

## SUPPORTS FOR FAMILIES OF CHILDREN & YOUTH WITH SPECIAL HEALTH CARE NEEDS: A 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/family members/caregivers of 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 with cultural liaisons.

#### No Wrong Door

In many states, the families who staff these organizations work at the same agency. As a result, they connect families with each other's programs so they get all needed supports. Even if they are located in different agencies, staff routinely refers families to the organization that has the expertise the family needs.

### 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, America Samoa, and the Northern Mariana Islands and three 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 F2Fs<sup>1</sup> help families navigate health care and community supports; collaborate with health providers; and build leadership skills.

Find the [FVAO/F2F in a state, territory, tribal nation](https://familyvoices.org/affiliates/) (<https://familyvoices.org/affiliates/>) that can assist a family that needs help:

- Finding services for a CYSHCN
- 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
- Finding support for a caregiver

<sup>1</sup> 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.

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## PARENT TO PARENT USA (P2P USA)

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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, disability and other child/family related life experiences.

Find the [P2P program \(https://www.p2pusa.org/parents\)](https://www.p2pusa.org/parents) that can assist a family that:

- 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 A STATE, CONTACT ANY THE P2P PROGRAM IN A NEIGHBORING STATE OR CALL P2PUSA AT (484) 272-7368.

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

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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.

Find the [NFFCMH affiliate \(https://www.ffcmh.org/our-affiliates\)](https://www.ffcmh.org/our-affiliates) that can assist 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
- Additional information on the [Families, Parents and Caregivers Resources](#)
  - Learn about working with the police to keep the entire family safe
  - Setting up a plan so the police and EMTs will know they are responding to a home where there is a child with aggressive behaviors
  - More...

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## THE CENTER FOR PARENT INFORMATION AND RESOURCES

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The [Center for Parent Information and Resources](https://www.parentcenterhub.org/) (<https://www.parentcenterhub.org/>) 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.

Find the [PTI and/or CPRC](https://www.parentcenterhub.org/find-your-center/) (<https://www.parentcenterhub.org/find-your-center/>) that can assist a family that needs help:

- Understanding special education issues and services related to a child's health condition
- 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