Attachment 7 – Progress Report

ACCOMPLISHMENTS SUMMARY – SUMMARY PROGRESS REPORT
Nebraska Early Hearing Detection and Intervention Program
2011 – 2013

NOTE: "Quarters" column indicates the time in which the activity will occur, beginning with Quarter1 on April 1, 2011. A list of abbreviations can be found in Attachment 11.

Goal/Objective	Quarters	Results
Goal 1: The hearing of all newborns born in Nebraska will be screened during the birth admission for 100% of newborns, including transfers to NICUs.		
Program Objective 1.1. Birthing Facilities will submit hearing screening status reports for 100% of newborns, including transfers to NICUs.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	100% of the birthing facilities are submitting their hearing status reports, including transfers to NICUs.
Program Objective 1.2. Birthing facilities will have status and comparison reports available for quality improvement.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Semi-annual reports are generated and sent to each birthing facilities. The reports list specific information such as number of births, number of refers, number of parents educated, and how their numbers compare to the state as a whole.
Program Objective 1.3. Parents educated about hearing screening, per Infant Hearing Act.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Approximately 98% of parents are educated in the hospital about hearing screening and information is sent to all parents with a planned out-of-hospital birth.
System Goal 2: Newborns who "refer" on initial hearing screening will complete an outpatient re-screening and/or audiologic diagnostic evaluation prior to three months of age.		
Program Objective 2.1. Tracking of outpatient follow-up activities occurs with Primary Health Care Provider (PHCP) and/or parent(s).	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	The NE-EHDI Program staff has a system using ERS and Access for tacking outpatient activities on a daily basis. Approximately 800 infants needing outpatient screenings or diagnostic evaluations are tracked each year. Contact is made with the PCHP and/or parents.
Program Objective 2.2. Confirmatory testing facilities will	Q1 Q2 Q3 Q4 Q5 Q6	The NE-EHDI Program has found that in working with

obtain parent permission to release audiologic/screening reports to the NE-EHDI Program.	[✓ Q7 Q8 Q9 Q10] [✓ Q11 Q12]	hospitals and audiologists that a written permission form is not needed. Information is received from confirmatory facility and if not staff follows up.
Program Objective 2.3. Confirmatory testing facilities will submit individual audiologic diagnostic and amplification reports, including information about referrals.	[✓ Q1 Q2 Q3 Q4 Q5] [✓ Q6] [✓ Q7 Q8 Q9 Q10] [✓ Q11 Q12]	The NE-EHDI Program receives audiologic diagnostic and amplification reports, using a form that which includes information about referrals from confirmatory testing facilities.
Program Objective 2.4. Confirmatory testing facilities will submit the annual aggregate report required by statute.	Q1 Q2 Q3 Q4 [✓ Q5] Q6 Q7 Q8 [✓ Q9] Q10 Q11 Q12	Confirmatory testing facilities do not need to submit the data because the Program can create reports through ERS.
Goal 3: All infants with a confirmed hearing loss will have immediate access to high-quality technology and will begin receiving early intervention services prior to six months of age.		
Program Objective 3.1. Primary Health Care Providers and audiologists will refer all newborns and infants with suspected or confirmed hearing loss to the Early Development Network, other early intervention providers.	[✓ Q1 Q2 Q3 Q4 Q5] [✓ Q6] [✓ Q7 Q8 Q9 Q10] [✓ Q11 Q12]	Early intervention providers receive referrals from PHCP, NE-EHDI staff, audiologists, and others for newborns and infants with a suspected or confirmed hearing loss. Program staff also follow-up on diagnosed cases to ensure that the EDN has received the referral.
Program Objective 3.2. Parents will access early intervention services through a coordinated point of entry.	[✓ Q1 Q2 Q3 Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	The State’s Early Development Network serves as the coordinated initial point of entry whenever a referral is made.
Program Objective 3.3. Audiologists will conduct or refer, as appropriate, all infants with a confirmed hearing loss for assistive listening device evaluations and services, including HearU Nebraska (Nebraska Children’s Hearing Aid Bank).	[✓ Q1 Q2 Q3 Q4 Q5] [✓ Q6] [✓ Q7 Q8 Q9 Q10] [✓ Q11 Q12]	HearU Nebraska (formerly the Nebraska Children’s Hearing Aid Bank) has been fully operational since March 2007. Located at the University of Nebraska-Lincoln it processes hearing aid loans and repairs.
Program Objective 3.4. Audiologists will recommended, as appropriate, all infants with confirmed hearing loss for	Q1 [✓ Q2] Q3 Q4 Q5 [✓ Q6] Q7 [✓ Q8] Q9 [✓ Q10]	The NE-EHDI Program participated in an audiologist survey, with other states who are members of Heartland Regional

medical evaluation, genetic evaluations and family support.	Q11 [✓ Q12]	Genetics and Newborn Screening Collaborative, funded by HRSA. The survey examined audiologists knowledge of genetics. Based on the results, Heartland Regional intends to develop a webinar or series of webinars that will provide training for audiologists on genetics as it pertains to hearing loss.
Program Objective 3.5. The Early Development Network, Medically Handicapped Children's Program, Regional Programs for Students who are Deaf or Hard of Hearing, and other early intervention providers will submit individual and annual aggregate reports of early intervention.	Q1 Q2 Q3 Q4 [✓ Q5] Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	Protocols were developed for the EDN/Part C referrals for children with a diagnosed hearing loss. Program staff contact the deaf/hard of hearing coordinator in their region and conduct a "joint" home visit. They also give the family specific resources related to the diagnosis. The NE-EHDI Program verifies whether the family is receiving services for those children with a diagnosed hearing loss.
System Goal 4: All infants with a confirmed hearing loss will have access to a medical home.		
Program Objective 4.1. Birthing facilities will identify and report to the NE-EHDI Program the Primary Health Care Provider of each newborn who refers on the initial hearing screening, including transfers to NICUs.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Using the Electronic Registration System (ERS-II), birthing facilities enter the name of the PCHP which is verified by the Program staff and follow-up is initiated on infants requiring an outpatient screening.
Program Objective 4.2. Primary Health Care Providers will refer, as appropriate, infants with suspected or confirmed hearing loss for otologic, genetic, and audiologic evaluations and for early intervention services.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Periodic individual status reports are exchanged between the Primary Health Care Providers and the NE-EHDI Program.
Program Objective 4.3. Primary Health Care Providers will submit individual status reports of children with a confirmed hearing loss.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Periodic individual status reports are exchanged between the Primary Health Care Providers and the NE-EHDI Program.
System Goal 5: Families of young children with a confirmed hearing loss will		

have access to a family support system.		
Program Objective 5.1. Families of young children with a confirmed hearing loss will have access to a family support system.	[✓ Q1 Q2 Q3 Q4 Q5] [✓ Q6] [✓ Q7 Q8 Q9 Q10] [✓ Q11 Q12]	Staff regularly review available services for both new services and possible updating of information that is included in the Parent Resource Guide. It will also be included on the web site. The Guide includes a myriad of helpful information and a follow-up phone call to the family is made by the Community Outreach Coordinator. The Guide also includes a parental release of information that when signed and returned to the NE-EHDI Program permits staff to share their contact information with Guide By Your Side.
Program Objective 5.2. Organizational support will be provided to develop family-to-family support services.	[✓ Q1 Q2 Q3 Q4 Q5] [✓ Q6] [✓ Q7 Q8 Q9 Q10] [✓ Q11 Q12]	The NE-EHDI Program continues to support and be involved in the planning and implementation of the Roots and Wings parent weekend organized by Boys Town National Research Hospital. This brings in parents who have a child up to the age of three, with a hearing loss. The Program is also building on the successes of parent workshops held around the state that provide networking opportunities and opportunities to develop family-to-family support. A parental release form was created by the NE-EHDI Program that when signed and returned permits the Program to share contact information with Guide By Your Side.
Program Objective 5.3. Early intervention providers will submit annual aggregate and individual reports of families participating in family-to-family support activities.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	The Community Outreach Coordinator currently does not work with the Early Development Network providers to collect such information.
System Goal 6: Young children, in Nebraska, will have access to periodic hearing screening.		

Program Objective 6.1. Primary Health Care Providers will refer young children at risk for late-onset hearing loss for audiologic monitoring.	Q1 Q2 Q3 [✓ Q4] [✓ Q5] [✓ Q6] Q7 Q8 Q9 Q10 Q11 Q12	This objective will be discussed by the NE-EHDI Program Advisory Committee.
Program Objective 6.2. Early Head Start programs will conduct OAE screenings of enrolled children aged birth to three years.	Q1 [✓ Q2] [✓ Q3] Q4 Q5 [✓ Q6] [✓ Q7] Q8 Q9 [✓ Q10] [✓ Q11] Q12	Currently, one Head Start/Early Head Start program is screening enrolled children and sharing the results with the NE-EHDI Program. If successful, it will be expanded to other Head Start/Early Head Start programs.
Program Objective 6.3. Community-based health services will conduct OAE screenings.	[✓ Q1] [✓ Q2] [✓ Q3] [✓ Q4] [✓ Q5] [✓ Q6] [✓ Q7] [✓ Q8] [✓ Q9] [✓ Q10] [✓ Q11] [✓ Q12]	Community-based services have not been trained to conduct OAE screenings.
Program Objective 6.4. Hearing screening and monitoring status reports will be submitted to the NE-EHDI Program.	[✓ Q1] [✓ Q2] [✓ Q3] [✓ Q4] [✓ Q5] [✓ Q6] [✓ Q7] [✓ Q8] Q9 Q10 [✓ Q11] [✓ Q12]	Currently, one Head Start/Early Head Start program is screening enrolled children and sharing the results with the NE-EHDI Program. If successful, it will be expanded to other Head Start/Early Head Start programs.
System Goal 7: Professionals working with young children will a hearing loss will increase their capacity to provide appropriate services to young children.		
Program Objective 7.1. Training needs of hearing health professionals will be assessed.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	A Professional Development Needs Assessment survey was sent to Nebraska birthing facilities. Out of 58 surveys that were mailed, 34 were returned. Questions included asking if they needed additional training, what materials would be helpful, what degree of need that they saw in areas such as communicating with parents, cultural competency, and quality assurance. This information is used to discuss what type of format might work best to deliver the training in terms of effectiveness and efficiency. It was also used to determine hospital visits by NE-EHDI staff.
Program Objective 7.2.	Q1 [✓ Q2] Q3 Q4 Q5	Educational opportunities will be

Professional development resources will be inventoried annually.	Q6 Q7 Q8 Q9 Q10 Q11 Q12	included and updated on the NE-EHDI web site which should be live in 2014. In addition. NE-EHDI Program staff, Advisory Committee members, and parents have taken advantage of training webinars, online courses, conferences, and workshops.
Program Objective 7.3. Professional development opportunities will be promoted to the hearing professionals.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Health professionals will be surveyed for professional development needs and various ways of providing training will be researched. Opportunities will also be posted on the NE-EHDI Program web site.
Program Objective 7.4. The effectiveness of professional development activities will be evaluated.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Surveys will be developed and the effectiveness of development activities will be analyzed.

Nebraska Early Hearing Detection and Intervention Program: Project Abstract

Project Title: Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program

Applicant Organization Name: Nebraska Department of Health and Human Services, Division of Public Health, Community and Environmental Health Services, Lifespan Health Services Unit, Newborn Screening and Genetics Program, Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program.

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Grant Program Funds Requested in Application: HRSA, [redacted]

Brief Description: The Nebraska Early Hearing Detection and Intervention Program will reduce the loss to follow-up/lost to documentation by 5% a year in the years 2014 through 2017. This will be accomplished using quality improvements methodology that will include the creation of Task Force to assist in quality improvement. Based on this application, the Trask Force will create an aim statement, review the change strategies, implement Plan-Do-Study-Act (PDSA) cycles to decide what changes lead to improvement, and then spread the successful changes throughout the system.

Project Narrative

INTRODUCTION

NOTE: Acronyms used in this grant proposal can be found as Attachment 8.

The Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program will build upon the accomplishments, relationships, and resources of the Early Hearing Detection and Intervention (EHDI) system that has been developed in Nebraska since 2000. The Infant Hearing Act of 2000 (Neb. Rev. Stat. §71-4735) specifies four purposes for the EHDI system in Nebraska:

- To provide early hearing detection of hearing loss in newborns at the birthing facility, or as soon after birth for those children born outside of a birthing facility.
- To enable these children and their families and other caregivers to obtain needed multidisciplinary evaluation, treatment, and intervention services at the earliest opportunity.
- To prevent or mitigate the developmental delays and academic failures associated with late detection of hearing loss; and
- To provide the state with information necessary to effectively plan, establish, and evaluate a comprehensive system for the identification of newborns and infants who have a hearing loss.

Nebraska has consistently met or exceeded the two benchmarks established by Nebraska's Infant Hearing Act of 2000. One hundred percent of the birthing facilities provide newborn hearing screening and over 95 percent of newborns have their hearing screened during birth admission. All of the birthing facilities, regardless of size, have been conducting newborn hearing screening since 2003 and the hearing of nearly 99% of newborns has been screened during birth admission since 2005.

The NE-EHDI Program has been developed based on recommendations of the NE-EHDI Program Advisory Committee and the requirement identified in the Infant Hearing Act (Neb. Rev. Stat. §71-4735 and §71-4744) to "…determine and implement the most appropriate system…to track newborns and infants identified with a hearing loss" and "…to effectively plan and establish a comprehensive system of developmentally appropriate services for newborns and infants who have a potential hearing loss or who have been found to have a hearing loss and shall reduce the likelihood of associated disabling conditions." (Neb. Rev. Stat. §71-4737). Required activities of the NE-EHDI Program include the following:

1. Develop, implement, and monitor statewide systems to track newborns with or at-risk of hearing loss (Neb. Rev. Stat. §71-4737) and adopt and promulgate rules and regulations to implement the Infant Hearing Act (Neb. Rev. Stat. §71-4742 and §71-4744).
2. Gather required data and generate annual reports (Neb. Rev. Stat. §71-4739 and §71-4741).
3. Establish guidelines for referral to early intervention services (Neb. Rev. Stat. §71-4743).

4. Educate parents with out-of-hospital births about newborn hearing screening (Neb. Rev. Stat. §71-4742 and §71-4740).
5. Apply for all federal funding to implement the Infant Hearing Act (Neb. Rev. Stat. §71-4742 and §71-4740).

Newborn hearing screening, however, is only the first (though crucial) step in the Early Hearing Detection and Intervention (EHDI) process. This fact is reflected in the mission statement of the Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program, which states: *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*.

To ensure newborns and infants identified with a hearing loss, and their families, receive appropriate and timely high quality services, the NE-EHDI Program has developed eight system goals. These goals focus on newborn hearing screening, diagnostic evaluations, early intervention, medical home, family support, periodic screenings, professional development, and quality improvement.

To reach these goals, the NE-EHDI Program will continue implementing the following strategies:

- Increase the awareness of parents and professionals about the importance of newborn hearing screening and early intervention.
- Provide additional parent resource materials that are linguistically, culturally, and educationally appropriate.
- Increase capacity of newborn hearing screening staff in birthing facilities to more effectively screen hearing and work with parents.
- The NE-EHDI Program will continue to provide and expand educational opportunities and information and provide understanding by professionals and the public to provide information and understanding about the NE-EHDI Program
- Increase knowledge of Early Development Network (EDN/Part C Early Intervention) services coordinators regarding infant hearing loss, family support, and communication options through partnerships with the Regional Programs for Students Who Are Deaf or Hard of Hearing.
- Provide immediate access to high-quality amplification, when desired, by the parents/guardians.
- Nurture and expand the opportunities to establish medical homes, family-to-family supports, and periodic early childhood hearing screening in a variety of health, early care, and education settings.
- Strengthen existing and develop new collaborative approaches to link the providers of EHDI services and supports and to stress the importance of collaboration to reduce lost to follow/lost to documentation (LTF/LTD).

Nebraska participated in the first National Institute for Children's Healthcare Quality (NICHQ) Learning Collaborative in 2006 to reduce the number of babies "Lost to Follow-Up/Lost to Documentation" at all points of the NE-EHDI Program services and transitions. The participation provided the NE-EHDI Program with experience with NICHQ's Model of Improvement and the Plan-Do-Study-Act (PDSA) cycle, in which small tests of change are tested, modified and, if successful, implemented and spread throughout the NE-EHDI system.

Examples of successful small tests of change from participation in the initial NICHQ Learning Collaborative that have spread throughout the NE-EHDI Program system include the following:

- The reduction of reading level of parent letters from an 11.0 grade level to a 7.3 reading grade level.
- Revision of the NICHQ *Parent Roadmap* to guide parents and professionals through the diagnostic and intervention pathways and the resources available at the state and national level.
- Development of a comprehensive Parent Resource Guide portfolio for parents with children who have recently been identified with a hearing loss.
- Development of a "fax-back" or e-fax system with Primary Health Care Providers (PHCP) for notification when a child's status changes in the NE-EHDI Program tracking system.
- Development of a one-page reporting form that parallels the specifications for the audiologic diagnostic evaluation (HAUDIO) module of the Nebraska Electronic Registration System (ERS-II).

