Operationalizing Disability Justice in Title V Programs

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Agenda

- Systems Change level setting
  - *STRETCH* framework
  - *The Water of Systems Change* framework
- Ableism in public health
  - Mental models of disability
- Foundations of disability justice in Title V—using the *Blueprint for Change*
  - Existing Title V strategies
- Small Group Discussion

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"Systems thinking is about investigating what set of factors and interactions are contributing to or could contribute to a possible outcome."

-Steve Brown, Deputy Director of Collaborative Learning and Strategic Insight at Southern New Hampshire University
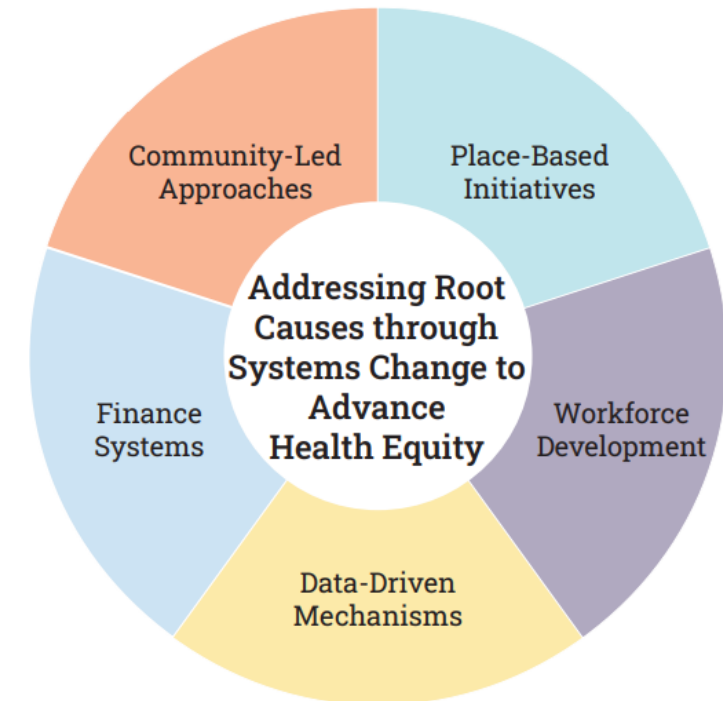
Strategies to Repair Equity and Transform Community Health (STRETCH) Framework
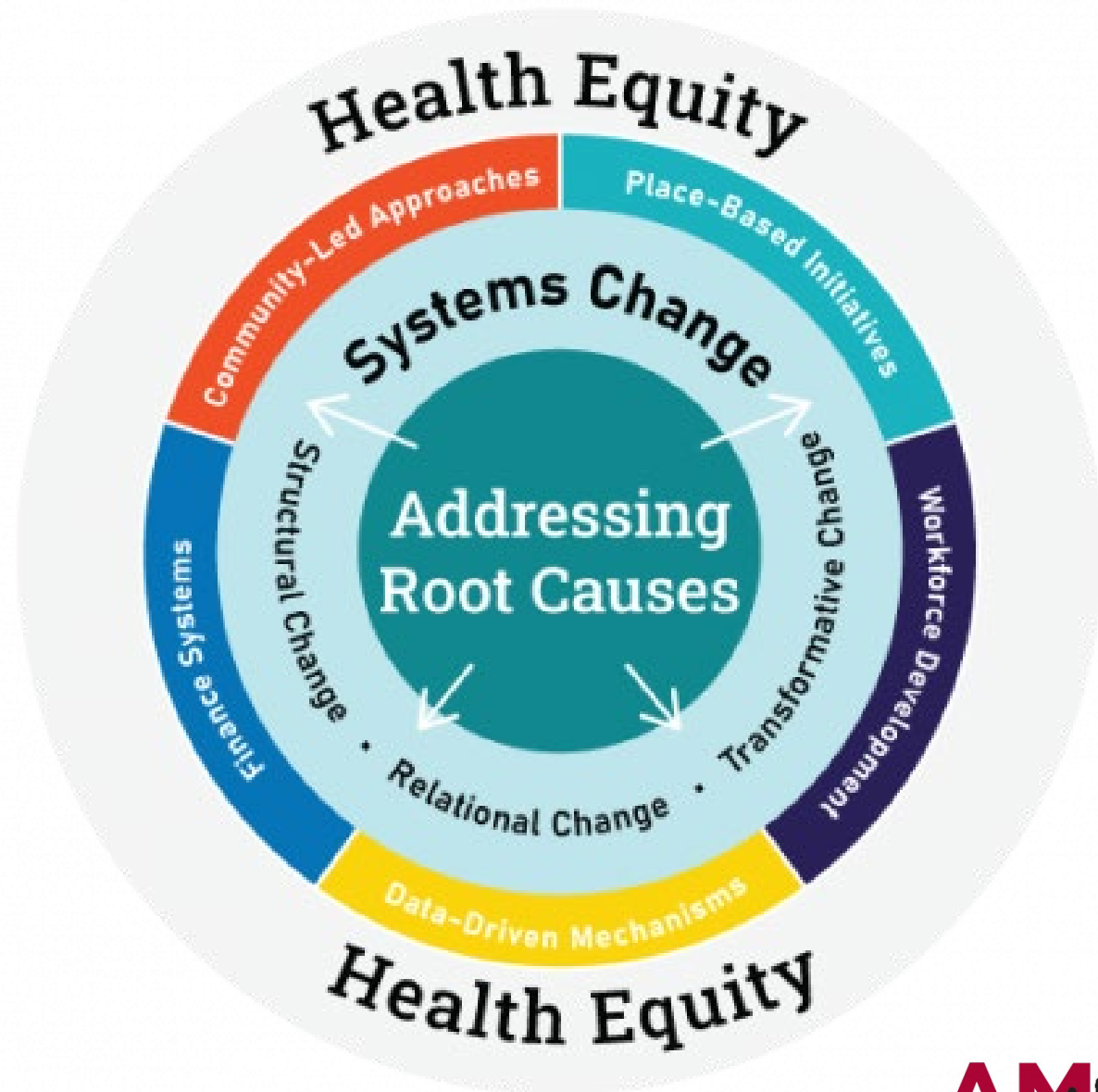
STRETCH Framework Domains

