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## Issue Brief: A Framework for Assessing Family Engagement in Systems Change

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### Abstract

Families of children and youth with special health care needs (CYSHCN) have unique perspectives about the complexities of systems of care because they are involved with so many aspects of these systems. As their children's primary caregivers, families are deeply affected by systems-level issues, such as care fragmentation, which are often a direct result of ineffective or outdated health care policies and practices.<sup>1</sup> Families' lived experiences make them uniquely qualified to partner in shaping systems-level policies that can improve systems of care for all children, especially CYSHCN.<sup>2,3,4,5,6</sup>

Family Voices is a national, non-profit, family-led organization that works to promote quality health care for all children and youth, particularly those with special health care needs and those from diverse communities. To explore strategies for ensuring, enhancing, and supporting the meaningful engagement of families at the systems level of health care, Family Voices conducted an environmental scan of existing literature and a series of key informant interviews with family leaders and professionals.

This Issue Brief summarizes what we learned from these activities, describing barriers to effective family engagement and identifying four domains and corresponding key criteria that provide a framework for considering how well organizations and agencies are engaging families.

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### Introduction

In December 2015, the Lucile Packard Foundation for Children's Health hosted a symposium, *Designing Systems That Work for Children with Complex Health Care Needs*,<sup>7</sup> where families and professionals shared experiences and visions for improving care for CYSHCN.

Discussion topics ranged from care planning and coordination to insurance issues and costs. A key issue was the fragmentation of care for

children served by an array of health care providers and programs that work independently with little communication or coordination. In each session, families and professionals alike recognized that, "working closely with families may be the best way to affect health care outcomes."<sup>8</sup>

Existing evidence shows that family engagement with health care professionals improves care coordination and health outcomes

at the *individual* level – for that child, and that family.<sup>9</sup> Family Voices recognizes that meaningful family engagement at all levels – including at the *systems* level where existing policies, programs, and services are created or amended – has the potential to be a powerful catalyst for reducing system fragmentation, removing barriers to health care, and improving quality of health care.<sup>2,3,4,5,6,10</sup> Meaningful engagement of families at this level acknowledges the importance of basing policies, programs, and services on the lived experiences of families who have dealt with this fragmentation and these barriers.<sup>11</sup> Family engagement leverages personal knowledge to ultimately improve health systems and outcomes.<sup>12</sup>

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Despite the seeming agreement on the value of family involvement, it is still rare for patients to have more than a token amount of power and influence. This work was undertaken to improve understanding of what is needed for effective systems-level family engagement and to begin a process for developing tools that can be used to assess and improve families' meaningful participation.

## Findings and Recommendations

This project employed multi-modal engagement activities that are increasingly typical of initiatives based on meaningful family engagement. These activities included:

- Oversight by an expert workgroup of family leaders and professionals.
- A literature review of academic articles and reports.
- Key informant interviews with ten family leaders and nine professionals.
- Review and feedback from the diverse national Family Voices network.

The literature review found qualitative evidence that family engagement at the individual child/provider level resulted in increased satisfaction for both families and health care providers, while noting that family engagement at the systems level has the potential to transform systems of care by improving quality, efficiency, and effectiveness of health care, as well as to result in overall improved health and quality of family life for CYSHCN.<sup>10</sup> However, assessment tools for examining the effectiveness of family engagement are lacking. The literature review also suggested that family engagement was often undertaken without clear goals in mind, perhaps because it was legislatively mandated, encouraged by funders, or required as part of medical home certification.

In the key informant interviews, family leaders and professionals identified barriers to effective family engagement. One key informant noted that, ironically, “The very thing that makes a family member an important player [in systems-level change] – having a child with special health care needs – is often a barrier”<sup>13</sup> because caring for the child is so time consuming.

Other key informants noted that professionals can be barriers to effective family engagement if they are not receptive to family input and assume they know what is best for families and their children. As one interviewee explained,

when some organizations feel that they are not getting “what they want [from family participants] they start pushing them out and replacing them with people they know.”<sup>14</sup>

In one example of family and provider engagement with a payer system, the barrier for both participating families and health care providers was fear. Families were afraid their participation would affect their health care benefits. The health care providers were concerned that their participation would affect their future relationship with the payer.

