CollN to Advance Care for Children with Medical Complexity

Video conference access – PRE-REGISTER

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- ○ 669-900-6833 **or** 548-554-4398 **or** 646-876-9923

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Boston University School of Social Work
Center for Innovation in Social Work & Health

ColIN to Advance Care for Children with Medical Complexity

Webinar: Introduction to the FESAT
Wednesday, November 6, 2019
2:00pm – 3:30pm ET

Boston University School of Social Work
Center for Innovation in Social Work & Health

BOSTON UNIVERSITY

Housekeeping & Hellos

- This call is being recorded
- Make sure to mute your phone when you are not speaking
  - Press the "mute" button on your handheld or press *6 to mute and *6 again to unmute
- Please do not put us on hold
- Please do not use speaker phone if at all possible
- Participation is essential
- Chat box – send tech issues to Libbi and content questions to the whole group
- If using phone audio, please take a minute now to link your phone with your computer

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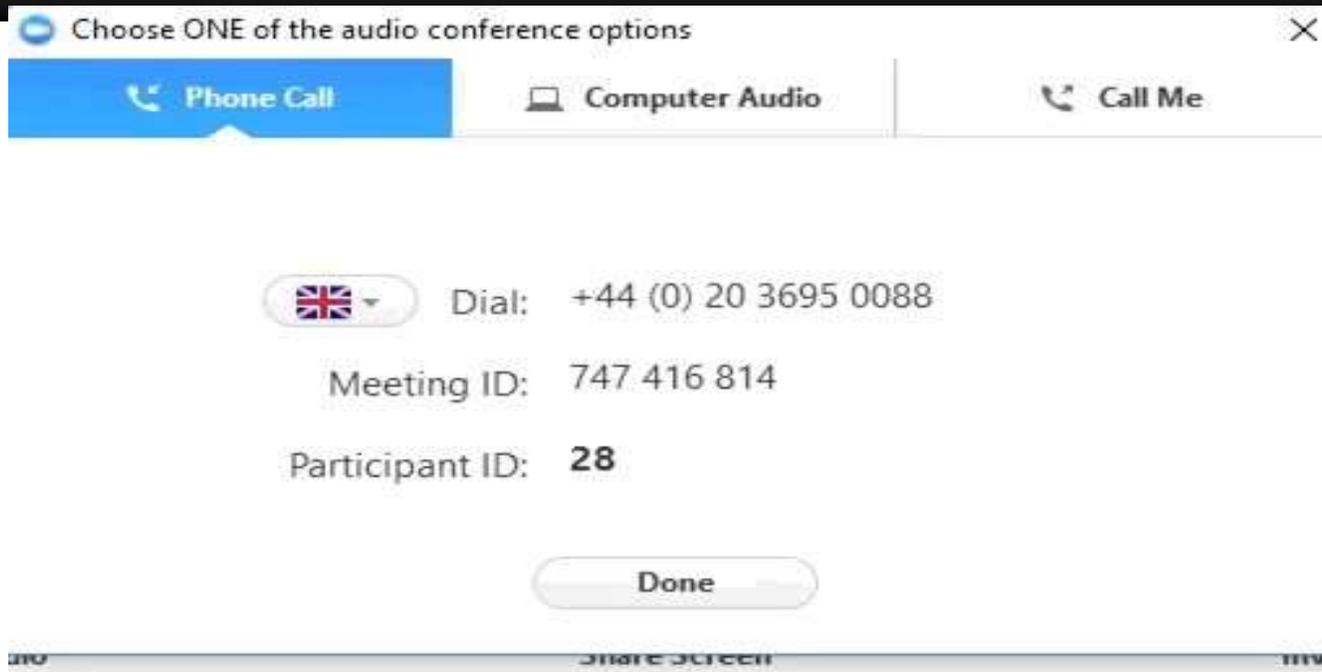
If you join by computer <u>AFTER</u> calling in via phone: You can enter the Participant ID to bind your phone and computer session together by entering #**Participant ID**# on your phone. Your participant ID usually pops up for easy access on the webinar platform, but you can find it under "join audio" if it does not.

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WELCOME!

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Center for Innovation in Social Work & Health

Agenda

- **Welcome and Housekeeping (10 minutes)**

- **Introduction to the FESAT (45 minutes)**

- **State Team Breakouts (20 minutes)**

- **Breakout Group Sharing (10 minutes)**

- **Wrap Up & Next Steps (5 minutes)**

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Family Engagement in Systems Assessment Tools
FESAT, User's Guide, FES Toolkit, Scoresheet

Family Voices, Inc.
888-835-5669
P.O. Box 37188, Albuquerque, NM, 87176
www.familyvoices.org

Familyvoices.org

Levels of Family Engagement

Individual
Partner with providers

Advisory
Participate on a family or youth council or project team

Systems-level
Active role in creating or improving policies, and other systems-level initiatives

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Systems-level Family Engagement

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.

