



# Parent Support in a Hospital Setting

A New Approach for State EHDI Systems

March 5, 2019

# Learning Objectives

- **1. New Opportunities to engage families and family support organizations**
- **2. How family relationships influence state EHDI systems**
- **3. State EHDI Program justification/funding methodology**
- **4. Lessons Learned**

# Introduction – A Parent’s Journey



# Relationships For Parents

## Parent and child



## Parent and provider(s)



## Parent and State EHDI System



- Every relationship requires trust and communication. The frequency and intensity of these relationships is associated with the EHCI journey for the family
- A Parent guide in hospital setting addresses all three relationships in one setting

# Family Voices - PEARS

**FAMILY VOICES**  *of Tennessee*  
*part of a national grassroots network of families and friends  
speaking on behalf of children with special health care needs*

**Parent Guides provide  
individualized peer support to  
families with children who are deaf  
or hard of hearing.**



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## TN EHDI: Program History and Timeline

- 1996** – Newborn Hearing Program started with Human Resources Services Administration (HRSA) funding
- 2001** – HRSA funding supported an audiology consultant and a parent consultant
- 2002** – Hospitals started reporting hearing results to TDH
- 2006** – Universal screening in all birthing hospitals w/o a mandate
- 2008** – Claire's Law passed making universal NHS and data reporting a mandate (T.C.A. §68-5-9)
  - CDC funding on EHDI data tracking and information system
- 2011** – Continued statewide family support with increased number of parent guides contracted with Tennessee Disability Coalition
- 2014** – Quality Improvement Office established within the Newborn Screening Program; Continued statewide contractual family support services
- 2017** – Nurse Health Educator position created in Central Office; New EHDI Coordinator hired; Coordinator requested parent guide recommendations for enhanced family support; Completed justification and hospital services funded
- 2018** – First parent guide established in hospital setting March, 2018

# TN State EHDI System Collaboration with Parents

- Parents of children who are deaf or have hearing loss
- Family Voices PEARS – Parents Empowerment Advocacy Resource and Support – contracted family support organization with 6 parent guides
- 5 Regional Task Force Meetings – attendees include parents and additional family support organization members
- Central Office Staff: EHDI Coordinator (parent)



- **High LFU for West Region on the State –**  
From 2008-2017, more than 2,700 infants who failed initial hearing screening received diagnostic testing from a large children’s hospital in the western region of the state. Among them, 317 children with hearing loss were confirmed, accounting for 20% of all hearing loss infants diagnosed
- **Existing Referral system for parent support – requires 24-48 hour waiting period for contact from parent guide for emotional support**
- **Need to fully utilize HRSA federal funding**

# How Did TN Create A Hospital Based Parent Guide?

## IT WAS A PROCESS!

- Identified existing relationships family support organization had with birth hospitals and diagnostic centers across the state
- Collaboration with Director of Audiology at children's hospital regarding lost to follow up and need for parent support
- Parent guide completed volunteer and background check
- Audiologists provided private meeting room for parent guide and family/patient



# How Does TN EHDI Monitor Parent Support Activities?



# General Family Support Program Objective Report

## Program Objective Report for Family Voices Newborn Hearing Program

Objective		Performance Data	Jul-Aug-Sep '18	Oct-Nov-Dec '18	Jan-Feb-Mar '19	Apr-May-Jun '19	Totals
Number of individual Parent Guides	1	# of Individual Parent Guides for this time period	6				
Parent Support Services for Hearing Loss	1	# of Confirmed Hearing Loss Referrals Received	31				
	2	# of Fluctuating Conductive & Unspecified HL Referrals	20				
	3	# of Follow-up Contacts (calls, letters) to Confirmed Cases	172				
	4	# of Families with at Least One Home Visit	17				
	5	# of Total Home Visits	20				
	6	# of Diagnosed Cases Lost to Follow-up	0				
	7	# of Hearing Loss Referrals that were not a Hearing Loss	4				
Outreach Education*	1	# of Community Outreach Activities	14				
	2	# Hours in outreach	43.5				
	3	# Outreach attendees*	596				
	4	# Miles traveled to activities	370				
	5	# Health Care Professionals	263				
	6	# Others	333				

