Contents

Introduction .......................................................................................................................... 3
Using the FESAT .............................................................................................................. 4
Scoring the FESAT .......................................................................................................... 5
Using the FESAT Results ............................................................................................... 6
FESAT Feedback ................................................................................................................ 7
Appendix A: Example uses of the FESAT ...................................................................... 8
Appendix B: Glossary of Terms ....................................................................................... 9
Introduction

Child- and family-serving organizations must partner with families and family-led organizations to ensure the development of effective policies and programs that govern the services that children, youth, and families receive.

Evidence shows that family engagement in health care initiatives leads to better health outcomes, patient safety, and improved health care policies. However, families report that they frequently feel more like a token participant than a partner and that the invitation to participate on decision-making groups seems more to fulfill a requirement to have a family member present than to authentically incorporate family perspectives that might alter priorities. State agencies, organizations, and other health entities often struggle to recruit families who represent the populations they serve, or fail to provide families with the information and supports they need to participate to their maximum potential and make meaningful contributions to the work.

Family Voices created the Family Engagement in Systems Assessment Tool (FESAT) to assess family engagement in policies, practices, and other systems-level initiatives. We created a companion Family Engagement in Systems (FES) Toolkit to provide strategies, resources, and guidance to promote and strengthen effective family engagement.

Health care entities that serve children, youth, and families, in collaboration with their family and family-led organizational partners can use the FESAT to:

- **Assess** how well they engage families in systems-level initiatives
- **Improve** efforts over time toward meaningful family engagement
- **Guide** the design of systems-level initiative to ensure family engagement

Organizations also can use the FESAT to encourage and spread family engagement strategies, promote and share best practices for family engagement, and create learning opportunities among partner organizations.

Examples of systems-level initiatives might include:

- A **Title V program** engages with 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 with family leaders to identify barriers to services, and works with families together to improve policies.
- A **university research team** engages family leaders to create a research project to ensure that interventions are family-centered.
- A **hospital** engages families in a quality improvement initiative to evaluate the discharge planning process.

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Using the FESAT

The organization staff and family leaders who are participating (or who participated) in the systems-level initiative should complete the FESAT. If preferred, a staff person or family leader can use this Guide to facilitate the FESAT process.

Tip: Sometimes a group of organizations engages family leaders in a systems-level initiative. In this case, the collective group (for example, Title V, Medicaid, other state agencies) is the “organization”.

These instructions provide guidance for three uses of the FESAT. Users may adapt these to the needs of an organization for supporting meaningful family engagement at the systems level.

1. Assess How Well an Organization Engages Family Leaders in a Systems-level Initiative
   Organization **staff and family leaders** use the FESAT to assess completed or ongoing initiatives (see example in Appendix A #1).
   a) Staff and family leaders work together to write a short description of the initiative (see examples in the FESAT). Enter this description on page 2 of the FESAT. All participants will use this same description to complete the FESAT.
   b) Staff and family leaders complete the FESAT individually or discuss each item and decide on a group response.
   c) After each participant or group has completed the FESAT, staff and family leaders discuss similarities and differences in responses, come to a shared understanding and, if possible, a consensus response for each item.
   d) Complete the score sheet (see instructions on page 5).
   e) Identify domains of strength and domains for improvement. Work together to make an action plan for improving family engagement in systems-level initiatives.

   Tip: See action planning strategies, links to sample action plans and additional resources in Domain 4 Impact of the FES Toolkit or [Contact Family Voices](#) for individualized technical assistance.

2. Improve Family Engagement in an On-Going Initiative over Time
   Organization **staff and family leaders** use the FESAT to track progress of family engagement efforts (see example in Appendix A #2).
   a) Complete the FESAT as described above to provide an initial assessment of family engagement to date and establish a baseline score.
   b) Complete the FESAT again at scheduled intervals as the initiative progresses.
   c) Compare the results for each domain and overall family engagement results to the baseline established with prior use.
      i. Note and discuss what may have led to identified improvements.
      ii. Examine whether or not there were fewer “Not Sure” responses.
   d) Use the FES Toolkit or [contact Family Voices](#) for technical assistance about any additional areas for improvement.
3. Guide the Design of Meaningful Family Engagement in Initiatives

Organizations just beginning to engage families in systems-level initiatives use the FESAT and FES Toolkit to guide the design of an initiative to help ensure that family leaders and staff have the supports they need to understand and succeed in their partnership roles (see example in Appendix A #3).

a) Review the family engagement checklist in the FES Toolkit.

b) Select items that will help support and strengthen meaningful family engagement in the policy, program, or other systems-level initiative that the organization is undertaking.

c) Explore the other sections of the FES Toolkit for additional resources and strategies to help address the selected items from step (b) above, or contact Family Voices for technical assistance.

Scoring the FESAT

1) Download the FESAT Score Sheet from the Family Voices website and enter the team’s consensus score for each item in the Team Points Column.

   **Note: The assessment team is the families and staff who worked together on the initiative.**
   - Never = 0; Rarely = 1; Sometimes = 2; Usually = 3; Always = 4
   - Do not score items where the response was Not Sure/Not Applicable

2) When entering the scores into the spreadsheet:

   - A domain score will be calculated based on the maximum (max points) total for the items the team scored in each domain.

