



Linking Families  
to Genetics



# Understanding Family Engagement in Genetics Services

*"Engagement is a full scope of practice from the individual, to clinical, to systems level with family and patients as partners and leaders."*

*— Family Leader*

## Acknowledgments

We are grateful for all the family leaders and Regional Genetics Network staff who shared their perspectives to further family engagement in the genetic healthcare delivery system. Thank you to Peter Antal from Antal Consulting, LLC who supported the data collection and analysis of this work. A special thank you to Molly Martzke, Jamie Loey, and Dr. Eboni Drummond for the development of this report.

This report was finalized in August 2022.

This report is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of an award totaling \$400,000 with 0 percent financed with non-governmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by HRSA, HHS, or the U.S. Government. For more information, please visit [HRSA.gov](https://www.hrsa.gov).

## Table of Contents

<b>Acknowledgments</b> .....	<b>1</b>
<b>Executive Summary</b> .....	<b>3</b>
<b>Background</b> .....	<b>4</b>
<b>Introduction</b> .....	<b>5</b>
<b>Methods</b> .....	<b>6</b>
<b>What We Discovered About Meaningful Family Engagement</b> .....	<b>7</b>
<b>Defining Family Engagement</b> .....	<b>7</b>
Facilitators for Successful Family Engagement .....	7
Considerations for Engaging with Families .....	8
Supporting and Understanding Families as Individuals.....	8
Supporting and Understanding Families as System Stakeholders .....	9
Barriers to Successful Family Engagement .....	9
<b>Strengthening the Relationship Between Families and Organizations</b> .....	<b>10</b>
The Value of Families to Organizations .....	10
The Value of Organizations to Families .....	11
<b>Areas of Consideration</b> .....	<b>11</b>
<b>Additional Education and Training for System Partners</b> .....	<b>12</b>
<b>Draft Measurement Areas for Assessing Family Engagement in the Genetics Healthcare Delivery System</b> .....	<b>13</b>
Infrastructure Domain .....	13
Operations Domain.....	14
Impact Domain.....	15
<b>Limitations</b> .....	<b>15</b>
<b>Recommendations</b> .....	<b>16</b>
Define Family Engagement Within the RGN system .....	16
Measure the Impact of Family Engagement in the Current Funding Cycle .....	16
Establish Family Engagement Performance Measures .....	17
<b>Conclusion</b> .....	<b>17</b>
<b>Appendix</b> .....	<b>18</b>
<b>Discussion Questions</b> .....	<b>18</b>
<b>Additional Resources and Information</b> .....	<b>18</b>
<b>Report Acronyms</b> .....	<b>19</b>

## Executive Summary

As the number of conditions screened for and detected by genetic testing expands leading to more families looking for genetic medical support, access to diagnostic and preventive services and the dissemination of reputable information is critical. Engaging individuals with or those who are at-risk of developing genetic conditions, as well as their families in the genetic healthcare delivery system is necessary to improve the overall system of care for families. This engagement includes understanding barriers and opportunities to accessing quality genetic services, acknowledging specific needs around medical and health information, and building solutions together. Patient and family engagement are key tenants of the National Genetics Education and Family Support Program (Family Center) as well as the Regional Genetics Networks (RGNs).

Family engagement encompasses the range of approaches through which families are involved and interact with the genetics healthcare delivery system. This includes a spectrum of interactions from the clinical level to discussions, consultation, collaboration, partnership, integration, leadership, and shared decision-making. Assessment and reporting of family engagement in the genetics healthcare delivery system are complex and underutilized. To better understand family engagement within this system, the Family Center conducted six focus groups across the United States with family leaders from multiple family organizations to discuss their understanding of what meaningful family engagement means in practice.

Focus groups discussed what meaningful family engagement means to them and ways to strengthen the relationship between family leaders and organizations. The work of this project identified a variety of key qualities that facilitate successful family engagement along with special considerations and barriers from the family leader's perspective. In addition, family leaders proposed ideas for the training and education of stakeholders to ensure that the system was prepared to engage with them. Additionally, three domains identifying more specific measures for genetics healthcare delivery were proposed.

This report provides a summary of these findings to advise the development of family engagement measures for the Health Resources and Services Administration (HRSA) to use in future Family Center and RGN initiatives. The Family Center intends to incorporate these findings and suggestions into a pilot project. It will also continue to monitor ongoing regional family engagement activities and barriers, challenges, and best practices.

