Addressing Inequities among CSHCN in Your State

CATALYST CENTER

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

June 20, 2016

The Catalyst Center is funded by the Division of Services for Children with Special Health Needs, Maternal & Child Health Bureau, Health Resources and Services Administration, U.S. Department of Health and Human Services, under cooperative agreement #U41MC13618.
MCHB/HRSA Project Officer: LCDR Leticia Manning, MPH

Center for Advancing Health Policy and Practice

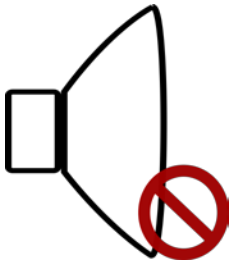
BU Boston University School of Public Health

Housekeeping

- Welcome
- Health Care Coverage & Financing for CSHCN: A Tutorial to Address Inequities

  http://cahpp.org/resources/inequities-tutorial
- Interactive Worksheet

  http://cahpp.org/wp-content/uploads/2016/05/inequities-tutorial-worksheet.pdf



Phones on mute for now…

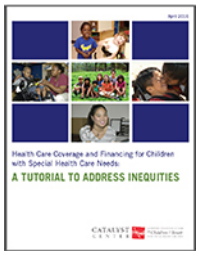
Presenters

in order of appearance

- Introduction by LCDR Leticia Manning, HRSA project officer
- Overview of Inequities Tutorial - Kasey Wilson, Catalyst Center
- Alaska State Example:
  - Becky Morisse, Alaska CYSHCN Director
  - Jimael Johnson, Autism and Pediatric Medical Home Program Manager
  - Stephanie Wrightsman-Birch, MCH Director
- Michigan State Example:
  - Brenda Jegede, Coordinator for PRIME
  - Lonnie Barnett, Michigan CSHCS Division and Title V CYSHCN Director
- Evaluation - Beth Dworetzky, Catalyst Center

Webinar Goals

- Introduction
- Get acquainted with our Inequities Tutorial
- Hear state examples
- How to evaluate progress towards health equity for CSHCN
- Questions/Discussion



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

A Tutorial to Address Inequities

- **MCHB definition of CSHCN:** "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"[1]

- **CSHCN are diverse! 15.1% all kids are CSHCN**[2]

	% total CSHCN	≥ 1 periods w/o insurance (%)
Hispanic	**11.2**	**15.9**
White, non-Hispanic	**16.3**	**7.3**
Black, non-Hispanic	**17.5**	**9.9**
Other, non-Hispanic	**13.6**	**9.4**

[1]McPherson, M., Arango, P., Fox, H., et al. "A new definition of children with special health care needs." Pediatrics (1998.) 102:137 – 140.
National Survey of Children with Special Health Care Needs. NS-CSHCN 2009/10. Data query from the Child and Adolescent Health
[2]Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 6/15/2016 from www.childhealthdata.org.

MCHB Core Outcomes for CSHCN

Percentage of CSHCN whose families are partners in shared decision-making for child's optimal health, by primary household language		
Hispanic child/English language household	65.5%	65.6%
Non-Hispanic child	75.4%	71.6%
Hispanic child/Spanish language household	69.9%	59.5%
Percentage of CSHCN whose families are partners in shared decision-making for child's optimal health, by household income		
0-99% FPL	63.6%	61.8%
100-199% FPL	68.3%	67.3%
200-399% FPL	69.7%	72.6%
400% or more FPL	82.8%	77.2%
Percentage of CSHCN whose families are partners in shared decision-making for child's optimal health, by race/ethnicity		
Hispanic	67.0%	63.5%
White non-Hispanic	77.1%	74.2%
Black non-Hispanic	58.7%	64.7%
Other non-Hispanic	73.3%	66.8%

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

Catalyst Center Chartbook http://cahpp.org/projects/the-catalyst-center/state-data-chartbook/

What are Health Care Coverage and Financing Inequities?