- **Community-Led Approaches:** Health equity actions centered on the community and prioritizing their needs to improve their health.

- **Place-Based Initiatives:** Collaborative, long-term approaches to build thriving communities defined by place, interest or action.

- **Workforce Development & Organizational Infrastructure:** Ensuring the quality and capacity of the human assets to meet the current and future public health challenges and improve health and equity outcomes for the communities served.

- **Data-Driven Management:** How the health data infrastructure is modernized to re-imagine how data is collected, shared and used to illuminate the needed investments to improve health equity.

- **Finance Systems:** How agencies can get the finances organized and in place for long-term sustainability and success.

Community-Led Approaches | Place-Based Initiatives

Finance Systems

Addressing Root Causes through Systems Change to Advance Health Equity

Workforce Development

Data-Driven Mechanisms

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STRETCH Framework: Community-Led Approaches

- What is the balance between departmental expertise and community-based guidance?

- How do you ensure community members feel like their needs have been adequately addressed?

- What power-sharing dynamics exist and how have those been informed by community needs?

- How do existing programs and structures within your department help or inhibit partnerships with community stakeholders?

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STRETCH Framework: Workforce Development & Organizational Infrastructure

- Describe the outreach approach to including racial and ethnic groups in recruitment opportunities (full time, part time, interns, consultants, partners, etc.).

- What expertise is needed among staff/personnel to address structural racism and ableism and implement health equity strategies?

- Describe the training needs across agency staff to advance understanding of structural racism and ableism.

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THE WATER OF SYSTEMS CHANGE

JOHN KANIA, MARK KRAMER, PETER SENGE

June 2018

Structural Change

Relational Change

Transformative Change

Six Conditions of Systems Change

Policies

Practices

Resource Flows

Relationships & Connections

Power Dynamics

Mental Models

Mental Models

Habits of thought-deeply held beliefs and assumptions and taken-for-granted ways of operating that influence how we think, what we do, and how we talk.

Definition from FSG's "The Water of Systems Change"

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Ableism in Public Health

What is Ableism?

"Ableism is a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other." -Center for Disability Rights

Medical Model vs Social Model

Medical Model

The person is disabled by the abnormalities and deficits of their own body and/or brain.

Disabled people are broken, abnormal, or damaged versions of human being and should be fixed, cured, and/or prevented.

Since the disabled person's impairments prevent them from functioning normally, they need caregivers and professionals to make decisions for them. The disabled person is an object of charity and receiver of help.

