

EHDI Advisory Committee Meeting May 19, 2022 Nebraska Children's Home Society



Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES EARLY HEARING DETECTION & INTERVENTION PROGRAM

NE-EHDI Funding Sources and Requirements

Only receive Federal Funding (NO State funding)

- 1. Health Resources & Services Administration (HRSA) Grant
 - a. 4 year funding period from April 2020 March 2024 (\$235,000 maximum amount annually)
 - b. Reduced all of the EHDI Programs' funding from \$250,000 to \$235,000 annually during this time period
- 2. Centers for Disease Control and Prevention (CDC) Cooperative Agreement
 - a. 4 year funding period from July 2020 June 2024
 - b. Decreased # of awards NE-EHDI is very thankful to receive the funding
 - c. Increased amount of awards from \$150,000 to \$160,000 less restrictions on how the funding can be used
- 3. Maternal and Child Health (MCH) Title V Block Grant
 - a. Request funding as needed to cover necessary program operation costs
 - b. Approximately \$51,000 for 4/1/2021 3/31/2022

HRSA – 4 Year Funding Requirements from 4/1/2020 – 3/31/2024

- Develop a plan to address diversity and inclusion in the EHDI system by 3/31/2022
 - Ensure NE-EHDI system activities are inclusive of and address the needs of the populations it serves -including geography, race, ethnicity, disability, gender, sexual orientation, family structure, socio-economic status
- Expand our capacity to support hearing screening, diagnosis, and enrollment into El for those infants who pass a newborn hearing screen but later develop hearing loss up to 3 years of age (data collection and reporting)
 Required to develop a plan by 3/31/2022
- Increase by 10% the number of families <u>enrolled</u> in D/HH adult-to-family support services by 9 months of age by 3/31/2024
 - o HRSA has no definition for age of adult
 - Required to be a trained adult when serving as a D/HH Role Model or Mentor
- Continue to improve the 1-3-6 goals
- Reduce Loss to Follow-up/Loss to Documentation
- Continue to allocate 25% of annual funding for family engagement and family support activities
- Increase by 20% from the year 1 baseline, the number of families enrolled in family-to-family support services by 6 months of age by 3/31/2024
- Increase by 10% from the year 1 baseline, the number of health professionals and service providers trained on key
 aspects of the EHDI Program by 3/31/2024

CDC - 4 Year Funding Requirements from 7/1/2020 – 6/30/2024

Short-term Outcomes

- Recipients meet the "Shall" requirements of the CDC EHDI Functional Standards
- Improved collaboration between audiologists and jurisdictional EHDI program
- Increased knowledge and skills among audiologists in the jurisdiction about reporting hearing results

Intermediate Outcomes

- More audiologists in the jurisdiction report high quality diagnostic hearing results
- Improved accuracy, completeness and timeliness of follow-up and intervention enrollment data
- Increased targeted dissemination of information among internal and external stakeholders
- Increased the timely submission of standardized patient-level datasets to CDC (excluding PII)
- Increased standardization and comparability of EHDI follow-up data by CDC at national level

Long term Outcomes

- Use of timely patient-level data among EHDI programs for tracking and to inform decision making
- Increased the number of infants who receive a diagnosis no later than 3 months of age
- Increased enrollment in Early Intervention services no later than 6 months of age, for infants who are D/HH

Project to Expand Capacity to Expand Hearing Screening beyond Newborns up to Age 3

- Current status will be provided during meeting
- Plan must be developed by 3/31/2023
- HRSA Requirement:
 - Expand capacity to support hearing screening, diagnosis, and early interventions for those infants who pass a newborn hearing screening but later develop hearing loss up to age 3



