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

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

- **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,[1] 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.[2] 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).[1, 3] Individuals without children also qualify, but at lower incomes – up to $20,000 per year, depending on marital status.[1] 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.[1]

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.[1] 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.[4] 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.[5] 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.[6] Increasing the income eligibility level for children's Medicaid can help cover more children.[7] 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.[7] Additionally, CSHCN who are covered through CHIP have better access to health care services than CSHCN who are uninsured.[8] 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.[9] 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[10]
- 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.[19]

- 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.[11] 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.[12] 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).[12]

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.[13] 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.[14] 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.[15] 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.[15] 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.[16 17]

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.[18]

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.[19, 20]

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.[21] 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.[21] 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.[23] 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.[23]

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.

*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*
State Earned Income Tax Credit List of states that supplement the federal EITC with state dollars[1]			
Increased Medicaid Income Eligibility Income eligibility levels for children in each state's Medicaid and CHIP programs[2]	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		
Family Opportunity Act (FOA) Medicaid Buy-In			
TEFRA/Katie Beckett State Plan Option Visit the Catalyst Center Chartbook to see if your state has a TEFRA option[3]			

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

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

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

[3] http://chartbook.cahpp.org/

Policy	Enacted	Not Enacted	Notes*
The Legal Immigrant and Children's Health Improvement Act (ICHIA) Option List of states that cover legally residing immigrant children in their Medicaid and/or CHIP programs[4]			
Other policies/programs in your state 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.)			

[4]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.

References

1. Center on Budget and Policy Priorities. (2015). *Policy basics: The Earned Income Tax Credit.* Retrieved from http://www.cbpp.org/cms/?fa=view&id=2505

2. National 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://childhealthdata.org

3. Internal Revenue Service. (2016). 2016 EITC income limits, maximum credit amounts and tax law updates. Retrieved from https://www.irs.gov/Credits-&-Deductions/Individuals/Earned-Income-Tax-Credit/EITC-Income-Limits-Maximum-Credit-Amounts-Next-Year

4. Arno, P. S., Sohler, N., Viola, D., & Schechter, C. (2009). Bringing health and social policy together: The case of the earned income tax credit. *Journal of Public Health Policy, 30*(2), 198-207.

5. Centers for Medicare and Medicaid Services. *The Children's Health Insurance Program (CHIP).* Retrieved from https://www.healthcare.gov/medicaid/chip/childrens-health-insurance-program/

6. Centers for Medicare and Medicaid Services. *Children.* Retrieved from http://www.medicaid.gov/medicaid-chip-program-information/by-population/children/children.html

7. Kaiser Family Foundation. (2014). *Children's health coverage: Medicaid, CHIP and the ACA.* Washington, D.C.: Rudowitz, R., Artiga, S., & Arguello, R.

8. Zickafoose, J. S., Smith, K. V., & Dye, C. (2015). Children with special health care needs in CHIP: Access, use, and child and family outcomes. *Academic Pediatrics*, 15(3), S85-S92.

9. Deficit Reduction Act of 2005 (2006). Chapter 6—Other provisions, Subchapter A—Family Opportunity Act. Section 6061: Opportunity for Families of Disabled Children to Purchase Medicaid Coverage for Such Children. Public Law 109-171

10. Social Security Administration. (2015). Disability evaluation under social security: Listing of impairments, childhood listings. Retrieved from http://www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm

11. Catalyst Center. (2012). *The TEFRA Medicaid state plan option and Katie Beckett waiver for children – Making it possible to care for children with significant disabilities at home.* Boston, MA: Catalyst Center. Retrieved from http://cahpp.org/resources/resourcestefra-medicaid-state-plan-option-katie-beckett-waiver-children/

12. Centers for Medicare and Medicaid Services. H*ome & Community-Based Services 1915 (c).* Retrieved from http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-c.html

13. Honberg, L. E., Kogan, M. D., Allen, D., Strickland, B. B., & Newacheck, P. W. (2009). Progress in ensuring adequate health insurance for children with special health care needs. *Pediatrics, 124*(5), 1273-1280.

14. Javier, J. R., Huffman, L. C., Mendoza, F. S., & Wise, P. H. (2010). Children with special health care needs: How immigrant status is related to health care access, health care utilization, and health status. *Maternal and Child Health Journal, 14*(4), 567-579.

15. National Health Law Program. (2013). *Q & A on ICHIA: The Legal Immigrant Children's Health Improvement Act.* Washington, D.C.: Youdelman, M.

16. Kaiser Family Foundation. (2015). *Medicaid and CHIP income eligibility limits for children as a percent of the Federal Poverty Level*. Retrieved from http://kff.org/health-reform/state-indicator/medicaid-and-chip-income-eligibility-limits-for-children-as-a-percent-of-the-federal-poverty-level/

17. Georgetown University Health Policy Institute. (2016). *CHIP and Health Coverage for Lawfully Residing Children.* Retrieved from http://ccf.georgetown.edu/wp-content/uploads/2015/06/ichia_fact_sheet.pdf

18. Javier, J. R., Huffman, L. C., Mendoza, F. S., & Wise, P. H. (2009). Children with special healthcare needs: How immigrant status is related to health care access, health care utilization, and health status. *Maternal and Child Health Journal*, 14, 567-579.

19. Yu, S. M., Nyman, R. M., Kogan, M. D., Huang, Z. J., & Schwalberg, R. H. (2004). Parent"s language of interview and access to care for children with special health care needs. *Ambulatory Pediatrics, 4*(2), 181-187.

20. Yu, S. M., & Singh, G. K. (2009). Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics,* 124, S414-S419.

21. Centers for Medicare and Medicaid Services. (2010). Memo to state Medicaid directors and health officials: Increased federal matching funds for translation and interpretation services under Medicaid and CHIP. Retrieved from http://downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SHO10007.pdf

22. Aligning Forces for Quality. (2011). *Disparities reduction and minority health improvement under the ACA.* Washington, D.C.: Cartwright-Smith, L., Rosenbaum, S., & Mehta, D.

23. Joint Center for Political and Economic Studies. *Health reform at the crossroads: Will the Affordable Care Act help eliminate health inequities?* Washington, D.C.: Smedley, B. D.

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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