



The Family Voices Family Engagement in Systems Assessment Tools: Case Studies to Highlight Three Uses of the Tools

July 2022



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PART I: EXECUTIVE SUMMARY

As their children's primary caregivers, families are deeply affected by systems-level issues such as care fragmentation or delayed or forgone care due to complex prior approval processes. Families' lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially children and youth with special health care needs (CYSHCN).

As part of Family Voices efforts to improve family engagement in systems-level initiatives, staff created the [Family Engagement in Systems Assessment Tool](#) (FESAT). The FESAT is a suite of tools and resources that child- and family-serving organizations can use to plan, assess, and improve family engagement in policy, practice, Quality Improvement (QI) projects, and other systems-level activities.

At the time of this publication, the FESAT, which was publicly released in November 2019, has been downloaded almost 700 times by individuals and organizations in 48 states, the District of Columbia, and three territories.

This publication includes background information about the FESAT, and profiles three organizations that used the FESAT to ensure meaningful family engagement in systems change. The resulting case studies highlight three uses of the FESAT. Massachusetts Families Organizing for Change (MFOFC), a statewide, grassroots coalition of individuals with disabilities and/or chronic illnesses and their families used the FESAT to plan a family engagement initiative to address new supports that families needed at the start of the COVID-19 pandemic. The Alabama Children's Rehabilitation Service used the FESAT to assess current family engagement as part of a Continuous Quality Improvement (CQI) effort to improve services for their target populations and develop action plans for improving future family engagement efforts. As part of the Children with Medical Complexity Collaborative Improvement and Innovation Network (CoIIN) initiative, the Minnesota (MN) Title V CYSHCN program, Family Voices of MN, and the Complex Care Clinic at Gillette Children's Specialty Healthcare used the FESAT to assess and improve family engagement over time.

Family Voices interviewed organizational staff and their family partners to learn how they used the FESAT and what they learned about family engagement in systems. We wrote up their experiences and shared with the staff and families to ensure that each case study correctly reflects the work their teams accomplished together. We thank them for sharing their time and detailed information about how they used the tool.

PART II: BACKGROUND

INTRODUCTION TO THE FAMILY ENGAGEMENT IN SYSTEMS TOOLS

In 1987, Surgeon General Koop's [Surgeon General's Report on Children with Special Health Care Needs](#) proposed action steps towards achieving "comprehensive, coordinated, family-centered, community-based services for children with special needs and their families." These action steps included the need for family/professional collaboration in program development, implementation, evaluation, and in policy formulation. Today, it continues to be vitally important that individuals and families who receive services from a system of care have a voice in creating new, or improving existing, policies, practices, and supports that govern the services their children and families receive.

Increasingly, child- and family-serving organizations are expected, or even required, to engage families in systems-level initiatives. However, these same organizations often struggle with how to engage families and provide the information and supports needed by families, family-led and community-based organizations, and their own staff to ensure that they can partner, participate in, and contribute to systems-level initiatives in meaningful ways.

To support these organizations and their staff in policy-making groups, QI activities, research, and as collaborators in other systems-level initiatives, Family Voices created the Family Engagement in Systems Assessment Tools.

The tools include:

- The **Family Engagement in Systems Assessment Tool (FESAT)**, a 20-item self-assessment tool that organizational staff and families use in partnership to assess family engagement in policies, programs, QI initiatives, and other systems-level initiatives.
- The **FESAT User's Guide** provides instructions for use of the FESAT. Appendices include example uses of the tools.
- The **FESAT Score Sheet**, an Excel worksheet that calculates scores for the four family engagement domains and automatically populates a bar graph to help organizations understand how well they are providing the supports and information that families and staff both need to partner, participate in, and contribute to systems-level initiatives.
- The **Family Engagement in Systems (FES) Toolkit**, a collection of strategies and resources to help improve family engagement in systems-level initiatives.
 - The **Family Engagement Checklist**, included in the FES Toolkit, is a resource that helps organizations plan the design of systems-level initiatives and establish the necessary supports to ensure meaningful family and staff engagement.

The items in the FESAT were selected from a large-item pool that was generated from a comprehensive literature review and 19 key informant interviews with family leaders and staff

from Title V, Medicaid, private payers, pediatricians, measurement experts, and other academics. A qualitative analysis of these data resulted in the identification of the four domains of family engagement.ⁱ Input from an expert workgroup of family leaders and professionals, followed by cognitive testing, helped narrow the pool to 20 items. Pilot testing of the FESAT demonstrated that the 20 items are effective in helping child- and family-serving organizations plan, assess, and improve family engagement in systems-level initiatives.

The FESAT, FESAT Score Sheet, and the FES Toolkit are organized into four domains of family engagement (Figure 1).

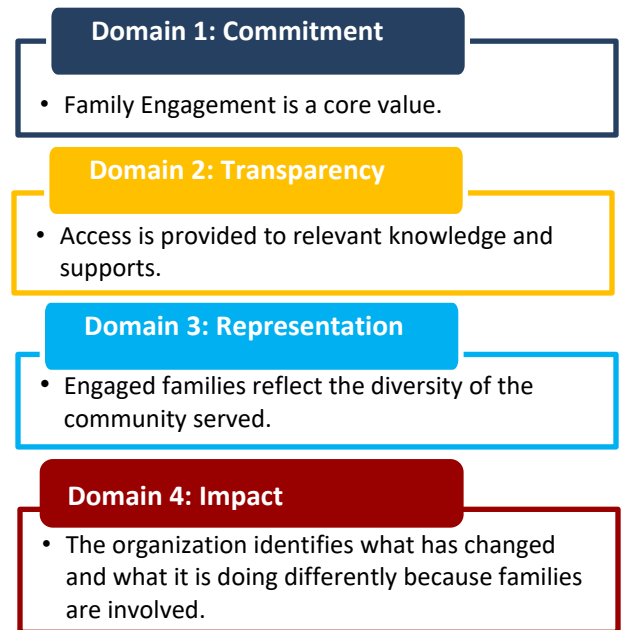


Figure 1: Four domains of family engagement.