Module 1

- **Language**: Inequities vs. inequalities vs. disparities?
  - Different words often used to describe the same thing: Differences in health insurance status, access to services, and health outcomes
  - We use “inequities”
    - Relationship between differences in health and social disadvantage/oppression
    - These differences are unjust or unethical
- **Aren’t all CSHCN vulnerable?:** Certain groups are at greater risk
  - MCHB Core Outcome: Families of CSHCN have adequate private and/or public insurance to pay for needed services
    - Coverage and financing inequities stand in the way of this goal
- **Coverage vs. financing inequities**

How do Inequities Impact Children with Special Health Care Needs?

Module 2

- **What do the national data show?**: CSHCN are less likely to be insured or have adequate coverage if they are:
  - Black or Latino
  - From low-income families
  - From families in which English is not the primary language
  - Immigrants or from mixed-immigration status families
  - More limited in their functional abilities
- **How do I know what these inequities look like in my state?**
  - Catalyst Center State-at-a-Glance Chartbook
  - Childhealthdata.org

How Can Policies and Programs Reduce Inequities in Your State?

Module 3

- **What policies and programs exist in your state?**
  - EITC
  - Increased Medicaid/CHIP income eligibility
  - FOA Medicaid buy-in
  - TEFRA/Katie Beckett & HCBS waivers
  - ICHIA
  - CHIPRA translation reimbursement
- **Ask yourself some other questions about your state's policy landscape**

How Does the Affordable Care Act (ACA) Impact Inequities?

Module 4

- **Does the ACA help?**: Provisions that address inequities
  - Medicaid expansion
  - 12-month continuous eligibility for adults
  - Marketplaces
  - Navigators and in-person assistors
- **What more could be done?**

How Can You Partner with Other Stakeholders to Address Inequities?

Module 5

- **Why partnerships?**: Families know their children's needs best!
  - Partnership means a two-way flow of information and collaboration between families and professionals (including providers, public and private payers, policy makers, and family leaders)
- **Where to go for guidance?:** National and state-based organizations focused on partnerships
  - Family Voices
  - National Center for Family/Professional Partnerships
  - Family-to-Family Health Information Centers
  - State Office of Minority Health

State of Alaska

Autism System Development:

Strategies in Response to Access and Health Inequity

Alaska Title V Program

Stephanie Birch
Jimael Johnson
Becky Morisse

June 2016

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Objectives

1. History of Alaska's Autism program and response to health inequity in rural Alaska.

2. Current status of the program

3. Future Plans for autism screening, diagnosis and workforce development

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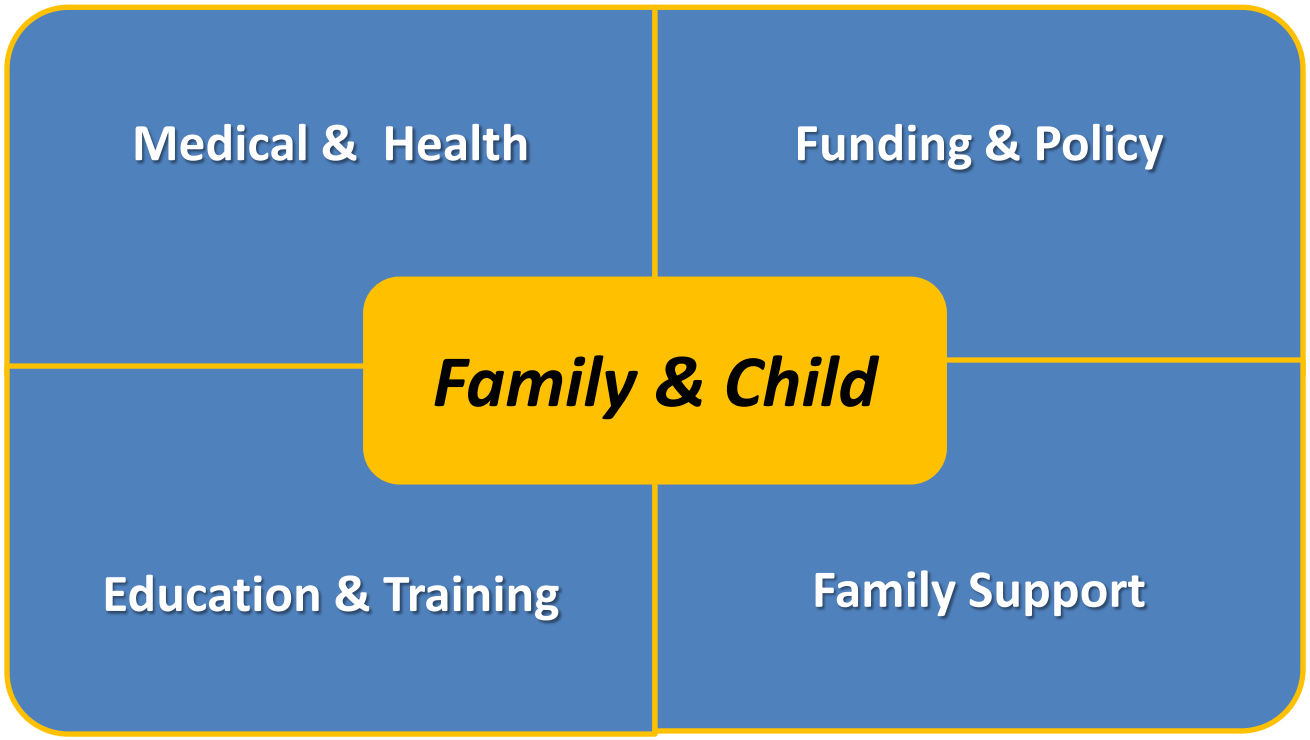
The Governor's Council on Disabilities and Special Education

