



MODULE 2

How do inequities impact children with special health care needs?

What Do the National Data Say about Inequities among Children with Special Health Care Needs?

Coverage and financing inequities impact vulnerable subgroups of children with special health care needs (CSHCN).¹ Throughout this tutorial, we will focus on the following demographic variables:

- **Race or ethnicity**
- **Primary household language**
- **Household income**
- **Number of functional difficulties**

National data show that black and Latino CSHCN fare worse than white CSHCN along several coverage and financing indicators. Black and Latino CSHCN are more likely than white CSHCN to be uninsured and to have inadequate insurance.^{2, 3, 4} You may remember from Module 1 (*What are health care coverage and financing inequities?*) that the MCHB has established six core outcomes to improve the system of care for CSHCN (see page 8). The health insurance core outcome states that “families of CSHCN have adequate private and/or public insurance to pay for the services they need.”⁵ Latino CSHCN are the least likely of any racial or ethnic group to meet this core outcome.⁶

Additionally, Latino CSHCN living in Spanish-speaking households are less likely to meet the core outcome than Latino CSHCN living in English-speaking households.^{4, 6} In general, CSHCN with non-English speaking parents are more likely to either lack adequate insurance or be uninsured than those with English-speaking parents.^{7, 8}

In addition to inequities based on race or ethnicity and language, poor CSHCN fare worse than those from more affluent families. CSHCN whose household income is below 200% of the federal poverty level (FPL) (about \$48,600 for a

family of four⁹) are the most likely to have one or more gaps in insurance coverage throughout the year and are the least likely to have insurance coverage.^{10, 11}

Finally, CSHCN with more functional difficulties are less likely than those with fewer functional difficulties to have adequate insurance and are more likely to have one or more periods without insurance during the year.^{2, 6}

The “Your Turn” section of this module on page 14 provides national data about the percent of CSHCN without health insurance by race and ethnicity, language, household income, and number of functional difficulties. The *How to Retrieve Data* section on pages 16 - 23 provides detailed instructions on how to obtain these data for your state to use in comparison.

Where Can I Find Data about Inequities among Children with Special Health Care Needs?

While national data on coverage and financing inequities among CSHCN can help identify the gaps that exist for certain subgroups of CSHCN,¹² the way that inequities look may be very different from one state to another. For example, some states may have conspicuous racial and ethnic inequities, but access to coverage and financing of care may be distributed equitably based on functional status. Other states may have inequities based on functional status, but no discernable coverage or financing inequities based on race or ethnicity. Understanding state-specific data can be helpful in shaping policies and programs that will adequately address the specific inequities-related issues that may exist in your state. The following two data sources can help you explore inequities among CSHCN in your state:

About the Catalyst Center Online State-at-a-Glance Chartbook on Coverage and Financing of Care for Children and Youth with Special Health Care Needs

The Catalyst Center Chartbook provides data on selected indicators of health coverage and health care financing for CSHCN in every state, the District of Columbia (DC), and Puerto Rico. Several of these indicators are helpful in understanding coverage and financing inequities,¹³ including:

- Percentage of all children by race or ethnicity and percentage of CSHCN by race or ethnicity, language, income, and number of functional difficulties
- State Medicaid eligibility levels, as a percentage of the federal poverty level (FPL), for pregnant women and children
- Percentage of CSHCN who are uninsured, underinsured, or who have private or public insurance coverage (or a combination of both) by race or ethnicity, language, income, and number of functional difficulties
- Percentage of CSHCN who meet the MCHB core outcomes by race or ethnicity, language, income, and number of functional difficulties

Using the online Chartbook, you can access data for your state and easily compare it with both national averages and other states' data. You can access the Catalyst Center Chartbook at <http://chartbook.cahpp.org/>

On the next page, you will find an example of how to use the Catalyst Center Chartbook to learn how racial inequities in uninsurance among CSHCN in New Jersey compare to those in Colorado.