Domain 1: Commitment. The organization demonstrates its overall commitment to family engagement. Commitment means that the organization routinely engages family members in all systems-level initiatives that affect the policies and programs that govern services for children, youth, young adults, and families.

Domain 2: Transparency. The organization ensures that families, family-led and community-based organizations, and staff can easily access and understand the information they need to participate fully. Transparency occurs when the organization clearly documents and communicates how it identifies issues faced by the children, youth, young adults, and families it serves and provides the information and supports families and organization staff need to partner and participate to their maximum potential in a specific systems-level initiative.

Domain 3: Representation. The diversity of individuals and family members who participate in a specific systems-level initiative. Representation occurs when participants reflect the diversity of the community served by a specific initiative or the organization as a whole.

Domain 4: Impact. The organization collaborates and shares decision making with individuals and family members for a specific systems-level initiative. Impact describes the areas in which the organization used individual's and families' ideas and input to create new, or improve existing policies, programs, and services.

Figure 2 below outlines three ways that health care entities, Title V, Medicaid, and other state agency programs, as well as research teams, schools, and other organizations that serve children, youth, and families, might use the Family Engagement Checklist, FESAT, and FES Toolkit in collaboration with families, and family-led and community-based organizational partners to:

1. **Plan** the design of systems-level initiatives by reviewing the supports they have in place and identifying additional supports to enhance engagement of families and staff.
2. **Assess** how well an organization engages families in systems-level initiatives and identify strengths and areas for improvement.
3. **Improve** family engagement in systems-level initiatives over time.

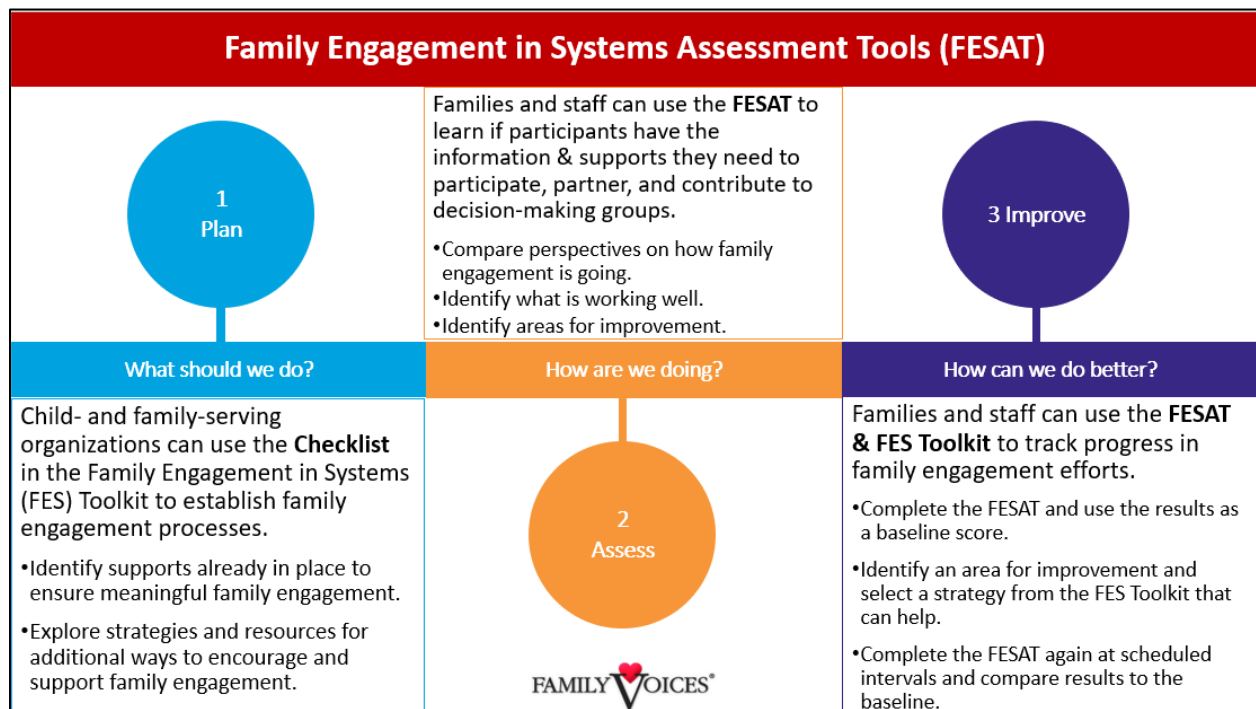


Figure 2: Uses of the FESAT to plan, assess, and improve family engagement in systems over time.

The three uses of the FESAT, as described above, are not mutually exclusive. As you will read below, there is overlap between how Alabama Children’s Rehabilitation Services (Case Study 2) and Team Minnesota (Case Study 3) used the tools. Alabama began by assessing current family engagement efforts with plans to use the FESAT again at a future time. As a new initiative, Minnesota used the FESAT one year into their work to first assess family engagement efforts and used the FESAT again a year later to see if they improved family engagement in systems change over time.

PART III: CASE STUDIES

CASE STUDY 1: PLANNING FOR MEANINGFUL FAMILY ENGAGEMENT

Introduction

The FES Toolkit includes a Family Engagement in Systems Checklist, that lists the same 20 items that make up the FESAT. Child- and family-serving organizations that are first planning to

engage families in a systems-level initiative can use the checklist to assess the supports they already provide, and identify additional supports they might need, to support meaningful family engagement. Additionally, the response options (yes, no, somewhat, don't know) can highlight staff awareness of supports. For example, does the organization have a family engagement policy? If staff members "don't know," this is an opportunity to raise awareness of an existing policy. Moreover, if the organization does not have a family engagement policy, the FES Toolkit includes strategies and resources to guide the development of a policy. A family engagement policy is important because it sets an expectation that families should be included in decision-making groups. In addition, the FES Toolkit includes resources that organizations can reference for guidance in creating a line item in the budget for stipends to acknowledge families' time, any expenses they incur, and to ensure meaningful and equitable family engagement.

