



Loss to Documentation Or Loss to Follow-up?

An Assessment of Loss to Documentation
At Rescreen and Diagnostic Stages in Tennessee

Funding Acknowledgment and Disclaimer

- The projects were partially funded by the Centers for Disease Control and Prevention EHDI grant NU50DD000063.
- The opinions expressed by authors do not necessarily reflect the views of the Centers for Disease Control and Prevention.



The Newborn Hearing Screening Program

Holli Allen, BA | Program Director

Who We Are

- Tennessee HRSA EHDI and CDC EHDI-IS are housed within the Tennessee Department of Health, Division of Family Health and Wellness.
- Programs are part of the Newborn Screening (NBS) program.
- Staff include:
 - EHDI Coordinator
 - Two Epidemiologists
 - Part-time Deaf Educator
 - Contracted Family Support Organization
 - Contracted Audiology Consultant
 - Two Nurse Case Managers assigned monthly
 - Nurse Educator
 - Quality Assurance Nurse
 - Administrative Support

Hearing Follow-Up Procedures

- Initial hearing screening results are received from hospitals, midwives, and audiologists from across the state.
- Follow-up is conducted until hearing test results are received that denote the disposition of the child's hearing.
 - If no hearing screening is submitted, the hospital, family, and PCP are contacted.
 - Parents and PCPs are notified for all infants with a 'Fail' reported.
 - PCPs and audiologists are contacted for follow-up on babies who failed previous screens or never received a rescreen.
 - Letters are sent to parents of babies with reported hearing loss risk factors.
- Confirmed hearing loss:
 - Referrals are made to Children's Special Services (CSS), Tennessee Early Intervention Services (TEIS), Family Voices PEARS, and genetic centers.

Hearing Follow-Up Procedures

- Graduate Audiology Student Programs
 - TN EHDI maintains no-cost contracts with four universities across the state.
 - If hearing test results are not received after contact with nurse case management, cases are sent to graduate audiology students for additional follow-up.
 - Students attempt contact with parents and PCPs to obtain final hearing results and/or provide education about the need for follow-up.
 - If no follow-up is received after 30 days, cases are closed as Loss to Follow-Up (LTFU).

Addressing Loss to Follow-Up

- Loss to Follow-Up vs Loss to Documentation
 - CDC EHDI-IS funding.
 - Contracted audiology student contacted audiology providers across the state to determine if the cases closed as LTFU were true LTFU or loss to documentation (LTD).
- CHANT Project
 - CHANT is a care coordination service offered in each of the local health departments at no cost to the family.
 - Cases closed as LTFU are referred to the Community Health Access and Navigation in Tennessee (CHANT) program for additional follow-up by CHANT Care Coordinators.



Loss to Documentation At Diagnostic Stage

Yinmei Li, MD PhD | Epidemiologist II

Background Information

Basic Annual Stats

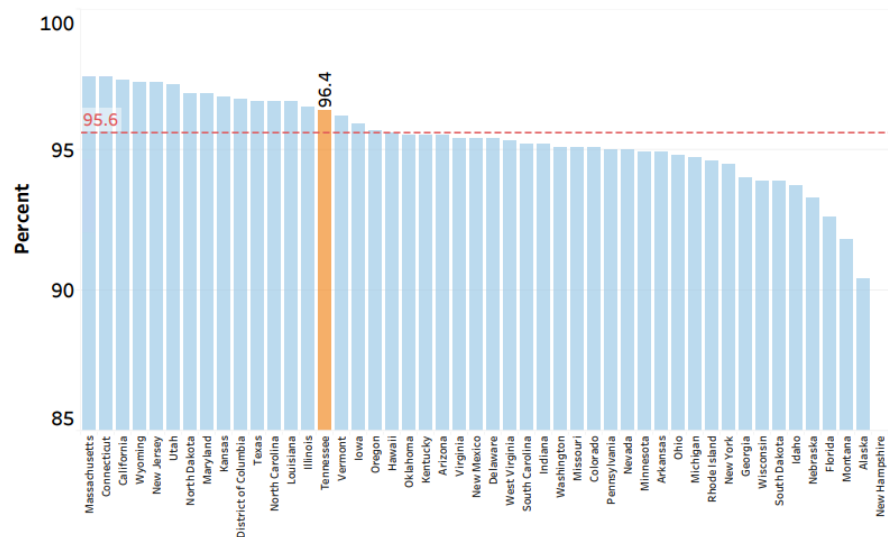
- ~88,000 births
- 1,800 failing hearing screening
- 160 hearing loss cases
- HL incidence 1.8/1,000

1-3-6 Benchmarks (2022 Births)

