

# Building a Family Support Network

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# Introductions

- Tabitha Belhorn
- Sandra Domoracki
- Allyson VanHorn

# Objectives

- You will learn how the Ohio EHDI program collaborated with family support organizations to meet HRSA requirements and are working together to develop a stronger family support infrastructure in the state.
- You will learn how Ohio EDHI system addressed consistency of services among family support systems after changes in state systems occurred.
- You will learn about at least three new family support resources developed through EHDI collaborative activities.

# Collaborative Opportunity

Recommendations from the Ohio Universal Newborn Hearing Screening Subcommittee

- Provide consistent statewide family support services
  - Diagnosis before 3 months of age
  - Enrollment in Part C Early Intervention before 6 months of age
  - Statewide family mentors who represent all communication modalities

# Consistency of Services

Enhance Ohio EHDI system for better coordinated care

- Encourage parents/families to be active participants throughout continuum of care
- Provide resources to support Ohio parents/families
- Provide resources to support Ohio professionals

# Grant Outcomes

- Tool Kit for Families
  - Brochures/Road Map for Families
  - Regional Resource List
- Parent to Parent Support Program Draft
- Professional Development Training Series
  - Diagnosing Audiologists
  - Central Coordination Staff
  - Early Intervention Providers

# Tool Kit for Families, Brochures

- Purpose
  - Develop education materials for families that involve family representation within the development of free toolkit materials.
- Layout
- PDSA

**HEARING  
SCREENING  
INFORMATION**

Date: \_\_\_/\_\_\_/\_\_\_ Time: \_\_\_\_\_

Completed by (Hospital): \_\_\_\_\_

Location: \_\_\_\_\_

**SCREENING  
RESULTS**

**RIGHT EAR**

**LEFT EAR**

[ ]	REFER	[ ]
[ ]	PASS	[ ]
[ ]	NOT SCREENED	[ ]

**FIRST MONTH**



**COMMUNICATION  
TIPS**

**BIRTH TO 1 MONTH:**

- Bond with your baby through frequent touch and eye contact.
- Smile at your baby and show them a variety of facial expressions.
- Hold your baby often. Try skin-to-skin contact.
- Soothe your baby through movement, touch, talking, and sound.

**PARENT  
ACTION  
ITEMS**

**PASS RESULT**

- If your baby passed the newborn hearing screening, no more action is needed at this time.
- Continue to monitor all developmental milestones.

**REFER RESULT**

- Schedule appointment with Pediatric Audiologist (See Resources for regional list of providers)

**PEDIATRICIAN**

- Be sure to give all test results to your baby's doctor
- Continue all well visit checkups, including at 1 month.

**PARENT NOTES:**

# FIRST MONTH TAKEAWAYS:

## RESOURCES:

- **Hands & Voices – Loss & Found Video:**  
[http://handsandvoices.org/resources/video/inf\\_cap.html](http://handsandvoices.org/resources/video/inf_cap.html)
- **ODH Infant Hearing:**  
<https://www.odh.ohio.gov/en/odhprograms/cmh/Infant-Hearing/About-Infant-Hearing>
- **NCHAM:** [www.infanthearing.org](http://www.infanthearing.org)
- **Resources:**  
<https://www.odh.ohio.gov/odhprograms/cmh/Infant%20Hearing/Audiologists.aspx>

