



Family Engagement
in Systems Change

FAMILY VOICES®

Family Engagement in Systems (FES) Toolkit

Strategies and Resources



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Introduction

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.

Family Voices created the Family Engagement in Systems (FES) Toolkit to inspire and support child- and family-serving organizations working to engage families and family-led organizations in systems-level initiatives. The FES Toolkit can be used as a standalone resource or as a companion document to the Family Engagement in Systems Assessment Tool (FESAT). The FESAT is a tool that organizations can use to **assess and improve** family engagement in systems-level initiatives, helping to ensure that the voices of the individuals, families, and communities who receive services are included in the creation of the policies and practices that govern those services.

The FES Toolkit and FESAT are based on a framework of four strategic domains (Figure 1).¹

¹ Dworetzky, B., Hoover, C.G. & Walker, D.K. Family Engagement at the Systems Level: A Framework for Action. *Matern Child Health J* (2023). <https://doi.org/10.1007/s10995-023-03619-2>

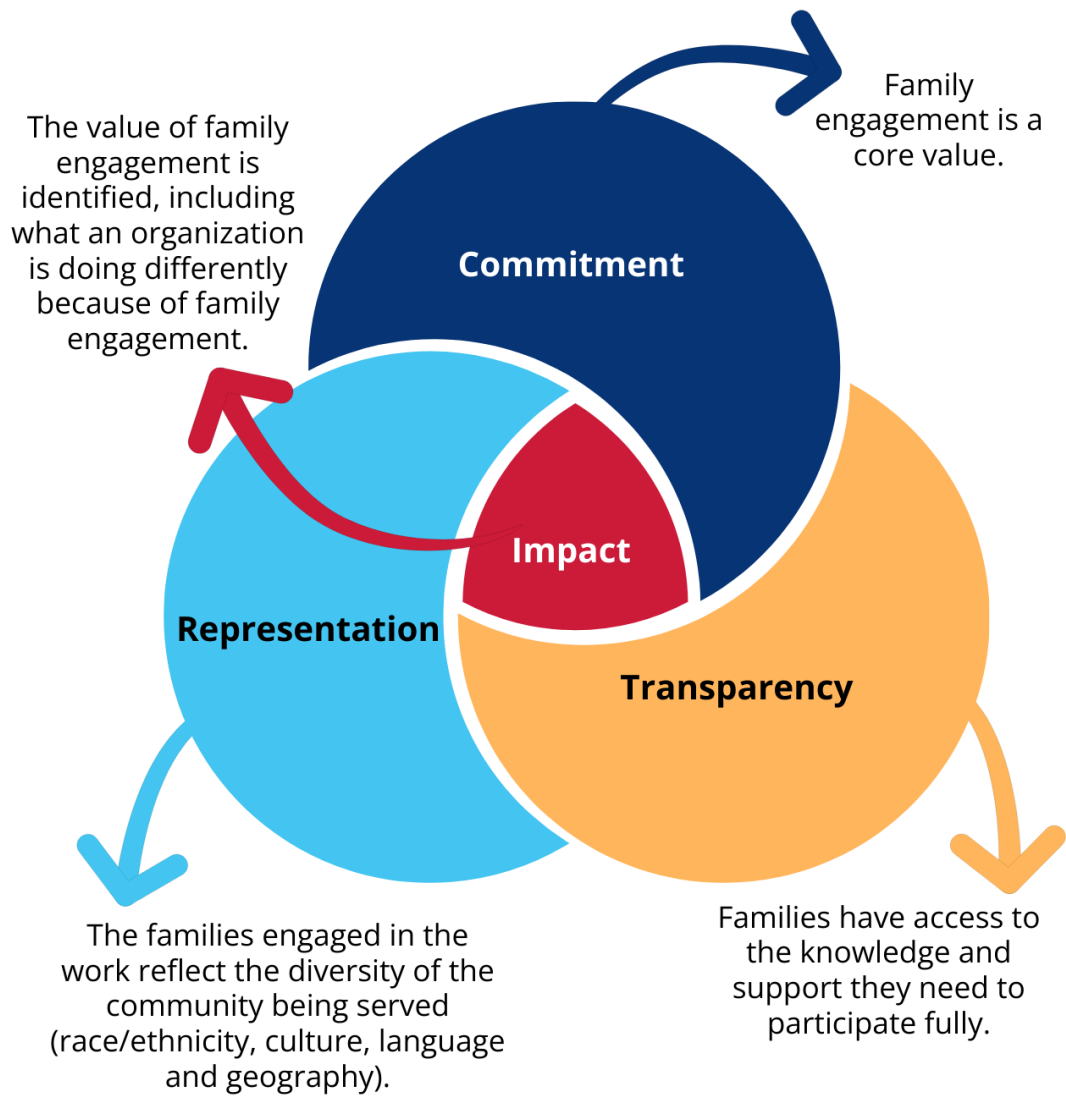


Figure 1: Revised Framework for Assessing Family Engagement 2019.

We encourage organizations to use the strategies and resources in this toolkit to promote, strengthen, and improve family engagement in systems-level initiatives.

