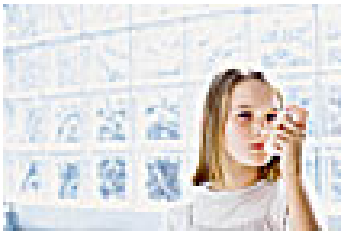
Children With Special Health-Care Needs in North Dakota

Using Data From the
National Survey of Children With Special Health-Care Needs




A Report for
Policymakers, Advocacy Groups and Families

NORTH DAKOTA
DEPARTMENT *of* HEALTH

Prepared by:

Data Resource Center for Child & Adolescent Health
Your Data… Your story
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National Survey of Children With Special Health-Care Needs

A Report for Policymakers, Advocacy Groups and Families

Prepared by
CAHMI – The Child and Adolescent Health Measurement Initiative
Oregon Health & Science University

for
North Dakota Department of Health
Division of Children's Special Health Services

Dr. Terry Dwelle, State Health Officer
John Hoeven, Governor

November 2008

NORTH DAKOTA
DEPARTMENT *of* HEALTH

Data Resource Center for Child & Adolescent Health

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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, room for improvement – through policy reform, programmatic development and implementation, and family advocacy – still exists.

In North Dakota, approximately one in eight children has special health-care needs as defined by the U.S. Department of Health and Human Services, Maternal and Child Health Bureau:

"...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."[1]

This definition 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 and families for children with special needs served by the state Title V block grants administered by the Maternal and Child Health Bureau.

Information in this report comes from the 2005-2006 National Survey of Children With Special Health-Care Needs (NS-CSHCN)[2] and the 2001 NS-CSHCN. 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 pertaining to CSHCN. In addition, the survey assesses whether CSHCN have medical homes, adequate health insurance, and access to needed services. The survey also evaluates functional difficulties, chronic medical conditions, care coordination, satisfaction with care, and adolescent transition services, to examine the extent to which CSHCN need a wide range of medical and support services.

Section 1 of the report provides an overview of CSHCN in North Dakota, including prevalence of CSHCN in North Dakota as compared to the region and nation, and comparison of North Dakota CSHCN with non-CSHCN in North Dakota and CSHCN in the region and nation according to key characteristics: age, sex, race/ethnicity, income, and rural/urban status. This section also offers a summary of the health and functioning of CSHCN and the range of conditions and functional limitations they experience.

In Section 2, North Dakota's performance on each of the six MCHB Core Outcomes is 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, data tables, and maps showing North Dakota's performance on each of the MCHB Core Outcomes in the context of surrounding states and the nation.

Executive Summary

Prevalence and Demographics of CSHCN in North Dakota and Nationwide

- Approximately 16,500 children in North Dakota, 12.2% 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 2005-2006 National Survey of Children With Special Health-Care Needs.
- The prevalence of Children With Special Health-Care Needs (CSHCN) in North Dakota (12.2%) is slightly lower than nationwide (13.9%), but the difference is statistically significant at the 95% confidence level.
- The prevalence of CSHCN in North Dakota did not change between 2001 (12.4%) and 2005-2006 (12.2%).
- About four in 10 (39.1%) of North Dakota's CSHCN live in urban core areas of the state; just over one-third (34.9%) live in small towns or isolated rural areas.
- Compared to children without special health-care needs, CSHCN in North Dakota are significantly more likely to be male (59.1 % of CSHCN vs. 50.3% of non-CSHCN) and school-aged (72.9% of CSHCN vs. 65.4% of non-CSHCN).
- The proportion of children who are white, non-Hispanic (85%), American Indian (9%), or some other race/ethnicity (6%), is the same among CSHCN as it is among non-CSHCN in North Dakota.

Health Characteristics of CSHCN in North Dakota

- Compared to the U.S. overall, North Dakota has a significantly higher percentage of CSHCN whose health conditions are managed by a combination of prescription medication and specialized services or therapies (26.7% in North Dakota vs. 20.7% nationwide).
- An estimated 6,300 to 7,800 CSHCN (42.4%) in North Dakota depend primarily upon prescription medication to manage their chronic health conditions.
- Another 5,300 to 7,400 CSHCN (39.5%) in North Dakota require one or more types of medical, mental health, educational or other specialized services, either alone or in conjunction with prescription medications, to manage their ongoing health conditions.
- Almost one in five or approximately 2,600 to 3,700 CSHCN (18.1%) 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 and are satisfied with the services they receive.

- 63.0% of CSHCN in North Dakota met the criteria for successfully receiving health care services in which parents feel partnered and satisfied with child's care, significantly more than in the U.S. overall (57.4%).
- Although most CSHCN in North Dakota are a great deal more likely to have families that feel included as partners by their children's doctors (91.0%), only about two-thirds (64.4%) report being "very satisfied" overall with the services their children receive.
- CSHCN in North Dakota are MORE likely to meet the criteria for outcome #1 if they are:
  - White, non-Hispanic (65.3%).
  - Privately insured (65.4%).
  - Managing their chronic health conditions primarily through prescription medication (71.2%).
  - Living in higher income households (73.1% of CSHCN at 400% of Federal Poverty Level or higher).
- The percentage of CSHCN in North Dakota who met this outcome changed little between 2001 (61.5%) and 2005-2006 (63.0%).

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

- 51.2 percent of CSHCN in North Dakota receive care within a medical home, about the same proportion as at the national level (47.1%).
- Among CSHCN in North Dakota, 92.7 percent have at least one doctor or nurse who knows them well, and 90.9 percent have a place they usually go to for preventive care and medical treatment.
- Nearly one-third of CSHCN in North Dakota (30.7%) do not have family-centered care, according to medical home criteria.
- Two-thirds of CSHCN in North Dakota (66.2%) did not need a referral to see a specialist or receive services in 2005-2006. Of the one-third who did need a referral, more than 80 percent had no problems getting it.
- Three of every four CSHCN in North Dakota (73.5%) needed help with care coordination; 63.0 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 (53.8%).
  - Privately insured (57.5%).
  - Living in higher-income households (65.0% of CSHCN at 400% of Federal Poverty Level or higher).

- Managing their chronic health conditions primarily through prescription medication (67.2%).

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

- In 2005-2006, 68.2 percent of CSHCN in North Dakota had insurance that was adequate for their needs; 5.3 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 62.0 percent to 68.2 percent.
- CSHCN in North Dakota are LESS likely to have adequate insurance coverage if they:
  - Live in households with income just above the poverty line (51.3% of CSHCN between 100% and 200% of Federal Poverty Level).
  - Are Hispanic, African American, Asian or multiethnic (53.5%).
  - Have health-related functional limitations (60.1%).
- Most CSHCN in North Dakota had continuous insurance coverage over the previous 12 months (90.4%); however, one-quarter (26.0%) 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 national average on Outcome #3 (68.2% in North Dakota vs. 62.0% nationwide), more than three in 10 (31.8%) still do not have consistent and adequate insurance coverage.

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

- In 2005-2006, 57.5 percent of CSHCN in North Dakota received health care that included preventive medical and dental care, significantly fewer than nationwide (63.8%).
- CSHCN in North Dakota are MORE likely to meet outcome #4 if they:
  - Are privately insured (61.7%).
  - Live in higher-income households (70.8% of CSHCN at 400% of Federal Poverty Level or higher).
- The proportion of CSHCN who did not receive regular preventive medical care is considerably higher in North Dakota (31.7%) than nationwide (22.9%).
- Overall, more CSHCN in North Dakota received preventive dental care (79.1%), than preventive medical care (68.3%).

Outcome #5: Services for CSHCN are organized in ways that families can use them easily.

- In 2005-2006, 92.3 percent of CSHCN in North Dakota had no difficulties using needed services, a significantly higher proportion than in the U.S. overall (89.1%).
- CSHCN in North Dakota are LESS likely to meet outcome #5 if they:
  - Are uninsured (74.0%).
  - Have functional limitations (83.5%).

Outcome #6: Youth with special health-care needs receive services necessary for their transition to appropriate adult health care, work and independence.

- Only about half (51.2%) of CSHCN ages 12 through 17 in North Dakota receive health care that appropriately addresses their eventual transition to adult health care.
- CSHCN ages 12 through 17 in North Dakota are LESS likely to have adequate transitional support if they are:
  - Male (44.1%).
  - Living in low-income households (32.3% of CSHCN below Federal Poverty Level and 30.2% of those at 100% to 199% of FPL).
- North Dakota exceeds national performance on outcome #6 overall (51.2% in North Dakota vs. 41.2% nationwide), and on each of its component measures: anticipatory guidance (56.6% vs. 47.4% either received or did not need it), and self-management skills (84.0% vs. 78.0%).
- Among adolescent CSHCN in North Dakota, girls are much more likely than boys to receive help developing age-appropriate self management skills (92.0% of females vs. 78.1% of males); a similar but slightly smaller differential appears for anticipatory guidance (61.9% of females vs. 53.0% of males).

Family Impact of CSHCN Needs in North Dakota

- In North Dakota, roughly 6,500 CSHCN (41.3%) 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 one in five CSHCN (21.9%) in North Dakota paid more than $1,000 out-of-pocket for medical expenses in the past 12 months.
- Similar proportions of CSHCN in North Dakota have experienced family financial problems resulting from the child's health-care needs (18.1%), or family members had to cut back or stop working (18.5%).
- One in 11 CSHCN in North Dakota (9.1%) report that family members spend more than 11 hours per week coordinating or providing care for them.
- Significantly fewer CSHCN in North Dakota than in the U.S. overall had family members who had to cut back or stop working as a result of their chronic health conditions (18.1% in North Dakota vs. 23.8% nationwide).
- CSHCN whose families are most heavily impacted financially (Indicators #12 and #13) are:
  - CSHCN who were not covered by health insurance at the time of the survey.
  - CSHCN who have complex health-care needs (functional limitations or health conditions requiring both prescription medications and specialized services).
- CSHCN whose families are most likely to be impacted by demands on their time are:
  - CSHCN living in households with income below federal poverty level.
  - CSHCN who have publicly funded health insurance or are uninsured.
  - CSHCN who have functional limitations.

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:

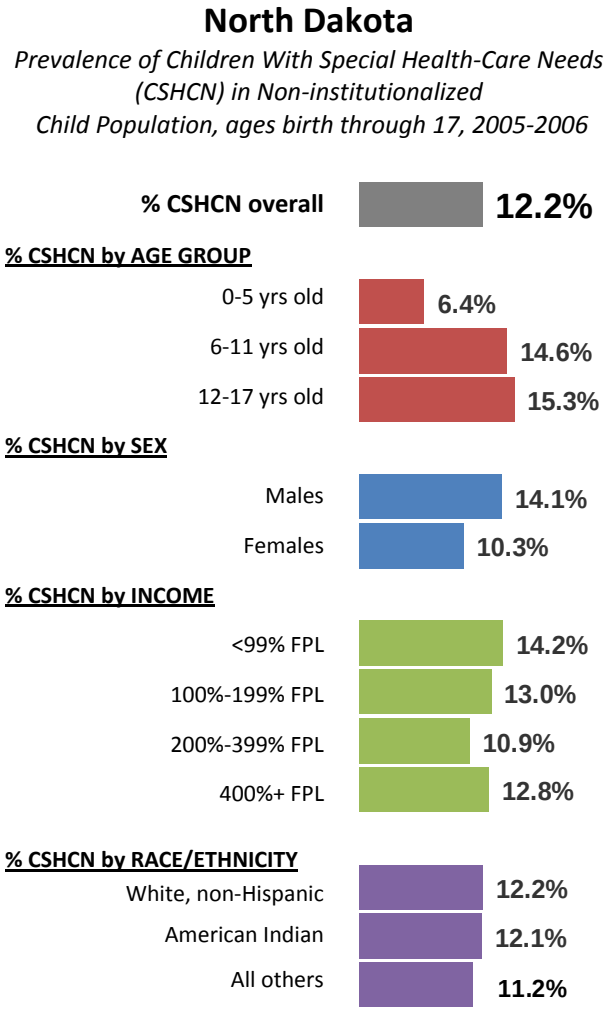
> *"Those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally….*[1]*"*

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 2005/06, 4,027 households in North Dakota were contacted, and 7,755 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.

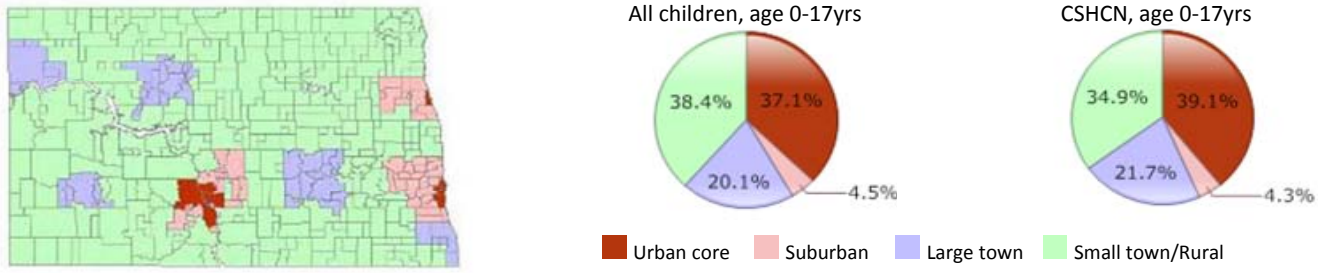
Based on the 2005-2006 NS-CSHCN…

- **Approximately 16,500 children (12.2%) in North Dakota meet the MCHB definition for having special health-care needs.**
- **The prevalence of CSHCN in North Dakota is significantly lower than the national average.**
  12.2 percent prevalence of CSHCN in North Dakota is statistically different from the 13.9 percent prevalence of CSHCN nationally.
- **CSHCN prevalence in North Dakota is not increasing.**
  The prevalence of CSHCN in 2005/06 is basically the same as found by the NS-CSHCN in 2001 (12.2% vs. 12.4%, respectively).
- **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 race/ethnicities.
  - With different household income levels.



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

Figure A_1: Geographic distribution of CSHCN population versus all children: North Dakota, 2005-06



Key Findings for North Dakota…

- The geographic distribution of North Dakota's CSHCN population does not differ from that for the child population as a whole. (Fig. A_1)
- About 40 percent of North Dakota's CSHCN live in the urban core areas of the state, and just over one-third live in small towns or isolated rural areas. (Fig. A_1)
- CSHCN are significantly 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)

Figure A_2: Age distribution for CSHCN vs. non-CSHCN populations: North Dakota, 2005-2006

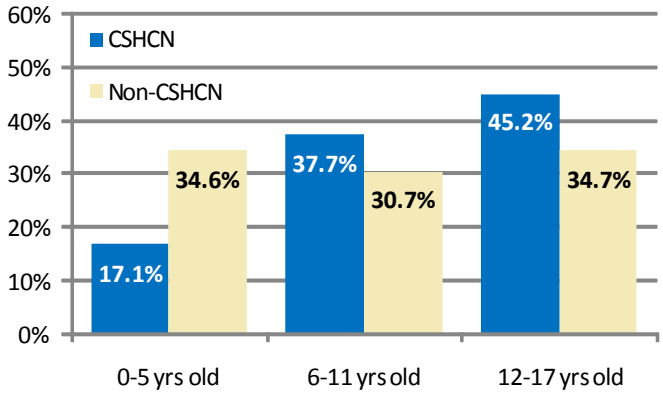


Figure A_3: Gender distribution for CSHCN vs. non-CSHCN populations: North Dakota; 2005-2006

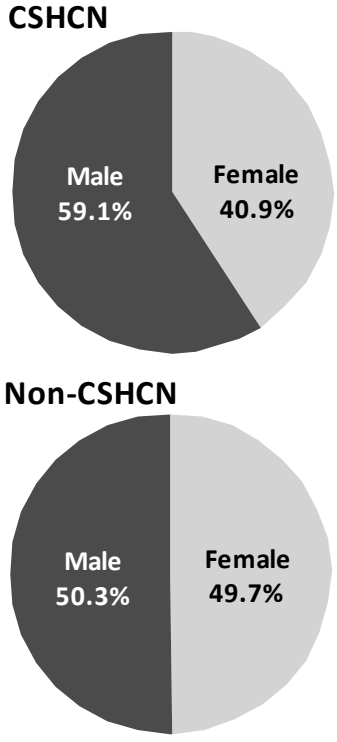
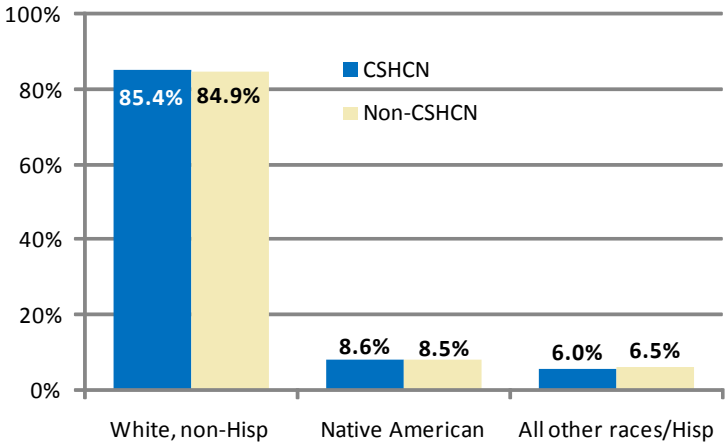


Figure A_4: Race/ethnicity distribution for CSHCN vs. non-CSHCN populations: North Dakota, 2005-2006



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 2005/06 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.[1,3,4] 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.

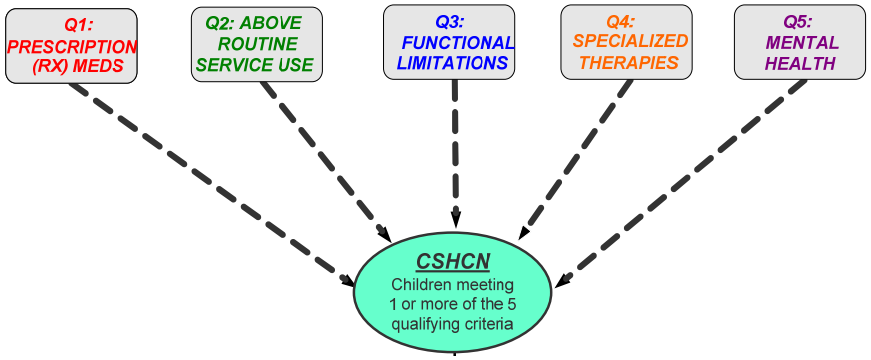
The CSHCN Screener is composed of five questions. The first part of each question asks if the child experiences one of the following:

- ***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 2005-2006 NS-CSHCN, approximately 16,500 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



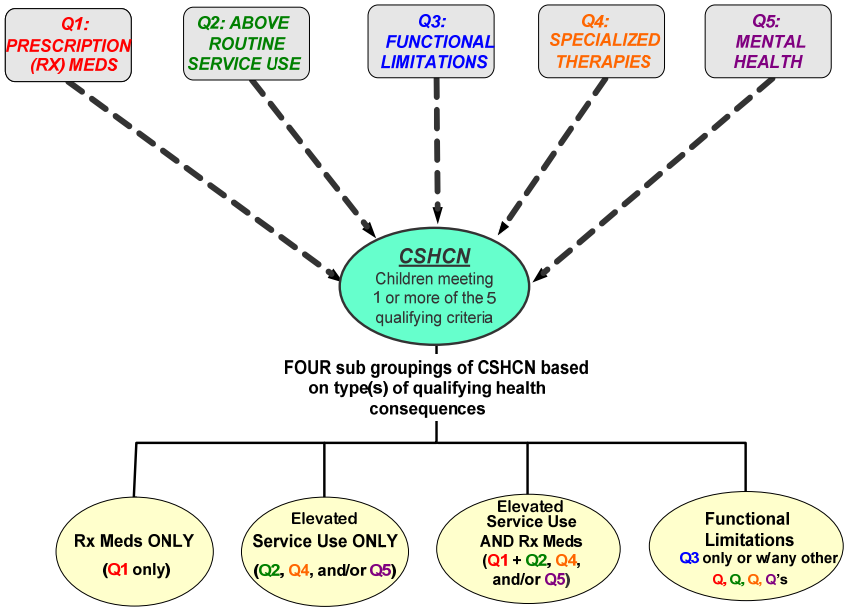
Differentiating Special Health-Care Needs

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 [5,6] supports using qualifying CSHCN screener criteria as the basis for differentiating the array of special needs identified under the broad, inclusive MCHB definition.

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 subgroupings as follows:

- 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.

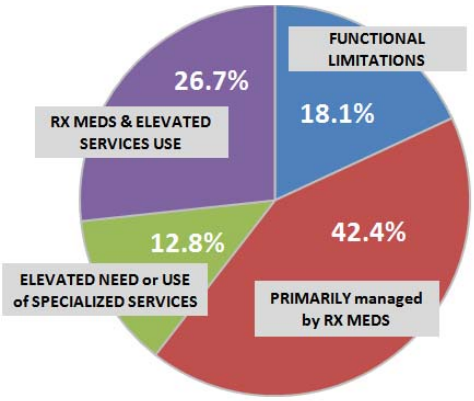
Figure B_2: CSHCN subgroupings based on types of qualifying screener criteria



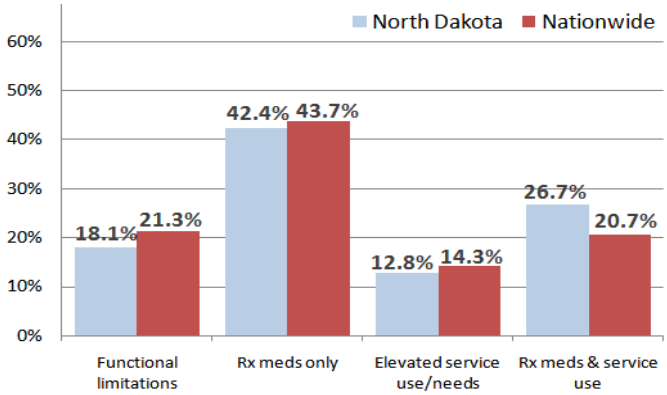
North Dakota – *Who Are Children With Special Health-Care Needs?*

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

CSHCN: North Dakota, 2005-2006



CSHCN: North Dakota vs. Nationwide, 2005-2006



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 – with one exception: North Dakota has a significantly higher percentage of CSHCN managed by a combination of prescription medication and specialized services or therapies (26.7% vs. 20.7%).
- An estimated 6,300 to 7,800 CSHCN (42.4%) 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.
- Another 5,300 to 7,400 CSHCN (39.5%) in North Dakota require one or more types of medical, mental health, educational or other kinds of specialized services, either alone or in conjunction with prescription medications, to manage and treat their ongoing health conditions.
- Finally, almost one in five, or approximately 2,600 to 3,700 CSHCN (18.1%), in North Dakota experience one or more limitations in functioning as a result of their chronic health conditions – in addition to needing specialized health services and/or prescription medication management.

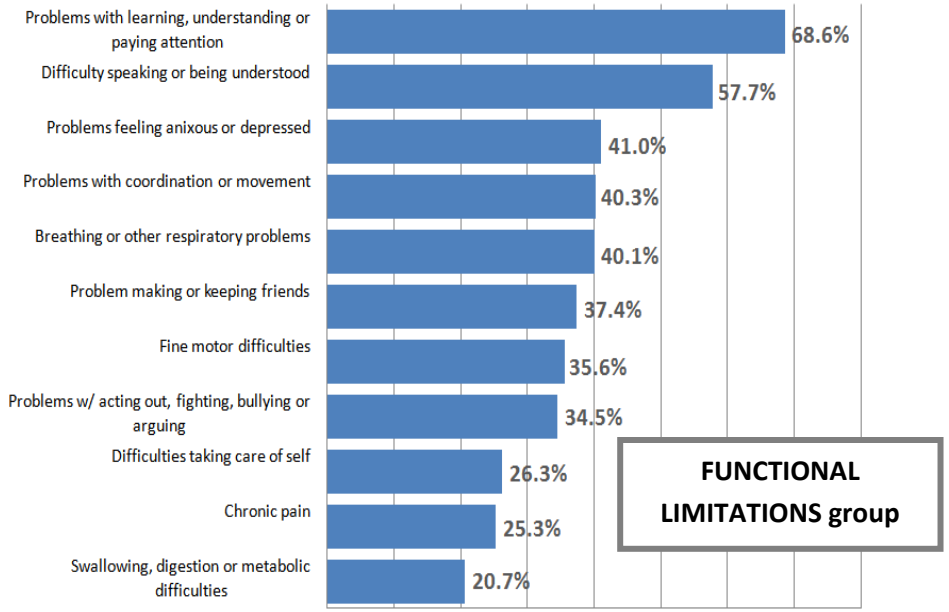
What specific types of health problems do CSHCN in North Dakota experience as a result of their chronic conditions or disabilities?

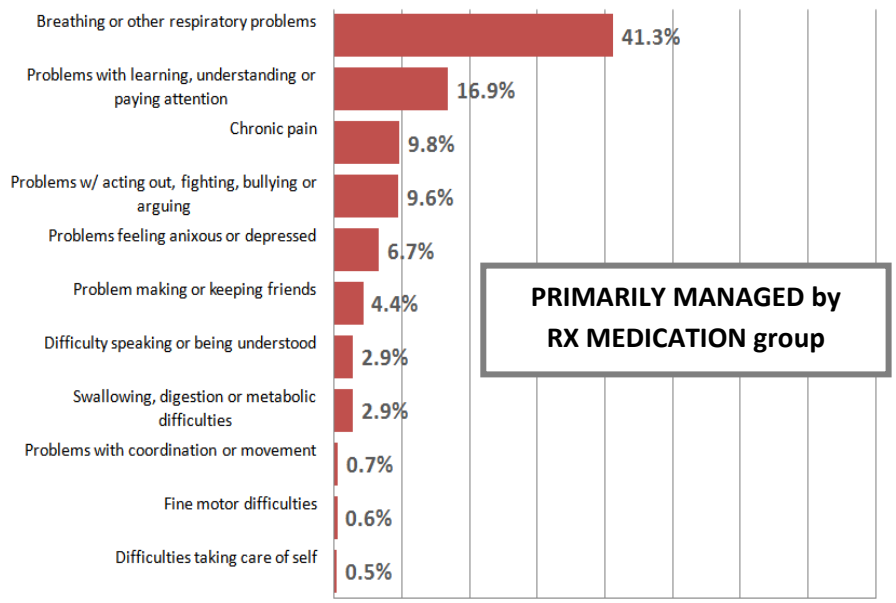
For the first time in 2005/06, the NS-CSHCN collected information about the types of health issues CSHCN experience as a result of their current health conditions. Parents were asked if their children have any of 14 specific health problems or difficulties from a list in the survey.

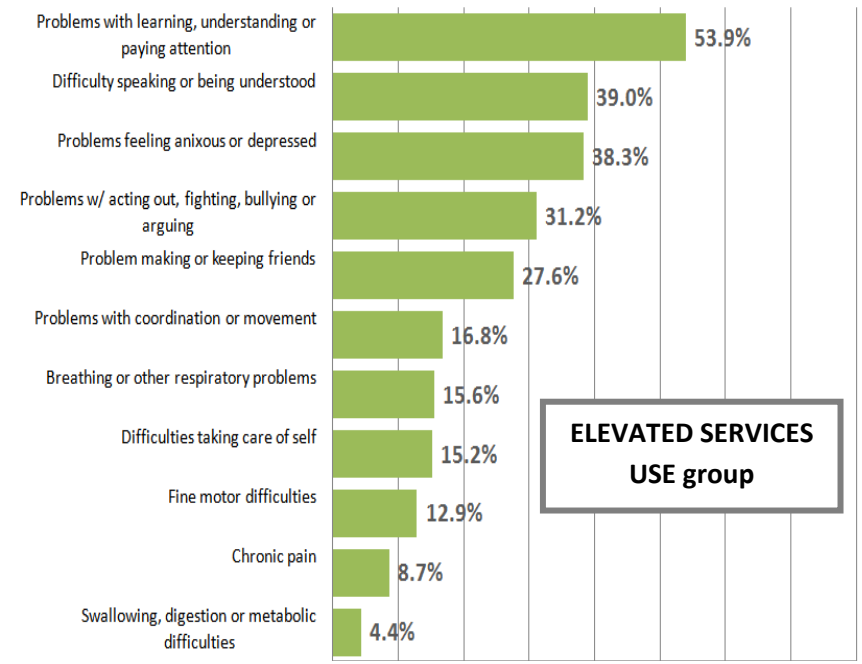
Figure B_5 on the next page shows the frequency of different health problems experienced by CSHCN in each of the four qualifying screening criteria subgroups. Details about the type and relative frequency of health problems experienced by different groups of CSHCN provides useful context for interpreting the performance results in this report and can help guide program planning and improvement.

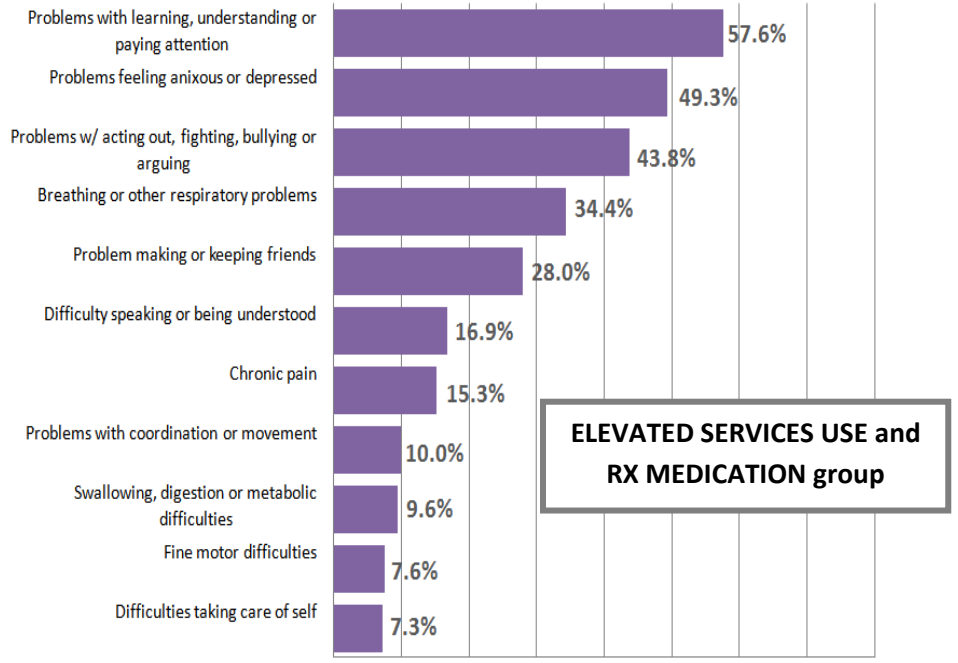
Figure B_5: Percentage of CSHCN in North Dakota experiencing specific problems as result of their health conditions, by qualifying screening criteria subgroups*

(Presence of health related difficulties is based on parent-reported responses to a discrete list of problems asked in 2005/06 NS-CSHCN)









*The number of responses for vision difficulties even with glasses or contacts, use of hearing aids, and problems with blood circulation were too low in some groups to be displayed. The results for these health issues are included in the conditions table on the next page.

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 2005/06 NS-CSHCN also collected for the first time 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, at least 50 percent of CSHCN in North Dakota experience two or more of the conditions asked in the survey. Finally, the population prevalence 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 specific chronic conditions based on parent report, by qualifying screening criteria subgroups: 2005-2006 NS-CSHCN

≈ denotes estimates not meeting reliablity standards due to small sample size	***Functional limitations group***	***Elevated services use group***	***Elevated services use AND Rx medications group***	***Managed primarily by Rx medications group***	**CSHCN overall**
	%	***%***	***%***	***%***	***%***
ADD/ADHD	35.1	26.1	60.0	20.0	33.9
Allergies	49.3	21.0	35.9	47.5	41.5
Anemia or sickle cell disease*	4.7	2.1	2.0	1.4	2.3
Arthritis or other joint problems*	10.5	3.5	3.5	1.8	4.2
Asthma	31.7	≈	30.2	39.3	31.3
Autism or ASD*	16.7	6.7	3.7	≈	5.4
Cerebral palsy*	6.5	1.6	0.4	0.4	1.9
Cystic fibrosis*	≈	≈	≈	≈	0.3
Depression, anxiety, or other emotional problems	29.9	27.9	39.0	5.3	20.6
Diabetes*	1.8	0.4	3.5	1.0	1.6
Down Syndrome*	3.7	0.7	≈	≈	1.0
Epilepsy or other seizure disorder*	9.1	1.1	3.7	1.4	3.5
Heart problems, including congenital heart disease*	7.7	4.7	3.3	1.2	3.5
Mental retardation or developmental delay	34.7	17.9	6.8	≈	11.0
Migraine or frequent headaches	20.7	≈	15.2	10.6	13.3
Muscular dystrophy*	0.9	≈	≈	≈	0.3
Other health issues:					
Vision difficulties even with glasses/contacts*	6.1	3.1	1.4	1.8	3.6
Problems with blood circulation*	6.4	1.6	1.6	≈	2.1
Uses hearing aids*	2.5	1.7	≈	≈	1.0

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

Section II: MCHB Core Outcomes Measures

MCHB Core Outcome #1:

Families of children with special health-care needs will partner in decision-making at all levels, and will be satisfied with the services they receive.

This outcome is evaluated using two questions from the National Survey of Children With Special Health-Care Needs (NS-CSHCN): whether the doctor makes the parent feel like a partner in the child's care, and the parent's level of satisfaction with the child's health services. Children whose parents reported that they usually or always feel like a partner and that they are very satisfied with care are considered to meet the overall criteria for the outcome.[7]

Highlights…

- **More than six in 10 CSHCN in North Dakota successfully meet this outcome.**
  In 2005-06, more than 10,000 CSHCN (63%) in North Dakota met the criteria for successfully receiving health-care services in which parents feel partnered and satisfied with child's care.
- **North Dakota is one of 10 states doing *better* than the national average on this outcome.**
  CSHCN in North Dakota are significantly *more* likely to meet this outcome than CSHCN nationally (63% vs. 57.4%). See Appendix C.
- **Similar percentages of CSHCN in North Dakota met this outcome in 2001 and 2005-2006 (61.5% vs. 63.0%, respectively).**
- **CSHCN in North Dakota successfully meeting this outcome are more likely to be:**
  - White, non-Hispanic.
  - From higher income families.
  - Insured.
  - Managing chronic conditions primarily through prescription medication.
- **The percentage of CSHCN meeting this outcome in North Dakota did NOT vary meaningfully across:**
  - Age groups.

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

Figure 1.1: North Dakota vs. Nation
Percentage meeting Outcome #1 in 2005/06 (Ages 0-17)

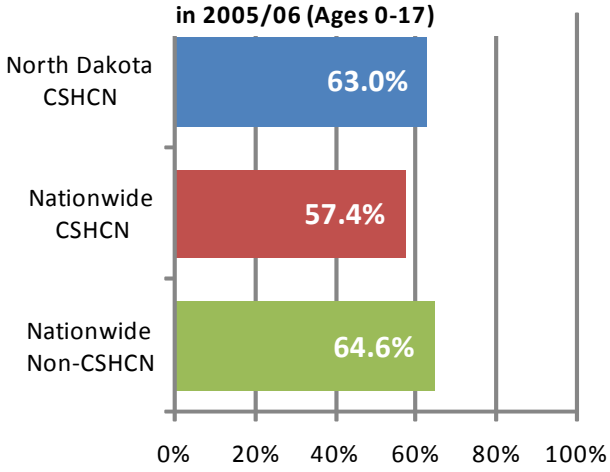
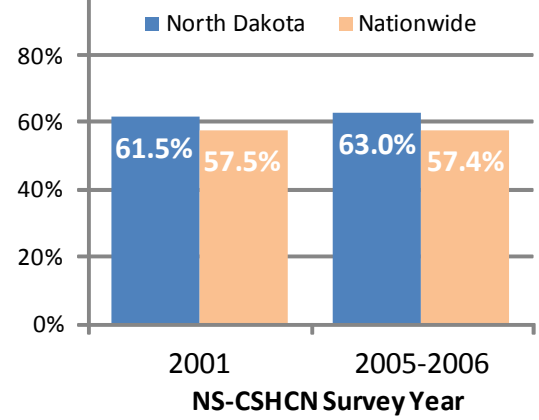


Figure 1.2: 2001 vs. 2005/06
Percentage meeting Outcome #1 CSHCN ages 0-17

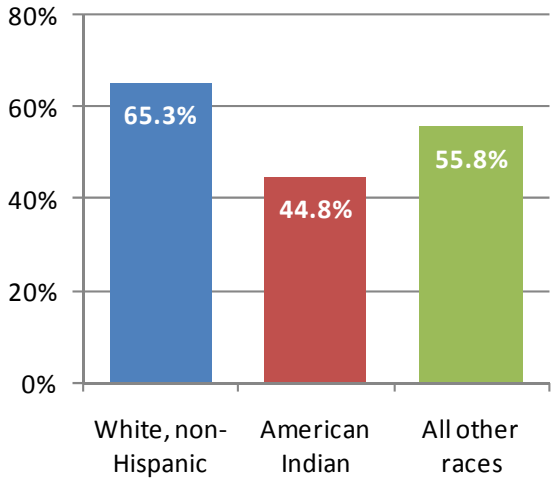


MCHB Core Outcome #1: Families of children with special health-care needs will partner in decision-making at all levels, and will be satisfied with the services they receive.