Massachusetts Families Organizing for Change (MFOFC) is a statewide, grassroots coalition of individuals with disabilities and/or chronic illnesses and their families. MFOFC focuses on advocacy and leadership training to families that works towards building inclusive communities, and creating policies that provide better-designed, flexible supports that address individual and family needs.

On March 13, 2020, Massachusetts schools closed as one of many measures to protect residents from potential exposure to, and limit the spread of, COVID-19. Families watched as school programs, along with publicly funded, eligibility-based services provided by schools and the Department of Developmental Services (DDS), shut down. Families were overwhelmed as they realized how many additional roles they would assume in the absence of school or day programming. Some families struggled to decide whether they could bring family members home from residential settings and provide them with needed care. Those who feared they could not support and care for their family members outside of a residential placement agonized over how long it would be until they could visit their loved ones, and whether their loved ones would be safe.

In the uncertain landscape of COVID-19, the Northeast Region of MFOFC realized that the coronavirus pandemic was an opportunity to redesign family support services to meet the rapidly changing needs of all families during the coronavirus pandemic and beyond. They organized Community Calls with their networks, other family-led organizations, disability advocates, DDS staff, representatives from the state protection and advocacy organization, and support program staff from pediatric hospitals. The calls were an opportunity for family leaders to share families' concerns and needs with their organizational partners and work together to develop strategies for meaningful support during the pandemic.

For example, upon learning that a priority for many families was obtaining personal protection equipment, the DDS Family Support programs redirected financial resources, earmarked to

provide in-person training, to family leaders for the purchase of thousands of KN95 masks for families throughout the state whose children had complex medical needs.

While this rapid response effort helped to ensure safety for this population, the national call for equity that followed the murder of George Floyd in May 2020 led to a necessary examination of family representation on the Community Calls. The families were predominantly white, upper-middle-class mothers from heteronormative households, who worked in paid family leader positions. The call organizers experienced a collective “Oh my gosh!” moment at the sudden realization that they were not reaching or engaging families who were representative of the families DDS was serving. They realized the need to engage all families whose children or other family members had special health care needs/disabilities. A subset of stakeholders formed an advisory group to create a plan for reaching and engaging families who are representative of the race, ethnicity, culture, and language of families in Northeastern MA to learn more about their needs during the pandemic.

Methodology

The Northeast Coordinator for MFOFC learned about the FESAT during a presentation at the 2019 Family Voices Leadership Conference. She stated that “The language in the FESAT sets a standard for family engagement and for what meaningful family engagement in a systems-level change looks like.”

At the suggestion of the coordinator, the advisory members agreed to use the checklist to plan for and ensure more meaningful representation in their group. The coordinator worked with Family Voices staff to customize the checklist by adding, “The MFOFC-NE Advisory Group ensures all members of the advisory group and participants in the Community Calls...” to the beginning of each checklist item so the members would have clear context for responding to each item. Table 1 below provides an example of how the MFOFC checklist was personalized.

The language in the FESAT sets a standard for family engagement and for what meaningful family engagement in a systems-level change looks like.

~Northeast DDS Family Support Director

Table 1: Original Checklist Item	Personalized Checklist Item
<i>Family leaders are representative of the races and ethnicities of the populations served by the initiative.</i>	<i>The MFOFC-NE Advisory Group ensures that all members of the Advisory group and participants in the Community Calls are representative of the races and ethnicities of the populations served by the initiative.</i>

As the group was meeting virtually, the coordinator uploaded the customized Family Engagement in Systems Checklist to a Google Doc so each advisory member could complete it. She then aggregated the results.

Results

After the Advisory Group members completed the checklist and reviewed the aggregated responses, they were taken aback to learn that only 50% of the families they were engaging felt supported in their role. The results were an important reminder that agency staff and family leaders working in paid leadership positions may benefit from professional development in the principles of family engagement.

Discussion

The Family Engagement Checklist served as a jumping off point for the advisory group members to renew their commitment to family engagement and shift to a more equity-focused, inclusive, and as the coordinator shared, “not white-centric disability movement.” Based on their findings, the advisory group realized they needed to be more data-driven to ensure diverse representation of families. This is Strategy 3.1 in the Representation Domain of the FES Toolkit: *Use data to understand the demographics of the population the organization serves.* As a starting point, the advisory group surveyed its regional members to capture the demographics, including city or town of residence for each member. They used census data to better understand the races and ethnicities in the Northeast region of Massachusetts, as well as the entire Commonwealth. The group also consulted DDS for any internal data they had about the demographics of the families they were serving.

To address weaknesses in the Commitment Domain, the advisory group explored options for providing stipends to family participants who were not receiving compensation for sharing their time and expertise as part of the advisory group (Strategy 1.5: *Develop a mechanism for reimbursing families for their time and/or other costs they incur*). They agreed that if the agency staff and parent professionals are paid for their time, the other family members should also be paid for sharing their time and expertise. The group recognized that the provision of stipends or other forms of honoraria is also an equity issue, as many families cannot afford the costs they incur to participate, such as lost time from work, time away from their children, or travel. Most importantly, providing compensation demonstrates a commitment to inclusivity in order to engage families meaningfully in systems-change work.

The group addressed weaknesses in the Transparency Domain and improved how they shared information about the Community Calls. They implemented Strategy 2.8, *Ensure meeting materials are written in plain language and are culturally and linguistically appropriate for all participants*, and stopped using acronyms.

Conclusion

The Northeast Coordinator for MFOFC first introduced the Family Engagement in Systems Checklist after the Community Calls had begun. In retrospect, the group realized that if they had used the Checklist in the beginning, as part of the planning for the Community Calls, it would have ensured that the family participants were representative of the communities and populations most affected by the COVID-19 pandemic.

The advisory group felt overwhelmed by the number of changes they needed to make to ensure equitable representation of families within their group and on the Community Calls as a whole. However, as stated by the Northeast DDS Family Support Director, a member of the advisory group, “The items in the tool are really well designed and get at the heart of the family engagement issue.” In addition, the group agreed that the organization of the Family Engagement Checklist, FESAT, and FES Toolkit into the four domains of Family Engagement (Figure 1) made it easy to make needed changes one domain at a time, rather than tackling all changes at once.

