



Health Care Coverage and Financing for Children with Special Health Care Needs:

# A TUTORIAL TO ADDRESS INEQUITIES



# ACKNOWLEDGMENTS

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LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.

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# INTRODUCTION

## What's this all about?

Children with special health care needs (CSHCN) require more health care services than children generally, but there are differences in access to insurance coverage and ways of paying for health care services among this broad group of children. A large body of research examines differences in access to health insurance coverage and health care services as well as differences in health outcomes among children based on race, ethnicity, family income, immigration status, language spoken, or disability status.<sup>1, 2, 3</sup> A growing body of literature explores these differences among CSHCN specifically.<sup>4, 5, 6, 7, 8, 9</sup> These differences create an uneven playing field whereby some groups of CSHCN are less likely to get the care they need and more likely to face barriers to achieving optimal health and functioning. As a result, they are less likely to grow and thrive in their communities. For researchers, policy makers, family members, and all of us who share our communities and lives with individuals with special health care needs, investment in overcoming these barriers should be a top priority. This will help ensure that all CSHCN have access to the care they need regardless of their social or economic background.

The Catalyst Center has become increasingly concerned about the differences in health insurance coverage and financing of care that exist among CSHCN based on race, ethnicity, family income, immigration status, language spoken, and disability status. This tutorial is part of our effort to analyze and address the underlying structural disadvantage faced by certain vulnerable subgroups of CSHCN. We are focused not only on the differences that exist within the population of CSHCN based on race, ethnicity, income, immigration status, language, and level of functional difficulty, but also on how these differences are impacted by barriers within the system of care. To address these barriers and help create a fairer outlook on health and life for all CSHCN, policy- and health systems-level change needs to be a top priority.

The tutorial was created to clarify language used to describe these differences and to provide tools and examples of policies, programs, and partnerships that users can adopt in their states to improve access to coverage and financing of care for the most vulnerable children. It contains six modules:

- Module 1 explains differences in access to coverage and financing among various groups of CSHCN and clarifies the language used to describe these differences
- Module 2 provides a brief overview of what the national data say about these coverage and financing differences and provides some guidance on how to access additional data

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This tutorial was created to clarify language used to describe coverage and financing differences in health care among certain vulnerable subgroups of children with special health care needs (CSHCN) and to provide tools and share policies, programs, and partnerships that users can adopt in their states to improve coverage and financing of care for CSHCN.

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- Module 3 describes some current policy and program initiatives that may help address coverage and financing differences among CSHCN
- Module 4 describes the impact of Affordable Care Act (ACA) provisions on these coverage and financing differences
- Module 5 describes how inter-organizational partnerships can be helpful in addressing these differences and provides some examples of effective partnerships that states have used
- Module 6 provides sample questions for evaluating the impact of efforts to reduce health care inequities among sub-groups of CSHCN

## About the Tutorial and Worksheet to Address Inequities in Your State

### Policy and Program Opportunities to Improve Health Care Coverage and Financing for Children with Special Health Care Needs: Find Out in Your State

This tutorial is designed to help identify the policy and program opportunities in your state to improve health care coverage and financing for children with special health care needs (CSHCN). It is intended to help you apply the information presented in *Health Care Coverage and Financing for Children with Special Health Care Needs: A Tutorial to Address Inequities* which can be found on the web at <http://cahpp.org/resources/inequities-tutorial>

At the end of each module there is a “Your Turn” section where you can use the information presented in the module to help identify health care coverage and financing inequities that may exist for CSHCN in your state or organization as well as opportunities to address those inequities. Once you have completed all the modules, the completed worksheet will provide information that may serve as a starting point for discussions in how to address inequities for CSHCN in your state.

A complete interactive tutorial worksheet that includes the “Your Turn” sections for modules 1 - 5 is available online at <http://cahpp.org/inequities-tutorial-worksheet.pdf>. You can find instructions for filling out this worksheet electronically on page 51.

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As you read each module, please keep the following questions in mind:

- Was the information helpful for you in understanding coverage and financing inequities among CSHCN?
- Did you gain a clearer conceptualization of what these inequities might look like in your state?
- Have you strengthened or created new policies or programs to address inequities in your state?

We welcome your feedback. At the end of the tutorial are links to a survey where you can provide feedback. If you prefer, you may also email your comments to [cyshcn@bu.edu](mailto:cyshcn@bu.edu)

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## MODULE 1

# What are health care coverage and financing inequities?

The language used to describe differences in health insurance status, access to services, and health outcomes varies. Sources refer to “health disparities,” “health inequalities,” and “health inequities” or some combination of these terms. Throughout this tutorial, we use “health inequities,” which takes into account the association between differences in population health and social disadvantage or oppression. Health inequities typically connotes the unjust or unethical nature of these differences.<sup>1</sup> **For example, Latino CSHCN are overrepresented among uninsured CSHCN and, thus, may face increased barriers to accessing the care they need. These differences may be due to structural disadvantages experienced by Latinos in the U.S. (e.g., residential segregation in neighborhoods that have fewer health care resources).**<sup>2,3</sup>

Indicators of health and health care differences include differences in health outcomes, differences in access to health care services, and differences in access to health insurance or to other ways of paying for care. **For example, black CSHCN are more likely to be uninsured than white CSHCN (health insurance).**<sup>2,3</sup> **They may have less access to the health care services they need (health care services) and they have higher rates of asthma than white children (health outcomes).**<sup>2</sup>

There are a variety of explanations about the causes of health inequities among different population groups. These include individual-level explanations, such as those that focus on biological differences, differences in health behaviors or differences in use of health services between groups; health systems explanations, such as provider bias (conscious or unconscious); and structural-level explanations, which focus on the health impact of structural disadvantages experienced by certain groups.<sup>4</sup>

The choice to use “health inequities” represents an effort on the part of the Catalyst Center to continually recognize, analyze, and address the underlying structural disadvantage faced by certain vulnerable subgroups of CSHCN.

## Aren't all CSHCN vulnerable?

The Maternal and Child Health Bureau (MCHB) defines 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.”<sup>5</sup> Because CSHCN, by definition, have greater health and health care needs than other children, they can be considered more vulnerable as a group. Because of this vulnerability, many

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**Health inequities** are differences in health and health care outcomes among different groups of children with special health care needs that are caused by structural disadvantage in society.

Only 3.5% of children with special health care needs are uninsured, compared with 5.5% of children generally.

However:

- 6.6% of Latino CSHCN are uninsured
- 3.6% of black CSHCN are uninsured

Compared to 2.5% of uninsured white CSHCN

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programs and policies have attempted to address the health insurance coverage and financing needs of all CSHCN. You may be wondering why this is important, as only 3.5% of CSHCN are uninsured compared with 5.5% of children generally.<sup>6</sup> However, while the uninsurance rate among CSHCN is low, certain subgroups of CSHCN have higher uninsurance rates. **For example, 3.6% of black CSHCN and 6.6% of Latino CSHCN are uninsured compared to 2.5% of white CSHCN.**<sup>6</sup>

MCHB has outlined six core outcomes to improve access to care and needed services for CSHCN (see sidebar). One of these core outcomes is that families of CSHCN have adequate health insurance to pay for the services their children require.<sup>5</sup> In order to achieve this goal, all families of CSHCN must have access to health insurance coverage and other ways of paying for care. And, this coverage must be adequate to cover the costs of all the services CSHCN require. Coverage and financing inequities stand in the way of achieving this goal, and we must address inequities if we want to “move the needle” on ensuring access to coverage for all CSHCN.