Outcome #1: Key Findings for North Dakota

- **Less than half of American Indian CSHCN have families who feel like partners in decision-making and are satisfied with services children receive.**

Figure 1.3: Percentage of CSHCN in North Dakota meeting Outcome #1 by race/ethnicity, 2005-2006



In North Dakota…

Non-Hispanic white CSHCN are more likely than other groups to meet this outcome.

American Indian CSHCN are significantly less likely than other CSHCN in North Dakota to meet this outcome – a performance gap observed in each of the seven states with data for American Indian CSHCN in 2005/06.

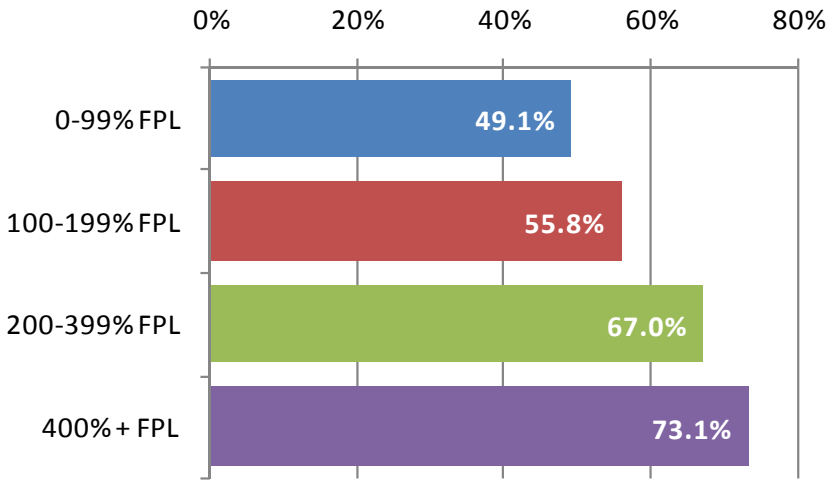
- **CSHCN from families with higher incomes are more likely to feel like partners in decision-making and to feel satisfied with services children receive.**

In North Dakota…

Less than one-half of CSHCN living at or below poverty level have parents who report feeling like partners in decision-making and being satisfied with services children receive.

In contrast, almost three-quarters of CSHCN in the highest income group successfully met the criteria for this outcome.

Figure 1.4: Percentage of CSHCN in North Dakota meeting Outcome #1 by income level, 2005-2006



MCHB Core Outcome #1: Families of children with special health-care needs will partner in decision-making at all levels, and will be satisfied with the services they receive.

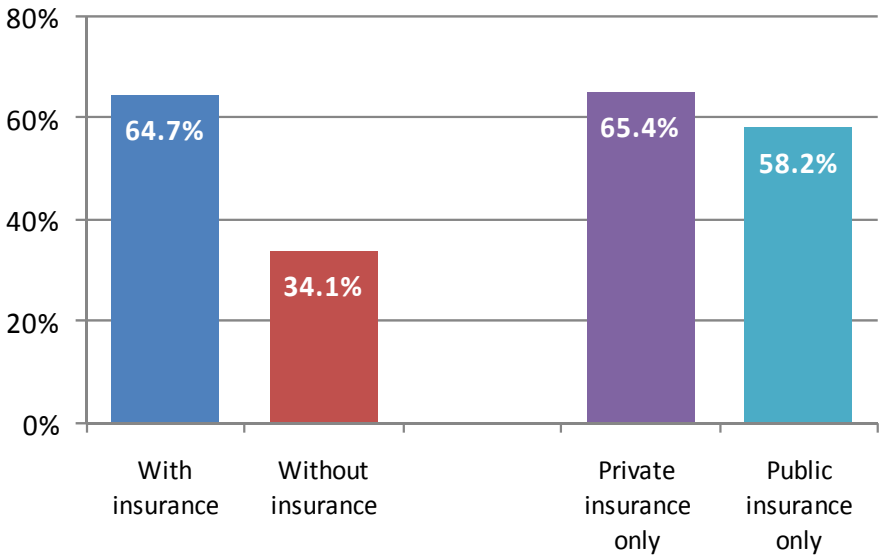
- **Uninsured CSHCN in North Dakota are significantly less likely to have families who feel like partners in decision-making and feel satisfied with services children receive.**

In North Dakota…

Having health insurance makes a dramatic difference in whether CSHCN successfully meet this outcome (64.7% vs. 34.1%, respectively).

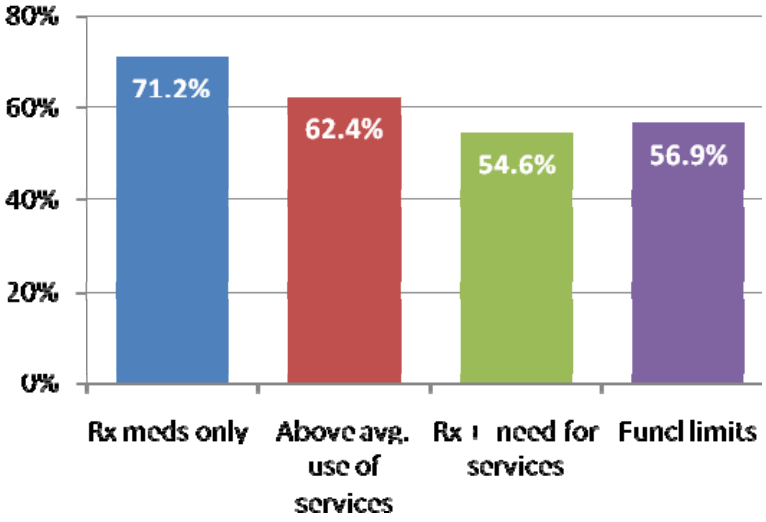
On the other hand, type of insurance is not as strongly associated with the likelihood of meeting this outcome. Publicly insured CSHCN were only somewhat less likely than those with private coverage to meet Outcome #1.

Figure 1.5: Percentage of CSHCN in North Dakota meeting Outcome #1 by insurance status and type of insurance, 2005-2006



- **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 1.6: Percentage of CSHCN in North Dakota meeting Outcome #1 by type of qualifying special needs, 2005-2006



In North Dakota…

Of CSHCN whose chronic health conditions are managed primarily through prescription medicine (Rx meds only), about seven in 10 meet Outcome #1 criteria for shared decision-making and satisfaction with care.

In contrast, only slightly more than half of CSHCN with more complex health conditions or elevated services needs experienced shared decision-making and high family satisfaction.

MCHB Core Outcome #1: Families of children with special health-care needs will partner in decision-making at all levels, and will be satisfied with the services they receive.

Outcome #1: Key Subcomponent Findings for North Dakota

MCHB Core Outcome #1 is measured using responses from two questions asked in National Survey of Children With Special Health-Care Needs (NS-CSHCN). The questions are:

1) **During the past 12 months, how often did (child name)'s doctors or other health-care providers help you feel like a partner in his/her care? Would you say never, sometimes, usually or always?**

2) **Thinking about (child name)'s health needs and the services he/she receives, how satisfied or dissatisfied are you with those services? Would you say very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied?**

A response of **"Usually or Always"** to feeling like a partner AND a response of **"Very Satisfied"** with services received are needed to meet Outcome #1. CSHCN with one or both responses that do not meet these criteria are classified as not meeting Outcome #1. The percentages of CSHCN in North Dakota with qualifying responses on each of these questions overall, and by selected subgroups, are presented below.

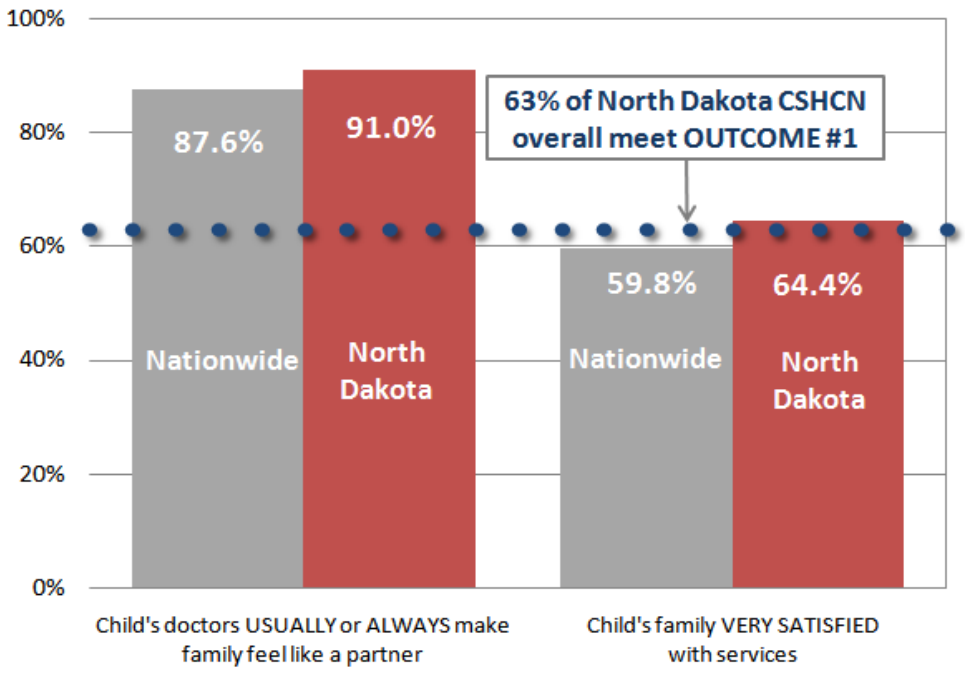
In North Dakota …

Overall, the families of CSHCN in North Dakota are a great deal more likely to feel included as partners by their children's doctors than to report being "very satisfied" overall with the services their children receive.

At the same time, the families of CSHCN in North Dakota are significantly more likely to be "very satisfied" overall with services than are families of CSHCN nationwide (64.4% vs. 59.8%).

Although North Dakota performed better than the national average on OUTCOME #1 overall, there are still at least one in three CSHCN in the state whose families are less than "very satisfied" with the services their children are getting.

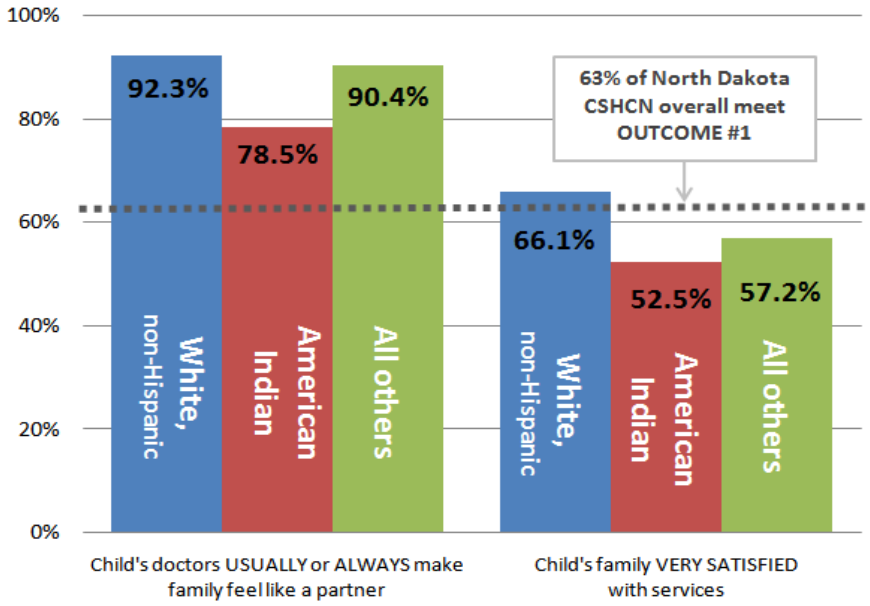
Figure 1.7: North Dakota vs. Nation Percentage of CSHCN with qualifying responses on each of the subcomponents of Outcome #1, 2005-2006



MCHB Core Outcome #1: Families of children with special health-care needs will partner in decision-making at all levels, and will be satisfied with the services they receive.

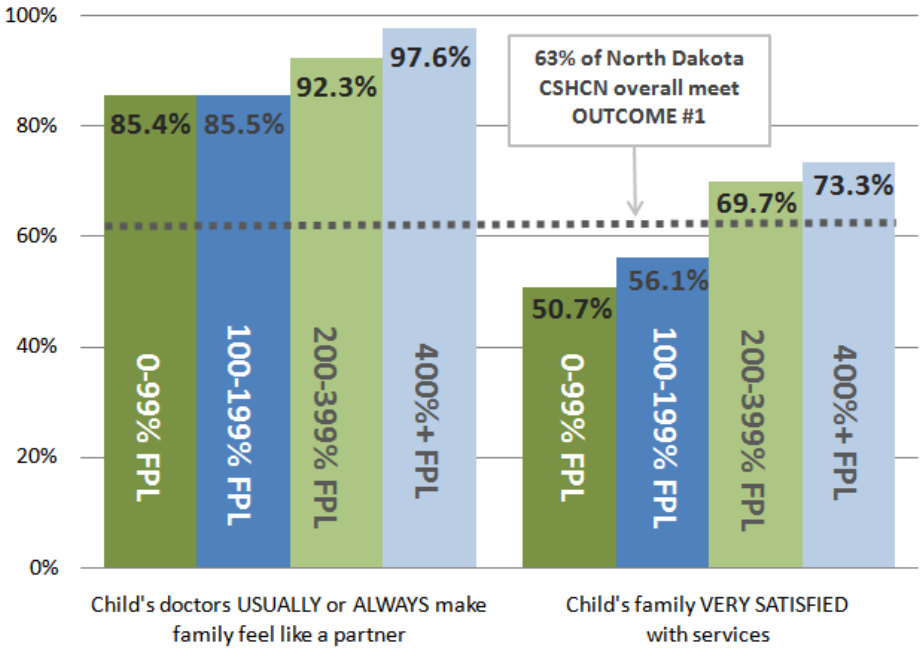
- The families of non-white CSHCN are less likely to be "Very satisfied" with the services their children receive. A lower level of satisfaction with services is a strong contributor to variation in performance on OUTCOME #1 for CSHCN from different race/ethnicity backgrounds (Fig.1.8).

Figure 1.8: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by race/ethnicity, 2005-2006



- Satisfaction with services is strongly associated with income. Only half of CSHCN living in households with incomes below or near the federal poverty level (0-199% FPL) have families who report being "Very Satisfied" with the services their children are receiving. Although lower income families are also somewhat less likely to report that doctors make them feel like a partner in their child's care, the majority of the income-related variation in performance on Outcome #1 is because families of lower income CSHCN report less satisfaction with services (Fig 1.9).

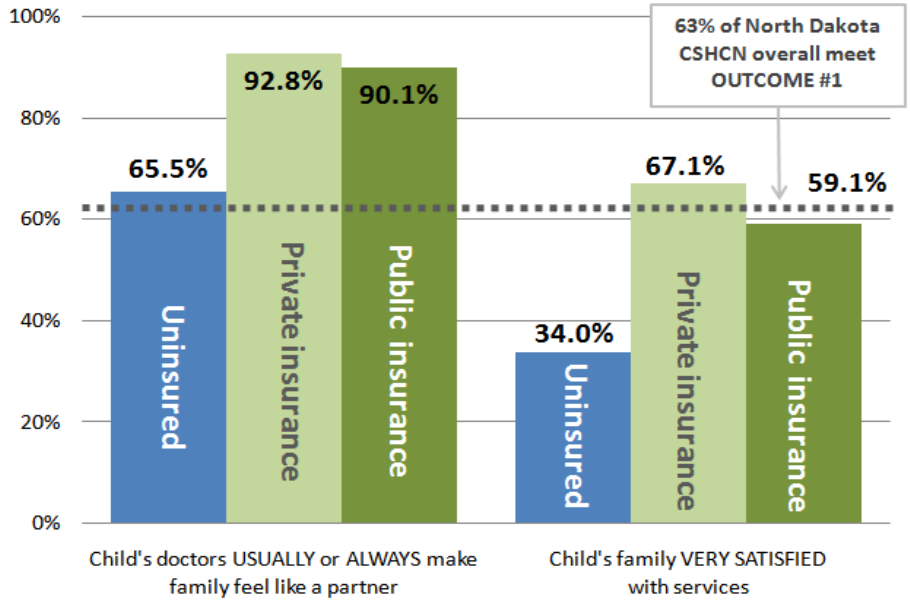
Figure 1.9: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by federal poverty level (FPL), 2005-2006



MCHB Core Outcome #1: Families of children with special health-care needs will partner in decision-making at all levels, and will be satisfied with the services they receive.

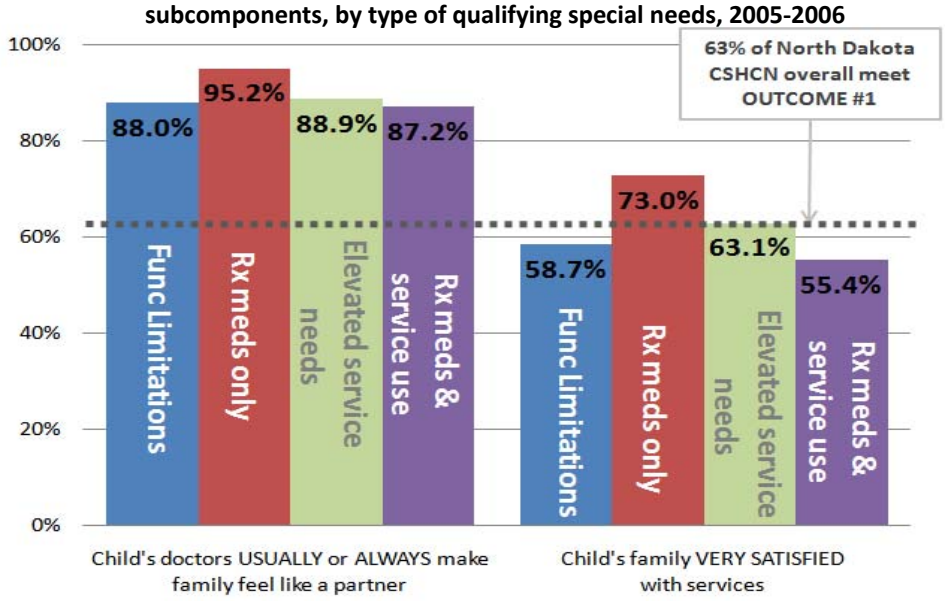
- Not surprisingly, both satisfaction with services and partnerships with children's doctors are significantly lower among uninsured CSHCN in North Dakota. Privately insured CSHCN have somewhat higher levels of satisfaction and partnership than those with public insurance – but overall, type of insurance was not a strong factor in determining whether CSHCN in North Dakota achieved Outcome #1 (Fig.1.10).

Figure 1.10: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by insurance status, 2005-2006



- The families of CSHCN whose chronic health conditions are managed primarily through prescription medicine are generally more satisfied with services and more likely to feel included as partners by their children's doctors. Lower level of satisfaction with services is the main reason why CSHCN whose special needs are more complex or require a wider range of services are less likely to meet the criteria for Outcome #1.

Figure 1.11: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #1 subcomponents, by type of qualifying special needs, 2005-2006



MCHB Core Outcome #2:

All children with special health-care needs will receive coordinated, ongoing, comprehensive care within a medical home.

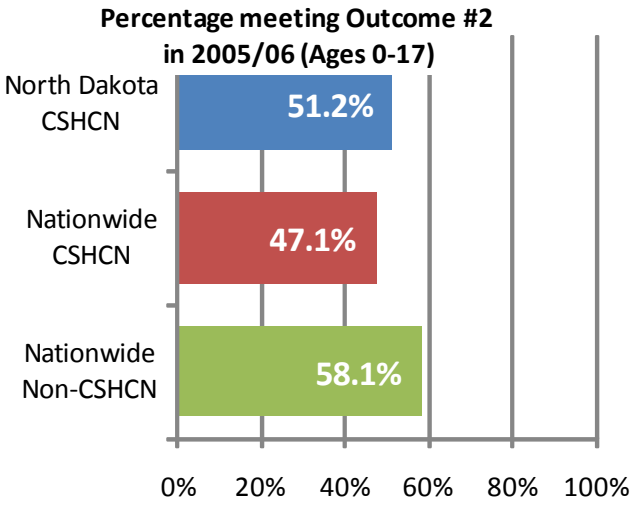
The American Academy of Pediatrics' concept of "medical home"[8] lists seven defining components: accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective. Ideally, these seven components are delivered by a doctor or other health professional who knows the child well. Five of the seven components of medical home are assessed by the 2005-2006 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.[7]

Highlights…

- **About half of CSHCN in North Dakota receive care within a medical home.**
  In 2005-06, 51.2 percent or about 8,000 CSHCN in North Dakota met criteria for having a medical home — about the same as CSHCN nationwide, but less than non-CSHCN nationwide.
- **North Dakota is one of 17 states performing *close* to the national estimate for this outcome.**
  CSHCN in North Dakota are somewhat more likely to meet this outcome than CSHCN nationally (51.2% vs. 47.1%), 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.
  - Managing chronic conditions primarily through prescription medication.
- **The percentage of CSHCN meeting this outcome in North Dakota did NOT vary meaningfully by:**
  - Age group.

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

Figure 2.1: North Dakota vs. Nation



2001 vs. 2005-2006

Not Available

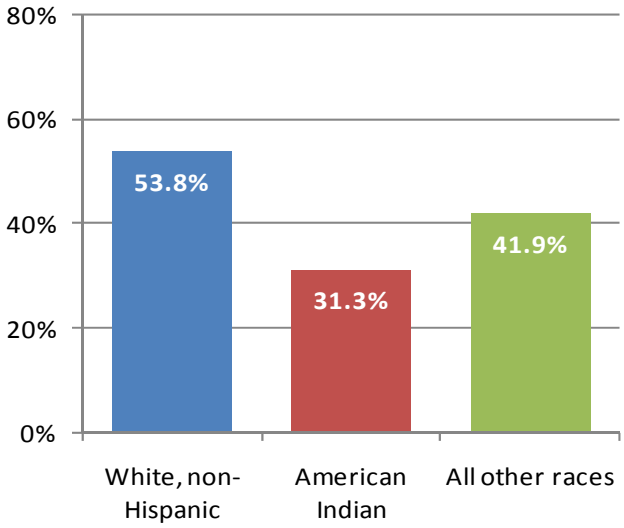
In the 2005-2006 NS-CSHCN, significant changes and additions were made to the set of questions used to assess the Care Coordination and Access to Needed Referrals components of the medical home composite measure. The result is an improved and more robust assessment of these important aspects of the medical home model.

MCHB Core Outcome #2: All children with special health-care needs will receive coordinated, ongoing, comprehensive care within a medical home.

Outcome #2: Key Findings for North Dakota

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

Figure 2.2: Percentage of CSHCN in North Dakota meeting Outcome #2 by race/ethnicity, 2005-06



In North Dakota…

Non-Hispanic, white CSHCN are significantly more likely than other 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 70 percent did not receive care meeting the medical home criteria during 2005/06 compared to fewer than half of white, non-Hispanic CSHCN.

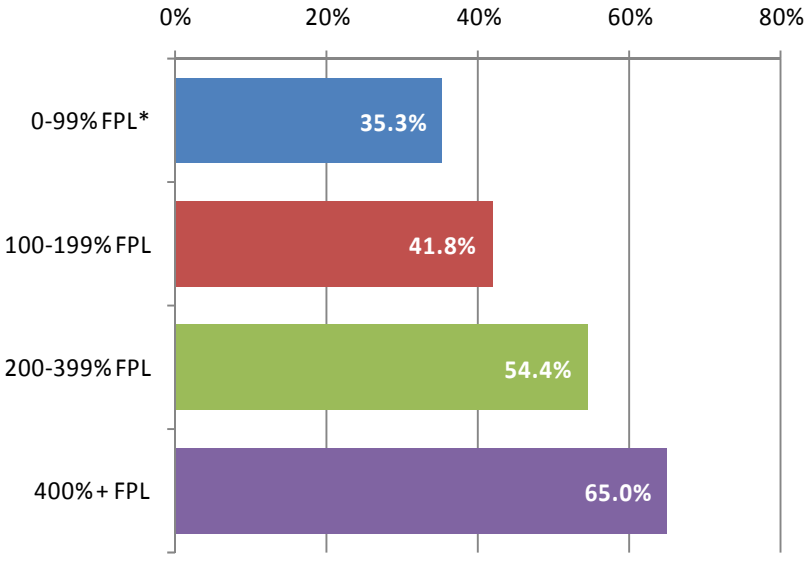
- **Lower income CSHCN are significantly less likely to receive care within a medical home.**

In North Dakota…

Only about one-third of CSHCN living below poverty level have medical homes.

CSHCN from more affluent households are one and one-half to two times more likely to have a medical home than CSHCN living in the state's poorest households.

Figure 2.3: Percentage of CSHCN in North Dakota meeting Outcome #2 by federal poverty level (FPL), 2005-2006

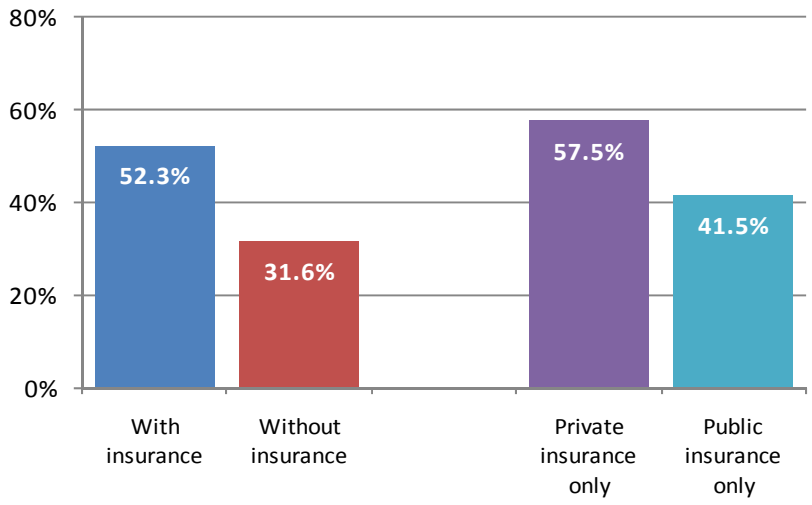


*FPL = Federal Poverty Level

MCHB Core Outcome #2: All children with special health-care needs will 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.**

Figure 2.4: Percentage of CSHCN in North Dakota meeting Outcome #2 by insurance status and insurance type, 2005-2006



In North Dakota…

Fewer than one in three uninsured CSHCN have a medical home; in contrast, more than 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 (57.5% vs. 41.5%, respectively).

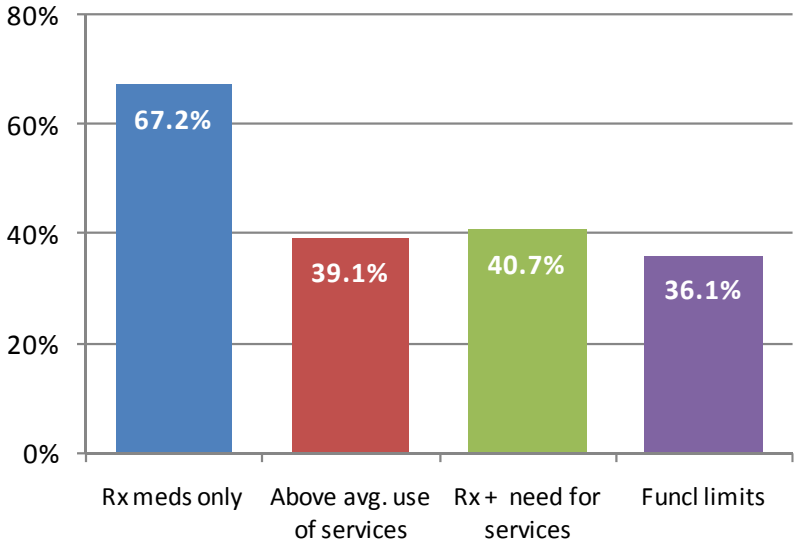
- **CSHCN whose health conditions require a range of specialized or community-based services in addition to medical care are less likely to meet the medical home outcome.**

In North Dakota…

CSHCN whose conditions are managed primarily through prescription medicine are more likely than other CSHCN to meet the medical home outcome.

CSHCN with the types of health needs that often require coordination across services such as specialist care, mental health treatment, school or community-based programs, specialized therapies, etc., are LESS likely to have health care that reflects the medical home model.

Figure 2.5: Percentage of CSHCN in North Dakota meeting Outcome #2 by qualifying type of special needs, 2005-2006



MCHB Core Outcome #2: All children with special health-care needs will 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.

Subcomponent # 2: Child has usual sources for both sick and well care.

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

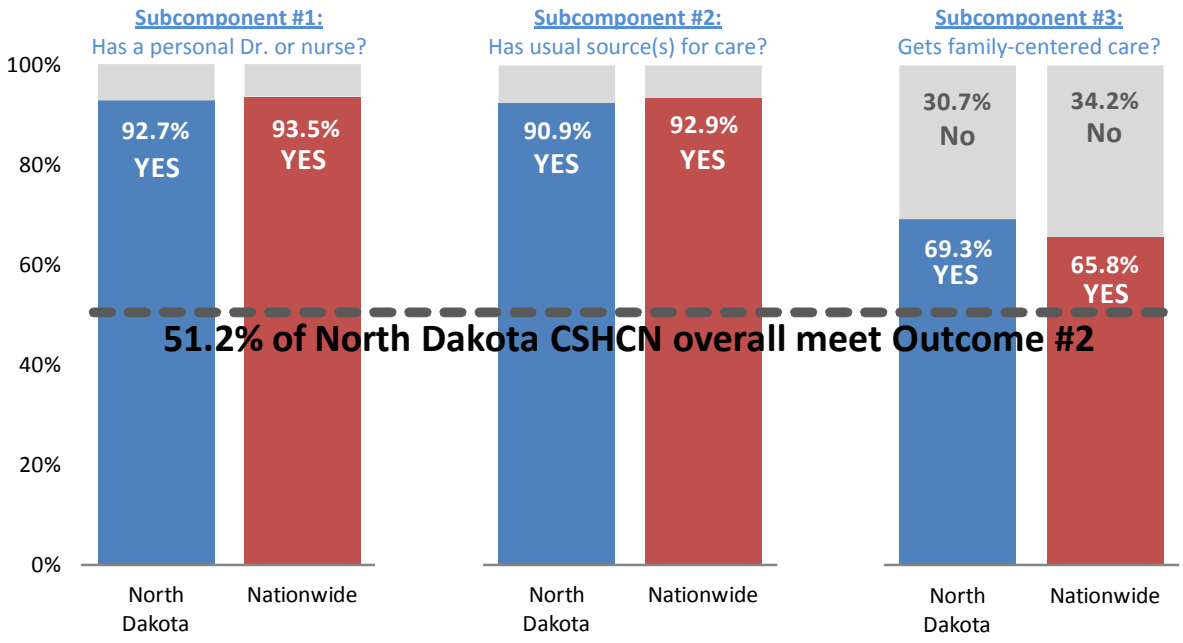
Subcomponent # 4: Child gets needed referrals without problems.

Subcomponent # 5: Child receives needed types of care coordination.

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.

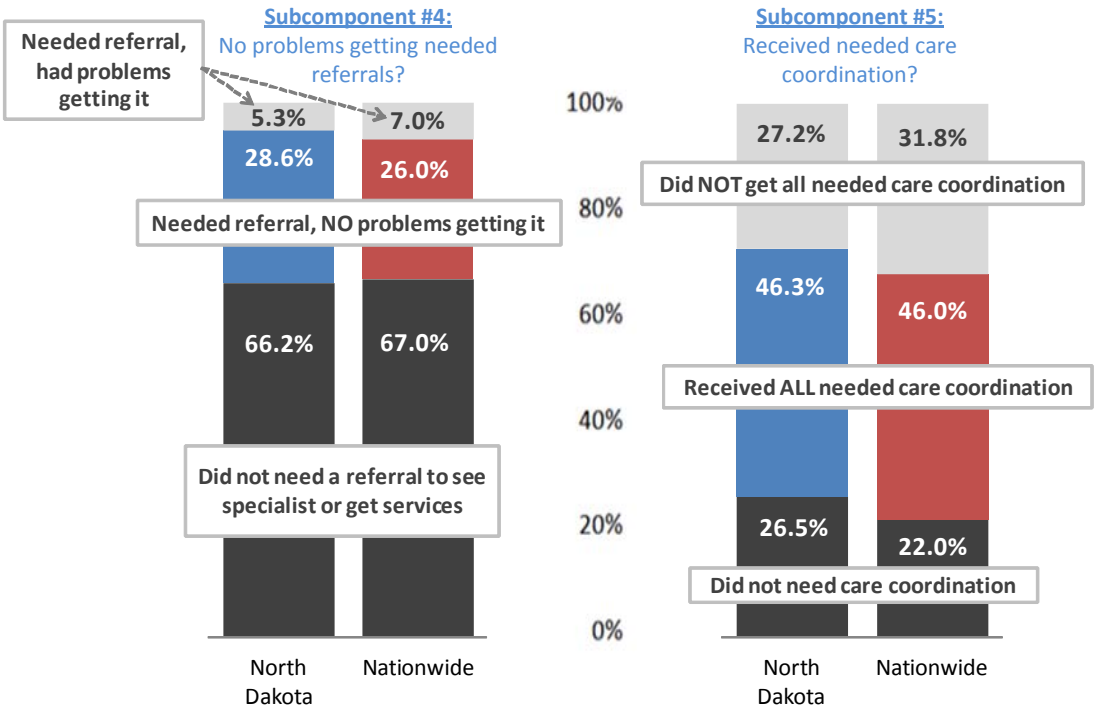
Three of the five subcomponents of Outcome #2 assess aspects of medical home care that apply to all CSHCN; the remaining two subcomponents (getting referrals, care coordination) address types of care typically needed by only a subset of the CSHCN population. The percentages of CSHCN in North Dakota and nationally meeting the threshold criteria on medical home outcome subcomponents are shown below and on the next page (Fig. 2.6 and Fig. 2.7).

Figure 2.6: North Dakota vs. Nation
Percentage of CSHCN meeting threshold criteria on Outcome #2 subcomponents for all CSHCN, 2005-2006



MCHB Core Outcome #2: All children with special health-care needs will receive coordinated, ongoing, comprehensive care within a medical home.

Figure 2.7: North Dakota vs. Nation
Percentage of CSHCN meeting threshold criteria on Outcome #2 subcomponents for subsets of CSHCN needing referrals and CSHCN needing care coordination, 2005-2006



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 similar percentage have places they usually go when sick or need preventive care (Fig. 2.6).
- 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. 2.6).
- The majority of CSHCN overall in North Dakota (66.2%) did not need a referral to see a specialist or receive services, and more than 80 percent of those needing a referral had no problems getting one (Fig. 2.7; Fig. 2.9).
- Three in four CSHCN in North Dakota (73.5%) needed one or more aspects of care coordination. Of that group, nearly two-thirds received all needed care coordination (Fig. 2.7; Fig. 2.11).

