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Moving Beyond the Family Engagement Checkbox:

Promoting Meaningful Family Engagement in Systems Change

ASHEW National Chapter Meeting
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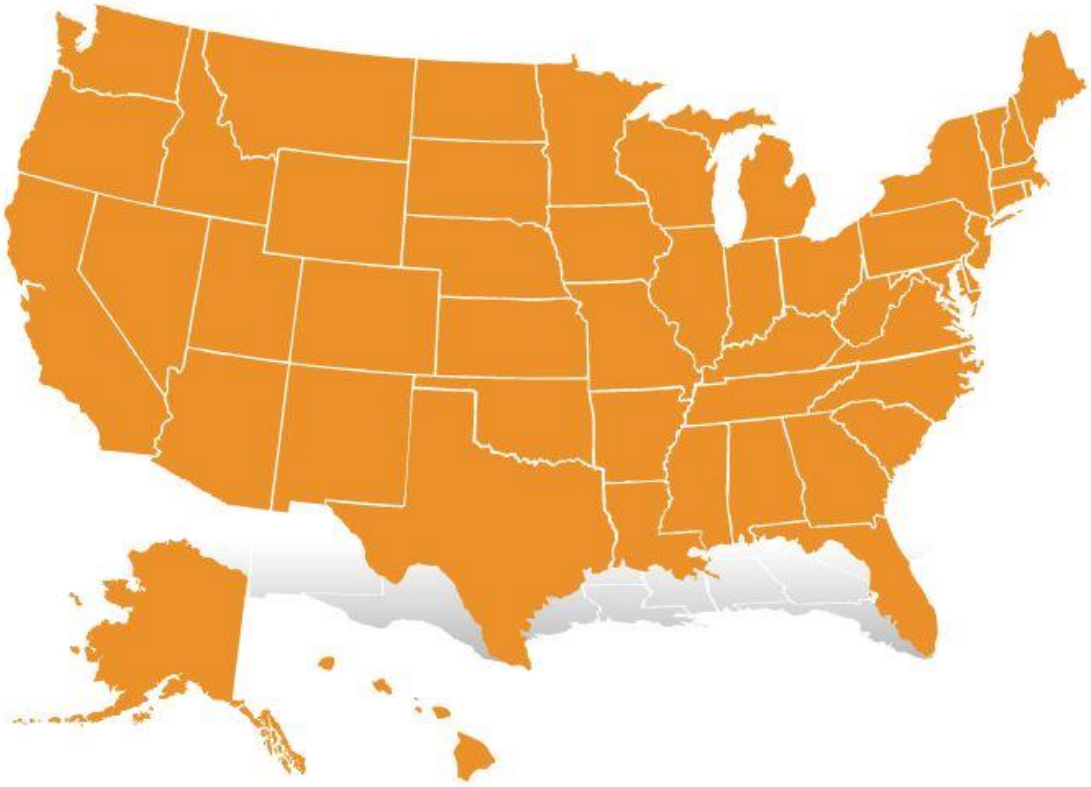
FamilyVoices.org



ENLARGE MAP

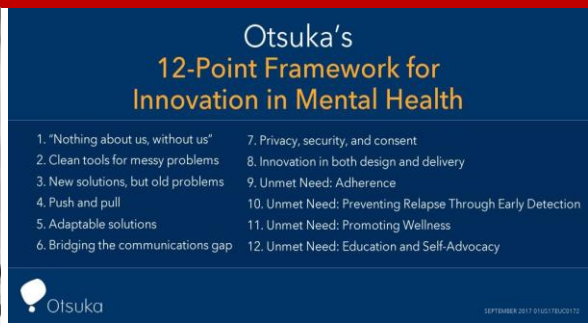
Click on the map or select a state or territory:

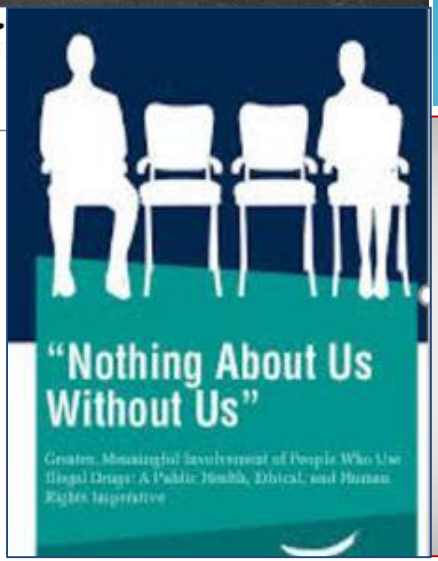
Select a state

About F2Fs

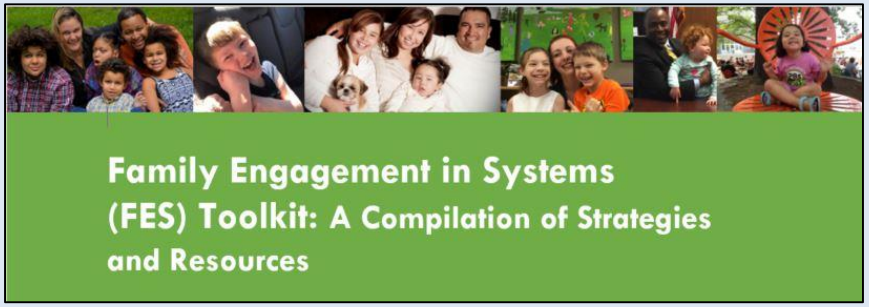
About FVAOs

Systems-level Family Engagement





Family Engagement in Systems Tools



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Family Engagement in Systems Assessment Tools (FESAT)

Families and staff can use the FESAT to learn if families have the information 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.

