



Family Engagement  
and Leadership in  
Systems of Care



# Engaging Families and Communities in Advancing Equity

## **Moderator:**

Allysa Ware, Ph.D., MSW  
Executive Director of  
Family Voices

## **Presenters:**

Nikki Montgomery  
Bethlyn Houlihan  
Pattie Archuleta



# Land Acknowledgement



- We acknowledge the Native Peoples on whose ancestral lands we work.
- We thank them for their stewardship of the land that now sustains us all.
- We pay our respects to elders past and present.

# Effective Partnership





# About This Session

This is a facilitated discussion panel that features family and community voices.

## **You will learn about:**

- What families have heard from Title V
- Ways to ensure authentic engagement and partnership moving forward
- How families and communities can support Title V to advance equity in state programs

# Health Equity Focus



- The intersection of immigration status, language, culture, race, diagnosis, identity, and geography negatively impacts access to care for many CYSHCN.
- Social determinants of health such as poverty, unequal access to health care, lack of education, stigma, and racism contribute to health inequities.
- Health equity is the state in which everyone has a fair and just opportunity to attain their highest level of health.
- Health equity requires efforts to address avoidable inequalities, historical and contemporary injustices, and social determinants of health — and to eliminate disparities in health and health care.

# Family Engagement Framework



- **Commitment** – Family engagement is a core value; the organization always engages families they serve in decision-making groups that are working to improve or create the policies, programs, and services that children, youth, and families receive.
- **Transparency** – The organization documents and communicates relevant knowledge and supports.
- **Representation** – Engaged families reflect the diversity of the community served (race, ethnicity, culture, language, geography, gender, age, disability, and other...).
- **Impact** – How and where the organization used families' input and ideas to improve existing policies and practices or to create new ones.





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# Effective Communications to Drive Engagement

**Pattie Archuleta**

Project Director, Family Voices



# Effective Communications to Drive Engagement



## Presenters

### Pattie Archuleta

- Project Director, Family Voices
- Parent of a young adult with special needs
- Sibling of a person with a disability





# Effective Communications to Drive Engagement

- Health Literacy
- Plain Language
- Language Access



# Health Literacy



Basic health literacy is fundamental to putting sound public health guidance into practice and helping people follow recommendations.

National Action Plan to Improve Health Literacy  
U.S. Department of Health and Human Services



# Health Literacy



## Personal

The degree to which individuals can **find, understand, and use information** and services to inform health-related decisions and actions for themselves and others

## Organizational

The degree to which organizations **equitably enable** individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others

# Health Literacy



## Principles

- **Find, understand, and use** information to support positive health outcomes
- Accurate, **accessible** and **actionable**
- Situational, so make information **as easy as possible** to understand,

## Considerations

- Only **12 percent** of English-speaking adults have proficient health literacy
- **Universal** precautions
- Organizations are responsible for **enabling** health literacy **equitably**

# Health Literacy (CDC)



- Clear communication means presenting words, numbers, and images **in ways that make sense** to the people who need the information.
- **Test and ask for feedback** before releasing information to the public.
- Clear communication **builds trust** with your audience.
- Choosing to use **jargon is an act of exclusion.**
- Using clear communication **advances health equity.**
- Clear communication **streamlines the translation process.**