• Activities that have occurred so far

- We have met with the Early Head Start Programs and will be piloting with 4
 Early Head Start Programs. Those that will be piloting the project will be Dodge
 County Head Start & Early Head Start; Blue Valley NE Community Action
 Partnership EHS (serves Butler, Fillmore, Gage, Jefferson, Polk, Saline, Seward,
 Thayer & York Counties); Northeast NE Community Action Partnership EHS
 (serves 14-county area of Northeast Nebraska, including the counties of Antelope,
 Burt, Cedar, Cuming, Dakota, Dixon, Dodge, Knox, Madison, Pierce, Stanton,
 Thurston, Washington and Wayne); Central NE Community Action Partnership
 & EHS (Serving the Counties of: Blaine, Boone, Boyd, Brown, Colfax, Custer,
 Garfield, Greeley, Hall, Hamilton, Holt, Howard, Keya Paha, Loup, Merrick,
 Nance, Platte, Rock, Sherman, Valley, Wheeler).
- We have finalized the agreements for this, and plan to reach back out to these programs in the late summer/early fall to get a process in place to submit data on a quarterly basis.
- We will continue working with the Pediatric Audiologists, who are already asked to submit results on children up to age 3 to EHDI.
- We plan on contacting the ESUs provided to see if they are interested in working with us.
- We will continue to try outreach to Primary Care Providers to get more information about hearing screenings during regular appointments
- Need assistance/ideas of other entities that may help NE-EHDI collect data of hearing screenings for this age. Please reach out to amanda.adams@nebraska.gov to provide input

Deaf & Hard of Hearing (D/HH) Mentor/Role Model/Guide Planning Workgroup



- Current status will be provided during the meeting
- Implement a statewide Deaf and Hard of Hearing (D/HH) Mentor/Role Model/Guide Program

• HRSA Requirement:

- Increase by 10% the number of families enrolled in D/HH adult-to-family support services by the time the child is 9 months of age by 3/31/2024
 - HRSA has no definition for age of adult
 - HRSA requires the adult to be trained when serving as a D/HH Role Model or Mentor
 - HRSA has no specifications regarding the training program to be used

• NE-EHDI's Goal is:

• To start implementing a statewide formal D/HH Mentor/Role Model/Guide Program by 3/31/2023.

• Timeline of Planning

- Fall 2019 Started discussing with a variety of partners to see what services are currently being provided in Nebraska for D/HH Role Models or Mentors.
- April 2020 Received HRSA funding for a 4 year funding cycle through March 31, 2024.
- July-August 2020 Developed a parent survey with input from the NE-EHDI Advisory Committee & other parents.
- August 31, 2020 E-mailed survey to parents statewide to find out needs and wants for a statewide D/HH Role Model or Mentor Program.
- August-September 2020 NE Hands & Voices and NE-EHDI partnered to interview individuals who are D/HH with a variety of experiences and communication choices.
- October 2020 Organizational Meeting.
- Jan-Feb-March 2021 A parent work group met each month to review the results of the parent survey and prioritize areas of importance.
- Feb 2021 A Primary Planning Work Group was established.
- March-July 2021 Gathered information from other states who have similar programs to find out what has worked well and what has been challenging.
- April 2021-March 2022 Nebraska Association of the Deaf has been identified as the operating program and a subaward has been drafted
- April 2022-March 2023 The operating program will hire coordinator(s), D/HH mentors/role models/guides, interpreters, and ensure training is completed.
- April 2023-March 2024 Manage, operate, and sustain the program and continue ongoing after 2024.

LB 741- Congenital Cytomegalovirus (cCMV)

• Link: <u>https://nebraskalegislature.gov/FloorDocs/107/PDF/Final/LB741.pdf</u>; Section 34



- Signed 4/18/22 by the Governor, DHHS is obligated to develop and publish informational materials for women who may become pregnant, expectant parents, and parents of infants that include the following information:
 - Incidences of CMV
 - o Transmission of CMV
 - Methods of diagnosing cCMV
 - Birth defects caused by cCMV
 - Available preventative measures to avoid infection
 - o Early interventions, treatment, and services available to children diagnosed with cCMV
- DHHS shall publish informational materials on its website and make materials available to:
 - Child Care Facilities
 - o School Nurses
 - o Hospitals
 - o Birthing Facilities
 - May provide information on testing opportunities as well as an opportunity to test prior to infant's discharge
 - Health Care Providers offering care to pregnant women and infants
 - May provide these informational materials
 - Audiologists completing follow up appointments
 - May provide clarifying information regarding cCMV as required by parents
- DHHS will have materials developed and have a distribution plan by 7/18/2022
 - Will report to the advisory committee in the Fall on outcomes/ongoing implementation
 - o Materials will be available on the NE-EHDI website, as well as available to order
- NE-EHDI will continue to meet with birthing facilities, hospitals, and audiologists
 - o Will discuss cCMV education and advise/assist with communication of information

