

2004 Family Survey Summary Report



A comprehensive statewide need assessment of children with special health care needs and their families in North Dakota

Conducted by the Children's Special Health Services Unit,
Medical Services Division, ND Department of Human Services

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Purpose

The 2004 Family Needs Assessment Survey is one of many primary and secondary data collection efforts used as a part of the 5-year needs assessment process for the maternal and child health population in North Dakota for the MCH Block Grant. The purpose of the survey was to assess the health and related services needs of children with special health care needs and their families from a number of perspectives.

Methodology

The sample size included all children served by Children's Special Health Services between the dates of October 1, 2002 and February 29, 2004. Children residing in Minnesota or south Dakota who were served by CSHS were included in the survey, however, children who were known to be deceased, had moved out of state, or had no known mailing address were not included.

If there were more than one child in a family served by CSHS, only one survey was mailed to the family and the parent was instructed to fill out the survey on behalf of the child they considered to have the most serious health problems.

If the CSHS client was age 18 or older, the survey was mailed to them rather than their parent and the client was encouraged to fill out the survey on their own.

If a completed survey was filled out for more than one child, the survey was considered a completed survey but demographic information for the children was not included.

1,528 surveys were sent out. If a survey was returned with a change of address, the survey was re-mailed to the new address, except if the new address was out of state. Of the 1,528 surveys sent out, 55 were returned that could not be forwarded leaving a remaining total of 1,473.

The survey instrument was modeled after a similar survey conducted in 1999. Where possible, results from this survey were compared to results from the earlier survey.

Response Rate

Of the 1,473 surveys sent out, 438 surveys were returned (5 surveys were returned but were not filled out) for a total of 433 completed surveys. This represents a 29.4% response rate, an increase from 25.9% in 1999.

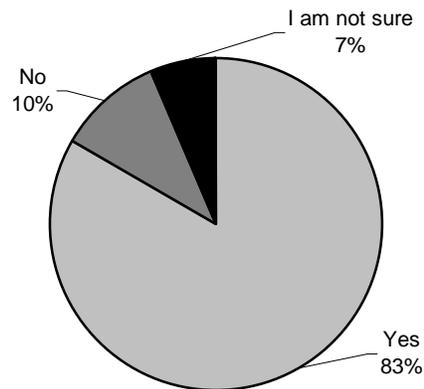
Results

Section I: Child Health Status

Respondents were asked to review a list of diagnosis and check all that applied to their child. The most common diagnosis checked was heart condition (43.4%) followed by allergies (15.7%), cleft lip and/or palate (12.9%) and asthma/respiratory (12.7%).

More than eighty-three percent of respondents indicated they felt that all of their child's health care needs were being met, similar to the response in the 1999 survey. Ten percent indicated that all of their child's health needs were not being met and seven percent were not sure. (Chart 1)

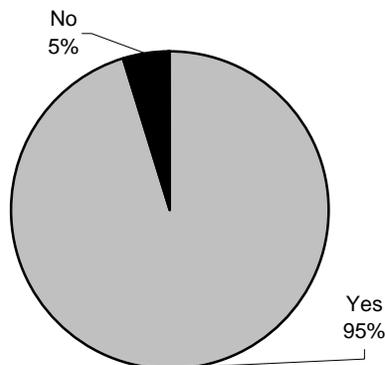
Chart 1: Parent's Perceptions That All Of Child's Health care Needs Were Being Met



