

# 2004 Family Survey Executive Summary



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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## **Background and Methods**

- The CSHS Unit in the Medical Services Division conducted a family survey in the spring of 2004.
- The survey was one of several data sources used for the 5-year Title V needs assessment for the MCH Block Grant.
- The purpose of the survey was to assess the health and related service needs of children with special health care needs and their families served by the CSHS program.
- 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.
- The survey was mailed to all children served by CSHS between October 1, 2002 and February 29, 2004.
- 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.

## **Child Health Status**

- The most common diagnosis checked were heart condition, followed by allergies, cleft lip and/or palate, and asthma/respiratory.
- Five in six respondents (83.4%) felt all of their child's health care needs were being met.

## **Satisfaction**

- More than 95% of respondents indicated 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.
- One in seven respondents (14.5%) indicated they had gone out of state to obtain specialty medical care. Most respondents listed Minnesota, Minneapolis, Mayo, or Rochester as the place they went out of state. Unavailability of the specialty care needed in state or a referral or recommendation from the child's doctor were the two most common reasons given for going out of state.
- Three-fourths of respondents indicated their child received routine or preventive care such as a well child visit during the least year. Of those, three-fourths were very satisfied with their child's well child check up and one-fourth said they were satisfied.

## **Community Programs and Services**

- About six in ten respondents indicated they knew about the CSHS state office, county social worker, or clinics. The programs respondents knew about most often were: WIC (91%), Medicaid (89%), Head Start (87%), Public Health Nursing (81%), and Shriner's Hospitals (79%).
- Health professionals (62%) and community agencies (43%) were the two most common sources of information about health and other services available to their child and family.

## **Family Impact**

- One in eight respondents (13%) indicated they were not able to access childcare or daycare for their child when they needed it over the last year.
- Twenty percent of respondents indicated they or their spouse missed more than 5 workdays due to their child's special health needs during the last year.
- More than one-fourth of the primary caretakers said their employer offered no paid leave and another 13% said their employer offered paid leave, but for employee illness only.
- One-fourth of respondents said that having a child with special health care needs had affected their employment. Of those whose employment had been affected, 31% had not changed jobs because the change would have meant losing benefits, and 24% accepted a lower paying job with more flexibility or fewer demands.

## **CSHS Program**

- Eighteen percent of respondents indicated they attended a cardiac clinic, 12% a cleft lip/palate clinic, and 9% a scoliosis clinic.
- More than 95% of those who attended a clinic were satisfied with the services their child received at the clinic and 91% indicated the clinic made a positive difference in their child's overall care.
- The ways the clinic made a positive difference mentioned most often were: provided information/education/reassurance, provided diagnostic/evaluation and/or treatment, and provided coordinated/comprehensive care.
- Nineteen percent of the respondents knew of the CSHS toll-free number and 14% said they had called the number. Of those who said they called the toll-free number, 91% said they were satisfied with the response they received.
- Just over half of the respondents had contact with a CSHS county social services worker. The most common service they or their child received from the county worker were: provided information on financial or medical eligibility (49%), helped complete the

application for CSHS (46%), referred them or their family to appropriate services (35%), and helped assess family needs (33%).

- Eighty-six percent indicated they were satisfied with the services they received from the CSHS county social service worker.

### **Health Care Costs and Financing**

- The most frequently mentioned source of payment for their child's health care was private insurance (78%). The second most common source was self-pay, such as from personal income or savings (49%), followed by CSHS (40%), and Medicaid (23%).
- The source that paid for most of the health care needed by their child was private insurance (65%) followed by Medicaid (10%), CSHS (8%), and self-pay (5%).
- The most frequently mentioned out-of-pockets costs paid during the last year were co-pays (68%), insurance premiums (64%), and deductibles (54%).
- Sixty percent of respondents said that their source of health care coverage did not pay for all of the health care services needed by their child during the last year. The most common services their health care coverage source did not pay for were dental/orthodontic care (32%), vision exams/glasses (30%), and prescription medications (27%).
- One third of respondents indicated that at the present time they were not able to pay for the financial costs resulting from their child's health care concerns.
- The most frequently mentioned out of pocket costs were medicine/prescriptions (63%), health care related transportation (49%), and dental or orthodontic care (38%).
- More than forty percent said that the amount they have paid out of pocket for their child's health care expenses had been a financial burden.

### **Demographic**

- Twenty-four percent of the children were under age 5, 30% age 6 through 11, 35% age 12 through 17, and 11% age 18 or older.
- Forty-seven percent of the children were boys and 53% girls.
- Ninety-four percent of the children were White, 4% American Indian, and 2% multi-racial or another race.
- Nearly one in five respondents indicated they had another child living in their home that also had special health care needs.
- Eighty percent of the respondents were married.

- Twenty two percent of the respondents had graduated from high school and another 73% had attended or graduated from college.
- Thirty seven percent of respondents lived in Burleigh, Cass, Grand Forks or Ward County, 45% another North Dakota county, and 18 % were out of state or did not indicate a ND county of residence.

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