## Coverage inequities vs. financing inequities

Health insurance coverage is most often the way that families of CSHCN pay for the services their children need. As noted above, some CSHCN fare worse than others when it comes to having health insurance coverage; these differences are referred to as coverage inequities. However, even among CSHCN who have insurance, financing gaps may exist. Private or public insurance may not cover all the services a child needs and may not provide access to needed health care providers. In addition, a family’s out-of-pocket costs due to deductibles, copays, or coinsurance may be a financial hardship and other costs for transportation to appointments, parking, and lost time at work may contribute to a family’s financial burden as well. Differences in these other financial hardships between groups are referred to as “financing inequities.”<sup>7</sup>

### The Maternal and Child Health Bureau Core Outcomes for Children with Special Health Care Needs (CSHCN)

1. Families of CSHCN partner in decision-making regarding their child’s health.
2. CSHCN receive coordinated, ongoing, comprehensive care within a medical home.
3. Families of CSHCN have adequate private and/or public insurance to pay for needed services.
4. Children are screened early and continuously for special health care needs.
5. Community-based services are organized so families can use them easily.
6. Youth with special health care needs receive the services necessary to make transitions to adult health care.

Source: <http://mchb.hrsa.gov/cshcn0910/core/co.html>



## WORKSHEET TO ADDRESS INEQUITIES IN YOUR STATE - MODULE 1

**YOUR TURN: What are health care coverage and financing inequities?****Overview**

Module 1 provided an overview of health care coverage and financing inequities. Health inequities are differences in health and health care outcomes among different groups of children with special health care needs (CSHCN) that are caused by structural disadvantage in society. While CSHCN, as a group, are more vulnerable than children generally, certain subgroups of CSHCN are more vulnerable than others and may experience inequities in health insurance coverage and other ways of paying for the services they need.

**Identify an inequities-related issue that you think exists within your state**

- The issue may focus on differences that you notice among subgroups of CSHCN or a policy or program that seems to contribute to these inequities.
- Keep this issue in mind as you continue through the tutorial and learn more about coverage and financing inequities among CSHCN.

**Describe the issue**

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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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## 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).<sup>1</sup> 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.<sup>2, 3, 4</sup> 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.”<sup>5</sup> Latino CSHCN are the least likely of any racial or ethnic group to meet this core outcome.<sup>6</sup>

Additionally, Latino CSHCN living in Spanish-speaking households are less likely to meet the core outcome than Latino CSHCN living in English-speaking households.<sup>4, 6</sup> 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.<sup>7, 8</sup>

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 four<sup>9</sup>) 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.<sup>10, 11</sup>

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.<sup>2, 6</sup>

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,<sup>12</sup> 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,<sup>13</sup> 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.

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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.

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## 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.”

The screenshot shows the Catalyst Center website header with the logo and navigation links: home, get data, get help, about, contact us. Below the header is a banner for the State-at-a-Glance Chartbook. The main content area is divided into three columns: 'WHAT YOU'LL FIND HERE', 'SEE STATE DATA', and 'COMPARE TWO STATES'. The 'COMPARE TWO STATES' section has a red box around the dropdown menus for 'New Jersey' and 'Colorado', and a red arrow pointing to the 'GET DATA' button below them. The 'SEE STATE DATA' section has a dropdown for 'Select a state' and a 'GET DATA' button. The 'TIPS FOR USING THE DATA' and 'DATA SOURCES' sections each have a 'VIEW' button.

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

■ sign up for our e-newsletter  
■ about us

home get data get help about contact us

**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

GET DATA

**TIPS FOR USING THE DATA**

How to interpret and use the data accurately.

VIEW

**DATA SOURCES**

Where the data comes from: full sources and methods.

VIEW

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%
<i>Source: National Survey of Children’s Health (2011–2012)</i>			
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<i>Source: National Survey of Children with Special Health Care Needs (2009–2010)</i>			
Percentage of CYSHCN without health insurance at some point in the past year, by sex			
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<i>Source: National Survey of Children with Special Health Care Needs (2009–2010)</i>			
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%
<i>Source: National Survey of Children with Special Health Care Needs (2009–2010)</i>			
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."

The screenshot shows the 'Explore Your Data' section of the ChildHealthData.org website. It features a heading 'National, Regional, & State-Level Data' and a sub-heading 'Select a pathway to explore data:'. There are three numbered pathways: 1. 'See a State, National or Regional Snapshot', 2. 'Browse by Survey & Topic', and 3. 'Learn About Our Surveys and Methods'. The 'Quick Data Search' button is highlighted with a red box under pathway 2. Below pathway 3, there are several survey options with right-pointing chevrons: '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', and '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

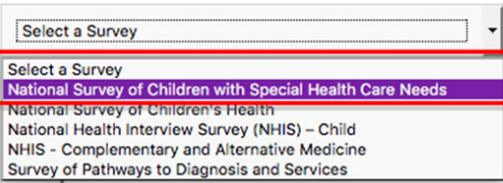
To begin your interactive data search:

- 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 State/Region

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

3) Select your **measure**.

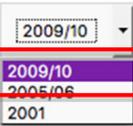
These steps will direct you to a results page where you can compare across states, regions and by numerous subgroups.

**1. Select a Survey, Year, and Geographic Area**

Select a Survey

National Survey of Children with Special Health Care Needs

Select a Year



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 dropdown menu titled "Select a State/Region" with a list of states and "Nationwide". The state "New York" is highlighted in purple and circled with a red rectangle. Other states listed include Louisiana, Maine, Maryland, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, and Oregon.

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

The screenshot shows the "2. Select a Starting Point/Topic" section. Under the "MCHB Core Outcomes and Key Indicators" category, the option "Health Insurance Coverage and Program Participation" is selected with a blue radio button and circled in red. A red arrow points to this selection. Other options include "MCHB Core Outcomes for CSHCN", "CSHCN Health and Functional Status", "Health Care Needs and Access to Care", "Care Coordination and Family Centered Care", and "Impact on Families".

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 - 1.0)
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.	_____ (Your State)	_____ (Comparison State)
	% of CSHCN without health insurance at some point in the past year		
<b>Race/Ethnicity</b>			
Hispanic	15.9%		
White, non-Hispanic	7.3%		
Black, non-Hispanic	9.9%		
Other, non-Hispanic	9.4%		
<b>Language</b>			
Hispanic child, Spanish language household	22.2%		
Hispanic child, English language household	12.6%		
Non-Hispanic child	8.0%		
<b>Household Income</b>			
0-99% FPL	14.2%		
100-199% FPL	14.1%		
200-399% FPL	8.5%		
400% FPL or more	2.3%		
<b>Number of Functional Difficulties</b>			
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:



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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>

### Suggested citation:

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LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.



## MODULE 3

# How can policies and programs improve inequities in your state?

In Modules 1 (*What are health care coverage and financing inequities?*) and 2 (*How do inequities impact CSHCN?*), we explored:

- What inequities in coverage and financing of care are
- What this means for access to coverage and care for children with special health care needs (CSHCN)
- How you can get more information about the impact of inequities on CSHCN in your state and throughout the country

So, how can policy and program options help reduce inequities and expand access to coverage and care for all CSHCN? Can these options be targeted to CSHCN who are most at risk for uninsurance or underinsurance and/or are most likely to have other difficulties accessing services? The information in this module will help you begin to answer these questions.

## Policies and Programs that Impact Inequities

The first step in addressing inequities in coverage and financing of care among CSHCN is to understand the policy and program landscape in your state. Being familiar with your state's current health and social policies and programs will help you understand and assess how well they work. From there, you can consider how to strengthen existing policies and programs and/or implement new options to address inequities. You may want to consult with your Title V, Medicaid, and/or Family-to-Family Health Information Center for help identifying policies and programs that are working and where there may be gaps to fill.

Existing policies or programs that may impact inequities in coverage and financing of care among CSHCN include:

- **Policies specific to insurance coverage among CSHCN:** For example, Medicaid waivers that expand Medicaid coverage to children with disabilities even if household income exceeds the state's eligibility guidelines
- **Other health policies or programs targeted at children or adults:** For example, increased reimbursement for targeted outreach and enrollment or translation services for individuals for whom English is not the primary language

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If you have questions about

- Specific policies enacted in your state and how they work
- How policies in your state may impact inequities
- Other questions regarding insurance coverage and financing of care for children with special health care needs

the Catalyst Center may be able to help.