MCHB Core Outcome #2: All children with special health-care needs will 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:

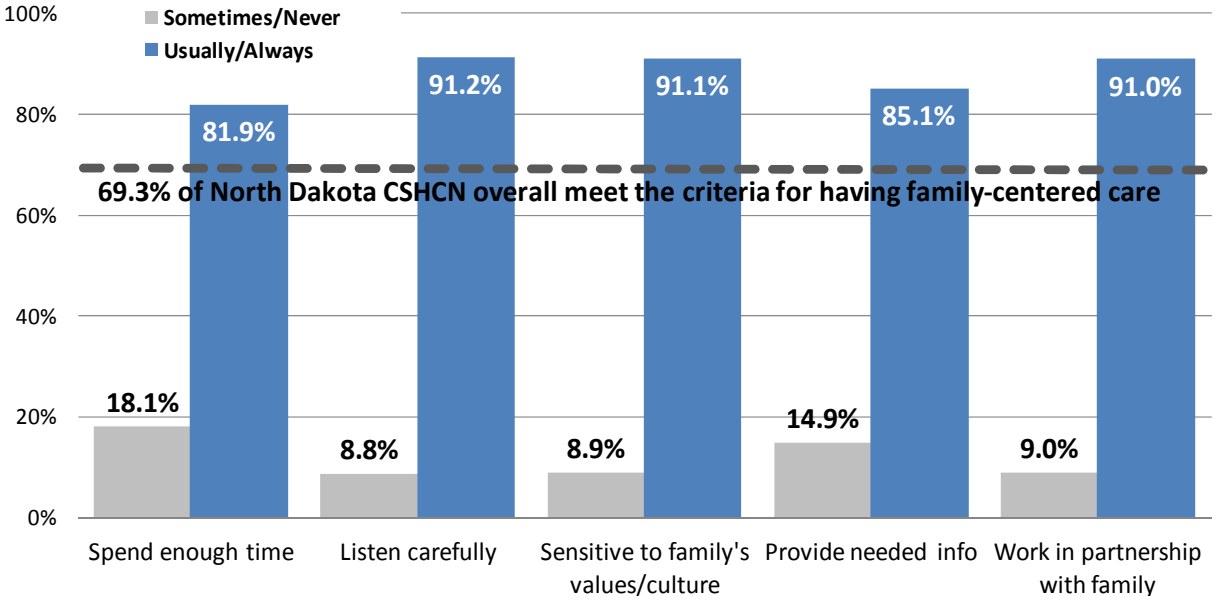
1) **Spend enough time with him or her?**
2) **Listen carefully to you?**
3) **Are sensitive to the family's values and customs?**
4) **Give the specific information you need about your child's health or health care?**
5) **Help you feel like a partner in your child's care?**

Responses of **"Usually or Always"** to all five family-centered care questions (and if applicable, the availability of interpreter services question*) 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 child and provision of needed information is what determines the overall results on the Family-Centered Care subcomponent (Fig. 2.8). 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 2.8: Percentage of CSHCN in North Dakota usually or always receiving each of five different aspects of family-centered care, 2005-2006

How often do the child's doctors and other health care providers do each of the following...



* In the 2005-2006 NS-CSHCN, no CSHCN in the North Dakota sample needed interpreter services during health care visits; thus, the question about access to interpreter services was not included as part of the Family-Centered Care subcomponent scoring.

MCHB Core Outcome #2: All children with special health-care needs will 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, one in three CSHCN in North Dakota needed a referral to see other doctors or get services. Among CSHCN who needed a referral, more than 80 percent had no problems getting one (Fig. 2.9).
- The level of need for referrals ranged from 50 percent of children in the functional limitations group to about one-quarter of CSHCN with conditions managed primarily by prescription medicine (Fig. 2.10).
- Compared to other CSHCN in North Dakota, those with functional limitations are twice as likely to have problems getting the referrals they need (Fig. 2.10).

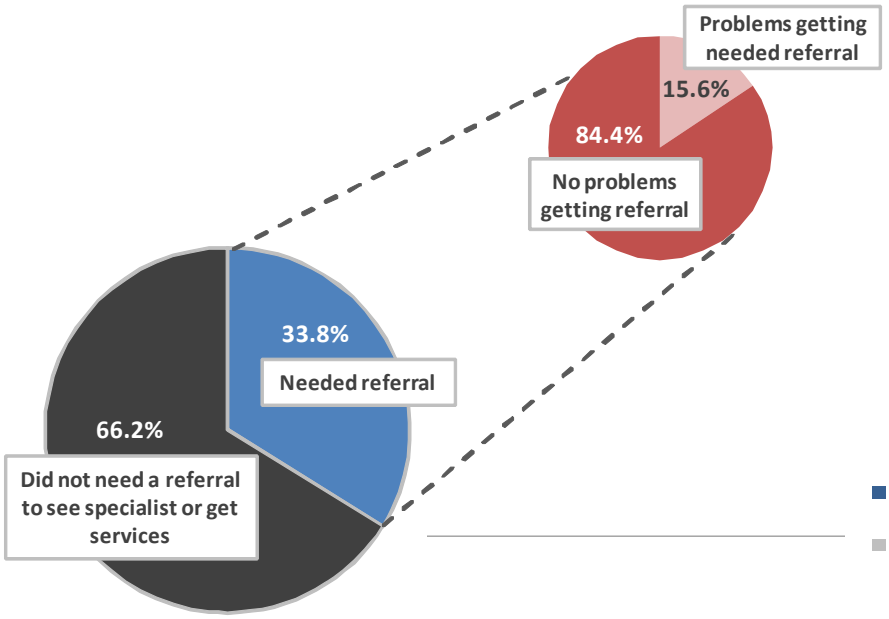


Figure 2.9: Of CSHCN in North Dakota who needed referrals, percentage with no problems getting one, 2005-2006

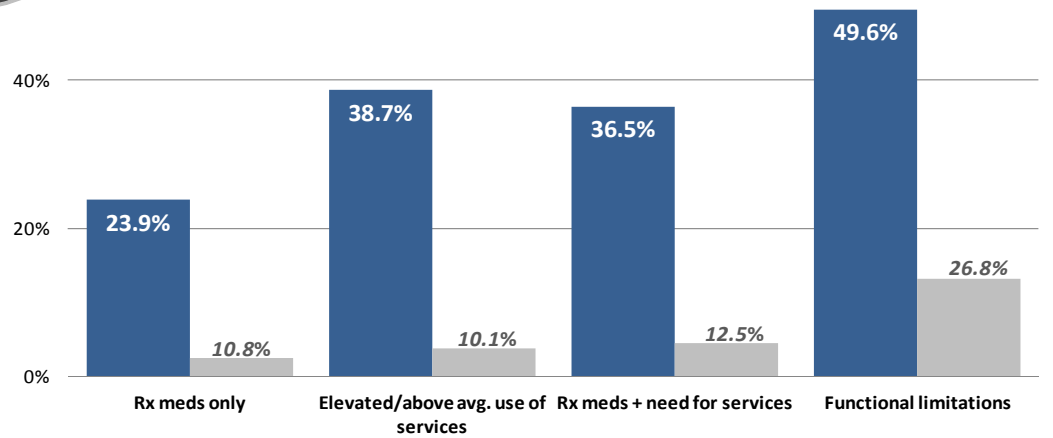


Figure 2.10: Of CSHCN in North Dakota needing referrals, percentage with no problems getting one, by type of qualifying special needs, 2005-2006

MCHB Core Outcome #2: All children with special health-care needs will receive coordinated, ongoing, comprehensive care within a medical home.

Subcomponent # 5: Getting Needed Care Coordination

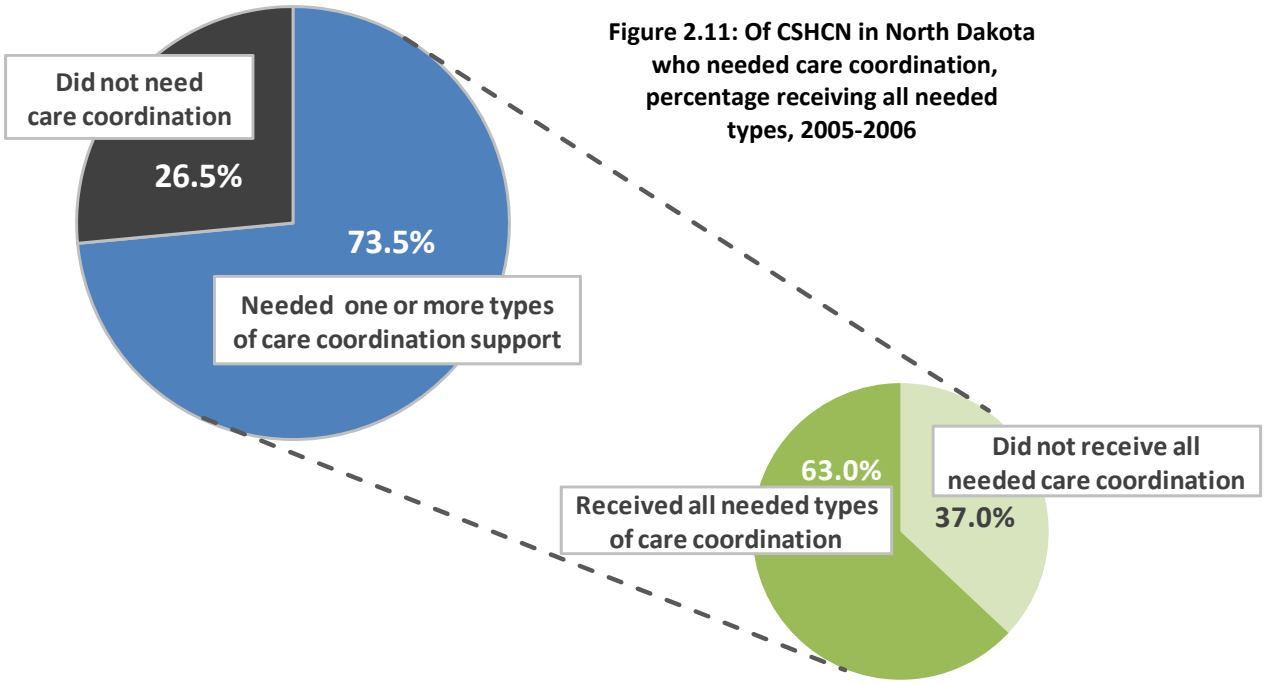
To qualify as needing care coordination, children must first have survey responses indicating they used one or more health-related services during the past year. The Getting Needed Care Coordination subcomponent of the medical home outcome uses six questions to identify children needing one or more of 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 communication 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 2005/06 NS-CSHCN (Fig. 2.11). Among CSHCN who needed some type of care coordination, close to two-thirds (63%) received the support needed (Fig. 2.11).
- The percentage of CSHCN in North Dakota who needed and received all care coordination is not significantly different from that for CSHCN nationally (63% vs. 59.1%, respectively; p = .117).

Figure 2.11: Of CSHCN in North Dakota who needed care coordination, percentage receiving all needed types, 2005-2006



MCHB Core Outcome #2: All children with special health-care needs will receive coordinated, ongoing, comprehensive care within a medical home.

Of the three different types of care coordination assessed, CSHCN in North Dakota are the most likely to need their doctors or other health-care providers to communicate and share information with each other. Nearly two in three CSHCN needed this type of care coordination (Fig. 2.12).

- CSHCN in North Dakota are most likely to lack adequate care coordination in the area of communication between their doctors/other providers and schools or other programs (Fig. 2.12). Nearly half of CSHCN in North Dakota (45.1%) who needed health-care providers to communicate with schools and other programs did not receive the level of coordination needed.
- CSHCN with functional limitations and those whose special health needs are managed by a combination of prescription medicine and specialized services are less likely than other CSHCN in North Dakota to have all of their care coordination needs met (Fig. 2.13).

Figure 2.12: Of CSHCN in North Dakota who needed each of three types of care coordination, percentage NOT getting needed type, 2005-2006

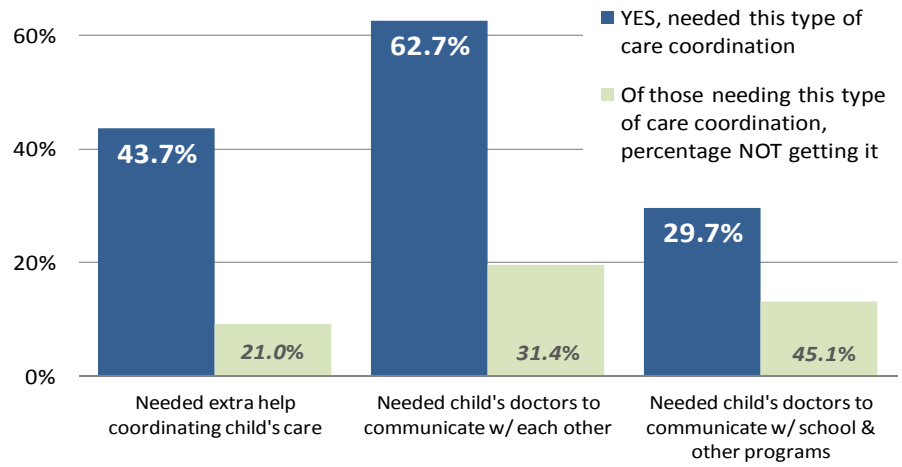
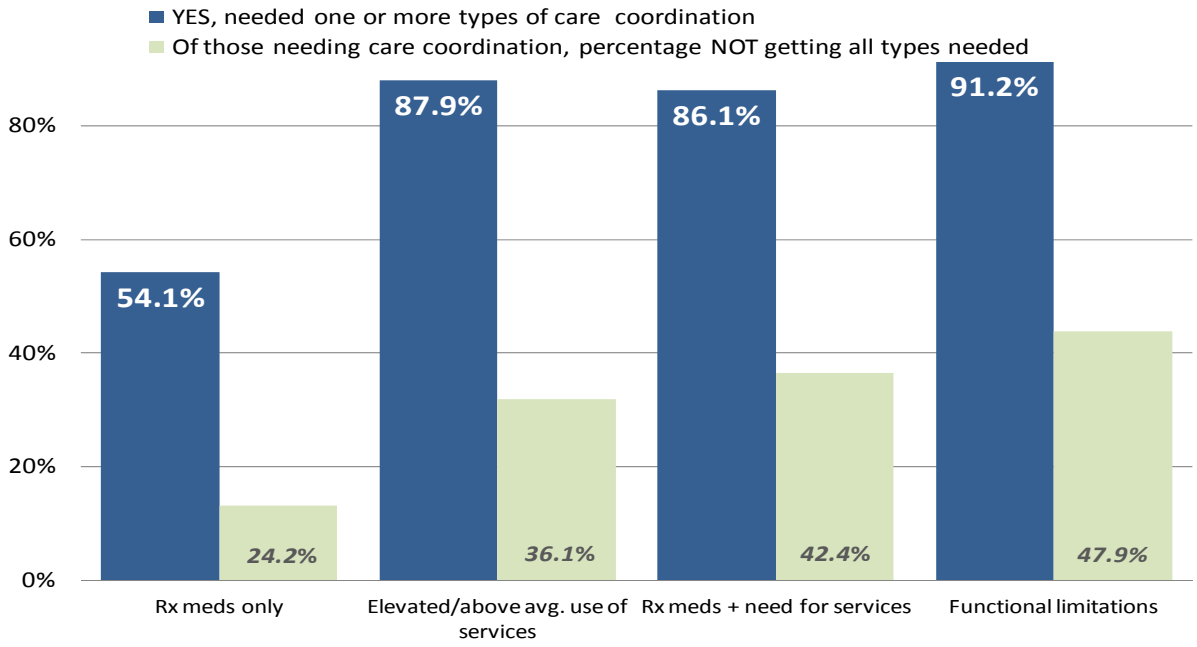


Figure 2.13: Of CSHCN in North Dakota who needed care coordination, percentage NOT getting all needed care by type of qualifying special needs, 2005-2006



MCHB Core Outcome #3

All families of children with special health-care needs will have 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.[7]

Highlights…

- **More than two-thirds of CSHCN in North Dakota have adequate insurance to pay for needed services.**
  In 2005-06, close to 11,000 CSHCN (68.2%) in North Dakota had insurance coverage adequate for their needs.

- **North Dakota is one of 12 states doing better than the national average on this outcome.**
  CSHCN in North Dakota are significantly *more* likely to meet this outcome than CSHCN nationally (68.2% vs. 62.0%, respectively). See Appendix C.

- **In 2005/06, the proportion of CSHCN in North Dakota experiencing adequate insurance coverage increased slightly compared to 2001 (68.2% vs. 62.0%, respectively).**

- **CSHCN in North Dakota successfully meeting this outcome are more likely to be:**
  - From households with higher incomes OR households with incomes below the poverty level.

- **The percentage of CSHCN meeting this outcome in North Dakota did NOT differ meaningfully by:**
  - Age group.
  - Child's race/ethnicity.
  - Public or private insurance coverage.

See Appendices for details and additional results for Outcome #3.

Figure 3.1: North Dakota vs. Nation

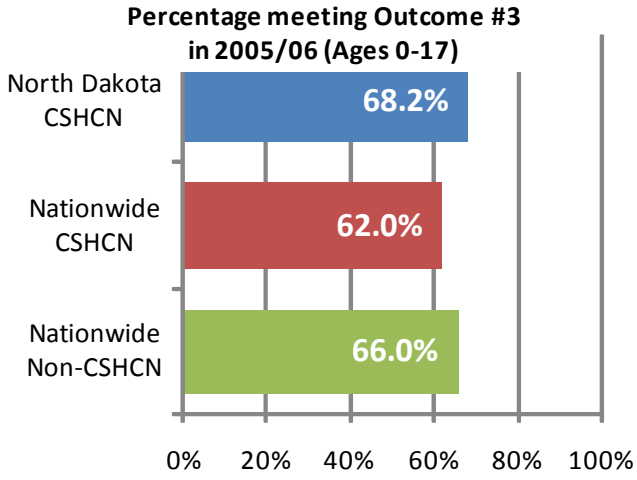
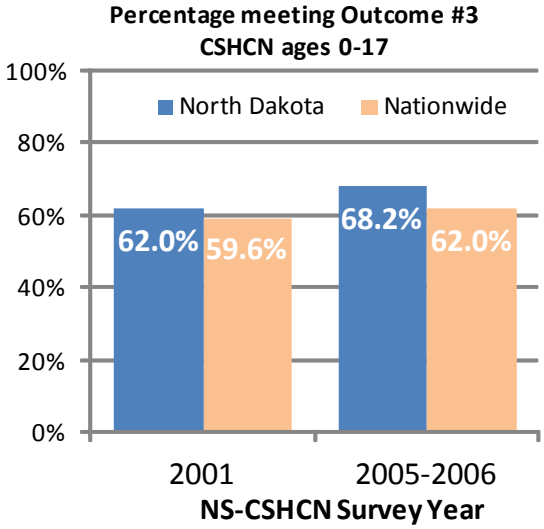


Figure 3.2: 2001 vs. 2005/06

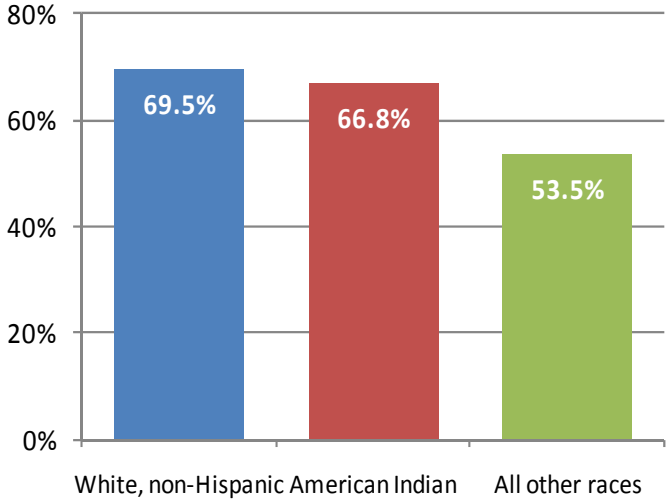


MCHB Core Outcome #3: All families of children with special health-care needs will have adequate private and/or public insurance to pay for the services they need.

Outcome #3: Key Findings for North Dakota

- **Race/ethnicity of CSHCN is not strongly associated with having adequate insurance.**

Figure 3.3: Percentage of CSHCN in North Dakota meeting Outcome #3 by race/ethnicity, 2005-2006



In North Dakota…

American Indian and white, non-Hispanic CSHCN are equally likely to experience adequate health insurance coverage.

A higher proportion of American Indian CSHCN in North Dakota had adequate insurance than American Indian CSHCN in other states with data for this group in 2005-2006.

CSHCN from other minority groups are less likely to have adequate insurance than white, non-Hispanic and American Indian CSHCN; however, this disparity gap is not statistically different due to the small sample size on which the estimate is based.

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

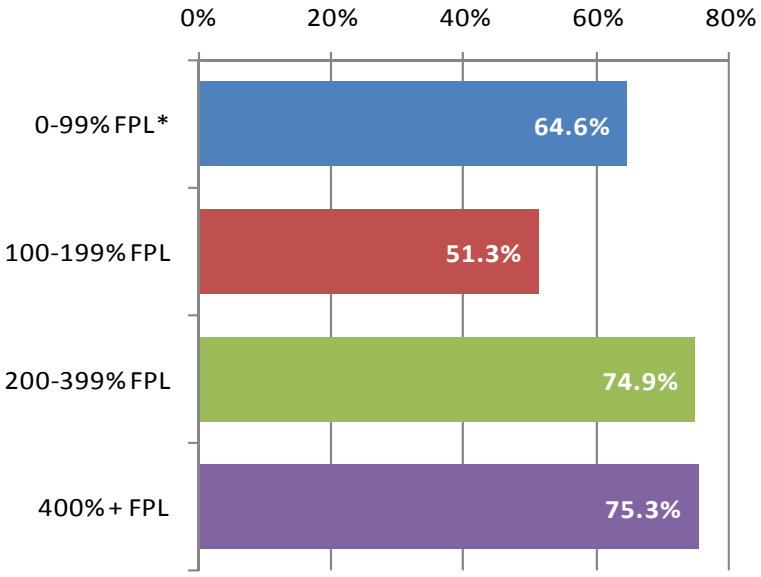
In North Dakota…

Findings suggest CSHCN from households at or just above the federal poverty level are less likely to have adequate insurance than those living in the state's poorest households (below 100% of FPL).

Only half of CSHCN from households at or just above the federal poverty level met Outcome #3 in 2005-2006, compared to nearly two-thirds of CSHCN in families living below the poverty line.

In contrast, 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), 2005-2006

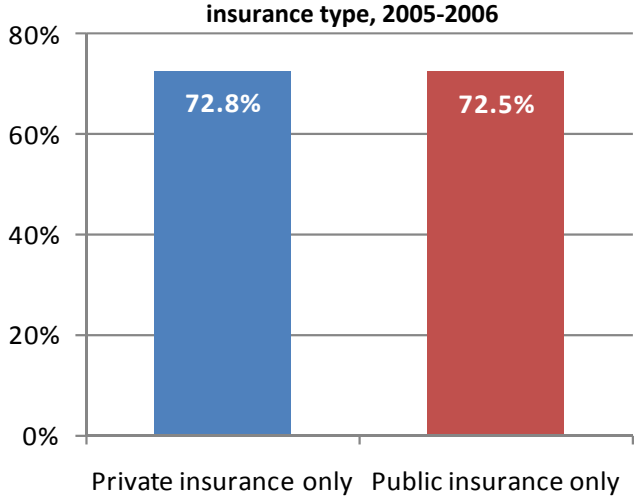


*FPL = Federal Poverty Level

MCHB Core Outcome #3: All families of children with special health-care needs will have 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, 2005-2006

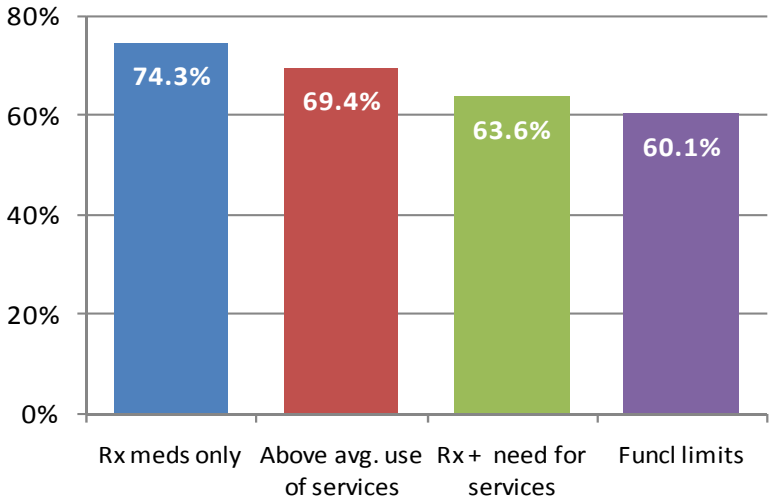


In North Dakota…

CSHCN in public insurance programs are 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 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, 2005-2006



In North Dakota…

CSHCN in North Dakota fared better than CSHCN nationally on this outcome overall; however, at least 5,000 CSHCN (32%) in the state did not have adequate insurance coverage during 2005-2006.

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

In 2005/06, 40 percent of CSHCN with functional limitations did not have insurance that adequately covered the services and types of care needed during the year.

MCHB Core Outcome #3: All families of children with special health-care needs will have 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). The two subcomponents are:

1) **Currently insured with no gaps in insurance coverage during the past 12 months –** derived from the extensive set of questions in the survey on insurance status.
2) **Adequacy of current insurance coverage –** derived from three questions asking how often current insurance covers different aspects of the child's care.

A response of **"Yes"** to currently insured with no gaps in coverage during 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 …

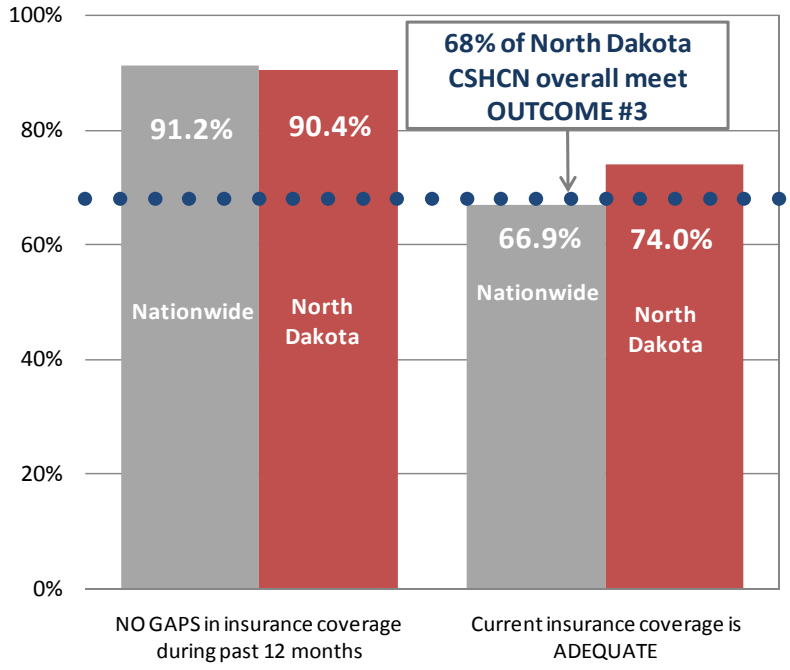
CSHCN categorized as having gaps in insurance coverage include those who were uninsured at the time of the survey **and** those for whom there were periods of no coverage during the past 12 months.

In North Dakota, 5.3 percent of CSHCN overall were uninsured at the time of the 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.

Although North Dakota performed better than the national average on Outcome #3, still at least one in four CSHCN reportedly have inadequate health insurance coverage.

Figure 3.7: North Dakota vs. Nation
Percentage of CSHCN with qualifying responses on the subcomponents of Outcome #3, 2005-2006



MCHB Core Outcome #3: All families of children with special health-care needs will have 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 child's health insurance offer benefits or cover services that meet his/her needs?
  - Does child's health insurance allow him/her to see the health-care providers he/she needs?
  - Are the costs not covered by child's health insurance reasonable?

Criteria for adequate insurance were responses of "usually" or "always" to all three component questions. The strongest contributor to inadequate coverage among insured CSHCN is the relatively low proportion (73.9%) who report that health care costs not covered by their insurance are reasonable (Fig. 3.8).

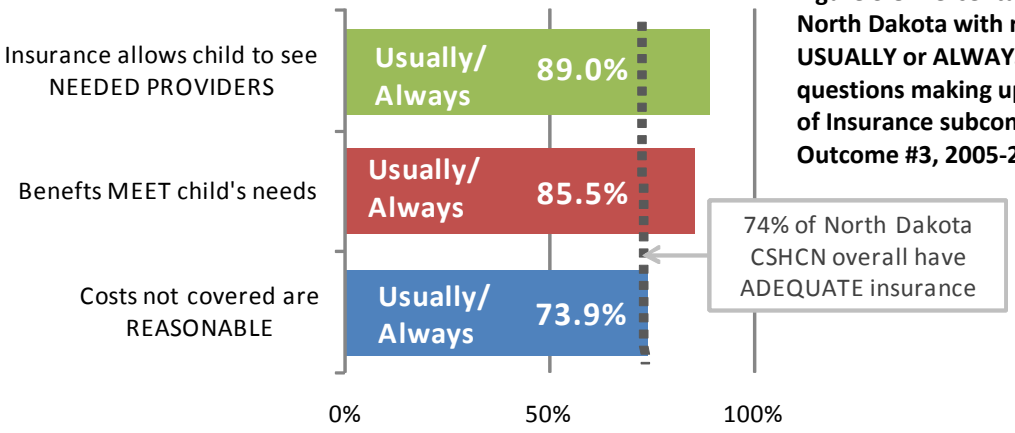
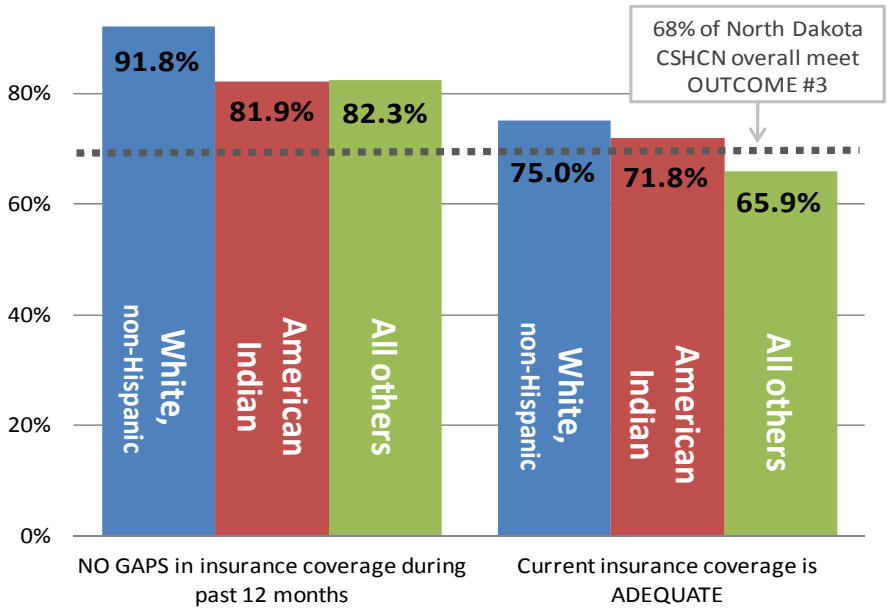


Figure 3.8: Percentage of CSHCN in North Dakota with responses of USUALLY or ALWAYS on the questions making up the Adequacy of Insurance subcomponent of Outcome #3, 2005-2006

- 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 that other CSHCN to be insured for entire 12 month period prior to the survey. The association between adequate insurance coverage and race/ethnicity is not as strong.

Figure 3.9: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #3 subcomponents, by race/ethnicity, 2005-2006



MCHB Core Outcome #3: All families of children with special health-care needs will have adequate private and/or public insurance to pay for the services they need.

- Continuity in insurance coverage is associated with higher income. Still, more than 80 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. However, even insured CSHCN from the highest income families experience some degree of underinsurance – with CSHCN in the 100% to 199% FPL group being the least likely to have adequate coverage – perhaps due to the fact that families in this income bracket often do not qualify for SCHIP. The majority of the income-related variation in performance on Outcome #3 is because of underinsurance among the insured group, particularly among CSHCN in the 100% to 199% FPL income bracket (Fig 3.10).

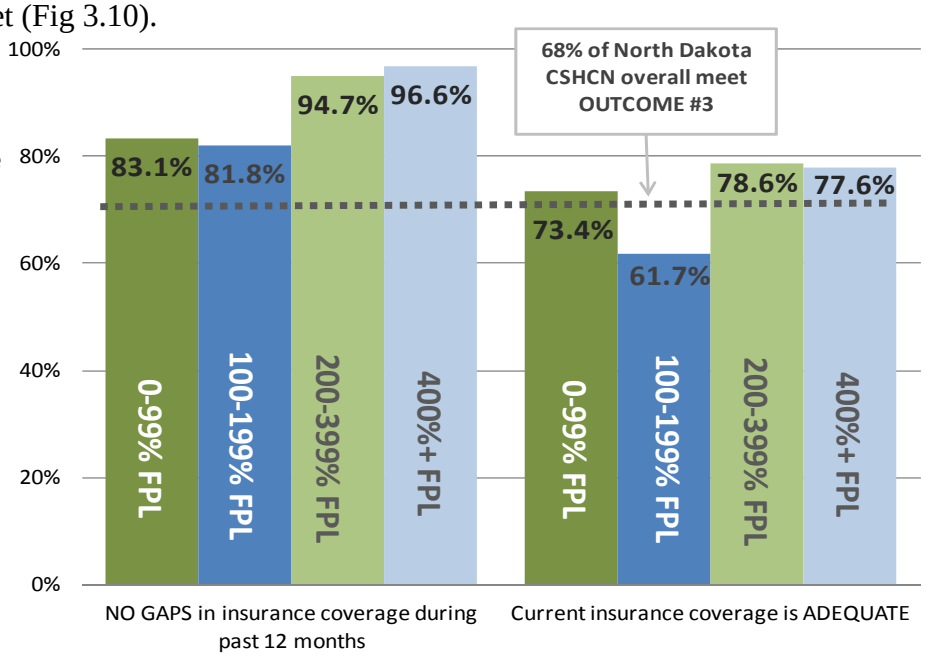


Figure 3.10: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #3 subcomponents, by federal poverty level (FPL), 2005-2006

- 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 a combination of medication and services more often experienced underinsurance compared to CSHCN with other types of qualifying needs (Fig. 3.11).

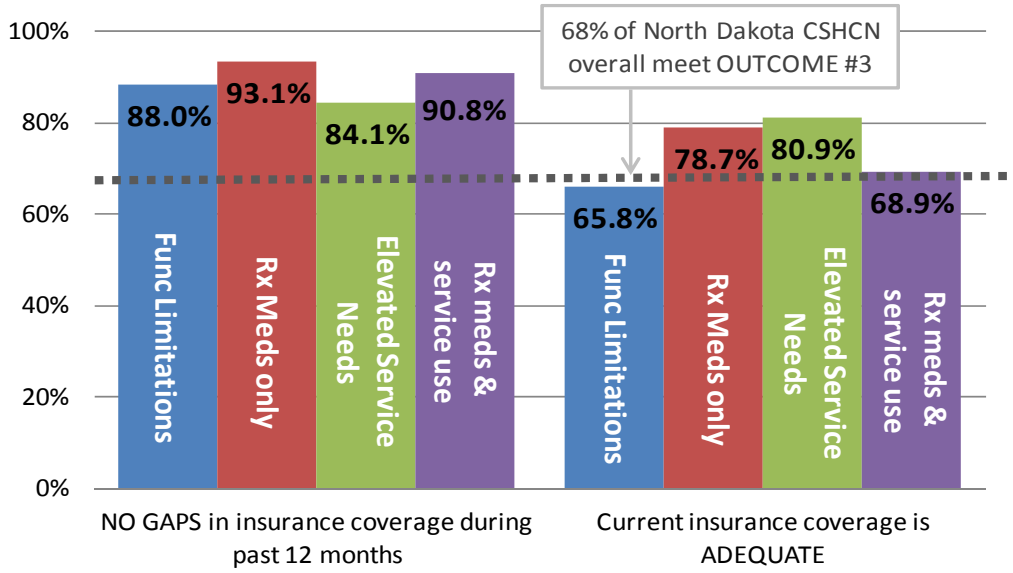


Figure 3.11: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #3 subcomponents, by type of qualifying special needs, 2005-2006

MCHB Core Outcome #4

All children 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 asked whether CSHCN received any routine preventive medical care or routine preventive dental care during the past year.[7] CSHCN needed to receive BOTH types of preventive care during the past year to meet the ongoing screening and surveillance component of Outcome #4.