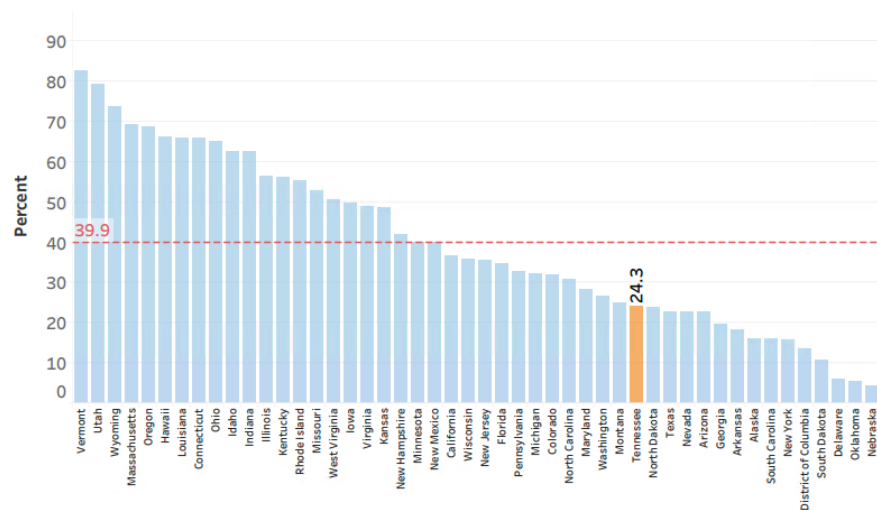
- 96.4% screened by 1M
- 24.4% completed diagnostic follow-up by 3M
- 29.4% HL children enrolled in early intervention by 6M

Background Information

Percent Screened by One Month of Age
2022 Births, USA

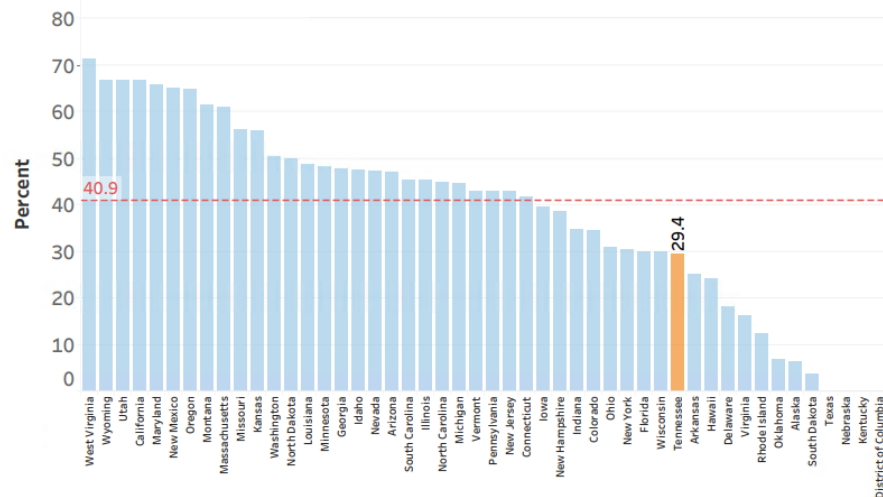


Diagnostic Follow-up by Three Months of Age
Among Those Who Failed Screening
2022 Births, USA



Background Information

EI Enrollment by Six Months of Age
Among Those with Hearing Loss
2022 Births, USA



Background Information

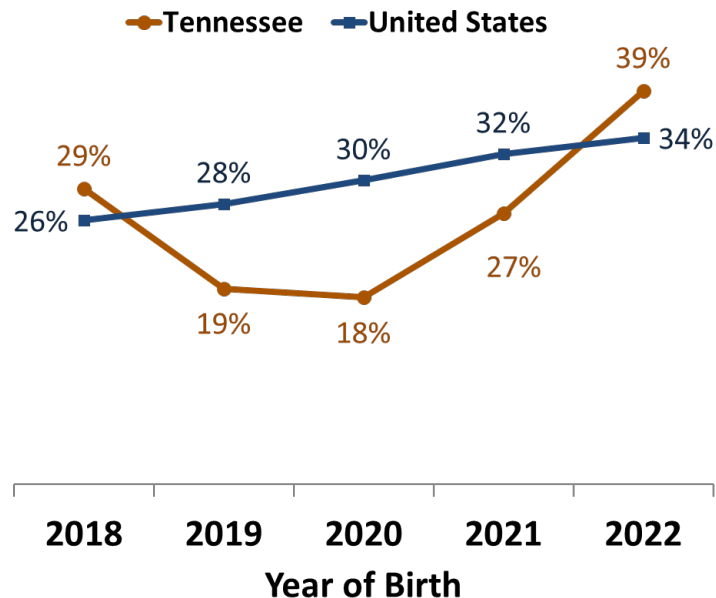
Challenge

Rising rate of loss to follow-up in recent years.

