



2020 Annual Report



ILLINOIS

Early Hearing Detection and Intervention (EHDI)

Contents



Introduction



The Illinois Early Hearing Detection and Intervention (EHDI) program works to support all infants and families through newborn hearing by screening no later than **1** month of age; diagnosing no later than **3** months of age; and initiating intervention, including family to family support services, no later than **6** months of age.

Early identification, intervention, and connections to family-based organizations are key to improving outcomes for infants who are deaf and hard of hearing (D/HH) and their families.

The EHDI team provides follow-up tracking, education, and referrals for every infant born in an Illinois birthing facility.

EHDI Collaborators



UIC DSCC* - University of Illinois at Chicago, Division of Specialized Care for Children
NCHAM* - National Center for Hearing Assessment and Management
DHS Early Intervention* - Department of Human Services

National Goals

1-3-6



1
Screen No
Later than
1 Month
of Age

3
Diagnose No
Later than 3
Months of Age

6
Enroll in
Intervention No
Later than 6
Months of Age

If an infant does not pass in one or both ears, the infant moves to the diagnosis goal.

If an infant has a hearing loss in one or both ears, the infant moves to the intervention goal.

Screening Information

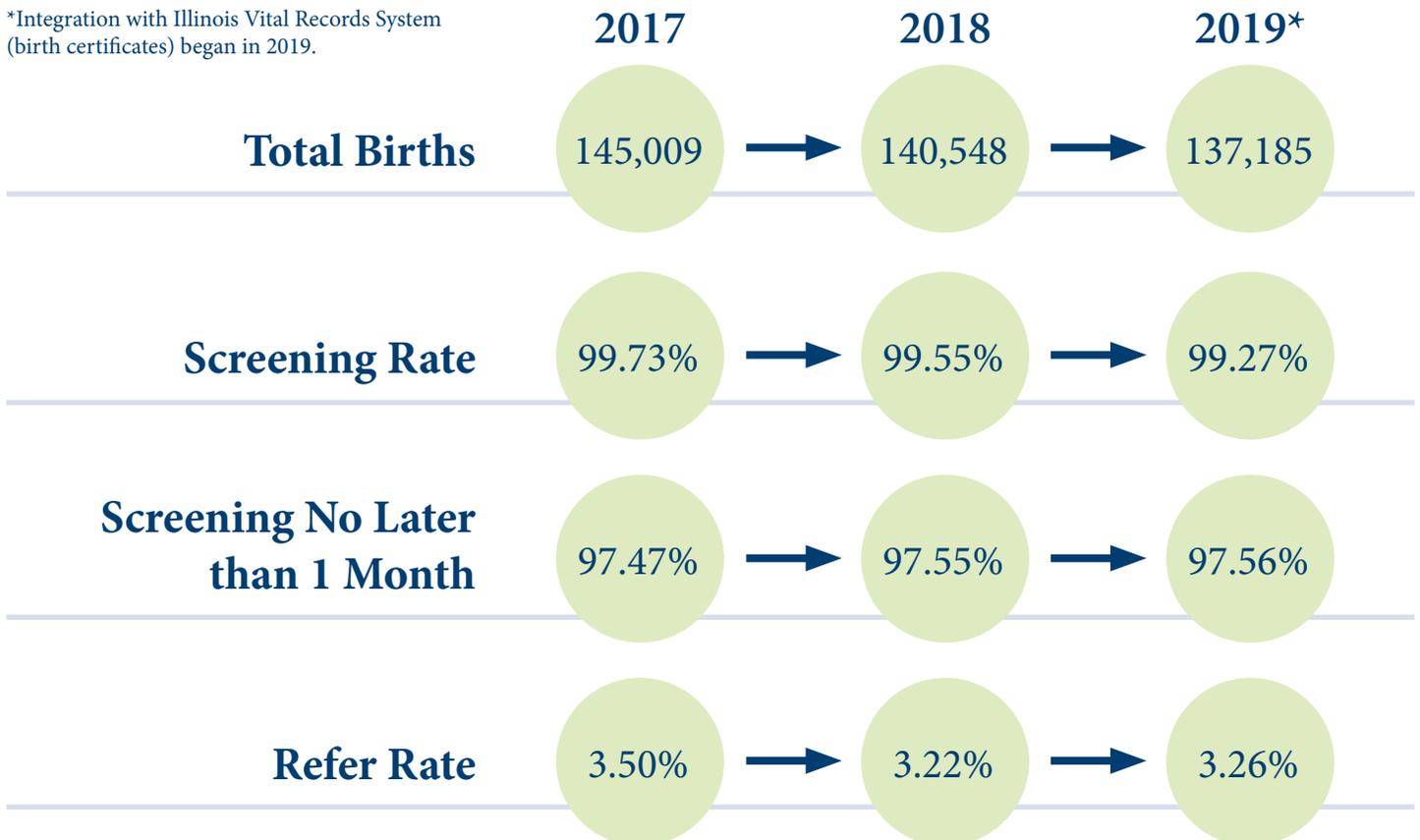


Newborn hearing screening is the foundation for identifying a potential hearing loss. This step is vital in providing timely diagnosis and intervention to support communication and language development.

