



What is Family Engagement in Early Childhood Systems?

How Can the Family Engagement in Systems Assessment Tool (FESAT) Help?

August 28, 2023



Objectives



1. Identify the meaning and importance of family engagement.
2. Understand the domains of family engagement.
3. Explain how a Patient and Family Advisory Council can help with family engagement.
3. Understand the importance of measuring family engagement.
4. Identify how the FESAT can be used assess and improve family engagement in systems-level initiatives.

What is Family Engagement in Early Childhood Systems?

PRESENTERS



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About Family Voices



Family Voices is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that **promotes partnership with families** —including those of cultural, linguistic and geographic diversity—to **improve healthcare services and policies for children.**

Learn more at familyvoices.org.

About our F2F Network



- Family-to-Family Health Information Centers (F2Fs) are family-led centers funded by the Health Resources and Services Administration (HRSA). There are F2Fs in all 50 states, the District of Columbia, five U.S. territories, and three nations.
- Each F2F is staffed by highly-skilled, knowledgeable family members who have firsthand experience and understanding of the challenges faced by families of CYSHCN. They provide critical support to families caring for CYSHCN.
- F2Fs also assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve CYSHCN and their families.
- **Find your local F2F at familyvoices.org.**

Early Childhood

- The **ECDHS: Evidence to Impact Center** supports states and communities to build equitable and family-centered early childhood systems that improve the health and well-being of young children and their families.
- The Center is led by ZERO TO THREE with several leading health and early childhood organizations:



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.

Image source: Parent Information Center of New Hampshire

Why We Engage Families



- **Care fragmentation** occurs when the delivery of health care is spread across an excessively large number of poorly coordinated providers. (nber.org)
- Families are deeply affected by issues such as care fragmentation that results from:
 - Lack of communication
 - Lack of education
 - Ineffective and outdated health care policies
- Evidence indicates that family partnership at the individual level improves care coordination and health outcomes.
- Engagement is a powerful catalyst for reducing system fragmentation, removing barriers to health care, and improving the quality of health care.

Meaningful Partnership



- Meaningful partnership at the systems level integrates the importance and value of basing policies, programs, and services on the lived experiences of families who navigate fragmented systems that create barriers in their everyday lives.
- Families bring context to data and solutions, and **early childhood is a critical time to engage families.**

The Importance of Family Engagement in Systems Change



- Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care.
- Systems-level issues, such as care fragmentation, are often a direct result of ineffective or outdated health care policies and practices.

Families' lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially CYSHCN.

Reason for Systems-Level Engagement



Nothing about us
without us.