# Organizational Health Literacy Strategies

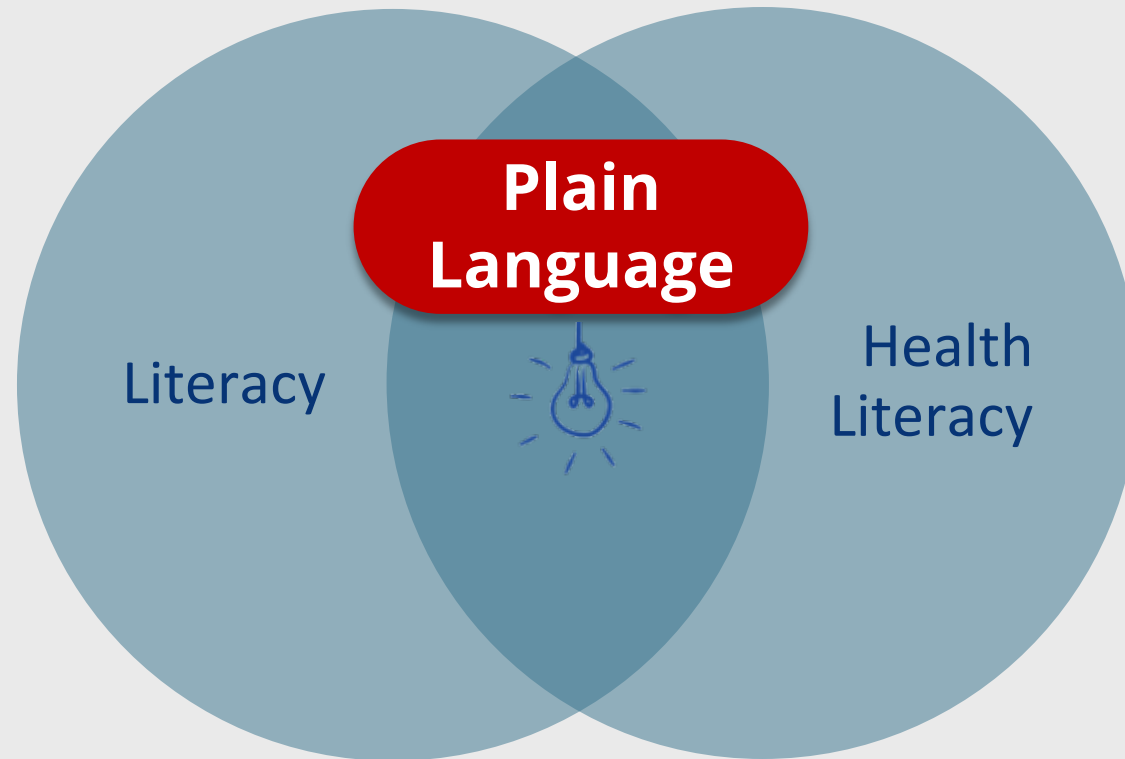


- Apply improvement methods
- Improve verbal communication and written communication
- Links to supportive systems
- Engage families as partners in improvement efforts
- Attributes of a Health Literate Organization





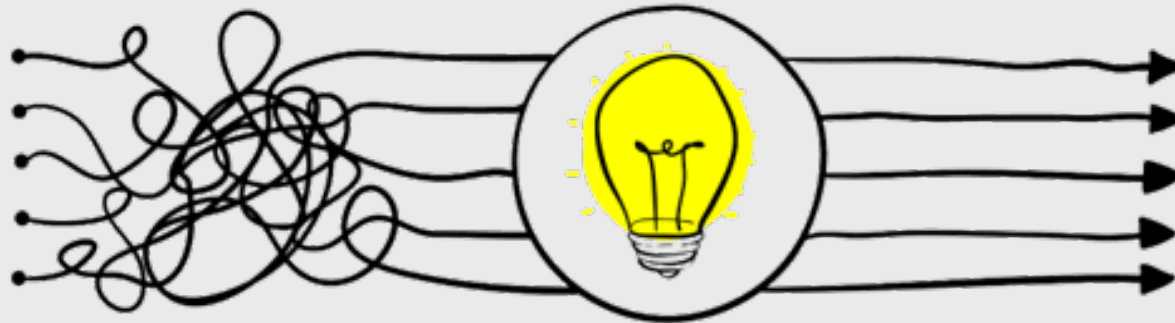
# Intersection of Health Literacy and Literacy





# What is Plain Language?

Plain language is communication your audience can understand the first time they read or hear it.



# Why is Plain Language Important?



- Plain language writing saves time.
- Plain language is good customer service and makes life easier for the public.
- Plain language gets your message across in the shortest time possible.
- More people can understand your message.
- Requirement for federal agencies (*Plain Language Writing Act of 2010*)

From [plainlanguage.gov](http://plainlanguage.gov)

# Plain Language Examples



XXX honors the centrality and expertise that families hold in child well-being. XXX regards families as experts and is committed to co-creating solutions with families throughout all aspects of the XXX Learning Community.

For a decision, there must be 75% of governing body members present (9 of 12), including 80% of parent/family leaders (4 of 5) and at least one representative of each Proof Point Community (including the parent/family leader).



Children and families are at the center of our work.



Families are experts on their lived experiences.



We co-create solutions with families in everything we do.

For a decision:

AT LEAST

**75%**

OF MEMBERS MUST BE PRESENT (or 9 of the 12 members)

AT LEAST

**80%**

(or 4 of the 5) PARENT MEMBERS MUST BE PRESENT

AT LEAST

**1**

REPRESENTATIVE FROM EACH PROOF POINT COMMUNITY MUST BE PRESENT

# Can you measure readability?



The **Flesch–Kincaid Grade Level Formula** shows readability as a U.S. grade level. The lower your score, the easier the text is to read.



