Patient Engagement: Tools to Move Past the Story

Beth Dworetzky, MS
Associate Director of Programs, Family Voices

LaToshia Rouse
PFE Consultant and Doula, NNPQC Executive Committee

NOVEMBER 9, 2020
1:00-2:00PM ET
Welcome!

Thank you for joining the call! We will get started shortly.

• You may be muted upon entry to the call
• You **DO have the ability** to unmute yourself
• We encourage participants to remain muted in an effort to reduce background noise

• If you are in a room with multiple participants, only one of you will need to connect to audio (see next slide)
Connecting to the Audio Conference

Join Zoom Meeting by **clicking Zoom Meeting link** & launching the Zoom application

An audio conference box will appear
  ◦ If you do not see the box click the ‘**Join Audio**’ button

From the audio conference box: Select to “**Phone Call**” or “**Computer Audio**”

If using the phone:
  ◦ dial the number next to “Dial”
  ◦ You will be prompted to enter the “**Meeting ID**”
  ◦ Then you will be prompted to enter the “**Participant ID**”
Ways to Participate: Chat

At the bottom of the Zoom window, you will see a ‘Chat’ button.

After you click the ‘Chat’ button, a sidebar will appear where you can chat to all participants.

Chat here to everyone!
Ways to Participate: Raise Hand

At the bottom of the window, you will see a ‘Participants’ button.

After you click the ‘Participants’ button, a sidebar will appear where you see ‘non-verbal functions’.

Click here to raise your hand!
Partnering for Improved Birth Outcomes

The Institute for Healthcare Improvement (IHI) Better Maternal Outcomes Initiative and the National Network of Perinatal Quality Collaboratives (NNPQC), coordinated by NICHQ, are partnering to provide participants with a valuable set of webinars on health equity, respectful care and other critical maternal health topics. This partnership recognizes the shared commitment of these two initiatives to improve hospitals and health systems by elevating and spreading evidence-based efforts and examples of improvement from across the country so that families experience better birth outcomes. By bringing all participants together to engage in shared learning, the NNPQC and the Better Maternal Outcomes Initiative will encourage collaboration and innovation among teams with a shared mission, and ultimately accelerate national improvement.
The IHI Better Maternal Outcomes Initiative aims to reduce maternal morbidity and mortality by supporting national efforts to implement reliable evidence-based care for women and newborns around the time of birth, and by facilitating locally driven, co-designed rapid improvements in four communities, targeting the interface of health care delivery, the experience of birthers, and community support systems.

The National Network of Perinatal Quality Collaboratives (NNPQC), coordinated by NICHQ, supports the development and enhances the ability of state perinatal quality collaboratives to make measurable improvements in statewide maternal and infant healthcare and health outcomes by providing resources and expertise to nationwide state-based perinatal quality collaboratives (PQCs).
Today’s Speakers: Beth Dworetzky & LaToshia Rouse

**Beth Dworetzky, MS** is the Associate Director of Programs at Family Voices, where she manages multiple projects that focus on building the capacity of systems of care to promote meaningful family engagement at all levels of care. Ms. Dworetzky is the team lead for the development, dissemination, and implementation of the Family Voices Family Engagement in Systems Assessment Tools. Her expertise includes the analysis of qualitative and quantitative data and the development of evaluation and assessment tools.

**LaToshia Rouse** is the owner of Birth Sisters Doula Services, where she is a birth and postpartum doula. She is also the mother of a 10-year-old 36-weeker and 7-year-old triplets born at 26 weeks. These experiences help shape her perspective as a National Patient and Family Partner. Ms. Rouse began quality improvement work when her triplets were 2 years old as a parent partner. Her work since has been at the hospital, state, and national level on projects relating to patient and family engagement, policy, research, measurement development, and equity in the pediatric, maternal, and infant arena. As a sought-after speaker, her passion is helping parents find their voice and helping clinicians learn from their experiences.
Patient Engagement: Tools to Move Past the Story
NNPQC/ IHI Thematic Webinar
November 9, 2020

Beth Dworetzky
Associate Director of Programs,
Family Voices

LaToshia Rouse
PFE Consultant and Doula
NNPQC Executive Committee
FamilyVoices.org

Keeping families at the center of children’s health care.
Objectives

- Introduce the Family Voices Family Engagement in Systems Assessment Tools
- Demonstrate 3 uses of the tools
- Ideas for next steps
Levels of Family Engagement

- Individual
- Advisory
- Systems-level
Systems-level Family Engagement

Our Six Pillars of Learning

The Fundamental Essentials of Nursing Care
Exeter Nurses will be nurses first and foremost. They will be expert at caring for individuals, and in helping them perform the care activities that contribute to health, recovery or dignified death. Activities that the individual would perform by themselves if they had the necessary strength, will or knowledge.

