

Health care access data for children and adolescents from the National Survey of Children with Special Health Care Needs and the National Survey of Children's Health*

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Abstract

Standardized data that examine health care access for children and adolescents can be used to inform policymakers, evaluate programs, and monitor disparities among subgroups over time. Two nationally representative surveys provide these data for children and children with special health care needs aged 0 to 17 years old: the National Survey of Children with Special Health Care Needs (NS-CSHCN), and the National Survey of Children's Health (NSCH). Both surveys were sponsored by the Federal Maternal and Child Health Bureau and conducted by the National Center for Health Statistics using the State and Local Area Integrated Telephone Survey (SLAITS) mechanism, and both provide multiple data points over time. Several examples are presented to demonstrate the analytic utility of SLAITS health care access and utilization variables and how they can be used to support trend analysis on health care access and utilization for children at the national and state levels.

Key Words: Access to care, Children, Children with Special Health Care Needs, National Survey of Children's Health, National Survey of Children with Special Health Care Needs.

1. Introduction

Access to care is the availability and use of a variety of health care services such as mental, medical, and dental services; prescription medications; medical supplies and equipment; and special therapies. Whether these services can be accessed efficiently and whether they can be culturally sensitive, family centered, and comprehensive can greatly impact the use of health care services by families. A major factor associated with improving or impeding the use of health care services is having consistent and adequate health insurance. Not being able to access health care services for children can result in an increased number of unmet health care needs, poor overall health, visits to the emergency room, and an increased burden on the children and families (Honberg, McPherson, Strickland, Gage, & Newacheck, 2005; M. D. Kogan, Newacheck, Honberg, & Strickland, 2005).

This paper highlights access to health care data for children and adolescents from two large national surveys conducted using the State and Local Area Integrated Telephone

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Surveys (SLAITS) platform and provides examples of how SLAITS data can be used to produce national and state prevalence estimates of access to health care among children over time.

2. Methods

2.1 Data Sources

The National Center for Health Statistics (NCHS) uses SLAITS, a data collection platform, to gather cross-sectional data using random digit dial telephone surveys to produce national and state-level estimates to address various program and policy needs (National Center for Health Statistics, 2009a). The National Survey of Children's Health (NSCH) and the National Survey of Children with Special Health Care Needs (NS-CSHCN) are conducted by NCHS using the SLAITS platform and sponsored by the Federal Maternal and Child Health Bureau (MCHB). They collect information exclusively on children aged 0 to 17 (Blumberg SJ, Foster EB, Fraiser AM, & ; Blumberg SJ, et al., 2005; Blumberg SJ, et al., 2008; Blumberg, et al., 2003). Each survey collects data from all 50 states and the District of Columbia and has been implemented twice. The purpose of the NSCH is to produce standardized, comparable national and state estimates of numerous child healthcare and well-being indicators for all children. The NSCH was first conducted from January 2003 to July 2004 ("NSCH 2003", sample size = 102,353), and it was repeated from April 2007 to July 2008 ("NSCH 2007", sample size = 91,642). In contrast, the NS-CSHCN collects detailed national and state-level data to examine the prevalence and characteristics of children with special health care needs (CSHCN). The first NS-CSHCN ("NS-CSHCN 2001") was conducted in October 2000 to April 2002 and the second ("NS-CSHCN 2005-2006") from April 2005 to February 2007 (sample size = 38,866 in and sample size = 40,804 respectively). The respondent in each survey was an adult aged 18 years or older who was knowledgeable about the health and health care of the children and who lived in the household at the time of the interview. Each survey was conducted in English with the option of doing the survey in Spanish. Three of the four surveys could be conducted in several other languages (Blumberg SJ, et al.; Blumberg SJ, et al., 2005; Blumberg SJ, et al., 2008; Blumberg, et al., 2003).

2.2 Key Definition and Analysis Variables

2.2.1 *Children with special health care needs*

Children who have a special health care needs are defined by MCHB as "Children at increased risk of chronic physical, developmental, or emotional conditions and children who require health and related service of a type or amount beyond that required by children generally" (McPherson, et al., 1998). The national prevalence of special health care needs among the US child population is approximately 13% to 14% (Blumberg SJ, et al., 2008; Blumberg, et al., 2003).

2.2.2 *CSHCN Screener*

CSHCN are identified using the CSHCN Screener (Bethell CD, et al., 2002). NS-CSHCN and NSCH respondents were asked five main stem consequence-based questions about

each child in the household. NSCH respondents were asked these questions about one randomly selected child. The stem questions examined the child's need for or use of prescription medication(s); need for or use of medical, mental, or educational services; any functional limitation(s); need for or receipt of special therapy; and need for or receipt of treatment or counselling. A child is classified as a CSHCN if he/she has at least one of the characteristics which has lasted or is expected to last for 12 months or longer (Bethell, Read, Blumberg, & Newacheck, 2007).

