

The Evolution of Data Sharing

Between Louisiana Early Hearing Detection and Intervention (LA EHDI)
and the Louisiana DeafBlind Project (LA DBP)

Louisiana Early Hearing Detection and Intervention



2023

54,972
babies born

5,307
born with risk factors for hearing loss

1,675
needed further testing after newborn
hearing screening

125
identified as deaf or hard of hearing (D/HH)

29
identified as D/HH and at risk for deafblindness

Louisiana DeafBlind Project

- Part of the national network funded by the U.S. Department of Education, Office of Special Education Programs (OSEP).
- Housed within the Human Development Center at Louisiana State University Health Sciences Center.
- Responsible for annual Deafblind child count, ages 0-22.

Louisiana DeafBlind Project

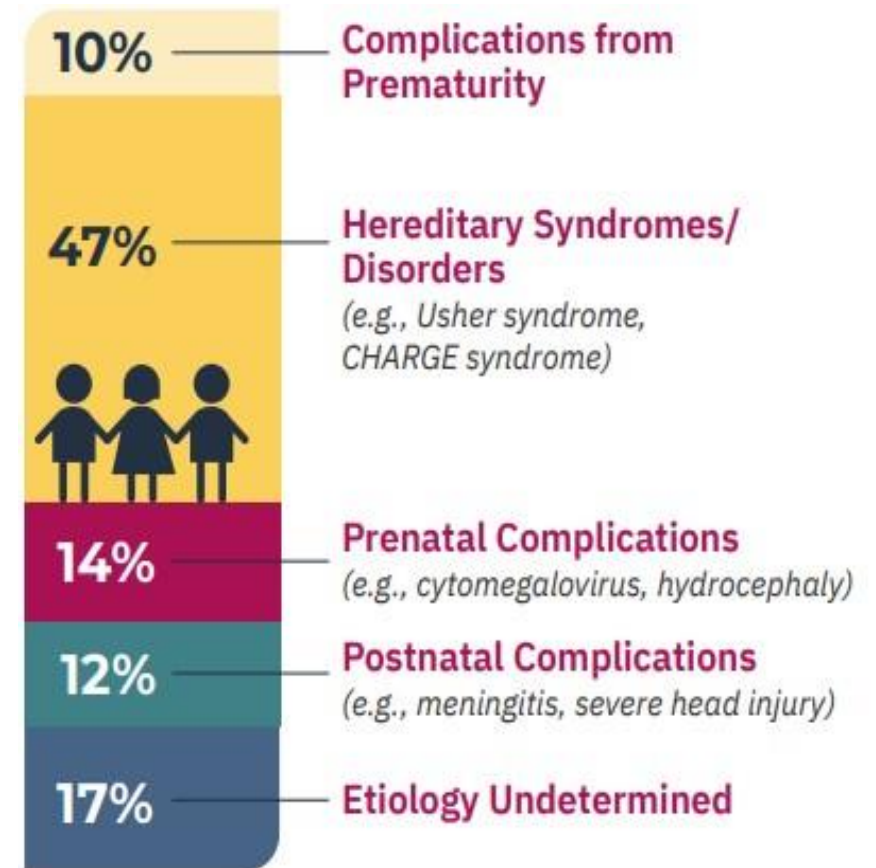
- Provides ongoing family support across childhood, training and consultation for professionals, professional development, outside referrals and more.
- Available to families and all professionals working with children who are DeafBlind.

About DeafBlindness

- A diverse group with a wide variety of hearing and vision levels

- Per the National Center on DeafBlindness, *An Overview of Deafblindness*:

- 10,000 children who are DeafBlind identified nationwide
- 85% have additional disabilities
- 50% have complex healthcare needs



LA Early Hearing Detection and Intervention (LA EHDI) Referral Process

Child Identified as Deaf or Hard of Hearing



LA EHDI Intervention coordinator contacts the family



With verbal, documented consent, LA EHDI refers to:



Part C Early Intervention

Non-Part C Specialized Early Intervention

LA Hands & Voices Guide By Your Side



**LA
Deafblind
Project**

Process of Developing Our Agreement

- Developed a collaborative working relationship.
- Louisiana Early Hearing Detection and Intervention staff participated in the Louisiana DeafBlind Project Advisory Board meetings.
- A referral process was initiated between programs prior to the data-sharing agreement.



Process of Developing Our Agreement

- Regular meetings and follow-up calls occur between programs.
- Review of other Louisiana Early Hearing Detection and Intervention Program data-sharing agreements.
- Draft, review, revise, legal review, revise, wait, approve!



What is in Our Data Sharing Agreement?

- Background and purpose
- Method of data sharing
- Period of agreement
- Justification
- Data management and responsibility



What About the Health Insurance Portability and Accountability Act (HIPAA)?

- Early Hearing Detection and Intervention Program obtains verbal consent from families to refer to the Louisiana DeafBlind Project.
- The verbal consent script must be documented and dated in the Early Hearing Detection and Intervention Program database.
- The referral is considered a “warm handoff” for coordination of care (see More Information slide for link).

Sample Script for Obtaining Family Consent for Referral

“The Louisiana DeafBlind Project (DBP) offers support for families whose children have been identified as deaf or hard of hearing and also have diagnosed or potential vision concerns.

While the DBP is not an early intervention provider, a referral to the DBP could improve follow-up care and support connection to specialty intervention for children who are deafblind or at risk.

Do I have your permission to refer you to the DeafBlind Project?”



Benefits to Both Programs



- Earlier referral and identification of children who are DeafBlind
- Access to early hearing detection and intervention (EHDI) database to view audiological testing results for children who are DeafBlind
- Access to knowledgeable EHDI staff
- Earlier support for families of children who may be DeafBlind

Benefits to Both Programs



- Additional resources for families
- LA DeafBlind Project (DBP) collaborates with EHDI, parent support organizations and early intervention providers
- LA DBP occasionally refers babies to EHDI
- Access to knowledgeable DeafBlind project staff

Challenges

- Referral process is not automated
- Early hearing detection and intervention (EHDI) programs only receive anecdotal information
- Vision differences may not be identified in infancy
- Professionals may not realize a child is considered DeafBlind and qualifies for support
- High volume of EHDI risk factor data with potential for vision concerns

Lessons Learned

- It all begins with the relationship. 😊
- A data sharing agreement is **not** required for a referral process.
- Collaboration improves outcomes for children and families.
- Explore and try new ideas.



Where We are Now

- Supporting families is a common goal.
- Collaborating to build knowledge and skills of early intervention partners.
- Exploring Early Hearing Detection and Intervention Program risk factor data to identify babies at risk for deafblindness.

Where We are Now

- Planning to identify data points to monitor for success.
- Increasing number of children receiving support from the Louisiana DeafBlind Project.

	<u>2013</u>	<u>2023</u>
Ages 0-2	0	7
Ages 3-5	1	13



More Information

- [Information on “warm handoffs”](#)
- [An Overview of Deafblindness Fact Sheet from the National Center on Deafblindness](#)
- [2022 National Deafblind Child Count Report](#)

Contact Us

Louisiana DeafBlind Project

Nicky Gillies,
Project Director
ngilli@lsuhsc.edu

Louisiana Early Hearing Detection and Intervention

Dana Hubbard,
Program Manager
dana.hubbard@la.gov

Terri Ibieta,
Coordinator
terri.ibieta@la.gov