

Children with Special Health-Care Needs in North Dakota

Using Data from the 2009-2010 National Survey of Children with Special Health-Care Needs



A Report for
Policymakers, Advocacy Groups and Families

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Introduction

This report is designed to assist key stakeholders – policymakers, advocacy groups, community-based organizations, and parents – in understanding the health and well-being of children with special health-care needs (CSHCN) in North Dakota. While the health needs of many CSHCN in the state are being met, and improvements have been made through policy reform, programmatic development and implementation, and family advocacy, many challenges still exist.

In North Dakota, approximately one in seven children (13.9%) has special health-care needs, according to the 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN)¹. The definition of special health-care needs is broad and inclusive and emphasizes the common characteristics among CSHCN in order to give a consistent source of national and state data on the health status of CSHCN. Its purpose is to guide the development of family-centered, coordinated systems of care for children with special needs and their families served by the state Title V block grants administered by the Maternal and Child Health Bureau.¹⁰

The central focus of the NS-CSHCN is to assess progress towards a comprehensive, family-centered, community-based, coordinated system of care for CSHCN, as measured by the Maternal and Child Health Bureau's six Core Outcomes- namely whether CSHCN (1) families partner in shared decision-making, (2) receive coordinated care within a medical home, (3) families have adequate health insurance, (4) are screened early and continuously for special health-care needs, (5) have access to community-based services, and (6) receive services for transition to adulthood. The survey also evaluates the impact among CSHCN families in regard to out-of-pocket medical expenses, financial problems, time required for child's care, and addresses specific types of health-care needs and chronic conditions.

Information in this report comes from the 2009-2010 NS-CSHCN database¹ and Child and Adolescent Health Measurement Initiative (CAHMI) website⁹. Staff from the Data Resource Center for Child and Adolescent Health provided technical assistance of these data throughout the project development. Trend data from the 2005-2006 NS-CSHCN² and the 2001 NS-CSHCN³ was utilized when available and appropriate. Analyses were performed using the Statistical Package for the Social Sciences (SPSS)¹¹.

Section 1 of the report provides an overview of CSHCN in North Dakota, including prevalence as compared to the nation and among non-CSHCN where available, according to key characteristics: age, sex, race/ethnicity and income status. This section also offers a summary of the health and functioning of CSHCN and the range of conditions and limitations experienced.

In Section 2, North Dakota's performance on each of the six Maternal and Child Health Bureau (MCHB) Core Outcomes and outcome subcomponents are compared to national results. This section highlights key differences among and between CSHCN along five key subgroups: age, race/ethnicity, income level, insurance status and type, and qualifying type of special needs. The report is supplemented with appendices explaining the methodology of the NS-CSHCN and analytical processes used in this report, detailed data tables comparing North Dakota to Region VIII and the nation, and maps showing North Dakota's performance on each of the MCHB Core Outcomes in the context of surrounding states and the nation.

The Maternal and Child Health Bureau (MCHB) defines children with special health-care needs (CSHCN) as children having or at “increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”.¹⁰ In this report, we assigned CSHCN into four mutually exclusive subgroups in order to examine system performance for children with different underlying types of special needs: 1) Rx meds only 2) elevated or above routine services use 3) elevated services use and Rx meds and 4) functional limitations.

Executive Summary

Prevalence and Demographics of CSHCN in North Dakota and Nationwide

- ▶ Approximately 20,000 children in North Dakota, 13.9 percent of all children younger than 18, have special health-care needs as defined by the Maternal and Child Health Bureau (MCHB), based on findings of the 2009-2010 National Survey of Children With Special Health-Care Needs (NS-CSHCN).
- ▶ The prevalence of Children with Special Health-Care Needs (CSHCN) in North Dakota (13.9%) is slightly lower than nationwide (15.1%), but the difference is not statistically significant.
- ▶ The prevalence of CSHCN in North Dakota increased slightly between 2005-2006 (12.2%) and 2009-2010 (13.9%).
- ▶ Compared to children without special health-care needs, CSHCN in North Dakota are more likely to be male (61.7% of CSHCN vs. 48.8% of non-CSHCN) and school-aged (81.1% of CSHCN vs. 62.3% of non-CSHCN).
- ▶ Among CSHCN in North Dakota, a majority are between the ages of 12 through 17 (46.3%).
- ▶ The majority of CSHCN in North Dakota are white, non-Hispanic (79.3%), with American Indian equating to nearly 10 percent (9.7%), and all other races equaling 11.0 percent.

Access and Health Characteristics of CSHCN in North Dakota

- ▶ Compared to the U.S. overall, North Dakota has a lower percentage of CSHCN without insurance at time of the survey (3.1%) or at any point during the past year (7.3%).
- ▶ However, a higher percentage of CSHCN families reported that their insurance is inadequate (35.9%) and that their non-covered charges are sometimes/never reasonable (30.6%).
- ▶ Compared to the U.S. overall, North Dakota has a higher percentage of CSHCN whose health conditions are managed by a combination of prescription medication and specialized services or therapies (23.1% vs. 21.4%, respectively) and health conditions managed with prescription medications alone (41.8% vs. 39.3%, respectively).
- ▶ Approximately 8,200 CSHCN (41.8%) in North Dakota depend solely upon prescription medication to manage their chronic health conditions.

- More than one in five or approximately 4,000 CSHCN (20.5%) in North Dakota experience one or more limitations in functioning as a result of chronic health conditions, whether or not they also need specialized health services and/or prescription medication.

MCHB Core Outcomes for CSHCN in North Dakota

Outcome #1: CSHCN's families are partners in decision-making for child's optimal health.

- 75% of CSHCN in North Dakota met the criteria for successfully receiving health-care services in which parents feel partnered in shared decision-making for their child's optimal health, compared to the nation (70.3%).
- CSHCN in North Dakota are MORE likely to meet the criteria for outcome #1 if they are:
 - White, non-Hispanic (78.4%).
 - Currently insured (75.8%) and privately insured (81.3%).
 - Managing their chronic health conditions primarily through prescription medication (78.3%) and prescription plus need for services (77.5%).
 - Living in higher income households: 80.6% of CSHCN at 200-399% Federal Poverty Level (FPL) (significantly higher than U.S. percentage of 72.6) and 81% of CSHCN at 400% of FPL or higher.
- The percentage of CSHCN in North Dakota who met this outcome is not comparable between 2005-2006 and 2009-2010 survey years.

Outcome #2: CSHCN have coordinated, ongoing, and comprehensive care within a medical home.

- Nearly half (47.8%) of CSHCN in North Dakota receive care within a medical home, slightly higher than the national level (43%), although a slight decline from the 2005- 2006 survey (51.2%).
- Nearly one-third of CSHCN in North Dakota (31.5%) do not have family-centered care, which is lower than the national average (35.4%), according to medical home criteria.
- Nearly two-thirds of CSHCN in North Dakota (60.8%) did not need a referral to see a specialist or receive services in 2009-2010. Of those who did need a referral, over three-fourths (78.2%) had no problems getting it.
- Three of every four CSHCN in North Dakota (74%) needed help with care coordination; 59.5 percent of CSHCN who DID need help received all the care coordination they needed.
- CSHCN in North Dakota are MORE likely to have care that meets outcome #2 if they are:
 - White, non-Hispanic (51.7%).
 - Privately insured (56.6%).
 - Living in higher-income households (56.5% of CSHCN at 200-399% of FPL and 53% of 400% of FPL or higher).
 - Managing their chronic health conditions primarily through prescription medication (59.4%).

Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

- ▶ In 2009-2010, nearly two-thirds (60.1%) of CSHCN in North Dakota successfully achieved this outcome; 3.1 percent reported having no insurance coverage.
- ▶ From 2001 to 2005-2006, the proportion of CSHCN in North Dakota who had adequate insurance coverage increased from 62 percent to 68.2 percent, then decreased to 60.1 percent in 2009-2010.
- ▶ CSHCN in North Dakota are LESS likely to have adequate insurance coverage if they:
 - Live in households with income just above the poverty line (53.3% of CSHCN between 100% and 199% of FPL) or below the poverty line (53.4% of CSHCN between 0-99% FPL).
 - Are of other non-Hispanic minority race (49%).
 - Have above routine need/use of services (56%) or functional limitations (51.5%).
- ▶ CSHCN in 0-99% FPL had decreased by nearly one-fifth and those in 200-399% FPL had decreased by over one-tenth, compared to 2005-2006.
- ▶ Most CSHCN in North Dakota had continuous insurance coverage over the previous 12 months (92.7%); however, over one-third (35.9%) report that they have insurance that does not adequately meet all of their special health-care needs.
- ▶ Although North Dakota performed significantly better than the nation on Outcome #3 in 2005-2006 (68.2% in North Dakota vs. 62% nationwide), in 2009-2010 the state performed worse than the nation (60.1% in North Dakota vs. 60.6% nationwide).
- ▶ In 2009-2010, more than one in three CSHCN (35.1%) did not have consistent and adequate insurance coverage over the past 12 months.
- ▶ In 2009-2010, adequacy of insurance coverage decreased from 2005-2006 among CSHCN qualifying under functional limitations (51.1% vs. 65.8%, respectively) and service use (50.7% vs. 80.9%, respectively).

Outcome #4: CSHCN who are screened early and continuously for special health-care needs.

- ▶ In 2009-2010, 66.8 percent of CSHCN in North Dakota received health care that included a well-child check-up and preventive dental care, significantly fewer than nationwide (78.6%).
- ▶ CSHCN in North Dakota are MORE likely to meet outcome #4 if they:
 - Are school-ages (6-17 years); nearly half of children 0-5 years of age (48.4%) did not meet this outcome.
 - Are privately insured (70.7%) or publicly insured (63.3%); 41.8 percent of those with both private and public insurance did NOT meet this outcome measure.
 - Live in higher-income households (73.7% of CSHCN at 400% of FPL or higher); nearly two-fifths (39.6%) of families below FPL (0-99% FPL) did not meet this measure.

- ▶ The proportion of CSHCN who did not receive regular preventive well-child check-ups is significantly higher in North Dakota (20.4%) than nationwide (9.6%).
- ▶ Overall, more CSHCN in North Dakota received preventive dental care (83.2%) than well-child check-up preventive visits (79.6%).

Outcome #5: CSHCN who can easily access community-based services.

- ▶ In 2009-2010, 67.9 percent of CSHCN in North Dakota successfully achieved this outcome (13,100 CSHCN), a higher proportion than in the U.S. overall (65.1%).
- ▶ Individual components of difficulties or delays to receiving services among North Dakota CSHCN with the highest prevalence were problems getting appointments (15.8%), delays due to availability (13.5%), and delays relating to cost issues (9%).
- ▶ CSHCN in North Dakota are MORE likely to meet outcome #5 if they:
 - Have private insurance (74.9%).
 - Have limitations managed by prescription medications (79%).
 - Live in higher-income households (78.4% of CSHCN at 400% of FPL or higher); nearly two-fifths (41.1%) of families below FPL (0-99% FPL) did not meet this measure.

Outcome #6: Youth with special health-care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence.

- ▶ Slightly less than half (46.5%) of CSHCN ages 12 through 17 in North Dakota receive health care that appropriately addresses their eventual transition to adult health care. This is a decline from over half (51.2%) in 2005-2006.
- ▶ CSHCN ages 12 through 17 in North Dakota are LESS likely to have adequate transitional support if they are:
 - Males (56.3%).
 - Living in a single-parent household (71.9%).
 - Living in low-income households (80.7% of CSHCN below FPL and 66.9% of those at 100% to 199% of FPL).
 - Experiencing four or more functional difficulties (72.1%).
 - Without a medical home (69.8%).
- ▶ North Dakota exceeds national performance on outcome #6 overall (46.5% in North Dakota vs. 40% nationwide) and on each of its component measures: anticipatory guidance (37.4% vs. 31.6% either received or did not need it), and self-management skills (78.8% vs. 78%).
- ▶ Among adolescent CSHCN in North Dakota, females are much more likely than males to usually or always receive help developing age-appropriate self-management skills (85.5% of females vs. 74.2% of males); a similar but slightly smaller differential appears for anticipatory guidance (56.9% of females vs. 47.8% of males).

Family Impact of CSHCN Needs in North Dakota

- ▶ Roughly 9,500 CSHCN (48.2%) have ongoing health conditions that have impacted their families' financial status, ability to maintain employment, or required them to spend considerable extra time and/or money for their care.
- ▶ Families of more than one in four CSHCN in North Dakota (26.7%) paid more than \$1,000 out-of-pocket for medical expenses during the past 12 months.
- ▶ CSHCN whose families are MOST likely to have annual out-of-pocket expenses of \$1,000 or more:
 - Are ages 12 through 17 years (33.7%).
 - Are privately insured (34.1%).
 - Have complex health conditions (31.7% of CSHCN having functional limitations and 31.5% needing medication and specialized therapies or services).
 - Have higher household incomes (34.5% of CSHCN having incomes of 400% FPL or more and 30.6% of CSHCN having incomes of 200-399% FPL).
- ▶ Nearly one in four CSHCN in North Dakota have experienced family financial problems resulting from the child's health-care needs (22.2%).
- ▶ CSHCN whose families are MOST likely to have financial problems due to the child's health conditions:
 - Are less than six years of age (26.2%).
 - Have both public and private insurance (39.2%) or only public insurance (27%).
 - Have health-related functional limitations (46.8%).
 - Have a household income just above poverty level (39.7% of those at 100% to 199% FPL) or below poverty level (22%).
- ▶ More than one in 10 CSHCN in North Dakota (10.1%) report that family members spend more than 11 hours per week coordinating or providing care for them.
- ▶ CSHCN whose family members are most likely to spend 11 or more hours per week providing or coordinating their care:
 - Are younger than 6 years of age (18.3%).
 - Have public insurance (16.1%).
 - Have health-related functional limitations (23.1%).
 - Have a household income below FPL (25.5%).
- ▶ More than one in five CSHCN had family members that cut back and/or stopped working due to health conditions (21.6%).
- ▶ CSHCN whose family members were most likely to cut back or stop working:
 - Are younger than 6 years of age (34.2%).
 - Have both public and private insurance (43.9%) and public insurance alone (33.2%).
 - Have health-related above routine need/use of services (39.2%) or health-related functional limitations (38%).
 - Have a household income around the FPL, 0-99% (34.9%) or 100-199% (30.7%).

Section I: Children with Special Health-Care Needs in North Dakota

North Dakota: Prevalence of Children with Special Health-Care Needs

The federal Maternal and Child Health Bureau (MCHB) defines children with special health-care needs (CSHCN) as:

"...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.¹⁰"

This definition serves as a guide for development of family-centered, coordinated systems of care for children with special health-care needs and their families who are served by state Title V block grants administered by the Maternal and Child Health Bureau.

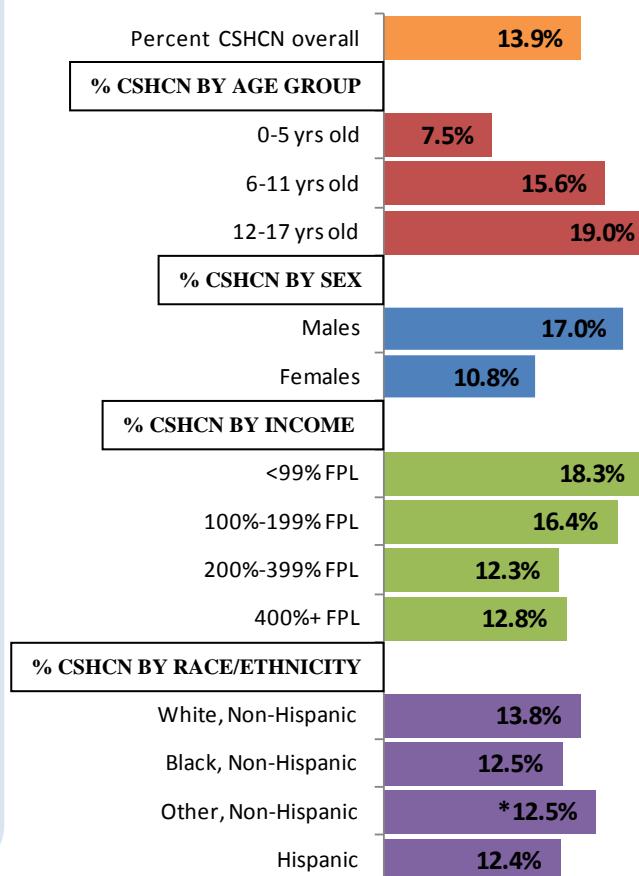
The National Survey of Children with Special Health-Care Needs (NS-CSHCN) uses a validated screening tool used to identify children meeting the MCHB definition. In 2009-2010, 3,886 households in North Dakota were contacted, and 7,748 children were screened for having special health-care needs. Results from the survey are weighted to reflect the state's non-institutionalized child population ages birth through 17. This resulted in 797 full-length special needs interviews.

Based on the 2009-2010 NS-CSHCN...

- ▶ **Approximately 20,000 children (19,748) in North Dakota meet the MCHB definition for having special health-care needs.**
- ▶ **The prevalence of CSHCN in North Dakota is slightly lower than the national prevalence.**
13.9 percent of CSHCN in North Dakota is not statistically different from the 15.1 percent prevalence of CSHCN nationally.
- ▶ **CSHCN prevalence in North Dakota is increasing.**
The prevalence of CSHCN in 2009-2010 is higher than the NS-CSHCN in 2005-2006 (12.2%) and in 2001 (12.4%).
- ▶ **Compared to children not identified as having special health-care needs, CSHCN in North Dakota are more likely to be:**
 - Male.
 - School-aged.
- ▶ **The prevalence of CSHCN in North Dakota is similar among children:**
 - Of different races/ethnicities.
 - With household income at 200 percent or higher of federal poverty level (FPL).

North Dakota

Figure A_1: Prevalence of Non-institutionalized Children With Special Health-Care Needs (CSHCN) in North Dakota Child Population, ages birth through 17, 2009-2010



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

North Dakota: Children With and Without Special Health-Care Needs

Key Findings for North Dakota...

- CSHCN are more likely to be male and school-aged, compared to children without special health-care needs. (Figs. A_2 and A_3)
- Minority groups are equally likely to have special health-care needs; the distribution of race/ethnicity is similar for CSHCN and non-CSHCN populations in North Dakota. (Fig. A_4)
- Among all North Dakota CSHCN 0-17 (13.9%, see Fig A_1), the estimated majority of CSHCN children are white, non-Hispanic race (81.7%); Nearly one in five CSHCN are estimated to be of a minority race (18.3%). (Fig. A_4)
- American Indian children with special health-care needs equal 9.7 percent of all CSHCN. (Fig. A_5)

Figure A_2: Age distribution within CSHCN vs. non-CSHCN populations: North Dakota, 2009-2010

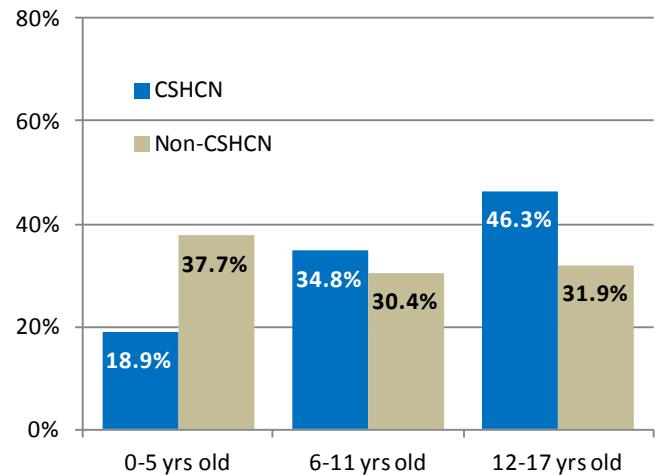
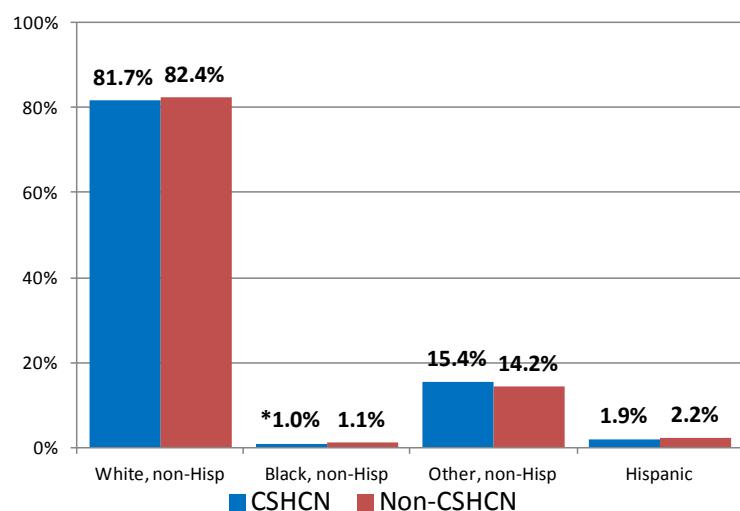
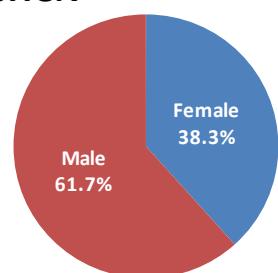


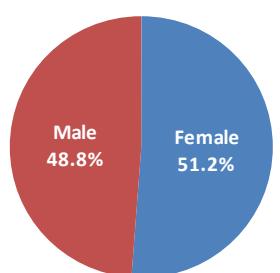
Figure A_4: Race/ethnicity distribution within the CSHCN and Non-CSHCN population: North Dakota, 2009-2010



CSHCN



Non-CSHCN



AMERICAN INDIAN

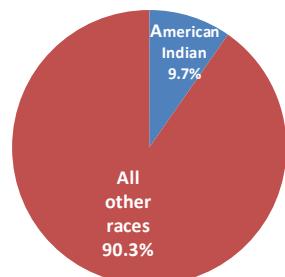


Figure A_5:
Prevalence of
American Indian
children within
North Dakota
CSHCN, 2009-2010

North Dakota: Who Are Children With Special Health-Care Needs?

Identifying CSHCN

The information about children with special health-care needs presented in the report comes from the 2009-2010 National Survey of Children with Special Health-Care Needs (CSHCN). The CSHCN Screener, a well-tested, validated instrument, is used to identify CSHCN for the survey according to the federal Maternal and Child Health Bureau's non-categorical definition of special health-care needs.^{5,10,12} Children are classified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an ongoing physical, emotional, behavioral, developmental or other health condition.

The CSHCN Screener is composed of five questions. The first part of each question asks if the child experiences one of the following:

Question 1: Needs or uses medication prescribed by a doctor (other than vitamins)

Question 2: Needs or uses more medical care, mental health or educational services than typical for most children of the same age

Question 3: Experiences functional or activity limitations not typical for others of same age

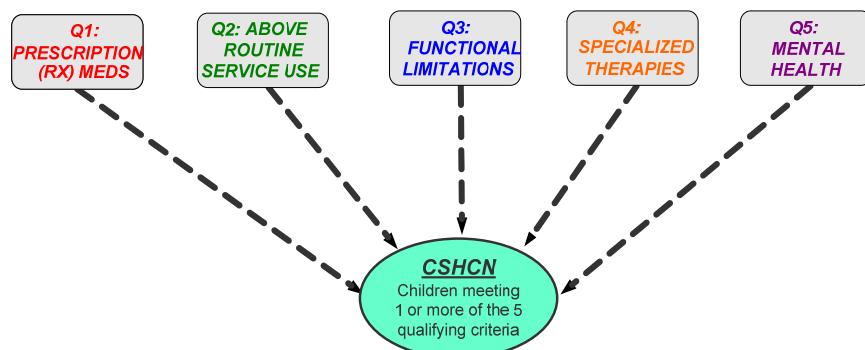
Question 4: Needs or uses specialized therapies (OT, PT, speech, etc.)

Question 5: Has emotional, developmental or behavioral problems that require treatment or counseling

When the first part of a screening question is answered YES, two follow-up components are asked to determine whether the health consequence is due to an ongoing medical, emotional or other type of health condition lasting or expected to last for at least 12 months.

Responses of YES to all three parts of a screener question (in the case of question 5, two parts) are required for a child to have special health-care needs. Children can qualify by meeting the criteria for a single screening question or any combination of two or more of the five questions. (Figure B_1). In the 2009-2010 NS-CSHCN, approximately 19,700 children in North Dakota met one or more CSHCN Screener criteria for having special health-care needs. A technical summary of the CSHCN Screener is included in Appendix D.

Figure B_1: CSHCN Screener criteria for identifying children with special health-care needs



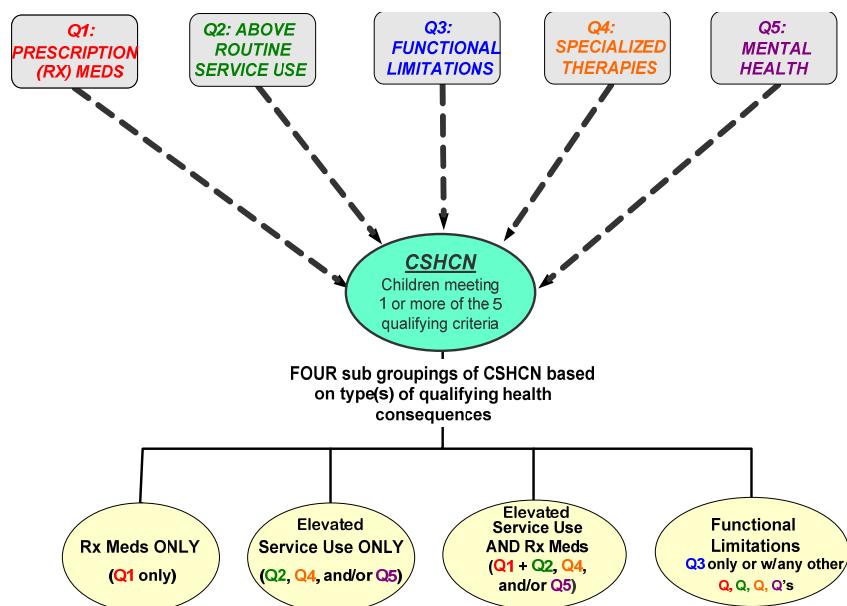
Differentiating Special Health-Care Needs

The diversity of health and services needs in the CSHCN population presents a special challenge for the state and federal programs and agencies charged with developing community-based systems of care responsive to the needs of CSHCN and their families. Fortunately, recent research supports using qualifying CSHCN screener criteria as the basis for differentiating the array of special needs identified under the broad, inclusive MCHB definition.^{6,7}

In this report, we assigned CSHCN into four mutually exclusive subgroups in order to examine system performance for children with different underlying types of special needs. (See Fig. B_2.) CSHCN were classified into these four subgroups:

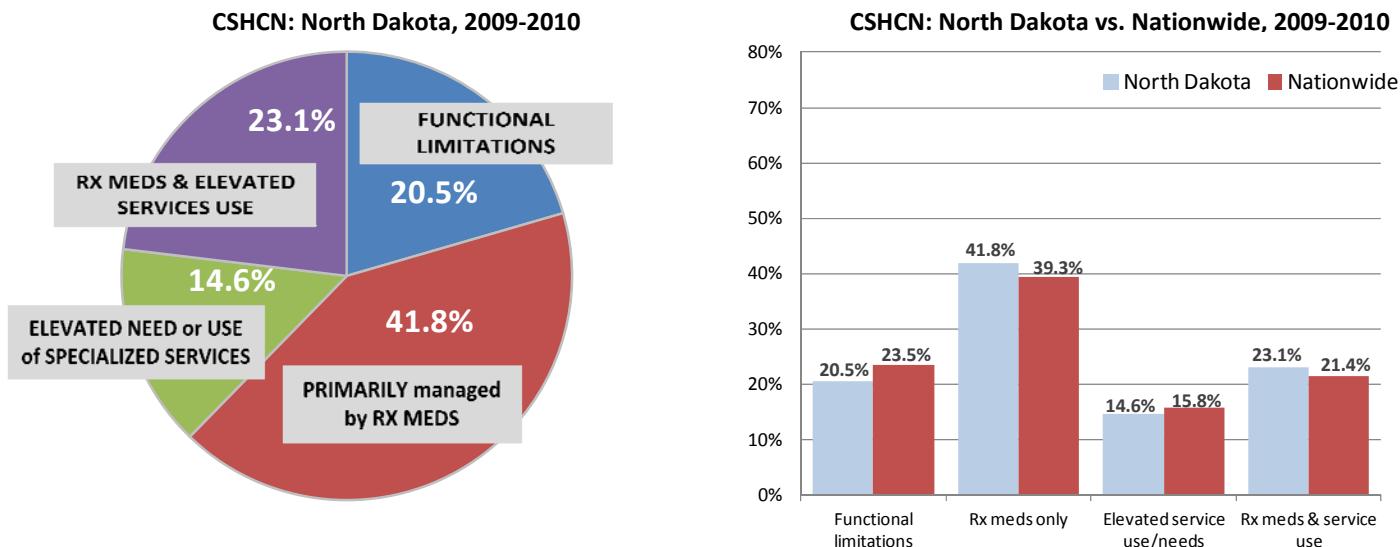
- **RX MEDS ONLY:** Children in this group experience chronic health conditions that are managed primarily through prescription medication – often quite successfully as long as they have access to medical care and needed medication.
- **ELEVATED or ABOVE ROUTINE SERVICES USE:** Children in this group qualify on one or more of the three screening criteria addressing elevated need or use of specialized services or therapies. The children in this group rely on one or more of a wide array of services – such as pediatric specialist care; early intervention; mental health care; developmental disabilities; special education; physical, occupational or speech therapies – to manage their chronic health conditions.
- **ELEVATED SERVICES USE and RX MEDS:** Children in this group experience health needs that require both medication management and specialized services or therapies. These children qualify on one or more of the three screening criteria addressing elevated service use AND on the prescription medication screening criteria.
- **FUNCTIONAL LIMITATIONS:** Children in this group qualify on the functional limitations criteria, nearly always in conjunction with one or more other screening criteria. In addition to other types of special needs, these children currently experience one or more functional limitations as a result of their ongoing health conditions.

Figure B_2: CSHCN subgroupings based on types of qualifying screener criteria



North Dakota – Who Are Children with Special Health-Care Needs?

Figure B_3: Distribution of special needs subgroupings based on types of qualifying screener criteria



In North Dakota...

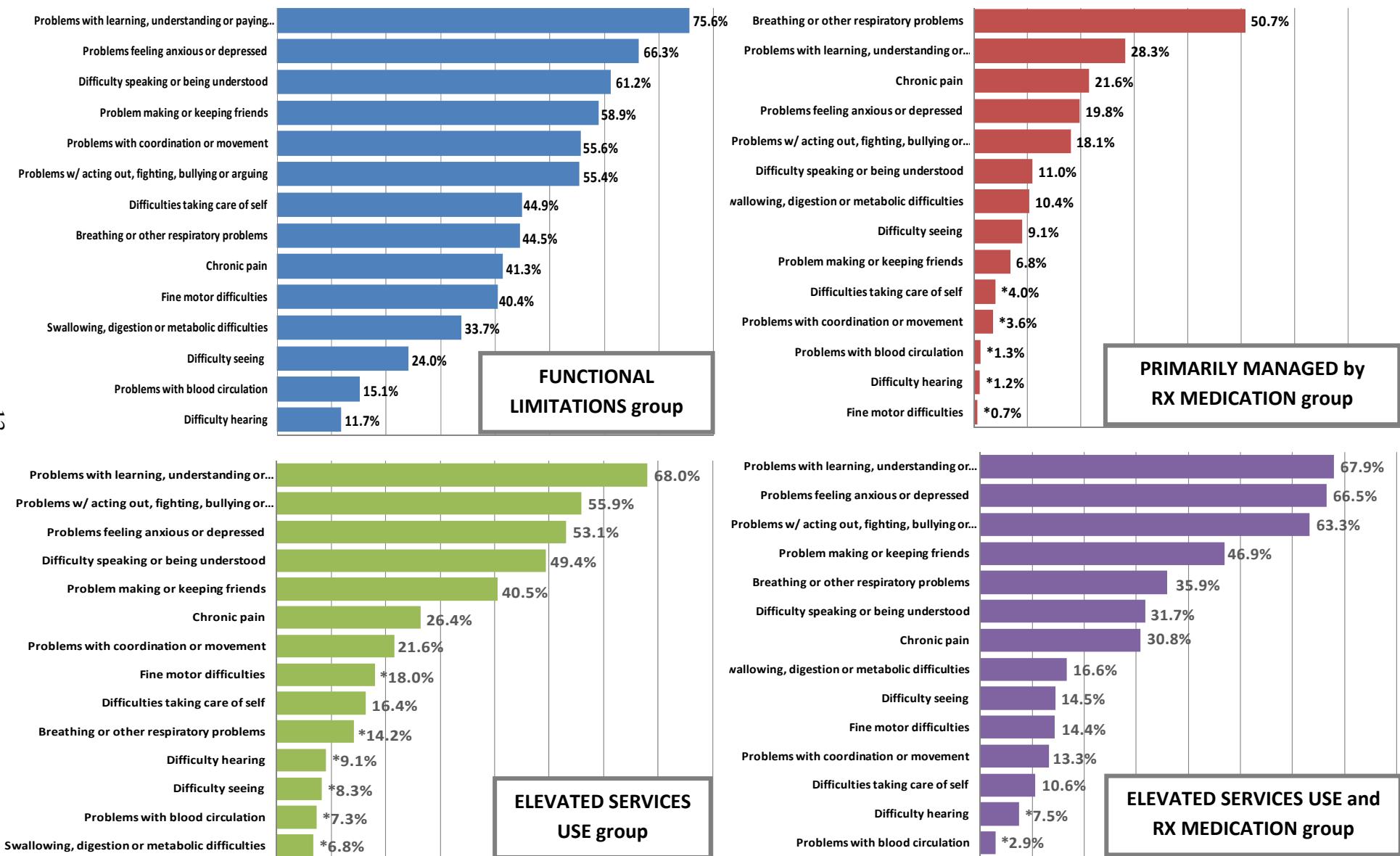
- ▶ The distribution of subgroups based on types of qualifying screening criteria in the state's CSHCN population is similar to that found nationwide.
- ▶ Compared to 2005-2006, the proportion of North Dakota CSHCN has increased among those who qualified under functional limitations (20.5% vs. 18.1%) and elevated service use/needs (14.6% vs. 12.8%).
- ▶ An estimated 8,200 CSHCN (41.8%) in North Dakota depend primarily upon prescription medication to manage their chronic health conditions. This group of CSHCN represents a “success story” of sorts because they experience little, if any, disability or functional limitations as long as they have access to the medical care and the prescription medicine they need.
- ▶ Approximately 4,500 CSHCN (23.1%) in North Dakota require one or more types of medical, mental health, educational or other kinds of specialized services in conjunction with prescription

What specific types of health problems do CSHCN in North Dakota experience as a result of their chronic conditions or disabilities?

The 2009-2010 NS-CSHCN collected information about the types of health issues CSHCN experience as a result of their current health conditions. Parents were asked if their children have any of 14 specific health problems or difficulties from a list in the survey.

Figure B_4 on the next page shows the frequency of different health problems experienced by CSHCN in each of the four qualifying screening criteria subgroups. Details about the type and relative frequency of health problems experienced by different groups of CSHCN provides useful context for interpreting the performance results in this report and can help guide program planning and improvement.

Figure B_4: Percentage of CSHCN in North Dakota experiencing specific problems as result of their health conditions, by qualifying screening criteria subgroups*
(Presence of health-related difficulties is based on parent-reported responses to a discrete list of problems asked in 2009-2010 NS-CSHCN)



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

North Dakota – Who Are Children with Special Health-Care Needs?

What specific chronic conditions do CSHCN in North Dakota currently experience?

In addition to information about CSHCN health problems and difficulties, the 2009-2010 NS-CSHCN also collected information on a limited number of childhood chronic conditions. Table 1 below shows the percentage of CSHCN in each of the qualifying screener criteria subgroups reported to currently have one or more of 16 different chronic conditions asked about in the survey.

When using these data, it is important to keep in mind that the list of chronic conditions asked about in the survey is not comprehensive, and the long list of other conditions that CSHCN may have is not represented. Other limitations to these data include being based on parent-report, rather than clinical records. Although the results are listed separately, over one-half (56.3%) of CSHCN in North Dakota experience two or more of the conditions asked in the survey. Finally, the population prevalence (currently have condition) of certain childhood chronic conditions (e.g., cystic fibrosis) is so low that it is difficult or impossible to obtain reliable state-level estimates using random sampling methodology. In these instances, the national prevalence estimates are reported in the table below.

Table 1: Percentage of CSHCN in North Dakota with current specific chronic conditions based on parent report, by qualifying screening criteria subgroups: 2009-2010 NS-CSHCN

Chronic Condition	Functional limitations group	Elevated services use group	Elevated services use AND Rx medications group	Managed primarily by Rx medications	CSHCN overall
	%	%	%	%	%
ADD/ADHD	40.9	*18.3	58.1	23.7	34.4
Allergies	38.2	22.8	42.1	47.8	40.9
Anemia or sickle cell disease	1.5	1.1	1.4	0.9	4.2
Arthritis or other joint	7.2	1.8	2.7	1.0	2.9
Asthma	26.2	*9.1	25.3	42.9	30.5
Autism or ASD	22.2	8.9	5.3	0.5	7.9
Cerebral palsy	5.6	0.8	0.5	*0.1	1.6
Cystic fibrosis	0.6	*0.0	0.7	*0.0	0.3
Depression, anxiety, or other emotional problems	18.2	*15.6	25.2	*2.8	13.0
Diabetes	2.1	*0.2	3.6	1.1	1.7
Down Syndrome	3.4	1.2	*0.4	*0.1	1.1
Epilepsy or other seizure disorder	8.2	0.6	2.7	1.3	3.1
Heart problems, including congenital heart disease	6.1	3.1	2.7	1.3	3.0
Mental retardation or developmental delay	18.7	4.0	2.5	*0.6	5.8
Migraine or frequent headaches	15.2	*10.3	14.0	*9.5	11.8
Muscular dystrophy	0.9	*0.2	*0.1	*0.0	0.3

Note: National estimates are presented for conditions in bold text because state level samples are too small for reliable estimate

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section II: MCHB Core Outcomes Measures

MCHB Core Outcome #1:

CSHCN whose families are partners in shared decision-making for child's optimal health.

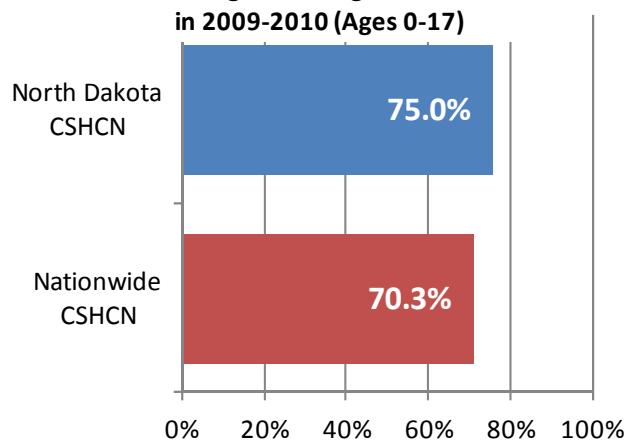
This outcome is evaluated using four questions from the National Survey of Children with Special Health-Care Needs (NS-CSHCN): 1) how often did doctors discuss a range of health-care/treatment options; 2) how often did doctors encourage parents to ask questions or raise concerns; 3) how often did doctors make it easy for parents to ask questions or raise concerns, and 4) how often did doctors respect parent's treatment choices. Children whose parents reported "usually" or "always" to each of the four questions meet the overall criteria for the outcome.¹³

Highlights...

- ▶ **Three in 4 CSHCN in North Dakota successfully meet this outcome.**
In 2009-2010, more than 14,000 CSHCN (75%) in North Dakota met the criteria in which families are partners in shared decision-making for their child's optimal health.
- ▶ **North Dakota is doing better than the national average on this outcome.**
CSHCN in North Dakota are more likely to meet this outcome than nationally (75% vs. 70.3%). See Appendix C.
- ▶ **CSHCN in North Dakota successfully meeting this outcome are more likely to:**
 - Be school age (6-17).
 - Have private insurance only.
 - Come from a two parent household.
 - Have an adult in the household with more than a high school education.
 - Have income above the poverty level.
- ▶ **The percentage of CSHCN meeting this outcome in North Dakota varied significantly across:**
 - Presence of a medical home (91.7% vs. 61.5%).
 - Adequacy of current health insurance (82% vs. 65%).
 - Having 3 or more functional difficulties.

See Appendices for details and additional results for Outcome #1.

Figure 1.1: North Dakota vs. Nation Percentage meeting Outcome #1



2005-2006 vs. 2009-2010

Not Available

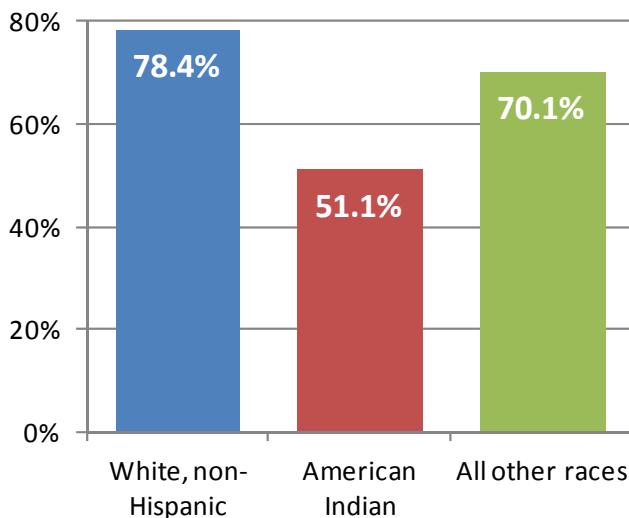
In the 2009-2010 NS-CSHCN, significant changes and additions were made to the set of questions used to assess family partnership in shared decision-making for their child's optimal health composite measure. The result is an improved and more robust assessment.

MCHB Core Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.

Outcome #1: Key Findings for North Dakota

- Just over half of North Dakota American Indian CSHCN (51.1%) have families who feel like partners in decision-making and are satisfied with services children receive.

Figure 1.2: Percentage of CSHCN in North Dakota meeting Outcome #1 by race/ethnicity, 2009-2010



In North Dakota...

White, non-Hispanic CSHCN are more likely than other groups to meet this outcome.

American Indian CSHCN are significantly less likely than white non-Hispanic CSHCN in North Dakota to meet this outcome.

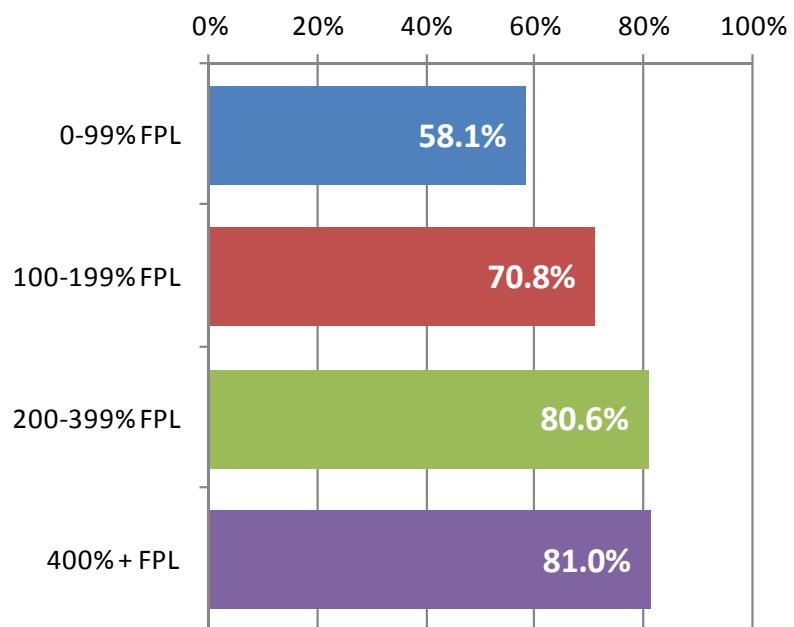
- CSHCN from families with higher incomes are more likely to feel like partners in decision-making and to feel satisfied with services children receive.