Examples of systems-level initiatives include:

- A **Title V program** engages with a family-led organization in the Block Grant Needs Assessment to ensure state-identified priorities reflect the needs of diverse populations.
- A **Medicaid** program engages with family leaders to identify barriers to services and works with them to improve policies.
- A **university research team** engages with family leaders to create a research project to develop a family-centered intervention.
- A **hospital** engages with families in a quality improvement initiative to evaluate the discharge planning process.

Organizations can use the Family Engagement in Systems Checklist (page 4) and the strategies and resources in the FES Toolkit to ***plan the design*** of a systems-level initiative to ensure that families and organization staff have the supports they need to participate and contribute to their maximum potential.

Plan the Design of an Initiative to Ensure Family Engagement

When an organization begins to engage families in systems-level initiatives, the **Family Engagement Checklist** can help identify the supports the organization already provides as well as supports that can be implemented to ensure meaningful family engagement. Explore the FES Toolkit to identify strategies and resources to encourage and support family engagement.

Family Engagement in Systems Checklist

Domain 1: Commitment	Yes	No	Some what	Don't know
The organization uses written policy that requires family engagement in systems-level initiatives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization has one or more champions of family engagement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization acknowledges the contributions family leaders make to systems-level initiatives.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization's budget includes funding for family leaders' time and/or other costs they incur (for example, travel, childcare).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization provides adequate time for staff to implement changes that result from family engagement in systems-levels initiatives (for example, educating staff about new policies).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Domain 2: Transparency	Yes	No	Some what	Don't know
The organization conducts activities to understand the issues faced by the children and families they serve (for example, used data or conducted a focus group).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all staff and families have a clear understanding of the initiative they will work on together.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization provides the supports families and staff need to understand their partnership role (for example mentors/coaching).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all participants have the supports they need to participate in meetings (for example, physical access, interpreters, time away from other work responsibilities).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The organization ensures all participants have the information they need to participate in meetings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Domain 3: Representation	Yes	No	Some what	Don't know
Family leaders are representative of the races and ethnicities of the populations served by the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family leaders are representative of the cultures of the populations served by the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family leaders are representative of the languages spoken by the populations served by the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family leaders are representative of geographic areas in which populations served by the initiative live.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Domain 4: Impact	Yes	No	Some what	Don't know
Organization staff listen to family leaders' ideas.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff engage family leaders in choosing goals for the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff work together with family leaders to implement the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff work together with family leaders to evaluate the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff use family leaders' input to improve the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organization staff can explain how family leaders contribute to the initiative.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If one or more of the four demographic characteristics in Domain 3: Representation, do not match your priorities for the populations served by the initiative you are assessing, you can replace them with criteria that do match your priorities. For example, your organization may be looking for family leaders of certain ages, race, disabilities, gender, sexual identity, socio-economic status, and other characteristics that contribute to an individual's unique identity.

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. For example, does the organization have a family engagement in systems policy – yes or no? When it comes to budgets, especially if different programs have different budgets, is there a line item for compensating family partners? That could be yes, no, somewhat (depending on the program) or don't know - especially if there are new staff.

The FESAT should be completed by staff and families who worked together towards systems change. The response options (0 - Never, 1- rarely, 2 - sometimes, 3 - usually, 4 - always) will generate individual domain and overall family engagement scores.

Overarching Strategy to Promote Family Engagement in Systems

Strategy: Collaborate with a family-led or community-based organization to identify representative families, ensure they have needed mentorship and support, and that both family leaders and organization staff have access to skill-building opportunities.

Examples of mutually beneficial reasons for organizations to partner with family-led or community-based organizations are described below.

1. **Capacity Building:** In its [IMPACT! How Consumers Have Shaped Health System Delivery Reform](#) report, the Center for Consumer Engagement in Health Innovation at Community Catalyst recognized that “it takes time, expertise, and resources to make meaningful and sustained consumer engagement work.” The Center leveraged partnerships with state-based networks and coalitions, provided technical assistance, information, and funding to support their work to help consumers build the skills they needed to effectively and meaningfully engage with policymakers to change health system policies and practices.² Similarly, family-led organizations can help build the capacity of organizations by providing resources, expertise, and the perspectives of many family members rather than just one.

² Mullin, A. IMPACT! How Consumers Have Shaped Health System Delivery Reform. April 2019. Available at <https://www.healthinnovation.org/resources/publications/impact-how-consumers-have-shaped-health-system-delivery-reform>

2. **Providing Important Data:** Family-led organizations often track data about the families who contact them for information and assistance. These data include problems families encounter with different systems of care (such as health insurance, Medicaid/CHIP and other public benefits, state agency services, and educational services). Once de-identified, family-led organizations can share aggregated data with organizations to identify areas where they need to engage families to change or create policies to improve services.