Learn more at  
<http://cahpp.org/project/the-catalyst-center/>  
or contact the Catalyst Center at [cyshcn@bu.edu](mailto:cyshcn@bu.edu)

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- **Broader social and economic policies that impact health:**

For example, the earned income tax credit (EITC), which decreases taxes owed and/or increases the tax refund of low- to moderate-income workers,<sup>1</sup> to help families afford and keep insurance

States have flexibility in some policy choices they make, which is why Medicaid eligibility and the EITC are not the same in every state. The following section includes an overview of some policy options that have the potential to reduce inequities in coverage and financing of care among CSHCN based on race or ethnicity, family income, immigration or documentation status, primary household language, and functional status.

## Earned Income Tax Credit (EITC)

Family income is a source of coverage inequities among CSHCN. As you may remember from Module 2 (*How do inequities impact CSHCN?*), CSHCN with family incomes of less than 200% of the federal poverty level (FPL) are less likely to be insured than CSHCN with higher family incomes. If they do have insurance, they are more likely to experience gaps in coverage.<sup>2</sup> Policies or programs that help increase families' wages may help families afford and keep insurance so their children can receive the health care they need.

The EITC is a federal program that provides tax credits for workers with dependent children who have incomes up to \$53,505 per year (exact income guidelines depend on marital status and family size).<sup>1,3</sup> Individuals without children also qualify, but at lower incomes – up to \$20,000 per year, depending on marital status.<sup>1</sup> The amount of the tax credit an individual or family will receive increases as earned income rises, up to a certain income level (depending on marital status and family size) and then begins to gradually decrease until families reach an income level high enough that they no longer qualify for the credit. In addition to the federal EITC, 26 states have created state-based EITCs to supplement the federal program.<sup>1</sup>

In 2012, the EITC increased the wages of working families with children by about \$250 per month and in 2013 lifted more than three million children out of poverty.<sup>1</sup> Some research suggests that children in families receiving the EITC are more likely to be insured than those in similar families who are not eligible for the credit.<sup>4</sup> Because low-income CSHCN have higher uninsurance rates than CSHCN whose families have higher incomes, the EITC has the potential to address income-based coverage inequities among children generally and CSHCN specifically.

## Increased Medicaid and CHIP Income Eligibility

Medicaid and CHIP (Children's Health Insurance Program) provide coverage to a significant number of CSHCN with low family incomes.<sup>5</sup> However, families whose incomes are just slightly too high to qualify may struggle to pay for private coverage or other cost sharing for health care services. Expanding Medicaid and CHIP coverage to more families can help address income-based inequities that lead to uninsurance. It also can address the need for additional services that private insurance may not cover.

Federal guidelines require all states to extend Medicaid eligibility to children with family income at or below 138% of the federal poverty level (FPL),\* but states can choose to cover children at higher income levels.<sup>6</sup> Increasing the income eligibility level for children's Medicaid can help cover more children.<sup>7</sup> Medicaid coverage is particularly helpful for CSHCN because of its Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, which requires that all medically necessary services be covered.<sup>7</sup> Additionally, CSHCN who are covered through CHIP have better access to health care services than CSHCN who are uninsured.<sup>8</sup> Thus, increasing the Medicaid and CHIP income eligibility levels for children will ensure that more CSHCN have access to health care coverage and, through EPSDT, a more robust array of services. (For more on EPSDT and the Children's Health Insurance Program, see the sidebar on the next page.)

\* The ACA MAGI (Modified Adjusted Gross Income) rule described at § 435.601 and § 435.602 (<http://bit.ly/aca-magi>) allows for a standard 5% income disregard, so we use 138% FPL rather than 133% FPL. More information is available from the Kaiser Family Foundation at <https://kaiserfamilyfoundation.files.wordpress.com/2013/04/8391.pdf>

## Family Opportunity Act (FOA) Medicaid Buy-in

Expanding Medicaid can also help address inequities among CSHCN with disabilities and/or more functional difficulties. Many CSHCN may benefit from the array of services covered by Medicaid, even if they do not qualify based on family income. These options for expanding Medicaid help relieve the financial burden that families with higher incomes also experience when caring for a child with high cost, complex health care needs.

The Family Opportunity Act (FOA) includes a state option to implement a Medicaid Buy-In program for children with disabilities.<sup>9</sup> States can choose to create a pathway to Medicaid eligibility for children who meet certain disability and family income criteria. Specifically, children become eligible for Medicaid through the buy-in program if they:

- Are less than 18 years old
- Have a medical, mental, or behavioral health condition that is described by the listing of impairments for children established by the Social Security Administration<sup>10</sup>
- Have a family income that exceeds the state's Medicaid income eligibility, but is less than 300% of the federal poverty level (FPL)

If the child has other health insurance, Medicaid pays for uncovered services. In addition, as a secondary payer, Medicaid pays for any deductibles, coinsurance, and copayments a family incurs for an eligible child. If a child has no other health insurance, Medicaid will be the sole payer. Under the FOA, states may charge a premium for a family to “buy in” to Medicaid. Because the child will receive full Medicaid benefits, including the federally mandated EPSDT benefit, Medicaid Buy-In programs help ensure children with disabilities receive all medically necessary services while reducing cost-sharing for the family.

## TEFRA/Katie Beckett State Option and Home- and Community-based Services Waivers

The Tax Equity and Fiscal Responsibility Act (TEFRA)/Katie Beckett state option provides states with an additional option to create a pathway to Medicaid for children who:

- Are less than 18 years old
- Have complex health needs
- Require an institutional level of care

### A note about CHIP

The Children's Health Insurance Program (CHIP) is another option states have for providing public health insurance coverage to children. CHIP works similarly to Medicaid (and in some states the two programs are jointly run) and provides coverage for children who do not have access to other affordable insurance and whose family incomes are too high to qualify them for Medicaid. CHIP benefits vary from state to state and may or may not include the comprehensive EPSDT benefit included in Medicaid, depending on the state.<sup>19</sup>

- Have a family income that is too high to qualify for Medicaid

This option allows families to provide care to children in the home, rather than in a nursing home or other institutional setting, as long as the cost of providing Medicaid benefits in the community is equal to or less than the cost of care in a long-term care setting.<sup>11</sup> TEFRA/Katie Beckett provides full Medicaid benefits, which includes EPSDT.

States can also take advantage of home- and community-based services (HCBS) waivers to expand Medicaid to more children. Like the TEFRA/Katie Beckett state option, HCBS waivers allow states to expand Medicaid coverage to children who may not already qualify due to family income and to specific groups of children, such as those with intellectual disabilities or specific diagnoses.<sup>12</sup> These waivers also allow children to receive care in the community, rather than in long-term care settings. Because these HCBS programs are waivers (rather than state options like TEFRA/Katie Beckett), eligible children may also receive additional supports that are not available to all children enrolled in Medicaid (e.g., respite care, home or vehicle modifications).<sup>12</sup>

FOA Medicaid Buy-in programs, TEFRA/Katie Beckett state options, and HCBS waivers for expanding Medicaid to children with complex care needs who otherwise would not qualify for Medicaid can go a long way to reducing inequities based on functional or disability status. Children with the most functional limitations are also more likely to be uninsured.<sup>13</sup> FOA, TEFRA/Katie Beckett, and HCBS waivers can help ensure that children with the most significant health care needs are covered for the services they require.

## The Legal Immigrant and Children's Health Improvement Act (ICHIA)

Health inequities also are linked to immigration status. CSHCN in immigrant families are less likely to have continuous coverage and are more likely to be uninsured.<sup>14</sup> Policies or programs that increase access to coverage and care for CSHCN with a variety of immigration and documentation statuses can help address these inequities.

The Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 (commonly known as “welfare reform”) contained a provision that barred legally residing immigrants from receiving Medicaid for their first five years in the U.S.<sup>15</sup> This exclusion applies to adults and children. However, when the Children's Health Insurance Program (CHIP) was reauthorized in 2009, it contained a state plan option, known as the Legal Immigrant and Children's Health Improvement Act (ICHIA), that allows states to waive this five-year waiting period for immigrant children who are legally residing in the U.S. This state plan option allows states to cover children in Medicaid and CHIP during their first five years in the country.<sup>15</sup> Currently, 30 states and the District of Columbia (DC) cover legally residing immigrant children in their Medicaid and/or CHIP programs during their first five years in the U.S.<sup>16,17</sup>

Waiving the five-year waiting period is an important step in closing gaps in coverage for immigrant CSHCN. In the 30 states that have waived the waiting period and in the District of Columbia (DC), lawfully residing immigrant CSHCN who meet the state's residency and income requirements can receive the comprehensive EPSDT benefit through their state's Medicaid program. For CSHCN, who require more health care services than their peers, a five-year gap in insurance coverage can negatively impact their health and their family's finances. The state plan option to waive the waiting period is a good step toward closing immigration-related coverage inequities that exist among CSHCN.<sup>18</sup>

## CHIPRA Reimbursement for Translation Services

As you may remember from Module 2 (*How do inequities impact CSHCN?*), CSHCN whose parents do not speak English are more likely than those with English-speaking parents to be uninsured or to have inadequate coverage.<sup>19, 20</sup>

The Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 includes a provision that allows states to receive increased reimbursement from the federal government for providing translation or interpretation services in their Medicaid and CHIP programs.<sup>21</sup> Prior to CHIPRA, states received reimbursement from the federal government at a 50% match for translation services. CHIPRA

allows states to receive an increased match of at least 75% for these services.<sup>21</sup> Increased reimbursement for translation and interpretation services gives states more flexibility to provide information, outreach, and enrollment to individuals for whom English is not the primary language, and can help reduce uninsurance rates.

## Questions to Consider

Once you are familiar with some of the policies and programs in your state that impact CSHCN, you can begin to ask specific questions about their content, how they are implemented, and how they might impact inequities in health insurance and financing of care for CSHCN. Some policies or programs may have a direct impact, through specific language or provisions that aim to target inequities. For example, the Affordable Care Act (ACA) contains provisions aimed at increasing the racial and ethnic diversity of the health care work force.<sup>23</sup> Other policies or programs might not focus on reducing inequities, but some of the provisions may do so as an indirect result. For example, the Medicaid expansion provision of the ACA aims to increase coverage for Americans in general, but may have a greater impact on African Americans, who are more likely to be uninsured and low-income.<sup>23</sup>

Think about the type of inequities you want to address before making a decision about strengthening existing policies and/or implementing new ones. Some policies may impact inequities based on race or ethnicity, but will not address inequities based on immigration or documentation status. Here are some questions to consider as you explore policies and programs in your state (as well as U.S. policies) that may impact inequities among CSHCN:

- Does this policy have specific provisions or guidelines around reducing inequities? Is there language in the policy about inequities?
- Is this policy inclusive of children and families from a variety of racial and ethnic backgrounds?
- Does this policy have provisions or guidance around providing culturally competent services?
- If this policy provides funding to community-based organizations or otherwise requires staff, is there guidance around hiring staff from a variety of racial and ethnic backgrounds and/or staff who are representative of the communities served?
- Is this policy specific to low- or moderate-income children or families (e.g., Medicaid, EITC)? If not, does it include financial assistance for low- or moderate-income beneficiaries or provide guidance around how people from different income levels will access and pay for health care services or other supports?

Some policy options that may have the potential to reduce inequities in coverage and financing of care among children with special health care needs in your state include:

- Earned Income Tax Credit (EITC)
- Increased Medicaid Income Eligibility
- Family Opportunity Act Medicaid Buy-In
- TEFRA/Katie Beckett State Option and Home- and Community-based Services Waivers
- The Legal Immigrant and Children’s Health Improvement Act (ICHIA)
- CHIPRA Reimbursement for Translation Services

- Does this policy include rules or guidance around providing coverage or paying for services for children (or other family members) with a variety of immigration and documentation statuses? Is there particular guidance around children (or family members) who have undocumented immigration status?
- Does this policy include guidance on how services will be provided to families who do not speak English or for whom English is not the primary language?
- If this policy is specific to CSHCN (or children with disabilities), does it include provisions or guidance on providing services to children with a variety of disabilities (e.g., children with physical disabilities as well as those with intellectual, developmental, and behavioral health diagnoses)?

Of course, this is not an exhaustive list; there are many questions to consider in understanding whether or how policies might impact inequities. These questions may differ depending on the type of policy, the population targeted, or other circumstances that impact policy and program development in your state.\*

The “Your Turn” section of this module on the next page will help you track whether the policy and program options discussed in this section have been adopted in your state and may provide some ideas for additional policies or programs to consider in addressing insurance coverage and financing inequities among CSHCN.

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\*Contact the Catalyst Center for technical assistance specific to your state. (See sidebar on page 24.)



**WORKSHEET TO ADDRESS INEQUITIES IN YOUR STATE - MODULE 3**

**YOUR TURN: How can policies and programs improve inequities in your state?**

Module 3 contains a list of policies that may help address inequities in coverage and financing of care among children with special health care needs (CSHCN). Complete the following checklist to show which policy options your state has enacted and which might be effective options for your state to consider in moving forward to address inequities. There may also be other community or regional policies or programs in your state that help reduce inequities and that could be replicated in more areas.

**Policy Options that May Address Inequities for Children with Special Health Care Needs in \_\_\_\_\_**

(your state)

Policy	Enacted	Not Enacted	Notes*
<b>State Earned Income Tax Credit</b>  List of states that supplement the federal EITC with state dollars <sup>1</sup>			
<b>Increased Medicaid Income Eligibility</b>  Income eligibility levels for children in each state’s Medicaid and CHIP programs <sup>2</sup>	Every state (including DC) must provide Medicaid to children, age 0 to 19 at income less than 138% FPL. Many states have higher income eligibility.  Your state’s income limits for Medicaid: Ages 0-1: _____% FPL Ages 1-5: _____% FPL Ages 6-18: _____% FPL		
<b>Family Opportunity Act (FOA) Medicaid Buy-In</b>			
<b>TEFRA/Katie Beckett State Plan Option</b>  Visit the Catalyst Center Chartbook to see if your state has a TEFRA option <sup>3</sup>			

\*You may wish to review the list of Questions to Consider on pages 29 - 30 and note any comments or ideas you have.

<sup>1</sup><https://www.irs.gov/Credits-&-Deductions/Individuals/Earned-Income-Tax-Credit/States-and-Local-Governments-with-Earned-Income-Tax-Credit>

<sup>2</sup><http://kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/>

<sup>3</sup><http://chartbook.cahpp.org/>

Policy	Enacted	Not Enacted	Notes*
<p><b>The Legal Immigrant and Children’s Health Improvement Act (ICHIA) Option</b></p> <p>List of states that cover legally residing immigrant children in their Medicaid and/or CHIP programs<sup>4</sup></p>			
<p><b>Other policies/programs in your state</b></p> <p>Ideas might include outreach/enrollment programs or those targeting recruitment of minorities to professional positions. (See the list of Questions to Consider on pages 28-29 for more ideas of policies or programs to consider.)</p>			

<sup>4</sup><http://www.medicaid.gov/medicaid-chip-program-information/by-topics/outreach-and-enrollment/lawfully-residing.html>

\*You may wish to review the list of Questions to Consider on pages 28 - 29 and note any comments or ideas you have.

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LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.



## MODULE 4

# How does the Affordable Care Act (ACA) impact inequities?

## The Impact of Health Reform

The Affordable Care Act (ACA) includes several provisions that may help address inequities in coverage and financing of care among children with special health care needs (CSHCN). In this section, we will review some of these provisions and discuss their impact on the most vulnerable CSHCN.

