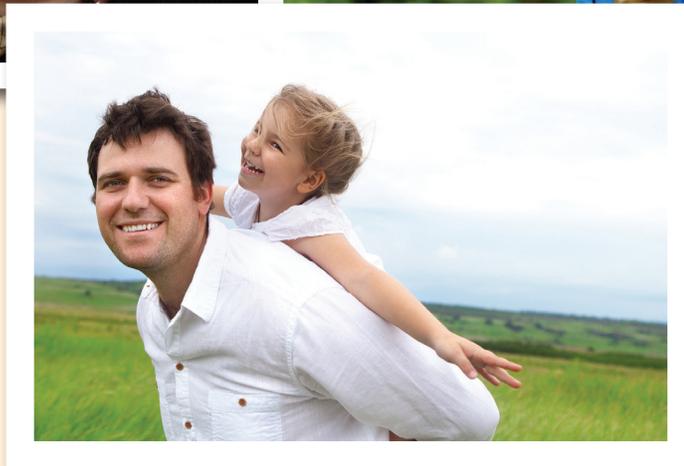


Overview of Children with Special Health Care Needs in North Dakota



NORTH DAKOTA
DEPARTMENT *of* HEALTH
Children's Special Health Services

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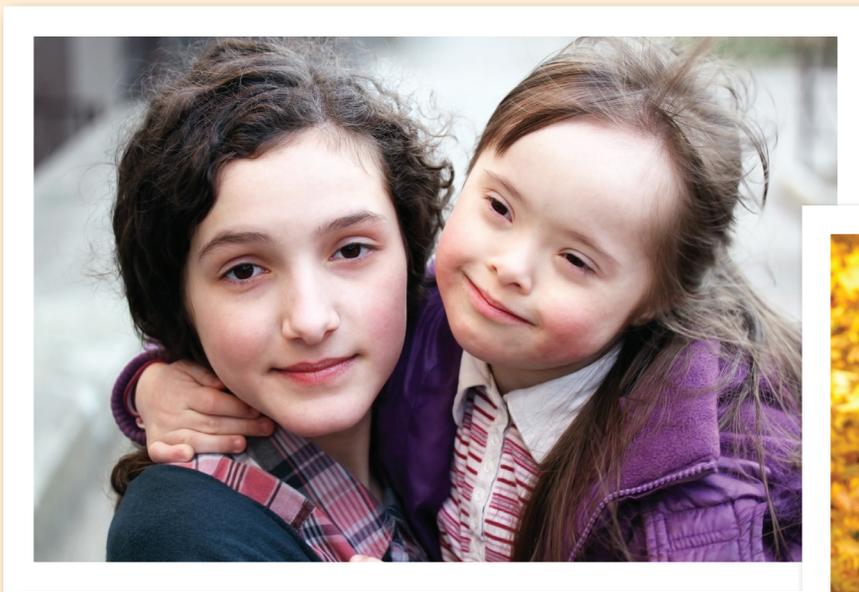
INTRODUCTION

This report provides findings from the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). Topics included in this report are the Prevalence of North Dakota's CSHCN, Health Insurance Coverage, Access to Care, Family-Centered Care, Care Coordination, Impact on Family and Maternal and Child Health (MCH) Core Outcomes.

Definition of Special Health Care Needs: The Maternal and Child Health Bureau (MCHB) define children with special health care needs as "... those who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally."

