FELSC Family Engagement and Leadership in Systems of Care

FAMILY VOICES®

Measuring What Matters

Tools to Assess and Strengthen Family Engagement in Systems Transformation



About Family Voices



Family Voices is a family-led organization that transforms systems of care to better work for all children and youth, especially those with special health care needs and disabilities. By putting families at the forefront and centering their leadership and lived expertise, we build a culture that includes everyone and fosters equitable outcomes.

Learn more at familyvoices.org.

Funding Acknowledgment



Family Engagement and Leadership in Systems of Care (FELSC) is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U4000149. The information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.

Lucile Packard Foundation for Children's Health funded the development of many of the tools presented in this webinar.

Today's Agenda



1. Review of the framework
2. Context of engagement
3. Conditions of meaningful engagement
4. Continuum of engagement
5. Assessing family engagement
6. The FES Toolkit & support from Family Voices
7. Questions and discussion

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Review of the Framework

How the pieces fit together and where to begin

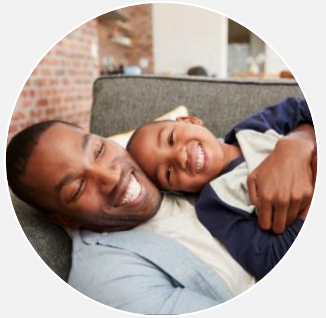


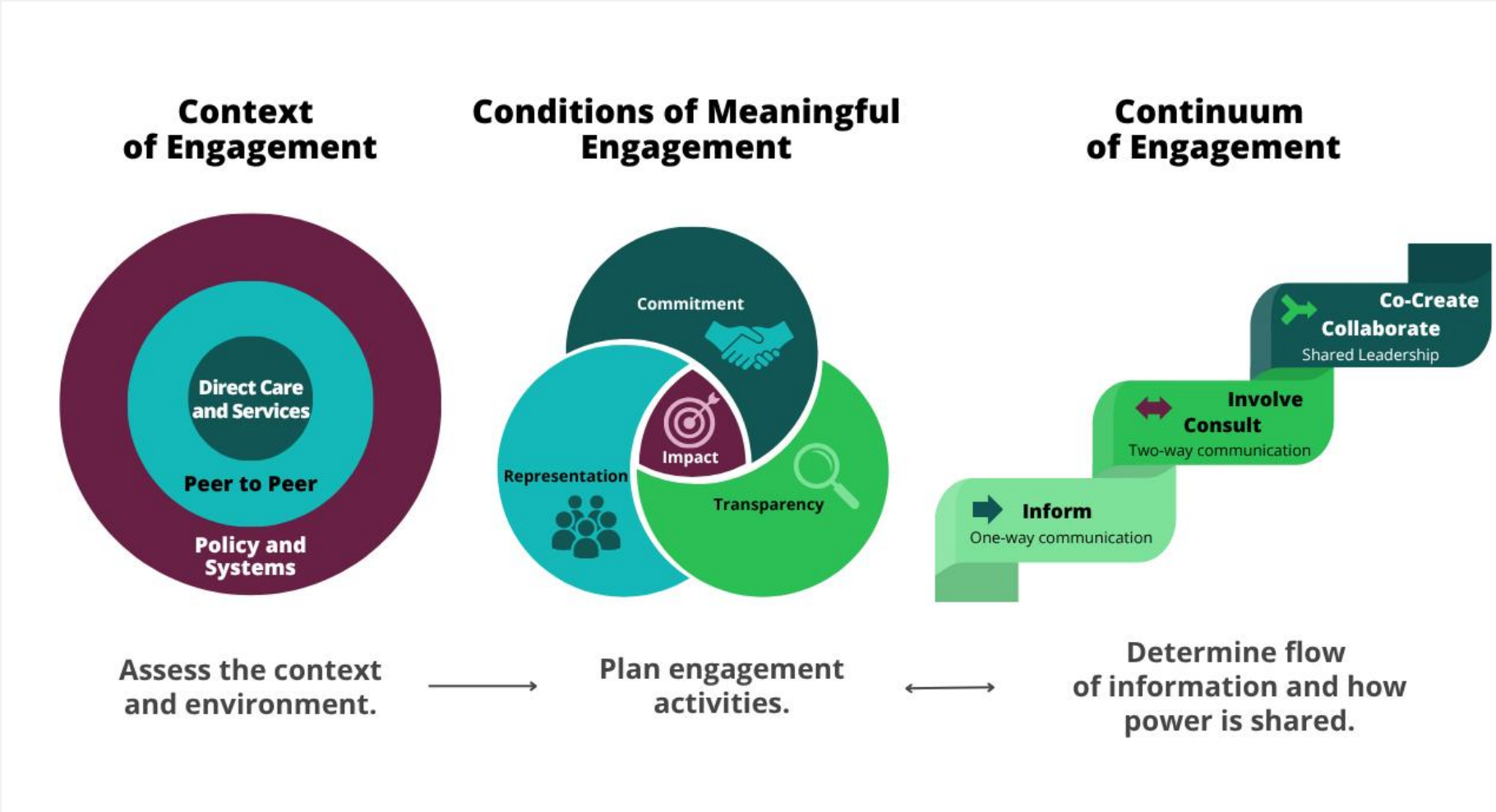
What is family engagement?



- An **intentional partnership** between families, youth, and health-related service providers across systems of care
- Grounded in **mutual respect and shared decision-making**
- Recognizes the **unique expertise** families and youth bring through lived experience

The Framework at a Glance





How It All Works Together



- **Start with context**: Who are the families, and what shapes their experience?
- **Plan with the conditions**: Are commitment, transparency, representation, and impact in place?
- **Choose where you are on the continuum**: How will information flow, and who decides?
- Planning and the continuum inform each other.