Patient and Public Involvement
Exeter Nurses will uphold the principle of nothing about us without us in all their interactions with patients, carers and members of the public. The people we care for are our equals and partners.

Evidence for Practice
The Exeter nurse will be a scientist practitioner, accessing, using and producing the research evidence for their practice when planning and delivering care in every nursing encounter.

No Health Without Mental Health
The Exeter Nurse will always consider and act to ensure the mental health of patients and the public is as important as their physical health.

Leadership and Management
The Exeter Nurse will lead by example, ensuring that healthcare is efficient, effective and evidence-based and inspiring confidence in others who are delivering, or receiving, healthcare.

Global Health
The Exeter nurse will deliver health care in the context of a drive for worldwide health improvement (including mental health), reduction of disparities, and protection against global threats that disregard national borders.

Nothing About Us Without Us

Otsuka’s 12-Point Framework for Innovation in Mental Health
1. “Nothing about us, without us”
2. Clean tools for messy problems
3. New solutions, but old problems
4. Push and pull
5. Adaptable solutions
6. Bridging the communications gap
7. Privacy, security, and consent
8. Innovation in both design and delivery
9. Unmet Need: Adherence
10. Unmet Need: Preventing Relapse Through Early Detection
11. Unmet Need: Promoting Wellness
12. Unmet Need: Education and Self-Advocacy
Systems-Level Family Engagement

Authentic partnerships between professionals and patients and families who reflect the diversity of the communities they represent, working together at the systems level to develop and implement better policies and practices.
### Family Engagement in Systems Tools

#### Family Engagement in Systems Assessment Tool (FESAT)

**User's Guide**

#### Family Engagement in Systems Assessment Tool (FESAT)

**Family Engagement in Systems (FES) Toolkit: A Compilation of Strategies and Resources**

<table>
<thead>
<tr>
<th>Domain 1: Commitment</th>
<th>Yes</th>
<th>No</th>
<th>Some what</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The organization uses written policy that requires family engagement in systems-level initiatives.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization has one or more champions of family engagement.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization acknowledges the contributions family leaders make to systems-level initiatives.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization's budget includes funding for family leaders' time and/or other costs they incur (for example, travel, child care).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives (for example, educating staff about new policies).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Domain 2: Transparency</th>
<th>Yes</th>
<th>No</th>
<th>Some what</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>The organization conducted activities to understand the issues faced by the children and families they serve (for example, used data or conducted a focus group).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization ensures all staff and families have a clear understanding of the initiative they will work on together.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization provides the supports families and staff need to understand their partnership role (for example mentors/coaching).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization ensures all participants have the supports they need to participate in meetings (for example, physical access, interpreters, time away from other work responsibilities).</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>The organization ensures all participants have the information they need to participate in meetings.</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Family Engagement in Systems Assessment Tools (FESAT)

1. Plan
   - Identify supports already in place to ensure meaningful family engagement.
   - Explore strategies and resources for additional ways to encourage and support family engagement.

2. Assess
   - Families & professionals score the tool.
   - Compare perspectives.
   - Identify what is working well
   - Identify areas for improvement.

3. Improve
   - Complete the FESAT to set a baseline.
   - Identify an area for improvement.
   - Select a strategy from the FES Toolkit that can help.
   - Complete the FESAT again at scheduled intervals; compare results to the baseline.
During our PQC initiative, we will make room for PFPs to provide ideas about things they would like to see improved. Could they offer a best practice for patient engagement for consideration?

The PQC has patients be a part of the learning sessions when with adequate time to review data findings prior to the meeting.