Two data sources to help you find data about inequities among children with special health care needs:

Catalyst Center
State-at-a-Glance Chartbook
<http://chartbook.cahpp.org/>

and

Childhealthdata.org
<http://childhealthdata.org>

See the “How to Retrieve Data...” sections on pages 12 - 20 for information on how to use these resources.

How to Retrieve Data from the Catalyst Center Online State-at-a-Glance Chartbook on Coverage and Financing of Care for Children and Youth with Special Health Care Needs

Using the example of comparing racial inequities in uninsurance between New Jersey and Colorado, below are the step-by-step instructions to guide you in using the Catalyst Center Chartbook:

1. At the website <http://chartbook.cahpp.org/> under “compare two states,” choose New Jersey and Colorado and click “get data.”

CATALYST CENTER IMPROVING FINANCING OF CARE for Children & Youth WITH SPECIAL HEALTH CARE NEEDS

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WHAT YOU'LL FIND HERE

- Data on carefully selected indicators of health coverage and health care financing for CYSHCN in every state plus DC and Puerto Rico
- A detailed guide to interpreting and using the data
- An “inspiration database” of ways states are addressing tough financing problems
- A user-friendly introduction to key health care financing strategies and related terms

From the **Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs**, a National Center funded by the Maternal and Child Health Bureau.

Welcome to the Catalyst Center State-at-a-Glance Chartbook
on Coverage and Financing for Children and Youth with Special Health Care Needs

GET DATA GET HELP

Look up or compare state coverage and financing data.

SEE STATE DATA
Select a state

COMPARE TWO STATES
New Jersey
Colorado

TIPS FOR USING THE DATA
How to interpret and use the data accurately.

DATA SOURCES
Where the data comes from: full sources and methods.

2. Scroll down to the dark blue box labeled “factors influencing health insurance coverage.”

FACTORS INFLUENCING HEALTH INSURANCE COVERAGE

Uninsured	New Jersey	Colorado	US
Percentage of children without health insurance at some point in the past year	7.6%	13.5%	11.3%

Source: National Survey of Children's Health (2011–2012)

Percentage of CYSHCN without health insurance at some point in the past year, by age groups			
0–5 years	6.9%	14.6%	9.1%
6–11 years	6.0%	10.2%	9.2%
12–17 years	7.6%	9.1%	9.4%

Source: National Survey of Children with Special Health Care Needs (2009–2010)

Percentage of CYSHCN without health insurance at some point in the past year, by sex			
Male	6.7%	8.8%	9.5%
Female	7.1%	12.9%	8.9%

Source: National Survey of Children with Special Health Care Needs (2009–2010)

Percentage of CYSHCN without health insurance at some point in the past year, by race/ethnicity			
Hispanic	9.6%	20.3%	15.9%
White non-Hispanic	5.2%	8.4%	7.3%
Black non-Hispanic	11.9%	1.8%	9.9%
Other non-Hispanic	1.3%	5.3%	9.4%

Source: National Survey of Children with Special Health Care Needs (2009–2010)

Percentage of CYSHCN without health insurance at some point in the past year, by primary household language			
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3. Under the light blue box labeled “uninsured,” scroll down to the section labeled “percentage of CYSHCN without health insurance at some point in the past year, by race/ethnicity.”

FACTORS INFLUENCING HEALTH INSURANCE COVERAGE			
Uninsured	New Jersey	Colorado	US
Percentage of children without health insurance at some point in the past year	7.6%	13.5%	11.3%
Source: National Survey of Children's Health (2011–2012)			
Percentage of CYSHCN without health insurance at some point in the past year, by age groups			
0–5 years	6.9%	14.6%	9.1%
6–11 years	6.0%	10.2%	9.2%
12–17 years	7.6%	9.1%	9.4%
Source: National Survey of Children with Special Health Care Needs (2009–2010)			
Percentage of CYSHCN without health insurance at some point in the past year, by sex			
Male	6.7%	8.8%	9.5%
Female	7.1%	12.9%	8.9%
Source: National Survey of Children with Special Health Care Needs (2009–2010)			
Percentage of CYSHCN without health insurance at some point in the past year, by race/ethnicity			
Hispanic	9.6%	20.3%	15.9%
White non-Hispanic	5.2%	8.4%	7.3%
Black non-Hispanic	11.9%	1.8%	9.9%
Other non-Hispanic	1.3%	5.3%	9.4%
Source: National Survey of Children with Special Health Care Needs (2009–2010)			
Percentage of CYSHCN without health insurance at some point in the past year, by primary household language			
Hispanic child/Spanish language household	9.2%	15.1%	22.2%
Hispanic child/English language household	9.8%	22.6%	12.6%
Non-Hispanic child	6.2%	7.7%	8.0%

