



State of Illinois
Illinois Department of Public Health

2021 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



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

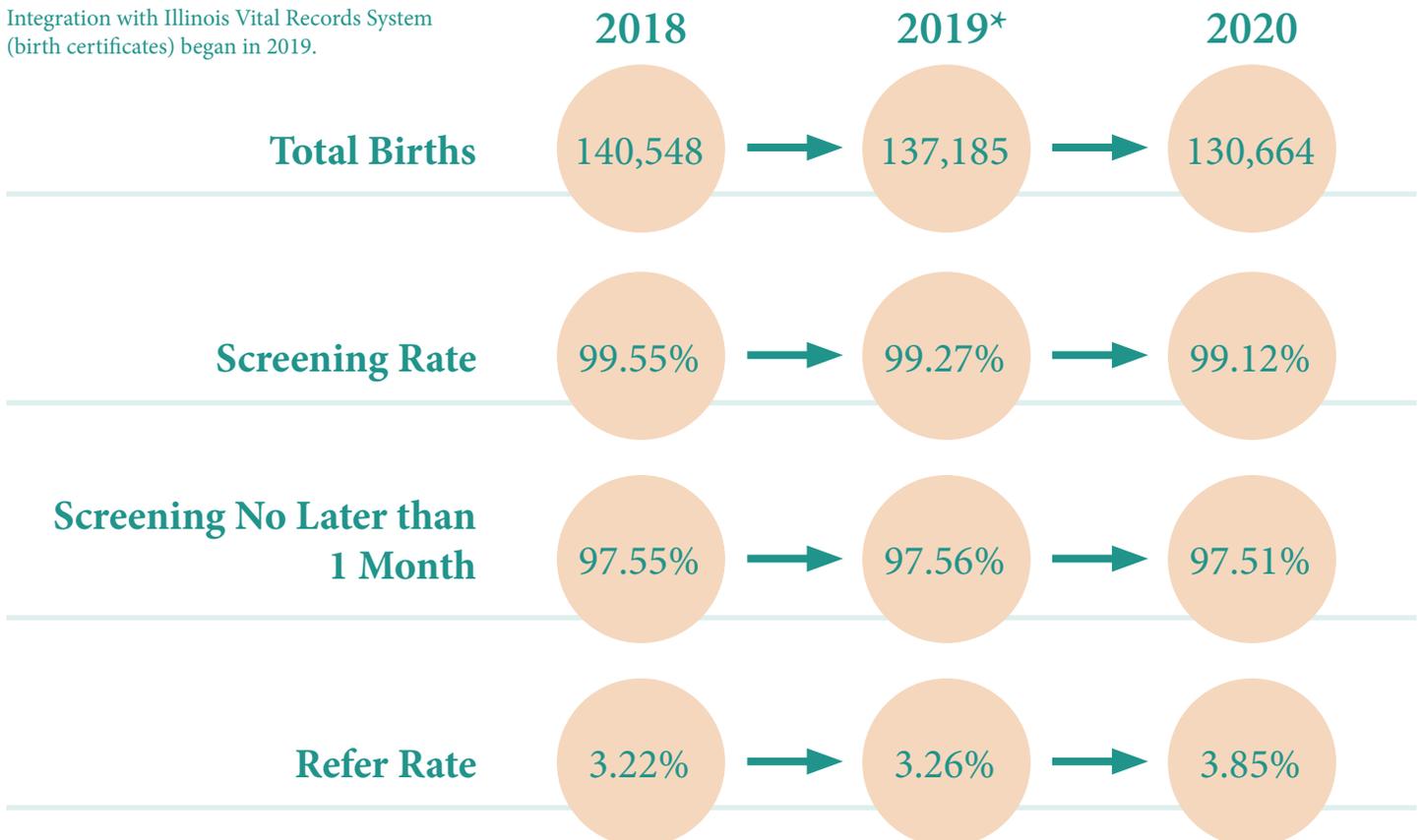


Newborn hearing screening is the foundation in identifying a potential hearing loss. This step is vital in providing timely diagnosis and intervention to support communication and language development.

Each year, the program strives to sustain a 99% overall screening rate, a 97% screening rate no later than 1 month of age, and a refer rate between 1% and 4%.