Section II: Satisfaction

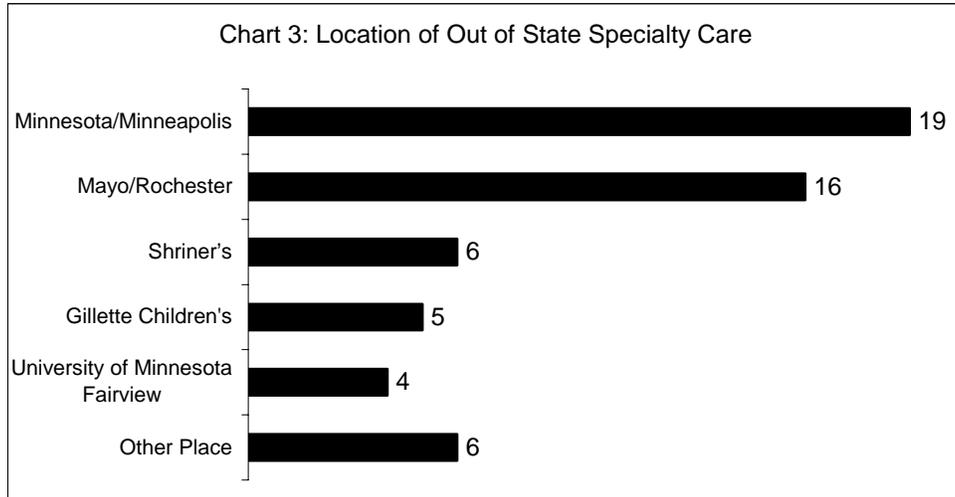
More than ninety-five percent of respondents indicated that, as parents, they have been satisfied with the involvement they have had with their child's health care team in making decisions about what care was being provided to their child (Chart 2).

Chart 2: Parent's Satisfaction with Involvement in Child's Health Care Team

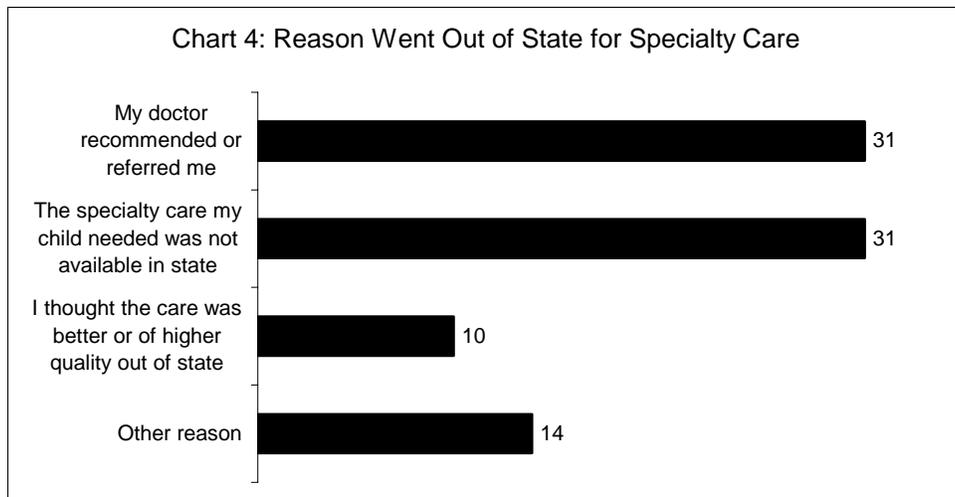


Nearly one in seven respondents (14.5%) indicated that during the past 12 months they had gone out of state to obtain specialty care for their child, slightly higher than the percent in the 1999 survey.

Of the respondents who answered “Yes”, when asked to indicate where they went for the out of state for care, nineteen wrote in “Minnesota” or “Minneapolis” and sixteen wrote in “Mayo” or “Rochester” (Chart 3).



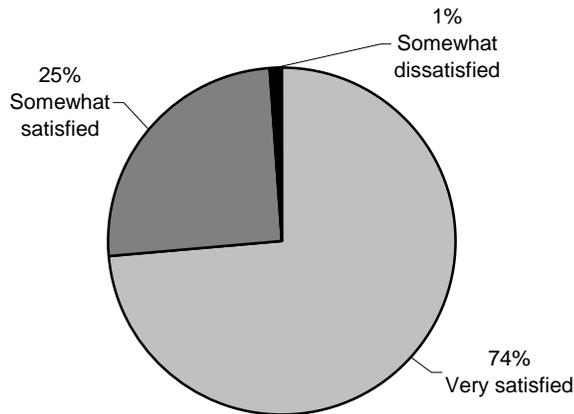
Of those that went out of state, thirty-one said their doctor recommended the out of state care or referred them and thirty-one said that the specialty care their child needed was not available in state. Ten said they thought the care was better or of higher quality out of state (Chart 4).