### Medicaid Expansion

As you may remember from previous modules, Latino CSHCN and those with low family income are more likely to be uninsured than other subgroups of CSHCN.<sup>1</sup> The Medicaid expansion provision of the ACA may improve coverage for these groups and narrow inequities based on race or ethnicity and income.

The Medicaid expansion provision [section 2001(a)(1) of the Affordable Care Act<sup>2</sup>] allows states to expand Medicaid to more low-income adults. Prior to the passage of the ACA, in the majority of states, childless adults ages 19 to 64 were not eligible for Medicaid at any income level, unless the state created a waiver.<sup>3</sup> The ACA's Medicaid expansion provision, which is optional for states, creates a pathway to Medicaid for childless adults who have no disabilities, are not pregnant, and whose income is less than 138% of the federal poverty level (FPL) (about \$27,000 per year for a family of three).<sup>4,5</sup> While parents were a mandatory coverage group for state Medicaid programs prior to the ACA, many states limited a parent's eligibility to those with incomes less than 100% of the FPL (about \$20,000 per year for a family of three<sup>5</sup>). In states that chose to expand Medicaid, parents are now eligible based on the 138% FPL standard.<sup>4\*</sup> As of March 2016, 31 states and the District of Columbia (DC) have implemented the ACA Medicaid expansion. In states that have not chosen to expand their Medicaid programs in this way, many low-income parents may remain uninsured.<sup>5,7</sup>

The new 138% FPL income eligibility standard for all adults means more parents are now eligible for Medicaid coverage in states that expand the program.<sup>8</sup> In 2012, about 12% of children eligible for public coverage (through Medicaid or CHIP programs) were unenrolled.<sup>9</sup> Children are more likely to be enrolled in Medicaid when their parents also are enrolled,<sup>10,11,12</sup> so increased parental enrollment through the Medicaid expansion will impact these eligible, but unenrolled children. About

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\* The ACA MAGI (Modified Adjusted Gross Income) rule described at § 435.601 and § 435.602 (<http://bit.ly/aca-magi>) allows for a standard 5% income disregard, so we use 138% FPL rather than 133% FPL. More information is available from the Kaiser Family Foundation at <https://kaiserfamilyfoundation.files.wordpress.com/2013/04/8391.pdf>

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The Affordable Care Act includes several provisions that may help address inequities in coverage and financing of care among children with special health care needs, including:

- Medicaid expansion
  - Twelve-month continuous eligibility for adults
  - State health insurance Marketplaces
  - Navigators and in-person assistors
-

11% of Latino children have a special health care need and, by definition, they require more health care services than their peers.<sup>1</sup> Latino CSHCN are the most likely of any racial or ethnic group to be uninsured. Among Latino CSHCN, 15.9% are uninsured, compared to 7.3% of white CSHCN and 9.9% of black CSHCN.<sup>1</sup> Thus, coverage gains for Latino parents that extend to their CSHCN will have a positive impact on a group of children for whom access to insurance is a first step to accessing the increased level of care they need.<sup>13</sup> In addition to higher uninsurance rates, Latinos also have lower median incomes and a higher poverty rate than whites,<sup>14</sup> suggesting they may be more likely to benefit from the expansion of public coverage for low-income individuals.

Because of the demonstrated link between parents' coverage and children's enrollment,<sup>10, 11, 12</sup> the optional Medicaid expansion for all adults will likely also have an impact on low-income CSHCN of all racial and ethnic groups who are eligible for, but not enrolled in, Medicaid. Thus, the adult Medicaid expansion may help address inequities among CSHCN based on race or ethnicity and socioeconomic status.<sup>13, 7</sup>

## Twelve-month Continuous Eligibility for Adults

Not only does parents' insurance status impact the insurance status of their child, it also affects the continuity of the child's insurance. Parents who are insured for fewer months are more likely to have uninsured children.<sup>15</sup> In May 2013, the Centers for Medicare and Medicaid Services (CMS) issued a bulletin that outlined five strategies for facilitating enrollment in Medicaid and the Children's Health Insurance Program (CHIP). One of these strategies was a state option to provide twelve-month continuous Medicaid eligibility for parents. This would ensure parents could keep Medicaid benefits for the year regardless of changes in household income or family size. Additionally, if the state also extended twelve-month continuous eligibility for children, it would standardize the renewal dates for the entire family, and minimize gaps in coverage.<sup>16</sup>

Low-income CSHCN are more likely to have inconsistent insurance coverage than those in families with higher incomes.<sup>1</sup> Twelve-month continuous eligibility for parents and children may help address inequities among CSHCN

based on socioeconomic status by improving continuity of coverage among low-income families who are enrolled in public insurance programs.<sup>7</sup>

## State Health Insurance Marketplaces

CSHCN in immigrant families are particularly vulnerable to the negative effects of uninsurance and gaps in coverage.<sup>20</sup> The ACA-created Marketplaces and the availability of financial supports, in the form of tax credits and subsidies, to purchase insurance through them may help address inequities among CSHCN based on immigration status.<sup>23</sup>

The ACA created health insurance Marketplaces (also called "exchanges") where individuals can purchase coverage if they do not have access to affordable, adequate employer-sponsored insurance (ESI). Federal subsidies are available for those with household income between 100% and 400% FPL to help offset the cost of purchasing private insurance policies. As you may remember from Module 3 (*How can policies and programs improve inequities in your state?*), the Personal Responsibility and Work Reconciliation Act (PRWORA) of 1996 prohibited legally residing immigrants from receiving Medicaid for their first five years in the U.S.<sup>19</sup> However, the 2009 reauthorization of the Children's Health Insurance Program (CHIPRA) contained a provision giving states the option to waive this five-year waiting period for immigrant children and pregnant women who are legally residing in the U.S. This state plan option allows states to cover legally residing immigrant children in Medicaid and CHIP,<sup>19</sup> which currently, 29 states do.<sup>20</sup>

In states that have not waived the five-year waiting period, immigrant CSHCN and their parents remain ineligible for public coverage until they have been in the U.S. for at least five years. However, lawfully present parents of CSHCN can purchase insurance for themselves and their child(ren) in the Marketplace and receive federal assistance based on household income.<sup>21</sup> If they are not eligible for Medicaid due to the five-year waiting period, they can still purchase Marketplace coverage and receive subsidies, without a five-year waiting period, if income is less than 100% FPL.<sup>21</sup> Thus, the ACA-created Marketplaces and available subsidies may help address inequities among CSHCN based on immigration status by creating a pathway to coverage for a group of immigrants who previously had few options for affordable coverage.<sup>18</sup>

## Navigators and In-Person Assistors

As described in previous modules, CSHCN from families where English is not the primary language have higher uninsurance rates than those from English-speaking families.<sup>1</sup> The availability of enrollment assistance may help address inequities based on language differences.

The ACA includes funding for navigator entities – often community-based organizations – that provide education, outreach, and enrollment assistance to families as they enroll in public insurance coverage and Marketplace plans. Only about half of parents with limited income believe their CSHCN are eligible for public coverage, but more than 90% of these parents said they would enroll their children if they were eligible.<sup>22</sup> Thus, consumer assistors may help families – especially those with limited income – learn more about whether their child is eligible for coverage and address inequities among CSHCN based on socioeconomic status. Navigators provide culturally competent, accessible information to help individuals and families understand eligibility for Medicaid and CHIP and options for Marketplace health insurance coverage. Navigators can help enroll low-income CSHCN who were already eligible for Medicaid, but remained uninsured because of lack of knowledge or misinformation about eligibility.<sup>23</sup> While all states have consumer assistance programs, in-person assistance is only required in states with partnership Marketplaces and at the state's option in state-based Marketplaces. In-Person Assistors (IPAs) may help address inequities among CSHCN based on language, as families for whom English is not the primary language can work with an IPA who speaks their preferred language. IPAs are not available in states with federally facilitated Marketplaces (although other organizations, such as [Family-to-Family Health Information Centers](#),\* may provide this type of help).