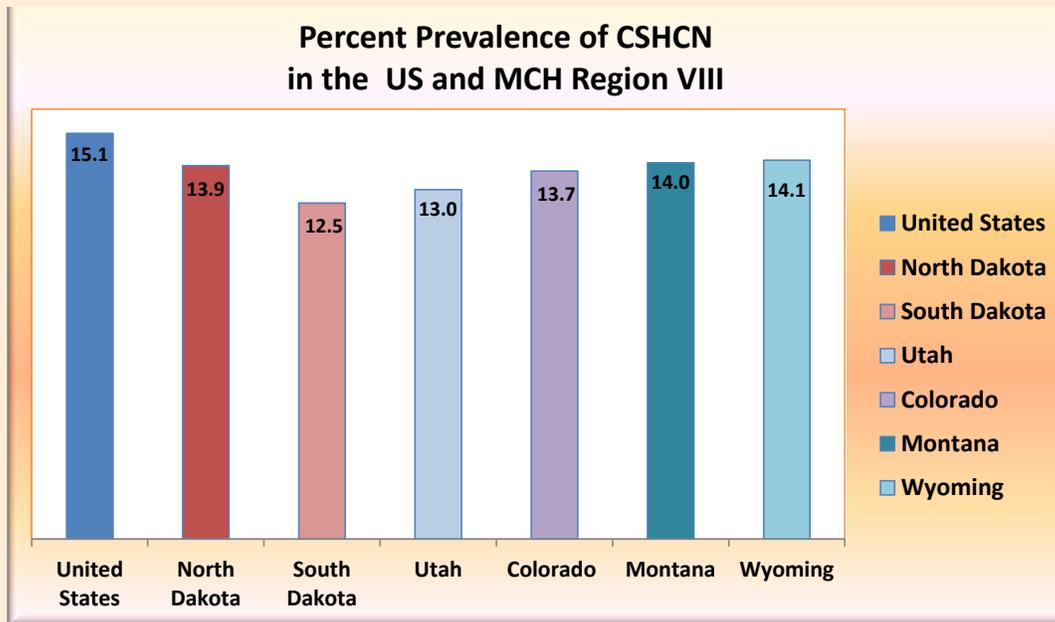
PREVALENCE

- ◆ The rate of CSHCN in North Dakota increased from 12.2 percent (an estimated 16,541 children) in 2005/2006 to 13.9 percent (an estimated 19,748 children) in 2009/2010.
- ◆ In 2009/2010, North Dakota had the third highest rate of children with special health care needs among the Health and Human Services Region VIII states.
- ◆ All six states in Region VIII have lower prevalence rates of children with special health care needs than the national rate of 15.1 percent, with rates ranging from 12.5 percent to 14.1 percent.



NORTH DAKOTA'S CSHCN POPULATION

- ◆ In North Dakota, teenagers (ages 12 through 17) had the highest rate of special health care needs (19%) followed by children ages 6 through 11 (15.6%). The youngest age group (birth through age 5) had the lowest rate of special health care needs (7.5%) in North Dakota.
- ◆ Special health care needs were more prevalent among boys (17%) than among girls (10.8%). Special health care needs were less prevalent among Hispanic children (12.4%) than non-Hispanic children (13.8%).
- ◆ Children in North Dakota with family incomes 0 to 99 percent of the federal poverty level (FPL) had the highest rate of special health care needs (18.3%) and families raising CSHCN at 100 to 199 percent of the FPL had a higher rate in North Dakota (16.4%) compared to (15.4%) in the nation. The rate of special health care needs was the lowest among children with family incomes 200 to 399 percent of the FPL (12.3%).



Prevalence By Demographics of CSHCN (%)	ND	US
Percent of Children with Special Health Care Needs (CSHCN)	13.9	15.1
Prevalence of children 0 through 5 years of age	7.5	9.3
Prevalence of children 6 through 11 years of age	15.6	17.7
Prevalence of children 12 through 17 years of age	19.0	18.4
Percent of CSHCN that are male	17.0	17.4
Percent of CSHCN that are female	10.8	12.7
Percent of families raising CSHCN at 0%-99% Federal Poverty Level	18.3	16.0
Percent of families raising CSHCN at 100%-199% Federal Poverty Level	16.4	15.4
Percent of families raising CSHCN at 200%-399% Federal Poverty	12.3	14.5
Percent of families raising CSHCN at 400% Federal Poverty Level or greater	12.8	14.7
Percent of CSHCN who are Non-Hispanic	13.8	16.2
Percent of CSHCN who are Hispanic	12.4	11.2
Percent of CSHCN who are White	13.8	16.3
Percent of CSHCN who are Black	12.5	17.5
Percent of CSHCN who are of Multiple Races	14.9	13.6
Percent of Hispanic CSHCN of an English-Speaking Household	14.1	14.4