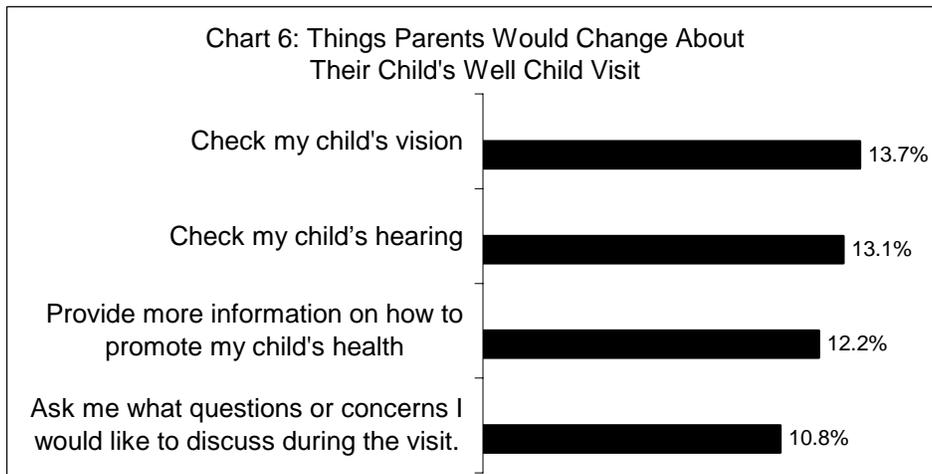
More than three-fourths of respondents indicated their child received routine or preventive care such as a well child check up during the past 12 months. A similar question in the 1999 survey found 52.5 percent of children had received a well child check up. However, since the former survey referred only to well child checkups, comparison of responses between the two surveys is not valid.

Of those that indicated their child had a well child check up, nearly three-fourths said they were very satisfied and one-fourth were somewhat satisfied with the check up. (Chart 5)

Chart 5: Satisfaction with Child's Well Child Check Up

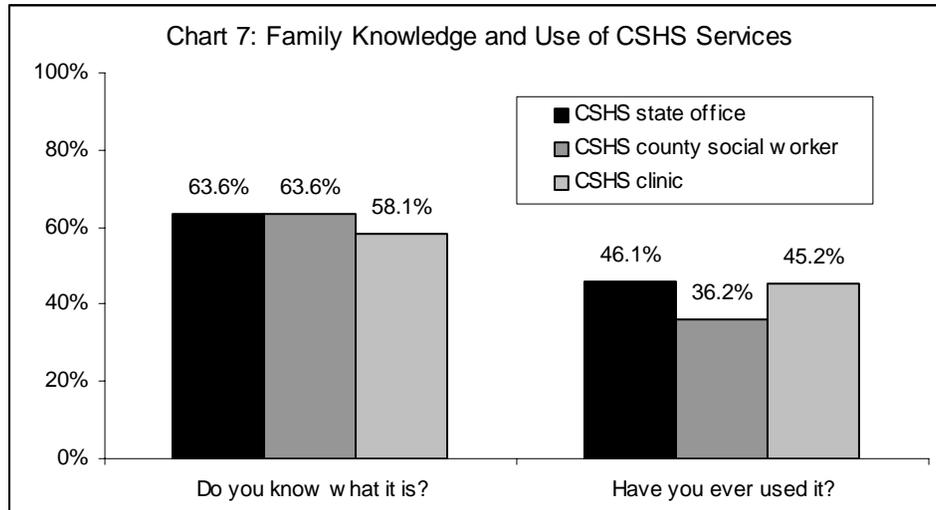


When asked what one thing they would change about their child's well child visit, fourteen percent said they would have wanted to have their child's vision checked and thirteen percent their hearing checked. Twelve percent would have like more information about things to expect before the next visit and eleven percent would have like to have been asked what questions or concerns they would like to discuss during the visit (Chart 6)

