The Nebraska Early Hearing Detection and Intervention Program develops, promotes, and supports systems to ensure all newborns in Nebraska receive hearing screenings, family-centered evaluations, and early intervention as appropriate.

COVID-19

As the pandemic persists, NE-EHDI continues to strive to achieve the JCIH 1-3-6 goals for as many newborns and infants as possible. However, we understand the reasons for delays in follow-up during this uncertain time. Like you, we have been working hard to ensure no babies are missed! Each week our team typically follows around 90-100 newborns who need a repeat hearing screening and/or diagnostic evaluation. However, the volume of babies needing follow up more than doubled for several months during the spring and summer. We found there were two main reasons for the increased numbers:

- Babies were discharged from the birth hospital before 24 hours due to COVID, resulting in higher refer rates and fewer opportunities for a 2nd screen prior to discharge.
- For a few months, some audiology clinics had reduced hours, were closed, or parents didn’t feel comfortable taking their infant to the appointment due to COVID.

Fortunately, in mid-October, our active follow up numbers finally decreased back to around 100 babies each week. This very welcome return to normalcy was no doubt due to the tireless efforts of our Nebraska partners including audiologists! We will continue to work with families and professionals to accommodate any coming changes due to limited access to care.

The NE-EHDI team thanks each of you for your hard work over the past several months to ensure that hearing screenings, diagnostic evaluations, and referrals to EDN are caught up as quickly as possible so no child is missed or overlooked. As COVID numbers rapidly increase, we are concerned that it may be more difficult in the coming months to achieve timely follow up. Please let us know if you have any changes in protocols, staffing, and/or clinic hours during the next wave of the pandemic so we can work with you to adjust our follow up process if needed.
01 Audiology Summary & Reporting Guidelines

Per the 2019 JCIH Position Statement, the NE-EHDI Audiology Guidelines have been revised to state that the screenings in the well-baby nursery (not NICU) may be accomplished via OAE or ABR, with the second screen being conducted using either technology. Re-screening with OAE after not passing an ABR is acceptable with the caveat that a baby with auditory neuropathy will be missed. However, the recommendation to rescreen using ABR technology continues to be the preferred protocol. Please inform parents verbally and in writing that OAE doesn’t rule out all types of hearing loss, including auditory neuropathy.

02 Diagnostic Reporting Form

The instructions on this form were revised to state: “Always re-screen both ears and that ABR is required on NICU graduates.”

03 2019 Annual Report

The Infant Hearing Act requires an annual report to be prepared for Nebraska’s Legislature by the NE-EHDI Program. An aggregate data report was developed from statistical results based on individually-identifiable data submitted by all birthing facilities. The Annual Report provides data on the number of babies as they progress through each component of the NE-EHDI Program system, following the JCIH 1-3-6 recommendations and the type-degree-laterality of all diagnosed hearing loss. The annual report, developed in conjunction with the metabolic (dried blood spot) screening program, is disseminated to all state legislators and the NE-EHDI Program Advisory Committee. Electronic copies are also sent to the CDC and the HRSA Federal Project Officers. Reports are available on the NE-EHDI website [NE-EHDI Legislative Reports](#).
Risk Factor Reporting Form

- The Risk Factor Reporting form was revised to match the 2019 JCIH Recommendations.
- The risk factors have been separated into 2 categories: Perinatal and Perinatal/Postnatal.
- Recommended diagnostic follow-up timelines have been added to the JCIH Position Statement.
- The risk factor form should be completed for all babies who have at least one risk factor.
- NE-EHDI will provide parents and PCPs information annually about the importance of having appropriate follow-up hearing screenings according to the JCIH recommendation until the child is 3 years of age.

Risk Factor Assessment Checklist for Reporting to NE-EHDI

Date: ____________________

Event type: □ Inpatient Screening
□ Outpatient Screening

Name: ____________________ DOB: ____________ MRN: ____________

Physician: ____________________________________

Joint Committee on Infant Hearing (JCIH) Risk Factors:

Perinatal:

☑ Family history* of early, progressive, or delayed onset permanent childhood hearing loss
☑ Neonatal intensive care of more than 5 days
☑ Hyperbilirubinemia with exchange transfusion regardless of length of stay
☑ Aminoglycoside administration for more than 5 days**
☑ Asphyxia or Hypoxic Ischemic Encephalopathy
☑ Extracorporeal membrane oxygenation (ECMO)*
☑ In utero infections, such as herpes, rubella, syphilis, toxoplasmosis, cytomegalovirus (CMV), Zika
☑ Birth conditions or findings such as:
   □ Craniofacial malformations including microtia/atroresia, ear dysplasia, oral facial clefting, white forelock, and microphthalmia
   □ Congenital microcephaly, congenital or acquired hydrocephalus
   □ Temporal bone abnormalities
   □ Syndromes associated with hearing loss or progressive or late-onset hearing loss. (For information on the over 400 syndromes, visit HereditaryHearingLoss.org)