2.2.3 Access to care items available in the NSCH & NS-CSHCN

The access to care items presented here are extracts from each survey's chartbook, which can be found on the SLAITS website. (National Center for Health Statistics, 2009b; U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau, 2004, 2005, 2007, and forthcoming).

2.2.3.1 Health insurance coverage

The following health insurance indicators are available in most SLAITS surveys to examine coverage patterns: 1) health insurance status, e.g., being insured or not insured at the time of the interview; 2) type of health insurance, categorized as private only, public only, both private and public, other comprehensive insurance, or uninsured; 3) consistency of health insurance (the child had no gaps in health insurance coverage throughout the past year from date of interview); 4) adequacy of current health insurance coverage; and 5) out-of-pocket medical expenditures paid by the child's family (to assess annual expenditures that may not be fully covered by the child's insurance plan). Adequate health coverage is a derived variable, created from three questions that are on most SLAITS surveys: whether the plan allowed the child to see needed health care provider(s); whether the plan offered benefits and covered services that met the child's needs; and whether the costs not covered by the insurance plan were reasonable.

2.2.3.2 Health care service use

In both iterations of the NS-CSHCN, questions were asked about receipt of various services and products, such as: prescription drugs; preventive routine medical or dental care; specialty care; eyewear/vision care; mental health care; various therapies; disposable and durable medical supplies/equipment; hearing aids/hearing care; home health care; mobility aids/devices; substance abuse treatment; and communication aids/devices. Responses are aggregated to create a derived health indicator representing the percentage of CSHCN with unmet health care service and product needs (U.S. Department of Health and Human Services, et al., 2004, 2007).

Both iterations of the NSCH included questions on the use of routine preventive medical and dental care services and on whether the child had visited the emergency room (and if so, how many times). Questions were also asked about the need for and receipt of mental/medical care services and prescription medications (U.S. Department of Health and Human Services, et al., 2005, and forthcoming).

2.2.3.3 *Medical home*

A medical home is defined by the American Academy of Pediatrics as “primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective” (Blumberg SJ, et al., 2008; Blumberg, et al., 2003). To assess whether a child received primary health care services within a medical home, respondents were asked about provision of care for five main subcomponents: 1) having a usual source of care, which was the place, if any, in which the child received sick or wellness care; 2) having a personal doctor(s) or nurse(s) who were familiar with the health and history of that child; 3) having problems obtaining a referral for their child’s care; 4) receiving care coordination, which included effective communication among health care providers and the family on care arrangements; and 5) receipt of family centered care, which evaluated the availability of support services and the sensitivity of the health care provider to the child’s family and values. Researchers should note that medical home subcomponent variables may have changed in order to integrate new research findings (for example, the 2003 NSCH did not include questions on usual source of care) (Blumberg SJ, et al.; Blumberg SJ, et al., 2005; Blumberg SJ, et al., 2008; Blumberg, et al., 2003).

2.3 Description of Analytic Examples

For all analytic examples described here, questions were first evaluated for comparability between surveys. The first analytic example compares access to care items from NSCH or NS-CSHCN for all children and for CSHCN (Tables 1 & 2). The second example shows how two state-level health insurance indicators can be compared (Figures 1-4). The third demonstrates trend analyses across all surveys for two access to care indicators stratified by demographic variables (Figures 5–11).

The primary independent variables used to stratify each access to care indicator were: 1) the child’s age in years at the time of the interview, categorized as 0 to 5, 6 to 11, and 12 to 17; 2) total family income in the year prior to the date of interview, categorized as poor (<100% of Federal poverty level), near poor ($\geq 100\%$ and <200% of the Federal poverty level), and not poor ($\geq 200\%$ of the Federal poverty level); and 3) the child’s race and ethnicity, categorized as non-Hispanic white, non-Hispanic black, Hispanic, and non-Hispanic multiracial (non-Hispanic with other races/ethnicities were not used in these examples).

Data were analyzed with SAS 9.2 and SUDAAN10 to account for the complex sample designs of each survey (Research Triangle Institute, 2008; SAS Institute Inc., 2008). The statistical significance of differences between estimates was assessed using two-sided significance tests at the 0.05 level.

3. Results

3.1 Access to Care (NSCH & NS-CSHCN)

The following shows how access to care estimates can be examined within each survey. Table 1 compares access to care indicators between the 2003 and 2007 NSCH. Significant increases in public health insurance coverage (27.7% vs. 29.1%) and having a

personal doctor or nurse (83.3% vs. 92.2%) were observed. There was also a significant increase in the percent of all children with public health insurance coverage (27.7% vs. 29.1%). For CSHCN, there was a significant increase in the percent of children who had a personal doctor or nurse (90.0% vs. 94.7%). For both the NSCH 2003 and NSCH 2007, CSHCN have higher estimates for each indicator than all children, except for: mental health care counselling and adequate health insurance coverage and its three components.