The dynamic EHDI Information System (EHDI-IS) supports program staff in performing education and audits, tracking, and data analysis.

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



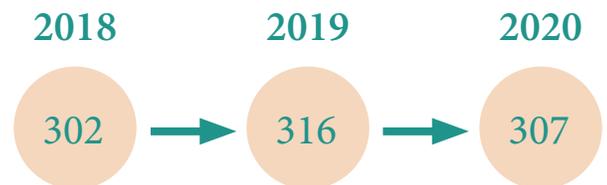
Newborn Hearing Diagnostics

- 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.

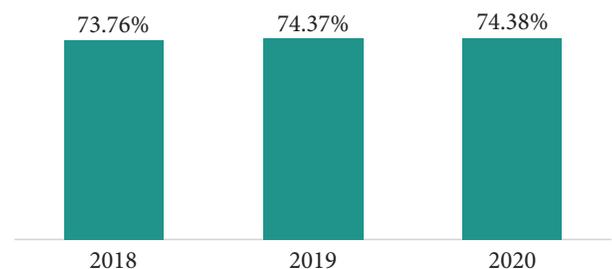


Total Infants Diagnosed with Permanent Hearing Loss



The total number of infants diagnosed with hearing loss per year in Illinois, which are shown above, remains relatively static. The chart below shows those infants diagnosed with hearing loss. The number diagnosed no later than 3 months of age is on the rise.

Diagnosed No Later than 3 Months of Age



Lost to Diagnostic Follow-Up

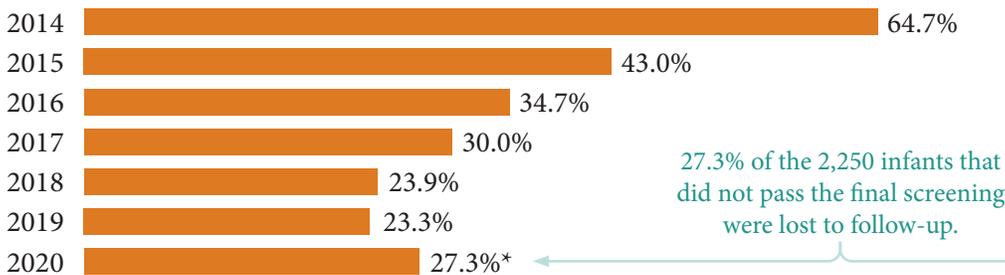
- Nationwide, approximately 30% or about 3 out of every 10 infants are lost to follow-up. These infants did not pass their final screening and did not complete a diagnostic evaluation. These infants represent potential diagnoses of permanent congenital hearing loss that are lost to follow-up. Each year the EHDI Program seeks to consistently decrease the number of infants lost to follow-up. Collaborating with hospitals, screeners, nursing staff, health care 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 (birth certificates). The addition of demographic data supports both identification of barriers and opportunities for improvement related to diagnosis.
- Clear communication with parents at the birthing facility prior to discharge can directly improve timeliness of care and decrease loss to follow-up.

For more information, visit the CDC EHDI website at www.cdc.gov/ncbddd/hearingloss/index.html.

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.