In North Dakota...

Nearly three-fifths of CSHCN living below poverty level have parents who report feeling like partners in decision-making and being satisfied with services their children receive.

In contrast, over four-fifths of CSHCN in the highest two income groups successfully met the criteria for this outcome.

Figure 1.3: Percentage of CSHCN in North Dakota meeting Outcome #1 by income level, 2009-2010



MCHB Core Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.

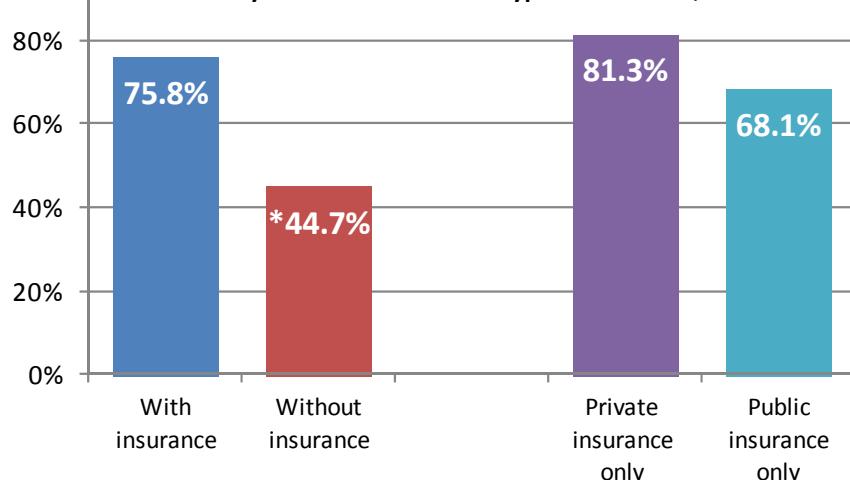
- Uninsured CSHCN in North Dakota are less likely to have families who feel like partners in decision-making and feel satisfied with services children receive.

In North Dakota...

Having health insurance makes a dramatic difference in whether CSHCN successfully meet this outcome (75.8% vs. 44.7%, respectively).

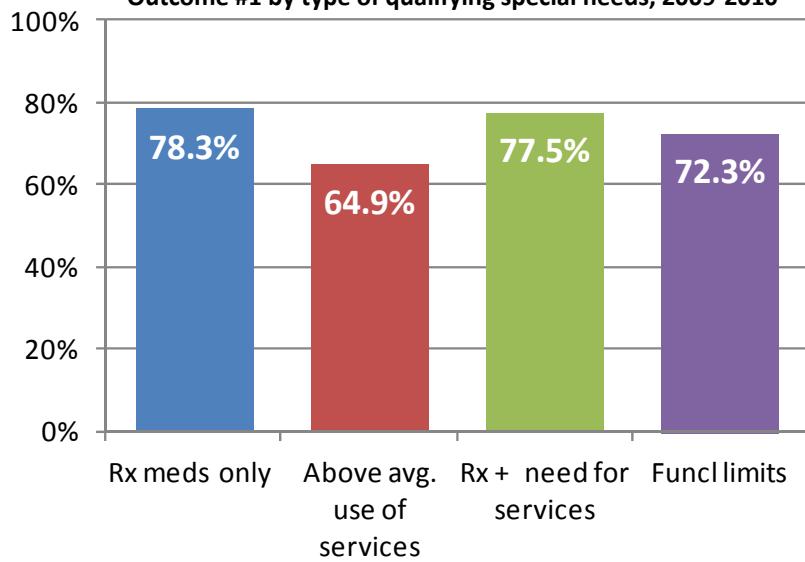
On the other hand, type of insurance is not as strongly associated with the likelihood of meeting this outcome. The percentage of CSHCN with insurance has increased since the 2005-2006 survey (81.3% vs. 65.4% - private insurance) and (68.1% vs. 58.3% - public insurance).

Figure 1.4: Percentage of CSHCN in North Dakota meeting Outcome #1 by insurance status and type of insurance, 2009-2010



- CSHCN whose conditions are more complex or require a wider range of services are somewhat less likely than other CSHCN to meet this outcome.

Figure 1.5: Percentage of CSHCN in North Dakota meeting Outcome #1 by type of qualifying special needs, 2009-2010



In North Dakota...

Of CSHCN whose chronic health conditions are managed primarily through prescription medicine (Rx meds only), about four in five meet Outcome #1 criteria for shared decision-making and satisfaction with care.

Each specific type of qualifying category increased since the 2005-2006 survey. Over three-fourths of CSHCN with prescription needs plus needs for services and nearly three in four with functional limitations met outcome #1.

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.

Outcome #1: Key Subcomponent Findings for North Dakota

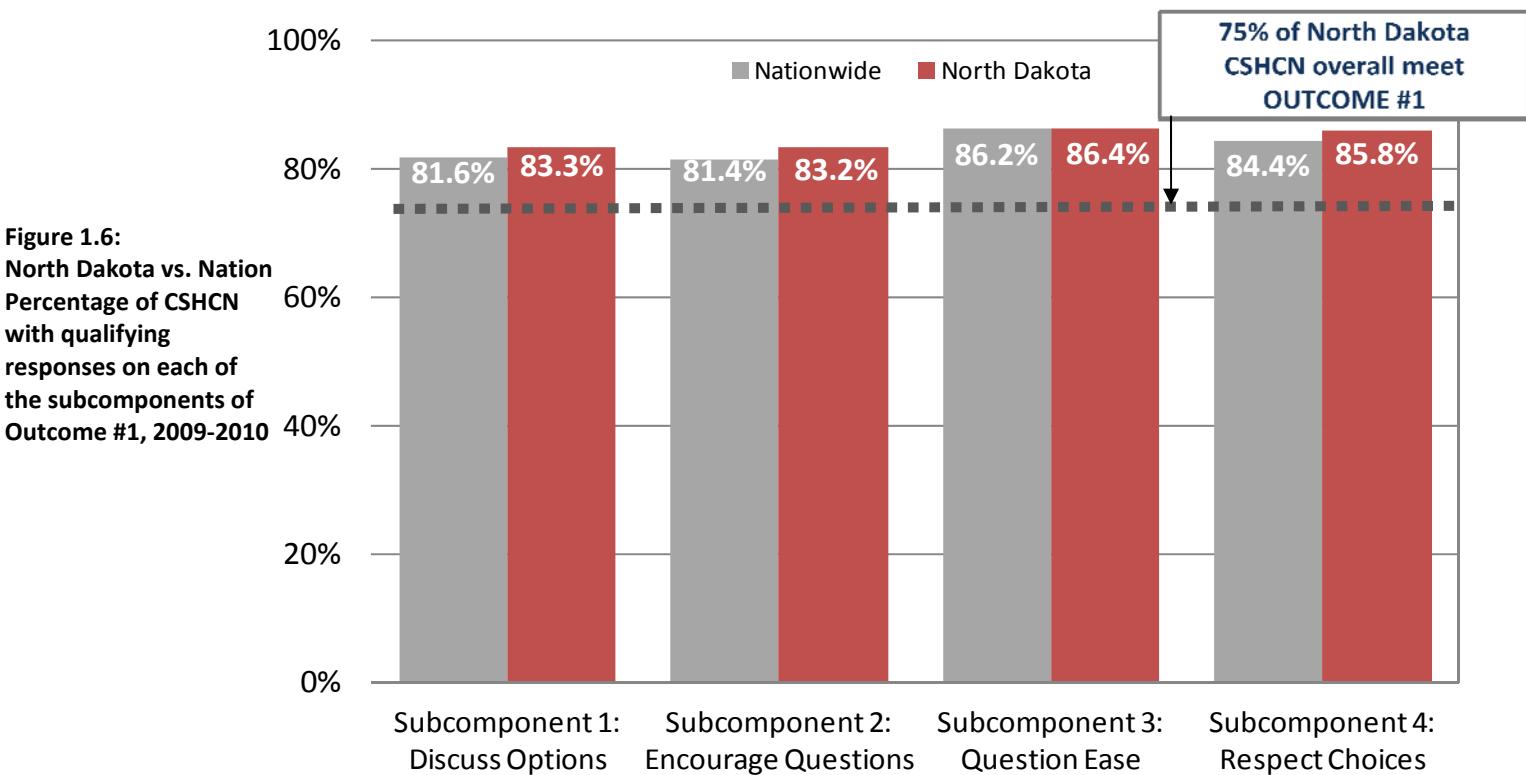
The items used to develop this measure were revised substantially between 2005-2006 and 2009-2010. This measure is now based on responses whether CSHCN families answer usually or always to all four questions below⁹:

We want to know about how [S.C.]'s doctors or other health-care providers work with you to make decisions about [his/her] health-care services and treatment. During the past 12 months...

- 1. How often did [S.C.]'s doctors or other health-care providers discuss with you the range of options to consider for [his/her] health care or treatment? (C6Q21)**
- 2. How often did they encourage you to ask questions or raise concerns? (C6Q22)**
- 3. How often did they make it easy for you to ask questions or raise concerns? (C6Q23)**
- 4. How often did they consider and respect what health care and treatment choices you thought would work best for [S.C.]? (C6Q24)**

In North Dakota ...

In each subcomponent, a strong majority of families of CSHCN in North Dakota report that providers usually or always encourage discussion. North Dakota performed better than the national average on OUTCOME #1 overall and among each of the four subcomponents. Refer to Figure 1.6 below.



MCHB Core Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.

The families of non-white CSHCN are less likely to report to “usually” or “always” agree with outcome #1 subcomponents. A lower level of agreement with services frequency is a strong contributor to variation in performance on OUTCOME #1 for CSHCN from different race/ethnicity backgrounds (Fig. 1.7).

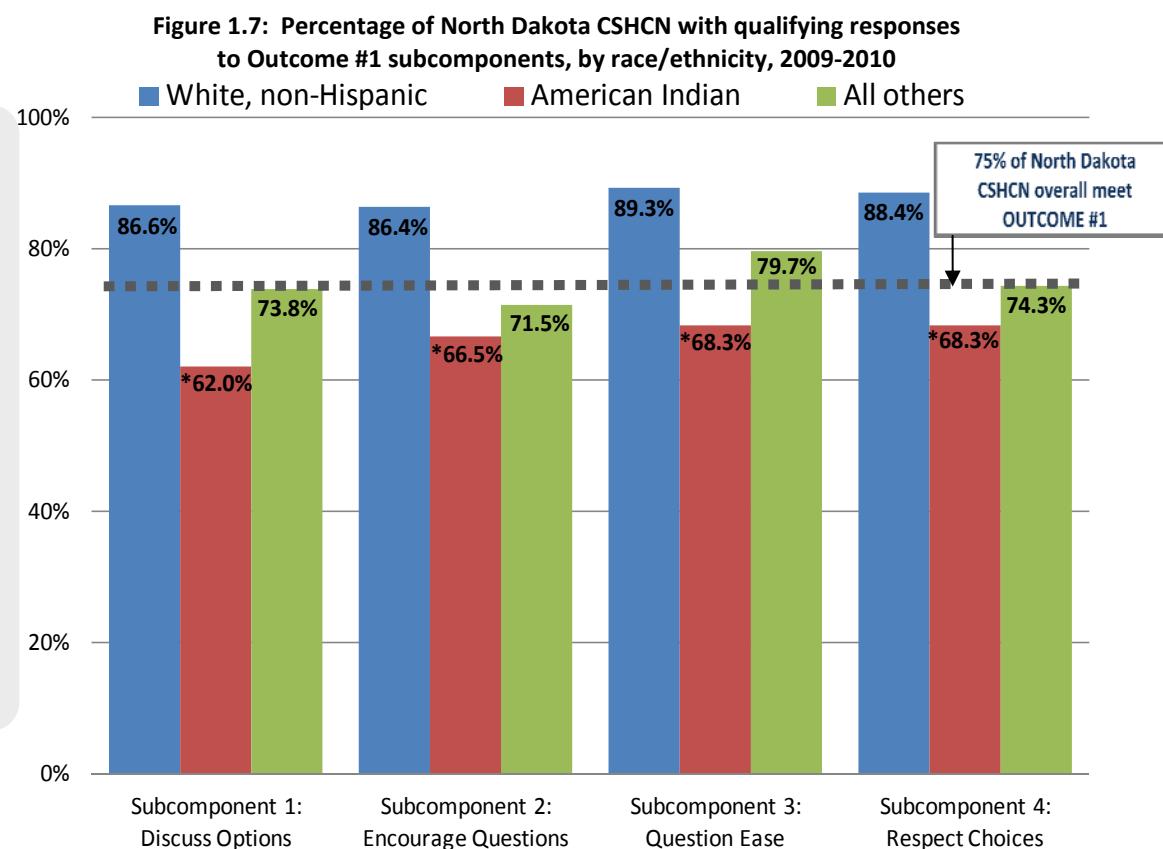
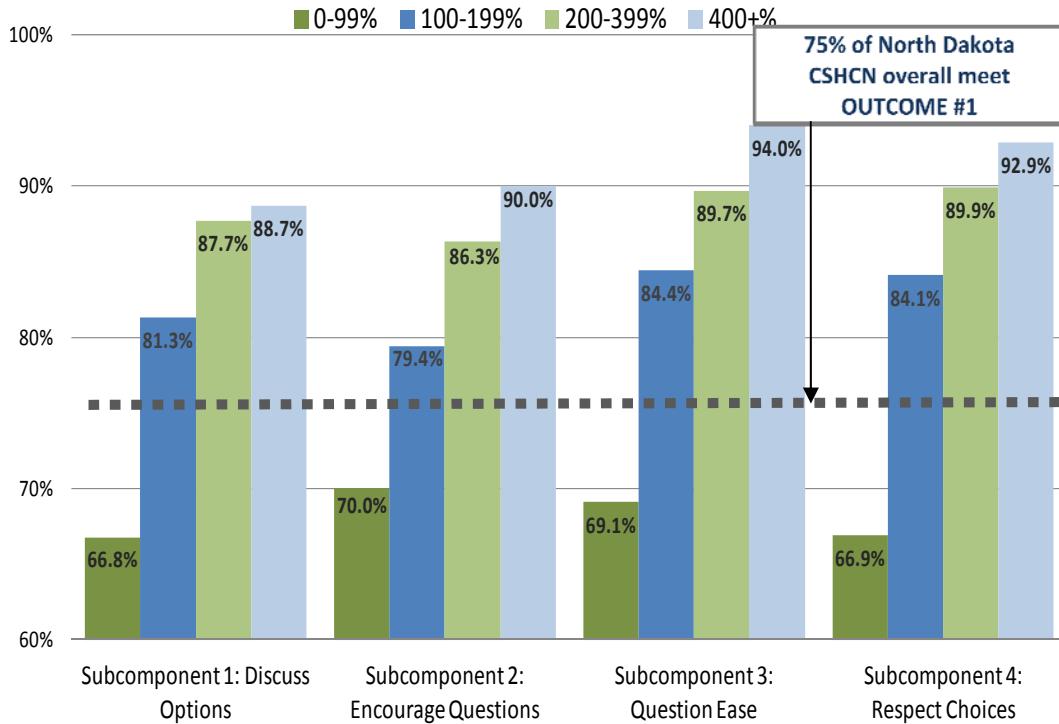


Figure 1.8: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by federal poverty level (FPL), 2009-2010



Agreement with service frequency is strongly associated with income. Just over two-thirds of CSHCN living in households with incomes below the federal poverty level (0-99% FPL) have families who report to “usually” or “always” agree with each subcomponent (Fig. 1.8).

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.

Figure 1.9: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by insurance status, 2009-2010

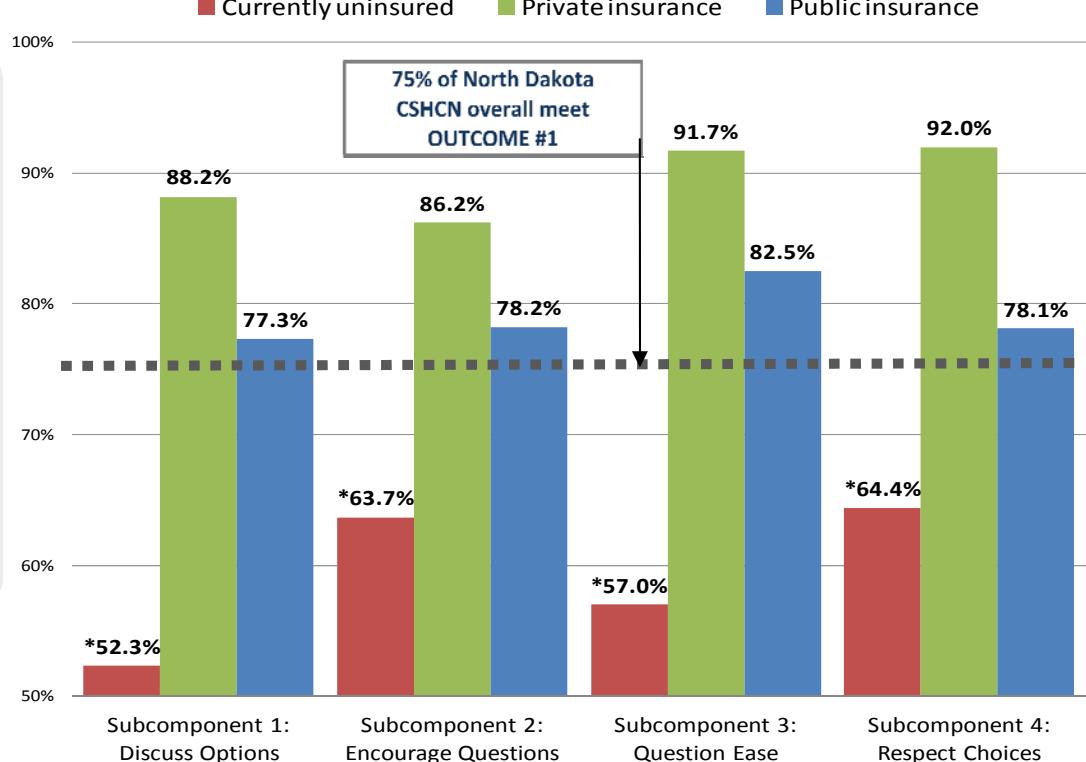
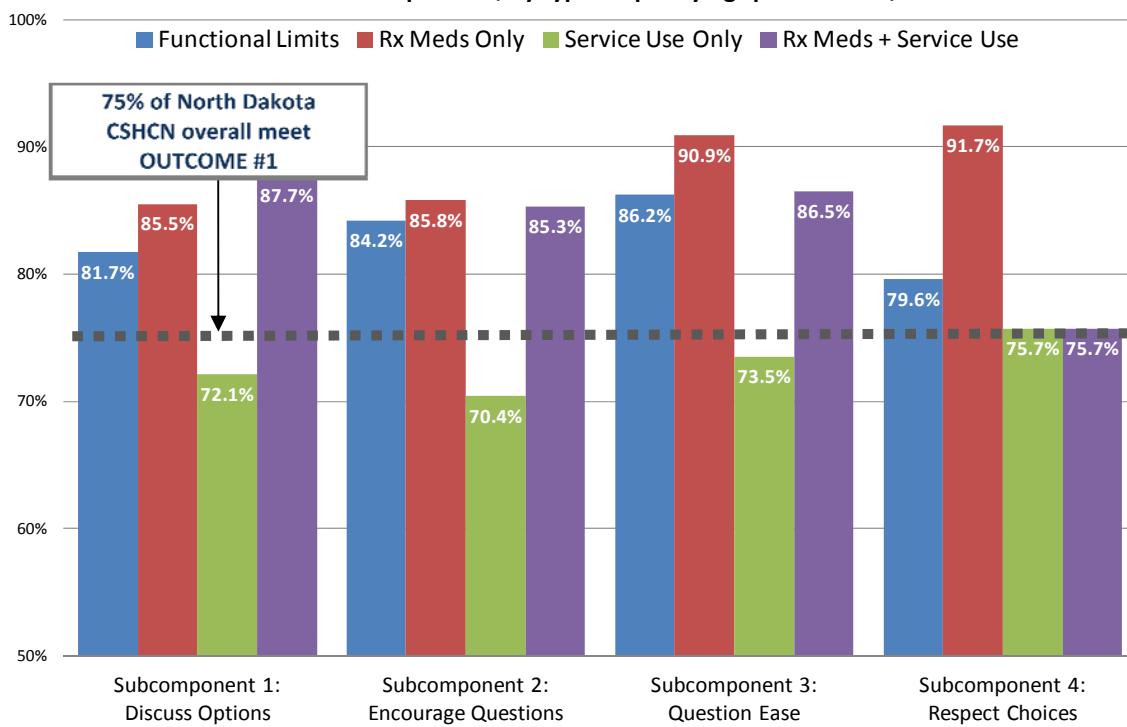


Figure 1.10: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by type of qualifying special needs, 2009-2010



The families of CSHCN whose chronic health conditions are managed primarily through prescription medicine are more likely to report to “usually” or “always” agree with each subcomponent. CSHCN whose special needs are more complex or require a wider range of services are less likely to meet the criteria for Outcome #1 (Fig. 1.10).

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

MCHB Core Outcome #2:

CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

The American Academy of Pediatrics' concept of "medical home"⁴ lists seven defining components: accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective. Ideally, these seven components are delivered by a doctor or other health professional who knows the child well. Five of the seven components of medical home are assessed by the 2009-2010 National Survey of CSHCN. The outcome is evaluated using a composite score derived from 21 different survey items. To qualify as having a medical home, a child must have a personal doctor or nurse and meet the five criteria measured: coordinated, accessible, comprehensive, family-centered and compassionate.¹³

Highlights...

- ▶ **About half of CSHCN in North Dakota receive care within a medical home.**
In 2009-2010, 47.8 percent or about 9,000 CSHCN in North Dakota met criteria for having a medical home — slightly higher than CSHCN nationwide.
- ▶ **North Dakota performs above the national estimate for this outcome.**
CSHCN in North Dakota are somewhat more likely to meet this outcome than CSHCN nationally (47.8% vs. 43%), but the difference is not statistically significant. See Appendix C.
- ▶ **CSHCN in North Dakota successfully meeting this outcome are more likely:**
 - White, non-Hispanic.
 - Living in higher income households.
 - Insured.
 - Privately insured.
 - Fewer number of difficulties.
 - Managing chronic conditions primarily through prescription medication or prescription medications plus service needs.

See Appendices for details and additional results for Outcome #2.

Figure 2.1: North Dakota vs. Nation

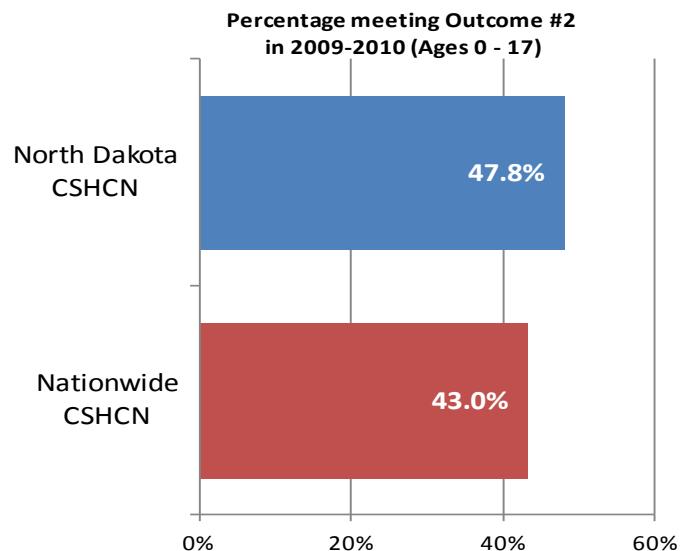
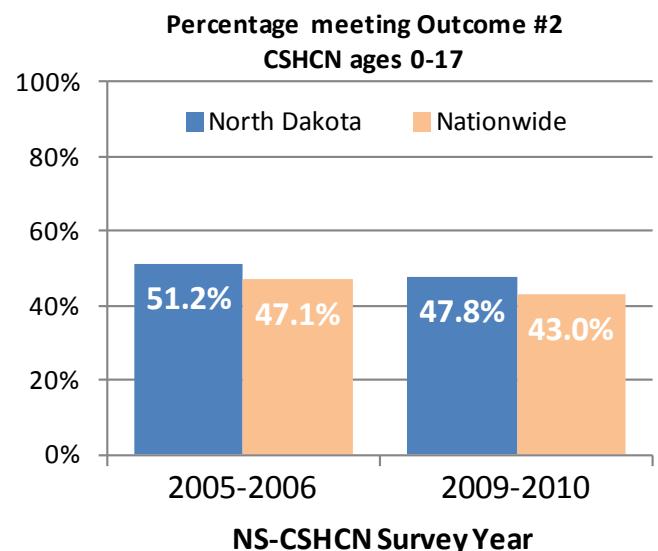


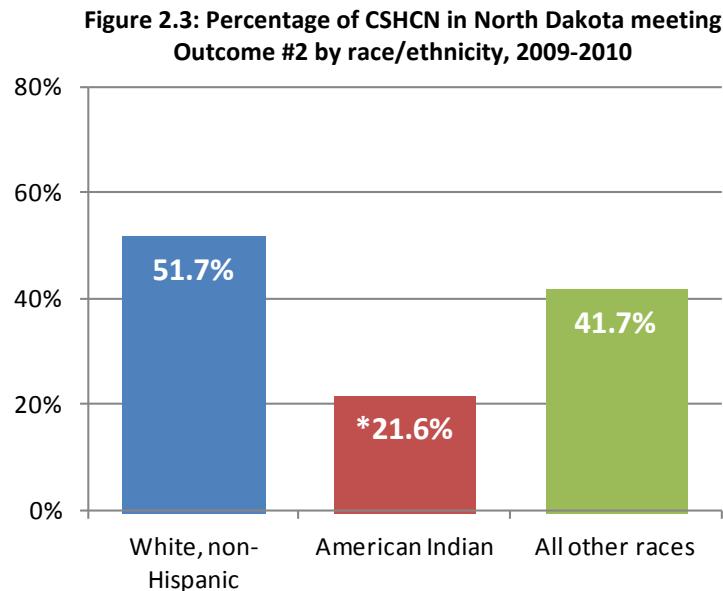
Figure 2.2: 2005-2006 vs. 2009-2010



MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

Outcome #2: Key Findings for North Dakota

- Less than one-half of American Indian CSHCN receive care that meets the medical home criteria.



In North Dakota...

Non-Hispanic, white CSHCN are significantly more likely than American Indian CSHCN to receive care reflecting the medical home model.

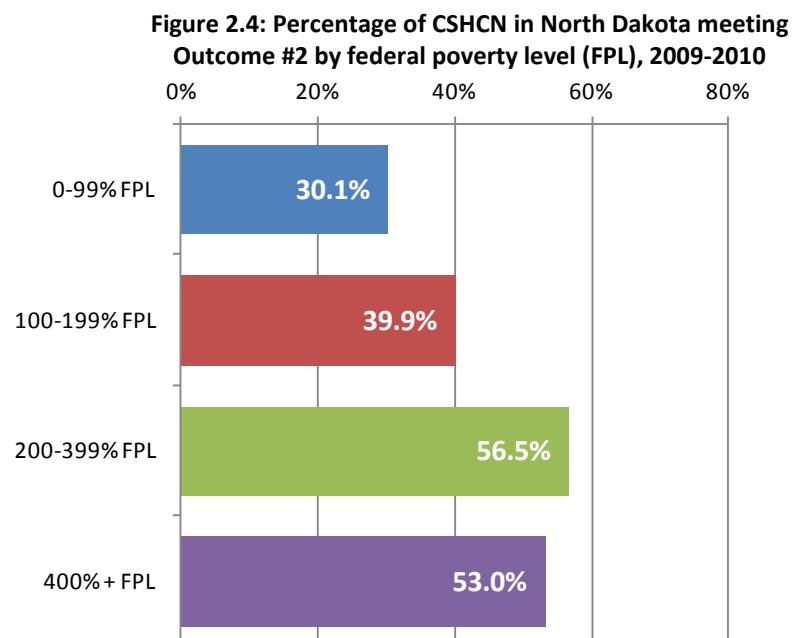
American Indian CSHCN in North Dakota are at highest risk for not having a medical home. About 80 percent did NOT receive care meeting the medical home criteria during 2009-2010, compared to fewer than half of white, non-Hispanic CSHCN (Fig. 2.3).

- Lower income CSHCN are significantly less likely to receive care within a medical home.

In North Dakota...

Only about one-third of CSHCN living below poverty level (0-99% FPL) have medical homes (30.1%).

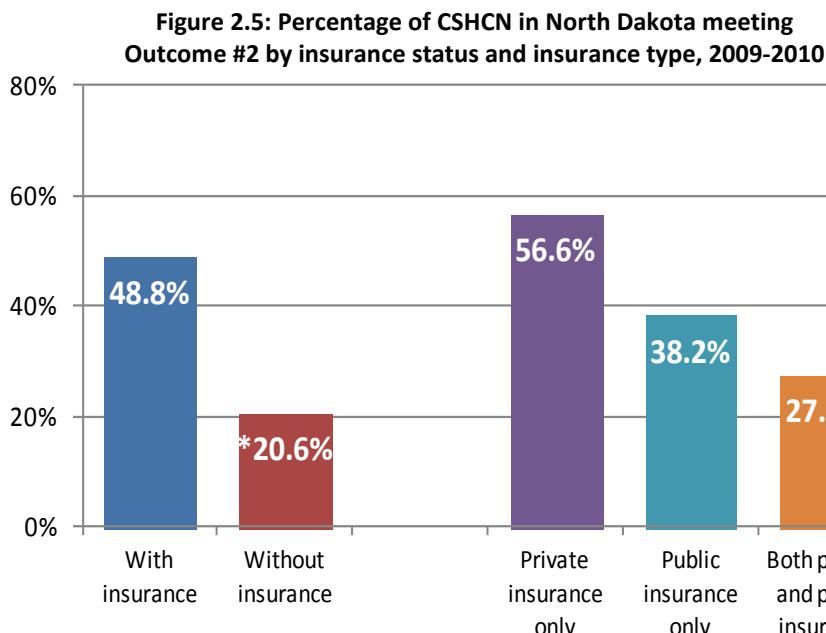
CSHCN from more affluent households are more likely to have a medical home than CSHCN living in the state's poorest households (Fig. 2.4).



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

- Insurance status and type of coverage both make a difference in whether CSHCN receive care that meets the medical home model.



In North Dakota...

Approximately one in five uninsured CSHCN have a medical home. In contrast, nearly half of currently insured CSHCN receive this type of care.

CSHCN with private health insurance are significantly more likely to have a medical home than CSHCN with public insurance coverage (56.6% vs. 38.2%, respectively) or both private and public insurance (56.6% vs. 27.5%) (Fig. 2.5).

- CSHCN whose health conditions require a range of specialized or community-based services in addition to medical care are less likely to meet the medical home outcome.

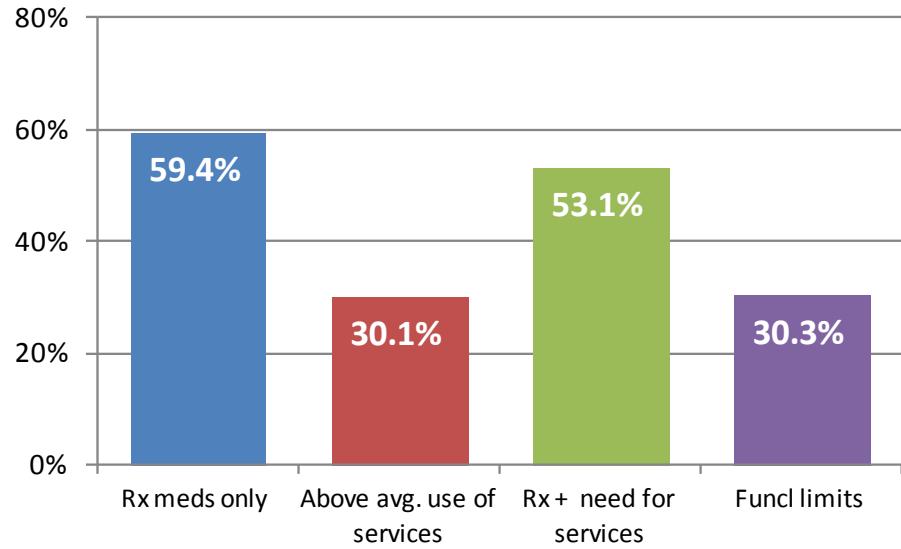
In North Dakota...

CSHCN whose conditions are managed primarily through prescription medicine (59.4%) are more likely than other CSHCN to meet the medical home outcome (Fig. 2.6).

CSHCN with the types of health needs that often require coordination across services are LESS likely to have health care that reflects the medical home model.

The percent of CSHCN qualifying with medications plus needed services has increased since 2005-2006 (40.7% vs. 53.1%, respectively).

Figure 2.6: Percentage of CSHCN in North Dakota meeting Outcome #2 by qualifying type of special needs, 2009-2010



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

Outcome #2: Key Subcomponent Findings for North Dakota

MCHB Core Outcome #2 is measured using 21 questions from the National Survey of Children with Special Health-Care Needs (list of questions provided in Appendix E). The questions assess five subcomponents, each of which addresses a different aspect of the medical home concept:

Subcomponent # 1: Child has at least one personal doctor or nurse (PDN, C4Q02A).

Subcomponent # 2: Child has usual sources for both sick and well care (C4Q01-D, C4Q01-2).

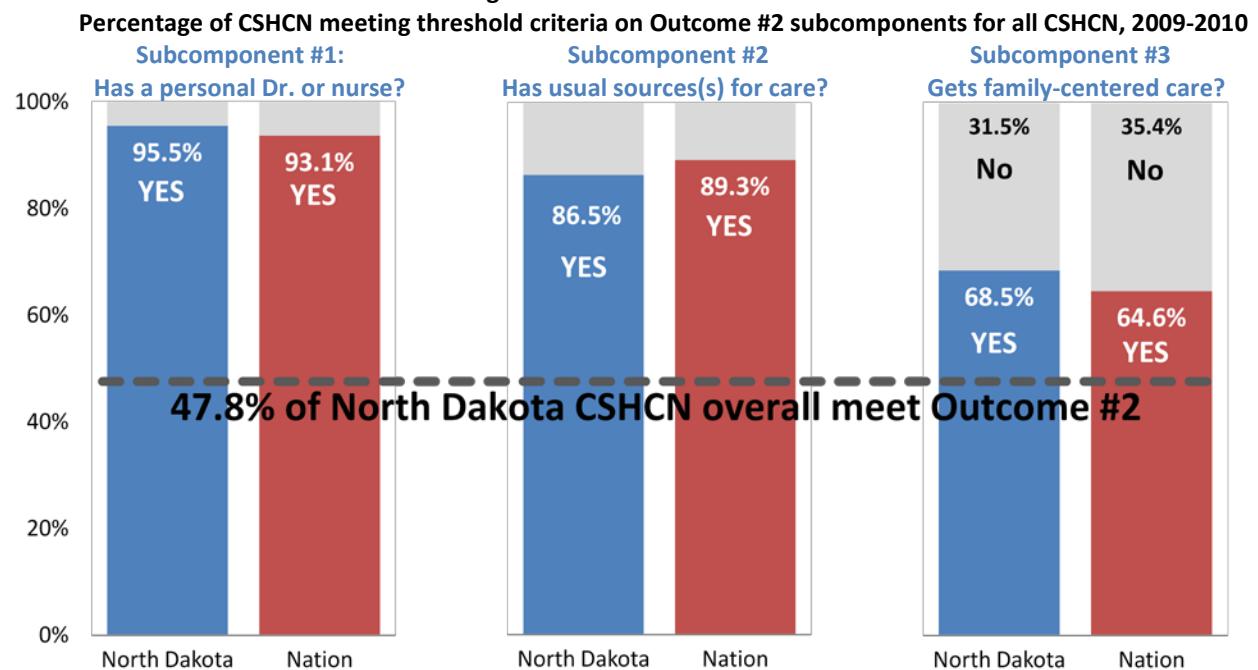
Subcomponent # 3: Child receives family-centered care from all doctors and other health-care providers (C6Q01-C6Q06).

Subcomponent # 4: Child gets needed referrals without problems (C5Q11,C4Q07).

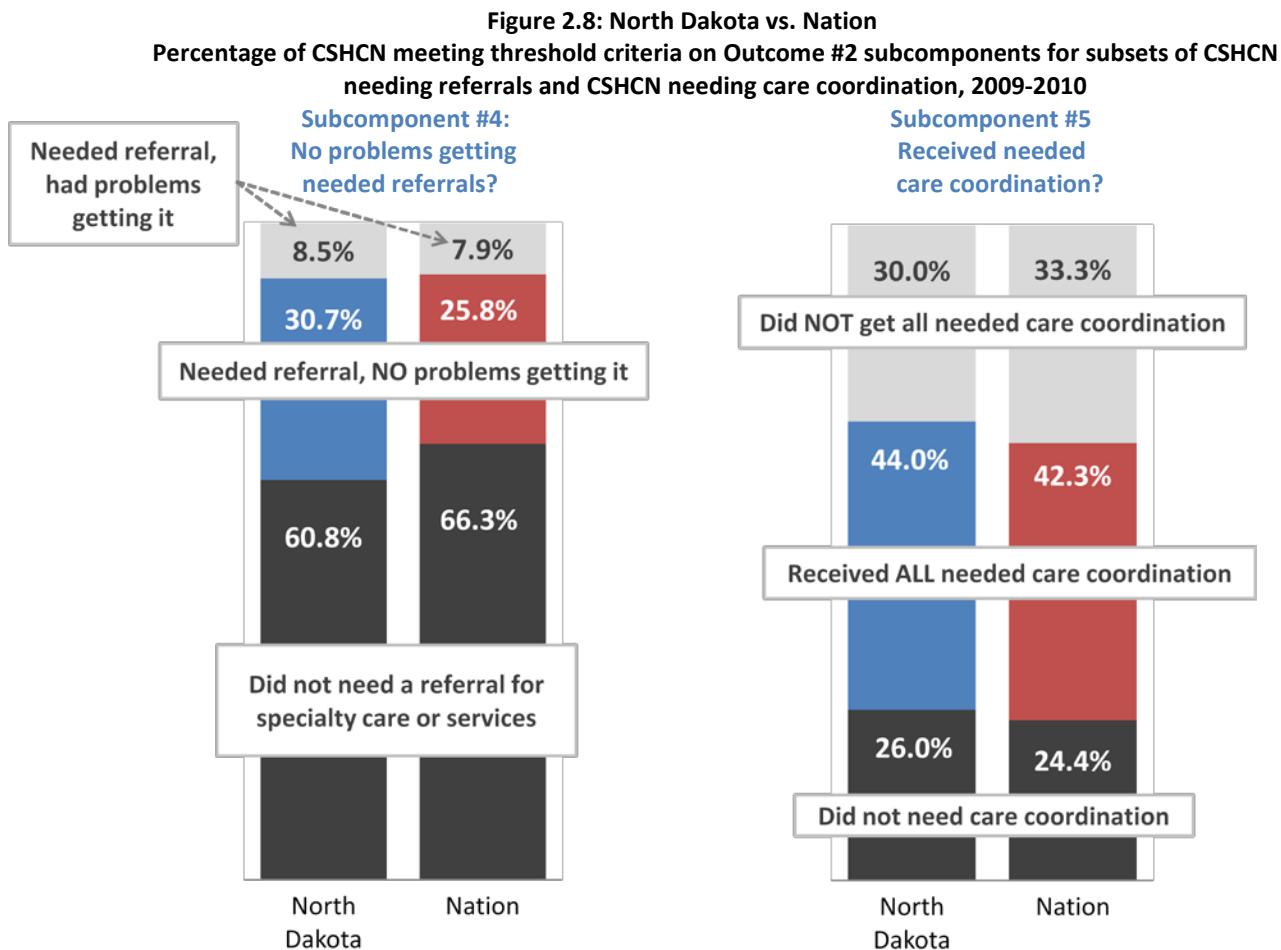
Subcomponent # 5: Child receives needed types of care coordination (C5Q05-06, C5Q09-10, C5Q12-17).

In a final step, the results from the subcomponents are combined into a single composite measure of the medical home outcome. To qualify as having a medical home, a child must get care that meets the threshold criteria for EVERY needed subcomponent of the medical home measure. CSHCN whose care fails to meet the threshold criteria for one or more needed subcomponents do not meet Outcome #2. Details of the threshold scoring for each subcomponent are shown in Appendix E. Three of the five subcomponents of Outcome #2 assess aspects of medical home care that apply to all CSHCN. The remaining two subcomponents (getting referrals and care coordination) address types of care typically needed by only a subset of the CSHCN population. The percentages of CSHCN in North Dakota and nationally meeting the threshold criteria on medical home outcome subcomponents are shown below and on the next page (Fig. 2.7 and Fig. 2.8).

Figure 2.7: North Dakota vs. Nation



MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.



In North Dakota ...

North Dakota performed close to the national estimate for medical home overall. In a similar manner, the medical home subcomponent results for CSHCN in North Dakota did not vary significantly from those for CSHCN nationally.

Within North Dakota, CSHCN fared better on some aspects of medical home care than on others:

- Nearly all CSHCN in North Dakota have established sources for health care. More than 90 percent have at least one doctor or nurse who knows them well, and a slightly lower percentage have places they usually go when sick or need preventive care (Fig. 2.7).
- Having regular sources for care does not ensure that the care is family-centered. Nearly one third of CSHCN in North Dakota did not consistently get family-centered care (Fig. 2.7).
- The majority of CSHCN overall in North Dakota (60.8%) did not need a referral for specialty care or services (Fig. 2.8; Fig. 2.10).
- Nearly three in four CSHCN (74%) in North Dakota needed one or more aspects of care coordination. Of that group, nearly six in 10 (59.5%) who did need help received all needed care coordination (Fig. 2.8; Fig. 2.12).

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

“UNBUNDLING” the Subcomponent Content: The scoring method used to create the composite measure for the medical home outcome allows further “unbundling” of content for some of the subcomponents. The next section presents “unbundled” content for the three Outcome #2 subcomponents where this is most relevant: Family-Centered Care, Getting Needed Referrals, and Care Coordination.

Subcomponent # 3: Family Centered Care

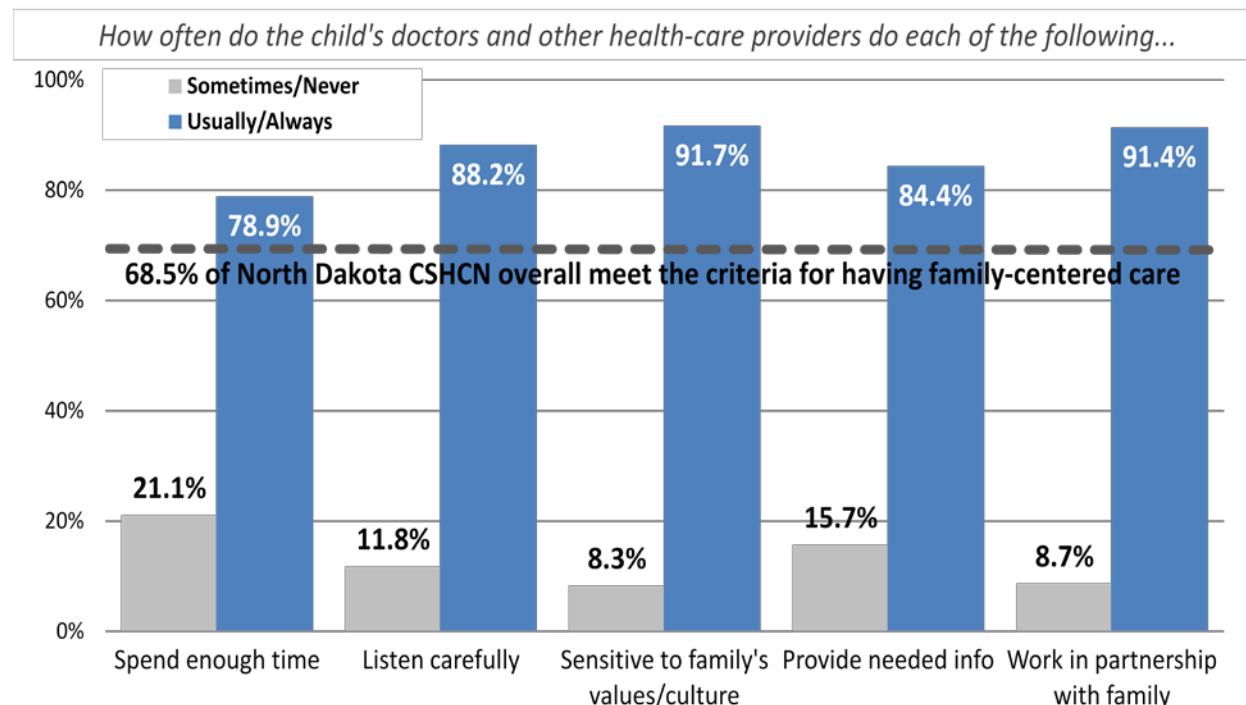
The Family-Centered Care subcomponent of the medical home outcome is based on five questions that ask HOW OFTEN the child’s doctors and other health-care providers:

- 1) Spend enough time with him or her?
- 2) Listen carefully to you?
- 3) Are sensitive to the family’s values and customs?
- 4) Give the specific information you need about your child’s health or health care?
- 5) Help you feel like a partner in your child’s care?