The **Flesch Reading Ease Score** grades your writing from 0 to 100. The higher your score, the more readable your content is.

# Language Access



- Language access means providing reasonable access to the same services as English-speaking individuals.
- **Title VI of the Civil Rights Act of 1964** outlaws discrimination based on race, color, religion, sex, or national origin. This antidiscrimination law regarding national origin includes access to language services.



# Language Access in Health Care



Effective family engagement in health care can improve outcomes for CYSHCN, especially for families with low literacy and people whose preferred language is not English.

## Core Concepts of Language Access in Health Care

- Health Equity
- Cultural Responsiveness
- Plain Language
- Accessible Communication



# Language Access



## Translation

- Written words
- Change written words from one language to another

## Interpretation

- Spoken language
- Interpreters talk or sign
- Help people communicate when they speak different languages, including ASL



# Learn More



## Resources

- Download the Family Engagement in Systems Assessment Tools at [familyvoices.org/FESAT](https://familyvoices.org/FESAT). You can also request technical assistance.
- [Issue Brief: Moving Beyond the Family Engagement Check Box](#)
- Language Access Resources: [familyvoices.org/languageaccess](https://familyvoices.org/languageaccess)

# Why are Health Literacy, Plain Language, and Language Access Important?



## Inclusion and Access



# Effective Communications to Drive Engagement

**Thank you!**

Questions and Discussion





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# Co-Creating Systems with Communities

Bethlyn Houlihan, MSW, MPH





# Co-Creating Systems with Communities



## Presenters

### Bethlyn Houlihan

- Strive to be a trusted ally
  - Personal intersectionality and privilege
- Master's in Social Work and Public Health
- Commitment to:
  - Community-driven co-design of systems innovations
  - Equity in complex health and social needs across the life course
  - Advocacy for disability justice
  - Braiding quantitative with qualitative data to humanize outcomes

## Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity FREE

Stefanie G. Ames, MD, MS ; Rebecca K. Delaney, PhD; Amy J. Houtrow, MD, PhD, MPH; Claudia Delgado-Corcoran, MD; Justin Alvey, MD; Melissa H. Watt, PhD; Nancy Murphy, MD

# What is the cause of racial disparity in child welfare?

 childwelfaremonitor  April 30, 2023  11 Minutes

Original Manuscript

## Racial/Ethnic Differences in Child Services Reporting, Substantiation Placement, With Comparison to Non-CPS Risks and Outcomes: 2005–2019

Brett Drake<sup>1</sup> , Dylan Jones<sup>1</sup> , Hyunil Kim<sup>2</sup> , John Richard P. Barth<sup>5</sup>, Sarah A. Font<sup>6</sup> , Emily Putnar, Johanna K. P. Greeson<sup>3</sup> , Victoria Cook<sup>4</sup>, Patricia

SUPPLEMENT ARTICLE | JUNE 01 2022

## Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future

Amy Houtrow, MD, PhD, MPH; Alison J. Martin, PhD, MA; Debbi Harris, MA, MS; Diana Cejas, MD, MPH; Rachel Hutson, MSN, RN, CPNP; Yasmin Mazloomdoost, MPH, MSW; Rishi K. Agrawal, MD

[journals.sagepub.com/home/cmxc](https://journals.sagepub.com/home/cmxc)  


## Out-of-school suspensions applied disproportionately to students of color and those with disabilities

By Nancy Kirsch · May 4, 2023



# Shared moral distress



“ Clinicians report feeling troubled – often profoundly so – when they feel unable to provide the care they think is best based on their professional standards of practice and their values. ”

[nam.edu/Perspectives](http://nam.edu/Perspectives)

# New ways of thinking



*“The focus on family engagement has been central to Title V for way longer than the 13 years I’ve been with the program. The [Children with Medical Complexity] CollN made it real. It changed my whole lens. I don’t look at things the same now – every day I see opportunities to improve family engagement in ways I didn’t before.”*

Ivy Goldstein, TX Title V

# What is creativity?



- “Our best thinking got us here.”
- The ability to think in new ways and **apply fresh perspectives to old problems.**
- Critical skill that enables people to **adapt and create unique approaches** that may be even better suited than tried-and-true methods.
- Creativity is a **necessary prerequisite for innovation**, but they are not the same thing.