2006 Alaska State Autism Plan



1. Universal Screening
2. Diagnostic Clinic Expansion
3. Enhance Referral and Training
4. Workforce Training
5. Time Limited Intensive Autism Services

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Combating Autism Act Initiative
Alaska State Demonstration Grant

- **Goal #1:** In rural Alaska, develop new processes to support the system of developmental screening, early identification, and diagnosis for children with ASD/DD
- **Goal # 2:** Children birth to three years old will successfully connect with early intervention services and a medical home for earlier initiation of services
- **Goal #3:** Aligned with goals established by the Autism Alliance and ECCS to assure continuity and sustainability

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Medical Providers: William Walker, MD; Beth Ellen Davis, MD

Clinic Coordinator: Meghan Clark-Center for Human Development/LEND

Family Navigator: Stone Soup Group

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Learn the Signs. Act Early

Developmental Milestone Awareness Campaign

- Family Focus Groups
- Materials Localized
- Direct Mailing to Families of Newborns
- Radio PSA Broadcast
- Part C Child Find Activity Integration

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Did we succeed?

- The average age of identification for rural kids decreased to 3-4 years. In many communities, the average is younger than 3
- While we are no longer able to visit as many communities every year, the clinic has transitioned to providing diagnostic services
- Children referred to the clinic generally come with some type of prior screening

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Pediatric Medical Home Program

"Move the Needle"

- **By 2017, increase the proportion of CYSHCN receiving care through a patient/family-centered medical home model approach by 20% over 2009/2010 levels of 42.8%**

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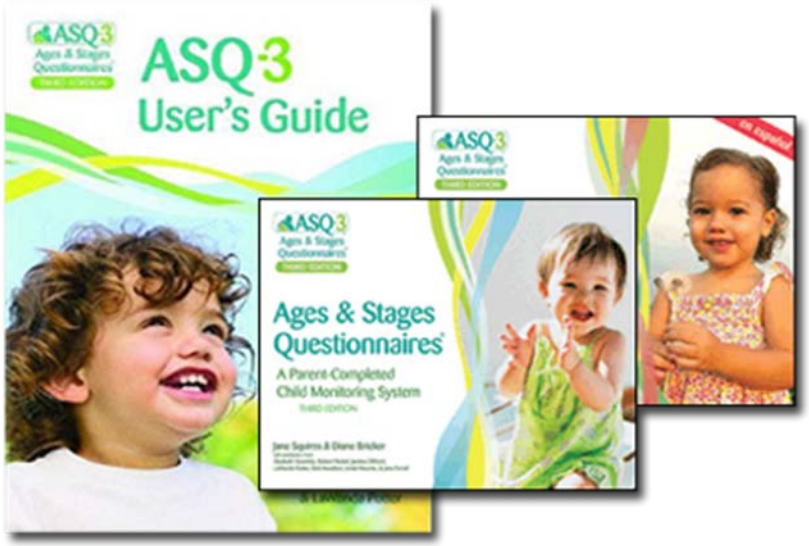
ASQ and Developmental Screening