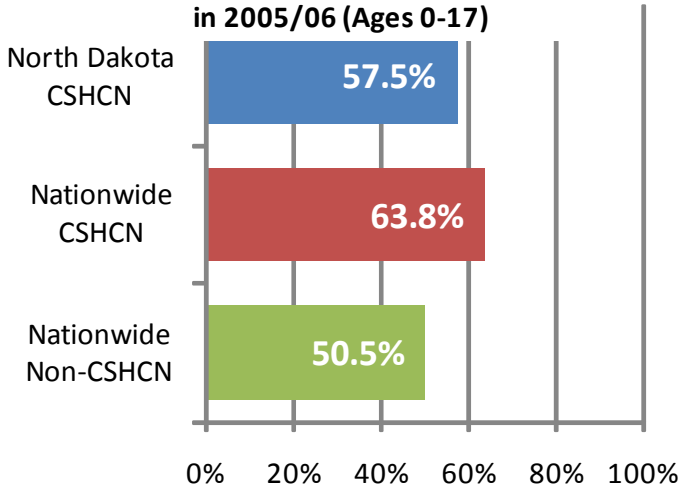
Highlights…

- **About six in 10 CSHCN in North Dakota had BOTH medical and dental preventive care visits.**
  In 2005-2006, approximately 9,000 (57.5%) CSHCN in North Dakota received the types of care that facilitate ongoing screening and surveillance.
- **North Dakota is one of 10 states performing *below* the national estimate for this outcome.**
  CSHCN in North Dakota are significantly *less* likely to meet this outcome than CSHCN nationally (57.5% vs. 63.8%). See Appendix C.
- **CSHCN in North Dakota successfully meeting this outcome are more likely to:**
  - Live in higher income households.
  - Have health insurance.
- **The percentage of CSHCN meeting this outcome in North Dakota did NOT vary meaningfully by:**
  - Age group.
  - Child's race/ethnicity.

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

Figure 4.1: North Dakota vs. Nation

Percentage meeting Outcome #4 in 2005/06 (Ages 0-17)



2001 vs. 2005/06

Not Available

Outcome #4 was assessed by the NS-CSHCN for first time in 2005-2006.

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

Outcome #4: Key Findings for North Dakota

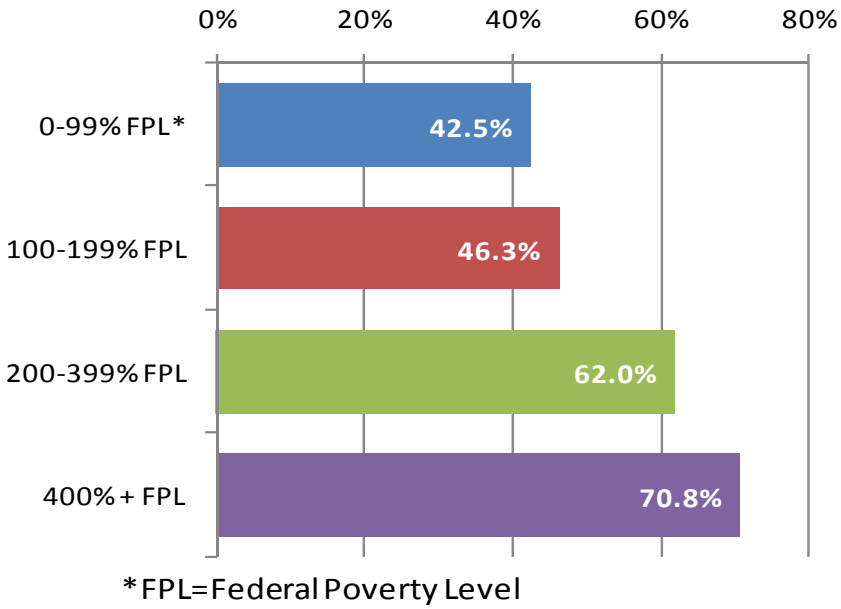
- **CSHCN from lower income households are significantly less likely to receive the types of care that facilitate ongoing screening for both medical and dental issues.**

In North Dakota…

Less than half of CSHCN living in the state's poorest households received BOTH medical AND dental preventive care in 2005-2006.

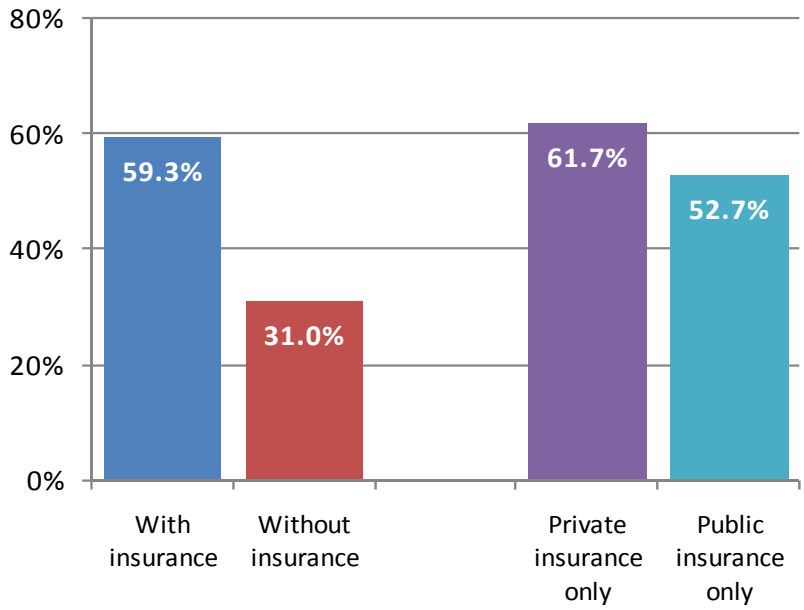
In contrast, more than 70 percent of CSHCN from the state's more affluent households had both types of preventive care visits during the same time period.

Figure 4.2: Percentage of CSHCN in North Dakota meeting Outcome #4 by federal poverty level (FPL), 2005-2006



- **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 4.3: Percentage of CSHCN in North Dakota meeting Outcome #4 by insurance status and type of insurance, 2005-2006



In North Dakota…

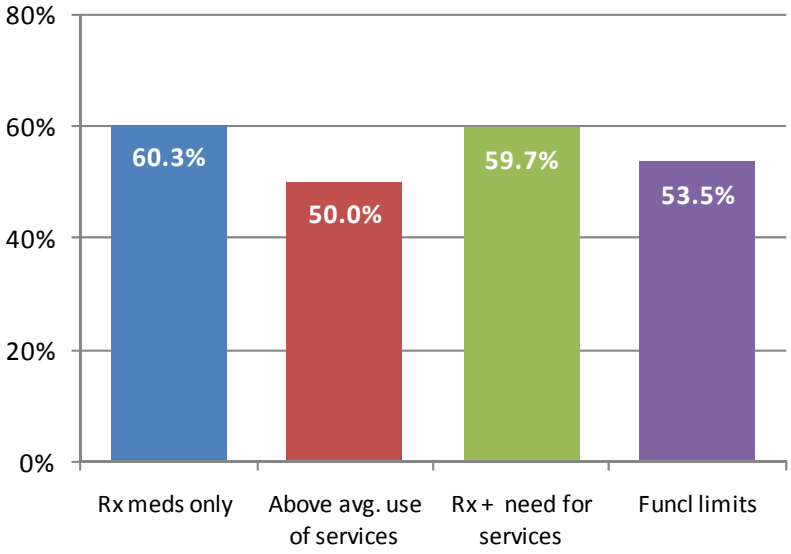
CSHCN without insurance were half as likely as those with current coverage to meet this outcome (31% vs. 59.3%, respectively).

Publicly insured CSHCN were somewhat less likely than CSHCN with private coverage to receive BOTH medical and dental preventive care during 2005-2006.

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

- **Complexity or type of special health-care needs is not strongly associated with whether CSHCN receive care that facilitates ongoing screening for both medical and dental issues.**

Figure 4.4: Percentage of CSHCN in North Dakota meeting Outcome #4 by qualifying type of special needs, 2005-2006



In North Dakota…

At least 7,000 CSHCN overall (43%) missed important opportunities for ongoing medical and dental screening during 2005-2006.

CSHCN with more complex needs or functional limitations were no more likely than other CSHCN to get the types of care that facilitate ongoing screening for medical and dental issues.

MCHB Core Outcome #4: All children 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 CHSN 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).

1) **During the past 12 months, did child receive all the routine preventive care that he/she needed, such as a physical examination or a well-child check-up? Did child get any routine preventive care during the past 12 months?**
2) **During the past 12 months, did child receive all the preventive dental care that he/she needed, such as check-ups and dental cleanings? Did child get any preventive dental care during the past 12 months?**

CSHCN less than a year old whose response was "Yes" to either of the questions about routine preventive medical care meet Outcome #4. CSHCN ages 1 through 17 meet the outcome criteria if their response was "Yes" to either question on routine preventive care AND preventive dental care. The percentages of CSHCN in North Dakota with qualifying responses on the Outcome #4 component measures, overall and by selected subgroups, are presented in this section.

In North Dakota …

Significantly fewer North Dakota CSHCN received both medical and dental preventive care than in the nation overall (57.5% in North Dakota vs. 63.8% nationwide).

About a third of CSHCN living in North Dakota (31.7%) did not receive regular preventive medical care, significantly more than nationwide (22.9%).

On the other hand, the proportion of North Dakota CSHCN receiving preventive dental care is comparable the rest of the U.S., at 79%.

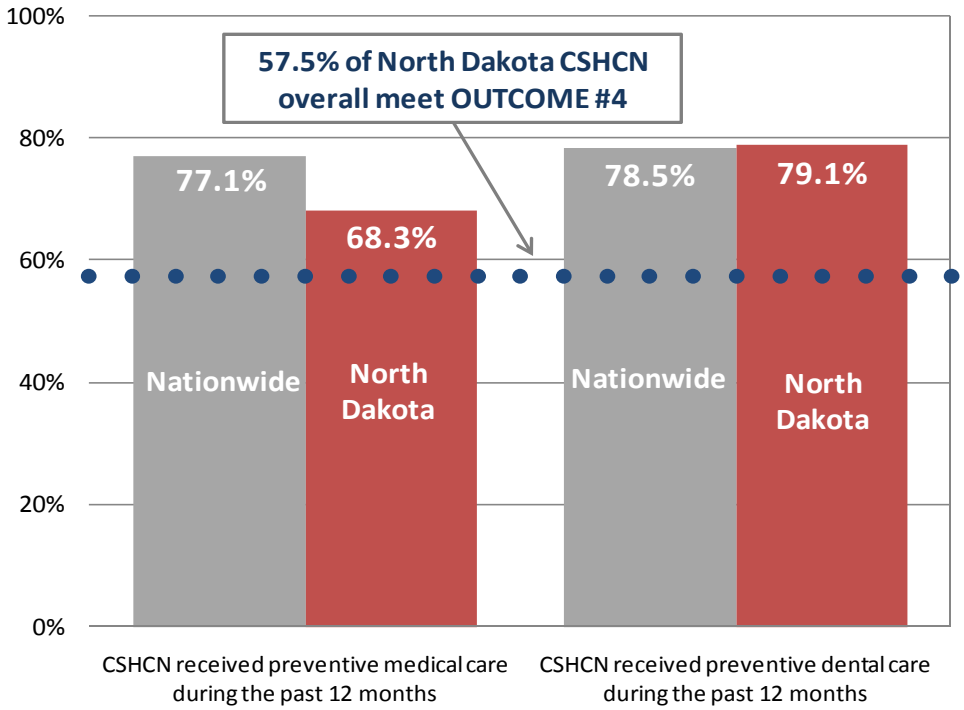
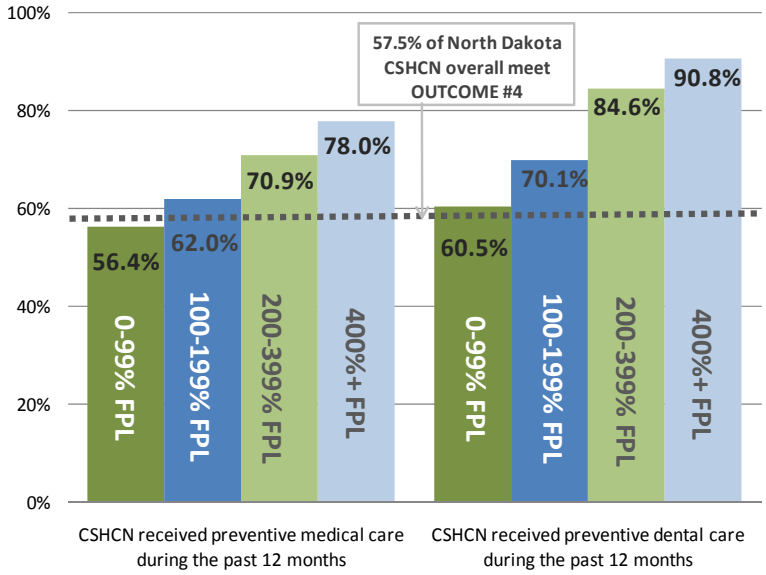


Figure 4.5: North Dakota vs. Nation Percentage of CSHCN with qualifying responses on the subcomponents of Outcome #4, 2005-2006

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

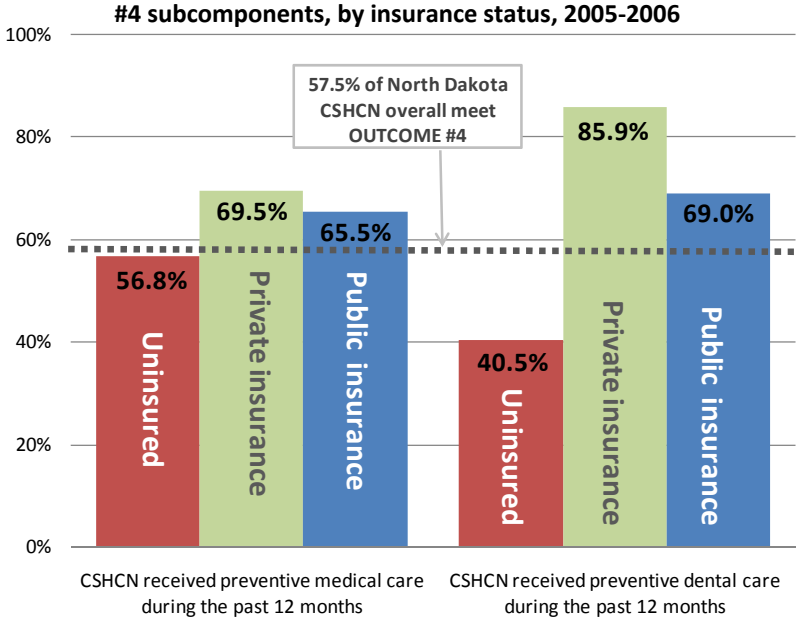
- The trend toward better access to preventive health services among CSHCN from higher income families holds true for both components of Outcome #4. The income differential is especially apparent for dental care. Nine of every 10 CSHCN living in higher income households had preventive dental services within the previous 12 months, compared to six out of 10 in the lowest income category (Fig.4.6).

Figure 4.6: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by federal poverty level (FPL), 2005-2006



- Health insurance is an important factor in access to preventive and screening services among CSHCN in North Dakota. CSHCN who are uninsured are considerably less likely than insured CSHCN to have had preventive medical or dental care. As with income, the impact of insurance is much stronger for dental than for medical care. Regular preventive dental care occurs significantly more often among CSHCN who have private insurance (85.9%) than either publicly insured (69.0%) or uninsured CSHCN (40.5%, Fig.4.7).

Figure 4.7: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by insurance status, 2005-2006



MCHB Core Outcome #4: All children 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. While the percentage of CSHCN receiving preventive dental care was similar for both sexes, a much lower proportion of boys than girls had routine medical care (64.7% and 74.9%, respectively, Fig 4.8). Preschool-age CSHCN are significantly more likely than older children to have routine preventive medical care and less likely to have had a dental checkup (Fig. 4.9).

Figure 4.8: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by sex, 2005-06

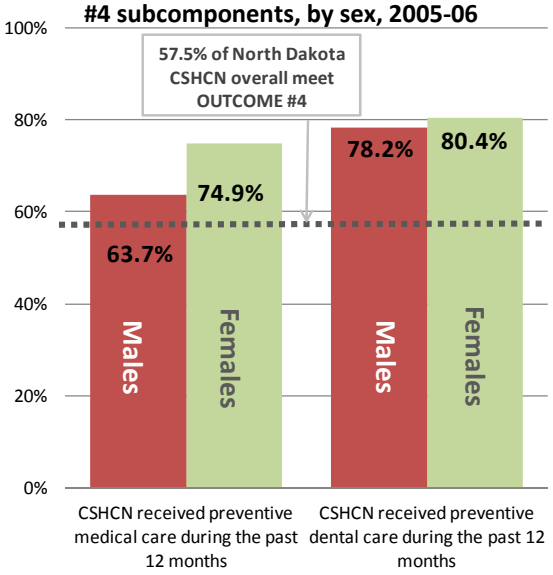
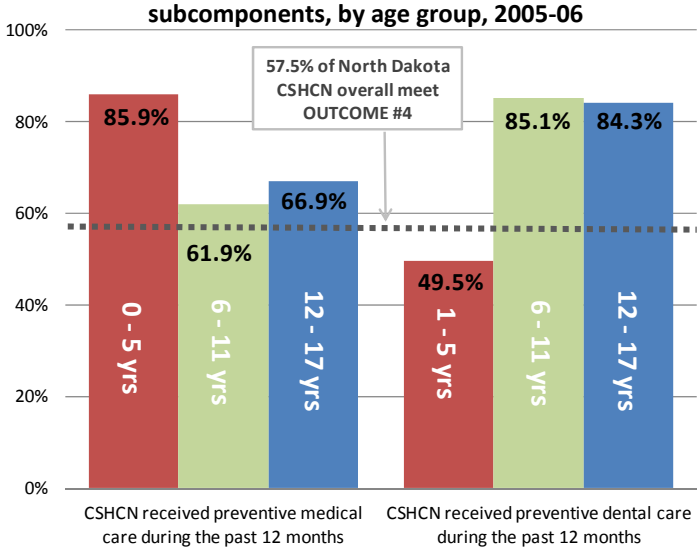
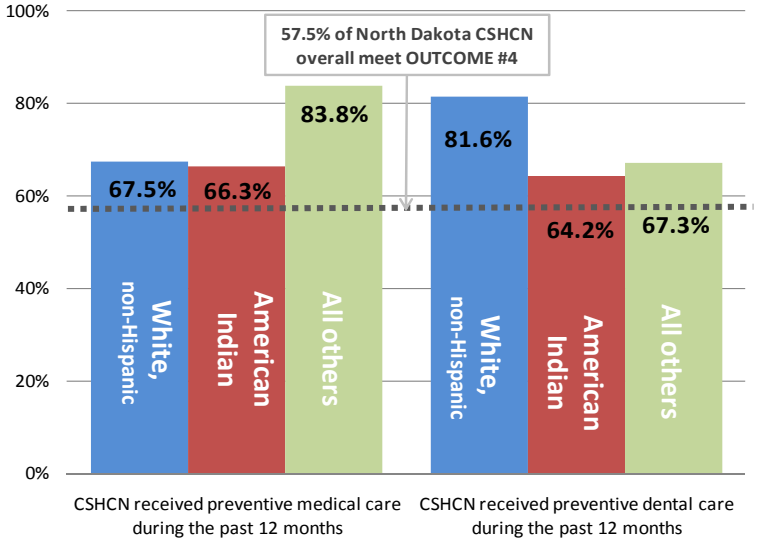


Figure 4.9: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by age group, 2005-06



- Because CSHCN in North Dakota are predominately white, the results of the components of Outcome #4 among white non-Hispanic CSHCN (Fig. 4.10 below) reflect the overall results for both subcomponents (Fig. 4.5) in North Dakota. However, it is worth noting that the likelihood of having preventive medical care is elevated among non-white, non-American Indian CSHCN. For dental services, however, receipt by minority CSHCN falls considerably short of the level for non-Hispanic white CSHCN (Fig. 4.10).

Figure 4.10: Percentage of CSHCN in North Dakota with qualifying responses to Outcome #4 subcomponents, by race/ethnicity, 2005-06



MCHB Core Outcome #5:

Services for children with special health-care needs and their families will be organized in ways that families can use them easily.

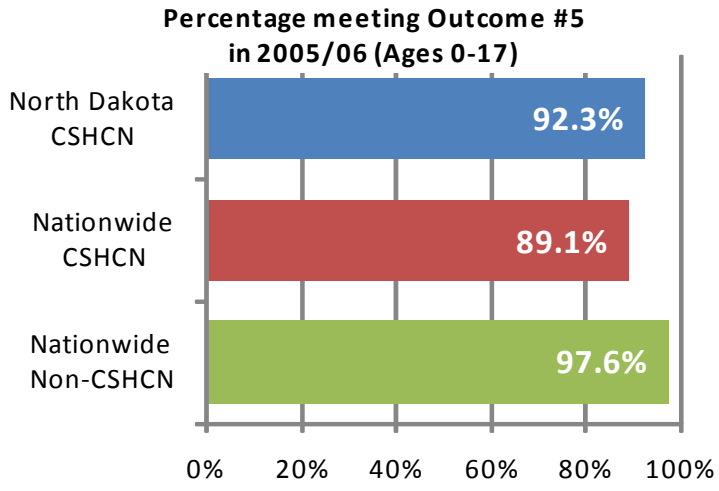
This outcome is assessed by the 2005/06 National Survey of Children With Special Health-Care Needs (NS-CSHCN) using a single question asking parents whether they experienced any difficulties trying to use the range of services their children needed over the past year.[7] In addition to medical care, the question listed services such as early intervention programs, child-care facilities, vocational education and rehabilitation programs, and other community programs.

Highlights…

- **More than nine in 10 CSHCN in North Dakota had no difficulties using needed services.**
  In 2005-06, more than 15,000 CSHCN in North Dakota successfully met this outcome.
- **North Dakota is one of nine states doing *better* than the national estimate for this outcome.**
  CSHCN in North Dakota are significantly *more* likely to meet this outcome than CSHCN nationally (92.3% vs. 89.1%). See Appendix C.
- **CSHCN in North Dakota successfully meeting this outcome are more likely to be:**
  - Insured.
  - 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.
  - Household income status.

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

Figure 5.1: North Dakota vs. Nation



2001 vs. 2005/06 Not Available

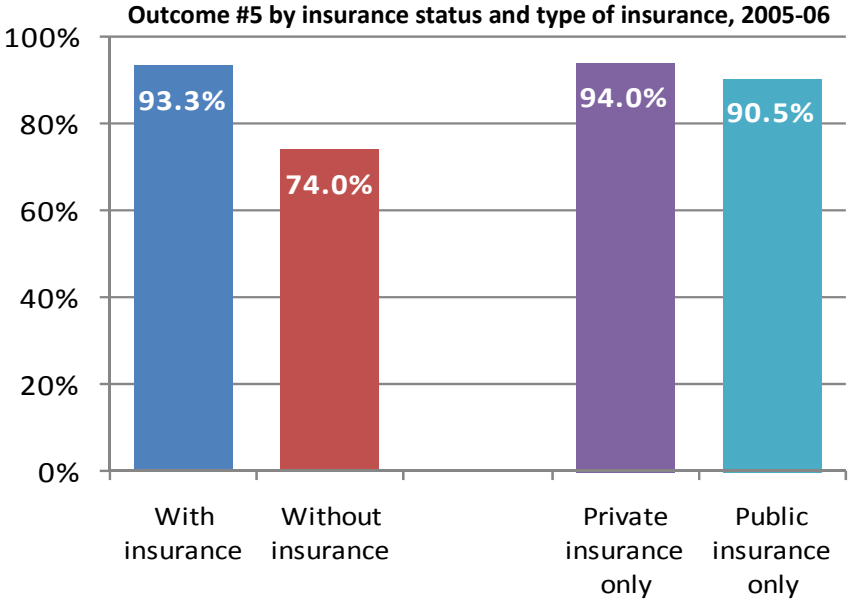
Estimates for Outcome #5 cannot be compared across survey years because of changes to the questions used to measure the outcome.

MCHB Core Outcome #5: **Services for children with special health-care needs and their families will be organized in ways that families can use them easily.**

Outcome #5: Key Findings for North Dakota:

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

Figure 5.2: Percentage of CSHCN in North Dakota meeting Outcome #5 by insurance status and type of insurance, 2005-06



In North Dakota…

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

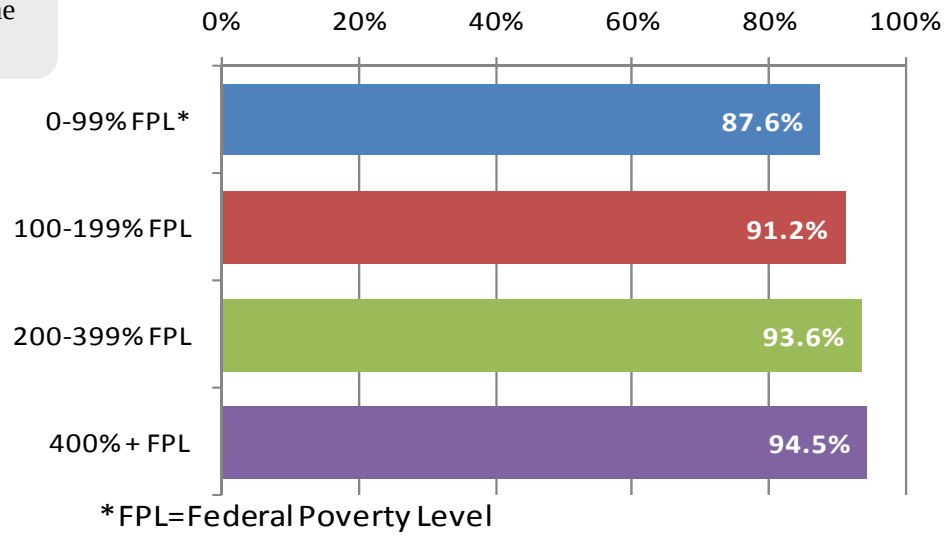
Similar proportions of CSHCN with private and public insurance coverage report little difficulty using needed services.

- **Families from all income levels have little difficulty using needed services for CSHCN.**

In North Dakota…

The level of difficulty using the services needed by CSHCN was similar for families across the income spectrum.

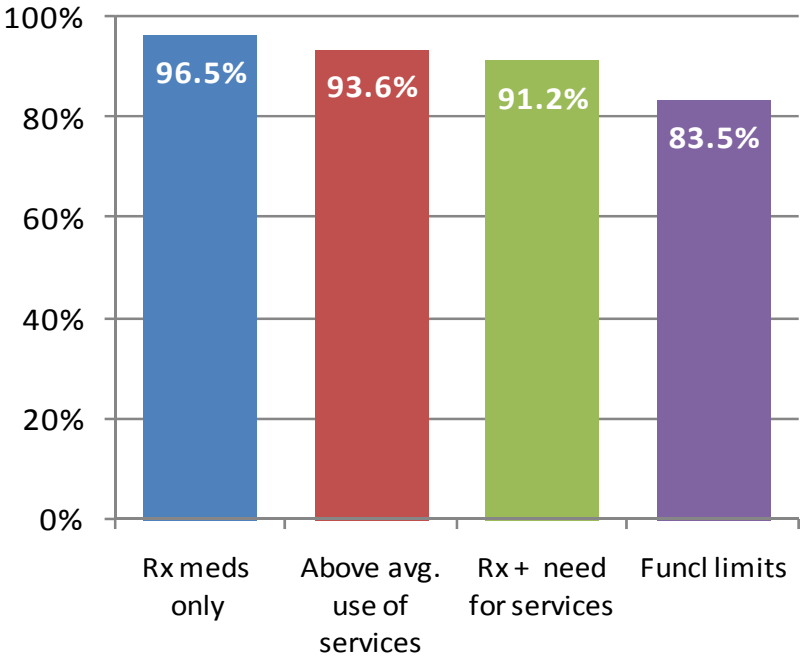
Figure 5.3: Percentage of CSHCN in North Dakota meeting Outcome #5 by federal poverty level (FPL), 2005-06



MCHB Core Outcome #5: **Services for children with special health-care needs and their families will be organized in ways that families can use them easily.**

- **CSHCN whose special health needs include functional limitations are more likely than other CSHCN to experience difficulty using needed services.**

Figure 5.4: Percentage of CSHCN in North Dakota meeting Outcome #5 by type of qualifying special needs, 2005-06



In North Dakota…

CSHCN with functional limitations are less likely to meet this outcome than those with other types of special needs.

One in six CSHCN (16%) with functional limitations encountered some kind of difficulty using services such as:

- Medical services.
- Early intervention programs.
- School-based programs.
- Child-care facilities.
- Vocational education programs.
- Rehabilitation programs.
- Other community programs.

MCHB Core Outcome #6

All youth with special health-care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.

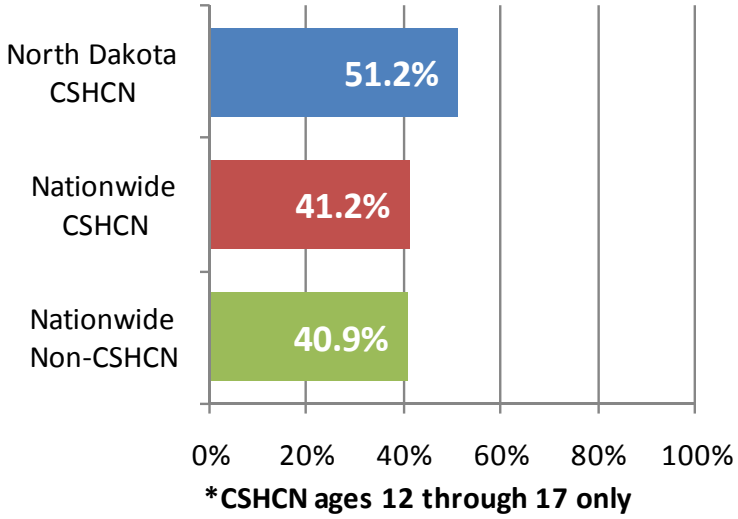
This outcome was evaluated for CSHCN ages 12 through 17 using responses to four questions: whether doctors discussed the shift to adult providers, whether doctors had discussed the child's changing needs as he or she approached adulthood, whether anyone had discussed insurance coverage in adulthood, and whether the child was usually or always encouraged to take responsibility for his or her health.[7]

Highlights…

- **About half of CSHCN ages 12 through 17 in North Dakota receive health care addressing their eventual transition to adult health care.**
  In 2005-06, about 3,600 CSHCN in North Dakota met this outcome.
- **North Dakota is one of 12 states doing *better* than the national estimate for this outcome.**
  CSHCN in North Dakota are significantly *more* likely to meet the transition to adulthood outcome than CSHCN nationally (51.2% vs. 41.2%). See Appendix C.
- **CSHCN ages 12 through 17 in North Dakota successfully meeting this outcome are more likely to be:**
  - Female.
  - Living in higher income households.
  - Managing chronic conditions primarily through prescription medication.
- **The percentage of CSHCN ages 12 through 17 meeting this outcome in North Dakota did NOT vary meaningfully by:**
  - Public or private insurance.
  - Child's race/ethnicity.

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

Figure 6.1: North Dakota vs. Nation*
Percentage meeting Outcome #6 in 2005/06 (Ages 12 through 17)



***CSHCN ages 12 through 17 only**

2001 vs. 2005/06 Not Available

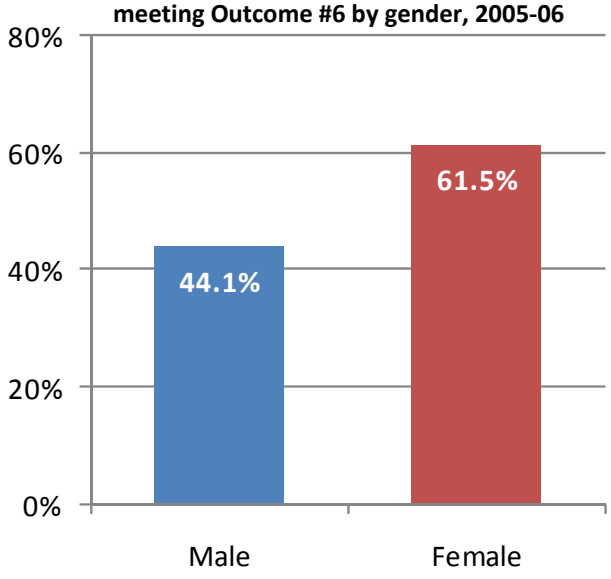
Estimates for Outcome #6 cannot be compared across survey years because of changes to the questions used to measure the outcome.

MCHB Core Outcome #6: **All youth with special health-care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.**

Outcome #6: Key Findings for North Dakota

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

Figure 6.2: Percentage of CSHCN in North Dakota meeting Outcome #6 by gender, 2005-06



In North Dakota…

Only 44 percent of adolescent boys with special health-care needs received health care that addressed transition to adulthood topics during 2005/06, compared to 60 percent of adolescent female CSHCN.

Gender disparities in receiving services designed to help with transition to adult health care are particularly concerning given that boys represent a higher percentage of the CSHSN population overall.

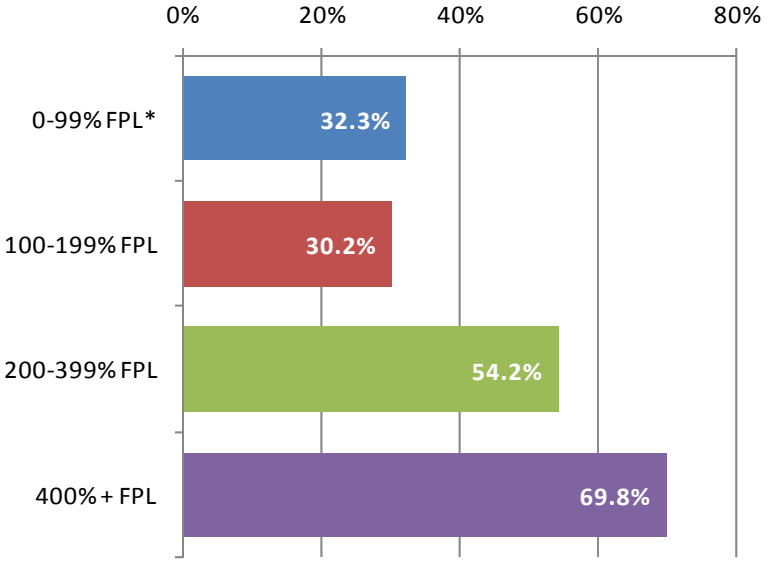
- **Lower income CSHCN are significantly less likely to receive health care that addresses their eventual transition to adulthood.**

In North Dakota…

Less than one-third of CSHCN ages 12 through 17 living in the state's poorest or near poor households met the transition to adulthood outcome in 2005/06.

In contrast, nearly 70 percent of CSHCN ages 12 through 17 living in the state's more affluent households received health care that met the criteria for this outcome during the same time period.

Figure 6.3: Percentage of CSHCN in North Dakota meeting Outcome #6 by federal poverty level (FPL), 2005-06

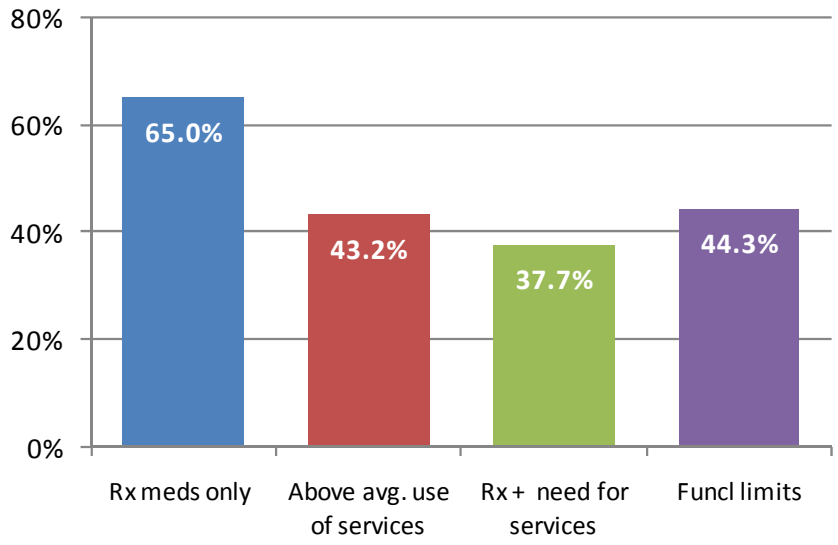


*FPL=Federal Poverty Level

MCHB Core Outcome #6: **All youth with special health-care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.**

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

Figure 6.4: Percentage of CSHCN in North Dakota meeting Outcome #6 by type of qualifying special needs, 2005-06



In North Dakota…

CSHCN ages 12 through 17 with conditions managed primarily through prescription medicine are significantly more likely than other CSHCN to have their adult health care transition needs addressed by their doctors.

CSHCN with health needs that often require coordination of services – such as specialist care, mental health treatment, school or community-based programs, specialized therapies, etc. – are less likely to have adult health-care transition needs addressed by their doctors.

MCHB Core Outcome #6: All youth with special health-care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.