Table 1: Selected measures of access to healthcare for all children and CSHCN, aged 0-17, by survey year; National Survey of Children's Health 2003 & 2007.

<i>Access to Health Care Indicators</i>	<i>Percent (Standard Error)</i>				<i>Percent (Standard Error)</i>			
	<i>2003</i>				<i>2007</i>			
	<i>All Children</i>		<i>CSHCN</i>		<i>All Children</i>		<i>CSHCN</i>	
	<i>(n=102,353)</i>	<i>(n=18,578)</i>			<i>(n=91,642)</i>	<i>(n=18,352)</i>		
Percent with any kind of health care coverage	91.2	(0.17) ^c	94.8	(0.30)	90.9	(0.27) ^d	93.9	(0.48)
Percent with public health insurance coverage	27.7	(0.27) ^{ac}	34.2	(0.66)	29.1	(0.40) ^d	35.7	(0.86)
Percent with consistent health insurance coverage	85.1	(0.21) ^c	87.4	(0.47)	84.9	(0.33) ^d	87.7	(0.64)
Percent with adequate health insurance	76.5	(0.38) ^d	70.6	(0.89)
Health insurance usually or always meets child's needs	92.8	(0.24) ^d	90.2	(0.58)
Uncovered costs are usually or always reasonable	81.7	(0.34) ^d	77.3	(0.82)
Health insurance usually or always allow child to see needed health care providers	94.9	(0.22) ^d	92.5	(0.56)
Percent who needed & received mental health care counselling of some type (ages 2-17 yrs).	59.0	(1.15)	60.9	(1.22)	60.0	(1.49)	61.7	(1.55)
Percent with a personal doctor or nurse	83.3	(0.23) ^{ac}	90.0	(0.42) ^b	92.2	(0.23) ^d	94.7	(0.41)
Percent with a usual source of care when sick	93.1	(0.25) ^d	94.8	(0.50)

^a Estimates for children in NSCH, 2003 compared with NSCH, 2007 differ significantly at the 0.05 level

^b Estimates for CSHCN in NSCH, 2003 compared with NSCH, 2007 differ significantly at the 0.05 level

^c All children compared to CSHCN in NSCH, 2003 differ significantly at the 0.05 level adjusted for covariation

^d All children compared to CSHCN in NSCH, 2007 differ significantly at the 0.05 level adjusted for covariation

... Variable was not included in NSCH 2003

n = sample size

Data Source: NSCH, 2003 & NSCH, 2007

Table 2 compares access to care for CSHCN in 2001 and 2005-2006. In 2005-2006, CSHCN were significantly more likely than CSHCN in 2001 to be currently insured; have public health insurance coverage; have insurance that usually or always met their needs; have insurance that usually or always allowed them to see needed health care providers; have a usual source of care when sick; have a personal doctor or nurse; and were more likely to have higher family expenditures to pay for out-of-pocket costs. CSHCN in 2005-2006 were less likely, as compared to CSHCN in 2001, to have any unmet health care need, be without insurance at some point in the past year; and have reasonable costs for services not covered by health insurance.

Table 2: Selected measures of access to healthcare for CSHCN, aged 0-17, by survey year; National Survey of Children with Special Health Care Needs, 2001 and 2005-2006.

<i>Access to Health Care Indicators</i>	<i>Percent (Standard Error)</i>			
	<i>2001</i> <i>(n=38,866)</i>		<i>2005-2006</i> <i>(n=40,634)</i>	
CSHCN without insurance at some point during the past year	11.6	(0.34)	8.8	(0.24) ^a
CSHCN with any kind of health insurance at the time of the survey	94.8	(0.21)	96.5	(0.15) ^a
CSHCN with public insurance coverage	21.6	(0.41)	28.0	(0.40) ^a
Of currently insured CSHCN with coverage that is adequate	66.2	(0.47)	60.0	(0.43) ^a
Current health insurance usually or always meets the needs of CSHCN	85.5	(0.36)	87.3	(0.30) ^a
Uncovered costs by current health insurance are usually or always reasonable	71.6	(0.45)	64.2	(0.42) ^a
Current health insurance usually or always allows CSHCN to see needed health care providers	87.8	(0.36)	90.7	(0.27) ^a
CSHCN with any unmet needs for specific health care services	17.7	(0.41)	15.2	(0.32) ^a
CSHCN with a usual source of care when sick	90.7	(0.26)	94.3	(0.21) ^a
CSHCN with a personal doctor or nurse	89.0	(0.32)	93.5	(0.22) ^a
CSHCN whose families pay more than \$1000 per year out-of-pocket for child's medical expenses	11.2	(0.29)	20.0	(0.32) ^a

^a Estimates for CSHCN in NS-CSHCN, 2001 compared with NS-CSHCN, 2005-2006 differ significantly at the 0.05 level
n = sample size

Data Source NS-CSHCN, 2001 & NS-CSHCN, 2005-2006

3.2 Comparison of Two Health Insurance Indicators by State, NSCH & NS-CSHCN

The following results are examples of how changes at the state level can be analyzed over time with SLAITS survey data. Figures 1 and 2 show US maps that depict the magnitude and direction of statistically significant differences in state-level estimates for all children from the 2003 and 2007 NSCH for two health insurance indicators: children with current health insurance coverage, and children with consistent insurance coverage during the past year. Figures 3 and 4 show similar maps for CSHCN, using data from the 2001 and 2005-2006 NS-CSHCN. Actual state-level estimates are available in published reports

(National Center for Health Statistics, 2009b; U.S. Department of Health and Human Services, et al., 2004, 2005, 2007, and forthcoming).

