









Family Support in Rural and Urban Communities









Objectives:



-To better understand the community



-To meet people where they are at and elevate their experience

-To improve access for underserved populations







Who Are We?



We are **families** supporting **families** of children with special healthcare needs, chronic illnesses or disabilities.



We enjoy what we do because we "get it!"







History:

Family Voices of Tennessee **started in 1993** as a program of the Tennessee Disability Coalition and became the **first state chapter** formally sanctioned by the national organization in the last quarter of 2000. Family-Voices of Tennessee was **one of six** Family-Voices state programs during 1999-2001 to participate in a pilot program to develop Family-to-Family Health Information Centers (F2FHICs).







What Do We Do?

We **connect** families with each other and community resources.

We train families to advocate and lead in their communities and beyond.

We educate healthcare providers and others on Family-Centered Practice.

We serve families and children across all diagnoses and all ages.







Take a beat to introduce yourself:

- At a glance who are you:
 - Name
 - Where do you live?
 - Where are you from?

What is your why :

- What do you do?
- Why do you do it?
- How do you message that to your families?







Why is this important?

How are you making the connection to the community you are serving?:

- You don't have to live there to make a connection
- It builds trust between you and the family

Services Offered:

- What do you do?
- Why do you do it?







How do we recognize these areas?

It is important to think outside of the box.

What resources are most critical?

How do we address the need?







Challenges faced by families:

Transportation

Limited access to healthcare and community services

Lack of Disability specific service providers

Social Isolation







Why is Family Support so important?

Raises awareness of important resources and where to find them.

Provides relevant information and education.

Making these connections can help to remove stigma and barriers.







Benefits to Rural and Urban Family Support:

- Enhances community engagement.
- Strengthens family networks.
- Improves access to healthcare and support services.







Community Based Organizations:

Develop relationships with local organizations already there. Many already provide pathways to resources and self-advocacy.

DON'T BE A STRANGER TO THE COMMUNITY!







A few strategies that have been successful:

Understanding the technology access of families.

Organizing community events and workshops or partnering with or that are already doing this.

Train local volunteers, parents, or advocates to provide additional support. Peer Support is a game changer!







Family #1: Rural 2019

Dad is Deaf, Mom is Hard of hearing. Their two children are hard of hearing and wear hearing aids. In the audiology clinic mom immediately discloses physical abuse Social work was contacted. Social Work concluded that there was no cause for removal. Family relies on transportation services through state insurance. What would you do to provide support?







Family #1: Rural 2019- Current

Family has experienced being unhoused for 6 months. They now have 4 children. 3 of the 4 are Hard of Hearing and wear hearing aids. Grandmother is also Hard of Hearing but has custody and doesn't want the children to attend the School for the Deaf despite the recommendation from the LEA. What does continued support look like to you?







Family #2: Urban 2018-current

Referral from the Children's Hospital Legal Clinic. Mom has been told that her child no longer meets the criteria for services at the Oral School. During the transition IEP nobody is acknowledging this parents efforts or anger. How do you support this parent that has been provided limited resources and is now transitioning to a Total Communication Program they know nothing about.







Family #2: Urban 2023-current

Referral from the Children's Hospital Audiology Clinic. It is transition time. During the transition IEP the team is only addressing the child's Autism and not hearing level diagnosis. It is Mild to moderate mom is also Deaf and uses both listening and spoken language and ASL with her child. The IEP team says the child does not meet the criteria for the Total Communication program and the functional skills room is at capacity.







Rural Family 2: 2018- Current

Foster mom has traveled 2.5 hours for appointments and is seeking resources local to her. Bi-lateral CI however previous caregivers have not maintained services due to lack of support.







Urban Family 3: 2018- Current

Self referral-

Deaf Mom suspects that her youngest child is also Deaf. Father is a CODA mother became Deaf due to illness. after 6 "failed" screenings the infant has finally "passed" the 7th hearing screening. Infant has shown no changes in behavior that lead parent to believe she had different hearing levels.







What can you do?

Encourage community involvement:

Hybrid meetings, Community Conversations, Focus Groups

Support policy change:

Encourage families to understand how policy is made and provide pathways to involvement.

Share the importance of self-advocacy:

Become genuinely interested in their experience. Pay attention to the quiet ones.





Questions/Comments?

http://www.tndisability.org/familyvoices/ 1-888-643-7811 toll free



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