Beginning in 2004, the NE-EHDI Program began the development of an electronic data reporting and tracking system. In 2007, the NE-EHDI Program reporting and tracking system was rolled out as an integrated module of the State's Vital Records Electronic Registration System (ERS-II) developed by Netsmart Technologies.

The data system now includes hearing information on all the babies born in Nebraska since 2007 and is designed so that most of the data is generated from the birth certificate registry system with limited data entry by hospital personnel for hearing screening results or non-screening details. With the integrated electronic hearing screening data reporting system more accurate, timely, and comprehensive hearing screening data is available for babies born in 2007 – 2013.

This integrated hearing component of the ERS-II data system consists of four types of records: Hearing Information (HINFO) records, Hearing Screening (HSCREENING) records, Hearing Contact (HCONTACT) and Hearing Audiologic Diagnostic (HAUDIO) records. Below is a brief description of those records:

1. The Hearing Information (HINFO) record is the basic record for each occurrent birth and is populated from the birth certificate with identifying data of the newborn, mother and father. Hearing screening event data for all newborns who pass the birth admission hearing screening is entered into two fields of the HINFO record by authorized birth facility personnel.
2. The second type of record is the HSCREENING record in which screening event data is entered by authorized hospital personnel for newborns who did not pass the

birth screening admission, including transfers to a Neonatal Intensive Care Unit (NICU). Additional parent and disposition data, including Primary Health Care Provider (PHCP) name, preferred parent language, and parent phone number(s) are entered to facilitate follow-up activities. Outpatient hearing screening results, including both pass and “refer,” are also entered into HSCREENING records.

3. The HAUDIO record is available to record the data about every audiologic evaluation, including procedures, diagnostic results, recommendations, and disposition.
4. Additionally, selected information from the HSCREEENING and HAUDIO records are automatically transferred to the summary sections of the HINFO record in the event of a child 1) not passing the inpatient hearing screening, 2) not receiving an inpatient screening or 3) receiving an outpatient screening or diagnostic evaluation. The most recent section added to the HINFO record supports the recordings of risk factors of later-onset or progressive hearing loss that are listed in the *Joint Committee on Infant Hearing (JCIH) 2007 Position Statement*.
5. The HCONTACT record is available only to the NE-EHDI staff to log all correspondence for each HINFO record where there is any follow-up. This record is linked to the HINFO record and logs all outgoing and incoming correspondence (phone calls, faxes, letters, emails, etc.).
6. The data system includes basic search functions for the HINFO, HSCREENING, and HAUDIO records. Four work queues in which pending records are placed for easy access for hospital personnel to enter data. The four work queues include the following: one for newborns in the well-baby nursery, one for NICU babies and two for outpatient results.
7. The maternal demographics of education level, race/ethnicity, age, and payment source for each occurrent birth are available to the NE-EHDI Program through the integrated Vital Records system which includes birth defects and newborn hearing screening modules.

Each week, an exception report is generated to identify HINFO records without data entry to report results or report a reason for non-screening event (discharge without a screening, transfer to NICU, child expiring, etc.) of newborns that are more than 21 days old. The hospital-specific reports are faxed to birth facilities responsible for reporting the results, followed by a phone call from the Business Analyst to provide technical assistance in completion of the overdue record. This weekly exception report typically indicates about 35 overdue records out of approximately 500 per week.

The NE-EHDI Program Business Analyst developed an Access® database in-house that imports data from the ERS-II data system, generates and tracks the necessary letter/reporting form correspondence and supports developing a more powerful set of tracking reports, all at a considerable savings. This system allows more flexibility than ERS-II by supporting the easy modification of letters and reports and making changes to meet the needs of other stakeholders such as audiologists, Head Start/Early Head Start (HS/EHS) programs and primary health care practices.

The number of birthing facilities conducting newborn hearing screening has increased rapidly since 2000 when only 11 hospitals were conducting either targeted or universal newborn hearing screening. Since 2003, 100% of the birthing facilities in Nebraska have been conducting hearing screenings. In 2013, 56 of the 57 birthing facilities conducted the hearing screenings prior to discharge and one conducted the-screenings on an outpatient basis following discharge. Twenty-nine of the birthing facilities conduct otoacoustic emissions (OAE) screenings, 23 conduct auditory brainstem response (ABR) screening, and the remaining five use a two-step method consisting of an initial OAE screening, followed by an ABR screening if the baby did not pass the initial screenings. More than 80% of Nebraska newborns receive an ABR inpatient screening in Nebraska hospitals. All babies in the NICU receive ABR screenings prior to discharge in accordance with JCIH guidelines.

"Refer" rates vary, depending on the type of screening, with an overall average of 3.8% since December 2008. Since the fourth quarter of 2007, the NE-EHDI Program has regularly sent quality assurance reports to each of the birthing hospitals, at least semi-annually, to provide the individual hospital with its "refer" rate, "lost to follow-up/lost to documentation" rate and other statistics for their hospital, as well as providing the state comparison percentages for all hospitals with the same screening technique (Attachment 9). This process was established through small tests of change in 2009.

The cover email letter includes the following, based on the Joint Commission on Infant Hearing (JCIH) 1-3-6 EHDI guidelines:

- For rescreening, a complete screening on both ears is recommended, even if only one ear failed the initial screening.
- Inpatient well-infant screening protocols recommend one hearing screening and, when necessary, a repeat screening no later than at the time of discharge from the hospital, using the same technology both times.
- All infants should have access to hearing screening using a physiologic measure at no later than **one month** of age.
- All infants who do not pass the initial hearing screening and the subsequent rescreening should have appropriate audiological and medical evaluations to confirm the presence of hearing loss at no later than **three months** of age.
- All infants with confirmed permanent hearing loss should receive early intervention services as soon as possible after diagnosis but at no later than **six months** of age.

Each hospital can also check their own hospital statistics by using the batch reports available on ERS-II data reporting system, simply by entering a date range. During 2012, there were 14 birthing facilities with high "refer" rates (greater than 10% for OAE screenings and greater than 5% for ABR or two-step screenings) and of those, seven were small hospitals with less than 100 births.

This case status usually is the result of 1) unreported outpatient results, 2) the parent(s) not keeping an outpatient screening appointment, or 3) not completing an audiologic evaluation. LTF/LTD is a category that was first developed with the NE-EHDI Program

Advisory Committee in 2005. When the tracking and follow-up protocol of three letters to the PHCP and two letters to the mother (over a two-month period) has yielded no follow-up activity or results, the record status is changed to LTF/LTD.

Table 1 below shows the NE-EHDI Program LFU/LTD numbers and percentages based upon data submitted on the CDC annual survey. The LFU/LTD numbers and percentages are only for those children born in Nebraska who 1) did not pass the last inpatient screening and did not have an outpatient screening or 2) did not pass the most recent outpatient screening. It does not include children who did not have a hearing screening (e.g. homebirths without any screening, missed inpatient screening) which is tracked by the NE-EHDI Program. At this time, it appears that the numbers for 2013 will be about the same as 2012 which will be less than 30% for LFU/LTD.

2009 – 2011 Lost to Follow-up/Lost to Documentation

Year	Total Screened	Total Not Passed	Percent Not Passed	# LFU/LTD*	Percent LFU/LTD*
2009	27,013	327	1.2%	109	33.3%
2010	26,039	263	1.0%	108	41.1%
2011	25,915	175	0.7%	36	20.0%

Table 1

*Parents/Family Contacted but Unresponsive + Unable to Contact + Unknown

Various services are available for children identified with a permanent hearing loss. The Early Development Network (EDN), the Part C Early Intervention Program in Nebraska, is one of the main services. For those infants who were born and reside in Nebraska in 2012, 38 were diagnosed with a permanent hearing loss and were referred to the Nebraska Early Development Network. Another service for Nebraska families is the Medically Handicapped Children's (Children with Special Health Care Needs) Program. This program, under the Nebraska Department of Health and Human Services, offers coordination/case management, access to specialty physicians, and payment of treatment services.

There is also a family support network available to families of young children identified with a hearing loss. The four Regional Programs for Students Who Are Deaf or Hard of Hearing (RPSDHH) have provided professional-driven family support activities since 1997. The Parent Training and Information-Nebraska (PTI-NE) Program provides family support services for children with disabilities but not specifically hearing loss. Likewise, the Nebraska Family Voices provides family-to-family support services for children with all disabilities, but not specifically focused on hearing loss.

Beginning in 2006, with financial assistance from the NE-EHDI Program, a chapter of Hands and Voices began to be organized. The Nebraska Chapter was officially formed in 2007 and became a 501(c)(3) not-for-profit organization in 2010. In 2013, the Chapter received approval from the National Guide By Your Side (GBYS) Program to establish a Nebraska GBYS Program. A part-time coordinator has been hired and parent guides recruited and trained. The NE-EHDI Program was a participant in writing the application and the request for Part C funds to support the program. The NE-EHDI Program and GBYS have created a parent release form that permits the NE-EHDI Program to release parent contact information to GBYS.

Another expansion of family support services has been the development and implementation of the Roots and Wings parent weekend through a contract with Boys Town National Research Hospital (BTNRH). The workshops provide education and networking opportunities for parents with newly identified or young children with hearing loss. There have been six parent weekends since the initial one in the spring of 2009. The NE-EHDI Program will continue to provide staff and some financial support for child care, presenters, and room costs.

The NE-EHDI Program Advisory Committee is currently comprised of 18 stakeholders representing many disciplines and perspectives. It has been active in providing leadership for implementing the Nebraska Infant Hearing Act of 2000 and the expansion and development of the NE-EHDI Program. Members also provide direction to the program and in setting goals and objectives. In 2011, the Advisory Committee passed a Charter which includes the mission statement, term obligations, representation, and an elected Chair and Vice-Chair.

NEEDS ASSESSMENT

Any description of the health systems in Nebraska must first begin with an overview of the State's geography. Nebraska is a relatively large state with a sparse population. According to the Census Bureau, the 2012 population was estimated at 1,855,525. Nebraska covers 76,872 square miles. The relatively small population and large geographic area results in an average population density of 23.8 persons per square mile. Over half the population lives in the three largest counties, Douglas, which includes Omaha, the state's largest city; Lancaster, which includes the capital city of Lincoln and second largest city; and Sarpy County which is part of the Omaha Metropolitan area. Douglas County alone has more than a quarter of the state's population. The three counties are located in the eastern part of the state with Lincoln and Omaha approximately 50 miles apart.

This combination of vast spaces and uneven concentration of population impacts many aspects of the service delivery systems such as availability of providers, transportation to services, economic viability of sustaining services in remote communities, and competition between urban and rural interests. For instance, of Nebraska's 93 counties, all or part of 45 are considered Primary Care Health Professional Shortage Areas and all or part of 71 are designated as Medically Underserved or Medically Under Served Populations. In 2010, 60 of the 93 counties experienced a shortage of family practice physicians and 77 had a shortage of general pediatricians and eight counties had a partial shortage.

Audiologists and medical specialists tend to be disproportionately clustered in the two major metropolitan areas in eastern Nebraska, resulting in decreased availability for diagnostic evaluations and treatment for hearing loss. Over two-thirds of the audiologists and pediatric health care providers (physicians, physician's assistants, nurse practitioners, and otolaryngologists) practice within these two metropolitan areas.

Nebraska has also seen important shifts and trends in its population, particularly a growing proportion of racial/ethnic minorities. In 2009, the minority population was 16.5% of the total, up from 12.7% in 2007 and 7.4% in 1990. Still, 2012 census data shows 89.9% white, 2.8% Black or African American alone, 2.0% Asian alone, 0.1% Native Hawaiian and Other Pacific Islander alone. Two or more races are 1.9% and Hispanic or Latino, 9.7%.

In 2011, there were 26,096 babies born in Nebraska and in 2012, there were 26,283. The maternal demographics of education level, race/ethnicity, age, and payment source for each occurrent birth are available to the NE-EHDI Program through the integrated Vital Records system. The primary language is also collected for those babies who do not pass or did not receive a hearing screening during birth admission. In Table 2 below, the LTF/LTD counts and percentages are displayed by maternal education level for babies born in 2012.

2012 Date of Birth Data – LTF/LTD by Maternal Education Level

Maternal Education Level	Inpatient Refers	Percent of Inpatient Refers	LTF/LTD Status	Percentage of Inpatient Refers LTF/LTD
Less than High School	155	18.5%	8	25.0%
High School or GED	201	24.0%	10	31.3%
Some College or AA/AS	271	32.4%	12	37.5%
College Grad or Above	209	25.0%	2	6.3%
Unknown	1	0.1%	0	0.0%
TOTAL	837	100%	32	100%

Table 2

Table 2 above reveals that mothers without any post high school education have a disproportionate percentage in the "percentage of inpatient refers LTF/LTD" compared to "percent of inpatient refers" (56.3% "LTF/LTD" versus 42.5% of the "refers").

Table 3 shows LTF/LTD counts and percentages within maternal race groups for babies born in 2012.

2012 Date of Birth Data – LTF/LTD by Maternal Race

Maternal Race	Inpatient Refers	Percent of Inpatient Refers	LTF/LTD Status	Percentage of Inpatient Refers LTF/LTD
White	613	73.2%	23	71.9%

Black	46	5.5%	3	9.4%
Asian	10	1.2%	0	0.0%
American Indian & Alaska Natives	18	2.2%	3	9.4%
Pacific Islands	0	0.0%	0	0.0%
Other (Hispanic)	142	17.0%	3	9.4%
Other (Non-Hispanic)	8	1.0%	0	0%
Unknown	0	0.0%	0	0.0%
TOTAL	837	100%	32	100%

Table 3

As can be seen in the two tables, the highest percentages in LTF/LTD are babies of mother's with a high school/GED or less education. Because Nebraska has so few minorities (Table 3), it is not surprising that the highest number and percentage in LTF/LTD is for those whose maternal race is White.

The NE-EHDI Program's LTF/LTD numbers are the highest for home births. In Nebraska midwives are prohibited, by law, from attending home births. The NE-EHDI Program will continue to work at reducing the number of home births that do not receive a hearing screening with guidance and assistance from the NE-EHDI Program Advisory Committee and American Academy of Pediatrics (AAP) Chapter Champion. This will be considered as a possible PDSA in the future.

Beginning in early 2008, all of the audiologists licensed by the State of Nebraska were surveyed to determine the equipment available for screening and diagnostic evaluations. Nebraska has 80 audiologists at 37 sites who self-identified as providers of pediatric audiologic diagnostic services in 2012. The newest listing is included in the NE-EHDI Program Parent Resource Guide, along with revised protocols. Although this approach does not clearly identify the audiologist proficient in providing audiologist services to very young children, it begins to assist the primary consumers, parents and PHCPs, with information necessary to make an informed decision. This information and more will be available through EHDI-PALS (www.ehdipals.org) which is a web-based, interactive resource for finding audiology facilities, parent resources, professional resources, and helpful web sites. The NE-EHDI Program Coordinator is a member of the Advisory Group which also includes the Health Resources and Services Administration (HRSA), American Academy of Audiology (AAA), America-Speech-Language-Hearing Association (ASHA), Centers for Disease Control (CDC), Hands and Voices, National Center for Hearing Assessment and Management (NCHAM), and pediatric audiologists.

In the most recent reports, five audiology facilities conducted 85% of the outpatient screenings and 86% of diagnostic evaluations. Boys Town National Research Hospital in Omaha conducts the majority of initial or confirmatory diagnostic evaluations in the state.

In addition to having birthing facilities conducting newborn hearing screenings and audiologists capable of conducting comprehensive audiologic diagnostic evaluations, knowledgeable PHCPs are important to ensure that the EHDI system works effectively and efficiently to minimize the number of babies who are categorized as LTF/LTD. In 2005 and 2012, the NE-EHDI Program mailed the *Newborn and Infant Hearing Screening Survey*, developed by Boys Town National Research Hospital and the National Center for Hearing Assessment and Management (NCHAM), to all pediatricians and family practice physicians in the state. Responses were received from 149 physicians in 2005 and 107 in 2012.

The 2005 data shows that 44% of the physicians selected three months or younger as the earliest age a child could begin wearing hearing aids compared to 38% in 2012. The 2005 data shows that 68% selected three months or younger as the age at which a child with a permanent hearing loss should be referred to early intervention services compared to the 2012 data which shows that 55% selected three months or younger.. Although the results indicate that respondents have a good understanding of the need to get additional testing, the lack of knowledge and understanding of when a child can begin wearing hearing aids and can be referred to early intervention indicates an opportunity for professional development.

