

# USE YOUR VOICE



# Things you will learn from this session:

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- ❧ Definition of Children and Youth with Special Health Care Needs
- ❧ Definition of Family Centered-Care
- ❧ How to be part of the “team.”
- ❧ The importance of the family’s role.
- ❧ The different support programs that are available from Family Voices of TN

# Children and Youth with Special Healthcare Needs

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*"those who have or are at increased risk for a chronic physical, development, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally"*

Adopted by the AAP (October 1998). McPherson M, Arango P, Fox HB, A new definition of children with special health care needs. *Pediatrics*. 1998;102:137-140.

# Family Centered Care



Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

Adapted from: <http://mchb.hrsa.gov/grants/fcclcguid2007.pdf>

# The Decision Making Team

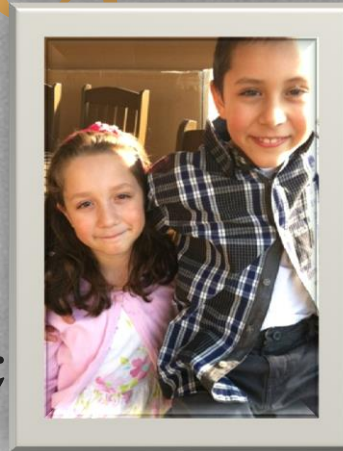
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# Collaboration



- ❧ Work as a team
- ❧ Shared decision-making
- ❧ Not one is always right; not one is always wrong
- ❧ Mutually Beneficial Partnership



# Being the most important member of your health care team

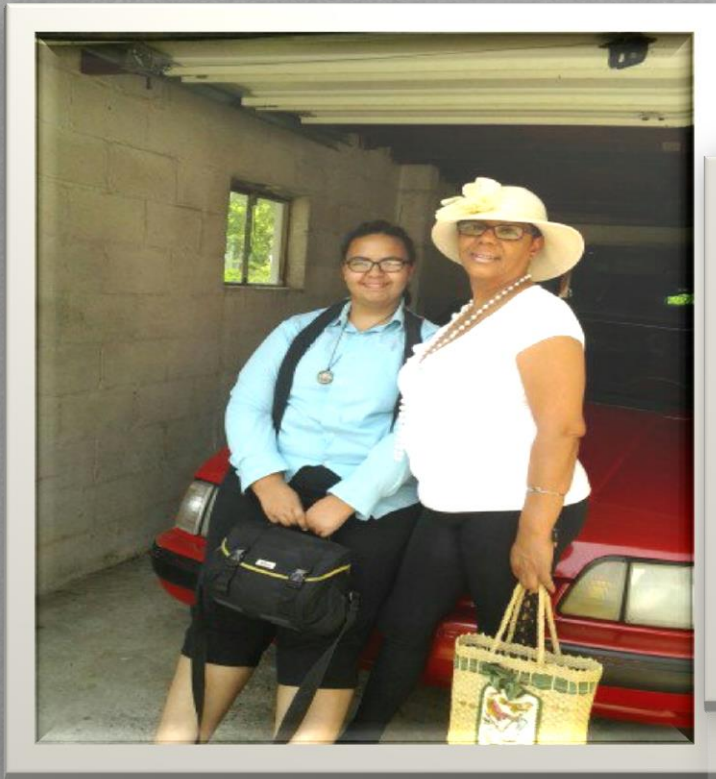


- ❧ Write down question.
- ❧ Keep a log of what you and the provider talked about.
- ❧ What to do when you disagree with the provider.
- ❧ How much you want to be part of the team is your decision.
- ❧ Yes, you are the most important member of your health care team, BUT you are still part of a team.



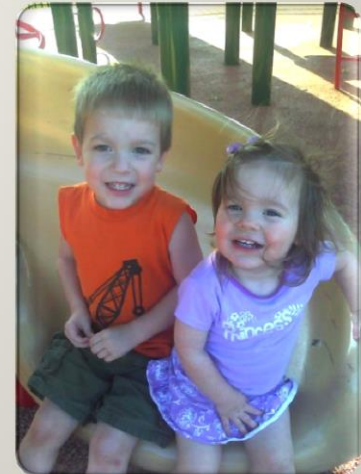
# Supporting the Family's Role

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# FAMILY VOICES of Tennessee



# Staff=Family



- ☞ All employees of FV of TN are either family members of children with special health care needs, or have special health care needs themselves.
- ☞ We enjoy what we do because we “get it”



# Family to Family Health Information Center (F2FHIC)

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- ❧ Assist families as they navigate public and private health systems and insurance plans
- ❧ Educate families about how to access services and resources for their children and how to work with health providers
- ❧ Work with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for children with special health care needs

# TN GBYS



**Tennessee Hands & Voices (TN H&V) Guide By Your Side™ (GBYS) program is for families of a child who is Deaf or hard of hearing**

TN H&V GBYS is dedicated to directly supporting families and their infants and toddlers who are identified with any degree of hearing loss by offering them the opportunity to talk to or meet face-to-face with a Parent Guide.



# parent 2parent

tennessee



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## *Teen GAIN*

GAINING knowledge, GAINING Advocacy skills, GAINING relationships, GAINING Independence, GAINING happiness

- Discussion group for teens 12-17, w/ special health care needs
- Learn skills on how to better their relationship with their health care provider.



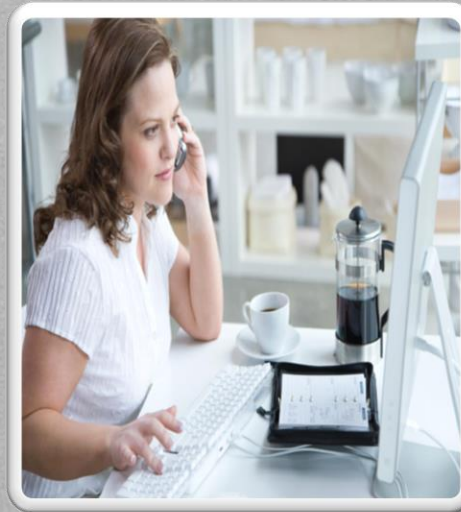
# parent parent

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## *Parent Matching*

- Provides one-one support
- Support in navigating the maze of health care
- Provides Mentor Training
- Empowers families to be strong advocates



# Why is this important to our Children?



# Interested in learning more:



FAMILY VOICES *of Tennessee*

<http://tndisability.org/familyvoices>

Family to Family Resource Center

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GUIDE BY  
YOUR SIDE

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