The items in the tool are really well designed and get at the heart of the family engagement issue. ~Northeast DDS Family Support Director

The advisory group noted that the wording of each item provided the participants with the language they needed to articulate the core components of family engagement that need to be incorporated before they make policy decisions.

For example, the commitment domain includes an item that asks if the organization has one or more champions of family engagement. This helped the group realize the importance of having a staff person to champion family engagement to educate others about why it is essential to integrate the lived experiences of the families they serve into systems-change work. Moreover, engaging families helps to ensure that the work aligns with identified family priorities and that policy decisions, often made at the convenience of the organization, are a family-driven effort to improve a system of care.

Moving forward, the Massachusetts DDS plans to incorporate the language in the Family Engagement Checklist (a resource in the FES Toolkit) into their contract language and Requests for Responses (RFRs), especially around the roles proposed for Family Advisory Councils.

As the Community Calls progress, the advisory group could assess their family engagement efforts by having the family and staff representatives complete the FESAT to see how they are doing. They can use the results to identify additional improvements they might make to

continue to strengthen family engagement and create an action plan to continue to improve family engagement over time.

CASE STUDY 2: ASSESSING CURRENT FAMILY ENGAGEMENT IN SYSTEMS

Introduction

While the FESAT was created to assess a specific systems-level initiative, organizations can use the tool to assess overall efforts to engage families in policymaking and as partners on other decision-making groups that govern the services their children and families receive. This use of the FESAT sets a baseline from which to improve, followed by creating action plans for improvement.

The Alabama Children’s Rehabilitation Service (CRS) is a division of the Alabama Department of Rehabilitation Services (ADRS), which administers the Children with Special Health Care Needs (CSHCN) portion of the Maternal and Child Health Services Title V Block Grant program. CRS is the statewide system of services for children and youth with special health care needs (CYSHCN), their families, and adults with hemophilia.

CRS leadership recognized that engaging the individuals and families who use their services is a critical component of their Continuous Quality Improvement (CQI) efforts to improve services for their target populations. CRS leadership decided to use the FESAT to guide efforts to improve meaningful family engagement and strengthen family partnerships in the eight District Offices throughout the state. Starting in Fiscal Year (FY) 2021, and continuing through FY 2025, teams of state office staff, district staff and family consultants will score the FESAT each year. Each district will also develop a CQI initiative tailored to the needs of the individuals and families they are serving. The initiatives must include a family representative in creating an action plan with strategies for accomplishing the goals of the initiative. The individual domain and overall FESAT scores from FY 2021 will serve as the baseline scores for assessing improved family engagement in subsequent years.

Methodology

In preparation for use of the FESAT, CRS leadership invited Family Voices FESAT Coaches to present a webinar about the use of the FESAT to CRS state office staff, district supervisors, and parent consultants. The coaches explained why and how the tools were created, the four domains of family engagement, and the importance of the items in each domain. The presentation included an overview of the FESAT, FESAT scoring, and demonstrated the alignment between the items in the FESAT and the strategies and resources in the FES Toolkit.

CRS state office staff, district supervisors, and the parent consultants from each district all participated in the baseline scoring of the FESAT. Each participant scored the FESAT based on his or her own experience within CRS as an agency.

After the individual scoring, CRS leadership invited their program evaluators from the Applied Evaluation and Assessment Collaborative within the University of Alabama Birmingham (UAB) School of Public Health to facilitate the post-scoring discussion and arrive at a consensus score for each item. This consensus score will be the baseline score for comparison in FY 2022. Due to the continued public health emergency, the group met by Zoom. The group met twice for 90 minutes each so they could discuss their responses to each of the twenty items in the tool. During each 90-minute meeting, participants shared their initial scores (Initial Vote in Figure 3 below) for each item in a Zoom poll. The UAB evaluators noted the variation in scores and facilitated a short discussion about the item. After the discussion of each item, UAB staff re-launched the poll so each participant could enter a final vote that reflected his or her experience after hearing everyone's perspectives. A consensus score for each item was selected based on the majority score for that item in the final vote (Figure 3).

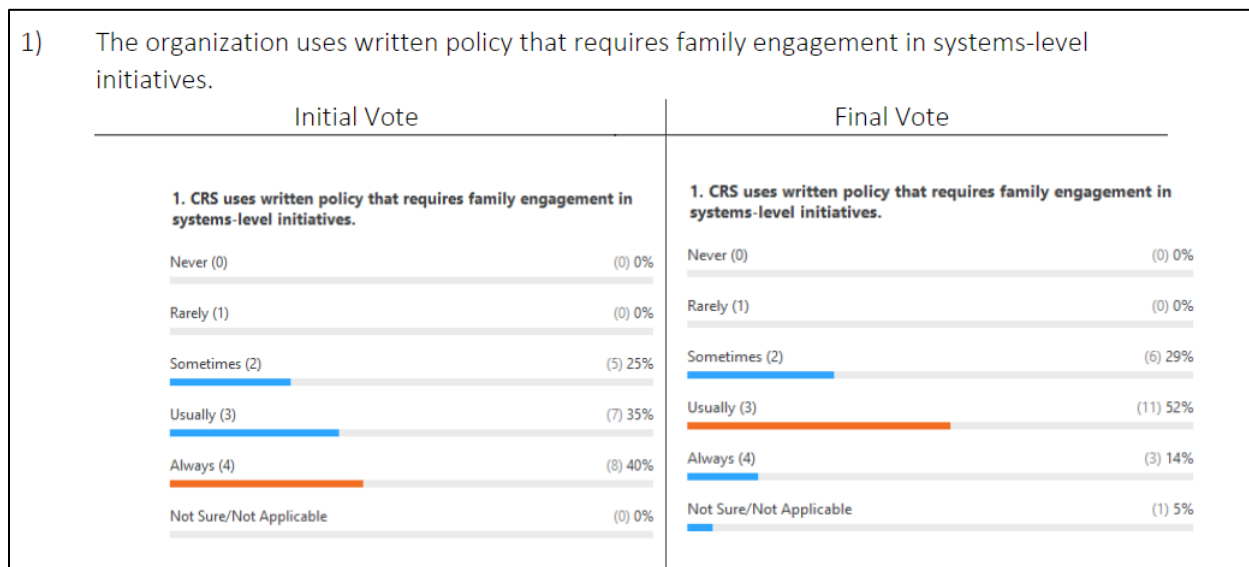


Figure 3: Example of initial and final vote for item 1 in the FESAT.