Each year, the program strives to sustain a 99.00% overall screening rate, a 97.00% screening no later than 1 month of age rate, and a refer rate between 1.00% and 4.00%.

The dynamic EHDI Information System supports program staff in performing audits, tracking, and data analysis.

*Integration with Illinois Vital Records System (birth certificates) began in 2019.



Newborn Hearing Diagnostics

- If an infant does not pass on an outpatient rescreen, the Joint Committee on Infant Hearing (JCIH) statement recommends that a referral to a pediatric audiologist should be made immediately.
- It is best practice to schedule the outpatient screening or diagnostic audiology appointment before the family leaves the birthing facility.
- A diagnostic evaluation should be completed no later than 3 months of age.
- EHDIPALS.org is a national web-based directory of facilities that offer pediatric audiology services. This site also offers professional family resources to aid in screening, diagnosis, intervention, and family support.
- Illinois has seen a steady improvement in the numbers of infants diagnosed no later than 3 months of age.

For more information, view the JCIH statement at www.JCIH.org.

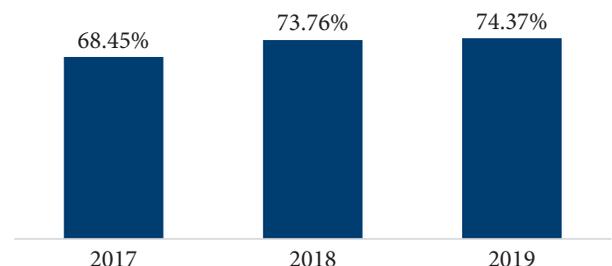


Total Infants Diagnosed with Permanent Hearing Loss



While the total numbers of infants diagnosed with hearing loss per year in Illinois, which are shown above, remains relatively static, the chart below shows that of those infants diagnosed with hearing loss, more and more diagnoses are occurring no later than 3 months of age.