The disabled person should adjust to fit into society, since they are the one who is not normal. Being part of society means rising above disability.

Social Model

The person is disabled by their environment and its physical, attitudinal, communication, and social barriers.

Disabled people are normal, valid varieties of human being and should have equal rights and access to society, just as they are.
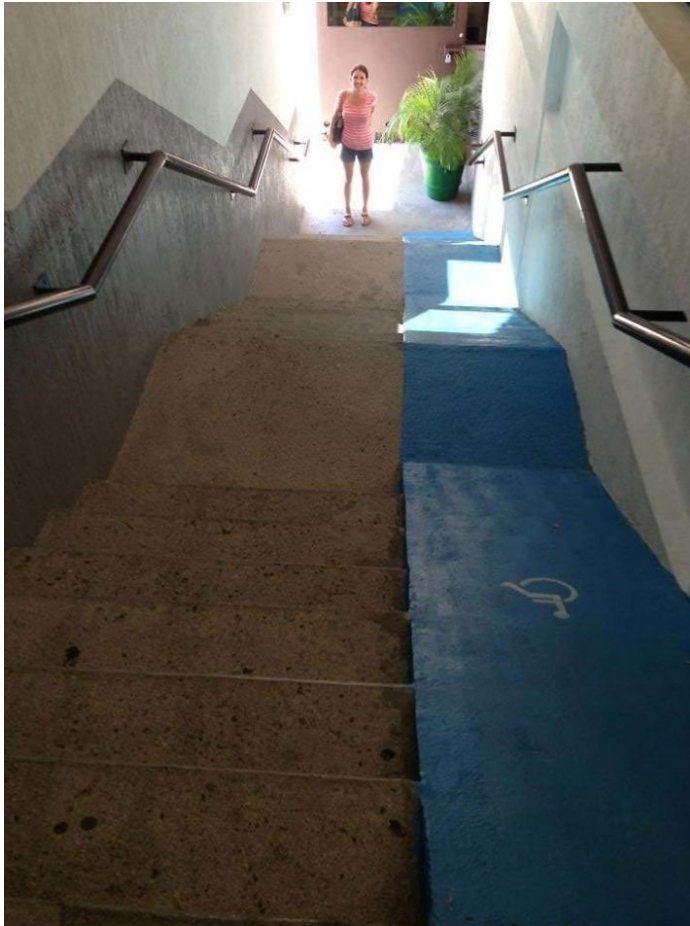
Since the disabled person is inherently equal, they have a right to autonomy, choice, and free and informed consent in their own lives.

The disabled person should be supported by society, because they are equal and have a right to inclusion. Their community should adjust its own barriers and biases.

https://eisforerindotcom.files.wordpress.com/2017/08/disability101socialmodel.pdf

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Think about your day to day:

#accessibilityFAIL

https://avacaremedical.com/blog/wheelchair-accessibility-fails.html

https://www.boredpanda.com/extreme-wheelchairing-accessibility-fails/?utm_source=google&utm_medium=organic&utm_campaign=organic

Ableism in Policy

- Visitor Policy- Disabled patients unable to have advocate, or support people with them

- Rationing healthcare (medical professionals deciding whose quality of life is "better")

- [Forced DNR for people with disabilities](#)

- Those with chronic illnesses, unable to access routine/preventative care

- Overall, 26.4% (95% CI, 25.5%-27.2%) of households reported that ≥1 child or adolescent had missed or delayed a preventive visit because of COVID-19
https://pubmed.ncbi.nlm.nih.gov/34969335/

- [Doctors are Failing People with Disabilities](#), The Atlantic

PUBLIC HEALTH WORKFORCE

- In 2022, about 21 percent of people with a disability in the U.S. were employed, up from about 19 percent in 2021, according to the U.S. Bureau of Labor Statistics (BLS).

- Who makes up your agency? Your state offices? Who are the people involved at all levels of public health, not just involved as "stakeholders" or those on the receiving end of programs?

- How can you leverage your position to bring up discussions of making sure the right people are at the table?

https://www.bls.gov/news.release/disabl.nr0.htm#:~:text=Employment%20The%20employment%2Dpopulation%20ratio,to%2021.3%20percent%20in%202022.

Disability Justice

A multi-issue political understanding of disability and ableism, moving away from a rights-based equality model and beyond just access, to a framework that centers justice and wholeness for all disabled people and communities.