HEALTH INSURANCE COVERAGE

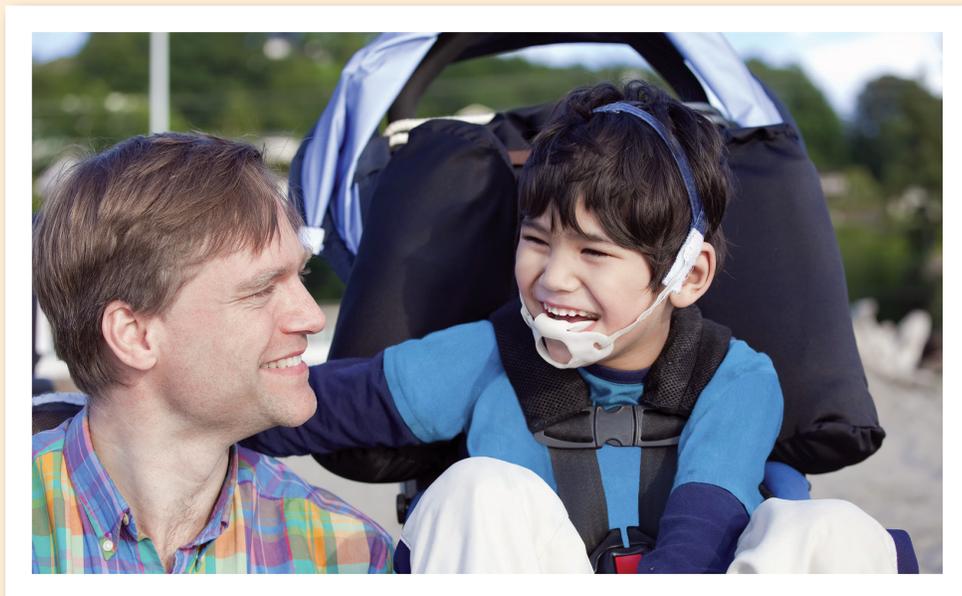
- ◆ Health insurance is essential to access care for children with special health care needs.
- ◆ Without health insurance, children are more likely to go without necessary preventative health care. When children are sick, acute care can leave families with overwhelming medical bills.

Health Insurance Coverage of CSHCN (%)	ND	US
Without insurance at some point in past year	7.3	9.3
Without insurance at time of survey	3.1	3.5
Whose insurance is inadequate	35.9	34.3
Whose insurance benefits sometimes / never meet child's needs	10.5	13.2
Whose non-covered charges are sometimes / never reasonable	30.6	28.7
Whose insurance sometimes / never allows child to see needed providers	8.0	10.5

ACCESS TO CARE

- ◆ Children with special health care needs require a broad range of services, from primary and specialty medical care to prescription medications, medical equipment, and therapies.
- ◆ In addition to the needs of the child, families of CSHCN may need additional services, such as respite care, family counseling or genetic counseling.
- ◆ In North Dakota, there has been a significant increase in CSHCN without a usual source of care when sick or who rely on emergency room service (from 6.3 percent in 2005/2006 to 12 percent in 2009/2010.)

Access to Care for CSHCN (%)	ND	US
With any unmet need for specific healthcare services	15.5	23.6
With any unmet need for family support services	6.3	7.2
Without a usual source of care when sick (or rely on the emergency room)	12.0	9.5
Without a personal doctor or nurse	4.5	6.9
Needing a referral who have difficulty getting it	21.8	23.4



FAMILY-CENTERED CARE

- ◆ Family-centered care is an approach to the planning, delivery and evaluation of health care whose cornerstone is active participation between families and professionals. Family-centered care was measured using core elements of time spent, listening, information, sensitivity and partnering.
- ◆ There were 31.5 percent CSHCN in North Dakota without family-centered care compared to 35.4 percent in the nation in 2009/2010.

