

Nebraska Early Hearing Detection and Intervention Program

Application CFDA 93.251

Reducing Loss to Follow-up after Failure to Pass Newborn Hearing Screening

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PROGRAM NARRATIVE

INTRODUCTION

Nebraska has consistently met or exceeded the two benchmarks established by Nebraska's Infant Hearing Act of 2000: 100% of birthing facilities will provide newborn hearing screening and over 95% of newborns will have their hearing screened during birth admission. All of the birthing facilities, regardless of size, have been conducting newborn hearing screening and the hearing of over 98% of newborns has been screened during birth admission since 2004. Newborn hearing screening, however, is only the first, though crucial, step in the Early Hearing Detection and Intervention (EHDI) process, as expressed by the mission statement of the NE-EHDI program:

"The Nebraska Early Hearing and Detection Program develops, promotes and supports systems to ensure all newborns in Nebraska receive hearing screening and those who do not pass receive timely, family-centered evaluations and early intervention."

To ensure that newborns and infants identified with a hearing loss and their families are receiving appropriate and timely high quality services, the NE-EHDI has developed nine system goals focusing on newborn hearing screening, diagnostic evaluations, early intervention, medical home, family support, periodic hearing screenings, professional development, program development and EHDI promotion. To reach the goals, the NE-EHDI will continue to:

- 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 and culturally appropriate,
- increase the capacity of newborn hearing screening staff in birthing facilities to more effectively screen hearing and work with parents,
- develop and access professional development opportunities for professionals who provide services, including increasing the expertise of audiologists serving newborns and infants,
- engage more Primary Health Care Providers in early hearing detection and intervention, establishment of medical homes for all children, and referrals to Early Intervention,
- increase the knowledge of Early Development Network (Part C Early Intervention) services coordinators regarding infant hearing loss, family support, and communication options through partnership with deaf educators from 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 and early care and education settings,
- expand the analysis of the dried blood spot (DBS) from the newborn metabolic and genetic screening program to determine the etiology of hearing loss,
- engage stakeholders in evaluating and developing the EHDI program,
- revise and expand the electronic data reporting and tracking system that is a module of the integrated Vital Records birth registry system for all occurrent births, and
- strengthen existing and develop new collaborative approaches to link the providers of EHDI services and supports.

Participation in the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative to reduce the number of babies "lost to follow-up" at all points of EHDI services and transitions has provided the NE-EHDI program with experience with NICHQ's Model of Improvement, the Plan-Do-Study-Act (PDSA) cycle, in which small tests of change are tested, and, if successful, implemented and spread throughout the EHDI system. One example of a successful small test of change that was later spread throughout the EHDI system was the reduction of reading level of parent letters from an 11.0 grade level to a 7.3 reading grade level. Extensive effort has been invested in revising 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. This particular intervention is currently in the implementation stage, having been successful at the testing stage.

Since its inception in 2001, the NE-EHDI program has been organizationally located in the Newborn Screening and Genetics Program in the Office of Family Health (now Lifespan Health Services) which has provided opportunities for cooperation with other maternal and child health programs in the state, including Title V. The Advisory Committee, composed of 22 stakeholders representing many disciplines and perspectives, has been active in providing leadership for implementation of the Infant Hearing Act of 2000 and the expansion and ongoing development of the EHDI system.

Throughout each of the many individual activities that collectively constitute the EHDI system, three over-arching and inter-woven processes will receive focused, purposeful attention: prevention of a baby from being "lost to follow-up" throughout the EHDI system, quality improvement of services, and collaboration and partnership of all providers.

NEEDS ASSESSMENT

Any description of systems in Nebraska must first begin with an overview of the state's geography and its population. Nebraska is a relatively large state with a sparse population. According to the 2006 Census estimates, Nebraska's total estimated population is 1,789,597. Nebraska covers 76,872 square miles. The relatively small population and a large geographic area results in an average population density of 23.3 persons per square mile, with 32 of its 93 counties designated as Frontier (6 or fewer persons per square mile) and 43% of its population living in its two metropolitan population centers, Omaha and Lincoln.

This combination of vast spaces and uneven concentration of population impacts many aspects of 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 Under Served Areas or Medically Under Served Populations. In 2007, 60 of the 93 counties experienced a shortage of family practice physicians and 87 of the counties experienced a shortage of pediatricians. Audiologists and medical specialists tend to be disproportionately clustered in the two major metropolitan areas in Nebraska, resulting in decreased availability for diagnostic evaluations and treatment for hearing loss. Over two-thirds of audiologists, pediatric health care providers (physicians, physician assistants, nurse practitioners) and otolaryngologists practice within the two metropolitan areas in the eastern part of the state.

Nebraska has also seen important shifts and trends in its populations, particularly a growing proportion of racial/ethnic minorities. From 1990 to 2000, the minority population rose by 83.5%, and an additional (estimated) 24.7% by 2006, constituting an estimated 15.2% of the

total population in 2006. The proportion of children under 5 that are racial/ethnic minorities was estimated at 24.6% in 2004. For this age group, 13.2% were Hispanic, compared to 7.3% of the overall population. From 1995 to 2004, live births among Hispanic women increased by 114% while live births among non-Hispanic women increased by 6%.

In 2006 there were 26,889 babies born in Nebraska and, during the first eight months of 2007, there have been 18,290 birth certificates filed. The maternal demographics of educational 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 (see Table 1). Additionally, the primary maternal language is collected for those babies who do not pass or did not receive a hearing screening during birth admission.

Education Level	2006 Percent	2007 Percent	Race/Ethnicity	2006 Percent	2007 Percent
Less than high school diploma	15.5%	15.5%	White	78.9%	80.3%
High school graduate or some college	44.6%	44.1%	Black	6.1%	6.0%
Associate or Bachelors Degree	32.0%	32.3%	American Indian	1.0%	1.0%
Masters or Doctorate Degree	7.6%	7.9%	Other (less than 1.0%) or Unknown	12.0%	12.6%
Unknown	0.2%	0.2%	Hispanic (all races)	14.0%	13.9%
Age	2006 Percent	2007 Percent	Payment Source	2006 Percent	2007 Percent
12-20 years	12.1%	12.4%	Private Insurance	58.9%	56.3%
21-29 years	53.1%	53.4%	Medicaid/SCHIP	33.0%	35.7%
30-38 years	31.8%	31.2%	Self-pay	2.8%	3.0%
39-48+ years	3.0%	2.9%	Other, unknown	5.3%	5.1%

Table 1. Maternal demographics for 2006 and 2007 (first 8 months) Nebraska births (some categories combined).

