

Best Practices to Integrate Family-led Organizations in Systems Improvement

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Increasingly, healthcare practices, programs, and state agencies seek family members with lived experience to serve as participants in the planning, development, implementation, and evaluation of programs that help and support children, youth, and young adults with special health care needs and their families. Family-led organizations have established best practices in integrating new and seasoned family leaders in programmatic and systems change.

Patient and family-centered care has been recognized as the gold standard approach to delivering care since the 1980s. Pediatric health systems, organizations, and agencies have occasionally incorporated the essential principles of patient-and-family-centered care into their mission and vision statements. Sometimes, they have worked to change their cultures to include these critical components. The tenets of patient-and-family-centered care not only address the care of the individual child or youth but require including families as members of the care team or as colleagues at the inception of the program and policy planning, implementation, and evaluation.

The principles of patient-and-family-centered care were first articulated in the 1980s by Surgeon General Dr. C. Everett Koop and the Association for the Care of Children's Health. However, we have yet to fully realize families as colleagues in their child's care or policy and program improvement. When **families** are viewed **as colleagues**, there can be an understanding that everyone comes to the table with unique experience and expertise and equal value regardless of credentials, formal education, or position. For example, families with lived experience bring a distinct perspective to quality improvement because they are not constrained by the culture and history of the systems or by being employed by the system. They experience the system not by how it was designed to work but by how it actually works. This allows families to identify problems and come up with unique solutions to improve services and test quality improvements.

Family-to-Family Health Information Centers (F2F) and Family Voices State Affiliate Organizations (AO) have a long history of participating in and leading policy and system improvement in their states and nationally. Family leaders from these organizations have been, for many years, at the forefront of representing families in local, regional, statewide, and national initiatives and quality improvement activities. Family-led organizations employ staff on the pulse of what children and families experience and need from systems across their entire state. They elevate those voices in every project in which they participate, every workgroup or advisory board on which they serve, and in their advocacy initiatives.

F2Fs and AOs also take great care to foster leadership and advocacy in each family to whom they provide services so that when they are ready, they can also participate in policy and systems change efforts. However, the work these organizations do to advocate for and prepare families to do so must be funded to be sustainable. Often when family-led organizations join a team in a quality improvement project, for example, they must not only work to have their content contributions, and expertise valued equally as the team sits around the table working, but they must also have their time valued in terms of compensation in the same way as their other professional colleagues.



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During this time of focus on health equity, there has been a shift to more intentional family engagement. However, the compensation for participating families often does not reflect colleague status. Other professional colleagues at the table receive payment for their time either from the project or their institution. Still, a family leader engaged in the same activity is compensated with a gift card or a stipend for a substantially lower amount (that typically does not cover the number of hours worked). It is time for healthcare organizations, state agencies, and systems of care to ensure that their budget reflects the principles and values of family-centered care.

Time must be spent discussing fair compensation for the engagement of families as colleagues. Family-led organizations are typically non-profit organizations funded by grants. They, therefore, do not have the career ladders with protected time, incentives, or unrestricted funds to cover time spent on critical quality improvement projects. Perhaps the first step in a quality improvement project is a team discussion, and PDSA cycle focused on ensuring parent-professional colleagues are compensated and valued equally. Without this step, family-led organizations often cannot join in the effort or have to do so on their own personal time; other professional colleagues do not

Return on Investment: Sustainability for Families as Colleagues. The following are concrete strategies and ex-amples of how F2Fs and AOs utilize as colleagues in systems transformation work.:

1. Strengthening Organizations for Integrating Family Leaders

Organizations and programs must be ready to support and integrate family leaders into their work. If they do not have the expertise and are not prepared to support family leaders, it will be a frustrating experience.

- a. State F2Fs/AOs can assist with identifying and recruiting family leaders, especially family members from underrepresented and underserved populations.
- b. State F2Fs/AOs can support the integration of family representation and partnership in all initiatives, and at all levels of work, including planning, development, implementation, and evaluation.
- c. State F2Fs/AOs can assist partner organizations with tools, processes, and training to help agency/program staff members collaborate with and support family leaders in their projects.
- d. State F2Fs/AOs can understand the requirements of family involvement and participation from funders in all grant projects.

Sample strategy employed by F2F/AOs as partners on the CMC CoIIN state teams: Family leaders utilized the [Family Engagement in Systems Assessment Tool \(FESAT\)](#) to assess the 4 domains of family partnership: commitment, transparency, representation and impact. The assessment process encouraged consensus discussions between inter-professional team members that level set as to how to start or deepen meaningful partnership and then led to action plans. One team chose to focus on the commitment domain first by working on developing a job or role description for a family leader on the CMC CoIIN team. Another group focused efforts on representation and created a welcome packet and onboarding orientation to the CMC CoIIN

2. Preparing Family Leaders

Emerging family leaders must be prepared to serve as advisors and leaders. Families will benefit from both formal and informal training opportunities.



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- a. State F2Fs/AOs offer access to leadership training programs that increase family skills and knowledge, so they are ready to be integrated into projects at the planning, development, implementation, and evaluation phases of work.
- b. State F2Fs/AOs advocate for the inclusion of cultural considerations in recruiting and preparing family leaders for participation.

Sample Strategy employed by F2F/AOs on the CMC CoIIN state teams: As part of the launch of a family workgroup, the F2F/AO family leader offered leadership and serving on groups training during each meeting in the first few months of formation to prepare those families new to leadership, as well as ensure that all workgroup members got to know each other. Additionally, one member of the core state workgroup was required to attend the family workgroup meeting each month. They introduced themselves, their work and got to know each of the family leaders.

3. Supporting Family Leaders

Family leaders must have ongoing support as advisors or participants.

- a. State F2Fs/AOs provide peer mentoring and support to emerging family leaders as they take on participation in these new roles.
- b. State F2Fs/AOs advocate that family leaders at all levels should not be the sole family members in program and policy committees or workgroups.
- c. State F2Fs/AOs advocate that all family leaders need orientation to new programs and projects.
- d. State F2Fs/AOs can support partner programs, organizations, and agencies to provide best practice strategies to integrate families into their work.

Sample strategy employed by F2F/AOs on the CMC CoIIN state teams: F2F/AOs tried to participate in all CMC CoIIN work as “2 by 2.” Meaning, at least 2 family leaders participated in each initiative to mentor each other, support expression of diverse voices, and advocate.

4. Sustaining Family Organizations and Family Leaders as Part of the Healthcare Workforce

Families are part of the healthcare workforce at all levels. There must be intentional, continual support for family-led organizations and family leaders to be influential members of system improvement activities.

- a. Provider organizations and associations should incorporate family-led organizations that provide training, support, and mentorship of family leaders into the foundation of their organizations, including their budgets.
- b. State F2Fs/AOs must receive sustainable financial support for their vital work to prepare and support family leaders.
- c. Family leaders must be part of the essential workforce and receive financial support for their work. State F2Fs/AOs support and mentor emerging family leaders by modeling the involvement of families for both the emerging family leader and partner agencies.
- d. State F2Fs/AOs support and mentor emerging family leaders to grow in their roles and become supporters and mentors of new emerging family leaders.
- e. Family leaders who are supported in these roles will feel that the experience and expertise they bring to these projects are valuable and valued

Sample strategy employed by F2F/AOs on the CMC CoIIN state teams: F2F/AO family leaders were paid for all work in the CMC CoIIN. Some family leaders were paid hourly and others were paid stipends for specific mini-projects, participation in a time limited group or event. When staffing changes occurred in the leadership of the state team, an F2F/AO became co-lead of the project.



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