



Leveraging Parent Perspectives to Inform EHDI System Change

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EHDI 2024

Learning Objectives:

- **Examine the use of parent focus groups** to inform EHDI system change, including the methodology, recruitment, and validity.
- **Compare & contrast findings from four focus groups** of EHDI families with children of similar ages who differ in location, hearing status, and language/culture.
- **Apply elements of a focus group methodology** in planning for data gathering to **inform their own programs and systems** (*and tell you what we did with our information*).

Introduction to Presenters & Partnership

OUR TEAM

Michaela (Perspective): Parent Leader, Project Manager

Karen (Training): Career in NHS, NCHAM Resource Builder

Sarah (Data): Practice-Based Research in EHDI, Parent Project Support

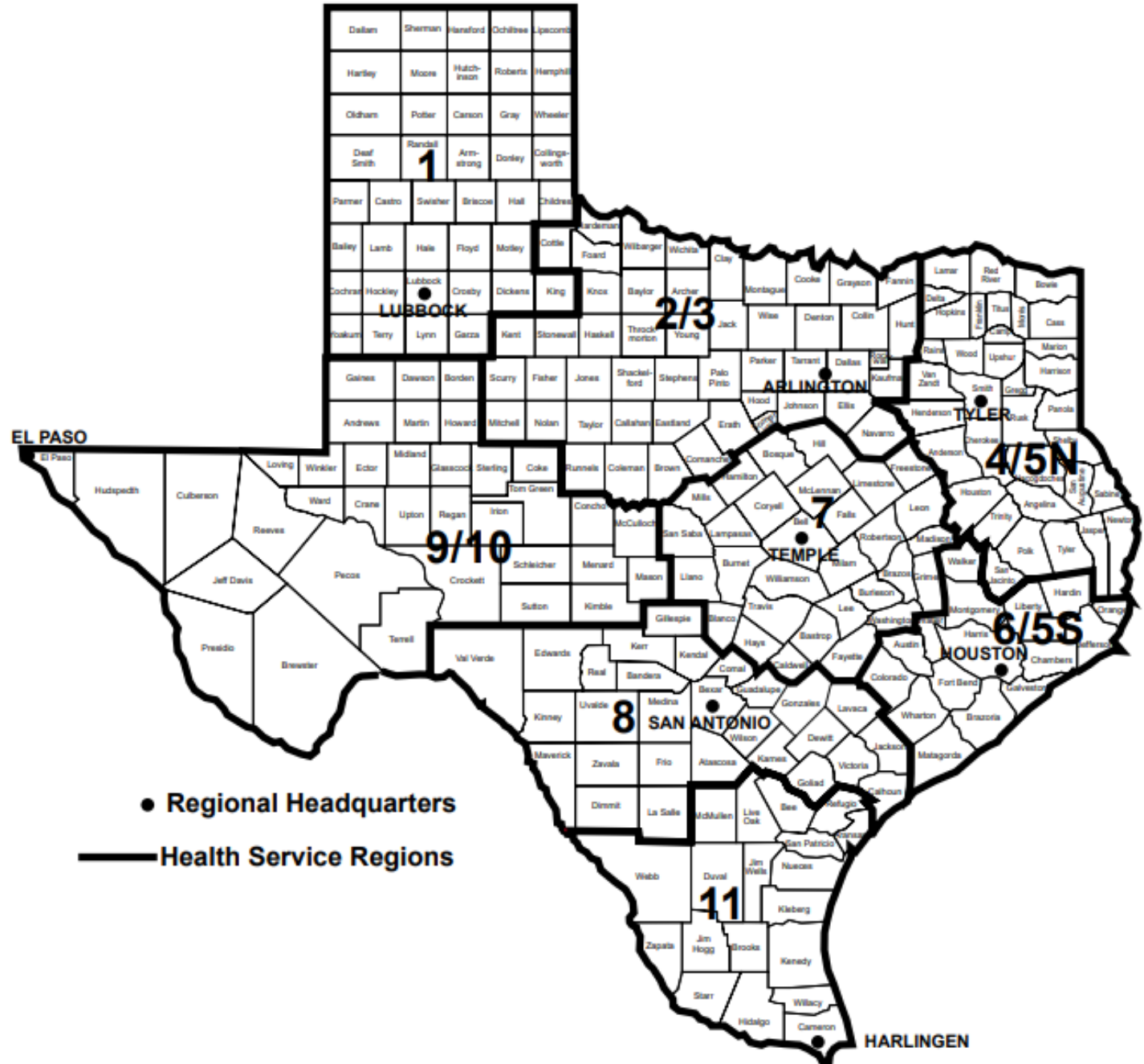
Lana, Paulina, Trayce & Yuliana (BOTG): Regional Parent Guides

OUR PROJECT

- A collaborative project with Texas EHDI to provide targeted, family-centered training to providers in three regions.
- Elements included hosting “summits” (live & virtual) in each region targeting continuum of providers
- Provider needs survey also completed.