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, CSHCN youth must either have received guidance or not need it at the time of the survey for all three of the following items:

1) **If CSHCN's health-care providers treat only children, have they discussed transitioning to providers who treat adults?**
2) **Have doctors or other health-care providers discussed the child's changing health care needs as he or she approaches adulthood?**
3) **Has anyone discussed how to maintain health insurance coverage during the child's transition to adult care?**

The second component is met if the youth's doctors or other health-care providers usually or always encourage him or her to take responsibility for self-care, such as taking medication, understanding his or her health, or following medical advice.

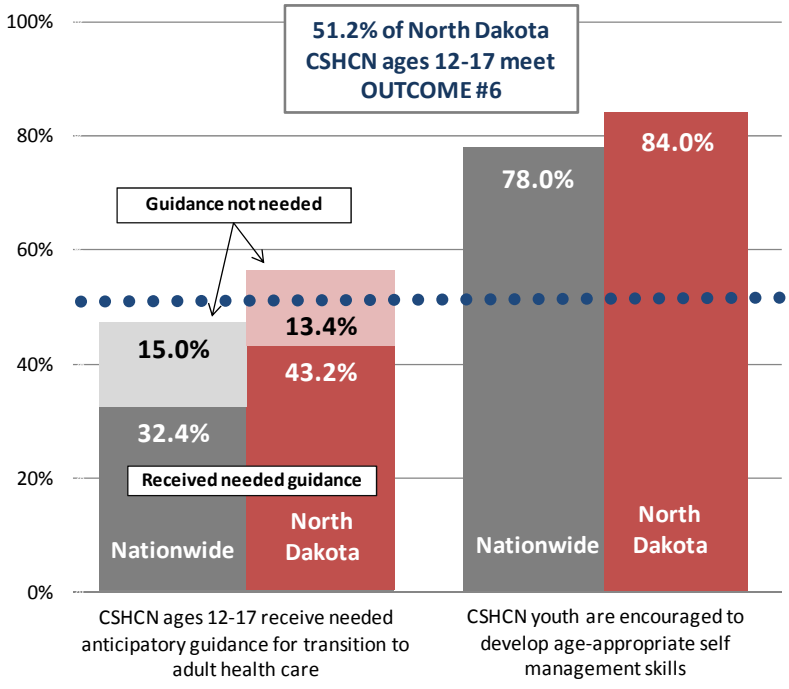
In North Dakota …

North Dakota exceeds national performance on both components of Outcome #6 – 57 percent vs. 47 percent for anticipatory guidance, and 84 pecent vs. 78 percent on self-management.

For every CSHCN youth in North Dakota who needed and received all three elements of anticipatory guidance (43.2%), another did not receive needed guidance in one or more areas (43.4%).

Parents of most (84%) 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.

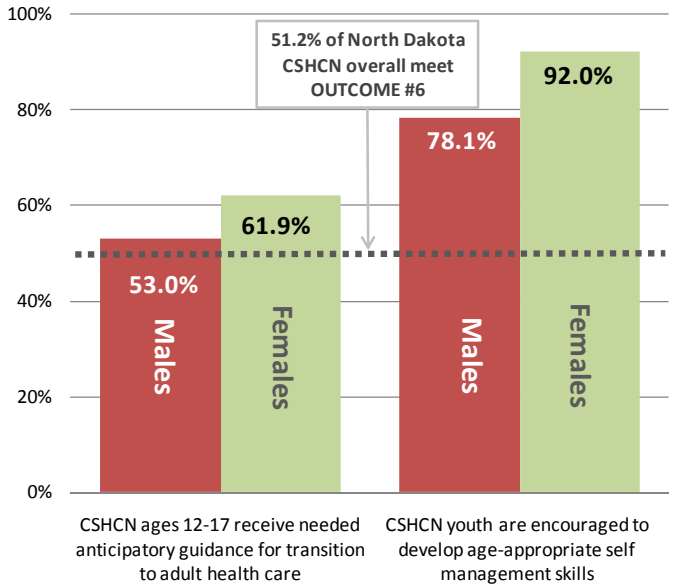
Figure 6.5: North Dakota vs. Nation
Percentage of CSHCN ages 12 through 17 with qualifying responses on subcomponents of Outcome #6, 2005-2006



MCHB Core Outcome #6: All youth with special health-care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.

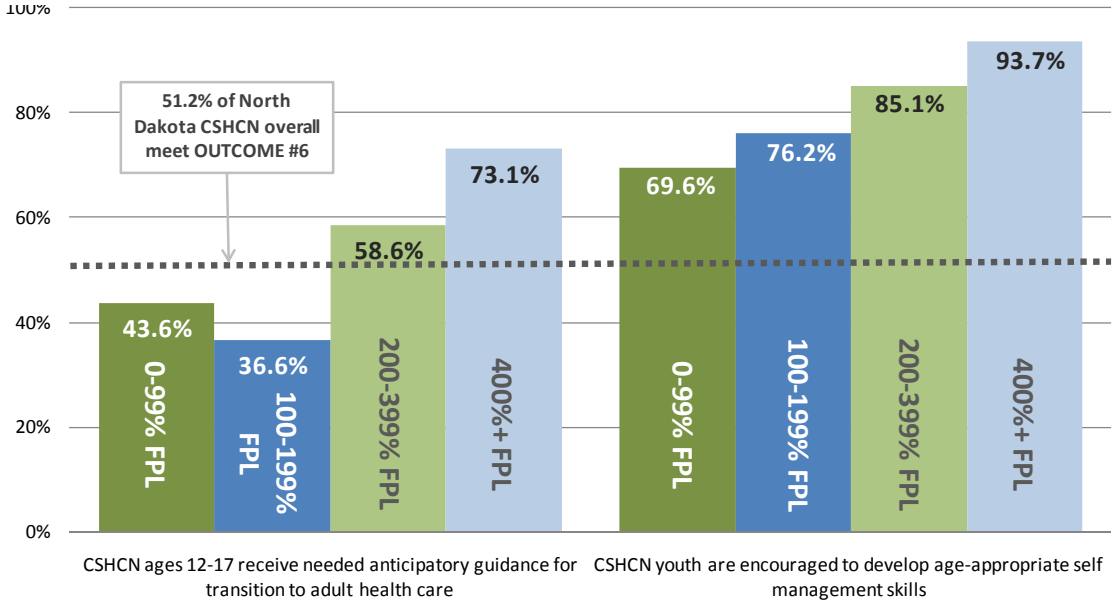
- The difference in the proportion of male and female CSHCN youth meeting Outcome #6 is evident in both subcomponents. However, only the self-care measure is statistically significant. Both male and female adolescent CSHCN fare better on the self-care component than on guidance for transitioning to adult health care services (Fig. 6.6).

Figure 6.6: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, by sex, 2005-06



- Family income is associated with both components of Outcome #6. Twice as many CSHCN youth from higher income families (four times Federal Poverty Level or more) as those with income just above poverty level (1 to 2 times FPL) met all three criteria for transition to adult health care (73.1% and 36.6%, respectively). The proportion of CSHCN youth receiving help learning to manage their own health increases with income, from 70 percent to 94 percent (Fig 6.7).

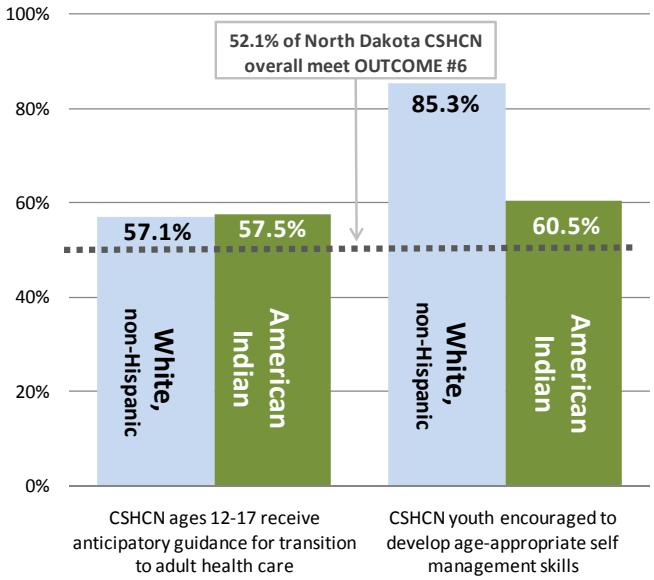
Figure 6.7: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, by income as a percentage of Federal Poverty Level (FPL), 2005-06



MCHB Core Outcome #6: All youth with special health-care needs will receive the services necessary to make appropriate transitions to adult health care, work and independence.

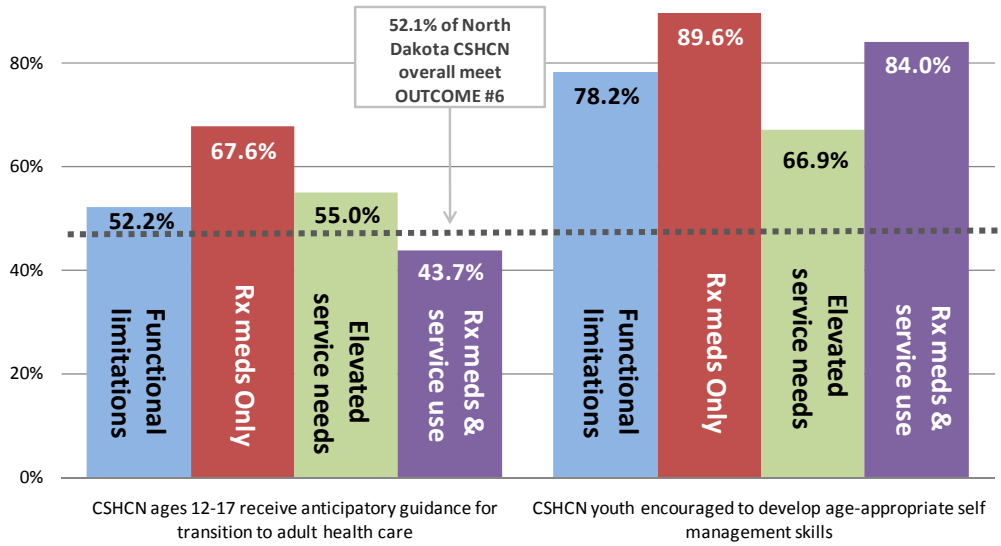
- Although in North Dakota the number of American Indian CSHCN youth participating in the survey was too small to establish statistical significance for subcomponents of Outcome #6, the results suggest that their doctors or other health care providers may be less likely to encourage them to take responsibility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

Figure 6.8: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, white (non-Hispanic) and American Indian, 2005-06



- 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.6.9). CSHCN requiring both medication and special services receive help with health care transition less often (43.7%). Interestingly, CSHCN youth whose main need is for special services are less likely to be encouraged to manage their own health care (66.9%).

Figure 6.9: Percentage of CSHCN ages 12-17 in North Dakota with qualifying responses to Outcome #6 subcomponents, by type of qualifying special needs, 2005-06



Section III: CSHCN 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 2005-2006 NS-CSHCN were designed to assess how having a CSHCN affects finances, employment availability, and mental health of families:

- 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.

Family Impact Highlights…

- **Families of about 6,600 CSHCN in North Dakota report significant difficulties due to their children's health needs in 2005-2006.**

  In North Dakota, 40.7 percent of CSHCN meet one or more of the four family impact indicators, slightly fewer than nationwide (43.3%, Fig. F_1).

- **The proportion of North Dakota CSHCN affected ranges from 9.1 percent whose family members spend 11 or more hours providing or coordinating medical care, to 21.9 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 under one-fifth of CSHCN in the state (18.5 % and 18.1%, respectively, Fig. F_2).

- **CSHCN in North Dakota are significantly less likely than in the nation overall to have family members whose employment was affected by their health conditions.**

  18.1 percent of North Dakota CSHCN meet criteria for Indicator #15, compared to 23.8% nationwide (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, 2005-2006

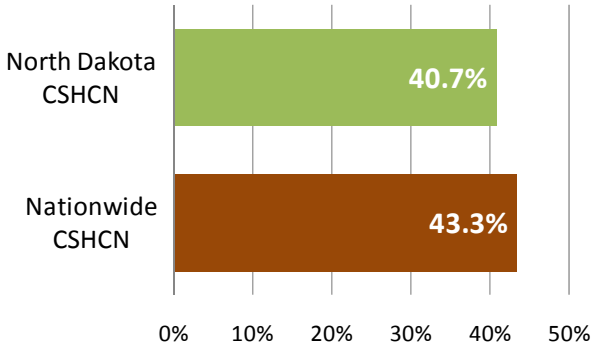


Figure F_3: North Dakota
Number of Family Impact Indicators met by CSHCN, 2005-2006

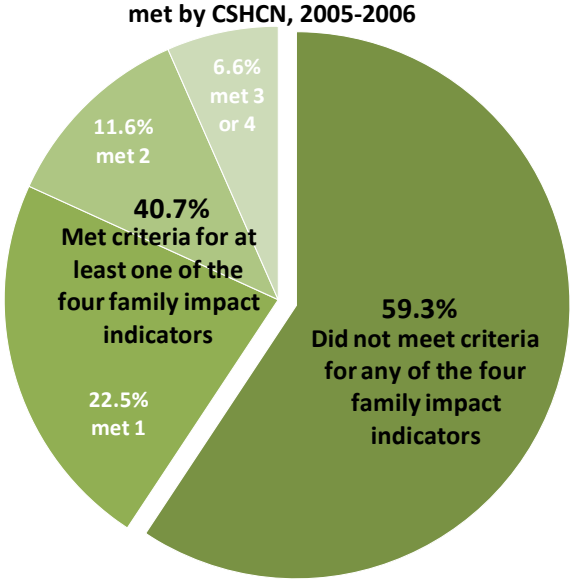
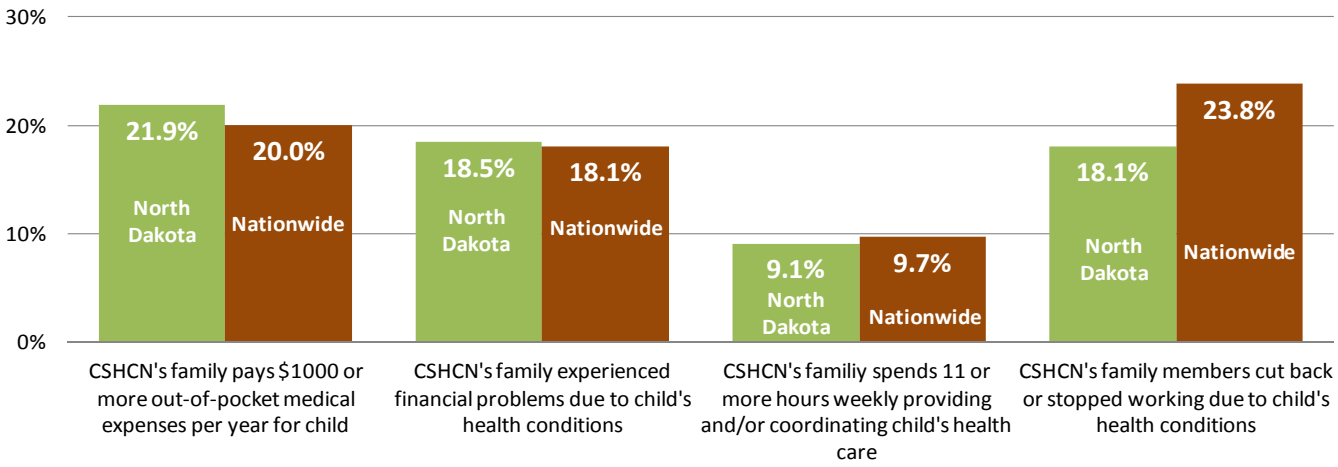


Figure F_2: North Dakota vs. Nation
Percentage of CSHCN who met each of four measures of family impact, 2005-2006



Indicator #12:

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

Highlights…

- **One in five 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 reflects nationwide results for CSHCN (21.9% vs. 20.0%, respectively, Fig. 12.1).
- **At the national level, CSHCN are about 2.5 times as likely as other children to have significant out-of-pocket medical costs.**
  About 8 percent of non-CSHCN spend $1,000 or more annually, compared to 20.0 percent of CSHCN (Fig. 12.1).
- **In 2005-2006, nearly two-thirds of CSHCN in North Dakota reported spending $250 or more each year on medical costs not covered by insurance.**
  Families of more than one-third (37.1%) pay more than $500 per year, including 21.9 percent whose families pay $1,000 or more in out-of-pocket medical expenses and 15.2 percent who pay $500 -$1,000 (Fig. 12.2).
- **CSHCN whose families are MOST likely to have annual out-of-pocket expenses of $1,000 or more are:**
  - Uninsured (38.1%).
  - Have complex health conditions (29.8 % of CSHCN needing medication AND specialized therapies or services).
  - Age 12 through 17 (27.5%).

Figure 12.1: North Dakota vs. Nation
Percentage of CSHCN meeting Indicator #12, 2005-2006

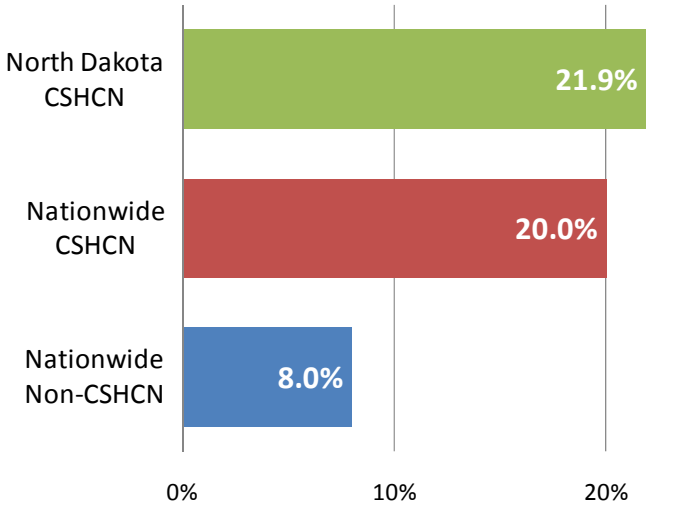
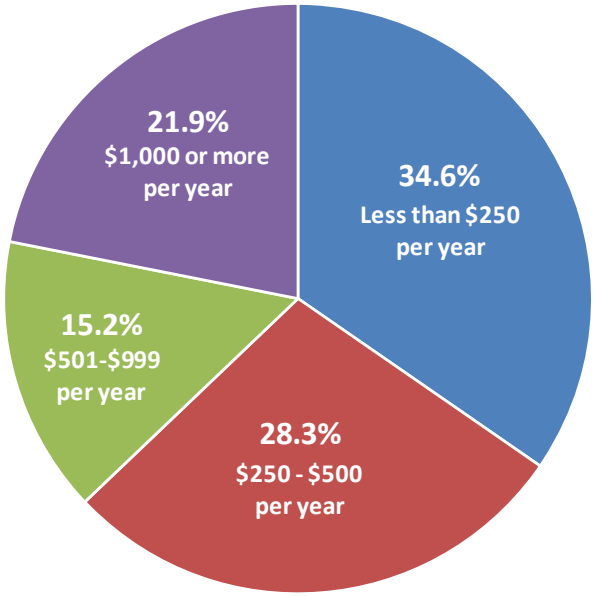


Figure 12.2: North Dakota -- Indicator #12
Yearly out-of-pocket medical expenses paid by CSHCN's family, 2005-2006



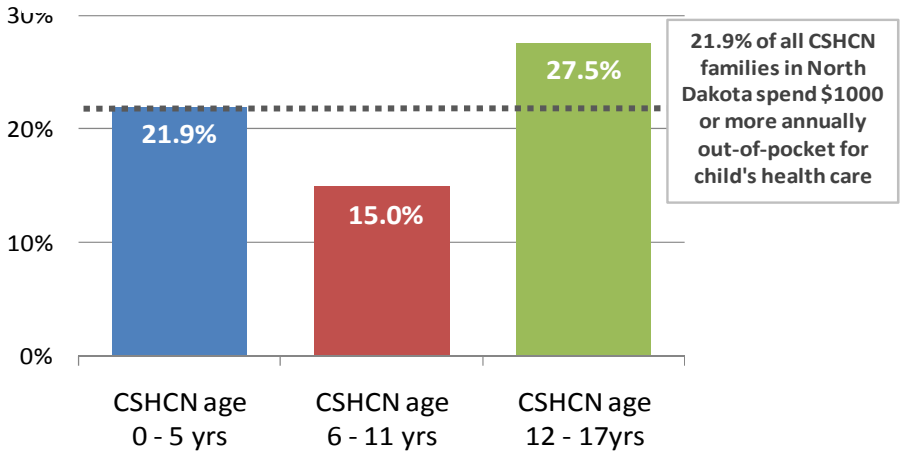
Indicator #12: Key Findings for North Dakota

- **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 …

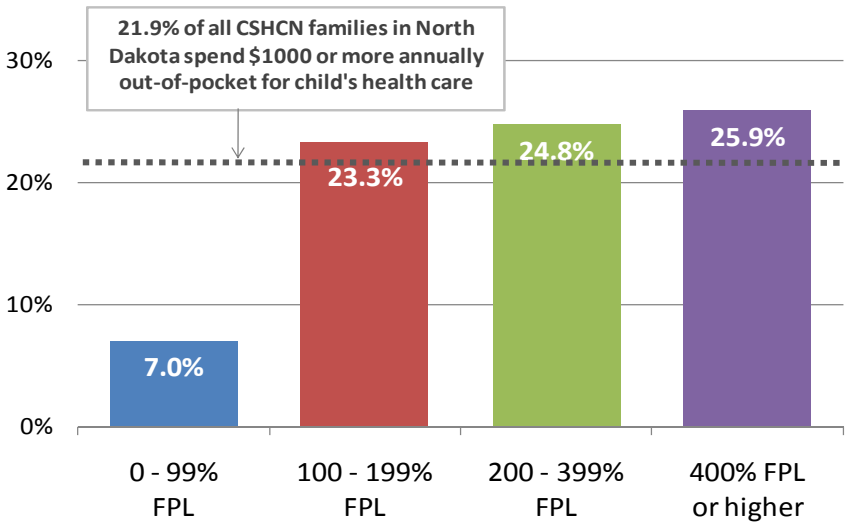
Adolescent CSHCN are nearly twice as likely as those of grade school age to have out-of-pocket medical expenses of $1,000 or more (27.5 percent vs. 15.0 percent, Fig. 12.3)

Figure 12.3: Percentage of CSHCN in North Dakota meeting Indicator #12 by age group, 2005-2006



- **For CSHCN whose family income is above poverty level, income level is not associated with excessive out-of-pocket medical expenses – in all three groups one quarter 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), 2005-2006



In North Dakota …

Only a small proportion – 7.0 percent – of CSHCN who live in households with income below Federal Poverty Level (FPL) say their families spent $1,000 or more on their health care in 2005-2006 (Fig. 12.4).

Families of two-thirds (69.2%) of below-poverty CSHCN spent less than $250, compared to 36.4 percent of CSHCN just above poverty level and one-quarter among the two higher income groups (see Appendix B).

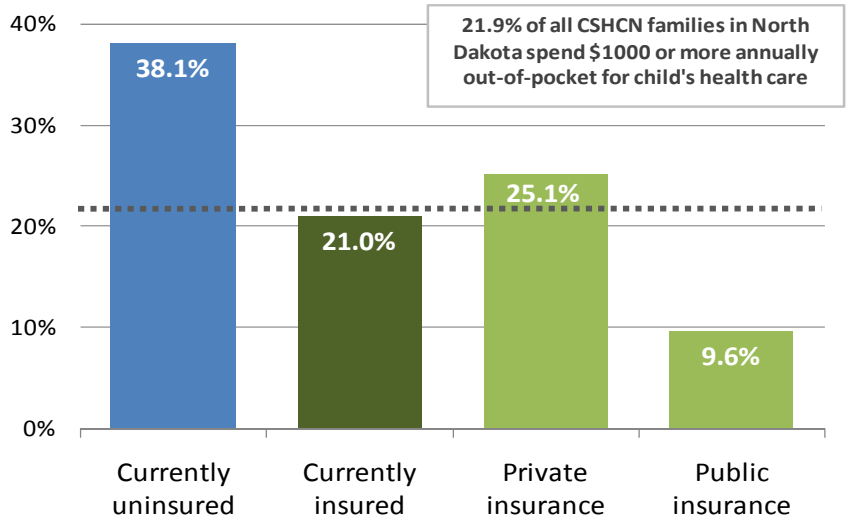
Indicator #12: CSHCN whose families spend $1,000 or more out-of-pocket in medical expenses per year for the child

- **Families of four in 10 uninsured CSHCN in North Dakota pay upwards of $1,000 every year in expenses not covered by insurance, compared to less than one in 10 covered by publicly funded insurance.**

In North Dakota …

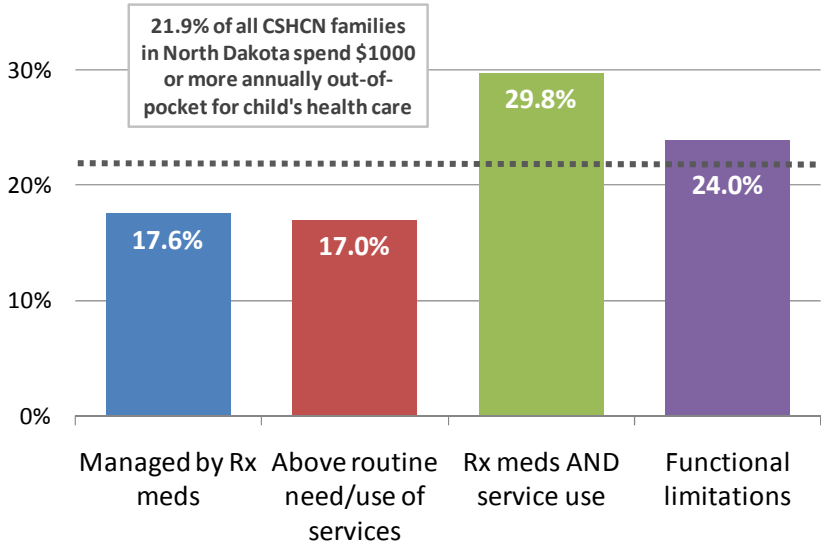
Families of CSHCN with public health insurance are least likely to pay $1,000 or more for medical costs not covered by insurance (9.6%), compared to those with private insurance (25.1%) and CSHCN who had no insurance coverage (38.1%) at the time of the 2005-2006 NS-CSHCN (Fig. 12.5).

Figure 12.5: Percentage of CSHCN in North Dakota meeting Indicator #12 by insurance status and type, 2005-2006



- **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, 2005-2006



In North Dakota …

CSHCN whose families are most at risk for having financial problems as a result of their health conditions are those who need both prescription medications AND specialized therapies or services to manage their ongoing health conditions (29.8%, Fig. 12.6).

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

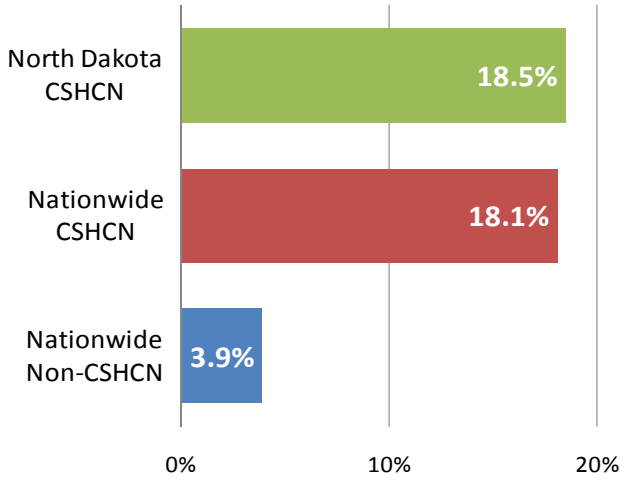
Highlights…

- **Nationally, families of nearly one in five CSHCN meet Indicator #13 criteria, more than four times the rate among non-CSHCN**

  In North Dakota, about 3,000 CSHCN (18.5%) report family financial problems resulting from their health conditions, mirroring the national result of 18.1 percent (Fig. 13.1).

- **CSHCN whose families are MOST likely to have financial problems due to the child's health conditions:**
  - Uninsured (60.4%).
  - Have health-related functional limitations (36.7%)
  - Household income just above poverty level (31.4 % of those at 100% to 199% FPL) or below poverty level (26.6%)

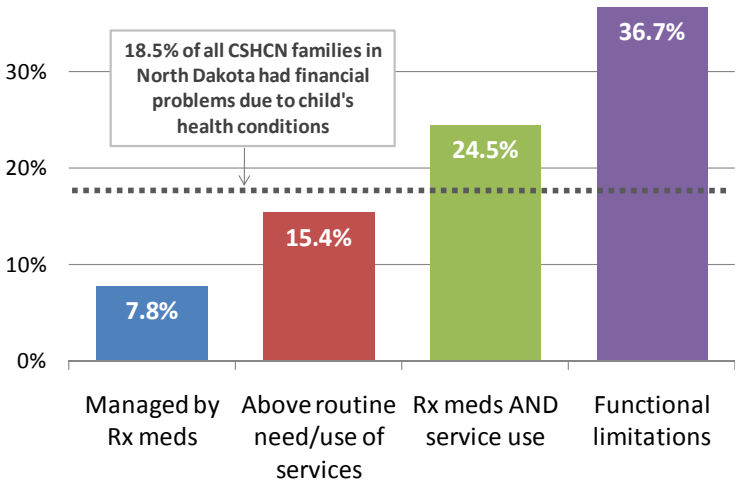
Figure 13.1: North Dakota vs. Nation
Percentage meeting Indicator #13, 2005-2006



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, 2005-2006



In North Dakota …

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

Of CSHCN who manage their health conditions primarily with prescription medications, families of only 7.8 percent have had financial problems, significantly fewer than the overall rate of 18.5 percent.

More than one-third (36.7%) of CSHCN who have functional limitations report family financial problems due to their health conditions.

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

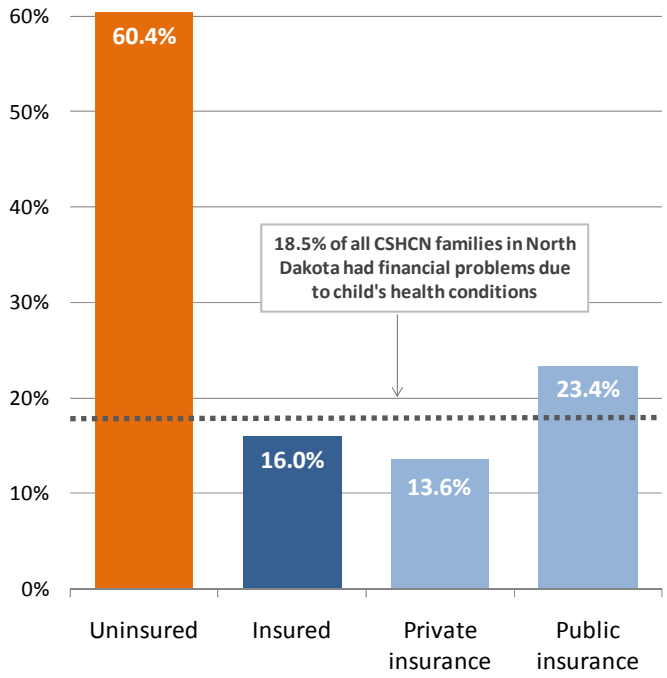
- **Six of every 10 CSHCN who are uninsured have had financial difficulties because of their health conditions.**

In North Dakota …

Although only 5.3 percent of North Dakota's CSHCN (about 900 children) are uninsured, having health insurance cuts the risk of health-related financial troubles for their families by a factor of four – 60.4 percent of uninsured, compared to 16.0 percent of those who have health insurance (Fig. 13.3).

Of CSHCN who are insured, those with public insurance are somewhat more likely to report financial difficulties than those with private health insurance (23.4 % vs. 13.6%).

Figure 13.3: Percentage of CSHCN in North Dakota meeting Indicator #13 by insurance status and type, 2005-2006



- **CSHCN in families with incomes near poverty level are more likely than those at 200 percent or more above Federal Poverty Level to experience financial problems as a result of their health conditions.**

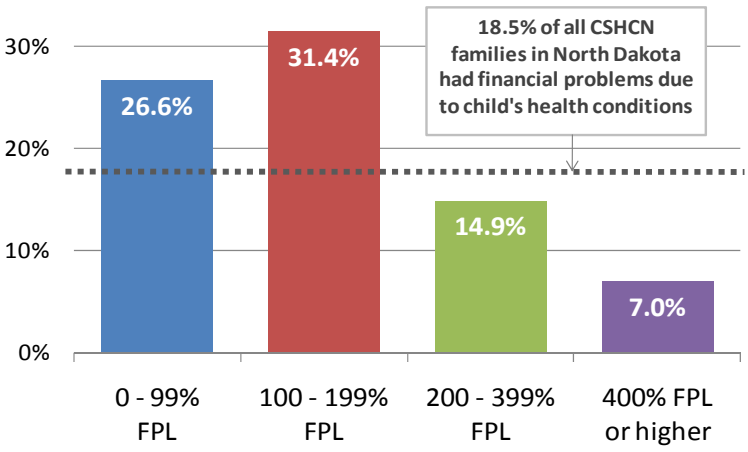
In North Dakota …

Almost one-third (31.4%) 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 (26.6%).

The income bracket least affected financially is, not unexpectedly, CSHCN in households with income 400% of FPL or higher, of whom only 7.0 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), 2005-2006



Indicator #14:

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

Highlights…

- **An estimated 1,500 CSHCN in North Dakota have family members who spend 11 or more hours per week on their health-care needs.**

  Nationally, about the same proportion of CSHCN meet Indicator #14 criteria (9.7%) as in North Dakota (9.1%, Fig. 14.1).

- **In the national sample, CSHCN were three times as likely as non-CSHCN to have health-care needs that consume 11 or more hours a week of family members' time.**

  While 2.8 percent of non-CSHCN meet Indicator #14 criteria, the proportion among CSHCN is 9.7 percent nationwide and 9.1 percent in North Dakota (Fig. 14.1).

- **Half 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 (32.9%) spend one to four hours per week; another 7.4 percent spend five to 10 hours weekly, and 9.1 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:**
  - Household income below Federal Poverty Level (27.5%).
  - Public insurance (22.3%). or uninsured (18.8%).
  - Have health-related functional limitations (20.7%).