Coverage may improve for Latinos and low-income families in states that have expanded Medicaid, but inequities will persist in states that have not.<sup>4, 13</sup> The adoption of the provision by all 50 states will help further reduce racial/ethnic- and income-related inequities and will also address geographic disparities.

Additionally, while the ACA-created Marketplaces create a new pathway to coverage for immigrant CSHCN and their families, even with tax credits and subsidies, the availability of subsidized Marketplace plans may be too costly for some low-income immigrant families. States that opt to remove the five-year waiting period for lawfully residing immigrant children and pregnant women would create a pathway to public coverage that would help reduce inequities based on immigration status.

## The Future of Health Reform?

While the ACA contains a number of provisions that may address inequities among CSHCN based on race or ethnicity, language, immigration status, or income, gaps still remain and future work advancing health care reform is necessary to make an impact on addressing inequities in coverage and financing of health care.

\*<http://www.familyvoices.org/page?id=0034>

WORKSHEET TO ADDRESS INEQUITIES IN YOUR STATE - MODULE 4



# YOUR TURN: How does the Affordable Care Act (ACA) impact inequities?

Module 4 contains a list of ACA provisions that may help address inequities in coverage and financing of care among children and youth with special health care needs (CSHCN). Complete the following checklist to show which ACA provisions your state has enacted and which might be effective options for your state to consider in moving forward to address inequities.

## ACA Provisions that May Address Inequities for Children with Special Health Care Needs in \_\_\_\_\_ (your state)

Policy	Enacted	Not Enacted	Notes*
<b>Adult Medicaid Expansion</b>  List of states that have expanded Medicaid <sup>1</sup>			
<b>12-month Continuous Eligibility for Children</b>  List of states that have 12-month continuous eligibility for children in their Medicaid and/or CHIP programs <sup>2</sup>			
<b>In-person Assisters</b>  What type of ACA Marketplace each state runs <sup>3</sup>  List of consumer assistance organizations in each state <sup>4</sup>	In-person assisters (IPAs) are available in state-partnership Marketplaces and some state-based Marketplaces. Navigators (but not IPAs) are available in federally facilitated Marketplaces.  Type of Marketplace: _____		

\*You may wish to review the list of Questions to Consider on pages 28 - 29 and note any comments or ideas you have.

<sup>1</sup><http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>

<sup>2</sup><http://www.medicaid.gov/medicaid-chip-program-information/by-topics/outreach-and-enrollment/continuous.html>

<sup>3</sup><http://kff.org/health-reform/state-indicator/state-health-insurance-marketplace-types/>

<sup>4</sup>[http://www.statecoverage.org/files/KidsWell\\_Helping\\_Consumers\\_Enroll.pdf](http://www.statecoverage.org/files/KidsWell_Helping_Consumers_Enroll.pdf)

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LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.



## MODULE 5

# How can you partner with other stakeholders to address inequities?

## The Importance of Partnerships

Our health care landscape is very complicated – families need information and support from family leaders, providers, and others in the health care system to ensure that they understand the services to which they are entitled and how to navigate the system. However, it is also integral that professionals get input from families about their experiences with the system of care. Partnership means a two-way flow of information and collaboration between families and professionals (which includes providers, public and private payers, policy makers, and family leaders).

## Who Can You Partner With?

This section provides information on national and state-based organizations that focus on partnerships to improve coverage and financing for children with special health care needs (CSHCN) and to reduce health inequities.<sup>1</sup> You may be able to partner with the organizations listed in this section to improve coverage and care for and reduce inequities among CSHCN in your state. In fact, you may already have connections with these organizations in your state that you can strengthen or draw from to create opportunities for reducing inequities.

### Family Voices

Family Voices is a national organization that provides extensive information and support to families of CSHCN around their health care and other service needs. Family Voices also provides information and training to family leaders around the country to support them in working directly with families and advocates to improve local-, state-, and federal-level policies that impact CSHCN and their families.<sup>2</sup> For more information, visit the Family Voices website at <http://www.familyvoices.org>

### National Center for Family/Professional Partnerships (NCFPP)

The National Center for Family/Professional Partnerships (NCFPP) is a project of Family Voices that provides technical assistance to families, family leaders, and other professionals around fostering family/professional partnerships to improve care for CSHCN.<sup>3</sup> NCFPP focuses on the importance of partnerships for improving outreach to diverse families of CSHCN, fully implementing provisions

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You may already have connections with the organizations listed in this section to improve coverage and care for and reduce inequities among CSHCN in your state:

- Family Voices  
<http://www.familyvoices.org>
  - National Center for Family/Professional Partnerships (NCFPP)  
<http://www.fv-ncfpp.org/>
  - Family-to-Family Health Information Centers (F2Fs)  
<http://www.familyvoices.org/page?id=0034>
  - State Offices of Minority Health  
<http://www.nasomh.org>  
(National Association of State Offices of Minority Health)
-

of the Affordable Care Act (ACA), and strengthening the primary care workforce to be more family-centered. Among a variety of other organizations, NCFPP provides technical assistance to Family-to-Family Health Information Centers (F2Fs) throughout the country.<sup>3</sup> For more information, visit the NCFPP website at <http://www.fv-ncfpp.org/>

## Family-to-Family Health Information Centers (F2Fs)

Each state and the District of Columbia (DC) has an F2F, which provides information and outreach to families of CSHCN to help them make informed health care-related decisions. F2Fs also partner with health care and other organizations as well as government agencies to advocate for collaboration between families and professionals.<sup>4</sup> F2F staff members are family members of CSHCN who have first-hand knowledge about how to navigate complex health care systems.<sup>4</sup>

From 2013-2014, F2Fs throughout the country served more than a million families and almost 400,000 professionals.<sup>4</sup> F2Fs serve a racially diverse array of families, with about 40% of those served being families of color.<sup>4</sup> Additionally, 65% of F2Fs are involved in initiatives around cultural and linguistic competence and 55% are involved in initiatives around immigrant families and families of diverse cultures.<sup>4</sup> F2Fs represent an opportunity in each state to ensure collaboration among diverse families of CSHCN and organizations, state agencies, policy makers, and providers to ensure that the needs of diverse CSHCN are being met. For more information, visit the F2F section of the Family Voices website at <http://www.familyvoices.org/page?id=0034>

## State Offices of Minority Health

The Federal Office of Minority Health (OMH) focuses on health policies and programs to reduce racial and ethnic health disparities throughout the U.S. OMH provides funding to community-based organizations, distributes information to improve awareness about health disparities, and fosters partnerships that help improve health and reduce disparities.<sup>5</sup> Additionally, each state has its own Office of Minority Health. These offices perform many of the same tasks as OMH, but at the state level, and often have more direct connection to their state's health care workforce and

may have fostered partnerships within communities throughout their state.<sup>5</sup> For more information, visit the National Association of State Offices of Minority Health website at <http://www.nasomh.org/>

## Partnerships to Address Inequities

This section provides examples of state-based organizations that have utilized partnerships to create or strengthen programs that address inequities among CSHCN. These examples may provide inspiration for new or innovative programs that could be created or expanded in your state. Contact information available in the links in the “Your Turn” section of this module on page 44 can also help you connect with other organizations with whom you may partner to create similar innovative programs to address inequities among CSHCN.