Putting Each Piece into Action



1. Define family engagement and learn why it matters.
2. Assess your readiness.
3. Follow your pathway:

Level 1 Prepare for meaningful engagement.

Level 2 Assess engagement using the FESAT.

Level 3 Expand, sustain, and show impact.

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Context of Engagement

Direct Care and Services, Peer-to-Peer, and Policy & Systems: A tool for each level



Context of Engagement



Direct Care and Services: each family's own experience of care

Peer-to-Peer: the people, family leaders, and organizations supporting families

Policy & Systems: the organizations, initiatives, and policies that serve families



Assess the context before you plan.

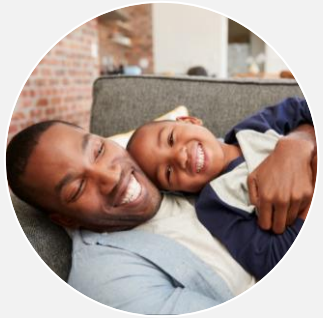
Direct Care and Services: The FCCA



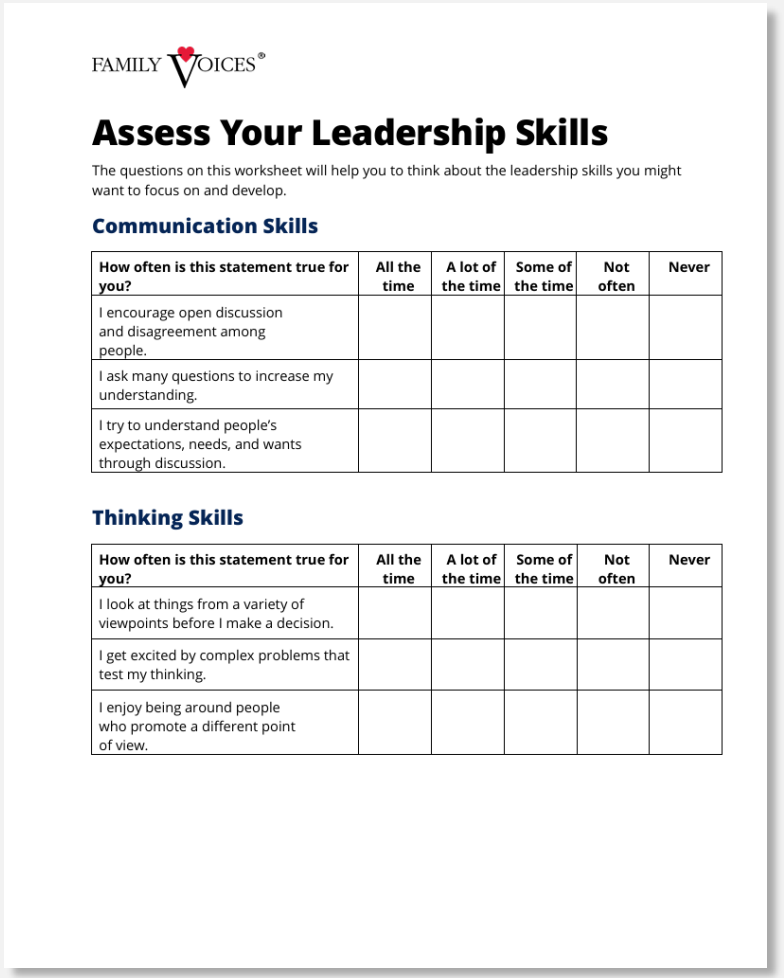
- A quality measurement questionnaire developed by Family Voices
- Families and providers rate how family-centered a child's care is
- Measures collaboration, mutual respect, trust, and shared decision-making
- Supports reflection and quality improvement over time



Peer-to-Peer Level: Leadership Skills



- A self-reflection worksheet for family leaders and staff
- Three skill areas: communication, thinking, and innovation
- Rate how often you do each behavior, from "all the time" to "never"
- Sample item: "I encourage open discussion and disagreement among people."



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Assess Your Leadership Skills

The questions on this worksheet will help you to think about the leadership skills you might want to focus on and develop.

Communication Skills

How often is this statement true for you?	All the time	A lot of the time	Some of the time	Not often	Never
I encourage open discussion and disagreement among people.					
I ask many questions to increase my understanding.					
I try to understand people's expectations, needs, and wants through discussion.					