- ILP statewide initiative
- ECCS alignment
- EPSDT workgroup
- Help Me Grow

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Help Me Grow Alaska

- Four Core Components:

Child Health Care Provider Outreach
- To support screening

Family & Community Outreach
- To identify resources

Centralized Telephone Access Point

Data Collection & Monitoring
- Including service gap analysis

* Builds collaboration across sectors to improve access
* Identifies gaps and barriers to access systems

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Plans for the future

- November 6, 2015 – Title V convened a one-day meeting of stakeholders to do strategic planning for the future
- Included participation from in-state and out-of-state partners
- Discussion on current processes and recommendations for future diagnostic service delivery

Outreach Clinics

- Develop a multi-disciplinary approach to the clinics
- Leave complex cases to pediatric neurodevelopmental specialists
- Consultation and support from a Medical Director

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Updated Autism Five Year Plan 2015-2020

Priorities:

1. Screening and Diagnosis
2. Workforce Development and Training
3. Early Intervention and Educational Systems (age 0-22)
4. Integrated and Comprehensive Services
5. Funding, Billing and Systems Issues

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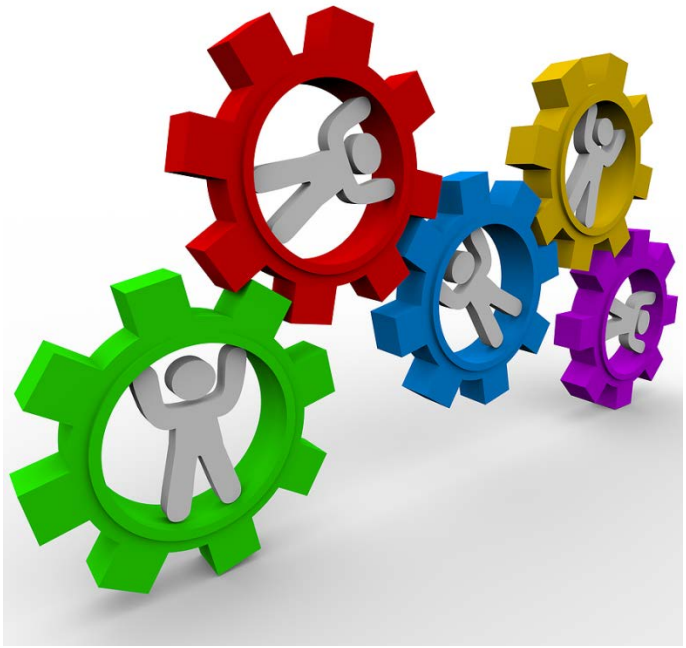
Capacity Building and Workforce Development



- **Leadership & Education in Neurodevelopmental & Related Disabilities (LEND) credential**
  - Focus on rural leadership development
- **Board Certified Behavior Analyst (BCBA) certification**
  - Targeted recruitment to decrease rural access inequities and use of telehealth for delivery of services
- **Pediatric Care Coordination training**
  - Distance delivered university continuing ed. course with rural/cultural competence focus
- **On-line curriculum for primary care providers**
  - Screening and diagnosis
  - Referrals to Early Intervention
  - Medication Management and treatment
  - Billing

Project ECHO

- Develop a Project ECHO for Alaska related to autism and neurodevelopmental disorders
- Create a provider community of practice on autism and other neurodevelopmental conditions

Thank You

State of Alaska Title V

Section of Women's Children and Family Health

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Michigan's Practices to Reduce Infant Mortality through Equity (PRIME)

Brenda Jegede, Coordinator, PRIME

Lonnie Barnett, Director, Children's Special Health Care Services Division

Practices to Reduce Infant Mortality through Equity (PRIME)