### Arkansas Disability Coalition

The F2F organization in Arkansas, the Arkansas Disability Coalition, partnered with two elementary schools in the Little Rock School District to provide cultural competency training to better equip the school district to provide support to Latino families.<sup>6</sup> This program has reportedly increased awareness of available health care services and supports among Latino families and has increased the school district's understanding of the needs of local Latino communities.<sup>6</sup> By increasing awareness and improving support for Latino families, this partnership may help address the high uninsurance rates among Latino CSHCN.<sup>7</sup>

### Oregon Family-to-Family Health Information Center

The Oregon F2F conducts regular family gatherings with diverse families of CSHCN – specifically with Latino families and those from rural areas. Oregon F2F partners with other community-based organizations to host these gatherings at local venues that are familiar to and comfortable for diverse families.<sup>5</sup> At these gatherings, Oregon F2F staff members share information with families about the extensive network of family groups and professional organizations within the state. These meetings allow Latino families and those from rural areas, who may be more secluded from other families and services, to connect with one another and to learn about

services and supports that are available in their county.<sup>5</sup> Thus, this program helps address inequities by expanding outreach and information to some of the most vulnerable groups of CSHCN. Because Latino CSHCN are more likely than other CSHCN to be uninsured,<sup>6</sup> this increased outreach may help increase insurance rates and close racial gaps in coverage.

### Alaska Title V CSHCN Program

The Alaska CYSHCN program staff received reports from health care providers in some of the rural villages that some children were entering school with limited language competency and were demonstrating behavioral challenges such as self-regulation, cooperative play, and following directions. They found that within the tribal communities, especially in rural locations, parents are not readily alarmed when their children do not speak fluently by school age. This is because, within the Alaska Native culture, adults oftentimes will talk for their children, and as long as a child is participating in cultural activities, parents are not as concerned. As a part of the neurodevelopmental and autism screening clinic, the Title V parent services manager offered community education sessions in the rural villages and talked about autism spectrum disorders as well as other common elements of developmental delays. These community sessions continue to be offered in each community with every Neurodevelopmental/Autism Screening Clinic. The community work helped to normalize the screening process and increased the understanding of what it meant to have a possible autism or developmental delay diagnosis. With a better understanding in the community, there was a sharp increase in the number referrals to the screening clinics with a notable increase in the number of children 0-3 years. This resulted in an increase in the number of referrals to the early intervention program. The ongoing outreach clinics are offered in 8-10 communities annually and help to facilitate ongoing communication and collaboration between the health provider community, the early intervention programs, public health nursing, early head start and the Title V/ CYSHCN program. This collaboration has resulted in a decrease in the age of children who need to be referred to the diagnostic clinic in Anchorage, an increase in the number of children identified prior to kindergarten, and an increase in the number of qualified children receiving intervention in the early intervention program in their home community. The improved outcomes helped to inform the legislature who passed a law to annually appropriate dollars to support

intensive intervention services for children diagnosed with autism. Regulations and development of licensing and credentialing procedures for Applied Behavior Analysis (ABA) therapists are underway in Alaska to support this new service.

### Minnesota Title V CSHCN Program

The Minnesota CSHCN program hires staff that is representative of the populations to whom they provide services. Currently, they are working with the Somali population around autism and connections to services including insurance coverage. They have formed a Somali public health advisors group that helps Title V staff identify emerging health issues in the Somali community. These advisors also connect with families to identify their needs and build trust between the health department and families in underserved populations.

In addition, to facilitate connections to families from diverse communities, Title V staff has partnered with the Minnesota Family-to-Family Health Information Center to identify other new family leaders. Prior to the Affordable Care Act, the Title V program also had partnerships with community-based organizations that provide services to culturally diverse families and those who speak languages other than English. Many of these organizations now serve as navigator or consumer assistor entities. So while Title V does not have a direct partnership with the Minnesota Health Benefits Marketplace, their partnerships with these community-based organizations helps ensure that underserved families raising CSHCN have access to information and benefits counseling around insurance coverage.

### Michigan Title V and CSHCN Program

Beginning in 2010, the Michigan Department of Community Health, Bureau of Family, Maternal and Child Health made a commitment to examine their work through a “health equity lens” in response to disparities in infant mortality rates among Whites, Blacks, and American Indians. The PRIME (Practices to Reduce Infant Mortality through Equity) initiative, funded by the W.K. Kellogg foundation, is an intra- and inter-agency effort to raise awareness of institutional racism, increase cultural competence, and build the capacity of the state health department, including the Children’s Special Health Care Services (CSHCS) program, to reduce health disparities. The

CSHCS program engaged in these efforts by taking self-assessments, participating in health equity learning labs, developing and implementing health equity plans, and working with Medicaid to remove barriers to covered services.

## North Dakota Medicaid

In order to ensure Native Americans are aware of Medicaid and CHIP program eligibility for their children, the North Dakota Healthy Steps program contracts with a vendor that specializes in Native American outreach. Good Health TV is one of their outreach initiatives. Good Health TV is a health and wellness network that broadcasts in the Indian Health Services and other tribal clinics across the state, and promotes health-related topics specific to Native Americans. This specialized vendor has produced two creative video segments to air on the network promoting Medicaid and Healthy Steps. They also employ a Native American woman who provides, “boots on the ground” outreach to the community, specifically to tribal employers. In addition to her work with employers, she conducts outreach and helps families enroll in coverage at job fairs. She also assists schools with outreach and enrollment as part of their back-to-school campaigns.

## Conclusion

Partnerships are important for reducing inequities among CSHCN for several reasons. Professional partnerships between Title V and Medicaid programs may help ensure that the information families receive is coordinated, while partnerships with policy makers can ensure that the needs of CSHCN are addressed in federal- and state-level health policies. Partnerships among F2Fs, community-based organizations, and informal networks, such as faith-based organizations or schools, may facilitate outreach to more vulnerable families who do not already have strong connections to the health care system. These partnerships can also help promote cultural competency when they include organizations or family leaders who can make sure that communication is provided in families’ preferred language(s) and is accurate and trustworthy. Finally, organizations that partner directly with families ensure that the real needs of families are heard and met. Innovative partnerships can be a vehicle for providing outreach and information to the most vulnerable families, who may not receive the services and supports they need using traditional outreach methods.<sup>1</sup>

WORKSHEET TO ADDRESS INEQUITIES IN YOUR STATE - MODULE 5



## YOUR TURN: How can you partner with other stakeholders to address inequities?

Module 5 provided you with some information about family/professional partnerships to address inequities among CSHCN. The examples from Arkansas, Oregon, Alaska, Minnesota, Michigan, and North Dakota may inspire similar initiatives in your state. There are various opportunities for partnerships that may help address the specific needs of CSHCN and may support innovative strategies to reduce inequities. Use the table below to explore organizations with whom you may partner to improve coverage and financing of care for CSHCN in your state.

### Opportunities for Partnerships in \_\_\_\_\_ (your state)

Family Voices (national)	National Center for Family/Professional Partnerships	Family-to-Family Health Information Center (F2F)	State Offices of Minority Health	Other Organizations in Your State
More information on Family Voices <sup>1</sup>	More information on the National Center for Family/Professional Partnerships <sup>2</sup>	Use this list of F2F organizations <sup>3</sup> to identify the F2F in your state.  <b>Your state's F2F:</b>  _____	Use this interactive map <sup>4</sup> to identify the state office of minority health in your state.  <b>Your state's office of minority health:</b>  _____	

<sup>1</sup><http://www.familyvoices.org/>

<sup>2</sup><http://www.fv-ncfpp.org/>

<sup>3</sup><http://www.fv-ncfpp.org/f2fhic/find-a-f2f-hic/>

<sup>4</sup><http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=2&lvlid=6>

Now, take a look back at the “Your Turn” section for Module 3: *How can policies and programs improve inequities in your state?* on pages 30 - 31. Were there any policies or programs to reduce inequities that your state has **not enacted**? If so, you can use the below table to fill those in and think about which organizations or stakeholders you might partner with in your state to get these or similar programs enacted.