There is a patient and family engagement initiative at the PQC level and the hospital level.
FESAT User’s Guide

appendices
introduction
scoring
glossary
instructions
using results
examples
FESAT

Commitment
Families are included in all systems-level initiatives that impact the organization’s policies, programs, services, and practices.

Transparency
Family leaders can easily access and understand the information they need to participate effectively.

Representation
Family leaders reflect the diversity of the community served by the organization.

Impact
Family leaders’ ideas are incorporated at the systems level to improve policies, programs, services, and practices.
Domain 1: **Commitment** means that the organization routinely engages family leaders in all systems-level initiatives that affect the policies and programs that govern services for children, youth, and families.

<table>
<thead>
<tr>
<th>In my experience:</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Not Sure/Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The organization uses written policy that requires family engagement in systems-level initiatives.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>2. The organization has one or more champions of family engagement.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3. The organization acknowledges the contributions family leaders make to systems-level initiatives.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4. The organization’s budget includes funding for the family leaders’ time and/or other costs they incur (for example, travel, childcare).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5. The organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives (for example, educating staff about new policies).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
**Domain 2: Transparency** occurs when the organization clearly documents and communicates about how it identifies issues faced by the children and families they serve; provides the information and supports family leaders need to participate to their maximum potential in the systems-level initiative.

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Not Sure/Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. The organization conducted activities to understand the issues faced by the children and families they serve (for example, used data or conducted a focus group).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>7. I had a clear understanding of the initiative that staff and families worked on together.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8. I had the support I needed to understand my partnership role (for example, a mentor within or outside of the organization).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9. I had the support I needed to participate in meetings (for example, physical access, interpreters, time away from other work responsibilities)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10. I had the information I needed to participate in meetings.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
**Domain 3: Representation** occurs when family leaders reflect the diversity of the community served by the policy, program, practices, and services provided by the organization.

<table>
<thead>
<tr>
<th>Family leaders who collaborated in the initiative were representative of:</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Not Sure/Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. <strong>Races and ethnicities</strong> of the populations served by the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>12. <strong>Cultures</strong> of the populations served by the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>13. <strong>Languages</strong> spoken by the populations served by the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>14. <strong>Geographic areas in which populations</strong> served by the initiative live.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
Domain 4: Impact describes the areas where family leaders’ ideas were incorporated at the systems level to improve policies, programs, services, and practices.

<table>
<thead>
<tr>
<th>In my experience, organization staff:</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Not Sure/Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Listened to family leaders’ ideas.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>16. Engaged family leaders in choosing goals for the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>17. Worked together with family leaders to implement the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>18. Worked together with family leaders to evaluate the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>19. Used family leaders’ input to improve the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>20. Could explain how family leaders contributed to the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>
# FESAT Score Sheet

## Domain 1: Commitment

<table>
<thead>
<tr>
<th>Team Points</th>
<th>Max Points</th>
<th>Domain Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>

1. The organization uses written policy that requires family engagement in systems-level initiatives.
2. The organization has one or more champions of family engagement.
3. The organization acknowledges the contributions family leaders make to systems-level initiatives.
4. The organization’s budget includes funding for the family leaders’ time and/or other costs they incur (for example, travel).
5. The organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives (for example, educating staff about new policies).

## Domain 2: Transparency

<table>
<thead>
<tr>
<th>Team Points</th>
<th>Max Points</th>
<th>Domain Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>0</td>
<td>0%</td>
</tr>
</tbody>
</table>

6. The organization conducted activities to understand the issues faced by the children and families they serve (for example, used data or conducted a focus group).
7. I had a clear understanding of the initiative staff and families worked on together.
8. I had the support I needed to understand my partnership role (for example, a mentor within or outside of the organization).
9. I had the support I needed to participate in meetings (for example, physical access, interpreters, time away from other work).
10. I had the information I needed to participate in meetings.
### Family Engagement in Systems Assessment Tool Score Sheet

#### Domain 1: Commitment

<table>
<thead>
<tr>
<th></th>
<th>Team Points</th>
<th>Max Points</th>
<th>Domain Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4</td>
<td>4</td>
<td>70%</td>
</tr>
<tr>
<td>2</td>
<td>4</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

- The organization uses written policy that requires family engagement in systems-level initiatives.
- The organization has one or more champions of family engagement.
- The organization acknowledges the contributions family leaders make to systems-level initiatives.
- The organization’s budget includes funding for the family leaders’ time and/or other costs they incur (for example, travel, childcare).
- The organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives (for example, educating staff about new policies).