Opportunity

CDC EHDI funding to support a pilot study on LTD.

Loss to Follow-up Rate Among Infants With a Referred Hearing Screening



Project Goals



Primary Goal

To determine the extent of LTD among cases LTFU at the **diagnostic stage**.



Secondary Goal

To obtain diagnostic information on the LTD cases.

Method

Time period

- August – December 2023

Study population selection

- Infants born in TN between 2020-2023
- Failed hearing screening
- Referred to and/or seen for audiology evaluation
- Dispositioned as loss to follow-up

LTFU data by audiology practices

- Summary stats
- List of LTFU cases

An invitation letter to the audiologists

Method

A part-time audiology graduate student

- Sent the invitation letter to the audiologists
- Called the practices to schedule virtual meetings.
- Reviewed the list of LTFU cases.
- Recorded information about the cases.
- Compared with the information in the newborn screening data system.
- Determined the status as LTD or LTFU.
- Shared info with case managers who updated data in the newborn screening data system and/or initiated further follow-up activities.

Results

509
unique
LTFU
children

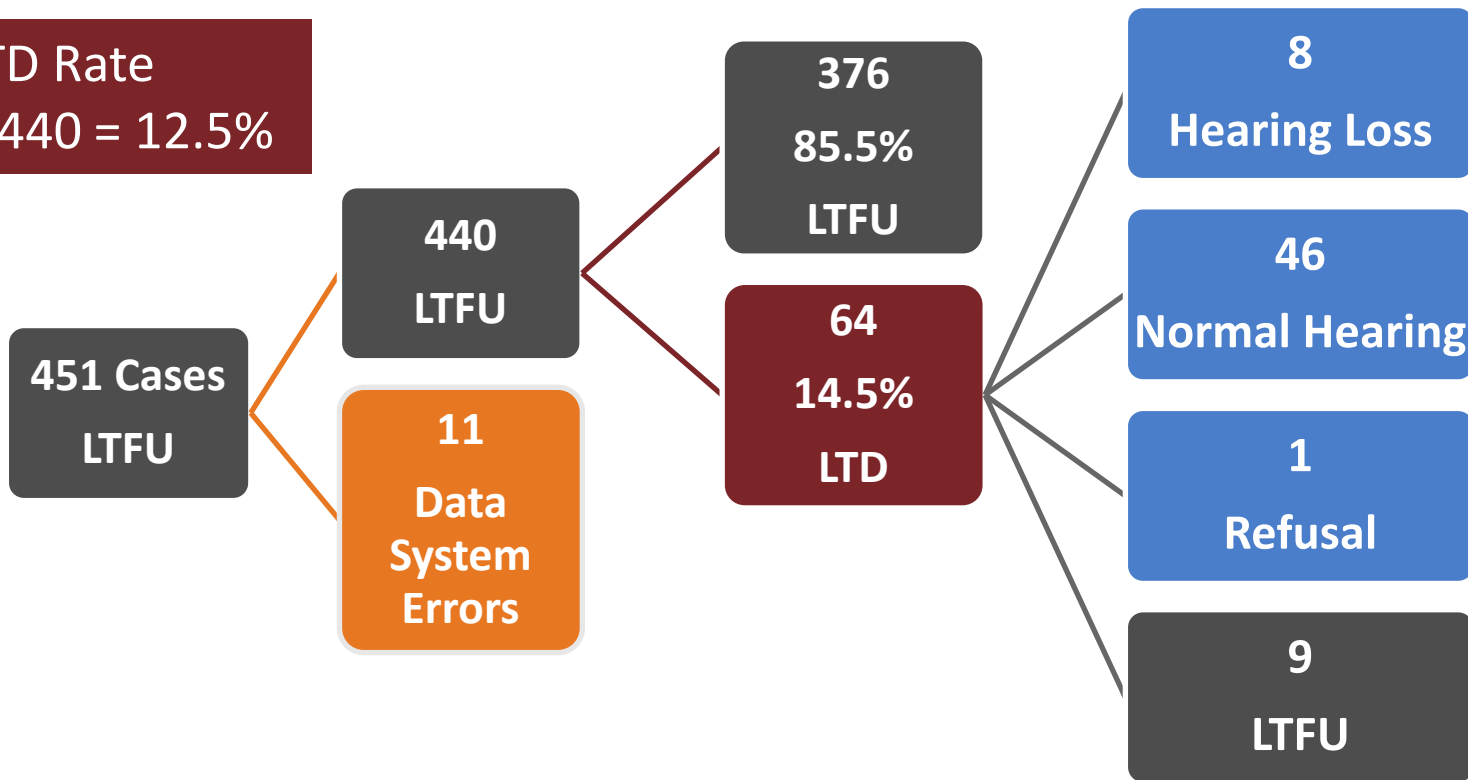
91
audiology
practices

Established
communications
with **60** practices

Obtained info for
451 LTFU children
(**88.6%** success rate)