1 Plan

What should we do?

Child- and family-serving organizations can use the Checklist in the Family Engagement in Systems (FES) Toolkit to establish family engagement processes.

- 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

How are we doing?

3 Improve

How can we do better?

Families and staff can use the FESAT and FES Toolkit to track progress in family engagement efforts.

- Complete the FESAT and use the results as a baseline score.
- Identify an area for improvement and select a strategy from the FES Toolkit that can help.
- Complete the FESAT again at scheduled intervals and compare results to the baseline.

Request the FESAT (https://familyvoices.org/fesat-request-form/)
For questions or technical assistance, email Beth Dworetzky (bdworetzky@familyvoices.org)

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Checklist to Guide the Design of Family Engagement Initiatives

Domain 1: Commitment	Yes	No	Some what	Don't know
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 family leaders' time and/or other costs they incur (for example, travel, child care).	☐	☐	☐	☐
The organization provides adequate time for staff to implement changes that result from family engagement in systems-levels initiatives (for example, educating staff about new policies).	☐	☐	☐	☐
Domain 2: Transparency	**Yes**	**No**	**Some what**	**Don't know**
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).	☐	☐	☐	☐
The organization ensures all staff and families have a clear understanding of the initiative they will work on together.	☐	☐	☐	☐
The organization provides the supports families and staff need to understand their partnership role (for example mentors/coaching).	☐	☐	☐	☐
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).	☐	☐	☐	☐
The organization ensures all participants have the information they need to participate in meetings.	☐	☐	☐	☐

Domain 3: Representation	Yes	No	Some what	Don't know
Family leaders are representative of the races and ethnicities of the populations served by the initiative.	☐	☐	☐	☐
Family leaders are representative of the cultures of the populations served by the initiative.	☐	☐	☐	☐
Family leaders are representative of the languages spoken by the populations served by the initiative.	☐	☐	☐	☐
Family leaders are representative of geographic areas in which populations served by the initiative live.	☐	☐	☐	☐

NOTE: If one or more of the four demographic characteristics in Domain 3: Representation, do not match your priorities for the populations served by the initiative you are assessing, you can replace them with criteria that do match your priorities. For example, your organization may be looking for family leaders of certain ages, disabilities, gender, etc.

Domain 4: Impact	Yes	No	Some what	Don't know
Organization staff listen to family leaders' ideas.	☐	☐	☐	☐
Organization staff engage family leaders in choosing goals for the initiative.	☐	☐	☐	☐
Organization staff work together with family leaders to implement the initiative.	☐	☐	☐	☐
Organization staff work together with family leaders to evaluate the initiative.	☐	☐	☐	☐
Organization staff use family leaders' input to improve the initiative.	☐	☐	☐	☐
Organization staff can explain how family leaders contribute to the initiative.	☐	☐	☐	☐

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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.

In my experience:	Never	Rarely	Some-times	Usually	Always	Not Sure/ Not Applicable
1. The organization uses written policy that requires family engagement in systems-level initiatives.	0	1	2	3	4	
2. The organization has one or more champions of family engagement.	0	1	2	3	4	
3. The organization acknowledges the contributions family leaders make to systems-level initiatives.	0	1	2	3	4	
4. The organization's budget includes funding for the family leaders' time and/or other costs they incur (for example, travel, childcare).	0	1	2	3	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).	0	1	2	3	4	

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.

	Never	Rarely	Some-times	Usually	Always	Not Sure/ Not Applicable
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).	0	1	2	3	4	
7. I had a clear understanding of the initiative that staff and families worked on together.	0	1	2	3	4	
8. I had the support I needed to understand my partnership role (for example, a mentor within or outside of the organization).	0	1	2	3	4	
9. I had the support I needed to participate in meetings (for example, physical access, interpreters, time away from other work responsibilities)	0	1	2	3	4	
10. I had the information I needed to participate in meetings.	0	1	2	3	4	

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.

Family leaders who collaborated in the initiative were representative of:	Never	Rarely	Some-times	Usually	Always	Not Sure/ Not Applicable
11. **Races and ethnicities** of the populations served by the initiative.	0	1	2	3	4	
12. **Cultures** of the populations served by the initiative.	0	1	2	3	4	
13. **Languages** spoken by the populations served by the initiative.	0	1	2	3	4	
14. **Geographic areas in which populations** served by the initiative live.	0	1	2	3	4	

Domain 4: Impact describes the areas where family leaders' ideas were incorporated at the systems level to improve policies, programs, services, and practices.