4. Here you will see the uninsurance rate for CSHCN in New Jersey, Colorado, and the U.S. broken down by race/ethnicity.

Percentage of CYSHCN without health insurance at some point in the past year, by race/ethnicity			
Hispanic	9.6%	20.3%	15.9%
White non-Hispanic	5.2%	8.4%	7.3%
Black non-Hispanic	11.9%	1.8%	9.9%
Other non-Hispanic	1.3%	5.3%	9.4%
Source: National Survey of Children with Special Health Care Needs (2009–2010)			

About ChildHealthData.org

Childhealthdata.org provides information and data on child and adolescent health from the National Survey of Children with Special Health Care Needs (NS-CSHCN). These data are publicly available and free to use. You can browse the NS-CSHCN by national data, region, or by state and get information about:

- Families' out-of-pocket costs
- The impact of a child's special health care need on family finances
- The impact of a child's special health care need on family members' work or employment

While childhealthdata.org provides a lot of general information about CSHCN, you can edit the search criteria to explore inequities in your state or throughout the U.S. After retrieving data for a measure (either nationally or in your state), you can compare subgroups of CSHCN along this measure by race or ethnicity, language, income, or functional status.

You can access childhealthdata.org at <http://childhealthdata.org>

Below, you will find an example of how to use the childhealthdata.org website to learn about racial inequities in uninsurance among CSHCN **in the state of New York**.

How to Retrieve Data from ChildHealthData.org

1. At the website <http://childhealthdata.org>, scroll down the page and click the button "Quick Data Search."

Explore Your Data:
National, Regional, & State-Level Data

Select a pathway to explore data:

- 1 See a State, National or Regional Snapshot
- 2 Browse by Survey & Topic
 - Quick Data Search
- 3 Learn About Our Surveys and Methods
 - National Survey of Children's Health (NSCH) >
 - National Survey of Children with Special Health Care Needs (CSHCN) >
 - National Interview Survey (NHIS) Child Complementary and Alternative Medicine (CAM) Supplement >
 - National Health Interview Survey Child Component >
 - Survey of Pathways to Diagnosis and Services >

2. Under “Select a Survey,” choose “National Survey of Children with Special Health Care Needs.”

Browse by Survey & Topic

To begin your interactive data search:

- 1) Select a **survey**, **survey year**, and **geographic level**.
- 2) Select your desired **topic/starting point** (**at-a-glance content maps** are available to view/download at this step).
- 3) Select your **measure**.

These steps will direct you to a results page where you can compare across states, regions and by numerous subgroups.

1. Select a Survey, Year, and Geographic Area

Select a Survey

Select a Survey

Select a Survey
National Survey of Children with Special Health Care Needs
 National Survey of Children's Health
 National Health Interview Survey (NHIS) – Child
 NHIS – Complementary and Alternative Medicine
 Survey of Pathways to Diagnosis and Services

Select a State/Region

3. Under “year,” select 2009/10. (This is the most recent year for which data are available.)

3) Select your **measure**.

These steps will direct you to a results page where you can compare across states, regions and by numerous subgroups.