States highlighted in red depict a statistically significant increase in insurance coverage between 2003 and 2007. If the state is highlighted in blue, a statistically significant decrease in insurance coverage occurred from 2003 and 2007. States not highlighted in any color had no significant differences over time.

The observed change in the national estimate for current health insurance among all children between 2003 and 2007 was not statistically significant. This is reflected in the state-level map (Figure 1), which shows very few statistically significant differences. Although the national estimates of the percent consistently insured were also not significantly different over time, differences are noted at the state level for this indicator (Figure 2). Notably, Arkansas, Illinois, Massachusetts, Oklahoma, and West Virginia showed significant increase in consistent health coverage. However, these gains were counterbalanced by significant decreases in two states (Mississippi and South Carolina).

Among CSHCN, national estimates for current and consistent health insurance indicators varied significantly between 2001 and 2005-2006 (Table 2). Figure 3 shows that fifteen states had significant increases in current health coverage among CSHCN, and the remaining states had no significant changes in percent of CSHCN currently insured. This pattern is maintained when examining consistent health care coverage among CSHCN by state (Figure 4): thirteen states showed increases, and the remaining had no significant changes. Figures 3 and 4 show no signs of decrease between 2001 and 2005-2006.

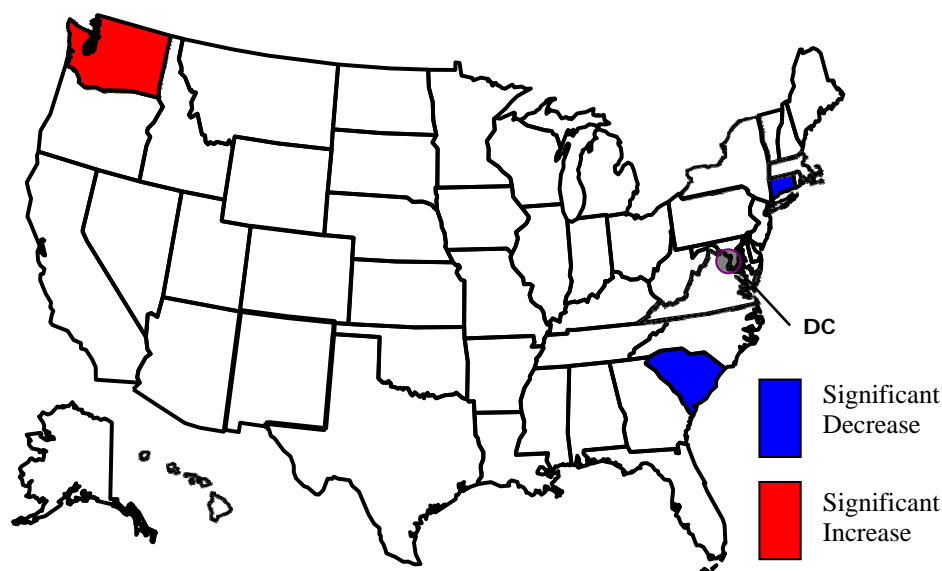


Figure 1: Significant direction change in percent of US children currently insured, by state and the District of Columbia, 2003 to 2007.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007.

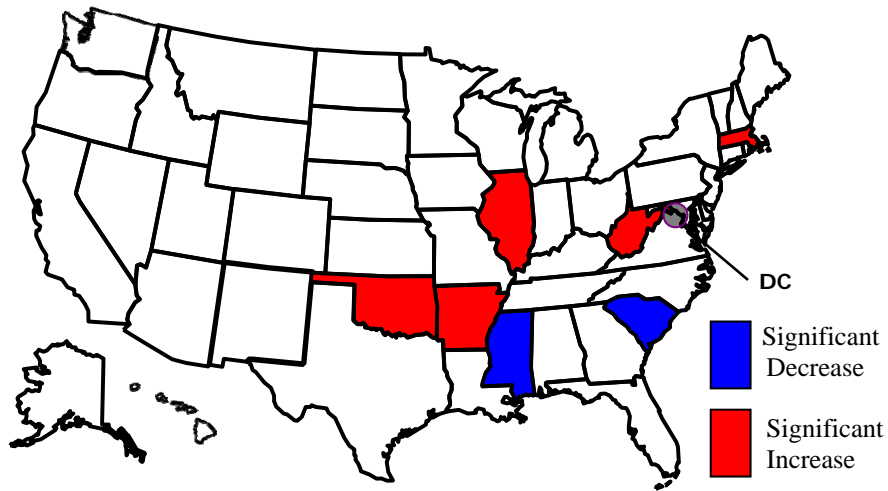


Figure 2: Significant direction change in percent of US children consistently insured during past year, by state and the District of Columbia, 2003 to 2007.
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007.