Nebraska Newborn Hearing Hospital Champion Campaign

For details about the Hospital Champion program, visit the Campaign home page:

http://dhhs.ne.gov/Pages/Nebraska-Newborn-Hearing-Hospital-Champion-Campaign.aspx



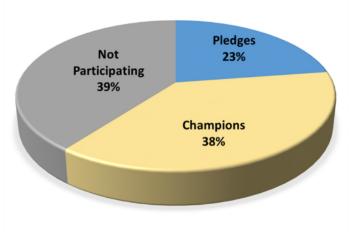
Current Pledges & Champions:

Pledges		<u>Champions</u>	
1.	Memorial Community Hospital &	1.	St Francis Memorial Hospital - West Point
	Health System - Aurora	2.	York General Hospital - York
2.	Howard County Medical Center - St.	3.	Bryan Medical Center - Lincoln
	Paul	4.	Box Butte General Hospital - Alliance
3.	Perkins County Health Services -	5.	CHI Health St. Francis - Grand Island
	Grant	6.	CHI Health Lakeside - Omaha
4.	Mary Lanning Healthcare - Hastings	7.	CHI Health Creighton University Medical Center
5.	Butler County Health Care Center -		Bergan - Omaha
	David City	8.	CHI Health St. Elizabeth - Lincoln
6.	CHI Health Good Samaritan -		CHI Health St. Mary's - Nebraska City
	Kearney		CHI Health Immanuel Medical Center - Omaha
7.	Grand Island Regional Medical		CHI Health Mercy - Council Bluffs, IA
	Center - Grand Island	12.	Methodist Fremont Health - Fremont
8.	Regional West Medical Center -		Fillmore County Hospital – Geneva
	Scottsbluff		Nebraska Medicine – Omaha
9.	Columbus Community Hospital -	15.	Methodist Jennie Edmundson Hospital -
	Columbus		Council Bluffs, IA *NEW*
10.	Tri Valley Health System –		Methodist Women's Hospital – Omaha *NEW*
	Cambridge		Beatrice Community Hospital – Beatrice *NEW*
11.	Thayer County Health Services –		CHI Health Schuyler – Schuyler *NEW*
	Hebron *NEW*	19.	Sidney Regional Medical Center – Sidney
12.	Providence Medical Center – Wayne		*NEW*
	NEW	20.	Brodstone Memorial Hospital – Superior * NEW *

Outcomes & Goals:

As of April 2022:

- 12 hospitals in pledge status
- 20 hospitals in champion status
- List of pledges and champions updated on website regularly
- Results in 61% participation rate statewide
- Goal is to achieve > 90% participation statewide by 2024
- Reminders are sent quarterly to encourage participation





JCIH 2019 Position Statement Frequently Asked Questions

Audiology

Q: The new risk factor table seems to recommend diagnostic audiology follow-up for all risk factors. If a baby has passed AABR, is re-screening with OAEs for the risk factor follow-up appropriate? Can the committee expand on this topic and the rationale for diagnostic testing?

A: For follow up due to risk factors, JCIH is recommending a comprehensive diagnostic audiologic evaluation including, tympanometry, OAE, acoustic reflexes and behavioral testing as the gold standard for hearing assessment when developmentally appropriate. Continued use of OAE alone for monitoring hearing is insufficient for assessing children with mild hearing loss.

Q: When should a sedated ABR be done?