Diagnosed No Later than 3 Months of Age



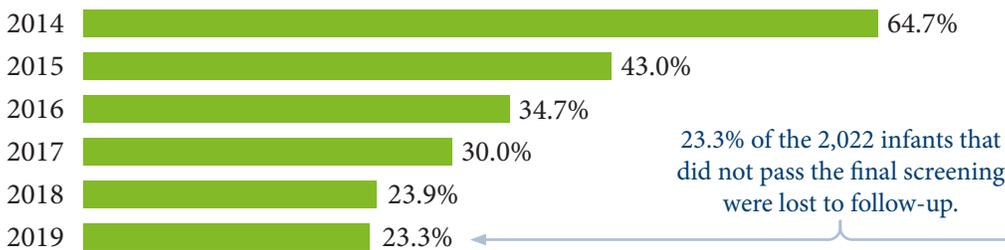
Lost to Diagnostic Follow-Up

- Nationwide, approximately 30%, or about 3 out of every 10 infants, are lost to follow-up. These infants did not pass their final screening and did not complete a diagnostic evaluation. These infants represent potential diagnoses of permanent hearing loss that are lost to follow-up. Each year the EHDI program seeks to consistently decrease the number of infants lost to follow-up. Collaborating with hospitals, screeners, nursing staff, healthcare providers, and pediatric audiologists throughout Illinois has allowed the program to steadily decrease the lost to follow-up percentage and align with national targets.
- Beginning with the 2019 birth cohort, the program integrated with the Illinois Vital Records System. The addition of demographic data supports both identification of barriers and opportunities for improvement related to diagnosis.
- Clear communication with parents at the hospital prior to discharge can directly improve timeliness of care and decrease loss to follow-up.

Total Infants that Did Not Pass Final Screening



Illinois' Improvement for Diagnostic Lost to Follow-Up



Nationwide, approximately 3 out of every 10 infants are lost to diagnostic follow-up.

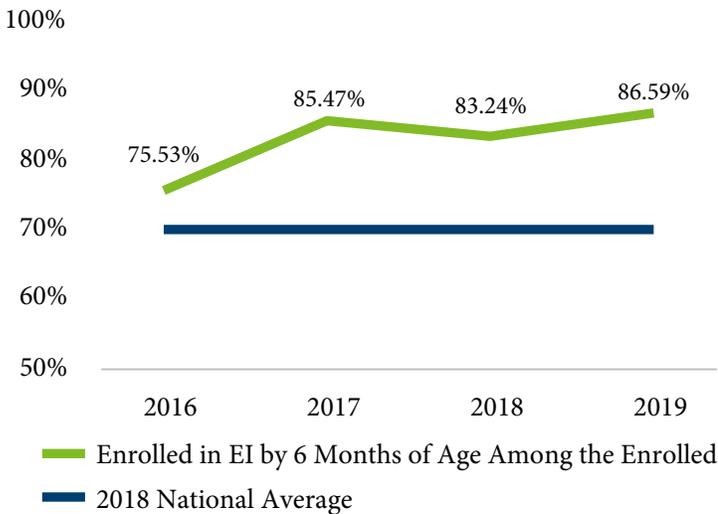


Early Intervention



For infants who are diagnosed with hearing loss, an expedient enrollment in interventions and family support is vital. Dating back to 1995, validated studies have supported primary EHDI principles including enrollment in intervention no later than 6 months of age. These principles support social, emotional, educational, communication, and language development. Over the past three years, Illinois has exceeded the national average and connected **8 out of every 10** eligible families to intervention services.

Enrolled in Early Intervention by 6 months of Age



Providing intervention and early exposure to language and to communication helps improve cognitive, social, emotional, and behavioral development for infants and toddlers. The EHDI 1-3-6 goals support kindergarten readiness.

Guide By Your Side

Organization Overview

The EHDI program has partnered with Guide By Your Side (GBYS), a program of Hands & Voices, for over a decade. GBYS is a family-based organization that provides parent-to-parent support to families of children who are D/HH. Beginning in 2020, the Illinois EHDI program initiated direct referrals to GBYS of infants who are D/HH. Their collaboration helps to decrease lost to follow-up for early intervention.