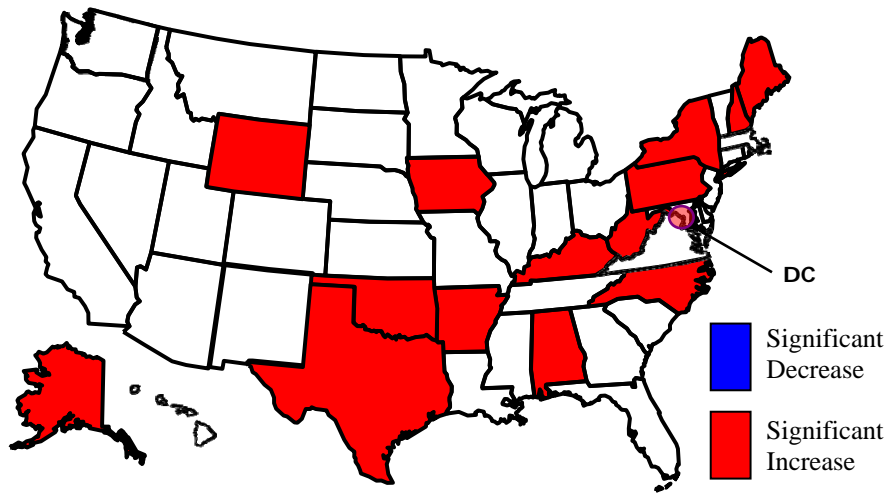


Figure 3: Significant direction of change in percent of US CSHCN currently insured, by state and the District of Columbia, 2001 to 2005-2006.
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NS-CSHCN, 2001 and 2005-2006.

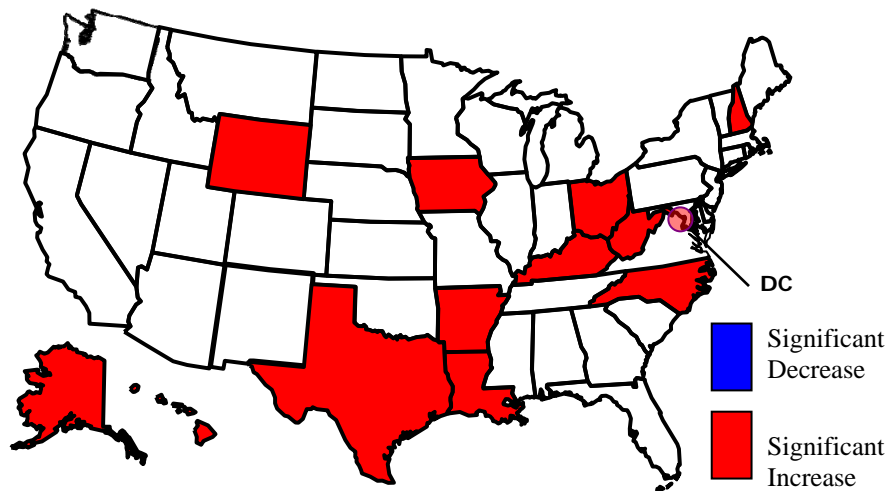


Figure 4: Significant direction of change in percent of US CSHCN consistently insured during the past year, by state and the District of Columbia, 2001 to 2005-2006.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NS-CSHCN, 2001 and 2005-2006.

3.3 Comparison of Access to Care Items

The following example shows how access to care items can be compared using time trend analysis across all four surveys: the 2003 and 2007 NSCH, and the 2001 and 2005-2006 NS-CSHCN. Since each survey screens for special needs status, the group that the four surveys have in common is CSHCN. Figure 5 shows changes in two access to care measures nationally from 2001 to 2007 for usual source of care and personal doctor or nurse. Figures 6 – 11 each show one access to care item stratified by a demographic factor.

Figure 5 shows an overall increase over time in having a personal doctor or nurse and a usual source of care among CSHCN nationally. Although this pattern is noted in Figures 6 to 11, some variation occurs by subgroup.

In figures 6 and 7, having a personal doctor or nurse and a usual source of care are stratified by age, but there are no significant variations between age groups. Figures 8 and 9 are stratified by poverty level. For both indicators, CSHCN who live in poor families report less access compared to CSHCN in families who are not poor at each time point. However, these figures show different trends in disparities. For the personal doctor or nurse indicator (Figure 8), the disparity between each poverty category narrowed between 2005 and 2007 compared to 2001 and 2003. In Figure 9, percent having a usual source of care for CSHCN who lived in near/not poor families continued to increase from 2001 to 2007, while the percent having a usual source of care did not change significantly from 2001 to 2007 for CSHCN in poor families.