Figure 14.1: North Dakota vs. Nation
Percentage of CSHCN meeting Indicator #14, 2005-2006

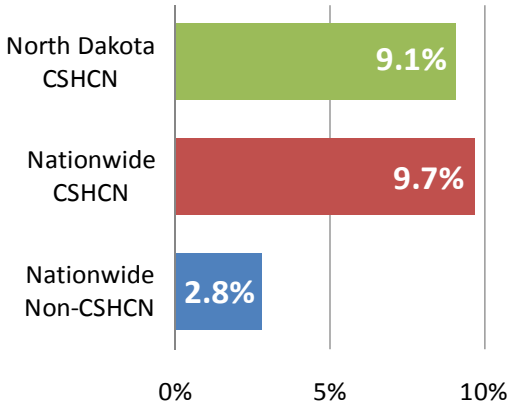
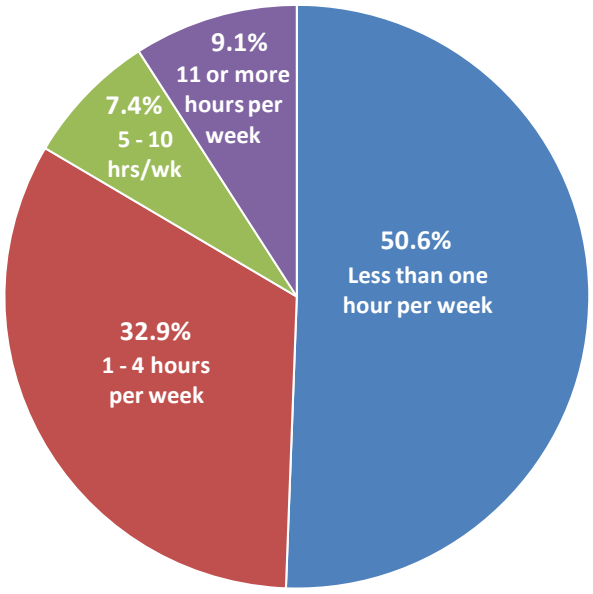


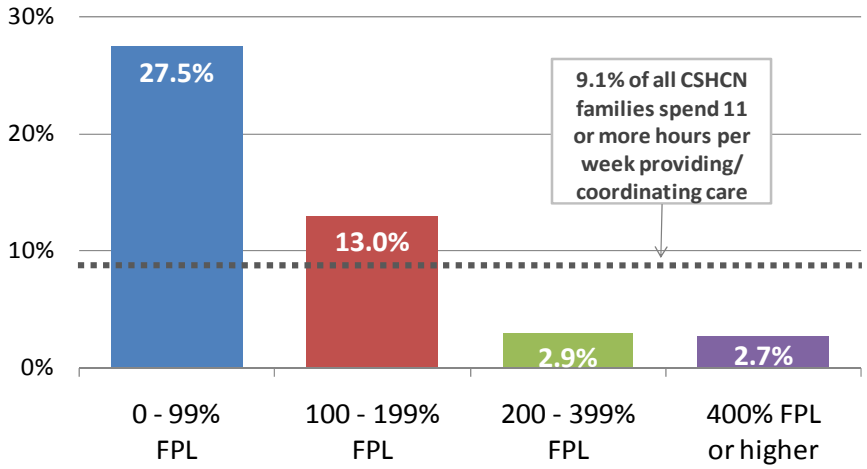
Figure 14.2: North Dakota -- Indicator #14
Hours per week CSHCN family members spend providing, arranging and/or coordinating health care for the child, 2005-2006



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.**

Figure 14.3: Percentage of CSHCN in North Dakota meeting Indicator #14 by household income as percentage of Federal Poverty Level (FPL), 2005-2006



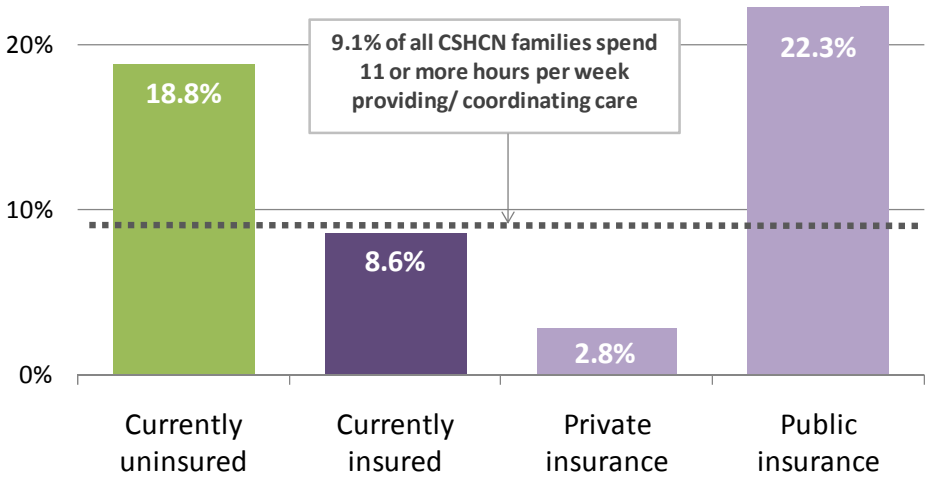
In North Dakota …

Being poor triples the chances that family members of CSHCN spend 11 or more hours a week on their care (27.5%), compared to all CSHCN (9.1%).

Among CSHCN in families with income at or above 200 percent of FPL, less than three percent meet Indicator #14 (2.9 % and 2.7%, 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.**

Figure 14.4: Percentage of CSHCN in North Dakota meeting Indicator #14 by insurance status and type, 2005-2006



In North Dakota …

Only 2.8 percent of privately insured CSHCN meet Indicator #14 criteria, compared to 22.3 percent of CSHCN with public insurance and 18.8 percent of uninsured CSHCN (Fig. 14.4).

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

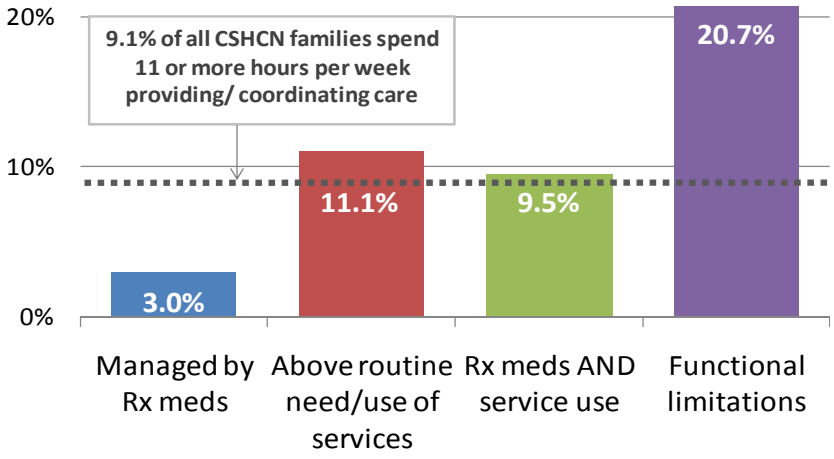
- **Two of the four mutually exclusive types of special needs (see Section 1B) are associated with Indicator #14: CSHCN whose conditions are managed mainly with medication and CSHCN with health-related functional limitations.**

In North Dakota …

Not surprisingly, one-fifth of CSHCN with functional limitations (20.7%) 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 3.0 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, 2005-2006



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

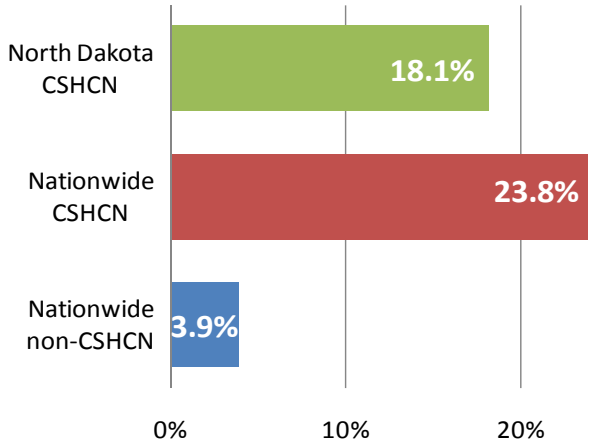
Highlights…

- **About 3,000 CSHCN in North Dakota (18.1%) have family members who had to reduce their work hours or quit a job in order to care for them.**

  North Dakota is among seven states that had significantly better results on Indicator #15 than the nation as a whole (23.8%, Fig. 15.1).

- **CSHCN whose family members are MOST likely to cut back or stopped working:**
  - Are uninsured (44.6%) or have health insurance through a public program (29.7%).
  - Have health related functional limitations (36.4%).
  - Live in households with income below Federal Poverty Level (32.5%).
  - Are less than 6 years of age (28.6%).

Figure 15.1: North Dakota vs. Nation
Percentage of CSHCN meeting Indicator #15, 2005-2006



Indicator #15: Key Findings for North Dakota

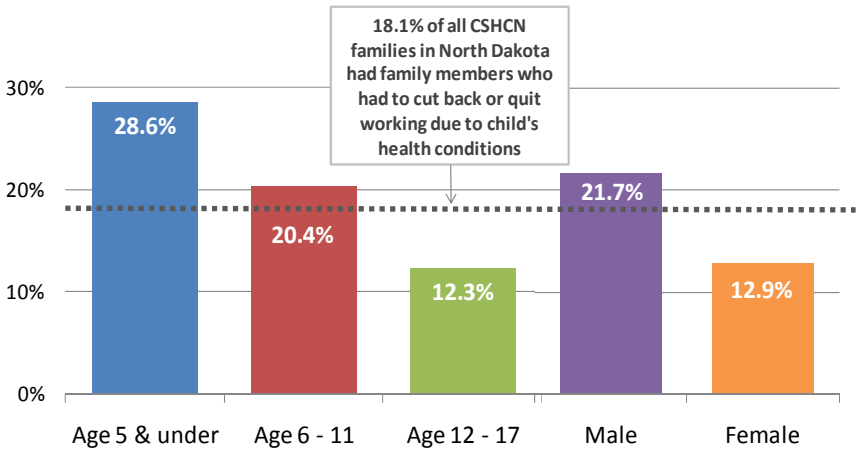
- **Age and sex of CSHCN are related to the risk of family members having to cut back or quit work due to the child's health care needs.**

In North Dakota …

Nearly three of every 10 CSHCN birth through 5 years old have family members whose employment has been affected by their health conditions (28.6%, Fig. 15.2).

Male CSHCN are about 1.7 times as likely as females to have health conditions that require family members to cut back or quit working (21.7 % of boys vs. 12.9 % of girls).

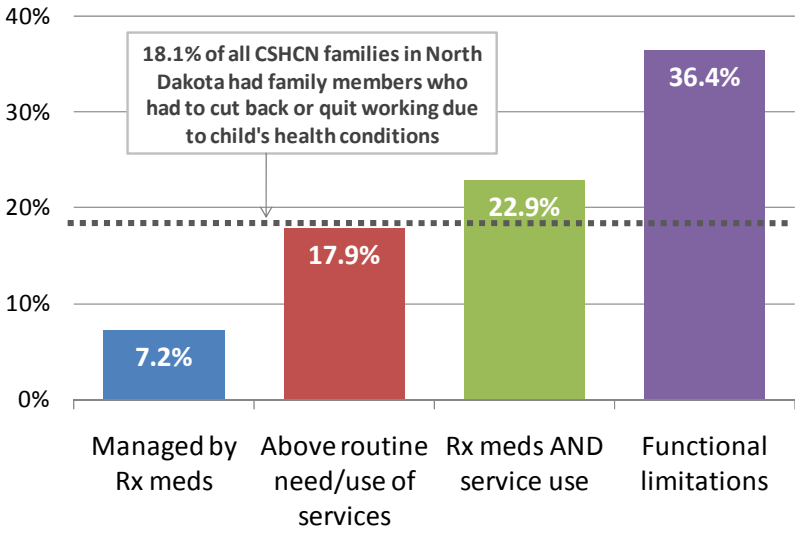
Figure 15.2: Percentage of CSHCN in North Dakota meeting Indicator #15 by sex and age, 2005-2006



Indicator #15: CSHCN whose 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, 2005-2006



In North Dakota …

One-third (36.4%) 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 (7.2%).

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

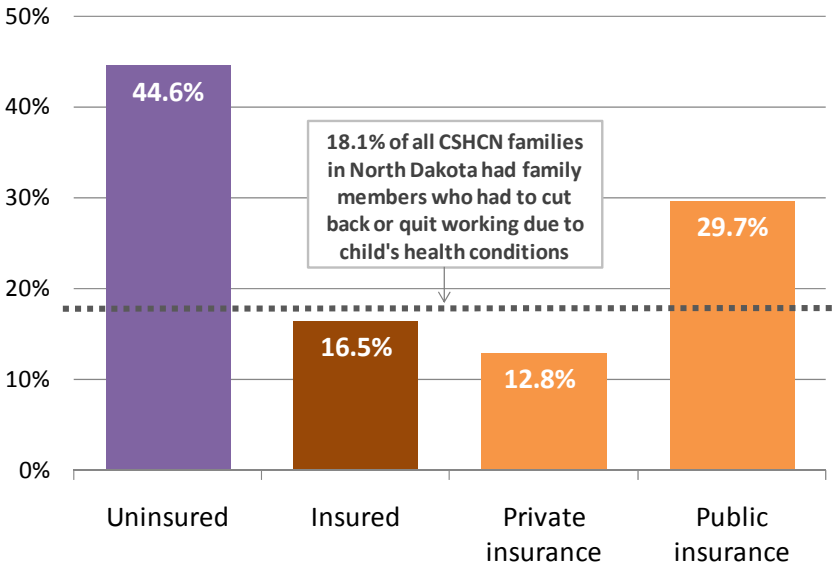
In North Dakota …

About 45 percent of CSHCN who are uninsured have family members who cut back or stopped working to care for them (Fig. 15.4).

Three of every 10 CSHCN with public health insurance (29.7%) have family members whose work was impacted by their health-care needs.

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

Figure 15.4: Percentage of CSHCN in North Dakota meeting Indicator #15 by insurance status and type, 2005-2006



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

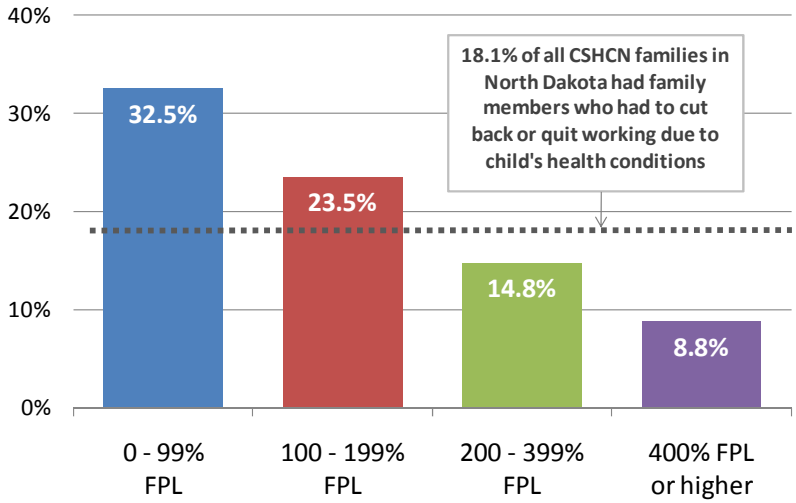
- **Income is directly assoicated with impact on employment of CSHCN's family members.**

In North Dakota …

One-third (32.5%) 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 8.8 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), 2005-2006



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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 2005-2006 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 2001. The central focus of the survey is the extent to which children with special health-care needs (CSHCN) have medical homes, adequate health insurance and access to needed services. Functional difficulties, chronic medical conditions, care coordination, satisfaction with care and adolescent transition services also are addressed in the survey questionnaire.

During the 2005-2006 NS-CSHCN, more than 3,000 randomly selected households with children were contacted by telephone and screened to identify at least 750 CSHCN in each state and the District of Columbia. Nationwide, a total of 364,841 children in 192,083 households were screened, resulting in 40,723 completed CSHCN interviews. In North Dakota, 7,755 children in 4,027 households were screened, to obtain a total of 761 in-depth CSHCN interviews.

For each CSHCN 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 child health indicators for the national "NS-CSHCN Chartbook 2005-2006" (http://mchb.hrsa.gov/cshcn05/).

The Data Resource Center for Child and Adolescent Health provides access to survey results at the state, regional and national levels, overall and by age, race, income, insurance status and other characteristics (http://cshcndata.org/Content/Default.aspx). The website also offers background information on the survey in easily understood formats, examples of publications and presentations using data from the survey, and links to relevant materials such as the National Chartbook for the 2005-2006 NS-CSHCN, National Center for Health Statistics information and documentation of survey methods and results, and resources for families with CSHCN.

This report focuses on the MCHB Core Outcome measures for CSHCN in North Dakota and, when appropriate, the nation. Subpopulations of interest are age group, race and ethnicity,

income level, insurance status and type, and complexity of special health-care needs. 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 was used for the two outcome measures that are comparable between the two surveys. Frequencies and cross tabulations with 95 percent confidence limits were generated using statistical software designed for analysis of complex survey samples.

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Appendix B-2: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #1: CSHCN whose families are partners in decision-making and satisfied with services

2005-2006 NS-CSHCN	North Dakota			HRSA Region VIII			Nationwide		
CSHCN who met MCHB Core Outcome # 1	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	64.3%	(53.3% - 75.3%)	1,711	66.1%	(61.3% - 70.9%)	42,395	64.2%	(62.2% - 66.1%)	1,335,199
6 - 11 yrs old	64.3%	(57.8% - 70.9%)	3,826	59.2%	(55.4% - 62.9%)	64,989	57.8%	(56.5% - 59.2%)	2,141,843
12 - 17 yrs old	61.4%	(55.9% - 67.0%)	4,553	53.9%	(50.5% - 57.3%)	73,117	53.6%	(52.3% - 54.9%)	2,237,272
Sex of child									
Male	60.9%	(55.6% - 66.1%)	5,811	57.0%	(54.1% - 60.0%)	103,537	56.8%	(55.7% - 57.9%)	3,357,642
Female	66.3%	(60.3% - 72.4%)	4,279	60.1%	(56.7% - 63.5%)	76,714	58.3%	(57.0% - 59.6%)	2,348,462
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, SD, ND			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	65.3%	(61.2% - 69.4%)	8,916	62.8%	(60.3% - 65.3%)	35,140	58.4%	(55.9% - 61.0%)	173,677
American Indian, non-Hispanic	44.8%	(27.9% - 61.7%)	638	42.1%	(33.0% - 51.3%)	2,212	46.9%	(40.1% - 53.8%)	11,571
All other race/ethnicities	55.8%	(39.6% - 72.0%)	505	53.6%	(45.1% - 62.1%)	2,828	51.0%	(47.0% - 55.0%)	80,993
Race/ethnicity of child									
Hispanic	56.4%	(29.0% - 83.7%)	206	48.5%	(40.9% - 56.1%)	19,775	46.4%	(43.6% - 49.2%)	545,037
White, non-Hisp	65.3%	(61.2% - 69.4%)	8,916	60.4%	(58.1% - 62.7%)	141,381	61.0%	(60.0% - 61.9%)	3,929,972
Black, non-Hisp	60.3%	(11.8% - 100.0%)	60	64.8%	(44.6% - 85.0%)	6,970	53.5%	(51.2% - 55.9%)	870,159
Multi-racial, non-Hisp	53.0%	(28.0% - 77.9%)	185	52.5%	(39.7% - 65.3%)	5,707	56.7%	(52.2% - 61.2%)	215,613
Other, non-Hisp	45.7%	(29.6% - 61.8%)	692	49.6%	(39.1% - 60.2%)	5,683	47.2%	(42.2% - 52.2%)	134,585
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	49.1%	(37.0% - 61.2%)	1,299	45.9%	(39.5% - 52.2%)	17,996	50.2%	(48.1% - 52.2%)	989,607
100% - 199% FPL	55.8%	(47.4% - 64.1%)	2,014	54.2%	(49.1% - 59.2%)	37,131	52.6%	(50.7% - 54.5%)	1,164,407
200% - 399% FPL	67.0%	(61.0% - 73.1%)	3,938	59.6%	(56.1% - 63.1%)	66,478	58.8%	(57.3% - 60.3%)	1,739,354
400% FPL or greater	73.1%	(66.4% - 79.7%)	2,839	65.3%	(61.3% - 69.3%)	58,898	64.7%	(63.2% - 66.2%)	1,820,947
Type of insurance									
Private insurance only	65.4%	(60.9% - 69.9%)	6,696	62.0%	(59.4% - 64.6%)	126,952	61.9%	(60.8% - 62.9%)	3,605,614
Public insurance only	58.2%	(47.8% - 68.6%)	1,879	52.6%	(47.1% - 58.1%)	32,793	52.2%	(50.5% - 53.9%)	1,479,228
Both private & public insurance	82.5%	(71.1% - 93.8%)	892	61.1%	(52.1% - 70.2%)	10,420	51.2%	(48.1% - 54.4%)	379,219
Uninsured	34.1%	(15.6% - 52.6%)	294	33.9%	(24.6% - 43.2%)	5,488	37.2%	(33.0% - 41.4%)	126,958
Specific types of special health needs									
Functional limitations	56.9%	(47.4% - 66.4%)	1,762	45.4%	(40.7% - 50.1%)	31,883	43.8%	(42.0% - 45.6%)	947,335
Managed by Rx meds	71.2%	(65.3% - 77.0%)	4,774	69.4%	(66.1% - 72.7%)	85,538	68.8%	(67.5% - 70.0%)	2,963,305
Above routine need/use of services	62.4%	(51.5% - 73.3%)	1,288	50.6%	(44.7% - 56.4%)	25,456	46.0%	(43.7% - 48.4%)	646,922
Rx meds AND service use	54.6%	(46.6% - 62.7%)	2,265	57.2%	(52.2% - 62.1%)	37,626	55.6%	(53.8% - 57.4%)	1,156,753

Source: 2005-2006 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] 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-2: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #2: CSHCN have a medical home

2005-2006 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	50.2%	(39.5% - 60.9%)	1,386	59.5%	(54.7% - 64.4%)	37,619	50.4%	(48.4% - 52.3%)	1,029,467
6 - 11 yrs old	51.9%	(45.0% - 58.8%)	3,007	45.9%	(42.1% - 49.8%)	49,154	47.4%	(46.1% - 48.8%)	1,720,270
12 - 17 yrs old	50.9%	(45.2% - 56.7%)	3,761	48.1%	(44.7% - 51.5%)	64,599	45.2%	(44.0% - 46.5%)	1,838,994
Sex of child									
Male	47.3%	(42.0% - 52.6%)	4,411	48.7%	(45.7% - 51.7%)	86,723	46.7%	(45.6% - 47.8%)	2,692,120
Female	56.7%	(50.4% - 63.1%)	3,743	51.2%	(47.7% - 54.7%)	64,514	47.8%	(46.5% - 49.2%)	1,890,520
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, SD, ND			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	53.8%	(49.5% - 58.1%)	7,378	52.8%	(50.2% - 55.4%)	28,985	49.6%	(47.0% - 52.2%)	143,943
American Indian, non-Hispanic	31.3%	(15.6% - 47.1%)	422	27.7%	(19.1% - 36.3%)	1,395	28.4%	(22.6% - 34.2%)	6,692
All other race/ethnicities	41.9%	(25.8% - 58.0%)	354	40.2%	(31.6% - 48.9%)	1,998	37.4%	(33.5% - 41.2%)	56,845
Race/ethnicity of child									
Hispanic	35.4%	(10.8% - 59.9%)	122	39.7%	(32.2% - 47.3%)	15,741	32.2%	(29.5% - 35.0%)	363,513
White, non-Hisp	53.8%	(49.5% - 58.1%)	7,378	52.6%	(50.3% - 55.0%)	121,703	52.8%	(51.8% - 53.8%)	3,354,175
Black, non-Hisp	18.8%	(0.0% - 48.2%)	19	32.0%	(10.7% - 53.2%)	3,273	36.6%	(34.3% - 38.9%)	571,494
Multi-racial, non-Hisp	59.2%	(34.4% - 84.0%)	182	43.9%	(30.7% - 57.1%)	4,626	46.8%	(42.3% - 51.3%)	173,304
Other, non-Hisp	31.4%	(16.5% - 46.4%)	452	49.3%	(38.6% - 60.1%)	5,559	40.0%	(35.2% - 44.8%)	110,560
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	35.3%	(23.6% - 46.9%)	875	33.1%	(27.2% - 39.0%)	12,353	34.0%	(32.0% - 36.0%)	637,297
100% - 199% FPL	41.8%	(33.4% - 50.2%)	1,503	45.6%	(40.5% - 50.6%)	30,423	41.2%	(39.3% - 43.0%)	873,984
200% - 399% FPL	54.4%	(48.0% - 60.8%)	3,236	51.1%	(47.4% - 54.7%)	56,423	51.1%	(49.6% - 52.6%)	1,482,963
400% FPL or greater	65.0%	(57.6% - 72.3%)	2,541	58.0%	(53.8% - 62.2%)	52,173	56.3%	(54.8% - 57.8%)	1,594,487
Type of insurance									
Private insurance only	57.5%	(52.8% - 62.1%)	5,969	53.3%	(50.5% - 56.0%)	108,667	53.3%	(52.2% - 54.3%)	3,083,257
Public insurance only	41.5%	(31.3% - 51.7%)	1,303	43.6%	(38.0% - 49.1%)	25,763	38.9%	(37.2% - 40.6%)	1,050,879
Both private & public insurance	42.0%	(25.5% - 58.6%)	455	50.8%	(41.2% - 60.4%)	8,540	37.0%	(34.0% - 40.0%)	264,948
Uninsured	31.6%	(12.9% - 50.4%)	254	24.4%	(16.5% - 32.3%)	3,786	26.5%	(22.8% - 30.2%)	87,003
Specific types of special health needs									
Functional limitations	36.1%	(26.7% - 45.6%)	1,054	38.9%	(34.1% - 43.7%)	26,358	32.2%	(30.4% - 33.9%)	666,106
Managed by Rx meds	67.2%	(61.5% - 72.9%)	4,651	62.9%	(59.5% - 66.3%)	77,169	58.9%	(57.6% - 60.2%)	2,520,191
Above routine need/use of services	39.1%	(28.1% - 50.1%)	779	36.8%	(31.2% - 42.5%)	17,720	35.8%	(33.5% - 38.1%)	482,585
Rx meds AND service use	40.7%	(32.8% - 48.6%)	1,670	45.7%	(40.6% - 50.7%)	30,125	45.2%	(43.4% - 47.0%)	919,849

Source: 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). All data are parent reported. For more information see www.childhealthdata.org

Notes: *Shaded 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-2: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #3: CSHCN have adequate public or private insurance

2005-2006 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	75.5%	(65.8% - 85.2%)	2,002	64.1%	(59.3% - 68.9%)	41,328	65.3%	(63.5% - 67.1%)	1,379,455
6 - 11 yrs old	68.4%	(62.2% - 74.7%)	4,065	58.3%	(54.5% - 62.1%)	63,569	60.4%	(59.0% - 61.7%)	2,257,027
12 - 17 yrs old	65.5%	(60.2% - 70.8%)	4,914	59.3%	(56.0% - 62.6%)	81,054	61.8%	(60.6% - 63.0%)	2,603,416
Sex of child									
Male	65.9%	(61.0% - 70.9%)	6,290	60.3%	(57.4% - 63.2%)	110,517	62.0%	(61.0% - 63.1%)	3,699,914
Female	71.8%	(66.1% - 77.5%)	4,691	59.4%	(56.0% - 62.8%)	75,168	61.9%	(60.7% - 63.2%)	2,531,236
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, SD, ND			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	69.5%	(65.6% - 73.4%)	9,632	62.1%	(59.6% - 64.6%)	34,862	60.6%	(58.1% - 63.0%)	181,553
American Indian, non-Hispanic	66.8%	(51.0% - 82.6%)	857	65.4%	(56.8% - 74.0%)	3,347	59.2%	(52.3% - 66.1%)	14,415
All other race/ethnicities	53.5%	(37.4% - 69.6%)	492	62.1%	(54.0% - 70.1%)	3,240	58.2%	(54.3% - 62.1%)	91,316
Race/ethnicity of child									
Hispanic	59.0%	(32.1% - 85.9%)	217	54.4%	(46.8% - 62.1%)	22,128	54.2%	(51.4% - 57.0%)	637,373
White, non-Hisp	69.5%	(65.6% - 73.4%)	9,632	60.8%	(58.5% - 63.1%)	143,955	63.8%	(62.8% - 64.7%)	4,175,875
Black, non-Hisp	85.7%	(57.9% - 100.0%)	85	57.3%	(34.9% - 79.7%)	5,459	60.7%	(58.4% - 63.0%)	980,150
Multi-racial, non-Hisp	31.6%	(9.5% - 53.6%)	114	62.3%	(50.2% - 74.4%)	6,617	65.6%	(61.7% - 69.5%)	252,171
Other, non-Hisp	67.9%	(53.0% - 82.8%)	933	59.6%	(48.9% - 70.4%)	6,572	58.7%	(53.7% - 63.6%)	173,528
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	64.6%	(53.3% - 75.9%)	1,661	48.6%	(42.1% - 55.0%)	18,866	56.7%	(54.7% - 58.7%)	1,111,479
100% - 199% FPL	51.3%	(43.0% - 59.7%)	1,793	49.6%	(44.6% - 54.6%)	33,373	57.7%	(55.9% - 59.6%)	1,266,558
200% - 399% FPL	74.9%	(69.3% - 80.5%)	4,469	61.2%	(57.7% - 64.6%)	68,662	61.9%	(60.4% - 63.3%)	1,854,274
400% FPL or greater	75.3%	(68.9% - 81.6%)	3,058	70.8%	(67.0% - 74.6%)	65,051	68.9%	(67.6% - 70.3%)	2,007,587
Type of insurance									
Private insurance only	72.8%	(68.7% - 76.9%)	7,714	65.5%	(63.0% - 68.1%)	136,177	65.0%	(64.0% - 66.0%)	3,876,642
Public insurance only	72.5%	(63.9% - 81.2%)	2,278	57.8%	(52.3% - 63.3%)	35,080	63.9%	(62.3% - 65.6%)	1,798,448
Both private & public insurance	60.5%	(43.7% - 77.4%)	642	70.0%	(62.2% - 77.8%)	11,685	62.6%	(59.6% - 65.7%)	462,056
Specific types of special health needs									
Functional limitations	60.1%	(50.7% - 69.5%)	1,795	52.6%	(47.9% - 57.3%)	36,568	53.7%	(51.9% - 55.5%)	1,156,203
Managed by Rx meds	74.3%	(69.0% - 79.5%)	5,091	69.2%	(66.1% - 72.4%)	86,150	67.9%	(66.7% - 69.1%)	2,991,451
Above routine need/use of services	69.4%	(58.9% - 79.9%)	1,426	49.3%	(43.5% - 55.2%)	24,735	55.1%	(52.8% - 57.4%)	773,875
Rx meds AND service use	63.6%	(56.0% - 71.2%)	2,669	58.2%	(53.2% - 63.2%)	38,497	62.7%	(61.0% - 64.4%)	1,318,368

Source: 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). All data are parent reported. For more information see www.childhealthdata.org

Notes: *Shaded 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-2: 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

2005-2006 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	49.7%	(39.1% - 60.3%)	1,404	47.9%	(43.0% - 52.9%)	31,351	49.5%	(47.6% - 51.5%)	1,055,744
6 - 11 yrs old	56.7%	(50.0% - 63.4%)	3,452	66.7%	(63.1% - 70.2%)	74,140	68.3%	(67.0% - 69.5%)	2,584,986
12 - 17 yrs old	61.2%	(55.6% - 66.7%)	4,602	66.0%	(62.9% - 69.2%)	91,343	66.9%	(65.8% - 68.1%)	2,845,141
Sex of child									
Male	53.3%	(48.1% - 58.6%)	5,162	61.3%	(58.3% - 64.2%)	113,226	63.4%	(62.3% - 64.4%)	3,819,558
Female	63.5%	(57.4% - 69.6%)	4,279	64.1%	(60.9% - 67.4%)	83,183	64.4%	(63.2% - 65.7%)	2,655,950
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, SD, ND			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	58.0%	(53.8% - 62.2%)	8,154	56.3%	(53.8% - 58.9%)	32,130	63.1%	(60.7% - 65.5%)	190,335
American Indian, non-Hispanic	56.3%	(39.6% - 73.1%)	802	55.5%	(46.4% - 64.6%)	2,944	53.7%	(46.9% - 60.6%)	13,024
All other race/ethnicities	54.1%	(38.2% - 70.0%)	502	57.6%	(49.4% - 65.8%)	3,070	58.0%	(54.1% - 61.9%)	93,152
Race/ethnicity of child									
Hispanic	47.8%	(21.7% - 73.9%)	185	58.7%	(51.2% - 66.2%)	24,138	55.5%	(52.7% - 58.3%)	659,645
White, non-Hisp	58.0%	(53.8% - 62.2%)	8,154	64.5%	(62.3% - 66.7%)	153,820	67.2%	(66.3% - 68.1%)	4,438,498
Black, non-Hisp	60.3%	(11.8% - 100.0%)	60	53.6%	(32.5% - 74.6%)	6,059	56.5%	(54.2% - 58.8%)	929,277
Multi-racial, non-Hisp	57.9%	(33.5% - 82.2%)	202	54.0%	(40.8% - 67.1%)	5,831	63.2%	(59.1% - 67.3%)	243,533
Other, non-Hisp	56.6%	(40.6% - 72.5%)	857	50.9%	(40.4% - 61.4%)	5,890	61.7%	(56.8% - 66.6%)	183,997
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	42.5%	(30.5% - 54.5%)	1,117	48.0%	(41.5% - 54.4%)	18,941	47.7%	(45.7% - 49.7%)	946,081
100% - 199% FPL	46.3%	(38.0% - 54.6%)	1,719	53.6%	(48.6% - 58.6%)	37,213	56.9%	(55.0% - 58.7%)	1,266,696
200% - 399% FPL	62.0%	(55.9% - 68.2%)	3,737	64.8%	(61.4% - 68.3%)	73,320	66.7%	(65.4% - 68.1%)	2,018,455
400% FPL or greater	70.8%	(64.0% - 77.6%)	2,885	72.5%	(68.9% - 76.2%)	67,360	76.9%	(75.7% - 78.2%)	2,254,638
Type of insurance									
Private insurance only	61.7%	(57.1% - 66.2%)	6,550	67.5%	(65.0% - 69.9%)	141,405	70.3%	(69.3% - 71.2%)	4,223,295
Public insurance only	52.7%	(42.3% - 63.1%)	1,715	56.0%	(50.6% - 61.4%)	35,027	54.7%	(53.0% - 56.3%)	1,552,921
Both private & public insurance	56.7%	(40.7% - 72.7%)	613	62.9%	(54.1% - 71.7%)	10,762	61.1%	(58.0% - 64.2%)	455,591
Uninsured	31.0%	(12.0% - 50.1%)	268	29.0%	(20.1% - 37.8%)	4,780	34.5%	(30.6% - 38.4%)	121,471
Specific types of special health needs									
Functional limitations	53.5%	(44.0% - 63.1%)	1,664	60.6%	(56.0% - 65.1%)	42,849	62.6%	(60.9% - 64.3%)	1,362,351
Managed by Rx meds	60.3%	(54.3% - 66.2%)	4,259	63.2%	(59.8% - 66.6%)	79,637	64.9%	(63.7% - 66.1%)	2,885,282
Above routine need/use of services	50.0%	(38.9% - 61.1%)	1,051	58.8%	(53.1% - 64.4%)	29,930	56.2%	(53.9% - 58.5%)	802,006
Rx meds AND service use	59.7%	(51.7% - 67.8%)	2,485	66.0%	(61.3% - 70.6%)	44,418	67.8%	(66.1% - 69.5%)	1,436,231

Source: 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). All data are parent reported. For more information see www.childhealthdata.org

Notes: *Shaded 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-2: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #5: Community-based service systems are organized for ease of use

2005-2006 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	93.3%	(87.3% - 99.3%)	2,615	90.5%	(87.6% - 93.4%)	59,152	91.3%	(90.2% - 92.4%)	1,937,571
6 - 11 yrs old	91.1%	(86.9% - 95.2%)	5,552	84.9%	(82.1% - 87.6%)	93,415	88.6%	(87.8% - 89.5%)	3,342,008
12 - 17 yrs old	93.0%	(90.3% - 95.7%)	7,034	89.2%	(87.1% - 91.3%)	122,410	88.4%	(87.6% - 89.2%)	3,744,925
Sex of child									
Male	92.3%	(89.5% - 95.2%)	8,981	87.3%	(85.3% - 89.2%)	159,670	88.5%	(87.9% - 89.2%)	5,313,984
Female	92.3%	(88.7% - 95.8%)	6,202	88.9%	(86.7% - 91.1%)	114,840	90.0%	(89.2% - 90.8%)	3,698,451
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, SD, ND			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	93.2%	(91.0% - 95.4%)	13,113	91.0%	(89.4% - 92.6%)	51,547	89.2%	(87.6% - 90.7%)	270,014
American Indian, non-Hispanic	83.9%	(70.8% - 97.0%)	1,194	83.4%	(76.2% - 90.5%)	4,409	82.9%	(77.4% - 88.4%)	20,494
All other race/ethnicities	91.7%	(84.3% - 99.2%)	862	87.2%	(81.8% - 92.6%)	4,701	86.4%	(83.6% - 89.2%)	138,932
Race/ethnicity of child									
Hispanic	92.3%	(80.7% - 100.0%)	358	85.5%	(80.0% - 91.1%)	34,466	84.1%	(82.0% - 86.2%)	995,498
White, non-Hisp	93.2%	(91.0% - 95.4%)	13,113	88.8%	(87.2% - 90.3%)	210,293	89.9%	(89.4% - 90.5%)	5,919,594
Black, non-Hisp	85.7%	(57.9% - 100.0%)	85	93.5%	(85.2% - 100.0%)	10,575	89.7%	(88.3% - 91.2%)	1,466,097
Multi-racial, non-Hisp	90.7%	(77.9% - 100.0%)	328	76.6%	(65.6% - 87.7%)	8,347	89.5%	(87.2% - 91.7%)	343,069
Other, non-Hisp	84.9%	(72.6% - 97.2%)	1,286	83.8%	(76.2% - 91.5%)	9,629	88.1%	(84.8% - 91.4%)	259,439
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	87.6%	(79.2% - 95.9%)	2,318	82.4%	(77.4% - 87.4%)	32,469	85.8%	(84.4% - 87.2%)	1,698,814
100% - 199% FPL	91.2%	(86.6% - 95.8%)	3,361	83.5%	(79.7% - 87.4%)	56,919	86.8%	(85.5% - 88.1%)	1,926,558
200% - 399% FPL	93.6%	(90.5% - 96.7%)	5,650	87.8%	(85.5% - 90.2%)	98,899	90.2%	(89.4% - 91.1%)	2,721,677
400% FPL or greater	94.5%	(91.0% - 98.0%)	3,872	93.7%	(91.9% - 95.6%)	86,690	92.0%	(91.2% - 92.8%)	2,677,454
Type of insurance									
Private insurance only	94.0%	(91.8% - 96.1%)	9,989	90.5%	(89.0% - 92.1%)	188,265	91.7%	(91.2% - 92.3%)	5,481,783
Public insurance only	90.5%	(84.2% - 96.8%)	2,965	83.6%	(79.4% - 87.7%)	52,318	86.4%	(85.3% - 87.6%)	2,450,338
Both private & public insurance	95.9%	(91.1% - 100.0%)	1,037	88.6%	(83.8% - 93.3%)	15,175	85.2%	(83.0% - 87.4%)	636,845
Uninsured	74.0%	(55.0% - 92.9%)	639	68.7%	(59.0% - 78.4%)	10,766	73.9%	(70.2% - 77.7%)	257,900
Specific types of special health needs									
Functional limitations	83.5%	(76.2% - 90.9%)	2,610	77.6%	(73.8% - 81.3%)	54,726	77.6%	(76.1% - 79.0%)	1,689,461
Managed by Rx meds	96.5%	(93.9% - 99.1%)	6,801	95.8%	(94.2% - 97.4%)	120,598	96.7%	(96.2% - 97.2%)	4,283,910
Above routine need/use of services	93.6%	(88.4% - 98.7%)	1,967	81.7%	(77.0% - 86.4%)	41,070	83.7%	(81.9% - 85.4%)	1,183,837
Rx meds AND service use	91.2%	(87.0% - 95.5%)	3,821	88.8%	(85.8% - 91.8%)	58,582	88.7%	(87.6% - 89.8%)	1,867,296