## Background

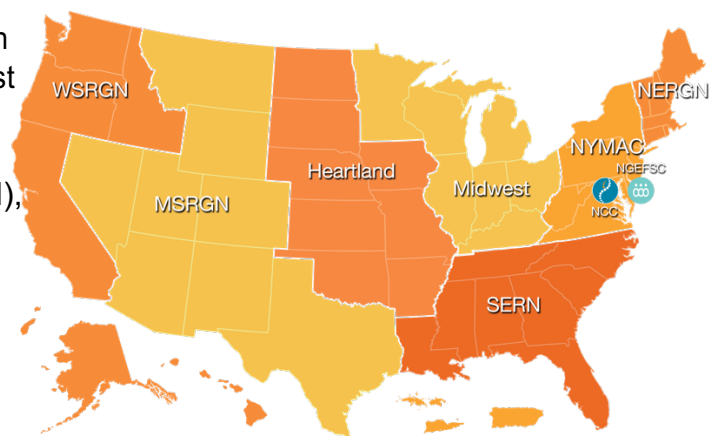
HRSA supports seven Regional Genetics Networks (RGNs) across the United States, a National Coordinating Center for the Regional Genetics Networks (NCC), and the National Genetics Education and Family Support Program (Family Center).

The Family Center is led by Expecting Health at Genetic Alliance in close partnership with SPAN Parent Advocacy Network and Parent to Parent USA. The Family Center's goal is to ensure that all individuals and families who have or are at risk of developing a genetic condition:

- Understand the implications of a genetic diagnosis;
- Have access to genetic services;
- Engage in their own care; and
- Have opportunities to engage in a meaningful way in national, regional, and local genetic healthcare delivery systems.

In addition to the above goal, the Family Center supports the RGNs by providing training, tools, and resources to facilitate family engagement in genetic services.

Current RGNs are New England Regional Genetics Network (NERGN), New York Mid-Atlantic Caribbean Regional Genetics Network (NYMAC), Southeast Regional Genetics Network (SERN), Midwest Regional Genetics Network (MGN), Heartland Regional Genetics Network (HRGN), Mountain States Regional Genetics Network (MSRGN), and Western States Regional Genetics Network (WSRGN). Each RGN is composed of up to ten U.S. states and territories. The goal of the RGNs is to increase access to genetic services and information for those with or at risk of developing genetic conditions and their families with a particular focus on medically underserved populations. The RGNs are a central component of the genetic healthcare delivery system in the United States, composed of healthcare providers, public health professionals, and family representatives (consumers, advocates, caregivers, and parents). The NCC supports the activities of the seven RGNs by providing infrastructure, coordination, technical assistance, and resources necessary to address issues of universal importance, allowing regions to focus on their unique areas of need.



## Introduction

In the past 15 years, the number of conditions screened for or detected by genetic testing has increased by nearly 500%.<sup>1</sup> The field of genetics and genomics continues to evolve towards a promise of earlier prevention, identification, and treatment of diseases. Even with these technical and clinical advances, a recent survey revealed that genetic knowledge among the public remains low.<sup>2</sup> Individuals who are less educated and part of medically underserved populations have a greater gap in knowledge of genetic conditions and access to genetic services. Additional barriers to access to genetic services include confusion around the misuse of genetic information, a lack of genetic referrals from primary care providers, and inadequate insurance coverage.<sup>3</sup>

Family engagement is one way to address such challenges for individuals with genetic conditions. Family engagement is defined as “patients, families, their representatives, and health professionals working in active partnership at various levels across the healthcare system to improve health and healthcare.”<sup>4</sup> It is one of six core outcomes that define a comprehensive and coordinated system of care for children and youth with special healthcare needs (CYSHCN).<sup>5</sup> To improve individuals’ and families’ access to genetic information and services, it is critical to engage family leaders at various levels across the genetic healthcare delivery system so their perspectives can help shape the care and resources that will be provided.

While there are many efforts underway to integrate family perspectives into the genetics healthcare delivery system, there has been little assessment or measurement done specifically to this system to understand the impact of family engagement. The engagement of families within the RGNs offers us an opportunity to understand how to assess and measure their integration into the broader system. This type of evaluation work can help all stakeholders better understand how certain strategies and efforts lead to improvements in the quality of genetic services, programs, and practices.