All birthing facilities are conducting newborn hearing screenings and the rate of follow-up re-screenings is good. However, Nebraska’s geography and population distribution impacts the availability and accessibility of specialty medical and audiologist services for infants who need diagnostic evaluations. All components of the NE-EHDI system are critical for effective referral, tracking, and reporting processes to reduce the number of babies who are LTF/LTD or diagnosed later or receive intervention services later.

These components include parent education, newborn hearing screening during birth admission, low refer rates, follow-up re-screening and audiologic diagnostic evaluations, medical home, specialty evaluations, early intervention services and family-to-family support and the linkages between each component.

METHODOLOGY

The NE-EHDI Program Logic Model (Attachment 6) depicts the relationship of the resources available, the activities that will be accomplished, the quantification of those activities, and the anticipated short, intermediate, and long-term outcomes. The primary NE-EHDI Program methodologies, as shown in the logic model, are Reporting, Tracking, and Follow-up; Education and Technical Assistance; and Evaluation and Quality Improvement.

The current NE-EHDI system will be expanded to better link birth admission hearing screenings, audiologic evaluations, medical evaluations and treatment, early intervention services, and family-to-family support services. Professional development activities will be more intentional, based on training needs assessments and incorporating available resources. Evaluation processes will incorporate revised and expanded reporting processes and quality improvement efforts will focus on using Plan-

Do-Study-Act (PDSA) cycles to try new ideas utilizing small tests of change, reflecting on the immediate results, revising as necessary, and continuing to refine and expand the changes.

Eight system goals/aims to implement the statutory requirements of the Infant Hearing Act were reviewed and refined by a cross-section of stakeholders, include the NE-EHDI Program Advisory Committee.

The eight system goals/aims are as follows:
System Goal/Aim 1: The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of-hospital, by one month of age.

System Goal/Aim 2: All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation prior to three months of age.

System Goal/Aim 3: All infants with a confirmed permanent hearing loss will have immediate access to high quality technology and will begin receiving early intervention services prior to six months of age.

System Goal/Aim 4: All infants with a confirmed hearing loss will have access to a medical home.

System Goal/Aim 5: Families of young children with a confirmed hearing loss will have access to a family support system.

System Goal/Aim 6: Young children in Nebraska will have access to periodic hearing screening.

System Goal/Aim 7: Professionals working to identify hearing loss in young children will increase their capacity to provide appropriate services.

System Goal/Aim 8: The NE-EHDI system will reduce the lost to follow-up rate at each step of the EHDI 1-3-6 process through quality improvement efforts.

Note about the format for the System Goals/Aims 1 – 8 of the Methodology Section: For each NE-EHDI Program System Goal/Aim, a general explanation of the activities that occur to meet that goal is provided. The current, on-going NE-EHDI Program activities are described for each of three methodologies (Reporting, Tracking and Follow-up; Education and Technical Assistance; and Evaluation and Quality Improvement), followed by any additional Improvement Activities specifically planned to continue reducing the "lost to follow-up" rate in 2014 – 2017. The Improvement Activities to Reduce "Lost to Follow-Up" listed for each goal/aim are ones that have been fully implemented as a result of PDSAs and Improvement efforts over the last seven years since the NE-EHDI Program participated in the first NICHQ Learning Collaborative.

<u>System Goal/Aim 1:</u> The hearing of all newborns born in Nebraska will be screened during birth admission or, if born out-of-hospital, by one month of age.

<u>EHDI System Activities:</u> Birthing facilities in Nebraska have four primary statutorily-required activities related to screening the hearing of newborns:

1. The parent(s) of newborns are educated about the hearing screening, the likelihood of hearing loss in newborns, the importance of follow-up, community resources (including early intervention services), and normal auditory, speech and language development (Neb. Rev. Stat. §71-4740).
2. A hearing screening is part of each birthing facility’s standard of care for newborns, effective 12/1/2002 (Neb. Rev. Stat. §71-4742). Following hospital protocols for the procedure, each newborn’s hearing in each ear is screened during birth admission using OAE and/or ABR screening techniques. A second screening is conducted within one to three weeks if the baby “refers” on the first screening.
3. The outpatient re-screening for those that “refer” during birth admission may occur at birthing facility or at a confirmatory testing facility.
4. A mechanism for compliance review is established for each birthing facility (Neb. Rev. Stat. §71-4742).

<u>Goal/Aim 1 - NE-EHDI Program Reporting, Tracking, and Follow-up:</u> Since January 1, 2007, the hearing screening results of all occurent births have been reported to the NE-EHDI Program using the electronic reporting system (ERS-II), ERS-II is an integrated module of the State of Nebraska’s Vital Records Birth Certificate Registry system. A hearing record (HINFO) is automatically created from the birth certificate by the ERS-II system and populated with baby, mother, and father information, contact information, and demographics (maternal age, race/ethnicity, payment status, maternal marital status, maternal education level). The birth clerk or hearing information clerk at each hospital enters the baby’s birth admission hearing screening results (pass, “refer”, did not screen) or, if not screened, the reason is selected. Additional information is entered for babies who did not pass (“refer”) or were discharged prior to screening: mother’s preferred language, telephone number, Primary Health Care Provider (PHCP) name, notification of the results to PHCP, and follow-up plans to re-screen at the birth facility or to refer to an audiology clinic. Birthing facilities are encouraged to report the hearing screening results within 14 days after birth

When newborns are transferred to another hospital in the state for a higher level of care, hearing screening results are entered by the NE-EHDI Program staff since the ERS-II system does not currently support the access of HINFO records by personnel at the receiving hospital. A one-page reporting form is faxed monthly to each receiving hospital for all babies who have been transferred to that particular facility. For babies who have been transferred to a hospital in another state, the tracking is completed manually by NE-EHDI Program staff since out-of-state staff do not have access Nebraska’s ERS-II Vital Records system.

The NE-EHDI Program now sends a letter to the parents at the same time as the first letter to the PHCP when notification of a failed inpatient hearing screening is received.

This was implemented because the PHCP listed on the child's discharge summary may not be the one the child would actually be seeing for follow-up care. In addition, receiving the notification would serve to remind parents to make an appointment or go to the follow-up appointment if it was already scheduled. This letter is followed by a second parent letter six weeks after the first letter is sent, and is the 'final request' for follow-up action on the failed screening. This raises the issue of better identification of the PHCP. Consideration will be given to using this as a PDSA.

Nebraska has approximately 100 out-of-hospital births reported to the NE-EHDI Program each year. The NE-EHDI Program is required by Neb. Rev. Stat. §71-4740 to educate the parents of babies who are not born in a birth facility about hearing loss, hearing screening, normal speech and hearing development, and resources available. Notification of out-of-hospital births occurs either when the birth certificate is filed in the ERS-II system or when notified by the metabolic/blood spot screening program that a blood spot has been collected, even if a birth certificate has not been filed. Consistent with the successful small tests of change with the basic parent letter, the literacy level of the letter to parents who have given birth to a baby out-of-hospital was reduced from the 12.2 reading grade level to an 8.5 grade level. The amount of materials included with the letter was reduced to those parents in an effort to specifically encourage the hearing screening. The NE-EHDI Program previously mailed a certified letter to the parent(s) of the baby but found that parents often did not pick up the certified letter. The Program now sends a letter through regular mail with a parent education brochure, a "Loss and Found" DVD, a list of screening facilities, a communication development wheel, and a reporting form. A second letter previously was sent if no results were received within one month. Now follow-up phone calls are made until a refusal to have a rescreening is received or the family agrees to obtain a hearing screening for their newborn.

Goal/Aim1 - NE-EHDI Program Education and Technical Assistance: Two basic parent education and follow-up brochures were developed in 2005 and revised in 2011. These brochures meet the requirements mandated by the Infant Hearing Act and are based on the *Universal Hearing Screening Toolkit* and suggestions from the NE-EHDI Program Advisory Committee. The brochures, written at an average health literacy level, have been translated and are available in English, Spanish, Vietnamese, Russian, Chinese (traditional), Arabic, French, and three Sudanese dialects (Dinka, Anuak, and Nuer) and are still in use. The parent education brochures and the English/Spanish videotape *Giving Your Baby a Sound Beginning* and the English/Spanish *Loss and Found* DVD are disseminated at no cost to birth facilities.

The recommended follow-up protocols for birth admission and outpatient hearing screenings with "refer" results and for audiologic evaluations indicating a permanent hearing loss are included in letters to the PHCP. The protocols have continued to be refined over the last few years to more clearly represent the current JCIH guidelines and to more accurately reflect changes in the EHDI follow-up system.

In October 2013, the NE-EHDI Program began an initiative to reach out to OB/GYNs to place educational brochures about the importance of newborn hearing screening in their waiting rooms and in the prenatal care packets given to parents before the baby is born. To date, two clinics have consented to having the brochures placed in their clinics.

Individualized technical assistance by telephone and email is provided to birthing facilities, as requested, to address equipment, screening technique, and quality issues. Problems with data entry are resolved by phone, email, or fax. On-site training is offered and provided for new birth facility personnel with responsibilities for newborn hearing screening and/or ERS-II reporting. Hospital visits and personal phone calls are also made with those birthing facilities that have high “refer” rates and/or have fallen behind in reporting results. Communication with hospitals has resulted in an improvement in refer rates and timeliness for reporting inpatient hearing screening results.

Goal/Aim 1 - NE-EHDI Program Evaluation and Quality Improvement: The Infant Hearing Act requires that each birthing facility have a system for compliance review and to report specific aggregate data to the NE-EHDI Program annually. The legislatively-related data, which is being cumulatively generated in birthing facilities and the NE-EHDI Program, is used to monitor the quality of the hearing screening programs and the NE-EHDI system.

A variety of administrative and ad hoc reports have been developed with ERS-II. To encourage timely reporting of newborn hearing screening results, an exception report is run weekly that identifies babies who are greater than 21 days of age (excluding those in NICUs) without screening results or without reasons for not having received a hearing screening in ERS-II. A small test of change conducted with the exception reports in which the age was extended from 21 to 28 days of age found that there was not a significant decrease in the numbers of overdue reports; therefore, the reports at 21 days of age are helpful in reminding the birth facility staff to complete the overdue reports and to support more timely follow-up. Since babies in the NICU are screened on a developmental basis, rather than by age, the status report for the NICUs is run monthly for those babies who are greater than 30 days of age.

Quarterly status reports, the NE-EHDI dashboard report, are compiled to monitor the follow-up progress of the newborns who referred, were discharged prior to screening, or were transferred. The reports include the numbers and percentages in the following status categories: closed, diagnosed, active follow-up, open (follow-up not started), LTF/LTD, expired and other (moved out of state, refused, medically fragile). The timeliness of the initiation of follow-up activities is also included in this report. Cumulative quarterly reports are generated for the Advisory Committee’s review. The status reports have been used for several years and are helpful in monitoring the number and percentages in comparison with the previous years to ensure that the initial follow-up activities are progressing as expected. For example, there was more than a 50% reduction in the number of babies classified as “lost to follow-up/lost to documentation” (LTF/LTD) between 2010 and 2011.

The reports derived from ERS-II provide a basic level of analysis of hearing screening outcomes for individual birthing facilities and the statewide hearing results statistics based upon data in ERS-II. Quality assurance reports, the birthing facilities' dashboard reports, have been developed that compare a birthing facility's "refer" rate with other birthing facilities using the same screening technique (OAE, ABR, two-step), and compares the rate of discharges prior to screening, including the specific reasons. Comparison numbers are provided in aggregate only. The NE-EHDI Program Advisory Committee endorsed providing this report to birthing facilities, including their CEOs, with analysis of the results.

The Infant Hearing Act requires that an annual report be prepared for Nebraska's Unicameral legislature by the NE-EHDI Program. It includes statistical results based on individually-identifiable data submitted by all birthing facilities. The annual report, developed in conjunction with the metabolic (dried blood spot) screening program, is disseminated to all state legislators, the Governor, and the NE-EHDI Program Advisory Committee. Copies are also sent to the Centers for Disease Control (CDC) and the Health Resources and Services Administration (HRSA) Federal Project Officers.

Goal/Aim 1 – Improvement Activities to Reduce LTF/LTD:

1. Each birthing facility will continue to have access to ERS-II reports to track performance and to identify areas for quality improvement that can be used internally within their own facility. In addition, the data system will continue to provide child-specific data and aggregate data in dashboard reports for the state.
2. Outreach calls will continue to be made by the NE-EHDI Program Community Health Educator to the parents with out-of-hospital births who have not completed the newborn hearing screening by one month of age to encourage completion of the hearing screening and assist with any barriers the family may be experiencing.
3. Analysis of two hearing screening outcomes (timeliness of initiation of follow-up activities and LTF/LTD) will continue to be studied with respect to the demographics available from the ERS-II HINFO (maternal age, race/ethnicity, language, educational level, marital status, and payment source) for development of strategies to reduce the number of babies who are LTF/LTD
4. Continue the basic parent education brochure which has been translated into other languages, based on the most common languages spoke by refugees with the state's refugee resettlement efforts and by the new residents in the state. The brochure has been modified to include photographs that better represent the ethnic and racial diversity of families in Nebraska. Population demographics will continue to be monitored for additional changes.
5. Evaluate hospital hearing screening statistics, including LTF/LTD, on a quarterly basis to determine the hospitals needing assistance by phone, email, or in person.
6. A web site for the NE-EHDI Program will soon be complete. It will be included as part of the Nebraska Department of Health and Human Services, *Newborn Screening in Nebraska* home page (www.dhhs.ne.gov/nehdi). The NE-EHDI Program web pages will include information for parents, birthing facilities, PHCPs, and audiologists; recommended screening and audiologic diagnostic evaluation procedures; links to reports, publications, resources, other appropriate web sites, and NE-EHDI Program contact information.

7. Continue to increase the number of OB/GYN offices and clinics, across the state, where educational brochures for parents are placed.

<u>System Goal/Aim 2:</u> All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation prior to three months of age.

<u>Goal/Aim 2 - EHDI System Activities:</u> The audiologic evaluation protocol that was developed and endorsed by the Advisory Committee in 2001 established that, in the interest of reducing costs, the first step in a follow-up hearing evaluation would be an outpatient re-screening using an OAE and/or ABR screening method. This would be done within the first six weeks of age rather than proceeding immediately to a comprehensive audiologic diagnostic evaluation. Some local community health systems have opted to have the outpatient rescreening completed at the birth facility in conjunction with the first well-baby check.

Newborns who have referred for one or both ears on the second hearing screening should receive a comprehensive audiologic diagnostic evaluation prior to reaching three months of age. The purpose of this evaluation is to confirm the presence of a hearing loss, to determine the type and degree of the hearing loss and to recommend medical evaluations and early intervention services.

In 2006, the Audiology Advisory Subcommittee was formed to review and revise the audiologic diagnostic and management protocols for infants up to six months old. The protocols were consistent with the America Speech-Language-Hearing Association (ASHA) revised guidelines for *Audiologic Assessment of Children Birth Through 5 year of Age.* The protocols are periodically reviewed to ensure they are consistent with newer guidelines such as the JCIH 2007 Position Statement. The comprehensive test battery includes:

- Case history
- Documentation of risk factors for hearing loss
- Otoscopic inspection
- Otoacoustic emissions (OAE) assessment
- Auditory brainstem response (ABR) assessment
- Middle ear measures

An otologic evaluation is also part of the assessment process but it may occur at a different facility and time.

Audiologists providing pediatric assessments should be able to conduct:

- ABR threshold to frequency-specified stimuli for air and bone conduction
- ABR suprathreshold to click stimuli with varied rate and polarity
- Tympanometry using the probe tones greater than 226 Hz
- Acoustic reflex threshold
- Transient-evoked (TEOAE) or distortion product (DPOAE)
- Behavioral audiometric test procedures that are developmentally appropriate

Successful infant audiologic assessment requires the audiologist to have skills and knowledge to fulfill the roles of diagnostician, counselor, and audiologic case coordinator. The audiologist should discuss the results with the family and report the audiologic results to the infant's health care provider and the NE-EHDI Program. Referrals and recommendations should be made consistent with the JCIH 2007 Position Statement.

The Subcommittee also assisted in developing a one-page reporting form that parallels the specifications for audiologic diagnostic evaluation (HAUDIO) module of ERS-II. Use of this form, which is now available as an electronic form, was one of the small tests of change with the NICHQ Learning Collaborative.

Goal/Aim 2 - NE-EHDI Program Reporting, Tracking, and Follow-up: The first step of the NE-EHDI Program tracking procedure is to send an e-fax to the PHCP for newborns who did not pass or were discharged prior to receiving a newborn hearing screening. The PHCP letter is generated within two days of data entry of the hearing screening report into the ERS-II Vital Records system. The letter reports the newborn hearing screening results and any recommendations made by the birthing facility and requests that the PHCP ensure that the recommended follow-up protocol is completed and submit the results to the NE-EHDI Program. A letter is also sent to the parent along with a brochure encouraging follow-up and to talk to their PHCP about hearing screening.

