



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

A TUTORIAL TO ADDRESS INEQUITIES

ACKNOWLEDGMENTS

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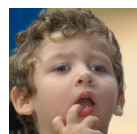
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INTRODUCTION

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.^{1, 2, 3} A growing body of literature explores these differences among CSHCN specifically.^{4, 5, 6, 7, 8, 9} 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

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.

- 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.

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

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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.¹ **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).**^{2,3}

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).**^{2,3} **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).**²

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.⁴

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.”⁵ 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

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

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.⁶ 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.**⁶

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.⁵ 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.”⁷

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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