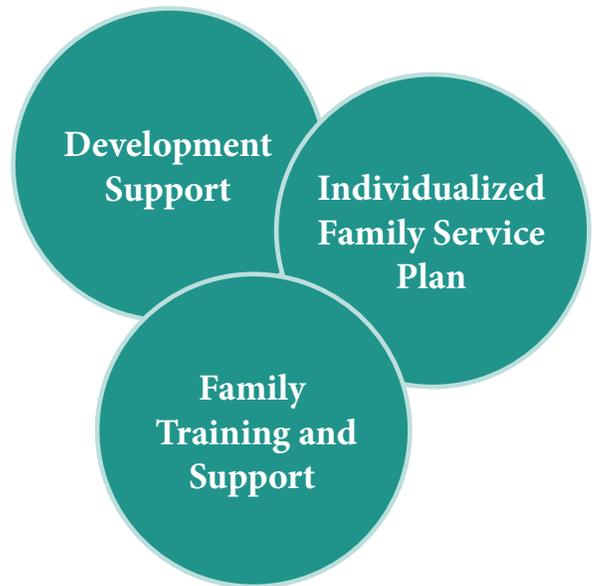
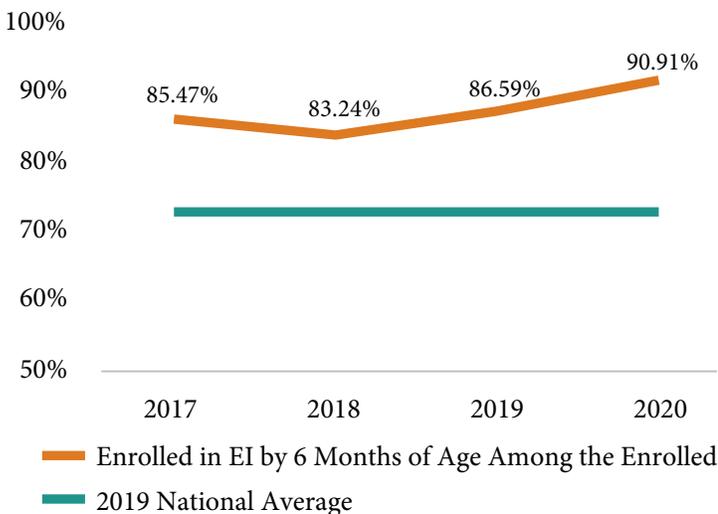
*2020 - COVID-19 pandemic impacted follow-up.

Early Intervention



For infants who are diagnosed with atypical hearing/ hearing loss, an expedient enrollment in interventions and family support is vital. Dating back to 1995, validated studies have supported primary EHDI principles including initiation of intervention no later than 6 months of age. These principles support social, emotional, educational, communication, and language development. Over the past four years, Illinois has exceeded the national average and now **9 out of every 10** eligible families enroll in 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. Adhering to the EHDI 1-3-6 goals supports kindergarten readiness.

Illinois Hands & Voices - Guide By Your Side

Organization Overview

The EHDI Program has partnered with Guide By Your Side (GBYS), a program of Illinois 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. The Illinois EHDI Program continues to provide direct referrals to GBYS of infants who are D/HH. A year of data collection shows that the collaboration has helped to decrease lost to follow-up for early intervention and reach all regions of the state. In 2021, GBYS focused on improved connections to early intervention for families and creating new education tools.

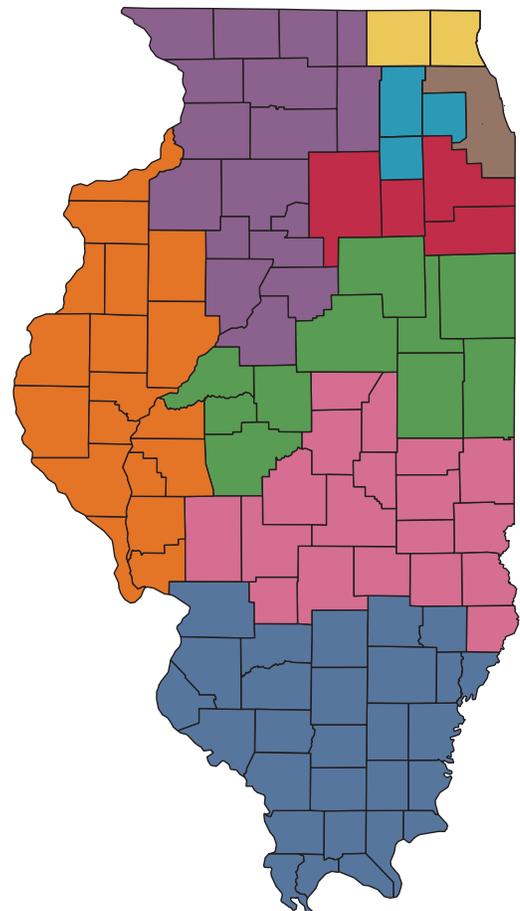
Parent Guides

In 2021, there were nine parent guides located throughout the state with firsthand experience in raising a child who is D/HH. Compassion and commitment drive guides to support Illinois families. The organization also includes a program coordinator, a lost to follow-up specialist, and a transition specialist.