If the results of the outpatient follow-up, either a screening or audiologic diagnostic evaluation, have not been received within three weeks, a second request is sent to the PHCP. Three weeks later a third request is sent to the PHCP stating that follow-up has still not been reported to the NE-EHDI Program and a second and final request is sent to the parent at that same time. Contact methods include mail, email, phone, and e-fax.

When all follow-up requests have been exhausted (mail, telephone, contact with the PHCP, etc.) the case is marked LTF/LTD and a letter and the *Loss and Found* DVD is sent to the parents. The letter includes information on the impact of undetected hearing loss on a child's speech, language, and social-emotional development.

The hearing status of some babies is not clearly established with the follow-up outpatient hearing screening or at the first audiologic diagnostic evaluation. The status of “Follow-up in Progress” is assigned when additional testing is needed. This category is further divided into those with middle ear dysfunction and an accompanying transient conductive hearing loss and those without any involvement of the middle ear system. Tracking becomes more individualized and letters and phone calls by the Community Health Educator to the PHCP are specific to the nature of the planned and are, based on audiologic and medication recommendations. There are approximately 60 babies in the “Follow-up in Progress” category at any time.

Goal/Aim 2 - NE-EHDI Program Education and Technical Assistance: The NE-EHDI Program will continue to provide and expand educational opportunities and information and provide technical assistance. The purpose of these activities is to increase awareness and understanding by professionals and the public to provide information and understanding about the NE-EHDI Program. For example, NE-EHDI Program staff and Advisory Committee representatives presented updated program information, entitled *Nebraska Early Hearing Detection and Intervention Program – Making it Work,* at the Nebraska Speech-Language-Hearing Association (NSLHA) Annual Convention in September 2013. The NE-EHDI Program also had a booth at the 2013 Public Health Association of Nebraska in October 2013.

Goal/Aim 2 - NE-EHDI Program Evaluation and Quality Improvement: One activity that was initiated as part of the NICHQ Learning Collaborative was surveying parents of babies identified with permanent hearing loss, using the *Experience of Care Parent Survey*. The survey consisted of four questions: 1) Who delivered the results of newborn hearing screening? 2) Did the PHCP have the results at the first well-child visit? 3) How often were various professionals helpful in the process of screening to confirmation of hearing loss? 4) How often was information about the various topics provided by health professionals during the process from diagnosis to early intervention services? In addition, the survey encouraged other comments from parents to respond in-depth about their experience.

The return rate has been very low for the survey with only six out of 48 returned in 2012. As a result, the Community Outreach Coordinator will intensify efforts to cover the survey when contacting the parents via the phone. A future PDSA may be to ask one audiologist who spends time with the parent(s) reviewing the Parent Resource Guide to point out the survey to determine if more focus on the survey results in a better response rate. If so, other audiologists could be trained to provide the same type of attention to the items in the Parent Resource Guide.

Quarterly status (dashboard) reports for the Advisory Committee are compiled to monitor the follow-up progress of newborns who “referred” or discharged prior to screening. The reports include the numbers and percentages in the following categories: closed (child passed a hearing screening), diagnosed (child has a permanent hearing loss), active follow-up, open (hearing screening results have not been data entered for the children), LTF/LTD, and expired (died). The timeliness of the initiation of follow-up activities is also included in this report.

The Annual Report, required to be prepared for the Legislature, includes statistical results from individually-identifiable data. The Annual Report tracks 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 CDC-EHDI survey is completed and submitted annually along with other national surveys as requested. The Center for Disease Control (CDC) collects aggregate data from state EHDI programs once a year through the CDC EHDI *Hearing Screening and Follow-up Survey* (HSFS). The annual CDC survey is divided into three parts. Part 1 of the survey is for infant screening, diagnostic and early intervention data. Part 2 is for data on infant hearing loss type and severity. Part 3 is for data on maternal demographics. The data is analyzed and survey results are published for each state on the CDC website. One CDC summary report is for the "Loss to Follow-up/Loss to Documentation" (LFU/LTD) for each state. For 2011 births, the national average percent reported for "No Diagnosis: LTF/LTD" was 35.3% while Nebraska had 20.0% LTF/LTD.

Along with the physician survey described in the Needs Assessment section above, the NE-EHDI Program participated in an audiologist survey conducted by the Heartland Regional Genetics and Newborn Screening Collaborative in 2012. The Heartland is funded by a federal Health Resources and Services Administration (HRSA) grant and represents eight nearby states. The survey was intended to assist EHDI coordinators and the Heartland Collaborative staff to develop targeted educational resources in order to provide educational opportunities about the genetics of hearing loss to audiologists. The results of the survey are being analyzed and will be discussed at the NE-EHDI Program Advisory Committee meeting in March 2014.

Goal/Aim 2 – Improvement Activities to Reduce "Lost to Follow-up"

1. The Community Health Educator, along with a part-time (.50 FTE) Community Outreach Coordinator, hired in October 2011, will continue to be active in follow-up by phone to the PHCP and parents at the first sign of system failure, such as a PHCP being incorrectly identified or the parent not following through with recommended follow-up.
2. The NE-EHDI Program will continue to use a form which is faxed to the PHCP to obtain outpatient hearing results. In 2011, the NE-EDHI Program switched from paper faxes to electronic or e-faxing the forms. The PHCP can fax the form back when results are received from the hearing screening facility or audiologist.
3. The one-page audiologic reporting form that parallels the HAUDIO module for ERS-II will continue to be utilized. In addition to serving as a hard-copy reporting form to the NE-EHDI Program, its use as a fax-back form from the audiologist to the referring PHCP will be tested.
4. EHDI-PALS (www.EHDI-PALS.org) is a web-based, interactive search tool for parents, professionals, providers, and EHDI Coordinators. In Nebraska, this replaces a paper survey that was sent out periodically to audiologists across the state. EHDI-PALS includes such information for parents as questions to ask your audiologists, locations of audiology facilities, and general information about hearing and hearing loss. It allows audiology facilities to create a profile of their services and has a variety of reports and information useful for state EHDI Coordinators.
5. The HAUDIO module of ERS-II which permits audiologists to access and report results of screening, diagnostic evaluations, and recommendations became available after beta testing in 2010. This module was developed with funding from the CDC cooperative agreement. The largest pediatric audiology clinic in Nebraska enters results directly into ERS-II and this clinic will be encouraged to keep using this data reporting option which is now available to all audiology clinics in Nebraska.
6. Protocols have been developed and activities will continue with Iowa and other neighboring states to facilitate the sharing of newborn hearing screening information and coordination of follow-up efforts consistent with the state of residency.

7. Ad hoc reports will be utilized in the Nebraska electronic data system to gain a more in-depth understanding of the progress of babies from one component to the next in the EHDI system. Analysis of various maternal demographics will be continued for the LTF/LTD group as well as efforts to identify the birthing facilities and PHCP practices with high LTF/LTD rates.
8. Strategies have been developed to increase the reporting of individual audiologic diagnostic evaluation results in a timely and comprehensive manner. This is currently in beta testing with one clinic and, if successful, will be expanded to other clinics using the PDSA method.
9. Several birthing facilities and audiology clinics will be engaged in developing small tests of change to ensure that parents keep their child's audiology appointment. It will involve the hospital making an appointment for the outpatient rescreening prior to the baby's discharge from birth admission and providing a contact person at the audiology clinic. The information will be shared with the NE-EHDI Program.
10. Also in consideration is having the Community Outreach Coordinator make a reminder appointment phone calls to the parents and provide directions to the audiologist's office if needed.
11. The part-time Community Outreach Coordinator will continue to follow-up by phone to the PHCP and parents at the first sign of system failure. The intensified follow-up has resulted in a reduction in the LTF/LTD rate by identifying situations where follow-up has been completed but not reported to the NE-EHDI Program (LTD) and by identifying problems being experienced by the parents(s) for which a linkage with available resources may resolve the barriers. The LTF/LTD rate has decreased from 41.1% in 2010 to 20.0% in 2011.
12. See also Goal/Aim 1 Improvement Activities 4, 6.

System/Aim Goal 3: All infants with a confirmed hearing loss will have immediate access to high-quality technology and will begin receiving early intervention services prior to six months of age.

Goal/Aim 3 - NE-EHDI Program System Activities: In Nebraska, the primary early intervention activities include services coordination from the Early Development Network (EDN)/Part C Early Intervention Program, Regional Programs for Students are Deaf or Hard of Hearing (RPSDHH), family support and advocacy training from Parent Training and Information-Nebraska (PTI-NE), and specialized medical services through the Medically Handicapped Children's Program (MHCP)/Children with Special Health Care Needs (CSHCN). A Nebraska Chapter of Hands and Voices is also positioned to provide family-to-family support for parents at the time that their baby is identified with a permanent hearing loss. In 2013, a Nebraska Chapter of Guide By Your Side was established and a part-time coordinator has been hired and parent guides trained. In addition, there are education programs such as preschool services at the Boys Town National Research Hospital and the Early Head Start programs.

In 2012, over 90% of the babies identified with a permanent hearing loss and reported to the NE-EHDI Program received Part C services coordination through EDN. Over 83% began receiving services prior to six months of age. Outreach to audiologists and

PHCPs by EDN's Planning Regional Teams (Local Interagency Coordinating Councils) to educate primary referral sources about the importance of early intervention and the mechanism to refer for services has continued in the last several years. EDN contact information is included on the basic parent education and the "refer" brochure, as well as the *Loss and Found* DVD, that has been developed and is disseminated by the NE-EHDI Program. Letters to the PHCPs and the recommended follow-up protocol, presented in the PHCP algorithm, include information and encourage the EDN referral.

Early intervention partners have developed a process for parents of very young children recently identified with a hearing loss to have a recognized coordinated initial point of entry into the early intervention system. The organizational partners for the plan included the EDN/Part C, RPSDHH, PTI-NE, MHCP, Hands and Voices, and the NE-EHDI Program who identified EDN/Part C as the initial point of entry.

EDN/Part C helps families support and promote child development within family activities and community life. There are 28 Early Childhood Planning Region Teams, each an Interagency Coordinating Council made up of schools, health, human service agencies, Head Start, families, and others. Anyone can make a referral directly to EDN.

Nebraska has a statewide hearing aid loaner bank, a partnership between NE-EHDI and the audiology program at the University of Nebraska-Lincoln (UNL) dating back to 2007. To date, 143 children have received one or more hearing aids. Currently, there are 47 children being served and 81 hearing aids being used. Hearing aids are loaned for a period of three years, with extensions as needed. Inventory includes new and recently refurbished hearing aids. Children must be referred by an audiologist and parents complete an application for the hearing aids. In most cases the hearing aids are loaned and then returned to HearU Nebraska to be used again.

Goal/Aim 3 - NE-EHDI Program Reporting, Tracking, and Follow-up: When an infant is identified with permanent hearing loss and reported to the NE-EHDI Program, the parent(s) receive the Parent Resource Guide from the audiologist and a notification letter is sent to the PHCP. Materials in the Parent Resource Guide include information about communication options, questions to ask the audiologist and other professionals, and the Funding Toolkit that is updated annually by the RPSDHH. A guide to family support services (through a collaboration of a graduate student in deaf education and the Nebraska Hands and Voices) is also included. A "roadmap" of services and the sequencing of those services was developed during the NICHQ Learning Collaborative, based on a template provided to the participants.

Based on feedback received from the parents who serve on the NE-EHDI Family Support Work Group and Advisory Committee, the Parent Resource Guide has been revised to be more "user" friendly. The content was organized in a more logical manner and the sections broken down into "steps" to help parents understand what to do next. In addition, a *User Manual* was designed to be used along with the Parent Resource Guide, so parents know where to find certain topics that may be of interest to them.

Some families have commented that due to the emotions some parents feel at the time of identification they may be so overwhelmed that they won’t open the Resource Guide right away. A new brochure that addresses the emotional impact of the identification was written to be given to the parents at the time the Parent Resource Guide is provided.

On a regular basis the NE-EHDI Business Analyst accesses the Nebraska CONNECT data system to check EDN/Part C referrals and verifications for infants who have been reported as having a permanent hearing loss. EDN data which the referral date, verification date, individual family service plan (IFSP) date, primary disability category, services coordinator, case status (active or closed) as well as other details. The EDN information for each child is then recorded in the ERS-II hearing information database table. One challenge of the CONNECT system is that only the primary verified disability is listed. Children with hearing impairment who also have other disabilities may be categorized according to a disability other than hearing impairment. This precludes a search of the database that would yield a comprehensive listing of all children with a verified hearing impairment.

Goal/Aim 3 - NE-EHDI Program Education and Technical Assistance: The NE-EHDI Program Manager has updated an online graduate course *Medically Fragile Infants* for the Special Education and Communication Disorders (SPED) offered at the University of Nebraska-Lincoln. The topic provides information and data on the NE-EHDI Program and its collaborative initiatives and relationships. The PowerPoint presentation is delivered with audio through the University’s Blackboard software. This has been an on-going activity since 2008.

Goal/Aim 3 - NE-EHDI Program Evaluation and Quality Improvement: The NE-EHDI Program status (dashboard) reports include the number of infants referred to EDN and the number of verified children enrolled. As discussed above, only the primary disability is specified. For those infants with hearing loss that have not been reported to the NE-EHDI Program (lost-to-documentation), and for whom hearing loss is not listed as the primary disability, they cannot be identified through the CONNECT system.

The NE-EHDI Annual Report, required to be prepared for the Nebraska Unicameral, includes information about the numbers and percentages of infants with hearing loss enrolled in Early Intervention (EDN)/Part C. Early Intervention data is reported as part of the annual CDC-EHDI national survey, as well as surveys by other organizations.

Goal/Aim 3 - Improvement Activities to Reduce “Lost to Follow-up

1. Many audiologists have begun to provide the Parent Resource Guide to parents at the time of a child’s diagnosis of permanent hearing loss. All have expressed positive experiences and have requested more Parent Resource Guides. This activity will continue by engaging additional audiologists in providing the Parent Resource Guide at the time of diagnosis.
2. Full implementation of the HearU Nebraska Hearing Aid Loaner Bank has occurred. As part of the program, parents are encouraged to access EDN/Part C and the RPSDHH services. The application for loaner hearing aids also includes a release of

information to these programs and the NE-EHDI Program. Funding for HearU Nebraska will continue to be pursued through a variety of foundations and fund raising events such as Huskers for Hearing 5K Fun Run by the Student Academy of Audiology at the University of Nebraska-Lincoln (UNL).
3. The initial Point of Entry occurs through EDN/Part C. This approach required a high degree of partnership and collaboration at the state level initially. One hundred percent of the babies, who are identified with a hearing loss and residing in Nebraska, are referred to the EDN for Part C services. The NE-EHDI Program Business Analyst will continue to access the CONNECT data system to verify that each child diagnosed with a hearing loss is referred to EDN/Part C and verify that the EDN details are recorded in the ERS hearing information database table.
4. Continue to include the release form for parents in the Parent Resource Guide so that their contact information can be shared with Guide By Your Side.
5. Include *Experience of Care Parent Survey* in the Parent Resource Guide and also the survey will be administered by phone by the Community Outreach Coordinator.
6. See also Goal/Aim 1 Improvement Activity 6.

System Goal/Aim 4: All infants with a confirmed hearing loss will have access to a medical home.

Goal/Aim 4 - NE-EHDI Program System Activities: In 2001, the NE-EHDI Advisory Committee established that the newborn's PHCP would be the primary focus of the immediate follow-up efforts and would be based on established follow-up protocols for the Nebraska Newborn Screening (dried blood spot) Program. The correct PHCP has been reported by birthing hospitals and been contacted by the NE-EHDI program for over 95% of the newborns reported as needing follow-up.

When an infant has been identified as having a hearing loss, the American Academy of Pediatrics (AAP) recommends that the child is best served in the context of a medical home. The current follow-up protocol for the newborns who do not pass the initial screening was reviewed by the Advisory Committee in 2008 and they recommended continuing the current system of coordinating follow-up through the PHCP.

This has been successful, with hearing sensitivity (normal hearing, permanent hearing loss) established for 84.2% of the 2010 newborns that were reported to the NE-EHDI Program as needing follow-up from the birth admission hearing screening. The tracking and follow-up protocol for infants identified with middle-ear dysfunction follows a similar schedule but is adjusted according to the recommended medical management.

Correct identification of a newborn's PHCP is very important for the follow-up to occur. The ERS-II list of physicians, physicians assistants, and nurse practitioners is updated periodically by the Business Analyst so that hospital data entry clerks can select from a dropdown list to record the PHCP for a newborn who does not pass the inpatient hearing screening. Occasionally a PHCP is not in the dropdown on the ERS-II screen and the clerk will have to type in the name of the PHCP. In this scenario, the Business Analyst will add this name to the ERS-II PHCP list. The Nebraska Newborn Screening

Program (metabolic/genetics blood spot testing) will also provide the name of a new PHCP to the NE-EHDI programs.