Our State

Targeted Regions 7, 8, 11



Focusing on Focus Groups

THE WHY AND HOW

Families are “End Users” of EHDI

- Families’ experiences with providers & TEHDI vary across and within regions.
- Family backgrounds shape experiences.
- Elements of “story” inform targeted training.
- Identification of “themes” provide credibility.

National Family Needs Assessment

Race	White	86%
	Hispanic	9%
	Black	3%
Parent	Mother	94%
	Father	5%
	Guardian	1%
Age of Child represented	0-2	35%
	3-4	33%
	5-6	32%
Primary Language	English	92%
	ASL	4%
	Other	4%
Yearly Income	>\$150,000	12%
	\$75,000-\$149,999	36%
	\$35,000-\$74,999	31%
	<\$25,000-\$34,999	21%

Gathering “Data” from Families’ Stories

OBJECTIVES OF FOCUS GROUPS

Gain insight on experiences & perspectives of stakeholders through structured discussions.

Identification of opinion, trends, patterns & specific information in verifiable way.

Perspectives from selected, small groups of somewhat homogenous characteristics.

Facilitated discussions with targeted questions

OUR APPROACH

Recruitment of TEHDI families of 0-5 within regions representing varied experiences.

Personal contacts of regional parent guides & “snowballing” method leveraged

Guidance from academia & peer coaching on how-tos (Shout out to Arkansas H&V!)

Zoom (transcribed) sessions of 2-4 families facilitated by parent guides.

Talking to the Right People

YEAH! OUR GROUPS INCLUDED:

All parents in targeted age range
Parents who speak primarily Spanish (hosted in Spanish)
Parents who are Deaf themselves
Parents who are rural & urban
A dad!
Parents from each region
Parents with DeafPlus
Parents with different communication choices

BUT OUR PICTURE IS INCOMPLETE

This is still a “select sample” of families who have been engaged on some level.
Other groups are not represented (ie military families)
This is a great collection with a limited scope – every family has an important & different & LONGER story.

Asking the right questions

Tell us about your experiences with hearing screening when your baby was born.

Tell us about your experiences with diagnosis at the audiologist.

Tell us about your experiences with support services like early intervention, therapy, or parent supports.

Tell us about your experiences with professionals that have worked with you and your child.

Tell us about the unique needs of your community, and what our state system should know about the resources and barriers for your family in getting services.

We want to pass along what we have learned today to our state program for Early Hearing Detection and Intervention. Is there anything we have not asked about that would be important for professionals or state leaders to know?

What We Learned

OUR TAKEAWAYS FROM FAMILIES

“It was easier to navigate the process of a heart transplant for my child, than to navigate services to address his hearing loss.”

TEXAS MOM FROM FOCUS GROUP

JULY 2023

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1. Characteristics of Professional Communication

Many families did not understand the importance of ECI services (nor did they have anyone explain the importance) so they declined them.

Enrolling in ECI services was delayed for many families and misinformation was shared. Parents felt confused about the delay and the ECI process with some families waiting as long as 6 months for services.

2. Challenges in Navigating Services

At the time of newborn hearing screening many families felt unsure of next steps and did not receive a message of urgency; There was little to no follow-up from any state agency afterwards.

Families were forced to navigate the system and research options themselves to get to the follow up screening.

Follow up screening felt overwhelming, and the process was not explained. They did not understand the types of hearing tests needed and were unprepared.

Families reached out to organizations like Texas Hands & Voices and the Statewide Outreach Center at Texas School for the Deaf (SOC) for guidance.

4. Perceived Bias in Information

Many audiologists provided only medical intervention and did not explain the communication options for the child. Seldom was sign language brought up as a choice.

Many mentioned the impact a Deaf/Hard of Hearing adult had on their family and their choices and wished that would have been part of the identification process instead of as a follow up services.

Some families noted feeling supported as long as they maintained a decision trajectory that matched the intervention provider, but not when they expanded their choices (ie added sign language).

5. Desire for Empathy

Providers lacked empathy in working with families. In each of the four separate focus groups, the need for empathy was brought up by participants. Families felt that appointments were rushed and when a diagnosis was made the information that was relayed felt cold, clinical, and many times insensitive.