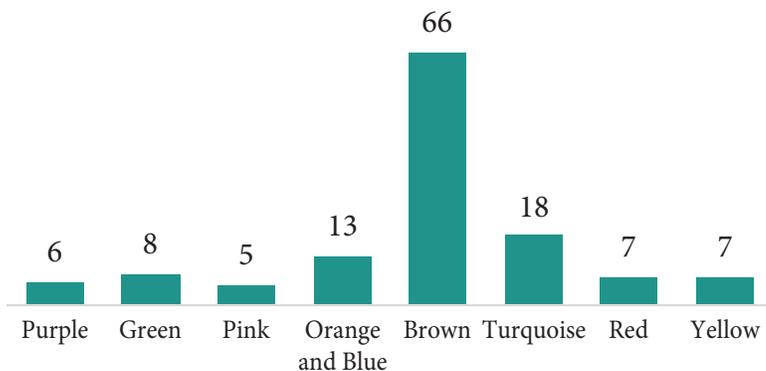
For more information, view the Hands & Voices website at www.ilhandsandvoices.org.



Breakdown of Guide Regions



2021 GBYS Enrollments per Region



GBYS breaks Illinois into nine colored regions to provide parent-to-parent support. Data capture for GBYS began in July 2020. The graph below shows the number of enrollments per region for 2021. GBYS has been able to reach families in all regions of the state through continuous improvements in equitable access to parent-to-parent support.

Guide By Your Side Impact

Connections to Early Intervention

GBYS receives referrals soon after the diagnosis of atypical hearing and is often the first to connect with families. During the initial call with the family, the GBYS team explains other available services and the timing of these services. Based on family feedback from previous contacts, a list of distinct resources was developed. A GBYS team member explains resources and sends a follow-up email that contains this additional information in a simple handout called a SNIPPET (Simple aNd Informative Parent-to-Parent Education Tools). Also, GBYS encourages families to answer phone calls from unknown numbers. These numbers can be from Illinois providers sharing information about available services. Sometimes families can be overwhelmed by the wealth of initial information and



decisions that must be made. Having an empathetic parent guide early on who has experience and can provide unbiased support is of great comfort. Families appreciate the detailed information and assistance in developing a plan of where to start their journey.

Total GBYS Enrollments per Year



Of the 130 families that enrolled in GBYS in 2021, **92%** were also enrolled in Early Intervention.