Previously the follow-up protocol for babies who “refer” (or were discharged prior to screening) was to fax three requests to the PHCP and send two letters to the parent(s) at specific intervals. In 2013, the procedure was changed to include a first letter to the parent(s) at the same time as the initial letter is sent to the PHCP. This was changed because sometimes the PHCP name was incorrect. This way the mother is notified within a week of the time a refer result is reported to the NE-EHDI Program.

The NE-EHDI Program uses dried blood spots from newborn metabolic/dried blood spot screening to assist in determining etiology of congenital hearing loss. By regulation, the dried blood spot is stored for 90 days and destroyed within the next 30 days. The Advisory Committees of the Newborn Screening and Genetics Program and the NE-EHDI Program developed procedures for the PHCP to retrieve the dried blood spot with parent consent to be tested for congenital cytomegalovirus (CMV) for those babies identified with a permanent hearing loss within 90 days of birth.

Goal/Aim 4 - NE-EHDI Program Reporting, Tracking, and Follow-up: As stated previously, the first step of the NE-EHDI Program tracking procedures for newborns who did not pass or were discharged prior to receiving a newborn hearing screening consists of a letter to the parents and an e-fax to the PHCP identified in the birthing facility report. The letter to the PHCP reports the newborn hearing screening results and any recommendations made by the birthing facilities, requests that the PHCP ensure that the recommended follow-up protocol is completed, and that the results are submitted to the NE-EHDI Program. The current PHCP contact information is updated if it is known to have changed. If the results of the outpatient follow-up, either a screening or audiologic diagnostic evaluation, have not been received within three weeks, a second request is sent to the PHCP via e-fax.

Occasionally, the hearing sensitivity of some babies is not clearly established with the follow-up outpatient hearing screening or at the first audiologic diagnostic evaluation. The status of “Follow-up in Progress” is assigned when additional testing is needed. This category is further divided into those with middle ear dysfunction and an accompanying transient conductive hearing loss and those without any indicated involvement of the middle ear system. Tracking becomes more individualized and letters specific to the nature of the planned follow-up, based on the audiologic and medical recommendations, are sent to the PHCP.

Goal/Aim 4 - NE-EHDI Program Education and Technical Assistance: Knowledgeable PHCPs are important to ensure that the EHDI system works effectively and efficiently to ensure that the number of babies who are LTF/LTD is minimized. The summary of results from the Newborn and Infant Hearing Screening Survey in 2005 and 2012 were summarized on page 11. Although the results indicate that the respondents had a good understanding of the need to get additional testing, the lack of knowledge and understanding of when a child can begin wearing hearing aids and can be referred to early intervention services at the earliest possible age, indicates an opportunity for professional development. This data will be further analyzed and submitted for review and discussion at the March 2014 Advisory Committee meeting to determine possible professional development approaches.

The primary method of educating PHCPs about newborn hearing screening has been to clearly and succinctly present the information at the time it is needed for the recommended next step in the context of the follow-up protocol.

Goal 4 - NE-EHDI Program Evaluation and Quality Improvement: The follow-up completion rate of over 85% in 2012 indicates the PHCPs, as well as parents and the professionals at the birthing facilities and audiology sites, understand the need to complete the recommended follow-up in a timely manner.

Goal/Aim 4 – Improvement Activities to Reduce "Lost to Follow-up

1. The Community Health Educators and Community Outreach Coordinator will continue to follow-up by phone and e-fax to the PHCP and by mail to the parents at the time "refer" results are reported to the NE-EHDI Program. This more intensive follow-up effort has resulted in a reduction in the LTD/LTF rate by identifying situations where follow-up has been completed but not reported to the NE-EHDI Program. The Community Health Educator and Community Outreach Coordinator will follow-up by telephone to the PHCP and parents at the first sign of system failure, such as the PHCP being incorrectly identified, a missed hearing screening appointment or the parent not following through with the recommended follow-up.
2. The NE-EHDI Program will continue to use a form which is e-faxed to the PHCP to obtain outpatient hearing results. The PHCP can e-fax or fax the form back when results are received from the hearing screening facility or audiologist.
3. Continue using the one-page audiologic reporting form as an e-fax form for audiologists to provide results to the referring PHCP and the NE-EHDI Program.
4. Ad hoc reports will continue to be utilized from ERS-II to gain more in-depth understanding of the relationship of various maternal demographics to the timeliness of initiation of follow-up and to the "lost to follow-up/lost to documentation" and the communities, birthing facilities, and PHCP practices with high loss to follow-up rates.
5. Engage the NE-EHDI Program AAP Chapter Champion with efforts to reach out and educate PHCPs.
6. See also Goal/Aim 1 Improvement Activity 6, Goal/Aim 2 Improvement Activity 4.

System Goal/Aim 5: Families of young children with a confirmed hearing loss will have access to a family-to-family support system.

The Family Support Work Group of the NE-EHDI Advisory Committee meets as needed and includes representatives from the EDN/Part C, PTI-NE, RPSDHH, Nebraska Commission for the Deaf and Hard of Hearing, and parents. They provide guidance in developing the NE-EHDI Program family support system through reviewing and suggesting improvements to the work plans, materials, and support activities.
During the summer of 2007, a group of parents, primarily from the Omaha area, began an effort to establish a chapter of Hands and Voices with some financial support from the NE-EHDI Program. A statewide meeting was held to explain Hands and Voices and

to generate additional interest in organizing a chapter. The meeting originated at Boys Town National Research Hospital and was down-linked to three sites across the state. The NE-EHDI Program supported the effort by contracting with Janet DesGeorges of the national Hands and Voices to present and by arranging for the down-link sites. The chapter was organized in November 2010 but didn't receive official recognition as a 501(c)(3) non-profit until August 2013.

Work towards establishing a Guide By Your Side (GBYS) family-to-family support program for Nebraska was finally realized in 2013. The NE-EHDI Program assisted with the development of a state plan with broad stakeholder support, creation of a budget, and application for funding by EDN/Part C funds. The NE-EHDI Program will provide on-going financial support beginning in April 2014.

A part-time GBYS coordinator has been hired and the NE-EHDI Program was one of several agencies and organizations that participated in the Parent Guide training in August 2013. There are currently six trained Parent Guides, including one located in the rural, sparsely populated western part of Nebraska.

The NE-EHDI Program is focusing on strengthening support for families with young children identified with a hearing loss through financial and staff support of the Roots and Wings Parent Weekend workshop. This workshop is for parents of young children with hearing loss and operates through a contract with Boys Town National Research Hospital. The workshops provide education and networking opportunities for parents with young children with a hearing loss. There have been six parent weekends with one in the spring of 2009, two in 2010 (one in the spring and one in the fall), two in 2011 (spring and fall) and the most recent one in September 2012.

In September 2012, 18 newly identified families (36 parents/guardians and 39 children) attended the Roots and Wings Parent Weekend supported by the NE-EHDI Program and Boys Town National Research Hospital (BTNRH) and Hands and Voices. An additional six families (12 adults and 13 children) attended the workshops as host families to provide parent-to-parent support.

The NE-EHDI Program has also been collaborating with other agencies and organizations to provide half-day workshops across the state, a need identified by the Parent Support Work Group. Partners include the RPSDHH, PTI-NE, the Nebraska Commission for the Deaf and Hard of Hearing, Hands and Voices, and Boys Town National Research Hospital. Meals, child care, and interpreters are provided.

Goal/Aim 5 - NE-EHDI Program Reporting, Tracking, and Follow-up: The NE-EHDI Program has been working with the newly established Nebraska Chapter of GBYS to facilitate the referral of parents who may be interested in family support. The NE-EHDI Program worked with the Nebraska Department of Health and Human Services (DHHS) legal representatives and developed a parent release form that was acceptable to DHHS and GBYS and that is now included in the Parent Resource Guide. The initiative started in October 2013 and there has been one referral to GBYS. The NE-EHDI

Program will track the number of release forms signed and not signed and how many families become involved with the GBYS program. In conjunction with a possible PDSA with the *Experience of Care Parent Survey* in the Parent Resource Guide, this activity could also include a focus on the Guide By Your Side parent release form.

Goal/Aim 5 - NE-EHDI Program Education and Technical Assistance: A spring and a fall Roots and Wings parent weekend is planned for 2014; one in the eastern part of the state where most of the families reside and a smaller one, possibly just one day, is planned for the western part of the state. In addition to keynote, plenary, and roundtable sessions, the workshop includes lodging, child care, and social activities for the families.

Additional half-day workshops are scheduled for March 2014 in Ashland and Kearney. The Ashland and Kearney workshops will feature family consultant Stephanie Olson, a consultant to Colorado Children's Hospital, who draws on her experience as a hard-of-hearing woman. Her presentation, *Featuring the Nest,* give parents a glimpse of what other deaf and hard-of-hearing adults have said were the best things about their "nests" growing up. Her unique perspective helps families understand what tools they can use to create a safe haven for their children with a hearing loss.

Goal/Aim 5 - NE-EHDI Program Evaluation and Quality Improvement: The family-to-family support system is largely parent-driven with professional staff support. The NE-EHDI Program with oversight and input from the Family Support Group will evaluate the success and feedback from the family support workshops being held around the state and the assistance parents receive from the GBYS Program. They will also examine conducting a follow-up survey of the parents who participated in the Roots and Wings weekends to examine their experience in the event and if it had an impact on them after six months or more have passed since their participation in the weekend event.

Goal/Aim 5 – Improvement Activities to Reduce "Lost to Follow-Up"

1. The Family Support Work Group will continue development of resource materials, a joint parent workshop with Iowa, continued regional one-day or half-day workshops, and development of web-based support mechanisms. The NE-EHDI Program and the Iowa EHDI Program are in preliminary talks about holding a joint parent weekend or perhaps a one-day workshop. Nebraska and Iowa share a border and have two cities, Omaha, Nebraska and Council Bluffs, Iowa that are across the river from each other. Additionally, many Iowa families travel to Omaha to take advantage of the services at the Boys Town National Research Hospital (BTNRH), nationally recognized as a leader in the medical fields of audiology and cochlear implants.
2. Continue meeting support, such as cost of meeting rooms or down-link sites, for family-to-family support initiatives.
3. Continue to support the Nebraska GBYS program.
4. Track parent release forms in order to determine how many parent(s) permit their information to be shared with GBYS.
5. Continue to provide financial and staff support for the parent workshops across the state. The half-day workshops are a collaborative effort of the NE-EHDI Program,

Hands and Voices, RPSDHH, PTI-NE, GBYS, BTNRH, and the Commission for the Deaf and Hard of Hearing.

6. Continue to partner with BTNRH to organize Roots and Wings, for parents of young children up to age three years who have recently been identified with a hearing loss, especially those in the rural parts of state. The purpose of the weekend will be to continue to provide an opportunity for parents to connect with other parents, begin to fulfill the psychosocial needs, and using “toolkits” to understand the various aspects of hearing loss and its impact on their family.
7. Continue to include the *Experience of Care Parent Survey* in the Parent Resource Guides.

<u>System Goal/Aim 6:</u> Young children in Nebraska will have access to periodic hearing screening.

<u>Goal/Aim 6 - NE-EHDI Program System Activities:</u> Monitoring the later-onset or progressive hearing loss has not been part of the NE-EHDI Program protocol other than to continue to provide the risk factors identified by the JCIH 2007 Position Statement to PHCPs as part of the educational material when a baby does not pass the newborn hearing screening. The “risk factors” section of the HINFO record, in which risk factors for progressive/later-onset hearing loss can be recorded, was moved to production in April 2009. Although the birth defects registry and the hearing module are parts of the integrated Vital Records ERS-II system, birth defects information related to hearing loss cannot be transferred to the hearing module to be used for monitoring for hearing loss, based on the Nebraska Department of Health and Human Services legal department’s interpretation of the Nebraska birth defects statute. The NICU risk factor is routinely recorded by hospitals on the HINFO record in ERS-II.

The NE-EHDI Program was an early adopter of National Center for Hearing Assessment and Management’s (NCHAM) Early Childhood Hearing Outreach (ECHO) Initiative’s work with training Early Head Start programs to conduct OAE screenings. Six programs were trained, all of which have continued implementation of OAE screening.

In 2013, the NE-EHDI Program held discussions with the Community Action Program of Lancaster and Saunders Counties Early Head Start (CAP-EHS) Program that includes regarding sharing hearing screening results. The first set of hearing results was sent to the NE-EHDI Program through a web-based “drop box.” It is anticipated that hearing results from CAP-EHS will be copied into the Nebraska “drop box” website each quarter in 2014. Tentative discussions have also been held with the director of the Head Start/Early Head Start Program in the Hastings area. If successful, other Head Start/Early Head Start Programs will be engaged.

<u>Goal/Aim 6 - Improvement Activities to Reduce “Lost to Follow-up”</u>

1. Work with Early Head Start programs to facilitate reporting of hearing screening results to the NE-EHDI Program to search for a match with the LTF/LTD status cases in ERS-II. Discuss the need to provide parent materials to the families with a child identified with a hearing loss.
2. Proceed with determining how best to adapt the Early Head Start data systems to support hearing screening protocols.

3. As success occurs with a limited number of Early Head Start expand the program to other Early Head Start programs.

System Goal/Aim 7: Professionals working to identify hearing loss in young children will increase their capacity to provide appropriate services.

The progress in providing education and technical assistance to hearing health professionals has been presented above in the Education and Technical Assistance section of Goals 1 – 6. In addition, several educational activities focus on providing information to more diverse audiences.

A presentation by NE-EHDI Program staff was developed at the request of the College of Public Health at the University of Nebraska Medical Center in April 2013. The presentation was part of the Grand Rounds series held for faculty and staff and provided information and statistics on the NE-EHDI Program and will be repeated upon invitation.

Two audiologists from the Advisory Committee and NE-EHDI staff will present on the successes of the NE-EHDI Program at the 2014 Annual EHDI Meeting in Florida. NE-EHDI Program staff will also be part of presentation by the Centers for Disease Control (CDC) iEHDI Project. Beginning in 2010 thorough 2013, the CDC conducted a project in collaboration with Indiana, Iowa, and Nebraska EHDI programs to redefine the CDC approach to national surveillance through the collection of de-identified child-specific data. The "iEHDI project" successfully gathered detailed data from the EHDI programs on maternal and paternal demographics, hearing screening results, newborn hearing evaluation testing, early intervention services, and risk factors for children born in 2010. The project focused on the accuracy and completeness of the data and the CDC provided a data validation application "tool" to the states. The CDC analyzed the data for any correlation of the demographic data with the lost-to-follow-up trends for infants relating to receiving hearing screenings, hearing diagnostic evaluations, and early intervention services.

Goal/Aim 7 - Improvement Activities to Reduce "Lost to Follow-up"

1. Many audiologists have begun to provide the Parent Resource Guide to parents at the time a child's diagnosis of permanent hearing loss. All have expressed positive experiences and have requested more Parent Resource Guides. This activity will continue to be spread by engaging additional audiologists in providing the Parent Resource Guide at the time of diagnosis.
2. See also Goal/Aim 1 Improvement Activities 4, 6; Goal/Aim 2 Activity 4; Goal/Aim 5 Activities 1, 2, 3; Goal/Aim 6, Activities 1, 2, 3.

System Goal/Aim 8 – The NE-EHDI system will reduce the lost to follow-up rate at each step of the EHDI 1-3-6 process through quality improvement efforts.

Goal/Aim 8 – NE-EHDI Program System Activities: A Model for Improvement Task Force will be formed as part of the NE-EHDI Advisory Committee to plan, oversee, and evaluate the results of the multiple PDSAs and determine how successful changes will be spread. The Task Force will include, at a minimum, the NE-EHDI Program

Coordinator and Business (data) Analyst, a birthing facility representative, a pediatric audiologist, an otolaryngologist or pediatrician, a hospital association representative, and Advisory Committee members representing Part C/Early Intervention and parents of children who are deaf/hard of hearing. Additional members will be added for specific PDSAs.

The initial focus of the Task Force will be to establish a meeting schedule, both in-person and using technology, to understand the Model for Improvement process including the strategies that have been shown to be successful during the NICHQ Learning Collaboratives, and to review the improvements that have contributed to reducing the lost to follow-up rate since the NE-EHDI program participated in the first NICHQ Learning Collaborative in 2006.

The Task Force will review the aim statement that was developed in 2006 for the NICHQ Learning Collaborative. Since that aim statement does not meet current criteria because it does not specify the amount of improvement or the time by which it will be met, the Task Force will need to significantly revise that aim statement or devise a new one.

The Task Force will also develop a "dashboard" of key program indicators to monitor that changes are resulting in improvements and that no unintended consequences are occurring in other parts of the system. The NE-EHDI has been monitoring key indicators with data monitoring for many years. This "dashboard" report will continue and additional indicators may be added, such as the number and percentages at each follow-up step in the EHDI process in the Work Plan table below.