3. **Identifying and Supporting Family Partners:** Family-led organizations have connections with many other family- and community-led organizations, as well as individual families. Organizations can collaborate with family-led organizations to help identify, mentor, and support family members, including diverse family members, to participate as partners in systems-level initiatives.³ Linking families to family organizations for mentoring and support around their partnership roles can help drive improvements in the system of care.⁴ It also makes families aware that their participation does not have to be limited to their own personal experience.⁵

4. **Providing leadership building workshops:** Family-led organizations can provide training and skill-building workshops for organization staff and family members to help ensure successful collaborations. Staff and family

³ Ferreira, K., "Actualizing Empowerment: Developing a Framework for Partnering with Families in System Level Service Planning and Delivery" (2011). Graduate Theses and Dissertations. Available at <https://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=4298&context=etd>.

⁴ ibid

⁵ ibid

participants gain an understanding of effective partnership roles and learn that family members' participation is not limited to their own personal experiences.⁶ A June 2019 study found that parents with income less than 250 percent of the federal poverty level who were connected to community organizations valued the training and support provided to them, and that linking families to community supports helped drive improvements in the system of care.⁷

5. **Disseminating Information:** Family-led organizations can leverage their partnerships with other state- and community-based organizations to help disseminate needs assessment surveys, conduct outreach to families to participate in focus groups, and identify families for key informant interviews, particularly diverse and underserved families.

Resources for identifying family-led and community-based organizations

- Family Voices connects a national network of family-run organizations in every state, the District of Columbia, five territories and three serving Tribal nations. These include:
 - Family Voices Affiliate Organizations (FVAOs). FVAOs are statewide, family-led, non-profit organizations that work to advance the mission, vision, and principles of Family Voices in 44 states and a Tribal Nation. Staff provide

⁶ ibid

⁷ Schleifer, D., Diep, A., & Kirk, G. It's About Trust: Low-Income Parents' Perspectives on How Pediatricians Can Screen for Social Determinants of Health. A report from Public Agenda. June 2019. Available at <https://www.publicagenda.org/reports/its-about-trust-low-income-parents-perspectives-on-how-pediatricians-can-screen-for-social-determinants-of-health/>.

support, information, resources, and skill-building opportunities for families and professionals, and advocate at the state and national level for improved policies for children and youth with special health care needs (CYSHCN) and their families. They collect data and can share de-identified, aggregated data with partner organizations to help identify areas of improvement and gaps in the system of care.

- [Family-to-Family Health Information Centers \(F2Fs\)](#). F2F programs are funded by the Maternal and Child Health Bureau (MCHB) to provide information, education, technical assistance and peer support to families of CYSHCN and the professionals who serve them. There are 59 F2Fs, one in every state, the District of Columbia, Puerto Rico, the Virgin Islands, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands, and three that serve tribal nations. Families of CYSHCN staff the F2Fs. They help families navigate the state's system of care and help them partner at all levels of the health care system. They track and report data about issues and barriers families experience. They also collect data and can share de-identified, aggregated data with partner organizations to help identify areas of improvement and gaps in the system of care. In many states, the F2F program is co-located with the state FVAO.⁸

- [Community-based Organizations in the Health Sector: A Scoping Review](#).⁹ For organizations looking to collaborate with community-based organizations (CBOs), this article identifies the important roles they play in helping to identify

⁸ FVAOs and F2Fs are often part of larger non-profit organizations, Department of Public Health Title V programs, or universities. Therefore, the names of each FVAO and/or F2F vary, depending on the vendor organization.

⁹ Wilson, M.G., Lavis, J.N., & Guta, A. (2012). Health Research Policy and Systems (10:36).

individuals and families and ensure public engagement in policies that affect the services they receive.

- Family-led organizations can help professional organizations connect with the specific families and communities with whom they would like to collaborate to work on systems changes. These national networks of family-led organizations can help child- and family-serving organizations connect to state and local groups as well. National family-led networks include, but are not limited to, the organizations below.
 - The [Association for Library Service to Children](#) (ALSC) maintains a list of national organizations who serve children and youth.
 - [Hands and Voices](#) – A national organization that has built a strong network of families, professionals in all related fields, state/federal tech support resources, modality-based groups, institutions of higher education, service providers, and consumers who are deaf or hard of hearing. They work on issues at the local and national level to improve educational and social outcomes for children who are deaf or hard of hearing.
 - [National Federation of Families](#) - A national family-run organization linking more than 120 chapters and state organizations focused on the issues of children and youth with emotional, behavioral, or mental health needs and substance use challenges and their families.
 - [National Foster Parent Association](#) - A non-profit organization that works to address the concerns of several independent groups of foster parents and child welfare professionals to provide foster families with opportunities for advocacy, networking, and education.

- [National Military Family Association](#) – Works to provide support and enhance the quality of life for every military family through bold advocacy, innovative programming, and dynamic and responsive solutions.

The following sections of this toolkit provide strategies and resources to help organizations support meaningful family engagement in each of the four domains that make up the Framework for Assessing Family Engagement in Systems Change (Figure 1, page 3) and the [Family Engagement in Systems Assessment Tool](#) (FESAT).

Strategies to Support and Improve Family Engagement



Domain 1: Commitment

Commitment means that the organization routinely engages family leaders in all activities that affect the policies and programs that govern services for children, youth, and families.

