



## **PATIENTS AND FAMILIES SERVING AS ADVISORS AND COLLEAGUES IN HEALTHCARE**

*“Making patients and their families truly the force that drives everything else in health care is perhaps the most revolutionary tool of all. Its importance is evident at the system level, but it comes though even more strongly at the personal level.”*

*Donald Berwick, Former CEO  
The Institute for Healthcare Improvement*

**Patient and Family-Centered Care** is an approach to the planning, delivery, and evaluation of health care that is based on partnerships among health care providers, patients, and families. Patient- and family-centered care is working with patients and families, rather than doing things to or for them. Relationships between patients, families, and providers are essential partnerships with each bringing expertise to decision-making.

Patient-and-family-centered care exists when:

- People are treated with respect and dignity.
- Health care providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
- Individuals and families build on their strengths through participation in experiences that enhance control and independence.
- Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

### **Why is it important that health providers have patient and family partners?**

Patients and families are the experts based on their experiences of being service consumers. They bring the perspective that 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.

### **Patients and Families are important Resources To:**

- Help make care better.
- Explain how services really work
- Shed light on the unique experiences of patients/families.
- Suggest creative ideas for improvement
- Inform clinics if improvements are working before they are fully implemented.
- Help professionals understand other systems and resources

### **Everyone benefits when patients/families and health providers work together in partnership to improve health services.**

#### **Benefits for Patients and Families:**

- Improved services for everyone in the system
- Opportunities to bring about meaningful change.
- Opportunity to contribute
- Satisfaction of giving back to the system.
- Opportunities to network with other patients and families.
- Opportunity to expand knowledge and skills.

#### **Benefits for Providers:**

- Improvement in the planning process.
- Increases their knowledge and skills.
- Helps them do their job better.
- Brings fresh perspectives to problems.
- Provides an ally to advocate for better services for everyone. Increases their empathy for and understanding of families.

*“Being a part of the Medical Home team has been a very rewarding experience. It has been an honor to share some of our experiences and help structure services and resources for other families. Most of all, it is rewarding to help each child reach their maximum potential!”*

*Clair, Minnesota Medical Home Team Parent*

## Tips for Being a Successful Advisor

1. Begin with your own experience. Share your thoughts and information about your experiences in ways that others can learn from it. Strive to be positive. Your story is very powerful. Be brief and make sure that the story you are telling has to do with the topic/conversation at hand.
2. **Learn about the community:** Learn who the people and programs are and what they do. Don't be afraid to say, "I don't understand", ask for clarification.
3. **Develop the big picture:** Educate yourself about the issues that concern all people affected by the service system. See beyond your own personal experiences and to represent the needs of other patients and families who have had different experiences than you. Some ways to learn about the experience of other patients and families is to participate in patient and family networking groups, ask to see a summary of the clinic's satisfaction surveys.
4. **Learn to Collaborate** – with providers and other consumers. Praise other team members for their willingness to work together. Stay involved, you can be the energy in the group. Don't 'demand' respect from professionals, 'expect' it by being prepared for meetings, coming on time, and giving input and suggestions that can make a difference. Listen, listen, and listen.
5. **Be patient** – sometimes change takes longer than you would like, it is worth the wait.
6. **Be prepared:** . Read information sent for the meeting. Ask questions.
7. **Learn to say "no":** Don't take on too much. Know when you need a break.
8. **Share the spotlight:** Suggest other patients or families who can also participate in advisory activities. Provide encouragement and support to them; such as offering to drive if that is an option or meet with them before or after the meeting to discuss the meeting. This extra support is especially helpful for families who may be typically under-represented, such as new immigrant families and families for whom English is a second language.
9. **Assume the best about people:** Build bridges. Respect the perspectives of others. Work in partnership with others. Keep an open mind and an open heart.

## **Let your needs be made known**

- Ask for more orientation to your state system, if you need it.
- If meetings are at a totally inconvenient time for you, offer other times that are better and/or participate via phone/video conferencing.
- Clearly identify the person on the team who can assist you with reimbursement and other issues.
- If you need reimbursement for child care and mileage, talk to your team leader.
- If a word or phrase is used and you don't know what it means, find out or write it down and ask later, or the person next to you...

## **Concrete suggestions for being actively engaged:**

- Take the lead when you can.
- Participate in discussions actively and with confidence. You are an equal partner! The other members of the team should treat you as an equal partner!
- Try not to call yourself “**just** a patient or parent” – you are a colleague with valuable knowledge and information that has equal value!
- If you think a topic is getting bogged down or don't believe it pertains to real patients' needs, speak up! It is the patient/parent's voice that often drives change.
- If direction from your team is vague, ask for specifics.
- 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, let the team know when it will be done.
- **Always remember that your voice is necessary for change!**

## **RESOURCES THAT MAY BE HELPFUL**

**Family Voices of Minnesota:** [www.familyvoicesofminnesota.org](http://www.familyvoicesofminnesota.org)

**Parent to Parent USA:** [www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx](http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx)

**Institute for Patient and Family Centered Care:** [www.ipfcc.org](http://www.ipfcc.org)

**Center for Medical Home Improvement:** [www.medicalhomeimprovement.org](http://www.medicalhomeimprovement.org)

**Institute for Healthcare Improvement:** [www.ihl.org/IHI/Topics/PatientCenteredCare/](http://www.ihl.org/IHI/Topics/PatientCenteredCare/)

**Remaking American Medicine:** [www.pbs.org/remakingamericanmedicine/care.html](http://www.pbs.org/remakingamericanmedicine/care.html)

**Agency for Healthcare Research and Quality:**  
[www.innovations.ahrq.gov/content.aspx?id=1764](http://www.innovations.ahrq.gov/content.aspx?id=1764)