

# Listening to the Parent Voice

## Findings from a National Needs Assessment



Vicki Hunting BA



Alyson C. Ward M.S., IA, CHES

**“ Every system is perfectly designed to achieve exactly the results it gets.”**



# Disclosures

- Nothing to disclose
- Funding for this project is supported by HRSA,  
UJ1MC30748-01-00

# Who we are:

## National Center for Hearing Assessment

- NTRC for newborn hearing screening programs (HRSA U52MC04391)
- Conduct research, provide technical assistance, EHDI-IS systems, international outreach, promote awareness, and advocacy

## Hands & Voices

- Parent-led/driven, non-profit
- Supports families with children who are deaf or hard of hearing without bias around communication modes or methodology.
- Family Leadership in Language and Learning (FL3) (HRSA UJ1MC30748-01-00)

# Agenda:

- 1) Background and Purpose
- 2) Methods
- 3) Results
- 4) Discussion
- 5) Questions and Wrap-up



# Background and Purpose

# Background and Purpose

- Data is not final, evaluation and analysis is still in progress
- Evolution of MCH Public Health Programs
- Origin of the needs assessment
  - Funding from HRSA/MCHB
  - Partnership between H&V and NCHAM
  - Needs Assessment vs. Evaluation
- Purpose
  - The purpose of the needs assessment is to guide the FL3 in meeting the **needs of organizations** who support families with children who are DHH and **EHDI programs**. The FL3 aims to **develop and disseminate tools and resources** for all families with children who are DHH, ensuring to engage those who are underrepresented or come from diverse backgrounds. The needs assessment is **not** a pre/post evaluation of the outcomes of the FL3's work.



# Methodology



# Overarching Research Questions:

1. What types of support do **families** wish they had when their child was diagnosed as deaf or hard of hearing and what would have been the optimal timing to receive those supports?
2. What do **family support organizations** need from the Family Leadership in Language and Literacy program to better serve families who have a child who is deaf or hard of hearing?
3. What supports do **EHDI programs** need to ensure effective family engagement in ensuring the EHDI programs meet the needs of all families of children with or at risk for being deaf or hard of hearing?

# Review of Extant Data:

- What do we already know?
- What do we want to know?
- What existing sources answer our questions?
- Creation of a comprehensive outline, example:

Population	Areas to Assess	Extant Data	Methods
General population of families DHH <6	<ol style="list-style-type: none"><li>1. Confidence in leadership</li><li>2. Preferences of how and when contacted</li><li>3. Opportunity to engage with diverse families</li></ol>	<ol style="list-style-type: none"><li>1. EI SNAPSHOT</li><li>2. NECAP survey</li><li>3. H&amp;V Leadership Conference learning</li><li>4. MN Lifetrack DHH Wilder Report</li></ol>	<ol style="list-style-type: none"><li>1 &amp; 2 Gather through Social Media outlets</li><li>3 Focus groups with under-rep groups</li></ol>

# Institutional Review Board Approval:

- Research with human beings
- Scientifically Sound
- Risks are minimized
- Risks are reasonable in relation to benefits
- Participation selection is equitable
- Safeguards are in place for vulnerable populations
- Compensation

# Target Populations:

- Adult **caregivers**, typically the mother or father, of children ages birth to 6 years who are deaf or hard of hearing (DHH).
- All **coordinators** of state and territory EHDI programs and
- **Family-based organization** directors who are contracted with their state EHDI programs

# Survey Participants

## EHDI Coord

- 56/59 = 95%
- 4 island coordinators

## Parents

- 1,000
- 23 island parents
- 67 families from SNAPSHOT

## FBOs

- 41/59 states
- 48 orgs

# Recruiting Participants:

## Parents

- ▣ Sub-set through existing pool
  - ▣ Emails and texting
- ▣ Through FBO social media outlets
  - ▣ Email, Facebook and Twitter
- ▣ Focus groups randomly selected off of survey responses

## EHDI Coordinators

- ▣ Email and phone calls
- ▣ Focus groups randomly selected from list of programs

## FBO

- ▣ Email and phone calls
- ▣ Focus groups randomly selected from organization list

# Data Collection:

- Followed Dillman survey design
- Implemented modified-Dillman modes-contacted multiple ways and frequently
- Followed a contact timeline for each target population
- Collected data through REDCap- HIPAA compliant
  - Via email, phone, text

*“The key to a successful integration of hearing loss into a family is the degree to which parents are able to integrate hearing loss into their lives”*