Perinatal/Postnatal:

☑ Culture-positive postnatal infections associated with sensorineural hearing loss***, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis, or encephalitis.
☑ Events associated with hearing loss:
   □ Significant head trauma, especially basal skull/temporal bone fractures
   □ Chemotherapy*
   □ Caregiver concern**** regarding hearing, speech, language, or developmental delay

* Infants at increased risk of delayed onset or progressive hearing loss
**Infants with toxic levels or with a known genetic susceptibility remain at risk
***Syndromes (Van Camp & Smith, 2016)
****Parental/caregiver concern should always prompt further evaluation.
Newborn Hearing Screening Hospital Champion Program

For parents whose babies refer for further testing on the newborn hearing screening, there is an anxiety-inducing gap between the time the baby is screened inpatient and the follow-up audiology evaluation. Many parents have said that it seems like an eternity when waiting for the audiology appointment. We know that medical professionals strive to do what is best for each family, but they may not realize that certain words like “failed” can increase parental anxiety.

Therefore, NE-EHDI and Nebraska Hands & Voices – Guide By Your Side (GBYS) partnered with families right here in our state to develop a Parent Perspectives video. This new educational tool incorporates a training curriculum for the newborn nursery staff. To incentivize hospitals to watch the video and update their protocols, NE-EHDI launched the Newborn Hearing Hospital Champion Program in December 2019 to all birthing facilities statewide.

This campaign aligns with two previous Nebraska Department of Health and Human Services (NE DHHS) Safe Babies Campaigns. Many Nebraska hospitals have already been recognized as champions in Safe Sleep and Abusive Head Trauma Prevention. The goal of the Nebraska Newborn Hearing Hospital Champion Campaign is to provide evidence-based education to birthing hospital staff who work directly with families and recognize Nebraska birth hospitals that incorporate the changes into their policies and procedures. The success of meeting the 1-3-6 benchmarks depends on professionals being well trained on educating parents about the importance of early hearing detection and intervention to protect babies from missing out on the most critical period in early childhood for speech and language development. To date, four hospitals have become champions, and 18 more have taken the pledge.

NE-EHDI is excited to partner with Nebraska hospitals because they impact the lives of newborns, parents, and caregivers by educating them about the importance of early hearing detection and intervention. Early identification protects babies from missing out on the most critical period in early childhood for speech and language development.

5 Steps to Become a Champion:

- Take the Newborn Hearing Hospital Champion Pledge
- Develop or update current Newborn Hearing Screening Policy
- Hospital personnel education and education plan
- Provide patient/client education
- Complete Internal audits annually

Watch the Parent Perspectives video now!
06

**EHDI Family Support Page**

The Nebraska Hands & Voices/Guide by Your Side program offers unbiased support to families of children who are deaf or hard of hearing.

Parents and caregivers of children who are deaf or hard of hearing who reside in Nebraska are fortunate to have a wealth of family support resources at their disposal. However, finding all the available resources can sometimes be confusing and overwhelming, especially early on after identification. To make things easier for families, NE-EHDI has launched a web page specific to family support resources so families can quickly identify what supports are available to them. Since family support plays such a critical role in positive outcomes for children who are d/hh, NE-EHDI and Nebraska H&V want to make sure that families don't have to work too hard to find the support they need. Please direct families to our web page for more information!

07

**Parent Education Video**

A parent education video providing a brief overview of what newborn hearing screening is and why it is important was revised with the suggested changes discussed at the November 2019 Advisory Meeting. An overview of the changes is outlined in the corresponding meeting minutes posted on the NE-EHDI website. Other dissemination ideas discussed by the Advisory Committee will be implemented in the future. The video is available in English, Spanish and is captioned.

**Working Together**

To help children identified as Deaf or Hard of Hearing reach their full potential!

Thank you for all the work you do to provide quality services to families in Nebraska!
Upcoming Projects & Future Initiatives

1 Looking Beyond the Newborn Hearing Screening

Per the current HRSA EHDI Grant requirements, NE-EHDI is expanding our capacity to support hearing screening, diagnosis, and enrollment into early intervention for those children up to age three who pass a newborn hearing screen but later develop hearing loss. NE-EHDI will be partnering with Early Head Start programs to develop a plan and have it in place by March 31, 2022. This will help us to continue to monitor and identify children who have late-onset or progressive hearing loss up to age 3 so they can be identified and enrolled in early intervention as soon as possible. It will also allow us to report the data as requested by HRSA.

2 Clear Masks

Thanks to a $10,000 COVID funding grant for PPE from HRSA, NE-EHDI is collaborating with Nebraska Hands & Voices to distribute PPE to families with children who are D/HH with priority given to ages birth to 3. If there is funding left, PPE will then be provided to the professionals who serve this population.

Do you know of other agencies who are providing early childhood hearing screenings? If so, please reach out to us with your recommendations!