Responses of **“Usually or Always”** to all five family-centered care questions are required to meet the threshold criteria for having family-centered care.

- ▶ Of the five topics addressed by the Family-Centered Care questions, doctors and other health-care providers in North Dakota are the least likely to spend enough time with CSHCN and provide needed information about the child’s health and health care.
- ▶ A higher percentage of NEVER/SOMETIMES responses regarding time spent with the child (21.1%) and provision of needed information (15.7%) is what determines the overall results on the Family-Centered Care subcomponent (Fig. 2.9). This pattern is not unique to North Dakota- these specific aspects of family-centered care are also those less often experienced by CSHCN nationally.

Figure 2.9: Percentage of CSHCN in North Dakota usually or always receiving each of five different aspects of family-centered care, 2009-2010



MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

Subcomponent # 4: Getting Needed Referrals

The Getting Needed Referrals subcomponent of the medical home outcome is based on responses from two questions:

- 1) In the past 12 months, did (child name) need a referral to see any doctors or receive services?
 - 2) If YES to question above: Was getting referrals a big problem, small problem, or not a problem?
- Overall, over one in three CSHCN in North Dakota needed a referral to see other doctors or get services (39.2%). Among CSHCN who needed a referral, more than one in three (78.2%) had no problems getting one (Fig. 2.10).
 - The level of need for referrals ranged from 55.7 percent of children in the functional limitations group to 22.3% of CSHCN with conditions managed primarily by prescription medicine (Fig. 2.11).
 - Compared to other CSHCN in North Dakota, those with functional limitations are more likely to have problems getting the referrals they need (Fig. 2.11).

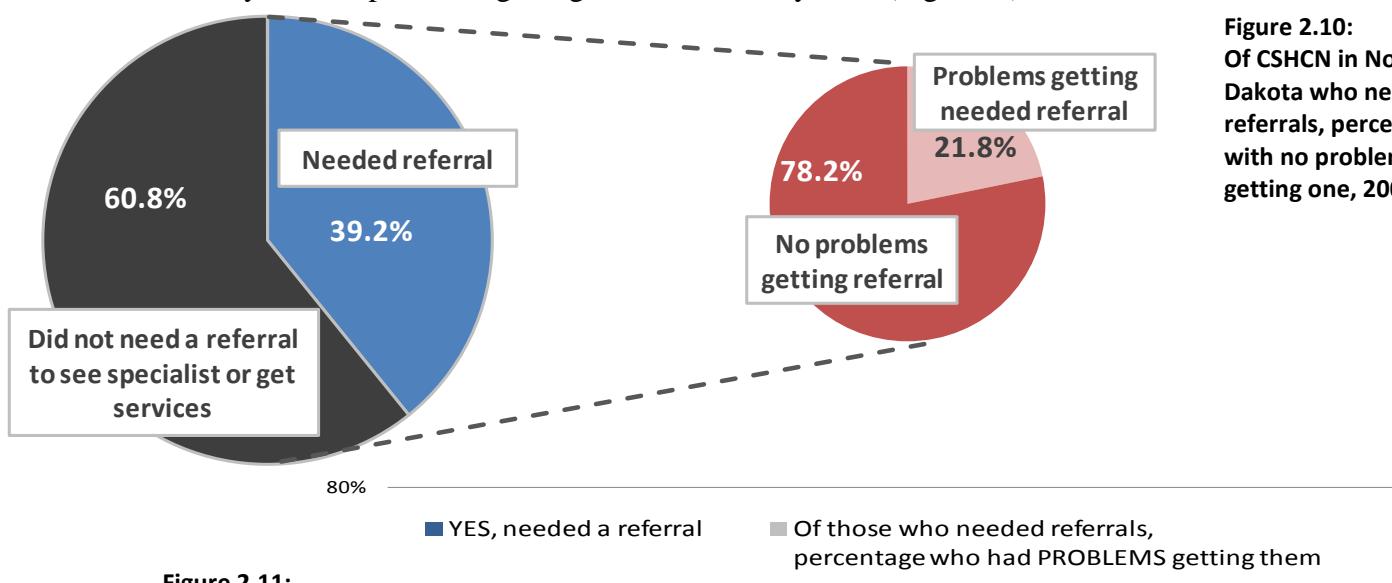
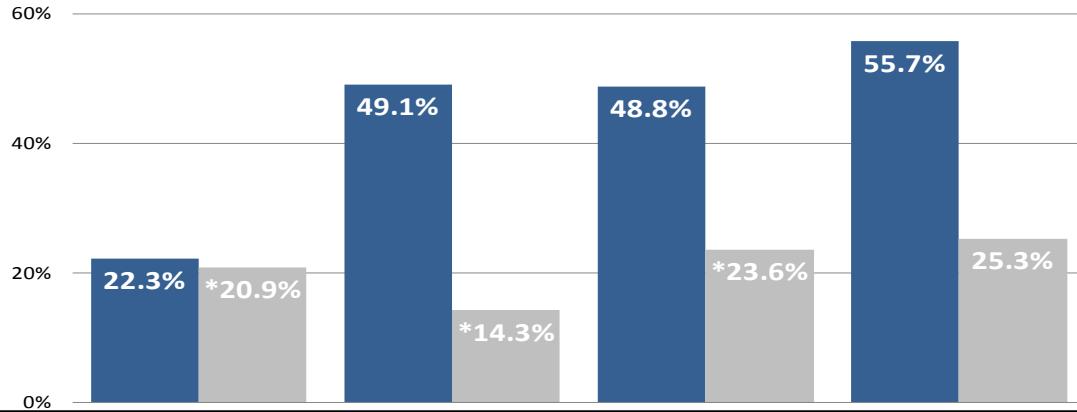


Figure 2.11:
Of CSHCN in North Dakota needing referrals, percentage with no problems getting one, by type of qualifying special needs, 2009-2010



* Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

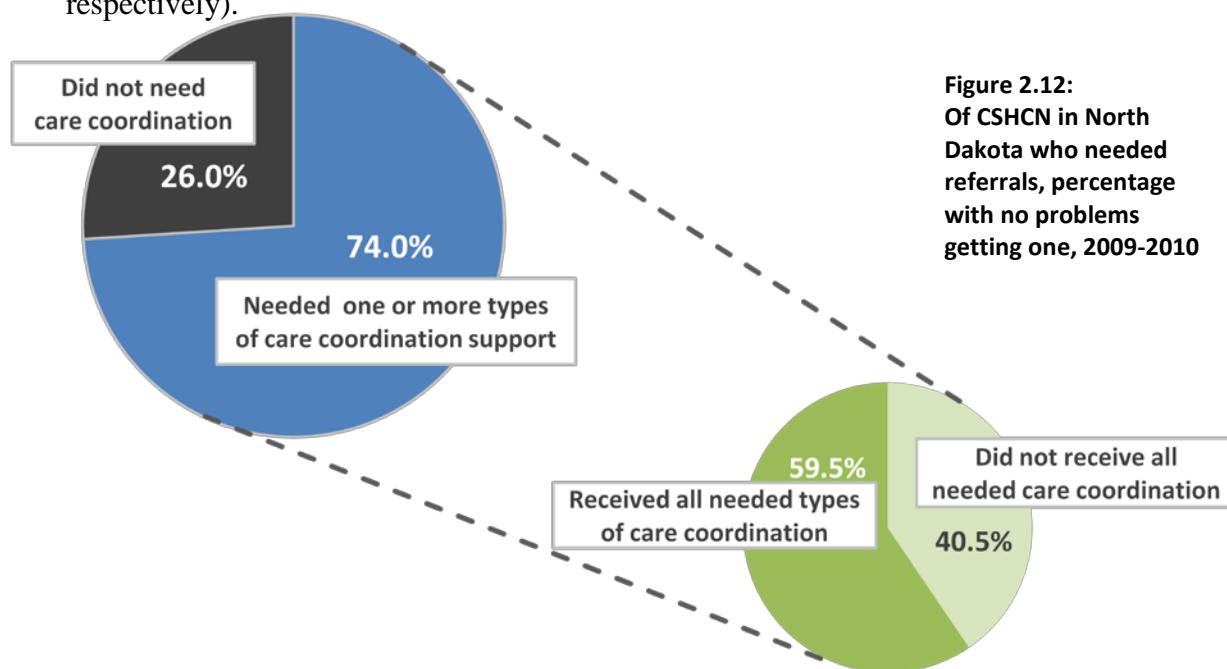
Subcomponent # 5: Getting Needed Care Coordination

To qualify as needing care coordination, children must first have survey responses indicating they used one or more health-related services during the past year. The Getting Needed Care Coordination subcomponent of the medical home outcome uses six questions to identify children needing one or more of three specific types of care coordination:

- 1) **Needed extra help with coordinating or arranging child's care among different health-care providers or services during the past 12 months.**
- 2) **Needed child's doctors or other health-care providers to communicate with each other.**
- 3) **Needed child's doctors or health-care providers to communicate with his/her school, child care or other programs.**

For CSHCN whose families needed extra help coordinating or arranging the child's care, responses indicating that they currently get such help or "Usually" received it when needed qualify as getting needed care coordination. For the groups who needed health-care providers to communicate with each other or with school/other programs, responses indicating that their families are "Very Satisfied" with such communication qualify as getting needed care coordination.

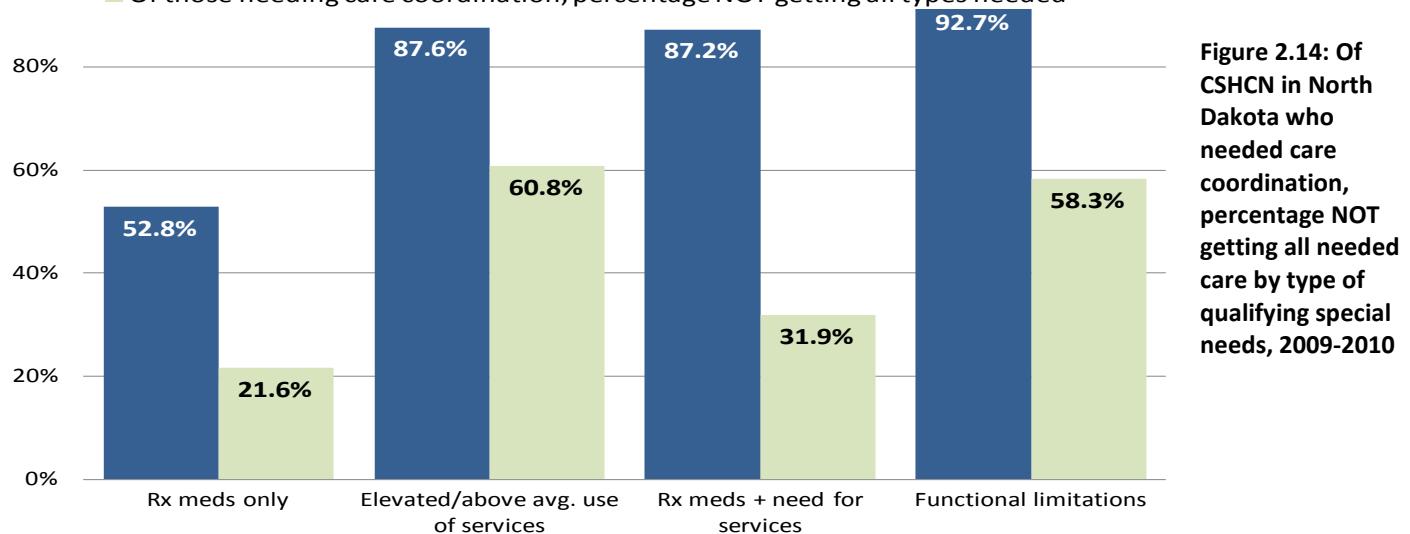
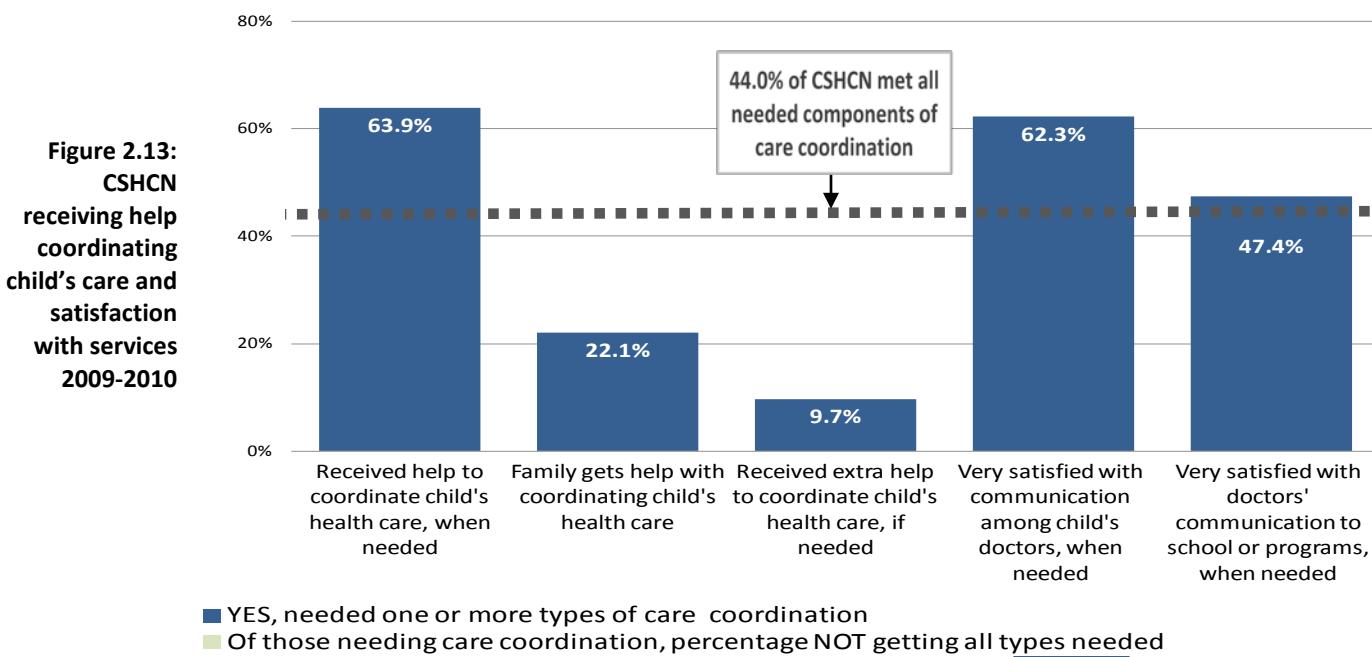
- ▶ Overall, about three-quarters of CSHCN in North Dakota needed one or more of the three types of care coordination assessed in the 2009-2010 NS-CSHCN (Fig. 2.12). Among CSHCN who needed some type of care coordination, close to three-fifths (59.5%) received the support needed (Fig. 2.12).
- ▶ The percentage of CSHCN in North Dakota who needed and received all care coordination is not significantly different from that for CSHCN nationally (59.5% vs. 56%, respectively).



MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

The effective care coordination part of Medical Home summary measure is derived from three separate components: 1) CSHCN's families receive some type of help with care coordination; 2) CSHCN's families are VERY SATISFIED with communication; and 3) when such interactions are needed, families are VERY SATISFIED with how child's doctors communicate with school, day care or other programs.⁹

- ▶ CSHCN in North Dakota are most likely to lack adequate care coordination in the area of families getting help (including extra help, if needed) with coordinating health care and being satisfied with communication between their doctors/other providers and schools or other programs (Fig. 2.13).
- ▶ North Dakota CSHCN whose special health needs are managed by elevated/above average use of services (60.8%) or functional limitation (58.3%) are less likely than other CSHCN in the state to have all of their care coordination needs met (Fig. 2.14).



MCHB Core Outcome #3

CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

Adequacy of insurance is assessed in the National Survey of Children with Special Health-Care Needs (NS-CSHCN) using three questions: whether or not health insurance benefits met the child's needs, whether non-covered charges were reasonable, and whether the plan allows the child to see providers he or she needs. In addition, children without any insurance at the time of the survey or without coverage for any period of time in the past year were considered *not to* have adequate insurance.¹³

Highlights...

- ▶ **More than three in five CSHCN in North Dakota have adequate insurance to pay for needed services.**
In 2009-2010, close to 12,000 CSHCN (60.1%) in North Dakota had insurance coverage adequate for their needs.
- ▶ **In 2009-2010, the proportion of CSHCN in North Dakota experiencing adequate insurance coverage decreased compared to 2005-2006 (60.1% vs. 68.2%, respectively).**
- ▶ **CSHCN in North Dakota successfully meeting this outcome are more likely to:**
 - Be from households with higher incomes.
 - Be privately insured.
 - Be from a two parent biological or adoptive family.
 - Be birth through 11 years old.
 - Be managed by prescription medication.
 - Have a medical home.

See Appendices for details and additional results

Figure 3.1: North Dakota vs. Nation Percentage meeting Outcome #3 in 2009-2010 (Ages 0-17)

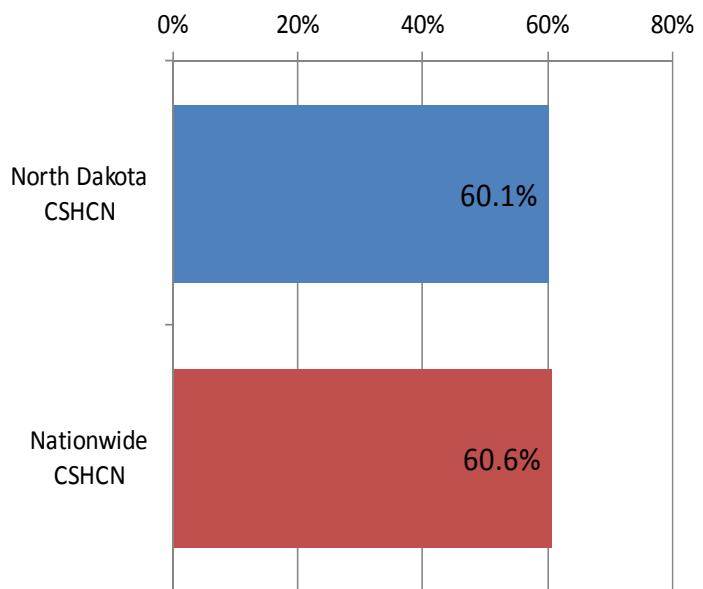
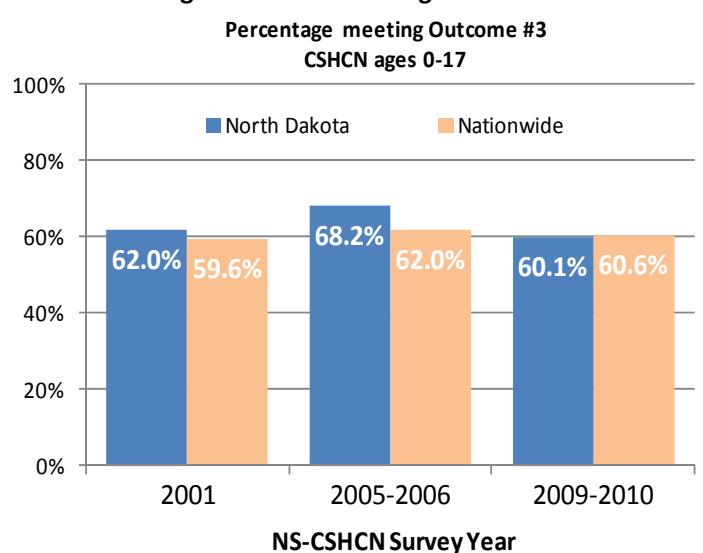


Figure 3.2: 2001 through 2009-2010 Percentage meeting Outcome #3 CSHCN ages 0-17

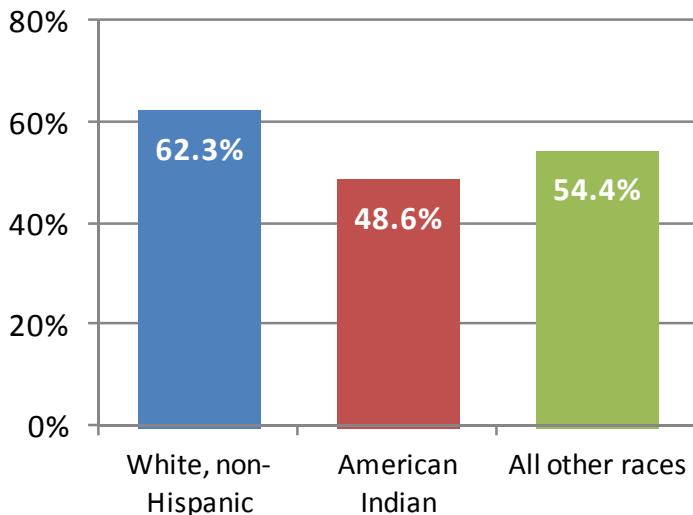


MCHB Core Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

Outcome #3: Key Findings for North Dakota

- Race/ethnicity of CSHCN is associated with having adequate insurance.

Figure 3.3: Percentage of CSHCN in North Dakota meeting Outcome #3 by race/ethnicity, 2009-2010



In North Dakota...

White, non-Hispanic CSHCN are more likely to experience adequate health insurance coverage.

- CSHCN from households at or just above the federal poverty level (FPL) are at greatest risk for not having adequate insurance coverage.

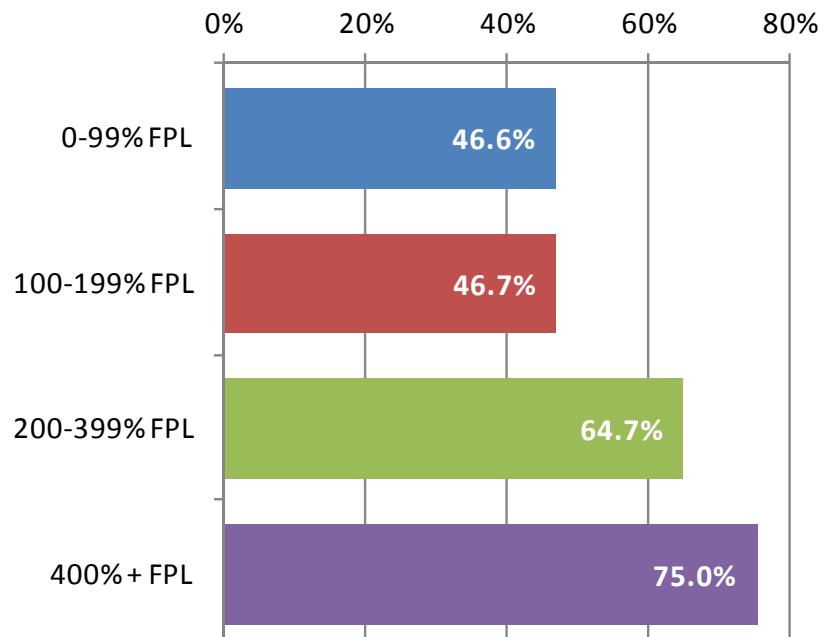
In North Dakota...

Findings suggest CSHCN from households at or just above the federal poverty level are less likely to have adequate insurance (below 200% of FPL).

Nearly half of CSHCN from households at or just above the federal poverty level met Outcome #3 in 2009-2010, compared to nearly two-thirds of CSHCN in families living slightly above the poverty line (200-399%).

Three-quarters of CSHCN from more affluent households (200% FPL and above) had adequate insurance coverage during the same time period.

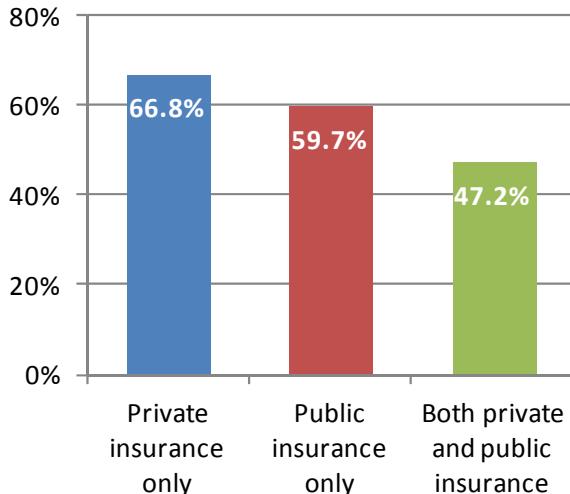
Figure 3.4: Percentage of CSHCN in North Dakota meeting Outcome #3 by federal poverty level (FPL), 2009-2010



MCHB Core Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

- Type of insurance is not related to adequacy of coverage for CSHCN in North Dakota.

Figure 3.5: Percentage of CSHCN in North Dakota meeting Outcome #3 by insurance status and insurance type, 2009-2010

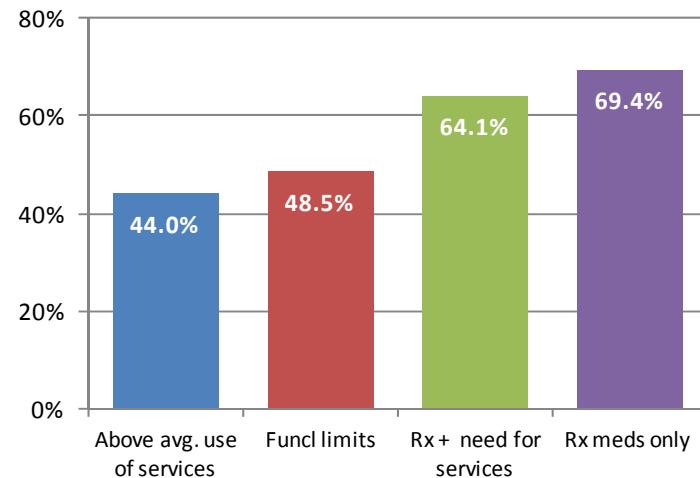


In North Dakota...

CSHCN with only public insurance or with both private and public insurance are not as likely as those with private coverage to have benefits that adequately address their care and service needs.

- CSHCN whose chronic conditions result in some type of functional limitations and above use of services are somewhat less likely than other CSHCN to have adequate insurance coverage.

Figure 3.6: Percentage of CSHCN in North Dakota meeting Outcome #3 by type of qualifying special needs, 2009-2010



In North Dakota...

CSHCN in North Dakota fared slightly worse than CSHCN nationally on this outcome overall (60.1% vs. 60.6%); at least 7,768 CSHCN (39.9%) in the state did not have adequate insurance coverage during 2009-2010.

CSHCN whose health needs are more complex or require a range of services are more likely than other CSHCN to lack adequate insurance.

In 2009-2010, only 44 percent of CSHCN with above routine need/use of services and 48.5 percent of CSHCN with functional limitations had insurance that adequately covered the services and types of care needed during the year.

MCHB Core Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

Outcome #3: Key Subcomponent Findings for North Dakota

MCHB Core Outcome #3 is measured using responses from two sets of questions asked in the National Survey of Children with Special Health-Care Needs (NS-CSHCN). CSHCN meet Outcome 3 when the respondent answers that:

- 1. Their child was insured at the time of the survey and has had no gaps in coverage in the previous 12 months (UNINS, UNINS_YR).**
- 2. Their child's health insurance offers benefits that usually or always meet the child's needs (C8Q01_A).**
- 3. The non-covered insurance charges are usually or always reasonable (C8Q01_B).**
- 4. Their child's health insurance usually or always allows him or her to see needed providers (C8Q01_C).**

A response of “Yes” to currently insured with no gaps in coverage during the past year AND responses of “Usually” or “Always” to all three of the insurance adequacy questions are needed. Only CSHCN who meet criteria for both subcomponents are classified as meeting Outcome #3. The percentages of CSHCN in North Dakota with qualifying responses on each of these questions overall and by selected subgroups are presented below.

In North Dakota ...

CSHCN categorized as having gaps in insurance coverage include those who were uninsured at the time of the survey **and** those for whom there were periods of no coverage during the past 12 months.

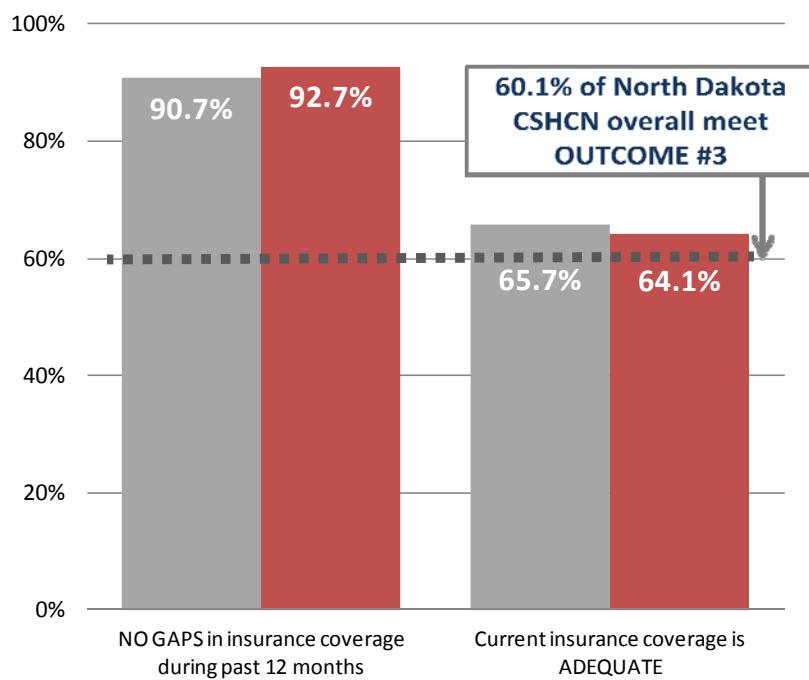
In North Dakota, 3.2 percent of CSHCN overall were uninsured at the time of this survey.

CSHCN in North Dakota are a great deal more likely to have consistent insurance coverage, without gaps, than they are to have adequate coverage.

North Dakota performed slightly worse than the nation on Outcome #3; more than one-third CSHCN reportedly have inadequate health insurance coverage (35.9%). Current insurance coverage inadequacy has increased by 10 percent compared with 2005-2006 (35.9% vs. 26%, respectively).

Figure 3.7: North Dakota vs. the Nation
Percentage of CSHCN with qualifying responses on the subcomponents of Outcome #3, 2009-2010

■ National ■ North Dakota



MCHB Core Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

- Adequacy of insurance is a composite measure consisting of three questions:
 - How often does the child's health insurance offer benefits or cover services that meet his/her needs?
 - Does the child's health insurance allow him/her to see the health-care providers he/she needs?
 - Are the costs not covered by the child's health insurance reasonable?

Criteria for adequate insurance were responses of "usually" or "always" to all three component questions (Fig. 3.8).

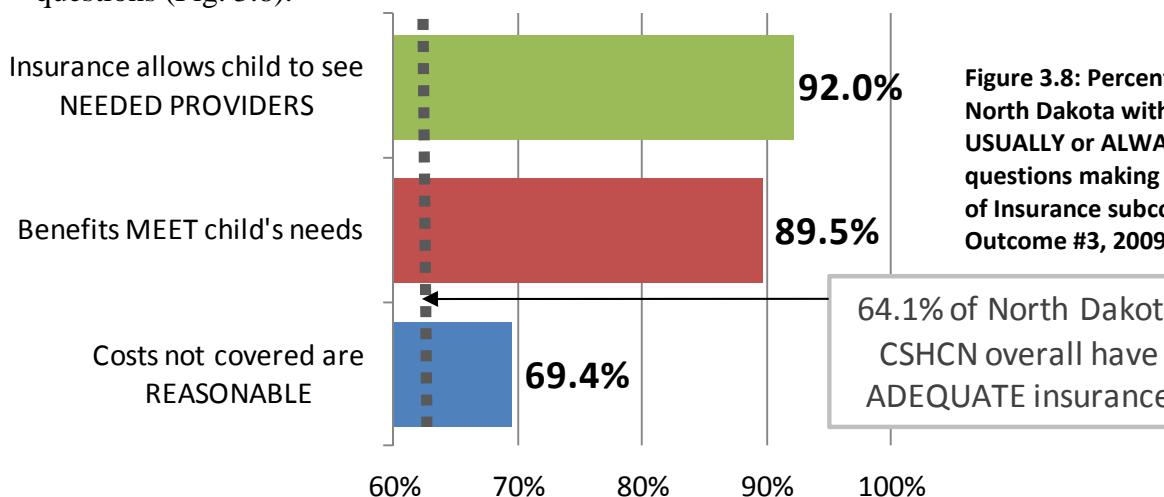
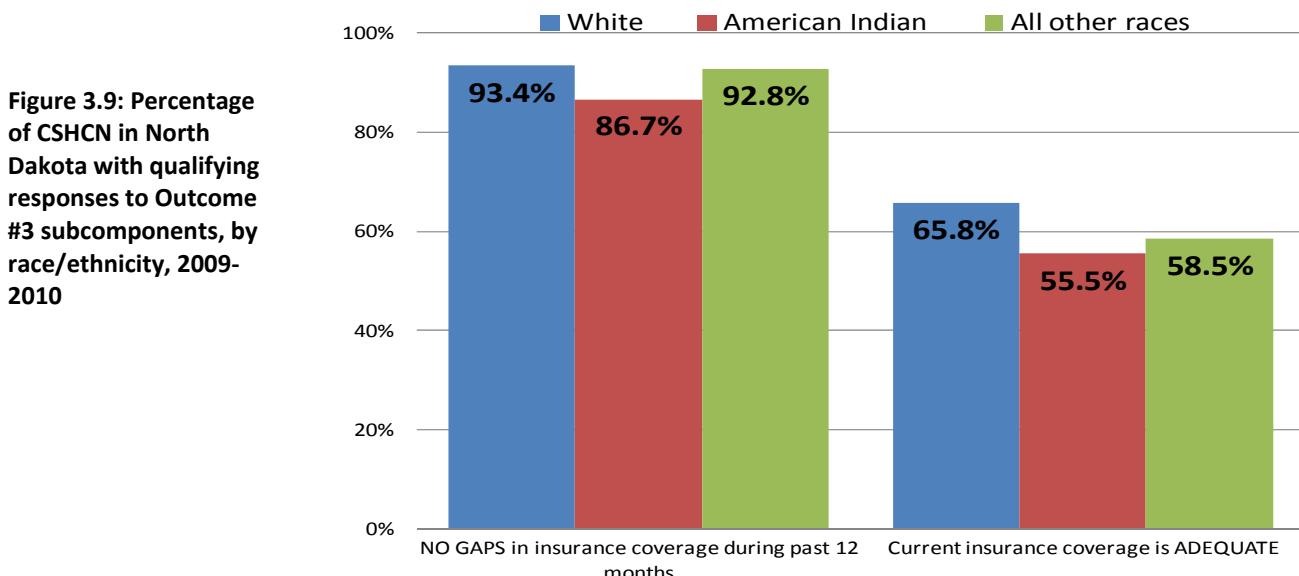


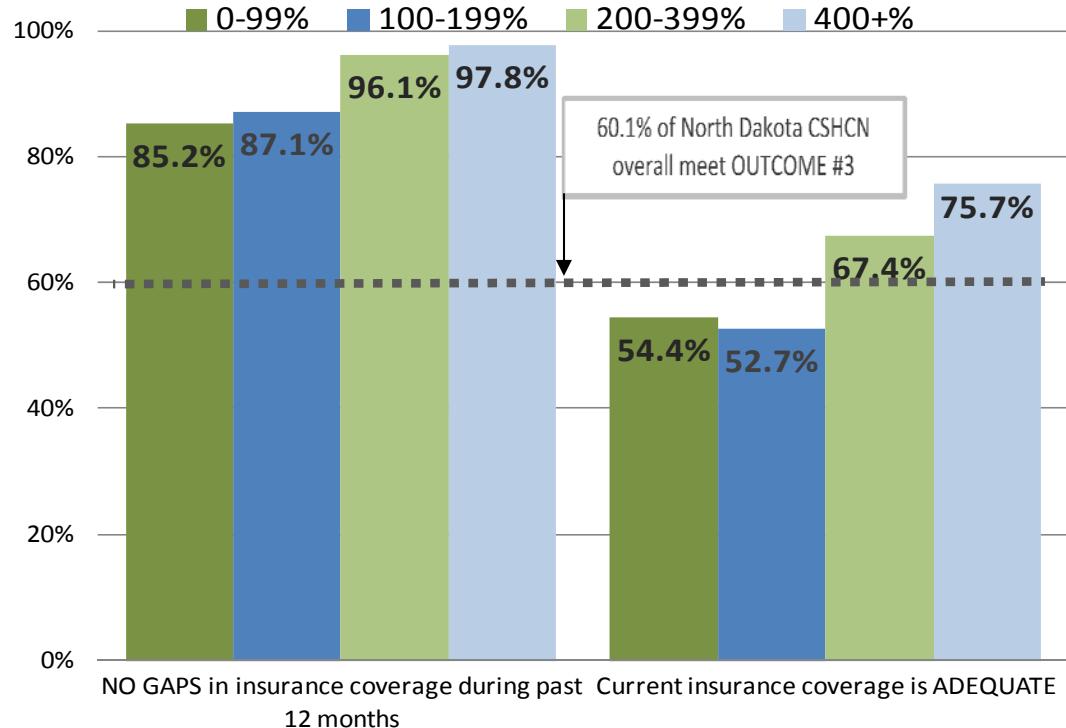
Figure 3.8: Percentage of CSHCN in North Dakota with responses of USUALLY or ALWAYS on the questions making up the Adequacy of Insurance subcomponent of Outcome #3, 2009-2010

- Gaps in coverage play a role in the slight variation in performance on Outcome #3 for CSHCN from different race/ethnicity backgrounds (Fig. 3.9). Non-white CSHCN are less likely than other CSHCN to have adequate insurance without gaps in coverage. However, association between insurance coverage for the entire 12-month period prior to the survey is not as strong. Compared to 2005-2006, adequacy of insurance among CSHCN decreased and a higher proportion of CSHCN were continuously insured.

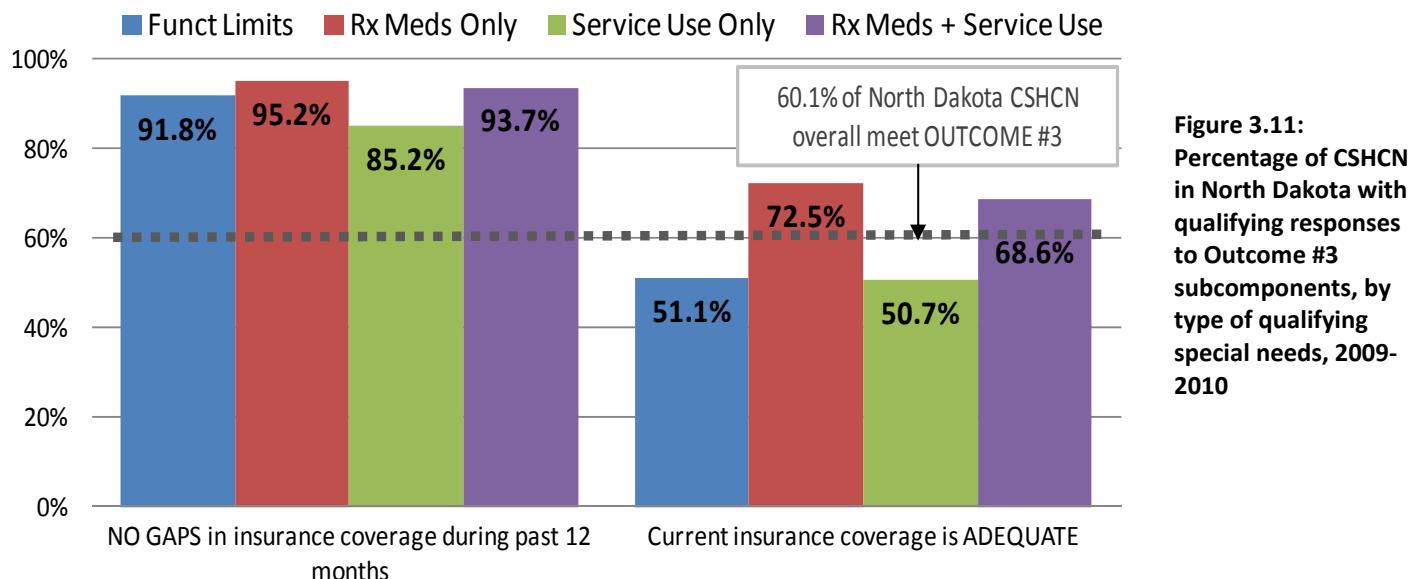


MCHB Core Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need.

- Continuity and adequacy of insurance coverage is associated with higher income. Still, more than 85 percent of CSHCN living in households with incomes below or near the federal poverty level (up to 199% FPL) were insured for the entire year without any gaps. Just over half of CSHCN at or slightly above FPL (0-199%) did not have adequate insurance coverage (Fig 3.10).



- Underinsurance for specific groups was a key factor in performance variation on Outcome #3 for CSHCN with different types of qualifying special health needs. In North Dakota, CSHCN whose special needs include functional limitations and those whose health conditions are managed by services more often experienced underinsurance compared to CSHCN with other types of qualifying needs (Fig. 3.11).



MCHB Core Outcome #4

CSHCN will be screened early and continuously for special health-care needs.

The National Survey of Children with Special Health-Care Needs (NS-CSHCN) addressed the ongoing screening and surveillance component of this outcome. The estimate for this outcome was arrived at using two survey questions that assessed whether CSHCN received a well-child check-up or routine preventive dental care in the past 12 months.¹³ CSHCN needed to receive BOTH types of preventive care during the past year to meet the ongoing screening and surveillance component of Outcome #4.

Highlights...

- ▶ **Nearly seven in 10 CSHCN in North Dakota had BOTH a well-child check-up and preventive dental visit.** In 2009-2010, approximately 13,000 (66.8%) CSHCN in North Dakota received the types of care that facilitate early and continuous screening.
- ▶ **CSHCN in North Dakota are significantly less likely to meet this outcome than CSHCN nationally (66.8% vs. 78.6%).** See Appendix C.
- ▶ **CSHCN in North Dakota successfully meeting this outcome are more likely to:**
 - Be school-age children
 - Live in higher income households.
 - Have private health insurance.
 - Have a medical home.
 - Be part of a two-parent family.
 - Not have above routine need/use of services.
 - Be consistently insured.
- ▶ **The percentage of CSHCN meeting this outcome in North Dakota did NOT vary meaningfully by:**
 - Child's race/ethnicity.

See appendices for details and additional results for Outcome #4.