* W.K. Kellogg Foundation Award
* Create a training and practice model that promotes health equity practices within MCH programs, policies and resource distribution
* Focuses on improving equity in maternal and infant health for African Americans and Native Americans

Figure 1. PRIME intervention design

Staff Workshops

Undoing Racism ™

The People's Institute for Survival & Beyond

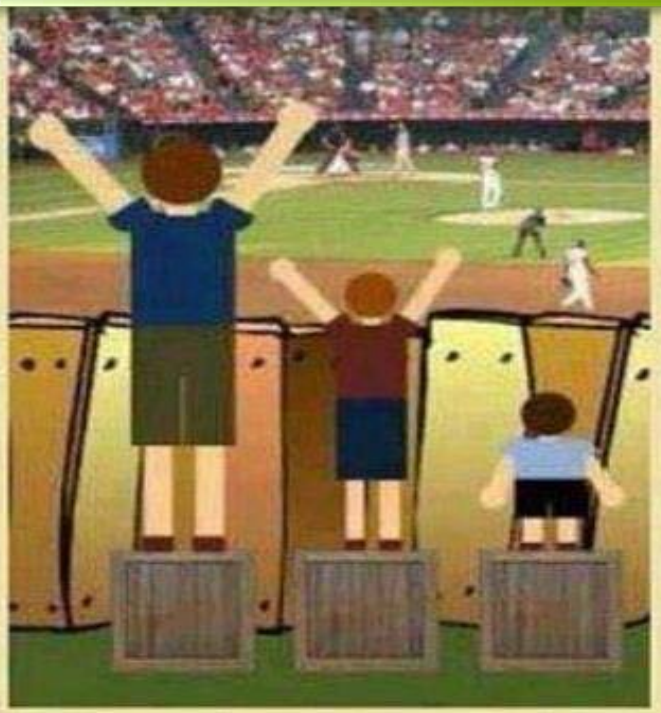
Health Equity Social Justice

Ingham County Health Department, Lansing, MI / Michigan Public Health Institute

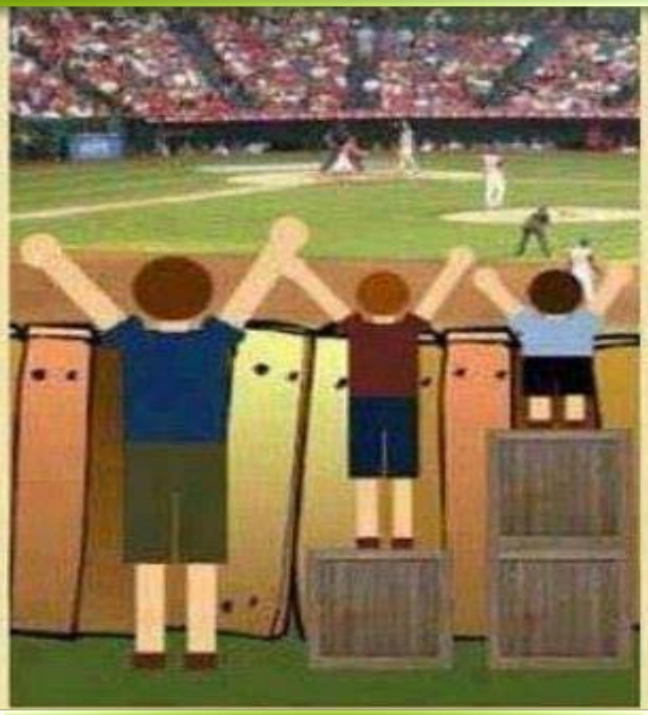
Native American History, Culture & Core Values

Inter-Tribal Council of Michigan

With Equity, inputs may need to be different to achieve equal outcomes



This is Equality



This is Equity

MDCH, Health Equity Learning Labs 2013, provided by Hogan, V., Rowley, D., Berthiaume, R. and Thompson, Y, University of North Carolina at Chapel Hill. Adapted from http://indianfunnypicture.com/search/equality+doesn%27t+mean+justice

Learning Lab Sessions
Action Plan Development

1 Where Have We Been, Where Are We Going? 2 hrs

Review health equity concepts, form teams.