--Mia Mingus, Disability Justice activist

Foundations of Disability Justice in Title V

"Although the vision of the Blueprint for Change is for broad use and adaptation across the larger population of CYSHCN, it is important to note the heterogeneous nature of CYSHCN and the complexities involved in developing policies and programs for a diverse population. There is currently no consensus on the definition of being "at increased risk." **However, the reality is that all children are at risk of developing a special health care need.** *The intended focus of this definition of CYSHCN is on the heightened health care and related needs of the child, youth, or family, not their differences."*

*"Structural racism and ableism in public policies and institutional practices limit access to health care and education. **Sectors, policies, and the workforce can perpetuate inequities and presume "ablebodiedness,"** which impedes progress in improving outcomes for CYSHCN and their families."*

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"Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society."
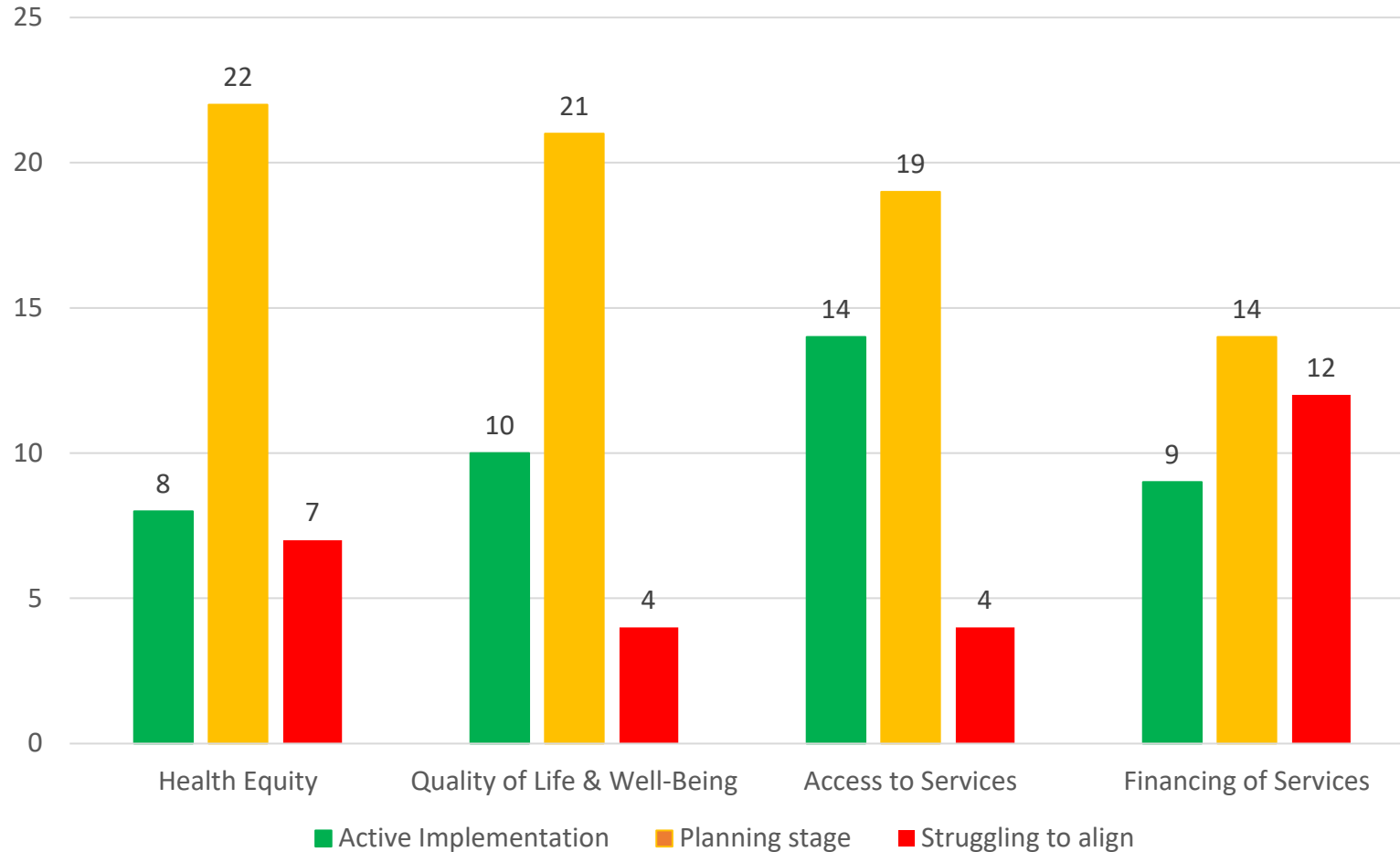
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Implementation Readiness