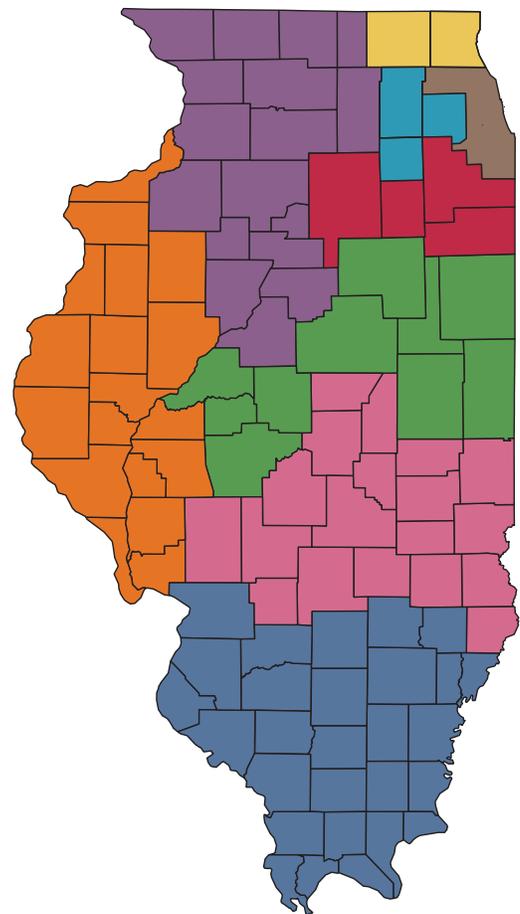
Parent Guides

There are 16 parent guides located throughout the state who have firsthand experience in raising a child who is D/HH. Compassion and commitment drive guides to support Illinois families.

For more information, view the Hands & Voices website at www.ilhandsandvoices.org.



Breakdown of Guide Regions



GBYS breaks down Illinois into nine colored regions to provide parent-to-parent support. Data capture for GBYS began in July 2020.

Guide By Your Side Impact

Timeliness

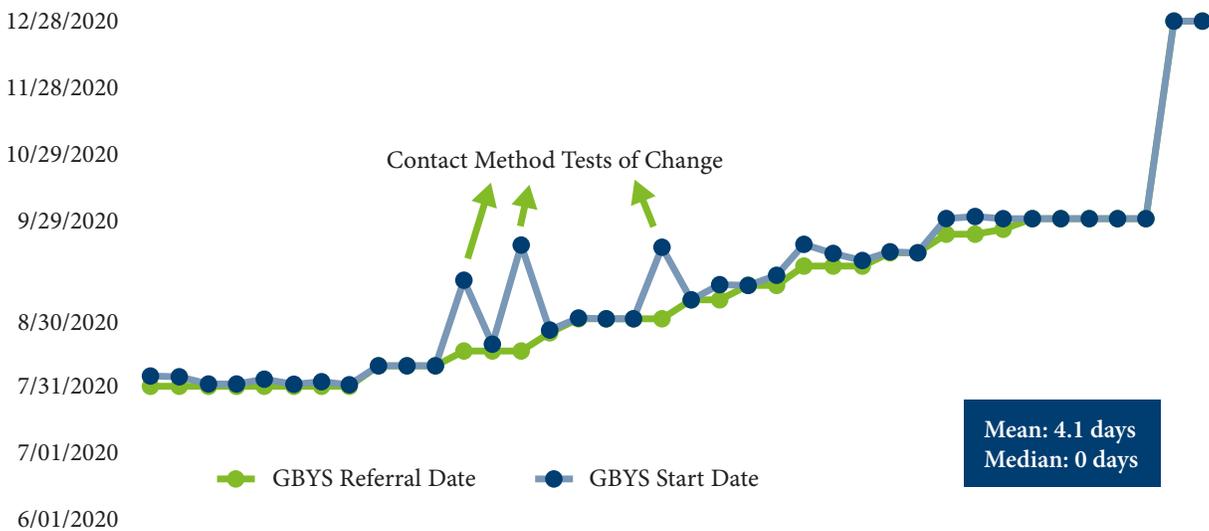
Timeliness is essential in all steps of the newborn hearing process. GBYS works to initiate services efficiently and quickly. This is seen in the chart below. The GBYS referral date is shown in green, and the GBYS start date is shown in blue. GBYS's diligence is shown through the referral and start date being near or on the same date. The average time from when GBYS receives a referral to enrolling a family into parent-to-parent support is 4.1 days. Outliers shown in the line chart led to analyzing methods of contact to help improve the process. While the primary contact method is a phone call, the outliers shown below preferred text messages. Even though GBYS data capture is

in its infancy, GBYS data analysis has already contributed to enhanced program decision-making and collaboration with Illinois EHDI to improve parent-to-parent support.