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Systems-level Initiatives: Examples

- A **Title V program** engages a family-led organization in the planning and 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.
- A **hospital** engages families in a quality improvement initiative to evaluate the discharge planning process.
- The **TX CMC CoIIN** team engages families as part of a stakeholder collaboration to transform workflows into an integrated care delivery model that provides family-driven care, optimizes patient/family satisfaction and improves health outcomes.

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Framework for Family Engagement

FAMILY VOICES®   Lucile Packard Foundation *for* Children's Health

April 2018

Issue Brief: A Framework for Assessing Family Engagement in Systems Change

by Clarissa Hoover, MPH, Mary Jo Paladino, MSA, Beth Dworetzky, MS, and Nora Wells, MSEd

Abstract

Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care because they are involved with so many aspects of these systems. As their children's primary caregivers, families are deeply affected by systems-level issues, such as care fragmentation, which are often a direct result of ineffective or outdated health care policies and practices.[1] 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.[2,3,4,5,6]

Family Voices is a national, non-profit, family-led organization that works to promote quality health care for all children and youth, particularly those with special health care needs and those from diverse communities. To explore strategies for ensuring, enhancing, and supporting the meaningful engagement

Tools to Assess Family Engagement
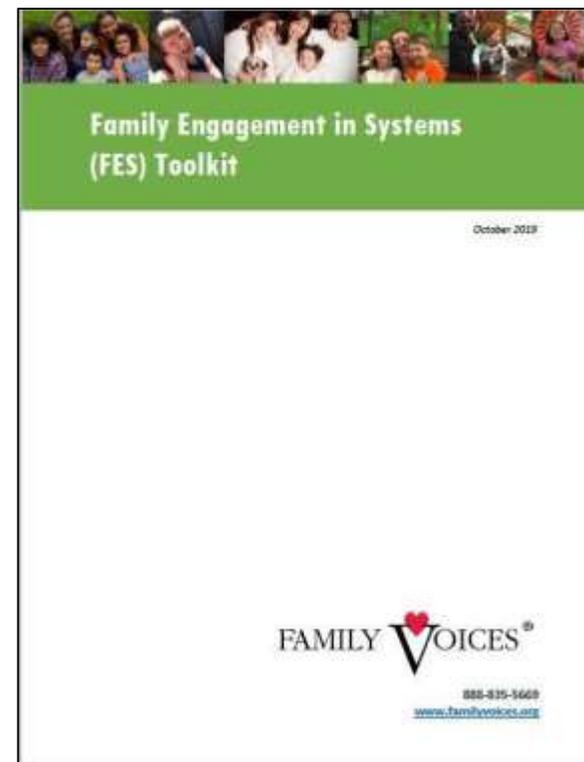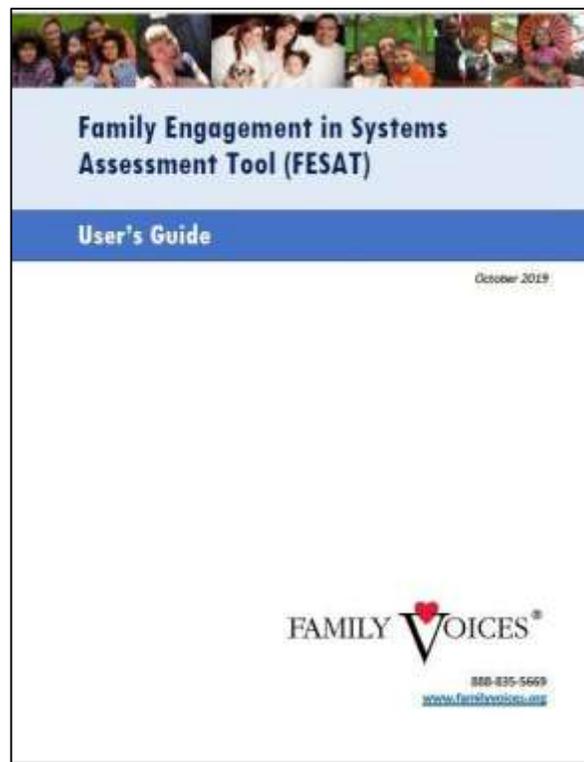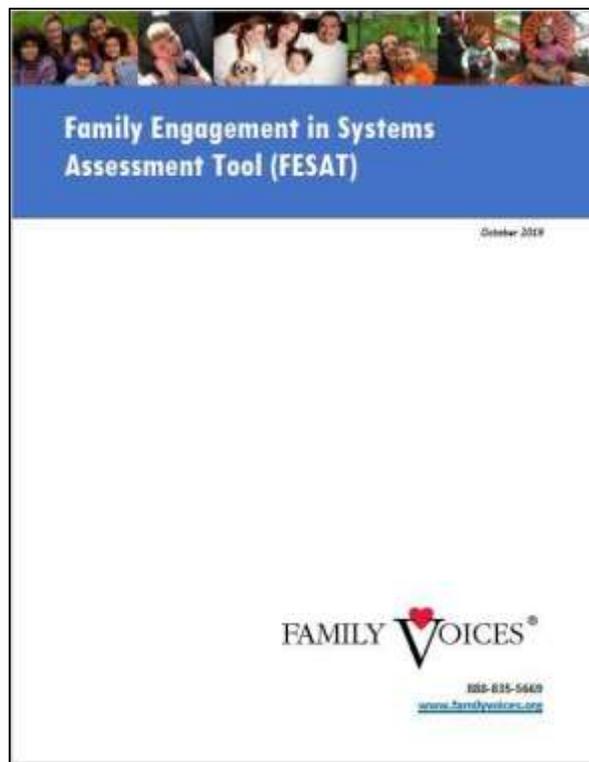
Family Engagement in Systems Assessment (FESAT) User's Guide