#### Domain 2: Transparency

<table>
<thead>
<tr>
<th></th>
<th>Team Points</th>
<th>Max Points</th>
<th>Domain Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>4</td>
<td>4</td>
<td>70%</td>
</tr>
<tr>
<td>7</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

- The organization conducted activities to understand the issues faced by the children and families they serve (for example used data or conducted a focus group).
- I had a clear understanding of the initiative staff and families worked on together.
- I had the support I needed to understand my partnership role (for example, a mentor within or outside of the organization).
- I had the support I needed to participate in meetings (for example, physical access, interpreters, time away from other work).
- I had the information I needed to participate in meetings.

#### Domain Scores

- **Commitment**: 70%
- **Transparency**: 70%
- **Representation**: 25%
- **Impact**: 63%

#### Team Points Whole Score

- **Team Points**: 47
- **Max Points**: 80
- **Engagement Score**: 59%
What would it look like if...

- The hospital NICU partners with families to do a QI initiative to improve hospital discharge planning for micropreemies.
- I have used the tool to develop a plan to address a gap we didn’t know we had relating measuring the impact of patient engagement in our facility.
- The tool has helped me learn how to find funding for compensation for our PFPs at the hospital level.
FES Toolkit

- Organized by the 4 domains of family engagement
- Collection of strategies and resources organizations can use to improve family engagement
- Use as a standalone resource or as a companion document to the FESAT
FES Toolkit: Commitment

Domain 1: Commitment

Commitment means that the organization routinely engages family leaders in all activities that affect the policies and programs that govern services for children, youth, and families.

Strategy: Create a written policy that requires family engagement in systems-level initiatives

Resources
- Examples of family engagement policies include:
  - This evidence-based guide, developed by U.S. Department of Health and Human Services’ Agency for Healthcare Research and Quality, was created for hospitals. However, the strategies, such as including family engagement in the hospital’s mission and vision statements, and strategic plan, can be used by any child- and family-serving organization to guide the design of a written policy for engaging families in systems-level initiatives.
  - Policy Statement on Family Engagement from the Early Years to the Early Grades, from the U.S. Department of Health and Human Services, U.S. Department of Education.
  - Developing a Written Parent and Family Engagement Policy: A Guide for Districts and Schools. This 2018 document from the Tennessee Department of Education includes tools and resources for writing family engagement policies for engaging families at the advisory/district level, beyond the education of their individual child.

Strategy: Ensure the organization has one or more champions of family engagement.

Resources
- Guide to Patient and Family Engagement: Environmental Scan Report. This report, prepared by the American Institutes for Research for AHRQ, documents the importance of having an internal champion as a strategy for implementing organizational change. Champions for family engagement can ensure consistent communication throughout an initiative.
- Family Voices conducted a series of key informant interviews with family leaders and professional partners during the development of the Framework for Assessing Family Engagement in Systems Change. Findings included not only the importance of a champion of family engagement, but also the importance of documenting family engagement (see strategies for creating a family engagement policy) to ensure a continuous culture of family engagement, even if the organization’s leadership changes.
Commitment Strategy & Resource

<table>
<thead>
<tr>
<th>In my experience:</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Usually</th>
<th>Always</th>
<th>Not Sure</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The organization uses written policy that requires family engagement in systems-level initiatives.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. The organization has one or more champions of family engagement.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. The organization acknowledges the contributions family leaders make to systems-level initiatives.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. The organization’s budget includes funding for the family leaders’ time and/or other costs they incur (for example, travel, childcare).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. The organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives (for example, educating staff about new policies).</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Strategy: Engage at least two or more family leaders in the initiative.**

**Resource**

- **Tokenism in Patient Engagement:** Many organizations see patients and families as a symbolic or token effort of engagement in research or other initiatives. West et al. identified the importance of building relationships and trust to ensure intentional engagement of stakeholders representing multiple perspectives.