The initial scoring across all eight district offices helped the CRS state office staff assess current family engagement efforts. Moving forward, each district created their own action plan for improving family engagement in future work. To help each district team create action plans, CRS staff developed a CRS Family Engagement Quality Improvement Initiative Action Plan template and provided District Office staff with instructions for use (Figure 4).

Family Engagement Quality Improvement Initiative Action Plan					
District:					
Team members involved in developing the plan (include name and title):					
FESAT Domain: Commitment			Goal: Ensure all district staff are aware of the importance of family engagement / partnerships in providing services to CSHCN.		
Objective: Develop a written family engagement / partnership policy outline the vision of the district and share with all district staff.					
Strategies	Person Responsible	Start Date	End Date	Resources and Methods	Metric
	Indicate the individual(s) accountable for this task.	Determine deadlines and due dates.	Determine deadlines and due dates.	Record details about the methods to be used for the task and resources required to complete the task.	Record the metric(s) that will monitor this strategy from start to finish.
Establish a Family Engagement / Partnership team					
Use the FES Toolkit to find examples of existing family engagement policies					
Hold quarterly meetings to draft a district family engagement policy					

Figure 4: Example Alabama CRS Family Engagement Quality Improvement Initiative Action Plan

The template, when completed by each district team, will detail the district's goal, the team members, the family engagement domain they will address, the strategies they will use to accomplish their goals, and the person responsible for ensuring that each strategy is accomplished. For example, two districts are using the following strategies from the Commitment Domain.

- Strategy 1.2 *Ensure the organization has one or more champions of family engagement.*
- Strategy 1.3 *Provide mentoring and support to ensure families and staff understand their roles and can participate and contribute to the full extent possible.*

One district is using the strategy below from the Impact Domain.

- Strategy 4.1 *Listen to family leaders' ideas and work together to implement the initiative.*

The action plan template also includes space for listing resources and tools district staff might need to do the work, and a metric for knowing whether a strategy was implemented or a goal was accomplished.

Teams submitted their family engagement QI plans to the CRS Maternal and Child Health Coordinator for review. As of January 2022, each district office submitted a quarterly progress report. CRS management team meetings include time for district staff to share their work, learn from each other, and request any needed technical assistance or consultation.

Results

Twenty-one people from all eight District Offices participated in the consensus scoring process. As noted above, UAB evaluators posted a virtual poll for each item in the FESAT using the FESAT responses, an interval Likert scale from 0 to 4 that corresponds to Never, Rarely, Sometimes, Usually, and Always, respectively. There is an additional Not Sure/Not Applicable response

option that is not scored as part of the individual domain and overall family engagement scores. Each participant entered an initial score. The UAB evaluators facilitated a discussion after the initial vote. This was an opportunity for staff and families to understand each other's perspectives about why and how they scored each item and reconsider their own initial score. After the discussion, the evaluators posted a second, final vote poll and asked the participants to score the item a final time. Universally, there was a change in the final score for each item once participants understood the thought processes and reasons why staff and family leaders selected a score for each item. The majority final score for each item was entered into the FESAT Scoresheet.

CRS's overall Family Engagement Score was 76%. Individual domain scores are shown in Figure 5 below.

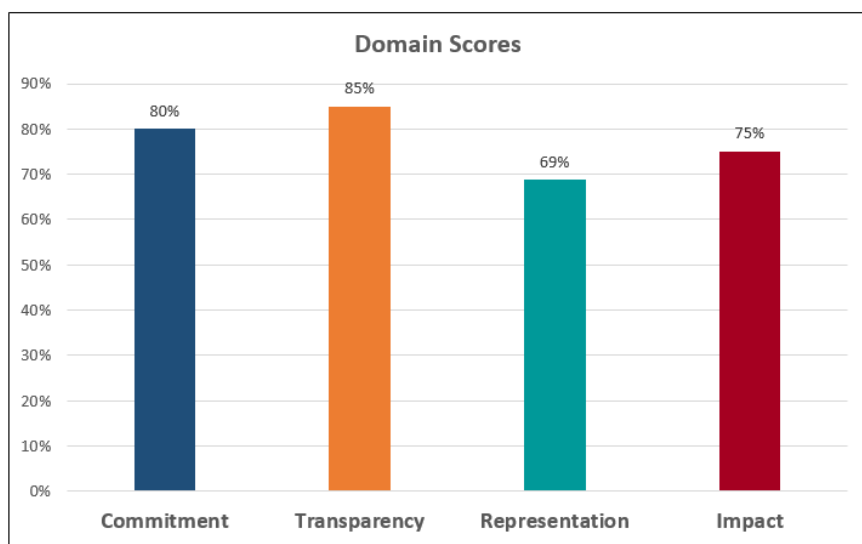


Figure 5: AL CRS baseline FESAT scores.

The results reported above are aggregated scores for all eight districts. Examination of the individual scores highlighted horizontal and vertical variations in family engagement at the state and district levels. There were also variations of parent consultant involvement and experiences between district office.

The initial scores included six Not Sure/Not Applicable responses. Four of these were in the Commitment Domain; two in the Transparency Domain, as noted in Table 2.

The change in Not Sure/Not Applicable responses is notable. After the discussion, staff and families had increased knowledge about the importance of having a champion of family engagement, a budget to support families' time, and other supports that help ensure meaningful staff and family engagement in systems-level initiatives.

One participant changed his or her vote about the organization's family engagement policy. While it is not possible to know if it was the same participant, clearly, at least one person needed more clarity and information about the use of a family engagement policy. The same can be said for the Transparency Domain where one participant needed more information about how District Office staff communicated about each member's partnership roles and responsibilities as part of the systems-level work they were doing.