Source: 2005-2006 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] 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-2: Percentage of CSHCN Meeting MCHB Core Outcomes in North Dakota, HRSA Region VIII & Nationwide

Outcome #6: CSHCN youth (ages 12 through 17) receive services needed for transition to adulthood

2005-2006 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	44.1%	(36.7% - 51.6%)	1,858	41.4%	(36.9% - 45.9%)	29,968	38.8%	(37.2% - 40.5%)	876,209
Female	61.5%	(52.8% - 70.1%)	1,793	52.4%	(47.2% - 57.5%)	29,534	44.4%	(42.5% - 46.4%)	752,981
Race/Ethnicity - American Indian/Alaska Native				Region VIII states with AI/AN: MT, SD, ND			AI/AN States only: AK, AZ, MT, ND, NM, OK, SD		
White, non-Hispanic	53.1%	(47.0% - 59.2%)	3,348	50.6%	(46.9% - 54.3%)	12,330	46.4%	(42.6% - 50.1%)	57,722
American Indian, non-Hispanic	32.8%	(5.8% - 59.9%)	163	31.2%	(17.4% - 45.0%)	533	36.4%	(25.1% - 47.7%)	2,755
All other race/ethnicities	43.4%	(17.7% - 69.1%)	140	42.8%	(29.9% - 55.8%)	987	31.1%	(25.7% - 36.5%)	17,379
Race/ethnicity of child									
Hispanic	na	na	na	34.1%	(22.4% - 45.8%)	5,640	26.3%	(21.9% - 30.7%)	105,946
White, non-Hisp	53.1%	(47.0% - 59.2%)	3,348	49.6%	(46.1% - 53.2%)	49,367	46.5%	(45.0% - 48.0%)	1,256,181
Black, non-Hisp	na	na	na	29.7%	(2.1% - 57.3%)	1,357	28.7%	(25.4% - 32.1%)	175,858
Multi-racial, non-Hisp	67.8%	(37.4% - 98.3%)	125	32.1%	(16.5% - 47.8%)	1,222	41.8%	(35.2% - 48.5%)	55,599
Other, non-Hisp	34.0%	(8.1% - 59.8%)	179	39.3%	(23.5% - 55.1%)	1,357	33.9%	(26.1% - 41.8%)	32,444
Household income as % of Federal Poverty Level (FPL)									
0% - 99% FPL	32.3%	(12.6% - 51.9%)	291	30.9%	(20.0% - 41.8%)	3,871	24.1%	(21.3% - 26.9%)	163,655
100% - 199% FPL	30.2%	(18.9% - 41.5%)	421	35.3%	(27.7% - 42.9%)	9,350	33.9%	(30.9% - 36.8%)	291,332
200% - 399% FPL	54.2%	(45.3% - 63.0%)	1,501	49.0%	(43.6% - 54.5%)	22,161	43.4%	(41.2% - 45.6%)	513,296
400% FPL or greater	69.8%	(60.1% - 79.6%)	1,438	54.2%	(48.3% - 60.2%)	24,214	53.7%	(51.4% - 55.9%)	662,663
Type of insurance									
Private insurance only	55.1%	(48.6% - 61.6%)	2,809	51.9%	(47.9% - 55.9%)	46,952	49.1%	(47.5% - 50.7%)	1,217,081
Public insurance only	41.3%	(23.8% - 58.9%)	424	35.1%	(25.6% - 44.7%)	7,367	27.5%	(25.0% - 29.9%)	268,017
Both private & public insurance	34.6%	(12.9% - 56.3%)	147	26.7%	(16.0% - 37.5%)	1,603	32.1%	(27.1% - 37.2%)	85,633
Uninsured	27.5%	(1.0% - 53.9%)	91	23.8%	(11.3% - 36.3%)	1,667	18.2%	(13.8% - 22.6%)	27,475
Specific types of special health needs									
Functional limitations	44.3%	(29.7% - 59.0%)	498	34.7%	(27.9% - 41.6%)	10,030	29.9%	(27.2% - 32.6%)	267,898
Managed by Rx meds	65.0%	(56.9% - 73.2%)	2,023	57.4%	(52.2% - 62.6%)	30,495	49.9%	(48.0% - 51.9%)	819,501
Above routine need/use of services	43.2%	(23.8% - 62.6%)	306	38.1%	(28.0% - 48.2%)	5,890	31.6%	(27.9% - 35.2%)	158,950
Rx meds AND service use	37.7%	(27.5% - 47.9%)	823	42.0%	(35.1% - 49.0%)	13,182	42.0%	(39.4% - 44.6%)	384,598

Source: 2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN). All data are parent reported. For more information see www.childhealthdata.org

Notes: *Shaded 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 C

State Ranking Maps: 2005-2006 NS-CSHCN

MCHB Core Outcomes & Family Impact Indicators

Outcome #1: CSHCN whose families are partners in decision making and satisfied with services

Outcome #2: CSHCN have a medical home

Outcome #3: CSHCN have adequate private and/or public insurance

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

Outcome #5: Community-based services are organized for ease of use

Outcome #6: CSHCN Youth receive services needed for transition to adulthood (age 12-17 only)

Indicator #12:CSHCN whose families pay $1,000 or more out-of-pocket

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

Indicator #14: CSHCN whose families spend 11 or more hours per week providing health care

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

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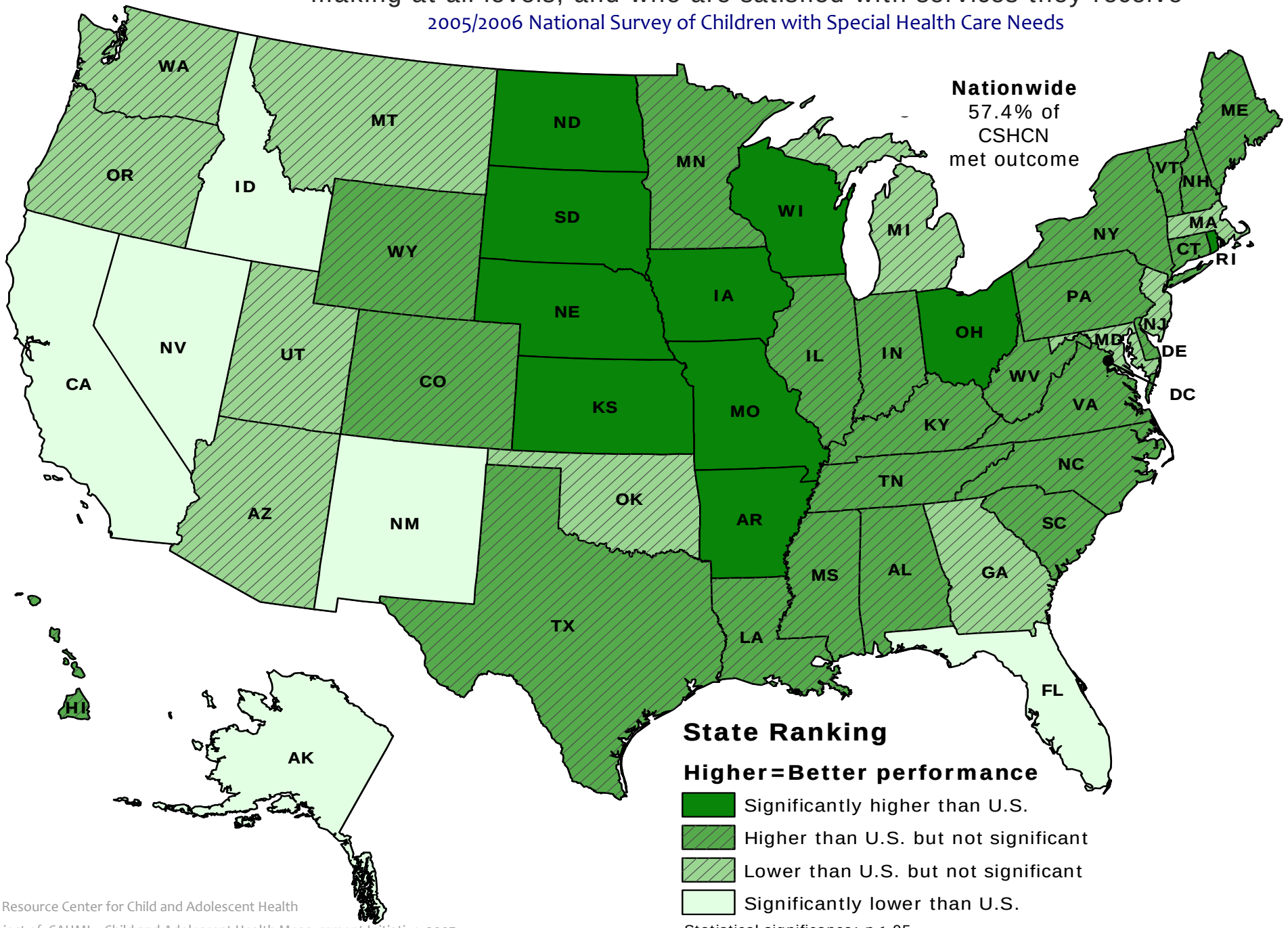
MCHB Core Outcome #1: CSHCN whose families are partners in decision making at all levels, and who are satisfied with services they receive

2005/2006 National Survey of Children with Special Health Care Needs



MCHB Core Outcome #1: CSHCN whose families are partners in decision making at all levels and satisfied with the services they receive

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		**57.4%**	
HIGHER than US; Statistically Significant	Nebraska	65.7%	
	Kansas	65.6%	
	Ohio	65.4%	
	Wisconsin	65.3%	
	Iowa	64.7%	
	Missouri	64.1%	
	South Dakota	63.4%	
	North Dakota	63.0%	
	Arkansas	61.7%	
	Rhode Island	61.4%	
HIGHER than US; Not Significant	Louisiana	62.2%	*
	Delaware	61.1%	
	Tennessee	60.7%	
	Maine	60.7%	
	Pennsylvania	60.6%	
	South Carolina	60.4%	
	Mississippi	60.3%	
	Illinois	60.3%	
	Minnesota	60.3%	
	New Hampshire	60.0%	
	Alabama	59.9%	
	Vermont	59.8%	
	Virginia	59.8%	
	Indiana	59.3%	
	Hawaii	59.3%	
	West Virginia	59.2%	
	Colorado	59.1%	
	New York	59.0%	
	Kentucky	58.6%	
	North Carolina	58.2%	
	Texas	57.9%	
	Connecticut	57.8%	
	Wyoming	57.5%	
LOWER than US; Not Significant	Massachusetts	57.1%	
	Oklahoma	56.9%	
	Montana	56.5%	
	Michigan	56.4%	
	Washington	55.7%	
	Oregon	55.5%	
	New Jersey	55.4%	
	Utah	55.1%	
	Maryland	54.8%	
	Georgia	54.0%	
	Arizona	53.6%	
	District of Columbia	53.1%	
LOWER than US; Stat. Significant	New Mexico	53.2%	*
	Idaho	52.7%	
	Alaska	51.8%	
	Florida	50.2%	
	Nevada	47.4%	
	California	46.6%	

NOTES:

Higher %'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.

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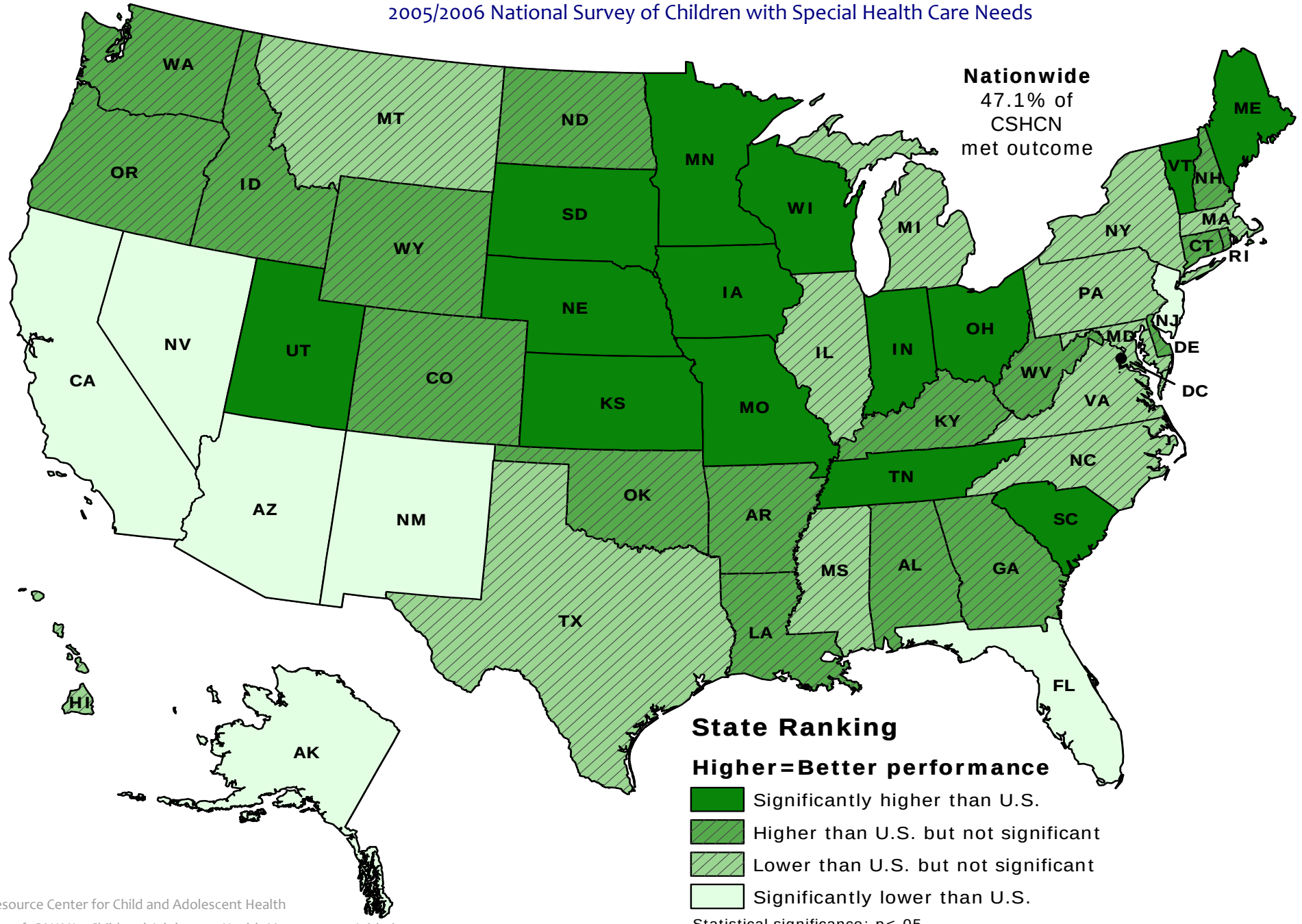
MCHB Core Outcome #2: CSHCN who receive coordinated, ongoing comprehensive care within a medical home

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		47.1%
HIGHER than US; Statistically Significant	Iowa	57.4%
	Ohio	55.6%
	Kansas	55.3%
	Indiana	54.6%
	Wisconsin	54.6%
	Nebraska	54.2%
	South Dakota	53.8%
	South Carolina	53.1%
	Tennessee	52.7%
	Utah	52.2%
	Minnesota	51.8%
	Missouri	51.8%
	Maine	51.7%
	Vermont	51.5%
HIGHER than US; Not Significant	North Dakota	51.2%
	Rhode Island	50.9%
	West Virginia	50.5%
	Arkansas	50.2%
	Alabama	50.0%
	Oklahoma	49.7%
	Louisiana	49.6%
	New Hampshire	49.6%
	Wyoming	49.1%
	Connecticut	48.5%
	Washington	48.3%
	Colorado	48.2%
	Delaware	48.1%
	Idaho	47.7%
	Oregon	47.4%
	Kentucky	47.3%
	Georgia	47.3%
LOWER than US; Not Significant	North Carolina	46.5%
	Texas	46.3%
	Michigan	45.9%
	Montana	45.9%
	Pennsylvania	45.8%
	Massachusetts	45.7%
	Maryland	45.6%
	Hawaii	45.2%
	New York	45.2%
	Illinois	45.1%
	Mississippi	45.0%
	Virginia	43.9%
LOWER than US; Statistically Significant	California	42.2%
	Florida	41.9%
	New Mexico	41.6%
	Nevada	41.2%
	New Jersey	40.8%
	Arizona	40.4%
	Alaska	39.3%
	District of Columbia	36.9%

NOTES:

Higher %'s = Better performance

Statistical significance: p <.05

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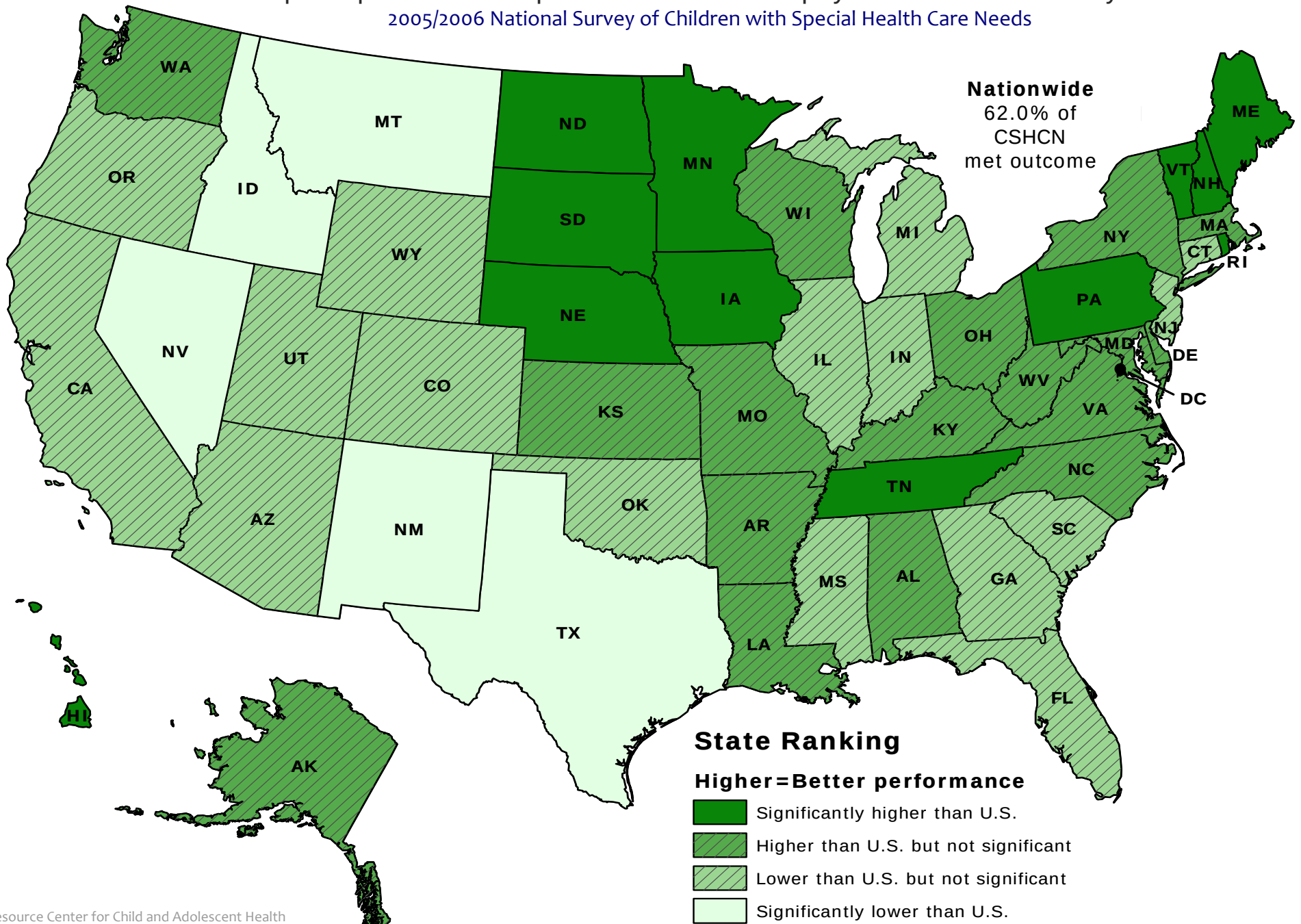
MCHB Core Outcome #3: CSHCN whose families have adequate public and/or private insurance to pay for the services they need

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		62.0%	
HIGHER than US; Statistically Significant	Hawaii	73.5%	
	Maine	70.0%	
	Vermont	69.4%	
	Iowa	68.6%	
	North Dakota	68.2%	
	Rhode Island	68.1%	
	Tennessee	67.7%	
	New Hampshire	67.3%	
	South Dakota	66.7%	
	Minnesota	66.3%	
	Pennsylvania	66.2%	
	Nebraska	65.9%	
HIGHER than US; Not Significant	Maryland	65.5%	
	Louisiana	65.5%	
	Washington	65.3%	
	Arkansas	65.3%	
	Alabama	65.0%	
	Missouri	64.8%	
	Kentucky	64.7%	
	Ohio	64.6%	
	West Virginia	64.2%	
	Virginia	63.7%	
	North Carolina	63.7%	
	Delaware	63.2%	
	Massachusetts	63.1%	
	Wisconsin	63.0%	
	Kansas	62.9%	
	District of Columbia	62.7%	
	Alaska	62.3%	
	New York	62.1%	
LOWER than US; Not Significant	Indiana	61.8%	
	Connecticut	61.7%	
	Oklahoma	61.6%	
	Oregon	61.5%	
	Georgia	61.2%	
	South Carolina	61.2%	
	Michigan	60.8%	
	Wyoming	59.9%	
	New Jersey	59.9%	
	California	59.6%	
	Utah	59.5%	
	Illinois	59.2%	
	Colorado	59.1%	
	Mississippi	58.7%	
	Arizona	58.1%	
	Florida	58.0%	
LOWER than US; Stat. Significant	Texas	58.2%	*
	Idaho	56.9%	
	New Mexico	56.6%	
	Montana	55.2%	
	Nevada	53.5%	

NOTES:

Higher %'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.

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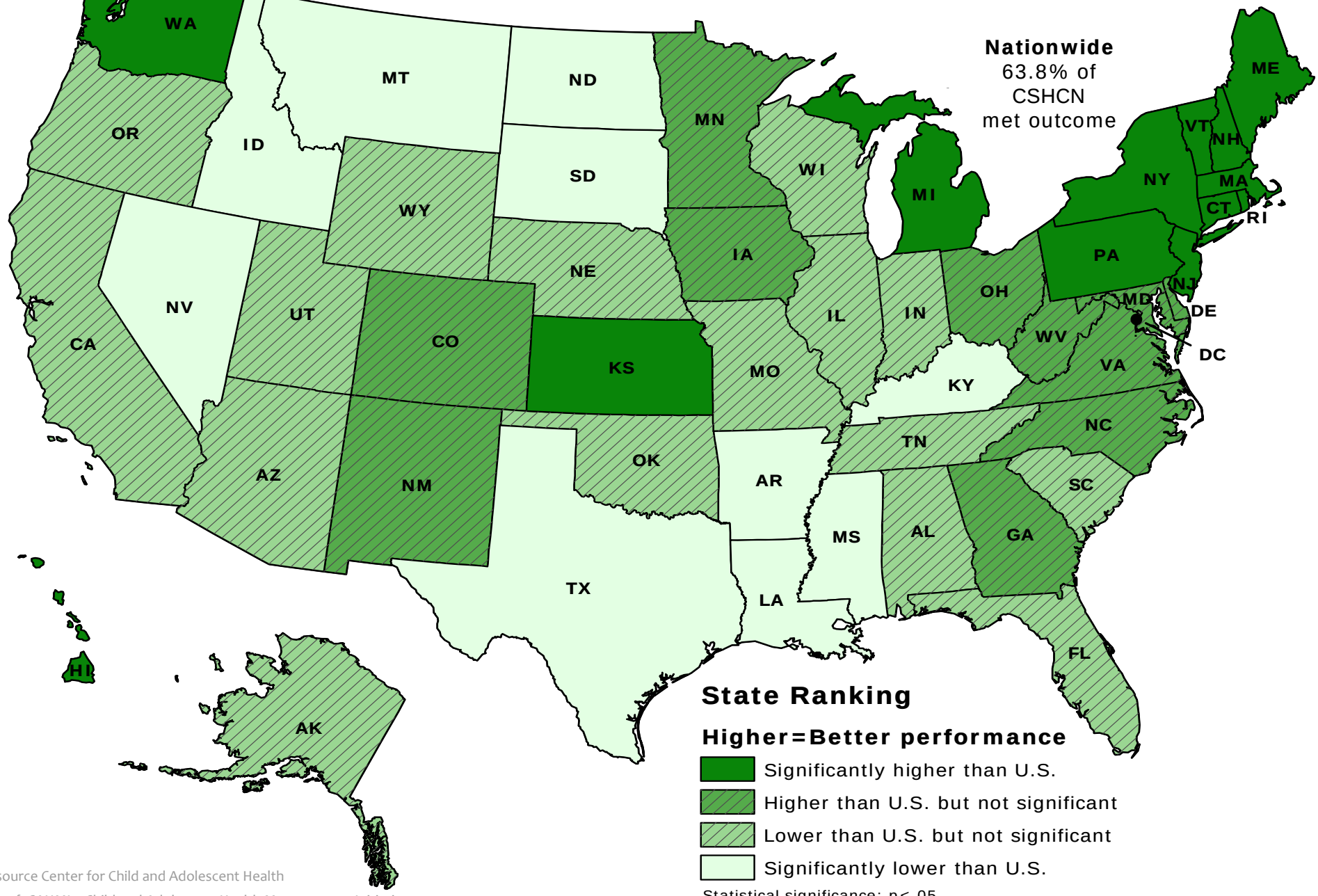
MCHB Core Outcome #4: CSHCN who are screened early and continuously for special health care needs

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		63.8%
HIGHER than US; Statistically Significant	New Hampshire	79.9%
	Massachusetts	75.8%
	Vermont	74.4%
	Rhode Island	74.1%
	New Jersey	71.7%
	Connecticut	70.6%
	Maine	70.1%
	Hawaii	69.7%
	Pennsylvania	69.7%
	Michigan	68.8%
	Kansas	68.5%
	Washington	68.5%
	New York	67.7%
HIGHER than US; Not Significant	Delaware	67.2%
	Maryland	65.7%
	Iowa	65.6%
	Colorado	65.5%
	Georgia	65.3%
	Ohio	65.1%
	North Carolina	65.0%
	Minnesota	64.9%
	West Virginia	64.6%
	Virginia	64.5%
	New Mexico	64.1%
LOWER than US; Not Significant	Wyoming	63.4%
	Nebraska	63.1%
	Indiana	63.1%
	District of Columbia	62.8%
	California	62.7%
	Illinois	62.7%
	Alabama	62.3%
	Missouri	62.1%
	Utah	62.1%
	Wisconsin	62.0%
	Alaska	62.0%
	Oklahoma	61.4%
	Arizona	61.1%
	South Carolina	60.0%
	Oregon	59.9%
	Tennessee	59.8%
	Florida	59.8%
LOWER than US; Statistically Significant	Texas	58.6%
	North Dakota	57.5%
	Kentucky	57.4%
	Idaho	57.2%
	Nevada	56.3%
	South Dakota	56.3%
	Montana	55.7%
	Louisiana	54.3%
	Mississippi	51.4%
	Arkansas	50.3%

NOTES:

Higher %'s = Better performance

Statistical significance: p <.05

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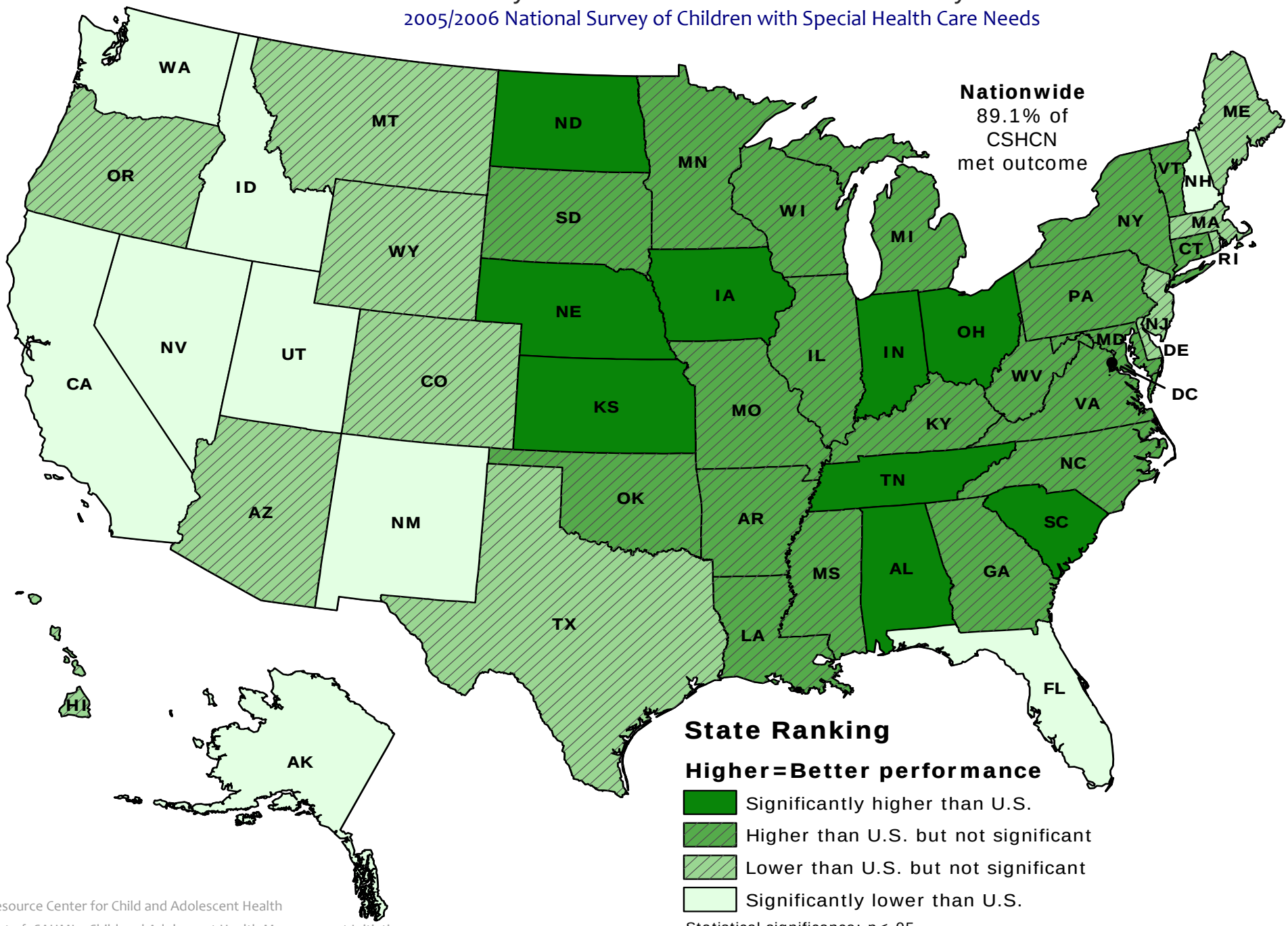
MCHB Core Outcome #5: CSHCN whose services are organized in ways that families can use them easily

2005/2006 National Survey of Children with Special Health Care Needs



MCHB Core Outcome #5: CSHCN whose services are organized in ways that families can use them easily

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		89.1%
HIGHER than US; Statistically Significant	Indiana	94.3%
	Iowa	92.9%
	Kansas	92.5%
	North Dakota	92.3%
	Ohio	92.2%
	Nebraska	91.9%
	Tennessee	91.8%
	South Carolina	91.7%
	Alabama	91.7%
HIGHER than US; Not Significant	Kentucky	91.4%
	Georgia	91.0%
	Mississippi	90.9%
	Michigan	90.9%
	Minnesota	90.7%
	New York	90.6%
	South Dakota	90.4%
	Oklahoma	90.3%
	Missouri	90.1%
	Wisconsin	90.0%
	Illinois	89.8%
	West Virginia	89.7%
	Virginia	89.6%
	Pennsylvania	89.5%
	Connecticut	89.4%
	Louisiana	89.3%
	Maryland	89.3%
	North Carolina	89.3%
	Vermont	89.3%
	Arkansas	89.2%
LOWER than US; Not Significant	District of Columbia	88.8%
	Hawaii	88.8%
	Wyoming	88.8%
	Montana	88.6%
	Oregon	88.3%
	Texas	88.2%
	Delaware	88.1%
	New Jersey	88.0%
	Colorado	87.8%
	Maine	87.6%
	Rhode Island	87.6%
	Massachusetts	87.6%
	Arizona	86.5%
LOWER than US; Statistically Significant	Utah	86.2%
	Idaho	85.9%
	Florida	85.9%
	New Hampshire	85.7%
	New Mexico	85.7%
	Washington	85.4%
	California	85.3%
	Alaska	85.1%
	Nevada	82.6%

NOTES:

Higher %'s = Better performance

Statistical significance: p <.05

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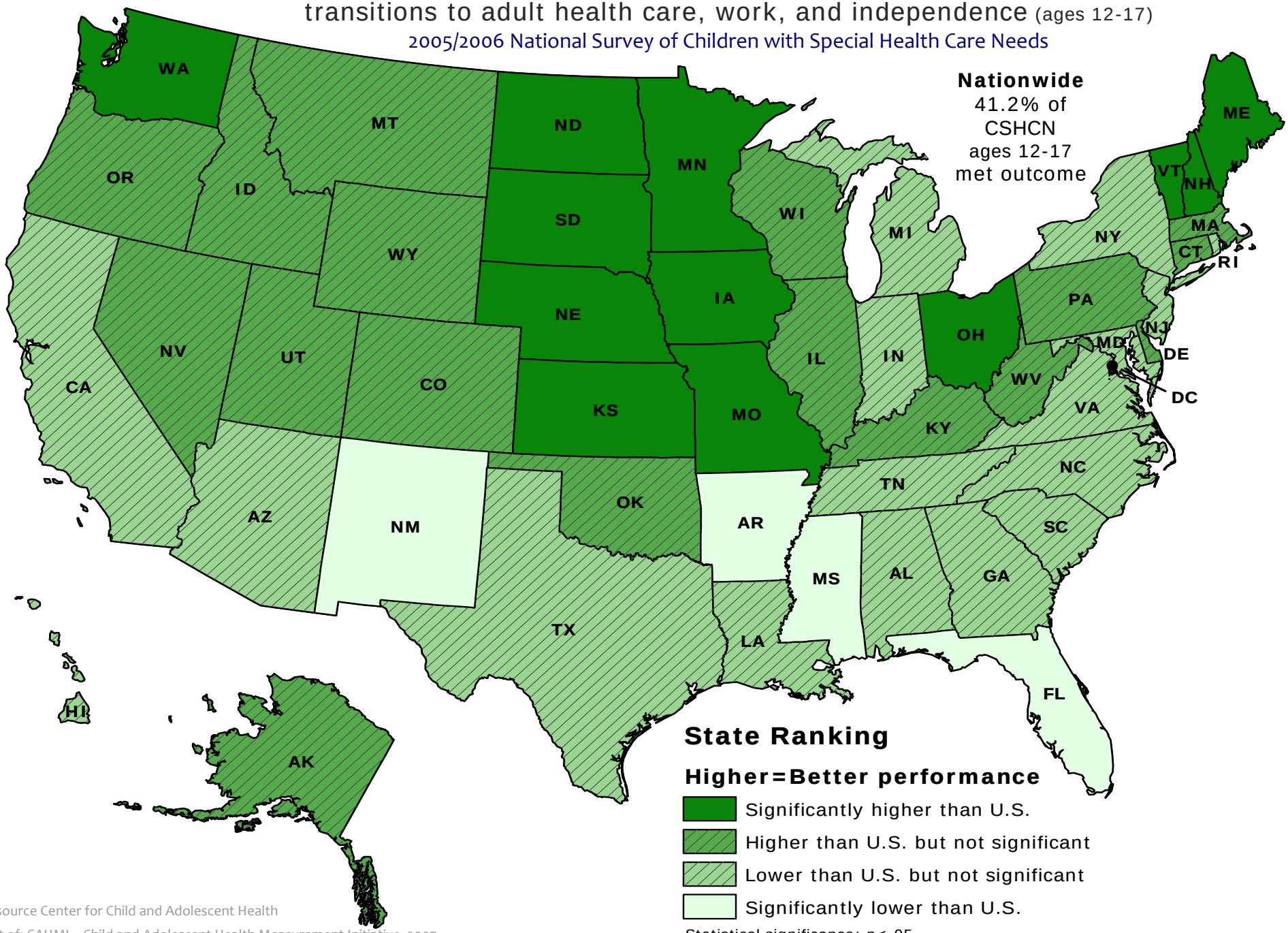
MCHB Core Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence (ages 12-17)