The "lost" percent is 27.3% for Nebraska births in 2012. Table 4 below shows the goals that the NE-EHDI Program will target to reduce the lost to follow-up/lost to documentation by 5% a year for the next three years.

Breakdown of Projected Lost to Follow-up/Lost to Documentation

	LTF/LTD - 2012	**LTF/LTD Goals in Three Years**	
Protocol Progress	**Count**	**Count**	**Percent Reduced**
Only inpatient Screening (Refer)	14	6	57%
Outpatient Refer – No Diagnostic Evaluation	14	6	57%
Only Initial Evaluation – No Confirmatory Evaluation	5	3	40%
Evaluation – No Early Development Network/Part C Referral/No Contact	0	0	0%
Total	33	15	55%
Projected CDC LTF/LTD			
Counts	33/121*	15/121*	
Percentages	27.3%	15%	

*Babies that referred on the last screening event Table 4

The Task Force will determine the process to identify both areas of strength and weakness in the statewide EHDI system by examining the extensive data that's currently available through the ERS-II data system. Examples to review include data about individual hospitals (refer rates, average number of days to report results, reasons for missing any birth admission screening, Lost to Follow-up/Lost to Documentation (LTF/LTD) outcomes, etc.), individual health care practices including LTF/LTD outcomes, maternal demographics linked to timeliness and LTF/LTD outcomes. Possible change strategies will be proposed and examined, with a limited number selected based upon the predicted impact on LTR/LTD reduction, suitability for small tests of change utilizing the PDSA cycle, and identification of willing partners to implement the initial PDSA cycles. The data points to be tracked on run charts will be determined and the process to collect and review the run chart will be established.

The Task Force will be very actively involved during the initial PDSA cycles for each change strategy to review the results and determine what factors may have influenced both successful and unsuccessful results. The implementation plans will be adjusted to maximize successful outcomes for subsequent cycles of the PDSA. The Task Force will also guide the expansion of the PDSA cycles to additional settings while maintaining an active reflection on both the results that occur and the possible factors contributing to those results, therefore permitting additional adjustments and modifications as the change strategy spreads to system-wide implementation.

New PDSAs will be developed and implemented using the same process as the initial ones to move toward system-wide implementation.

The NE-EHDI Program has identified three change strategies for the Task Force to initially consider for development of PDSAs. These strategies that have been shown to be effective either through NICHQ Learning Collaboratives or the ECHO Initiative's work with Early Head Start programs and state EHDI programs. All three of these strategies are focused on reporting, tracking and follow-up, one of the three primary methodologies for the NE-EHDI Program.

PDSA #1: Birthing facilities will provide the NE-EHDI Program with a second point of contact including name, phone number, and other contact information.

System Goal/Aim 2: *All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation prior to three months of age.*

<u>Obstacle</u>: The Community Health Educator contacts parents by phone to encourage completion of outpatient re-screenings and audiologic evaluations. Phone numbers are not always current or accurate as reported by the birthing facility on the hearing record. Currently, the NE-EHDI Program Community Health Educator accesses various internal systems with the State of Nebraska that provide parent contact information when the

phone number is missing or incorrect. But that does not always guarantee the accuracy of the information.

Hypothesis: Parents may provide temporary cell phone numbers or errors are made in recording phone numbers. Providing a second contact will increase the ability of the NE-EHDI program to contact parents due to have correct, viable contact information.

Plan: Select one medium-to-large hospital with a high LTF/LTD rate (baseline data) to collect a second point of contact name, phone, address, and email address if possible for the next five babies that refer on the birth admission screening. Planning with the hospital screening and data staff (typically the birth certificate clerk) will explore if the second point of contact information is currently available in the hospital records and, if so, where it is located and how it will be accessed. If not currently available, planning will involve when that information will be collected, by whom, and how it will be recorded so that it can easily be accessed to be entered into ERS-II as part of the hearing information.

Do: Hospital staff will obtain a second point of contact information according to the plan and report it on the ERS-II hearing screening record for five babies who don't pass the birth admission hearing screening.

Study: The Community Health Educator will record how many contacts were made successfully from both the primary and the secondary contact information in the hearing record and enter on a run chart. The hospital staff involved will be interviewed to determine what went well and what didn't, in which case alternative actions will be suggested for the next iteration of the PDSA. The Task Force will review the initial data and determine what modifications, if any, need to be made in the collection and reporting of the additional information. The Task Force will also plan the subsequent PDSA cycle in partnership with the hospital staff, including the number of parents to be included in the subsequent PDSA.

Act: Repeat the PDSA with more parents (to be determined) including modifications to the collection and reporting process for the second point of contact information.

Subsequent PDSAs:
- Frequent discussions with hospital staff will continue to improve the process.
- Make any adjustments to ensure that the additional contact information is collected for babies who don't get screened (missed due to early discharge, equipment malfunction, etc.) and babies who don't pass the birth admission screening (refer, not screened) are included.
- The PDSA cycle will be repeated but with a larger number of families for a longer period of time.
- The Business Analyst will run weekly reports to determine 1) the number and percentage of hearing records with a second point of contact, 2) the number of outpatient re-screenings or evaluations that were completed, and 3) the number of days to complete the outpatient event. The data will be recorded in run charts for review and analysis by the Task Force.

- The number of hospitals conducting this PDSA will be expanded, initially by one or two, and then with slightly larger groups. Particular attention will be paid to hospitals with different recording and reporting processes to develop modifications.

PDSA #2: Outpatient Appointment Made Prior to Discharge.

System Goal/Aim 2: *All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation prior to three months of age.*

Obstacle: Birthing facilities differ in how they arrange for outpatient follow-up. Some small facilities that are co-located with the PHCP offices arrange for the baby to return as part of the one-week check. Some larger facilities provide referral information for a specific audiology facility. In other facilities the PHCP takes the responsibility for arranging for a re-screening, either in the PHCP clinic or at an audiology facility.

Hypothesis: Regardless of how a birthing facility or PHCP arranges for an outpatient re-screening, assisting a parent in arranging a specific appointment will increase the follow-through by the parent, therefore reducing LTF/LTD.

Plan: One birthing facility that currently does not conduct the outpatient re-screening, and has had some LFU/LTD will be selected to participate. In coordination with the baby's PHCP and a local re-screening site (audiology facility, PHCP clinic, educational system, etc.), the discharge planner will make an appointment for outpatient re-screening prior to the baby's discharge from birth admission for the next three babies who refer on the hearing screening.

Do: The baby's parent(s) will receive both verbal and written appointment information and contact information for the re-screening site. The birthing facility will also enter this data on the ERS-II HScreening module when reporting the birth admission "refer" results to the NE-EHDI Program.

Act: Expand to include three other birthing facilities in year two and three more in year three, and determine impact on lost to follow-up/lost to documentation.

Study: The information entered by the hospitals for follow-up action will need to be compared by the NE-EHDI Program Business Analyst to the dates and location of the outpatient/evaluation event to determine if the infant was seen on the planned appointment date. If the birth facility does not enter the new data (appointment and contact information) then the NE-EHDI Program will need to determine what obstacles occurred for recording this data. The NE-EHDI Community Health Educator will check with the baby's parent(s), hospital staff, baby's PHCP, and re-screening site will be interviewed to determine what went well and what didn't, in which case alternative actions will be suggested for the next iteration of the PDSA. The Task Force will review the initial data and determine what modifications, if any, need to be made in the collection and reporting of the additional information. The Task Force will also plan the subsequent PDSA cycle in partnership with the hospital staff, including the number of parents to be included in the subsequent PDSA. The Task Force will begin the process of identifying how each birthing facility in the state currently plans for re-screenings to determine other strategies to be developed for future PDSAs.

Act: Repeat the PDSA with additional babies who refer (number to be determined by the Task Force) including any modifications suggested by the parent(s), hospital staff, PHCP, and re-screening site personnel.

Subsequent PDSAs:
- Frequent discussions with all stakeholders will continue to fine tune the process.
- The PDSA cycle will be repeated but with a larger number of parents for a longer period of time.
- Make any adjustments to ensure that the appointments are made for babies who are discharged on weekends or who don't get screened (missed due to early discharge, equipment malfunction, etc.) and babies who don't pass the birth admission screening (refer, not screened) are included.

Add additional birthing facilities that do not currently make an outpatient appointment, several at a time, as the process becomes more effective and results are positive.
- Add birthing facilities and PHCP practices that use a variety of different approaches for outpatient re-screenings, as identified by the Task Force during the initial Study component of this PDSA.
- The Community Health Educator will collect anecdotal records of reasons that appointments were not kept as planned. The Business Analyst will run weekly reports to determine 1) the number and percentage of hearing records with completed outpatient appointment information, 2) the number of outpatient re-screenings or evaluations that were completed, and 3) the number what were completed as scheduled. The data will be recorded in run charts, which track the data over time, for review and analysis by the Task Force.

PDSA #3: Reporting Periodic Hearing Screening Results by Early Head Start Programs.

System Goal/Aim #6: *Young children in Nebraska will have access to period hearing screening.*

Obstacle: Two of the approved evidence-based Maternal, Infant, and Early Childhood Home Visiting (MIECHV) models, Early Head Start (EHS) and Parents As Teachers (PAT), are required to conduct hearing screenings. There are 10 EHS grantees in Nebraska serving over 1,000 infants and toddlers and 10 PAT programs, most of which are also EHS programs. At least seven of the 10 EHS programs are conducting otoacoustic emissions (OAE) hearing screenings, having been trained by NCHAM's Early Childhood Hearing Outreach (ECHO) Initiative beginning in 2004. There are no state regulations or guidelines that the mandate results of periodic early childhood hearing screenings be submitted to the State.

Hypothesis: Some of the babies who are LTF/LTD are enrolled in EHS and/or PAT programs and have received an objective hearing screening as part of the program requirements. State EHDI programs have begun to find children who have been categorized as LTF/LTD when early childhood programs submit individually-identifiable hearing screening results.

Plan: Work with one Early Head Start program to facilitate reporting of hearing screening results to the NE-EHDI Program to search for a match in the "lost to follow-up/lost to documentation" category. Determine the type of hearing screening data that resides in the EHS program's data system, the mechanism for data transfer, the process the program uses to obtain parental consent to release hearing screening results, and the reporting timeframe that is workable for both the NE-EHDI Program and the EHS program. A mechanism for the EHS program to receive newborn hearing screening results from the NE-EHDI Program, as needed, will be determined.

Do: The Community Action Program of Lancaster and Saunders Counties EHS program health coordinator will submit individually-identifiable OAE hearing screening and follow-up results on the ECHO Initiative's data submission log through a secure web-based "drop box" used by the Nebraska Department of Health and Human Services for protected health information transfer. The data will be input into ERS-II HScreening records with positive matches made based on child name, date of birth, birth facility, and mother's name.

Study: Review the data as it is submitted and determine the number of children who are already in ERS-II with birth hearing screening results and any who are "lost to follow-up/lost to documentation" in ERS-II. Determine ease of reporting the results, including the amount of time required, through discussions with the EHS health coordinator and the NE-EHDI Program staff who process the results. A process will be determined to more immediately report children identified with a permanent hearing loss. The Task Force, which will be expanded to include EHS staff, will review the results and suggest possible modifications and expansion of subsequent PDSAs. The NE-EHDI Program will determine how to transmit early childhood hearing screening results to other state EHDI programs when a child was born in another state.

Act: Regularly review and revise reporting and recording protocols, as needed, for subsequent PDSAs.

These are the three initial PDSAs that the Model for Improvement Task Force will review and perhaps modify before implementation. Other possible changes to consider and subsequent PDSAs to consider will result from the Task Force's analysis of the status of the NE-EHDI Program.

Subsequent PDSAs:

- Audiologists will encourage parents to complete the Experience of Care survey as part of orientation to the Parent Resource Guide. This could also include the parent release of information form for the Guide By Your Side Program.
- Re-establish dialogue with the director of another EHS/PAT program in Nebraska who is also president of the Nebraska Head Start Association. Resolve previously

identified issues, primarily related to ease of submission without taking much staff time, to determine if this program would be willing to participate in the second PDSA cycle.

- Engage the Head Start State Collaboration Office Director in the Task Force for the purpose of facilitating the spread of reporting to other EHS programs.
- The NE-EHDI Business Analyst will review EHS data systems to identify possible export reports that could be easily submitted to the NE-EHDI Program through the secure "drop box."
- Community Outreach Coordinator to make a reminder appointment phone calls to the parents and provide directions to the audiologist's office, if needed.
- Work with the NE-EHDI Program Chapter Champion to educate the primary PHCPs involved in unplanned home births.

WORK PLAN 2014 – 2017 Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screen

Note: "Quarters" column indicates the time in which the activity will occur, beginning with Quarter 1 on April 1, 2011. Model for Improvement-PDSA = small test of change included in this activity. List of Abbreviations in Attachment 8.

Note: Activities contained within <> brackets are activities based on small tests of change over the years and/or a result of activities of National Initiative for Children's Healthcare Quality (NICHQ) model of improvement in previous years.

<table>
<tr><td colspan="3"><u>System Goal/Aim 1</u> - The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of-hospital, by one month of age.
Outcome Measures – Increase in the percentage of babies with completed screenings at 1 month of age from 99.7% to 99.8%.
Reduction of the percentage of babies LTF/LTD at the screening step in the EHDI process from 12% to 5% over a three-year period.</td></tr>
<tr><td>Program Objective 1.1 – Birthing facilities will submit hearing screening status reports for 100 percent of newborns, including transfers to NICUs.</td><td colspan="2">Healthy People 2020 (28-11)
ENT-VSL-1.1 Increase the proportion of newborns who are screened for hearing loss no later than age 1 month.</td></tr>
<tr><td colspan="3">Process Measures – Number and percent of "refers," number and percent of discharges prior to screening, reasons for discharge, timeliness of reporting, error rate. One-to-one match of birth records with hearing records in ERS-II, timeliness of data entry, and accuracy of data entry.</td></tr>
<tr><th>Activities</th><th>Quarters</th><th>Person(s) Responsible</th></tr>
<tr><td>Individual hearing screening status reports data submitted electronically within 14 days of discharge from the hospital.</td><td>Q1 Q2 Q3 Q4 Q5 Q6
Q7 Q8 Q9 Q10 Q11 Q12</td><td>CHEII; Hosp Staff</td></tr>
</table>

Individual hearing screening status reports submitted electronically during birth certificate registry process.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII; Hosp Staff
Transfers to different hospitals reported electronically with follow-up, reporting, and input completed electronically.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII; Hosp Staff
Training and orientation of hospital staff; technical assistance provided.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; BAnalyst, CHEII; Hosp Staff
Program Objective 1.2 – Birthing facilities will have status and comparison reports available for quality improvement.	**Process Measures –** Number born, parents educated, screened, pass, refer, and recommended for follow-up; refer rate by type of screening. **Process Measures** – Accurate ERS-II reports available to hospitals with number born, parents educated, screened, pass, refer, and recommended for follow-up; refer rate by type of screening.	
Activities	**Quarters**	**Person(s) Responsible**
Monthly activity report generated at hospital for verification of screenings completed.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst; Hosp Staff
Weekly exception reports developed.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst
Status reports available at hospital for local quality assurance; at the NE-EHDI Program for system quality assurance.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII; Prgm Mgr, Hosp Staff
Monthly/quarterly comparison reports available to each hospital for local quality assurance.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst, CHEII; Hosp Staff
<Technical assistance planning process developed.>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Hosp Staff
<Effects of demographics on two outcomes evaluated.>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; CHEII; Hosp Staff; Auds, Adv Cmte
<Strategies developed to ensure that baby has initial link with PHCP.>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; TFKF, BTNRH, Hosp Staff
Annual hearing screening reports generated for annual legislative report, other reports and surveys, analysis.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	Prgm Mgr; CHEII; Hosp Staff; Auds, Adv Cmte

Program Objective 1.3 - Parents educated about hearing screening, per Infant Hearing Act.	**Process Measures** – Number and percent of hearing screenings completed for out-of-hospital births. Number and percent of hearing screenings completed for out-of-hospital births; evidence of timely mail delivery of educational letter/brochure to parents.	
Materials provided to parents with out-of-hospital births.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII
<Follow-up phone calls if hearing screening not completed for out-of-hospital birth.>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII

System Goal/Aim 2 – All newborns who "refer" on the initial hearing screening will complete an outpatient re-screening, by one month of age, and/or audiologic diagnostic evaluation prior to three months of age.

Outcome Measures -

Increase in the percentage of babies with completed audiologic diagnostic evaluations by 3 months of age from 35% to 55%.

Reduction in the percentage of babies LTF/LTD at the hearing loss identification step in the EHDI process from 12% to 5%.

Healthy People 2020

ENT-VSL-1.2 Increase the proportion of newborns who receive audiologic evaluation no later than age months for infants who did not pass the hearing screening.