**Policies and Programs Enacted/Not Enacted in \_\_\_\_\_**  
(your state)

Policy	Enacted	Not Enacted	Potential Partners for Planning/Future Enactment
<b>State Earned Income Tax Credit (EITC) Program</b>			
<b>Increased Medicaid Income Eligibility</b>	Every state (including DC) must provide Medicaid to children, age 0 to 19 at income less than 138% FPL. Many states have higher income eligibility.  Your state's income limits for Medicaid: Ages 0-1: _____ % FPL Ages 1-5: _____ % FPL Ages 6-18: _____ % FPL		
<b>TEFRA/Katie Beckett State Plan Option</b>			
<b>The Legal Immigrant and Children's Health Improvement Act (ICHIA) Option</b>			

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5. Office of Minority Health. (2015). *About the Office of Minority Health*. Retrieved from: <http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=1&lvlid=1>
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7. Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved from <http://www.childhealthdata.org>

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>

### Suggested citation:

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LCDR Leticia Manning, MPH, MCHB/HRSA Project Officer.



## MODULE 6

# How can you evaluate your efforts?

Congratulations on making it to Module 6! Modules 1 through 5 covered a lot of material that we hope you will be able to use in working to reduce inequities in coverage and financing of care for children with special health care needs (CSHCN). Once you've implemented a program, policy, ACA provision or other strategy, you may want to assess the impact of your efforts to address and mitigate health insurance coverage and financing inequities among CSHCN in your organization or state.

If you have not yet arrived at the implementation stage – that's okay. You can use the questions to help identify an outcome measure that will help you quantify progress toward your goal to reduce any health insurance coverage and financing inequities-related issues you identified in the Module 2 section of your worksheet (Page 22 in Module 2 or page 4 in the [complete worksheet](#)). For example, choosing a desired outcome, such as increasing the percent of lawfully present immigrant CSHCN who are insured or increasing adequacy of health insurance for CSHCN with the most functional difficulties, may help inform the policy, program, ACA provision, or other solution you want to implement.

The complete interactive worksheet can be found on the web at <http://cahpp.org/inequities-tutorial-worksheet.pdf>. This worksheet contains the "Your Turn" sections from Modules 1 through 5 that were included in the tutorial. These sections guide you as you examine current data and identify an inequities-related issue in your state. The worksheet also contains a final section titled *Putting It All Together* which is designed to help you formulate a strategy to implement and identify the stakeholders with whom you could partner to address inequities.

As you begin to implement your strategy, it is helpful to identify a set of questions that may help you to evaluate the impact of your efforts. On the next page you will find examples of questions that may inform your work.

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### Share Your Successes!

The Catalyst Center is eager to hear from our partners about what's working!

If you've implemented a policy, program, ACA provision, or other strategy to address health insurance coverage or financing inequities among CSHCN in your state or have made other progress towards reducing inequities that you would like to share, please send a paragraph or two about what you accomplished (and how you did it) to us at [cyshcn@bu.edu](mailto:cyshcn@bu.edu).

With your permission, we would love to share your success on our website and via our monthly email updates!

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## Sample Evaluation Questions

Below are examples of the types of questions that may aid your efforts to evaluate the impact of the policy, program, ACA provision, or other strategy you implemented.

1. State the goal or outcome measure you hope to achieve. (Example: Increase the percent of families who report their insurance is adequate to meet the needs of their children with the most functional difficulties.)

2. Briefly state the policy, program, ACA provision, or other strategy you implemented (or plan to implement) to reduce inequities in your state or organization. (Example: Implement a FOA Medicaid buy-in program to increase adequacy of coverage for children with the most functional difficulties whose family income is too high for Medicaid but less than 300% FPL.)

3. Identify a data source to use in measuring progress toward achieving your outcome measure. For example, you might partner with your state's Medicaid program to monitor and report on enrollment data in a new Family Opportunity Act (FOA) program. You might survey families to better understand the impact of the program on access to care, family finances, and employment choices.

4. What do the data tell you about how useful this policy, program, ACA provision, or other strategy was in advancing the outcome measure you identified in question 1?

- Extremely useful
- Very useful
- Useful
- Somewhat useful
- Not useful

5. Describe any additional benefits or outcomes that resulted from the policy, program, ACA provision, or other strategy you implemented. (For example, implementing a FOA Medicaid buy-in may also decrease inequities in health insurance coverage among CSHCN with the most functional difficulties by race. Potential outcome measures may include: 1) Increased percent of black and Latino CSHCN whose insurance is adequate; 2) Decreased percent of black and Latino families raising CSHCN with the most functional difficulties who report their out-of-pocket expenses are unreasonable.)

6. What new partnerships did your organization or state develop (or how did you strengthen existing partnerships) in your efforts to reduce health insurance coverage and financing inequities among CSHCN in your organization or state? (Potential process measure: number of new or strengthened inter-organizational partnerships.)

7. Lessons learned (in other words, what would you do differently next time)?

8. If you are a Title V program, which, if any, programs, policies, ACA provisions, or other strategies can serve as an evidence-based strategy to advance one or more of the National Performance Measures (example, NPM #15 – adequate health insurance)?

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### Let us Know What You Think

As part of the Catalyst Center’s efforts to assess the impact of our work, we welcome feedback about how helpful this tutorial was in addressing health insurance coverage and financing inequities for CSHCN in your organization or state.

Please take 10 minutes to fill out the survey at the link below. Your responses are anonymous.

Catalyst Center Follow-Up Impact Assessment Survey:  
<https://bostonu.qualtrics.com/>

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## Putting It All Together

After reviewing Modules 1 and 2, you identified an inequities-related issue or issues that exist within your state and looked at data regarding uninsurance among certain groups of children with special health care needs (CSHCN) to uncover issues around inequities that may exist in your state. After reviewing Modules 3 and 4, you identified ACA provisions and other policies that have been enacted in your state that may help address inequities as well as additional ACA provisions and other policy options your state might consider enacting in the future. Finally, after reviewing Module 5, you identified organizations in your state that you have partnered or might considering partnering with to address inequities among CSHCN. Armed with your new knowledge, go to the Section titled “Putting It All Together” in the [worksheet](#) (page 10 in the complete worksheet; this worksheet can be found at <http://cahpp.org/inequities-tutorial-worksheet.pdf>) and summarize the issues you have discovered in your state and what additional information you need to move forward. The Catalyst Center exists to support your efforts -- please enlist our help in addressing these barriers. Together we can create a fairer outlook on health and life for all children with special health care needs.

Please contact the Catalyst Center at [cyshcn@bu.edu](mailto:cyshcn@bu.edu) with your questions about

- Specific policies enacted in your state and how they work
- How policies in your state may impact inequities
- Insurance coverage and financing of care for children with special health care needs

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## ABOUT THE WORKSHEET:

# Putting it all together to address inequities in your state

## Policy and Program Opportunities to Improve Health Care Coverage and Financing for Children with Special Health Care Needs: Find Out in Your State

This tutorial is designed to help identify the policy and program opportunities in your state to improve health care coverage and financing for children with special health care needs (CSHCN). It is intended to be used together with an interactive worksheet that can help you apply the information presented.

The complete interactive tutorial worksheet, including the “Your Turn” section for each module, is available online. To fill out the complete worksheet for all modules electronically, please follow these instructions:

1. Locate the link to the complete interactive worksheet at <http://cahpp.org/resources/inequities-tutorial> (Direct link to the pdf file: <http://cahpp.org/inequities-tutorial-worksheet.pdf>)
2. Save the pdf file containing the interactive worksheet to your computer.
3. As you work through each section of the tutorial, fill out the corresponding section of this worksheet for your state.
4. Save the completed worksheet on your computer.

Download the interactive tutorial worksheet, which includes the “Your Turn” section of each module, at <http://cahpp.org/inequities-tutorial-worksheet.pdf>

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### We welcome your feedback.

Please let us know what you think about the tutorial and worksheet. Specifically:

- Was it helpful for you in understanding coverage and financing inequities among CSHCN?
- Did you gain a clearer conceptualization of what these inequities might look like in your state?
- Have you strengthened or created new policies or programs to address inequities in your state?

We rely on your feedback to improve our work.

Please take 10 minutes to complete a quick, anonymous survey at <https://bostonu.qualtrics.com/>

or send comments to [cyshcn@bu.edu](mailto:cyshcn@bu.edu)

Thank you!

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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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