Thinking Skills

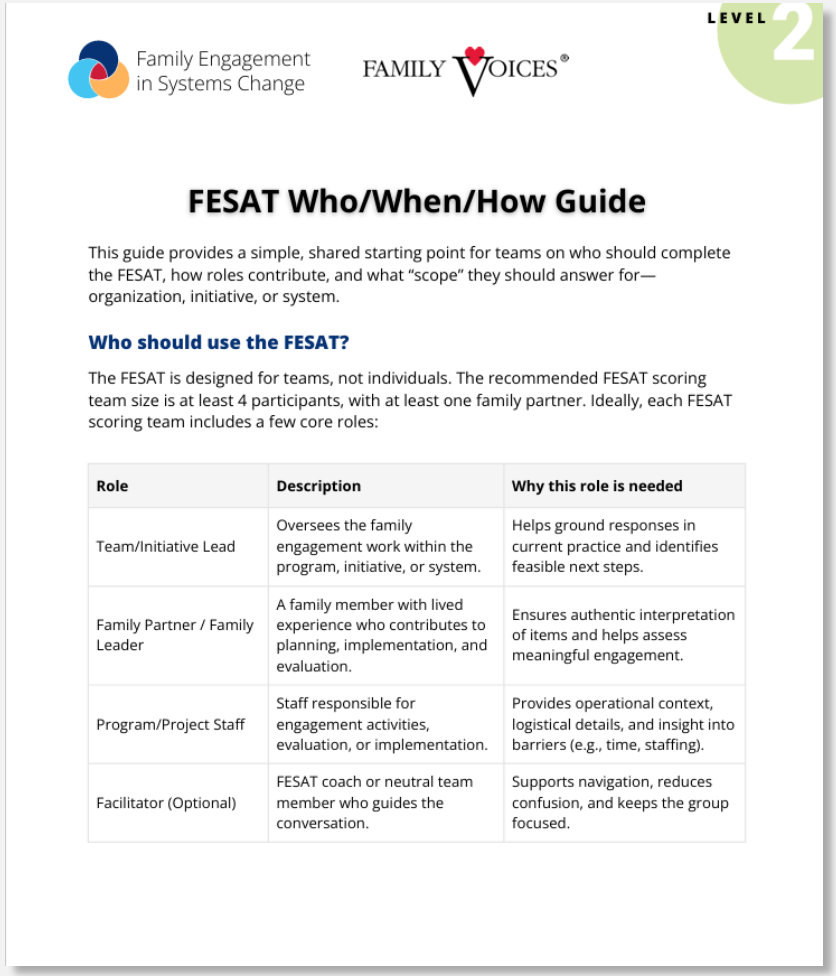
How often is this statement true for you?	All the time	A lot of the time	Some of the time	Not often	Never
I look at things from a variety of viewpoints before I make a decision.					
I get excited by complex problems that test my thinking.					
I enjoy being around people who promote a different point of view.					

Policy & Systems Level: FESAT Scope



Before scoring, decide what you're answering about:

- **Organization**: a single agency or program
- **Initiative**: several organizations working on one shared project (recommended for collaboratives)
- **System**: a broader system, such as a state Title V program or Medicaid division



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LEVEL 2

FESAT Who/When/How Guide

This guide provides a simple, shared starting point for teams on who should complete the FESAT, how roles contribute, and what "scope" they should answer for—organization, initiative, or system.

Who should use the FESAT?

The FESAT is designed for teams, not individuals. The recommended FESAT scoring team size is at least 4 participants, with at least one family partner. Ideally, each FESAT scoring team includes a few core roles:

Role	Description	Why this role is needed
Team/Initiative Lead	Oversees the family engagement work within the program, initiative, or system.	Helps ground responses in current practice and identifies feasible next steps.
Family Partner / Family Leader	A family member with lived experience who contributes to planning, implementation, and evaluation.	Ensures authentic interpretation of items and helps assess meaningful engagement.
Program/Project Staff	Staff responsible for engagement activities, evaluation, or implementation.	Provides operational context, logistical details, and insight into barriers (e.g., time, staffing).
Facilitator (Optional)	FESAT coach or neutral team member who guides the conversation.	Supports navigation, reduces confusion, and keeps the group focused.

How Each Might Be Used



FCCA: Families measure how family-centered care is in a practice or clinic

Leadership Skills Inventory: Family leaders and staff reflect on strengths and plan development

FESAT: A team of 4 or more, including a family partner, assesses engagement in an organization, initiative, or system

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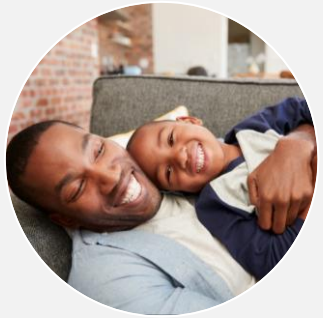
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Conditions of Meaningful Engagement

Commitment, Transparency, Representation, and Impact



Conditions of Meaningful Engagement



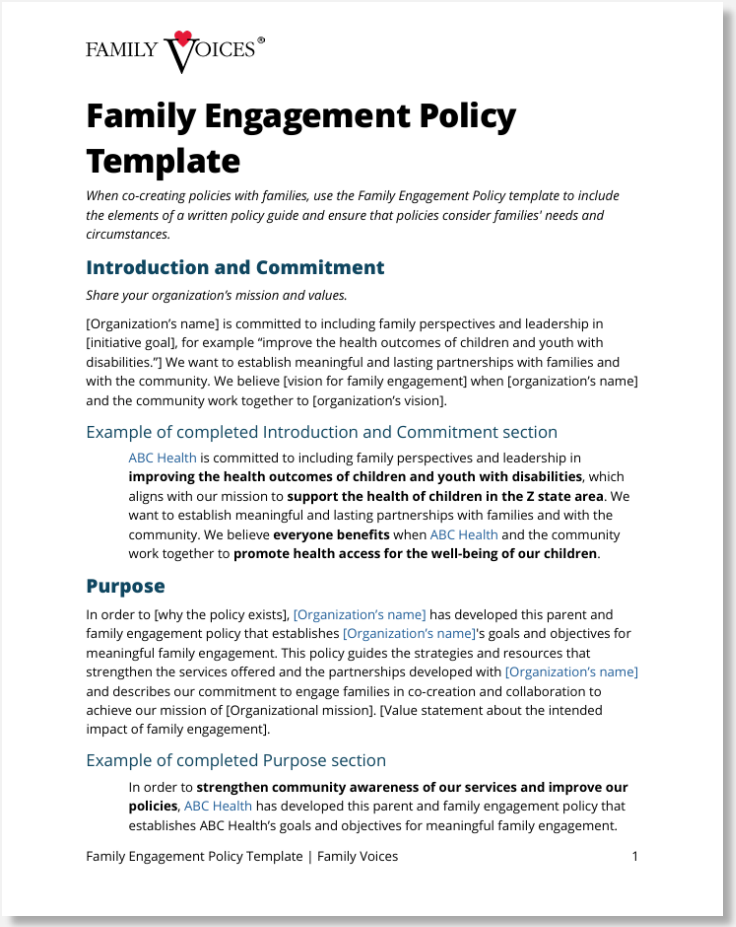
- **Commitment**: Family engagement is a core value.
- **Transparency**: Families have the knowledge and support to participate fully.
- **Representation**: The families engaged reflect the community served.
- **Impact**: The organization can show what it does differently because of family engagement.