## WORDS TO KNOW:

- **Amplification:** use of electronic devices to increase access to sound including hearing aids, cochlear implant, bone aid, FM systems.
- **Audiologist:** a healthcare professional who provides identification, diagnosis, and evidence-based treatment of hearing loss. An audiologist is trained to fit amplification as needed. Audiologists who specialize in working with children are called **Pediatric Audiologists**. Please see attached resources to help you find a pediatric audiologist near you.
- **Deaf:** medically or clinically speaking refers to hearing in the severe to profound range which does not allow for language to be developed through hearing alone. When the word deaf is used with the capital letter D, "Deaf", it refers to the cultural heritage and community of deaf individuals who communicate primarily through sign language.
- **Hard-of-Hearing:** typically refers to people who use residual hearing to access language.
- **Hearing Loss:** when your ability to hear is reduced. A hearing loss makes it more difficult for you to hear speech and other sounds, making it difficult for infants and toddlers to have typical language development. There are three kinds of hearing loss: sensorineural (nerve), conduction (middle ear) or mixed (both nerve and middle ear).
- **Hearing Screening:** a procedure used to identify an infant or child's ability to hear sound. Babies receive a hearing screening at birth and also throughout their school years. Hearing screenings identify a possible hearing loss and can require additional testing to determine hearing loss.
- **Hearing Test (Audiological Assessment/Diagnostic):** a test of hearing ability which includes tests for the ear and the brain's response to sound. The hearing test can be used to determine a hearing loss and the kind of hearing loss: sensorineural, conductive, or mixed.
- **Parent/Family/Caregiver:** this is you! And all the people in your child's life who love and support her/him. It is your role to care for child and be the leader of your support team.
- **Pediatrician:** a physician who specializes in working with children, many pediatricians do not have special trained skills or knowledge of hearing loss and/or deafness.

# Tool Kit for Families, Regional Resource List

- Divided the states by comparing with other agency divisions
- Comprehensive List
  - Regional
  - State
  - National Resources
- PDSA



## RESOURCES: NORTHEAST OHIO



LORAIN – CUYAHOGA – ASHTABULA – LAKE – GEauga – TRUMBULL – MEDINA –  
SUMMIT - PORTAGE – WAYNE – STARK – MAHONING – COLUMBIANA – HOLMES –  
CARROLL – JEFFERSON – TUSCARAWAS



### **ASHTABULA COUNTY**

#### ***University Hospitals Ashtabula Medical Center***

2131 Lake Avenue Suite 5  
Ashtabula, Ohio 44004  
Phone: 440-214-8013  
Website: [www.uhhospitals.org](http://www.uhhospitals.org)

### **CUYAHOGA COUNTY**

#### ***Rainbow Babies & Children's Hospital – Audiology Services***

11100 Euclid Avenue  
Cleveland, Ohio 44106  
Phone: 216-844-7191

#### ***University Hospitals Cleveland Medical Center***

11100 Euclid Avenue  
Deforia Lane 1200  
Cleveland, Ohio 44106  
Phone: 216-844-7191

### **STATEWIDE RESOURCES:**

OHIO DEPARTMENT OF HEALTH – INFANT HEARING \* DODD & COUNTY BOARDS OF DD \* HELP ME GROW \* OHIO HANDS & VOICES \* OHIO AG BELL \* CMH (BCM)H \* OHAAP \* PARENT MENTORS OF OHIO \* OCECD \* OCALI \* OCBDE \* CCHAT

### **NATIONAL RESOURCES:**

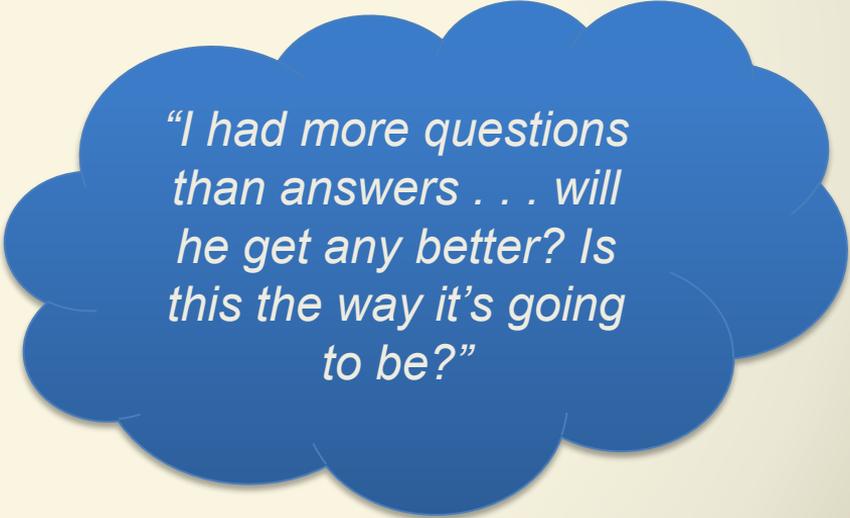
AG BELL \* AMERICAN SOCIETY FOR DEAF \* BEGINNINGS \* BOYS TOWN \* CLERC CENTER \* EHD (CDC) FAMILY LEADERSHIP IN LANGUAGE AND LEARNING (FL3) \* HANDS & VOICES \* HEARING FIRST \* JOHN TRACY CLINIC \* NATIONAL CENTER FOR DEAFBLINDNESS \* NATIONAL CUED SPEECH \* NATIONAL ASSOCIATION FOR THE DEAF \* NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT (NCHAM) \* VL2 PARENT PACKAGE