Strategy 1.1: Create a written policy that requires family engagement in systems-level initiatives

Resources

- Examples of family engagement policies include:
 - [Supporting Patient and Family Engagement: Best Practices for Hospital Leaders](#) is an evidence-based guide, developed by U.S. Department of Health and Human Services' Agency for Healthcare Research and Quality. While created for hospitals, the strategies, such as including family engagement in the hospital's mission and vision statements, and strategic plan, can be used by any child- and family-serving organization to guide the design of a written policy for engaging families in systems-level initiatives.
 - [Policy Statement on Family Engagement from the Early Years to the Early Grades](#), from the U.S. Department of Health and Human Services, U.S. Department of Education.

- [Developing a Written Parent and Family Engagement Policy: A Guide for Districts and Schools](#). This 2018 document from the Tennessee Department of Education includes tools and resources for writing family engagement policies for engaging families at the advisory/district level, beyond the education of their individual child.

Strategy 1.2: Ensure the organization has one or more champions of family engagement.

Resources

- [Guide to Patient and Family Engagement: Environmental Scan Report](#). This report, prepared by the American Institutes for Research for the Agency for Healthcare Research and Quality (AHRQ), documents the importance of having an internal champion as a strategy for implementing organizational change. Champions for family engagement can ensure consistent communication throughout an initiative.
- Family Voices conducted a series of key informant interviews with family leaders and professional partners during the development of the [Framework for Assessing Family Engagement in Systems Change](#). Findings included the importance of a champion of family engagement, a written policy (see Strategy 1.1 for examples of policies), and the importance of documenting families' contributions (see Strategy 1.6 for examples ways to document family contributions) to ensure a continuous culture of family engagement, even if an organization's leadership changes.¹⁰

¹⁰ Family Voices key informant interviews, 2017.

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.

If the organization employs family leaders on staff, they will be valuable liaisons to both internal staff and recruited family partners in developing and implementing family engagement efforts. It is also very important to identify and work with external family leaders/family organizations to ensure perspectives from outside the organization.

Resource

- See [Overarching Strategy to Promote Family Engagement in Systems](#) (page 10)

Strategy 1.4: Engage at least two family leaders in the initiative.

Resource

- [Tokenism in Patient Engagement](#). Many organizations include patients and families as a symbolic or token effort of engagement in research or other initiatives. Hahn et al.¹¹ identified the importance of building relationships and trust to ensure intentional engagement of stakeholders representing multiple perspectives.

¹¹ Hahn et al. Tokenism in patient engagement. (2017). Family Practice 34(3). Available at <https://academic.oup.com/fampra/article/34/3/290/2503177>

- [The Dimensions of Tokenism in Patient and Family Engagement: A Concept Analysis of the Literature](#).¹² This 2020 paper addresses what happens when patient engagement “goes wrong” due to power differences between families and providers, families have limited information and supports that limit the impact they can make.

Strategy 1.5: Develop a mechanism for reimbursing family leaders for their time and/or other costs they incur.

If organization staff and other stakeholders are paid for their time participating in systems-level initiatives, the family participants should be paid as well.¹³ Families incur expenses for transportation, childcare, and lost time at work. If families are not compensated for their time and related expenses, it precludes the participation of many families and reduces diversity. Compensating families demonstrates that an organization values their time, input, and expertise.

Resource

- [What Does it Look Like to Equitably Engage People with Live Experience?](#) This publication from the Assistant Secretary for Planning and Evaluation (ASPE) provides guidance about equitable engagement and compensation and other benefits. Monetary compensation for people with lived experience should be at

¹² Majid U. The Dimensions of Tokenism in Patient and Family Engagement: A Concept Analysis of the Literature. J Patient Exp. 2020 Dec;7(6):1610-1620. doi: 10.1177/2374373520925268. Epub 2020 May 19. PMID: 33457621; PMCID: PMC7786693.

¹³ Ferreira, K., "Actualizing Empowerment: Developing a Framework for Partnering with Families in System Level Service Planning and Delivery" (2011). Graduate Theses and Dissertations. Available at <https://scholarcommons.usf.edu/cgi/viewcontent.cgi?article=4298&context=etd>.

a rate that aligns with industry standards for other experts. In addition to monetary compensation, other benefits may include skills development, opportunities to attend conferences, contributions to written reports, and other professional development activities.

- [Partnering with Youth & Families in Research: A Standard of Compensation for Youth and Family Partners](#). [CYSHCNet](#), a national research network focused on CYSHCN, provides guidance about payment for youth and family partners who participate on research projects.

Strategy 1.6: Acknowledge how family leaders contributed to systems-level initiatives.

Family leaders' ideas can be highlighted in meeting minutes and organizational newsletters. Families can also co-author reports, articles, and other publications. Acknowledging families' contributions is a way to encourage other families to participate, as they see a demonstrated commitment to listen to and follow up on families' ideas.

Resource:

- [How Patient-Centeredness Dramatically Benefits Research](#). A blog entry from the Patient-Centered Outcomes Research Institute (PCORI) that demonstrates this strategy to acknowledge the contributions of family leaders.



Domain 2: Transparency

Transparency occurs when the organization clearly documents and communicates about how it:

- Identifies issues faced by the children and families it serves.
- Provides the information and supports family leaders and organization staff need to partner and participate to their maximum potential.