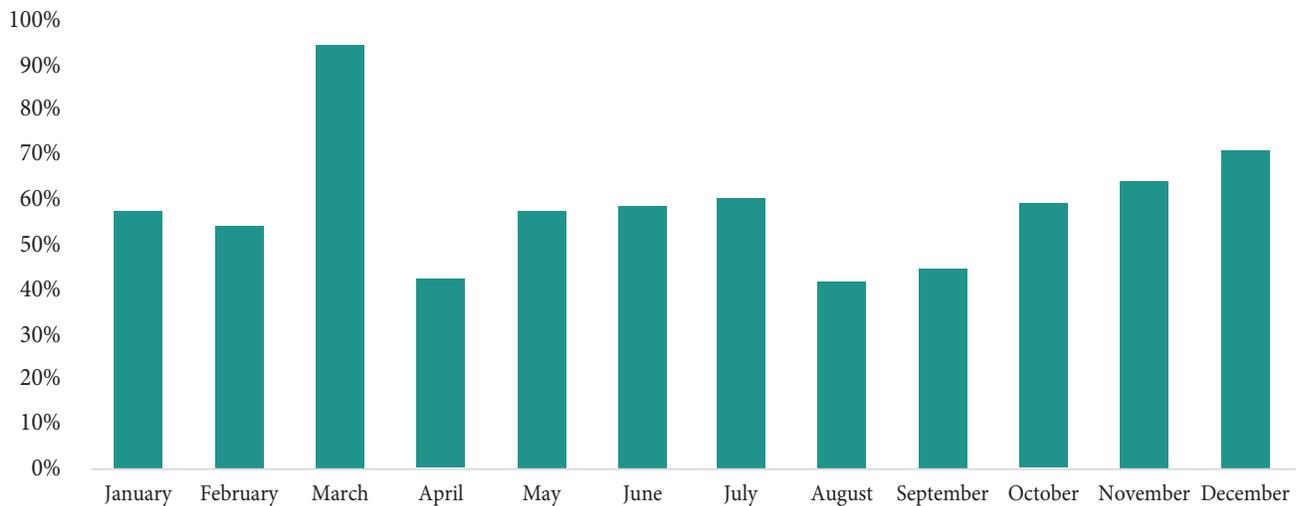
Guide By Your Side New Role

Transition Specialist

In October 2020, a Transition Specialist was piloted into the Illinois GBYS program. The specialist follows up with families transitioning out of Part C/ EI and into Part B (U.S. special education services under the Individuals with Disabilities Education Act). The GBYS Transition Specialist documents EI enrollment status and history, educates the family on the upcoming transition, answers questions and provides resources.

For families that were not able to be reached by phone or text, GBYS followed up with a “Happy 3rd Birthday” card that is sent to the family. This card explains why GBYS is trying to reach them and includes a QR code that links back to a resource directory. It was due to the feedback from stakeholders that a resource directory was created. The directory is also available in Spanish.

2021 Percentage of Successful Family Contact by Transition Specialist per Month



Due to the collaboration established in 2020 between Guide By Your Side and the Illinois EHDI Program, family outreach has expanded across the state. The transition specialist was able to contact families with children of transition age each month in

2021. The chart above displays the percentage of families that were successfully reached each month. Texting and phone call outreach protocols were tested as part of continuous quality improvement. This has led to a promising trend of successful parent contact.

Guide By Your Side SNIPPETS

After receiving referrals directly from the EHDI Program, GBYS quickly saw the need for simple, concise, linguistically appropriate handouts that could be shared with families. The “Leave-it” handouts for parent advocacy support were created by Andrea Marwah, executive director of Illinois Hands & Voices. The Illinois GBYS team modified this approach to create SNIPPETS (Simple and Informative Parent-to-Parent Education Tools). The SNIPPETS include brief summaries of information on a specific topic. In addition to the information, there are 3 to 4 QR codes that the user can choose to scan for more in-depth learning. Currently, there

are 17 SNIPPETS handouts available. These handouts will be translated into Spanish in the future. The SNIPPETS topics available currently are: All About ASL, Auditory Neuropathy Spectrum Disorder, Aural Rehabilitation, Audiologists, Conductive Hearing Loss, Cytomegalovirus (CMV) Prevention, Communicating with Your Child, Developmental Therapists – Hearing (DTHs), Microtia/ Atresia, More than Hearing Loss, Unilateral Hearing Loss, What is CMV?, and What is DSCC? The SNIPPETS can be found in the parent section of the EHDI Program’s Illinois Sound Beginnings website: www.IllinoisSoundBeginnings.org.

Simple & Informative
SNIPPET
Parent-to-Parent Education Tools

Navigating EI in Illinois

What does Early Intervention (EI) in Illinois look like for children who are deaf/hard of hearing?

- EI helps eligible babies and toddlers from birth to 3 years old with disabilities or delays to learn and grow.
- A medical professional may refer a family to EI, or a family can contact their local Child and Family Connections (CFC) office directly to request an evaluation.
- There are 25 CFC offices in the state of Illinois, and each has a number based on location.
- Once you call your local CFC or they receive your referral, you will be assigned a service coordinator who will meet with you to talk about your concerns for your child.
- After the intake meeting with the service coordinator, the team will complete an evaluation and assessment of your child's development with your consent.
- All children who are deaf/hard of hearing are eligible for Early Intervention services from birth to age 3, regardless of degree or type of loss. You will, however, still need to complete the assessment to help the team better understand the individual needs of your child.
- After determining eligibility, the EI team (which includes the parents) will determine which services are needed for each individual child and how often as well as which professional will coach the family in implementing the strategies the team develops.
- Some families may have to pay a portion of the costs. Cost of services depends on family size and income.
- Many children who are deaf/hard of hearing receive developmental therapy-hearing services and/or speech therapy.
- EI can provide assistance for Hearing Assistive Technology. Assistive Technology equipment may include hearing aid(s), bone conduction sound processor(s) with softband, dispensing fee, earmolds, pediatric care kit and batteries. Additional testing such as hearing aid checks and evaluations are also available.

