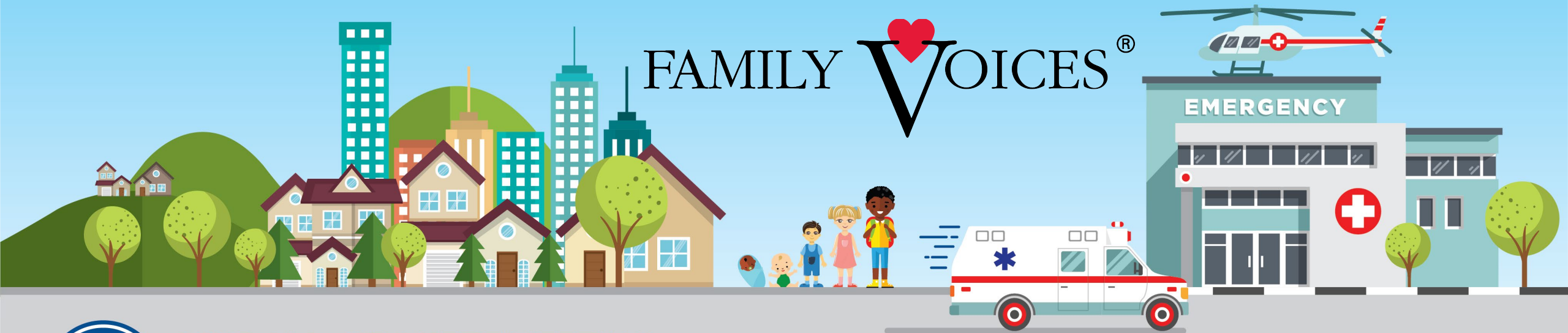


The Zac Johnston and Carter Mears Memorial Lecture - Family Centered Care

The Family Engagement in Systems Assessment Tools (FESAT)

FAMILY  VOICES[®]



2023 ALL-GRANTEE MEETING

CULTIVATING COMMUNITY GROWING COLLABORATION

Speaker Disclosure

“I have no financial interests or relationships to disclose.”



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Objectives

Learners will be able to:

- Understand what Family Voices does
- Explain why we engage families in our improvement work
- Identify and describe the difference between individual and systems-level family engagement activities
- Explain the three uses of the Family Engagement in Systems Tools to plan, assess, and improve family engagement in systems over time



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About Family Voices, Inc.

Family Voices is a **national family-led organization** of families and friends of children and youth with special health care needs (CYSHCN) and disabilities.

We connect a **network of family organizations across the United States** that provide support to families of CYSHCN.

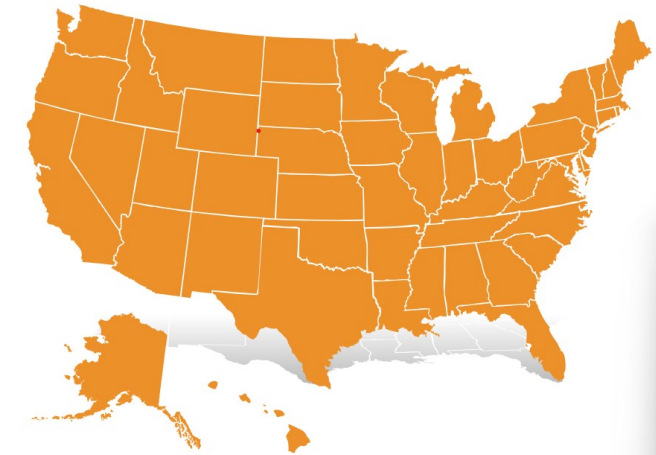
We promote partnership with **families at all levels of health care—individual and policy decision-making levels**—in order to improve health care services and policies for children.



» WHAT ARE F2Fs?

Family-to-Family Health Information Centers (F2Fs) are **family-led centers funded by the Health Resources and Services Administration (HRSA)**. There is one F2F in each state, in the District of Columbia, in five U.S. territories, and there are three F2Fs serving tribal communities. Each F2F is **staffed by highly-skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families of CYSHCN**. These uniquely qualified staff provide **critical support to families caring for CYSHCN**, particularly families of **children with complex needs** and those from **diverse communities**.

F2Fs also **assist providers, state and federal agencies, legislators, and other stakeholders** to better understand and serve CYSHCN and their families.



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What is Family Engagement?

Family engagement is an authentic partnership between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems level to develop and implement better policies and practices.



How Do We Cultivate Family Engagement?