1. Select a Survey, Year, and Geographic Area

Select a Survey

National Survey of Children with Special Health Care Needs

Select a Year

2009/10

2009/10
 2005/06
 2001

Region

Nationwide

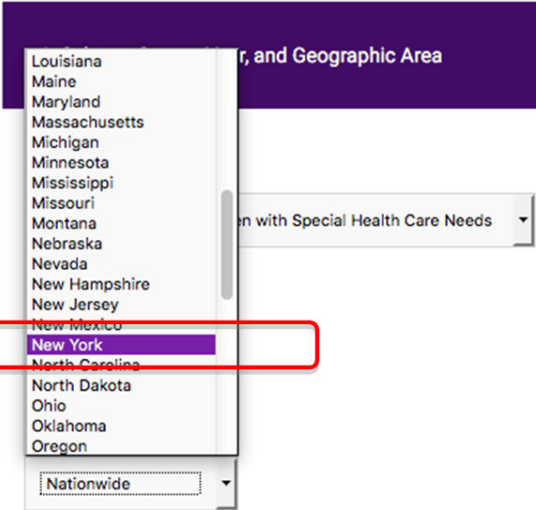
4. Under “Select a State/Region,” choose New York.

Browse by Survey & Topic

To begin your interactive data search:

- 1) Select a **survey**, **survey year**, and **geographic level**.
- 2) Select your desired **topic/starting point** (**at-a-glance content maps** are available to view/download at this step).
- 3) Select your **measure**.


These steps will direct you to a results page where you can compare across states, regions and by numerous subgroups.




The screenshot shows a web interface with a dark purple header. Below the header, there is a dropdown menu titled 'Geographic Area'. The menu is open, showing a list of US states and 'Nationwide'. The state 'New York' is highlighted in purple. A red rectangle is drawn around the 'New York' option. To the right of the state list, there is another dropdown menu with the text 'Population with Special Health Care Needs' and a downward arrow.

5. Under “MCBH Core Outcomes and Key Indicators,” choose “Health Insurance Coverage and Program Participation.”

2. Select a Starting Point/Topic

 **MCHB Core Outcomes and Key Indicators** [\(Content Map\)](#)
CSHCN performance measures and key indicator results

- ☐ MCHB Core Outcomes for CSHCN
- ☐ CSHCN Health and Functional Status
- ☒ **Health Insurance Coverage and Program Participation**
- ☐ Health Care Needs and Access to Care
- ☐ Care Coordination and Family Centered Care
- ☐ Impact on Families

 **CSHCN Prevalence and Demographics** [\(Content Map\)](#)
Child or household level data for children with and without special health care needs

6. Under “Select a Survey Question,” choose “Type of health insurance coverage.”

2009/10 NS-CSHCN Survey Sections
Responses to questions asked in each section of the CSHCN Interview

Title V Block Grant Measures (available from NS-CSHCN only)
Title V Maternal and Child Health Block Grant National Performance and Outcome Measures

3. Select a Survey Question (click the [i](#) for more information on the question)

Indicator 3: CSHCN without insurance at some point during the past year [i](#)

Indicator 4: CSHCN without insurance at the time of the survey [i](#)

Indicator 5: Currently insured CSHCN whose insurance is inadequate [i](#)

Type of health insurance coverage [i](#)

Early Intervention Services, CSHCN age 0-2 years [i](#)

Special Education Services, CSHCN age 3-17 years [i](#)

7. On the top right, you will see a box labeled “Edit Search Criteria.” Under “Compare Subgroups,” choose “Race/ethnicity.”

Current Search Criteria

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

Starting Point: MCHB Core Outcomes and Key Indicators

State/Region: New York

Topic: Health Insurance Coverage and Program Participation

Question: Type of health insurance coverage (details)

Edit Search Criteria

Compare States:
Select a State or Region

Compare Subgroups:
Select a Subgroup

Select a Subgroup

Age - 3 groups

Sex of child

Race/ethnicity

Highest education of adult in household

Primary language for Hispanic CSHCN

Number of CSHCN Screener criteria met

Specific types of special health needs

Emotional/behavioral/developmental issues

Current ADD/ADHD (2-17 years)

Current autism (2-17 years)

Current asthma

Number of functional difficulties

Family structure

Household income

Household income (CHIP)

Presence of medical home

Urban/Rural residence -- 2 categories

What type of health insurance coverage, if any, did [child] have at the time of the survey? (details)