All of the birthing facilities in Nebraska have been conducting newborn hearing screening since 2003. All but one of the 63 hospitals perform the newborn hearing screening during birth admission with one small hospital scheduling outpatient hearing screenings prior to one month of age. Thirty of the birthing facilities conduct otoacoustic emissions (OAE) screenings, 23 (including Children's Hospital, a non-birthing facility) conduct auditory brainstem response (ABR) screening, and the remaining 11 use a 2-step method consisting of an initial OAE screening, followed by an ABR screening if the baby did not pass the initial screening.

Beginning in 2007, the new integrated electronic hearing screening reporting system in Nebraska, a module of the Vital Records birth registry, provides the hearing screening results for each occurrent birth. Prior to this, only babies who did not pass the hearing screening during birth admission ("refer," discharge prior to screening, or transfers to other hospitals) were reported. In addition to those individually-identifiable reports, an annual aggregate report was

filed by each birthing facility. These two reporting processes did result in conflicting numbers at times. With the new integrated electronic hearing screening reporting system, however, more accurate, timely, and comprehensive hearing screening information is available for babies born in 2007. All but five of the 18,290 babies born during the first eight months of 2007 have a basic hearing information (HINFO) record in the data system. There are 47 out-of-hospital births registered which is consistent with the number of out-of-hospital births reported in the previous four years. Of the babies with HINFO records, 98.2% have had a newborn hearing screening completed, 1% are still in a Neonatal Intensive Care Unit (NICU) pending a hearing screening at a developmentally appropriate time, and the remainder consist of babies who did not receive a birth admission hearing screening due to several reasons (expired, discharged prior to screening due to technical problems, parent refusal, or failure of the hospital to follow protocol) or who were born out-of-hospital with no hearing screening conducted or reported. The overall “refer” (did not pass) rates this time period are 3.3% for well-baby nurseries and 7.5% for NICUs.

The refer rates also vary by type of screening. Quality assurance reports that include the refer rate are available to each birthing facility as part of the data reporting system. During the first eight months of 2007, there are 15 birthing facilities with high refer rates (greater than 10% for OAE screenings and greater than 5% for ABR or 2 step screenings) and, of those 11 are very small hospitals with less than 50 births annually. In addition to quality assurance reports available to each individual birthing facility, the NE-EHDI Advisory Committee approved a comparison report to be provided to each hospital in which that hospital’s refer rate is compared with the average for all hospitals using the same screening technique and the discharge prior to screening rate is compared with all other birthing facilities in the state. The reports will be provided to the birthing facilities on at least a quarterly basis, beginning with the last quarter of 2007, and will provide a foundation for training and technical assistance plans to be developed in partnership with each facility.

“Lost to follow-up” is a category that was developed with the NE-EHDI Advisory Committee in 2005 and is used when the tracking and follow-up protocol of two letters to the Primary Health Care Provider (PHCP), one fax to the PHCP, and two letters to the mother over a two month period has yielded no follow-up activity or results. In 2006, there were 954 individually-identifiable babies who were reported by the birthing facilities as “refers” or “discharges prior to screening.” Of those, 106 (11.1%) were categorized as “lost to follow-up” with 83 having no follow-up activities initiated or reported to NE-EHDI, 23 had outpatient hearing screenings or diagnostic evaluations begun but hearing status was not conclusively established or reported. Additionally, there were 11 babies who were diagnosed with middle ear dysfunction and an accompanying temporary conductive hearing loss for whom final results of permanent hearing status had not been received by July, 2007. Of the 68 babies born out of hospital, no hearing screening was received or reported for 33 of them. There were 107 babies who expired either prior to receiving a hearing screening or before follow-up activities were completed. Eight parents refused the newborn hearing screening at the birthing facility. Comparison of the statutorily-required aggregate report with the individually-identifiable reports submitted for babies who did not pass or were not screened prior to discharge, as many as 177 additional babies did not complete the necessary follow-up. In total, there were 442 babies (1.6% of 2006 births) for whom normal hearing or permanent hearing loss was not established for all of the above reasons.

An additional category of ‘lost to follow-up’ includes those infants identified with a permanent hearing loss but not referred to the Early Development Network (EDN), the Part C

Early Intervention program. In 2006, eight of the 26 infants diagnosed with permanent hearing loss, for whom individually-identifiable reports were available, were not referred for Early Intervention Services. This information is based on individually-identifiable reports from the CONNECT data system which contains data about enrollment and services for EDN and for the Medically-Handicapped Children's (Children with Special Health Care Needs) Program. The CONNECT system also contains medical home information and for the 16 infants born in 2006 with permanent hearing loss receiving EDN services, 14 of them have a medical home.

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

In 2006, four stakeholders of the NE-EHDI program attended the Investing in Family Support conference. A product of that conference was a plan to foster and support a family-to-family support system. The plan was approved by the NE-EHDI Advisory Committee and a family support sub-committee was officially established. During the summer of 2007, a group of parents in the Omaha area began organizing to become a chapter of Hands and Voices, a national non-profit, parent-driven organization focused on supporting parents with children who are deaf or hard of hearing without bias about communication modes or methodologies. The NE-EHDI program provided funding for a statewide teleconference in September, 2007. The Nebraska chapter of Hands and Voices is now a "start-up" chapter in the process of recruiting parent and professional members, organizing a board of directors, and becoming a non-profit organization.

Nebraska has 65 audiologists at 28 sites who self-identified as providers of pediatric audiologic diagnostic services in 2006 and have been listed in the NE-EHDI Resource Guide. Those sites are surveyed annually to provide aggregate reports, required by statute, about hearing screening, diagnostic and amplification activities. In the most recent reports, six sites with a total of seven audiologists reported not having conducted any follow-up screenings or audiologic diagnostic evaluations for babies born in 2006, six sites with ten audiologists reported conducting follow-up screenings only, and 16 sites with a total of 48 audiologists reported conducting both follow-up screenings and audiologic diagnostic evaluations. Boys Town National Research Hospital in Omaha conducts the majority of initial or confirmatory diagnostic evaluations in the state.