---

<sup>1</sup> Diamonstein, C., Stevens, B., Hashmi, S. S., Refuerzo, J., Sullivan, C., & Hoskovec, J. (2018). Physicians’ awareness and utilization of genetic services in Texas. *Journal of Genetic Counseling*, 27(4), 968-977. <https://doi.org/10.1007/s10897-017-0199-z>

<sup>2</sup> Chapman, R., Likhanov, M., Selita, F., Zakharov, I., Smith-Woolley, E., & Kovas, Y. (2019). New literacy challenge for the twenty-first century: Genetic knowledge is poor even among well educated. *Journal of Community Genetics*, 10(1), 73-84. <https://doi.org/10.1007/S12687-018-0363-7>

<sup>3</sup> Beene-Harris, R. Y., Wang, C., & Bach, J. V. (2007). Barriers to access: Results from focus groups to identify genetic service needs in the community. *Public Health Genomics*, 10(1), 10-18. <https://doi.org/10.1159/000096275>

<sup>4</sup> Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health affairs*, 32(2), 223-231. <https://doi.org/10.1377/hlthaff.2012.1133>

<sup>5</sup> National Agenda for Children with Special Health Care Needs: Achieving the Goals 2000. Washington, DC: Health Resources and Services Administration (1999).

To identify understanding and successes in family engagement, the Family Center conducted an assessment to explore the perspectives of family leaders (who are involved in the work of the RGNs) about family engagement efforts and activities, both within their own networks and across the larger genetic healthcare delivery system. Conducting a family leader-focused study provides data that can be used to show how families participate as stakeholders in the genetic healthcare delivery system. This report provides a summary of findings, showcases opportunities for improvement in organizational engagement with families, and includes recommendations for increased involvement of family within the genetics healthcare delivery system.

## Methods

The Family Center utilized two approaches to identify activities and determine the need for family engagement: 1) qualitative methods approach through in-depth focus group interviews with RGN-identified family leaders, and 2) materials review of two other HRSA- funded, family engagement focused organizations (Family Voices<sup>6</sup> and Hands & Voices<sup>7</sup>). The materials review helped the team gain a better understanding of family engagement across different systems of care for CYSHCN.

Six focus groups were held between April and May of 2021. The groups were made up of family leaders from six of the seven RGNs. Staff from each RGN recommended that active family leaders participate. Family leaders were offered a stipend for their participation. Conversation prompts were generally exploratory, with little guidance from the facilitator to allow for more open-ended responses. Several themes arose from this open approach which helped to inform the critical takeaways and lessons learned on ways to improve family engagement efforts.

The discussion questions that guided the conversation were:

- Within the context of genetic services that families are reliant on in your area, what does meaningful family engagement mean to you?
- What are the barriers to successful engagement?
- What do families bring to the table that you think organizations need to be more aware of?
- What additional opportunities do organizations bring to families? Why should they consider becoming more involved?

---

<sup>6</sup> Family Voices. (n.d.). *Family engagement in systems toolkit*. <https://familyvoices.org/familyengagementtoolkit/>

<sup>7</sup> Hands & Voices. (n.d.). *Data to impact*. <https://www.handsandvoices.org/fl3/resources/needs-assessment.html>

A fifth question was added to the series after the second focus group discussion. The topic emerged that both families and professionals need support for effective family participation in healthcare systems. This two-part question was added to the following four focus groups.

- Are professionals ready to engage with families? What trainings might be helpful?

## What We Discovered About Meaningful Family Engagement

### Defining Family Engagement

There are many examples of family engagement within the genetics healthcare delivery system, such as family members as staff within RGNs, awarding contracts to family-based organizations to support RGN work, and having family leaders to

serve on advisory groups. The family leaders in the focus groups spent time defining what meaningful family engagement meant to them.

*“It is viewed as a practice or discipline, and engagement is a full scope of practice from the individual, to clinical, to systems level with family and patients as partners and leaders.”*

*~ Family Leader*

They responded by sharing what they found valuable, what they believed to be important considerations agencies people should be aware of, and made suggestions for working with different groups.

### Facilitators for Successful Family Engagement

Across all focus group discussions, respect, clear communication, and authentic involvement emerged as key qualities that facilitate family engagement [Figure 1]. Examples of respect included active listening and a shared honoring of individuals’ cultures, experiences, and input. Participants also saw appropriate compensation for a family’s time and related expenses as a form of respect. In addition, participants highlighted the importance of clear communication project staff clearly articulating the purpose of engaging with families. This helps the family leader understand the expectations and objectives of their time while providing participants a strong foundation for further work together.