Source: <https://www.businessnewsdaily.com/6848-creativity-vs-innovation.html>



## Process

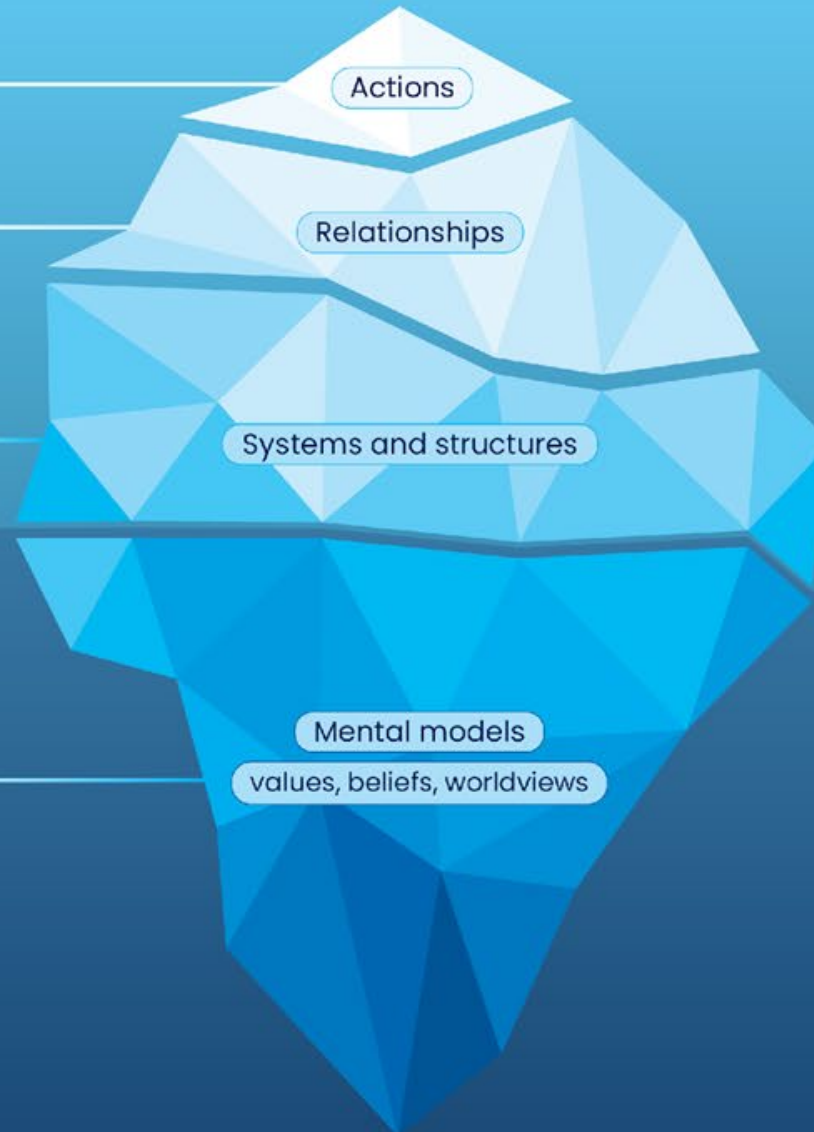
## Outcome

How do we demonstrate equity in our implementation steps/tasks?

How do we demonstrate equity in our interactions with others?

How do we demonstrate equity in our institutions (e.g., policies, organizations)?

How do we understand and approach the world in an equitable and just way?



Have we fostered more equitable conditions?

Are we making strides towards establishing fairness and justice?