DHHS.NEEHDI@nebraska.gov
Deaf and Hard of Hearing Role Model/Mentor Program

The NE-EHDI Program received grant funding in April 2020 to create a statewide Deaf and Hard of Hearing (D/HH) Role Model or Mentor Program. NE-EHDI will collaborate with parents, individuals who are D/HH, advocates for individuals who are D/HH, family support professionals, a variety of organizations, and other individuals to develop the D/HH Role Model or Mentor Program over the next 2-3 years. The objective of our federal funding partner is to connect interested families with an adult who is D/HH and is trained to be a Role Model or Mentor by the time their child who has been identified as D/HH is 9 months of age. Or if the family is not ready when their child is 9 months of age, the family can inform program staff when they are interested in being connected with a D/HH Role Model/Mentor. NE-EHDI recognizes that it is important to have D/HH Role Models/Mentors for parents and also for children who are D/HH. However, initially, we are focusing on connecting parents with D/HH Role Models/Mentors, which the child will also benefit from the interaction. Once this program is implemented and operating successfully, then the program can be expanded to offer other opportunities. NE-EHDI understands that some areas of Nebraska have D/HH role models or mentors for families and children who are D/HH. However, there is not a statewide formal D/HH Role Model or Mentor Program in Nebraska.

NE-EHDI developed a parent survey with input from the EHDI Advisory Committee & other parents. The survey link was e-mailed to parents statewide to find out their needs and wants for a statewide D/HH Role Model or Mentor Program. THANK YOU goes out to Hands & Voices, Regional Programs for Students Who are D/HH, Deaf Educators, Audiologists, and the Nebraska Speech-Language-Hearing Association for disseminating the survey link to parents! THANK YOU also to the parents who took the survey! The response has been amazing. There have been 90 parents so far who have taken the survey. The Organizational Meeting for this program was conducted on October 23, 2020, with 41 participants. There have been 67 individuals who have expressed interest to help with the planning of this program. They are parents, individuals who are Deaf and Hard of Hearing (D/HH), advocates of individuals who are D/HH, family support professionals, deaf educators, and audiologists. The plan is to have a primary workgroup of 20 people and then involve other interested individuals in sub workgroups. We are contacting other states who already have a similar program to gather information to have a foundation for the starting point for this program and then can be modified to meet the need of Nebraska. NE-EHDI will be e-mailing a survey in December/January to interested individuals to capture more information. A parent workgroup will meet once each month January-March 2021 to review the results of the parent survey and prioritize areas of importance (16 interested in this workgroup at this time). The primary workgroup and sub workgroups will meet to plan this program from April 2021-March 2022. During the time period of April 2022-March, 2023 or possibly sooner will identify the organization/program/agency or if several need to be involved to implement (hire coordinator(s), hire D/HH role models/mentors, hire interpreters, and ensure training is completed), manage, and maintain the program. The goal is to start implementing the program by March 2023. NE-EHDI has received a small amount of funding from April 2020-March 2024 to help implement and operate this program, but not enough to sustain on-going. We are asking for other organizations/programs that are interested in providing this program for families in Nebraska to help with funding to implement and sustain this program.

Inclusive Workgroup

NE-EHDI is forming a workgroup to review procedures, forms, letters, brochures, videos, social media, and website content to ensure the NE-EHDI system activities are all-inclusive and address the needs of the populations served including geography, race, ethnicity, disability, gender, sexual orientation, family structure, and socioeconomic status. The work group will be meeting virtually from March 2021 – September 2021.

If you would like to volunteer to serve on the workgroup or know someone who would, please let us know! DHHS.NEEHDI@nebraska.gov
Have you ever wondered how the Nebraska 1-3-6 achievements measure up when compared with US averages? This chart represents the most current 1-3-6 comparison data available.

<table>
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<th>Nebraska</th>
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<tr>
<td></td>
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<td>70%</td>
</tr>
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</table>

With the leadership of Dr. Stacie Ray, Nebraska EHDI stakeholders are working with UNL Barkley, Nebraska Commission for the Deaf and Hard of Hearing, Nebraska Hands and Voices, Early Development Network (EDN), and Regional Programs to produce a "Resources" YouTube Video for families and those who provide services to the families and children. The purpose of the video is to provide a quick overview of all the resources available in Nebraska that serve children who are Deaf or Hard of hearing. The video will be added to the NE-EHDI Family Support page on our website once finished.

Dr. Hannah’s Ditmars played a pivotal role in implementing tele-audiology services for Nebraska and is now lending her expertise to a Tele-audiology Steering Committee. Nebraska EHDI “alum” Jeff Hoffman is leading the nationwide effort for NCHAM. The project will expand tele-audiology services to address the post-COVID-19 surge. The goal is to serve children ages birth to 5 years. Types of testing will include ABR, OAE, Immittance, VRA, and CPA, conventional audiometry, hearing aid services, CI services, counseling, intervention, and therapy. Hannah will be a valuable contributor to the committee!