In the absence of a specialty designation of pediatric audiologist and state statutes or regulations to certify or designate authorized diagnostic centers, work began in 2006 to more clearly define those audiologists who are capable of providing appropriate, comprehensive audiologic diagnostic evaluations for babies up to 6 months old. An audiology sub-committee of the NE-EHDI Advisory Committee was formed to review the recommended screening and diagnostic procedures. A cross-section of audiologists from hospital, university, public school, ENT clinic and private practice sites revised the recommended evaluation protocols and specified the types of equipment needed to conduct them. The evaluation protocols were presented at the EHDI workshop at the Nebraska Speech Language Hearing Association workshop in 2007 but further explanation and discussion is warranted with audiologists in their clinics or in small groups. In early 2008, all of the audiologists licensed by the State of Nebraska

will be surveyed to determine the equipment available for screening and diagnostic evaluations. The listing will be included in the NE-EHDI Resource Guide, along with the revised protocols. Although this approach will not clearly identify the audiologists proficient in providing audiologic services to very young children, it will begin to assist the primary consumers, parents and PHCPs, with the information necessary to make an informed decision.

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 and that the number of babies who are lost to follow-up is minimized. In 2005, the NE-EHDI program mailed the Newborn and Infant Hearing Screening Survey, developed by Boys Town National Research Hospital (BTNRH) and National Center for Hearing Assessment and Management (NCHAM), to all pediatricians and family practice physicians in the state. Responses were received from 149 (17%) of the physicians; 35% of whom were pediatricians and 58% of whom were family practice physicians. Several key findings from this survey are:

- 89% of physicians received newborn hearing screening results from the birthing facility.
- 89% knew that additional testing should be completed prior to 3 months of age.
- 22% thought that an infant could not be fitted with a hearing aid before 12 months of age.
- 12% thought an infant could not be referred to Early Intervention before 12 months of age.

Although the results indicates that the respondents had a good understanding of the initial benchmarks for EHDI, the lack of knowledge and understanding about accessing basic early interventions at the earliest possible age indicates an opportunity for professional development.

All birthing facilities are conducting newborn hearing screenings and the rate of follow-up re-screenings and audiologic diagnostic evaluations is good. However, Nebraska's geography and population distribution impacts the availability and accessibility of specialty medical and audiologic services for those infants who need diagnostic evaluations. Survey results indicate the ongoing need to provide professional development opportunities. All components of the EHDI system, including parent education, newborn hearing screening during birth admission, follow-up re-screenings and audiologic diagnostic evaluations, medical home, specialty evaluations, early intervention services and family-to-family support and the linkages between each component, are critical for effective referral, tracking, and reporting processes to reduce the number of babies who are lost to follow-up.

METHODOLOGY

The Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program will build on the accomplishments and resources of the early hearing detection and intervention (EHDI) system that has been developed in Nebraska in the last seven years. The Infant Hearing Act of 2000 (Neb. Rev. Stat. § 71-4735) specifies four purposes for the EHDI system in Nebraska:

- “To provide early 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 the information necessary to effectively plan, establish, and evaluate a comprehensive system for the identification of newborns and infants who have a hearing loss.”

The NE-EHDI Program has been developed based on the recommendations of the NE-EHDI Program Advisory Committee and the requirements identified in the Infant Hearing Act (Neb. Rev. Stat. §71-4735 - §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:

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. §71-4740).
5. Apply for all available federal funding to implement the Infant Hearing Act (Neb. Rev. Stat. §71-4738).

The EHDI system goals were reviewed and refined by a cross-section of stakeholders, including the NE-EHDI Advisory Committee, during a strategic planning session in June, 2007. The nine EHDI system goals are:

System Goal 1 - The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of hospital, by 1 month of age.

System Goal 2 - All newborns who “refer” on the initial hearing screening will complete an outpatient re-screening and/or audiologic diagnostic evaluation prior to 3 months of age.

System 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 6 months of age.

System Goal 4 - All infants with a confirmed hearing loss will have a medical home.

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

System Goal 6 - The hearing of young children in Nebraska will be screened periodically.

System Goal 7 - Professionals working with young children with a hearing loss will increase their capacity to provide appropriate services to young children.

System Goal 8 - The NE-EHDI Program will provide an effective structure for the early hearing detection and intervention system in Nebraska.

System Goal 9 - The Early Hearing Detection and Intervention system will be promoted.

The NE-EHDI Program logic model (Appendix A) 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, including NICHQ’s Model for Improvement. These methodologies are developed and implemented through a Collaborative Approach. The current EHDI system will be fine-tuned to improve the efficiency and effectiveness of the newborn hearing screening, follow-up, and reporting

processes. The system will be extended to better link 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 initiatives.

Note about the format for System Goals 1-6 of the Methodology section:

For each EHDI System Goal, a general explanation of the activities that occur to meet that goal is provided. The current ongoing NE-EHDI Program activities are described for each of the three methodologies (Reporting, Tracking and Follow-up; Education and Technical Assistance; and Evaluation and Quality Improvement), followed by any additional activities specifically planned to reduce the lost to follow-up rate in 2008-2009. At the end of each system goal, the Model for Improvement section for that particular goal describes the “small tests of change,” the initial part of the Plan-Do-Study-Act (PDSA) cycle, that are initially tried to determine the degree of feasibility and contribution toward a desired outcome.

System Goal 1 - The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of hospital, by 1 month of age.

EHDI System Activities. 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). The Department of Health and Human Services (DHHS) is responsible for educating the parent(s) of newborns not born in a birthing facility (Neb. Rev. Stat. §71-4740).
2. A hearing screening is part of each birthing facility’s standard of care for newborns, effective 12/1/03 (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. The outpatient re-screening for those that “refer” during birth admission may occur at the birthing facility or at a confirmatory testing facility.
3. A mechanism for compliance review is established for each birthing facility (Neb. Rev. Stat. §71-4742).
4. Annual reports are submitted to the NE-EHDI Program, that indicate the following numbers: born in the birthing facility, recommended for screening, received screening during birth admission, passed screening, did not pass screening, and recommended for monitoring and follow-up (Neb. Rev. Stat. §71-4739).

NE-EHDI Reporting, Tracking and Follow-up.

Beginning on January 1, 2007, the hearing screening results of all occurrent births have been reported to the NE-EHDI Program using a new electronic reporting system (ERS-II), developed by Netsmart (formerly QS Technologies). ERS-II is an integrated module of the State of Nebraska’s Vital Records Birth Certificate registry system. At the birthing facility, a birth clerk or hearing information clerk creates an individual hearing record (HINFO) from the birth certificate. Each newborn’s HINFO record is automatically populated with baby, mother and

father identifying information, contact information, and demographics (maternal age, race/ethnicity, payment status, maternal education level). Each baby's birth admission hearing screening results are entered (pass, refer, did not screen) or, if not screened, the reason is selected. For babies who did not pass (refer) or were discharged prior to screening, including a transfer to an NICU, additional information is collected: 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 seven days after the birth.