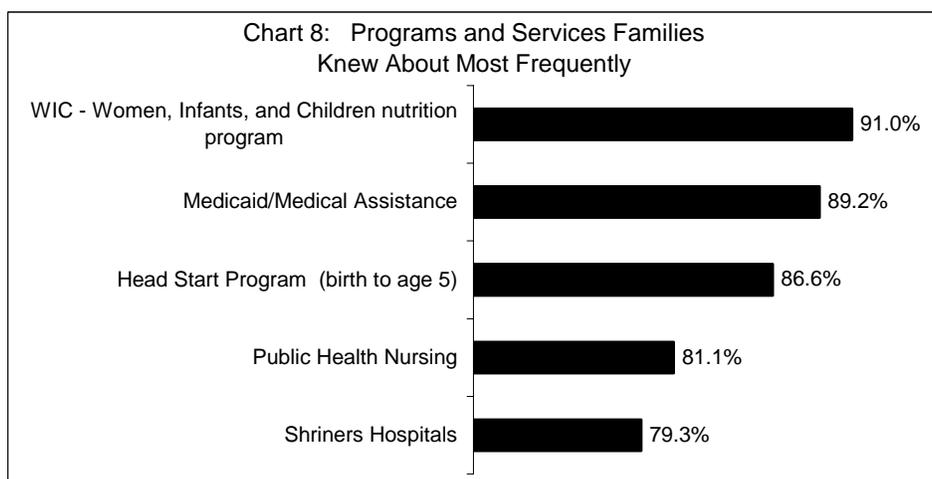


Section III: Community Programs and Services

Survey respondents were provided a list of community programs and services and asked to check whether they knew what it was and if they had ever used it. Generally, a higher percentage of respondents to the 2004 survey were aware of most of the programs and services than respondents in the 1999 survey. Although all respondents had children served by CSHS, fewer than half reported ever having used the CSHS state office, county social worker, or clinic. (Chart 7)



Of all the programs and services listed, more than ninety percent of respondents reported having heard of the WIC program and nearly ninety percent the state Medicaid program. (Chart 8)



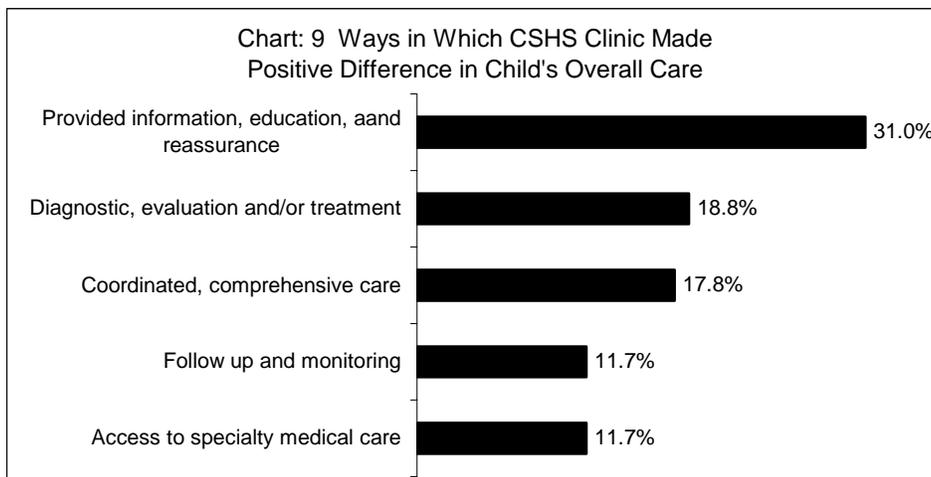
Nearly two-thirds of respondents indicated they found out about health and other services that are available to their child and family from health professionals (62.4%) followed by a community agency (43.2%).

Section IV: Children’s Special Health Services Program

When asked to write in the type of multidisciplinary clinic or specialty program administered or sponsored by CSHS that their child attended, nearly one-third of the respondents did not answer the question, and nearly one-fourth wrote in another type of clinic (i.e. name of facility or health system). Of those that did indicate their child attended a clinic, eighteen percent attended the Cardiac Care for Children Program, 11.5 percent a cleft lip/palate clinic, and nine percent a scoliosis clinic.

More than nine in ten (91.3%) of respondents indicated they felt the clinic or clinics made a positive difference in their child’s overall care. This compares to 86.2% who answered “Yes” on the 1999 survey.