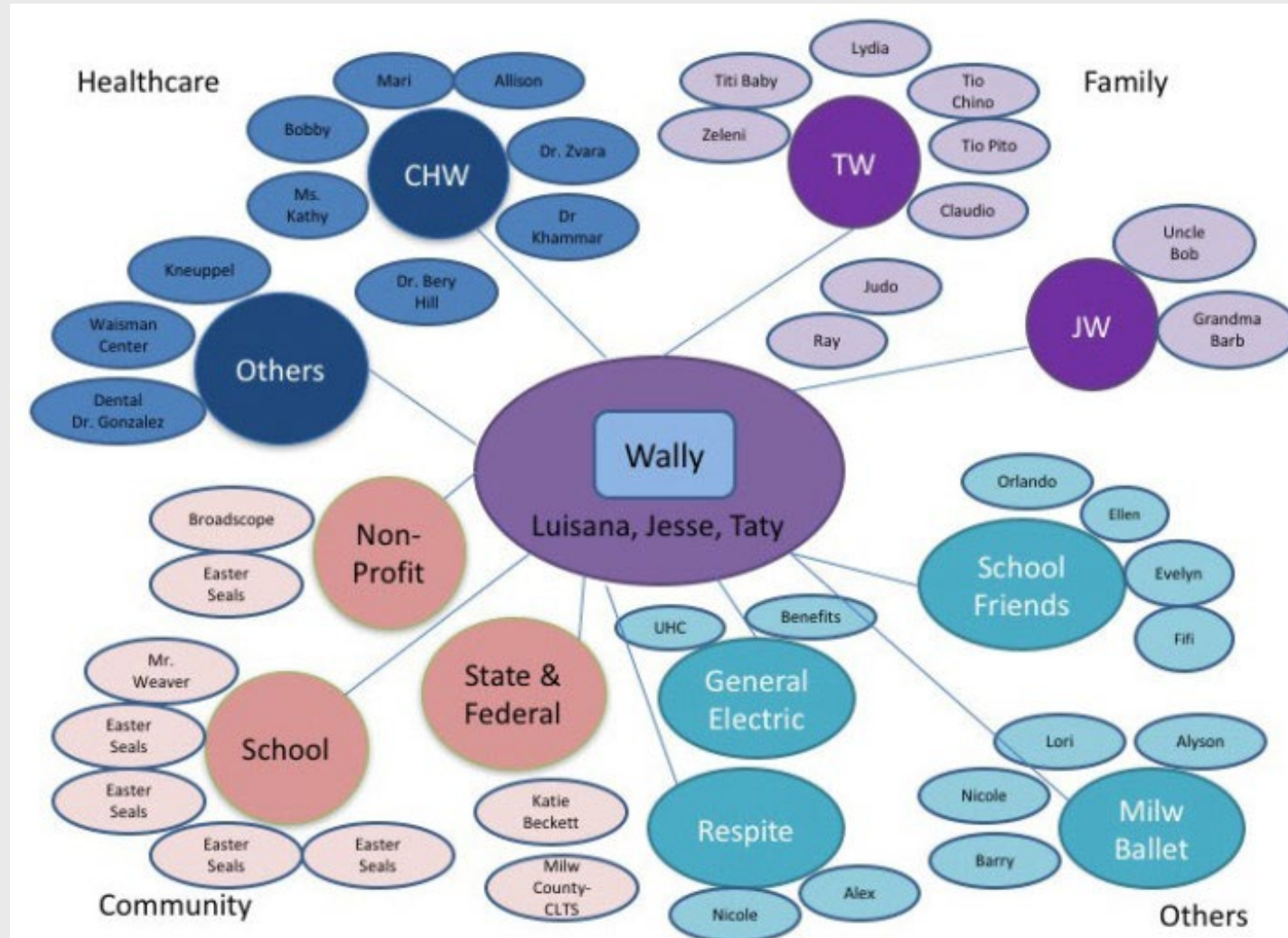


# Relationships



## Focus areas:

1. Sharing Power
2. Being Trustworthy



# Relationships: Sharing Power



*“We, meaning Title V CYSHCN, are responsible for creating settings  
– or mentoring our partners on how to create settings – in which  
family and youth leaders can access power.”*

Alison Martin, OR Title V





# Access to Real Power



*“Power includes access to information and knowledge, cultural norms, influence, and money. Family leaders need to have access to real power – **decision-making authority, compensation to participate in meetings, provision of information needed to participate, voice in determining how a project runs.**”*