*Figure 1. Key qualities of successful family engagement.*

Lastly, participants shared that families need authentic involvement from beginning to end, meaning thoughtful inclusion in the project phases including evaluation, data collection, and implementation. Participants recognized that bringing families in at the beginning of the project may be a bit challenging but emphasized the value of family feedback throughout the process. This sentiment was further echoed when one participant commented that families need to influence what happens in the project rather than providing just reactions to the project



While respect, clear communication, and authentic involvement are the core themes for successful family engagement, participants shared more nuanced aspects of family engagement that contribute to success. For example, engagement can heavily depend on personal relationships and the steps an organization has taken to integrate family leaders (i.e., written policies on engaging families as stakeholders). In addition, participants also noted that the focus of a project may influence the type and level of family engagement that is needed and provided. For example, if there is an initiative that is focused specifically on metabolic disorders, there may not be a high level of engagement from individuals if they are not already interested in the topic. There may be few families engaged but their engagement may be deeper or longer lasting because the topic is relevant to them, in this case, because they have a metabolic diagnosis. These facilitators to successful family engagement culminate into one critical point summarized by a participant: “Information gets shared because trust is established.”

### Considerations for Engaging with Families

Participants shared specific aspects of family engagement that are important to consider for two groups in particular: Individual families and family leaders as stakeholders. When interacting with either group, it is important to recognize the different aspects of a family’s identity, such as race and ethnicity, geographic location, language, and military involvement. These intersecting aspects are part of a family’s history and identity that influence their healthcare decisions, such as preferences around in-person vs. virtual communication, fear of testing, discussion of a condition with other family members, privacy, comfortability with outsiders, and how to show culturally-sensitive respect. Because every family is different, it’s important to allocate adequate time, energy, and resources to the families and populations an organization is serving to better understand how to meet their needs.

### Supporting and Understanding Families as Individuals

Participants shared that when working with parents of children with different diagnoses and conditions, language is especially critical. It is important that providers educate themselves on how to explain conditions in a realistic but not in a pessimistic way and work with the parents so they can become better engaged and support their child (particularly when there are challenges with meeting basic family needs). Lastly, participants noted the importance of partners dedicated to family engagement who recognize a social model approach and not only a medical model approach to care. To work in family engagement there must be an understanding of not only the multiple health systems the child participates in, but also the child as part of the family, and the family as part of a community system because each component impacts multiple aspects of their healthcare and can be part of the solution to wellness.

## Supporting and Understanding Families as System Stakeholders

Participants shared that it is imperative to ensure all involved stakeholders know what family engagement means, why it is vital, what family organizations are, and what they do. Participants emphasized the importance of building a mutual, long-term relationship with family-based organizations. To do this, it is important to tailor an organization's approach to each family group, consider the tone of emails, and clearly articulate why that family-based organization is being asked to engage. As part of this, it is important to recognize that there are often multiple demands on family-based organizations' staff without compensation. This results in the need for organizations to discern who they can work with and in which projects they invest their time.

Oftentimes people think of an organization or family leader in only one way (i.e., bilingual staff thought only of their translation skills). Participants stressed that stakeholders should be considerate of the multiple skills and abilities of family leaders. Lastly, the stakeholder and the family-based organization should convene after the use of the family-based organization's network of families for engagement. This allows for reflection on areas that worked and those that didn't go as planned.

## Barriers to Successful Family Engagement

Participants shared several barriers to family engagement citing individual realities, organizational readiness, and healthcare system challenges. Participants highlighted that families caring for a child with a challenging health condition may face barriers at the individual level that are intertwined with their family's unique journey. This includes dismissive encounters with state healthcare systems, family experiences dealing with the emotions brought on by diagnoses, challenges around guardianship, and general helplessness of not knowing what they do not yet know. These are just a few of the concerns families face, often, more than one at a time. It is helpful for those committed to increasing family engagement in their work to be aware of the realities that families of children with special healthcare needs are navigating.