- Introduction
- Instructions
- How to score results
- Using your results
- Example uses
- Definition of terms

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FESAT: Four 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.

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Family Engagement in Systems (FES) Toolkit

Family Engagement in Systems 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.

Commitment 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.

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Family Engagement in Systems (FES) Toolkit

Q **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

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Family Engagement in Systems (FES) Toolkit

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

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Family Engagement in Systems (FES) Toolkit

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

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Family Engagement in Systems (FES) Toolkit

Checklist to Guide the Design of an Initiative to Ensure Family Engagement

When your organization begins to engage families in systems-level initiatives, use the check list below to identify the supports your organization is already providing as well as supports that you can implement to ensure meaningful family engagement. Discuss what more you could be doing to encourage family engagement and explore this Toolkit for strategies and resources to support your efforts.

Domain: Commitment	Yes	No	Somewhat	Don't know
We have a written policy that requires family engagement in systems-level initiatives.	☐	☐	☐	☐
We have one or more champions of family engagement.	☐	☐	☐	☐
We have a process for documenting how family leaders contribute to the work.	☐	☐	☐	☐
Our budget includes funding for family leaders' time and other costs they incur (for example, travel, child care).	☐	☐	☐	☐
We provide adequate time for staff to implement changes that result from family engagement (for example, educating staff about new policies).	☐	☐	☐	☐
Domain: Transparency	Yes	No	Somewhat	Don't know
We conduct activities to understand the issues faced by the children and families we serve.	☐	☐	☐	☐
We make sure all staff and families have a clear understanding of the work they will do together.	☐	☐	☐	☐

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Family Engagement in Systems Assessment Tool (FESAT)

Assess   how well an organization engages families

Improve   efforts over time towards meaningful family engagement

Guide   the design of systems-level activities to ensure family engagement

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The "Organization"

- CoIINs are multidisciplinary teams of federal, state, and local leaders (including family leaders) working together to tackle a common problem.

- CMC CoIIN state teams are made up of people from a vast array of systems: Departments of Health, Title V, Medicaid, children's hospitals, other health systems, family-led organizations.

- For the purposes of the FESAT the health-systems representatives on the CoIIN (ex: DPH, Title V, Medicaid, hospital staff, etc) = the Organization. The families are the individuals on the CoIIN whose primary role on their state team is as a family leader.*

*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.

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Domain 1: Commitment: 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	Sometimes	Usually	Always	Not Sure/NA
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 how family leaders contributed to the work.	0	1	2	3	4	
4. The organization's budget includes funding for the family leaders' time and 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 (for example, educating staff about new policies).	0	1	2	3	4	

Domain 1: Commitment: 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

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2. The organization has one or more champions of family engagement.	0	1	2	3	4	
3. The organization acknowledges how family leaders contributed to the work.	0	1	2	3	4	
4. The organization's budget includes funding for the family leaders' time and 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 (for example, educating staff about new policies).	0	1	2	3	4	

Family Engagement in Systems 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.

Commitment 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.
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  - 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.

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	Sometimes	Usually	Always	Not Sure/NA
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, as a mentor within or outside of the organization).	0	1	2	3	4	
9. I had the information I needed to participate in meetings.	0	1	2	3	4	
10. I had the supports I needed to participate (for example, physical access, interpreters, time away from other work responsibilities).	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	Sometimes	Usually	Always	Not Sure/NA
11. **Races and ethnicities** of the population served by the initiative.	0	1	2	3	4	
12. **Cultures** of the population served by the initiative.	0	1	2	3	4	
13. **Languages** spoken by the population served by the initiative.	0	1	2	3	4	
14. **Geographic area** served by the initiative.	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	Sometimes	Usually	Always	Not Sure/NA
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. Showed an understanding of how family leaders contributed to the work.	0	1	2	3	4	

Before you begin

Identify the organization and your role in the systems-level initiative (family leader or organization staff person). The organization is the entity that has engaged the family leaders in the systems-level initiative.