Commitment: Family Engagement Policy



- A written policy makes family engagement part of how the organization works.
- Seven sections: Introduction and Commitment, Purpose, Definitions, Procedures, Responsibilities, Building Capacity, & Evaluation
- Procedures cover meeting schedules, materials in multiple languages and formats, and paying families for their expertise
- Tools: Family Engagement Policy Guide and Template



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Family Engagement Policy Template

When co-creating policies with families, use the Family Engagement Policy template to include the elements of a written policy guide and ensure that policies consider families' needs and circumstances.

Introduction and Commitment

Share your organization's mission and values.

[Organization's name] is committed to including family perspectives and leadership in [initiative goal], for example "improve the health outcomes of children and youth with disabilities."] We want to establish meaningful and lasting partnerships with families and with the community. We believe [vision for family engagement] when [organization's name] and the community work together to [organization's vision].

Example of completed Introduction and Commitment section

ABC Health is committed to including family perspectives and leadership in **improving the health outcomes of children and youth with disabilities**, which aligns with our mission to **support the health of children in the Z state area**. We want to establish meaningful and lasting partnerships with families and with the community. We believe **everyone benefits** when ABC Health and the community work together to **promote health access for the well-being of our children**.

Purpose

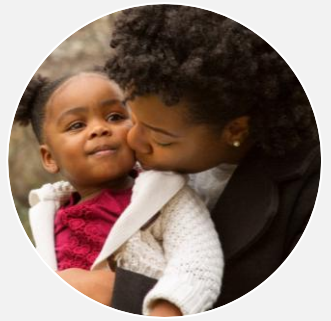
In order to [why the policy exists], [Organization's name] has developed this parent and family engagement policy that establishes [Organization's name]'s goals and objectives for meaningful family engagement. This policy guides the strategies and resources that strengthen the services offered and the partnerships developed with [Organization's name] and describes our commitment to engage families in co-creation and collaboration to achieve our mission of [Organizational mission]. [Value statement about the intended impact of family engagement].

Example of completed Purpose section

In order to **strengthen community awareness of our services and improve our policies**, ABC Health has developed this parent and family engagement policy that establishes ABC Health's goals and objectives for meaningful family engagement.

Family Engagement Policy Template | Family Voices 1

Commitment in Action



Before: Family advisors were invited "when there was time" and were not paid.

1

Procedures: Monthly workgroups with at least two paid family leaders; materials in English and Spanish

2

Responsibilities: Two staff champions with protected time

3

Capacity and evaluation: Storytelling training for families; annual family survey

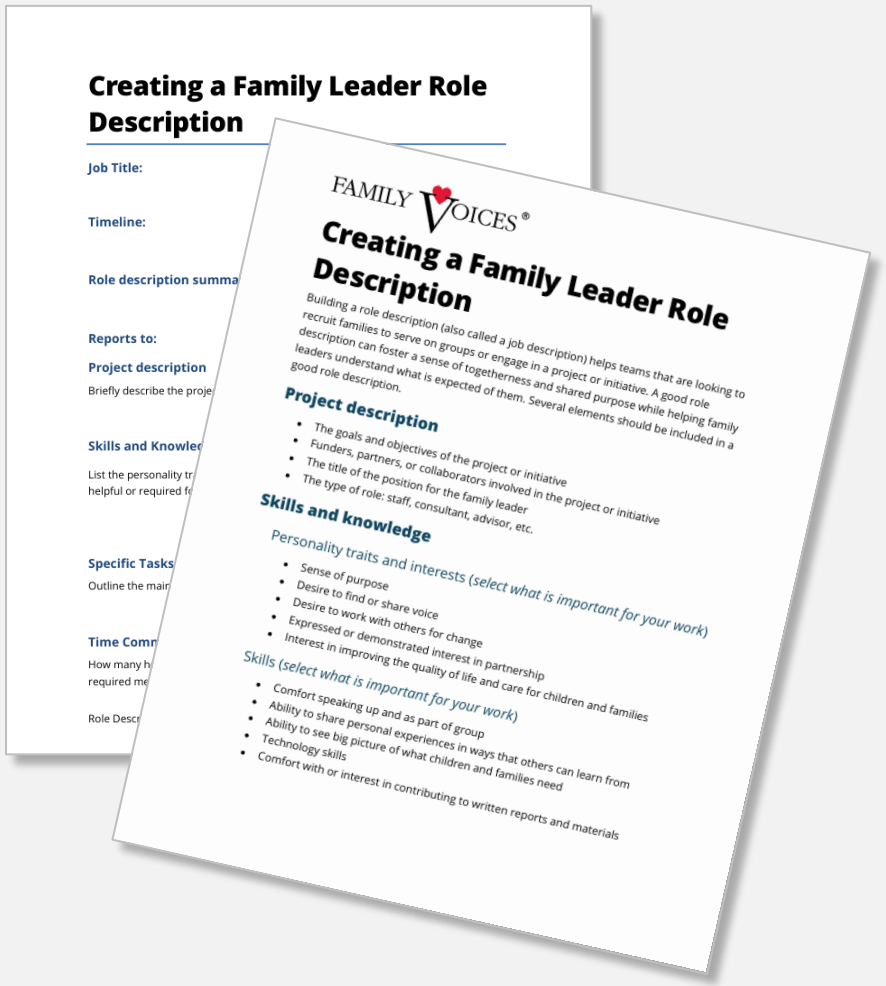
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Why it matters: Engagement became a requirement, not a favor.