Alison Martin, OR Title V

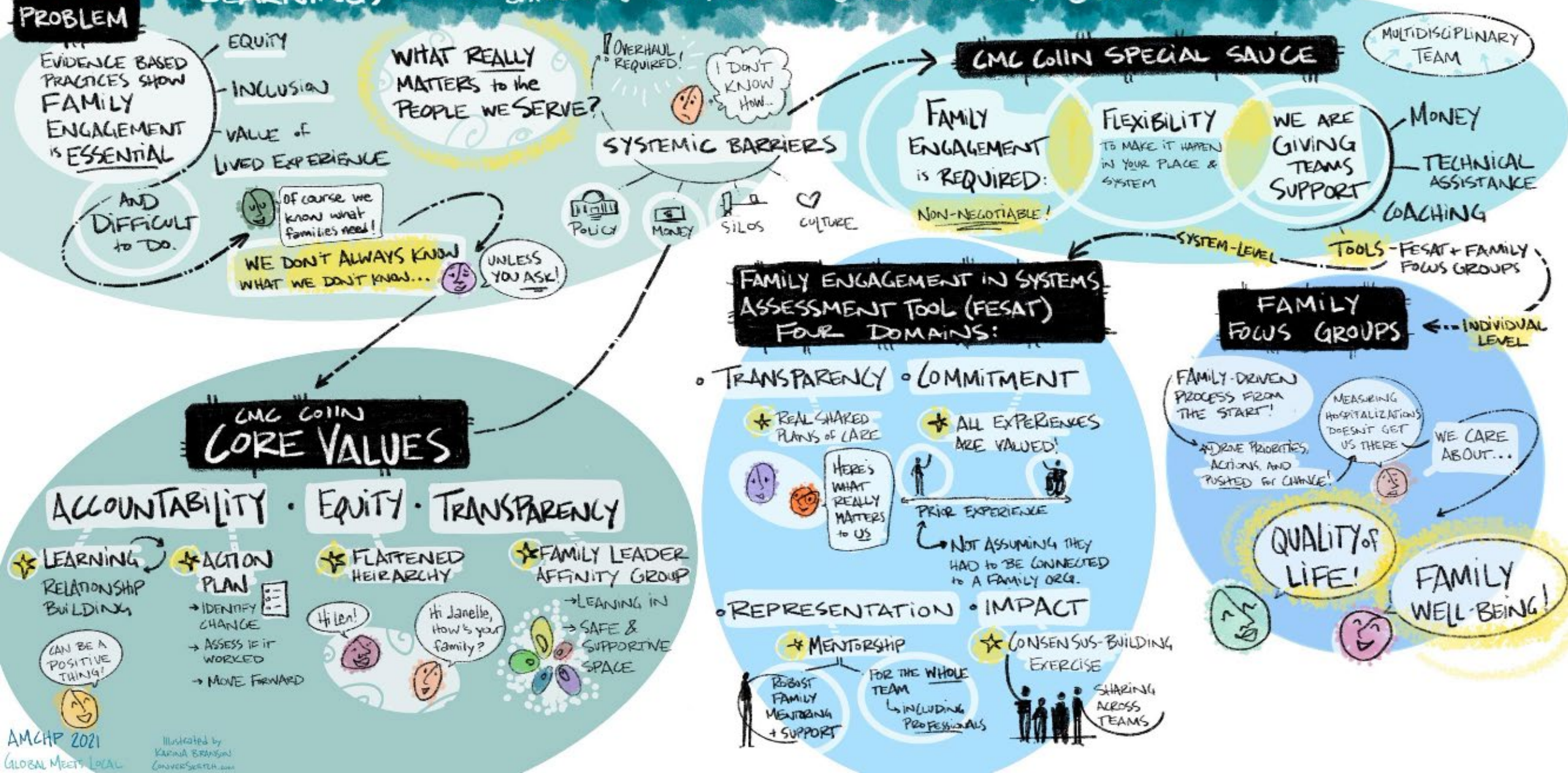
*“It’s been wonderful having a formalized opportunity to provide meaningful, practical input on policy and planning... Without the CoIIN structure, we [families] would still be trying to influence and improve systems from a distance.”*

CMC CoIIN State Team Key Informant



# EFFECTIVE FAMILY PARTNERSHIP TOOLS TO DRIVE GLOBAL and LOCAL IMPROVEMENTS:

## LEARNINGS from the CHILDREN with MEDICAL COMPLEXITY (CMC) COLIN





# Structures to Ensure Power Sharing w/ Family Partners



## Leadership

- Family Voices National as partner
- National Advisory Committee & Subcommittee
- PI = CMC parent
- FP as focal point for learning

## Network

- Affinity group/mentoring
- Workgroups
- Family-reported outcomes
- Family focus groups (2x)

## State Team

- Core group member on each state team
- Additional roles: advisory members, interviewers
- FV FESAT consensus-driven action plan



# Empowerment



*“Following our family leader-led presentation at the 2019 AMCHP conference, our **family leaders said that they didn’t realize the value of family engagement and family voice until that meeting.** They said that they felt empowered on our project.”*

Alison Martin, OR Title V

# Reach out to new parents



*“Our OSCHN Adv Council had a few parents on for a long time. They brought a wealth of knowledge but we wanted to broaden and open it up to different backgrounds. When I approached parents to ask, it was interesting that they didn’t recognize how important they were to the game:*

*‘Why do you want me?’*

*‘You could really bring something to the table we could learn from.’*

*A lesson from pandemic: reach out to parents to **help them recognize their value** to us.”*

Pat Purcell, formerly of KY Title V



*“Tamara Bakewell, OCCYSHN FIP Manager & OR F2F HIC Director, provided me with some suggestions (e.g., mentorship) that allowed me to realize ways of working with family leaders that I had been itching to try. As we offered opportunities to our amazing **family leaders, and provided them with mentoring and encouragement, they wanted and kept doing more.** Their journey has been so exciting and fulfilling to watch.”*