Resources:

- QR code: [IDHS - Early Intervention](#)
- QR code: [All about EI](#)
- QR code: [EI Office Locator](#)

THIS PROJECT WAS SUPPORTED IN PART BY THE ILLINOIS DEPARTMENT OF PUBLIC HEALTH EARLY HEARING DETECTION AND INTERVENTION PROGRAM AND THE CENTERS FOR DISEASE CONTROL AND PREVENTION, PREVENTIVE HEALTH AND HEALTH SERVICES (PHHS) BLOCK GRANT AND ITS CONTENTS ARE SOLELY THE RESPONSIBILITY OF THE AUTHORS AND DO NOT NECESSARILY REFLECT THE VIEWS OF THE FUNDING SOURCE.



Institute for Parents of Preschool Children who are Deaf or Hard of Hearing

Illinois completed its 76th Institute for Parents of Preschool Children who are Deaf or Hard of Hearing in 2021. The institute was a two-week virtual program for parents of children (through age 7) who have atypical hearing/hearing loss. This event was provided at no cost to parents. Parents and caregivers learned about hearing loss and their child's individual strengths and needs. Participants met other parents of children who are deaf or hard of hearing. Forty families registered for this modified event.

The mission of the institute is to provide information and support to families so they can make informed decisions on behalf of their child who is deaf or hard of hearing. The institute was summarized by one parent as “an incredibly useful week to... prepare my child for a life of learning.”

Parents attended daily lectures via Zoom from experts in the field to learn about raising a child with atypical hearing/hearing loss. They also met virtually in small groups to discuss specific concerns and to connect with other caregivers. Parents also had the opportunity to learn about various communication modes used with deaf or hard of hearing individuals.



Lecture topics included:

- Child Development
- Language Development
- Types of Hearing Loss
- Parent Rights
- Communication Choices
- School Programming
- Hearing Aids, Cochlear Implants
- Deaf Culture

The Institute received support from:

- Illinois Department of Human Services (DHS) - Division of Rehabilitation Services (DRS)
- Illinois School for the Deaf (ISD)
- University of Illinois Chicago's Division of Specialized Care for Children (DSCC)
- Illinois State Board of Education (ISBE)
- Illinois Department of Public Health (IDPH)
- Ann & Robert H. Lurie Children's Hospital of Chicago

Family EHDI (FEHDI)



The FEHDI (Family Early Hearing Detection and Intervention) initiative began after a discussion between EHDI coordinators, the directors of Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA), and Family Based Organizations (FBO) leaders at the National 2020 EHDI Meeting. Shortly after that meeting, Illinois took the lead to bring these groups together with the common goals of unifying understanding of state and territory measurements around family support. Five states met over a year's time to discuss data points, definitions, and other considerations for reporting parent-to-parent support. Consensus-based definitions were developed to allow for national uniformity in reporting parent-to-parent support data. This data will be collected by federal partners as part of EHDI funding opportunities. At the end of the project, the group proposed nine data points that FBOs should collect and share with their EHDI programs.

The Illinois EHDI team took the activity one step further and integrated a data collection protocol within the Illinois EHDI information system and shared the format and input with other state programs who were using the same information system. Overall, the goal behind this initiative was to improve the standardization and quality in reporting between state programs and allow for progress comparison across states. The efforts are leading the Centers for Disease Control and Prevention (CDC) to add optional parent support data elements to the annual hearing screening and follow-up survey in the coming year. Acknowledging the importance and necessity of data collection in parent-to-parent support can create improvements in measurable family outcomes.



0-3 Years Old Hearing Screening



Strata Reporting

Because on-site collaboration with home visiting programs was not possible during 2020, the EHDI Program displayed its flexibility and re-directed efforts toward foundational elements for hearing screening in infants and toddlers. Because the incidence of hearing loss doubles between birth and school-age, targeting the 0-3 age group is critical in identifying potential hearing losses in this population.