Transparency: Role Description



- Project overview, goals, and role type
- Skills, knowledge, and experience needed
- Meeting schedule, format, and the family leader's role
- Time commitment
- Expectations and supports (childcare, interpretation, captions)
- Compensation and benefits
- How to apply and when decisions are made



Transparency in Action



Recruiting families for a care coordination redesign workgroup

→

Role description: 2 hours a month for 9 months, virtual meetings, stipend amount, interpretation available

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Family leaders co-facilitate one session

→

Why it matters: More families applied, fewer dropped out, and expectations were clear on both sides.

Representation: Mapping Partnerships



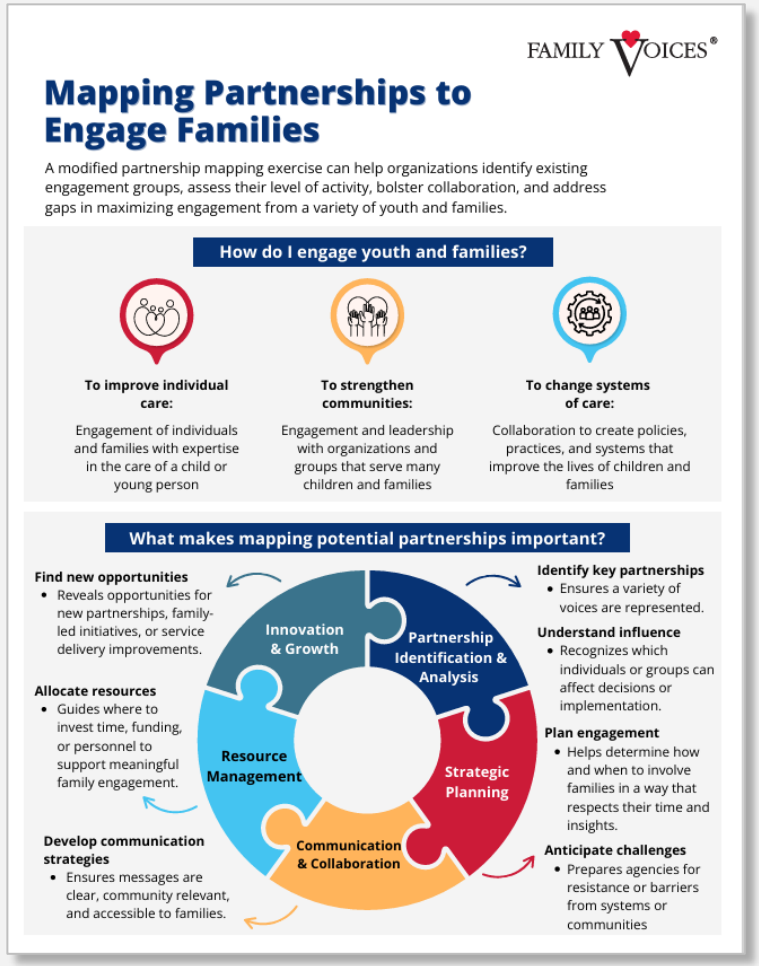
1. Identify Existing Groups: including faith-based and school-based groups

2. Analyze Organizations: mission, goal alignment, capacity to collaborate

3. Map Relationships: connect your goals to partner strengths; find gaps

4. Prioritize Level of Engagement: place each partner on the continuum

Pair with **Four Simple Questions** from Leading by Convening.



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Mapping Partnerships to Engage Families

A modified partnership mapping exercise can help organizations identify existing engagement groups, assess their level of activity, bolster collaboration, and address gaps in maximizing engagement from a variety of youth and families.

How do I engage youth and families?

To improve individual care:
Engagement of individuals and families with expertise in the care of a child or young person

To strengthen communities:
Engagement and leadership with organizations and groups that serve many children and families

To change systems of care:
Collaboration to create policies, practices, and systems that improve the lives of children and families

What makes mapping potential partnerships important?

Find new opportunities
- Reveals opportunities for new partnerships, family-led initiatives, or service delivery improvements.

Allocate resources
- Guides where to invest time, funding, or personnel to support meaningful family engagement.

Develop communication strategies
- Ensures messages are clear, community relevant, and accessible to families.

Innovation & Growth
Partnership Identification & Analysis
Strategic Planning
Communication & Collaboration
Resource Management

Identify key partnerships
- Ensures a variety of voices are represented.

Understand influence
- Recognizes which individuals or groups can affect decisions or implementation.

Plan engagement
- Helps determine how and when to involve families in a way that respects their time and insights.

Anticipate challenges
- Prepares agencies for resistance or barriers from systems or communities

Representation in Action



Population data: 30% of families served speak Spanish at home, but no family advisors did.

Mapping showed no relationships in two rural counties.