In some cases, participants cited barriers due to the organizational-level challenges of the stakeholders wishing to engage with them. They emphasized issues pertaining to an organization's limited understanding of the benefits of family engagement. Often the organizations were unable to view the whole individual and family, and only viewed them through the lens of a diagnosis. This leaves out all the experiences of how the individual or family functions within society. Participants also shared concerns about assumptions from professional stakeholders regarding parental knowledge and the ability to grasp complex concepts around genetics without a similar critique of the stakeholder. While there is often discussion about what makes a family representative ready to be a leader, there needs to be more discussion, training, and attention to ensure organizations and stakeholders are ready to engage with family leaders in a productive and inclusive manner.

When reflecting specifically on barriers to accessing healthcare, participants noted further challenges the individual must navigate: the challenges presented by insurance coverage, fears around testing, ability to access services (impact of geography and time), and how to have an effective telehealth visit. Additionally, concerns were raised about the inability of staff from different specialty areas to grasp the complex range of challenges posed by a genetic condition and provide effective care.

Participants also shared professionals often do not understand what families go through to get the right services to care for their child, with many caregivers having to quit their jobs or find alternate jobs, fill out complex application packages for federal or state support, and sometimes receive only a minimal level of agency support for their child.

While neither a facilitator nor barrier, power dynamics between families and organizations emerged as a complex aspect of family engagement. Families work closely with organizations to share their expertise, yet organizations are often in the position of power as they are the ones employing families and seeking out their opinions. These power dynamics come into play with how families and organizations collaborate and set expectations. It is important that this dynamic not only be acknowledged but also addressed by establishing clear communication and expectations for all involved.

## Strengthening the Relationship Between Families and Organizations

Activities around family engagement need to be mutually beneficial to achieve the desired effect of actively including families in efforts to change the system. It is critical that all stakeholders understand the vision, goals, and benefits of working together. Actively engaging families as equal partners in their child's health

care and decision-making has been associated with reduced unmet

*“Everyone needs to be on board with this new way of doing business. They need to be willing to use first names [instead of title] and not be hierarchical.”*

*~ Family Leader*

health needs, fewer reported problems accessing specialist referrals, lower out-of-pocket expenses, and improved physical and behavioral function in children.<sup>8</sup> To strengthen family engagement, both organizations and families need to value the idea that each has unique experiences and perspectives as stakeholders in the system of care.

### The Value of Families to Organizations

Participants shared multiple areas where organizations can gain a better appreciation of the positive impacts of family engagement. These benefits include serving as content experts as well as working on projects and programs. Families have unique and intimate knowledge of how a genetic condition impacts them beyond the diagnosis. They have lived experiences of how the

<sup>8</sup> Health Resources and Services Administration, Funding Opportunity HRSA-20-049, p.3.

healthcare system can exceed or fall short in meeting family needs, what gaps exist in current systems, and how to prioritize opportunities. In addition to providing lived experiences, families can also be integral in supporting project implementation. They can help to inform the allocation of resources based on the needs and motivations of a community, assist in diversifying partnerships, improve data collection and assessment efforts, find funding, and help to translate information to families who are not yet connected to the organization.

Families can drive change at every level of the healthcare system, whether in a clinic or through legislation. Participants discussed how families have played a critical role in identifying needs, launching new innovations, creatively addressing problems and barriers, improving access and opportunity, reducing healthcare costs, and helping providers to see the full potential of the child and the family and to take action to help them reach it.

### The Value of Organizations to Families

While organizations can benefit from family engagement, families can also benefit from the unique opportunities, resources, and infrastructure that a partnership with an organization can provide. Being involved with an organization can directly help an individual family and provide an opportunity to help other families on the local, state, and national levels. On the individual level, families can build their own professional skills, expand their own network, and earn financial support for their efforts.

In addition to providing professional development opportunities, organizations can support a peer-to-peer learning environment, where families can connect with one another to share their own stories, provide advice, and recommend local resources. This peer-to-peer environment is critical in fostering relationships and creating a system of support. One participant highlighted that by “emphasizing the strength in numbers and the opportunities to improve the system, [families] can celebrate and share being together for positive change.”

Ultimately, families and organizations can be mutually beneficial to one another when the collaboration is thought out and designed by both. By centering the expertise that families bring and leveraging the opportunities that organizations provide, they can work together to support communities and increase their impact to ensure that family needs are met.

### Areas of Consideration

The conversations held with the family leaders during the spring of 2021 were incredibly rich and dynamic as each group brought a new lens for consideration through which to engage with families effectively and with purpose. While many family associations and families themselves are ready to engage more fully, we require an increase in knowledge, skills, and dedication by all partners if efforts to improve systems of care are going to be successful.