Results

Final LTD Rate
 $(64-9)/440 = 12.5\%$



Results

- Hearing loss rate among those who failed hearing screening
 - **14.8%** for children who were LTD at the diagnostic evaluation stage
 - **11.6%** for children who were **not** LTFU
 - The difference in rates was not statistically significant

2020-2023 Data	Normal Hearing	Hearing Loss	Percent with HL
LTD Cohort	46	8	14.8%
TN Statewide	4,447	583	11.6%



Loss to Documentation At Rescreen Stage

Charles Lechner, MS | Epidemiologist

Background

- Idea: Connect with other programs and foster collaboration to improve outreach to LTFU cases.
 - Sparked from discussing the results of the LTD project.
 - Minimize or eliminate additional costs to the program.
 - Local program coordinators could have better odds of successfully contacting families.
- CHANT collaboration began in April 2024.

Method

- 1 Cases closed as loss to follow-up are sent to CHANT quarterly.
- 2 Local CHANT Care Coordinators contact families and record any new information on hearing follow-up. Enrollment in CHANT services is also offered.
- 3 Updated information is returned to TN EHDI one month later.
- 4 Staff review and/or reopen the case for further follow-up activities. Case information is updated as needed.

Method

- Dataset: The first three batches of cases sent to CHANT
 - Cases closed as LTFU between 1/1/2024 – 8/31/2024.
 - Cases that CHANT were able to connect with and which were lost at the rescreen stage were included for analysis.

Primary Goal

Determine the extent of LTD among cases lost at the **rescreen stage**.