ENT-VSL-5 Increase the number of persons who are referred by their primary care physician or other health care provider for hearing evaluation and treatment

Program Objective 2.1 – Tracking of outpatient follow-up activities occurs with PHCP and/parent(s).	**Process Measures –** Timeliness of PHCP/parent letters/faxes; timeliness of initiation of follow-up re-screening/audiologic evaluation; numbers in each status, “border baby” agreements.	
Activities	**Quarters**	**Person(s) Responsible**
<Per protocol, first, second, and third request letters/calls will be mailed/faxed/phoned to PHCP; first, second request letters/calls mailed/phoned to parent(s).>	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, PHCP
Based on outpatient results, status is assigned.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII
Per protocol, additional request/confirmation letters/calls will mailed/faxed/phoned to PHCP.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, PHCP, Prgm Mgr
Protocols with neighboring states will be maintained to share results and coordinate follow-up.	[✓ Q1 Q2 Q3 Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
Program Objective 2.2 – Confirmatory testing facilities will obtain to release audiologic/screening reports to NE-EHDI Program.	**Process Measures** – Comparison of number of individual reports received with annual aggregate report. Comparison of reports received with estimates reported in EHDI-PALS. Results reports received by the NE-EHDI program from audiology clinics.	
Activities	**Quarters**	**Person(s) Responsible**
Subcommittee will develop standardized referral and release of information form.	[✓ Q1 Q2 Q3 Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; Adv Cmte, auds, all EI partners
Template will be disseminated to audiologists with orientation provided.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; NSLHA, Auds
Audiologists will request parental permission to submit audiologic reports to NE-EHDI Program.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Auds

Program Objective 2.3 – Confirmatory testing facilities will submit individual audiologic diagnostic and amplification reports, including information about referrals.	**Process Measures** – Number of infants evaluated, number with and without hearing loss; type, degree of hearing loss; number evaluated for amplification; number referred to each early intervention provider.	
Activities	**Quarters**	**Person(s) Responsible**
<Audiologic and amplification narrative reports will be provided to referring PHCP and NE-EHDI Program (manual, electronic).>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Auds, PHCP, CHEII
Results will be entered by NE-EHDI Program into data system. Results will be entered directly into ERS-II by the audiology clinic, copied into the NE Guardian drop-box or faxed to the NE-EHDI Program.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII
<Notification for follow-up reported and case status mailed/e-faxed to referral.>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII

System Goal/Aim 3 - All infants with a confirmed hearing loss will have immediate access to high-quality technology and will begin receiving early intervention services prior to six months of age.

Outcome Measures -

Increase (or maintenance) in the percentage of infants with confirmed hearing loss who are referred to EDN (Part C) by six months of age 85% to 90%.

Increase (or maintenance) in the percentage of infants with confirmed hearing loss who are enrolled in EDN (Part C) by six months of age from 83% to 88%.

Increase the percentage from 85% to 90% of infants with confirmed hearing loss who are referred to EDN (Part C) by six months of age. Increase in the percentage of infants with confirmed hearing loss who are enrolled in EDN (Part C) by six months of age from 83% to 88%.

Healthy People 2020

ENT-VSL-1.3 Increase the proportion of infants with confirmed hearing loss who are enrolled for intervention services no later than age 6 months.

ENT-VSL-3 Increase the proportion of persons with hearing impairments who have ever used a hearing aid or assistive listening devices or who have cochlear implants.

ENT-VSL-3.2 Increase the proportion of persons who are deaf or very hard of hearing and who have new cochlear implants.

Program Objective 3.1 – Primary Health Care Providers and audiologists will refer all newborns and infants with suspected or confirmed hearing loss to the Early Development Network, other early intervention providers.	**Process Measures** – Number of referrals made to each EI provider. Percentage of infants referred to EDN, based upon reports of confirmed or suspected infants with hearing loss.	
Activities	**Quarters**	**Person(s) Responsible**
Referral protocols reviewed with EI and NE-EHDI Program subcommittee.	[✓ Q1 Q2 Q3 Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	Prgm Mgr; EDN; MHCP, RPSDHH, PTI-NE, Adv Cmte, EHDI Chapter Champion
Referral protocols, including promotional information, disseminated to PHCP and audiologists.	[✓ Q1 Q2 Q3 Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	Prgm Mgr; EDN and Planning Region Teams, MHCP, NSLHA, EHDI Chapter Champion
<Audiologists and PHCP will provide Parent Resource Guide, including "roadmap," Experience of Care survey, and postcards to support providers to parents soon after diagnosis.>	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Auds, PHCP, CHEII, Planning Region Teams
Referral reports submitted to NE-EHDI Program for children less than six years of age.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, Auds, PHCP
Program Objective 3.2 – Parents will access early intervention services through a coordinated initial point of entry.	**Process Measures** – Number of referrals and requests made through ChildFind.	
Activities	**Quarters**	**Person(s) Responsible**
Coordinated initial Point of Entry plan will continue.	[✓ Q1 Q2 Q3 Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; EDN; MHCP, RPSDHH, PTI-NE, H&V Adv Cmte

Program Objective 3.3 – Audiologists will conduct or refer, as appropriate, all infants with confirmed hearing loss for assistive listening device evaluations and services, including the HearU Nebraska.	**Process Measures** – Number of referrals made, results of referrals (hearing aid fittings, hearing aid loans, etc.).	
Activities	**Quarters**	**Person(s) Responsible**
Hearing aid loans completed within one week of request.	$\boxed{\text{Q1 Q2 Q3 Q4 Q5 Q6}}$ $\boxed{\text{Q7 Q8 Q9 Q10 Q11 Q12}}$	UNL
HearU Nebraska will be funded through a variety of funding mechanisms.	$\boxed{\text{Q1 Q2 Q3 Q4 Q5 Q6}}$ $\boxed{\text{Q7 Q8 Q9 Q10 Q11 Q12}}$	Prgm Mgr, UNL
Program Objective 3.4 – Audiologists will recommend, as appropriate, all infants with confirmed hearing loss for medical evaluations, genetic evaluations, and family support.	**Process Measures** – Number of referrals made for medical, genetic or family support services compared to the number of ERS-II cases with "diagnosed" or "follow-up" case status.	
Activities	**Quarters**	**Person(s) Responsible**
Referral and reporting protocols developed by subcommittee and review of sources of payment for amplification.	$\boxed{\text{Q1}}$ Q2 Q3 Q4 $\boxed{\text{Q5}}$ Q6 Q7 Q8 $\boxed{\text{Q9}}$ Q10 Q11 Q12	Prgm Mgr; Adv Cmte, EHDI Chapter Champion
Referral and reporting protocols disseminated to audiologists.	Q1 $\boxed{\text{Q2}}$ Q3 Q4 Q5 $\boxed{\text{Q6}}$ Q7 Q8 Q9 $\boxed{\text{Q10}}$ Q11 Q12	Prgm Mgr, NSLHA
Reports of recommendations results submitted to NE-EHDI Program.	Q1 Q2 Q3 $\boxed{\text{Q4}}$ Q5 Q6 Q7 $\boxed{\text{Q8}}$ Q9 Q10 Q11 $\boxed{\text{Q12}}$	CHEII, Auds, Med Specialists
Program Objective 3.5 - The Early Development Network, Medically Handicapped Children's Program, RPSDHH, and other early intervention providers will provide data or access to detailed data on children referred for early intervention services.	**Process Measures** – Number of referrals and enrollment to each program, number eligible, number and types of services provided.	
Activities	**Quarters**	**Person(s) Responsible**
Reporting protocols developed with NE-EHDI Program subcommittee, EDN, MHCP, Regional Programs and other early intervention providers.	$\boxed{\text{Q1 Q2 Q3 Q4}}$ Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; EDN; MHCP, RPSDHH, Adv Cmte, BTNRH
Reporting protocols disseminated to		Prgm Mgr;

early intervention providers and orientation completed.	Q1 Q2 Q3 [✓ Q4 Q5] Q6 Q7 Q8 Q9 Q10 Q11 Q12	EDN and Planning Region Teams, MHCP, BTNRH
Individual reports of services provided are available to NE-EHDI Program.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	CHEII; EDN, MHCP, RPSDHH, BTNRH

System Goal/Aim 4 - All infants with a confirmed hearing loss will have access to a medical home. **Outcome Measures -** Maintain 99% success rate of properly identifying and communicating with PHCP's regarding their patients that need follow-up on the newborn hearing screening.		
Healthy People 2020 n/a		
Program Objective 4.1 – Birthing facilities will report to NE-EHDI Program, the identity of the Primary Health Care Provider of each newborn who refers on the initial hearing screening or was discharged prior to the hearing screening, including transfers to NICUs.	**Process Measures** – Accuracy of listing of PHCP on reports.	
Activities	**Quarters**	**Person(s) Responsible**
NE-EHDI Program orients hospital staff about rationale for accurate PHCP identification.	[✓ Q1] Q2 Q3 Q4 [✓ Q5] Q6 Q7 Q8 [✓ Q9] Q10 Q11 Q12	Prgm Mgr; Hosp Staff
PHCP listed on hearing screening record of electronic data reporting system.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII; Hosp Staff
Verification requested through NE-EHDI Program notifications of hearing screening results to PHCP.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII; PHCP
Program Objective 4.2 – Primary Health Care Providers will refer, as appropriate, infants with suspected or confirmed hearing loss for otologic, genetic, and audiologic evaluations and for early intervention services.	**Process Measures –** Number of medical homes established, number of referrals.	
Activities	**Quarters**	**Person(s) Responsible**
<"Roadmap" to recommended services and evaluations will be provided to PHCP to assist with parent follow-through for	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgm Mgr, CHEII, PHCP

referrals.>		
PHCP will retrieve dried blood spot to help to determine etiology for babies identified with permanent hearing loss.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgm Mgr, Newborn Screening & Genetics Program Manager, PHCP
Program Objective 4.3 – Primary Health Care Providers will submit individual status reports of children with confirmed hearing loss.	**Process Measures** – Number of individual status reports received annually. Number of children with hearing loss with completed status reports on file.	
Activities	**Quarters**	**Person(s) Responsible**
On-going, interactive reporting, based on AAP Patient Checklist for Pediatric Medical Home Providers.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgrm Mgr, Adv Cmte, EHDI Chap Champion, NeFPA, NePAA
Periodic individual status reports will be exchanged between PHCP and NE-EHDI Program.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, Prgm Mgr, PHCP

<u>System Goal/Aim 5</u> - Families of young children with a confirmed hearing loss will have access to family-to-family support system. **Outcome Measures –** Increase the number/percentage of families with young children with a confirmed hearing loss who attend Roots and Wings family support workshop within one year of identification from 18/50% to 20/55%. Baseline 36 Increase the number/percentage of families with young children with a confirmed hearing loss who participate in the Guide By Your Side Program from 8/25% to 12/35%. Baseline 36		
Healthy People 2020 – n/a		
Program Objective 5.1 – Families of young children with a confirmed hearing loss will receive a resource guide of support services.	**Process Measures** – Number of resources available, number of print guides distributed, number of web hits.	
Activities	**Quarters**	**Person(s) Responsible**
Review and update local, state, regional, and national support services.	[✓ Q1] Q2 Q3 Q4 [✓ Q5] Q6 Q7 Q8 [✓ Q9] Q10 Q11 Q12	Prgm Mgr; PTI-NE
Update the print and web-based resource	Q1 Q2 [✓ Q3] Q4 Q5 Q6	CHEII

guide of available family support resources.	[✓ Q7] Q8 Q9 Q10 [✓ Q11] Q12	
Disseminate to families of children with a confirmed hearing loss.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, PTI-NE
Disseminate to PHCP, audiologists, EDN service coordinators.	Q1 Q2 [✓ Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII
Program Objective 5.2 – Organizational support will be provided to maintain family-to-family supports.	**Process Measures** – Number of initial sessions held, number of new groups established.	
Activities	**Quarters**	**Person(s) Responsible**
Support Guide By Your Side.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgm Mgr, EDN, H&V
Support Roots and Wing Parent Weekend.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgm Mgr, BTNRH, H&V, GBYS
Partner in organization of weekend workshop for parents.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	PTI-NE, BTNRH, EDN, RPSDHH, Prgm Mgr
Program Objective 5.3 – Early intervention providers will submit annual aggregate and individual reports of families participating in family-to-family support activities.	**Process Measures** – Number of families engaged in family-to-family support groups, type of groups.	
Activities	**Quarters**	**Person(s) Responsible**
Individual reports of family-to-family support services provided are submitted to NE-EHDI Program.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	PTI-NE, H&V, BTNRH, RPSDHH, CHEII
Annual aggregate reports of family-to-family support services are submitted.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	PTI-NE, H&V, BTNRH, RPSDHH, CHEII

<u>System Goal/Aim 6</u> - Young children, in Nebraska, will have access to periodic hearing screening.

Outcome Measures –

Maintain-the number of individual early childhood programs/health clinics reporting periodic early childhood hearing screenings. Baseline: 32

Increase in the number of individual hearing screening results submitted by early childhood programs/health clinics. Baseline: 550

Increase in the number of hearing screening results for children previously categorized as LTF/LTD that are reported by early childhood programs/health

clinics. Baseline: 2		
Healthy People 2020 ENT-VSL-4 Increase the proportion of persons who have had a hearing examination on schedule.		
Program Objective 6.1 – Primary Health Care Providers will refer young children at risk for late-onset hearing loss for audiologic monitoring.	**Process Measures** – Number of infants with risk factors, number of infants at-risk who are monitored, number of infants with confirmed hearing loss. Number of infants with risk factors, number of infants at-risk who are monitored, number of infants with confirmed late-onset hearing loss.	
Activities	**Quarters**	**Person(s) Responsible**
Develop on-going, interactive reporting process based on AAP/NCHAM Patient Checklist for Pediatric Medical Home Providers.	[✓ Q1 Q2] Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, Adv Cmte, EHDI Chap Champion, NeFPA, NePAA
Dissemination and orientation to risk factors for later-onset hearing loss and to need for periodic monitoring of hearing.	[✓ Q1] Q2 Q3 [✓ Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, Adv Cmte, EHDI Chap Champion, NeFPA, NePAA, NSLHA
Periodic individual status reports will be exchanged between PHCP and NE-EHDI Program.	Q1 Q2 Q3 Q4 [✓ Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, Prgm Mgr, PHCP
Program Objective 6.2 – Early Head Start programs will conduct OAE hearing screenings of enrolled children aged birth to three years and submit the quarterly reports to the NE-EHDI program.	**Process Measures** – Number of EHS infants-toddlers screened, number referred, number with hearing loss, number of NE-EHDI Program “lost-to-follow-up” screened.	
Activities	**Quarters**	**Person(s) Responsible**
Early Head Start (EHS) will conduct annual OAE screening infants and toddlers and report results to the NE-EHDI Program.	Q1 Q2 Q3 Q4 [✓ Q5 Q6] Q7 Q8 Q9 Q10 Q11 Q12	EHS Prgms
Determine the feasibility of EHS/HS reporting individual hearing screening results to the NE-EHDI Program.	Q1 Q2 Q3 Q4 [✓ Q5 Q6] Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
Adapt existing reporting processes to	Q1 Q2 Q3 Q4 Q5 Q6	HSSCO,

meet the needs of EHS/HS and the NE-EHDI Program.	[✓ Q7 Q8] Q9 Q10 [✓ Q11 Q12]	Prgm. Mgr, NeHSA, CHEII
Disseminate and orient EHS/HS to reporting process.	Q1 Q2 Q3 Q4 Q5 Q6 [✓ Q7 Q8] Q9 Q10 [✓ Q11 Q12]	HSSCO, Prgm Mgr, NeHSA, CHEII
Identify EHS programs interested in partnering with community health clinics.	Q1 [✓ Q2 Q3] Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, HSSCO
Conduct Hear and Now training with community health clinics.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	NCHAM, ECHO team

System Goal/Aim 7 – Professionals working to identify hearing loss in young children increase their capacity to provide appropriate services to young children.