The focus group participants discussed several next steps including development of measurement areas to determine baselines, assess improvements, and highlight achievement of successful family engagement within the genetics healthcare delivery system. They also recommended training sessions for organizational staff.

*“Professionals want to engage with families, [they] understand it is important. However, it takes time, and systems don’t always allow for the time it takes to form the relationships. Things are so fast paced – parent input becomes a last resort rather than a meaningful component.”*

*~ Family Leader*

## Additional Education and Training for System Partners

The need for training and education for families to engage as equal stakeholders in the system was a common theme among the focus groups. This support was expressed as a need for both family leaders and the systems that interact with them, but the content that was collected was specific to the question, “Are professionals ready to engage with families? What trainings might be helpful?”

*“Professionals need to come with the mindset that there is something to learn [from families].”*

*~ Family Leader*

Participants shared several ideas for education and training for professionals in the field to ensure that they were ready to engage with family leaders. The suggestions ranged from ideas for direct care providers to those engaging families at the system level. Suggested ideas related to professional development included:

- How to interact with families, not in a medical model but learning to see the importance of engaging with the parents to learn about the child rather than just the diagnosis.
- Understanding how genetics is perceived, and its role within different communities, cultures, and families.
- The importance of seeing families as equal stakeholders in the system where everyone can learn from one another because families bring unique ideas and perspectives, and problem-solving.
- Devoting time and effort to implementing family engagement.
- Stakeholders embrace the importance of having family leaders as equal partners in system improvement. For example, there needs to be a willingness to use first names and not be hierarchical.
- There is a general need for leadership training, specifically how to build effective teams.

## Draft Measurement Areas for Assessing Family Engagement in the Genetics Healthcare Delivery System

The following domain and measurement areas reflect the knowledge gained through the materials review, the Family Center’s knowledge gained on assessing family engagement in the 2018 report *Exploring the Role of Families in Regional Genetic Networks: A Summary of Engagement Activities and Recommendations*, as well as input from the discussions in this current project. Measurement areas reflect a general category within which more specific metrics should be developed. Organizations may review each area to determine which aspects fit the work they have underway and then develop specific measures that would help to document progress in each area.

### Domains

- Infrastructure: how an organization or initiative sets itself up to carry out the work.
- Operations: day to day activities involving families.
- Assessing Impact: addressing “what happened as a result of your efforts?”

### Infrastructure Domain

Activity or Focus Area	Potential Measurement Points
Needs Assessment	<ul style="list-style-type: none"> <li>• Design done from perspective of families, family-based organizations, state systems</li> <li>• Consider motivations and realities of families, not only what is missing/barriers</li> </ul>
Commitment	<ul style="list-style-type: none"> <li>• Written policy</li> <li>• Identified leaders</li> <li>• Acknowledgment</li> <li>• Budgeting for families</li> <li>• Time</li> <li>• Plain language</li> <li>• Family champion</li> </ul>
Clear expectations	<ul style="list-style-type: none"> <li>• Job descriptions</li> <li>• Deliverables</li> <li>• Feedback loops</li> </ul>
Accessible formats	<ul style="list-style-type: none"> <li>• Addressing technology barriers</li> <li>• Time and place of meetings</li> </ul>
Available support for effective engagement	<ul style="list-style-type: none"> <li>• Connections with family organizations</li> <li>• Family-to-family connections</li> <li>• Mentoring and leadership support</li> </ul>
Evaluation	<ul style="list-style-type: none"> <li>• Role of families in designing, interpreting, and reporting out on Quality Improvement and related activities</li> <li>• Multiple opportunities</li> </ul>

