One Size Does NOT Fit All

A REGIONAL APPROACH TO EHDI LOSS TO FOLLOW UP

A Partnership Progress in Process…

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Collaborating Audiologists with Texas Hands & Voices

Session Objectives:

Describe the relationships between the demographics of a region and barriers to EHDI follow-up

Identify varied data sources that inform strategic regional planning for EHDI programs

Develop regional needs assessments that facilitate targeted provider supports

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Loss to Follow-Up: It's tough in Texas!

Second largest birthing state with nearly 400,000 babies per year

Largest rural population in the U.S. and 269,000 square miles

Record levels of immigration…

More than one-third of children on Medicaid; Highest number of uninsured

Shortage of audiologists (roughly 1600 for the entire state of 30 million)

Loss to follow-up is a challenge:

- 52% at diagnosis (21% nationally)
- 61% at early intervention (16% nationally)

Partner Priorities

DSHS/TEHDI

- Replicable: Model that can be implemented across regions
- Sustainable: Development of regional, robust micro-networks
- Best-Practices: Implementation of evidence-based, interagency supports

TXHV

- Family-Centered: Coaching for families & providers that promote timely, informed parent decisions & optimal outcomes for children who are Deaf/HH.
- FBO Credibility: Demonstration of the effectiveness of partnering with H&V.

Find the leaks in our EHDI pipeline and plug them!

Provider Engagement: Addressing EHDI family barriers

Effective Communication & Informed Decisions

Communication barriers experienced between providers & families compromise system efficacy.

Best-Practices in Early Identification of Hearing Differences

Providers across disciplines are unaware of TEHDI supports and family needs.

Transitions to a Continuum of Supports

Systemic barriers impede timely 1-3-6 transitions.

Recognition of Risk Factors

There is no strategic plan to address late onset.

A Family-Based Organization: Why Us?

Family engagement promotes self-efficacy and promotes best outcomes:

Providing families

- **Evidence**
- **Skills**
- **Resources**

Building family-to-family support

"An organizational culture that prioritizes and facilitates family leadership is vital to sustain and improve mechanisms for family engagement and partnership over the long term and across the EHDI system."

From FL3 (H&V/HRSA)

"Equitable partnerships between families and EI programs and systems are critical to the success of EHDI programs and the achievement of optimal outcomes for children. Family leadership and involvement are critical when developing policies and programs…"

From JCIH, 2013

We Put Families First.

Identification of trained & experienced parent guides already engaged in outreach within the region.

Identification of informant families that represent varied experiences within targeted age range.

Organizing focus groups of families across region to hear families' stories of barriers & success – English & Spanish.

"Snowballing" connections to more providers and families.

Parent-provider partnerships are research-based best practices in EHDI.

International Consensus Statement

Qualitative data helps to understand the patterns of health behaviors, describe system experiences, design health interventions, and develop healthcare theories.

NIH

We checked the map.