A: In keeping with the 1-3-6 (or 1-2-3) EHDI goals, audiologic diagnosis should be completed no later than 2–3 months of age. This earlier age facilitates the diagnostic process as infants are more likely to sleep for prolonged periods of time required to complete all measures. In children with special health needs, delay in diagnosis of hearing loss may be unavoidable due to attention paid to other health/ time-urgent diagnostic and treatment procedures; however, every effort should be made to minimize the delays. When possible, audiologists can evaluate infants in the NICU, pediatric intensive care unit, or in conjunction with examinations or procedures conducted with general anesthesia or sedation. (p.11)

Electrophysiological testing (ABR) with sedation or anesthesia, when not medically contraindicated, is indicated if: 1. conventional/behavioral testing does not provide consistent, reliable, and valid information using the cross-check principle and/or results are inconsistent with parent/caregiver observations, and 2. electrophysiologic testing cannot be completed during natural sleep and 3. results of ABR evaluation will influence the treatment or management of the child.

Q: When middle ear fluid is found during the diagnostic assessment, how soon should an ABR reassessment be completed?

A: Diagnostic assessment should be completed before 3 months of age. The presence of middle ear fluid should not delay diagnostic assessments. Testing includes bone-conducted stimuli when air-conducted thresholds are elevated to rule out underlying sensory loss and facilitate intervention recommendations. When middle ear fluid is present and bone-conduction testing indicates permanent sensorineural hearing loss, hearing aid fitting, CI candidacy evaluation if indicated, and/or enrollment in early intervention should not be delayed.

As stated on page 15 "management of middle-ear fluid in the infant should be coordinated by the infant's pediatrician/primary-care provider and/or a pediatric otologist, with the audiologist's input, and in conjunction with the family's preferences." Ongoing audiologic monitoring should be completed following resolution of middle ear fluid.

Q: Why does the position statement recommend that very preterm babies in the NICU for an extended time have a diagnostic evaluation <u>before</u> discharge?

A: For an infant in the NICU whose duration of stay would impact the attainment of the 1-3-6 benchmarks, a diagnostic ABR is recommended to meet the 3-month diagnostic benchmark. This is best practice for babies to meet milestones.

Q: In the 2007 position statement it recommends at least one ABR be completed as part of the complete diagnostic evaluation for children younger than 3 for confirmation of a permanent hearing loss. But this is not included in the 2019 position statement. Is this no longer recommended? For example, if you have a 2 ½ year old who can complete ear-specific, behavioral testing that is reliable and valid, would you need to recommend an ABR to confirm?

A: If you cannot get ear specific responses at any age, then an ABR is recommended to obtain ear specific thresholds. If you have the ear specific information with a comprehensive test battery approach, you do not need to do the ABR. The rationale for this change involved two considerations:

- The recommendation to do an ABR on every child was primarily based on detecting auditory neuropathy spectrum disorder. Since 2007, there has been an increasing recognition from the literature that ANSD is relatively rare.
- Most children over 6 months of age will require sedation or anesthesia to have an ABR. There has been an increasing recognition since 2007 that anesthesia is expensive and has associated risks.

Q: What tests need to be included in a diagnostic ABR? If the test is reliable, is a confirmation ABR needed before moving ahead with intervention steps?

A: A complete diagnostic audiology evaluation should include a battery of physiologic tests that define type, degree, and configuration of hearing thresholds for each ear. Key components of a diagnostic audiologic evaluation are noted specifically on page 12. "Auditory brainstem response is the gold standard test for threshold estimation for infants and children who cannot complete behavioral audiologic assessment. ABR provides ear- and frequency-specific threshold estimates that are necessary for the diagnosis of the type, degree, and configuration of hearing loss and provision of amplification." (p.11)

- Frequency-specific (toneburst) stimuli are used to elicit neural responses that enable determination of thresholds and form the foundation for determining hearing aid amplification characteristics. Thresholds for both air-conducted and bone-conducted stimuli are measured to determine type (i.e., conductive, sensorineural, mixed) of hearing loss. Bone conduction thresholds are necessary to estimate additional hearing aid gain and output if there is a conductive component. (p.12) Click stimulus should be included in the ABR to assess for neural (ANSD) hearing loss when indicated.
- Confirmatory testing is not indicated to move forward with intervention recommendations if test results are reliable.