## Operations Domain

Activity or Focus Area	Potential Measurement Points
Ongoing Activities	<ul style="list-style-type: none"> <li>• Transparency (assessed needs for participation, clarity of roles, information for meetings, frequency of communication, timeliness of information, confidentiality policy)</li> <li>• Types and Quality of information regularly provided to families (will vary based on focus of services - family support, early intervention, referrals, financial, legal, pediatric providers, other)</li> <li>• Representation (serving families from diverse or underserved populations; race/ethnicity, culture, language, geography, socio-economic)</li> <li>• Ability to provide accommodations for reading and participating (other languages, defined acronyms)</li> </ul>
Training	<ul style="list-style-type: none"> <li>• Ensure families receive training to participate as equal stakeholders.</li> <li>• Training is provided to professionals on how to engage families as stakeholders.</li> <li>• Make sure families have access to mentorship support, peer leaders, educational materials, forums, leadership training events, and infrastructure support.</li> </ul>
Supporting Meaningful Participation	<ul style="list-style-type: none"> <li>• Ensure families are consistently participating in meaningful roles. This may consider the context of the continuum of involvement from the National Genetics Education and Family Support Center's work on the topics:               <ul style="list-style-type: none"> <li>○ Awareness (relationship development)</li> <li>○ Participation (project involvement) participating in volunteer opportunities)</li> <li>○ Commitment (ongoing collaboration)</li> <li>○ Leadership (shared decision-making)</li> </ul> </li> </ul>

## Impact Domain

The focus of the Impact Domain can vary across different types of genetic services organizations depending on their area of focus with family engagement. Some examples of impact areas might include improved access to information, timeliness of services, quality of care, and health outcomes. Regardless of the focus, there should be some summary of what changed because of family involvement.

- Did budget allocations change?
- Major decisions on the delivery of services?
- Did the evaluation design change?
- How did family input result in improvement in project outcomes?

A summary of what changed because of family involvement was a critical point that focus group participants discussed. It is recommended that organizations share with family participants a short summary describing what happened because of family engagement, lessons learned, recommendations identified, or planned changes for the upcoming year.

## Limitations

As with any process, there were limitations to the focus group interview approach. Our interviews with family leaders were subject to response bias, selection bias, and group influence. First, participants knew we were asking about family engagement and were aware of the interviewers' roles with the Family Center and broader Regional Genetics Networks. Due to a courtesy response bias, they may have been more likely to respond favorably to questions about their family engagement practices. Additionally, RGN staff provided our team with family representatives from their region to participate in the focus groups. This selection bias could have allowed RGNs the opportunity to provide family representatives they believed would positively reflect on their family integration practices. Our data collection method – semi-structured focus groups – also led to additional minor limitations. The Family Center conducted these interviews via an online meeting platform. Participants and interviewers were in different locations which allowed for occasional delays, disruptions, and deviations from the defined discussion guide. For example, some participants joined late and brought alternative agenda items for discussion which limited the time available for the interview. Finally, the data runs the risk of “group influence,” where some may take the ‘lead’ in a focus group making their opinion the loudest. There were moments in some discussions where participants seemed hesitant to share their true feelings or went along with what appeared to be the prevailing opinion.<sup>9</sup> These limitations are theoretical and are common in qualitative research design. Despite these limitations, we have no indication that they have drastically affected our findings.

---

<sup>9</sup> Smithson, J. (2000). Using and analyzing focus groups: Limitations and possibilities. *International Journal of Social Research Methodology*, 3(2), 103-119. <https://doi.org/10.1080/136455700405172>



Families engage within the genetics healthcare system in a variety of ways. While the focus of this project was limited in scope to the activities of the HRSA-funded portfolio of three genetics programs, there is a vast network of family-based organizations along with disease and condition-specific organizations that do not interact or have limited contact with these HRSA-funded projects. This creates a large number of family leaders whose thoughts and opinions are not reflected in this report.

## Recommendations

Through this project, the Family Center learned the variety of ways families are involved within the genetic healthcare delivery system and identified a gap in the reporting of family engagement activities and outcomes. Existing performance measures and project reporting criteria for the RGNs focus on the process of reaching individuals and families. While reaching individuals and families is a first step in engagement, teams must capture the ways in which individuals and families are involved in partnerships, participate in governance, consult, and support RGN decision-making along with other aspects of genetic healthcare delivery services. As family integration is a key strategy to improve access to genetic information and services, it is important that family engagement is adequately defined and captured in project reporting to develop the appropriate instruments to measure and assess the impacts of family involvement within the genetic healthcare delivery system.

### Define Family Engagement Within the RGN system

Shared definitions enable us to have a common understanding of a word or subject. Through the collection of data during this project, it is apparent that there is a global understanding of family engagement. However, to adequately define and capture data for reporting and to develop the appropriate instruments to measure and assess the impacts of family involvement within the genetic healthcare delivery system there needs to be a common understanding of language.

It is recommended that the Family Center along with system partners create guidelines that define family engagement measurement points. Adopting uniform definitions will allow programs to compare across regions and look at national progress in these areas.