Submit Quarterly Report by the 15th of the month following the end of each quarter by email to rachael\_s@tn.gov

# Added Hospital Parent Guide Report

## LeBonheur Parent Guide Report for Family Voices of TN PEARS

Objective		Performance Data	Mar-18	April- June 18	July - Sept '18	Oct - Dec 18	Totals
Parent Support Services for Hearing Loss	1	# of Families Provided Direct Parent to Parent Support in Clinic	4	8	15	12	39
	2	# of Families who had Follow up Home Visit outside of Clinic	0	5	12	3	20
	3	# of Follow-up Phone Calls, Emails, Letters to Clinic families	4	11	28	16	59
	4	# of these Families who returned for Follow Up Apptointments	3	6	13	6	28

Submit Quarterly Report by the 15th of the month following the end of each quarter by email to rachael\_s@tn.gov

Use supplemental form to detail education.

# Lessons Learned

- **Background Check/Security Clearance for parent guide to be present in the hospital**
- **Family compliance with Audiology Appointments improved**
- **State EHDI Benchmark justification changed from 3 month to 6 month based on children's hospital not being a birth hospital**
- **“Warm transfer” from Audiologist to Parent guide during hospital visit**

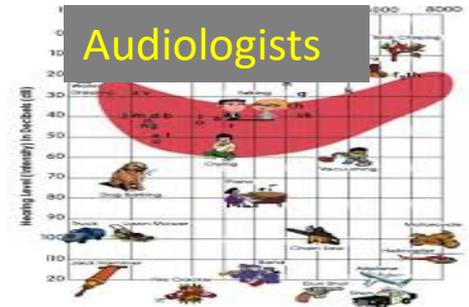
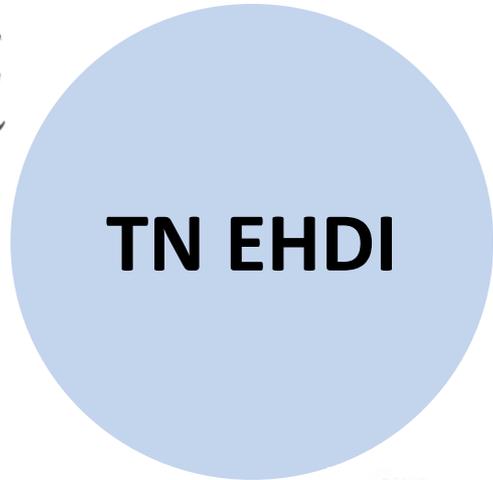
# What Is A “Warm Transfer”?

- **As families begin their journey from early identification to early intervention, they could be experiencing physical and emotional changes for both themselves and their baby. Audiologists provide the medical expertise for children and their families and can work collaboratively with other providers to ensure families are supported.**
- **In addition to medical expertise, families receive emotional support from audiologists to ensure their child has trusted information from the medical provider and feel comfortable sharing concerns throughout the hearing journey. This emotional support is continued from the audiologist to the parent guide during the visit.**
- **A warm transfer provides additional information during an appointment or phone call to make a family feel comfortable to use additional supports provided in the state.**
- **Examples: Use Introduction by provider to parent during audiology visit, sharing brochure, emphasizing this service is for additional support only and does not replace the child’s audiologist**

# Partnerships



Learn more and contact us:  
[tn.gov/education/section/early-learning](http://tn.gov/education/section/early-learning)  
1-800-852-7157



# Acknowledgements

- **Melanie Lindsay, Family Voices PEARS, parent guide program coordinator**
- **Leah Williamson, hospital-based parent guide**
- **Dr. Jennifer Bidelman, Au.D, CCC-A**
- **Dr. Yinmei Li, MD, PhD, Epidemiologist**



# Questions?

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