

FAMILY VOICES[®]



Introduction to the Family Engagement in Systems Assessment Tools

March 26, 2020

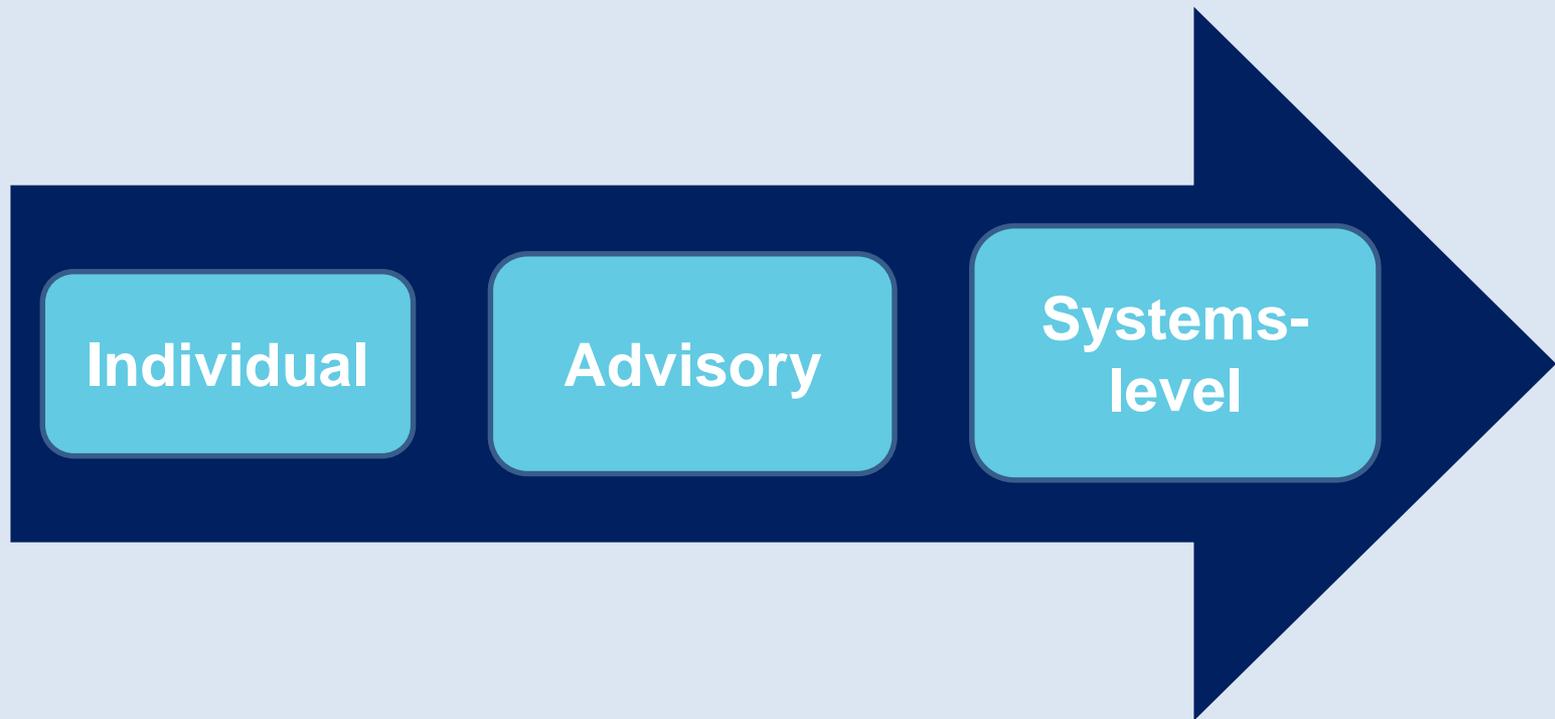
MSRGN Genetic Ambassadors

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Objectives

- Introduce the Family Voices framework for assessing family engagement in systems-level initiatives
- Overview of the Family Voices Family Engagement in Systems Assessment Tool (FESAT)
- Preview the Family Engagement in Systems (FES) Toolkit
- Discuss potential uses of the Tools to assess, enhance, & improve family engagement in systems-level initiatives within the RGNs.