LEVERAGING LOCAL RESOURCES

Population centers & county lines

DSHS & ECI

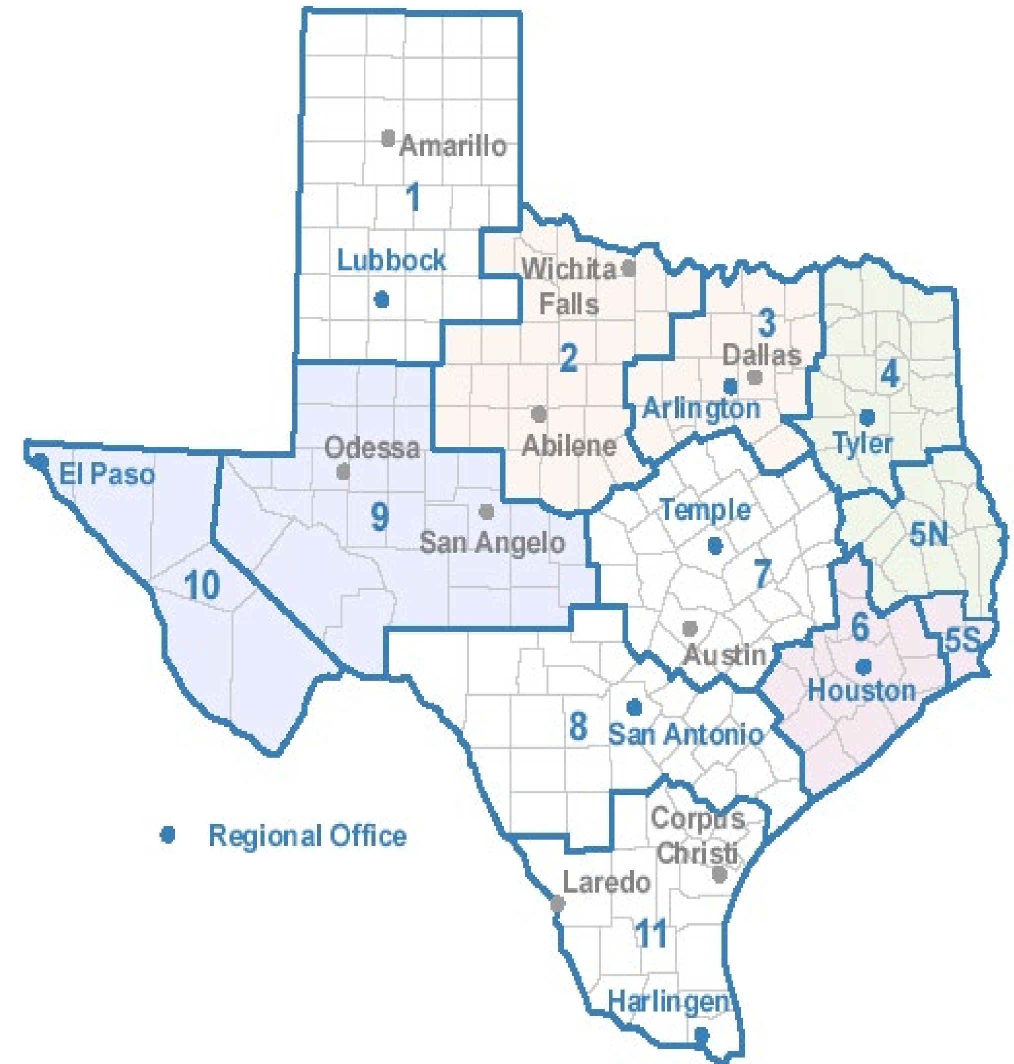
Birthing hospitals

Medical/clinical providers/audiologists

Regional Educational Service Centers and Regional Day School Programs for the Deaf

Military Bases

*Community based services (Midwifery, WIC)

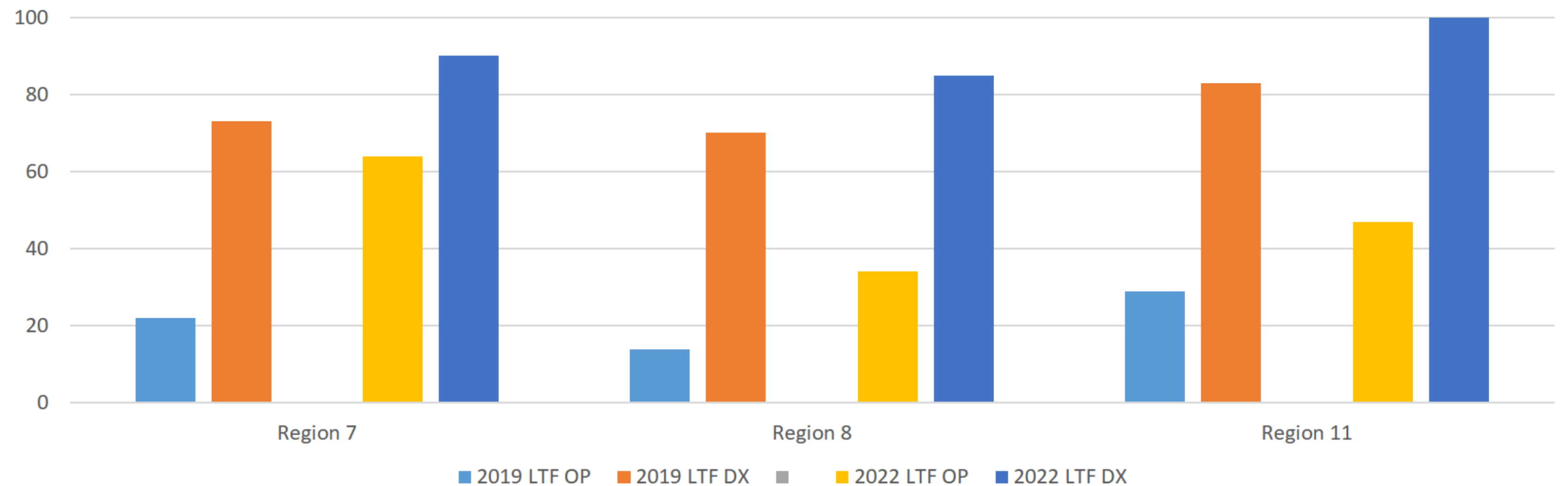


We reviewed the data.

The three target regions represent one-quarter of the population in Texas.

One of the three regions is screening more infants, the other two are screening fewer.

LTF is up across regions, at OP & Dx levels.



We asked the right questions.

Role, region, & representation

Background knowledge

Family communication, barriers

Training, skills, & confidence

Referral process & reporting

Desired training & resources

Background Knowledge: Providers have different backgrounds and perspectives. Please let us know about your perspectives on these items. (Tip: For these items, if you are uncertain, please take a guess!)

*7) In your professional opinion, at what age should a young child's hearing loss be diagnosed?

- Three months or less [Value=1]
- Within the first six months [Value=2]
- Within the first year [Value=3]
- Prior to three years [Value=4]

*8) How critical is hearing to a child's development?