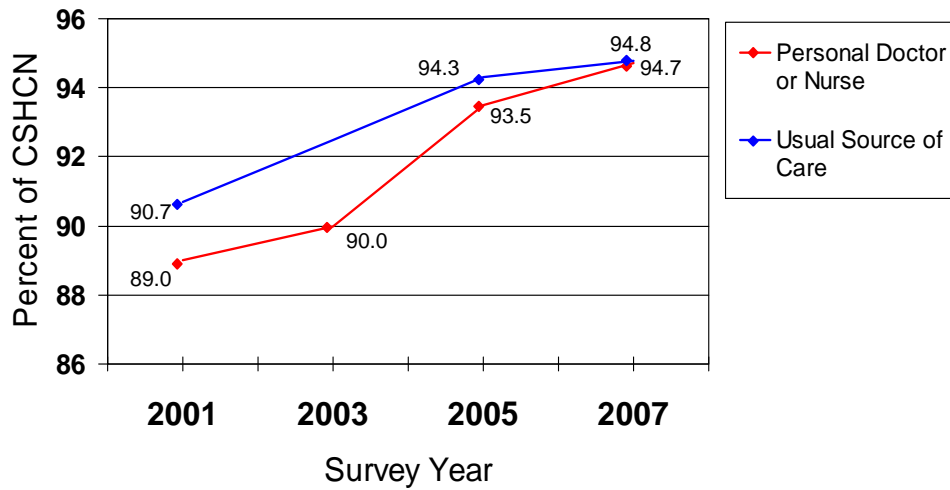


Figure 5: Percent of CSHCN who had a personal doctor or nurse, and percent with a usual source of care, by survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

Note: The usual source of care question was not asked in the 2003 NSCH.

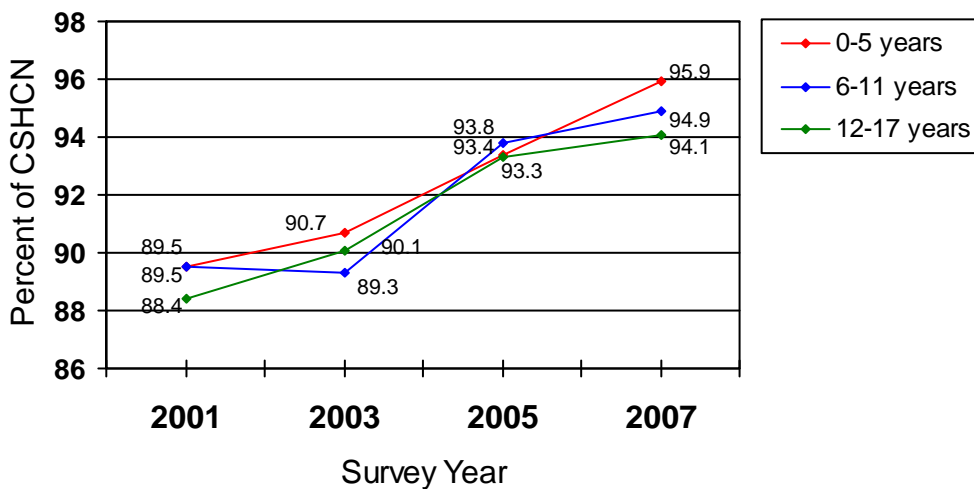


Figure 6: Percent of CSHCN who had a personal doctor or nurse, by age and survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

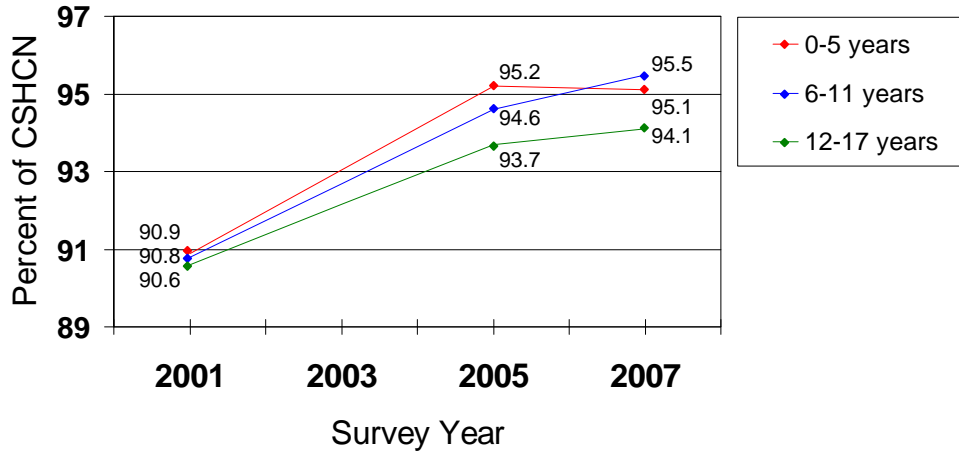


Figure 7: Percent of CSHCN with a usual source of care, by age and survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

Note: The usual source of care question was not asked in the 2003 NSCH.