Strategy 2.1: Partner with family leaders to conduct a needs assessment or other activities to identify and understand the issues children and families are facing.

Resources

- The Centers for Disease Control and Prevention, Division of Nutrition, Physical Activity, and Obesity, has a [Community Health Assessment and Group Evaluation \(CHANGE\) Tool](#). This includes assessment questions and spreadsheet templates that others can adapt for their own initiatives and use for focus groups, on-line surveys, and key informant interviews to learn about barriers to care or other issues that families experience with the identified system of care.
- [The Power of Community Voices for Enhancing Community Health Needs Assessments](#).¹⁴ This 2017 article by Cain et al. describes how Allina Health

¹⁴ Cain, CL, Orionzi, D., O'Brien, M., & Trahan, L. (2017). The Power of Community Voices for Enhancing Community Health Needs Assessments. *Health promotion practice*, 18(3), 437-443. Retrieved from <https://escholarship.org/uc/item/6xd9x3x2>

successfully engaged diverse community members in its community health needs assessment.

- The [Family-Centered Care Assessment](#) for Families (FCCA-F) was designed for use by individual families to assess the family-centeredness of medical care their children receive. The FCCA-F can also be used as a survey or as a foundation for discussion with family partners and to identify areas where families can be engaged in improving care. Family Voices [developed and validated](#) the FCCA-F through a family-led research partnership.

Strategy 2.2: Use data to learn about the issues and concerns that children, youth, and families are experiencing.

Resources

- [National Survey of Children’s Health](#). This interactive resource, from the Data Resource Center for Child & Adolescent Health, is a project of the [Children and Adolescent Health Measurement Initiative](#). It includes data for hundreds of child and family health measures, as well as data for the Title V Maternal and Child Health Services Block Grant National Performance Measures and National Outcome Measures. Users can stratify data queries by child and family demographics, adequacy of health insurance, health care access and quality, neighborhood safety, community and school activities, and more.
- The [National Maternal & Child Health Measures Compendium](#) is an interactive compendium of more than 1000 maternal and child health and well-being measures.
- [Family-to-Family Health Information Centers \(F2Fs\)](#) and Family Voices Affiliate Organizations (FVAOs). See [Overarching Strategy to Promote Family](#)

Engagement in Systems (page 4). F2Fs and FVAOs can leverage their partnerships with other state and community-based organizations throughout their state or territory to help disseminate online needs assessment surveys; recruit families to participate at in-person focus groups; and help identify families for key informant interviews, particularly diverse and underserved families.

- [Data and Statistics on Children’s Mental Health](#). A compilation of datasets for mental health and related conditions.
- See Internal and External Data Sources in [Domain 3: Representation](#) (page 17).

Strategy 2.3: Use assessment and implementation tools to ensure proposed policies and other systems-level initiatives are equitable and culturally responsive.

Resources

- [Racial Equity Impact Assessment Toolkit](#) from Race Forward, helps minimize unanticipated adverse consequences of policies, programs and other systems-level changes.
- [Is My Implementation Practice Culturally Responsive?](#) This REL (Race Ethnicity Language) publication from MPHI and the Implementation Group (2019) provides a cultural responsive self-assessment checklist that work is inclusive, and addresses issues of diversity and equity.
- [Race Equity and Inclusion Action Guide: Embracing Racial Equity: 7 Steps to Advance and Embed Race Equity and Inclusion within your Organization](#). This 2015 publication from the Anni E. Casey Foundation provides a racial equity and inclusion framework for understanding dimensions of racism, root causes of

racial inequities, key terms and concepts, and how to talk about race, and much more.

- [Developing an Equity Impact Statement: A Tool for Policymaking](#). A publication of the [Praxis Project](#), a national movement committed to capacity building for social change.

Strategy 2.4: Make sure all participants (family leaders and organization staff) have the information and supports they need to participate to their maximum potential.

Resources

- [Key Learnings for Strengthening Partnerships](#). This 2021 publication from the [Institute for Patient- and Family-Centered Care](#) documents the “how to” of successful patient and family advisory councils in U.S. children’s hospitals.
- [Strategically Advancing Patient and Family Advisory Councils in New York State Hospitals](#). This June 2018 report from the [Institute for Patient- and Family-Centered Care](#) outlines best practices for supporting all members of hospital advisory councils. These practices can support family engagement in other systems-level initiatives that local, state, and national groups, organizations, and agencies undertake.
- [A Roadmap for Patient + Family Engagement in Healthcare: Practice and Research](#)¹⁵ documents the supports families (pages 17 & 18 of the Roadmap)

¹⁵ Carman K.L. et al. A Roadmap for Patient and Family Engagement in Healthcare Practice and Research. (Prepared by the American Institutes for Research under a grant from the Gordon and Betty Moore Foundation, Dominick Frosch, Project Officer and Fellow; Susan Baade, Program Officer.) Gordon and Betty Moore Foundation: Palo Alto, CA; September 2014. www.patientfamilyengagement.org

and health care staff (pages 22 & 23 of the Roadmap) need to collaborate in systems-level activities. This includes plain language materials that describe the opportunity, mentorship, and training so everyone has background information and context for the initiative and understands his or her role and decision-making power.