Of those that indicated the clinic made a positive difference for their child, 31 percent felt the clinic provided information, education, or reassurance, 19 percent diagnostic/evaluation and/or treatment, and 18 percent coordinated/comprehensive care. (Chart 9)

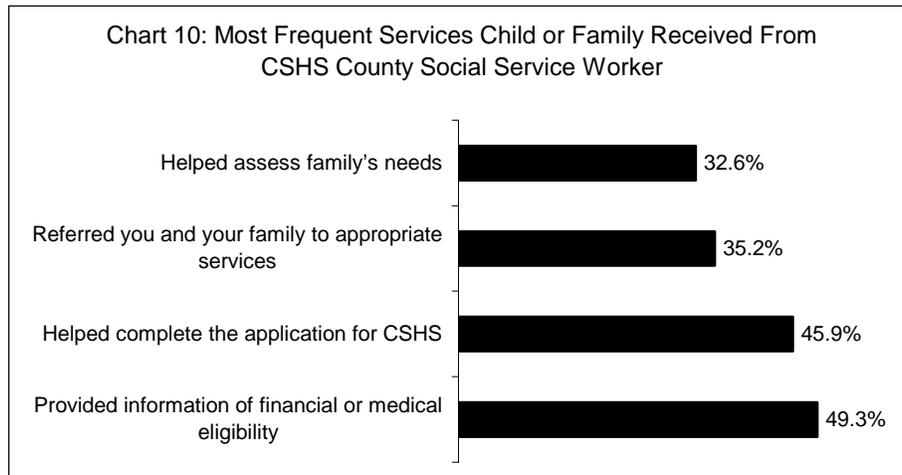


Ninety-seven percent of respondents indicated they were satisfied with the services their child received at the clinic or clinics. In 1999, 93% said they were satisfied with the services their child received at the clinic and 7% were not satisfied.

Nineteen percent of respondents indicated they were aware that CSHS had a toll-free number. This is less than the 21 percent who indicated they were aware of the CSHS toll-free number in the 1999 survey.

Fifteen percent of respondents indicated they had called the CSHS toll-free-number. In the 1999 survey, 14 percent of respondents indicated they had called the toll-free number. Of the respondents who had called the toll-free number, 91 percent indicated they were satisfied with the response they received.

Of the respondents who indicated they had contact with a CSHS county social service worker, nearly half said the county worker provided information on financial or medical eligibility. Forty-six percent said the county worker helped them complete the application for CSHS and more than one-third said the county worker referred them or their family to appropriate services (Chart 10)



Eighty-six percent of respondents indicated they were satisfied with the services they received from the CSHS county social services worker compared to 83 percent in 1999.

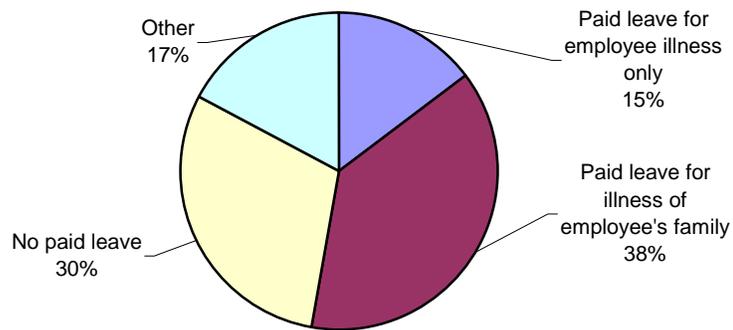
Section V: Family Impact

Six of seven respondents (87%) indicated they were able to access childcare or daycare for their child with special health care needs when they needed it during the past year. 147 respondents indicated childcare or daycare was not applicable to their child because it was not needed, a parent provides care for the child, or the child was too old for childcare/daycare.

Nearly forty percent of respondents indicated they or their spouse had missed 1 to 5 workdays in the past year due to their child's special health care needs. Ten percent missed 6 to 10 days and another ten percent said they missed more than 10 workdays.