We can cultivate family engagement in three ways:

- By building relationships,
- By fostering communication, and
- By engaging in **meaningful collaborations.**



Patricia Vitale-Reilly



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Why Engage Families?

- Meaningful partnership at the systems level integrates the **importance and value of basing policies, programs, and services on the lived experiences of families.**
- Families bring context to data and solutions that bring the fragments together.

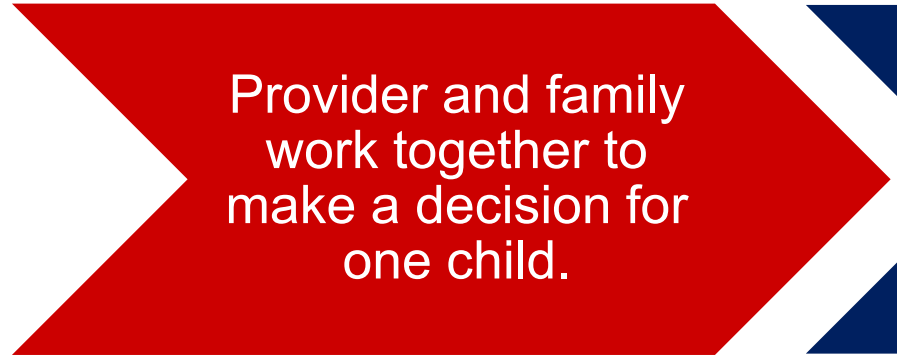


Why Engage Families?

- Families are deeply affected by issues such as care fragmentation that results from:
 1. lack of effective communication
 2. lack of health education
 3. ineffective and outdated health care policies
- Patient and Family engagement is a **powerful catalyst** for reducing system fragmentation, removing barriers to health care and improving the quality of health care.



Types of Family Engagement



Provider and family work together to make a decision for one child.

Individual



A council of families provide input on ways to improve care.

Advisory



Families, community members & providers co-create policies, programs & services they receive.

Systems-Level



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Individual-level Family Engagement

My child's doctor and I discuss my child's discharge plan. We both express goals, risks and plans for the next steps.



Advisory-level Family Engagement

A council of families provide input on ways to improve care received for cancer patients in the hospital.



Systems-level Family Engagement

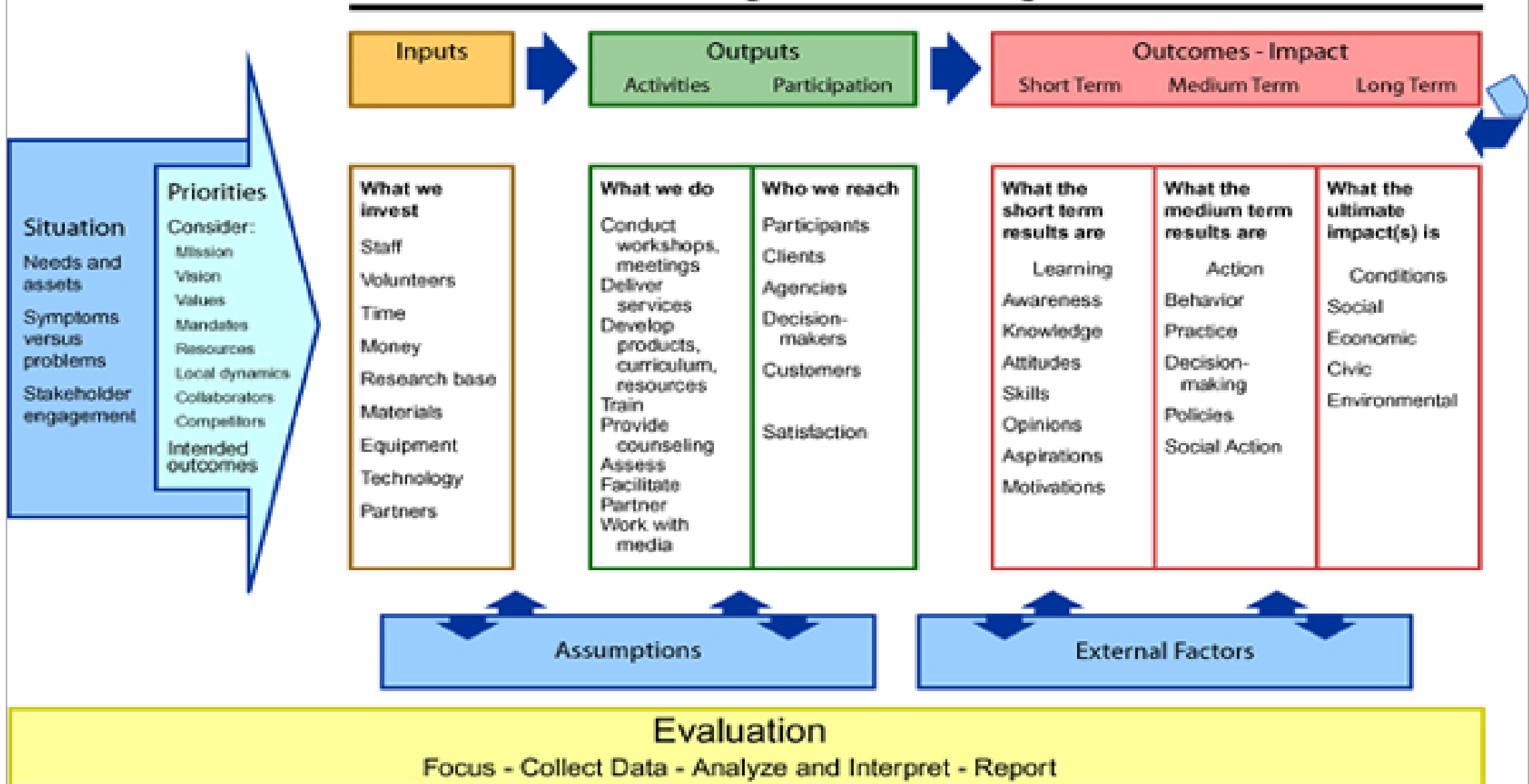
A children's hospital engaged families to co-design to improve processes for the staff as well as patients and families relating to effective discharge.



