



The Iowa Early Hearing Detection and Intervention (EHDI) program receives newborn hearing screening and diagnostic assessment results for children under the age of three through a web-based data entry database called Iowa Newborn Screening Information System (INSIS). The secure database not only collects initial and follow up hearing screens and diagnostic testing, it also collects information on enrollment into early intervention and risk factors associated with hearing loss. EHDI works closely with Iowa’s audiologists and early intervention program partners to assure timely referrals upon diagnosis, and to receive information about the enrollment status of children referred for early intervention services.

The EHDI program is responsible for submitting a national survey (aggregate data) to the Centers for Disease Control and Prevention (CDC) annually providing basic demographics, the number of children screened, diagnosed with hearing loss, and enrolled in early intervention each year. The EHDI program also uses this data to follow up on children in need of screening or assessment, to review program progress and determine areas of need. Therefore, it is vital to the success of the program and quality of data that the database contains complete and accurate information. More importantly, the program wants to ensure children in need of further hearing healthcare receive follow up in a timely manner. Finally, it helps avoid unnecessary follow up activities by the EHDI staff, primary care providers, audiologists, and hospitals when accurate and timely information is gathered in the database.

Following are helpful tips that will guide users to follow best practices when entering data in the EHDI database.

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Demographics

- Enter the child's demographic and hearing screen information within six working days from the time of birth. If the child is in the Neonatal Intensive Care Unit (NICU), the demographics information shall be entered within the same time frame and results entered at a later time when the child is stable. Birthing facilities are encouraged to compare children in INSIS with their birth census reports to ensure all children are accounted for in the EHDI database.
 - *This allows all children to be accounted for and ensures timely follow up, when needed.*
- Change the nursery to NICU if a child transfers from well-baby to NICU. Mark the risk factor 'NICU greater than 5 days' for the children who meet this criterion.
 - *This will allow children with this risk factor to receive a follow up letter as children identified with this risk factor require a follow-up hearing assessment when they are older.*
- Record all risk factors as 'yes' or 'no' in the database. The birth facility shall also notify the newborn's primary care provider of any identified risk factors. Any recommendations for risk factor monitoring and audiological follow-up should be documented on the discharge summary and be explained to the parent/responsible party prior to discharge.
 - *Hearing risk factors are associated with the potential for late onset or progressive hearing loss that warrants the need for ongoing, periodic audiological evaluations.*
- Enter the complete home address including the street name along with the apartment, house or P.O. Box number for the primary contact so letters are not returned as undeliverable.
 - *This will avoid unnecessary follow up phone calls to your facility, family or PCP for the family's correct home address.*
- Enter an accurate phone number for the primary contact for the child. It is important to collect cell phone number as this is a new field available in the data system and will be used in texting families.
 - *This will avoid unnecessary follow up phone calls to your facility, family or PCP for the family's correct phone number.*
- Select the family's primary language. **Do not** allow the database to default to English for non-English speaking families. If you are unable to find the appropriate language in the available options, include the language in the Other field.
 - *It is useful in arranging an interpreter for the family to avoid a delay in hearing follow up.*

Demographics (continued)

- It is strongly encouraged that primary contact's information including date of birth, race/ethnicity and education be included in the demographics section of the child's record.
 - *This will be helpful as this information is reported to the CDC.*
 - *This information also helps EHDl personnel to look at trends and what may or may not contribute to children being loss to follow up.*
- Enter a detailed case note in case of adoption or when a child is removed from the parent/legal guardian's custody. Include the name of the birth mom under primary contacts and uncheck the boxes 'Primary Contact' and 'Send letters'. Attempts will not be made to contact the birth parent, but this information is needed to ensure all children are accounted for based on vital records data. If a primary contact is unknown, please list the agency or individual that has accepted temporary responsibility for the child. In the 'Contact's Details' drop-down menu select the appropriate title (foster parent, social services, other, etc.).
 - *This will allow children to receive timely follow up, when needed.*
- Record the name of the child's Primary Care Provider (PCP) who will care for the child after discharge. If the PCP is unknown, please make a note in the case note section. The delivering provider shall not be added as the PCP unless this provider will accept responsibility of this child after discharge.
 - *This will allow follow up on children that missed or referred in one or both ears and have not returned for a hearing screen. The PCP information is also used for children with identified hearing risk factors as a letter is sent to the designated PCP alerting of the need for future follow up.*
- If a parent refuses the hearing screen, record the refusal in the database by changing the consent from 'Full' to 'None'. Upload a copy of the Refusal form found at <https://hhs.iowa.gov/providers#ehdi-forms> into the child's record signed by the child's guardian. Retain the hard copy in the hospital's record according to hospital policy and notify the child's PCP. If you are not able to scan the form to upload it into the child's record in INSIS, you can fax it to the EHDl program at (515) 242-6013.
 - *This is helpful to respect the family's decision and ensure no contacts are made to the family.*
- Ensure all children transferred into your facility have been entered in the database by the transferring facility. Birthing facilities are encouraged to compare children in eSP™ with their birth census reports to ensure all children are accounted for in the EHDl database.
 - *This will help avoid unnecessary follow up with the birthing facility on missing children's records and ensure timely follow up, when needed.*

- For children transferred out of your facility, enter the demographic and hearing screen information performed at your facility. Make a case note in the record indicating where the child was transferred to.
 - *This allows the collection of missing results from the receiving birth facility, when needed.*
- Change the location from inpatient to outpatient in the record once the child has been discharged. You will need to click on “Cancel” when you receive a CCHD prompt until the CCHD module is rolled out.
 - *This helps know when to begin following up with the family so they are not bothered while their child is still inpatient.*