Table 2: Pre/Post Consensus Discussion Changes in Not Sure/Not Applicable Responses		
Commitment	Initial Vote	Final Vote
Family Engagement Policy	0	1
Family Engagement Champion	1	0
Family Compensation	1	0
Adequate Staff time	1	0
Transparency	Initial Vote	Final Vote
Understanding partnership roles	1	1
Needed supports to participate in meetings	1	0

Each district proposed a FY 2022 Family Engagement Quality Improvement initiative based on the overall baseline FESAT consensus scores and identified needs of the individuals and families they serve. Each of the eight District Offices identified a priority for their district, noted in the list below.

- 1) Creating an active parent advisory council whose members will not only attend meetings but also meet with parents whose children receive direct services to create connections and provide parent-to-parent support.
- 2) Improving engagement of foster families.
- 3) Using PDSA cycles to identify needs of families who receive services in the Hemophilia Clinic.
- 4) Strengthening partnerships between CRS Care Coordinators and parent consultants to promote family engagement in service delivery.
- 5) Engaging families in the design of surveys to improve services.
- 6) Partnering with families to share resources and develop a Parent Network Exchange.
- 7) Engaging families to help improve the quality of services and workflow in the clinic.
- 8) Targeting youth and families to identify needed improvements.

Discussion

The consensus discussion, facilitated by the CRS program evaluators from the Applied Evaluation and Assessment Collaborative within the UAB School of Public Health, was an opportunity for participants to understand each other's points of view about current family engagement efforts. The discussion also raised awareness about the discrepancies in knowledge of policies and specific activities that exist between the state CRS office and the districts and created broader awareness about the need to share information about family engagement activities more broadly.

The use of an assessment tool to guide CQI initiatives was a new experience for the staff in the district offices. CRS leadership helped District Office Staff tie their work to the FESAT results and provided reminders about the necessity of including a family representative on their team. If they needed help to identify a family representative, the parent consultant in the CRS state office was available to assist in identifying a family and in implementing a method for reimbursement.

Initially, there was some resistance to the work, due to the time commitment, but overall, the district teams were excited about the use of the FESAT and recognized the value of assessing current family engagement efforts. It helped tremendously that the Commissioner and Assistant Commissioner within ADRS, themselves champions of family engagement, provided leadership and support for use of the FESAT to promote a transformation in the CRS system of care by embedding families' voices into the CQI process.

Conclusion

Eight CRS District Offices completed the FESAT to assess current family engagement in systems-level initiatives and set a baseline for improving family engagement over time. District Office staff and parent consultants will complete the FESAT again in FY 2022 and compare the new scores to the baseline established in FY 2021 to see if they have improved family engagement in one or more family engagement domains.

The CRS staff and parent consultant noted that the introductory webinar and FESAT domain infographics Family Voices provided for CRS and the district participants were tremendously helpful. It set the stage for why family engagement in systems is so important and highlighted the information and supports families need to participate meaningfully in decision-making groups.

The support from ADRS Leadership helped generate buy-in for the culture change CRS is working to create around family engagement in systems. Their leadership helped set an example and expectation for district staff.

CASE STUDY 3: IMPROVING FAMILY ENGAGEMENT OVER TIME

Introduction

Child- and family-serving organizations can use the FESAT and the strategies and resources in the FES Toolkit to improve and strengthen family engagement in systems-level initiatives over time. To begin, organization staff and family partners who are already participating in a specific systems-level initiative complete the FESAT to assess current family engagement efforts. The initial results serve as a baseline score and inform next steps the organization will take to improve family engagement over time. The participants then prioritize a domain for improving

family engagement and select one or more strategies from the FES Toolkit, or from other sources, that can drive improvement.

At a scheduled interval, family partners and staff complete the FESAT again and compare the new results to the baseline score. Groups may score just the one domain of family engagement where they implemented a new strategy and compare it to the baseline score for that domain. However, improvements in one domain often carry over to other domains and the organization may see improved family engagement in the other domains as well if they choose to score the entire FESAT again.

The Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau funded a Collaborative Improvement and Innovation Network (CoIIN) to test and spread promising care delivery strategies and payment models for Children with Medical Complexity (CMC). The primary goals of the four-year award were to improve quality of life for children with medically complex conditions and family well-being. The state teams aimed to achieve these goals using quality improvement (QI) methodology to identify gaps and implement evidence-based care coordination initiatives.

The Center for Innovation in Social Work & Health (CISWH) at Boston University was the lead organization for the CMC CoIIN. Staff recruited ten state teams. Each team included a clinical site, a family-led organization, and Title V staff. CISWH staff supported the teams with webinars, learning sessions, resources, and QI tools, which included the use of the FESAT to assess and improve family engagement over the four years of the project. CISWH also partnered with Family Voices staff who provided FESAT coaching to support each team in its use of the FESAT.

Team Minnesota (MN), comprising the MN Department of Health's Title V CYSHCN program, Family Voices of MN, and the Complex Care Clinic at Gillette Children's Specialty Healthcare, was one of the ten teams. Family Voices of MN is a family-led organization that provides information and support to MN families raising children with disabilities and extra needs. As part of their efforts to advance a system of comprehensive family-centered care coordination that supports families of CMC, Team MN worked to:

- 1) Promote shared plans of care as a tool to increase coordination of care across the child's providers and family,
- 2) Support families and providers to work as colleagues in the child's care, and
- 3) Promote the services and supports families need to care for CMC in the home successfully.

Family Voices of MN facilitated identification, training, and payment of parent advisors and this partnership would be integral to Team MN's success. They used the FESAT and FES Toolkit to understand and improve family engagement over time as part of their CMC CoIIN work.

Methodology

National Family Voices staff presented a webinar about the FESAT to all ten CMC CoIIN teams in November 2019. The webinar included an overview of the FESAT, FESAT Score Sheet, and FES Toolkit, definitions of terms, and examples of how to use the baseline results to improve family engagement over time.

