

HEALTH CARE COVERAGE INEQUITIES AND CHILDREN WITH SPECIAL HEALTH CARE NEEDS

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CSHCN Definition

- “Children 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”

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P., Perrin, J., Shonkoff, J., and Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*. 102:137-140.



MCHB Core Outcomes

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



CSHCN Prevalence



19.4% of children under 18



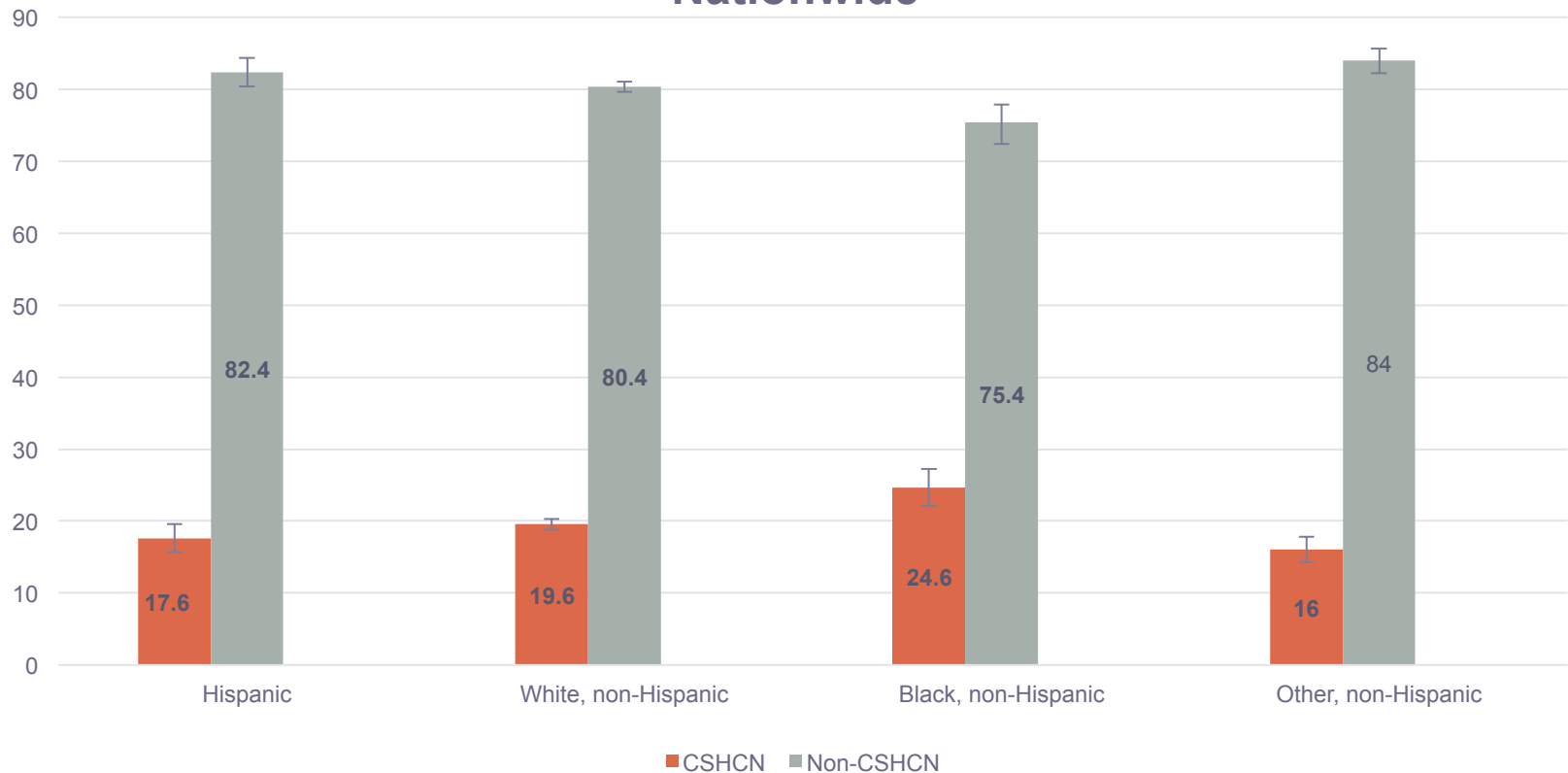
Data Resource Center. (2017) National Survey of Children's Health. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 11/25/17 from www.childhealthdata.org.

