK

May I please get your first name so they'll know who to ask for?
(Can you spell that for me, please?)

Logic Instructions (flow only):

QUESTION TYEND

Thank you very much for taking time for this interview. Your answers will be helpful to us.

Press "1" to continue...

Logic Instructions (flow only):
Skipto IntID

QUESTION INTID

Enter your interviewer ID number.

—>

Logic Instructions (flow only):

QUESTION ENDS

You may enter interviewer notes in the window below.

Press ALT-N or use the mouse to select NEXT or ENTER twice to end interview.

This Interview Took

Minutes

Logic Instructions (flow only):

End = SYSTIME

Bibliography





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