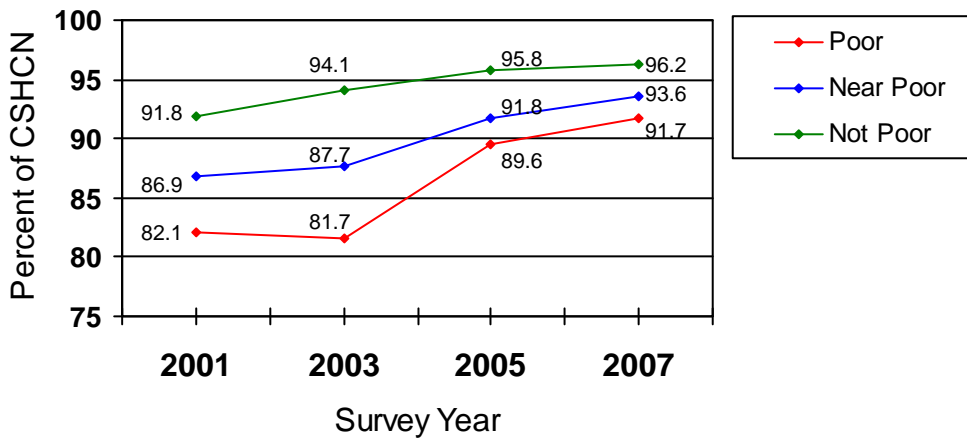


Figure 8: Percent of CSHCN who had a personal doctor or nurse, by poverty level and survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

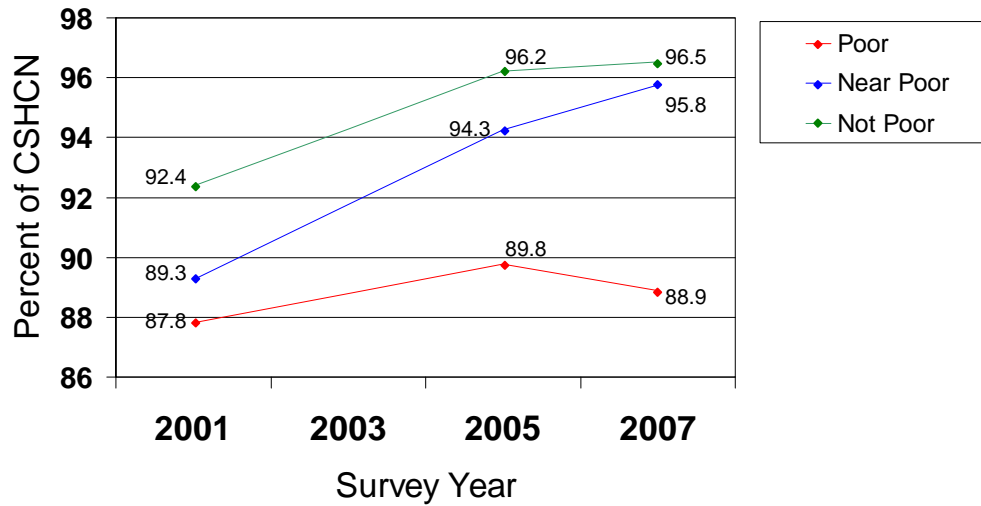


Figure 9: Percent of CSHCN with a usual source of care, by poverty level and survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

Note: The usual source of care question was not asked in the 2003 NSCH.