- Organization name: **CMC CoIIN State Team**

- Check the box that best describes your primary role in this initiative:
    - ❑ I participated in the initiative as a family/youth leader
    - ❑ I participated in the initiative as an organization staff person

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Before you begin

Staff and families who participated in the initiative agree on a short description of the on-going or recently completed systems-level policy, program, practice, or service initiative in which they were engaged.

Example: **[Organization]** engages (or engaged) families in [**short description of initiative**] to [**intended outcome**]

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Before you begin

CMC CoIIN State Team staff, family, and or youth leaders agree on a short description of the on-going or recently completed systems-level policy, program, practice, or service initiative in which they were engaged.

Example: **TX CMC CoIIN** team engages families as part of a **stakeholder collaboration** to **transform workflows into an integrated care delivery model that provides family-driven care, optimizes patient/family satisfaction and improves health outcomes**.

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Who scores the FESAT?

Organization and family/youth leaders engaging in the specific initiative

Ex: CMC CoIIN State Team staff, family, and or youth leaders who are participating in the initiative

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Consensus Scores

State Team Staff discuss individual scores → consensus

Family/Youth discuss individual scores → consensus

ALL PARTICIPANTS meet (in person or virtually) to discuss scores → consensus

Scoring
- Enter consensus scores into Column C (light blue) on Excel Spreadsheet
- Never = 0; Rarely = 1; Sometimes = 2; Usually = 3; Always = 4
- Do not score the "Not Sure" response – leave blank

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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 has a written policy that requires family engagement in systems-level initiatives.			
2 The organization has one or more champions of family engagement.			
3 The organization reported how family leaders contributed to the work.			
4 The organization's budget includes funding for the family leaders' time and other costs they incur (for example, travel, childcare).			
5 The organization provides adequate time for staff to implement changes that result from family engagement (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, as a mentor within or outside of the organization).			
9 I had the information I needed to participate in meetings.			
10 I had the supports I needed to participate (for example, physical access, interpreters, time away from other work responsibilities).			
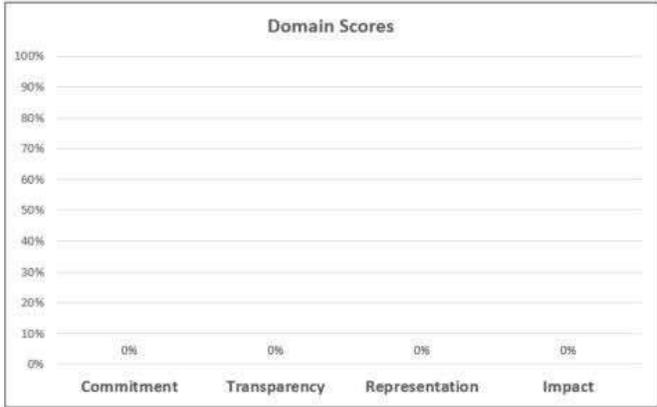
Domain Scores

		Team Points	0
		Max Points	0
		Overall Family Engagement Score	0%

Using your results

- The FESAT is a self-assessment tool
- As a team, identify domains of strength and domains where family engagement could be improved
- If using the FESAT for QI, initial cores serve as a baseline
- Compare subsequent uses to individual domain and/or overall family engagement scores
- Consult the FES Toolkit to choose strategies and find resources for improving family engagement in one or more domains

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Questions?

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Please provide feedback

[FESAT and FES Toolkit Feedback Survey](#)

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Please contact Family Voices with questions, for technical assistance, and if you'd like to speak with us directly about use of the these family engagement assessment tools!

Contact Information

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Family Voices	Family Voices	Family Voices
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Wrap-Up & Next Steps

Boston University School of Social Work
Center for Innovation in Social Work & Health

Next Steps

- ***Baseline FESAT –*** due by January 1, 2020

- ***Open Office Hours with Meg and Family Voices –*** *Tuesday* 11/12/2019 from 4:00pm to 5:00pm ET

- ***Monthly State Team Update –*** due 11/22/2019 (early due to Thanksgiving holiday)

- ***Look for an email*** regarding in-person meeting and consultation visit scheduling

- ***Round 2 of survey collection*** – November 2019 through April 2020

- Continue to ***upload documents for cross sharing*** on Box!

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Evaluation

https://www.surveymonkey.com/r/GWYG8VS