2005/2006 National Survey of Children with Special Health Care Needs



MCHB Core Outcome #6: Youth with special health care needs whose receive the services necessary to make appropriate transitions to adult health care, work, and independence (ages 12-17)

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		**41.2%**
HIGHER than US; Statistically Significant	Missouri	54.4%
	Nebraska	54.4%
	Minnesota	52.9%
	Vermont	52.0%
	New Hampshire	51.6%
	North Dakota	51.2%
	South Dakota	50.6%
	Kansas	50.3%
	Maine	49.0%
	Ohio	48.5%
	Iowa	47.3%
	Washington	47.3%
HIGHER than US; Not Significant	Colorado	47.0%
	Wyoming	47.0%
	Massachusetts	46.6%
	Montana	46.2%
	Pennsylvania	46.0%
	Idaho	45.8%
	Wisconsin	44.5%
	Illinois	44.2%
	Oklahoma	43.7%
	Oregon	43.7%
	Connecticut	43.3%
	Kentucky	42.8%
	Utah	42.5%
	Delaware	42.4%
	Alaska	42.2%
	Nevada	41.7%
	West Virginia	41.3%
LOWER than US; Not Significant	Indiana	41.1%
	Louisiana	40.9%
	Michigan	40.8%
	North Carolina	39.9%
	Tennessee	39.6%
	Arizona	39.4%
	Hawaii	39.4%
	New York	38.4%
	Alabama	38.3%
	New Jersey	37.9%
	Virginia	37.8%
	Rhode Island	37.6%
	Maryland	37.4%
	South Carolina	37.2%
	California	37.1%
	Texas	37.1%
	Georgia	37.0%
LOWER than US; Stat. Significant	Florida	33.8%
	New Mexico	33.7%
	Arkansas	33.1%
	Mississippi	30.9%
	District of Columbia	24.0%

NOTES:

Higher %'s = Better performance

Statistical significance: $p < .05$

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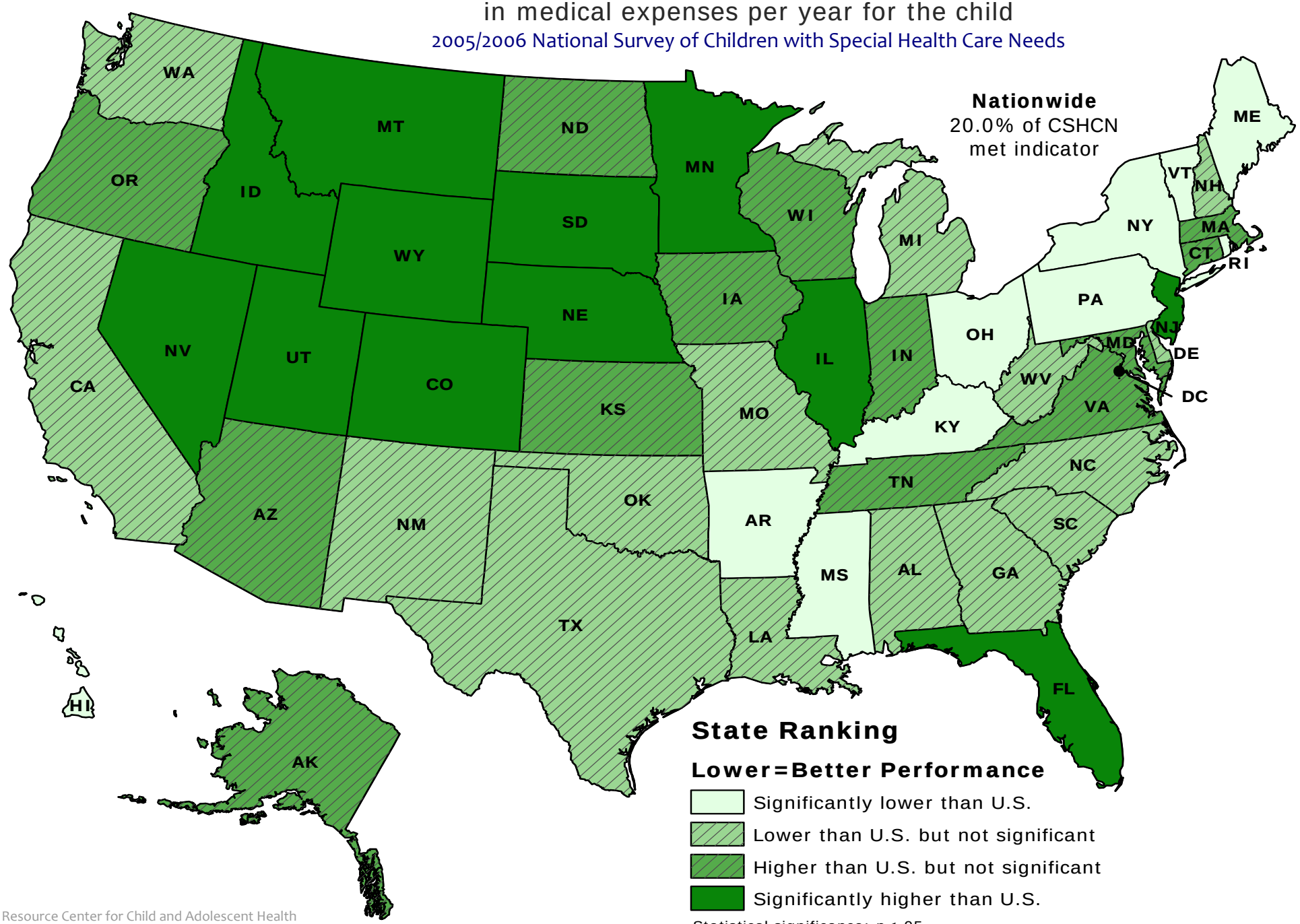
Indicator #12: CSHCN whose families spend $1,000 or more out of pocket in medical expenses per year for the child

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		**20.0%**	
LOWER than US; Statistically Significant	Hawaii	11.1%	
	Rhode Island	12.6%	
	District of Columbia	14.7%	
	Kentucky	15.6%	
	Arkansas	16.2%	
	Vermont	16.3%	
	Mississippi	16.5%	
	Ohio	16.6%	
	New York	16.8%	
	Pennsylvania	16.8%	
	Maine	17.2%	
LOWER than US; Not Significant	Delaware	17.4%	
	Alabama	17.9%	
	California	17.9%	
	West Virginia	18.0%	
	North Carolina	18.0%	
	South Carolina	18.2%	
	Washington	18.6%	
	New Hampshire	18.8%	
	Georgia	18.8%	
	Missouri	19.4%	
	Texas	19.5%	
	Michigan	19.7%	
	Louisiana	19.8%	
	New Mexico	19.9%	
	Oklahoma	19.9%	
HIGHER than US; Not Significant	Oregon	20.0%	
	Indiana	20.1%	
	Wisconsin	20.1%	
	Massachusetts	20.4%	
	Iowa	21.7%	
	North Dakota	21.9%	
	Kansas	21.9%	
	Connecticut	22.1%	
	Arizona	22.2%	
	Tennessee	22.6%	
	Virginia	22.7%	
	Alaska	23.1%	
	Maryland	23.5%	*
HIGHER than US; Statistically Significant	Illinois	23.4%	
	Nevada	23.7%	
	Minnesota	23.8%	
	Florida	23.9%	
	South Dakota	23.9%	
	Nebraska	24.6%	
	Idaho	25.4%	
	New Jersey	25.7%	
	Montana	26.2%	
	Utah	26.4%	
	Colorado	27.7%	
	Wyoming	29.2%	

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.

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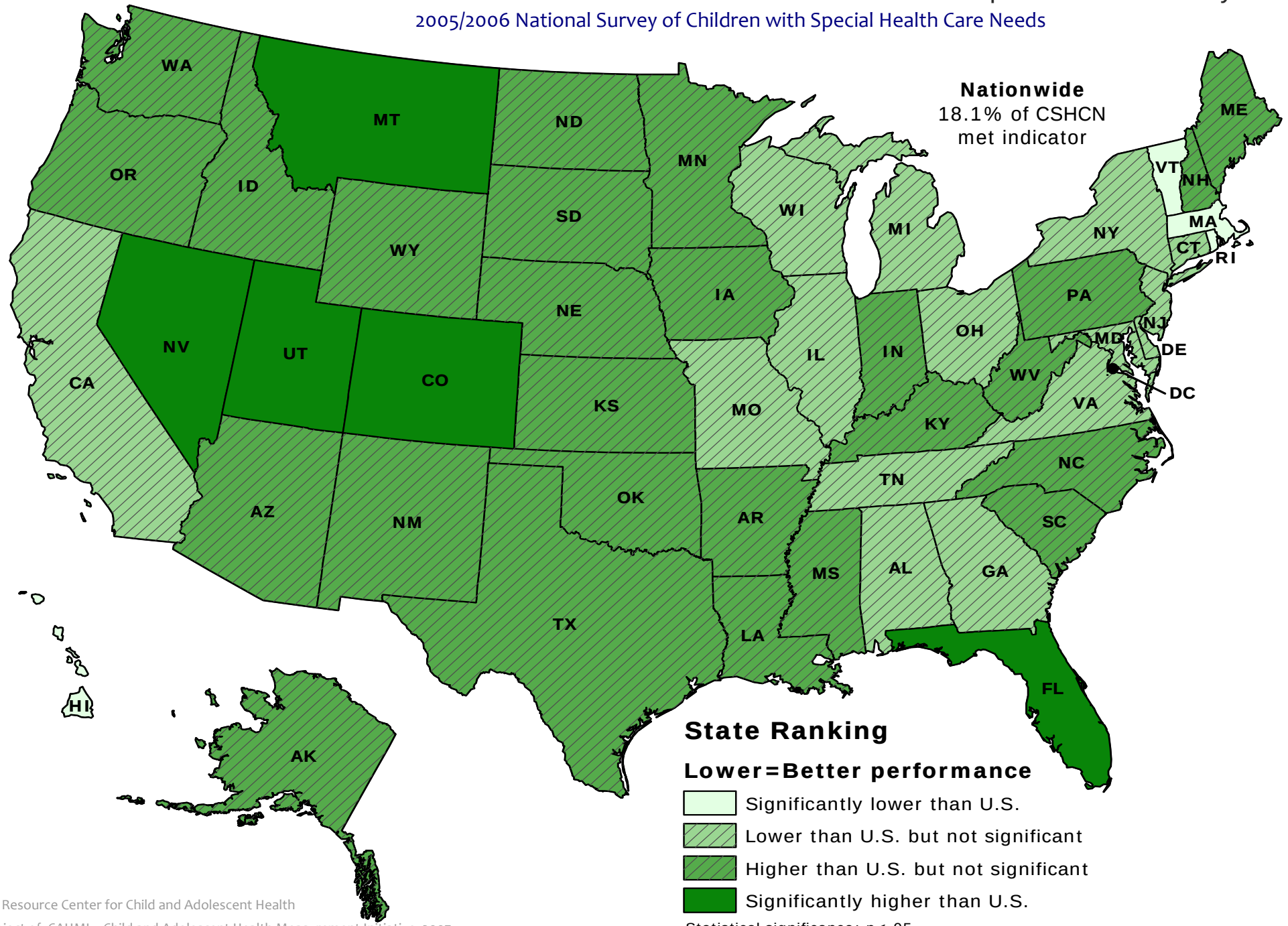
Indicator #13: CSHCN whose conditions cause financial problems for family

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		**18.1%**
LOWER than US; Stat. Significant	Hawaii	11.0%
	Rhode Island	14.0%
	District of Columbia	14.8%
	Massachusetts	15.0%
	Vermont	15.2%
LOWER than US; Not Significant	California	15.5%
	Alabama	15.5%
	Missouri	15.5%
	Connecticut	15.7%
	Ohio	16.0%
	Michigan	16.1%
	Georgia	17.1%
	Wisconsin	17.1%
	Delaware	17.4%
	New Jersey	17.4%
	Virginia	17.4%
	Maryland	17.5%
	New York	17.8%
	Illinois	17.9%
	Tennessee	17.9%
HIGHER than US; Not Significant	Oregon	18.1%
	Pennsylvania	18.2%
	West Virginia	18.2%
	North Carolina	18.3%
	Minnesota	18.3%
	Alaska	18.4%
	North Dakota	18.5%
	New Hampshire	18.6%
	Nebraska	18.7%
	Texas	18.8%
	Kentucky	18.9%
	Washington	19.1%
	Iowa	19.3%
	Maine	19.3%
	Mississippi	19.4%
	Idaho	19.5%
	Louisiana	19.8%
	Oklahoma	19.8%
	South Dakota	19.9%
	Arizona	20.2%
	New Mexico	20.4%
	South Carolina	20.5%
	Arkansas	20.5%
	Indiana	21.1%
	Wyoming	21.3%
	Kansas	21.4%
HIGHER than US; Stat. Significant	Florida	21.9%
	Utah	22.1%
	Nevada	23.2%
	Colorado	23.9%
	Montana	25.3%

NOTES:

Lower %'s = Better performance

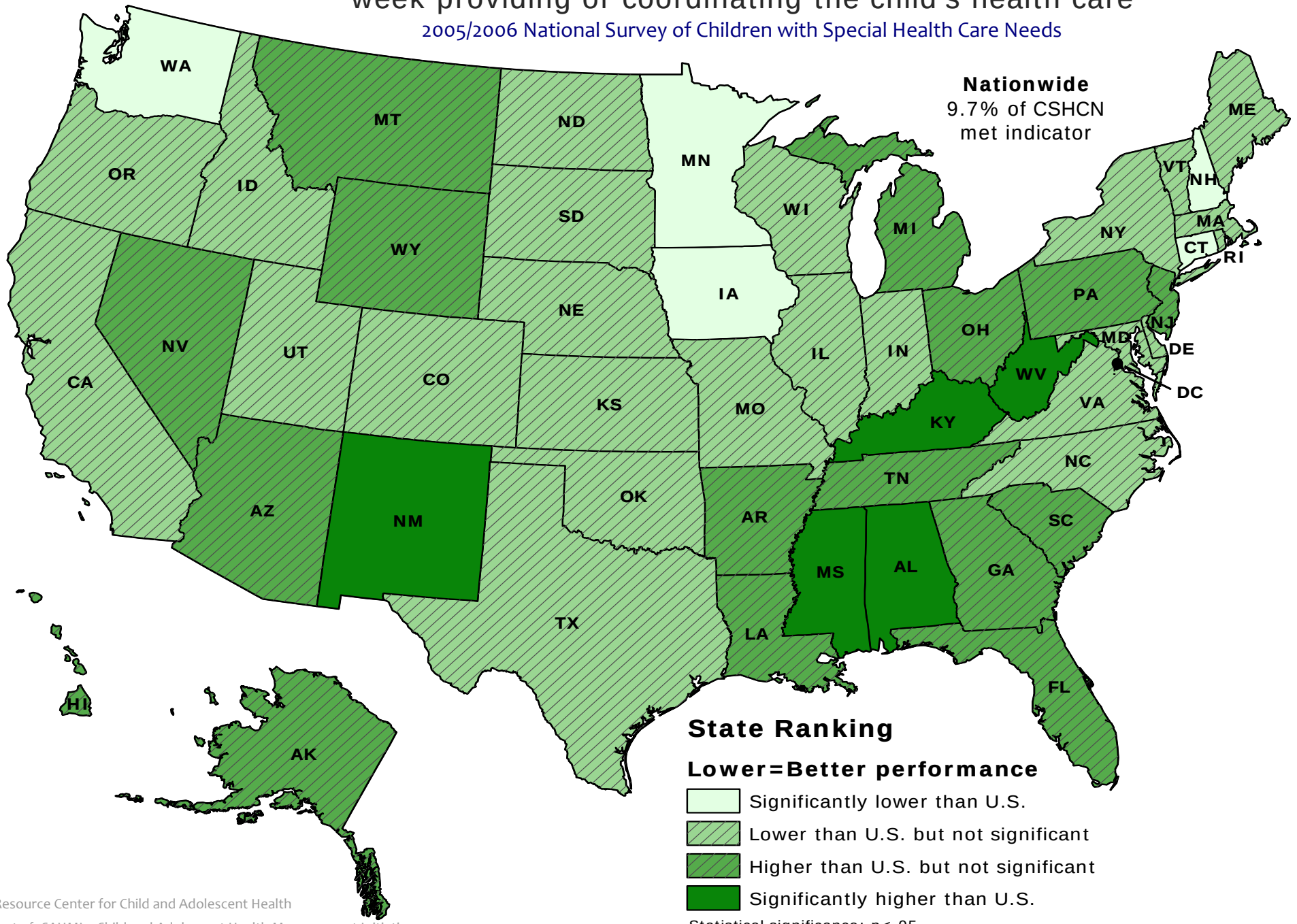
Statistical significance: p <.05

Data Resource Center for Child & Adolescent Health
Your Data… Your story

www.childhealthdata.org

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

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		9.7%
LOWER than US; Stat. Significant	New Hampshire	6.1%
	Iowa	6.2%
	Washington	6.3%
	Minnesota	7.2%
	Connecticut	7.5%
LOWER than US; Not Significant	Utah	7.8%
	Kansas	8.0%
	Massachusetts	8.0%
	Virginia	8.1%
	Maryland	8.1%
	Vermont	8.2%
	Delaware	8.4%
	Colorado	8.4%
	Illinois	8.5%
	New York	8.6%
	Idaho	8.6%
	Nebraska	8.6%
	Oregon	8.7%
	South Dakota	8.8%
	Oklahoma	9.0%
	Missouri	9.0%
	North Dakota	9.1%
	California	9.1%
	Maine	9.2%
	Texas	9.4%
	Indiana	9.4%
	North Carolina	9.6%
	Rhode Island	9.6%
	Wisconsin	9.6%
HIGHER than US; Not Significant	Georgia	9.9%
	Florida	10.0%
	Ohio	10.0%
	Alaska	10.5%
	South Carolina	10.9%
	Pennsylvania	11.0%
	Michigan	11.0%
	Tennessee	11.1%
	Hawaii	11.3%
	Arizona	11.3%
	Nevada	11.8%
	Wyoming	12.0%
	Louisiana	12.2%
	Arkansas	12.3%
	Montana	12.3%
	New Jersey	12.5%
	District of Columbia	12.7%
HIGHER than US; Stat. Significant	New Mexico	13.0%
	Mississippi	14.0%
	Alabama	14.0%
	West Virginia	14.3%
	Kentucky	14.6%

NOTES:

Lower %'s = Better performance

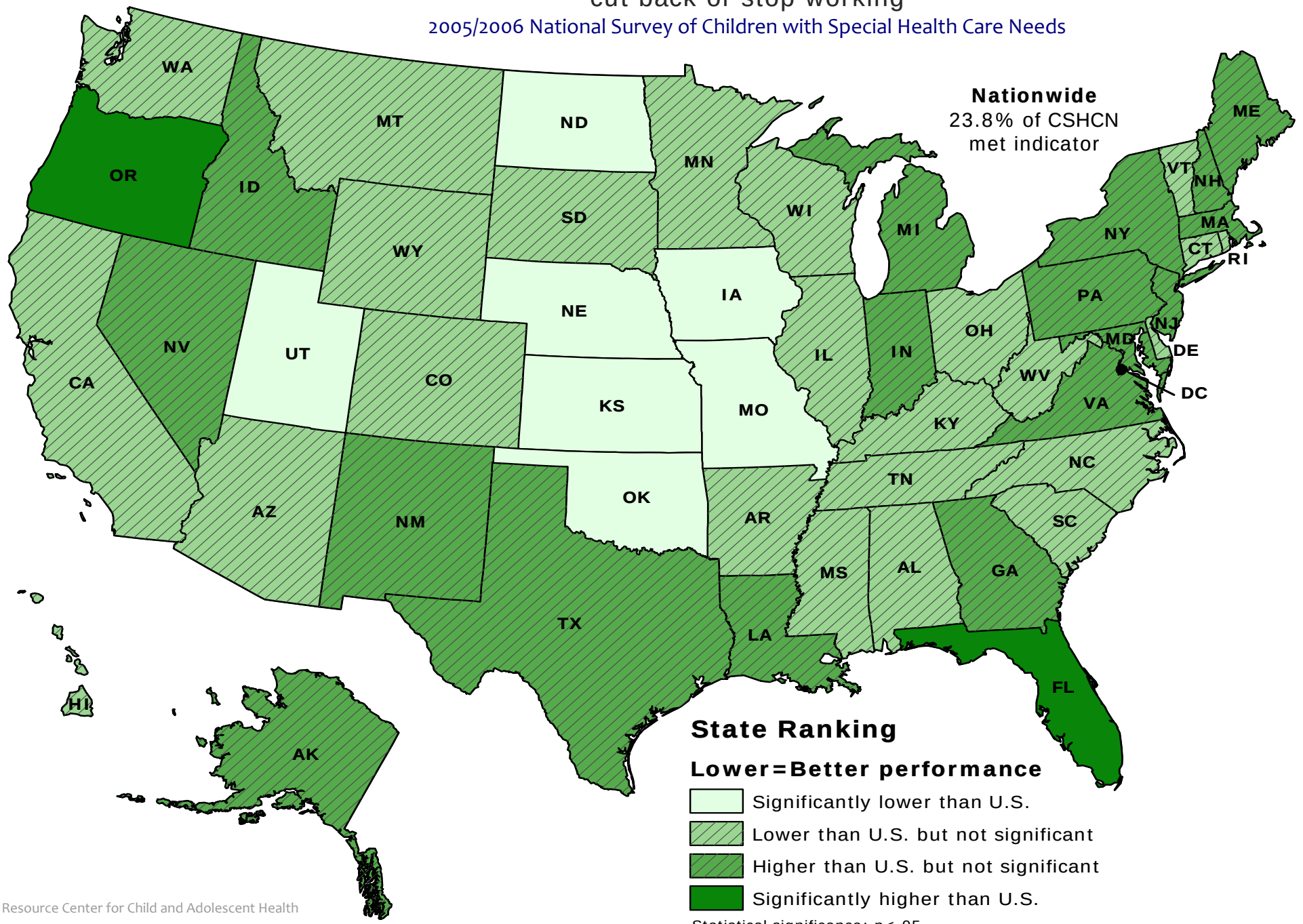
Statistical significance: p <.05

Data Resource Center for Child & Adolescent Health
Your Data… Your story

www.childhealthdata.org

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

2005/2006 National Survey of Children with Special Health Care Needs



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

2005/2006 National Survey of Children with Special Health Care Needs

US Prevalence		23.8%
LOWER than US; Stat. Significant	Iowa	17.0%
	Nebraska	17.2%
	North Dakota	18.1%
	Oklahoma	18.9%
	Missouri	19.5%
	Utah	19.9%
	Kansas	20.1%
LOWER than US; Not Significant	Colorado	20.6%
	Arkansas	20.7%
	South Dakota	21.0%
	Minnesota	21.1%
	West Virginia	21.1%
	Delaware	21.2%
	Wisconsin	21.7%
	Illinois	21.7%
	South Carolina	21.8%
	Kentucky	21.8%
	Connecticut	21.9%
	Montana	22.0%
	Hawaii	22.1%
	North Carolina	22.2%
	Alabama	22.5%
	Vermont	22.5%
	Washington	22.7%
	Tennessee	22.8%
	Wyoming	22.8%
	Rhode Island	23.0%
	Mississippi	23.1%
	Arizona	23.1%
	Ohio	23.4%
	California	23.7%
HIGHER than US; Not Significant	Georgia	23.8%
	Indiana	24.3%
	Pennsylvania	24.4%
	Maine	24.6%
	Massachusetts	24.7%
	Idaho	24.7%
	Virginia	24.9%
	New Mexico	25.1%
	Texas	25.3%
	Louisiana	25.3%
	New Jersey	25.5%
	New Hampshire	25.5%
	District of Columbia	25.6%
	Michigan	25.6%
	New York	25.7%
	Maryland	25.8%
	Alaska	25.9%
	Nevada	27.2%
†	Oregon	29.2%
	Florida	30.0%

† HIGHER than US; Statistically Significant

NOTES:

Lower %'s = Better performance

Statistical significance: p <.05

APPENDIX D

CSHCN Screener

CAHMI
The Child and Adolescent Health Measurement Initiative

CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) SCREENER©

Developed in Collaboration with:

AHRQ

NCQA

ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

FAMILY VOICES®

NESERVE.ORG

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 that was coordinated through FACCT—Foundation for Accountability during the development of the CSHCN Screener. The CAHMI is now located at the Oregon Health & Science University. 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, the National Survey on Children's Health and as part of 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.

[1]McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics.* 1998; 102:137-140.
[2]CAHPS® is a registered trademark of the Agency for Healthcare Research and Quality (AHRQ).
[3]HEDIS® 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 Pediatric*s. 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 Pediatric*s. 2002;2:29-37.

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

Debra Read, MPH
Senior Research Associate
CAHMI – Child & Adolescent Health Measurement Initiative
Telephone: 503.494.1276
E-mail: readd@ohsu.edu
www.cahmi.org

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 *e-mail (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.

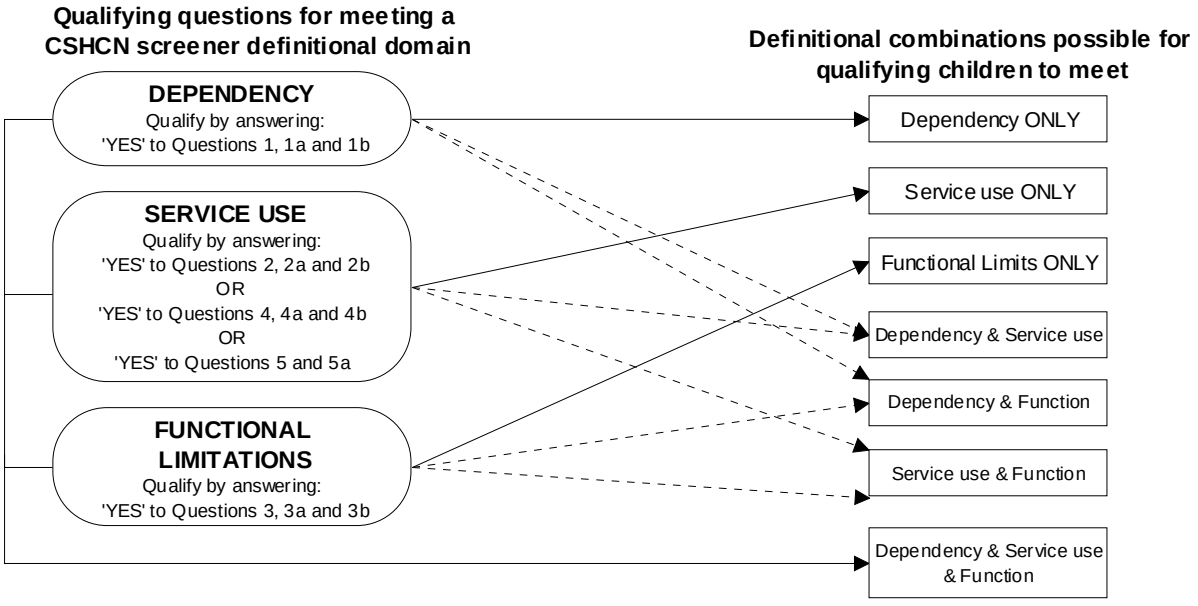
**NOTE: CSHCN screener question 5 is a two-part question. Both parts must be answered "yes" to qualify.*

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.

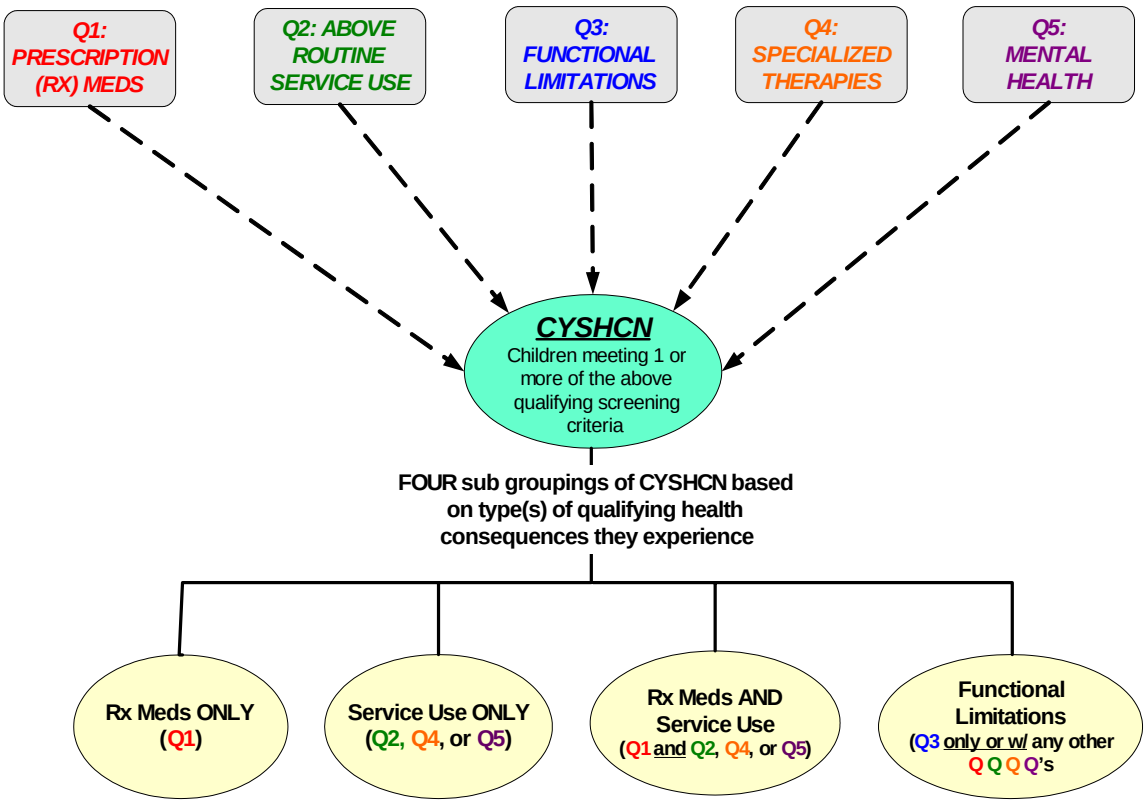
The CSHCN Screener© has three "definitional domains:"

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*).



MODEL FOR CREATING MUTUALLY-EXCLUSIVE SUBGROUPS OF CSHCN ACCORDING TO THEIR NEEDS FOR SERVICES AND FUNCTIONING



ACKNOWLEDGEMENTS

The following people participated in the Child and Adolescent Health Measurement Initiative (CAHMI) Living with Illness Task Force and contributed to the development and/or testing of the Children with Special Health Care Needs (CSHCN) Screener©:

Christina Bethell, Child and Adolescent Health Measurement Initiative (*CAHMI)*

Stephen Blumberg, *Centers for Disease Control and Prevention*

Julie Brown, *RAND*

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Paul Cleary, *Harvard Medical School*

Christine Crofton, *Agency for Healthcare Research and Quality*

Susan Epstein, *New England SERVE*

Jack Fowler, *University of Massachusetts*

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Maxine Hayes, *Washington State Department of Health*

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Charles Homer, *National Initiative for Child Healthcare Quality, Institute for Healthcare Improvement*

Alice Lind, *Washington State Medical Assistance Administration*

Margaret McManus, *Maternal & Child Health Policy Research Center*

Merle McPherson, *Federal Maternal and Child Health Bureau*

John Neff, *Center for Children with Special Needs*

Paul Newacheck, *University of California, San Francisco*

James Perrin, *Massachusetts General Hospital*

Debra Read, Child and Adolescent Health Measurement Initiative (*CAHMI)*

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Nora Wells, *Family Voices*

The Child and Adolescent Health Measurement Initiative
www.cahmi.org

APPENDIX E

Medical Home Measure

2005-2006 NS-CSHCN Items

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

2005/06 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
SECTION 4: ACCESS TO CARE -- UTILIZATION AND UNMET NEEDS	
C4q0a Is there a place that (S.C.) USUALLY goes when (he/she) is sick or you need advice about (his/her) health? *If Yes to C4q0a:* **C4q0b** Is it a doctor's office, emergency room, hospital outpatient department, clinic, or some other place?	(1) YES (2) THERE IS NO PLACE **[SKIP TO C4Q0D]** (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW **[SKIP TO C4Q0D]** (7) REFUSED **[SKIP TO C4Q0D]** (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]**
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? *If Yes to C4q0d:* **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?	(1) YES (2) THERE IS NO PLACE **[SKIP TO C4Q02A]** (3) THERE IS MORE THAN ONE PLACE (6) DON'T KNOW **[SKIP TO C4Q02A]** (7) REFUSED **[SKIP TO C4Q02A]** (1) YES **[SKIP TO C4Q02A]** (2) NO (6) DON'T KNOW **[SKIP TO C4Q02A]** (7) REFUSED **[SKIP TO C4Q02A]**
C4q02 What kind of place does (S.C.) go to most often when (he/she) needs routine preventive care?	(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

2005/06 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 **[SKIP TO C4Q03]** (6) DON'T KNOW **[SKIP TO C4Q03]** (7) REFUSED **[SKIP TO C4Q03]**
SECTION 5: CARE COORDINATION	
C5q11 During the past 12 months, did (S.C.) need a referral to see any doctors or receive any services? *If Yes to C5q11:* **C4q07** Was getting referrals a big problem, a small problem, or not a problem?	(1) YES (2) NO **[SKIP TO C5Q12]** (6) DON'T KNOW **[SKIP TO C5Q12]** (7) REFUSED **[SKIP TO C5Q12]** (1) Big problem (2) Small problem (3) Not a problem (6) DON'T KNOW (7) REFUSED
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? *If Yes to C5q17:* **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 **[SKIP TO C5Q10]** (6) DON'T KNOW **[SKIP TO C5Q10]** (7) REFUSED **[SKIP TO C5Q10]** (1) Never (2) Sometimes (3) Usually (6) DON'T KNOW (7) REFUSED
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

2005/06 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?	(1) YES (2) NO **[SKIP TO C6Q02]** (6) DON'T KNOW **[SKIP TO C6Q02]** (7) REFUSED **[SKIP TO C6Q02]**
If Yes to C5q05: **C5q06** Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?	(1) Very satisfied (2) Somewhat satisfied (3) Somewhat dissatisfied (4) Very dissatisfied (6) DON'T KNOW (7) REFUSED
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

2005/06 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?	(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? *If Yes to S5q13:* **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?	(1) YES **[SKIP TO S5Q13A]** (2) NO **[SKIP TO C6Q07]** (6) DON'T KNOW **[SKIP TO C6Q07]** (7) REFUSED **[SKIP TO C6Q07]** (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 2005/06 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. *2005/06 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. *2005/06 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. *2005/06 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. *2005/06 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. *2005/06 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.