Q: What if my hospital or clinic does not have the equipment to complete a diagnostic ABR, or does not have a pediatric audiologist who can perform diagnostic ABR?

A: If your facility does not have the equipment for a diagnostic ABR, we recommend using this document to advocate for diagnostic equipment and pediatric audiologist in your clinic and/or refer the baby to a facility where the equipment **and** pediatric audiologist are available.



JCIH 2019 Position Statement Frequently Asked Questions

← Medical Considerations ←

Q: I noticed that specifying ear tags and pits as a risk factor for follow-up was eliminated from the 2019 statement. Do you have any additional insight on this, specifically if the committee still recommends follow-up for these babies when they pass the NHS and what that timeline should be?

A: Isolated ear pits and tags have no higher reported incidence of hearing loss than other children (without ear pits and tags). The committee based their recommendations off papers such as <u>"Isolated preauricular pits</u> and tags: is it necessary to investigate renal abnormalities and hearing impairment" (2008). The main finding was that the prevalence of hearing loss and renal problems were similar to a control group without tags or other pinna anomalies. There is a similar recommendation from a 2017 paper, <u>"Is routine audiometric testing necessary for children with isolated preauricular lesions (2017)</u>).

The committee recognizes that programs may institute guidelines that are stricter than what is recommended in the current statement. There remains a lack of conclusive evidence that children with isolated external ear anomalies require additional care beyond universal newborn hearing screening.

- Fırat, Y., Şireci, Ş., Yakıncı, C. *et al.* Isolated preauricular pits and tags: is it necessary to investigate renal abnormalities and hearing impairment?. *Eur Arch Otorhinolaryngol* 265, 1057–1060 (2008). <u>https://doi.org/10.1007/s00405-008-0595-v</u>
- Grace T. Wu, Conor Devine, Allen Xu, Katie Geelan-Hansen, Samantha Anne. Is routine audiometric testing necessary for children with isolated preauricular lesions?, International Journal of Pediatric Otorhinolaryngology, Volume 93, 2017, Pages 68-70, ISSN 0165-5876, <u>https://doi.org/10.1016/j.ijporl.2016.12.032</u>.

Q: What about assisted ventilation? Is this still considered a risk factor for possible delayed HL? If so, what type(s) of devices are considered assisted ventilation?

A: The literature has supported the association of assisted ventilation to be an independent risk factor on hearing status (Hille et al 2007). The literature does not specifically describe the type of assisted ventilation.

Q: What is considered a 'prolonged stay in the NICU' and how are recommendations different for babies in a Special Care Nursery versus a NICU?

A: The definition of prolonged stay in the NICU is greater than 5 days (Table 1, risk factor 2). The rationale for including a prolonged stay in the NICU is related to literature findings that those who have been in the NICU has a higher rate of hearing loss as compared to the general population among populations of NICU graduates (Hille et al 2007, Coenraad et al 2010, Kraft 2014). Additionally, some authors have tried to tease apart the multiple potential risk factors associated with hearing loss (such as ECMO and needing ventilation) {Kraft 2014}.

It is most likely a compilation of multiple risk factors within NICU babies that prompt this high rate of hearing loss. Using the risk factor of NICU stay provides a readily identifiable event to ensure clinicians and public health systems can identify and monitor a specific child for late onset hearing loss. Considerations for babies in the special care nursery should be individualized for the infant based on specific risk factors.

- Hille ET, Van Straaten HI, and Verkerk PH. Prevalence and independent risk factors for hearing loss in NICU infants. *Acta Paediatr.* 2007;96, 1155-1158.
- Kraft CT, Malhotra S, Boerst A, and Thorne MC. Risk indicators for congenital and delayed-onset hearing loss. *Otol Neurotol.* 2014;35, 1839-1843.
- Coenraad S, Goedegebure A, Van Goudoever JB, and Hoeve LJ. Risk factors for sensorineural hearing loss in NICU infants compared to normal hearing NICU controls. *Int J Pediatr Otorhinolaryngol.* 2010;74, 999-1002.



