



Parents as EHDI Partners in Follow Up: A Quality Improvement Model



TEXAS
Health and Human
Services

**Texas Department of State
Health Services**

A REVIEW OF THE TEXAS
FOLLOW THROUGH GUIDE PROJECT



Parent partnerships are effective.

Session objectives:

Describe developments of EHDI-Parent Partnership

Identify barriers to follow up & parent-driven supports

Describe the FTG Project implementation & measures of effectiveness

Texas Follow Through Guide Project:

EHDI partnership between Texas Department of State Health Services and Texas Hands & Voices, funded by a grant from the U.S. Health Resources & Services Administration.

LTF/LTD is a TEHDI Priority.

Birth Year	National	Texas
2011	35%	74%
2012	37%	77%
2013	32%	61%
2014	34%	55%
2015	39%	54%

Rate of Loss to Follow Up/Loss to Documentation for diagnosis for the 400,000 babies born annually in Texas.

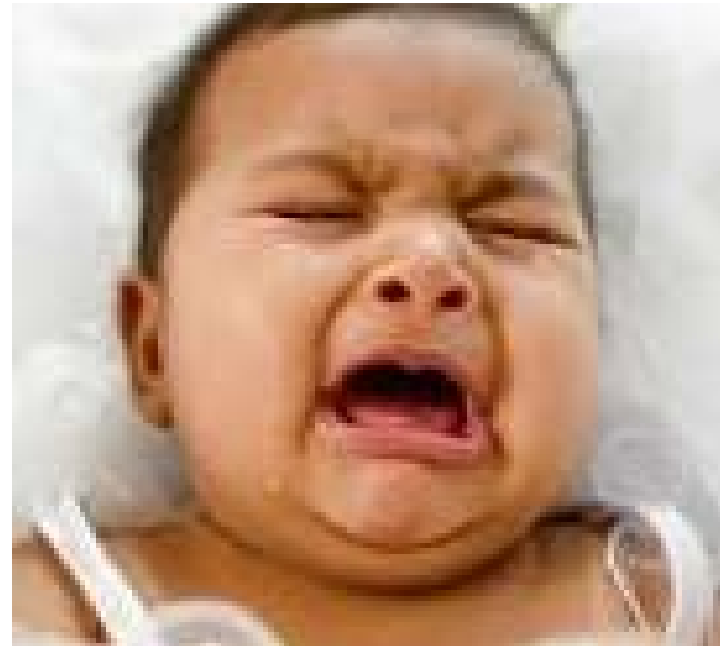
CDC Data indicating LTF/D at Diagnosis.

Many Texas EHDI babies miss ECI.

Texas has 77% EHDI loss to follow up for early childhood intervention (ECI).

We know that quality early intervention by the age of six months is the strongest predictor of long term positive outcomes for our children that are deaf or hard of hearing.

(Yoshinaga-Itano, 2003)



Resources & priorities are shared.

Partnership funded through grant from Health Resources & Services Administration focused on Loss to Follow Up and Loss to Documentation.

Leveraging parent-to-parent support to facilitate transitions for families from screening to diagnosis to intervention.

Follow through with providers to reinforce protocol, report on parent experiences and to share resources.

Trained parents implement shared plan.

LTF/LTD families identified by DSHS weekly.

Parent guides contact families to identify next steps & facilitate transitions.

All communication is by phone (text used to facilitate follow-up).

Scripts are used to ensure data collection is complete, with flexibility to follow family lead.

Specific follow up plan is in place.

TEHDI receives data & case notes; MIS updated.

Subsequent calls are made to providers.

Parent selection & training is vital.

QUALIFICATIONS

Experienced parents of children who are deaf/hh

Philosophically aligned with informed parent choice

Trained through TEHDI & TxH&V

Culturally competent & fluent in Spanish & ASL

UNIQUE CONTRIBUTIONS

Practical perspective

Sensitive engagement

Passionate about mission

FTG Project has expanded in cycles.

CYCLES

April – August 2014: Initiation with provider referrals only

August 2014-March 2015: Implementation with CIDs provided (cycle I)

June 2015-March 2016: Full implementation (cycle II)

April 2016-March 2017 (cycle III)

April 2017-present (cycle IV)

STAGES

Developing scripts & protocol

Sharing data cooperatively

Initial & follow up calls

Provider calls (fail to refer)

Texting follow up initiated

Expanding strategies

Targeting care coordination

Outcomes are measurable.

3,500 families of infants “lost” to the system after referring on the newborn hearing screening have been contacted by a parent guide, about one third in Spanish.

Over 200 service providers have received coaching on best practices and family-centered supports, impacting services for thousands more families.

Age of the infants at the time of outreach has dropped from 9 months to 4 weeks, with optimal opportunity to achieve the 1-3-6 EHDI targets.

The number of families who providers fail to appropriately refer to early intervention has been cut in half, from 32% to 14%.

...and more we can't measure as parent-to-parent connections are made.

Loss to documentation is reduced.

FTGs were able to provide updated information to DSHS on 1000 families, directly impacting LTF/LTD.

It should be noted that even for these families support was provided: Helping to explain results and confirming next steps.

System-based barriers are identified.

Referral Delay: Pediatrician/primary referral is required but delayed.

Scheduling Delay: Testing has been rescheduled, cancelled by provider or wait for next available appointment is 2 months or more.

Delayed Response: Family is awaiting a call back from provider.