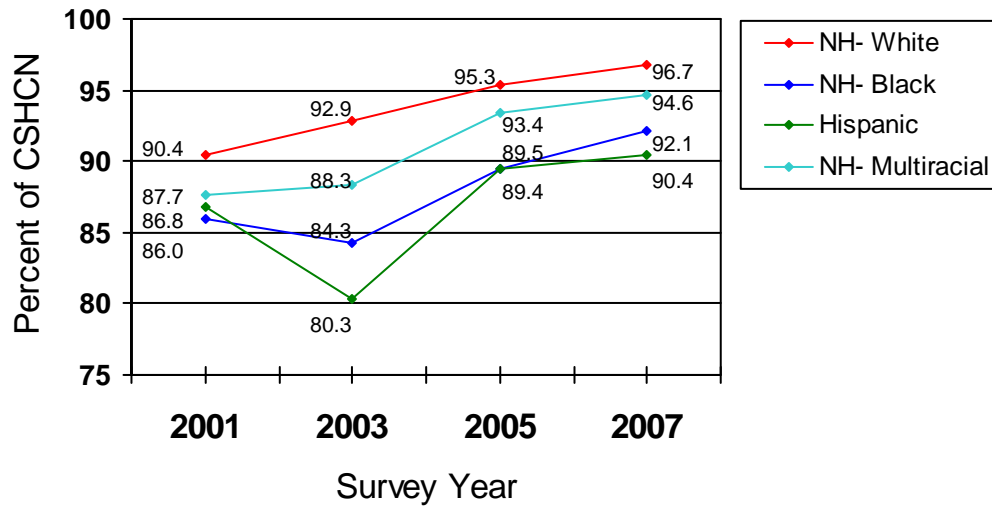


Figure 10: Percent of CSHCN who had a personal doctor or nurse, by race/ethnicity and survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

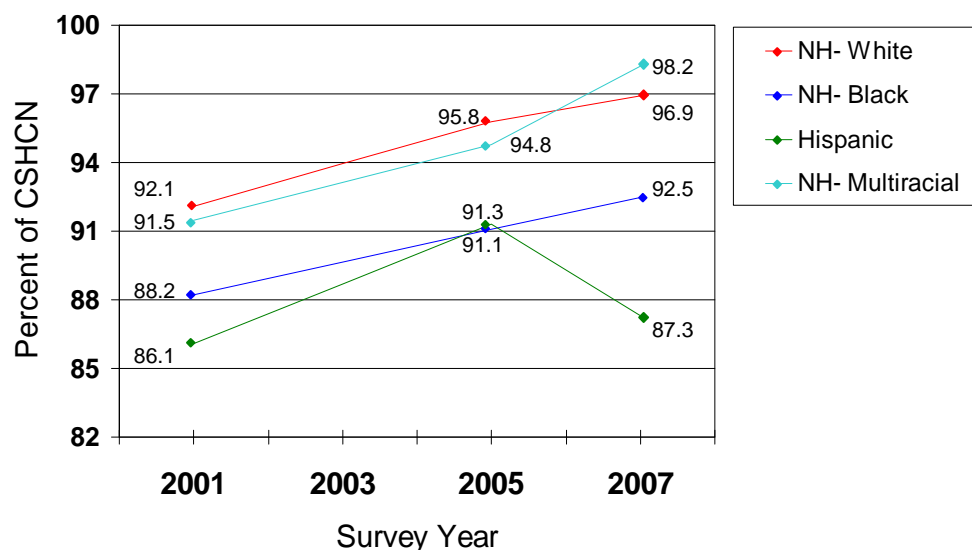


Figure 11: Percent of CSHCN with a usual source of care, by race/ethnicity and survey year.

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, NSCH, 2003 and 2007 & NS-CSHCN, 2001 and 2005-2006

Note: The usual source of care question was not asked in the 2003 NSCH.

In Figures 10 and 11, estimates of having a personal doctor or nurse and a usual source of care are stratified by race and ethnicity. In both figures, non-Hispanic whites CSHCN are more likely to have a personal doctor or nurse and usual source of care than CSHCN of minority backgrounds at all time points. In Figure 11, Non-Hispanic multiracial CSHCN are more likely to have a usual source of care than Hispanic and non-Hispanic black CSHCN at each time period. For Hispanic CSHCN, 2007 estimates were not significantly different from 2001 and 2005 estimates, whereas having a usual source of care significantly increased in 2007 compared to 2001 for all other racial/ethnic groups.

4. Discussion

The NSCH and the NS-CSHCN are among the largest surveys to have been conducted exclusively on children and more specifically on children with special health care needs (Bethell, et al., 2007; Michael D. Kogan & Newacheck, 2007; P. van Dyck, et al., 2004; van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). The large sample sizes allow researchers, policy makers, and program providers to identify areas of need by having state-level data on access to care. Since both the NSCH and NS-CSHCN have been implemented twice and comparisons can be made among the CSHCN population from all four surveys. There are more similarities within the NSCH or the NS-CSHCN, and thus more comparisons can be made in each survey. Comparable topic areas include: access to care indicators including insurance questions; indicators of health status including questions on chronic conditions; child and family health care impact;

neighbourhood and school characteristics; and a pediatric scale that screens for developmental delay (U.S. Department of Health and Human Services, et al., 2004, 2005, 2007, and forthcoming).

Some issues to consider when making comparisons among surveys are differences in the wording or placement of questions within each survey. Some questions may also be specific to a particular survey and not replicated in the others. It is important to consider that the methodology for the surveys may differ with regard to incentive use and survey design (U.S. Department of Health and Human Services, et al., 2004, 2005, 2007, and forthcoming).

To satisfy policy makers' and program providers' growing need for information on access to care, researchers can utilize SLAITS surveys to conduct various analytical projects. All SLAITS data sets, chartbooks, and other resources can be found online on the SLAITS website (National Center for Health Statistics, 2009b).

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