As part of the NE-EHDI Program's cooperative agreement with the Centers for Disease Control and Prevention (CDC), specifications were developed and submitted to Netsmart to revise the hearing screening reporting module to increase the ease of entry and to minimize reporting errors.

Newborns who are transferred to another hospital for a higher level of care are tracked manually because the ERS-II system does not currently support the access of HINFO records by personnel from facilities other than the birth facility. A one page reporting form is mailed or faxed weekly to each receiving hospital weekly for all babies who have been transferred to that particular facility.

Nebraska has had less than 75 out-of-hospital births reported to DHHS annually for the last four years. DHHS is required to educate the parents of babies who are not born in a birthing 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, of which EHDI is a module, 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. The NE-EHDI mails a certified letter to the parent(s) of the baby, along with a parent education brochure, a listing of screening facilities, and a reporting form. Consistent with the successful small test 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 a 12.2 reading grade level to an 8.5 reading grade level. The amount of materials included with the letter was reduced to those specifically needed to encourage the hearing screening.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – As part of the CDC cooperative agreement, the ERS-II hearing screening module will be revised. The data system will be further developed to generate and record follow-up requests to PHCP (written, eFax) and parents per the NE-EHDI Program tracking protocol. Access by receiving hospitals will be arranged to facilitate the electronic reporting of hearing screening results for babies who were transferred. Reports will be developed to provide real-time follow-up tracking status. Each birthing facility will access reports to track performance and to identify areas for quality improvement. In addition, the data system will provide aggregate reports for the state. Two new quality assurance/status reports (summary report and a detail report listing the status of all newborns) will be developed for each birthing facility.

2 – A second letter and an outreach phone call will be made by the NE-EHDI Community Health Educator to the parents with out-of-hospital births who have not completed the newborn hearing screening by 2 months of age to encourage completion of the hearing screening and assist with any barriers the family may be experiencing with the hearing screening.

3 – Analysis of two hearing screening outcomes (timeliness of initiation of follow-up activities and lost to follow-up) will be studied with respect to the demographics available from the ERS-II

HINFO record (maternal age, race/ethnicity, language, educational level and payment source) for development of strategies to reduce the number of babies who are lost to follow-up.

NE-EHDI Education and Technical Assistance.

A basic parent education brochure, meeting the requirements mandated by the Infant Hearing Act was developed in 2005, based on the Universal Newborn Hearing Screening Toolkit and suggestions from the Parent Resource Sub-committee of the 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). The parent education brochures and the English/Spanish videotape, Giving Your Baby a Sound Beginning, are disseminated at no cost to all birthing facilities.

As part of the on-site training about the ERS-II hearing screening reporting module for the newborn hearing screening coordinators, hearing information clerks and birth certificate clerks in the birthing facilities, the need for accurate identification of the PHCP, listing of mother's primary language and phone number, and reporting of hearing screening results to both the parents and PHCPs was emphasized.

Individualized technical assistance by telephone and email is provided to birthing facilities, as requested, to address equipment, screening technique and quality issues. Problems with the ERS-II data system and reporting, initiated either by the hospital reporting personnel or NE-EHDI staff, 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.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – The basic parent education brochure will be translated into other languages, based on the languages spoken by refugees with the state's refugee resettlement efforts and by new Americans in the state. The brochures will be modified to include photographs that better represent the ethnic and racial diversity of families in Nebraska.

2 - On April 16, 2008, a track for hearing screening coordinators will be included in the Lifespan Health Services conference. The content of the conference will include health disparities based on maternal demographics linked to outcomes (lost to follow-up, timeliness of initiation of follow-up), a training module in development by NCHAM, sharing of effective practices, parent panel of perspectives of newborn hearing screening and explanations of results, and NICHQ's Model for Improvement with development of individualized PDSAs/small tests of change.

3 - Individualized technical assistance will be offered to birthing facilities based on the results of monthly/quarterly comparison quality assurance reports.

NE-EHDI 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. This aggregate data has been useful not only to the NE-EHDI Program to annually evaluate the percentage of newborns not screened and the refer rates for those that were screened, but also has been used by the birthing facilities as a basic quality assurance measure. The legislatively-required data, which is now being cumulatively generated in birthing facility and statewide reports with ERS-II, will continue to assist both the birthing facilities and the NE-EHDI Program in monitoring the quality of the hearing screening programs and the EHDI system.

A variety of administrative and ad hoc reports have been devised during the first ten months of operation of the new data system. To encourage the timely reporting of newborn hearing screening results, an exception report is run weekly that identifies all babies who are greater than 21 days of age (except those in NICUs) without hearing screening results or without reasons for not having received a hearing screening in ERS-II. The overdue report is faxed or phoned by the Business Analyst to the primary data contact at the birth facilities. The number of overdue reports averages less than 20 per week (4% of the average 500 births per week statewide). Since babies in the NICU are screened on a developmental basis, rather than by age, the status report for NICUs is run monthly for those babies who are greater than 60 days of age. The ages specified for the well-baby and NICU reports is not yet firmly established. A small test of change recently 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.

Monthly 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, expired, and errors. The timeliness of the initiation of follow-up activities is also included in this report. Cumulative quarterly reports were generated for the Advisory Committee's review and are incorporated into the evaluation report for the CDC cooperative agreement. The status reports have been used for three years and are helpful in monitoring the number and percentages in comparison with previous years to ensure that the initial follow-up activities are progressing as expected. For example, there was a 9% reduction in the number of babies classified as "lost to follow-up" in 2006, the year the NE-EHDI Program was participating in NICHQ's Learning Collaborative, compared with the previous year.

The reports derived from the ERS-II system are beginning to provide a new level of analysis of hearing screening outcomes for individual birthing facilities and the statewide EHDI system. One quarterly comparison report has been developed that compares a birthing facility's refer rate with all other birthing facilities using the same screening technique (OAE, ABR, 2 step), and compares the rate of discharges prior to screening, including the specific reasons, with the system rates. The NE-EHDI Advisory Committee and the CDC cooperative agreement's Evaluation Committee approved providing this report to birthing facilities, including an analysis of the results.