Success through Process Improvement

In 2019, 40 families were connected to support and to resources, and, in 2020, 122 families were connected. This shows a 205% increase. Beginning July 2020, the Illinois EHDI program initiated direct referrals to GBYS. From January through June 2020, 29 families were connected to parent support. From July through December 2020, that number tripled to 93 families due to the collaboration.

GBYS Referral vs. Start Date



Total Enrollments per Year

2019

40

2020

122

2020 Program Achievements

Quality Improvement



The state has 10 perinatal networks that oversee birthing facilities. In collaboration with the EHDI team, perinatal networks have addressed quality by means of presentations, dissemination of quarterly performance reports, the annual query, and remediation plans for those facilities falling outside of program standards.

Information Transmission



The EHDI program transitioned to fax-based communication with healthcare providers due to the challenges of COVID-19. This expedited the exchange of information in efforts to improve the timeliness of follow-up.

Direct Referrals



The EHDI program entered a formal collaboration with Illinois Hands & Voices. This collaboration supports direct referrals of children with newly diagnosed hearing loss during a critical period of language and communication development.

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Audience Enhancement



In collaboration with the National Cytomegalovirus (CMV) Foundation, the EHDI program translated CMV materials to increase outreach to non-English speaking families.

The Newborn Hearing Screening brochures for families to be given at the time of hospital screening were also translated. The focus on translations was to increase parent knowledge and to reach a broader audience.

Data Definitions



Illinois collaborated with other EHDI programs across the nation to develop definitions for the collection of parent-to-parent support data. This is an important step in establishing consistency, reliability, and integrity of data as the program ventures into improved documentation.

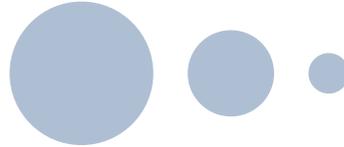
Outreach



The EHDI program and GBYS initiated a pilot program to assist families at the time of transition from Early Intervention to Early Childhood (school-aged) services. Families are given resources to support the individual needs of their child and improve kindergarten readiness.

The Year Ahead: 2021

Overall Program Enhancement



March

Improve Data Dissemination and Communication

Development of new hospital metric display and visualizations.

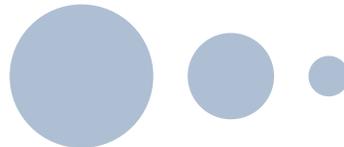
National EHDI Meeting

National EHDI and state stakeholder meeting held virtually.

Lost to Follow-Up Pilot Project

Pilot project to reduce lost to follow-up at the time of diagnosis through parent-to-parent outreach.

Monitor Goal: Screen No Later than 1 Month



May

Enrollment of Pediatric Audiologists in EHDI-PALS

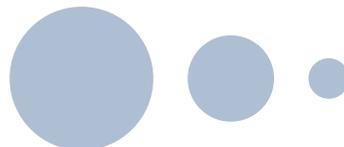
Updates to EHDI-PALS to assist Illinois families in finding a diagnostic provider near their home address.

Enhanced Statewide Training

Virtual Site Visit pilot begins. Three medical facilities are surveyed in order to identify both strengths and areas of need.

Release of revised Newborn Hearing Screening Training Curriculum (NHSTC).

Enhance Goal: Enroll in Intervention No Later than 6 Months



July

HiTrack Enhancement Development of data tracking in the EHDI-IS to reflect parent-to-parent outreach.

Integration of Parent 2 Field in Data Records

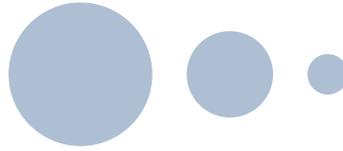
Integration of Parent 2 information field from Vital Records to enhance data management and to decrease loss to follow-up.

Education for Early Interventionists in EHDI System

Development of audio and visual support materials for parents of children who are D/HH and EHDI providers.