CSHCN Demographics

National Survey for Children's Health 2016

Children with special health care needs
Children age 0-17 years

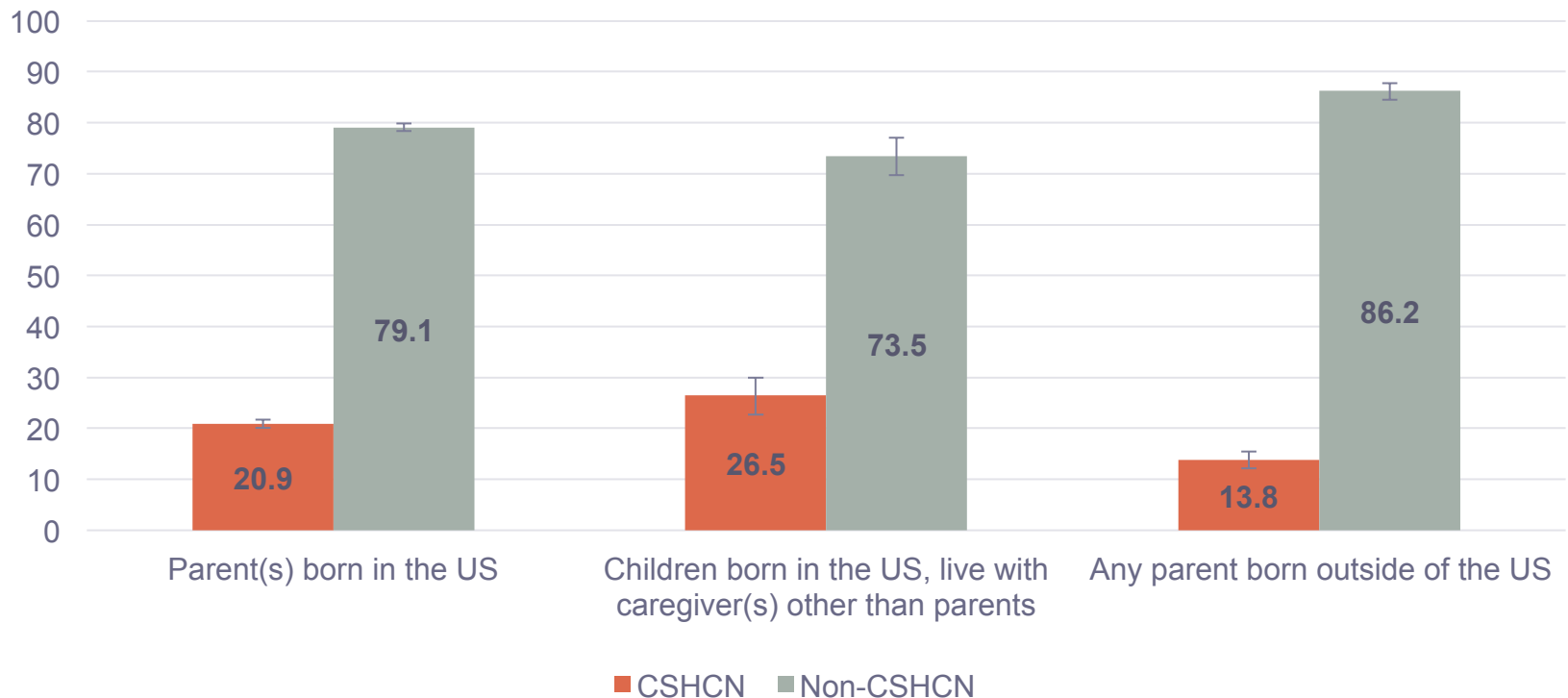
Nationwide



Data Resource Center. (2017) National Survey of Children's Health. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 11/25/17 from www.childhealthdata.org.

