



## Principles and Approaches to Partnering with Families and Youth on Research Teams

*The recommendations outlined in this document are designed to provide guidance to research teams in how to identify, orient, and support family and youth partners in a research team.*

One of the goals of the CYSHCNet is to meaningfully include the knowledge, expertise, and experience of families and youth in the research process. Family and youth will be partnering in all aspects of CYSHCNet projects from planning, through data collection, to reporting and dissemination. A family-centered approach that utilizes the valuable insights of families, youth and young adults will enhance the research process and outcomes.

This guide is provided to help investigators work in a meaningful way with CYSHCN and their families around research initiatives.

### **Understanding family-centered care**

Family-centered care is a philosophy of health care that recognizes and respects the pivotal role of the family in the lives of children. It promotes normal patterns of living and supports families in their natural care-giving roles, making medical decisions, and providing medical care to their child.

Family-centered care means partnering with patients and families, rather than doing things to or for them. Relationships between patients, families, and health care providers are essential alliances and partnerships with each bringing expertise to decision-making.

Family-centered care goes beyond the care of the individual child or youth but requires incorporating the expertise and experience of families in program, policy and system design, implementation, evaluation and research.

*“Making patients and their families truly the force that drives everything else in health care is perhaps the most revolutionary tool of all.” (Berwick 2010, p. xxii)*

### **Why have family partners on research teams?**

Families bring their own first-hand experience and the experiences of many other families which is invaluable for designing health-related research that is most meaningful for them, interpreting the results from their perspective, and putting the findings of such research into practice. Families bring a

perspective that health care providers and policy-makers do not have - the perspective of someone very close to the system but not constrained by the traditions of the system. They are experts who have experience with every single specialty and system that is important to their child. Families know how the system really works ... not how it was designed to work.

**Families are resources to:**

- Shed light on their unique experiences and the experiences of other families.
- Explain how services really work.
- Help professionals understand other systems and resources.
- Help make health care better.
- Suggest creative ideas for improvement.
- Support putting improvements in place.
- Assess if improvements are working before they are fully implemented.

**Benefits of research partnership for families:**

- It can potentially improve services for their child and for other children.
- It provides an opportunity to bring about meaningful change.
- It increases opportunities for a family to share information with other parents.
- It is satisfying to give back to the system.
- It expands a family's knowledge and skills.

**Benefits of family partnership for healthcare researchers:**

- It produces research findings that are relevant and interesting to families.
- It produces research findings that are framed in terms that families can understand.
- It integrates an accurate understanding of how health care is implemented in the home and community setting and across multiple systems of care.
- It improves the planning process.
- It increases professionals' knowledge and skills.
- It helps them do their job better.
- It brings fresh perspectives to problems.
- It provides an ally to advocate for better services for children and families.
- It increases professionals' empathy for and understanding of families.
- It fulfills many funders' requirements that family perspectives be included in research.

This guide will address the following considerations for research teams and family and youth partners:

- 1. Recruiting families and youth to serve on the research team**
- 2. Orienting families and youth to research project and team**
- 3. Supporting families and youth on the research team**
- 4. Guiding families and youth serving on research teams**

These considerations are discussed in detail below.

## Recruiting Families and Youth for the Research Team

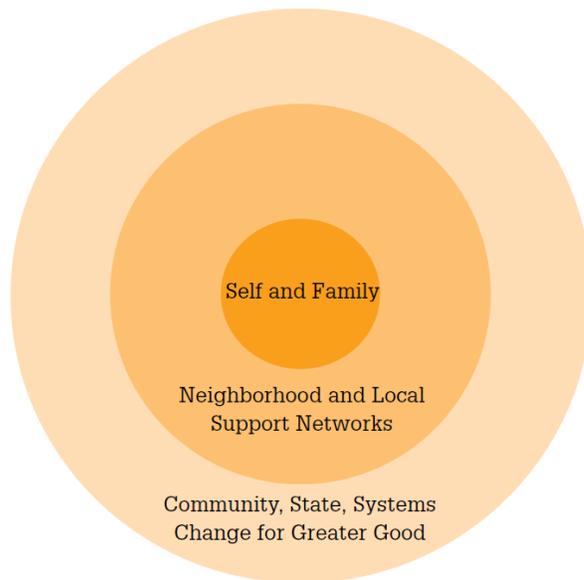
Recruit families and youth at the beginning of the process at the same time you are seeking other research team members. Do not wait to involve families when you are too far down the road in your project and may need to make changes to the project to incorporate family recommendations. Try to have at least two family or youth on your team to represent diverse experiences and expertise, and to avoid tokenism. To adapt to different sizes of groups, consider a ratio of 25 percent family and youth members on the team. The CYSHCNet Youth and Family Partnerships Team (YFPT) is available to help research projects recruit families and youth as partners.