An annual report, required to be prepared for Nebraska's unicameral legislature by the Infant Hearing Act, includes statistical results from individually-identifiable data and aggregate reports submitted by all birthing facilities. The 2006 Annual Report, developed in conjunction with the metabolic (bloodspot) screening program, was disseminated to 343 stakeholders. An executive summary of the 2006 Annual Report was disseminated to 2,050 stakeholders.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Continue to refine and expand the reports that can be created from the data in the ERS-II data system. As mentioned in the Reporting, Tracking and Follow-up section of this goal, study of two outcomes (loss to follow-up and timeliness of initiation of follow-up activities) with respect to maternal demographics is of primary interest in identifying factors for which intervention strategies can be developed.

2 – Development of technical assistance plans in partnership with birthing facilities based on administrative and ad hoc reports with the ERS-II system.

3 – For the 2007 Annual Report and the CDC EHDI survey, individually-identifiable hearing screening results for all occurrent births will replace the birthing facilities' aggregate reports. Although the percentages are not expected to vary significantly from previous years, based on data from the first eight months of 2007, the historical discrepancy between individually-identifiable and aggregate data will be resolved.

Model for Improvement for Goal 1.

1 - The designated hearing screening coordinator at each birthing facility will be invited to participate in the EHDI track of the Lifespan Health Services conference on April 16, 2008. A major portion of the training will be devoted to presenting the NICHQ Model for Improvement's Plan-Do-Study-Act (PDSA) cycle. Each participant will develop at least one PDSA to try a small test of change to address a quality issue based primarily on available data from the ERS-II system. Possible small tests of change may include, but will not be limited to, using scripts to present results to parents, identifying a second contact, confirming the PHCP or clinic, confirming the parent phone number, making an appointment for the follow-up screening at the birthing facility or audiology clinic, and making a reminder phone call the day prior to the appointment.

2 – A small test of change for the NE-EHDI Program will be to develop the approach and content of the outreach phone call to be made by the Community Health Educator to the parents with out-of-hospital births who have not completed the hearing screening by 2 months of age.

3 – The content and format of technical assistance plans will be developed by engaging a small number of hospitals in developing and refining the plans based on reported data.

System Goal 2 - All newborns who “refer” on the initial hearing screening will complete an outpatient re-screening and/or audiologic diagnostic evaluation prior to 3 months of age.

EHDI System Activities. The audiologic diagnostic evaluation protocol that was developed and approved 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 OAE and/or ABR screening methods within the first 6 weeks of age, rather than proceeding immediately to a comprehensive audiologic diagnostic evaluation. Being a state with the two major population centers located closely together in the eastern part of the state with vast expanses of sparsely populated land with few, if any, audiologists within a reasonable driving distance in the middle and western sections, some local community health systems have opted to have the outpatient re-screening completed at the birthing 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 early intervention services.

An Audiology Advisory Sub-committee of the NE-EHDI Advisory Committee was formed in 2006 to review and revise the audiologic diagnostic and management protocols, to determine how to increase the level and quality of reporting by audiologists to the NE-EHDI Program, and to develop approaches to presenting more objective information to consumers about pediatric audiologic services available in the state. The sub-committee consisted of eight

audiologists representing hospital, private practice, public school, ENT clinic and university settings. Based on the review the ASHA revised guidelines for Audiologic Assessment of Children from Birth Through 5 Years of Age, the final audiologic assessment recommendations for infants up to 6 months of age were:

“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 conduct a battery of tests that includes a case history, documentation of risk indicators for hearing loss, otoscopic inspection, evoked otoacoustic emissions (OAE) assessment, auditory brainstem response (ABR) assessment, and middle ear measures. An otologic evaluation is also part of the assessment process but it may occur at a different facility and time. The approach to services should be family-centered by promoting family and professional partnerships, responding to needs, building on strengths and respecting the diversity of families.

The Advisory Committee strongly recommends that any audiologist accepting infants for audiologic assessment should have the ability to complete the following procedures: ABR threshold to frequency-specific stimuli for air and bone conduction, ABR suprathreshold to click stimuli with varied rate and polarity, tympanometry using probe tones greater than 226 Hz, acoustic reflex threshold, transient-evoked (TEOAE) or distortion product (DPOAE) equipment capable of a variety of test parameters, and behavioral audiometric test procedures that are developmentally appropriate.

The audiologist should discuss the results with the family and report the audiologic assessment results to the infant’s primary health care provider and the Nebraska Early Hearing Detection and Intervention Program. Referrals and recommendations should be made consistent with the Joint Committee on Infant Hearing’s 2007 Position Statement. If a permanent hearing loss is identified, families should be given the Nebraska Early Hearing Detection and Intervention Program’s Parent Resource Guide.”

The Sub-committee also assisted in developing a one-page reporting form that parallels the specifications for the audiologic diagnostic evaluation (HAUDIO) module of ERS-II that will be developed through the CDC cooperative agreement in 2008. Use of this form was one of the small tests of change with the NICHQ Learning Collaborative. Multiple revisions were made based on the experience of those participating in the project.

The only activity required by statute for audiologists is that annual aggregate reports are to be submitted to the NE-EHDI Program that indicate the number of newborns who return for follow-up testing, who do not have a hearing loss and who do have a hearing loss (Neb. Rev. Stat. §71-4739).

NE-EHDI Reporting, Tracking and Follow-up.

The first step of the NE-EHDI Program tracking procedure for newborns who did not pass or were discharged prior to receiving a newborn hearing screening consists of a letter to the PHCP identified in the birthing facility report. The PHCP letter is generated within two days of downloading the ERS-II hearing screening report which is done three times each week. The letter, which has been simplified over the last three years, reports the newborn hearing screening results and any recommendations made by the birthing facility, requests that the PHCP ensure that the recommended follow-up protocol is completed and submit the results to the NE-EHDI program. Included with the PHCP letter is a parent education brochure, available in ten languages, an algorithm that displays the recommended follow-up protocol and a listing of

audiology testing sites. The audiology list is self-report only; there has been no objective determination of qualifications (knowledge, skills, experience, and instrumentation) of providers of infant audiology services. Current PHCP contact information is maintained from lists obtained from the Health Professions Tracking Center at the University of Nebraska Medical Center.

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 and a letter and parent education brochure are also sent to the mother. The letter to the mother explains the birthing facility hearing screening results, encourages follow-up and talking with the baby's PHCP about the hearing screening. As a small test of change during the NICHQ Learning Collaborative in 2006, the reading grade level of the parent letter was reduced from an 11.0 level to a 7.3 level. An increase in the number of phone calls received from the mothers and an increase in the reporting of results compared with the same time period the previous year led to the full implementation of the new letter.