Insurance Complication: Coverage, application, or process for Medicaid, private insurance is challenging, or co-pay is too much.

Navigation Difficulty: Process or implications or test findings have not been made clear to family,

Limited Providers: Unable to identify provider (location of family, limited availability of pediatric audiologists, or non-working equipment).

Family-based barriers are recognized.

Medical Needs: Other serious medical issues have precedence for infant.

Language Difference: Family has limited access to required information.

Parent Resistance: Family is “not ready” to move forward in process.

Limited Availability: Time demands of work/other responsibilities challenging.

Transportation Issues: Family is not able to travel to required appointments.

Limited Access: No computer or phone, or does not have reading ability.

Family Relocation: Relocation has disrupted access to system of providers.

Custodial Issues: Family arrangement make responsibility for followup unclear.

Connections are facilitated.

Early Intervention

- Families not effectively referred
- Families further educated
- Families who have not gotten a timely response

Audiology

- Families needing referrals
- Families needing insurance.
- Families needing guidance.

Parent to Parent

- Families who are interested in supports now
- Families who are interested in support later

EHDI families are supported.

JUST-IN-TIME SUPPORTS ARE PROVIDED

Guidance to facilitate transition to services

Information on hearing & identification procedures

Sharing of personal story when requested

Referrals to Early Intervention and parent to parent support

Consistent follow up occurs up to ECI enrollment

TEHDI IS INFORMED

Specific information about referral process

Narrative information about experiences & barriers

Misinformation is addressed.

Inappropriate “assessment”

Superficial issue only

Testing scheduled 6-12 mos

“Baby is fine “

Pass in one ear (flip-flop)

<10 days OP Screen

Not informed of results

While the number of families receiving misinformation is relatively small (5%), they may be the most concerning.

These families believe they are in compliance and acting in their child’s best interest, but they are not.

EHDI providers are informed.

FTG INFORMATION INFORMS TEHDI:

Update MIS

Connect to ECI

Identify providers not reporting

Inform about training needs

FTG INFORMATION SUPPORTS PROVIDERS:

Feedback on counseling needs

Reviews of protocol

Resource providers

System level improvements result, supporting more TEHDI families!

Providers are engaged.

Outreach

580 Connections

150 Providers/locations

Targeting

Loss of follow up – ECI

Compliance concerns

Resourcing

Specific record review

Updates on protocol

Connections to TEHDI

Clarification on policies

Affirmation of success

Role of guide is informing, sharing family-centered perspective & ethical obligation – NOT technical support.

Provider challenges are identified.

Training needed: Training needed on federal mandate, ECI services, consent procedures, referral process, MIS.

Materials needed: Hardcopy & digital materials requested for parents & professionals, in English & Spanish, on ECI and EHDI.

Guidance needed: Uncertainty related to confidentiality & consent, no access to MIS, no providers in region (Rio Grande Valley)

High turnover: Screeners & managers have little experience in the role.

Corporate management: Weak oversight from off-site or out of state management.

Outsourcing: Multiple contactors have inconsistent procedures.

Administrative structure: Non Department program managers (PT, triage, NICU, etc.) are less familiar and invested in EHDI.

Unique EHDI contributions of parent guides.

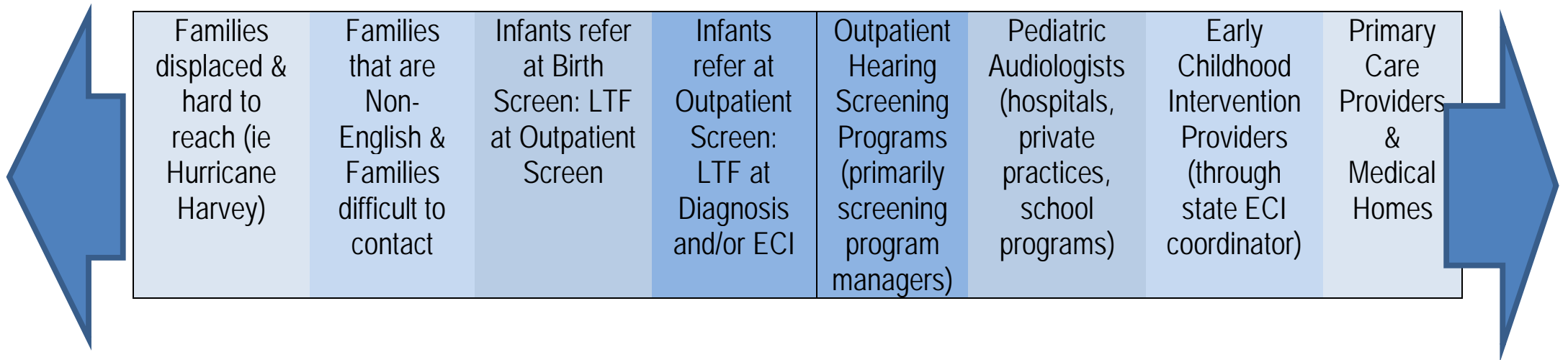
- Credibility and comfort based on lived experience.
- Accessibility of time, emotion, and location
- Understandability of communication in language and presentation
- Familiarity with “big picture” of EHDI & beyond
- Fluency in Spanish and English



FTG Project has expanded in scope.

TEHDI FAMILIES

TEHDI PROFESSIONALS



Thanks for letting us
share our Texas success
story!

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