CSHCN: Parental Nativity National Survey for Children's Health 2016

Children with special health care needs
Children age 0-17 years
Nationwide



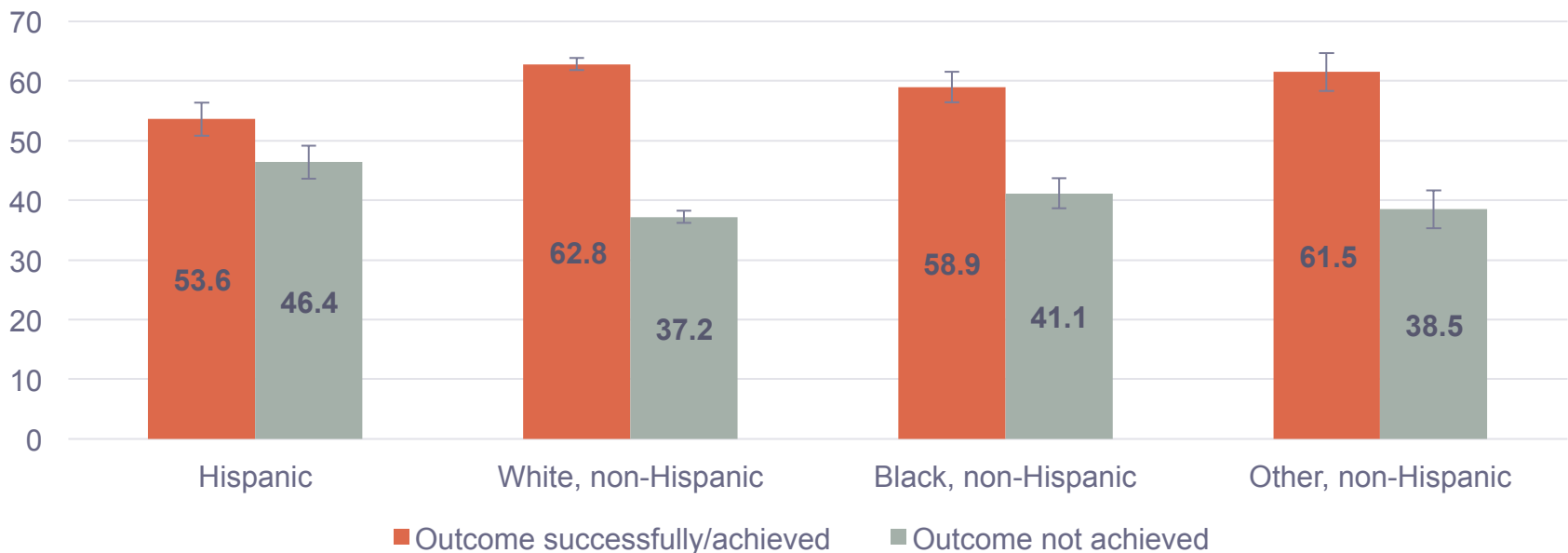
Data Resource Center. (2017) National Survey of Children's Health. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 11/25/17 from www.childhealthdata.org.

CSHCN Health Care Coverage Inequity

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

Outcome #3 CSHCN whose families have consistent and adequate private and/or public insurance to pay for the services they need

CSHCN age 0-17 years
Nationwide



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 11/25/17 from www.childhealthdata.org.

The Catalyst Center

- **Focuses on services and supports for CSHCN**
- **Provides technical assistance** about health care financing policy, practice, and implementation
- **Conducts policy research** to identify and evaluate financing innovations
- **Creates resources** such as our **State-at-a-Glance Chartbook**, **value-based purchasing primer**, **Medicaid and CHIP tutorial**, **Inequities Tutorial**, **webinars**, and more
- **Connects those interested in working together** to address complex financing issues