**Strategy: Have a mechanism for reimbursing family leaders for their time and/or other costs they incur.**

If organization staff and other stakeholders are paid for their time participating in systems-level initiatives, the family participants should be paid as well. Families incur expenses for transportation, childcare, and lost time at work. If families are not compensated for their time and related expenses, it precludes the participation of many families and reduces diversity. Compensating families demonstrates that an organization values their time, input, and expertise.

**Resource**

- **Participate with Youth & Families in Research: A Standard of Compensation for Youth and Family Partners, CyberOptic:** a national research network focused on children and youth with special health care needs, provides guidance about payment for youth and family partners who participate on research projects.
FES Toolkit: Transparency

Family Engagement in Systems Domain 2: Transparency

Transparency occurs when the organization clearly documents and communicates about how it:
- Identifies issues faced by the children and families they serve.
- Provides the information and supports family leaders and organization staff need to partner and participate to their maximum potential.

Transparency Strategy: Conduct a needs assessment or other activities to identify and understand the issues children and families are facing.

Resources
- The Centers for Disease Control and Prevention, Division of Nutrition, Physical Activity, and Obesity, has a Community Health Assessment and Group Evaluation (CHANGE) Tool. This includes assessment questions and excel files that others can adapt for their own initiatives and use for focus groups, on-line surveys, and key informant interviews to learn about barriers to care or other issues that families experience with the identified system of care.
- The Power of Community Voices for Enhancing Community Health Needs Assessments. This 2017 article by Cain, et al describes how Allina Health successfully engaged diverse community members in its community health needs assessment.

Transparency Strategy: Use data to learn about the issues and concerns that children, youth, and families are experiencing.

Resources
- See Internal and External Data Sources in the Representation (below)
- National Survey of Children’s Health. This interactive resource, from the Data Resource Center for Child & Adolescent Health, is a project of the Children and Adolescent Health Measurement Initiative. It includes data for hundreds of child and family health measures, as well as data for the Title V Maternal and Child Health Services Block Grant National Performance Measures and National Outcome Measures. Users can stratify data queries by
2.3 Strategy: Make sure all participants (family leaders and organization staff) have the information and supports they need to participate to their maximum potential.

Resources
- Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals. This June 2018 report from the Institute for Patient- and Family-Centered Care outlines best practices for supporting all members of hospital advisory councils. These practices can support family engagement in other systems-level initiatives that local, state, and national groups, organizations, and agencies undertake.
- A Roadmap for Patient + Family Engagement in Healthcare: Practice and Research documents the supports families (pages 17 & 18 of the Roadmap) and health care staff (pages 22 & 23 of the Roadmap) need to collaborate in systems-level activities. This includes plain language materials that describe the opportunity, mentorship, and training so everyone has background information and context for the initiative, and understands his or her role and decision-making power:
  - Create a job description so families have a clear understanding of their role and the value of the initiative.
  - If the organization is reaching out to a family-led organization to help recruit family leaders to participate in an initiative, provide details about:
    - The purpose and goals of the project.
    - Expectations for the family leaders and staff; expected timing and length of commitment.
Family Engagement in Systems Domain 3: Representation

Representation occurs when family leaders reflect the diversity of the community served by the organization.

Representation Strategy: Use data to understand the demographics of the population your organization serves.

Resources
Internal Data Sources
Collect and use organizational data on race, ethnicity, and primary language.
- The Health Research & Educational Trust (HRET) has a HRET Disparities Toolkit for collecting race, ethnicity, and primary language information. Learn about data collection, staff training, how to ask questions, and use of data.