*(D. Luterman, 2006)*

**Results: Parents**



# Simplified Survey: Parents

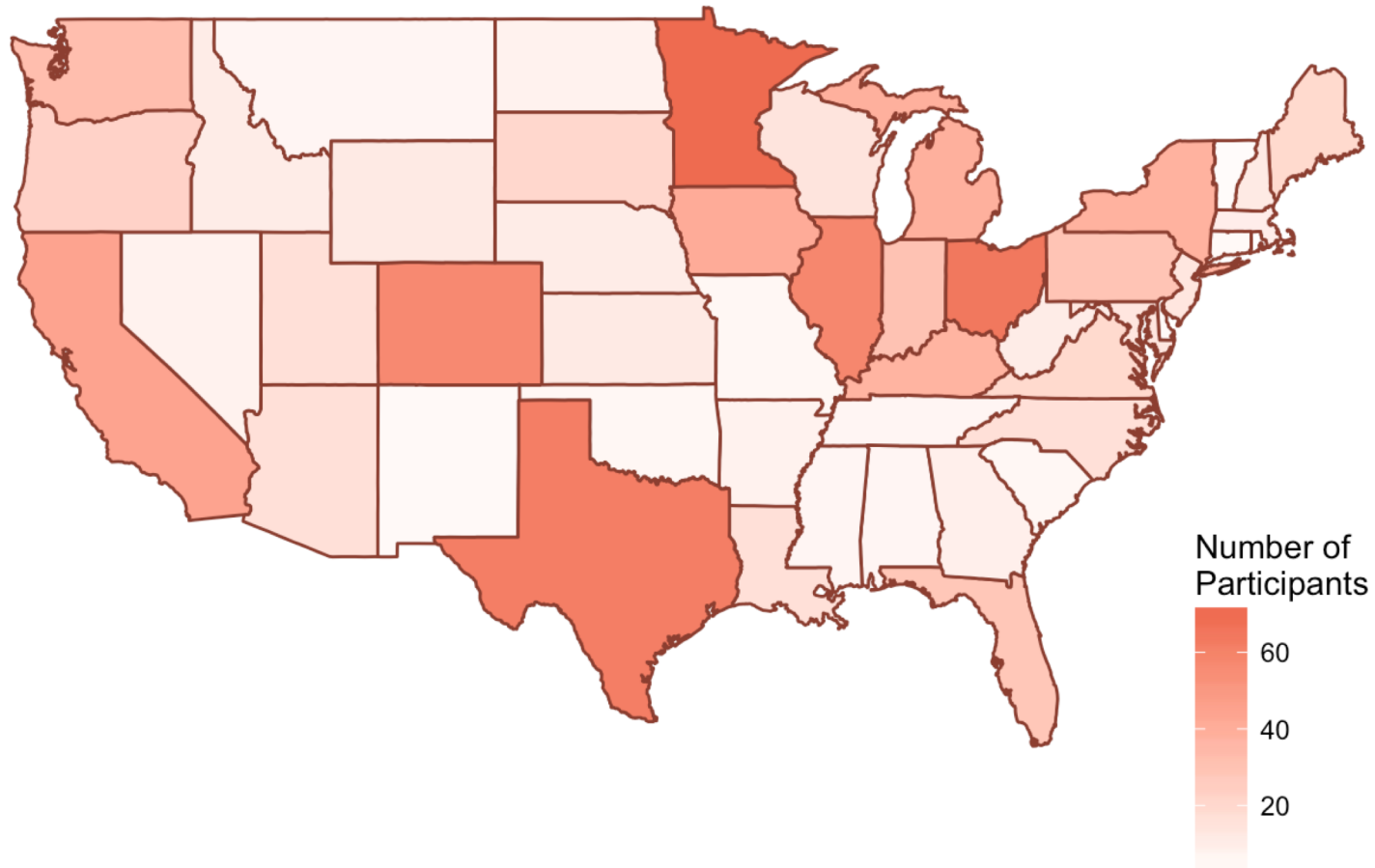
1. **Demographics** & basic family information
2. **How involved** are you with your state's newborn hearing screening or EHDI program and family support organization?
3. What **types of support** have you **received** and who provided these supports
4. What **resources** received and **who provided** these resources
5. **Confidence** in ability to access various **milestone** resources; language, literacy, social-emotional development
6. **Challenges** in becoming a family **leader**
7. Are there **resources you did not get**, but wish you had
8. Biggest **barrier to participating** in family-to-family support activities
9. Where you offered a **deaf role model**, did you meet with them, how were they helpful

# Parent Survey

- Survey was Piloted, minor edits prior to full distribution
- 5 Virtual Focus Groups;
  - 2 general parent groups
  - 1 each for; DHH Plus, Spanish/Latino, Fathers
  - Held via Zoom for 1 hour
  - Compensated
  - Informed Consent
  - Recorded/transcripts summarized for themes

*“Most information comes to me through my spouse, I would like to receive information 1<sup>st</sup> hand too.”* – Dad from Focus group

# Number of Respondents by State



# Parent Demographics

## Race

White 81%  
Hispanic 10%  
Black 3%

## Age of child represented

0-2 16.4%  
3-4 15.7%  
5-6 15.8%  
7-11 29.7%  
21.6%



## Parent

Mother 94.2%  
Father 4.5%

## Primary language

English 88%  
ASL 6%  
Other 6%

# Results: EHDI Coordinators

# Simplified Survey: EHDI Coordinators

1. To what extent are you **implementing activities** to support families who have children who are DHH?
2. Do you have a **resource guide** you provide to families and how do you provide it?
3. What **activities** do family leaders perform?
4. How do family leaders **participate in QI** and **evaluation**?
5. To what extent are you implementing strategies to **enhance and maintain strong family leaders**?
6. What challenges do you face in **getting family leaders active** in your EHDI system?
7. Do you plan to **evaluate the effectiveness** of your partnership with your FBO?
8. What are the **challenges or concerns** about your partnership with your FBO?
9. What **resources or support** would you like from the FL3 and how would you like to receive them?