- Create a description of the participant opportunity so families have a clear understanding of the initiative and how they might contribute.
- If the organization is reaching out to a family-led organization to help recruit family leaders to participate in an initiative, provide details about:
 - The purpose and goals of the project.
 - Expectations for the family leaders and staff; expected timing and length of commitment.
 - Meeting logistics (for example time, place, frequency, virtual, other).
 - Compensation or other remuneration.
 - Expected skills, such as use of Excel, experience with qualitative or quantitative analysis, comfort speaking up in a group or giving presentations, contributing to reports, and so on.
 - The Oregon Center for Children and Youth with Special Health Needs has an excellent worksheet for [Planning For Meaningful Family Involvement](#).

- [Creating and Sustaining Effective Hospital Family Advisory Councils: Findings from the California Patient and Family Centered Care Network of Pediatric Hospitals](#). This 2015 report from the Lucile Packard Foundation for Children's Health details the foundational elements for Family Advisory Councils, and discussed the challenges of establishing and sustaining them, along with a companion Fact Sheet.
 - [Fact Sheet: A Guide to Establishing Effective Hospital Advisory Councils](#)

Strategy 2.5: Prepare and send meeting agendas and materials in advance so all participants know what to expect, and have an opportunity to add items they wish to discuss.

Resource

- The Harvard Business Review's [A Checklist for Planning Your Next Big Meeting](#) provides a checklist and a list of dos and don'ts for planning effective meetings.

Strategy 2.6: Provide mentoring and support to ensure families and organization staff understand their partnership role and are prepared to participate as fully as possible.

Resources

- Dual Roles. Family leaders who are also organization staff can make unique contributions to systems-level initiatives using both perspectives to identify issues or barriers. However, this dual role may also be a conflict of interest. While it may be convenient to have a family leader on staff to represent all families on an initiative, this individual should not take the place of family

leaders from outside the organization who can represent the broader population of families served by the organization.¹⁶

- Engage a family-led or community-based organization to provide onboarding, peer support, and skill-building workshops so all participants understand their roles. See **Overarching Strategy to Promote Family Engagement in Systems** (page 4).

2.7 Strategy: Ensure staff have the information they need and time to participate in meetings; educate staff about new policies or practices.

Resources

- [Don't Just Tell Employees Organizational Changes Are Coming – Explain Why.](#) This 2018 article from the Harvard Business Review not only explains the importance of communicating organizational changes, but also why the changes are important. This helps managers and other leaders be “powerful ambassadors” of change for the entire organization.
- [4 Tips for Managing Organizational Change.](#) This 2019 article from the Harvard Business Review discusses how to drive organizational change through empowerment rather than by top-down mandate.

¹⁶ Hoover, C., Paladino, M.J., Dworetzky, B., & Wells, N. Framework for Assessing Family Engagement in Systems Change. (2018). Available at http://familyvoices.org/wp-content/uploads/2018/10/FamilyVoices_LPFCH_assessing_family_engagement_April2018.pdf

2.8 Strategy 2.8: Ensure meeting materials are written in plain language and are culturally and linguistically appropriate for all participants.

Resources

- The U.S. government has [federal plain language guidelines](#) with information about writing for the right audience, word choice, design, web standards, and more.
- The U.S Department of Health and Human Services Office of Minority Health has [National CLAS Standards for Culturally and Linguistically Appropriate Services in Health and Health Care](#) that aim to improve health care quality and advance health equity.
- [Limited English Proficiency](#) provides resources and information to help expand and improve language assistance services for individuals with limited English proficiency, in compliance with federal law.
 - [Limited English Proficient \(LEP\) Maps](#). The U.S. Department of Justice has a Language Map App for identifying data about LEP persons by state or county, along with a list of languages spoken to help ensure access to information, programs, and services.
- [Found in Translation](#). This Boston-based organization helps low-income bilingual women achieve economic security by learning to use their language skills to help reduce racial, ethnic, and linguistic disparities in health care by increasing the bilingual skills of the workforce. This [replicable model](#) provides the opportunity

for homeless, low-income, bilingual women to participate in a Language Access Fellowship program free-of-charge. They leave the program qualified to be medical interpreters who can advance healthcare access, improve patient outcomes, save lives, and reduce health care costs by preventing medical errors.

2.9 Strategy: Conduct polls to schedule meeting times and provide alternate ways for attendees to participate.

Resources

- Doodle is a free online application for creating polls to schedule meetings in [English](#) and [Spanish](#).
- [Zoom](#) is a video-conferencing application. The basic version, available for free, has some limitations. Maximum of 100 participants, limited to 40 minutes for group meetings.
- [Free Conference Call](#) numbers.



Domain 3: Representation

Representation occurs when family leaders reflect the diversity of the community served by the organization or initiative.

Strategy 3.1: Use data to understand the demographics of the population the organization serves.

Resources

Internal Data Sources

Collect and use organizational data on race, ethnicity, and primary language.

- The [Health Research & Educational Trust](#) (HRET) has a [HRET Disparities Toolkit](#) for collecting race, ethnicity, and primary language information. Learn about data collection, staff training, how to ask questions, and use of data.