# Parent to Parent Support Program Protocol

- Modeled after other program designs
- Support from the FL3 project
- Unbiased support for families
- Parent Leaders embedded in the program
- Includes training for all staff and basic support structure

# Professional Development Training Series

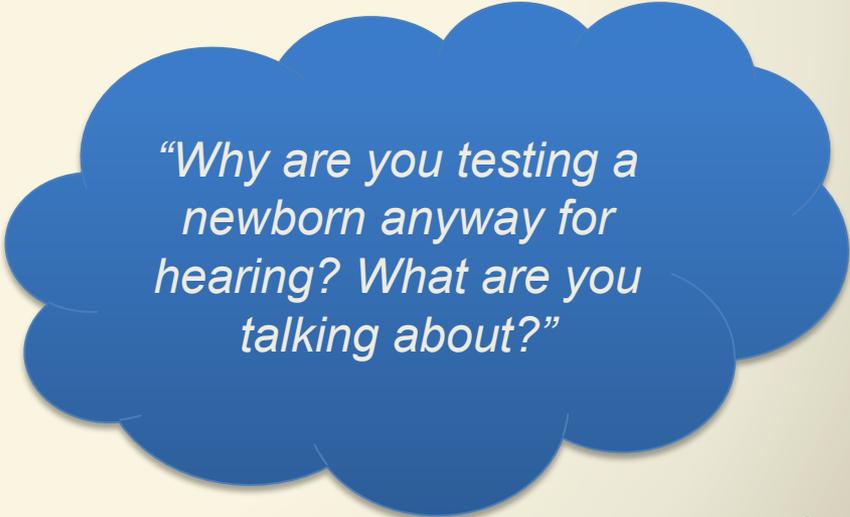
- Diagnosing Audiologists
- Central Coordination Staff
- EI Providers



*“I had more questions than answers . . . will he get any better? Is this the way it’s going to be?”*

# Follow the Family's Journey

- The trainings were developed around the families' Journey From UNHS Through Early Intervention
- Reinforced with Research and Evidenced Based Practice
- Through Parent Interviews
- 



*“Why are you testing a newborn anyway for hearing? What are you talking about?”*

# Based On EHDI Principles

- Joint Committee on Infant Hearing: National Standards for Early Hearing Detection and Intervention (EHDI) Document
- Twelve Principles and Guidelines for Early Intervention After Confirmation That a Child Is Deaf or Hard of Hearing
-

# Family Interviews

*"I'm not really sure  
what's ahead . . . I  
don't even know what  
all these appointments  
are for."*

- We conducted interviews/videoed our past and present families.
- Represented a variety of communication modalities, hearing technology, degree and nature of hearing loss and age of identification.
- The interviews captured each family's description of their experience and feelings on video beginning with UNHS through enrollment in EI. Positive and negative experiences were shared.

# Importance of Early Intervention

- Early identification and intervention is crucial
- Preventative
- Family training and support

# The Importance of Early Intervention

- Communication
- Development
- Brain Development
- Basic anatomy of the ear
- Urgency!!



*“I didn’t get to  
take in alot at  
that first  
meeting”*

# Training Audiologists



*“I heard  
nothing else, I  
thought about  
my perfect little  
baby”*

- For training the audiologists we knew they had all of the facts about the ear and hearing.
- Our intention to facilitate audiologists to understand the families perspectives and feelings
- Describe how to help the family on their journey
- Present best practice for providing information to families (Informational and Adjustment Counseling)
-

# Questions



# For More Information

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