# How do Family Leaders Participate in EHDl?

## ■ Top 5 Activities

- Parent rep on advisory committee
- Participate in decision making about EHDl goals
- Provide family-to-family connections
- Connecting families to statewide DHH resources
- Assistance navigating EHDl system (getting into dx & EI)



# Background of EHDI and FBOs

- EHDI programs encouraged to engage families since 2005
- Involvement of families in MCHB-funded NICHQ-run learning collaboratives between 2006-2013
- Required to involve families in advisory committees, QI teams, and learning communities on/off for last 10+ years.
- Required to financially support at least 1 FBO with 25% of total grant funding during 2017-2020 grant cycle.



# Challenges with FBO Partnership

- ❑ Do not have the infrastructure to fulfill tasks of the FBO (budget, reporting, insurance)
- ❑ Lack of professional skills (outreach, content expertise)
- ❑ Limited staffing and availability
- ❑ Jeopardizes staffing at EHDl program
- ❑ Sustainability for EHDl and FBO



# FL3 Support Requested

- Provide opportunities for state-to-state networking on family leadership efforts
- Creating evaluation plan for FBO
- Help training FBO on budgeting and service provision/workplans
- Providing quality leadership training for FBOs and families
- Help provide balanced communication information
- Deaf mentor curriculum and training



# EHDI Coord Focus Groups

- 2 Focus Groups
  - AM & PM to accommodate US and Territory Time zones
  - 12 Attendees
  - 12 States/Territories

- Held via Zoom for 1 hour

- Informed Consent

- Recorded/transcripts summarized for themes

“...more awareness out there for families, that their voice is needed and respected.”

-Coord. from focus group

“I think that the parents sometimes feel that the providers are supposed to be the experts... and then providers don't want to overwhelm parents...so information isn't given.”

-Coord. from focus group

# Results: Family-based Organizations (FBO)

# Simplified Survey: FBOs

1. How **experienced** is your organization in working with families who have a child who is DHH?
2. Current **responsibilities** of your organization in serving families who have a child who is DHH
3. **Confidence** in serving families with children who are DHH
4. What kinds of **outreach** on behalf of EHDI
5. How **aligned** are your organizations **objectives** to that in your contract with your EHDI program
6. What kinds of **data are you reporting** to your EHDI program and how confident do you feel in your ability to report?
7. How **involved** was your organization in the **development of the contract** with your EHDI program
8. What are the **challenges or concerns** you have in working with your EHDI program.
9. **What resources** would you like the FL# to develop and how would you like to receive them
10. What are ways your organization would like to be inclusive of serving all families

# Challenges with EHDl

- ❑ Unclear or high expectations
- ❑ Ability to get contact information for newly identified babies/family
- ❑ Legal issues and insurance
- ❑ Poor communication
- ❑ Inconsistent payment



# FL3 Support Requested

- Materials in languages other than English
- Visual materials (current resources too text heavy)
- Resources for children over age 3
- Materials to assist outreach to Learning Communities (LCs), providers, EI, etc.
- Guidance on measuring family engagement

# FBO Focus Groups

- 2 Focus Groups In-person
  - On-site at 2017 Hands & Voices Leadership Conference
  - 30 participants from 20 states/territories
  - EHDI Designated FBOs
- 1 via Zoom for non-Hands & Voices organizations
  - 13 participants from 13 states/territories
- Informed Consent
- Recorded/transcripts summarized for themes
  - “I feel supported and we have a good working relationship with the EHDI coordinator and they're collaborating on working on ways to increase referrals” - FBO staff from focus group*



Discussion:

# Questions?

## Alyson C. Ward M.S., IA, CHES

- National Center for Hearing Assessment and Management
- Researcher & Quality Improvement Advisor
- [www.infanthearing.org](http://www.infanthearing.org)
- [alyson.ward@usu.edu](mailto:alyson.ward@usu.edu)
- 1-435-797-9746



## Vicki Hunting, BA

- Hands & Voices
- Director of Data and Evaluation
- <http://www.handsandvoices.org/fl3/index.html>
- [vicki@handsandvoices.org](mailto:vicki@handsandvoices.org)
- 1-515-988-8512



HANDS &  
VOICES™