Team MN completed the FESAT for the first time later that year. The FESAT Coaches helped the team set up the FESAT and describe the initiative they would score. The parent advisors and the Complex Care Clinic staff completed the FESAT as separate groups. A nursing research specialist at Gillette Children's Specialty Healthcare facilitated a group discussion about the team's results and the development of action steps for improvement. Using the same strategy, Team MN completed the FESAT again in October 2020.

Results

In 2019, the first time Team MN completed the FESAT, there were significant differences between the parent advisor and Complex Care Clinic staff scores (Table 3).

The parent advisors scored the Commitment domain low. They reported a general lack of knowledge within the clinical site's organization about their role and recognition that parent advisors served a professional role that facilitated Team MN's QI work

and family engagement efforts. The action plan included strategies to increase the visibility and importance of parent advisors' roles. One way to accomplish this is to *ensure the organization has one or more champions of family engagement*, which is Strategy 1.2 in the FES Toolkit. The nursing research specialist, who also facilitated the use of the FESAT by Team MN, took it upon herself to champion the role of families within the Gillette systems and worked to educate the organization on the value of parent advisors and family engagement. In addition, Strategy 1.6 in the FES Toolkit is to *acknowledge how family leaders contributed to systems-level initiatives*. Including information about the work of the parent advisors on Team MN in hospital and external presentations and publications is one way that Team MN can share how families used their lived experience to improve complex care clinic services at Gillette.

There was agreement between the family partners and staff scores for the Commitment Domain item that addressed whether the organization provides adequate time for staff to implement changes that result from family engagement in systems-level initiatives. The entire team understood that staff have many responsibilities and gained an appreciation for the

Table 3	2019 Domain Scores	
Domain	Parent Advisors	Staff
Commitment	34%	81%
Transparency	50%	69%
Representation	19%	44%
Impact	29%	96%
Overall Family Engagement Score	34%	75%

immense workload placed on the complex care clinic's care managers. As a result, the team developed strategies to communicate more clearly the roles and responsibilities of the staff, prioritize initiatives that added value for family well-being and help Team MN advocate the need for additional care manager support.

Family partners and clinic staff both scored the Transparency Domain low. All felt the team needed refocusing on the guiding purpose of the QI team. Family advisors did not have a clear understanding of clinic staff workflow, especially for work that happens 'outside' the clinic room and recognized that they did not have the same background and organizational knowledge as staff. The action plan for this domain included training so that all participants understood their partnership roles and had a shared understanding of the work they would be doing together. This is addressed in Strategy 2.4 in the FES Toolkit: *Make sure all participants (family leaders and organization staff) have the information and support they need to participate to their maximum potential.*

Staff and family partners scored the Representation Domain low in recognition that all the members spoke English and were from the Twin Cities metropolitan area. The team discussed the need to engage families from rural parts of the state and non-English speaking families. In Gillette's complex care clinic, Somali speaking families are the largest immigrant group.

The action plan for this domain included collaborating with Family Voices of MN and community family leaders to help identify and mentor family partners who represent Somali families and rural families who receive care at the Complex Care Clinic. The FES Toolkit includes an overarching strategy about the importance of *collaborations with family-led or community-based organizations to identify representative families and ensure they have needed mentorship and support and that family leaders and organization staff both have access to skill-building opportunities.*

Similar to the other domains, staff and parent advisor scores for the Impact Domain were very different. Staff scored this domain very high (96%) because they valued the parent advisor role. Parent advisors scored this domain very low (29%) because of their initial experience with the QI team. At the onset, parent advisors felt clinic staff did not understand how to utilize their expertise and lived experience, and this improved over time. To address these issues, the action plan included strategies for helping staff 'hear' parent advisor expertise. For example, Team MN used parts of the

Table 4	2020 Domain Scores	
Domain	Parent Advisors	Staff
Commitment	60%	72%
Transparency	86%	72%
Representation	50%	48%
Impact	87%	82%
Overall Family Engagement Score	73%	70%

*Serving on Groups*¹ training to help the team understand how to deal with and resolve conflicts around choosing goals for the initiative (Strategy 4.2 in the FES Toolkit).

The team's initial domain scores and overall family engagement scores served as the baseline for assessing the changes they implemented to improve family engagement as their work progressed.

In October 2020, two parent advisors and three clinic team members from Team MN scored the FESAT again. There was increased alignment between family and organizational staff scores for each domain and in overall family engagement score compared to the initial scoring (Table 4). The overall staff score decreased to 70% from the initial baseline staff score of 75%. Family Voices has observed the tendency for staff to score themselves more harshly than family members do, once they become aware of the importance of having a family engagement policy and the information and supports families need to understand their role and contribute to systems change in meaningful ways.

Discussion

The strategies Team MN employed to increase visibility of the importance of including parent advisors as equal team members on the CMC Collin QI team were successful. There was also a COVID 'silver-lining.' Team MN originally met in person, with the option of attending remotely via speakerphone. The unpredictable caregiving demands of the parent advisors meant they often attended remotely. In response to COVID, Team MN initiated virtual-only team meetings in April 2020. Parent advisors were no longer the only participants 'not in the room.' Everyone joined virtually, which increased the feeling of equitable teamwork. As a result, Team MN decided to continue with virtual meetings, even after pandemic restrictions are lifted. They also created a Complex Care Clinic values statement about the importance of family engagement to guide the work moving forward (Strategy 3.4 in the FES Toolkit).

Team MN has prioritized the sustainability and expansion of the parent advisor role. As a result, the parent advisors are developing recruitment, orientation, and training materials for onboarding family advisors to the Team MN QI Team. Family Voices of MN conducts a nationally recognized leadership training program. Newly identified parent advisors will attend this training to develop family leadership and advocacy experience as needed.

Conclusion

The improvements in family engagement made it possible for parent advisors to make meaningful contributions to the QI work Team MN set out to accomplish. Parent advisors' ideas were incorporated into the initiatives and parent advisors helped design the PDSA (Plan, Do, Study, Act) cycles to implement and evaluate the initiatives. These activities contributed to the

¹A guidebook for individuals who want to make a difference in their community by serving on decision-making groups. Learn more at <https://www.servingongroups.org/>.

overall work of Team MN to advance a system of comprehensive family-centered care coordination that supports families of CMC.