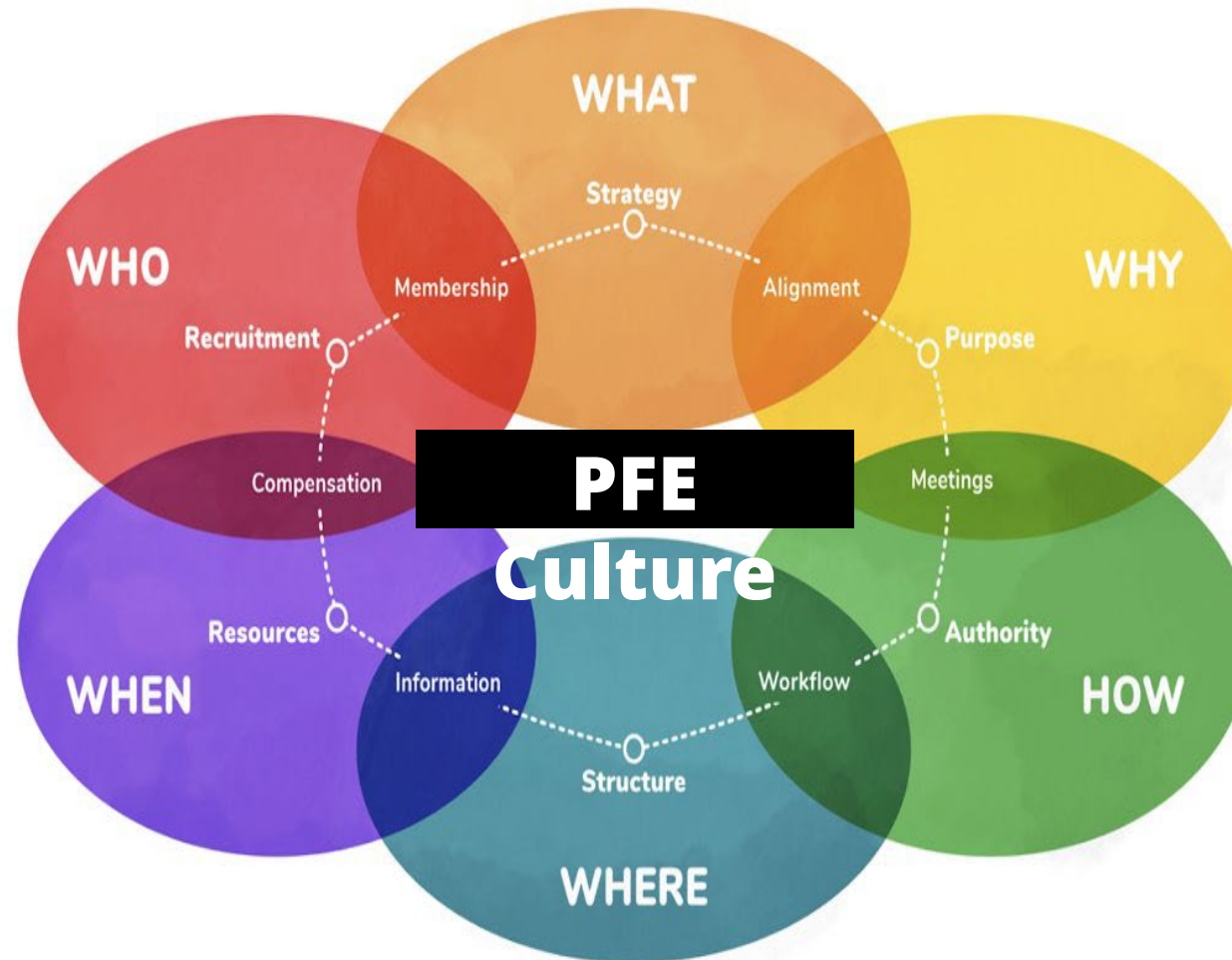
Takeaways



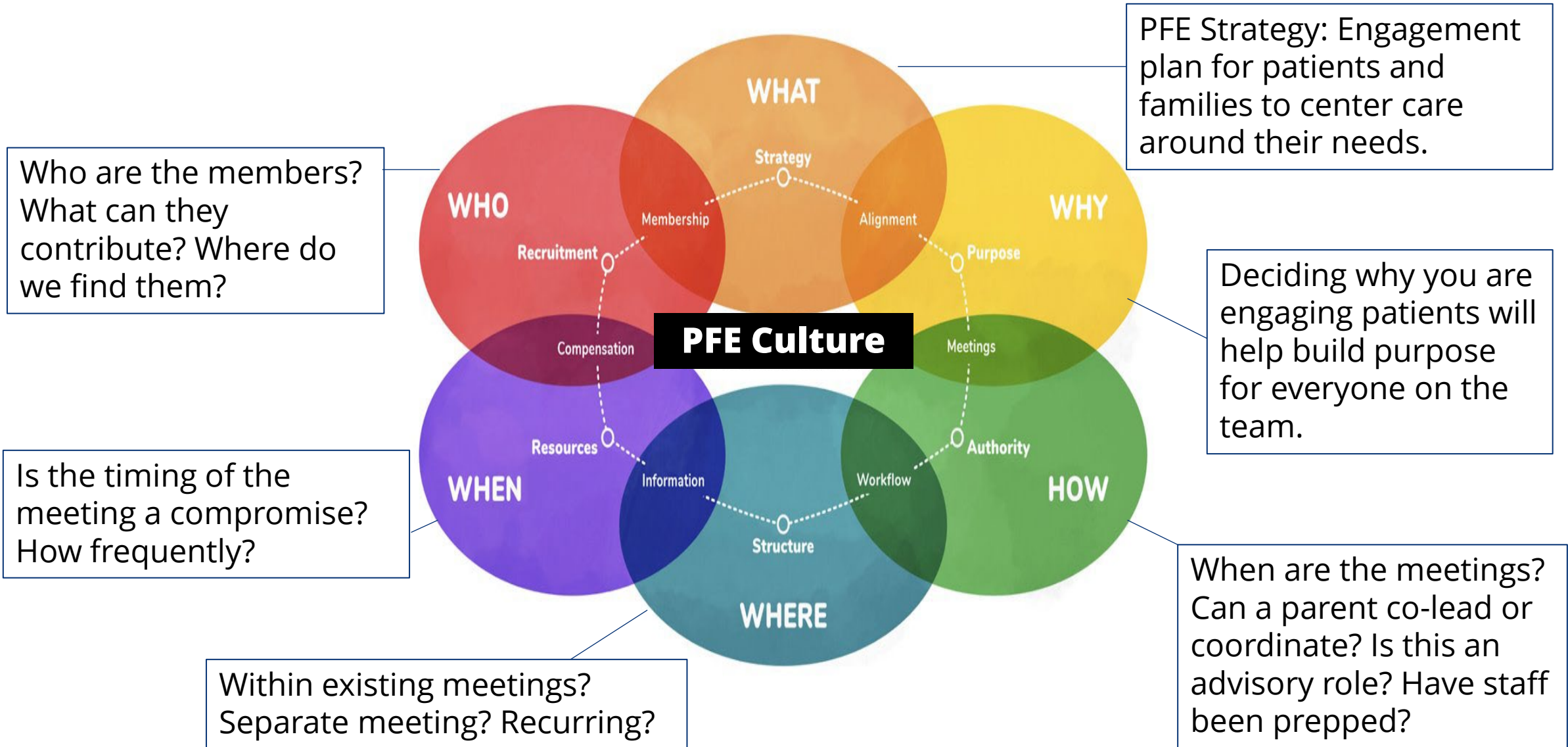
- It's critically important for families who receive early childhood services to have a voice in informing the policies and practices that govern the services they receive.
- This ensures policies, practices, services, supports, QI activities, research agendas and protocols, and other systems-level initiatives are family-centered and equitable.
- When child- and family-serving organizations engage families in systems change, there are fewer unanticipated adverse consequences.

What Makes PFE Culture?

Patient Family Engagement (PFE)



What Makes PFE Culture? Cont'd



Family Engagement Tool

- Family Voices created the Family Engagement in Systems Tools that early childhood organizations can use to plan, assess, and improve family engagement.
- Learn more about assessing family engagement at familyvoices.org/FESAT.

FAMILY VOICES[®]
RULES OF FAMILY ENGAGEMENT

Be Committed
Create a family engagement policy to set a standard for engaging families as partners on all policy-making groups.

Document Impact
Work with families to report how their input & ideas were used to improve existing policies or to create new ones.

Be Transparent
Ask families about the information & supports they need to partner, participate & contribute.

Be Representative
Engage families who represent the children & families the organization serves.

Learn How to Plan, Assess, & Improve Family Engagement
Download the Family Voices Family Engagement Tools

WWW.FAMILYVOICES.ORG/FESAT

Assessment Tools

Family Engagement in Systems Assessment Tools



Family Engagement in Systems Assessment Tool (FESAT)

User's Guide



Family Engagement in Systems Assessment Tool (FESAT)



Family Engagement in Systems Assessment Tool Score Sheet



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

Four Domains of the FESAT



- **Commitment** – Family engagement is a core value
- **Transparency** – Access is provided to relevant knowledge and supports
- **Representation** – Engaged families represent the diversity of the community served (race/ethnicity, culture, language, geography, etc.)
- **Impact** – The initiative identifies what has changed and what the organization is doing differently because families are involved.