Figure 4.1: Percentage of CSHCN in North Dakota meeting Outcome #4 by race/ethnicity, 2009-2010

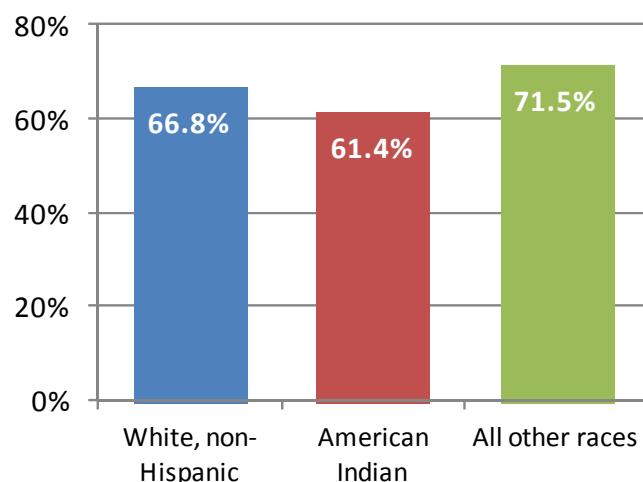
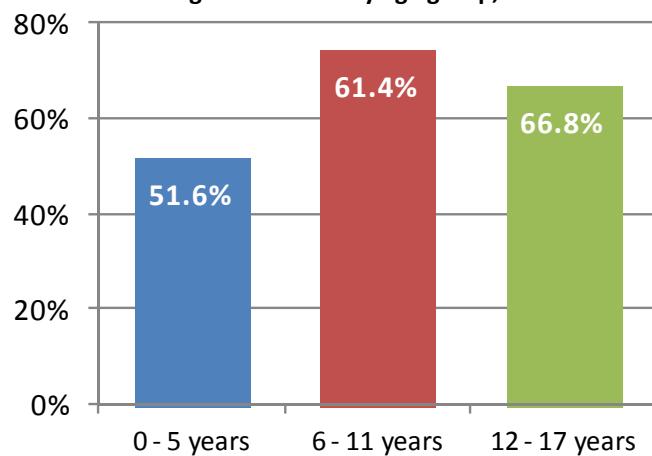


Figure 4.2: Percentage of CSHCN in North Dakota meeting Outcome #4 by age group, 2009-2010



2005-2006 vs. 2009-2010: Not Available

Estimates for Outcome #4 cannot be compared across survey years because of changes to the questions.

MCHB Core Outcome #4: CSHCN will be screened early and continuously for special health-care needs.

Outcome #4: Key Findings for North Dakota

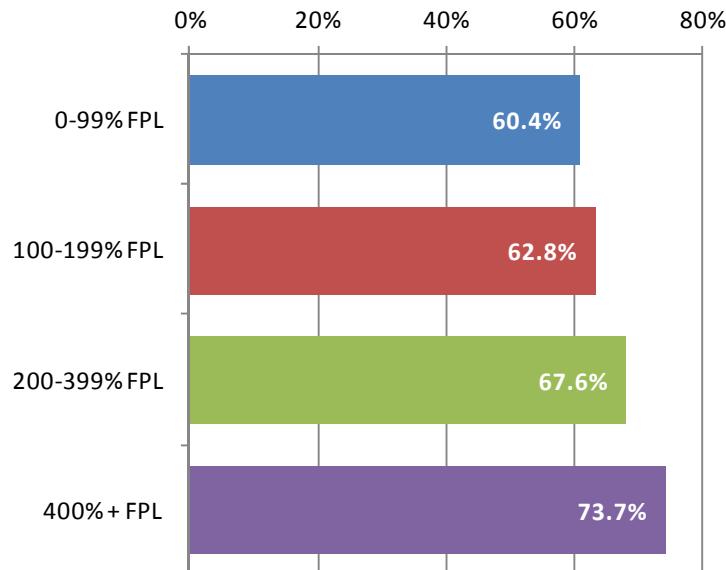
- CSHCN from lower income households are less likely to receive the types of care that facilitate ongoing screening for both medical and dental issues.

In North Dakota...

Two in five CSHCN living at or below the FPL (60.4%) received BOTH a well-child check-up AND dental preventive care in 2009-2010.

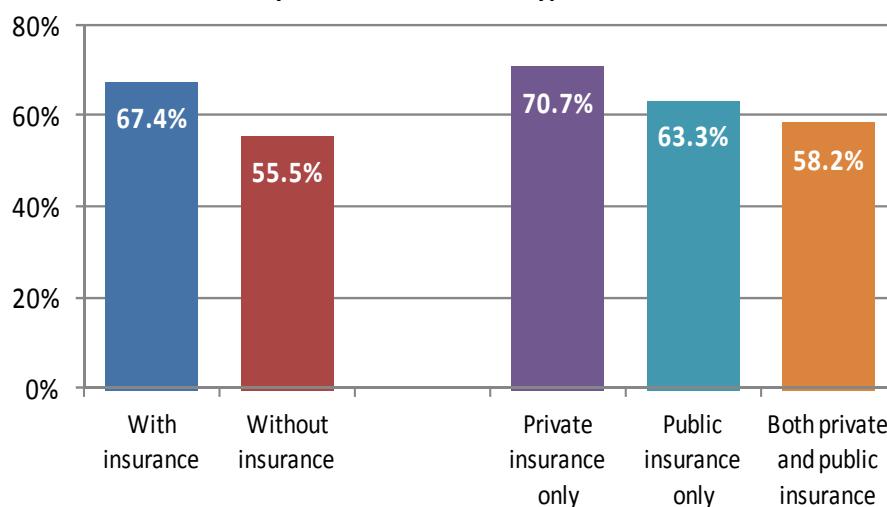
In contrast, nearly three-fourths of CSHCN from the state's more affluent households (400% + FPL) had both types of preventive care visits during the same time period.

Figure 4.3: Percentage of CSHCN in North Dakota meeting Outcome #4 by federal poverty level (FPL), 2009-2010



- Insurance status plays an important role in whether CSHCN in North Dakota receive the types of care that facilitate ongoing screening for both medical and dental issues.

Figure 4.4: Percentage of CSHCN in North Dakota meeting Outcome #4 by insurance status and type of insurance, 2009-2010



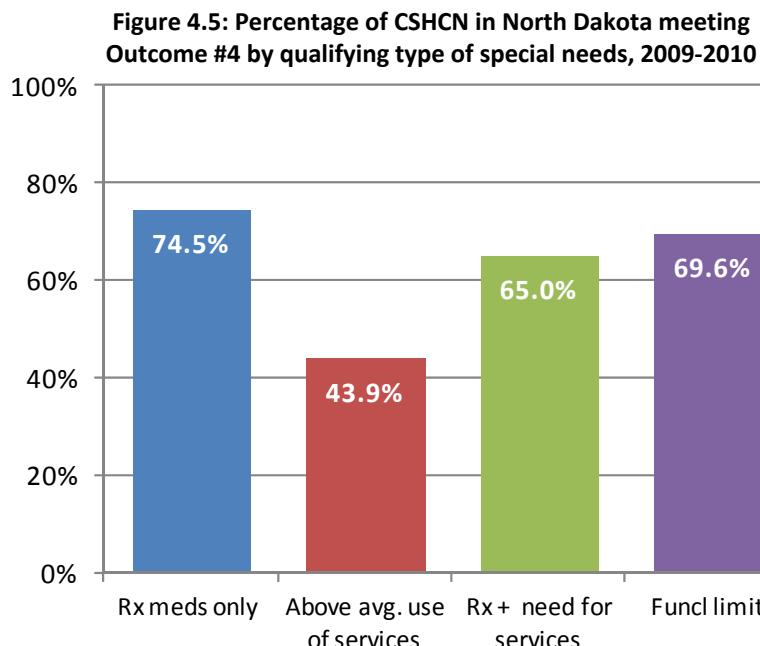
In North Dakota...

CSHCN without insurance are not as likely as those with current coverage to meet this outcome (55.5% vs. 67.4%, respectively).

CSHCN with only public insurance and those with both public and private insurance were less likely than CSHCN with only private coverage to receive BOTH medical and dental preventive care during 2009-2010.

MCHB Core Outcome #4: CSHCN will be screened early and continuously for special health-care needs.

- Complexity or type of special health-care needs is associated with whether CSHCN receive care that facilitates ongoing screening for both medical and dental issues.



In North Dakota...

At least 6,500 CSHCN overall (33.2%) missed opportunities for ongoing medical and dental screening during 2009-2010.

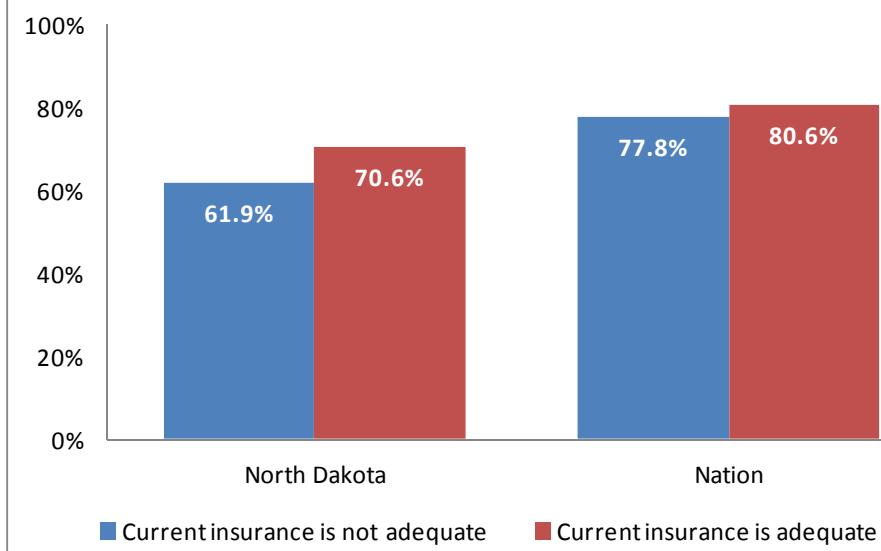
More than two-fifths of CSHCN that required above routine need/use of services (43.9%) receive ongoing screening for medical and dental issues, indicating that over more than half (56.1%) do not receive this screening.

Figure 4.6: Percentage of CSHCN in North Dakota meeting Outcome #4 by current insurance adequacy, 2009-2010

In North Dakota...

CSHCN with adequacy of current insurance are more likely to meet outcome measure #4.

The proportion of North Dakota CSHCN meeting outcome measure #4 and having adequate insurance is lower than the national estimates.



MCHB Core Outcome #4: CSHCN will be screened early and continuously for special health-care needs.

Outcome #4: Key Subcomponent Findings for North Dakota

MCHB Core Outcome #4 measures ongoing assessment of CSHSN health needs and is comprised of responses to two series of questions in the National Survey of Children with Special Health-Care Needs (NS-CSHCN)⁹.

1. [During the past 12 months / Since [his/her] birth], how many times did [child] receive a well-child check-up, that is a general check-up, when [he/she] was not sick or injured? (K4Q20)
2. [During the past 12 months / Since [his/her] birth], how many times did [child] see a dentist for preventive dental care, such as check-ups and dental cleanings? (age 1-17 years, K4Q21)

For CSHCN to meet Outcome 4, they must have had preventive medical and dental care in the prior 12 months (visits where screening may have occurred).

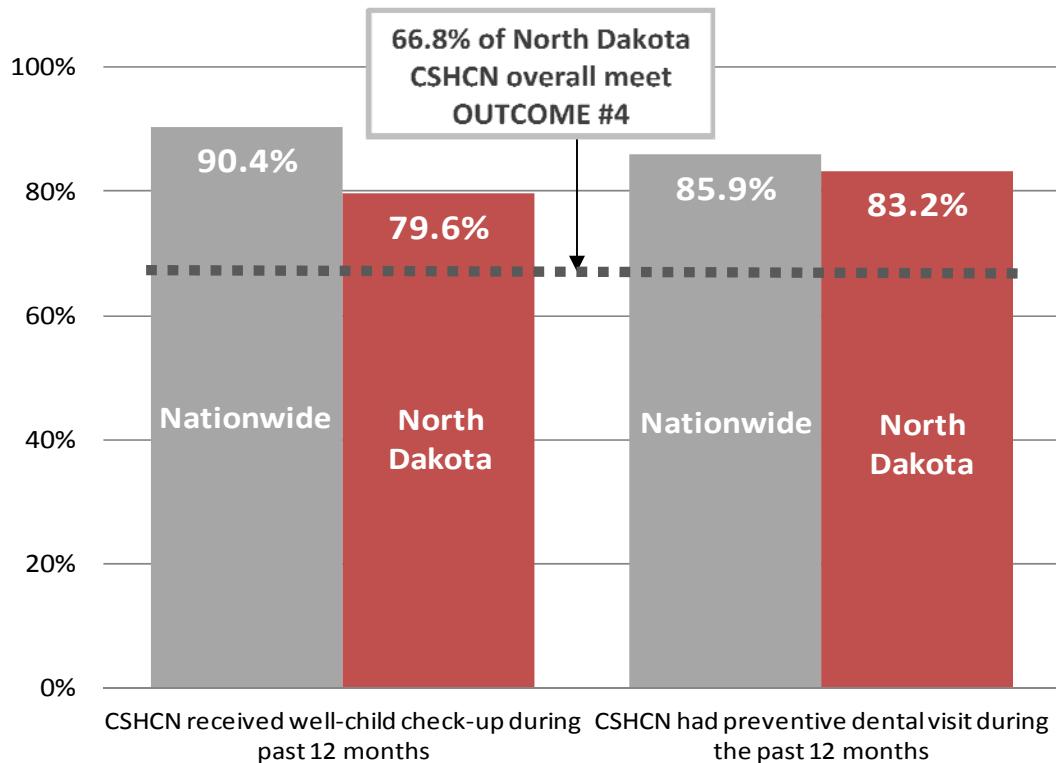
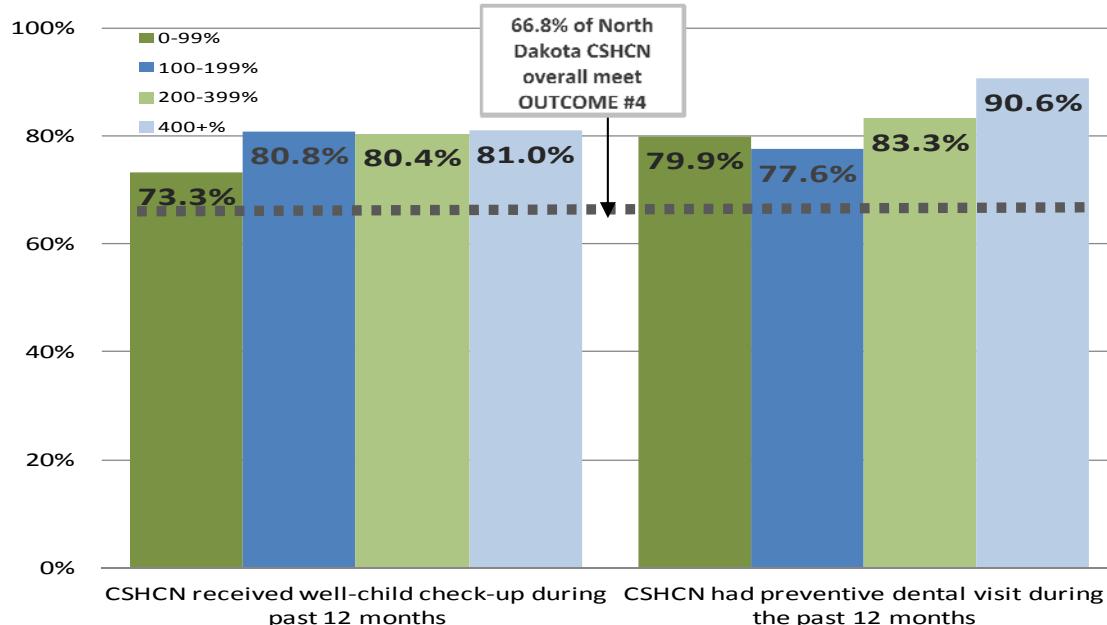


Figure 4.7:
North Dakota vs. Nation
Percentage of CSHCN
with qualifying
responses on the
subcomponents of
Outcome #4, 2009-2010

MCHB Core Outcome #4: CSHCN will be screened early and continuously for special health-care needs.

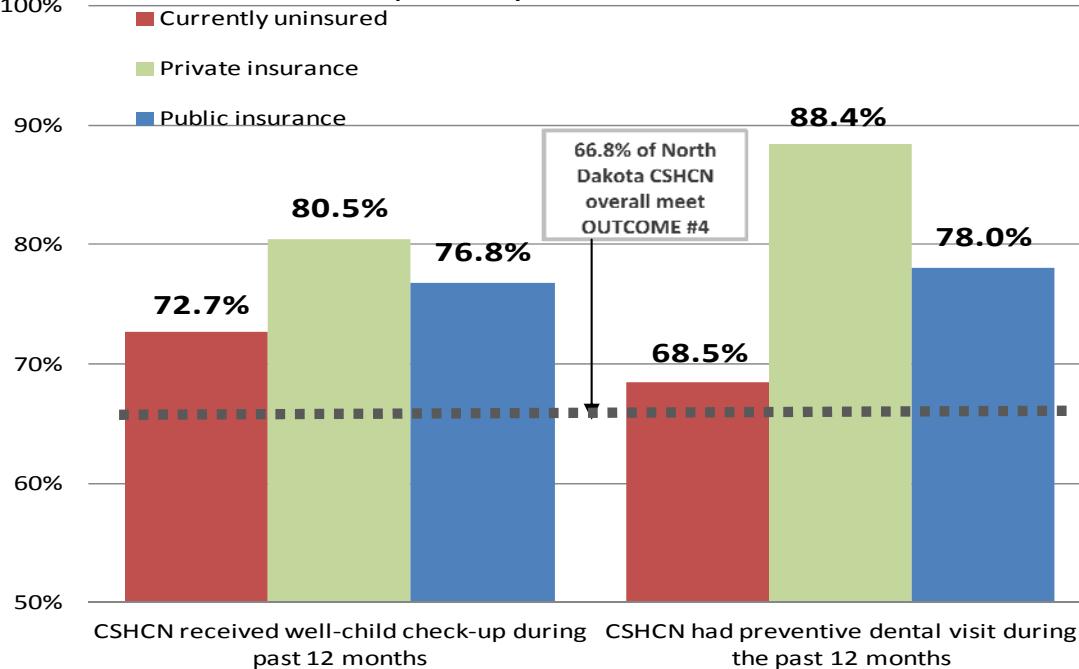
- The trend toward better access to preventive health services among CSHCN from higher income families is not apparent for well-child checkups (Fig.4.8). Only slightly more than three-fourths of CSHCN just above the FPL (100-199%) had a preventive dental visit.

Figure 4.8: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by federal poverty level (FPL), 2009-2010



- Health insurance is an important factor in access to preventive and screening services among CSHCN in North Dakota. CSHCN who are uninsured or only have public insurance are less likely than insured CSHCN to have had a well-child check-up or dental care (Fig.4.9).

Figure 4.9: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by insurance status, 2009-2010



MCHB Core Outcome #4: CSHCN will be screened early and continuously for special health-care needs.

- Separate assessment of the medical and dental components of Outcome #4 reveals different patterns according to both age and sex. The percentage of CSHCN receiving a well-child check-up and preventive dental visits was slightly higher among females (Fig 4.10). Preschool-age CSHCN are more likely than older children to have had a well-child check-up and less likely to have had a dental checkup (Fig. 4.11).

Figure 4.10: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by sex, 2009-2010

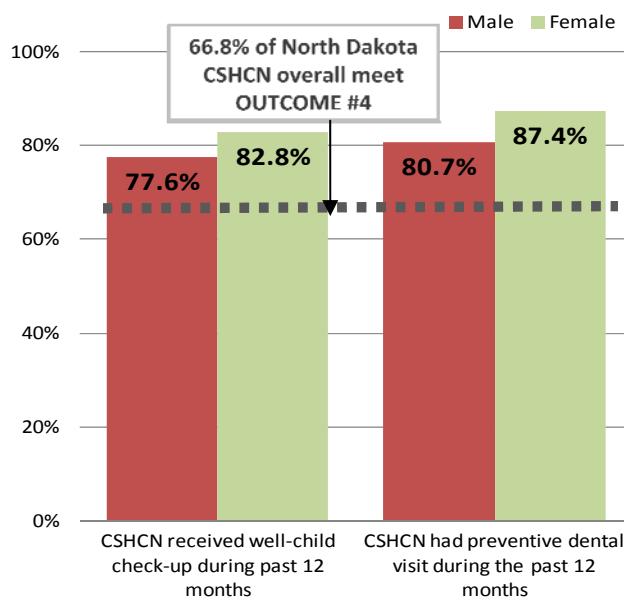
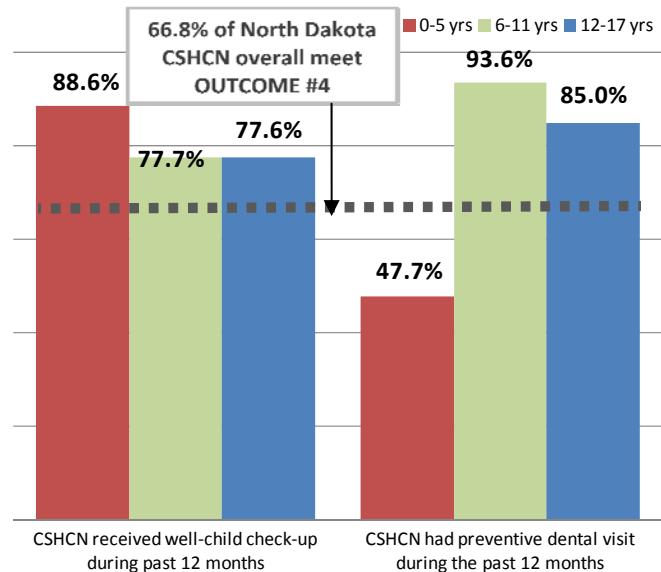
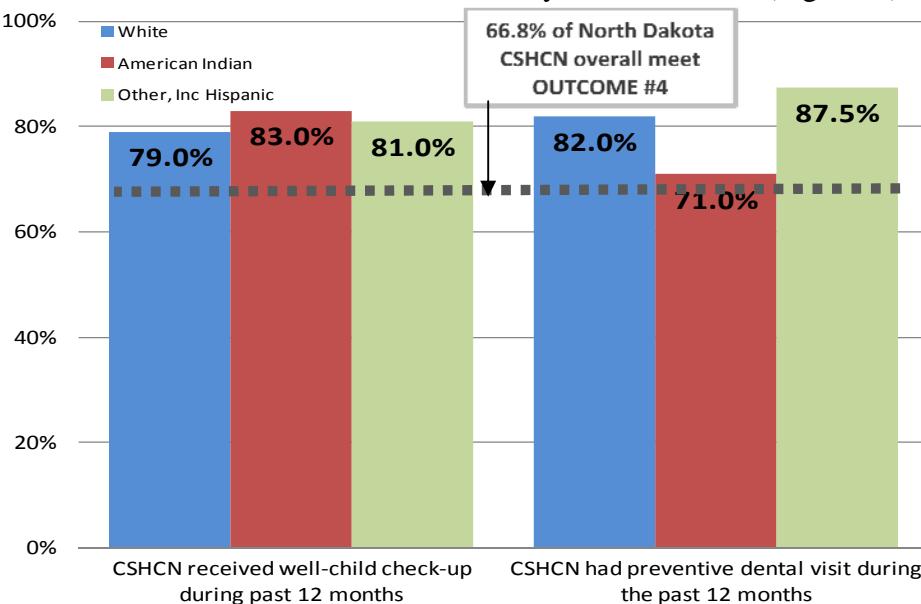


Figure 4.11: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by age group, 2009-2010



- The results of the components of Outcome #4 among white non-Hispanic CSHCN (Fig. 4.12) reflect the overall results for both subcomponents (Fig. 4.7) in North Dakota. The likelihood of having a well-child check-up is elevated among minority CSHCN. For dental services, however, receipt by American Indian CSHCN falls considerably short of whites (Fig. 4.12).

Figure 4.12: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by race/ethnicity, 2009-2010



MCHB Core Outcome #5:

CSHCN who can easily access community-based services.

This outcome is assessed by the 2009-2010 National Survey of Children With Special Health-Care Needs (NS-CSHCN) using multiple questions asking parents whether they experienced any difficulties or frustrations trying to obtain use of the range of services their children needed over the past year.¹³

Highlights...

- ▶ **Nearly seven in 10 CSHCN in North Dakota had no difficulties accessing needed community-based services.**
In 2009-2010, more than 13,100 CSHCN in North Dakota successfully met this outcome.
- ▶ **North Dakota is doing *better* than the national estimate for this outcome.**
CSHCN in North Dakota are more likely to meet this outcome than CSHCN nationally (67.9% vs. 65.1%, respectfully). See Appendix C.
- ▶ **CSHCN in North Dakota successfully meeting this outcome are more likely to be:**
 - Privately insured (74.9%).
 - Of higher income brackets.
 - Managing chronic conditions primarily through prescription medication.
- ▶ **The percentage of CSHCN meeting this outcome in North Dakota did NOT vary meaningfully by:**
 - Age group.
 - Race/ethnicity.
 - Gender.

See Appendices for details and additional results for Outcome #5.

Figure 5.1: North Dakota vs. Nation Percentage of CSHCN meeting Outcome #5 in 2009-2010 (Ages 0-17)

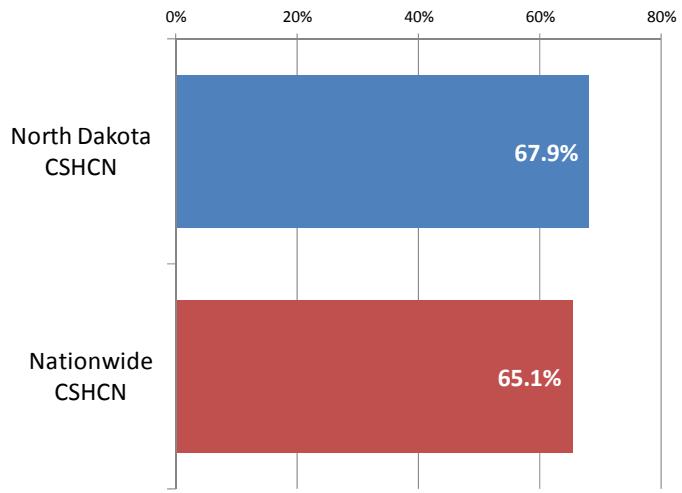
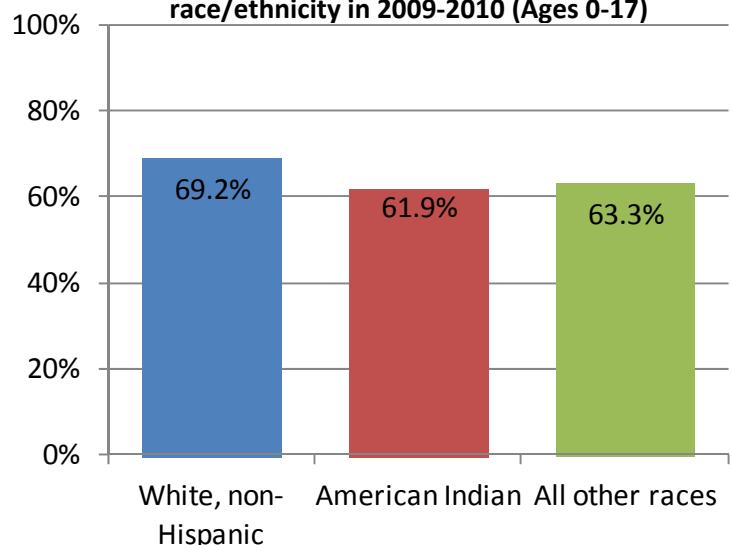


Figure 5.2: North Dakota Percentage of CSHCN meeting Outcome #5 by race/ethnicity in 2009-2010 (Ages 0-17)



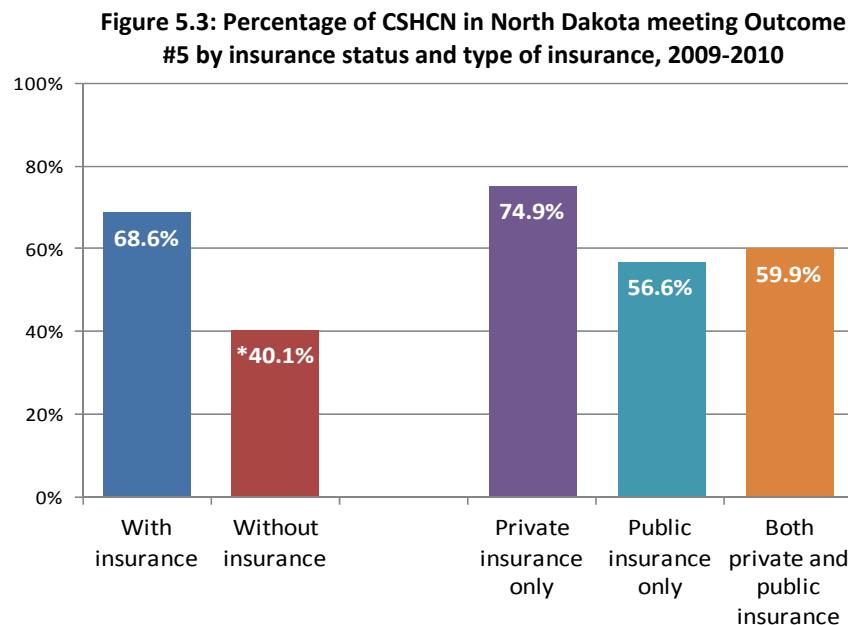
2005-2006 vs. 2009-2010: Not Available

Estimates for Outcome #5 cannot be compared across survey years because of changes to the questions.

MCHB Core Outcome #5: CSHCN who can easily access community-based services.

Outcome #5: Key Findings for North Dakota:

- Insurance coverage plays a role in ease of using services by CSHCN and their families.



In North Dakota...

Having health insurance increases the likelihood that CSHCN and their families do not experience any difficulties using needed services.

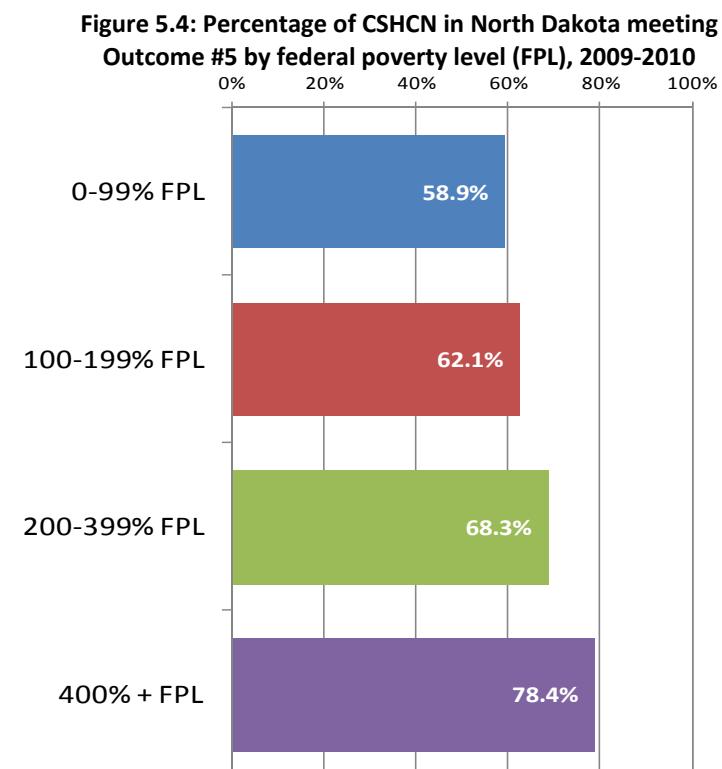
CSHCN with private insurance coverage (74.9%) are more likely to have little difficulty using needed services than those with only public insurance (56.6%) or both private and public insurance (59.9%).

- Income level relates to families having little difficulty using needed services for CSHCN.

In North Dakota...

A higher percentage of CSHCN families with income levels at or below federal poverty level (58.9%) reported having difficulty using needed services.

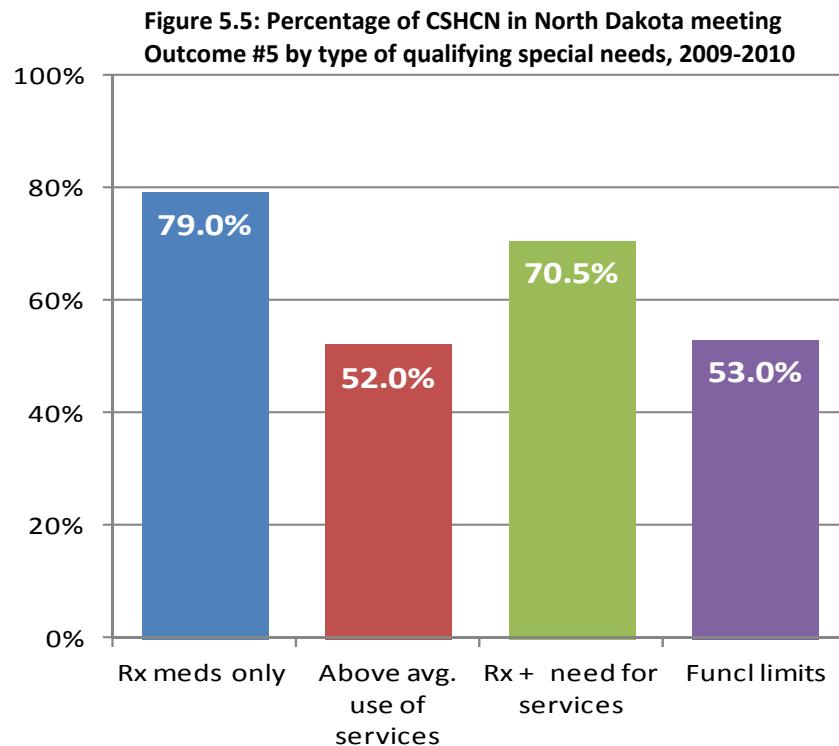
Approximately two-fifths of CSHCN in poverty (41.1%) or with incomes slightly higher than FPL (37.9%), did not meet outcome measure #5.



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #5: CSHCN who can easily access community-based services.

- CSHCN whose special health needs include prescription medications are more likely than other CSHCN to easily access needed services.



In North Dakota...

CSHCN with above routine need of services (52%) or functional limitations (53%) are less likely to meet this outcome than those with other types of special needs.

Approximately half of CSHCN with above average use of services or functional limitations encountered some kind of difficulty using services.

For CSHCN to meet Outcome 5, families must have no difficulties or delays in getting services, and be only sometimes or never frustrated in efforts to get services for CSHCN. It is based upon the following 7 questions:

During the past 12 months did you have any difficulties or delays getting services for [child] because...

1.[he/she] was not eligible for the services? (C4Q03_A)
2.the services [SC] needed were not available in your area? (C4Q03_B)
3.there were waiting lists, backlogs, or other problems getting appointments? (C4Q03_C)
4.of issues related to cost? (C4Q03_D)
5.you had trouble getting the information you needed? (C4Q03_E) Yes or no
6. During the past 12 months did you have difficulties or delays for any other reason? (C4Q03_F) Yes or no
7. During the past 12 months, how often have you been frustrated in your efforts to get services for [S.C.]? (C4Q04) Never, sometimes, usually or always

MCHB Core Outcome #5: CSHCN who can easily access community-based services.

**North Dakota vs.
Nationwide:**

Subcomponents of Outcome Measure #5 identify that approximately one-third of North Dakota CSHCN families not meeting Outcome #5 report difficulties or delays in services, although slightly lower than nationwide estimates.

Figure 5.6: Percentage of CSHCN Nationwide and in North Dakota not meeting Outcome #5 Subcomponents, 2009-2010

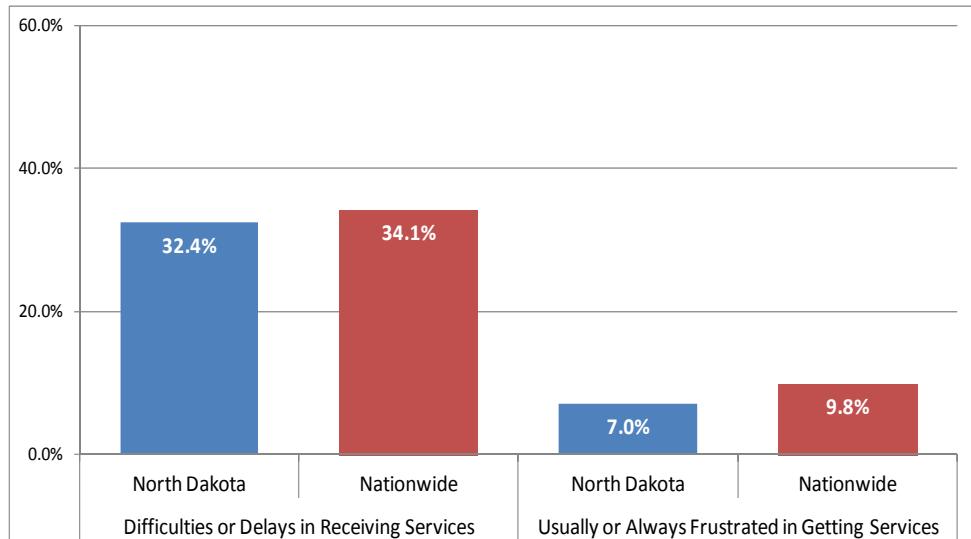
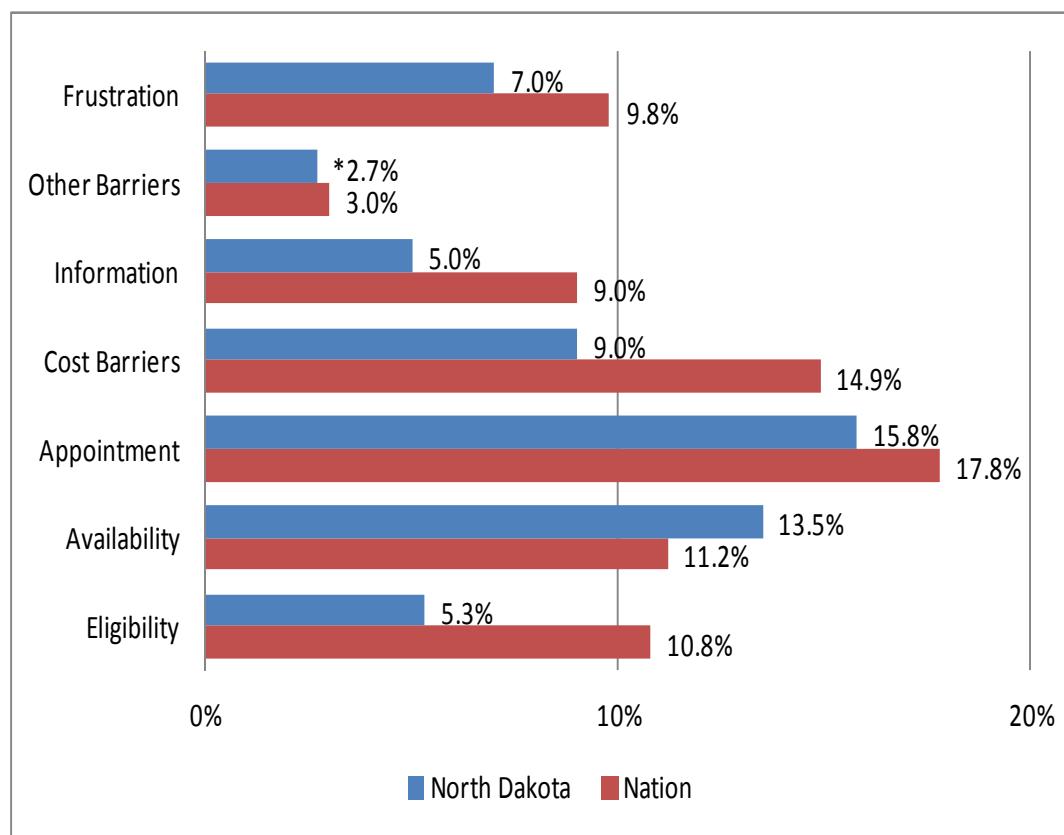


Figure 5.7: Prevalence of Specific Difficulties and Parental Frustration in Accessing Community-Based Services in North Dakota, 2009-2010



**North Dakota vs.
Nationwide:**

Individual components of difficulties or delays receiving services among North Dakota CSHCN with the highest prevalence were problems getting appointments (15.8%), delays due to availability (13.5%), and delays relating to issues related to cost (9%).

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #6

CSHCN youth receive services needed for transition to adulthood.

This outcome was evaluated for CSHCN ages 12 through 17 using responses to four questions: whether doctors discussed the shift to adult providers, whether doctors had discussed the child's changing needs as he or she approached adulthood, whether anyone had discussed insurance coverage in adulthood, and whether the child was usually or always encouraged to take responsibility for his or her health.¹³

Highlights...

- ▶ Nearly half of CSHCN ages 12 through 17 (46.5%) in North Dakota receive health care addressing their eventual transition to adult health care, a decrease from 2005-2006 (51.2%).
 - In 2009-2010, about 4,000 CSHCN in North Dakota met this outcome.
- ▶ CSHCN ages 12 through 17 in North Dakota successfully meeting this outcome are more likely to be:
 - Female (50.7%).
 - Living in higher income households (54.4% among 200-399% FPL and 63.7% among 400%+ FPL).
 - Managing chronic conditions primarily through prescription medication (65.9%).
 - Insured (47.8%).
- ▶ The percentage of CSHCN ages 12 through 17 meeting this outcome in North Dakota did NOT vary meaningfully by:
 - Child's race/ethnicity.

See Appendices for details and additional results for Outcome #6.

Figure 6.1: 2005-2006 vs. 2009-2010 Percentage meeting Outcome #6 CSHCN ages 12-17

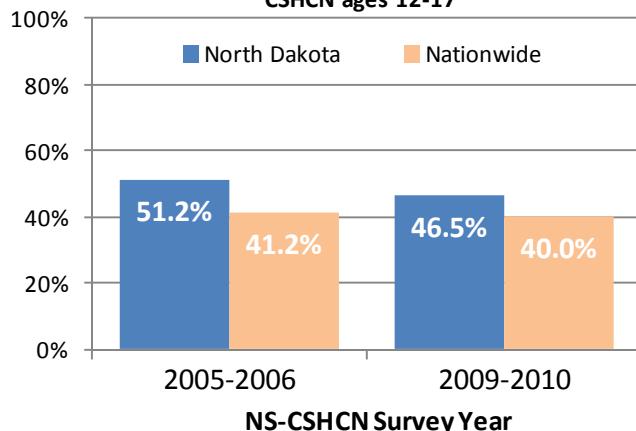
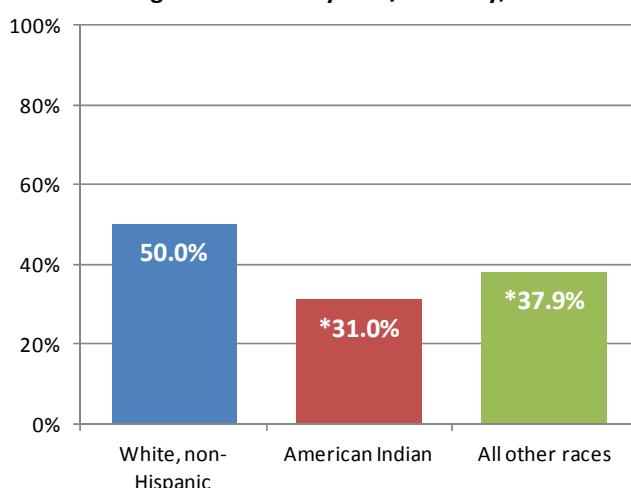


Figure 6.2: Percentage of CSHCN in North Dakota meeting Outcome #6 by race/ethnicity, 2009-2010



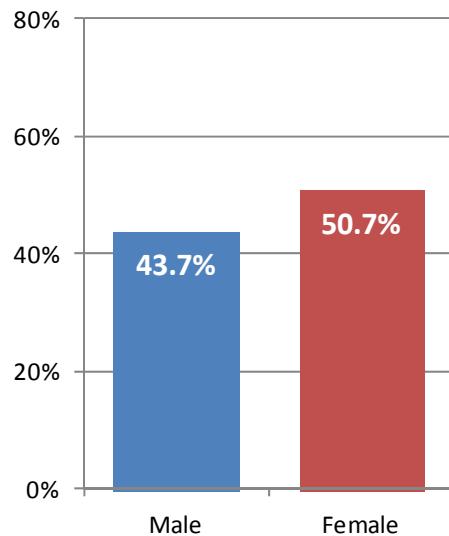
*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #6: CSHCN youth receive services needed for transition to adulthood.