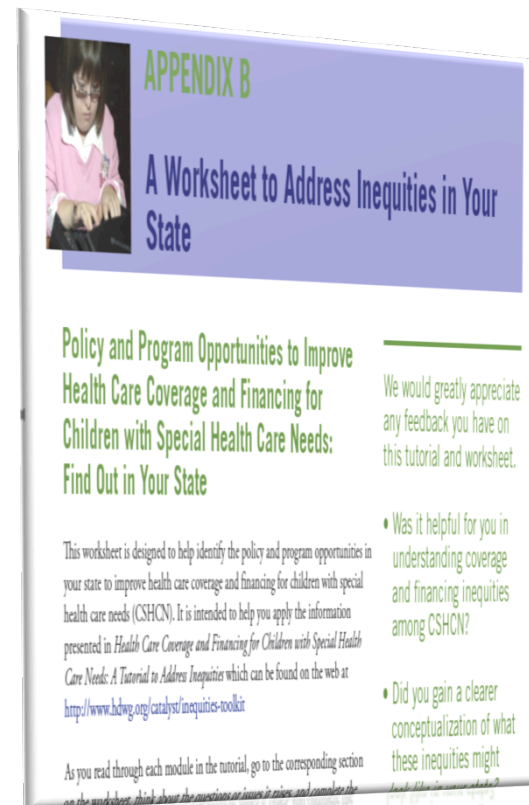
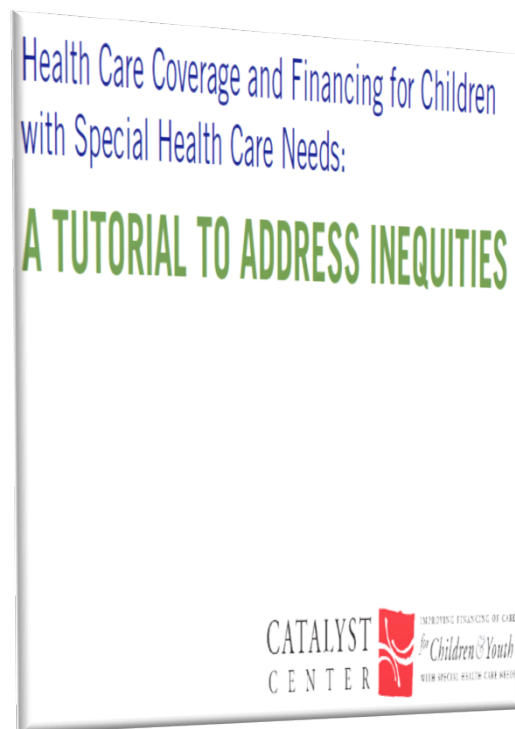


Inequities In Health Care Coverage among CSHCN

- Dimensions of Health Care Coverage Inequities
 - Household Income
 - Race/Ethnicity
 - Functional Status
 - Age
 - Primary Household Language
 - Immigration Status
 - Others
- Develop an agenda focused on inequities



Catalyst Center Resource: *Health Care Coverage and Financing for CSHCN: A Tutorial to Address Inequities*



Today's Presentation

- Results of:
 - Interviews with state OMH staff
 - Focus groups with members of the Somali community in Boston



Context for Today's Presentation

- Recognize our roles of power and privilege
- Training on cultural humility
- Collaborate with cultural broker
- Thank you to the women who shared their stories and our hard working community partners

Yeager, K. A., and Bauer-Wu, S. (2013). Cultural humility: Essential foundation for clinical researchers. *Applied Nursing Research : ANR*, 26(4), 10.1016/j.apnr.2013.06.008. <http://doi.org/10.1016/j.apnr.2013.06.008>



Office of Minority Health Interviews

- **Project Overview**

- Gather data from state officials who may not work specifically with CSHCN to identify general policies or programs that may impact CSHCN inequities.
- The Catalyst Center attempted to conduct interviews with staff from Offices of Minority Health (OMH) in all 50 states and the District of Columbia.
- Companion interviews to our regular interviews with Title V, Medicaid and Family leaders.



Office of Minority Health Interviews

- Methods
 - OMH staff invited to participate through email
 - Phone interviews guided by semi-structured protocol
 - Responses from 12 states



Office of Minority Health Interviews

- General Themes
 - Variety of structures for state OMHs
 - Office structure affects how they operate and with whom they collaborate
 - Most states have tailored interventions and outreach to address inequities
 - Few address coverage and financing
 - Very few address inequities in financing and coverage specifically for CSHCN



Office of Minority Health Interviews

- General Themes
 - OMHs undergoing organizational development and internal reflection
 - OMH Staff Training
 - Cultural competency workshops
 - Reviewing equity and racial justice policies



Somali Family Focus Groups- Background

- Little work on health care financing inequities among CSHCN
- Critically important to understand variations in experiences by race, ethnicity, culture and other characteristics
- Begin to explore topic with a specific population in Boston area
- Cultural broker to help us
- Process as important as outcome



Somali Family Focus Groups

- **The purpose of this research was to hear from Somali parents and caregivers of CSHCN about:**
 - Barriers the family may have faced in getting and maintaining health insurance and/or paying for care;
 - Resources or specific services they may have received that have helped your family overcome barriers; and
 - Continued barriers they may face, and what more can be done to support the family.