Why do health systems struggle with engagement?



Program Action - Logic Model



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The Family Engagement in Systems Assessment Tools

What is the FESAT?

Family Voices created the Family Engagement in Systems Tools (FESAT) that child- and family-serving organizations can use to plan, assess, and improve family engagement.



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Four Domains of the FESAT

Framework for Family Engagement in Systems Change

Domain 1: Commitment

- Family Engagement is a core value.

Domain 2: Transparency

- Access is provided to relevant knowledge and supports.

Domain 3: Representation

- Engaged families reflect the diversity of the community served (race, ethnicity, culture, language, and geography).

Domain 4: Impact

- The initiative identifies what has changed and what the organization is doing differently because families are involved.



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Domains of Family Engagement



Commitment

Commitment means that family engagement is normalized and included throughout the activities that impact the organization at the systems level.

Does your organization educate and inform all staff about the importance of engaging families at the systems level, valuing families' time, and respecting their contributions?

HOW TO "COMMIT" TO MEANINGFUL FAMILY ENGAGEMENT IN SYSTEMS



COMMITMENT

Organizations must always engage families they serve in decision-making groups that are working to improve or create the policies, programs, and services they provide for children, youth, and families.

CREATE A POLICY

- A family engagement policy sets a standard for engaging families in all systems-level initiatives & ensures that policies are family-centered & equitable.
- Provide compensation to recognize families time & expertise, reduce barriers to participation & ensure equitable representation.



IDENTIFY CHAMPIONS

- Designate one or more staff members to lead family engagement efforts.
- Support staff development to enhance understanding of the value of family partnership.



LEARN MORE

Visit the Assessing Family Engagement webpage and download the [Family Engagement in Systems Toolkit](#), a collection of strategies and resources to help improve family engagement in systems-level initiatives.



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Domains of Family Engagement


Transparency

Transparency assures access to the knowledge that allows all partners to fully participate in the process, and maximize their own effectiveness.

Does your organization provide the supports and information that both families and professionals need to be informed participants in systems-level change?

HOW TO ENSURE TRANSPARENCY IN FAMILY ENGAGEMENT IN SYSTEMS




TRANSPARENCY

Organizations must clearly document and communicate how they:


- Identify issues faced by the children, youth, and families it serves.
- Provide the information & supports families & staff need to partner, participate, & contribute to their maximum potential.


IDENTIFY THE ISSUES

- Partner with family-led or community-based organizations to learn what they are hearing from families.
- Reach families directly.
- Co-create needs assessments, surveys, conduct focus groups, other feedback mechanisms.
- Use data from a variety of sources.



PROVIDE INFORMATION & SUPPORT

- Develop clear role descriptions to help move families "beyond the checkbox."
- Provide mentors to help families learn how to use their live experiences to improve systems of care for all children.
- Share jargon-free materials before  meetings to ensure sufficient preparation time.