JCIH 2019 Position Statement Frequently Asked Questions

🗢 Newborn Hearing Screening 🗢

Q: The definition of universal newborn hearing screening is the screening of all newborn babies "prior to being discharged". Under certain circumstances the hearing screening was not completed "prior to discharge" but those babies were given an appointment within 7 days as outpatients for their first screening. Is this method appropriate?

A: It is appropriate to provide services to the best of your abilities. The JCIH position statement is meant to detail best practices but if staffing and equipment needs do not allow you to meet these guidelines you should strive to provide services as close as possible to those outlined in the statement.

Q: Is it accurate to say that if a baby passes the screen in both ears regardless of when each ear was tested as an inpatient, that this should be sufficient? Or should both ears be screened at the same time?

A: Both ears must be screened at the same time and both ears must yield pass results at that screening session to be considered an overall pass.

Q: We do not agree with not screening the ear opposite a unilateral atresia. Parents are typically upset by the atresia and want to know if the baby can hear in the "normal looking" ear. Since wait times for diagnostic testing can be approx. 3 months at our local Children's Hospital, it seems that waiting that long to screen the "normal" ear goes against the EHDI spirit. If parents know that the baby passes in the typical ear, there will likely be much relief. Why is atresia an automatic fail?

A: Atresia in one ear is an automatic failed screening. As a result, the baby needs a diagnostic ABR regardless of the results of the "typical" ear.

Updated 1/1/22

Q: When referring to preterm babies, does the committee mean actual age or adjusted age in their example of the 3-month-old in the NICU? Does this answer affect the recommendation?

A: The 1-3-6 benchmarks are based on full term newborns. Should the baby be premature, decisions about timing for diagnostic evaluation should be discussed with the physician and the pediatric audiologist.

Q: Our current practice in the NICU is to allow two screens total unless they refer in both ears on the first screen then they have only that screen and get scheduled for an outpatient diagnostic full ABR. Is this compatible with the new JCIH guidelines?

A: The JCIH position statement does not specify a limit to the number of re-screenings that can occur in the NICU, but the number of overall rescreening attempts should be limited to avoid delaying diagnostic assessment. The involvement of an audiologist in the NICU phase is a strength and will likely prevent prolonged duration for a complete hearing diagnosis. JCIH think that limiting the number of rescreening and including an audiologist during the NICU phase is consistent with the spirit of the position statement when it comes to rescreening.

The recommendation for referring an infant in the NICU to the diagnostic phase is based on the overall concept in the document to avoid multiple re-screening attempts that could delay the diagnostic assessment. The document talks about this concept on Page 10 in the context of outpatient rescreening. Rescreening in the NICU phase does not extend the timeframe that it might take an infant to get a diagnostic. In fact, if an audiologist is involved in the NICU rescreening process, that is completely in alignment with the intent of the document.

Q: If AABR is required for all infants in the NICU regardless of length of stay, are the recommendations for follow-up the same?

A: NICU stay of 5 days or greater is a risk factor in itself that requires follow-up with behavioral testing at 9 months. NICU stay less than 5 days, follow-up is recommended only when there is 1 other risk factor.

Q: What is the difference between a special care nursery vs NICU and how do we delineate that with regards to the JCIH recommendations?

A: The answer to this depends on the hospital. For some systems, the NICUs and special care nursery are placed under the same category. It is recommended that you consult with your hospital as well as with your state's policies and procedures.

Q: Could you provide clarification about the timing of hearing screening or other recommendations related to use of Loop Diuretics in the NICU?

A: The 2019 JCIH Position Statement does not specifically mention loop diuretics because they are frequently utilized in the management of premature babies who are already at a heightened risk level for hearing loss suggesting the need for hearing screening/assessment. These children often have multiple risk factors, and it is difficult to tease apart those factors specifically related to hearing loss. Loop diuretics are known to be in the class of ototoxic medications, however there is not strong data to provide robust guidance on late onset hearing loss after discontinuation of loop diuretics. Each child's unique constellation of risk factors is an important clinical consideration for managing hearing health.