Outcome #6: Key Findings for North Dakota

- Adolescent females with special health-care needs are significantly more likely than boys to receive care addressing their eventual transition to adult health care.

Figure 6.3: Percentage of CSHCN in North Dakota meeting Outcome #6 by gender, 2009-2010



In North Dakota...

Slightly more adolescent males with special health-care needs did not receive health care that addressed transition to adulthood topics during 2009-2010 (56.3%), compared to 49.3 percent of adolescent female CSHCN.

Gender disparities in receiving services designed to help with transition to adult health care are particularly concerning given that males represent a higher percentage of the CSHCN population overall (61.7% compared to 38.3% of females).

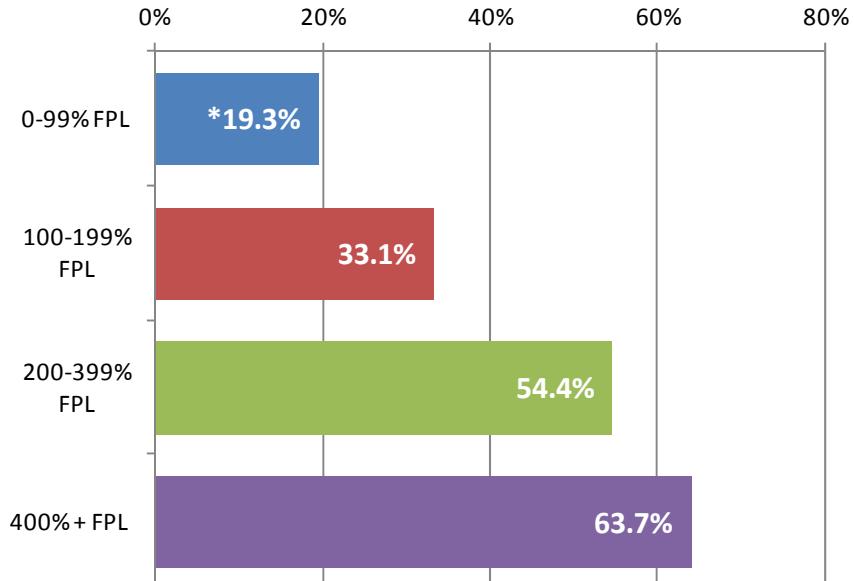
- Lower income CSHCN are significantly less likely to receive health care that addresses their eventual transition to adulthood.

In North Dakota...

Less than one-third of CSHCN ages 12 through 17 living in 100-199% FPL (33.1%) met the transition to adulthood outcome in 2009-2010.

In contrast, over half of CSHCN ages 12 through 17 living in the state's more affluent households (54.4% for 200-399% FPL, 63.7% for 400%+ FPL) received health care that met the criteria for this outcome during the same time period.

Figure 6.4: Percentage of CSHCN in North Dakota meeting Outcome #6 by federal poverty level (FPL), 2009-2010

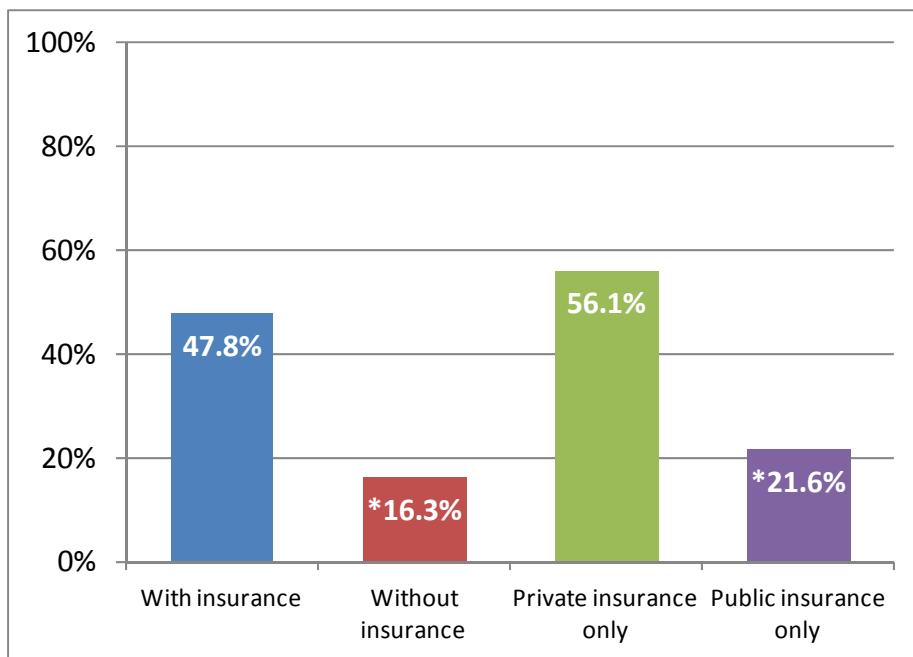


*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #6: CSHCN youth receive services needed for transition to adulthood.

Insurance status and type, as well as the necessity of additional services are variables to meeting the transition to adult health care outcome.

Figure 6.5: Percentage of CSHCN in North Dakota meeting Outcome #6 by type of insurance status and type, 2009-2010



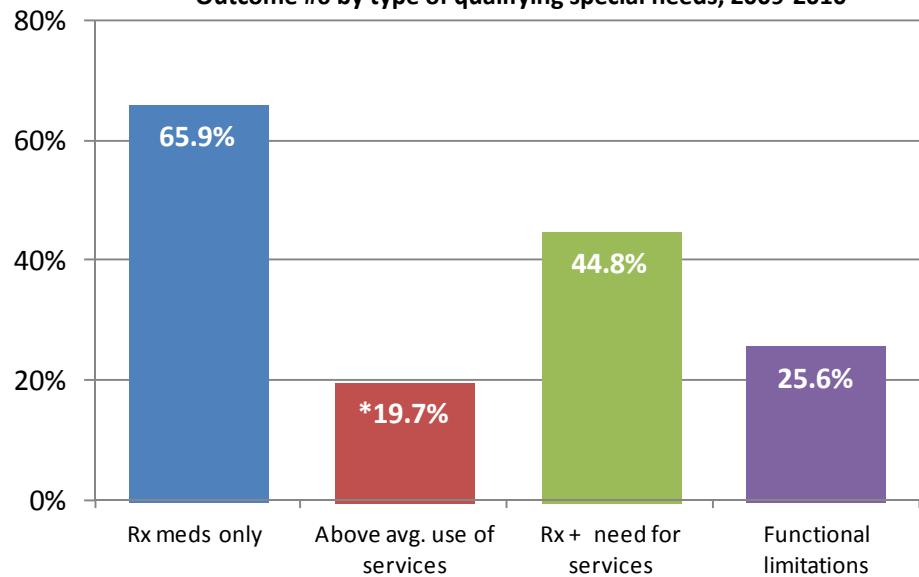
In North Dakota...

Approximately half of CSHCN with any form of insurance (47.8%) or those having only private insurance only (56.1%) are more likely to meet the transition to adult health care outcome.

In North Dakota...

CSHCN ages 12 through 17 with conditions managed primarily through prescription medicine alone are significantly more likely than other CSHCN to have their adult health care transition needs addressed by their doctors. Nearly three in four CSHCN with functional limitations did not meet this outcome measure (74.4%).

Figure 6.6: Percentage of CSHCN in North Dakota meeting Outcome #6 by type of qualifying special needs, 2009-2010



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #6: CSHCN youth receive services needed for transition to adulthood.

Outcome #6: Key Subcomponent Findings for North Dakota

Services to assist CSHCN as they transition to adulthood are measured with two components derived from NS-CSHCN responses. To meet the criteria for the anticipatory guidance component of Outcome #6, For CSHCN to meet Outcome 6, the following criteria must be met (CSHCN age 12-17 years only):

- 1. The youth's doctor has discussed each of the following three topics with him/her (or parent indicated that such discussions were not needed):**
 - Transitioning to doctors who treat adults (C6Q0A_B)
 - Changing health needs as youth becomes an adult (C6Q0A)
 - How to maintain health insurance as an adult (C6Q0A_E)
- 2. Doctor usually or always encourages the youth to take age-appropriate responsibility for managing his or her own health needs (C6Q08).**

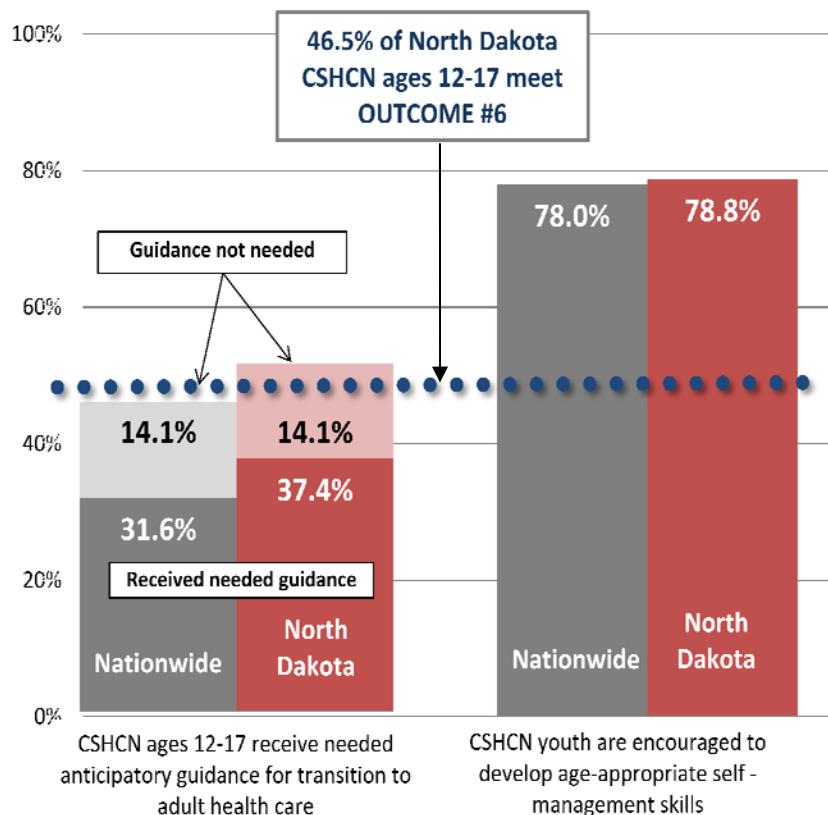
Figure 6.7: North Dakota vs. Nation
Percentage of CSHCN ages 12 through 17 with qualifying responses on subcomponents of Outcome #6, 2009-2010

In North Dakota ...

North Dakota exceeds national performance on both components of Outcome #6- 51.5 percent vs. 45.7 percent for anticipatory guidance, and 78.8 percent vs. 78 percent on self-management.

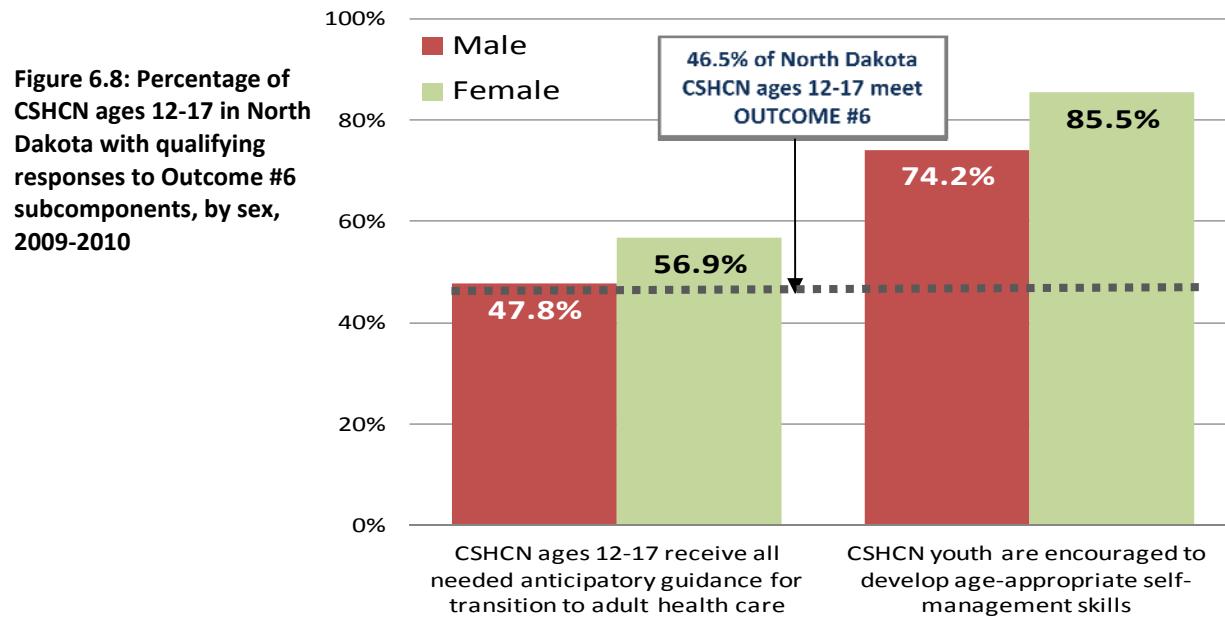
More than one in three CSHCN youth in North Dakota needed and received guidance (37.4%).

Parents of most (78.8%) of North Dakota's 12 through 17-year-old CSHCN report that doctors and other health-care providers encourage CSHCN youth to take responsibility for managing their health care as they transition to adulthood.



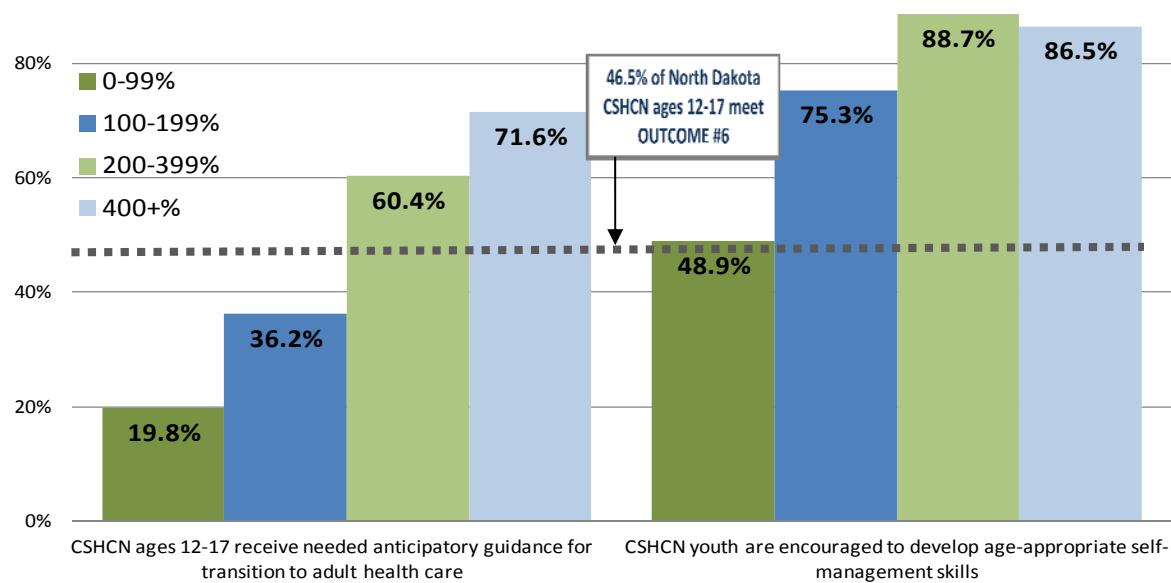
MCHB Core Outcome #6: CSHCN youth receive services needed for transition to adulthood.

The difference in the proportion of male and female CSHCN youth meeting Outcome #6 is evident in both subcomponents. However, neither measure is statistically significant. Both male and female adolescent CSHCN fare better on the self-care component than on guidance for transitioning to adult health-care services (Fig. 6.8).



- Family income is associated with both components of Outcome #6. Nearly twice as many CSHCN youth from higher income families as those with income just above poverty level (100-199% FPL) met all three criteria for transition to adult health care (75.3% and 36.2%, respectively). The proportion of CSHCN youth receiving help learning to manage their own health generally increases with income (Fig 6.9).

Figure 6.9: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, by income as a percentage of Federal Poverty Level (FPL), 2009-2010

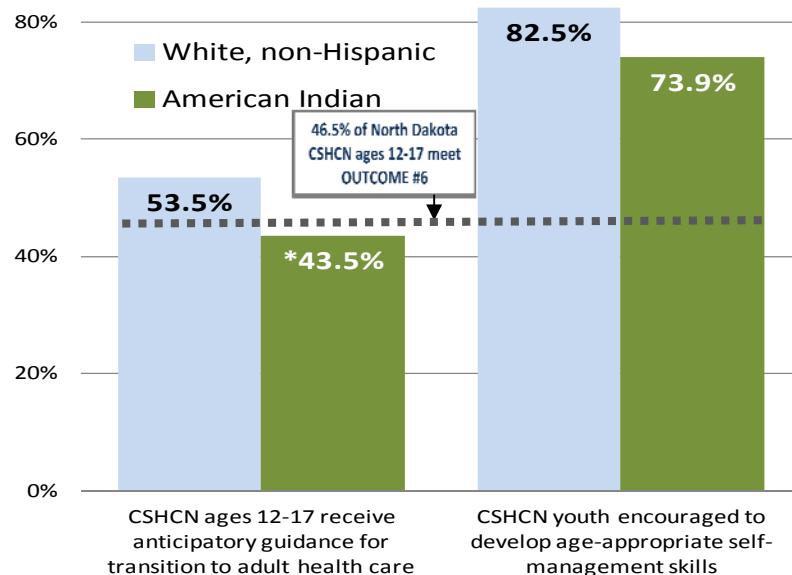


*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

MCHB Core Outcome #6: CSHCN youth receive services needed for transition to adulthood.

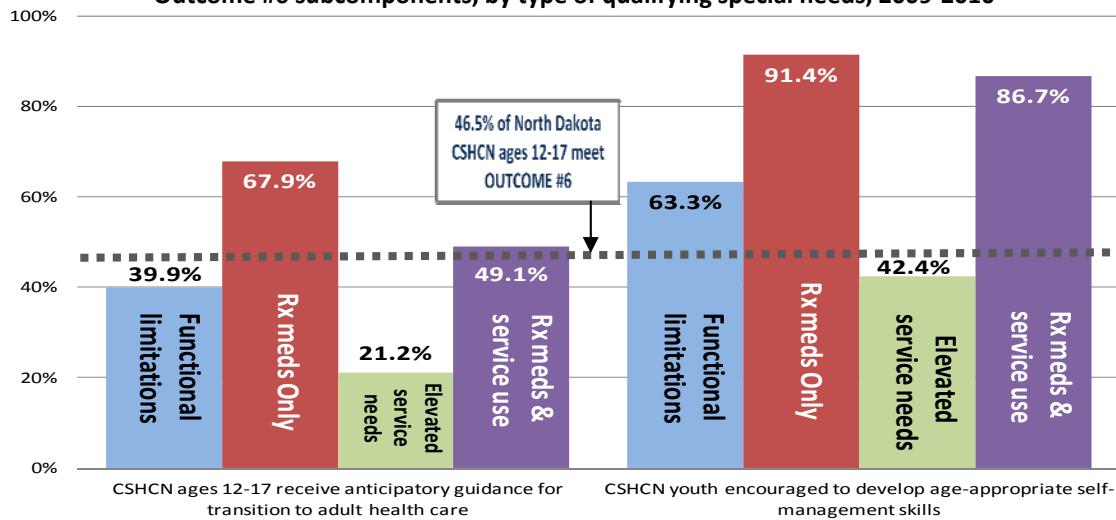
In North Dakota the number of American Indian CSHCN youth participating in the survey was too small to establish statistical significance for subcomponents of Outcome #6, although the results suggest that their doctors or other health-care providers may be less likely to encourage them to take responsibility for managing their health as they approach adulthood.

Figure 6.10: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, white (non-Hispanic) and American Indian, 2009-2010



- Transition services received by adolescent CSHCN in North Dakota differ according to the type of special health-care needs they have. Those most likely to meet both components are CSHCN whose medical conditions are managed primarily with prescription medications (Fig. 6.11). CSHCN requiring elevated service needs receive help with health-care transition less often. Interestingly, CSHCN youth whose main need is for special services are less likely to be encouraged to manage their own health care (42.4%).

Figure 6.11: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, by type of qualifying special needs, 2009-2010



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: CSHCN Family Impact Indicators

Section III: Family Impact Indicators

North Dakota: CSHCN Family Impact Indicators

Overview

This section illustrates some of the ways in which living with a child who has special health-care needs impacts family members. Parents may find that in order to meet the demands of caring for their child, they need to reduce their work hours or give up a job, or that expensive medications, equipment or services are not covered by their health insurance. The time and energy required to provide care directly, or arrange for and coordinate their child's care, is another issue typically faced by families of CSHCN.

Several questions in the 2009-2010 NS-CSHCN were designed to assess how having a CSHCN affects finances, employment availability, and mental health of families⁹:

- About how much did the family pay for the child's medical care in the past 12 months?
- About how many hours per week do family members spend providing health care at home for the child? How many hours arranging or coordinating care?
- Have the child's health condition(s) caused financial problems for the family?
- Have family members stopped working because of the child's health condition(s)? Have family members cut down on the hours of work because of the child's health?
- Did the family need additional income to cover the child's medical expenses?

Responses to these questions were used to construct four indicators of family impact:

Indicator #12:

CSHCN whose families spend \$1,000 or more out-of-pocket in medical expenses per year for the child

Indicator #13:

CSHCN whose conditions cause financial problems for the family

Indicator #14:

CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care

Indicator #15:

CSHCN whose conditions cause family members to cut back or stop working

This section describes how CSHCN in North Dakota fare in terms of these four measures of the extent to which their families are affected by their health-care needs.

Section III: Family Impact Indicators

Family Impact Highlights...

- Families of about 9,500 CSHCN in North Dakota report significant difficulties due to their children's health needs in 2009-2010.

In North Dakota, 48.2 percent of CSHCN meet at least one of the four family impact indicators, slightly higher than nationwide (47.4%) (Fig. F_1). Among CSHCN, nearly one in four (22.9%) met only one family impact indicator, and nearly one in five (17.7%) met two indicators.

- The proportion of North Dakota CSHCN affected ranges from 10.1 percent whose family members spend 11 or more hours providing or coordinating medical care, to 26.7 percent with \$1,000 or more annual out-of-pocket medical expenses.

The other two measures, family financial problems and cutting back hours or quitting work, affected just over one-fifth of CSHCN in the state (22.2% and 21.6%, respectively) (Fig. F_2).

Figure F_1: North Dakota vs. Nation
Percentage of CSHCN whose families experienced one or more impacts due to CSHCN's health conditions, 2009-2010

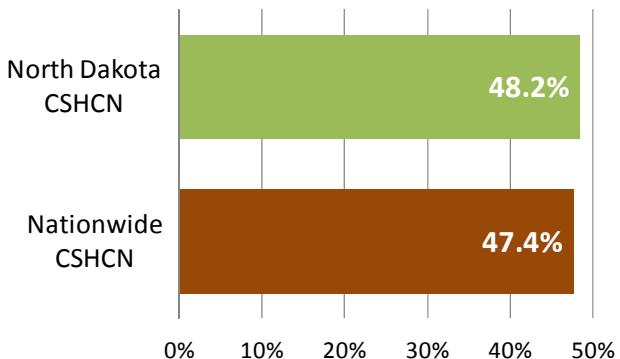


Figure F_3: North Dakota
Number of Family Impact Indicators met by CSHCN, 2009-2010

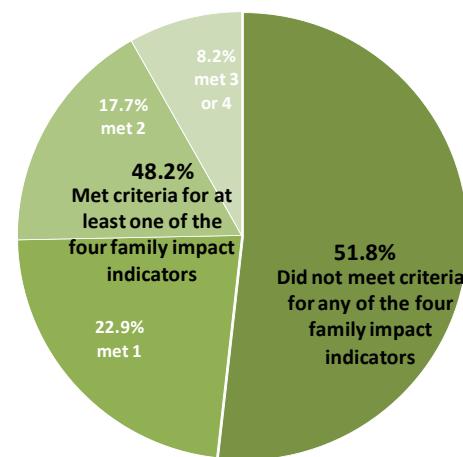
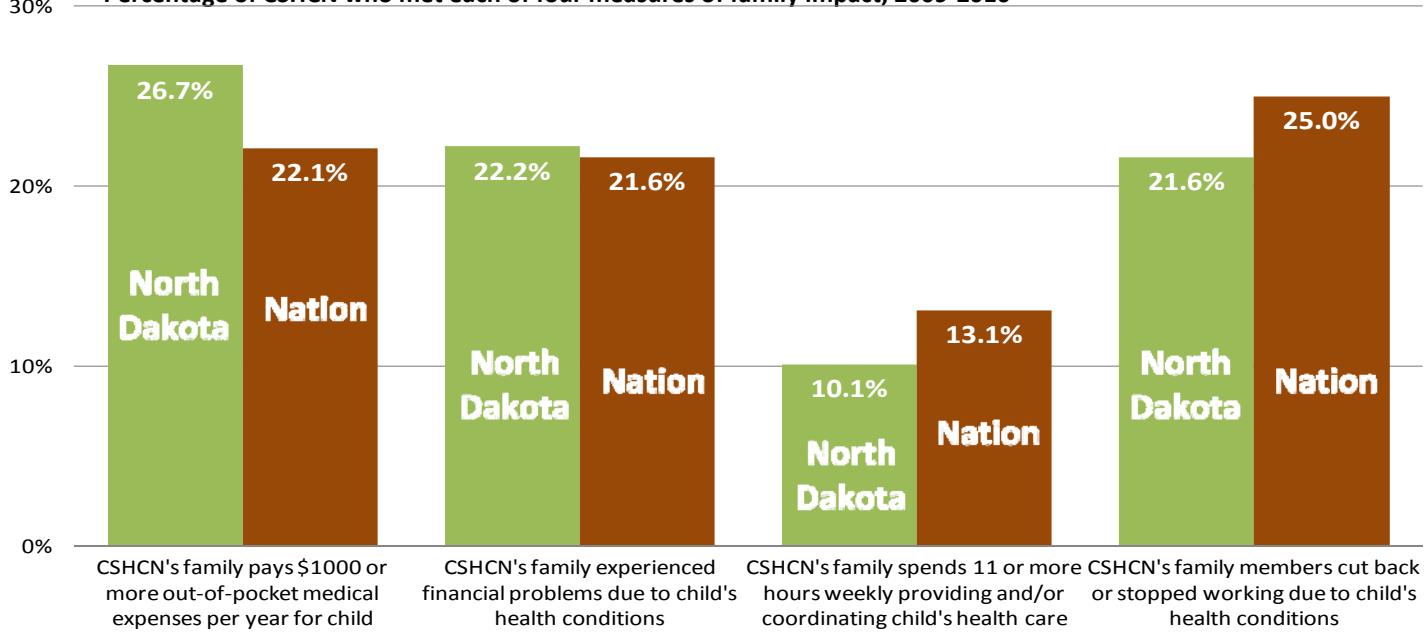


Figure F_2: North Dakota vs. Nation
Percentage of CSHCN who met each of four measures of family impact, 2009-2010



Section III: Family Impact Indicators

Indicator #12:

CSHCN whose families spend \$1,000 or more out-of-pocket in medical expenses per year for the child.

Highlights...

- ▶ More than one in four CSHCN's families pays \$1,000 or more yearly for medical expenses not covered by insurance.
The proportion of CSHCN in North Dakota who meet Indicator #12 is higher than nationwide results for CSHCN (26.7% vs. 22.1%, respectively) (Fig. 12.1).
- ▶ In 2009-2010, over two-thirds of CSHCN in North Dakota (68.1%) reported spending \$250 or more each year on medical costs not covered by insurance.
17.7 percent of CSHCN families report spending \$501-\$999 and 26.7 percent of families pay \$1,000 or more in out-of-pocket medical expenses (Fig. 12.2).
- ▶ CSHCN whose families are MOST likely to have annual out-of-pocket expenses of \$1,000 or more are:
 - Age 12 through 17 (33.7%).
 - Privately insured (34.1%).
 - Deal with complex health conditions (31.7% of CSHCN having functional limitations and 31.5% needing medication AND specialized therapies or services).
 - Of higher income brackets (34.5% of CSHCN having incomes of 400% FPL or more and 30.6% of CSHCN having incomes of 200-399% FPL).

Figure 12.1: North Dakota vs. Nation Percentage of CSHCN meeting Indicator #12, 2009-2010

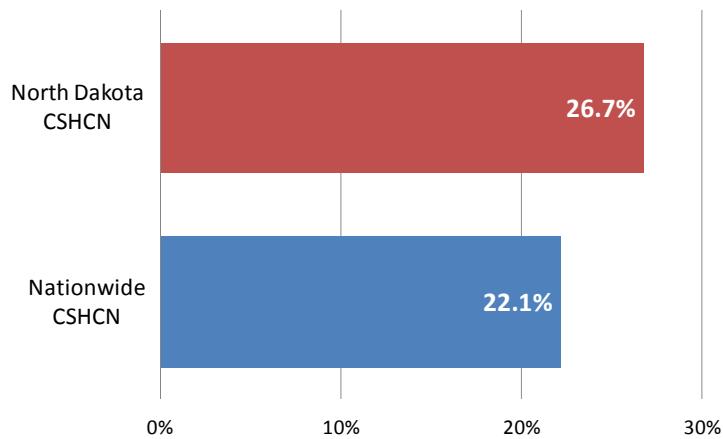
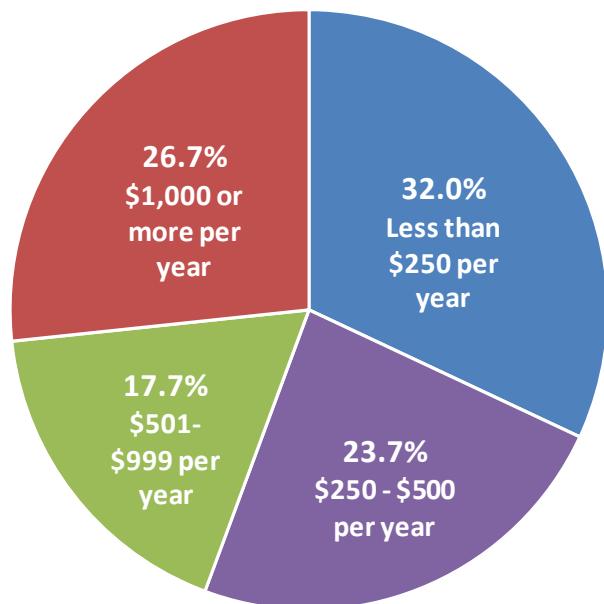


Figure 12.2: North Dakota -- Indicator #12 Yearly out-of-pocket medical expenses paid by CSHCN's family, 2009-2010



Section III: Family Impact Indicators

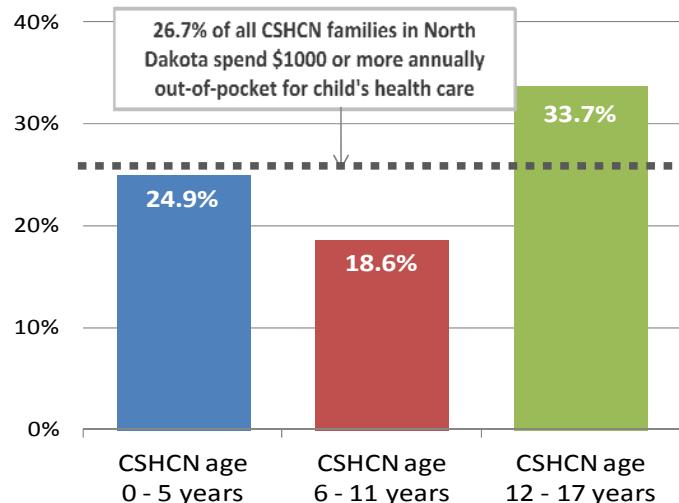
Indicator #12: Key Findings for North Dakota

- Adolescent CSHCN in North Dakota are twice as likely as younger school-aged CSHCN to have health conditions that result in excessive out-of-pocket expenses for their families.

In North Dakota ...

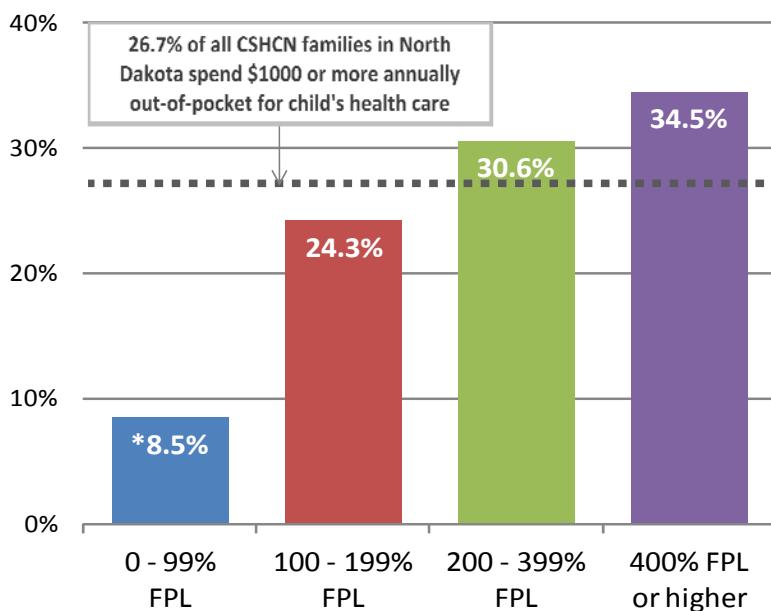
Adolescent CSHCN are nearly twice as likely as those of grade school age to have out-of-pocket medical expenses of \$1,000 or more (33.7 percent vs. 18.6 percent) (Fig. 12.3).

Figure 12.3: Percentage of CSHCN in North Dakota meeting Indicator #12 by age group, 2009-2010



- For CSHCN whose family income is above poverty level, income level is associated with excessive out-of-pocket medical expenses – more than three in 10 families with incomes above 200 percent FPL spend more than \$1,000 a year.

Figure 12.4: Percentage of CSHCN in North Dakota meeting Indicator #12 by household income as percentage of Federal Poverty Level (FPL), 2009-2010



In North Dakota ...

Nearly one in four CSHCN families (24.3%) with an income level at 100-199% of the FPL spent \$1,000 or more annually, compared with approximately one in three (34.5%) with an income level 400+ of the FPL.

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: Family Impact Indicators

Indicator #12: CSHCN whose families spend \$1,000 or more out-of-pocket in medical expenses per year for the child.

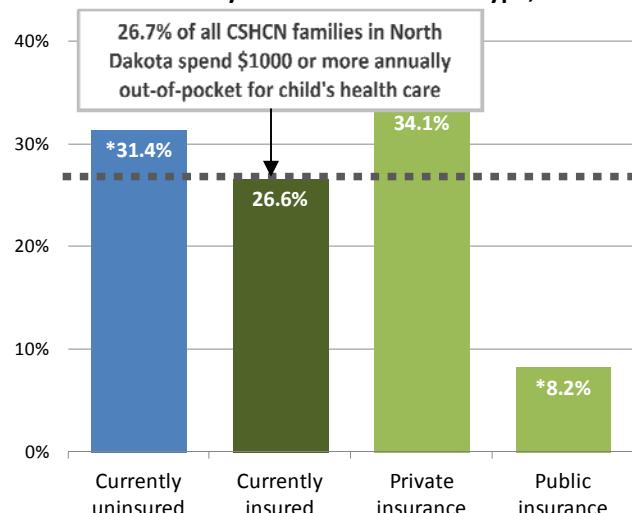
- Families of one in four currently insured (26.6%) CSHCN in North Dakota pay upwards of \$1,000 every year in expenses not covered by insurance.

In North Dakota ...

Families of CSHCN with public health insurance are least likely to pay \$1,000 or more for medical costs not covered by insurance (*8.2%), compared to those with private insurance (34.1%) and CSHCN who had no insurance coverage (*31.4%) (Fig. 12.5).

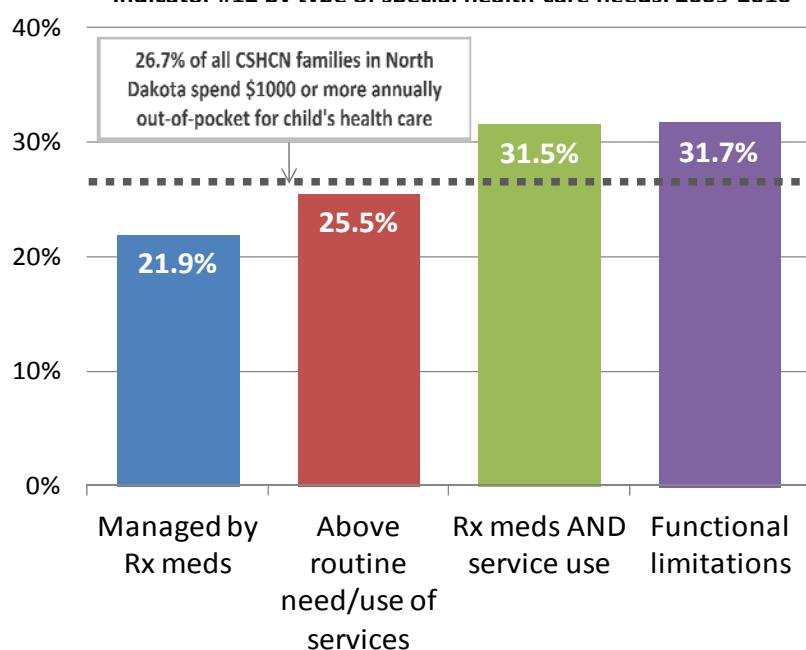
Compared with 2005-2006, a higher proportion of CSHCN with private insurance (25.1%) in 2009-2010 paid 1,000 or more; CSHCN with public insurance meeting this indicator has decreased from 9.6 percent in 2005-2006.

Figure 12.5: Percentage of CSHCN in North Dakota meeting Indicator #12 by insurance status and type, 2009-2010



- Families of CSHCN who have functional limitations or who need both medication and specialized services/therapies are more likely to pay \$1,000 out-of-pocket for their health-care needs, compared to CSHCN with less complex health conditions.

Figure 12.6: Percentage of CSHCN in North Dakota meeting Indicator #12 by type of special health-care needs. 2009-2010



In North Dakota ...

CSHCN whose families are most at risk for having financial problems as a result of their health conditions are those who have functional limitations (31.7%) or CSHCN that need both prescription medications AND specialized therapies or services to manage their ongoing health conditions (31.5%) (Fig. 12.6). The proportion of CSHCN in each category has increased since 2005-2006.

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: Family Impact Indicators

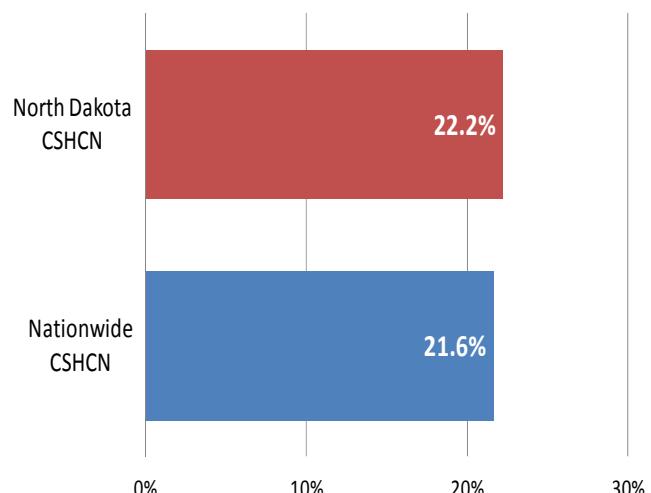
Indicator #13:

CSHCN whose health conditions cause financial problems for the family.

Highlights...

- ▶ In North Dakota, about 4,400 CSHCN (22.2%) report family financial problems resulting from their health conditions, mirroring the national estimate of 21.6 percent (Fig. 13.1).
- ▶ CSHCN whose families are MOST likely to have financial problems due to the child's health conditions have:
 - Both public and private insurance (39.2%) or only public insurance (27%).
 - Health-related functional limitations (46.8%).
 - Household income just above poverty level (39.7% of those at 100% to 199% FPL) or below poverty level (22.0%).
 - A Mother-only household (27.1%) or at least one stepparent (29.6%).

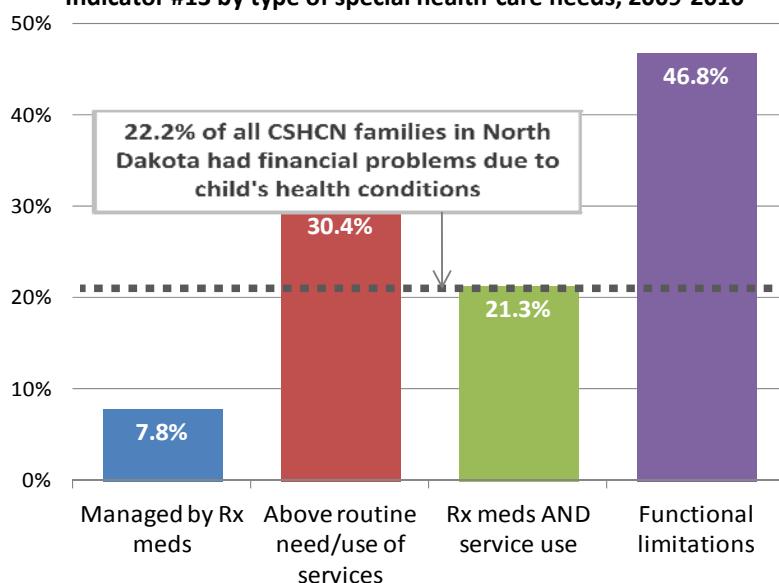
Figure 13.1: North Dakota vs. Nation Percentage meeting Indicator #13, 2009-2010



Indicator #13: Key Findings for North Dakota

- ▶ The complexity of CSHCN's health conditions is directly related to the likelihood that families experience financial difficulties as a result.

Figure 13.2: Percentage of CSHCN in North Dakota meeting Indicator #13 by type of special health-care needs, 2009-2010



In North Dakota ...

As the complexity of CSHCN's health needs increases, the general likelihood that families have encountered financial difficulties as a result of CSHCN health conditions increases (Fig. 13.2).

Of CSHCN who manage their health conditions primarily with prescription medications, families of only 7.8 percent have had financial problems, less than the overall rate of 22.2 percent.

Nearly one-half (46.8%) of CSHCN who have functional limitations report family financial problems due to their health conditions.

Section III: Family Impact Indicators

Indicator #13: CSHCN whose health conditions cause financial problems for the family.

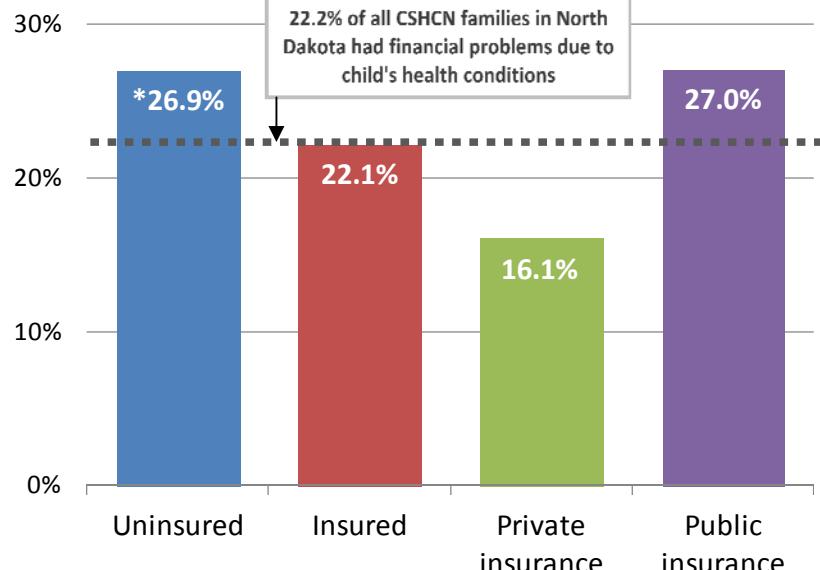
- ▶ Nearly one in three CSHCN who have public insurance have had financial difficulties because of their health conditions.

