

Family Voices of Tennessee: Changing Healthcare, One Family at a Time

Started in 1993, Family Voices of Tennessee (FVTN) provides a number of key services to families of children with special healthcare needs:

- Connecting families with each other, community resources, experienced parent mentors, and tools to navigate complex systems in healthcare,
- Training families to advocate for the needs of their children, and
- Educating healthcare providers, educators, and policy makers to promote real change in systems.

FVTN is supported by grants, state and federal contracts, and foundations. Because all FVTN staff members are parents or family members of children with special health care needs and chronic illnesses or disabilities, they truly understand how to support families and help them flourish.

Peer Support

Over the years, FVTN's services have expanded from its Family to Family Health Resource Center to also include one-on-one peer support. Families report that this parent match/mentorship is a lifeline that ends the overwhelming sense of isolation they often feel. *"Talking with other parents who share the same feelings helps me feel not so alone."* - Crystal, A Parent

In 2013, FVTN affiliated with Parent to Parent (P2P) USA to develop a more robust parent mentor/match program. All staff members of the P2P program are parents of children with special healthcare needs. As a result, they bring a special passion to their role of “meeting parents where they are” and helping them along the path toward advocacy for their children and for themselves.

Because of the strong relationships FVTN has developed with clinicians, hospitals, and state agencies, referrals to peer support sometimes occur directly from the Department of Health Birth Defect Surveillance and newborn hearing programs. Then, outreach to families can begin early. Strong partnerships with six hospitals across the state support additional parent referrals. An innovative program supports pregnant mothers admitted to hospitals on bed rest by providing peer mentors. The Parent’s Reaching Out (PRO) groups help families in the NICU; they are currently in three hospitals and meet weekly. In the last year, more than 450 individuals received services from PRO and over 150 mentors across the state provided them. Whether working with NICU parents or mothers on bedrest, P2P services teach skills that prepare parents for discharge from the hospital.

Partnerships and Education

Because of the unique perspective of FVTN staff members, they serve on a number of statewide councils involved in healthcare policy and program development. They also participate regularly in new employee orientation in hospitals to talk about the importance of family-centered care to outcomes. As a partner with the American Academy of Pediatrics, staff participated as faculty in Patient Centered Medical Home

Summits to ensure that the voice of the parent/patient was included. FVTN also has a strong partnership with the Cumberland Pediatric Foundation that services over 70 pediatric clinics and more than 100 physicians in Tennessee. In 2018, over 19,000 people across the state have been touched by various FVTN programs, offered in hospitals, churches, and other community settings.

Equally important is the opportunity to build leaders among families and individuals with the lived experience of navigating the healthcare system. In addition to P2P, FVTN also supports other programs that integrate the voice of those with lived experience into conversations about transformation of care:

- Voices for Choices – a leadership program to train parents to serve on advisory groups throughout the state.
- Youth Boot Camp – for youth 14-22 to help them use their voices to advocate. P2P also recruits and facilitates the Dept. of Health’s Youth Advisory Council that focuses largely on transitions.

FVTN also facilitates ongoing education for new parent mentors and healthcare providers on patient- and family-centered care, especially its implications for families’ interactions with healthcare providers. The training always emphasizes the important role of the family caregiver on the healthcare team. FVTN also works in collaboration with many statewide partners and staff members serve on a variety of councils. Some examples of partnership include:

- Cumberland Pediatric Foundation
- Tennessee American Academy of Pediatrics
- Vanderbilt Kennedy Center
- Dept. of Health’s Child and Family Wellness
- Dept. of Health’s Title V program
- Tennessee Disability Coalition

Program Impact

Whether providing parent mentors for families, training new staff on the lived experience of parents, or giving information and assistance to families navigating the healthcare system, Family Voices of Tennessee continually evaluates its impact on families. In 2018, over 1,000 parents have been served by P2P programs, including support groups, parent mentors, and follow up calls for additional services. Although FVTN impacts thousands of people in the state, it always focuses on the needs of

individual families and their children:

As Director of Family Voices of Tennessee, I think about the one family that now is able to cope just a little bit better because of a connection. I know that same family may later talk to their legislator to raise their awareness of how policy decisions impact families living with chronic health conditions. We don't want anyone to go on this journey alone. Positive change happens, one family at a time."

Kara Adams