I am already doing this work/high capacity to influence change in the critical area

I have thought about or am planning to infuse existing strategies from the Blueprint

I am struggling to align existing activities with the Blueprint or am experiencing other challenges to influence change in this critical area

Chart values:

Critical Area	Active Implementation	Planning stage	Struggling to align
Health Equity	8	22	7
Quality of Life & Well-Being	10	21	4
Access to Services	14	19	4
Financing of Services	9	14	12

Legend: ● Active Implementation ● Planning stage ● Struggling to align

Source: CYSHCN Directors meeting at 2023 AMCHP Annual Conference, New Orleans, LA | May 6, 2023

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Health Equity Critical Area Principle 1A

"Service sectors and policy makers recognize and address the fundamental causes of health disparities. Federal, state, and local policies and laws that systematize oppression are dismantled and replaced with equitable policies and laws."

Louisiana Bureau of Family Health's Health Equity Action Team (BFH-HEAT)

- A group of staff and community partners dedicated to promoting health equity in the Bureau's culture, workflow, and services.
- *weave compassion and accountability into Bureau operations, programs, and workflow.*

Public Health Professionalism

Organizational Cultures

Organizational Systems

Source: https://partnersforfamilyhealth.org/about/health-equity/

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Health Equity Critical Area Principle 2A

"Entities that serve CYSHCN and their families coordinate policies, practices, and procedures across sectors to mitigate the health effects of societal oppression."

Massachusetts Title V's Cross-Cutting Strategy: Promote access to safe and affordable housing and reduce environmental exposures through initiatives such as the Childhood Lead Poisoning Prevention Program.

- Cross-sector partnership between **Title V** (HRSA-funded) and the **Childhood Lead Poisoning Prevention Program** (CDC-funded).
- Focus on communities where racial and economic inequities cause the most risk for lead exposure and *perpetuate a cycle of lost potential, poverty, and injustice.*

Source: Massachusetts Title V MCH Block Grant 2023 Application/2021 Annual Report

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Family and Child Well-Being and Quality of Life Critical Area Principle 1B

"Service sectors promote and support flourishing, enhanced self-management, and peer-to-peer social connections and support for CYSHCN and their families, including but not limited to a sense of self-worth, purpose, and fulfillment; engagement; and positive, stable, and supportive relationships."


BrainSTEPS Brain Injury School Consulting Program in Pennsylvania

The BrainSTEPS Program was created in 2007 to build a bridge connecting the medical, rehabilitation, education sectors and families following student (K-12) acquired brain injury (ABI). BrainSTEPS provides brain injury-related consultation & training to school staff, students, & parents in all Pennsylvania Public Schools.

BrainSTEPS

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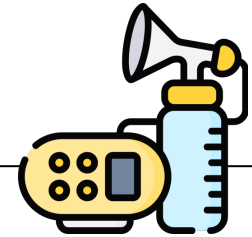ASSOCIATION OF MATERNAL & CHILD HEALTH PROGRAMS

Access to Services Critical Area Principle 1B

"CYSHCN and their families receive the appropriate accommodations and technologies they need to access services and supports."
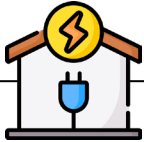
Florida's Emergency Preparedness and Response

Special Needs Shelter: Intended to provide, to the extent possible under emergency conditions, an environment that can sustain an individual's level of health. MCH staff and other public health employees deployed to provide relief support, included mobility assistance, supply logistics, medical staff oversight, shelter operations, and shelter safety.
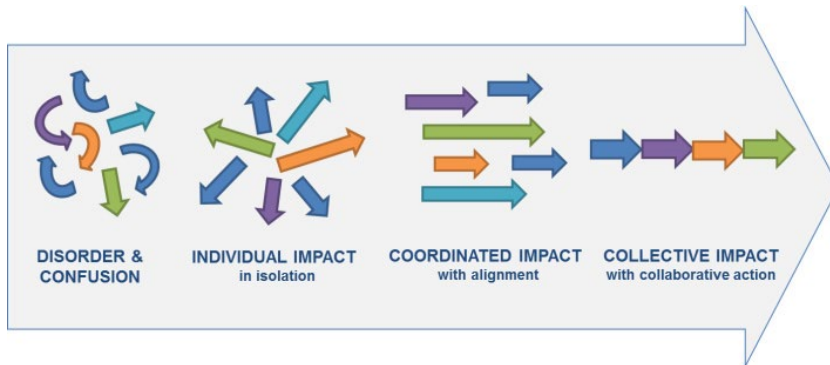
Breastfeeding support: The Department purchased and shipped 100 rechargeable breast pumps, 50 manual pumps, 100 portable chargers, 175 bottles, ice packs, and cooler bags to store breast milk to the counties most greatly impacted by Hurricane Ian.