In North Dakota ...

Having health insurance decreases the risk of health-related financial troubles for their families – *26.9 percent of uninsured, compared to 22.1 percent of those who have health insurance (Fig. 13.3). The percentage of CSCHN having financial difficulties without health insurance has decreased from 60.4 percent in 2005-2006.

Of CSCHN who are insured, those with public insurance are somewhat more likely to indicate having financial difficulties than those with private health insurance (27% vs. 16.1%).

Figure 13.3: Percentage of CSHCN in North Dakota meeting Indicator #13 by insurance status and type, 2009-2010



- ▶ CSHCN in families with incomes slightly above and below the poverty level are more likely than those at 200 percent or more above FPL to experience financial problems as a result of their health conditions.

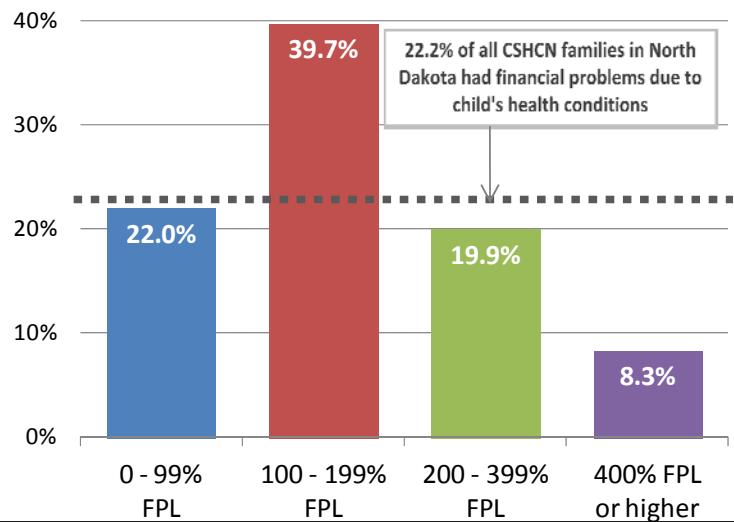
In North Dakota ...

More than one-third (39.7%) of CSHCN from low-income households (100% to 199% of Federal Poverty Level) report family financial difficulties (Fig. 13.4).

CSHCN from households with income below poverty also report financial problems more often (22%).

The income bracket least affected financially is, not unexpectedly, CSHCN in households with income 400% of FPL or higher, of whom only 8.3 percent say their families had trouble making ends meet due to the child's health conditions.

Figure 13.4: Percentage of CSHCN in North Dakota meeting Indicator #13 by household income as percentage of Federal Poverty Level (FPL), 2009-2010



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: Family Impact Indicators

Indicator #14:

CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care.

Highlights...

- ▶ An estimated 1,900 CSHCN in North Dakota have family members who spend 11 or more hours per week on their health-care needs.
Nationally, a slightly higher proportion of CSHCN meet Indicator #14 criteria (13.1%) as in North Dakota (10.1%) (Fig. 14.1).
- ▶ Over one-half (57.6%) of North Dakota's CSHCN need more than an hour a week devoted to their care by other family members.
Family members of one-third (35%) spend one to four hours per week; another 12.5 percent spend five to 10 hours weekly, and 10.1 percent meet Indicator #14 criteria of 11 or more hours per week (Fig. 14.2).
- ▶ CSHCN whose family members are MOST likely to spend 11 or more hours per week providing or coordinating their care have:
 - Household income below Federal Poverty Level (25.5%).
 - Public insurance (16.1%).
 - Health-related functional limitations (23.1%).
 - A two parent biological or adoptive family (8.5%).

Figure 14.1: North Dakota vs. Nation Percentage of CSHCN meeting Indicator #14, 2009-2010

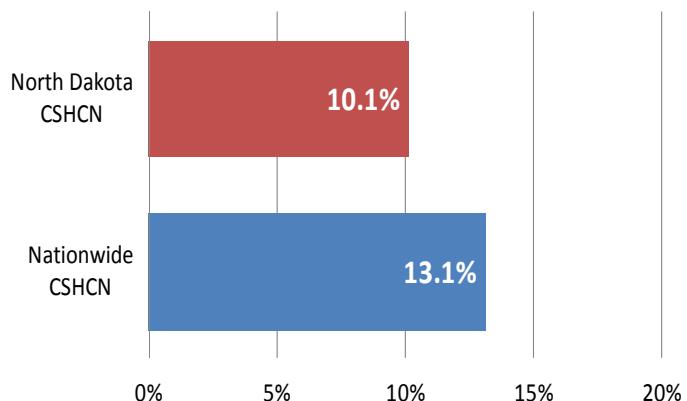
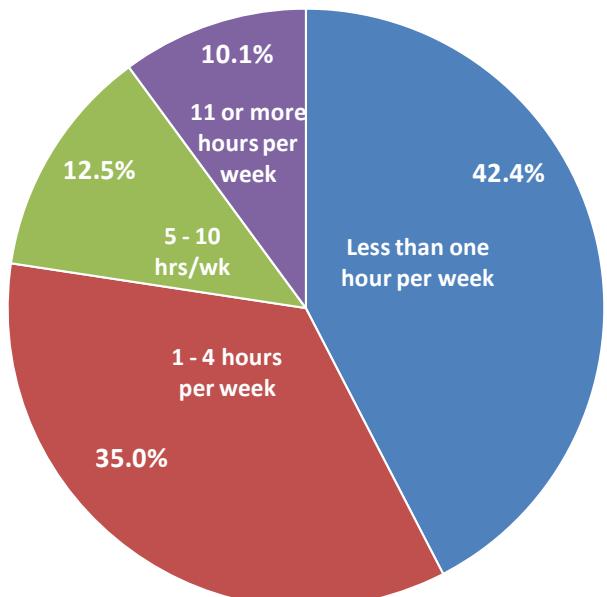


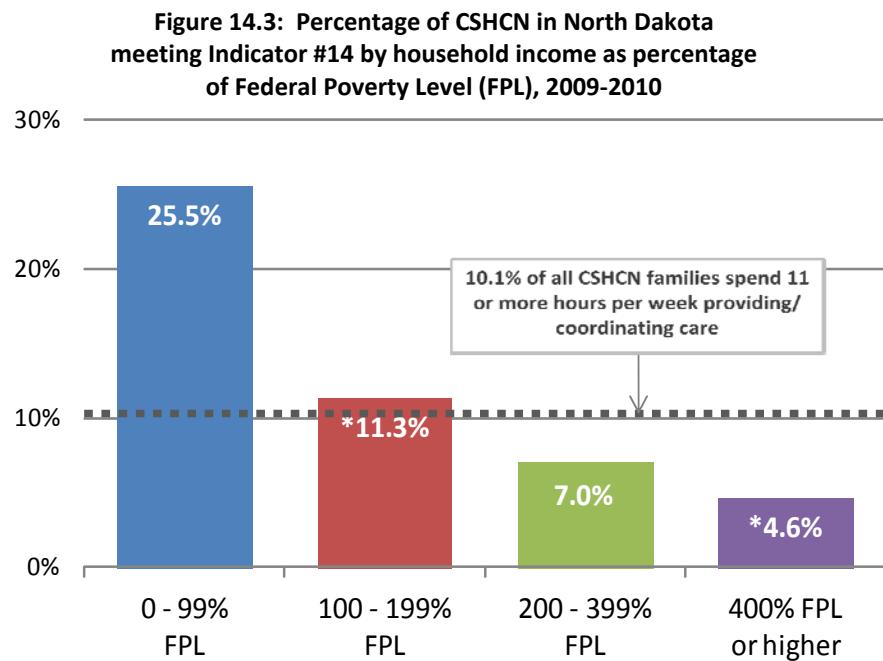
Figure 14.2: North Dakota -- Indicator #14 Hours per week CSHCN family members spend providing, arranging and/or coordinating health care for the child, 2009-2010



Section III: Family Impact Indicators

Indicator #14: Key Findings for North Dakota

- Families of CSHCN in low income households, particularly those below poverty level, are more likely than higher income CSHCN to spend significant amounts of time caring for and arranging care for their children.

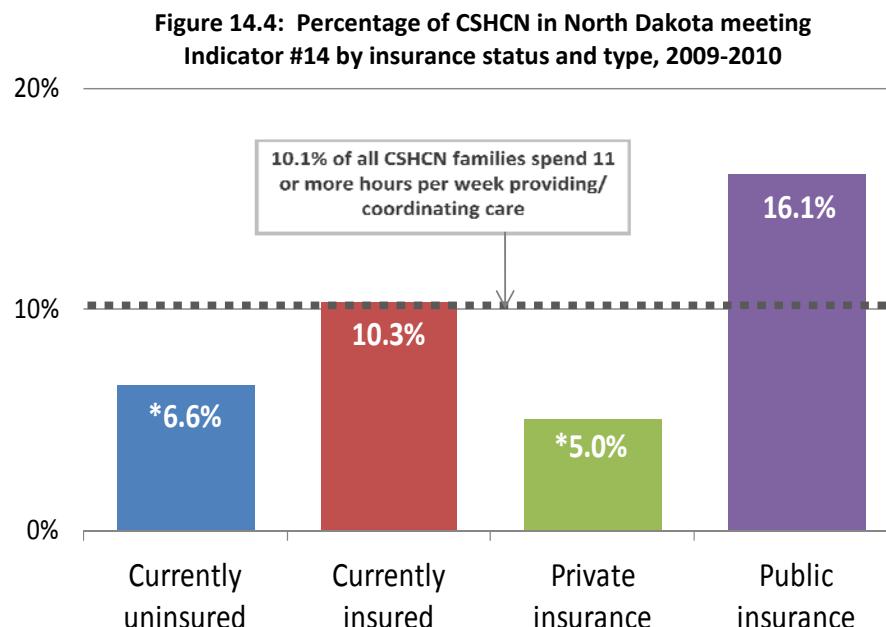


In North Dakota ...

Being poor increases the chances that family members of CSHCN spend 11 or more hours a week on their care (25.5%), compared to all CSHCN (10.1%).

Among CSHCN in families with income at or above 200 percent of FPL, few meet Indicator #14 (7% of 200-399% FPL) (Fig. 14.3).

- CHSCN with public health insurance and those who are uninsured are twice as likely as CSHCN overall to have family members who dedicate 11 or more hours a week to their care



In North Dakota ...

Approximately one in six CSHCN with public insurance meet this indicator (16.1 percent), a decrease from 2005-2006 (22.3%) (Fig. 14.4).

* Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: Family Impact Indicators

Indicator #14: CSHCN whose families spend 11 or more hours per week providing or coordinating the child's health care.

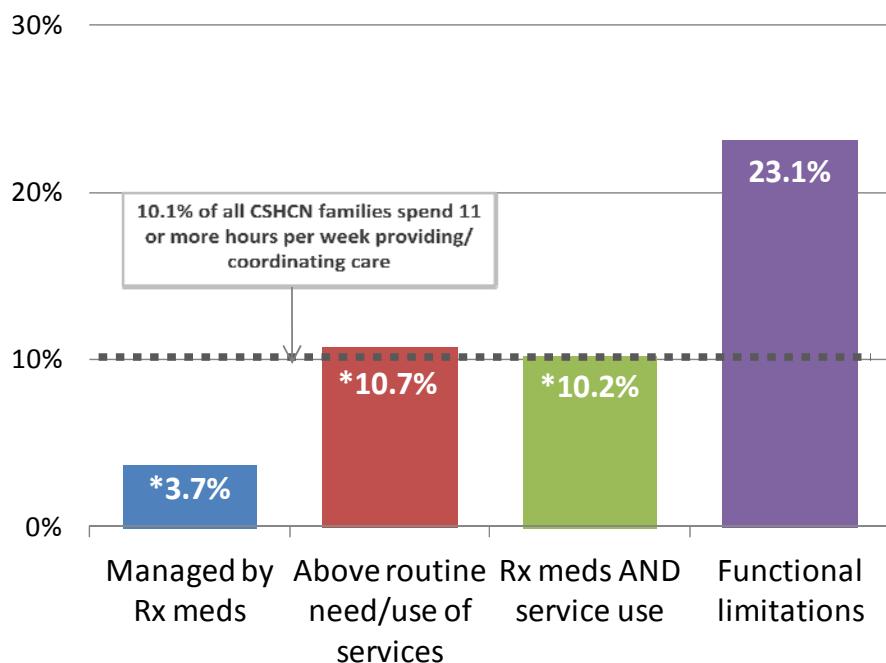
- ▶ CSHCN with functional limitations have the highest proportion meeting Indicator #14 (23.1%).

In North Dakota ...

Not surprisingly, nearly a quarter of CSHCN with functional limitations (23.1%) have family members who spend at least 11 hours per week providing, arranging, and/or coordinating their health care (Fig. 14.5).

On the other hand, only *3.7 percent of CSHCN whose health conditions are managed mainly with prescription medications meet criteria for Indicator #14.

Figure 14.5: Percentage of CSHCN in North Dakota meeting Indicator #14 by type of special health-care needs, 2009-2010



*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: Family Impact Indicators

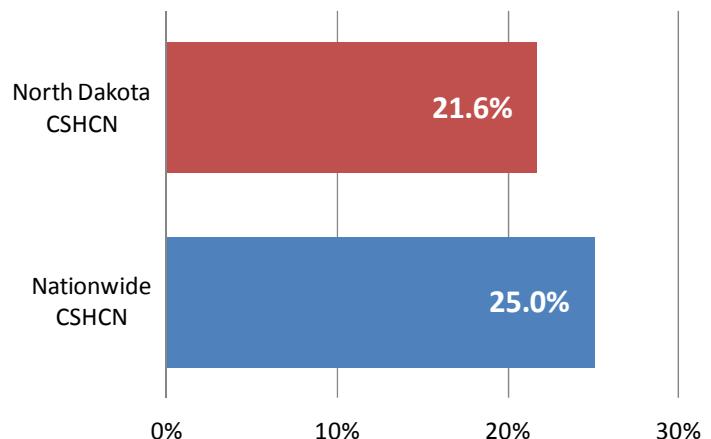
Indicator #15:

CSHCN whose health conditions cause family members to cut back or stop working.

Highlights...

- ▶ About 4,200 CSHCN in North Dakota (21.6%) have family members who had to reduce their work hours or quit a job in order to care for them.
- ▶ CSHCN whose family members are MOST likely to cut back or stop working:
 - Have both public and private insurance (43.9%) and public insurance alone (33.2%).
 - Have health-related above routine need/use of services (39.2%) or have functional limitations (38%).
 - Live in households with income below FPL (34.9%) or just above FPL (30.7%).
 - Are younger than 6 years of age (34.2%).
 - Come from a mother-only family structure (27.3%) or two-parent biological or adoptive family (18.6%).

Figure 15.1: North Dakota vs. Nation Percentage of CSHCN meeting Indicator #15, 2009-2010



Indicator #15: Key Findings for North Dakota

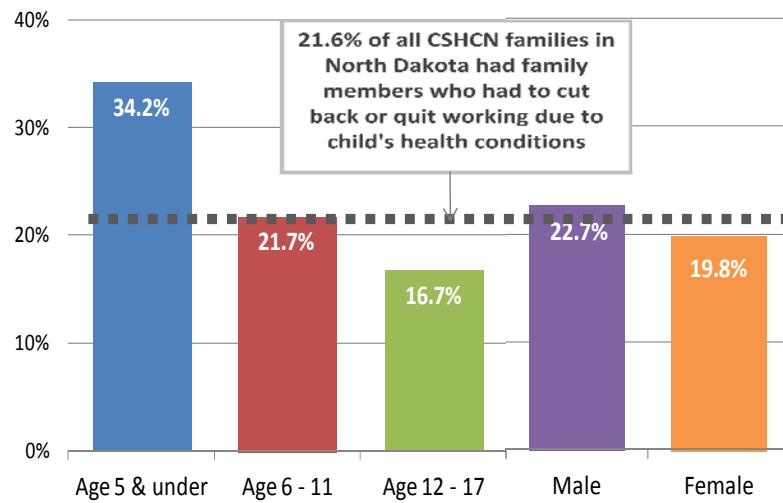
- ▶ Age and sex of CSHCN are related to the risk of family members having to cut back or quit work due to the child's health-care needs.

In North Dakota ...

More than one in three CSHCN birth through 5 years old have family members whose employment has been affected by their health conditions (34.2%) (Fig. 15.2).

Male CSHCN are slightly more likely to have health conditions that require family members to cut back or quit working (22.7 % of males vs. 19.8 % of females).

Figure 15.2: Percentage of CSHCN in North Dakota meeting Indicator #15 by sex and age, 2009-2010

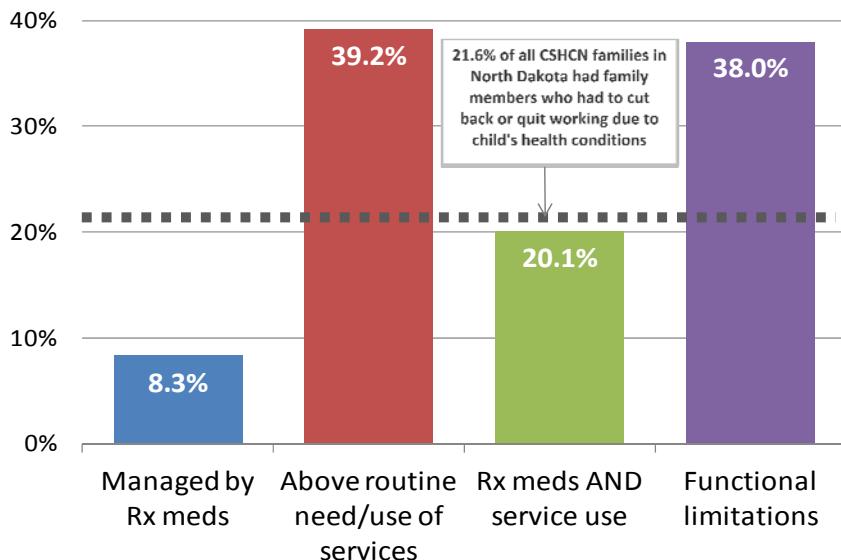


Section III: Family Impact Indicators

Indicator #15: CSHCN whose health conditions cause family members to cut back or stop working.

- Impact on employment of family members increases with the complexity of CSHCN health conditions.

Figure 15.3: Percentage of CSHCN in North Dakota meeting Indicator #15 by type of special health-care needs, 2009-2010



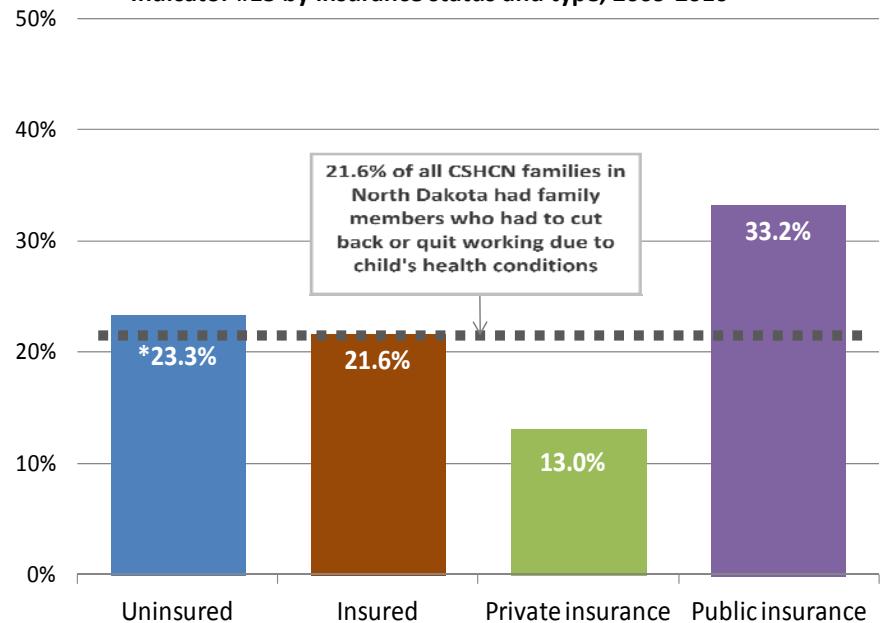
In North Dakota ...

More than one-third (38%) of CSHCN with functional limitations have family members who have had to quit or reduce work hours to care for them (Fig. 15.3).

Employment of family members of CSHCN whose conditions require only prescription medications is seldom affected (8.3%).

- CSHCN who are uninsured or have public health insurance more often have family members whose employment was affected by their health conditions.

Figure 15.4: Percentage of CSHCN in North Dakota meeting Indicator #15 by insurance status and type, 2009-2010



In North Dakota ...

One in 3 CSHCN with public health insurance (33.2%) have family members whose work was impacted by their health-care needs.

Family members of CSHCN with private insurance (13%) are much less likely to have cut back on work, compared to other CSHCN (Fig. 15.4).

*Estimates based on sample sizes too small to meet standards for reliability or precision. We suggest caution in using the data.

Section III: Family Impact Indicators

Indicator #15: CSHCN whose health conditions cause family members to cut back or stop working.

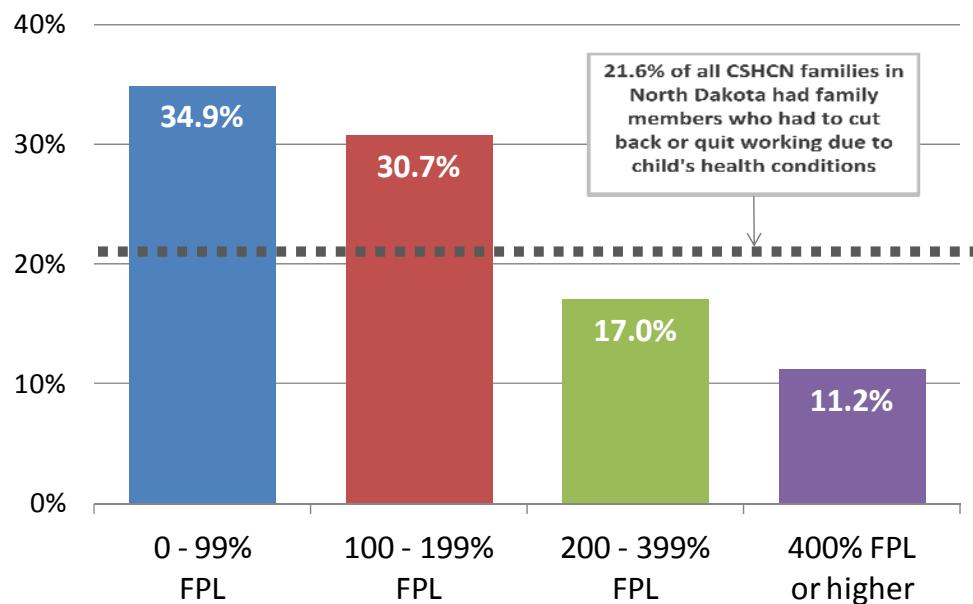
- Income is directly associated with impact on employment of CSHCN's family members.

In North Dakota ...

More than one-third (34.9%) of CSHCN living in poverty have family members who cut back hours or quit work because of their health conditions (Fig. 15.5).

Among CSHCN in families well above poverty level, only 11.2 percent had family members who reduced work hours to care for them.

Figure 15.5: Percentage of CSHCN in North Dakota meeting Indicator #15 by household income as percentage of Federal Poverty Level (FPL), 2009-2010



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Appendices

APPENDIX A

Methods

The National Survey of Children with Special Health-Care Needs (NS-CSHCN) is sponsored by the Maternal and Child Health Bureau of the U.S. Department of Health Resources and Service Administration and is conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC). The purpose of the 2009-2010 NS-CSHCN is to assess the prevalence and impact of special health-care needs among children younger than 18 in all 50 states and the District of Columbia, and to evaluate changes since the 2005-2006 survey. The central focus of the survey is the extent to which children with special health-care needs (CSHCN) or their families (1) partner in shared decision-making for child's optimal health, (2) receive coordinated, ongoing, comprehensive care within a medical home, (3) have consistent and adequate private and/or public insurance, (4) are screened early and continuously for special health-care needs, (5) can easily access community-based services, and (6) receive services for transition to adulthood. The survey also evaluates the impact among CSHCN families in regard to out-of-pocket medical expenses, financial problems, time required to provide and/or coordinate child's care and addresses specific types of health-care needs and chronic conditions.

Nationally, during the 2009-2010 NS-CSHCN, more than 196,000 randomly selected households with children were contacted by telephone and screened to identify at least 59,941 CSHCN. A total of 372,698 children in 196,159 households were screened, resulting in 40,242 completed CSHCN interviews. In North Dakota, 7,748 children in 3,886 households were screened, to obtain a total of 797 in-depth CSHCN interviews.

For each child selected as a participant, an in-depth telephone interview was conducted with the parent or guardian who is most familiar with the child's health and health care. Interviews were done in English, Spanish, Mandarin, Cantonese, Vietnamese and Korean. A national referent sample of approximately 5,000 children without special health-care needs also was selected, so that characteristics of CSHCN may be compared with characteristics of children without special health-care needs.

Survey respondents were selected according to scientific random sampling methods designed to provide a sample that is representative of the entire population of non-institutionalized children ages birth through 17 within each state and the District of Columbia. As a result, the NS-CSHCN provides estimates of the number and percentage of all CSHCN in each state, which can be compared with results for other states, regions and the nation. Results for individual questions have been analyzed and combined to create measures of the six Maternal and Child Health Bureau (MCHB) Core Outcomes that pertain to CSHCN, and 15 unique child health indicators.

The Data Resource Center for Child and Adolescent Health (DRC) provides access to survey results at the state, regional and national levels, overall and by age, race, income, insurance status and other characteristics. Trend data across survey years is available as the questions and methods are comparable.⁹ Survey data sets are also available from the DRC for researchers that wish to perform additional analyses.^{1,2,3} The DRC website also offers background information, syntax, completed publications and presentations from other researchers using data from the

survey, and links to relevant materials such as the Indicator and Outcome Variable Codebooks⁸, National Chartbook for the 2009-2010 NS-CSHCN¹³, National Center for Health Statistics information and documentation of survey methods and questions¹⁴, and resources for families with CSHCN.

This report focuses on the CSHCN prevalence, MCHB Core Outcome measures and subcomponents, and impact of families with CSHCN in North Dakota. Indicators were compared against Health and Human Service Region VIII and the nation, as appropriate. Access to NS-CSHCN data results and original databases were obtained from the DRC.⁹ Analyses were performed using the Statistical Package for the Social Sciences (SPSS).¹¹ Technical assistance was provided by the DRC during this project.

An example of subpopulations assessed for each measure are age group, race and ethnicity, income level, insurance status and type, and complexity of special health-care needs. When reported, population estimates were rounded to the nearest whole number. Because North Dakota has a significant population of American Indians, special comparisons were made with the seven states having at least 5 percent American Indian and Alaskan Native child population: Alaska, Arizona, Montana, New Mexico, North Dakota, Oklahoma and South Dakota. Data from the 2001 NS-CSHCN and 2005-2006 NS-CSHCN were used for the outcome measures that are comparable between the surveys. Frequencies and cross tabulations with 95 percent confidence limits were generated using statistical software designed for analysis of complex survey samples. Coefficient of variation and sample size was assessed for each measure prior to reporting.

APPENDIX B

Data Tables

Appendix B: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health

2009-2010 NS-CSHCN CSHCN who met MCHB Core Outcome # 1	North Dakota			HRSA Region VIII			Nationwide		
	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³
Age - 3 groups									
0 - 5 yrs old	66.7%	(55.3% - 78.2%)	2,314	70.0%	(63.2% - 76.8%)	50,330	70.4%	(68.5% - 72.4%)	1,617,123
6 - 11 yrs old	77.5%	(71.2% - 83.8%)	5,432	65.5%	(60.2% - 70.7%)	90,945	69.5%	(68.0% - 70.9%)	2,958,405
12 - 17 yrs old	76.2%	(70.2% - 82.2%)	6,698	72.6%	(69.0% - 76.2%)	111,755	71.0%	(69.7% - 72.3%)	3,157,621
Sex of child									
Male	73.8%	(68.4% - 79.2%)	8,818	70.4%	(67.0% - 73.7%)	148,870	69.5%	(68.4% - 70.6%)	4,518,105
Female	76.9%	(70.3% - 83.5%)	5,617	68.0%	(63.0% - 72.9%)	103,913	71.5%	(70.1% - 72.8%)	3,203,140
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, ND, SD			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	78.4%	(73.8% - 82.4%)	12,085	74.7%	(70.7% - 78.4%)	42,581	72.7%	(70.0% - 75.2%)	218,279
American Indian, non-Hispanic	51.1%	(34.4% - 67.5%)	903	49.2%	(37.8% - 60.7%)	3,622	60.1%	(48.1% - 71.0%)	22,132
All other race/ethnicities	70.1%	(54.3% - 82.2%)	1,456	76.7%	(67.7% - 83.8%)	6,525	63.6%	(59.2% - 67.7%)	135,694
Race/ethnicity of child									
Hispanic	88.1%	(74.2% - 100%)	344	59.2%	(49.7% - 68.7%)	34,820	63.5%	(60.9% - 66.1%)	1,165,808
White, non-Hisp	78.4%	(74.1% - 82.7%)	12,085	72.6%	(70.0% - 75.3%)	188,639	74.2%	(73.2% - 75.1%)	4,846,628
Black, non-Hisp	*32.8%	(0.0% - 72.9%)	112	56.9%	(27.7% - 86.2%)	6,938	64.7%	(62.1% - 67.2%)	1,144,218
Other, non-Hisp	61.1%	(48.9% - 73.3%)	1,903	66.5%	(57.4% - 75.5%)	22,634	66.8%	(63.5% - 70.1%)	576,495
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	58.1%	(44.8% - 71.4%)	1,659	58.1%	(50.1% - 66.1%)	33,823	61.8%	(59.8% - 63.7%)	1,504,294
100% - 199% FPL	70.8%	(60.9% - 80.8%)	3,320	66.9%	(60.9% - 72.9%)	51,765	67.3%	(65.2% - 69.3%)	1,619,110
200% - 399% FPL	80.6%	(74.6% - 86.6%)	5,753	70.1%	(65.2% - 75.0%)	94,489	72.6%	(71.0% - 74.1%)	2,275,095
400% FPL or greater	81.0%	(75.3% - 86.7%)	3,711	77.2%	(72.6% - 81.8%)	72,953	77.2%	(75.8% - 78.6%)	2,334,650
Type of insurance									
Private insurance only	81.3%	(76.6% - 86.0%)	9,282	74.5%	(71.2% - 77.8%)	164,595	76.0%	(75.0% - 77.0%)	4,241,706
Public insurance only	68.1%	(58.0% - 78.1%)	2,761	60.2%	(53.4% - 67.1%)	50,717	64.0%	(62.4% - 65.7%)	2,442,001
Both private & public insurance	63.6%	(48.5% - 78.7%)	1,482	67.1%	(57.5% - 76.7%)	16,103	67.3%	(64.2% - 70.4%)	589,789
Uninsured	*44.7%	(17.2% - 72.2%)	261	49.8%	(34.4% - 65.3%)	9,189	57.6%	(52.0% - 63.1%)	212,837
Specific types of special health needs									
Functional limitations	72.3%	(63.0% - 81.7%)	2,851	61.2%	(55.8% - 66.7%)	55,933	62.1%	(60.2% - 64.0%)	1,599,304
Managed by Rx meds	78.3%	(72.5% - 84.2%)	6,280	76.1%	(70.6% - 81.5%)	101,803	77.1%	(75.8% - 78.4%)	3,342,871
Above routine need/use of services	64.9%	(51.7% - 78.0%)	1,804	65.2%	(58.9% - 71.4%)	40,776	60.8%	(58.4% - 63.2%)	1,048,467
Rx meds AND service use	73.6%	(71.9% - 75.2%)	6,559	70.8%	(65.0% - 76.6%)	54,519	73.6%	(71.9% - 75.2%)	1,742,507

Source: 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN). All data are parent reported. For more information, see www.childhealthdata.org.

Notes:

* Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

¹ Weighted estimate of the proportion of CSHCN in each subgroup category.

² 95% confidence interval for the weighted proportion estimate.

³ Weighted estimate of the number of CSHCN in each category.

Appendix B: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home

2009-2010 NS-CSHCN: CSHCN who met MCHB Core Outcome # 2	North Dakota			HRSA Region VIII			Nationwide		
	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³
Age - 3 groups									
0 - 5 yrs old	43.0%	(31.9% - 54.1%)	1,472	41.0%	(34.8% - 47.3%)	27,917	44.2%	(42.2% - 46.3%)	996,827
6 - 11 yrs old	47.3%	(39.1% - 55.5%)	3,235	43.5%	(38.6% - 48.5%)	60,103	42.1%	(40.7% - 43.5%)	1,755,794
12 - 17 yrs old	49.9%	(43.1% - 56.8%)	4,449	46.3%	(42.3% - 50.4%)	69,159	43.1%	(41.8% - 44.5%)	1,861,041
Sex of child									
Male	44.3%	(38.5% - 50.1%)	5,219	44.0%	(40.4% - 47.6%)	90,677	42.6%	(42.2% - 45.0%)	2,709,993
Female	53.2%	(45.2% - 61.2%)	3,928	44.5%	(41.4% - 43.7%)	66,255	43.6%	(41.4% - 43.7%)	1,898,055
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, ND, SD			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	51.7%	(46.5% - 57.0%)	7,864	45.5%	(41.4% - 49.7%)	25,701	46.6%	(43.7% - 49.5%)	137,845
American Indian, non-Hispanic	*21.6%	(11.5% - 36.9%)	392	18.7%	(12.5% - 27.0%)	1,316	25.4%	(17.9% - 34.7%)	8,761
All other race/ethnicities	41.7%	(28.1% - 56.8%)	899	41.6%	(31.0% - 53.0%)	3,560	32.9%	(29.0% - 37.2%)	68,996
Race/ethnicity of child									
Hispanic	*38.5%	(12.6% - 64.3%)	146	36.9%	(27.8% - 46.1%)	20,594	33.2%	(30.5% - 35.8%)	587,755
White, non-Hisp	51.7%	(46.5% - 57.0%)	7,864	47.7%	(44.7% - 50.6%)	120,922	48.8%	(47.7% - 49.8%)	3,119,177
Black, non-Hisp	*16.9%	(0.0% - 41.5%)	58	*29.7%	(10.2% - 49.3%)	3,884	33.5%	(31.1% - 35.8%)	576,465
Other, non-Hisp	33.5%	(21.9 - 45.0)	1,088	35.7%	(25.4% - 46.1%)	11,780	39.1%	(35.9% - 42.2%)	330,265
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	30.1%	(18.4% - 41.8%)	861	34.2%	(26.5% - 41.9%)	19,577	30.9%	(29.0% - 32.8%)	731,098
100% - 199% FPL	39.9%	(29.6% - 50.2%)	1,822	37.7%	(32.2% - 43.1%)	27,728	37.5%	(35.6% - 39.5%)	876,722
200% - 399% FPL	56.5%	(49.2% - 63.9%)	4,051	45.0%	(40.2% - 49.8%)	59,728	47.4%	(45.8% - 49.0%)	1,460,383
400% FPL or greater	53.0%	(44.5% - 61.5%)	2,423	54.6%	(49.5% - 59.7%)	50,696	52.2%	(50.7% - 53.8%)	1,545,458
Type of insurance									
Private insurance only	56.6%	(50.7% - 62.5%)	6,463	49.7%	(46.1% - 53.2%)	107,453	51.2%	(50.1% - 52.4%)	2,810,201
Public insurance only	38.2%	(27.5% - 48.8%)	1,526	32.9%	(27.4% - 38.4%)	27,051	34.0%	(32.4% - 35.5%)	1,252,062
Both private & public insurance	27.5%	(15.3% - 39.7%)	624	39.7%	(28.4% - 51.0%)	9,080	35.3%	(32.1% - 38.6%)	302,493
Uninsured	*20.6%	(2.2% - 38.9%)	123	26.7%	(14.3% - 39.1%)	4,590	24.2%	(19.9% - 28.5%)	87,434
Specific types of special health needs									
Functional limitations	30.3%	(20.5% - 40.1%)	1,163	29.6%	(24.6% - 34.7%)	26,198	29.8%	(28.1% - 31.5%)	749,598
Managed by Rx meds	59.4%	(52.6% - 66.3%)	4,785	58.5%	(53.4% - 63.5%)	75,807	55.8%	(54.3% - 57.2%)	2,369,116
Above routine need/use of services	30.1%	(18.8% - 41.4%)	857	36.1%	(29.7% - 42.5%)	22,667	31.4%	(29.2% - 33.6%)	482,585
Rx meds AND service use	53.1%	(43.4% - 62.8%)	2,350	43.6%	(37.8% - 49.4%)	32,507	42.0%	(40.2% - 43.9%)	919,849

Source: 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN). All data are parent reported. For more information, see www.childhealthdata.org.

Notes:

¹ Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

² Weighted estimate of the proportion of CSHCN in each subgroup category.

³ 95% confidence interval for the weighted proportion estimate.

⁴ Weighted estimate of the number of CSHCN in each category.

Appendix B: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #3: CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need

2009-2010 NS-CSHCN: CSHCN who met MCHB Core Outcome # 3	North Dakota			HRSA Region VIII			Nationwide		
	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³
Age - 3 groups									
0 - 5 yrs old	62.4%	(51.0% - 73.7%)	2,162	52.4%	(45.6% - 59.2%)	37,184	63.2%	(61.2% - 65.2%)	1,444,655
6 - 11 yrs old	64.3%	(56.7% - 72.0)	4,487	54.3%	(49.3% - 59.4%)	75,515	60.3%	(58.9% - 61.8%)	2,549,394
12 - 17 yrs old	56.0%	(49.1% - 62.9%)	5,058	53.7%	(49.7% - 57.8%)	82,995	59.4%	(58.0% - 60.8%)	2,632,950
Sex of child									
Male	57.0%	(51.1% - 62.9%)	6,855	53.0%	(49.3% - 56.6%)	111,580	60.2%	(59.1% - 61.4%)	3,901,307
Female	65.2%	(57.5% - 73.0%)	4,852	54.9%	(50.1% - 59.6%)	84,087	61.0%	(59.7% - 62.4%)	2,715,352
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, ND, SD			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	62.3%	(57.0% - 67.3%)	9,647	57.7%	(53.4% - 61.9%)	33,136	59.1%	(56.1% - 62.0%)	176,687
American Indian, non-Hispanic	48.6%	(32.6% - 64.9%)	891	58.3%	(47.0% - 68.8%)	4,251	60.2%	(47.7% - 71.5%)	21,294
All other race/ethnicities	54.4%	(39.0% - 69.0%)	1,168	59.3%	(48.4% - 69.4%)	5,085	52.3%	(47.9% - 56.6%)	112,398
Race/ethnicity of child									
Hispanic	73.2%	(53.4% - 93.0%)	286	40.0%	(31.4% - 48.5%)	23,408	53.6%	(50.9% - 56.4%)	972,226
White, non-Hisp	62.3%	(57.1% - 67.4%)	9,647	55.2%	(52.2% - 58.1%)	142,943	62.8%	(61.8% - 63.8%)	4,085,428
Black, non-Hisp	*34.2%	(0.0% - 74.7%)	116	69.2%	(48.1% - 90.3%)	8,804	58.9%	(56.3% - 61.4%)	1,042,960
Other, non-Hisp	51.0%	(38.4% - 63.5%)	1,657	60.6%	(51.2% - 69.9%)	20,539	61.5%	(58.3% - 64.7%)	526,385
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	46.6%	(33.6% - 59.6%)	1,360	48.3%	(40.4% - 56.1%)	28,108	57.8%	(55.7% - 59.8%)	1,399,617
100% - 199% FPL	46.7%	(36.0% - 57.4%)	2,179	49.3%	(43.2% - 55.4%)	37,895	58.0%	(55.9% - 60.1%)	1,379,728
200% - 399% FPL	64.7%	(57.5% - 71.8%)	4,708	52.5%	(47.7% - 57.4%)	71,034	58.5%	(56.9% - 60.1%)	1,825,398
400% FPL or greater	75.0%	(68.5% - 81.5%)	3,461	62.4%	(57.3% - 67.5%)	58,656	67.0%	(65.5% - 68.5%)	2,022,256
Type of insurance									
Private insurance only	66.8%	(61.0% - 72.5%)	7,726	56.6%	(53.0% - 60.2%)	125,654	63.4%	(62.3% - 64.5%)	3,532,515
Public insurance only	59.7%	(48.8% - 70.7%)	2,491	62.5%	(56.2% - 68.8%)	51,712	63.3%	(61.6% - 64.9%)	2,386,176
Both private & public insurance	47.2%	(32.3% - 62.1%)	1,100	49.9%	(38.5% - 61.2%)	11,702	62.3%	(59.1% - 65.6%)	542,690
Specific types of special health needs									
Functional limitations	48.5%	(37.7% - 59.3%)	1,951	41.4%	(36.2% - 46.7%)	37,334	51.8%	(49.9% - 53.8%)	1,331,339
Managed by Rx meds	69.4%	(62.9% - 75.8%)	5,605	63.8%	(58.8% - 68.7%)	84,882	68.1%	(66.8% - 69.4%)	2,932,787
Above routine need/use of services	44.0%	(31.2% - 56.8%)	1,252	45.2%	(38.7% - 51.8%)	29,101	53.4%	(50.9% - 55.9%)	919,180
Rx meds AND service use	64.1%	(54.7% - 73.4%)	2,898	57.8%	(51.8% - 63.8%)	44,377	61.4%	(59.6% - 63.3%)	1,443,693

Source: 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN). All data are parent reported. For more information, see www.childhealthdata.org.

Notes:

*Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

¹ Weighted estimate of the proportion of CSHCN in each subgroup category.

² 95% confidence interval for the weighted proportion estimate.

³ Weighted estimate of the number of CSHCN in each category.