	Private insurance only	Public insurance only	Both public & private insurance	Uninsured
%	52.9	34.7	9.4	
C.I.	(48.4 - 57.4)	(30.2 - 39.1)	(6.6 - 12.2)	(1.0 - 14.0)
n	479	247	67	24
Pop. Est.	339,545	222,519	60,156	19,619

8. The “Uninsured” column lists uninsurance rates for CSHCN from each racial/ethnic group.

What type of health insurance coverage, if any, did [child name] have at the time of the survey? (details)

		Private insurance only	Public insurance only	Both public & private insurance	Uninsured	Total %
Hispanic	%	35.6	46.1	15.6	→ 2.7	100.0
	C.I.	(25.7 - 45.5)	(35.7 - 56.5)	(7.2 - 24.0)	(0.0 - 5.5)	
	n	57	78	22	4	
	Pop. Est.	44,091	57,158	19,299	3,361	
White, non-Hisp	%	64.5	23.9	9.2	→ 2.4	100.0
	C.I.	(58.8 - 70.1)	(18.6 - 29.2)	(5.6 - 12.9)	(0.8 - 4.0)	
	n	351	91	34	11	
	Pop. Est.	227,882	84,581	32,627	8,480	
Black, non-Hisp	%	34.3	54.1	5.6	→ 6.0	100.0
	C.I.	(23.3 - 45.4)	(42.2 - 66.0)	(1.1 - 10.1)	(0.0 - 11.9)	
	n	40	59	8	8	
	Pop. Est.	40,657	64,163	6,633	7,053	
Other, non-Hisp	%	58.7	36.2	3.5	→ 1.6	100.0
	C.I.	(42.4 - 75.0)	(20.2 - 52.2)	(0.0 - 8.6)	(0.0 - 4.7)	
	n	31	19	3	1	
	Pop. Est.	26,915	16,618	1,597	724	



WORKSHEET TO ADDRESS INEQUITIES IN YOUR STATE - MODULE 2

YOUR TURN: How do inequities impact children with special health care needs?

Module 2 describes some data sources that may help you determine where there may be inequities among CSHCN in your state. Using the information and instructions from Module 2, use the Catalyst Center Chartbook at <http://chartbook.cahpp.org/> or the **National Survey of Children with Special Health Care Needs** at <http://childhealthdata.org> to fill in the information for your state. Regarding the Chartbook, note that there is a column for another state. You can use the Chartbook to input information in this column from any other state, or the District of Columbia, and compare it to yours. U.S. data are already filled in, so you can compare your state to the national average as well.

Percent of Children with Special Health Care Needs Without Insurance at Some Point, by Characteristic

	U.S.	<div></div> <div>(Your State)</div>	<div></div> <div>(Comparison State)</div>
	% of CSHCN without health insurance at some point in the past year		
Race/Ethnicity			
Hispanic	15.9%		
White, non-Hispanic	7.3%		
Black, non-Hispanic	9.9%		
Other, non-Hispanic	9.4%		
Language			
Hispanic child, Spanish language household	22.2%		
Hispanic child, English language household	12.6%		
Non-Hispanic child	8.0%		
Household Income			
0-99% FPL	14.2%		
100-199% FPL	14.1%		
200-399% FPL	8.5%		
400% FPL or more	2.3%		
Number of Functional Difficulties			
None	4.4%		
1	5.9%		
2	9.0%		
3	9.9%		
4 or more	11.7%		

Source: Catalyst Center Chartbook. The Catalyst Center Chartbook includes other coverage and financing indicators (in addition to % of CSHCN without health insurance at some point in the past year). You can use this resource to find out how CSHCN in your state fare with respect to these other indicators and compare these data to any other state or DC and to the U.S.

Do these data indicate any inequities-related issues in your state of which you were unaware? Have they provided additional information about the issue you outlined in Module 1? Describe:

References

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13. Catalyst Center. (2014). *Making the case for financing health care for children and youth with special health care needs?* Retrieved from <http://cahpp.org/resources/inequities-tutorial>

This document, *Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities*, is available in its entirety on the web at <http://cahpp.org/resources/inequities-tutorial>

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