If results are still not received within one month, a third request is faxed to the PHCP, a second letter is sent to the mother, and the file is coded as "lost to system." The "lost to system" code was established by the NE-EHDI Advisory Committee in 2005 and marks the termination of active tracking by the NE-EHDI program. However, if follow-up results are received later, the coding is changed to reflect the new status, such as "Closed" or "Diagnosed."

The hearing 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 are sent to the PHCP, based on the audiologic and medical recommendations. There are approximately 40 babies in the "Follow-up in Progress" category at any time.

In 2006, aggregate reports on outpatient re-screenings from birthing facilities and audiology facilities indicate that 1,156 re-screenings were completed with 155 "refers." Aggregate reports from audiologists indicate 174 diagnostic audiologic evaluations were conducted for newborns/infants born in 2006. Of those, 103 were diagnosed with a hearing loss, of which 72 were permanent conductive, sensorineural or mixed hearing loss. The aggregate report does not include names so it is not possible to determine the number of babies who are reported multiple times when seen at different audiology clinics. Of the newborns/infants reported with permanent hearing loss on the required aggregate report, 26 individually-identifiable reports were submitted by audiologists to the NE-EHDI Program. Individually-identifiable reports facilitated tracking and follow-up and determining the type, degree, configuration, and ear-specificity of the each child's hearing loss.

In 2005, the NE-EHDI Advisory Committee recommended that the NE-EHDI Program track newborns/infants identified with a permanent hearing loss until age 5 years. As part of the NICHQ Learning Collaborative, a one-page status check form was developed to request the follow-up information from the PHCP. Responses from the PHCPs were good and use of the status check form has been fully implemented. It is mailed to the PHCP during the month prior to the child's birthday so that information can be obtained during the child's annual well-child check.

Plans for 2008-2009 to Reduce Lost to Follow-up

- 1 – The Community Health Educator, a new position with the NE-EHDI Program, will begin more active follow-up by phone to the PHCP and parents at the first sign of system failure, such as PHCP being incorrectly identified or the parent not following through with recommended follow-up.
- 2 – A fax back form to the PHCP, indicating the re-screening results and case status if the follow-up results are received from the birthing facility or audiologist before the PHCP report has been received by the NE-EHDI Program, will continue to be tested. This fax back form has been tested with PHCPs in one mid-sized city with good results and is ready for testing with additional practices.
- 3 – The one page audiologic reporting form that parallels the HAUDIO module in development for the ERS-II system will continue to be tested and will be spread throughout the year. In addition to serving as a reporting form to the NE-EHDI Program, it can potentially be used as a fax-back form from the audiologist to the referring PHCP. This application will be tried as a small test of change.
- 4 – The audiology resource list will be upgraded to make it more useful to consumers, both parents and PHCPs, in identifying audiologists with the necessary resources to conduct the recommended audiologic assessments. Currently, information about each provider includes information about the services provided for infants such as re-screening, hearing aid evaluation and fitting, and hearing aid loaners. Audiologic clinics will be surveyed to determine the equipment available and procedures, such as sedated ABRs, that can be performed. This resource list, coupled with the audiologic assessment recommendations developed by the Audiology Advisory Sub-committee, will assist PHCP and parents in making informed choices about accessing appropriate services.
- 5 – Meetings will be scheduled with audiologists in their local communities or clinics to discuss the new resources in the state (Nebraska Children's Hearing Aid Loaner Bank, Nebraska Families for Hands and Voices), the 2007 Position Statement of the Joint Committee on Infant Hearing (JCIH), the recommended audiologic assessment, equipment and procedure survey, the Parent Resource Guide, and one-page reporting form.
- 6 – As part of the CDC cooperative agreement, the ERS-II hearing screening module will be revised. The data system will be further developed to generate and record follow-up requests to the PHCPs, either written or using the State of Nebraska's eFax system, and parents according to the NE-EHDI Program tracking protocol.
- 7 – The HAUDIO module of ERS-II for audiologists to access and report results of screening, diagnostic evaluations, and recommendations will be developed and beta tested as part of the CDC cooperative agreement.
- 8 – Protocols will be developed with Iowa and fine-tuned with other neighboring states to facilitate the sharing of newborn hearing screening information and coordination of follow-up efforts consistent with the state of residency.

NE-EHDI Education and Technical Assistance.

A parent follow-up brochure, "Your Baby Needs Another Hearing Screening" was developed in 2005 and explains the "refer" result and the recommended follow-up activities. The brochure was based on the Universal Newborn Hearing Screening Toolkit and suggestions from the Parent Resource Sub-committee of the 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). The parent education brochures are disseminated at no cost to all birthing facilities to provide educational material to encourage follow-up. The follow-up brochure is also included with the first request letters to the PHCPs and parents.

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 three years to more clearly represent the guidelines and to more accurately reflect changes in the EHDI follow-up system.

Two graduate level classes are presented annually by the NE-EHDI program manager as guest lecturer at the University of Nebraska - Lincoln. One class is Introduction to Auditory Rehabilitation (SPA472) for audiology students and the second (SPED896E) was part of a year-long curriculum for the UNL Mountain-Prairie and Nebraska Professional Upgrade Project in Early Childhood and Deaf Education. Both classes provide an overview of relevant research, the components and status of the EHDI system at the national and state levels, and the impact of EHDI on services, interventions, and outcomes. The purpose of the classes is to increase the awareness and understanding by new professionals and to engage them in the EHDI process.

The NE-EHDI program manager serves on the continuing education committee of the Nebraska Speech-Language-Hearing Association (NSLHA) and helps plan the audiology track of the annual conference. Each year an EHDI workshop is presented, alternating between a status report and a more in-depth view of specific topics, such as early intervention partners or amplification considerations.

Katherine Beauchaine, Audiology Coordinator at Boys Town National Research Hospital, and the NE-EHDI program manager co-presented a workshop, Babies with Hearing Loss: First Steps for New Practitioners, at the American Speech-Language-Hearing Association (ASHA) annual convention in 2006. A feature article based on the workshop, Babies with Hearing Loss: Steps for Effective Intervention, was later published in the *The ASHA Leader* in February, 2007. The authors are currently developing a 2 hour eLearning course for ASHA, Babies with Hearing Loss: Providing Audiological Care to Foster Successful Outcomes.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Parent letters and surveys will be translated to be available in ten languages (English, Spanish, Vietnamese, Russian, Chinese (traditional), Arabic, French, Dinka, Anuak, and Nuer). The letters include the initial and subsequent letters to encourage follow-up for refers and discharges prior to hearing screening, letters when follow-up is in process but not completed, and materials upon diagnosis of a permanent hearing loss.