- A. Because young people are rapidly developing skills and knowledge, the most effective partners to represent CYSHCN in research have often aged out of pediatric services. Be clear about your definition of “youth,” while respecting that others may have different definitions that work for their own purposes. Family Voices typically considers a CYSHCN “youth” to be a young adult with an ongoing health condition that began in childhood, who is under the age of 30.
- B. It is important to seek families or youth who have experience that goes beyond their own personal experience and who are ready to participate in activities that will look at the needs of families across their community, state, or around the country. Like all professionals, family and youth leaders need contact with other families participating in similar experiences to maximize their learning and growth. It is very beneficial to recruit families who are connected to family-led organizations that can provide mentoring and support.

Figure 1: The Concentric Circle of Parent Leadership

*There is an evolution that families experience sometimes called The Concentric Circle Model of Parent Leadership. There is recognition that, through contact with other families, family leaders typically grow in their ability to see beyond their own experience and consider the “greater good” for all children.*

*The concentric circle demonstrates this growth. Parents/family often find themselves in the center of the circle. They manage the care of their children and their family without moving to the next circle, which is leadership in their community. The center is often a place families return to, for example, during a child’s surgery or crisis. Family leaders “flow in and out of the center,” but, with increased experience, can move from a personal level to the greater good in the outer circle.*



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Look for people who are:

- Interested in research
- Comfortable speaking in a group
- Able to use their experience constructively
- Able to see beyond their own experience
- Concerned about more than one issue or agenda
- Able to listen and hear differing opinions
- Connected to other families through a family-led organization, so that they bring a broad perspective on needs

Look for families or youth who have served on advisory committees or workgroups such as hospital advisory or special education advisory committees and families who have been involved with or participated in training programs from local, state, or national advocacy or family-led organizations such as Family Voices or ARC. Families who have these added experiences will bring knowledge and expertise beyond their own experience and have experience thinking at the systems level.

C. Determine what specific attributes you need represented:

- a. If your research requires a parent living in a specific geographic area, seek out families by contacting the state Family-to-Family Health Information Center or Family Voices organization or the state chapter of another advocacy organization like ARC. Building partnerships with these organizations in your state will also be helpful when you want to reach other families that may be needed for focus groups, surveys, or other activities.
- b. If you have a research project focused on a specific topic, condition, or type of family experience, contact the YFPT who can help you recruit.
- c. Youth or family leaders who have a specific lived experience can be reached through the broad national Family Voices network that can communicate with families and youth around the country.

### **Orienting families and youth to a research project and team**

Family and youth team members will need an orientation to the research project and your team. Family leaders may have very different expectations for what can be learned from research, what can be done with information and how quickly information will become available. They may also require an orientation to research methods; contact the YFPT for help identifying resources that will meet the needs of your family and youth partners.

A. Develop family-friendly informational materials about the project. Describe the roles of members of the team. Provide a detailed overview of the project goals and outcomes expected and provide any articles that may be helpful to better understand the project background or similar projects that have been done. Explain the overall timeframe and products that are expected to come out of the research, and what family participants may or may not be able to do with any information that is learned.