2 Where We Are 4 hrs

Review organizational self-assessment, consider specific practices where meaningful, sustainable change could occur.

3 What We Can Do 3 hrs

Analyze scenarios as opportunities for creating or supporting health

4 What We Will Do 3 hrs

Build preliminary work plan to implement a specific change in practice.

5 Commitment to Action 4 hrs

Present completed work plan, with timeline, persons responsible, and indicators.

Michigan Children's Special Health Care Services (CSHCS)

* Michigan's Title V CYSHCN Program
* Provides a medical care and treatment benefit to eligible children and some adults with a qualifying medical condition
* Approximately 40,000 enrollees served each year
* 40 staff members in the CSHCS Division
* Contracts with all 45 local health departments to assist with outreach, program advocacy, care coordination, systems navigation, etc.
* Medical care and treatment benefit aligned with Medicaid program

CSHCS Health Equity Plans

- ✓ Build an inclusive and equitable advisory committee membership that is diverse in representation
- ✓ Database improvements - ensure CSHCS is serving its families equitably
- ✓ Incorporate a "health equity review" process into the existing policy review process
- ✓ Policy change to cover medical foods and formula for life for clients with Inherited metabolic disorder
- ✓ Improve communication to promote a more efficient and seamless system of care for the client population

How to Incorporate Equity into the Work

- ✓ Equity training for staff and partners
- ✓ Standardize data collection process/analysis
- ✓ Allocate resources to support equity
- ✓ Apply a life course approach across systems
- ✓ Utilize an equity lens in program standards and protocols

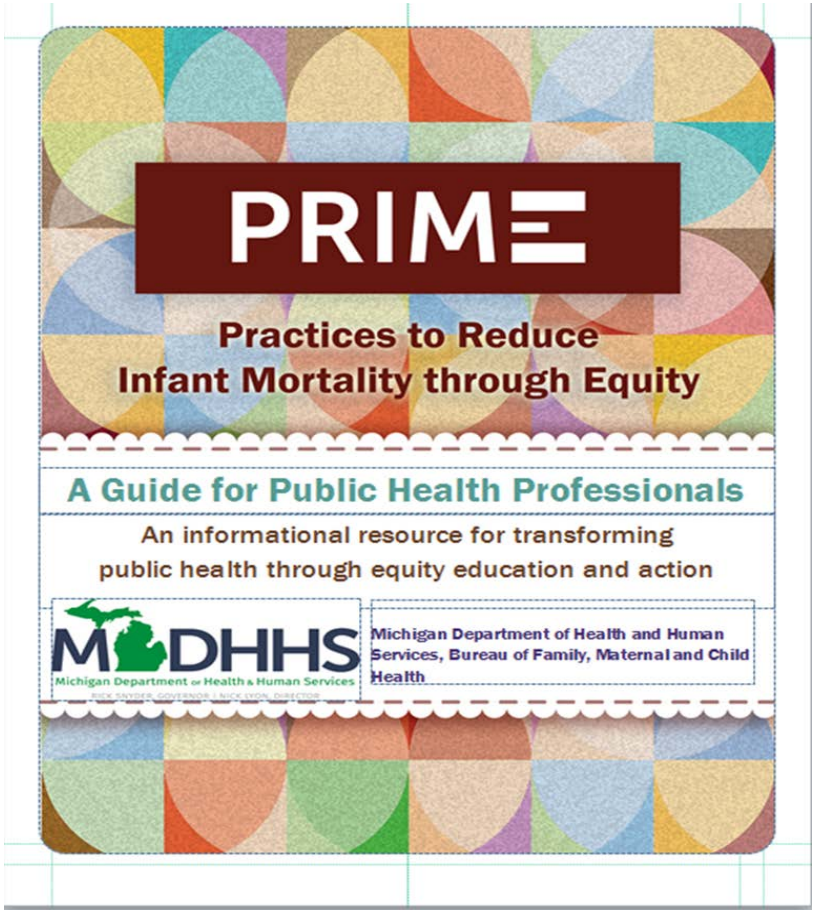
https://www.michigan.gov/documents/infantmortality/Infant_Mortality_16_FINAL_515908_7.pdf

