



Moving from Parent to Advocate: Navigating a New Diagnosis

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About Family Voices



Family Voices is a national organization and grassroots network of families and friends of children and youth with special health care needs and disabilities that **promotes partnership with families** —including those of cultural, linguistic and geographic diversity—in order to **improve healthcare services and policies for children.**

Learn more at familyvoices.org.

Objectives



Define patient and family centered care.



Describe the difference between parenting and advocacy.



Identify 2 – 3 skills/strategies to be an effective advocate.



Recognize reliable sources of information.

Partnering with your child's providers

Negotiating Patient- and Family-Centered Care



Patient- and Family-Centered Care



What is a family?

- A constellation of people who come together because of marriage, birth, adoption, or from a desire for mutual support.
- A culture unto itself with different values and unique ways of realizing family members hopes and dreams

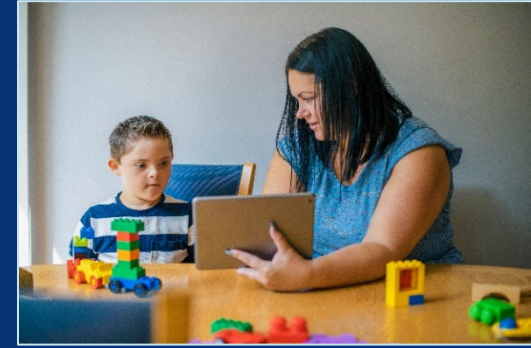
What is patient- and family-centered care?

- Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. (IPFCC, 2021)

Core Concepts of PFCC



What you should expect from your child's providers:



Dignity and Respect

- Listen to and honor your perspectives and choices
- Incorporate your family's knowledge, values, beliefs, and cultural backgrounds into planning of care

Information Sharing

- Communicate clearly and concisely
- Share complete, unbiased information with you and your child that are affirming and useful
- Timely, complete, and accurate information is shared to help you effectively participate in your child's care and decision-making

What you should expect from your child's providers:



Participation

- Providers partner with you and your family to:
 - Develop creative, flexible, and responsive plans of care
 - Encourage and support you and your child to fully participate in care, planning care, and shared-decision making

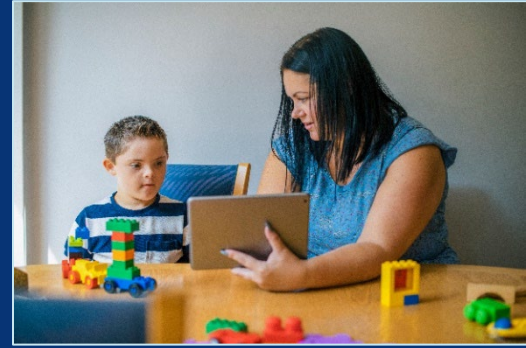
Collaboration

- Acknowledge trust as fundamental to family-professional partnerships
- Be willing to negotiate
- Integrate you and your child into the care team
- Value celebrations, challenges, and needs in planning and share decision making
- Encourage family-to-family and peer-to-peer support to navigate care

Understanding and balancing your role



Parent or Advocate?



Parenting

noun – the taking care of someone in the manner of a parent

*Based on the relationship between parent/caregiver and child, **emotions***

Advocacy

noun – the act or process of supporting a cause or proposal : the act or process of advocating

*Based on understanding needs, strengths and supports, **knowledge***

The Balancing Act



Parent > Advocate

- “Mama bear”, “Papa bear”
- Emotion before information
- Carrying the load without looking for support

Advocate > Parent

- Health goals become the only focus
- Not able to enjoy being a parent/caregiver

The Advocate's Journey



**Who You
Are**



**Your Lived
Experience**

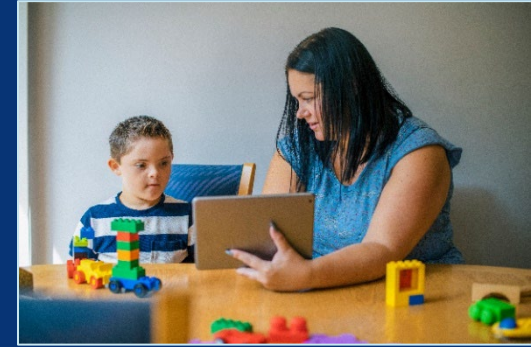


**Group +
Community**



**Policy +
Research**

What You Already Know



Who You Are

- Your **skills, life experiences** and **personality** are the starting point.
 - Relationship skills like conflict management
 - Work and education
 - Beliefs
 - Self-care and mental health

Your Lived Experience

- You **build on your skills** as you have more experiences.
 - Use the resources in your community
 - Find support and connect with others
 - Make decisions with professionals
 - Set goals