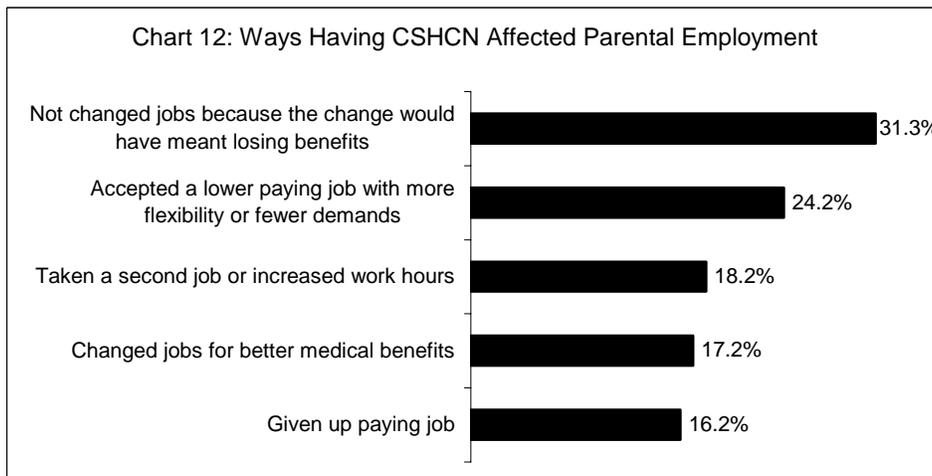
Of the primary care takers of CSHCN who were employed outside the home, three in ten had no paid leave and another fifteen percent paid leave for illness of the employee only. Only 38% had paid leave for illness of the employee's family (Chart 11)

Chart 11: Primary Caretaker of CSHCN's Employer's Policy Regarding Absences



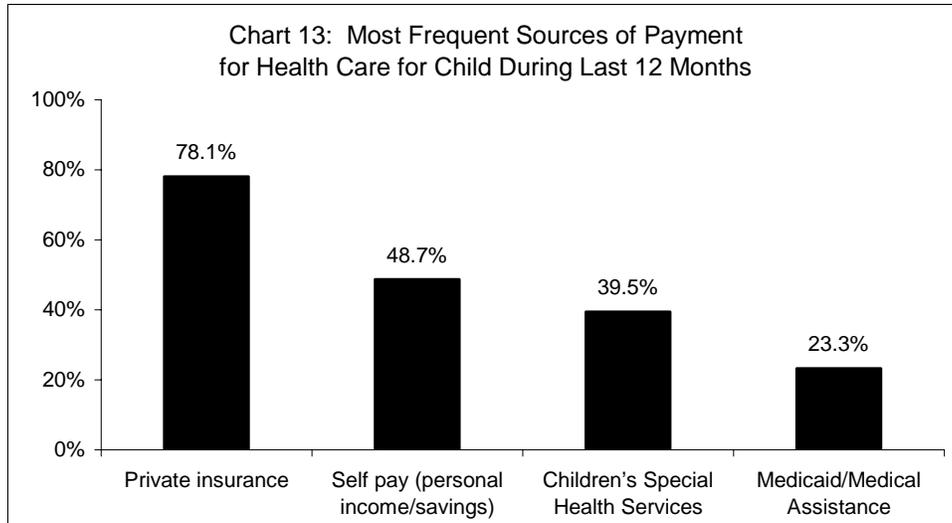
One-fourth of respondents indicated having a child with special health care needs had affected their employment. Of those, more than thirty percent said they had not changed jobs because the change would have meant losing benefits and nearly one-fourth said they had accepted a lower paying job with more flexibility or fewer demands. Also, nearly one-fourth of parents said they had either given up a paying job or lost a job due to their child health needs.