CSHCS Initiatives

- ✓ QI Project -- Health Equity Wall Challenge
  - ➢ Forms in Multiple Languages
  - ➢ Equitable Treatment of Staff
- ✓ Plain Language Training for Staff
- ✓ Revise Application to Collect Comprehensive Race/Ethnicity Data
- ✓ Training for Local Health Department Partners on Equity

Plain Language

Medical	Plain Language
Hypertension	High blood pressure
Insomnia	Can't sleep
Benign	NOT cancer
Hazardous	Dangerous
Disorder	Problem
Option	Choice
Routinely	Often
Adverse	Bad



ORGANIZATIONAL ASSESSMENT

PRIME Organizational Assessment
(pp. 19-24)

Pilot
Date: 2012
Respondents: Women, Infant & Children Division
Number of questions: 100

Revision
Date: 2013
Respondents: Children's Special Health Care Division
Number of questions: 49

WORKSHOPS

Undoing Racism Community Organizing
(pp. 25-31)
Date: 2011 (provided 6 times)
Participants: Division of Family & Child Health; Division of Health, Wellness & Disease Control
Format: 2-day workshop

Health Equity & Social Justice
(pp. 32-37)
Date: 2011-13 (provided 10 times)
Participants: Family & Community Health Division; Women, Infants & Children Division; Children's Special Health Care Services Division
Format: 2.5-day workshop

Native American History, Culture & Core Values
(pp. 38-42)
Date: 2014 (provided once)
Participants: Children's Special Health Care Services Division
Format: 4-hour workshop

LEARNING LABS

Health Equity Learning Labs Series Pilot
(pp. 43-55)
Date: 2012-13 (provided once)
Participants: Women, Infant & Children Division (non-management and management staff together)
Format: Series of 3 learning labs (12 hours each for a total of 36 hours)

Health Equity Learning Labs for Non-management & Management Staff
(pp. 56-68)
Date: 2014 (provided once)
Participants: Children's Special Health Care Services Division (non-management staff); Maternal & Child Health; Chronic Disease, Epidemiology, Health Disparities (management)
Format: Non-management staff: 5 monthly sessions for a total of 15 hours; management staff: 4 monthly sessions for a total of 11 hours; groups met jointly for the final session

www.michigan.gov\dchprime

For more information

* Brenda Jegede
* Jegedeb@michigan.gov
* 517-335-8493

* Lonnie Barnett
* BarnettL@michigan.gov
* 517-241-7186

* www.michigan.gov\dchprime

Putting it all together to address inequities in your state

Interactive worksheet

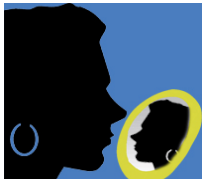
MODULE 5: How can you partner with other stakeholders to address inequities?

Module 5 (pages 40 - 46 of the tutorial) provided you with some information about family/professional partnerships to address inequities among children with special health care needs (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[1]	More information on the National Center for Family/Professional Partnerships[2]	Use this list of F2F organizations[3] to identify the F2F in your state. **Your state's F2F:**	Use this interactive map[4] to identify the state office of minority health in your state. **Your state's office of minority health:**	
		_____	_____	



How Can You Evaluate Your Efforts?

Module 6

- State the goal or outcome measure you hope to achieve
- State the policy, program, ACA provision, or other strategy you implemented (or plan to implement)
- Identify a data source
- Describe any additional benefits or outcomes
- What partnerships did you strengthen or develop?
- Lessons learned?
- For Title V programs, can any of the programs, policies, ACA provisions, or other strategies serve as an evidence-based strategy to advance one or more of the National Performance Measures (example, NPM #15 – adequate health insurance)?

Questions? Discussion

Thank You for Participating

- May we have 1 more minute of your time?
  - Please fill out the SHORT SURVEY that will launch when we exit the webinar
- Contact us for more information about reducing health coverage & financing inequities for CSHCN
  - **cyshcn@bu.edu**