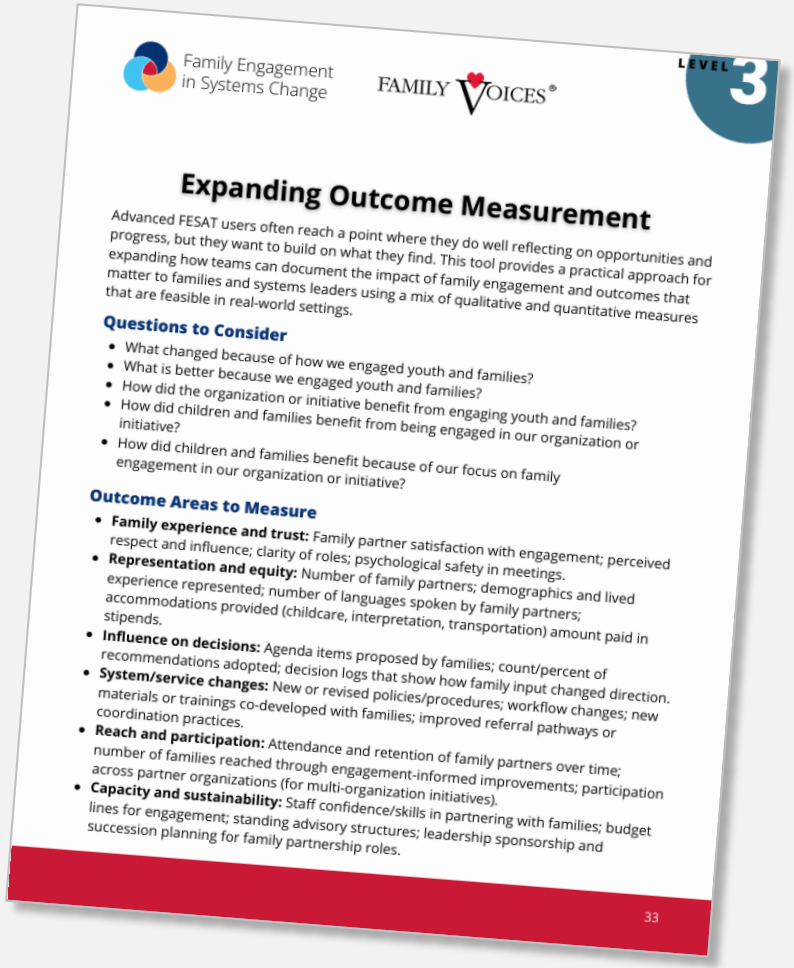
Collaborate: State Family-to-Family Health Information Center co-recruits and mentors family leaders.

Consult: A rural faith-based parent network hosts bilingual listening sessions.

Impact: Outcome Measurement



- **Outcome areas:** family experience and trust, representation and equity, influence on decisions, system changes, reach, sustainability
- **Data methods:** pulse checks, decision and change log, participation tracking, outcome stories, follow-up checkpoints
- **Workflow:** pick 3 to 5 outcomes, define a metric and story prompt for each, assign owners, set a cadence, close the loop



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LEVEL 3

Expanding Outcome Measurement

Advanced FESAT users often reach a point where they do well reflecting on opportunities and progress, but they want to build on what they find. This tool provides a practical approach for expanding how teams can document the impact of family engagement and outcomes that matter to families and systems leaders using a mix of qualitative and quantitative measures that are feasible in real-world settings.

Questions to Consider

- What changed because of how we engaged youth and families?
- What is better because we engaged youth and families?
- How did the organization or initiative benefit from engaging youth and families?
- How did children and families benefit from being engaged in our organization or initiative?
- How did children and families benefit because of our focus on family engagement in our organization or initiative?

Outcome Areas to Measure

- **Family experience and trust:** Family partner satisfaction with engagement; perceived respect and influence; clarity of roles; psychological safety in meetings.
- **Representation and equity:** Number of family partners; demographics and lived experience represented; number of languages spoken by family partners; accommodations provided (childcare, interpretation, transportation) amount paid in stipends.
- **Influence on decisions:** Agenda items proposed by families; count/percent of recommendations adopted; decision logs that show how family input changed direction.
- **System/service changes:** New or revised policies/procedures; workflow changes; new materials or trainings co-developed with families; improved referral pathways or coordination practices.
- **Reach and participation:** Attendance and retention of family partners over time; number of families reached through engagement-informed improvements; participation across partner organizations (for multi-organization initiatives).
- **Capacity and sustainability:** Staff confidence/skills in partnering with families; budget lines for engagement; standing advisory structures; leadership sponsorship and succession planning for family partnership roles.

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Impact in Action



Chose 3 outcomes: influence on decisions, family experience, and service changes

→

Tracked with a decision and change log, quarterly pulse checks, and two co-written outcome stories

↓

Showed that 6 of 9 family recommendations were adopted, including a plain-language care plan

→

Shared results with families and leadership

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Continuum of Engagement

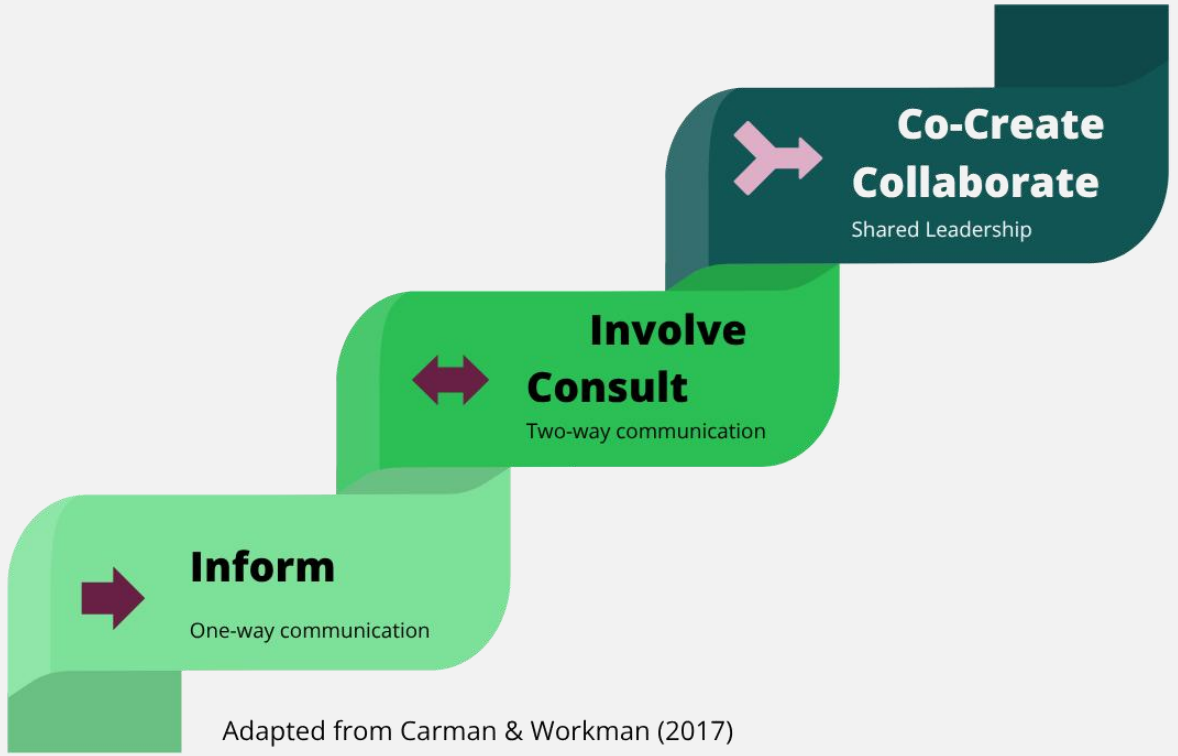
How information flows and how power is shared