Alison Martin, OR Title V

# Promising Strategies for Power Sharing in Systems



- *We [Title V] have influence/agency with contracting processes. I don't control the purse strings but can **recommend we require in contracts that families are central to project design/outset, implementation, and paid for their time. I think this could be transformative for Title V.***
- ***FESAT** – showed us we need more diverse representation on the family workgroup.*
- *Learned through the CMC CollN **the importance of identifying and measuring what matters to families.** It's not an easy process, but we can be more mindful about it. A north star. Our family workgroup developed outcome measures that we've added to current measures to come closer to measuring what families tell us matters most.*

Ivy Goldstein, TX Title V

# Relationships: Being Trustworthy



- Community = sense of belonging and being seen
- Honor bias and harm both historically and in current lived experience of children/youth/families with health care and government



## Real concerns from families:

- *If someone that I had a good rapport with, and felt really comfortable, like “I know you guys.”, or with people that get it, so [that] it’s easier [to respond truthfully about how I am doing].*
- *I usually just say fine just because I don’t like getting upset in front of my care providers. So, it's a struggle.*

Source: CMC CoIIN Family Focus Groups





# What does that look like?





# EFFECTIVE FAMILY PARTNERSHIP TOOLS TO DRIVE GLOBAL and LOCAL IMPROVEMENTS:

## LEARNINGS from the CHILDREN with MEDICAL COMPLEXITY (CMC) COLIN

### PROBLEM

EVIDENCE BASED PRACTICES SHOW FAMILY ENGAGEMENT IS ESSENTIAL

EQUITY  
INCLUSION  
VALUE of LIVED EXPERIENCE

AND DIFFICULT TO DO.

OF course we know what families need!

WE DON'T ALWAYS KNOW WHAT WE DON'T KNOW...

UNLESS YOU ASK!

WHAT REALLY MATTERS to the PEOPLE WE SERVE?

OVERHAUL REQUIRED!  
I DON'T KNOW HOW...

SYSTEMIC BARRIERS

POLICY  
MONEY  
SILOS  
CULTURE

### CMC COLIN SPECIAL SAUCE

FAMILY ENGAGEMENT IS REQUIRED:  
NON-NEGOTIABLE!

FLEXIBILITY TO MAKE IT HAPPEN IN YOUR PLACE & SYSTEM

WE ARE GIVING TEAMS SUPPORT

MONEY  
TECHNICAL ASSISTANCE  
COACHING

MULTIDISCIPLINARY TEAM

TOOLS - FESAT + FAMILY FOCUS GROUPS

### CMC COLIN CORE VALUES

ACCOUNTABILITY • EQUITY • TRANSPARENCY

LEARNING RELATIONSHIP BUILDING  
CAN BE A POSITIVE THING!

ACTION PLAN  
→ IDENTIFY CHANGE  
→ ASSESS IF IT WORKED  
→ MOVE FORWARD

FLATTENED HIERARCHY  
Hi Len!  
Hi Janelle, how's your family?

FAMILY LEADER AFFINITY GROUP  
→ LEARNING IN  
→ SAFE & SUPPORTIVE SPACE

### FAMILY ENGAGEMENT IN SYSTEMS ASSESSMENT TOOL (FESAT) FOUR DOMAINS:

TRANSPARENCY • COMMITMENT

REAL SHARED PLANS of CARE  
ALL EXPERIENCES ARE VALUED!  
HERE'S WHAT REALLY MATTERS to US  
PRIOR EXPERIENCE  
NOT ASSUMING THEY HAD TO BE CONNECTED to a FAMILY ORG.

REPRESENTATION • IMPACT

MENTORSHIP  
FOR THE WHOLE TEAM  
→ INCLUDING PROFESSIONALS  
ROBUST FAMILY MENTORING + SUPPORT

CONSENSUS-BUILDING EXERCISE  
SHARING ACROSS TEAMS

### FAMILY FOCUS GROUPS

INDIVIDUAL LEVEL

FAMILY-DRIVEN PROCESS FROM THE START!  
WE CARE ABOUT...  
MEASURING HOSPITALIZATIONS DOESN'T GET US THERE  
WE DRIVE PRIORITIES, ACTIONS AND PUSHED FOR CHANGE!

QUALITY of LIFE!  
FAMILY WELL-BEING!