- Critically important. A hearing loss is a developmental emergency and practitioners serving young children should be ready to address concerns. [Value=1]
- Significant to some aspects. Hearing loss could impact language and learning and should be monitored by some practitioners. [Value=2]
- Important, but only for a small segment of the population and a concern only to specialist practitioners. [Value=3]

*9) What levels of hearing loss can negatively impact language and learning?

- Hearing losses that result in language deficits are primarily in the severe to profound levels. [Value=1]
- Hearing levels must be at least at the moderate loss level to result in language deficits. [Value=2]
- Even mild hearing loss can result in language deficits. [Value=3]

*10) At what age should young children who have been diagnosed with hearing loss be enrolled in early intervention services?

- Before six months [Value=1]
- Before twelve months [Value=2]
- Before age two [Value=3]
- Before age three [Value=4]

We identified the players.

EHDI –PALS

Guides & Texas Hands & Voices

State registries of licenses & professional organizations

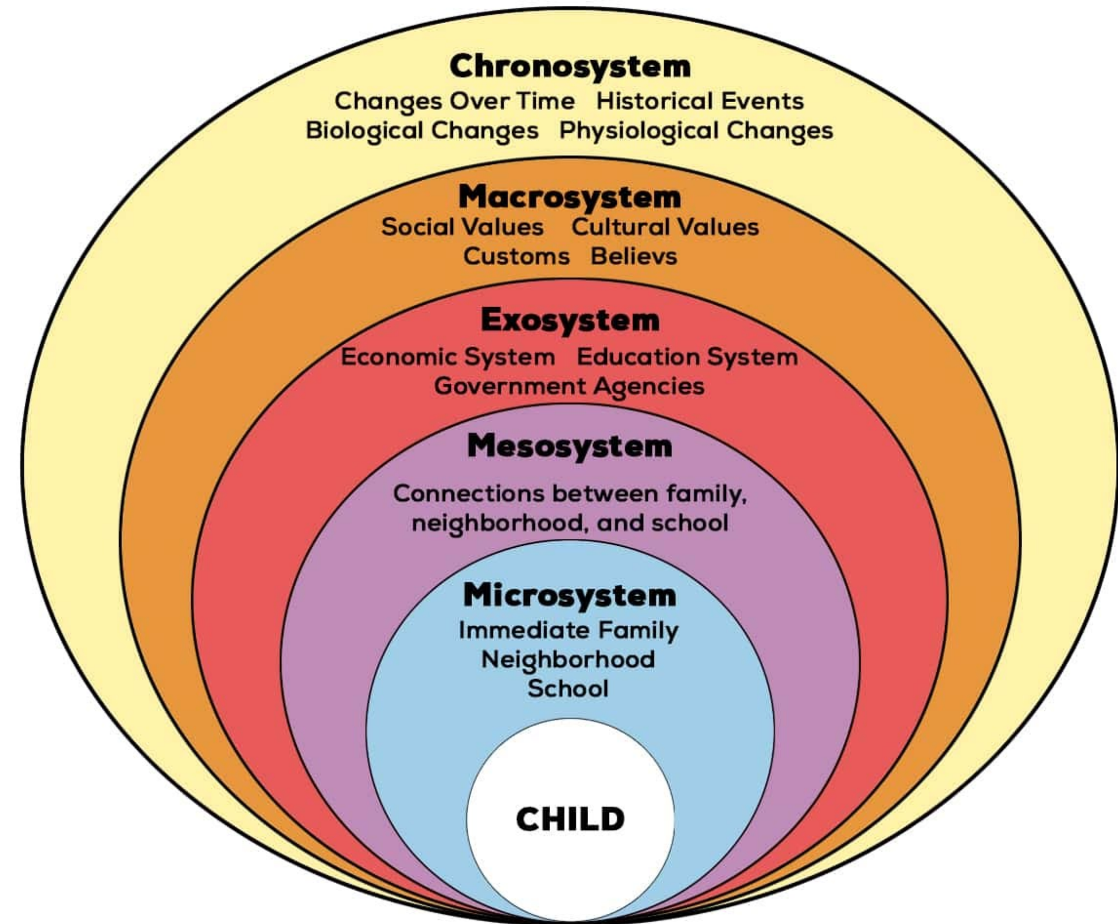
Screeners & contractors

Providers in MIS

PCPs (Targeting those with equipment) and nurse practitioners

ECI, RDSPDS, private SLPs, HeadStart

Snowballing…



We broadened the scope & narrowed the purpose.

THINK BIG

Broaden who we consider stakeholders in the continuum of care

Expand our target from 0-3 to prenatal to five years

STAY ON TARGET

Family engagement that promotes self-efficacy

Reducing loss to follow up

…and we are getting to work.

Building EHDI “micro networks”:

- ✓ Parent boots on the ground
- ✓ Real connections across stakeholders
- ✓ Authentic conversations
- ✓ Willingness to be dynamic/flexible/responsive
- ✓ Long term commitment

Enable families to navigate the system AND adapt the system to engage the families

The End…and the beginning.

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