Appendix B: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #4: CSHCN who are screened early and continuously for special health-care needs

2009-2010 NS-CSHCN: CSHCN who met MCHB Core Outcome # 4	North Dakota			HRSA Region VIII			Nationwide		
	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³
Age - 3 groups									
0 - 5 yrs old	51.6%	(40.3% - 63.0%)	1,786	62.3%	(55.8% - 68.9%)	44,218	64.8%	(62.8% - 66.8%)	1,477,732
6 - 11 yrs old	74.4%	(68.0% - 80.7%)	201	77.4%	(73.5% - 81.4%)	108,349	83.8%	(82.8% - 84.9%)	3,570,003
12 - 17 yrs old	66.8%	(60.0% - 73.6%)	6,046	77.4%	(74.2% - 80.6%)	119,405	80.6%	(79.5% - 81.8%)	3,593,346
Sex of child									
Male	63.5%	(57.7% - 69.2%)	7,669	74.4%	(71.3% - 77.5%)	157,716	78.5%	(77.5% - 79.4%)	5,111,834
Female	72.2%	(65.1% - 79.3%)	5,371	74.7%	(70.8% - 78.6%)	114,152	78.8%	(77.6% - 80.0%)	3,513,078
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, ND, SD			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	66.8%	(61.7% - 71.6%)	10,369	66.1%	(61.7% - 70.2%)	38,141	74.2%	(71.5% - 76.7%)	222,696
American Indian, non-Hispanic	61.4%	(44.3% - 76.1%)	1,132	67.6%	(56.2% - 77.3%)	5,056	68.5%	(54.9% - 79.6%)	25,878
All other race/ethnicities	71.5%	(56.1% - 83.1%)	1,548	78.8%	(70.0% - 85.6%)	6,828	78.1%	(74.6% - 81.3%)	168,910
Race/ethnicity of child									
Hispanic	73.4%	(53.1% - 93.8%)	286	68.7%	(60.1% - 77.4%)	41,397	74.9%	(72.5% - 77.3%)	1,373,654
White, non-Hisp	66.8%	(61.9% - 71.8%)	10,369	74.8%	(72.4% - 77.3%)	193,160	79.6%	(78.7% - 80.4%)	5,197,456
Black, non-Hisp	*34.2%	(0.0% - 74.7%)	116	86.3%	(70.5% - 100.0%)	11,265	78.8%	(76.7% - 80.9%)	1,390,662
Other, non-Hisp	69.5%	(58.2% - 80.8%)	2,277	77.6%	(71.3% - 83.9%)	26,149	78.7%	(76.1% - 81.4%)	679,309
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	60.4%	(47.5% - 73.3%)	1,762	68.5%	(61.0% - 76.0%)	40,591	73.2%	(71.3% - 75.0%)	1,773,569
100% - 199% FPL	62.8%	(51.8% - 73.8%)	2,942	68.5%	(63.2% - 73.8%)	52,660	75.0%	(73.2% - 76.7%)	1,802,964
200% - 399% FPL	67.6%	(60.8% - 74.4%)	4,943	73.1%	(68.9% - 77.3%)	98,791	78.6%	(77.2% - 80.0%)	2,463,623
400% FPL or greater	73.7%	(67.2% - 80.3%)	3,400	85.2%	(82.2% - 88.1%)	79,929	85.8%	(84.7% - 86.9%)	2,600,925
Type of insurance									
Private insurance only	70.7%	(65.4% - 76.1%)	8,195	75.6%	(72.5% - 78.6%)	166,531	82.1%	(81.2% - 83.0%)	4,593,130
Public insurance only	63.3%	(52.3% - 74.3%)	2,607	75.8%	(70.3% - 81.4%)	64,027	76.8%	(75.4% - 78.2%)	2,910,773
Both private & public insurance	58.2%	(43.3% - 73.0%)	1,358	75.1%	(66.7% - 83.4%)	18,080	78.8%	(76.1% - 81.5%)	682,116
Uninsured	55.5%	(28.5% - 82.5%)	331	58.2%	(43.9% - 72.5%)	11,093	51.4%	(45.8% - 57.1%)	195,708
Specific types of special health needs									
Functional limitations	69.6%	(59.7% - 79.6%)	2,765	71.7%	(66.7% - 76.6%)	60,352	75.5%	(73.9% - 77.2%)	1,943,906
Managed by Rx meds	74.5%	(68.6% - 80.4%)	6,089	79.9%	(76.6% - 83.2%)	107,154	80.6%	(79.5% - 81.7%)	3,488,204
Above routine need/use of services	43.9%	(31.1% - 56.6%)	1,253	66.0%	(59.3% - 72.8%)	42,545	71.9%	(69.6% - 74.2%)	1,245,156
Rx meds AND service use	65.0%	(55.8% - 74.2%)	2,941	75.5%	(70.1% - 80.8%)	57,920	83.2%	(81.8% - 84.5%)	1,963,816

Source: 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN). All data are parent reported. For more information, see www.childhealthdata.org.

Notes:

* Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

¹ Weighted estimate of the proportion of CSHCN in each subgroup category.

² 95% confidence interval for the weighted proportion estimate.

³ Weighted estimate of the number of CSHCN in each category.

Appendix B: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #5: CSHCN who can easily access community-based services

2009-2010 NS-CSHCN: CSHCN who met MCHB Core Outcome # 5	North Dakota			HRSA Region VIII			Nationwide		
	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³
Age - 3 groups									
0 - 5 yrs old	72.0%	(62.5% - 81.4%)	2,409	60.5%	(53.8% - 67.2%)	43,255	65.9%	(64.0% - 67.9%)	1,515,243
6 - 11 yrs old	68.6%	(60.9% - 76.4%)	4,792	60.9%	(55.8% - 65.9%)	85,286	64.8%	(63.3% - 66.2%)	2,758,438
12 - 17 yrs old	65.7%	(58.8% - 72.7%)	5,948	61.7%	(57.7% - 65.7%)	95,863	65.0%	(63.7% - 66.4%)	2,907,145
Sex of child									
Male	68.1%	(62.3% - 74.0%)	8,121	60.1%	(56.4% - 63.7%)	127,719	65.4%	(64.3% - 66.6%)	4,273,276
Female	67.4%	(63.3% - 66.1%)	5,019	62.6%	(57.8% - 67.3%)	96,352	64.7%	(63.3% - 66.1%)	2,897,495
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, ND, SD			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	69.2%	(64.0% - 74.0%)	10,623	62.0%	(57.8% - 66.1%)	35,780	62.5%	(59.6% - 65.4%)	188,438
American Indian, non-Hispanic	61.9%	(45.1% - 76.3%)	1,156	50.2%	(38.8% - 61.5%)	3,763	55.6%	(43.4% - 67.1%)	20,893
All other race/ethnicities	63.3%	(46.5% - 77.3%)	1,370	66.2%	(56.1% - 75.0%)	5,747	59.6%	(55.3% - 63.8%)	128,878
Race/ethnicity of child									
Hispanic	75.9%	(56.0% - 95.8%)	296	55.9%	(46.8% - 65.1%)	33,491	59.2%	(56.5% - 61.9%)	1,090,379
White, non-Hisp	69.2%	(64.2% - 74.2%)	10,623	63.9%	(61.1% - 66.8)	166,043	67.6%	(66.7% - 68.6%)	4,425,965
Black, non-Hisp	*55.9%	(7.9% - 100.0%)	190	49.9%	(23.4% - 76.4%)	6,516	64.1%	(61.6% - 66.7%)	1,138,568
Other, non-Hisp	61.8%	(49.3% - 74.2%)	2,039	53.6%	(43.9% - 63.3%)	18,354	60.8%	(57.6% - 64.1%)	525,914
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	58.9%	(45.8% - 72.0%)	1,703	55.0%	(47.2% - 62.7%)	33,016	59.4%	(57.4% - 61.4%)	1,451,158
100% - 199% FPL	62.1%	(51.2% - 73.0%)	2,830	51.3%	(45.2% - 57.4%)	39,436	59.2%	(57.1% - 61.3%)	1,427,796
200% - 399% FPL	68.3%	(61.0% - 75.6%)	4,992	59.6%	(54.7% - 64.6%)	80,870	65.6%	(64.0% - 67.2%)	2,067,273
400% FPL or greater	78.4%	(71.9% - 84.9%)	3,624	75.2%	(71.0% - 79.4%)	71,083	74.0%	(72.6% - 75.4%)	2,234,599
Type of insurance									
Private insurance only	74.9%	(69.4% - 80.4%)	8,645	67.5%	(64.2% - 70.8%)	149,571	71.8%	(70.8% - 72.9%)	4,014,419
Public insurance only	56.6%	(45.5% - 67.7%)	2,345	52.4%	(45.8% - 59.0%)	44,500	59.9%	(58.3% - 61.6%)	2,289,684
Both private & public insurance	59.9%	(45.1% - 74.6%)	1,323	50.4%	(39.1% - 61.7%)	12,018	60.2%	(56.9% - 63.4%)	526,348
Uninsured	*40.1%	(13.2% - 66.9%)	239	32.2%	(19.0% - 45.4%)	6,162	30.5%	(25.5% - 35.5%)	115,924
Specific types of special health needs									
Functional limitations	53.0%	(42.1% - 63.8%)	2,052	43.0%	(37.6% - 48.4%)	54,726	47.6%	(45.7% - 49.5%)	1,229,135
Managed by Rx meds	79.0%	(72.9% - 85.1%)	6,430	75.4%	(70.4% - 80.5%)	120,598	78.6%	(77.3% - 79.8%)	3,411,330
Above routine need/use of services	52.0%	(38.6% - 65.5%)	1,478	53.0%	(46.3% - 59.7%)	41,070	57.6%	(55.1% - 60.1%)	1,001,004
Rx meds AND service use	70.5%	(61.6% - 79.3%)	3,189	64.6%	(58.9% - 70.2%)	58,582	65.1%	(63.3% - 66.9%)	1,539,355

Source: 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN). All data are parent reported. For more information, see www.childhealthdata.org.

Notes:

* Estimates based on sample sizes too small to meet standards for reliability or precision. The relative standard error is greater than 30%.

¹ Weighted estimate of the proportion of CSHCN in each subgroup category.

² 95% confidence interval for the weighted proportion estimate.

³ Weighted estimate of the number of CSHCN in each category.

Appendix B: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #6: CSHCN youth receive services needed for transition to adulthood

2009-2010 NS-CSHCN: CSHCN who met MCHB Core Outcome # 6	North Dakota			HRSA Region VIII			Nationwide		
	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³	Est. % ¹	95% Confidence Interval ²	Pop. Est. ³
Sex of child									
Male	43.7%	(34.9% - 52.5%)	2,231	44.0%	(38.7% - 49.3%)	32,959	37.1%	(35.4% - 38.8%)	885,587
Female	50.7%	(40.1% - 61.3%)	1,790	47.5%	(41.5% - 53.6)	33,705	43.8%	(41.6% - 45.9%)	819,438
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, ND, SD			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	50.0%	(42.5% - 57.4%)	3,374	48.6%	(42.4% - 54.9%)	12,409	42.6%	(38.3% - 47.0%)	52,747
American Indian, non-Hispanic	*31.0%	(14.8% - 53.8%)	310	40.7%	(21.8% - 62.7%)	1,028	45.5%	(27.7% - 64.5%)	5,272
All other race/ethnicities	*37.9%	(18.3% - 62.4%)	337	48.5%	(29.8% - 67.7%)	1,732	32.5%	(25.6% - 40.2%)	23,873
Race/ethnicity of child									
Hispanic	*50.9%	(15.0% - 86.7%)	47	22.0%	(12.4% - 31.5%)	2,791	25.3%	(21.1% - 29.4%)	149,784
White, non-Hisp	50.0%	(42.5% - 57.4%)	3,374	47.9%	(43.4% - 52.3%)	54,880	45.7%	(44.1% - 47.2%)	1,275,024
Black, non-Hisp	*32.4%	(0.0% - 74.8%)	104	70.3%	(46.8% - 93.7%)	3,245	28.1%	(24.6% - 31.5%)	167,141
Other, non-Hisp	33.6%	(16.2% - 51.0%)	496	42.5%	(29.2% - 55.8%)	5,967	40.2%	(34.8% - 45.6%)	116,850
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	*19.3%	(5.7% - 32.9%)	263	27.9%	(17.0% - 38.7%)	5,118	25.4%	(22.3% - 28.5%)	207,588
100% - 199% FPL	33.1%	(18.4% - 33.1%)	619	43.4%	(34.7% - 52.2%)	11,446	31.0%	(28.1% - 34.0%)	281,942
200% - 399% FPL	54.4%	(43.8% - 64.9%)	1,779	44.1%	(37.8% - 50.5%)	26,326	43.3%	(40.9% - 45.7%)	534,330
400% FPL or greater	63.7%	(53.5% - 73.9%)	1,359	57.7%	(50.1% - 65.2%)	23,994	52.2%	(50.0% - 54.5%)	684,938
Type of insurance									
Private insurance only	56.1%	(47.9% - 64.4%)	3,199	51.7%	(46.6% - 56.7%)	49,830	50.2%	(48.5% - 51.9%)	1,182,748
Public insurance only	*21.6%	(8.1% - 35.1%)	363	30.0%	(21.6% - 38.4%)	7,977	25.8%	(23.4% - 28.3%)	335,961
Both private & public insurance	40.9%	(17.1% - 64.8%)	201	46.7%	(30.4% - 63.1%)	4,104	33.3%	(28.4% - 38.2%)	100,003
Uninsured	*16.3%	(0.0% - 36.6)	56	*27.8%	(10.1% - 45.5%)	2,033	19.6%	(12.2% - 27.0%)	33,174
Specific types of special health needs									
Functional limitations	25.6%	(13.5% - 37.6%)	420	30.1%	(22.9% - 37.4%)	10,179	26.2%	(23.7% - 28.6%)	258,353
Managed by Rx meds	65.9%	(56.5% - 75.3%)	2,277	56.4%	(49.6% - 63.1%)	30,381	51.4%	(49.3% - 53.5%)	871,929
Above routine need/use of services	*19.7%	(5.5% - 34.0%)	208	36.9%	(26.3% - 47.5%)	8,266	27.7%	(24.0% - 31.4%)	154,675
Rx meds AND service use	44.8%	(32.2% - 57.5%)	1,115	50.2%	(42.2% - 58.3%)	18,059	41.2%	(38.5% - 44.0%)	423,842

Source: 2009-2010 National Survey of Children with Special Health-Care Needs (NS-CSHCN). All data are parent reported. For more information, see www.childhealthdata.org.

Notes:

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² Weighted estimate of the proportion of CSHCN in each subgroup category.

³ 95% confidence interval for the weighted proportion estimate.

³ Weighted estimate of the number of CSHCN in each category.

APPENDIX C

State Ranking Maps: 2009-2010 NS-CSHCN *MCHB Core Outcomes & Family Impact Indicators*

Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health.

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home.

Outcome #3: CSHCN whose families have adequate private and/or public insurance to pay for the services they need.

Outcome #4: CSHCN who are screened early and continuously for special health care needs.

Outcome #5: CSHCN who can easily access community based services.

Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence.

Indicator #12: CSHCN whose families paid \$1000 or more out-of-pocket in medical expenses in past 12 months.

Indicator #13: CSHCN whose health conditions cause financial problems for the family.

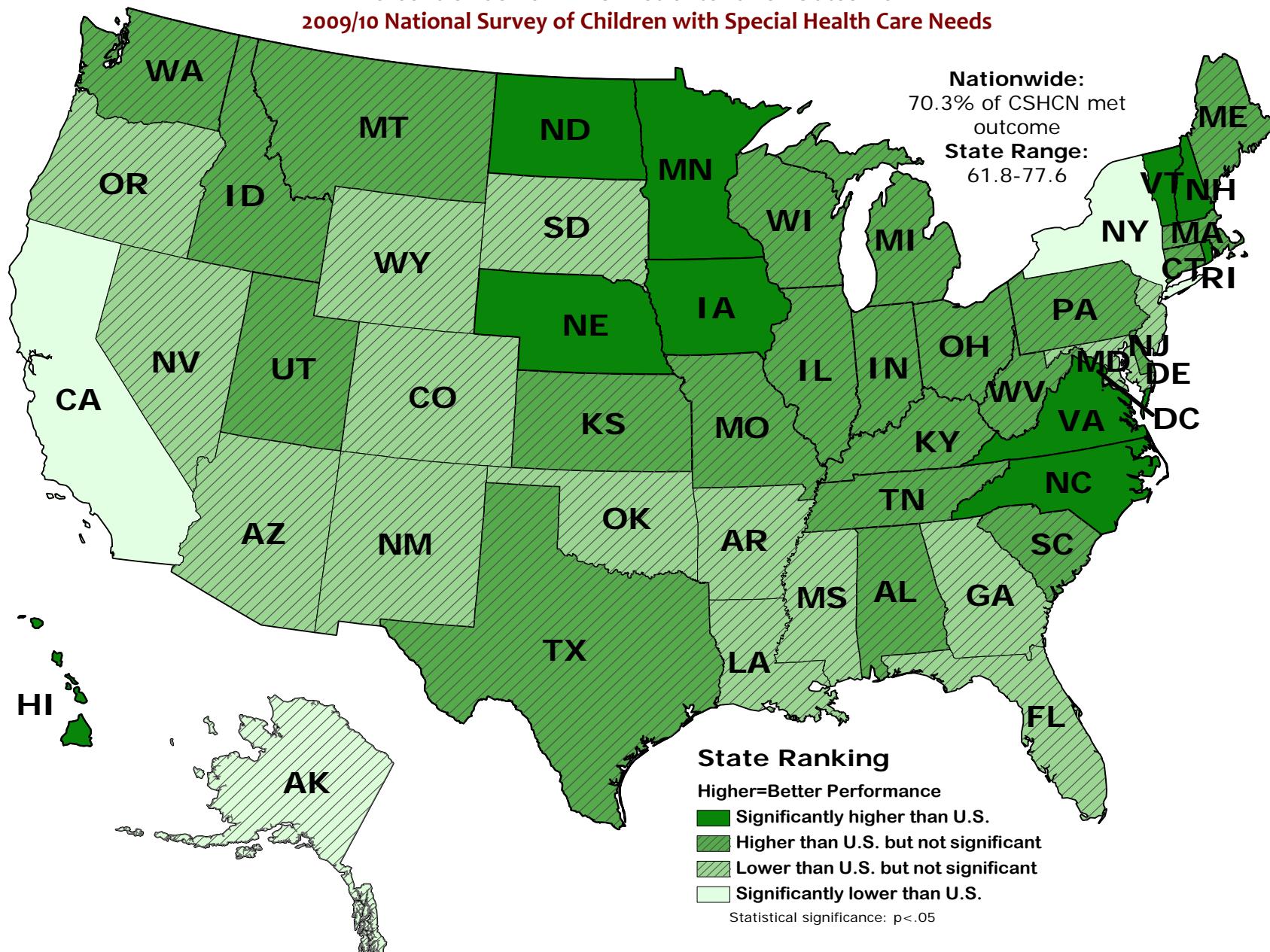
Indicator #14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's health care.

Indicator #15: CSHCN whose health conditions cause family members to cut back or stop working.

Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health

Percent of CSHCN who met criteria for Outcome #1

2009/10 National Survey of Children with Special Health Care Needs



Outcome #1: CSHCN whose families are partners in shared decision-making for child's optimal health

Percent of CSHCN who met criteria for Outcome #1

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		70.3%
LOWER Stat Sig	California	61.8%
	New York*	64.4%
LOWER than US; Not Significant	Nevada*	64.0%
	Arizona	66.2%
	Colorado	66.5%
	Alaska	66.8%
	Louisiana	67.0%
	District of Columbia	67.3%
	Georgia	67.6%
	Arkansas	67.8%
	New Mexico	67.9%
	Florida	68.2%
	Mississippi	68.7%
	New Jersey	69.2%
	Maryland	69.3%
	South Dakota	69.7%
	Oregon	69.7%
	Oklahoma	69.9%
	Wyoming	70.0%
HIGHER than US; Not Significant	Texas	70.3%
	Connecticut	70.4%
	Illinois	71.1%
	Utah	71.5%
	Delaware	72.0%
	West Virginia	72.0%
	Tennessee	72.3%
	Idaho	72.4%
	Missouri	72.5%
	Kansas	72.6%
	Indiana	72.6%
	Washington	72.8%
	Montana	72.9%
	Pennsylvania	73.1%
	South Carolina	73.6%
	Kentucky	73.6%
	Ohio	73.7%
	Alabama	74.0%
HIGHER than US; Statistically Significant	Massachusetts	74.1%
	Wisconsin	74.4%
	Maine	74.5%
	Michigan	74.5%
	North Carolina	74.6%
	New Hampshire	74.9%
	North Dakota	75.0%
	Vermont	75.4%
	Rhode Island	75.5%
	Nebraska	75.6%

NOTES:

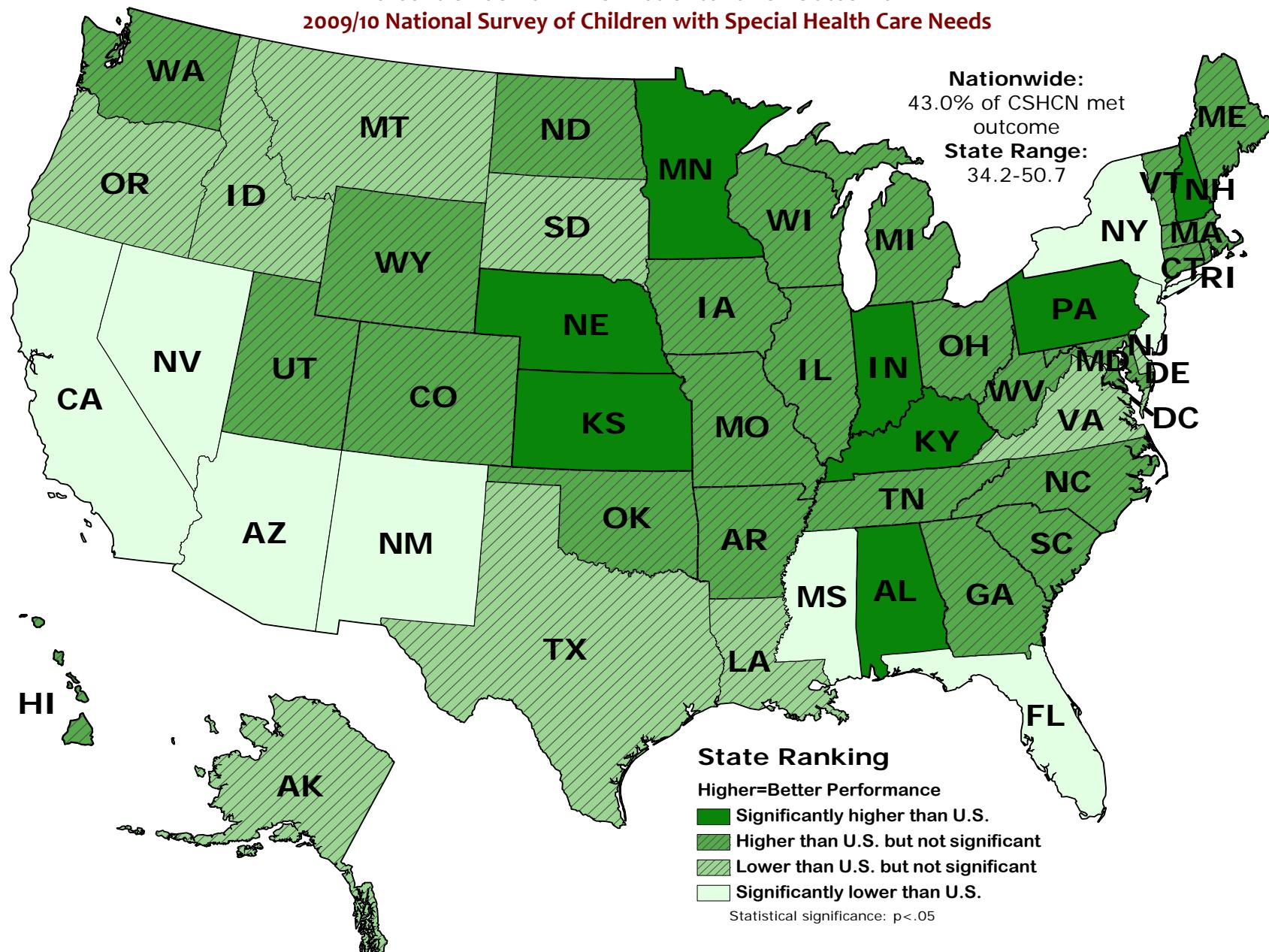
Higher %'s = Better Performance

Statistical Significance: p<.05

Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home

Percent of CSHCN who met criteria for Outcome #2

2009/10 National Survey of Children with Special Health Care Needs



Outcome #2: CSHCN who receive coordinated, ongoing, comprehensive care within a medical home

Percent of CSHCN who met criteria for Outcome #2

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		43.0%
LOWER than US; Statistically Significant	District of Columbia	34.2%
	New Mexico	34.9%
	Arizona	36.1%
	Florida	36.2%
	Nevada	36.8%
	Mississippi	36.8%
	California	38.3%
	New Jersey	38.3%
	New York	38.4%
	Montana	39.1%
LOWER than US; Not Significant	Texas	40.1%
	Louisiana	40.4%
	Oregon	41.1%
	Delaware	41.4%
	South Dakota	42.2%
	Virginia	42.4%
	Alaska	42.8%
	Idaho	42.9%
	Colorado	43.7%
	Michigan	43.7%
HIGHER than US; Not Significant	Arkansas	43.9%
	Rhode Island	44.0%
	Wisconsin	44.1%
	Maryland	44.2%
	Vermont	44.3%
	Illinois	44.5%
	Wyoming	44.6%
	Missouri	44.9%
	North Carolina	45.1%
	South Carolina	45.3%
	Hawaii	45.4%
	Washington	45.5%
	Georgia	45.7%
	Tennessee	45.9%
	Connecticut	46.0%
	Oklahoma	46.1%
	Utah	46.2%
	Ohio	46.4%
	West Virginia	46.7%
	Iowa	47.0%
HIGHER than US; Statistically Significant	Massachusetts	47.1%
	Maine	47.5%
	North Dakota	47.8%
	Pennsylvania	48.0%
	Minnesota	48.0%
	Nebraska	48.2%
	Indiana	48.5%

NOTES:

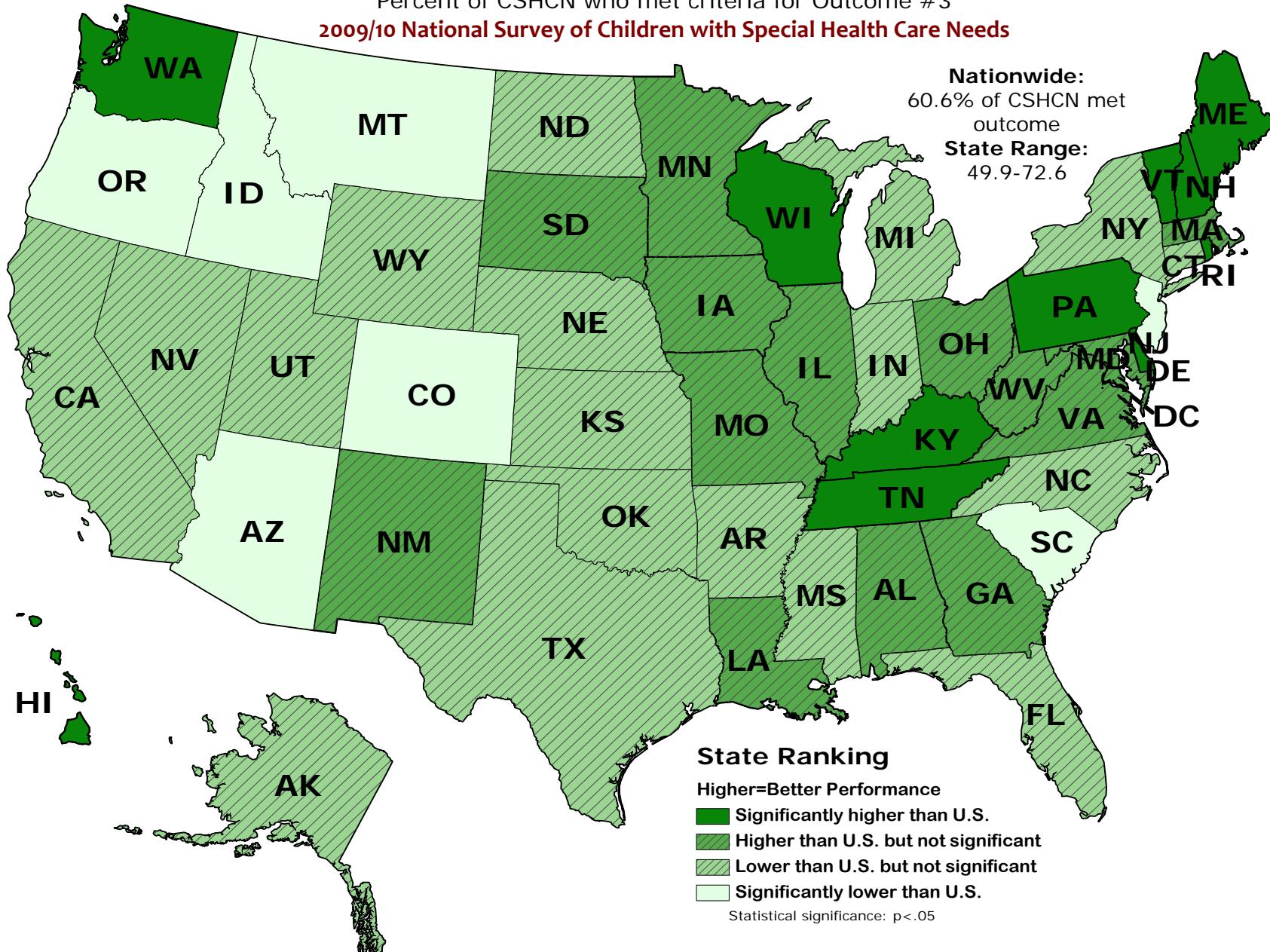
Higher %'s = Better Performance

Statistical Significance: p<.05

Outcome #3: CSHCN whose families have adequate private and/or public insurance to pay for the services they need

Percent of CSHCN who met criteria for Outcome #3

2009/10 National Survey of Children with Special Health Care Needs



Outcome #3: CSHCN whose families have adequate private and/or public insurance to pay for the services they need

Percent of CSHCN who met criteria for Outcome #3

2009/10 National Survey of Children with Special Health Care Needs

	US Prevalence	60.6%
LOWER than US; Statistically Significant	Colorado	49.9%
	Arizona	52.9%
LOWER than US; Not Significant	Montana	53.3%
	South Carolina	54.1%
HIGHER than US; Not Significant	New Jersey	54.9%
	Idaho*	55.2%
HIGHER than US; Statistically Significant	Oregon*	55.8%
	Nevada*	55.2%
Utah	55.9%	
Florida	56.5%	
Alaska	56.7%	
New York	56.8%	
Mississippi	57.4%	
Texas	57.9%	
Wyoming	58.2%	
North Carolina	58.5%	
Indiana	58.6%	
California	59.1%	
Arkansas	59.1%	
Oklahoma	59.3%	
Connecticut	59.6%	
Nebraska	59.7%	
Michigan	59.9%	
Kansas	60.0%	
North Dakota	60.1%	
New Mexico	60.6%	
Maryland	61.5%	
West Virginia	62.0%	
Illinois	62.1%	
Massachusetts	62.2%	
Georgia	62.2%	
South Dakota	62.4%	
Minnesota	62.5%	
Missouri	62.7%	
Louisiana	63.4%	
Iowa	64.6%	
Alabama	64.7%	
Ohio	64.8%	
Virginia*	65.2%	
Rhode Island*	65.0%	
Washington*	65.0%	
Wisconsin*	65.1%	
District of Columbia	65.8%	
New Hampshire	66.2%	
Kentucky	66.8%	
Vermont	68.9%	
Pennsylvania	69.0%	
Delaware	69.9%	
Maine	70.2%	
Tennessee	70.4%	
Hawaii	72.6%	

NOTES:

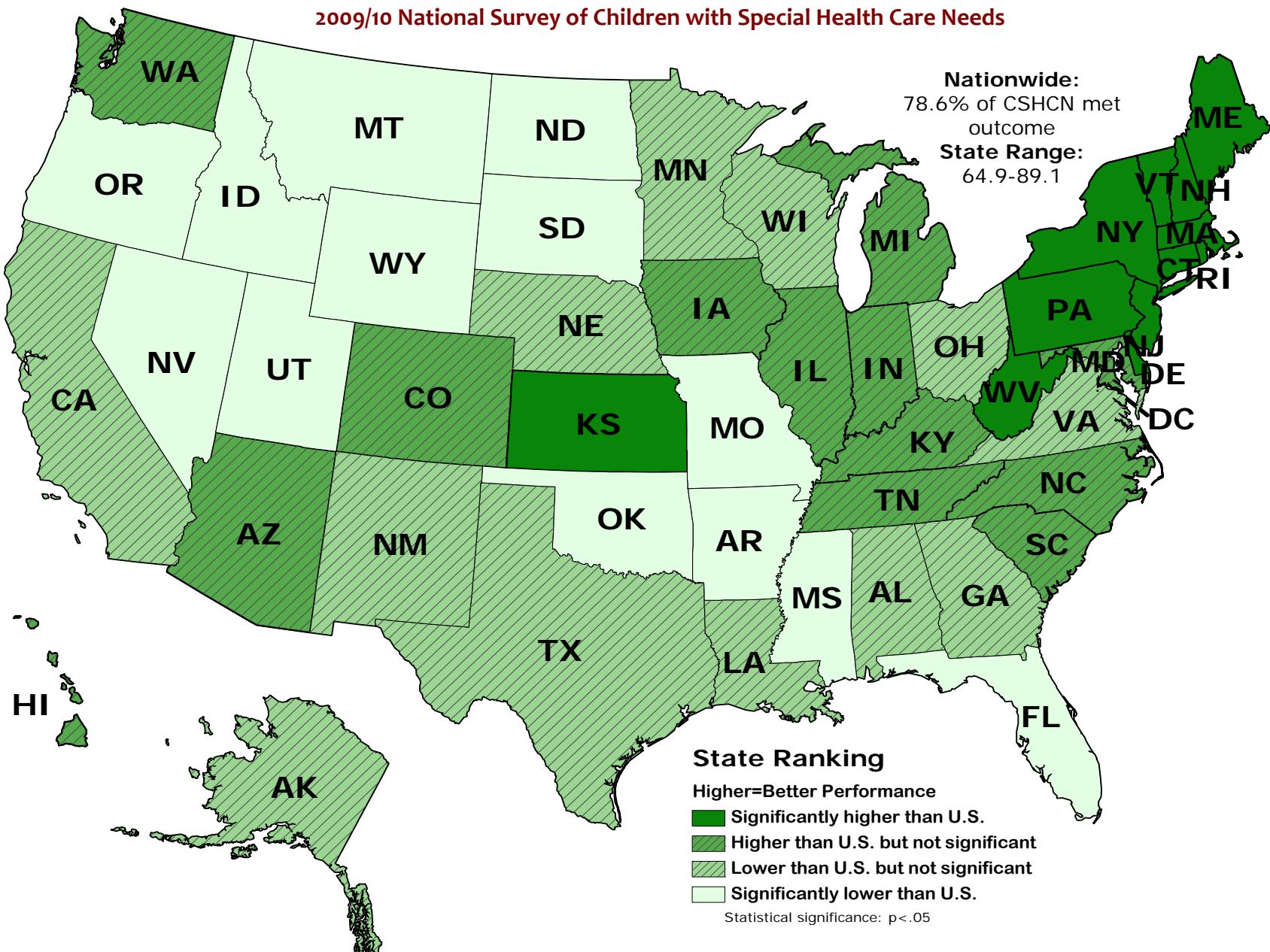
Higher %'s = Better Performance

Statistical Significance: p<.05

Outcome #4: CSHCN who are screened early and continuously for special health care needs

Percent of CSHCN who met criteria for Outcome #4

2009/10 National Survey of Children with Special Health Care Needs



Outcome #4: CSHCN who are screened early and continuously for special health care needs

Percent of CSHCN who met criteria for Outcome #4

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		78.6%
LOWER than US; Statistically Significant	South Dakota	64.9%
	North Dakota	66.8%
	Utah	68.6%
	Nevada	69.7%
	Montana	70.6%
	Oregon	71.1%
	Florida	71.4%
	Arkansas	71.5%
	Idaho	72.0%
	Wyoming	72.6%
	Oklahoma	73.2%
	Missouri	73.7%
	Mississippi	74.1%
	Minnesota	75.0%
	Nebraska	75.0%
	Alaska	75.3%
	Alabama	75.8%
LOWER than US; Not Significant	Virginia	76.6%
	Louisiana	76.7%
	Texas	76.8%
	Wisconsin	76.9%
	New Mexico	77.0%
	Ohio	77.2%
	California	77.5%
	Georgia	78.0%
	North Carolina	78.7%
	Arizona	78.7%
	Tennessee	79.1%
	Indiana	79.1%
	Michigan	79.3%
	Kentucky	79.7%
	South Carolina	79.9%
	Washington	80.7%
HIGHER than US; Not Significant	Hawaii	81.1%
	Iowa	81.1%
	Maryland	81.2%
	Illinois	81.3%
	Colorado	81.7%
	West Virginia	82.4%
	New York	82.8%
	Kansas	82.9%
	Maine	83.4%
	New Jersey	83.8%
	Delaware	84.6%
	Pennsylvania	86.2%
	Vermont	86.8%
	Connecticut	87.1%
	New Hampshire	87.4%
	Rhode Island	87.7%
	District of Columbia	88.2%
	Massachusetts	89.1%

NOTES:

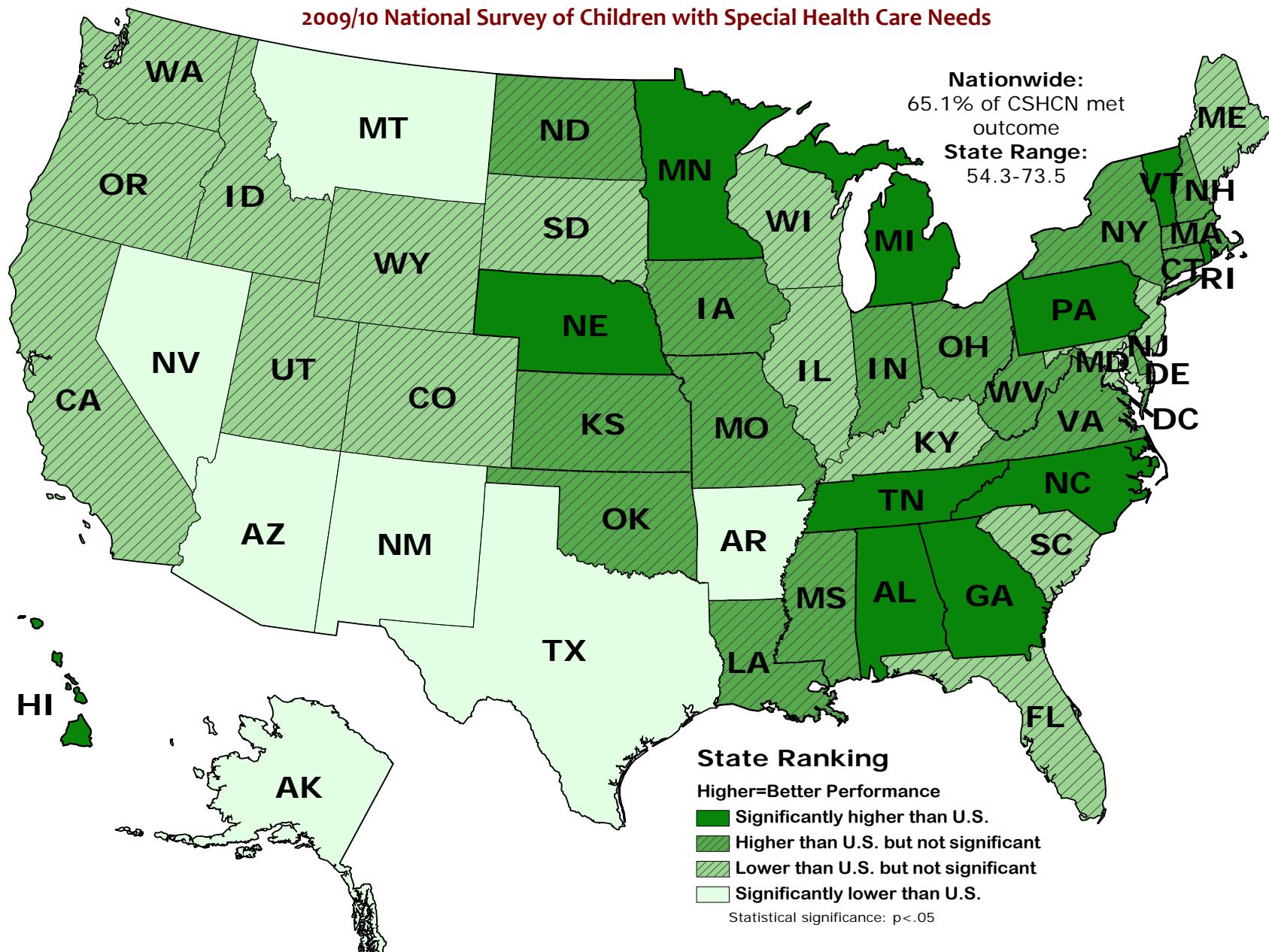
Higher %'s = Better Performance

Statistical Significance: p<.05

Outcome #5: CSHCN who can easily access community based services

Percent of CSHCN who met criteria for Outcome #5

2009/10 National Survey of Children with Special Health Care Needs



Outcome #5: CSHCN who can easily access community based services

Percent of CSHCN who met criteria for Outcome #5

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		65.1%
	LOWER than US; Statistically Significant	Montana 54.3%
		Alaska 55.2%
		New Mexico 55.5%
		Texas 56.6%
		Nevada 57.2%
		Arkansas 59.1%
		Arizona 59.7%
		Colorado 60.1%
		Utah 62.2%
		New Jersey 62.3%
		Washington 62.6%
		Florida 63.2%
		Oregon 63.4%
		Maine 63.7%
		Kentucky 63.8%
		Wyoming 63.9%
		South Carolina 63.9%
		Wisconsin 64.6%
		Illinois 64.6%
		Idaho 64.6%
		California 64.8%
		South Dakota 64.9%
		Maryland 65.1%
		Ohio 65.2%
		Mississippi 65.4%
		District of Columbia 65.5%
		Louisiana 65.5%
		Missouri 65.5%
		New York 65.6%
		Oklahoma 65.7%
		Indiana 65.9%
		West Virginia 66.5%
		Kansas 66.8%
		Connecticut 66.8%
		New Hampshire 67.0%
		Virginia 67.0%
		North Dakota 67.9%
		Iowa 68.0%
		Massachusetts 68.2%
		Delaware 69.0%
		Pennsylvania 69.4%
		Georgia 69.5%
		Minnesota 69.5%
		Vermont 70.3%
		North Carolina 70.3%
		Nebraska 70.7%
		Rhode Island 71.2%
		Tennessee 71.5%
		Hawaii 71.5%
		Michigan 71.7%
		Alabama 73.5%

NOTES:

