

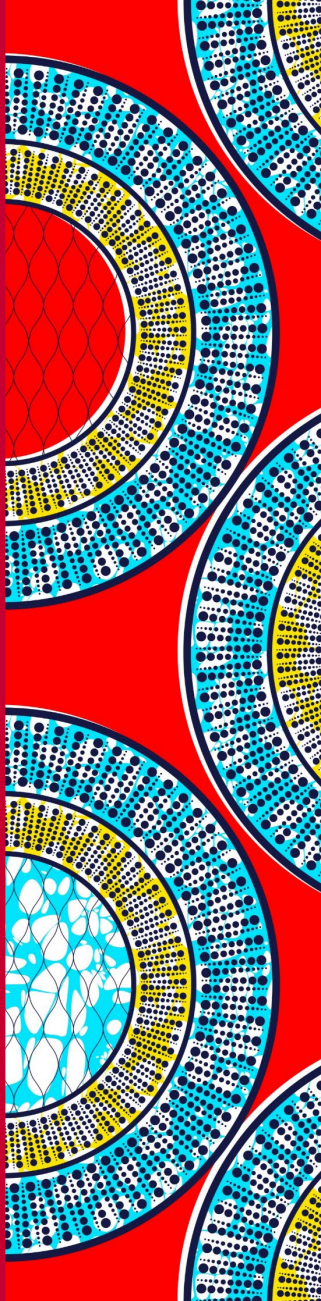
Lived Experience and Community Engagement

To Support Health Care System Transformation

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

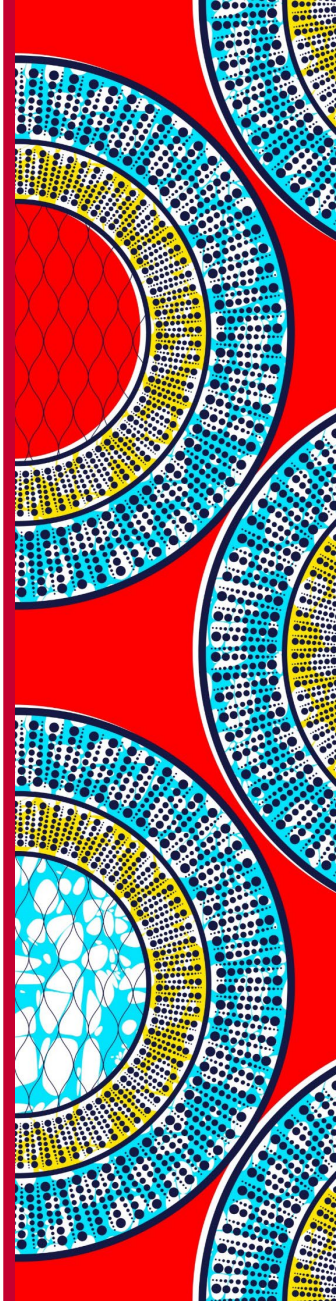
Program and Communications Manager

Family Voices, Inc.



Questions

- How should healthcare providers or healthcare systems be engaging families and communities in their care?
- What changes are needed in the child and adolescent health care system?
- What are patient and family expectations of high-quality care, evidence-based care, and health equity?
- What are promising policies and practices?