Other barriers informants noted included failure to provide plain-language materials, meetings held at times that do not accommodate families' schedules, and bringing families in at the end of an initiative, rather than including them from the beginning.

Professional and family leader key informants also identified key criteria that support meaningful family engagement. For example, families and professionals both noted the benefits of training, skill-building opportunities, and mentoring to help family leaders be effective and informed partners and active participants in the family engagement processes.

## Definition and Domains of Family Engagement

Integrating definitions of family engagement from the literature with findings from the key informant interviews led to the definition of family engagement as an *authentic partnership between professionals and family leaders who reflect the diversity of the communities they represent, working together at the systems*

*level to develop and implement better policies and practices.*

Based on a qualitative analysis of the key informant interview responses using NVivo software, the project team identified four domains that are important for promoting and ensuring meaningful and sustainable family engagement at the systems level. The four domains – representation, transparency, impact, and commitment – are explained in detail below. For each domain, the project proposed key criteria to help organizations support and enhance family engagement activities at the systems level. Organizations can use these criteria as an initial checklist or rephrase the criteria as questions to use as a self-assessment.

### Four Domains of Family Engagement in Systems

#### Representation

- Reflect the diversity of the community (race, ethnicity, language, income, education level, and geography)
- Partner with family-led and community-based organizations

#### Transparency

- Provide access to relevant knowledge
- Practice partnership in all parts of the process

#### Impact

- Identify what has changed and what the organization or system of care is doing differently because families were involved

#### Commitment

- Promote engagement as a core value
- Establish engagement at all levels, in all systems of care

## Representation

Representation is the process by which family leaders stand in for the rest of their community in systems-level activities such as needs assessment and strategic planning. Family leader representation should reflect the diversity of the community served by the agency in which the families are involved.

### **Does your organization partner with a family-led organization to help identify, support, and mentor family participation?**

Family leaders come from many different backgrounds and some may not be comfortable with professional skills – such as effective participation in meetings, constructive communication, making presentations, and understanding data – that are routine in the work environments of health professionals. Family-led organizations are key partners to ensure prepared, representative family-leaders in systems level participation.

### **Key criteria that help lead to successful representation:**

- Collaborate with family-led and community-based organizations for recruitment, training, and support of participants. Building relationships with organizations that regularly provide information, referral and peer support to families, such as Family Voices State Affiliate Organizations and Family-to-Family Health Information Centers, can help professional groups create a sustainable approach to engaging families at the systems level. These family-led organizations also can provide training and mentoring for families and professionals around effective, sustained relationships.
- Provide peer mentors to help family leaders learn the skills to participate effectively and address barriers to their participation. Do not expect family leaders to do something alone if they have not done it before, or if they are uncomfortable with a task. Having a mentor at their side is particularly important in activities that may be emotionally, as well as logistically, challenging, such as attending a professional conference for the first time.
- Ensure that family participants represent the race, ethnicity, language, income, education level, and geography of those who receive the services provided by the organization. Identify priority communities and stakeholders to be part of the family engagement process. Community-based organizations often serve specific populations of families and can provide cultural brokers to help recruit and support families to participate.
- Create a friendly, supportive environment that welcomes the contributions each participant brings to the process.
- Hold meetings that accommodate everyone's schedules to encourage regular attendance. In-person meetings facilitate relationship building between families and professionals.
- Compensate family organizations and family leaders for their time, expertise and the costs of participation, such as travel expenses and childcare.

- Provide special accommodations, including arrangements for access and comfort for participants with physical disabilities, and materials in multiple languages.

## Transparency

Transparency assures access to the knowledge that allows all partners to fully participate in the process, and maximize their own effectiveness.

### **Does your organization provide the supports and information that both families and professionals need to be informed participants in systems-level change?**

Families and professionals benefit from developing or enhancing key practices to support transparency and the associated values of openness and inclusion. Partnering with family-led organizations is critical to transparency.