PART IV: REFLECTIONS

To date, the organizations that have most successfully used the FESAT to improve family engagement are those that had a champion and/or a facilitator or other individual to coach and guide the participants' use of the tools. Having one or more champions of family engagement demonstrates a commitment to family engagement and models the attitudes and behaviors that all staff should display when engaging families at any level.

In Case Study 1, the MFOFC coordinator and DSS representative recognized the value of the family engagement checklist to improve in the Representation Domain. For Case Study 2, the AL CRS leadership supported the use of the FESAT, and in Case Study 3, the leadership of the nursing research specialist at Gillette and her guidance was vital to the successful use of the tools and to overall improvements in family engagement over time.

In working with the three organizations profiled in the case studies, and with other groups that have requested technical assistance in the use of the FESAT, we identified the following challenges that groups experienced, and how we worked with the individual or group to overcome them.

- When teams wanted to develop a deeper understanding of the importance of the items in the tools, the FESAT Coaches created infographics for each family engagement domain to provide explanations about the importance of many items in the tool (familyvoices.org/fesat/infographics).
- When an Early Childhood Comprehensive Systems (ECCS) CoIIN team wanted to use the FESAT to assess family engagement in a family support group, the coach explained the difference between individual and systems-level engagement and provided examples.
- Often groups struggled to articulate the systems-level initiative they wanted to assess. Coaches created a fill-in-the-blank template (below) to help.

[Organization] engages (or engaged) family leaders in [short description of the initiative] to [intended outcome].

- Once teams wrote a description of the initiative to assess, they still struggled to respond to each item in the context of the work they were doing. The coaches helped some teams add a stem to each item for added context, as depicted in Table 1.

The FESAT Sparked
*meaningful
conversation amongst
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and provided insights
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hadn't considered
before...* ~ Anonymous user

Groups that are using the FESAT report that the consensus discussion, which occurs after organization staff and family partners score the tool, is their favorite part. One user said the FESAT, “Sparked meaningful conversation amongst the collaboration group and provided insights about processes that we hadn’t considered before, such as the importance of doing short follow-up evaluations after assisting families.”

To guide productive consensus discussions some users invited an outside facilitator (as done by AL CRS). A member of Team MN facilitated their consensus discussion. To ensure

families would not feel judged or that the reasonings they used to score each item were “wrong,” a pediatric practice, looking to build relationships with the families on their advisory council, asked the family members to share their perspectives and scores first. Prior to the pandemic when users were meeting in person, one group hosted an evening meeting and served a meal. This created a relaxed, social atmosphere where all participants felt comfortable sharing. Another group, that met virtually, asked their FESAT Coach facilitate the discussion. Regardless of how the teams reach consensus, it is important that everyone listens to and respects each other’s points of view and experiences as members of the team so they can decide on a score for each item.

Users have shared innovations in the use of the tools. Alabama CRS leadership developed a Family Engagement Quality Improvement Initiative Action Plan (Figure 3) to standardize the information that each of the eight districts provided as part of their QI efforts. The Colorado CMC CoIIN Team added sheets to the FESAT Excel Score Sheet to track their scores and progress over time. They also kept detailed notes about how they made decisions for moving forward, and identified the participants each time, as there were personnel changes over the course of the CoIIN work. The MFOFC coordinator posted the Family Engagement Checklist in a Google doc and added a stem to each item (Table 1) so Advisory Group members had context for responding to each item and could respond online during the height of the COVID-19 pandemic. Use of Google Docs also allowed the coordinator to easily compile and share the results. Using a virtual platform, the Rhode Island Department of Public Health convened families and staff and used Jamboard, an interactive Google whiteboard, to review, discuss, and complete the Family Engagement Checklist.

Use of the FESAT, FES Toolkit, and Family Engagement in Systems Checklist is not limited to planning, assessing, and improving family engagement in systems change. Some state agencies have used the checklist as a template for writing community engagement plans. A family partner on the Texas CMC CoIIN team incorporated the Representation Domain into a *Turning*

the Tables: A Multicultural Healthcare Experience training she developed to help others understand the experiences of minority families whose children receive care from clinics that serve children with medically complex conditions. Others have incorporated the items in the tools into their professional development trainings about family engagement in systems to emphasize the supports and information families need to understand their partnership roles and contribute to systems change. Several universities have incorporated the FESAT into family-centered care curricula. In Minnesota, a special education cooperative is using the FES Toolkit to “reset and increase family engagement” post COVID pandemic. A California school district is using the FESAT to plan district-wide family engagement strategies family-school partnerships.

As Family Voices continues to learn from the organizations that are using the tools, we update the FES Toolkit with strategies and resources that are responsive to their needs. For example, the Representation Domain now includes resources for engaging individuals who identify as LGBTQIA2S+ and grandparents, as this was a need for the ECCS CoIIN teams. New resources in the Transparency Domain include tools for addressing healthy equity.

ABOUT FAMILY VOICES

Family Voices, a national, family-led, non-profit organization, works to improve health care services and supports for children and youth with special health care needs/disabilities (CYSHCN) and their families through effective partnerships with families and family-led organizations. Staff and network members, who are themselves families of CYSHCN, bring the voices of families representing the cultural, linguistic, ethnic, and geographic diversity of the nation to influence decisions at all levels of health care. This includes systems-level initiatives where policies, practices, services, and supports are created or amended to improve systems of care for all children, youth, and families. For more information, visit <https://familyvoices.org/>.

As part of Family Voices ongoing commitment to continued dissemination and meaningful use of the FESAT, we provide introductory webinars, general technical assistance, and FESAT coaching. Learn more about the FESAT and request a copy at <https://familyvoices.org/fesat/>. Email FESAT@familyvoices.org to request a presentation, for advice about best use for their organizational needs, or other assistance in use of the tools.

ⁱ Hoover, C., Paladino, M., Dworetzky, B., Wells, N. (2018) *Issue Brief: A Framework for Assessing Family Engagement in Systems Change*. Available at https://familyvoices.org/wp-content/uploads/2018/10/FamilyVoices_LPFCH_assessing_family_engagement_April2018.pdf.