Q: The previous position statement stated that if AABR was utilized as a screening method subsequent screening should be completed using AABR as well. The new statement approves the use of OAE following AABR for the well-baby population. Why?

A: Following AABR with OAEs in babies from the well-baby nursery was deemed acceptable because the incidence of Auditory Neuropathy/Auditory Dysynchrony (AN/AD) in the well-baby population is low. If (A)ABR is mandated as follow up, if the initial screening was with AABR, it may result in second screens being postponed, not happening because (A)ABR equipment may not be readily available.

Q: Our facility has a difficult time making the 1-3-6 benchmarks. What if we cannot make the 1-2-3 benchmark?

A: If your facility is currently meeting the 1-3-6 benchmarks, the next step would be to try to reach 1-2-3 benchmarks. It is reasonable for facilities to aspire for 1-2-3 for an individual child. It may not be possible for every child given medical, social, audiologic, etc. reasons. For facilities that are not meeting 1-3-6 benchmarks, they should first aim for 1-3-6. The committee recognizes that 1-2-3 is an aspirational program goal.

NE Hands & Voices/Guide By Your Side Report for 5/11/2022 NE-EHDI Advisory Committee

- Shelli works up to 16 hours a week assisting with EHDI follow-up for families and medical professionals, as well as providing education and family support. This is an opportunity for families to connect with a GBYS Guide with their first EHDI contact and allows Shelli to share GUIDE experiences and knowledge as appropriate.
- 2. Shelli worked with 543 families from 11/08/2021 4/25/2022.
- 3. There are currently **15** trained Parent Guides who provide support throughout Nebraska.
- 4. As of 4/19/2022 GBYS are serving 185 families and 132 families were referred by NE-EHDI (71%).
- 5. **Quotes from families served by GBYS, these are from the 2021-2022 annual survey:** Quotes about what families like best about their Parent Guide

"The ability to relate to her and her family. Her daughters were my child's age or older so they experienced things I had questions about & had a lot of great tips."

"Everything. I like everything about her, I like that I can trust in telling her anything and I like the way we both look for a solution to my worries." (Response from a Spanish speaking family)

"NOTHING that I do not appreciate. What I appreciate most about my Parent Guide is her kindness, patience, and emotional support. She is always there for me and has been an angel for my family."

"Very approachable & willing to talk whenever I needed advice but was never pushy or over involved."

Quotes about what families like about the GBYS Program.

"I never imagined how overwhelmed I was feeling up until my Guide called me. I will be forever grateful because I was going through my worst moment emotionally. I was the most opportune moment I have had in my life, today I realized I would not be able to do it alone."

"My experience with GBYS has been nothing but positive! We truly appreciate the support that has been given to us."

"We are so thankful for our Parent Guide! She has been a rock for us. Brainstorming for my medically complex kiddo has been very beneficial."

6. Hands & Voices and NE-EHDI collaborations since November 2021

- On-going Monthly activity "Rising Stars" Deaf & Hard of Hearing Youth Leadership Award –This is an opportunity to recognize a youth (up to age 21) once a month who is D/HH. It is empowering as well as helps promote our youth to become positive role models in the D/HH community. The selected youth receive an award certificate, a \$15 gift certificate, and is recognized on Nebraska H&V Facebook. The youth are excited to receive the award. There are a lot of D/HH youth doing amazing things.
- **H&V Monthly Newsletter** Newsletters cover the recent Rising Star, Guide Spotlight, favorite resources, agencies, apps, #notsoproudmomments, current news and upcoming dates.
- **Moody Monday** We pose a question on Facebook every Monday. The questions range in topic, this is a way to educate parents and professionals about D/HH topics and to share fun information. We choose a



GUIDE BY

winner randomly from the comments and they receive a prize courtesy of NE-EHDI (book, accessory, case for equipment etc.) This has been an effort to increase activity on Facebook and it has been working well.

- **Purchase of Books** NE EHDI has been very supportive in providing books to our H&V GBYS program to be distributed to parents and at our events. These books have been very popular and are appreciated by our families. Some of these books are targeted to kids and specific differences and some are more for parents.
- Through the sub-award between NE-EHDI and NE Hands & Voices –

Cody McEvoy and Shelli Janning completed an agreement that ran through March 31 to help NE-EHDI to research, plan, and facilitate the planning meetings for the D/HH Mentor/Role Model/Guide Program.

