

Framework for Assessing Family Engagement

PROJECT SUMMARY

The Family Voices project, *Framework for Assessing Family Engagement*, funded by a grant from the Lucile Packard Foundation for Children's Health, Palo Alto, California, investigated strategies state and federal agencies, as well as public and private organizations can implement for ensuring, enhancing, and supporting family engagement in the systems of care on which all children, including children and youth with special healthcare needs (CYSHCN), depend. Drawing on a literature review and key information interviews with families and professionals, the goal of the project was to define a framework and key criteria of effective family engagement in systems-level activities as a first step in developing a *Family Engagement in Healthcare Systems Assessment Tool* and Toolkit to help groups assess and improve the engagement of families in healthcare programs and policy.

In its 25-year history, working in partnership with the federal Maternal & Child Health Bureau, Family Voices has built a national network of family-led organizations in every state and the District of Columbia. These organizations provide leadership development, mentoring, and other supports to families who want to participate on advisory committees, workgroups, or other decision-making bodies affecting programs and policies that impact families. However, many systems-level groups do not provide opportunities for effective engagement of families or ensure that participating families are truly representative of the geographic, race/ethnicity, and socio-economic diversity of the population served. Even when organizations are successful in engaging families, they often have inadequate approaches to track, communicate, support, and improve the effectiveness of their family engagement efforts.¹ As noted by Carman et al (2013), "Ideally, at the partnership end of the continuum for [the systems] level, patients or their representatives set priorities and make policy and program decisions. However, it is still rare for patients to have more than a token amount of power and influence."

[I've] seen that patients get asked to sit on a board... maybe chosen at random or by convenience because they live in the area, but when the organization feels like they are not getting what they want, they start pushing people out and replacing them with people they know...someone with an advanced degree... Ideally, the organization should provide some training about what it means to be part of a board so the people served could help improve the system. (Shared by a professional key informant for this project.)

FOUR DOMAINS OF MEANINGFUL AND SUSTAINABLE FAMILY ENGAGEMENT

Under the guidance of an Expert Workgroup of ten family leaders and professional partners, Family Voices conducted a literature review of 44 articles, conducted key informant interviews with 19 family and professional leaders, and carried out extensive review and a qualitative analysis of the information collected. Based on an analysis of these activities, including the input of the Expert Workgroup and the Family Voices Network, the project identified four domains important for promoting and ensuring meaningful and sustainable family engagement at the systems level. These four domains are described below with proposed key success criteria for each domain.

¹ *Framework for Assessing Family Engagement Literature Review*, February 28, 2017, funded by the Lucile Packard Foundation for Children's Health.

1. Representation is the process by which patient and family leaders stand in for the rest of their community in systems-level activities such as needs assessment and strategic planning. Patient and family leader representation should reflect the diversity of the community they represent in both their personal backgrounds and in their connections with families of diverse backgrounds.

Key criteria that help ensure successful representation:

- Collaborate with family-led and community-based organizations for recruitment, training and support of participants. Building relationships with organizations such as Family Voices state affiliate organizations, Family-to-Family Health Information Centers, or Parent-to-Parent programs, who regularly provide information, referral and peer support to families, can help professional groups create a sustainable approach to engaging families in systems-level activities. These family-led organizations can provide training and mentoring for both families and professionals around effective, sustained relationships. These collaborations must be funded.
- Ensure that family participants represent the diversity of those who receive the services your organization provides. Identify priority communities and stakeholders to be part of the family engagement process. Community-based organizations often serve specific populations of families. They act as cultural brokers, help recruit families, and ensure families are representative of the population served.
- Create a friendly, supportive environment that welcomes the contributions each participant brings to the process. Provide mentoring support to help families participate.
- Encourage regular attendance at meetings, so that patient and family leaders and professionals build shared knowledge and values, and develop trusting relationships.
- Compensate patient and family leaders to cover the costs of their participation, such as missed work time, travel expenses, and childcare.
- Accommodate special needs, including making arrangements for access and comfort for participants with physical disabilities, and providing materials in multiple languages.

2. Transparency is the practice that allows all partners to fully participate in the process, with access to the knowledge they need to maximize their own effectiveness.

Key criteria that help ensure transparency:

- Patient and family leaders partner in all parts of the process, from brainstorming to evaluation.
- Committees, boards, and other groups with defined structures, have at least two positions reserved for patient and family leaders.
- People with dual roles may play a unique role, using their experience with both patient and professional perspectives to foster better communication and to identify barriers. They also may find themselves in a position of conflict of interest. In addition to dual-role families, include representatives from outside the setting.
- When using acronyms, spell them out and explain what they mean. Use plain language when writing and talking.
- Professionals champion family perspectives—including representation by patient and family leaders—in parts of the process where patient and family leaders have been overlooked or excluded.
- Minutes from meetings and other key materials are available to patient and family leaders, in formats they can access, in language they can understand, in a timely process.
- Confidentiality requirements are carefully explained.
- Both families and professionals have opportunities for training and support in understanding their roles and the process of engagement. Help everyone recognize their own cultural context and biases.
- Professional groups work to understand the strengths of patient and family leaders and of the patient community at large, and design activities to take advantage of those strengths.

3. Impact describes the differences patient and family leaders make at the systems level and how these translate to health-related outcomes for patients and their families.

Key criteria that help ensure impact and lead to successful system change:

- Work in partnership to select health-related outcomes that reflect goals and priorities identified by the patient community.
- Patient and family leaders take responsibility for or partner in concrete tasks that allow them to contribute directly to assessment/evaluation/research activities.
- Use rigorous methods of evaluation that follow best practice, including the use of validated measures and questionnaires when available.
- Use established frameworks for measuring health-related outcomes at the systems level, such as the Institute for Healthcare Improvement (IHI) Triple Aim or the CDC public health framework.
- Use different forms of evaluation, including both open-ended (qualitative) and structured (quantitative) methods.
- Plan, implement, analyze and share evaluation results together with all members of the partnership, and share with the larger patient community.

4. Commitment means that patient and family engagement is normalized and institutionalized throughout all of an organization's activities that have a systems-level impact.

Key criteria that demonstrate an organization's commitment to family engagement:

- Family engagement is embedded as a core value in the culture of an organization and does not change with changing leadership.
- Patient and family engagement is mandated by those who have the authority to do so, including funders, upper management, and policy makers.
- Patient and family engagement is funded, with a patient and family engagement plan included in budgeting activities whenever they occur.
- Journal articles, reports, and other publications describe the patient and family engagement activities supporting the work.
- Patients, family caregivers, and extended family have the opportunity to influence outcomes at the systems level through engagement activities, and are aware of engagement activities that are available and accessible to them.

References

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