Somali Family Focus Groups - Methods

- Recruited cultural brokers
 - Two Somali women heavily involved in Boston's Somali community
- Naima was an essential partner:
 - Critical review of focus group guide
 - Translated materials
 - Developed and implemented recruitment plan
 - Convened focus groups along with an assistant
 - Advised on interpreting results



Somali Family Focus Groups - Methods

- **Focus Groups 1 and 2**
 - Mid July 2017 at a local Mosque
- **Focus Groups 3 and 4**
 - Late December 2017 at same local Mosque



Somali Family Focus Group

- Lessons Learned:
 - A cultural broker with strong community ties is essential
 - Bridging the community/research connection
 - Make time for relationship building
 - Trust and understanding
 - Strong communication skills
 - Trial and error; cultural humility

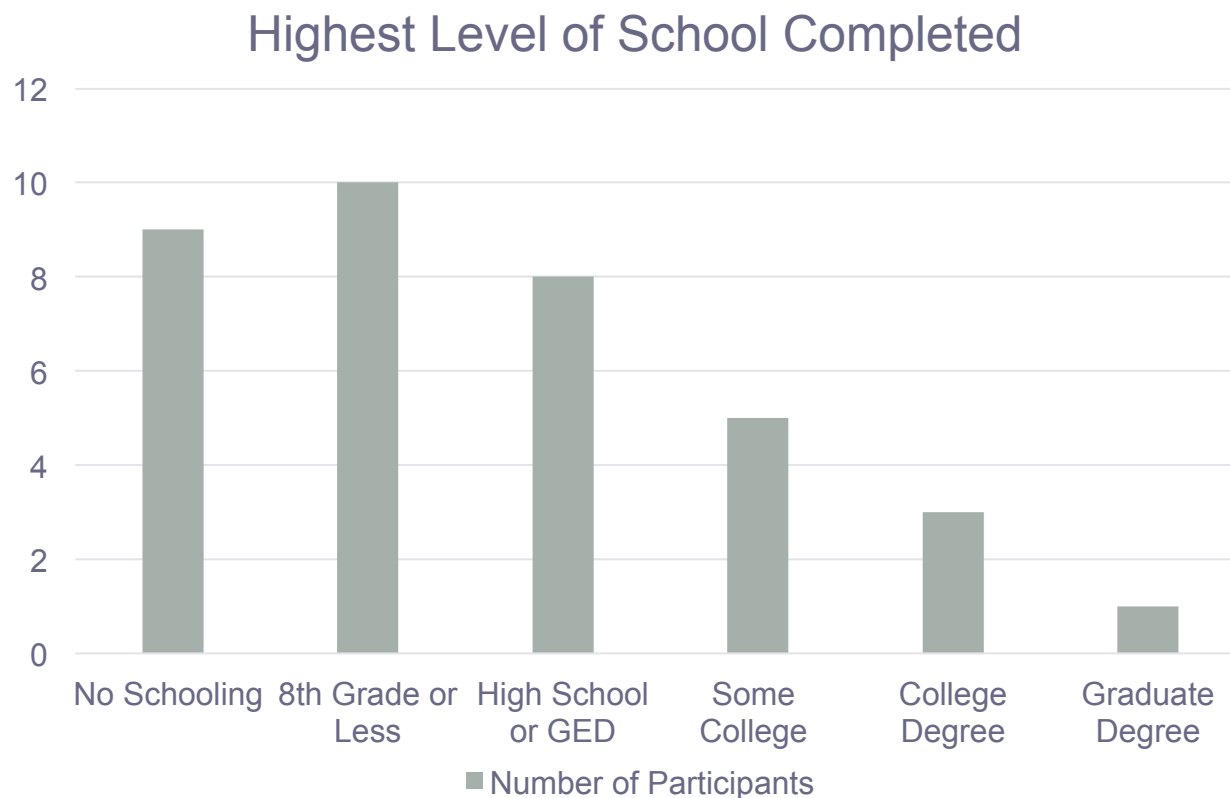


Somali Family Focus Group: Demographics

- 36 Participants
 - All mothers of at least one CSHCN
- 97% born in Somalia
- 75% have lived in the US over 10 years
- 86% spoke Somali as the primary language at home
 - 11% spoke Somali Bantu