Engaging Families and Communities

- Broadly
- Equitably
- With no excuses

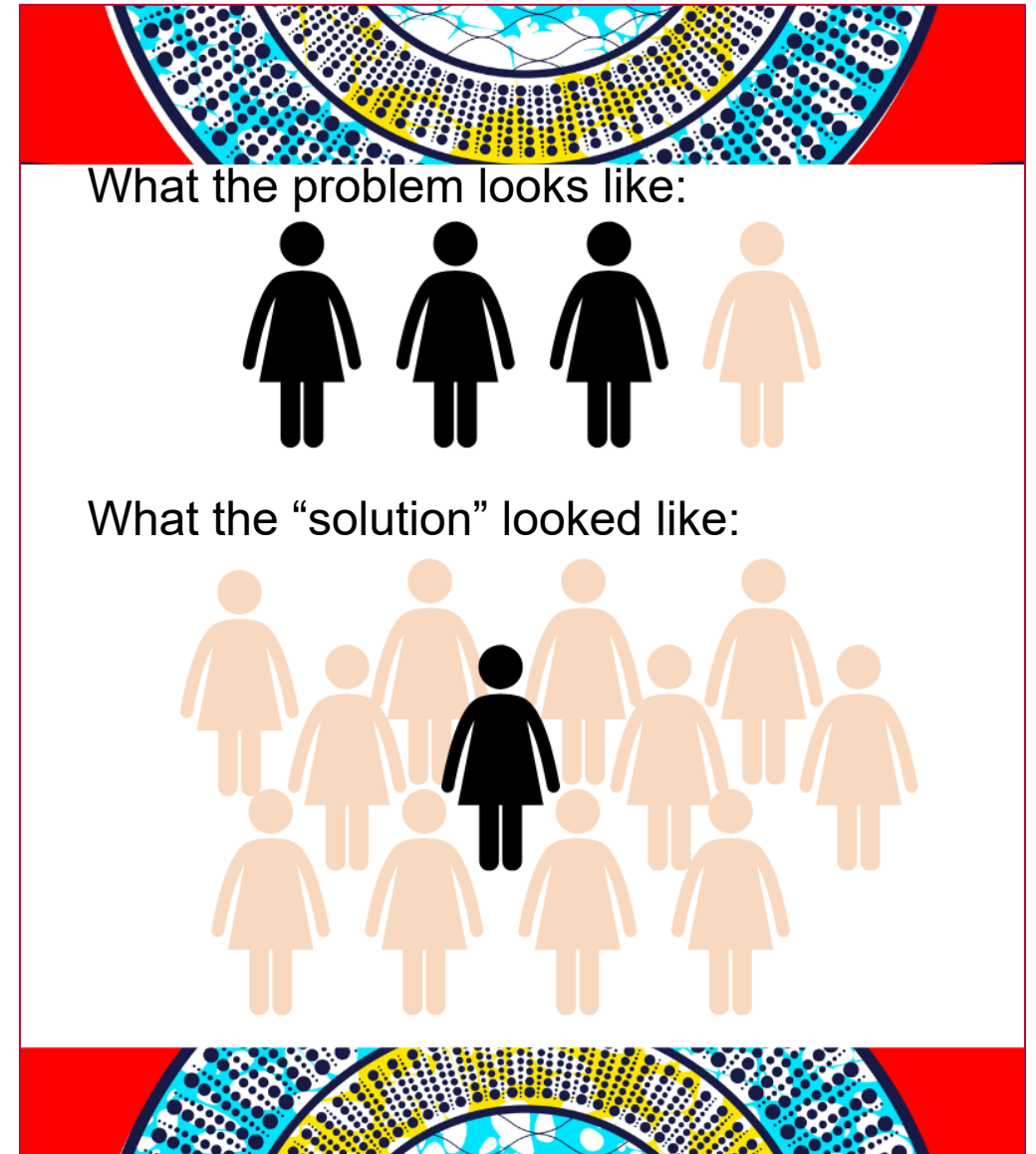


Broadly

- People are not “hard to reach”.
- Reaching populations you haven’t built trust with
- Knowledge of how to engage them
- Opportunities for learning