Source: Florida Title V MCH Block Grant 2024 Application/2022 Annual Report—MCH Success Story
https://www.floridahealth.gov/programs-and-services/emergency-preparedness-and-response/disaster-response-resources/spns-index.html

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Access to Services Critical Area Principle 2A

"Training programs promote and incentivize opportunities for individuals, particularly those from underrepresented populations and/or with relevant lived experiences, to participate meaningfully in the development, implementation, and monitoring of services, policy, and research."

DISORDER & CONFUSION | INDIVIDUAL IMPACT in isolation | COORDINATED IMPACT with alignment | COLLECTIVE IMPACT with collaborative action

Minnesota Title V CYSHCN reimagining Family Support and Connections Program
- Aiming for a **<u>systems level impact</u>**—especially those families of CYSHCN who have been *historically underserved* due to systemic racism, ableism, marginalization, and discrimination
- ***Collective Impact* framework**: *to support and build capacity*

Source: Minnesota Title V MCH Block Grant 2024 Application/2022 Annual Report

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Financing of Services Critical Area Principle 2D

"Health care financing systems and health care delivery financing models invest in strategies to mitigate implicit bias and structural racism to address racial and ethnic health disparities."

Oregon Center for Children and Youth with Special Health Needs' Policy Project

Partnership with the Oregon law Center to improve systems of care by addressing legal challenges faced by families of CYSHCN, such as:

- Rationing of healthcare to underserved populations
- Access to durable medical equipment
- Addressing denials of service to those eligible for Medicaid or CHIP
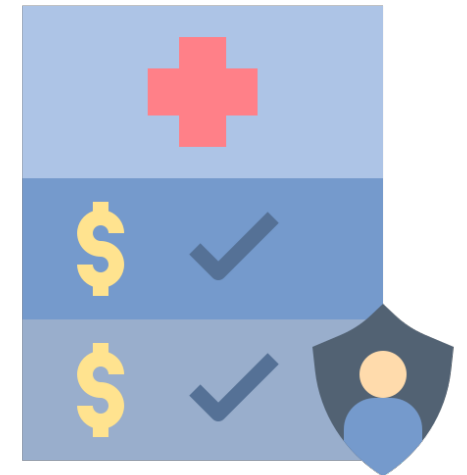
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PEER SHARING

Thank you!

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References

CDC Foundation, ASTHO, MPHI (2022). STRETCH Framework developed in partnership with the Strategies to Repair Equity and Transform Community Health (STRETCH) Initiative. CDC Foundation. Retrieved from: https://www.cdcfoundation.org/STRETCH-initiative-framework?inline

Kania, J. Kramer, M., Senge, P. (2018). The Water of Systems Change. FSG. Retrieved from: https://www.fsg.org/resource/water_of_systems_change/.

Smith, L. #Ableism. Center for Disability Rights. Retrieved from: https://cdrnys.org/blog/uncategorized/ableism/

Hudson, H. (2022). Moving from Disability Rights to Disability Justice. World Institute on Disability. Retrieved from: https://wid.org/moving-from-disability-rights-to-disability-justice/

Human, E. (2017). Disability 101: Medical Model vs. Social Model. Retrieved from: https://eisforerindotcom.files.wordpress.com/2017/08/disability101socialmodel.pdf

Fierce, T. and Corralez, L. (2022). Disability Justice 101: A webinar review. Disability Justice and Violence Prevention Resource Hub. Retrieved from: https://indisabilityjustice.org/disability-justice-101-a-webinar-review/

Louisiana Department of Health, Office of Public Health, Bureau of Family Health: https://partnersforfamilyhealth.org/about/health-equity/