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.

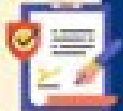
IDENTIFY CHAMPIONS

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



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.



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.

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.



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

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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

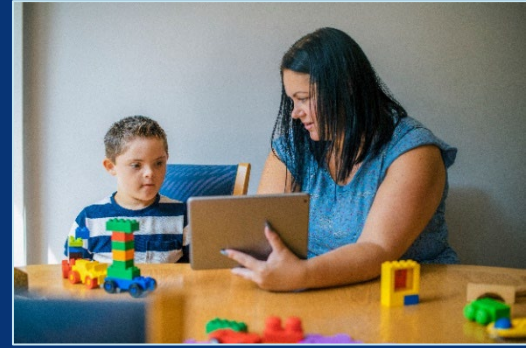
Ensure families feel welcome and have opportunities to provide input.

- 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.

Discussion



- What has worked for your team with engaging families in systems-level work?
- How did you get buy-in with your team around engaging families?
- What has been a challenge with engaging families in systems-level work?
- If you have an existing council, what has your experience been with engaging families?

Using the FESAT

1 Plan

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.

Full team (including families) will score the FESAT to learn if families and staff have the info and 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.

How are we doing?

2 Assess

3 Improve

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.

Can the FESAT tools be applied to create an advisory council?



Advisory Councils



- Starting an advisory council (also sometimes called a Patient and Family Advisory Council – PFAC) is often a first step organizations take to engage families in systems-level initiatives.
- Advisory councils are a way many families enter advocacy and engagement work.
- Families, even in early childhood, can offer insights about the care and services they receive.

Steps to Start an Advisory Council 1-2



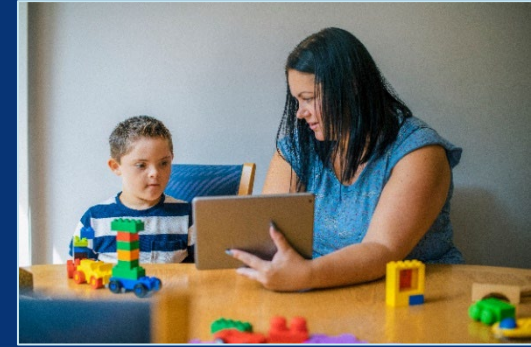
1: Determine your Composition

- Physicians, nurses, social workers, parent leaders, community-based organizations, etc.
- Preliminary ideas about the purpose of the council

2: Determine your PFAC Structure

- Meeting times
- Meeting locations (virtual and/or in-person)
- Transportation/parking
- Food provided
- Budgetary and administrative needs

Steps to Start an Advisory Council 3



3: Advisor Recruitment and Retention

- Number of council members
- Composition
- Member terms
- Attendance expectations (define attendance)
- Determine selection criteria
- Role description
- Recruitment flyer
- Email wording for CBOs describing your needs
- Keep list of all potential family leaders

Steps to Start an Advisory Council 4



4: Orientation

- Overview of organization
- Overview of work thus far
- Role of council
- Name liaisons
- Discuss confidentiality (forms)
- Information needed to participate (technology, what to bring, parking, bathrooms, refreshments)
- Attendance

Source: Institute for Patient and Family Centered Care

Steps to Start an Advisory Council 5



5: Determine Staff Support Members

- Support from Family Voices
 - Training
 - Individual and group technical assistance

6: Goals and Ongoing Engagement

- Brainstorm improvement ideas as a team
- Track accomplishments
- Celebrate successes

Best Practices for Developing Advisory Councils



PFAC structure and membership

- The PFAC has an executive sponsor and staff liaison.
- There is a defined relationship between the PFAC and the hospital/health system leadership and board of directors.
- More than 50% of PFAC members are PFAs; PFAs are representative of the patient populations served.