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**Improve
Goal: Diagnose
No Later than
3 Months**



September

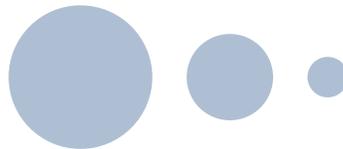
Web-Based Reporting

Pilot begins to allow direct submission of diagnostic reports by audiologists through EHDI-IS.

Website Enhancement

IllinoisSoundBeginnings.org will be updated.

**Overall
Program
Enhancement**



November

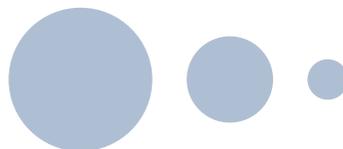
Outreach and Education

Dissemination of checklists and educational materials related to the 2019 Joint Committee on Infant Hearing (JCIH) position statement.

Quality Improvement Initiative

Quality improvement activities to enhance documentation and tracking of parent-to-parent outreach.

**Overall
Program
Enhancement**



**Year
End**

Program Evaluation

Annual aggregate data and grant progress report submitted to federal partners.

Enhancement Data Analysis

An increased number of demographic elements will be reported to the Centers for Disease Control and Prevention to enhance knowledge and analysis of populations.

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Program Partners

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**Illinois
Department of
Human Services
Early Intervention
(DHS/EI)**

Phone Number:

800-843-6154

Phone Number:

www.dhs.state.il.us/ei

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Data Calculations

Screening Rate = Total documented as screened/ (Total Occurrent Births-Not screened infant died-Not screened non-resident-Not screened unable due to medical reasons)

Screened Before 1 Month of Age = (Total Pass before 1 month of Age + No pass before 1 month of Age)/ Total Documented as Screened

Refer Rate = Total Referred/ Total Screened

Diagnosed No Later than 3 Months = (No Hearing Loss Before 3 Months of Age + Permanent Hearing Loss ID Before 3 Months of Age)/ (Total Infants Diagnosed with Permanent Hearing Loss + Total with No Hearing Loss (Initial Diagnosis))

Lost to Diagnostic Follow-Up = Lost to follow-up/ Total Not Pass

Enrolled in EI No Later than 6 Months of Age Among the Enrolled = Signed IFSP Before 6 Months of Age/ (Total Enrolled in Part C EI (IFSP Signed) - (No EI Services Infant Died - No EI Services Non-resident/ Our of Jurisdiction - Unable to Receive EI due to Medical Reasons))

Resources

www.cdc.gov/ncbddd/hearingloss/ehdi-data.html — EHDI program data across states and territories

www.cdc.gov/ncbddd/hearingloss/index.html — Information about childhood hearing loss

www.ehdipals.org — National directory of facilities that offer pediatric audiology services and resources for children (0-5 years of age)

www.eiclearinghouse.org — Illinois Part C Early Intervention resources for parents and professionals

dph.illinois.gov — Illinois Department of Public Health information related to health and wellness of the people of Illinois through the prevention, health promotion, regulation, and the control of disease and injury

www.ilhandsandvoices.org — Illinois Hands & Voices Guide By Your Side Parent-to-Parent Support Resources

www.illinoisoundbeginnings.org — Illinois EHDI program resources for parents and professionals

www.infanthearing.org — The National Center for Hearing Assessment and Management (NCHAM) website for training, including the NHSTC, and technical assistance

www.jcih.org — The Joint Committee on Infant Hearing Position Statements

www.nationalcmv.org — Parent and professional education on prevention and impact of CMV



Thank you

to all the stakeholders who work with the Illinois EHDI Program to positively impact infant outcomes and families. Through collaboration, hard work and dedication, the state continues to enhance quality and improve timeliness of care and interventions for all families.

Recommended Citation

Illinois Department of Public Health Early Hearing Detection and Intervention Program. (2021). 2020 Annual Report (EHDI Report No. 1). Retrieved from <http://www.illinoisoundbeginnings.org>