Levels of Family Engagement



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 core 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.



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 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.*

***Family leader** – a family member with lived experience who can participate in systems-level activities around policies and programs that affect the broader population of individuals who receive services.

Systems-level Initiatives

- A **Title V program** engages a family-led organization in the planning & implementation of the Title V needs assessment and related block grant development activities.
- A **Medicaid** program engages family leaders to identify barriers to services and works together to improve policies.
- Each **MSRGN** state team engages families to develop a state-specific project to improve access to genetic services for medically underserved and vulnerable families.

Domains of Family Engagement



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.

Family Engagement in Systems Tools





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, <u>travel</u> , 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.

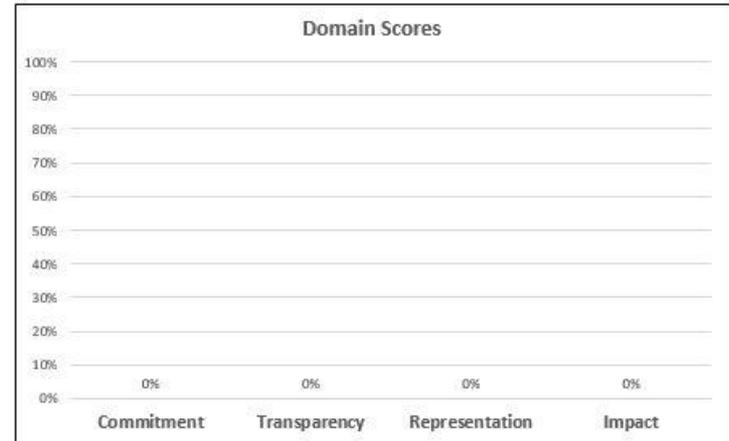
In my experience, organization staff:	Never	Rarely	Some- times	Usually	Always	Not Sure/ Not Applicable
15. Listened to family leaders' ideas.	0	1	2	3	4	
16. Engaged family leaders in choosing goals for the initiative.	0	1	2	3	4	
17. Worked together with family leaders to implement the initiative.	0	1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



Family Engagement in Systems Assessment Tool Score Sheet

		Team Points	Max Points	Domain Score
Domain 1: Commitment		0	0	0%
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).			



		Team Points	Max Points	Domain Score
Domain 2: Transparency		0	0	0%
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.			

Team Points	0
Max Points	0
Engagement Score	0%

Using Your Results

- Identify domains of strength – where families felt supported in their role – had all the information and support they needed to partner and participate
- Identify domains for improvement – where the organization could better support families and staff in their partnership roles so they can make meaningful contributions to the initiative

FESAT: Three Uses

- **Assess** how well an organization engages families
- **Improve** efforts over time towards meaningful family engagement
- **Guide** the design of systems-level initiatives to ensure meaningful family engagement

FES Toolkit



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

- 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.¹⁰

FES Toolkit: Commitment

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, <u>travel</u> , 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	

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

Resource

- [Tokenism in Patient Engagement](#). Many organizations include patients and families as a symbolic or token effort of engagement in research or other initiatives. Hahn et al.¹¹ 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.¹² 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

- [Partnering with Youth & Families in Research: A Standard of Compensation for Youth and Family Partners](#). [CYSHCNet](#), 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](#).¹⁴ 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

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

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](#)¹⁸ 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](#)¹⁹ 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

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](#).⁷ 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.

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.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization has one or more champions of family engagement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization acknowledges the contributions family leaders make to systems-level initiatives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization's budget includes funding for family leaders' time and/or other costs they incur (for example, travel, child care).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all staff and families have a clear understanding of the initiative they will work on together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization provides the supports families and staff need to understand their partnership role (for example mentors/coaching).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all participants have the information they need to participate in meetings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Questions, Comments, Discussion...



For Additional Questions & TA

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Download the FES Tools



Family Engagement in Systems Assessment Tool Score Sheet

<https://familyvoices.org/fesat-request-form/>



Thank You

