

Family Voices is a partner to the **Genetic Alliance's National Genetics Education and Family Support Center**. This tip sheet was created in response to the Regional Genetics Networks (RGN) request for information to support and ensure meaningful family engagement in genetic services. This information was adapted from the Family Voices [Framework for Assessing Family Engagement in Systems Change](#).

As part of their work, RGNs are expected to:

- Encourage family engagement at the individual level of care so that patients and families can partner in decision-making
- Engage families in project advisory groups or National Coordinating Center workgroups
- Collaborate with the National Genetics Education and Family Support Center to support both families and RGN staff needs for assistance around engaging families and skill building opportunities so everyone can participate in a meaningful way

Partnerships between healthcare providers and families improve outcomes for the individual child.¹ Patient and family engagement throughout all levels of the health care system – individual, advisory, policy-making – can improve the entire health care system.² Family Voices has created a framework for supporting meaningful family engagement in systems-level initiatives. This framework includes four domains: representation, transparency, impact, and commitment. For more information, read the entire [Framework for Assessing Family Engagement in Systems Change](#).

Implementing one or more of the following practices can ensure meaningful family engagement:

Representation

- **Connect with the [Family-to-Family Health Information Center](#) (F2F)** in each state in your region. F2F staff can help with outreach and identification of families, especially diverse and medically underserved families; provide peer-support, mentoring, and skill-building leadership opportunities.
- **Compensate family leaders** for their time, expertise, and the costs of participation, such as travel expenses and childcare.
- **Engage family leaders that represent the diversity, including race, socioeconomic status, and geographic location, of the population that you are serving.**

Transparency

- **Partner with families in all parts of the process**, from brainstorming to evaluation.
- **Reserve at least two positions for family leaders** in committees, boards, and other groups with defined structures.
- Provide families with **skill-building opportunities** so they can participate to their **maximum potential**. (*See Representation and importance of connections with F2Fs*).
- **Make meeting minutes and other key materials available to family leaders** in formats they can access, in language they can understand, and in a timely way.

Impact

- Ensure that families' know their **input is valued, acknowledged, and helps lead to change**.
- Allow participating families to **influence decisions about existing policies and programs and help select and prioritize new issues to address**.

Commitment

- Promote engagement as a **core value** of your organization.
- Establish **engagement at all levels** – individual, advisory, and policy.

¹ Cené, CW, Johnson, BH, Wells, N, Baker, B, Davis, R, and Turchi, R. (2016). A Narrative Review of Patient and Family Engagement: The "Foundation" of the Medical "Home". Med. Care, 54(7):697-705.

² <https://www.brookings.edu/research/the-future-of-children-policies-to-promote-child-health>