External Data Sources

- The [United States Census Bureau](#) provides new data annually. Indicators include age, education, housing, income, languages, race and Hispanic origin, health insurance coverage, geography, and more. Search by state, county, city, town, or zip code.
- [Henry J Kaiser Family Foundation Demographics and the Economy](#) collates data from the U.S. Census and other sources. It is a convenient way to look at demographic and economic data for a single state, select states, or for all states. Indicators for children include age, race, ethnicity, citizenship status, poverty

rate, household income, homelessness, SNAP (Supplemental Nutrition Assistance Program), and more.

- [School-based Health Alliance Children’s Health and Education Mapping Tool](#). Users can select a state and identify areas of need and local organizations with whom to engage to improve comprehensive, coordinated care for a community. Users can also identify communities with strong population health outcomes and services and form relationships to learn what works to spread best practices to other areas; includes a user guide and video tutorials.

Strategy 3.2: Connect with community liaisons, cultural brokers, family-led or community-based organizations to help identify and support family leaders, including fathers, grandparents, LGBTQIA+, individuals with specific disabilities, and diverse individuals and communities.

Resources

- [Engaging People with Lived Experience to Improve Federal Research, Policy, and Practice](#), from the Office of the Assistant Secretary for Planning and Evaluation (ASPE). Defines “lived experience” and provides tools for identifying and recruiting individuals and ensuring equitable engagement.
- [The Center for Faith and Opportunity Initiatives \(Partnership Center\)](#). An initiative of the U.S. Department of Health and Human Services (HHS), the Partnership Center leads the department's efforts to build and support partnerships with faith-based and community organizations in order to better serve individuals, families, and communities in need. Explore the links to the ten

regional offices as a way to identify potential partners and issues the organization may want to address.

- [Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers.](#)¹⁷ Community liaisons can help create linkages between individuals, families, communities, and organizations. Cultural brokers play a similar role. However, because cultural brokers are also knowledgeable about the community or a specific cultural group, and about the organization's services, and supports, they can help ensure organizations connect with groups and communities in ways that honor their values, beliefs, and practices.
 - [Who can fulfill the role of cultural brokers in health care settings?](#) The National Center for Cultural Competence developed a list of roles people have in health care settings (for example peer mentors, nurses, social workers, and health educators) and settings where organizations might connect with cultural brokers.
 - [Engaging Local Leaders to Foster Welcoming Communities.](#)¹⁸ Includes strategies for identifying community leaders and recommendations and strategies for leadership engagement that is inclusive of diverse communities.

¹⁷ Jones, W. & Thomas, T. Growing Your Capacity to Engage Diverse Communities by Working with Community Liaisons and Cultural Brokers. (2009). National Center for Family Professional Partnerships, Family Voices, Inc., Albuquerque, NM.

¹⁸ Written by Susan Downs-Karkos for Welcoming America: Building a Nation of Neighbors, September 2019.

- [Five Strategies for Building Diversity in a Patient Family Advisory Council](#). Tips from the National Institute for children’s Health Quality (NICHQ) about developing a comprehensive recruitment strategy.
- [Strategies to Build Trust and Recruit African American and Latino Community Residents for Health Research: A Cohort Study](#).¹⁹ Table 1 in this paper includes principles of CPPR and recruitment strategies that build relationships with and support participation by African American and Latino individuals.
- [Family Voices United to End Racism Against CYSHCN and their Families \(FAMU\)](#). A collection tools to increase understanding of Black Culture, engage youth and champion their engagement, and racism.
- [Black and African-American Outreach Guide](#). A publication of the National Hospice and Palliative Care Organization (NHPCO), provides information about outreach to, and the importance of including Black/African American communities in research.
- [All Children – All Families: Family Recruitment](#). This document from the Human Rights Campaign includes information about creating recruitment and training materials, and policies that are inclusive of LGBTQ individuals and families.
- [LGBT HealthLink, The Network for Health Equity](#). Includes best and promising practicing for engaging LGBT individuals and communities in specific health initiatives, which can be adapted for other initiatives.

¹⁹ Ibrahima C. Sankaré, et al Clin Trans Sci 2015; Volume 8: 412–420.

- National Responsible Fatherhood Clearing House ([English](#) and [En Español](#)). A compendium of proven and innovative strategies to encourage partnerships with dads. Includes blogs, programs, and a searchable library. Check out the Tip Cards for Fatherhood Practitioners.
 - [Recruitment](#) - Tips for outreach and recruitment methods to engage fathers.
 - [Program Attendance and Retention](#) – Provides strategies to increase program attendance, retention, and engagement.
 - [Building Effective Partnerships](#). Excellent resource about building and maintaining effective partnerships with fathers.
 - [Father-Friendliness Organizational Self-Assessment and Planning Tool](#). A self-assessment and planning to help organizations determine readiness for engaging fathers.
- [Raising Grandchildren: Support](#). The AARP has lists of supports for grandparents raising grandchildren, which includes schools, state agency children and family services, YMCAs, Boys and Girls Clubs. Contact these organizations/agencies and other community centers in your state or community as a way to identify and recruit grandparents in systems-level initiatives.
- [A Starter Kit on Engaging People with Lived Experience in Child Support Programs](#). A January 2022 publication from the Office of Child Support Enforcement, U.S. Department of Health and Human Services. A resource to help child support programs, grant recipients, and other stakeholders to

outreach to, recruit, and engage people with lived experience to enhance child support programs and practices.