The Illinois EHDI Program created a web-based information system as a technical resource and tracking tool for early childhood hearing screening (0-3 years) aggregate data. In the future, the EHDI Program will collaborate with community partners and stakeholders to create a model of best practices for addressing late onset and progressive hearing loss in the 0-3 population. Resources for early childhood hearing screening may be found at www.kidshearing.org.

2021 Program Achievements

Quality Improvement



- In collaboration with NCHAM, the National Virtual Site Visit project was completed. It included two tools, the Nurse Manager Worksheet and the Updated Newborn Hearing Screening Training Curriculum (NHSTC), which were utilized to assist birthing facilities with their newborn hearing screening programs. An abbreviated learning community was held with Perinatal Network 10 to rollout these new tools.
- A COVID-19 letter project helped the program to obtain information about how the pandemic impacted lost to follow-up.
- Parent packet materials were developed to aid parents during the transition period at the age of 3.

EHDI Information System



- The EHDI information system (EHDI-IS) was updated to include a second point of contact which was added to each infant record. Parent 2 was imported from IDPH Division of Vital Records to help improve outreach and lost to follow-up efforts.
- The EHDI-IS services tab was expanded to include other services data.
- Family EHDI (FEHDI) data forms were developed to capture parent-to-parent support information.
- Annual aggregate data and child-level, detailed data were submitted to the CDC.

Lost to Follow-Up



- Due to the EHDI Program's formal collaboration with Illinois Hands & Voices established last year, a new role was created to improve timeliness of infants receiving diagnoses.
- Lost to follow-up protocols were established for outreach of targeted populations across the state.
- The NHSTC was updated and highlighted the importance of scheduling and documenting outpatient screenings.

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Website Enhancement



- To increase outreach to non-English speaking families, EHDI brochures and cytomegalovirus (CMV) materials were translated into many languages and uploaded to the website.
- EHDIPALS was expanded and updated to include more Illinois audiologists.
- IDPH assumed the printing and distribution of brochures.
- The 2020 Illinois Annual EHDI Report was published.
- Illinoisoundbeginnings.org was revamped and content was updated, which will relaunch in 2022.
- In collaboration with the Illinois School for the Deaf, videos for parents relating to hearing loss care were created, interpreted, and captioned for the website.

Health Disparity Identification



- The Illinois EHDI Program worked with an epidemiology intern from the University of Illinois at Urbana-Champaign to identify health disparities through the newborn hearing screening process.
- Statistical models were created to better understand the predictor variables of not reaching the EHDI 1-3-6 national goals.

STRATA



- The initial build of the STRATA data system was finalized.
- Manuals were completed.
- Agencies and licensed screeners were imported into STRATA.

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Program Improvements



- Hospital tip sheets for birthing facilities and protocols for hospital liaisons were standardized.
- Administrative rules were updated and will be available in 2022.
- Data collaboration increased with hearing screening vendors, which helped to expand and improve data tracking and follow-up procedures.
- For a more robust review of infant records, iCARE was utilized to locate families who are lost to follow-up.
- The groundwork was laid for web-based audiology submissions by audiologists, which will be beta-tested in 2022.
- Birthing facility audits were expanded. Four members of the EHDI staff completed monthly audits, which allowed the program to reach more facilities. There is now a targeted approach to audits regarding on-staff audiologists, vendors, and location.
- From the collaboration with GBYS and the program's involvement in the FEHDI grassroots effort, the CDC included parent-to-parent support data was captured in the annual submission.

Early Intervention



- A two-way communication form was finalized to relay information between the EHDI Program and Early Intervention, which was integrated into the EHDI-IS. This form expanded feedback to include the reason for not enrolling in Early Intervention.
- The sharing of information between the EHDI Program and Early Intervention was embedded in the updated Early Intervention Program manual.
- The EHDI Program provided education and technical assistance to Child and Family Connection offices.
- The EHDI Program sponsored the virtual Early Intervention Vision and Hearing conference.

The Year Ahead: 2022

March

Strengthen Part C to Part B Transition

- Present to the ITDHHI stakeholders.
- Update parent resources.
- Continue quality improvement activities to strengthen the outreach process.