Somali Family Focus Group: Parent Demographics



Somali Family Focus Group: Demographics

- 50% of participants use an interpreter when communicating with their child's doctor
- 36% speak English when communicating with their child's doctor
- 14% have their child interpret when communicating with their child's doctor



Somali Family Focus Group: Demographics

- 39% of participants had four children
 - Family size ranged from one to eleven children
- 36% of the mothers have at least one child in the family with a behavioral or conduct related diagnosis
 - Examples: Oppositional Defiant Disorder or Conduct Disorder
- 47% of the diagnoses fall under a behavioral health diagnosis



Somali Family Focus Group: Demographics

- 33% of the mothers have at least one child with Asthma
- 19% of mothers have at least one child living with diabetes
- 14% have a child with an intellectual disability
- Other reported diagnoses were: seizures, autism, anxiety, depression, heart problems, developmental delays, allergies, ADD/ADHD, addiction, allergies, head injury, and heart, genetic, and congenital conditions.



Themes

- Linguistic barriers
 - Language access
 - Differing dialects
 - Need for interpreter education
 - Need culturally sensitive communication about treatment/plan service availability



“All this is because of the language. They send us a letter and we don’t know how to read it/don’t understand it”.



Themes

- Desire for benefits counseling and education about services
 - Only one participant reported hearing about CHIP
 - Many participants qualify for insurance but some believed that they don't
 - Ex. “I was told that people who work don't qualify for it (Mass Health/ Medicaid)”
 - Even for those insured concerns remain
 - Insurance churn, confusion about referrals and what services/insurance are available to their children



“My two children, one has diabetes and the other has a heart condition and sometimes I cannot get them to be seen because I did not do the referral paperwork for the specialist because I don’t understand how to do it.”

“When insurance expires, we apply it is always a problem, it comes late. If a child is sick then you get a bill and you have to fight it”

“Medicaid has never been explained to us.”



Themes

- Experiences of racism and unfair treatment by providers
 - Provider misunderstandings of religious and health beliefs
 - Can lead to changing providers or seeking care in multiple places
 - Can create dangerous and poor health outcomes



“For example, we are standing in a line waiting to be checked in and the person behind us, who is white, is asked “may I help you”. You ignore us and you treat like we don’t exist.”

“I think they assumed we were just poor Africans who had no ideas. They were not treating us better than animals. My child went into coma and almost died when he stopped breathing. He still has a mark on his chest from the attempts to bring him back (resuscitate). It took 5 years for them to figure this (allergy) out.”

“Our children are treated differently one way or another. Somalis got mistreated by providers because they are different and they assume that they don’t know things or are not citizens, or because they don’t have a good interpreter.”



Themes

- “Adversarial ally” relationship with the system of care
 - Feelings of distrust, confusion, fear, and worry
 - Abundant stories in the community of negative experiences
 - May be limited recourse due to faith beliefs

Kelly, C., and Chapman, C. (2015). Adversarial Allies: Care, harm, and resistance in the helping professions. *Journal of Progressive Human Services*, 26:1, 44-66



“He (the doctor) told me he has the power to take away my child. I brought this child from refugee camps. I carried him from hospital to hospital, from Somalia, to Kenya, to Uganda, to the US. I did all this to get him medical care. This man told me I did not know what I was doing. He accused me of making the child sick...He told me I failed in my duty as a mother by not giving my son the medication.”



Themes

- Stigma of illness and fear of seeking help
 - Fear of caseworkers reporting on the family
 - Fear of stigma from help seeking behavior
- Large range of feelings in the participants around this theme



“My husband’s last words before he passed was ‘case manager’s are the worst. Don’t let them into your home. When you allow people from outside your culture into your home they can cause you more problems’. My case manager told me you “have a lot of things you can access, for example, a chair to support your son in the shower.’ The case managers will pretend to help you. They come into your house and report your house is dirty...”