Recruitment

- Recruitment is an ongoing program rather than a one-time event.
- Recruitment strategies are designed to ensure that the PFAs reflect the diversity of communities served.
- Clinicians and staff members help identify potential PFAs; other contacts and resources available through the hospital are used (e.g., support groups, relationships with community organizations).

Onboarding and orientation

- Onboarding and orientation are provided to all PFAC members, covering the key elements of the role of a PFA and helping orient PFAs to hospital quality and safety work.

Source: Institute for Patient and Family Centered Care

Best Practices for Developing Advisory Councils (cont'd)



PFAC operations

- The PFAC meets regularly, approximately 10 times per year.
- There is an agenda for each PFAC meeting, ideally developed by a PFA chair or co-chair, or by the PFAC.
- Language/translation services, childcare, parking/transportation, and even stipends are provided to encourage participation, especially among disadvantaged populations.

Opportunities offered to PFAs

- The hospital offers a variety of ways to serve as PFAs, including virtual opportunities and full membership on key committees, quality improvement and safety teams, and governing boards.

Feedback, evaluation, and reporting

- PFAs receive feedback about the impact of their work.
- There is an annual PFAC evaluation that measures the outcomes and impact of PFAC activities and initiatives.
- An annual report is prepared to summarize PFAC accomplishments and future plans and shared broadly with the health system and the community.

Source: Institute for Patient and Family Centered Care

Request The FESAT

- To obtain the FESAT Tools, visit familyvoices.org/fesat and click **Request the FESAT**.
- Once you complete the form, you will be directed to a page where you can download the Users' Guide, FESAT, Score Sheet, and FES Toolkit.
- We will not share your information. We request this information to track usage of the FESAT and potentially to contact you to learn about your experience with the FESAT and offer technical assistance.
- There is no charge for the tools.

Questions and Discussion



THANK YOU!

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ECDHS: Evidence to Impact Center Feedback Survey

Please take a moment to complete a brief survey to support the Evidence to Impact Center in improving its training and technical assistance offerings and assessing program outcomes over time.

The survey is anonymous, voluntary, and should take no longer than 10 minutes to complete.

To complete the survey, please click on the link in the chat or scan the QR code below on a mobile device:



ECDHS: Evidence to Impact Center Presents "What Is Family Engagement? And How Can the Family Engagement in Systems Assessment Tool (FESAT) Help?"

Manage Product

✓ You are registered!

Includes a Live Web Event on 08/28/2023 at 4:30 PM (EDT)

Overview About CEU's Contents (6)

Key: Complete Next Failed Available Locked

What is Family Engagement? And How Can the Family Engagement an Assessment Tool (FE...
08/28/2023 at 4:30 PM (EDT) | 90 minutes

CEU Evaluation
Select the "Complete CEU Evaluation" button to begin.

Verification Code
Enter code to continue.
Enter the code provided at the end of the CEU Evaluation.

Quiz
0 Question | 1 attempt | 0/0 points to pass

Certificate
Live Viewing: 1.50 clock hours (0.2 CEUs) credits and certificate available

Additional Feedback Survey
Select the "Open Survey" button to begin.

 **ZERO TO THREE** ECDHS "What Is Family Engagement? (CEU Questions)
Early connections last a lifetime

If you would like, please share more information about your experience here:

How do you plan to use what you learned in the learning experience?

To receive CEUs copy and enter this code in the e-Learn platform: FESAT82823. *

- I have copied the code to earn CEUs
 do not need CEUs

Would you be willing to provide feedback through a brief survey to support the Evidence to Impact Center in improving its training and technical assistance offerings and assessing program outcomes? This additional survey is anonymous and should take no longer than 10 minutes.

If you have already completed the "Additional Feedback Survey" for this event, please skip this question.

- Yes
 No

CEUs

- To receive credit for today's training, please complete the following:
 - Select "CEU Evaluation."
 - Enter the verification code provided at the end of the CEU Evaluation. (Please note that the verification code is case sensitive.)
 - Complete the CEU Evaluation quiz.
 - Once all items are completed the certificate will become available for download.
- You have 30 days to return to the Event page and complete all items to receive credit.

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