2 - The parent follow-up brochure will be translated into other languages, based on the languages spoken by refugees with the state’s refugee resettlement efforts and by new Americans in the state. The brochure will be modified to include photographs that better represent the ethnic and racial diversity of families in Nebraska.

3 – A website for NE-EHDI will be developed. It will be included as part of the Newborn Screening home page (www.dhhs.ne.gov/nsp). It will include information for parents, birthing facilities, and PHCPs, audiologists; recommended screening and audiologic diagnostic evaluation procedures; reports and publications; links and resources; and contacts.

4 – A day-long pediatric amplification workshop, presented by one or more audiologists from Boys Town National Research Hospital, will be offered to audiologists across the state to increase their capacity to provide services to very young children.

5 - Katherine Beauchaine, Audiology Coordinator at Boys Town National Research Hospital, and the NE-EHDI program manager will complete the development of a 2 hour eLearning course for ASHA, Babies with Hearing Loss: Providing Audiological Care to Foster Successful Outcomes. The course will be released during Summer, 2008.

NE-EHDI Evaluation and Quality Improvement.

One activity that was initiated as part of the NICHQ Learning Collaborative was surveying parents of babies identified with a permanent hearing loss, using the “Experience of Care Parent Survey.” The survey consists of four questions: Who delivered the results of the newborn hearing screening? Did the PHCP have the results at the first well-child visit? How often were various professionals helpful in the process of screening to confirmation of hearing loss? How often was information about various topics provided by health professionals during the process from diagnosis to early intervention services? A previous semi-annual survey of parents whose babies had referred during the birth admission screening was much longer and resulted in a low return rate. The NICHQ survey had a much better rate of return for the small numbers to whom the survey was sent. In addition, the survey encouraged other comments that did lead some parents to respond in depth to their experience.

Monthly 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, expired, and errors. The timeliness of the initiation of follow-up activities is also included in this report. Cumulative reports were generated for the Advisory Committee’s review and are incorporated into the quarterly evaluation report to the Evaluation Committee for the CDC cooperative agreement.

The Annual Report, required to be prepared for the legislature by the Infant Hearing Act, includes statistical results from individually-identifiable data and aggregate reports submitted by audiologists. The report tracks the numbers of babies as they progress through each component of the EHDI system, a comparison of individually-identifiable and aggregate reports, and the type-degree-laterality of hearing loss diagnosed.

The annual national EHDI survey developed by CDC is completed and submitted. Other national surveys are completed as requested by various entities.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Ad hoc reports will continue to be developed for the ERS-II system to gain a more in-depth understanding of the progress of babies from one component of the EHDI system to the next, the relationship of various maternal demographics to the timeliness of initiation of follow-up and to lost to follow-up, and the communities, birthing facilities, and PHCP practices with high loss to follow-up rates.

2 – Strategies will be developed to increase the reporting of individual audiologic diagnostic evaluation results in a timely and comprehensive manner. Meetings with audiologists at their practices or in small groups will be organized to provide a more individualized discussion of pediatric evaluations, reporting protocols and resources available.

Model for Improvement for Goal 2.

1 – Several birthing facilities and audiology clinics will be engaged in developing small tests of change that will involve making an appointment for the outpatient re-screening prior to the baby's discharge from birth admission, providing a contact person at the audiology clinic, providing directions to the clinic, and making reminder phone calls the day prior to the follow-up appointment.

2 - The Community Health Educator (new position) will begin more active follow-up by phone to the PHCP and parents at the time of the third request for follow-up information when the baby is 2-3 months of age. This more intensified follow-up effort may result in a reduction in the lost to follow-up rate by identifying situations where follow-up has been completed but not reported to the NE-EHDI Program and by identifying problems being experienced by the parent(s) for which a linkage with available resources may resolve the barriers.

3 - A fax back form to the PHCP indicating the re-screening results and case status if the results are received from the birthing facility or audiologist before the PHCP report has been received by the NE-EHDI Program will continue to be tested. This fax back form has been tested with PHCPs in one mid-sized city with good results and is ready for testing with additional practices.

4 – The one page audiologic reporting form that parallels the HAUDIO module in development for the ERS-II system will continue to be tested and will be spread throughout the year.

5 – The use of the one-page audiologic reporting form as a fax-back form for audiologists to provide to the referring PHCP, in addition to the NE-EHDI Program, will be a small test of change used with several different types of clinical practices.

System 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 6 months of age.

EHDI System Activities.

In Nebraska the primary early intervention activities include services coordination from the Early Development Network (EDN)/Part C Early Intervention program, educator of the deaf support through the Regional Programs for Students Who 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. A state chapter of Hands and Voices is in start-up and will provide family-to-family support. In addition, there are educational programs, such as the Omaha Hearing School, preschool services at BTNRH and Early Head Start programs.

In 2006, two thirds (16) of the babies identified with a permanent hearing loss who were individually-identifiable by the NE-EHDI Program received Part C services coordination through EDN. Of those, 14 began receiving services prior to 6 months of age. However, one third (8) of babies with permanent were not referred to EDN. Outreach to audiologists and PHCPs by the EDN's Planning Region Teams (Local Interagency Coordinating Councils) educated the primary referral sources about the importance of early intervention and the mechanism to refer for services in the last several years. EDN contact information is included on the basic parent education and the "refer" brochure developed and disseminated by the NE-EHDI Program. Letters to the PHCPs and the recommended follow-up protocol, presented in the algorithm for PHCPs, include information encouraging the referral to EDN.

During the last year and a half, early intervention partners have met to develop a process for parents of very young children recently identified with a hearing loss to have a recognized initial point of entry into the early intervention system. The organizational partners for the plan included the EDN/Part C, RPSDHH, PTI-NE, MHCP and NE-EHDI programs. The start-up chapter of Hands and Voices will also be joining the partnership. Nebraska ChildFind has been identified as the single statewide point of entry with an immediate referral to EDN for services coordination. To provide the expertise necessary to work effectively with young children with hearing loss and their families, the RPSDHH will be engaged to provide support through their knowledge of hearing loss, its effect on a child's development, resources available, and educational/communication options. Although ChildFind is the recognized point of entry, the system is being designed so that parents will get connected regardless of what organization they initially contact. Progress was slowed because of turnover of two of the key partners, but the initiative is now revived and moving toward implementation. Before full implementation occurs, training will need to occur with the direct service staff in the partner programs and a joint release of information to meet the various program requirements will be developed.