### Measure the Impact of Family Engagement in the Current Funding Cycle

Measurement of the impact of family engagement shouldn't wait until it is directed. Instead, it should begin immediately. This measurement can begin at both the regional level as well as within the Family Center activities. The Family Center has identified an interested RGN to create a pilot project to assess the viability of measuring family engagement. The Family Center has additional plans to begin measuring the impact of family engagement within its own activities.

## Establish Family Engagement Performance Measures

As the genetics system of care continues to develop and mature, the measurement of family engagement's uniform data collection methods is essential to the evaluation of changes in access to services for patients with genetic conditions, especially the medically underserved. HRSA can support this effort by including definitions and requiring a metric of family engagement as one of the data points in future funding opportunities. By incorporating continuous accountability mechanisms to track, monitor, and manage the achievement of the goal of family engagement, we will ensure the fidelity in the system of care philosophy of the integration of families at all levels.

## Conclusion

The findings from this project exemplify the variety of ways family leaders understand and perceive family engagement within the genetics healthcare delivery system. Together with HRSA, the RGNs, the NCC, and other project partners, the Family Center will work to facilitate how to categorize, assess, and bolster meaningful family engagement specific to the context of RGN initiatives. As a next step, the Family Center intends to incorporate these findings and suggestions into a pilot project to assess the viability of measuring family engagement in the genetics healthcare delivery system with an identified and interested RGN. The Family Center will also continue to monitor ongoing regional family engagement activities and promote the sharing of barriers, challenges, and best practices. Future plans include setting clear expectations for family engagement as an essential component of the project and setting a clear process for identifying and communicating resulting impacts.

As both the concept and understanding of family engagement continue to evolve in the U.S. with growing awareness in many sectors about its importance in improving service delivery and outcomes, the Family Center will continue working to further advance the genetic healthcare delivery system understanding of how to authentically improve family engagement in the design, delivery, and assessment of services.

## Appendix

### Discussion Questions

- Within the context of genetic services that families are reliant on in your area, what does meaningful family engagement mean to you?
- What are the barriers to successful engagement?
- What do families bring to the table that you think organizations need to be more aware of?
- What additional opportunities do organizations bring to families? Why should they consider becoming more involved?
- Are professionals ready to engage with families? What training for professionals might be helpful?

### Additional Resources and Information

The following resources were identified by project participants as potentially useful to others engaged in genetics services as well as improving engagement efforts with families.

- Delivering a Disability Diagnosis: <https://www.ablenh.org/our-work/disability-diagnosis-dialogues/>
- Genetic Education Materials for School Success (GEMSS – New England Regional Genetics Network): <https://www.gemssforschools.org>
- Genetics Resource & Education Advocacy Tool (GREAT - Western States Regional Genetics Network): <https://www.westernstatesgenetics.org/project-activities/family-advocates-resource-project/>
- Family Engagement in Systems Toolkit (FESAT): <https://familyvoices.org/familyengagementtoolkit/>
- Supports for Families, Educators, and Young Adults:
  - F2Fs: <https://familyvoices.org/lfpp/f2fs/>
  - Parent Training & Information Centers: [www.parentcenterhub.org](http://www.parentcenterhub.org)
  - Understood: <https://www.understood.org/>
- Leading by Convening Framework: <https://ncsi.wested.org/resources/leading-by-convening/>
- Serving on Groups: <https://servingongroups.org/>
- The Patient-Centered Outcomes Research Institute's (PCORI) new training package for researchers and healthcare professionals as well as patients and family partners - "Research Fundamentals: Preparing You to Successfully Contribute to Research." - <https://www.pcori.org/engagement/research-fundamentals>
- "Carnegie Challenge Paper: Next Generation of Family Engagement." <https://www.carnegie.org/topics/topic-articles/family-community-engagement/engaging-families-help-children-succeed/>

## Report Acronyms

HRSA	Health Resources and Services Administration
NCC	National Coordinating Center for the Regional Genetics Networks
RGN	Regional Genetics Network
NYMAC	New York Mid-Atlantic Caribbean Regional Genetics Network
NERGN	New England Regional Genetics Network
MGN	Midwest Regional Genetics Network
HRGN	Heartland Regional Genetics Network
WSRGN	Western States Regional Genetics Network
SERN	Southeast Regional Genetics Network
MSRGN	Mountain States Regional Genetics Network