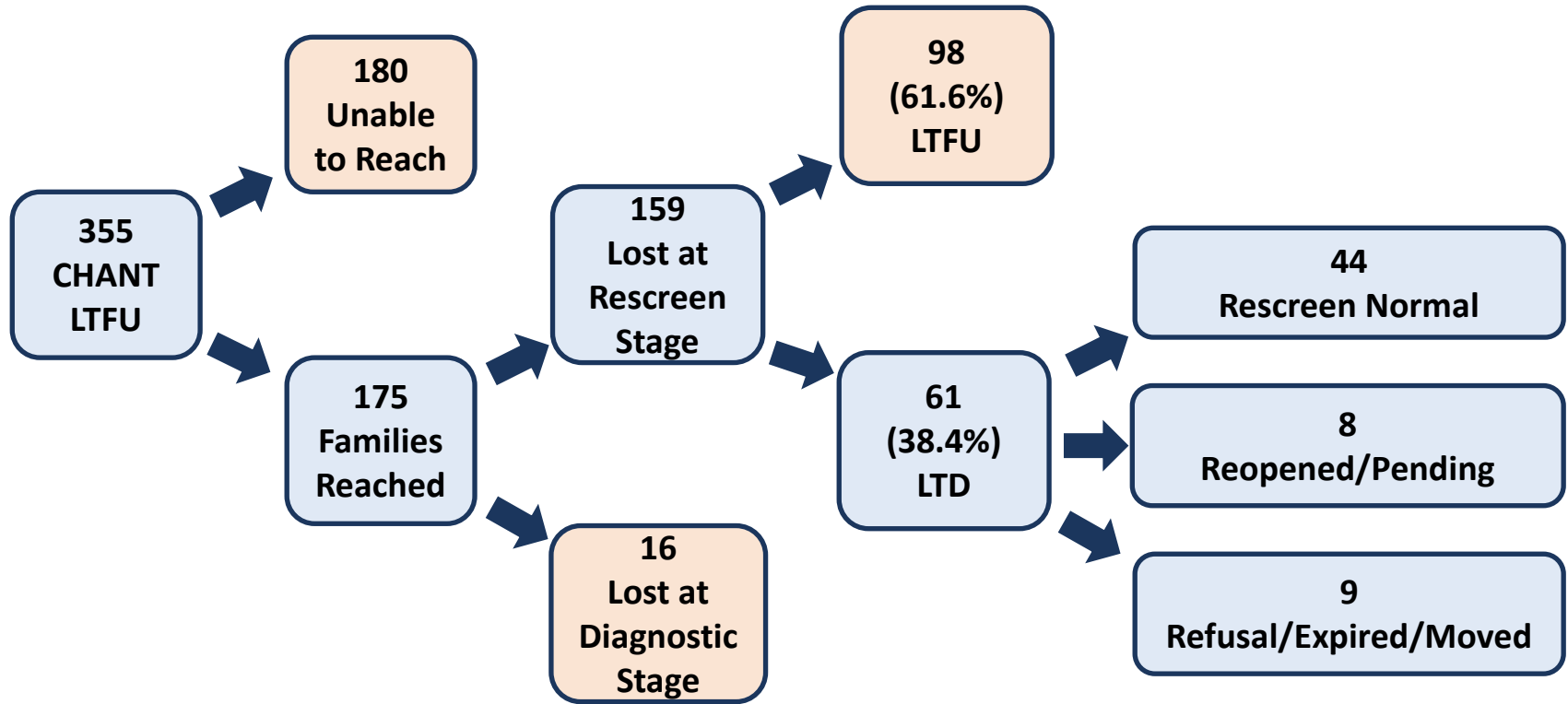
Secondary Goal

Compare family-reported data to our system's records.

Tertiary Goal

How many families were able to access additional services due to this collaboration?

Primary Goal Results – Extent of LTD



Secondary Goal Results – Family vs NBS-System Results

Out of the 159 cases determined to be lost at the rescreen stage:

State-System Results	Family-Reported Results				Total
	Rescreen Normal	Pending Appointment	Refused/Moved	Other (Medical, Insurance, Transportation)	
Rescreen Normal	34	6	2	2	44
Reopened/Pending	3	5	0	0	8
Refused/Expired/Moved	3	1	5	0	9
LTFU	26	32	26	14	98
Total	66	44	33	16	159

Secondary Goal Results – Family vs NBS-System Results

		Family-Reported Results		
		Rescreen Normal	Refused/ Moved	Total
NBS-System Results	Rescreen Normal	34	2	36
	Refused/ Expired/ Moved	3	5	8
	Total	37	7	44

Agreement
(Cohen's kappa)

Kappa: **0.599**
Moderate Agreement

Standard Error:
0.162

Tertiary Goal Results – CHANT Enrollment

16 out of 175 (9%) families enrolled in CHANT services!

Several families were already enrolled in CHANT. Care coordinators were able to use their system's contact info to attempt contact with the family.

Overall LTD Rate Estimation from Both Studies

- Weighted average
- $12.5\% * 9.1\% + 38.4\% * 90.9\% = \mathbf{36.0\%}$

LTD Stage	% of LTFU Cases (Weight)	% LTD
Diagnostic	9.1	12.5
Rescreen	90.9	38.4
Overall	100	36.0

Data Summary

- The LTD rates
 - **12.5%** at the hearing diagnostic evaluation stage.
 - **38.4%** at the rescreen stage.
 - **36.0%** estimated overall rate among LTFU cases at any stage.
- Self-reported follow-up results by the parents are in good agreement with the results obtained by case managers.

Outcomes and Lessons Learned

- Trends continue in the recent LTFU cases sent to CHANT.
- Collaboration can reduce the LTFU numbers.
 - Contact initiated by local coordinators may encourage families to be more responsive.
- Collaboration promotes access to care coordination services.

Next Steps

- A part-time audiology consultant works with primary care providers and audiology practices to
 - Identify barriers and challenges in reporting follow-up results.
 - Find feasible solutions to reduce LTD.
- Continue the CHANT collaboration.
- Future efforts to focus on PCPs since the vast majority of the LTFU occurred in the rescreen stage.

Other Contributing Authors

Tennessee Department of Health Staff

Amanda Ingram, RN, Director of Pediatric Case Management

Angela Keyton, RN, Case Management Coordinator

Hilary Fryman, RN, BSN, Nurse Educator

Kristen Gentry, CHANT Director

External Partners

University of Tennessee Health Science Center

Emily Podgorny, AuD and

Julie Beeler, MA, CCC-A/LP

Vanderbilt University Medical Center

Brittany Day, AuD

Thank you!

Tennessee Newborn Screening Program

Toll free: 855-202-1357

Fax: 615-532-8555

E-mail: nbs.health@tn.gov

Holli Allen, EHDI Program Coordinator

Holli.N.Allen@tn.gov, 615-291-5914

Yinmei Li, Epidemiologist II, EHDI-IS Grant PI

Yinmei.Li@tn.gov, 615-532-7836

Charles Lechner, Epidemiologist

Charles.R.Lechner@tn.gov, 615-532-4514