National EHDI Meeting

National EHDI and state stakeholder meeting held virtually.

May

EHDI-IS Upgrade

Complete the annual data system upgrade.

Spring Data

Submission of record level data for the CDC cooperative agreement.

June

Grant/ Agreements

Annual process for parent-to-parent support grant and EHDI-IS agreement.

Institute for Parents of Preschool Children who are Deaf or Hard of Hearing

In Jacksonville, Ill., June 12-17

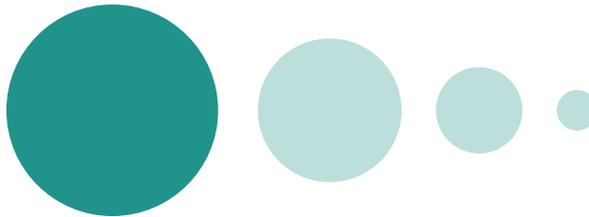
Early Intervention Vision and Hearing Conference

Continuing education opportunity for all developmental therapists-hearing and developmental therapists-vision who serve children in the EHDI system.

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September



Newborn Screening Administrative Rules

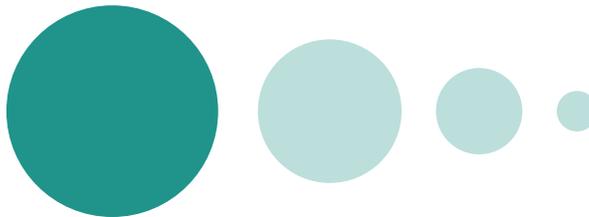
Stakeholder education for the anticipated release of updated administrative rules.

Audiology Online Data Submission
Pilot audiology online data submission for diagnostic testing.

Program Website Enhancement
Launch of the enhanced illinoissoundbeginnings.org website.



November



Quality Assurance

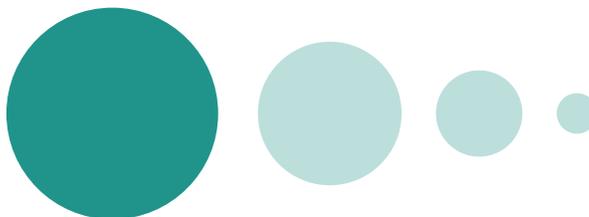
Ongoing hospital collaboration on data and quality assurance activities.

Fall Data

Submission of record level data for the CDC cooperative agreement.



Year End



Program Evaluation

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

Illinois Department of Public Health EHDI Program

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Program Partners

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Website:
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**University of
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Division of Specialized
Care for Children
(DSCC)**

Phone Number:
800-322-3722

Website:
www.dsc.uic.edu

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

Phone Number:
800-843-6154

Website:
www.dhs.state.il.us/ei

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EHDI Tools

Virtual Site Visit: The VSV Project is a step-by-step approach for EHDI programs to follow when conducting individual virtual site visits with birth facilities. It outlines eight steps for conducting a virtual site visit with instructions and tools to carry out each step. It is intended to be self-directed and easily implemented by EHDI program staff or a parent professional. This innovative project supports sustainability in quality newborn hearing programs. <https://www.infanthearing.org/virtual-site-visit/index.html>

Newborn Hearing Screening Training Curriculum: The NHSTC is a competency-based course designed to provide the learner with a thorough understanding of the components necessary for conducting quality newborn hearing screening. The recommended practices throughout the course are based on the Joint Committee on Infant Hearing (JCIH) Position Statement. By taking the course, screeners and stakeholders will have the necessary foundation to do a thorough job and feel confident in their role. <https://infanthearing.org/nhstc/index.html>

EHDI-PALS: EHDI-PALS is a web-based searchable national directory. It helps families, health care professionals, and state public health organizations to find pediatric audiology expertise for children ages birth to 5. The website provides information about childhood hearing to support families and professionals through the process of screening, diagnosis, and intervention. www.EHDI-PALS.org

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

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

www.handsandvoices.org/fl3 — The National Family Leadership in Language & Learning Center.

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. (2022). 2021 Annual Report (EHDI Report No. 2). Retrieved from <https://dph.illinois.gov/topics-services/life-stages-populations/newborn-screening/hearing.html>