Chart 12: Ways Having CSHCN Affected Parental Employment

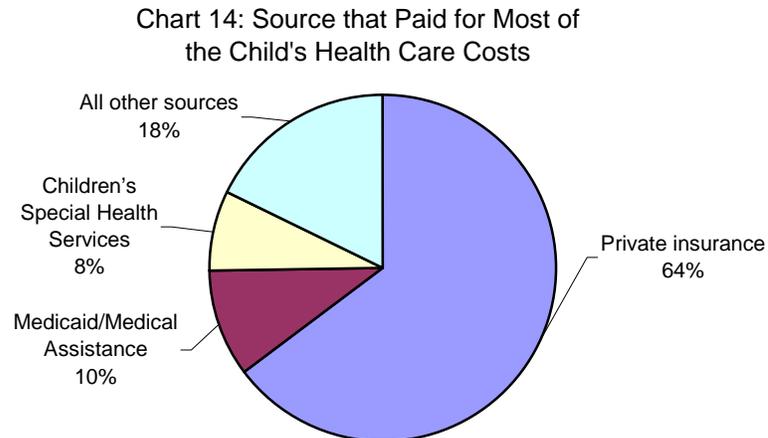


Section VI: Health Care Costs and Financing

Of the survey respondents, seventy-eight percent said private insurance was a source of payment for their child's health care followed by self pay (48.7%), CSHS (39.5%), and Medicaid/Medical Assistance (23.3%). (Chart 13)



When asked which one of the sources paid for most of the health care needed by their child, nearly two-thirds (64.7%) said that private insurance paid for most of their child's health care. Ten percent indicated Medicaid/Medical Assistance paid for most of their child's care followed by CSHS (7.6%). (Chart 14)

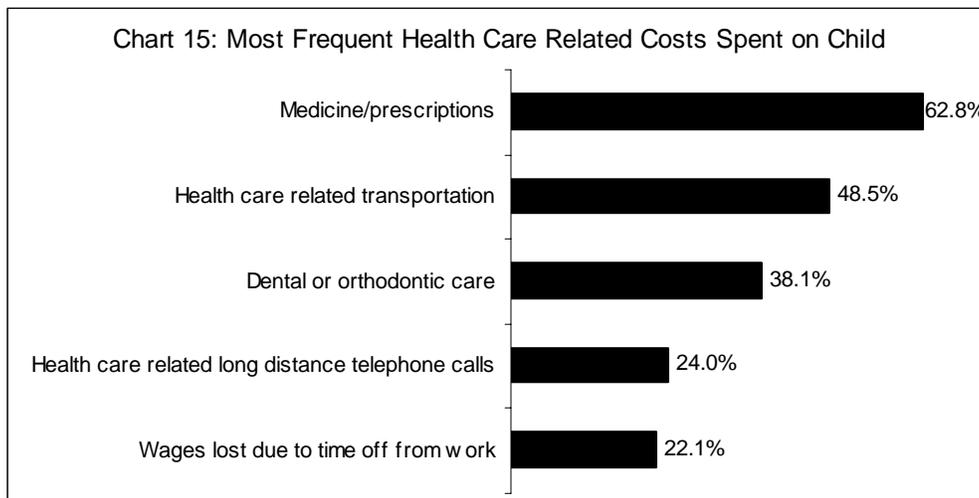


Two-thirds of respondents indicated they paid out of pocket costs for co-pays during the last 12 months. Sixty-four percent paid for insurance premiums out of pocket and fifty-seven percent for deductibles

More than half of respondents indicated their child’s source of health care coverage did not pay for all of the health care services needed by their child. Of those, the most frequent responses were dental/orthodontic care (32.1%), vision exams/glasses (30.3%), and prescription medications (27.0%).

One-third the respondents indicated they felt they were not able to pay for the financial costs resulting from their child’s health care concerns. More than forty percent indicated the amount they have paid out-of-pocket for their child’s health care expenses been a financial hardship on their family’s budget.

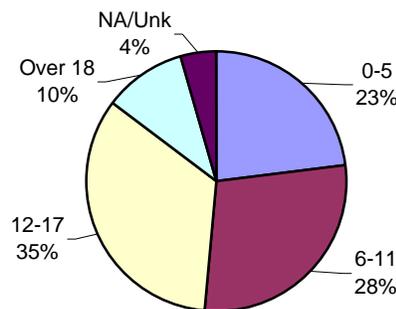
Medicine and prescriptions was the most frequently mentioned health care related cost that was spent out of pocket on their child during the last 12 months. Nearly half had costs for health care related transportation and more than one-third for dental or orthodontic care. (Chart 15)



Section VII: Family & Child Demographic Information

One-third of the children for whom the survey was completed were between age 12 and 17. Twenty-two percent were under age 6, twenty-eight percent age 6 through 11, and ten percent age 18 or older. (Chart 16)