# Structures to Ensure Power Sharing w/ Family Partners



## Leadership

- Family Voices National as partner
- National Advisory Committee & Subcommittee
- PI = CMC parent
- FP as focal point for learning

## Network

- Affinity group/mentoring
- Workgroups
- Family-reported outcomes
- Family focus groups (2x)

## State Team

- Core group member on each state team
- Additional roles: advisory members, interviewers
- FV FESAT consensus-driven action plan

If you have come  
to help me you are  
wasting your time.  
But if you have  
come because your  
liberation is bound  
up with mine, then  
let us work together.

ABORIGINAL  
ACTIVISTS  
GROUP



# Co-Creating Systems with Communities

**Thank you!**

Questions and Discussion







Family Engagement  
and Leadership in  
Systems of Care



# Engaging Diverse Families across Maternal and Child Health

Nikki Montgomery, M.A., M.Ed., GPAC

Director of Communications

Family Voices



# Engaging Diverse Families across Maternal and Child Health



## Presenters

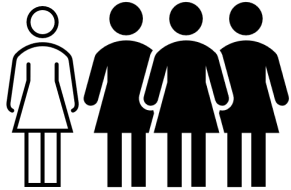
### Nikki Montgomery

- Parent of child with a rare condition and disabilities
- Sibling of a person with a rare condition
- Title V Block Grant Reviewer
- Background in:
  - Patient and family engagement and safety
  - Health equity and bias in health care
  - Health literacy for families of CYSHCN

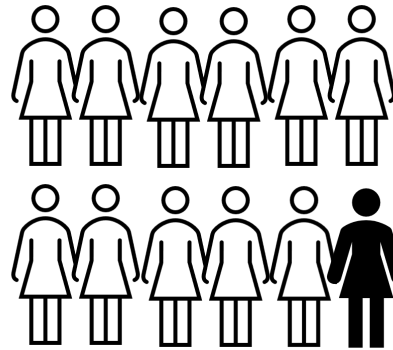
# Personal Experience of Family Engagement



Patient panel to develop a national measure for **maternal morbidity**



What the problem looks like



What the “solution” looked like

Discussed how and whether they could make the measure account for disparities

I received \$150 total for 18 months of quarterly meetings that required hours of preparation.

# Realities of Engagement for Diverse Family Partners



## Tokenism

- **"We have one."**
- Lack of equitable representation
- Undersampling from communities with the greatest risk or worst outcomes



## Paternalism

- **"We know how to help you."**
- Assumption that the public health entity has the answers
- Not understanding that communities have their own knowledge and solutions (and you won't solve a problem *about* them *without* them)



## Exploitation

- **"We don't need to pay family partners."**
- Believing families should just be happy to be in the room
- Undervaluing lived experience as expertise

# Ideal Family Engagement



## Equitable

- Informed by data on disparities, Needs Assessments
  - CAHMI Data Resource Center
- Family partners compensated for expertise and time

## Community-led

- Defining the problem and scope
- Understanding and building on existing solutions
- Developing true partnerships that last

# Barriers to Effective Engagement



- Treating communities as if they are “**hard-to-reach**”
- **Policies** that don’t support engagement
- Not preparing the **environment** for increased diversity
- Seeking “star parents” and “unicorns”
- Feeling **helpless** to solve the problems families identify
- Power dynamics



# Building Trust with Diverse Family Partners



- **Partner with trusted individuals**

- Be consistent, build trust over time.
- Close the feedback loop.

- **Connect with community partners**

- Community-based organizations as partners
- Share funding opportunities.

- **Engage with family partners**

- Pay family partners promptly.
- Schedule meetings when they are available.
- Provide access and accommodations.

- **Provide supports for family leaders**

- Mentorship
- Clear understanding of the role and responsibilities

# Family-to-Family Health Information Centers (F2Fs)



- Community-based, **family-led** organizations
- Focused on **peer-to-peer** support and navigation
- Build families' leadership skills
- Children and youth with special health care needs (**CYSHCN**)
- **Relationships** with diverse families
- Ready to **partner** with MCH agencies
- In all 50 states, 5 US Territories and 3 Tribal Nations; **Find your local F2F** at [familyvoices.org](https://familyvoices.org)

# About the FELSC Project



## Family Engagement and Leadership in Systems of Care

Family-to-Family Health Information Centers (F2Fs) are family-led organizations that support families of children and youth with special health care needs (CYSHCN). Family Voices houses the technical assistance center for the F2Fs and leads family engagement across MCH populations.

This project works with families, youth, and partner organizations to increase the impact of family and youth engagement and to support and develop the network of F2Fs.

**Learn more about the project at [www.familyvoices.org/FELSC](http://www.familyvoices.org/FELSC).**

# Engaging Diverse Families across Maternal and Child Health

**Thank you!**

Questions and Discussion