3. Disparities in Services

Spanish speaking families experienced difficulty in understanding and perceived less of a connection between the provider and family.

Families with parents who are Deaf/Hard of Hearing also felt a disconnect with providers and they faced challenges accessing interpreters and complete information.

At the point of identification, several families felt ill equipped to know what to do next, some audiologists identified next steps, many did not.

Our Shared Response

RECOMMENDING NEXT STEPS FOR TEXAS EHDI

Our Groups Reflect JCIH Priorities

HRSA & EHDI VALUE

Increasing parent engagement, leadership & partnership, as parents are trained to serve as family leaders in EHDI systems.

The focus group approach provided professional development for our parent guides & ownership the parent perspective.

FUTURE DIRECTIONS IN EARLY INTERVENTION

Family engagement in professional development

Inclusion of culturally diverse perspectives

Inclusion of Deaf community perspectives

Development of research agendas to guide practice

Shared with a Broad Continuum of Providers

- Identification & outreach for targeted training that included updated best practices, family-friendly communication & effective referrals.
- Collaboration with state and regional department of health staff within each region.
- Development of **micro-networks** of providers to address loss to follow-up/documentation
- Target: Model of robust, sustainable, replicable service networks for families

Our Pediatric Hearing Healthcare Continuum:

- Pediatric Audiologists
- Ear Nose & Throat Specialists
- Social Service Providers
- Private Practice Providers (ie SLPs)
- Medical Home Providers
- Early Intervention Service Providers
- Deaf Education Service Providers
- WIC Providers
- Head Start Providers
- Midwives

Perspectives that Inform Systems

- Identification of unrecognized barriers from family stories including:
 - Referrals to providers determined by documentation status & checkpoint locations
 - Practice requiring two visits versus one (ENT first, then pediatric audiologist)
 - Professional's use of fear-based guidance at time of identification related to communication decisions.
 - Within an area with few audiologists, the audiologist offer diagnostic services only morning a week.
- Clear need for expanded diagnostic services (ie teleaudiology & Medicaid support).
- Need for collaboration of EHDI stakeholders to lessen barriers (ie transportation & communication in the family's language).
- Reminder to providers that families have different levels of emotional “readiness” as they navigate next steps, reiterating need for empathy.

Perspectives that Guide OUR Next Steps

- Identify professionals within the micro-networks with skills, knowledge, and disposition to deliver high-quality EHDI services despite geographic, financial, and other barriers through technology.
- Prepare professionals with the knowledge and skills to provide services that are culturally and linguistically sensitive and responsive in all respects. (Try to teach Empathy)
- Inform providers of services within their immediate area by developing interpersonal networks within their communities.
- Provide resources and current standards of care to have available when an infant/child crosses their paths and needs additional services.
- Help to pull stakeholders out of their “Silos” that operate in isolation from others by increasing interactions with training, brainstorming, and informational meetings.

Perspectives that Complement Services

Even before you host Focus Groups, family-based organizations can provide timely support & guidance for newly identified families:

- Coaching on navigating next steps & emotional support for “readiness”
- Resourcing & connecting those who are outside of major metro areas/ rural
- Educational opportunities & guidance for those who are culturally & linguistically diverse
- Accurate, current & unbiased information about ALL language & communication opportunities
- Assistance with navigating the EHDI system with the state.
- Sharing vetted resources, state & national, educational & practical
- Exposure and access to perspectives from Deaf & hard of hearing adults

Perspectives Guide OUR FBO's Next Steps

- Identify professionals within the micro-networks with skills, knowledge, & disposition to deliver high-quality EHDI services despite barriers.
- Prepare professionals with the knowledge & skills for culturally responsive & linguistically services. (ie try to teach empathy)
- Facilitate interpersonal networks within communities that connect providers with other local services.
- Share current resources & standards of care with a family-centered perspective.
- Help to pull stakeholders out of practice “Silos” by increasing interactions with training, networking & exposure to family stories – like those from our focus groups!

Session ReCap & Resources

Family perspectives & family leadership are critical to effective EHDI systems

Focus groups are a tool for gathering targeted information from diverse subgroups of families across different services regions

Plan carefully for recruiting, questioning, facilitation & documentation

Share both themes & stories with stakeholders

You don't have to wait for a focus group to benefit from family-to-family support

We'd love to tell you more!
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Thanks to Our Parent Guides Back in Texas!
Lana Nissen, Trayce Stoenescu & Paulina Pena
& Yuliana Trujillo from SOC @ TSD