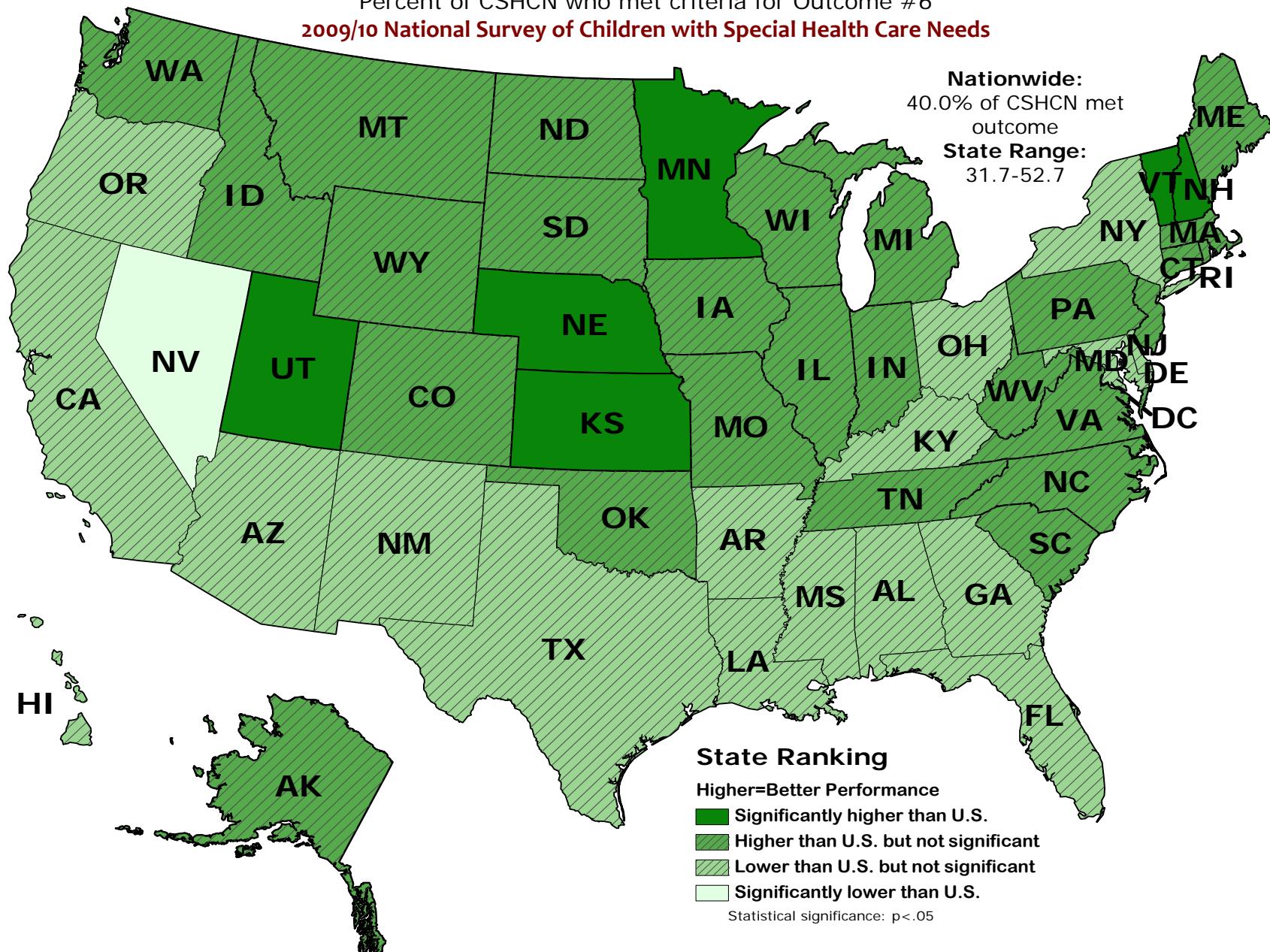
Higher %'s = Better Performance

Statistical Significance: p<.05

Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence

Percent of CSHCN who met criteria for Outcome #6

2009/10 National Survey of Children with Special Health Care Needs



Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence

Percent of CSHCN age 12-17 years who met criteria for Outcome #6

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		40.0%
LOWER S.S.	Nevada	31.7%
	Arkansas	32.4%
	Louisiana	32.8%
	District of Columbia	33.8%
	Georgia	33.9%
	Alabama	34.8%
	Texas	35.4%
	Ohio	35.6%
	Oregon	35.6%
	Arizona	35.6%
	New Mexico	35.7%
	Maryland	36.8%
	Florida	37.0%
	Kentucky	37.1%
	Hawaii	37.3%
	California	37.4%
	Delaware	38.4%
	Mississippi	38.5%
	New York	39.7%
LOWER than US; Not Significant	Pennsylvania	40.0%
	Missouri	40.3%
	Oklahoma	40.5%
	South Carolina	41.0%
	Michigan	41.2%
	West Virginia	41.6%
	Washington	41.7%
	Tennessee	41.8%
	New Jersey	41.8%
	Colorado	42.1%
	Maine	43.1%
	North Carolina	43.7%
	Rhode Island	43.7%
	Indiana	43.7%
	Wisconsin	44.4%
	Virginia	44.9%
	Alaska	45.0%
	Iowa	45.0%
	Illinois	45.3%
	Connecticut	46.0%
	North Dakota	46.5%
	Idaho	46.6%
	Massachusetts	46.6%
HIGHER than US; Not Significant	Wyoming*	47.4%
	South Dakota*	48.3%
	Montana*	48.6%
	Minnesota*	47.1%
	Nebraska*	47.6%
	New Hampshire	49.0%
	Utah	49.3%
	Vermont	51.8%
	Kansas	52.7%
HIGHER than US; Statistically Significant		

NOTES:

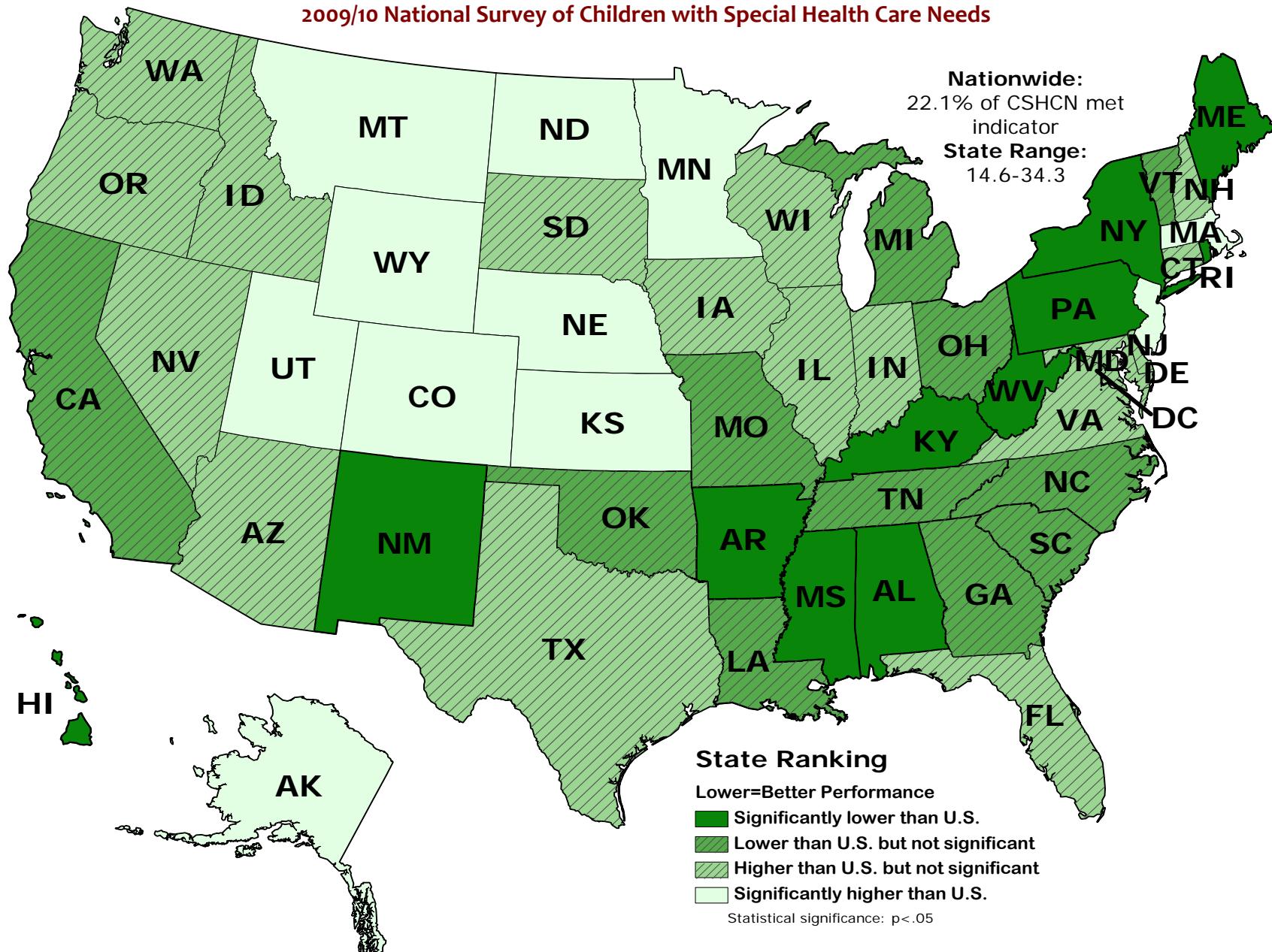
Higher %'s = Better Performance

Statistical Significance: p<.05

Indicator 12: CSHCN whose families paid \$1000 or more out-of-pocket in medical expenses in past 12 months

Percent of CSHCN who met criteria for Indicator #12

2009/10 National Survey of Children with Special Health Care Needs



Indicator 12: CSHCN whose families paid \$1000 or more out-of-pocket in medical expenses in past 12 months

Percent of CSHCN who met criteria for Indicator #12

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		22.1%
LOWER than US; Statistically Significant	Mississippi	14.6%
	Alabama	15.2%
	Hawaii	15.5%
	Rhode Island	16.8%
	West Virginia	16.8%
	Kentucky	16.8%
	Pennsylvania	16.9%
	Arkansas	16.9%
	Maine	17.4%
	District of Columbia	17.9%
LOWER than US; Not Significant	New Mexico	18.0%
	New York	18.0%
	Michigan	19.0%
	North Carolina	19.1%
	Georgia	19.4%
	Vermont	20.1%
	Ohio	20.2%
	South Carolina	20.7%
	Missouri	20.7%
	Louisiana	21.0%
HIGHER than US; Not Significant	California	21.8%
	Oklahoma	21.9%
	Tennessee	21.9%
	Maryland	22.3%
	Delaware	22.5%
	Illinois	22.6%
	Virginia	23.2%
	Indiana	23.5%
	New Hampshire	23.6%
	Idaho	23.6%
HIGHER than US; Statistically Significant	Texas	23.9%
	Iowa	24.3%
	Florida	24.3%
	Wisconsin	24.4%
	Connecticut	24.6%
	Oregon	24.7%
	Arizona	24.8%
	Washington	25.5%
	South Dakota	25.9%
	Nevada*	26.5%
	Massachusetts*	25.7%
	Alaska	26.6%
	North Dakota	26.7%
	Nebraska	27.2%
	Kansas	29.0%
	New Jersey	29.8%
	Minnesota	30.1%
	Colorado	30.3%
	Wyoming	31.0%
	Montana	31.3%
	Utah	34.3%

NOTES:

Lower %'s = Better performance

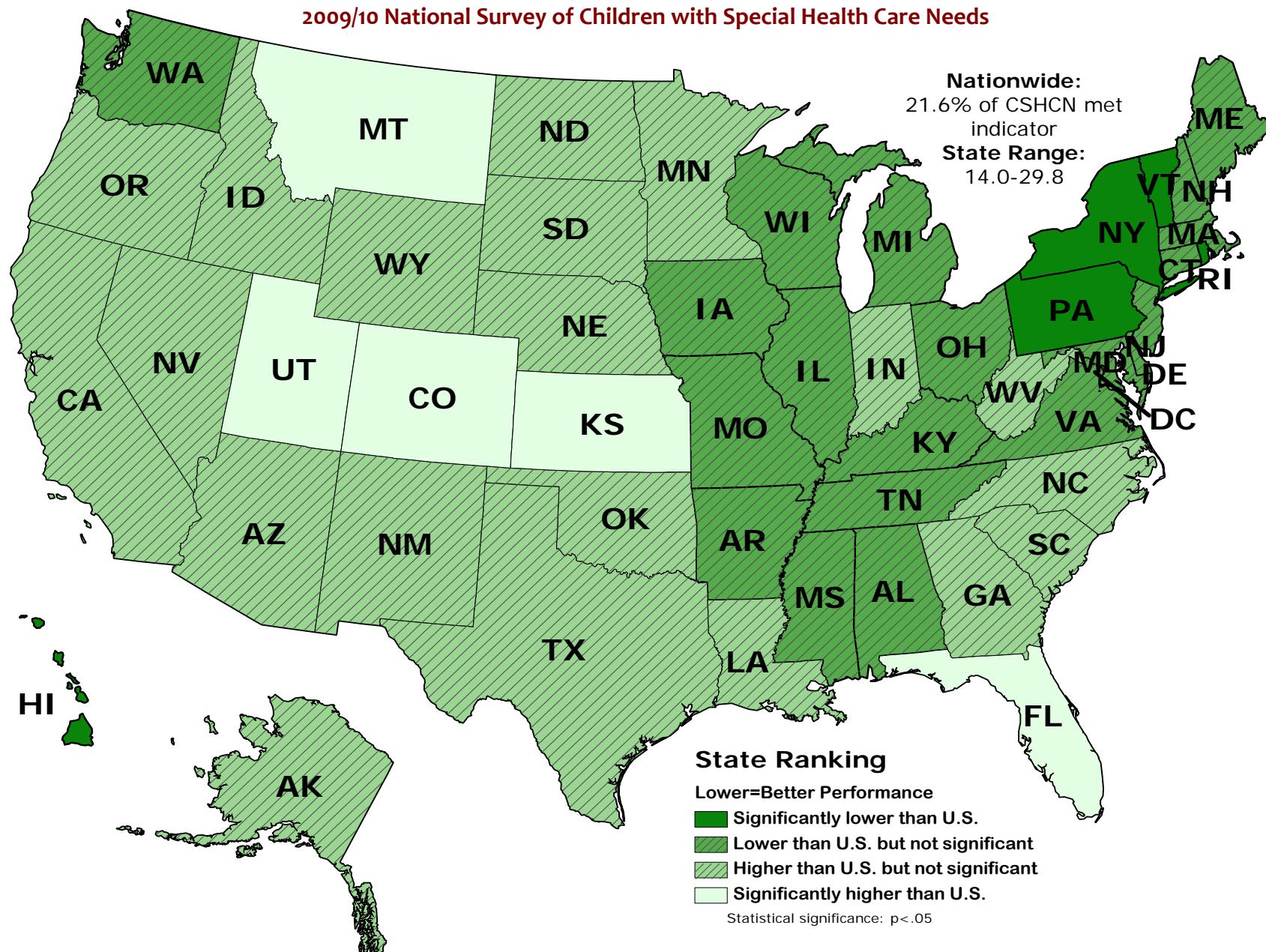
Statistical significance: $p < .05$

* Due to sampling error and other factors, some state estimates differ statistically from the national prevalence while other state estimates of similar or equal size do not.

Indicator 13: CSHCN whose health conditions cause financial problems for the family

Percent of CSHCN who met criteria for Indicator #13

2009/10 National Survey of Children with Special Health Care Needs



Indicator 13: CSHCN whose health conditions cause financial problems for the family

Percent of CSHCN who met criteria for Indicator #13

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		21.6%
LOWER than US; Statistically Significant		
	Hawaii	14.0%
	Rhode Island	14.7%
	District of Columbia	15.1%
	Pennsylvania	16.5%
	Vermont	17.3%
	New York	17.6%
	Michigan	18.2%
	Maryland	18.3%
	Ohio	18.3%
	Wisconsin	18.4%
	Maine	18.6%
	Connecticut	18.8%
	Alabama	19.0%
	Delaware	19.0%
	Massachusetts	19.1%
	Virginia	19.5%
	New Hampshire	19.6%
	Missouri	19.7%
	Tennessee	20.1%
	New Jersey	20.3%
	Iowa	20.6%
	Illinois	20.6%
	Kentucky	20.9%
	Mississippi	21.0%
	Arkansas	21.2%
	Washington	21.3%
	West Virginia	22.0%
	Idaho	22.2%
	North Dakota	22.2%
	Oklahoma	22.2%
	South Carolina	22.4%
	Georgia	22.4%
	North Carolina	22.5%
	Nebraska	22.5%
	Oregon	22.7%
	Minnesota	23.1%
	New Mexico	23.2%
	Wyoming	23.3%
	Louisiana	23.4%
	Alaska	23.6%
	California	24.2%
	Texas	24.2%
	Arizona	24.3%
	Indiana	25.0%
	Nevada	25.4%
	South Dakota*	27.3%
HIGHER than US; Statistically Significant		
	Florida*	26.0%
	Kansas*	26.3%
	Utah	28.3%
	Colorado	29.2%
	Montana	29.8%

NOTES:

Lower %'s = Better performance

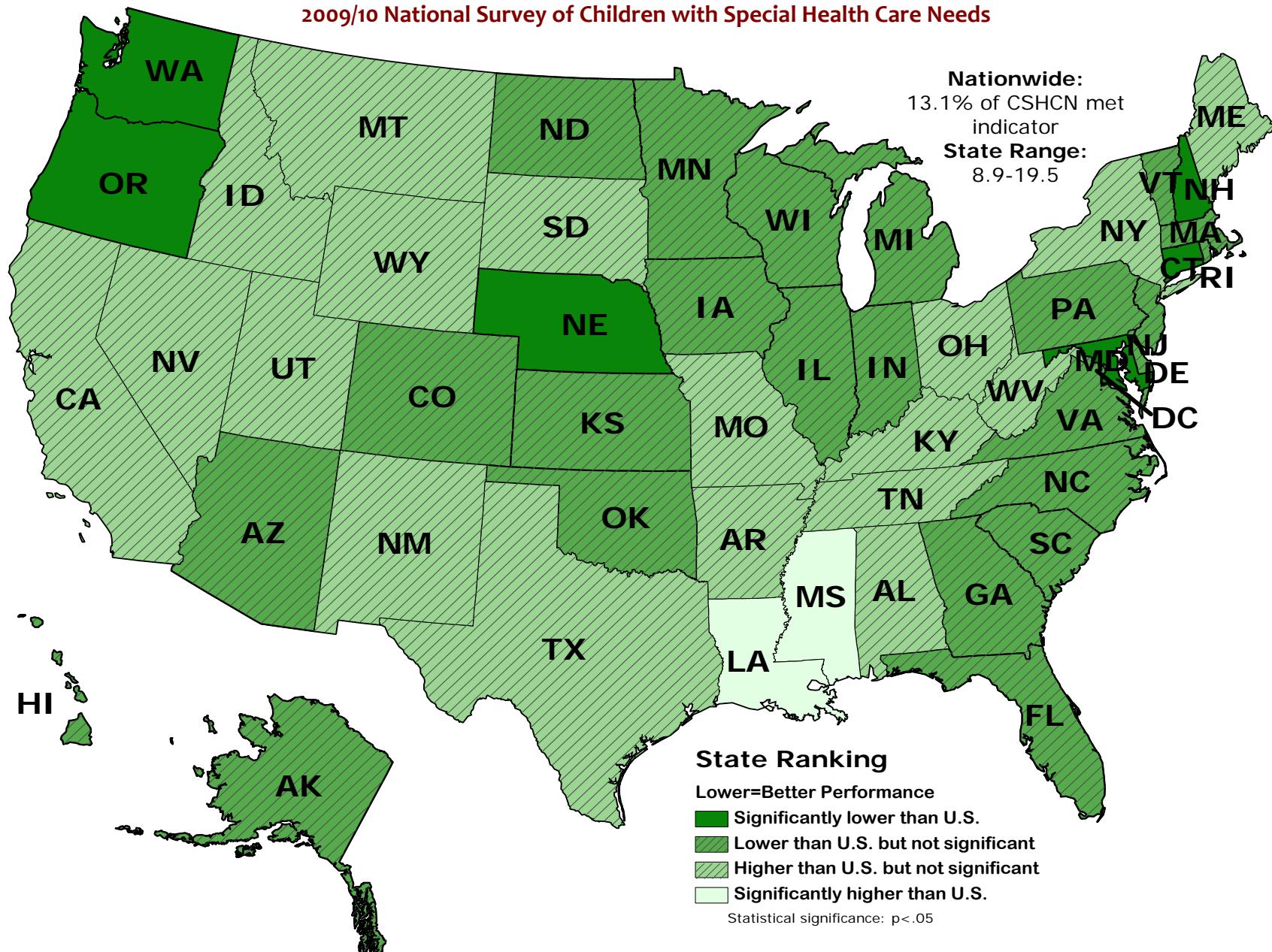
Statistical significance: $p < .05$

* Due to sampling error and other factors, some state estimates differ statistically from the national prevalence while other state estimates of similar or equal size do not.

Indicator 14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's health care

Percent of CSHCN who met criteria for Indicator #14

2009/10 National Survey of Children with Special Health Care Needs



Indicator 14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's health care

Percent of CSHCN who met criteria for Indicator #14

2009/10 National Survey of Children with Special Health Care Needs

US Prevalence		13.1%
LOWER than US; Statistically Significant	Nebraska	8.9%
	Maryland	9.0%
	New Hampshire	9.3%
	Washington	9.4%
	Connecticut	9.9%
	Oregon	10.0%
LOWER than US; Not Significant	North Dakota	10.1%
	Vermont	10.2%
	Illinois	10.7%
	Kansas	10.8%
	Iowa	10.9%
	Colorado	11.0%
	Wisconsin	11.0%
	Virginia	11.0%
	Michigan	11.0%
	Georgia	11.1%
	Rhode Island	11.3%
	New Jersey	11.3%
	Hawaii	11.3%
	Minnesota	11.4%
	Massachusetts	11.5%
	Oklahoma	11.7%
	District of Columbia	11.7%
	Pennsylvania	11.8%
	Alaska	12.0%
	South Carolina	12.2%
	Florida	12.4%
	Indiana	12.5%
	Arizona	12.6%
	Delaware	13.0%
	North Carolina	13.0%
	Montana	13.2%
HIGHER than US; Not Significant	Maine	13.4%
	Kentucky	13.7%
	Idaho	14.0%
	Missouri	14.0%
	South Dakota	14.2%
	Utah	14.3%
	New York	14.4%
	New Mexico	14.7%
	Texas	14.8%
	Wyoming	14.8%
	Alabama	15.0%
	Ohio	15.2%
	Nevada	15.3%
	West Virginia	15.4%
	Arkansas	15.8%
	California	16.3%
	Tennessee	16.4%
HIGHER Stat Sig	Louisiana	19.1%
	Mississippi	19.5%

NOTES:

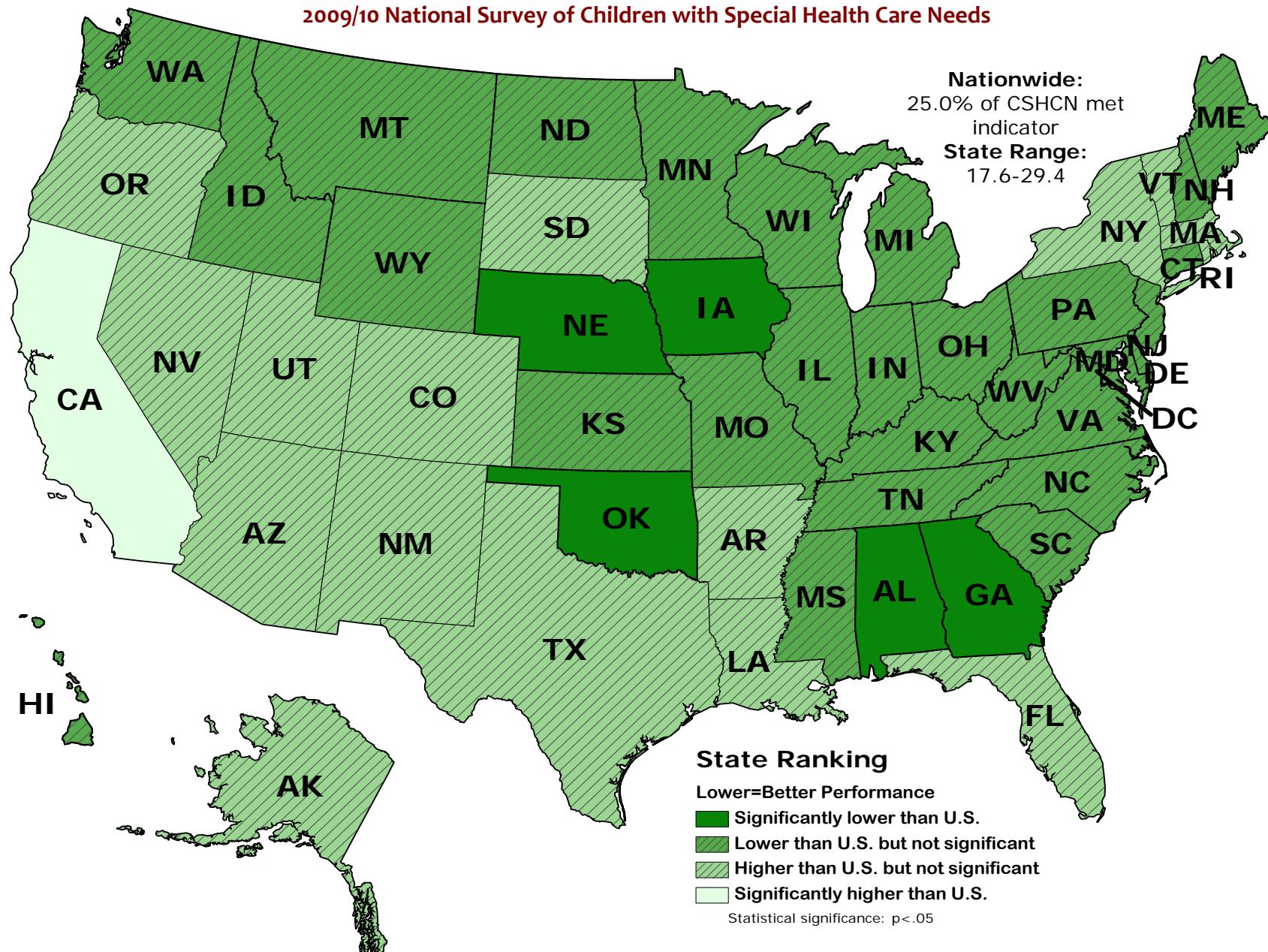
Lower %'s = Better performance

Statistical significance: p < .05

Indicator 15: CSHCN whose health conditions cause family members to cut back or stop working

Percent of CSHCN who met criteria for Indicator #15

2009/10 National Survey of Children with Special Health Care Needs



Indicator 15: CSHCN whose health conditions cause family members to cut back or stop working

Percent of CSHCN who met criteria for Indicator #15

2009/10 National Survey of Children with Special Health Care Needs

	US Prevalence	25.0%
LOWER than US, Statistically Significant	Iowa	17.6%
	Nebraska	17.7%
	Oklahoma	21.0%
	Georgia	21.1%
	Alabama	21.4%
	Delaware	21.6%
	North Dakota	21.6%
	Wyoming	21.8%
	Mississippi	21.9%
	Maryland	22.2%
	West Virginia	22.3%
	North Carolina	22.6%
	Virginia	22.7%
	Missouri	22.9%
	Tennessee	22.9%
	Kansas	23.0%
	New Hampshire	23.0%
	Montana	23.1%
	Michigan	23.3%
	Kentucky	23.4%
	Minnesota	23.6%
	Hawaii	23.6%
	Illinois	23.7%
	Pennsylvania	23.7%
	Maine	23.9%
	Wisconsin	24.5%
	Ohio	24.5%
	District of Columbia	24.6%
	New Jersey	24.6%
	Washington	24.7%
	Idaho	24.7%
	South Carolina	24.7%
	Indiana	24.9%
	Connecticut	24.9%
HIGHER than US; Not Significant	Arkansas	25.5%
	Utah	25.5%
	Rhode Island	25.6%
	Colorado	25.9%
	South Dakota	26.2%
	Arizona	26.4%
	Oregon	26.5%
	New York	26.7%
	Vermont	27.0%
	Texas	27.1%
	Alaska	27.3%
	Florida	27.5%
	Massachusetts	27.5%
	Nevada	28.3%
	Louisiana	28.7%
	New Mexico	28.7%
HIGHER; Stat Sig	California	29.4%

NOTES:

Lower %'s = Better performance

Statistical significance: p < .05

APPENDIX D

CSHCN Screener



CAHMI

The Child and Adolescent Health
Measurement Initiative

**THE
CHILDREN
WITH
SPECIAL
HEALTH
CARE NEEDS
(CSHCN)
SCREENER[©]**

Developed in Collaboration with:



NCQA



FAMILY VOICES



BACKGROUND

The Children with Special Health Care Needs (CSHCN) Screener[©] was developed through the efforts of the Child and Adolescent Health Measurement Initiative (CAHMI), a national collaboration coordinated by FACCT—The Foundation for Accountability. Beginning in June 1998, the CAHMI brought together federal and state policymakers, health care providers, researchers and consumer organizations into a task force for the purpose of specifying a method to identify children with special health care needs. During the course of this project, the task force met in person six times and more than a dozen times by teleconference.

The CSHCN Screener[©] is a five item, parent survey-based tool that responds to the need for an efficient and flexible standardized method for identifying CSHCN. The screener is specifically designed to reflect the federal Maternal and Child Health Bureau definition of children with special health care needs:

“Children who have special health care needs are those who have...a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.¹”

The CSHCN Screener[©] uses non-condition specific, consequences-based criteria to identify children with special health care needs for purposes of quality assessment or other population-based applications. Children are identified on the basis of experiencing one or more current functional limitations or service use needs that are the direct result of an on-going physical, emotional, behavioral, developmental or other health condition.

The non-condition specific approach used by the CSHCN Screener[®] identifies children across the range and diversity of childhood chronic conditions and special needs, allowing a more comprehensive assessment of health care system performance than is attainable by focusing on a single diagnosis or type of special need. In addition, the relatively low prevalence of most childhood chronic conditions and special health care needs often makes it problematic to find adequate numbers of children with a specific diagnosis or type of special need. A non-condition specific approach makes it possible in many cases to identify enough children to allow statistically robust quality comparisons across health care systems and/or providers.

The CSHCN Screener[®] is currently being used in several national surveys, including the National Survey of Children with Special Health Care Needs and as part of the CAHPS[®]² survey items in the Medical Expenditure Panel Survey (MEPS). The Agency for Healthcare Research and Quality (AHRQ) has included the screener as an integral part of the new CAHPS 2.0 Child Survey. The Screener is also formally integrated into the CAHPS 2.0H Child Survey to identify the Children with Chronic Conditions Measurement Set, a component of the National Committee for Quality Assurance's Health Plan Employer Data and Information Set (HEDIS[®]).³ English and Spanish versions of the CSHCN Screener[®] are available.

¹McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998; 102:137-140.

²CAHPS[®] is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ).

³HEDIS[®] is a registered trademark of the National Committee for Quality Assurance (NCQA).

For more information on the development, testing & application of the CSHCN Screener:

Bethell CD, Read D, Stein REK, Blumberg SJ, Wells N, Newacheck PW. Identifying children with special health care needs: development and evaluation of a short screening instrument. *Ambulatory Pediatrics*. 2002;2:38-47.

Bethell CD, Read D, Neff J, Blumberg SJ, Stein REK, Sharp V, Newacheck P. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambulatory Pediatrics*. 2002;2:49-57.

Van Dyck P, McPherson M, Strickland B, Nesseler K, Blumberg SJ, Cynamon M, Newacheck, PW. The national survey of children with special health care needs. *Ambulatory Pediatrics*. 2002;2:29-37.

For scoring programs or other technical support for the CSHCN Screener and its applications:

Christina Bethell, Director

CAHMI—The Child and Adolescent Health Measurement Initiative
Telephone: 503.494.1930
email: cahmi@ohsu.edu

For technical support for the CAHPS 2.0 Child Survey, please contact:

The CAHPS Survey User Network
800.492.9261 or www.cahps-sun.org

For technical support on the CAHPS 2.0H® Child Survey*, please contact:

NCQA Policy Clarification Support
hedis@ncqa.org

User's Form:

There is no cost to use the CSHCN Screener, however, we ask that you complete the enclosed User's Form. Your input helps us to develop an understanding of our key users and to provide updates.

Please submit the User's Form via *fax (503.494.2475)* or *email (cahmi@ohsu.edu)*.
We look forward to hearing from you!

*The National Committee for Quality Assurance has incorporated a version of the CAHPS 2.0 survey into the HEDIS measurement set. The version of the survey required for HEDIS is referred to as the "CAHPS 2.0H Survey."

Children with Special Health Care Needs (CSHCN) Screener[©]

(mail or telephone)

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
 Yes → Go to Question 1a
 No → Go to Question 2
 - 1a. Is this because of ANY medical, behavioral or other health condition?
 Yes → Go to Question 1b
 No → Go to Question 2
 - 1b. Is this a condition that has lasted or is expected to last for at least 12 months?
 Yes
 No
2. Does your child need or use more **medical care, mental health or educational services** than is usual for most children of the same age?
 Yes → Go to Question 2a
 No → Go to Question 3
 - 2a. Is this because of ANY medical, behavioral or other health condition?
 Yes → Go to Question 2b
 No → Go to Question 3
 - 2b. Is this a condition that has lasted or is expected to last for at least 12 months?
 Yes
 No
3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
 Yes → Go to Question 3a
 No → Go to Question 4
 - 3a. Is this because of ANY medical, behavioral or other health condition?
 Yes → Go to Question 3b
 No → Go to Question 4
 - 3b. Is this a condition that has lasted or is expected to last for at least 12 months?
 Yes
 No
4. Does your child need or get **special therapy**, such as physical, occupational or speech therapy?
 Yes → Go to Question 4a
 No → Go to Question 5
 - 4a. Is this because of ANY medical, behavioral or other health condition?
 Yes → Go to Question 4b
 No → Go to Question 5
 - 4b. Is this a condition that has lasted or is expected to last for at least 12 months?
 Yes
 No
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs or gets **treatment or counseling**?
 Yes → Go to Question 5a
 No
 - 5a. Has this problem lasted or is it expected to last for at least 12 months?
 Yes
 No

Scoring the Children with Special Health Care Needs (CSHCN) Screener[©]

The CSHCN Screener[©] uses consequences-based criteria to screen for children with chronic or special health care needs. To qualify as having chronic or special health care needs, the following criteria must be met:

- a) The child currently experiences a specific consequence.
- b) The consequence is due to a medical or other health condition.
- c) The duration or expected duration of the condition is 12 months or longer.

The first part of each screener question asks whether a child experiences one of five different health consequences:

- 1) Use or need of prescription medication.
- 2) Above average use or need of medical, mental health or educational services.
- 3) Functional limitations compared with others of same age.
- 4) Use or need of specialized therapies (OT, PT, speech, etc.).
- 5) Treatment or counseling for emotional or developmental problems.

The second and third parts* of each screener question ask those responding “yes” to the first part of the question whether the consequence is due to any kind of health condition and if so, whether that condition has lasted or is expected to last for at least 12 months.

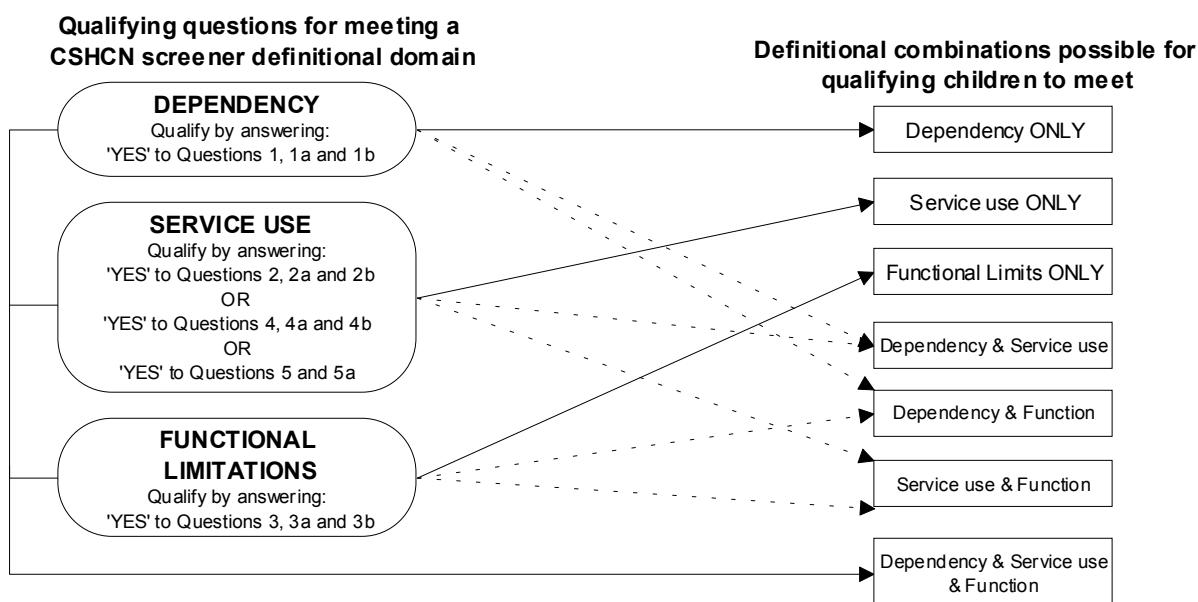
*NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered “yes” to qualify.

All three parts of at least one screener question (or in the case of question 5, the two parts) must be answered “yes” in order for a child to meet CSHCN Screener[©] criteria for having a chronic condition or special health care need.

The CSHCN Screener[©] has three “definitional domains”:

- 1) Dependency on prescription medications.
- 2) Service use above that considered usual or routine.
- 3) Functional limitations.

The definitional domains are not mutually exclusive categories. A child identified by the CSHCN Screener[©] can qualify on one or more definitional domains (see diagram).



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APPENDIX E

Medical Home Items

2009-2010 NS-CSHCN Items

Full text and response options for questions
used to assess MCHB Core Outcome #2: Medical Home

2009-2010 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
<u>SECTION 4: ACCESS TO CARE -- UTILIZATION AND UNMET NEEDS</u>	
C4q0a Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health?	<p>(1) YES [SKIP TO C4Q0D] (2) THERE IS NO PLACE [SKIP TO C4Q0D] (3) THERE IS MORE THAN ONE PLACE [SKIP TO C4Q0D] (6) DON'T KNOW [SKIP TO C4Q0D] (7) REFUSED [SKIP TO C4Q0D]</p>
<i>If Yes to C4q0a:</i> C4q0b Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?	<p>(01) DOCTOR'S OFFICE [SKIP TO C4Q0D] (02) HOSPITAL EMERGENCY ROOM [SKIP TO C4Q0D] (03) HOSPITAL OUTPATIENT DEPARTMENT [SKIP TO C4Q0D] (04) CLINIC OR HEALTH CENTER [SKIP TO C4Q0D] (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) [SKIP TO C4Q0D] (06) FRIEND/RELATIVE [SKIP TO C4Q0D] (07) MEXICO/OTHER LOCATIONS OUT OF US [SKIP TO C4Q0D] (08) SOME OTHER PLACE [SKIP TO C4Q0C] (09) DOES NOT GO TO ONE PLACE MOST OFTEN [SKIP TO C4Q0D] (96) DON'T KNOW [SKIP TO C4Q0D] (97) REFUSED [SKIP TO C4Q0D]</p>
C4q0d Is there a place that (S.C.) USUALLY goes when (he/she) needs routine preventive care, such as a physical examination or well-child check-up?	<p>(1) YES [SKIP TO C4Q02A] (2) THERE IS NO PLACE [SKIP TO C4Q02A] (3) THERE IS MORE THAN ONE PLACE [SKIP TO C4Q02A] (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p>
<i>If Yes to C4q0d:</i> C4q01 Is the [place selected in C4q0b] that (S.C.) goes to when (he/she) is sick the same place (S.C.) usually goes for routine preventive care?	<p>(1) YES [SKIP TO C4Q02A] (2) NO [SKIP TO C4Q02A] (6) DON'T KNOW [SKIP TO C4Q02A] (7) REFUSED [SKIP TO C4Q02A]</p>
C4q02 What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care?	<p>(01) DOCTOR'S OFFICE (02) HOSPITAL EMERGENCY ROOM (03) HOSPITAL OUTPATIENT DEPARTMENT (04) CLINIC OR HEALTH CENTER (05) SCHOOL (NURSE'S OFFICE, ATHLETIC TRAINER'S OFFICE, ETC) (06) FRIEND/RELATIVE (07) MEXICO/OTHER LOCATIONS OUT OF US (08) SOME OTHER PLACE [SKIP TO C4Q02_1] (09) DOES NOT GO TO ONE PLACE MOST OFTEN (96) DON'T KNOW (97) REFUSED</p>

2009-2010 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C4q02a A personal doctor or nurse is a health professional who knows your child well and is familiar with your child's health history. This can be a general doctor, a pediatrician, a specialist doctor, a nurse practitioner, or a physician's assistant. Do you have one or more persons you think of as (S.C.)'s personal doctor or nurse?	(1) YES, ONE PERSON (2) YES, MORE THAN ONE PERSON (3) NO (6) DON'T KNOW (7) REFUSED [SKIP TO C4Q03] [SKIP TO C4Q03] [SKIP TO C4Q03]
<u>SECTION 5: CARE COORDINATION</u>	
C5q11 During the past 12 months, did (S.C.) need a referral to see any doctors or receive any services? <i>If Yes to C5q11:</i> C4q07 Was getting referrals a big problem, a small problem, or not a problem?	(1) YES (2) NO (6) DON'T KNOW (7) REFUSED (1) Big problem (2) Small problem (3) Not a problem (6) DON'T KNOW (7) REFUSED [SKIP TO C5Q12] [SKIP TO C5Q12] [SKIP TO C5Q12]
C5q17 During the past 12 months, have you felt that you could have used extra help arranging or coordinating (S.C.)'s care among these different health care providers or services? <i>If Yes to C5q17:</i> C5q09 During the past 12 months, how often did you get as much help as you wanted with arranging or coordinating (S.C.)'s care?	(1) YES (2) NO (6) DON'T KNOW (7) REFUSED (1) Never (2) Sometimes (3) Usually (6) DON'T KNOW (7) REFUSED [SKIP TO C5Q10] [SKIP TO C5Q10] [SKIP TO C5Q10]
C5q10 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among (S.C.)'s doctors and other health care providers?	(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (5) NO COMMUNICATION NEEDED OR WANTED (6) DON'T KNOW (7) REFUSED

2009-2010 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C5q05 Do (S.C.)'s doctors or other health care providers need to communicate with (his/her) school, early intervention program, child care providers, vocational education or rehabilitation program? <i>If Yes to C5q05:</i> C5q06 Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?	(1) YES (2) NO (6) DON'T KNOW (7) REFUSED [SKIP TO C6Q02] [SKIP TO C6Q02] [SKIP TO C6Q02]
SECTION 6A: FAMILY CENTERED CARE	
C6q02 During the past 12 months, how often did (S.C.)'s doctors and other health care providers spend enough time with (him/her)?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
C6q03 During the past 12 months, how often did (S.C.)'s doctors and other health care providers listen carefully to you?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
C6q04 When (S.C.) is seen by doctors or other health care providers, how often are they sensitive to your family's values and customs?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
C6q05 During the past 12 months, how often did you get the specific information you needed from (S.C.)'s doctors and other health care providers?	(1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED

2009-2010 NS-CSHCN

Text and response options for questions used to assess Medical Home
(Listed in the order asked in the survey)

QUESTIONS	RESPONSE CATEGORIES AND SKIP PATTERNS
C6q06 During the past 12 months, how often did (S.C.)'s doctors or other health care providers help you feel like a partner in (his/her) care?	<ul style="list-style-type: none"> (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED
S5q13 During the past 12 months, did you (or S.C.) need an interpreter to help speak with (his/her) doctors or other health care providers?	<ul style="list-style-type: none"> (1) YES (2) NO (6) DON'T KNOW (7) REFUSED <p style="text-align: right;">[SKIP TO S5Q13A] [SKIP TO C6Q07] [SKIP TO C6Q07] [SKIP TO C6Q07]</p>
<i>If Yes to S5q13:</i> S5q13a When you (or S.C.) needed an interpreter, how often were you able to get someone other than a family member to help you speak with (his/her) doctors or other health care providers?	<ul style="list-style-type: none"> (1) Never (2) Sometimes (3) Usually (4) Always (6) DON'T KNOW (7) REFUSED

Threshold criteria for meeting OUTCOME #2 Medical Home sub-components

The threshold criteria for 2009-2010 NS-CSHCN versions of the medical home measure sub-components are briefly outlined below:

1. Child has at least one personal doctor or nurse
 - a. Constructed from a single question
 - b. *2009-2010 threshold criteria* = YES responses indicating child has one or more than one personal doctor or nurse
2. Usual source(s) for both sick and well care
 - a. Constructed from five questions
 - b. *2009-2010 threshold criteria* = responses across the relevant questions indicating child has regular sources other than hospital emergency room for both sick and well care
3. Receives family centered care
 - a. Constructed from five to seven questions
 - b. *2009/10 threshold criteria* = responses indicating child had 1 or more doctor visits during past 12 months AND responses of USUALLY or ALWAYS to all five family centered care questions, AND if needed, responses of USUALLY or ALWAYS to accessing interpreter services during child's health care visits
4. No problems obtaining referrals
 - a. Constructed from two questions
 - b. *2009-2010 threshold criteria* = YES response to referrals are necessary in order for child to see other doctors or receive services AND response of NOT A PROBLEM to getting the needed referrals
5. Receives effective care coordination
 - a. Constructed from six questions in 2005/06
 - b. *2009-2010 threshold criteria* = If child used 2 or more services during past year, affirmative responses indicating family currently receives help coordinating child's care and does not need extra help, OR if extra help was needed, family USUALLY received the help desired, AND if child used any of five different specialized services and communication between doctors was needed, responses of VERY SATISFIED with that communication, AND if needed, responses of VERY SATISFIED with communication between doctors and child's school or other programs.

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APPENDIX F

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