<table>
<thead>
<tr>
<th>Domain 1: Commitment</th>
<th>Team Points</th>
<th>Max Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 The organization uses written policy that requires family engagement in systems-level initiatives.</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2 The organization has one or more champions of family engagement.</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>3 The organization acknowledges the contributions family leaders make to systems-level initiatives.</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>4 The organization’s budget includes funding for the family leaders’ time and/or other costs they incur (for example, travel, childcare).</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>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).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Leave blank if the team responded Not Sure/ NA
Using the FESAT Results

The FESAT is a tool organizations can use to assess how well they are engaging families in specific systems-level initiatives. As a team:

- Staff and families should discuss their responses to the items.
- Where is there agreement and disagreement? Discuss the domains in which family engagement was strong and domains in which family engagement could be improved.
- For items in which Not Sure/NA was selected, discuss whether the item did not apply to the initiative or if the information needed to respond was unavailable. Is there additional information that the organization could provide so the team could respond? This will factor into how scores are interpreted and next steps for improving family engagement.
- Prioritize the area or areas to address, and explore the Family Engagement in Systems (FES) Toolkit to learn about strategies and resources that can help improve family engagement in one or more domains.
- If the initiative is ongoing, have participants score the FESAT again in 6 months (or other chosen time period). The initial scores for the individual domains and overall family engagement serve as a baseline for internal assessment. Compare subsequent scores to the initial findings to document progress in family engagement.

Tip: Consult the FES Toolkit for strategies and resources to help improve family engagement in one or more domains. Contact Family Voices for technical assistance around improving family engagement in systems-level initiatives.
FESAT Feedback

Please take a few minutes to complete a FESAT and FES Toolkit Survey. We will use the feedback you provide to make further improvements to these tools. We also would appreciate information about the systems-level initiative on which you collaborated and strategies and resources you found valuable, or any other feedback you can share with us.

If you would like to speak with us directly about your use of the FESAT, you are always welcome to contact Family Voices for technical assistance and general support.

Thank you.
Appendix A: Example uses of the FESAT

1. **Assess How Well an Organization Engages Family Leaders in a Systems-level Initiative**

   A state department of transportation created an advisory committee of family leaders with disabilities to monitor complaints and develop solutions to ensure that transportation was accessible and easy to use for everyone. The staff completed the FESAT as a group. The family leaders completed the FESAT individually and decided on a consensus response to each item. At the next advisory meeting, the staff and the family leaders discussed similarities and differences, arrived at a consensus score for each item, and completed the score sheet. The group identified the *Representation Domain* as an area of strength. Everyone agreed that the committee participants were truly representative of the individuals with disabilities who rely on transportation services. They identified the *Commitment Domain* as an area for improvement. The Transportation Authority provides bus passes so the family leaders can travel to and from the meetings. However, family leaders who needed childcare were not reimbursed for those costs, which prevented the active participation of some members who could not afford childcare. The staff and family leaders explored the FES Toolkit. As a result, the Transportation Authority created a budget line item to reimburse members for the childcare costs.

2. **Improve Family Engagement in an Ongoing Initiative over Time**

   Staff at a children’s hospital used the FESAT to assess family engagement with its family advisory council after the council had been meeting for a year. Based on the results of their one-year assessment, the families and hospital staff identified the *Representation* and *Impact Domains* as areas for improvement. Families on the council were not representative of the population the hospital served. Families also stated that staff asked families to react to policies and programs rather than engage them in developing them. In addition, all the families responded “Not Sure” to many of the items in the *Commitment Domain*. The staff and the families explored the FES Toolkit for resources and strategies to help them improve in these two domains. Staff also followed up with information about the items in the *Commitment Domain*. Six months after the first assessment, the families and staff completed the FESAT again. They improved in the *Representation* and *Impact Domains*. Families also had the information they needed to respond to all the items in the *Commitment Domain*.

3. **Guide the Design of Meaningful Family Engagement in a Systems-level Initiative**

   A national organization was planning an initiative to improve the social and emotional development of young children. The staff wanted to make sure they engaged families in a meaningful way. They used the family engagement checklist in the FES Toolkit to:
   - Ensure that they had organizational leadership to guide the design of their project (*Commitment Domain*).
   - Include stipends for families in the project budget (*Commitment Domain*).
   - Contract with a national family-led organization to recruit families to serve as an advisory committee (*Representation Domain*) and to provide the individual mentoring and other supports the families might need (*Transparency Domain*).
   - Practice family engagement in all phases of planning, implementing, and evaluating their project (*Impact Domain*).
Appendix B: Glossary of Terms

Collaboration – the relationship between groups of individuals who are working together to improve policies and programs for children, youth, and families.

Family engagement – collaborations between organizations and family leaders to develop and implement policies and programs that improve services for children, youth, and families.

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.

Family-led organization – an organization staffed and run by family leaders who help families connect with needed services and supports. Staff also help providers and other stakeholders understand the barriers families face in accessing services, and promote collaboration to improve access.

Organization – a health or other entity that serves children, youth, and families. Examples include hospitals, Title V and Medicaid programs, insurers, state agencies, and others.

Organization staff – representatives from an organization who participate in systems-level programmatic initiatives.

Systems-level initiative – an organizational initiative in which policies and programs are created or changed. Examples include needs assessments, strategic planning, quality improvement efforts, workgroups, or other initiatives that result in new or changed policies and programs that affect services for children, youth, and families.

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