Professional Contacts

- Record the name of the child’s Primary Care Provider (PCP) who will care for the child after discharge. If the PCP is unknown, please make a note in the case note section. The delivering provider shall not be added as the PCP unless this provider will accept responsibility of this child after discharge.
 - *This will allow follow up on children that missed or referred in one or both ears and have not returned for a hearing screen. The PCP information is also used for children with identified hearing risk factors as a letter is sent to the designated PCP alerting of the need for future follow up.*
- Notify the PCP of the results of the hearing screening. PCP’s should also be notified when a child is in need of a hearing screening due to risk factors.
 - *This will reinforce the need for hearing follow up when EHDI staff sends a letter to the parent and PCP when the child is approximately 2 months of age with guidance regarding recommended hearing follow up.*
- If a family plans to see a PCP out of state, include the name and contact information of the PCP in the case note section. This may happen especially in cases where a family resides on the border of the state.
 - *This will help when following up on children that missed or referred in one or both ears and have not returned for a hearing screen. The PCP information is also used for children with identified hearing risk factors as a letter is sent to the designated PCP alerting of the need for future follow up.*
- If a PCP cannot be located, search for the PCP under ‘Select a State’ in the drop down menu. This will allow you to search in providers that have an out of state address. Notify EHDI staff if a PCP is not listed under professional contacts and make a detailed case note in the child’s record. Include the physician’s name and contact information to ensure proper follow-up can be done once a child is discharged.
- *This will allow the EHDI staff to follow up with the medical boards if the provider is not included in*

the database. Providers are automatically updated monthly.

- For children transferred out of your facility, enter a case note to document the name of the receiving facility. Add that facility under 'Add Professional Contact' as a birth screen provider. **Do not** enter any hearing screen results if no hearing screen was performed. Only report actual results performed prior to transfer.
 - *This allows the collection of missing results from the receiving birth facility, when needed.*

Hearing Screening Results

- Enter all outpatient screens as 'Outpatient' under 'testing location' and 'test type'. **Do not** let the database default to 'Birth screen' for outpatient screens.
 - *This information is shared with the CDC and is a reflection on individual hospitals as well as EHDI in meeting national goals.*
- Enter the date and time when the hearing screen was performed. **Do not** let the system default to the date and time of when the hearing screen data is entered into the database.
 - *This information is used to calculate how soon the child was screened after birth and is also shared with the CDC at the end of the year.*
- Utilize the appointment feature by clicking 'Edit' and entering a location and date/time for future appointments when the child is scheduled for hearing follow up.
 - *This will help avoid unnecessary follow up with the family and PCP. This is also a reflection of best practices being used by your facility (assisting families in scheduling follow up screens prior to hospital discharge).*
- If a screener is unable to perform a successful screen in **both ears** due to excessive movement of the baby or baby being noisy, **do not** enter any screen results. Please assist the family in scheduling an appointment and document a case note.
 - *This information will be helpful when attempting to bring the family back in for further testing.*
- If a screener is unable to perform a successful screen in **one ear** due to excessive movement of the baby or baby being noisy, select "Tech Fail" for the ear that was not successfully screened. If the reason was due to equipment not working, select "Not Used" for the ear that was not successful screened. Please assist family in scheduling an appointment and document in a case note.
 - *This information will be helpful when attempting to bring the family back in for further testing.*
- Notify the EHDI staff when there is any error to screen results as they are the only ones able to override screen results once saved. **DO NOT** enter another set of results to correct the results entered as an error. Note that once hearing screening results are entered, they cannot be deleted.

- *This will ensure that the hearing screens reported for all children are accurate.*

Audiological Assessment Results

- Enter all diagnostic testing under the assessment section by clicking 'View/Edit Assessment Data'. Diagnostic testing includes Auditory Brainstem Response (ABR) testing or any other combination of diagnostic testing involving two or more methods (i.e. OAE and TYMPS, OAE and VRA, VRA and TYMPS, etc.). If only OAE or screening AABR is completed, enter these as an outpatient screen by clicking 'Enter Manual Screening Results'. Please note the **exception** is if there are previous testing results that have been entered in the assessment section ALL following results should be entered in the assessment section even if only OAE or screening AABR was completed.
 - *This will help the system recognize all testing done as once the results have been entered in the assessment section, the system will only recognize those results entered in such area.*
- Record detailed notes and recommendations for each assessment in the 'Recommendations' and 'Notes' areas of the assessment. Including referrals, recommendations for hearing aids, early intervention, other intervention or pertinent information.
 - *This will help to determine the specific needs of the child so appropriate follow up can be done with the parent, audiologist or primary care provider.*
- Click 'Save & Close' when finished entering the assessment results to ensure it doesn't show the results as "Session in Process." Notify the EHDI staff when there is any error to assessment results as they are the only ones able to override screen results once saved. **DO NOT** enter another set of results to correct the results entered as an error. Note that once an assessment is entered, it cannot be deleted.
 - *This will ensure that the hearing screens reported for all children are accurate.*
- Record hearing aid fitting dates or cochlear implant information as appropriate for each ear separately by clicking 'View/Edit Amplification/Intervention Data'.
 - *This will avoid contacts from the EHDI staff to gather information for amplification for children when recommended.*