Building on Your Lived Experience



Set goals for, and with, your child

- Physical
- Mental
- Social-emotional
- Therapy



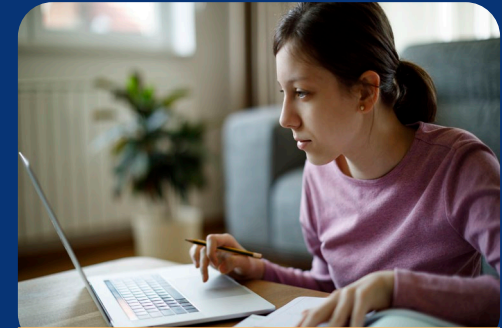
Find support

- Medical/therapy
- Personal/family
- Professionals
- School and community



Communicate

- Goals
- Needs and barriers
- Concerns
- Mutual understanding



Learn

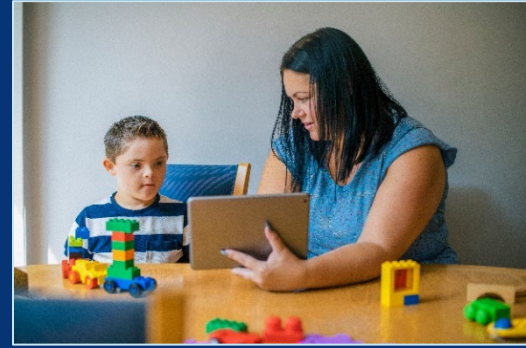
- Ask questions.
- Know the standard of care
- Reliable, evidence-based resources

“I learned a long time ago the wisest thing I can do is be on my own side, be an advocate for myself and others like me.”

Dr. Maya Angelou



Next Level



Group + Community

- Learn on purpose
 - Research, conferences
 - Local community and beyond
 - Noticing the gaps and the boulders

Policy + Research

- Be a representative
- Understand connections and disparities
- Specific interests and issues
- The bigger picture

Group + Community Advocacy



Go beyond your personal experience to learn from others

- Join online communities
- Join support groups
- Connect with condition-specific organizations
- Join playgroups
- Share your story

Group + Community Advocacy Skills



Widen your circle

- Learn from other people's experiences and barriers
- Build connections
- Less judgment, more understanding
- Who's missing?

Learn on purpose

- Blogs and articles
- Encountering new sources of information
- Research articles and books
- Conferences and seminars
- Local, state and national resources

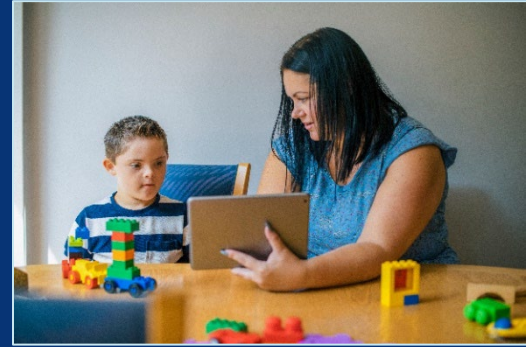
Policy + Research Advocacy



Represent the voices of others

- Learn how your story connects to others.
- Understand disparities.
- Learn how government and policymaking work.
- Work on local, state and national initiatives.
- Develop an area of focus.

Policy + Research Skills



Know the issues

- Learn about efforts to improve the lives of others
 - Learn about legislation that affects families like yours
 - Pay attention to current events and issues

Make contact

- Learn who makes the decisions.
- Join forces with organizations that care about the same issues.
- Be aware of local, state and national concerns.

It's All about Relationships



At every level, it is important to build relationships.

- Respectful
- Cooperative
- Honest

Evaluating Information



Unreliable Information

- Personal blogs
- Online groups
- Social media

Unreliable information is not always bad information; it is *more likely* to be bad information.

Reliable Information

- Research articles
- Information from a medical professional or organization
- Information from Family Voices and your F2F/FVAO

About our F2F and FVAO Networks



Family-to-Family Health Information Centers (F2Fs) are family-led centers funded by the Health Resources and Services Administration (HRSA). There are F2Fs in all 50 states, the District of Columbia, five U.S. territories, and three tribal nations. Family Voices Affiliate Organizations (FVAOs) are family-led organizations that operate in many states.

- Each F2F and FVAO is staffed by highly-skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families. They provide critical support to families caring for children and youth with special health care needs and disabilities.
- F2Fs and FVAOs help providers, state and federal agencies, legislators, and other stakeholders better understand and serve children and youth with special health care needs and their families.

Next Steps for Each Level

Personal

Make a care map. 

Create goals for, and with, your child.

Share your story.

Group + Community

Learn about local resources.

Meet other families with similar concerns.

Join family groups and advisory councils.

Policy + Research

Dive deeper into issues you care about.

Get involved with policy for organizations that serve you.

Consider leadership roles.

Advocates Create Change



Personal

More social interactions and support

Less isolation and stress

Better connection to services

Group + Community

Improve services

Improve understanding of the people they serve

Improve how they respond to concerns

Policy + Research

Provide perspectives to those who don't share our experiences

Create a more complete view of how policy affects people's lives

Create pathways to health equity

Kids Can Advocate, Too!



Children and youth can:

- Understand the goals and help set them.
- Participate as part of the team.
- Learn more about their own needs.
- Ask questions.
- Speak up.

If you think you are too small to make a difference, you haven't spent the night with a mosquito.

African Proverb



Questions and Discussion



THANK YOU!

- Where are you in your advocacy right now: personal, group + community, or policy?
- Where do you want to go next?
- What are your next steps to get there?