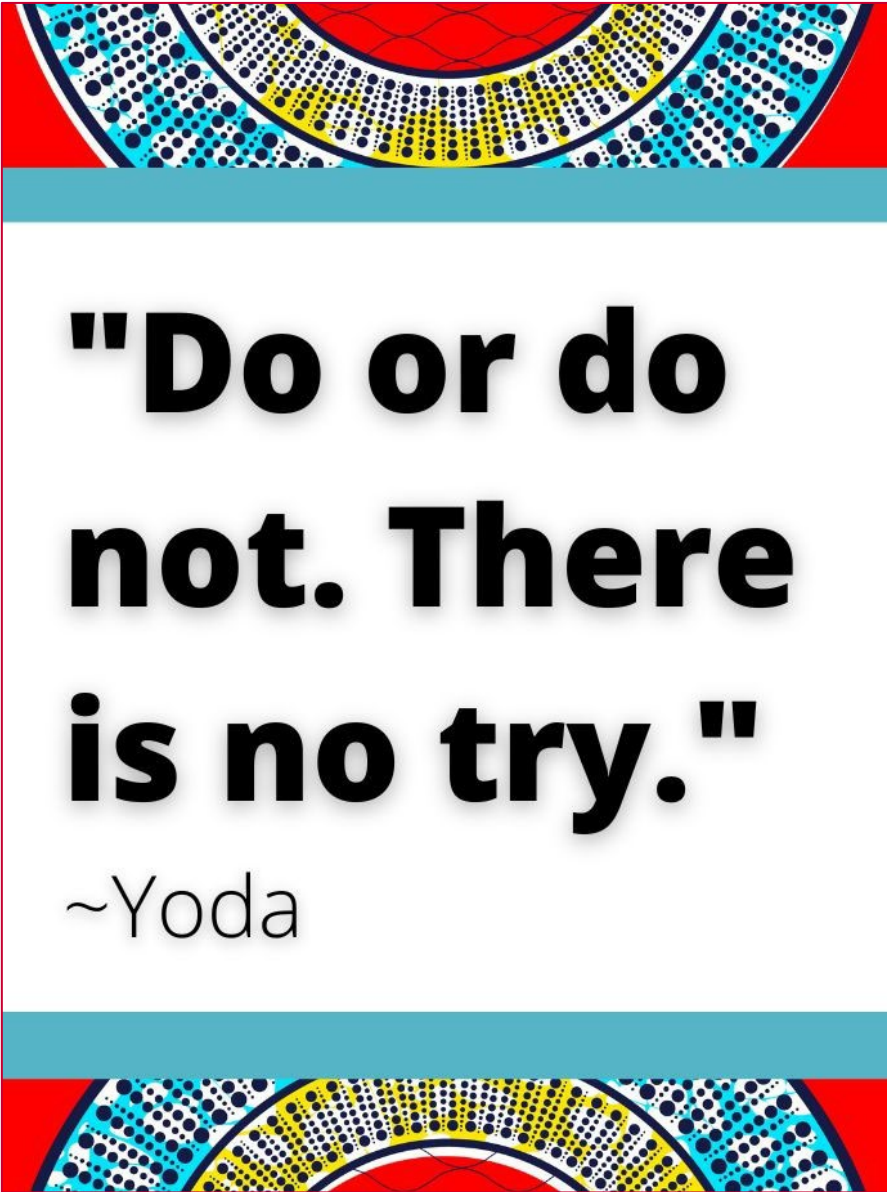
Equitably

- Who is experiencing the problem most acutely?
- Who needs the most attention in order to have positive outcomes?
- How are you ensuring that these voices are leading the conversation, not just invited?



With No Excuses

- You will either perpetuate existing disparities or work to eliminate them.
- You will either improve children's health or maintain (or worsen) the current state.
- You will either be part of the problem or part of the solution.



**"Do or do
not. There
is no try."**

~Yoda

Changes Needed

- Coordination
- Integration
- Communication

Care Coordination

- Families should not have to wrangle providers and systems to talk to one another.
- Families need information to make sense of the health care system; otherwise, they cannot be informed decisionmakers.

Integration

- Integrating systems and policies for the ease of the users
- Integrating family expertise to understand the user experience
- Integrating equity work with safety, quality and experience work

Communication

INDIVIDUAL

- Focus on health literacy
- Beyond stock images
- Accessibility

SYSTEMLEVEL

- Bi-directional
- Multimodal
- Culturally responsive

Patient and Family Expectations

INDIVIDUAL

- Work with families you serve to define what high -quality care, evidence-based care, and health equity mean to their child's care experience.
- The fragility of trust

SYSTEMLEVEL

- Invite and include family leadership in transforming systems to improve care and equity in non -tokenizing ways.
- Community partnerships that are non -exploitative

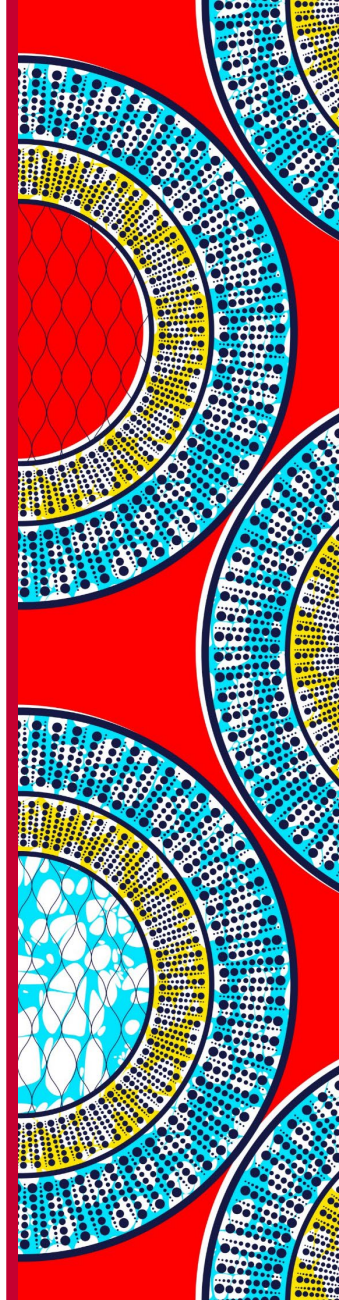
Promising Policies and Practices

Collect race, ethnicity and language data.

- Disaggregate data
- Publish and act on the data

Measure what you intend to improve.

- Family Engagement in Systems Assessment Tools
- www.familyvoices.org/FESAT



Final Thought

Getting good care should not require resilience.

The need for resilience indicates the presence of trauma.

Health care should not inflict trauma.