

Family Voices of Tennessee is an organization of families supporting other families of children with special healthcare needs, chronic illness, and disabilities. All of our services are free to families!

ABOUT FAMILY VOICES





We connect families with each other, community resources, experienced parent mentors, tools to navigate complex systems in healthcare and insurance and more.



We train families by empowering them to advocate for the needs of their child and to lead in their local communities and beyond.



We serve as leaders alongside families, we are educating healthcare providers, policy makers, teachers and others on the improved outcomes from including, listening to and honoring the voices of these families.

Phone Number: 615.383.9442 Email: familyvoices@tndisability.org Website: www.familyvoicestn.org. Follow us on Facebook!

Peer to Peer Support

Are you the parent of a child with a disability, chronic illness, or special healthcare need?

Family Voices of Tennessee has a parent to parent mentorship program that matches parents of a child with a new diagnosis to a trained parent mentor who has navigated a similar diagnosis/journey.

If you are **needing** a mentor or are interested in **becoming** a mentor, you can find additional information by visiting our website:

<u>familyvoicestn.org</u> OR scanning the QR code:





How to Support Siblings



It can be incredibly difficult for siblings when family life gets challenging. You can let your child know that you care about their well-being and that their feelings matter to you by actively listening to their concerns and validating their feelings. Remember to use age-appropriate language, so that your children can understand the situation and feel comfortable sharing their thoughts with you.

Sibshops provide young brothers and sisters with peer support and information in a lively, recreational setting.

Founded in 1990, the Sibling Support Project is the first national program dedicated to recognizing, promoting and addressing the life-long and ever-changing concerns of millions of siblings of people with developmental, health, and mental health concerns. For more information about support groups, workshops, and training visit: www.siblingsupport.org/



Medical Home

A "Medical Home" is a familycentered approach to health care that includes making families equal partners in their child's care.



Your child's primary care doctor and their office is accessible.

- Available after hours, on weekends and on holidays
- Accepts your child's health insurance
- Office and equipment physically accessible to your child
- Provides interpreter/translation services, as needed

Staff within your child's primary care office know and help you.

- Recognize and accommodate your child's needs
- Respond to requests for prior approvals, letters of medical necessity for your child's insurance, or documentation for programs and services
- Provide written materials in a language you understand

Medical Home



Your child's primary care doctor respects you and listens to you observations about your child

- Asks you to share your knowledge about your child
- Seeks your opinion when decisions are needed
- Talks to you about how your child's condition affects your family (other children in the family, child care, expenses, work, sleep)
- Acknowledges and respects your family's cultural values and religious beliefs

Your child's primary care doctor and office staff support you as a caregiver.

- Help you connect with family support organizations and other parents in your community.
- Provide information about community resources.
- Plan for adult health care services (if appropriate for your child's age).

Medical Home



As a Parent, How Can I Partner with my Child's Doctor?

- Share your views during appointments. You know your child better than anyone else.
- Help make decisions related to your child's care. When parents and doctors share decision-making, care for the child is often better.
- Be willing to try those activities or medications that you and your child's doctor decide are in his or her best interest. Keep track of what happens, and share this at your next appointment.

Questions to ask your physician:

- Do you have experience with my child's diagnosis?
- What is the turnaround time for answers to questions?

Follow this link to view a comprehensive guide for partnering with your doctor using a medical home approach.

Created by: Family Voices of Tennessee, Tennessee Department of Health, and American Academy of Pediatrics Tennessee Chapter

Telehealth Resources

How can telehealth improve my child's health care?



Telehealth can decrease travel time for specialty care and offer flexible appointments



Telehealth gives
you the opportunity
to coordinate care
with providers, and
caregivers all at the
same time



You can request translation services to communicate more effectively and confidently about your child's health care

How can I help my child participate in a telehealth visit?



Conduct the telehealth visit in a place that's comfortable for your child



Minimize distractions



Encourage your child to communicate and answer questions, if possible

Visit our website for additional resources: familyvoicestn.org

Telehealth Resources

How can I prepare for my child's telehealth visit?



Make sure you have access to the internet and the equipment your child needs to communicate



Role play with your child so they are comfortable discussing their health



Don't be afraid to ask questions! You are your child's best advocate!



Talk with the doctor about follow-up care, such as:

- ▶ Bloodwork and lab tests
- **▶** Changes in medication
- Plans to address behavior, emotional, or social concerns



Consider what you and your child would like to share with their provider, such as:

- Celebrations
- Health updates
- Concerns and challenges
- ► Information from other providers

Visit our website for additional resources: familyvoicestn.org





WHAT IS TNSTEP?

TNSTEP is another parent-led organization that supports families by providing free information, training, and support services to parents of children eligible to receive special education services under the Individuals with Disabilities Education Act (IDEA).

WHAT SERVICES ARE PROVIDED?

TNSTEP provides virtual and in-person trainings, webinars, brief handouts, toolkits, transition resources, and SO much more! For support with your child's educational needs we recommend TNSTEP.

AVAILABLE RESOURCES (English/Spanish):

- Quick Guide to Parent's Rights and Responsibilities
- Tennessee Special Education Eligibility Fact Sheet
- <u>Difference Between IEPS and 504's</u>
- <u>Conservatorship</u>, <u>Special Needs Trusts</u>, <u>and Wills</u>
 Information
- <u>Dude, Where's my Transition Plan? Booklet</u>
- Protections for Undocumented Students Fact Sheet

For additional information visit their website: tnstep.info



These are statewide programs that your child may qualify for:

Early Child (Age 0-5)

- <u>Tennessee Early Intervention Services (TEIS)</u>
- Katie Beckett Waiver
- Family Support Program
- Seating & Positioning Clinic
- Children's Special Services

School Age 6-14)

- Employment and Community First CHOICES (ECF)
- Katie Beckett Waiver
- Family Support Program
- Seating & Positioning Clinic
- TN START Assessment & Stabilization
- Children's Special Services

ransition Age 14-18

- Employment and Community First CHOICES (ECF)
- Katie Beckett Waiver
- Family Support Program
- Medicaid Alternative Pathways (MAPs)
- Seating & Positioning Clinic
- TN START Assessment & Stabilization
- Children's Special Services

Adult Age 18+)

- Employment and Community First CHOICES (ECF)
- Family Support Program
- Medicaid Alternative Pathways (MAPs)
- Seating & Positioning Clinic
- TN START Assessment & Stabilization
- Children's Special Services





Tennessee Justice Center (TJC) provides direct service help for families having difficulty navigating the TennCare and CoverKids program.

TennCare is Tennessee's Medicaid program. Every state has their own Medicaid program. For more information on eligibility <u>click here</u>.

TJC can help you apply

- Please call the TJC at 615-255-0331 or 877-608-1009 Toll-Free.
- To apply online on your own, <u>click here</u>. We recommend applying online but for other ways to apply <u>click here</u>.

CoverKids is a free health insurance program for children and pregnant women in Tennessee who don't have health insurance and meet other requirements. For more information on eligibility <u>click here.</u>

TJC can help you apply

- Please call the TJC at 615-255-0331 or 877-608-1009 Toll-Free.
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For additional information visit their website: tnjustice.org



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