External Data Sources
- The United States Census Bureau provides new data annually. Indicators include age, education, housing, income, languages, race and Hispanic origin, health insurance coverage, geography, and more. Search by state, county, city, town, or zip code.
- Henry J Kaiser Family Foundation Demographics and the Economy collates data from the U.S. Census and other sources. It is a convenient way to look at demographic and economic data for a single state, select states, or for all states. Indicators for children include age, race/ethnicity, citizenship status, poverty rate, household income, homelessness, SNAP (Supplemental Nutrition Assistance Program), and more.
- Family Voices State Data Reports and a National Aggregated Data Report — FVAOs and F2Fs collect and report data on the CYSHCN they serve, which can be shared with partner organizations in de-identified form to help identify areas of improvement and gaps in the system of care.
- School-based Health Alliance Children’s Health and Education Mapping Tool — Users can select a state and identify areas of need and local organizations with whom to engage to
# Representation Strategy & Resource

<table>
<thead>
<tr>
<th>Family leaders who collaborated in the initiative were representative of:</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Races and ethnicities of the populations served by the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Cultures of the populations served by the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Languages spoken by the populations served by the initiative.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Geographic areas in which populations served by the initiative live.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Strategy:** Connect with community liaisons, cultural brokers, family-led or community-based organizations to help identify and support diverse, marginalized, and underserved family leaders.

**Resources**
- **The Center for Faith and Opportunity Initiatives (Partnership Center).** An initiative of the U.S. Department of Health and Human Services (HHS), the Partnership Center leads the department’s efforts to build and support partnerships with faith-based and community organizations in order to better serve individuals, families, and communities in need. Explore the links to the ten regional offices as a way to identify potential partners and issues the organization may want to address.
- **Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers.** Community liaisons can help create linkages between individuals, families, communities, and organizations. Cultural brokers play a similar role. However, because cultural brokers are also knowledgeable about the community or a specific cultural group, and about the organization’s services, and supports, they can help ensure organizations connect with groups and communities in ways that honor their values, beliefs, and practices.
  - **Who can fulfill the role of cultural brokers in health care settings?** The National Center for Cultural Competence developed a list of roles people have in health care settings (for example, peer mentors, nurses, social workers, health educators) and settings where organizations might connect with cultural brokers.
  - **Engaging Local Leaders to Foster Welcoming Communities.** Includes strategies for identifying community leaders and recommendations and strategies for leadership engagement that is inclusive of diverse communities.
FES Toolkit: Impact

Family Engagement in Systems Domain 4: Impact

Impact describes the areas where the organization used family leaders’ ideas to improve policies and programs.

Impact Strategy: Listen to family leaders’ ideas and work together to implement the initiative.

Resource

- [IAP2 Spectrum of Public Participation](#): The International Association for Public Participation has a rubric that identifies the different ways organizations can promote meaningful public engagement that runs the gamut from informing to empowering by engaging public participants in finding solutions and implementing what the group decides.

Impact Strategy: Engage family leaders in choosing goals for the initiative.

Resources

- [Four Simple Questions](#): An exercise from the [Leading by Convening](#) framework for engaging stakeholders. Helps identify organizations and individuals who might work together on an issue; work that is currently underway; ways to work together towards common goals.
- [Defining Our Core](#): An exercise from the [Leading by Convening](#) framework for developing a unified purpose for the group of stakeholders, identifying what the group wants to accomplish, and how to assess the impact of the activity.

Impact Strategy: Use family leaders’ input to improve the initiative and document how family leaders contributed to the work.

Resources
Impact Strategy & Resource

Impact Strategy: Listen to family leaders’ ideas and work together to implement the initiative.

Resource
- IAP2 Spectrum of Public Participation. The International Association for Public Participation has a rubric that identifies the different ways organizations can promote meaningful public engagement that runs the gamut from informing to empowering by engaging public participants in finding solutions and implementing what the group decides.

Impact Strategy: Engage family leaders in choosing goals for the initiative.

Resources
- Four Simple Questions. An exercise from the Leading by Convening framework for engaging stakeholders. Helps identify organizations and individuals who might work together on an issue; work that is currently underway; ways to work together towards common goals.
- Defining Our Core. An exercise from the Leading by Convening framework for developing a unified purpose for the group of stakeholders, identifying what the group wants to accomplish, and how to assess the impact of the activity.
FES Toolkit: Overarching Strategy

**Strategy:** Collaborate with a family-led or community-based organization to identify representative families, ensure they have needed mentorship and support, and that both family leaders and organization staff have access to skill-building opportunities. Examples of mutually beneficial reasons for organizations to partner with family-led or community-based organizations are described below.