The Continuum of Engagement



- **Inform:** One-way, plain-language information
- **Consult:** Families respond; the organization decides
- **Involve:** Families serve as advisors or reviewers at set points
- **Collaborate:** Families hold leadership roles
- **Co-create:** Families and professionals share equal decision-making power



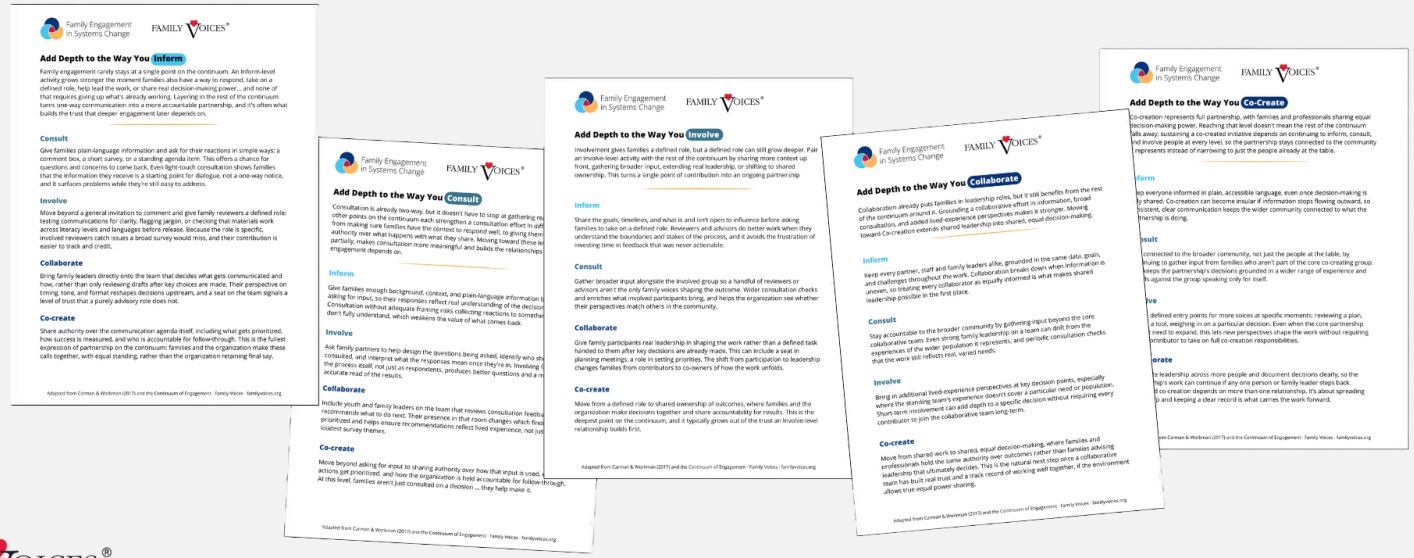
Adapted from Carman & Workman (2017)

Add Depth to the Way You Engage



Five one-pagers, one for each level of the continuum

- Start from what you're already doing.
- Each page shows how the other four levels can strengthen that activity.
- No need to give up what's working



The Continuum in Action



- **Inform**: A family newsletter
- **Consult**: Added a two-question survey to each issue
- **Involve**: Family reviewers test each issue for clarity and jargon
- **Collaborate**: A family leader joins the communications planning team
- **Co-create**: Next goal → families and staff set communication priorities together

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Assessing Family Engagement

Readiness, checklist, and the FESAT



Readiness Assessment



A growth tool: there is no "bad" score

- 24 true-or-false statements, 1 point each
- **Baseline (under 6):** Level 1 pathway
- **Questioning (6 to 11):** Level 1 pathway
- **Interested (12 to 17):** Level 2 pathway
- **Invested (18 or more):** Level 3 pathway
- Paper or online version



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Is Your Team Ready to Engage Families?

Readiness Assessment for Family Engagement

Family engagement requires not only the desire, but also the structures, planning and leadership to sustain their involvement. Take our readiness quiz to find out how ready your organization or team is to engage youth and families in your work.

The Readiness Assessment is a growth tool. **There is no "bad" score**. The assessment helps your team understand the most appropriate pathway to continue your youth and family engagement efforts.