- B. Develop a family-friendly “elevator pitch” to describe the basics of the project briefly. This can quickly orient potential family partners to the project and help determine their degree of interest, to see if they want to engage further.
- C. Conduct a proposal walk-through. Have a member of your team and member of the YFPT meet with family and youth partners to go over your proposal section by section. This is a good opportunity to make sure that your family and youth partners understand the expectations and restrictions placed on your research by the funder, as well as the research conventions (for example, specific aims) that shape your project.
- D. Provide a glossary of terms and jargon that are often associated with the project or topic. Please note that **words can hurt**; if there is language in your glossary that your youth or family partner is uncomfortable with, it may be necessary to change to language that is more respectful or supportive. Please also know that such mistakes are common, but easily worked through with mutual respect. Conduct a person-first language review (for example, replace “diabetic” with “person with diabetes”) if needed.
- E. Explain the commitment you are asking of the family or youth partner, such as how often the team will meet and for how long.
  - a. Describe work that may need to be done between meetings, such as reading articles or meeting minutes.
  - b. When scheduling meetings make sure you consider the family or youth partner’s schedule.
  - c. Specify the compensation that the family or youth partner will receive.

### **Supporting family and youth team members**

- A. When developing your budget, include the costs for giving family and youth partners a wage or stipend to compensate them for their time participating on the committee, expertise, and expenses.
  - a. Be sure to consider related expenses such as parking, child care, transportation needs, and so on.
- B. Assign a youth and family liaison from the team. This person should check in with youth and family partners regularly, including before and after meetings, to find out if they have any questions or concerns.
- C. Encourage family and youth partners to participate in regular YFPT group calls to talk about their experiences with other family and youth participating in research.
- D. Use good meeting practices; always have an agenda and meeting minutes sent in advance of the meeting. Jointly develop team ground rules at the first meeting and revisit them at all meetings.
- E. Spend time on introductions at the beginning of each meeting, especially if there are new members.
- F. Establish a supportive, responsive environment by having the Principal Investigator or Project Director discuss the concept of collaborating with family and youth partners and why it is so important.
  - a. Acknowledge that there may be tensions and differing opinion and perceptions when undertaking this kind of partnership and that everyone’s perspectives have equal value.
- G. Remind everyone not to use jargon.

- H. Specifically ask the family and youth partners their opinions during discussion, this will help validate their role as team members.
- I. If a personal story becomes too long, acknowledge the importance of the story and suggest how the team might learn from and use that experience. Give feedback after the meeting to help the family participant understand what would be most helpful going forward.

*“Everyone benefits when healthcare professionals and families work together to improve care. When patients and families are empowered to help improve the system; providers and staff gain new perspectives and build new skills; and healthcare organizations that support the creative solutions that result from these partnerships improve the quality of the services and programs they offer”.*  
(Aquino, et al, n.d.)

#### **Concrete suggestions for youth and family partners who join research teams:**

- Do the homework. Come to discussions prepared to contribute.
- Participate in discussions actively and with confidence. Take the lead when you can.
- Don’t call yourself “just a patient/parent” – you are a team member with expertise and experience that is essential to success. And there is nothing “just” about the perspective that you will bring to the table.
- If you think an approach is getting bogged down or don’t believe it will lead to addressing real patients’ needs, speak up! It is the voice of real-life experience that often drives change.
- One of the most important factors in gaining respect is follow through. If you say you are going to do something, take it seriously, and meet the deadline. If you can’t deliver on time, let the team know when it will be done.
- If meetings are at an inconvenient time for you, offer other times that are better or participate via phone or video conferencing.
- If you need additional help in understanding a task you’ve been given, ask for clarification.
- Prepare and debrief for meetings or other activities by talking with the project liaison and the YFPT, always respecting the confidentiality of all aspects of the research work.
- Clearly identify the person on the team who can assist you with reimbursement for time spent and other issues such as childcare, parking and mileage.
- Recognize that family and research professional priorities may have very different time lines and expectations for what will be accomplished with research.

## 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

**ABOUT CYSHCNET:** Funded by the Maternal and Child Health Bureau through 2022, CYSHCNET is a multi-site research network of committed researchers, families, clinicians, and administrative and policy partners who work together strategically to accelerate the generation and application of knowledge needed to best help CYSHCN and their families. CYSHCNET is founded on partnerships with families at all levels, including oversight, research, training, and dissemination activities. [www.CYSHCN.net](http://www.CYSHCN.net)

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