1. **Capacity Building:** In its [IMPACT! How Consumers Have Shaped Health System Delivery Reform](https://example.com) report, the Center for Consumer Engagement in Health Innovation at Community Catalyst recognized that “it takes time, expertise, and resources to make meaningful and sustained consumer engagement work.” The Center leveraged partnerships with state-based networks and coalitions, provided technical assistance, information, and funding to support their work to help consumers build the skills they needed to effectively and meaningfully engage with policymakers to change health system policies and practices. Similarly, family-led organizations can help build the capacity of the organizations by providing resources, expertise, and providing the perspectives of many family members rather than just one.

2. **Providing Important Data:** Family-led organizations often track data about the families who contact them for information and assistance. These data include problems families encounter with different systems of care (such as health insurance, Medicaid/CHIP and other public benefits, state agency services, educational services). Once de-identified, family-led organizations can share aggregated data with organizations to identify areas where they need to engage families to change or create policies to improve services.

3. **Identifying and Supporting Family Partners:** Family-led organizations have connections with many other family- and community-led organizations, as well as individual families. Organizations can collaborate with family-led organizations to help identify, mentor, and support family members, including diverse family members, to participate as

**Resources for identifying family-led and community-based organizations**

- **Family Voices Affiliate Organizations** (FVAOs). FVAOs are statewide, family-led, non-profit organizations that work to advance the mission, vision, and principles of Family Voices in 44 states and a Tribal Nation. Staff provide support, information, resources, and skill-building opportunities for families and professionals, and advocate at the state and national level for improved policies for children and youth with special health care needs (CYSHCN) and their families. They collect data and can share de-identified, aggregated data with partner organizations to help identify areas of improvement and gaps in the system of care.

- **Family-to-Family Health Information Centers** (F2Fs). F2F programs are funded by the Maternal and Child Health Bureau (MCHB) to provide information, education, technical assistance and peer support to families of children and youth with special health care needs and the professionals who serve them. There are 59 F2Fs, one in every state, the District of Columbia, Puerto Rico, the Virgin Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, and the three which serve tribal nations. Families of CYSHCN staff the F2Fs. They help families navigate the state’s system of care, and help them contact, at all levels of the health care system. They track and report data about issues and barriers families experience. They also collect data and can share de-identified, aggregated data with partner organizations to help identify areas of improvement and gaps in the system of care. In many states, the F2F program is co-located with the state FVAO.

**Community-based Organizations in the Health Sector: A Scoping Review** for organizations looking to collaborate with community-based organizations (CBOs), this article identifies the important roles they play in helping to identify individuals and families and ensure public engagement in policies that affect the services they receive.

There are many national networks of family-led organizations, including Parent-to-Parent USA; Federation of Families for Children’s Mental Health; National Foster Parent Association; National Military Family Association; and many others, including condition-specific organizations. There are also state and local groups that serve families. Many family-led organizations can help professional organizations connect with the particular groups with whom they are trying to partner.
A Birthing Hospital program wanted to ensure meaningful engagement of diverse families in its needs assessment.

- Used the Family Engagement Checklist in the FES Toolkit to identify supports already in place.
- Identified strategies to reach diverse and hard-to-reach families, such as:
  - Provide stipends and transportation.
  - Provide materials in multiple languages.
  - Hold focus groups in multiple languages at familiar gathering places in the community.

A PQC created a family advisory group and used the FESAT to assess how well they were engaging families. Findings included:

- Families were involved in choosing goals.
- Families felt listened to.
- Staff did not acknowledge if and how they used family input.

A PQC used the FESAT to improve family engagement in a year-long QI initiative to reduce implicit bias. Staff and families:

- Completed the FESAT and used the results as a baseline.
- All participants took the Harvard Implicit Bias test.
- Identified an area for improvement (staff and families needed to improve communication and partnership skills).
- Completed the FESAT again, compared new results to baseline and saw improvement.
Questions, Discussion, Ideas ...
Download the FES Tools

https://familyvoices.org/fesat-request-form/
Questions & TA about the Family Voices Family Engagement Tools?

Contact: Beth Dworetzky  
bdworetzky@familyvoices.org  
413-222-2909

Questions?

Contact: LaToshia Rouse  
www.PFEConsultant.com  
PFEngage@gmail.com  
919-322-9196
Thank You