



Supports For Families Of Children & Youth With Special Health Care Needs: A Quick Reference Guide to Family-Led Organizations

OVERVIEW OF FAMILY-LED ORGANIZATIONS

With a few exceptions, the four national, family-led organizations described below have affiliates in each state. In many states, one or more of these organizations are co-located at the same agency. In other states, the organizations are located in different agencies. Each project has a specific area of expertise: health care, emotional support, mental health supports, and special education. The family members who staff these organizations are parents/guardians of children and youth with disabilities/special health care needs (CYSHCN); some are siblings to CYSHCN. They understand families' concerns about their children and can connect them with the organization that can best advise them. Staff at these organizations come from diverse backgrounds and are able to connect with families of like backgrounds in their own native languages. In other instances, staff can connect families from diverse backgrounds to cultural brokers.

► FAMILY VOICES (FV)

FV is a national, family-led organization that works to keep families at the center of children's health care. FV has developed a national network of family-led Family Voices Affiliate Organizations (FVAOs) and Family-to-Family Health Information Centers (F2Fs) in every state, the District of Columbia (DC), Puerto Rico, the Virgin Islands, Guam, American Samoa, and the Northern Mariana Islands. Three additional F2Fs serve tribal nations. FVAOs are statewide, family-led, non-profit organizations that work to advance the mission, vision and principles of Family Voices. Often, the FVAO and the F2F are co-located. F2Fs, funded by the federal Maternal and Child Health Bureau, provide free, confidential support and training to families of CYSHCN and their professional partners. Both FVAOs and F2Fs¹ help families navigate health care and community supports; collaborate with health providers; and build leadership skills.

Visit www.familyvoices.org to find the [FVAO/F2F in your state](#) if you are speaking with a family that needs help:

- Finding services for a CYSHCN and the family
- Understanding eligibility for Title V, Medicaid, or other state agency services
- Finding financial support to supplement PT/OT/Speech & Language therapies
- Communicating with doctors
- Understanding a child's medical condition
- Connecting to a disability-specific support organization or group
- Finding support for a caregiver

¹ Note: FVAOs and F2Fs are often part of larger non-profit organizations, Department of Public Health Title V programs, or universities. Therefore, the names of each FVAO and/or F2F vary, depending on the vendor agency.

► **PARENT TO PARENT USA (P2P USA)**

P2P USA is a national organization committed to assuring access and quality in parent to parent support for families who have children of any age (pre-birth through aging), who have a disability, chronic illness, or other special health care need. P2P USA provides technical assistance and support to state programs by encouraging use of evidence-based and best practices, including the capacity to “match” families with diverse experiences, ethnicity, culture, race, language, socio-economic, disability and other child/family related life experiences.

Visit www.p2pusa.org to find the [P2P program in your state](#) if you are speaking with a family who:

- Needs emotional and/or grief support
- Needs supports for a brother or sister of a child with special health needs (sibshops)
- Wants to talk to someone who has similar life experiences and shares an understanding of a specific diagnosis, topic, and/or challenge, including transitional periods in a child and family’s life
- Is stressed, facing barriers or challenges, and wants to talk to someone who understands their life
- Is ready to share their own family circumstances, leadership skills, positive attitude, etc and wants to support other parents

If there is no P2P program in your state, contact any neighboring statewide P2P program or P2P USA.

► **NATIONAL FEDERATION OF FAMILIES FOR CHILDREN’S MENTAL HEALTH (NFFCMH)**

The NFFCMH is a national, family-run organization that works to ensure children and youth with emotional, behavioral, and mental health needs and their families can get the supports they need.

Visit www.ffcmh.org to find the [NFFCMH affiliate in your state](#) if you are speaking with a family that is:

- Worried about a child’s emotional health and behaviors
- Needs help identifying a mental health provider
- Needs help supporting a caregiver who is experiencing mental health stress

► **THE CENTER FOR PARENT INFORMATION AND RESOURCES**

The Center for Parent Information and Resources is a central hub with information about Parent Training and Information Centers (PTIs) and Community Parent Resource Centers (CPRCs)

PTIs, funded through the federal Individuals with Disabilities Education Act (IDEA), help families understand special education services for CYSHCN to age 22.

CPRCs help families who need additional language supports.

Visit www.parentcenterhub.org to find the [PTI and/or CPRC in your state](#) if you are speaking with a family that needs help:

- Understanding educational issues related to a child’s health condition
- Understanding a child’s rights to special education services
- Communicating with teachers, nurses, and other school staff
- Working with school staff to create an Individualized Educational Plan (IEP) or 504 Accommodation Plan for a child
- Finding support groups, educational specialists, legal assistance, and other resources