Chart 16: Percentage of Children by Age Group

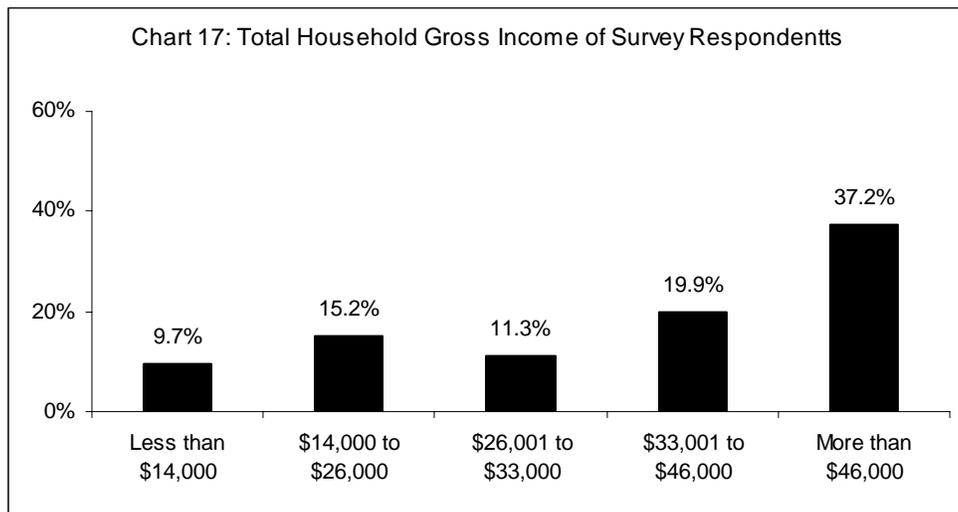


Fifty-one percent of the children for whom the survey was completed were girls and 45 percent were boys.

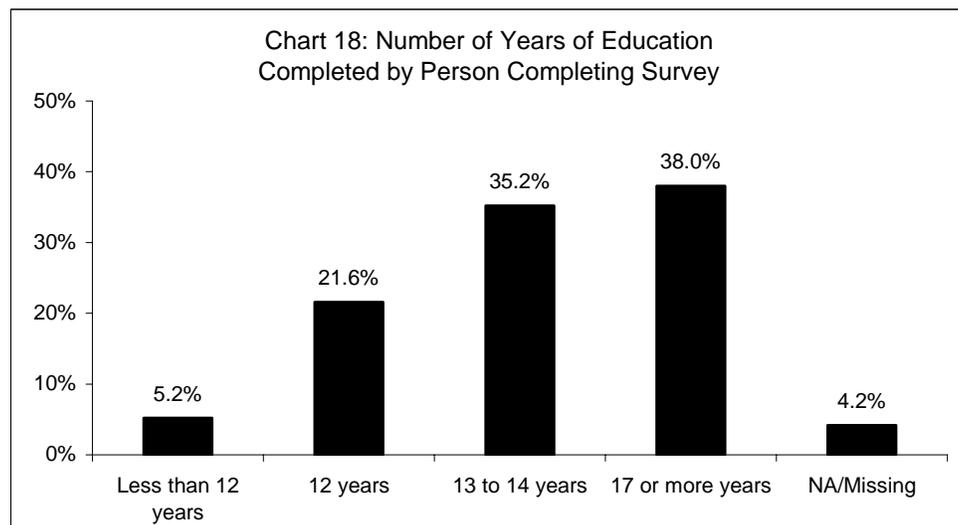
Ninety percent of the children for whom the survey was completed were White and only 3.5 percent Native American.

Nineteen percent of the survey respondents indicated they had one or more other children living in their home who had a special health need.

One in ten survey respondents (9.7%) had a household gross income of less than \$14,000 and another fifteen percent an income between \$14,000 and \$26,000. (Chart 17)



Nearly eighty percent of the respondents who completed the survey were married. Thirty-eight percent of respondents had completed seventeen or more years of education and thirty-five percent 13 to 14 years. Only five percent had less than a high school education. (Chart 18)



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