- [The Substance Abuse and Mental Health services Administration's \(SAMHSA\) Youth Engagement Guidance: Strategies, Tools, and tips for Supportive and Meaningful Youth Engagement in Federal Government-Sponsored Meetings and Events.](#)

Strategy 3.3: Provide mentoring and skill-building opportunities for the families and organization staff who participate in systems-level initiatives.

Resources

- Many [FVAOs and F2Fs](#) provide support, mentorship, and skill-building opportunities for families and their professional partners that help ensure meaningful engagement in systems-level initiatives. See **Overarching Strategy to Promote Family Engagement in Systems** (page 10).
- The [Serving on Groups](#) and [Leading by Convening: A Blueprint for Authentic Engagement](#) skill building trainings are excellent resources for helping families understand types of groups, their roles, and how to partner with professionals. Leading by Convening focuses on skill building for both families and professionals to work together as decision makers.

Strategy 3.4: Child- and family-serving organizations, organization staff, family leaders, and other stakeholders should be aware of their personal biases when engaging in systems-level initiatives.

Resources

- [Project Implicit](#), a non-profit organization, is an international collaboration between researchers who study implicit social cognition, the thoughts and feelings that arise outside of conscious awareness and control. The goal of the project is to educate the public about hidden biases and to provide a “virtual laboratory” for collecting data on the Internet. Individuals can learn about their own implicit biases by taking one or more of the tests. Users can take tests anonymously or register for the site to explore their own implicit biases about race, gender, age, disability, weight, mental health, anxiety, substance use, and more.
- [Some Core Principles, Assumptions, and Values to Guide the Work](#). The Center for Community Health and Development at the University of Kansas Community Tool Box includes a checklist and PowerPoint about the importance of using values, principles, and being aware of assumptions and biases to guide work that drives positive change.



Domain 4: Impact

Impact describes the areas where the organization used family leaders' ideas to improve policies and programs.

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

Resource

- [IAP2 Spectrum of Public Participation](#). The International Association for Public Participation has a rubric that identifies the different ways organizations can promote meaningful public engagement that runs the gamut from informing to empowering by engaging public participants in finding solutions and implementing group decisions.

Strategy 4.2: Engage family leaders in choosing goals for the initiative.

Resources

- [Four Simple Questions](#). This exercise from the [Leading by Convening](#),²⁰ a framework for engaging stakeholders, can be used to identify organizations and individuals who might work together on an issue, work that is currently underway, and ways to work together towards common goals.

²⁰ Cashman et al. *Leading by convening: A blueprint for authentic engagement*. (2014). Alexandria, VA: National Association of State Directors of Special Education.

- [Defining Our Core](#). An exercise from [the Leading by Convening](#)²¹ framework for developing a unified purpose for a group of stakeholders, identifying group goals, and assessing the impact of the activity.

Strategy 4.3: Use family leaders' input to improve the initiative and document how family leaders contributed to the work.

Resources

- [Community Engagement for Health via Coalitions, Collaborations, and Partnerships](#). The Evidence for Policy and Practice Information (EPPI) Centre identifies evidence to inform policy and practice by conducting systematic reviews and doing research to study the use/non-use of research as part of decision-making. They found that public health is improved when community members are included in the design, delivery, and evaluation of health interventions; communication is bidirectional; and the decision-making process is collaborative.
 - [Evidence-Informed Policy and Practice](#). Different types of evidence can be used to inform policy and practice. Examples include quantitative data such as statistics and qualitative data from narratives, surveys, interviews, and other types of assessments.

²¹ ibid

- [GRIPP2 Reporting Checklists: Tools to Improve Reporting of Patient and Public Involvement in Research](#).²² The items that improve reporting of patient and public involvement in research can be adapted to document the impact of family engagement in systems-level initiatives. These items, as noted in [Table 1 GRIPP2 long form](#), include describing the methods for involving patients and the public, reporting on the level of patient and public involvement used at various stages of the work, and using any quantitative or qualitative measures to assess their involvement.

Strategy 4.4: Develop an Action Plan to improve family engagement.

Resources

- Organizations that complete the FESAT and identify domains for improvement should work with family leaders to develop an action plan to improve family engagement. Below are some resources and templates to help guide that process.
 - The Center for Community Health and Development at the University of Kansas has a [Community Tool Box](#), which includes a section on [Developing an Action Plan](#).
 - The [Free Management Library](#) includes thousands of tools that help facilitate organizational change, include the [Basics of Action Planning](#).

²² Staniszewska et al. Research Involvement and Engagement 3, Article number: 12 (2017).

- The [S.M.A.R.T. Objectives Worksheet](#) from Wayne State University provides step-by-step instructions for developing action plans.
- The Massachusetts Libraries Board of Library Commissioners has an [Action Plan template](#).