“They send us case managers to help us. We need to stop being suspicious about case managers. When someone is coming into our home we should accept they are helping the children.”

“People often have stigma, when a child has a problem with an issue they won’t seek help.”

“The problem why mothers will not talk about their problems is that the person who comes to your home and you seek help from will go and talk about you and shame you in the community.”



Themes

- Need for more community support
 - Community support identified as a possible solution to many of the barriers identified
 - Offers guidance in navigating systems
 - May help address confusion, stigma, and reduce fear



“We need more community leaders, advocates to help us with health needs. This is their job to help with these things. You should do outreach, you have tell people what they need.”

“We need more community classes to explain health and how we can understand the system better and help our children.”



Summary of Results

- Focus groups played a dual role: research and education
- Participants who had been in the US for less than 5 years faced similar challenges to those who have lived for here over 10 years.
- Working at the intersection of multiple themes: CSHCN, family role, race, religion, fear, stigma and more



Implications

- Trust Building is essential
- Avoid becoming an “adversarial ally”
- More workforce development needed
- Think about Intersectionality
 - Additional and intentional work
- Education happening within the focus groups
- More community education & partnerships

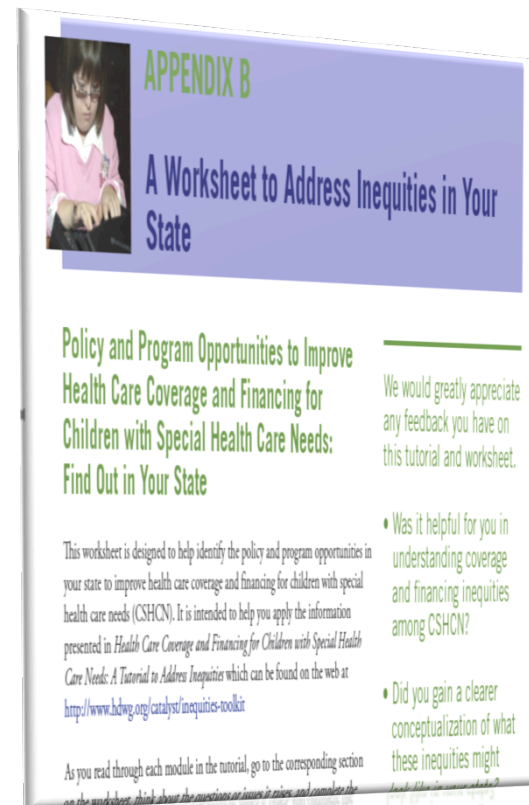
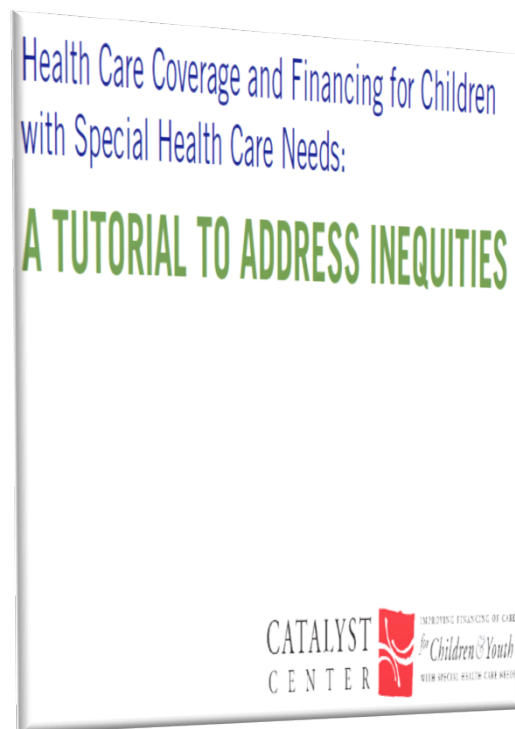


Implications for Title V

- Collaboration between families and professionals
- Examples of partnerships to address inequities
- Who can you partner with?



Catalyst Center Resource: *Health Care Coverage and Financing for CSHCN: A Tutorial to Address Inequities*



Next Steps

- Disseminate findings
- Develop partnerships to create best practice models
- Replicate process with other groups to look for common themes
- Create resources for Title V, family leaders and others



Thank you!

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