



TN Disability Coalition/Family Voices of TN TENNESSEE FAMILY-TO-FAMILY HEALTH INFORMATION CENTER (F2F) 2016 DATA REPORT

Family Voices of Tennessee (FVTN) operates the F2F as a member organization of the Tennessee Disability Coalition, an alliance of 38 organizations promoting the full and equal participation of people with disabilities in all aspects of life. The F2F assists families in navigating public and private health systems and insurance plans (including TennCare and commercial plans), and works with families, health care providers, public and private agencies, and advocacy/support groups to promote family-centered care and medical homes for children and youth with special health care needs (CYSHCN).

2016 IMPACT on a FAMILY

The TN F2F assisted a mom who needed help with expenses when she was stuck in Nashville with no money. She had twins born with Turner syndrome and was waiting for them to have heart surgery. She had to leave the Ronald McDonald house because she was only allowed to stay for 30 days despite her twins remaining in the hospital. The TN F2F was able to provide information, support, and \$500 out of the state's Family Support emergency fund so she could stay in a hotel and have money for food while her children received life-saving treatment.

2016 HIGHLIGHTS

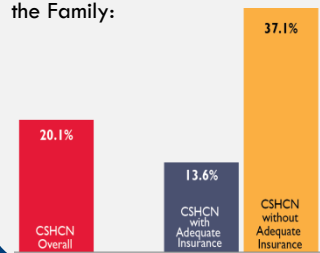
System Improvement: The TN F2F improved the current system of care for families whose infants have been diagnosed as deaf or hard-of-hearing by providing parent perspectives to Early Hearing and Detection Initiative (EHDI) stakeholders. By including parent stories in written materials provided to birthing hospitals, parents felt supported and encouraged to take their infants for follow-up hearing tests if the child was referred for further testing based on his/her Newborn Hearing Screen.

Youth Advocacy: The TN F2F staff collaborated with the LEND trainees and the TN Department of Health (Title V Maternal and Child Health program) to create the TN Department of Health Youth Advisory Council. This council includes 12 youths who have special health care needs/disabilities/chronic illnesses and was designed to work with the Children and Youth with Special Health Care Needs (CYSHCN) Section of the state Title V program to improve the quality and coordination of youth efforts and supports critical to improving outcomes for all youth, especially those with special needs. This Council will provide an opportunity for youth to gain leadership skills and learn from state leaders about policies that affect them. The TN F2F continues to expand its Parent Matching program. They have trained over 80 parents to be mentors to other parents and have successfully matched over 80 families. TN F2F also continues its leadership training for parents of children with special health care needs.

CSHCN in TN¹

- 255,692 children (17.2%)
- 64,135 children have inadequate insurance
- 70,890 children have conditions that consistently affect their activities
- 81,696 do not receive family-centered care

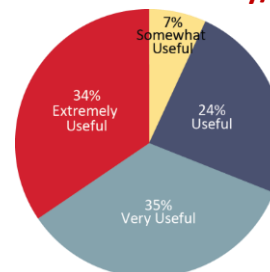
CSHCN Whose Conditions Cause Financial Problems for the Family:



OUTREACH²

Total Families Served: 16,912
Total Professionals Served: 13,668
Newsletter Subscribers: 16,975
Trainings: 1803

IMPACT on Family/Provider Relationships



Families rate the usefulness of the support, information, and/or resources they received from the TN F2F in increasing their ability to partner with their child's provider.

CONTACT

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¹National Survey of Children with Special Health Care Needs, NS-CSHCN 2009/10. Data query from the Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website. Retrieved 04/03/2014 from www.childhealthdata.org.

²FY2016 F2F data represents families and professionals served through one-to-one contact, training, and broader outreach from June 1, 2015 through May 31, 2016.

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