Family-Centered Care for CSHCN (%)	ND	US
Without family-centered care	31.5	35.4
Whose doctors never / sometimes spend enough time with child	21.1	22.5
Whose doctors never / sometimes listen carefully	11.8	12.3
Whose doctors are never / sometimes sensitive to family's values	8.3	11.1
Whose doctors never/sometimes help you feel like partners	8.7	13.0
Whose doctors/providers never/sometimes provide information	15.7	17.6

CARE COORDINATION

- ◆ Care Coordination for children with special health care needs is a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of children.
- ◆ Overall, 40.5 percent of CSHCN in North Dakota did not receive effective care coordination that met all components of care coordination, compared to 44 percent of CSHCN in the nation.

Care Coordination for CSHCN (%)	ND	US
Needing a referral who has difficulty getting it	21.8	23.4
Whose families had no help with coordinating child's health care	36.1	42.2
Whose families reported dissatisfaction with communication among child's doctors, when needed	37.7	37.3
CSHCN who did not receive effective care coordination	40.5	44.0

IMPACT ON FAMILY

- ◆ Having a child with special healthcare needs can affect a family's finances and employment status. The demands on families may require that parents cut down their work hours or give up a job, at the same time as they may face burdensome out-of-pocket health care costs.
- ◆ There was an increase in families paying \$1,000 or more in personal medical expenses from 21.9 percent in 2005/2006 to 26.7 percent in 2009/2010.

Impact on Family of CSHCN (%)	ND	US
Whose families pay \$1,000 or more out of pocket medical expenses per year for the child	26.7	22.1
Whose condition caused financial problems for the family	22.2	21.6
Whose families spend 11 or more hours per week providing or coordinating child's health care	10.1	13.1
Whose condition cause family members to cut back or stop working	21.6	25.0

Maternal Child Health (MCH) CORE OUTCOMES

MCH Core Outcomes (%)	ND	US
#1: CSHCN whose families are partners in shared decision-making for child's optimal health	75.0	70.3
#2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home	47.8	43.0
#3: CSHCN have consistent and adequate public or private insurance	60.1	60.6
#4: CSHCN who are screened early and continuously for special health care needs	66.8	78.6
#5: CSHCN who can easily access community-based services	67.9	65.1
#6: CSHCN youth receive services needed for transition to adulthood	46.5	40.0

SURVEY METHODOLOGY

Survey Methods in Screening for Special Health Care Needs: The survey screening questions include five stem questions about general health care needs that could be the consequence of chronic health conditions. If a child currently experiences one of these consequences, follow-up questions determine whether this health care need is the result of a mental, behavioral or other health condition, and whether the condition has lasted or is expected to last for 12 months or longer. Those with affirmative answers to the stem and both follow-up questions are considered to have a special health care need.

The NS-CSHCN was first conducted in 2001. The second survey, conducted in 2005/2006, was designed to produce prevalence estimates of CSHCN using standard screening questions to describe the types of services CSHCN need and use, and to assess areas of improvement in the system of care for CSHCN. The third National Survey of CSHCN was conducted in 2009/2010, which added the benefit of comparisons over time. In North Dakota, a total of 3,886 households were interviewed, screening 7,748 children for special needs. This resulted in 797 full-length completed special needs interviews.

REFERENCES

1. 2009/2010 National Survey of Children with Special Healthcare Needs – <http://www.childhealthdata.org/browse/survey>
2. State and Local Area Integrated Telephone Survey (SLATIS) – <http://www.cdc.gov/nchs/slaits/cshcn.htm>



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To view this fact sheet or other reports about CSHCN online, go to www.ndhealth.gov/cshs/cshs.html.