LEARN MORE

Visit the Assessing Family Engagement webpage and download the **Family Engagement in Systems Toolkit**, a collection of strategies and resources to help improve family engagement in systems-level initiatives.

FAMILY VOICES[®] www.familyvoices.org



Domains of Family Engagement



Representation

Representation is the process by which family leaders stand in for the rest of their community in systems-level activities such as needs assessment and strategic planning.

Does your organization partner with a family-led organization to help identify, support, and mentor family participation?

HOW TO ENSURE EQUITABLE REPRESENTATION OF FAMILIES IN SYSTEMS

REPRESENTATION

Engaged families must represent the diversity of the children, youth, families, and other individuals served by the organization.



KNOW THE POPULATION

Engage families who reflect the diversity of those served by the organization or the specific systems-level initiatives.

- Use internal or external data to learn about families served.
- Connect with a family-led or community-based organization to help recruit & support family partners.

OFFER TRAINING

Provide skill-building opportunities for family partners and staff. This might include:

- Workshops about family-professional partner and family engagement.
- Implicit bias training so all participants are aware of the assumptions they may make about others.



LEARN MORE

Visit the [Assessing Family Engagement webpage](#) and download the [Family Engagement in Systems Toolkit](#), a collection of strategies and resources to help improve family engagement in systems-level initiatives.



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Domains of Family Engagement



Impact

Impact describes what the organization is doing differently because it has engaged families in creating systems-level change.

What is your organization doing differently because of engaging families at the systems level?

HOW TO DEMONSTRATE THE IMPACT OF FAMILY ENGAGEMENT IN SYSTEMS

IMPACT



Organizations must report on how and where families' input and ideas were used to improve existing, or create new policies, programs, and services to benefit all children, youth, and families.

IDENTIFY CHANGES

- Recognize what the organization is doing differently because families were engaged in the initiative.
- Document families' contributions to the work.
- Work together to create an action plan to improve family engagement in systems-level initiatives.



LISTEN



Ensure families feel welcome and have opportunities to provide input.

- Families know what works well and what doesn't work about systems of care. Listen to their lived experience.
- Work together to identify areas for improvement.
- Work together to identify solutions.

LEARN MORE

Visit the Assessing Family Engagement webpage and download the **Family Engagement in Systems Toolkit**, a collection of strategies and resources to help improve family engagement in systems-level initiatives.



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Using the FESAT

1
Plan

Full team (including families) will score the FESAT to learn if families & staff have the info & supports they need to participate, partner, and contribute to decision-making groups.

- Compare perspectives on how family engagement is going.
- Identify what is working well.
- Identify areas for improvement.

3 Improve

What should we do?

Your team uses the Checklist in the Family Engagement in Systems (FES) Toolkit to establish a process that supports meaningful engagement of families.

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

How are we doing?

2
Assess

How can we do better?

Based on the first assessment, full teams will explore the FES Toolkit.

- Identify an area for improvement and select a strategy from the FES Toolkit that can help.
- Create an action plan for improvement.
- After a period of time determined by the group, score the FESAT again. Compare results to the baseline to see improvement in one or more domains.
- Repeat over time to continue to improve family engagement in systems change.

FESAT Score Sheet

Family Engagement in Systems Assessment Tool Score Sheet

	Team Points	Max Points	Domain Score
Domain 1: Commitment	5	20	25%
1 The organization uses written policy that requires family engagement in systems-level initiatives.	1	4	
2 The organization has one or more champions of family engagement.	3	4	
3 The organization acknowledges the contributions family leaders make to systems-level initiatives.	0	4	
4 The organization's budget includes funding for the family leaders' time and/or other costs they incur (for example, travel).	0	4	
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).	1	4	
Domain 2: Transparency	12	20	60%
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).	4	4	
7 I had a clear understanding of the initiative staff and families worked on together.	2	4	
8 I had the support I needed to understand my partnership role (for example, a mentor within or outside of the organization).	3	4	
9 I had the support I needed to participate in meetings (for example, physical access, interpreters, time away from other work).	0	4	
10 I had the information I needed to participate in meetings.	3	4	

Domain Scores

Team Points	47
Max Points	80
Engagement Score	59%



FESAT

The Family Engagement in Systems Assessments Tools



PLAN

Plan the design of meaningful family engagement in a systems-level initiative



ASSESS

Assess how well an organization engages family leaders in system level initiative



IMPROVE

Improve family engagement in an ongoing initiative over time

www.familyvoices.org/FESAT

Download the FESAT here:





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