Outcome Measures –

Increase in the number of hospital hearing screening staff who earn Certificates of Completion for NCHAM's Newborn Hearing Screening Curriculum. Baseline: 0

Increase in the number of audiology facilities capable of conducting diagnostic evaluation services consistent AAA and ASHA standards of care that are registered in EHDI-PALS. Baseline: 0 – 6 months 3, 6 months 3, 2 – 5years 3

Healthy People 2020 – n/a

Program Objective 7.1 – Training needs of hearing health professionals will be assessed.	**Process Measures** – Number of surveys returned, content of surveys.	
Activities	**Quarters**	**Person(s) Responsible**
Hearing screening staff in birthing facilities will be surveyed annually for training needs.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 [✓ Q8] Q9 Q10 Q11 [✓ Q12]	Prgm Mgr, CHEII

Program Objective 7.2 – Professional development resources will be inventoried annually.	**Process Measures** – Listing of training resources	
Activities	**Quarters**	**Person(s) Responsible**
Educational opportunities will be compiled and promoted by written and electronic announcements.	Q1 [✓ Q2] Q3 Q4 Q5 [✓ Q6] Q7 Q8 Q9 [✓ Q10] Q11 Q12	CHEII
New educational opportunities will be listed on website as they become available.	Q1 [✓ Q2] Q3 Q4 Q5 [✓ Q6] Q7 Q8 Q9 [✓ Q10] Q11 Q12	CHEII

Program Objective 7.3 – Professional development opportunities will be promoted to the hearing health professionals.	**Process Measures** – Listing of educational opportunities, level of participation.	
Activities	**Quarters**	**Person(s) Responsible**
<Outreach visits to audiologists to promote professional development opportunities and explain new resources, including Parent Resource Guide.>	[✓ Q1] Q2 Q3 Q4 [✓ Q5] Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Auds
Educational opportunities using distance learning will be developed for professionals in the EHDI field.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgm Mgr, BTNRH
Workshops will be presented at conferences.	[✓ Q1] Q2 [✓ Q3] Q4 [✓ Q5] Q6 [✓ Q7] Q8 [✓ Q9] Q10 [✓ Q11] Q12	NHA, NeFPA, NePAA, NeHSA
Staff from Early Head Start/Migrant Head Start, RPSDHH, and/or Educational Service Units will be trained to conduct OAE hearing screenings.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	ECHO team, ECTC, NCHAM
Educational activities, such as BTNRH's pediatric amplification evaluation training and physician web-portal on babyhearing.org, will be included on NE-EHDI Program website.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Prgm Mgr, CHEII, BTNRH, Auds
NE-EHDI Program newsletter will be developed and disseminated semi-annually.	Q1 [✓ Q2] Q3 [✓ Q4] Q5 [✓ Q6] Q7 [✓ Q8] Q9 [✓ Q10] Q11 [✓ Q12]	Prgm Mgr, CHEII
Program Objective 7.4 – The effectiveness of the professional development activities will be evaluated.	**Process Measures** – Analysis of evaluations.	
Activities	**Quarters**	**Person(s) Responsible**
Evaluations will be included as part of each professional development activity.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII
Evaluations will be compiled and analyzed.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	CHEII, Prgm Mgr, Adv Cmte

System Goal/Aim 8 – The NE-EHDI system will increase the rate of follow-up at each step of the EHDI process and decrease the LTF/LTD percentage each year. Outcome Measures – The LTF/LTD rate at each step will decrease by 5% each year. Screening: Decrease LTF/LTD from 11.6% to 5.0% Evaluation: Decrease LTF/LTD from 11.6% to 4.1% Intervention: Decrease LTF/LTD from 4.1% to 3.3%		
Healthy People 2020 – n/a		
Program Objective 8.1 – The NE-EHDI quality improvement initiative will have multidisciplinary leadership.	**Process Measures** – Advisory Committee agenda and minutes, Task Force agenda and minutes.	
Activities	**Quarters**	**Person(s) Responsible**
NE-EHDI Program Advisory Committee will form Task Force and create list of possible members.	[✓ Q1] Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Adv Cmte
Task Force members will be recruited.	[✓ Q1] Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Adv Cmte
Initial Task Force meetings will establish meeting schedule, learn about Model for Improvement method including PDSAs, review components and outcomes of NE-EHDI statewide system, and review effective practices.	[✓ Q1] Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Task Force
Program Objective 8.2 – Task Force will establish foundation for quality improvement effort.	**Process Measures** – Task Force minutes	
Activities	**Quarters**	**Person(s) Responsible**
Task Force will develop aim statement.	[✓ Q1] Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Task Force
Task Force will develop “dashboard” of key program indicators.	[✓ Q1] Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst, Prgm Mgr, Task Force
Program level data to be tracked on run charts will be identified.	[✓ Q1] Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst, Prgm Mgr, Task Force
Program Objective 8.3 – Initial PDSAs will be developed.	Process Measures – Task Force minutes, PDSAs	
Task Force will review potential PDSAs.	[✓ Q1 Q2] Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Task Force
Task Force will develop a maximum of three PDSAs for initial implementation.	[✓ Q1 Q2] Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Task Force
Program Objective 8.4 – Initial small tests of change will be introduced using	**Process Measures –** PDSA run data, interviews, Task Force minutes.	

PDSA cycle.		
Activities	**Quarters**	**Person(s) Responsible**
Each partner site will run through a very short, very small change.	Q1 [✓ Q2] Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Partner Site Staff
Results, both objective and subjective, will be gathered and analyzed by Task Force.	[✓ Q1 Q2 Q3 Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Partner Site Staff, BAnalyst, Prgm Mgr, Task Force
PDSAs will be modified based on ideas generated from the experience of the first round.	Q1 [✓ Q2] Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Partner Site Staff, BAnalyst, Prgm Mgr, Task Force
Program Objective 8.4 – PDSAs will be repeated with modifications and expanded with more sites.	**Process Measures** – PDSA run data, interviews, Task Force minutes.	
Activities	**Quarters**	**Person(s) Responsible**
The PDSA cycle will be repeated multiple times with each iteration following the same process.	Q1 [✓ Q2 Q3] Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Partner Site Staff, BAnalyst, Prgm Mgr, Task Force
Additional sites are recruited as the change becomes more proven and the results more promising.	Q1 [✓ Q2 Q3] Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Task Force
Change is adopted system-wide.	Q1 Q2 Q3 [✓ Q4] Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Task Force, Adv Cmte
Program Objective 8.5 – Model for Improvement using PDSAs to study and implement small tests of change will become established throughout the NE-EHDI system.	**Process Measures –** PDSAs, PDSA run data, interviews, Task Force minutes	
Activities	**Quarters**	**Person(s) Responsible**
Objectives 8.3 through 8.5 and associated activities will be repeated.	Q1 Q2 Q3 [✓ Q4 Q5 Q6] [✓ Q7 Q8 Q9 Q10 Q11 Q12]	Partner Site Staff, BAnalyst, Prgm Mgr, Task Force

Resolution of Challenges

As described in the *Needs Assessment,* Nebraska is a relatively large state with sparse population with over half of the population living in three counties that include Lincoln and Omaha. The cities of Lincoln and Omaha are approximately 50 miles apart.

As a result audiologists and medical specialists also tend to be disproportionately clustered in the two major metropolitan areas resulting in decreased availability for diagnostic evaluations and treatment for hearing loss in the western part of the state. Over two-thirds of the audiologists and pediatric health care providers (physicians, physician's assistants, nurse practitioners, and otolaryngologists) practice within the two metropolitan areas in the eastern part of the state.

This provides a major challenge to ensuring that the JCIH 1-3-6 goals are met and that children get adequate hearing screens and diagnostic evaluations. People in the rural areas may not have the means nor the ability to travel to the services located in Lincoln and Omaha. PTI-Nebraska will pay for gas for families who meet their qualifications. To take on this challenge, the NE-EHDI Program will explore telehealth options. A task force will be formed to examine and research the options and confer with state EHDI Programs that are taking advantage of telehealth and other new and evolving technologies. The Task Force will also contact the National Center for Hearing Assessment Management (NCHAM) which conducted a Telehealth Survey in 2010 to learn from their information and expertise.

This challenge also extends to the NE-EHDI Program Advisory Committee. Most of the representatives are from Lincoln and Omaha with one that commutes from Grand Island which is near the middle of the state and is about 100 miles to Lincoln where the NE-EHDI Program office is located. Advisory Committee meetings are held at Mahoney State Park which is about equal distance between Omaha and Lincoln along the Platte River. That is about a two-hour drive one-way for the Advisory Committee member.

The large distances also makes it difficult to recruit members for the Advisory Committee and other subcommittees and task forces that live outside of the Omaha-Lincoln metro area. The NE-EHDI Program will explore technology options that can be used with the equipment located at Mahoney State Park meeting facilities and State of Nebraska technology/software restrictions that would allow some sort of teleconferencing capabilities. This would also be useful for conducting trainings and hosting webinars.

Another challenge is getting home birth babies' hearing screened. Nebraska has about a 100 home births a year. As stated earlier, the NE-EHDI Program's lost to follow-up/lost to documentation numbers are the highest for home births. State law, in Nebraska, does not require that babies have their hearing screened so the program has no enforcement authority.

In Nebraska midwives are prohibited, by law, from attending home births. In reviewing the data, staff have found that most of the planned home births use the same two doctors.

The NE-EHDI Program will explore options for educating the doctors that participate in planned home births. Options will be explored with the Chapter Champion and discussed at a NE-EHDI Program Advisory Committee.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

A Model for Improvement Task Force will be formed as part of the NE-EHDI Advisory Committee to plan, oversee, and evaluate the results of the multiple PDSAs and determine how successful changes will be spread. The Task Force will include, at a minimum, the NE-EHDI Program Coordinator and Business (data) Analyst, a birthing facility representative, a pediatric audiologist, an otolaryngologist or pediatrician, a hospital association representative, and Advisory Committee members representing Part C/Early Intervention and parents of children who are deaf/hard of hearing. Additional members will be added for specific PDSAs.

The initial focus of the Task Force will be to establish a meeting schedule, both in-person and using technology, to understand the Model for Improvement process including the strategies that have been shown to be successful during the NICHQ Learning Collaboratives, and to review the improvements that have contributed to reducing the lost to follow-up rate since the NE-EHDI program participated in the first NICHQ Learning Collaborative in 2006.

The Task Force will review the aim statement that was developed in 2006 for the NICHQ Learning Collaborative. Since that aim statement does not meet current criteria because it does not specify the amount of improvement or the time by which it will be met, the Task Force will need to significantly revise that aim statement or devise a new one.

The Task Force will also develop a “dashboard” of key program indicators to monitor that changes are resulting in improvements and that no unintended consequences are occurring in other parts of the system. The NE-EHDI has been monitoring key indicators with data monitoring for many years. This “dashboard” report will continue and additional indicators may be added, such as the number and percentages at each follow-up step in the EHDI process in the Work Plan.

Since January 1, 2007, the hearing screening results of all occurent births have been reported to the NE-EHDI Program using an electronic reporting system (ERS-II), developed by Netsmart Technologies. ERS-II is an integrated module of the State of Nebraska’s Vital Records System. Most of the financial support for system maintenance and the Business Analyst in charge of the NE-EHDI Program’s Business Analyst is paid with Centers for Disease Control (CDC) funds.

A hearing record (HINFO) is automatically created from the birth certificate by ERS-II and populated with baby, mother, and father information, contact information, and demographics. The birth clerk or hearing information clerk at each hospital enters the baby’s birth admission hearing screening results (pass, “refer”, did not screen) and, if not screened, the reason is selected. Additional information is entered for babies who did not pass (“refer”) or were discharged prior to screening: mother’s preferred language, telephone number, Primary Health Care Provider (PHCP) name, notification of PHCP, and follow-up plans to re-screen at the birth facility or to refer to an audiology clinic. Birthing facilities are encouraged to report the hearing screening results within 14 days after birth.

Each week, an exception report is generated to identify HINFO records without data entry for reports or reason for discharge, (NICU, transfer, child expiring) of newborns that are more than 21 days old. The hospital-specific reports are faxed to birth facilities responsible for reporting the results, followed by a phone call from the Business Analyst. The Business Analyst has been with the NE-EHDI Program for over seven years, and provides technical assistance in completion of the overdue records. This weekly exception report typically indicates about 35 overdue records (approximately 7% of the weekly records created). ERS-II ad-hoc reports are also utilized by the Business Analyst to verify a one-to-one correspondence between the records on the ERS-II birth table and the ERS-II HINFO table.

Quarterly status reports are compiled to monitor the follow-up progress of the newborns who referred, were discharged prior to screening, or were transferred. The reports include the numbers and percentages in the following status categories: closed, diagnosed, active follow-up, open, “lost to follow-up/lost to documentation,” expired and other (refused, moved out of state, medically fragile). The timeliness of the initiation of follow-up activities is also included in this report. Cumulative quarterly reports are generated for the Advisory Committee’s review. The status reports have been used for several years and are helpful in monitoring the number and percentages in comparison with the previous years to ensure that the initial follow-up activities are progressing as expected. For example, there was a 50% reduction in the number of babies classified as “lost to follow-up/lost to documentation” between 2010 and 2011.

This vast amount of data that is collected through ERS-II and the reports it can generate, permit the NE-EHDI Program to constantly monitor the status of newborns hearing screens and initiate intensive follow-up when necessary.

ORGANIZATIONAL INFORMATION

The Nebraska Early Hearing Detection and Intervention Program (NE-EDHI) is located within the Newborn Screening and Genetics Program in the Lifespan Health Services Unit, Community and Environmental Health Services, in the Division of Public Health, Nebraska Department of Health and Human Services. It is staffed by one 1.0 FTE Program Manager, one 1.0 FTE Community Health Educator, one 1.0 FTE contracted Business Analyst, one .40 FTE temporary Community Health Educator, and one .50 FTE temporary Community Outreach Coordinator. (Attachment 5)

The NE-EHDI Program has an Advisory Committee that meets quarterly and currently has 19 active members. In June 2011, the Advisory Committee approved a Charter, elected a Chair and Vice-Chair and revised the mission statement. The mission statement of the NE-EHDI Program is: *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.

The charter outlines representatives who should be represented on the Committee as well as other details. Membership is capped at 20 voting members and include the following: Audiology, Deaf/Hard of Hearing Community, Early Intervention Services (e.g. teacher, Speech-Language Pathologist) and Early Intervention Coordination, Otolaryngologist or Otologist, Family Support, Hospitals (preferably hearing screening coordinator). Recruitment of membership is through recommendations of Committee members, staff, and community input. Meetings are held quarterly and last approximately four hours.

The Advisory Committee provides direction and guidance to the NE-EHDI Program regarding the newborn hearing screening system. Specific Advisory Committee activities include, but are not limited to, the following: to discuss and advise on the goals for the NE-EHDI Program, to advise on the improvement of reporting, tracking, and follow-up protocols to effectively link the NE-EHDI Program and the early intervention systems, to assist in increasing the program’s responsiveness to the expanding cultural and linguistic communities in the state, to guide the long-term planning and evaluation of the NE-EHDI system in the state, to review the quarterly newborn screening statistics and make recommendations for program improvements

Progress was made in 2013 on resolving two ongoing organizational issues with the Nebraska Early Hearing Detection and Intervention Program. The first one was reclassification of one of the temporary positions from a Staff Assistant II to a Community Health Educator. With this person currently in the position (over two and one-half years), it has evolved to be more active in the follow-up process by contacting Primary Health Care Providers (PHCP), parents, hospitals, audiology clinics, and other facilities to obtain current information on all children who require follow-up. In 2013, the NE-EHDI Program requested and received notice that a position was being reclassified as a permanent position.

Having the same person in the Community Health Educator position, is one reason for the drop in LTU/LTD numbers decreasing from 41.1% (108) in 2010 to 20.0% (36) in 2012. She has expanded the resources she can use to locate families and the facilities, birthing, audiologists, etc. know her.

<u>RESOURCES/CABABILITIES</u>

Data is collected from the Vital Records ERS-II system. The Business Analyst has been with the NE-EHDI Program over seven years and has been involved in the development of ERS-II and some of its programming. The software allows for the creation of ad-hoc and formal reports (through Report Builder and Shazam Reports).

Dozens of reports can be generated in “Shazam” such as the following: 1) a weekly child-specific overdue results listing and a monthly NICU/transfer listing of infants, 2) determination of missing, invalid data in hearing information (HINFO) records, 3) finding duplicate HINFO records and checking for a one-to-one correspondence between records on the HINFO table and the birth table, 4) numbers for periodic reports (Advisory Committee Status, CDC Survey, Annual Report, Quality Assurance Reports), and 5) numbers for special presentations and special requests/projects (the 2012-2013 CDC Sentinel Project for example).

Quarterly data reports are also presented to the NE-EHDI Advisory Committee meetings. Information includes the number of hospital and out-of-hospital births, percentage of babies screened inpatient and percentage passing the inpatient screening, how many receiving a audiologic diagnostic evaluation, how many are still being followed, and the number of: 1) lost to follow-up/lost to documentation, 2) families that have moved out of state, 3) refused screening, or 4) expired outpatient.

Semi-annually, reports are sent to the birthing facilities along with a cover letter reminding them of JCIH recommendations and best practices.

Birthing facilities were sent a Professional Development survey to determine training needs and how best to deliver the training. Staff has provided one-on-one training with some hospitals. The NE-EHDI Program is exploring other methods of training such as webinars and using other technologies to deliver training. Incorporating videos into the web site will also be examined.

Nebraska was one of the first states to participate in the NICHQ process. However, only one current staff was employed by the NE-EHDI Program at that time.

SUSTAINABILTY - FINANCIAL

The Advisory Committee has discussed potential sources of funds beside the HRSA federal grant and CDC cooperative agreement funds. Currently, the most viable options would be Early Development Networks (EDN)/Part C and possibly Title V funds.

EDN has provided funding for Guide By Your Side. The Regional Programs for Students who are Deaf or Hard of Hearing have provided financial support for the half-day workshops and Roots and Wings.