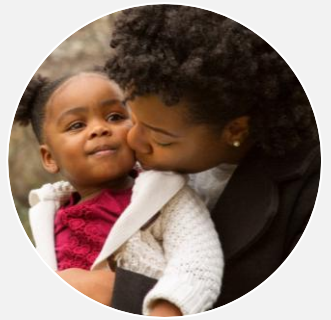
Each true statement is worth one point. Based on your answers to the 24 items in this readiness quiz, you will learn whether your team is at one of the following four levels of readiness: Baseline, Questioning, Interested, or Invested. After seeing where your team scores, take the next steps in building meaningful engagement plans; the goals is progress over perfection. You can use this form or take the online version.

- Our organization or team currently engages families or has a plan to engage families.
- Our team members have at least a minimal understanding of the processes behind family engagement.
- Families have shown interest in participating in initiatives and have support from our organization or team to engage.
- We have a staff member or champion assigned to support family leaders.
- Our organization has assessed the barriers to engaging families.
- Our organization has developed a plan to overcome the barriers to family engagement.
- Our organization or team recruits families to improve our policies or initiatives.
- The organization or team has a budget to compensate families.
- The organization or team has a budget for champions or mentors.
- The organization or team wants to recruit and work with families.
- The organization or team has a clear understanding of the value of families' perspectives.
- Families are included at early stages of our projects and initiatives and help to plan them.

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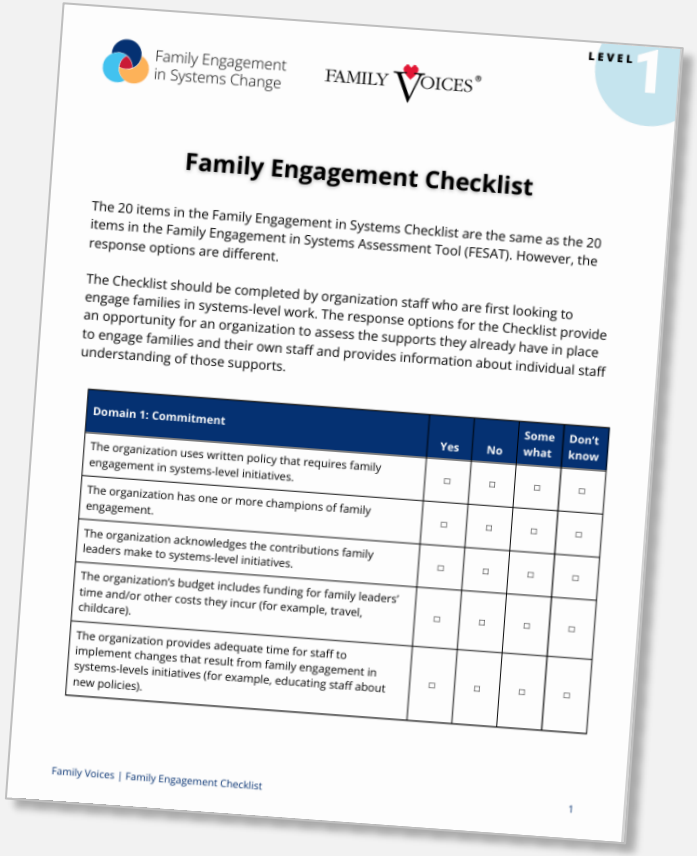
Family Voices | Family Engagement Readiness Assessment

The Family Engagement Checklist



Completed by staff who are first looking to engage families

- The same 20 items as the FESAT, organized by the four conditions
- Answer Yes, No, Somewhat, or Don't know
- Shows what supports are in place and how well staff understand them



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LEVEL 1

Family Engagement Checklist

The 20 items in the Family Engagement in Systems Checklist are the same as the 20 items in the Family Engagement in Systems Assessment Tool (FESAT). However, the response options are different.

The Checklist should be completed by organization staff who are first looking to engage families in systems-level work. The response options for the Checklist provide an opportunity for an organization to assess the supports they already have in place to engage families and their own staff and provides information about individual staff understanding of those supports.

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, childcare).	☐	☐	☐	☐
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).	☐	☐	☐	☐

Family Voices | Family Engagement Checklist

1

The FESAT Score Sheet



- 20 items across the four conditions
- Scored by a team of at least 4, including a family partner
- One 60- to 90-minute session using the Quick Start Guide
- **30-day on-ramp:** orient, assemble the team, score, then debrief and pick 1 to 3 actions
- **Three uses:** Plan, Assess, Improve

Tools by Readiness Level



- **Baseline**: A county early intervention program uses the Readiness Discussion Guide, Checklist, and Mapping Partnerships
- **Questioning**: A pediatric clinic uses the Checklist, FESAT infographics, and policy template
- **Interested**: Riverbend scores the FESAT and picks 1 to 3 improvement actions
- **Invested**: A children's hospital rescores, expands outcome measurement, and builds its case for funding

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Resources and Support

The FES Toolkit and technical assistance from Family Voices



The FES Toolkit

- An info sheet for each condition: Commitment, Transparency, Representation, Impact
- Each sheet includes strategies, tools, and resources
- Also includes the framework, readiness assessment, checklist, continuum guides, and FESAT guides
- familyvoices.org/FESAT



Support from Family Voices



- **Help your team get started:** choose your pathway and prepare to score the FESAT
- **One-day workshops**
- **6-month implementation jump start**
- **FESAT coaches & network partners**
- **Making the Case for Family Engagement:** a six-session sustainability training
- **Contact:** FESAT@familyvoices.org

Your Next Steps



This week: Visit familyvoices.org/FESAT/infographics

Take the Readiness Assessment with your team, including a family partner

Then: Follow the pathway your score points to

Questions? Email us at FESAT@familyvoices.org

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Questions and Discussion