In my experience, organization staff:	Never	Rarely	Some-times	Usually	Always	Not Sure/ Not Applicable
15. Listened to family leaders' ideas.	0	1	2	3	4	
16. Engaged family leaders in choosing goals for the initiative.	0	1	2	3	4	
17. Worked together with family leaders to implement the initiative.	0	1	2	3	4	
18. Worked together with family leaders to evaluate the initiative.	0	1	2	3	4	
19. Used family leaders' input to improve the initiative.	0	1	2	3	4	
20. Could explain how family leaders contributed to the initiative.	0	1	2	3	4	

FESAT Score Sheet

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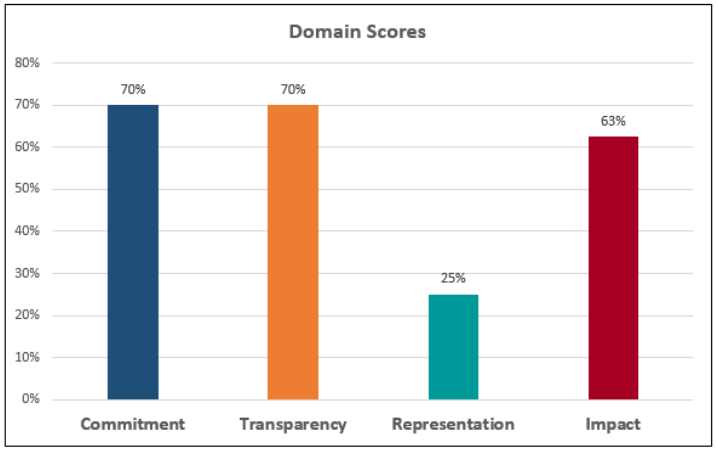
Family Engagement in Systems Assessment Tool Score Sheet

		Team Points	Max Points	Domain Score
	Domain 1: Commitment	14	20	70%
1	The organization uses written policy that requires family engagement in systems-level initiatives.	4	4	
2	The organization has one or more champions of family engagement.	4	4	
3	The organization acknowledges the contributions family leaders make to systems-level initiatives.	1	4	
4	The organization's budget includes funding for the family leaders' time and/or other costs they incur (for example, travel, childcare).	3	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).	2	4	

		Team Points	Max Points	Domain Score
	Domain 2: Transparency	14	20	70%
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.	3	4	
8	I had the support I needed to understand my partnership role (for example, a mentor within or outside of the organization).	2	4	
9	I had the support I needed to participate in meetings (for example, physical access, interpreters, time away from other work).	2	4	
10	I had the information I needed to participate in meetings	3	4	



Team Points	**47**
Max Points	**80**
Engagement Score	**59%**

Instructions | Score Sheet

Ready

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 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.[2] 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 three which serve tribal nations. Families of CYSHCN staff the F2Fs. They help families navigate the state's system of care, and help them partner 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 are co-located with the state FVAO.[1]

Community-based Organizations in the Health Sector: A Scoping Review.[2] 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.

FES Toolkit: Representation

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

Family leaders who collaborated in the initiative were representative of:	Never	Rarely	Some-times	Usually	Always	Not Sure/ Not Applicable
11. **Races and ethnicities** of the populations served by the initiative.	0	1	2	3	4	
12. **Cultures** of the populations served by the initiative.	0	1	2	3	4	
13. **Languages** spoken by the populations served by the initiative.	0	1	2	3	4	
14. **Geographic areas in which populations** served by the initiative live.	0	1	2	3	4	

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.[16] 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.[17] Includes strategies for identifying community leaders and recommendations and strategies for leadership engagement that is inclusive of diverse communities.

Family Engagement in Systems Assessment Tools (FESAT)

1
Plan

What should we do?

An AAP Chapter is creating a family advisory council to guide their work to improve screening and follow up related to maternal depression.

- **Identified they had data to understand issues with follow up.**
- **Created a "job description" so families would understand their roles and responsibilities as part of the FAC.**
- **Identified need to collaborated with a family-led organization to provide families with a mentor to support them in their advisory roles.**

2
Assess

How are we doing?

After 6 months, the FAC and AAP Chapter representatives scored the FESAT.

- **Families reported they had the info they needed to understand their role and participate.**
- **Identified families were not representative of the pop served.**
- **Identified a need to provide stipends in recognition of families time and expertise.**

3
Improve

How can we do better?

The FAC and staff selected strategies to implement from the FES Toolkit to increase diversity of FAC and provide stipends. After 12 months, they completed the FESAT again and compared results to their baseline score.

- **Found families were representative of the pop served by the chapter practices.**
- **Worked together to identify ways to acknowledge family contributions to protocols to improve screening and referrals for maternal depression.**

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Questions, Comments, Discussion…

Learn More

- Download the Family Engagement in Systems Assessment Tools
- Issue Brief: Moving Beyond the Family Engagement Check Box
- Request TA – it's FREE!

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Thank You