7. Events:

- October 22 & 23- Moms Night Inn Scottsbluff 10 people attended. Training included information about Executive Functioning and Self Advocacy, we held a Parent Café and a panel of D/HH students, and completed a craft (wooden door hanger).
- Jan 16 Family Gathering at PE 101- Omaha 7 families attended (12 adults, 7 d/hh children, 8 siblings). Goal was networking and play. Informal feedback was very positive. Families and kids seemed to enjoy getting together and connecting.
- Jan 22 & 23 Annual GBYS meeting Lincoln 12 Parent Guides and Jen attended in person and 3 Guides attended via Zoom. We spoke about program improvement and development and did a lot of team bonding. Lots of planning for continuous improvement of the support that we are able to provide families.
- Feb 12 & 13- Moms Night Inn Lincoln- 20 moms attended, 1 canceled due to covid. Feedback was very positive, we spoke about "what you don't know and preparing for transitions, Executive functioning and Sara Peterson spoke about the Nebraska Regional Programs (NRP's). We did a wrapping class for the craft. Panel of 6 students shared their perspective on Sunday. We received wonderful feedback.
- Feb 19- Family Gathering Kearney Childrens Museum. We had 15 families register and 4 families did not show (23 parents/grandparents, 11 D/HH kids and 14 siblings). This event was casual with about 20 minutes of an ice breaker and family introductions. We also spoke briefly about support and offered a book to the families who attended. Overall parents stated they were very happy with this opportunity.
- Feb 22- Family gathering Rock-N-Joes Lincoln (evening event)- 5 families attended (13 people). Informal meeting with introductions and lots of conversation.
- April 10- Easter Egg Hunt La Vista 20 families attended (36 adults-21 D/HH kids, and 21 siblings which totaled 78 people). We held introductions, a book reading of My Dawg Koa, an Easter Egg Hunt and then played at the park. Families seemed to mingle well lots of dads were there. We gave away about 20 books, courtesy of NE EHDI. We have children there aging from 4mo to 16yrs. The furthest a family came from was Lincoln. We had 4 culturally diverse families attend. We did not have a request for an interpreter, Gabby was there for the Spanish speaking population
- Various other events where H&V and EHDI are represented but we do not take the lead or assist in planning the events.
- MONTHLY ACTIVITIES
 - Lincoln coffee- Sept = 4 parents, Oct = 2 parents, Nov = 2 parents, Dec = 3 parents, Jan = 2 parents, Feb = 1 parent. We canceled due to low interest.
 - **Omaha Coffee** Dec = 3 parents, Feb = 2 parents. We canceled due to low interest.
 - \circ Spanish Zoom Held for 3 months and then canceled due to lack of attendance.

April 29, 2022

HearU Nebraska Annual Statistics

Last Five Years

107 hearing aids were fit on 68 children in 2017

58 hearing aids were fit on 34 children in 2018

51 hearing aids were fit on 33 children in 2019

45 hearing aids we fit on 28 children in 2020

54 hearing aids were fit on 29 children in 2021

2008 to Current

875 hearing aids have been fit on 533 children

-- Since September 19 2021

- 22 hearing aids have been dispensed to 13 children
 - o ages: 2 months through 15 years of age
 - o 24 new hearing aids and 16 chargers are currently in stock

--We purchased hearing aids for our stock this month in a variety of colors and models.

-- Financial Criteria took effect January 1, 2018 and since April 2021 we have had:

- 3 denials due to parents being well over income guidelines.
- Application numbers compared to previous years:
 - o 2021- total of 32 applications between January and December 2021
 - o 2020- Total of 26 applications between January and November 2020
 - o 2019 Total of 39 applications between January and October 2019
 - o 2018 Total of 41 applications between January and October 2018
 - o 2017 Total of 55 applications between January and October 2017
 - o 2016 Total of 35 applications between January and October 2016