#### **Key criteria that help ensure transparency:**

- 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 family leaders.
- People with dual roles (family of a CYSHCN who is also a professional or family member hired as a representative within an organization) may make a unique contribution, using their experience with both perspectives to foster better communication and to identify barriers. However, they also may find themselves in a position of conflict of interest. These dual-role

individuals should not take the place of family leaders from outside the organization who represent the broader patient community.

- Acronyms are spelled out and their meaning explained. Use plain language when writing and speaking.
- If family leaders are excluded from important activities, professionals champion family perspectives and work towards greater inclusion of family leaders.
- Meeting minutes and other key materials are available to family leaders, in formats they can access, in language they can understand, and in a timely way.
- Confidentiality requirements are carefully explained.
- Families and professionals both have opportunities for training and support in understanding their roles and the process of engagement. All participants are helped to recognize their own cultural context and biases.
- Professional partners work to understand the strengths of family leaders and of the community at large, and design activities to take advantage of those strengths.

## Impact

Impact describes what the organization is doing differently because it has engaged families in creating systems-level change.

**What is your organization doing differently because of engaging families at the systems level?** Family engagement succeeds when organizations work with family partners to learn from their experiences, and when they

implement changes to improve policies that reduce barriers to health care or resolve other systems-level issues. These successes provide the foundation for sustained family engagement because family leaders are willing to commit more time and energy when they know that they are making a difference. Successful family participation also can result in increased commitment from professionals to cultivate family engagement.<sup>10</sup>

### **Key criteria that help ensure the impact of family engagement at the systems level:**

- Family leaders' input is valued, acknowledged, and helps lead to change.
- Family leaders influence decisions about existing policies and programs and help select and prioritize new issues to address.
- Family leaders are able to influence the process for how decisions are made in policies and programs.
- Professional partners and family leaders can explain how family leaders contributed to improved outcomes or processes.
- Family leaders, family organizations and professionals partner in evaluation and improvement of family engagement activities.

### **Commitment**

Commitment means that family engagement is normalized and included throughout the activities that impact the organization at the systems level.

### **Does your organization educate and inform all staff about the importance of engaging**

### **families at the systems level, valuing families' time, and respecting their contributions?**

Professionals and family leaders need to celebrate and publicize successes and speak out when they see missed opportunities for family engagement.

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

- Family engagement is embedded as a core value in the culture of the organization, expressed in written policies, and does not change with changing leadership.
- Family engagement is mandated by those who have the authority to do so, including funders, payers, management, and policymakers.
- Family engagement is adequately funded; costs of a family engagement plan are included in the budget.
- Agency budgets ensure adequate staff time for implementing any changes made because of family engagement. This may include time for educating health care providers and other staff about different or new policies and practices.
- Journal articles, reports, and other publications are jointly authored with family partners, and describe the family-engagement activities that supported the work.
- Opportunities to become family leaders who influence outcomes at the systems level through engagement activities are available and accessible to a wide range of families and caregivers, supported by family-led organizations.

## Conclusions

Health care providers, payers, and systems of care increasingly focus on meaningful family engagement as a strategy to improve health care systems, enhance consumer and provider satisfaction, and reduce costs. This Issue Brief describes four domains that can contribute to

family engagement in systems-level change and lists key criteria organizations can use to assess how well they are engaging families. Analyzing the use of these criteria will help build an evidence base for how family engagement contributes to improving systems of care and health outcomes for CYSHCN and other populations.

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14. Shared by a professional key informant for this project.

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**ABOUT FAMILY VOICES:** Family Voices is a national family-led organization of families and friends of children and youth with special health care needs and disabilities. Family Voices supports a national network of family organizations, and promotes family/professional partnerships at all levels in order to improve health care services and policies affecting children. Family Voices is dedicated to social justice, health equity, and keeping families at the center of children's health care. **CONTACT:** Family Voices, P.O. Box 37188, Albuquerque, NM 87176, [www.familyvoices.org](http://www.familyvoices.org), 888-835-5669

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