Nebraska has just begun a statewide hearing aid loaner bank, a partnership of the audiology program at the University of Nebraska-Lincoln (UNL), the Nebraska Association for the Education of Young Children (NeAEYC), and the NE-EHDI Program. During the summer of 2006, two audiology graduate students researched hearing aid loaner banks in other states, potential funding sources, and brands of hearing aids dispensed by audiologists in the state. They developed a plan for the loaner bank which was approved by the NE-EHDI Advisory Committee and the NeAEYC Board of Directors. In March, 2007, the NE-EHDI Program contracted with UNL for management of the Nebraska Children's Hearing Aid Loaner Bank (NCHALB) and with NeAEYC, a 501c3 non-profit organization, for fiscal administration of the NCHALB (Appendix F). A group of stakeholders has met monthly with the UNL audiology graduate student who is organizing and managing the NCHALB to develop policies and procedures, application processes, website, funding proposals and promotional materials. The goal is to provide amplification within one week of the request an initial loan period of six months. The NCHALB received its first contribution of 40 hearing aids from one manufacturer and the first application was received the last part of October, 2007.

NE-EHDI Reporting, Tracking and Follow-up.

When an infant is identified with a permanent hearing loss and reported to the NE-EHDI Program, a Parent Resource Guide is mailed to the PHCP to give to the parent(s). The materials in the folder include flyers about each of the programs listed above. In addition, materials include information about communication options, questions to ask the audiologist and other professionals, and the Funding Toolkit that was developed by the RPSDHH in 2006. A one-page reporting form is included in the mailing to the PHCP. The form summarizes the recommendations for early intervention services made by the audiologist and requests that the PHCP indicate the referrals that have been made consistent with the recommendations and the dates that services began.

Each quarter the NE-EHDI Program provides a list of the infants identified with a permanent hearing loss to the EDN Part C co-coordinator under an interagency agreement for the exchange of information between the birth registry, Medicaid, metabolic screening, hearing screening, EDN, and MHCP. The coordinator checks the CONNECT data system that is an integrated management information system for six programs, including EDN and MHCP. All

referrals to EDN and MCHP are included in the system, along with the disposition of the referral. For those who are verified as having special needs warranting special education and/or related services, the referrals and services provided, including services coordination, are tracked, as well as identification of the medical home. 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.

In 2005, the NE-EHDI Advisory Committee recommended that the NE-EHDI Program track newborns/infants identified with a permanent hearing loss until age 5 years. As part of the NICHQ Learning Collaborative, a one-page status check form was developed to request the follow-up information from the PHCP. Responses from the PHCPs were good and use of the status check form has been routinely implemented. It is mailed to the PHCP during the month prior to the child's birthday so that information can be obtained during the child's annual well-child check.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – 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. Significant revision resulted from input by the NE-EHDI Advisory Committee and, based on very positive feedback from a variety of stakeholders, the resource is ready to be used. Three initial tests will be completed to explore the usefulness of the document. The “roadmap” will be provided to the PHCP to give to the parent(s) when an infant needs to be referred for an audiologic diagnostic evaluation, will be included in the Parent Resource Guide, and will be inserted into PTI-NE's health record folder.

2 – Several audiologists have begun to provide the Parent Resource Guide to parents at the time of the child's diagnosis of permanent hearing loss. All have expressed positive experiences and have requested more Guides. This activity will be spread by engaging additional audiologists in providing the Guide at the time of diagnosis. The Parent Resource Guides will continue to be provided to the PHCPs to give to the parents.

3 – Full implementation of the Nebraska Children's Hearing Aid Loaner Bank will occur. As part of this program, parents will be encouraged to access EDN and RPSDHH services. The application for loaner hearing aids includes a release of information to these programs and the NE-EHDI Program.

4 – Funding for the NCHALB will be pursued with a variety of foundations.

5 - The Initial Point of Entry will move toward implementation throughout the year. This approach requires a high degree of partnership and collaboration at the state level initially, which has occurred. Implementing at the local level will require time to build partnerships, beginning at local trainings, to be able to provide consistent, effective services to families in a collaborative manner.

NE-EHDI Education and Technical Assistance.

In late 2006, a panel of early intervention providers presented during the panel section of A Toolbox for Early Identification and Management of Hearing Loss, the EHDI workshop at the annual NSLHA conference. The MHCP medical director, EDN/Part C co-coordinator, PTI-NE supporting parent coordinator, state liaison for the RPSDHH, and the ChildFind coordinator

presented overviews of their programs, eligibility requirements, and referral processes to the 35 audiologists in attendance.

Eight participants from EDN and RPSDHH attended the Institute for Persons Who Are Hard of Hearing or Deaf (IHHD) online EHDI course, Family-Centered Programming: Partnering with Families, during the summer of 2006. Plans to enroll more participants in the online course did not materialize when the IHHD program was terminated.

A workshop on hearing, hearing loss, and the importance of periodic hearing screening was conducted at the Head Start Association annual conference in 2006 and 2007.

Two graduate level classes are presented annually by the NE-EHDI program manager as guest lecturer at the University of Nebraska - Lincoln. One class is Introduction to Auditory Rehabilitation (SPA472) for audiology students and the second (SPED896E) was part of a year-long curriculum for the UNL Mountain-Prairie and Nebraska Professional Upgrade Project in Early Childhood and Deaf Education. Both classes provide an overview of relevant research, the components and status of the EHDI system at the national and state levels, and the impact of EHDI on services, interventions, and outcomes. The purpose of the classes is to increase the awareness and understanding by new professionals and to engage them in the EHDI process.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 - A series of joint trainings for EDN services coordinators and educators of the deaf in the four RPSDHH districts will be developed and conducted in local areas to move the Initial Point of Entry plan toward implementation. Part of the training will include resources for parents, including the Infant Hearing Guide CD for use with parents.

NE-EHDI Evaluation and Quality Improvement.

The NE-EHDI status reports include the number of infants referred to EDN and MHCP, the number verified and enrolled in services in both programs, and the number with a medical home. These numbers are reported by the EDN co-coordinator from data in the CONNECT system based on a list of names provided by the NE-EHDI Program. As discussed above, the system lists only the primary verified disability. For those infants with hearing loss as a secondary disability, the system cannot identify them without individual names.

The Nebraska Department of Education's annual aggregate Child Count report (numbers of children verified with hearing loss being served on December 1) will continue to be accessed.

The NE-EHDI Annual Report, required to be prepared for the legislature by the Infant Hearing Act, includes information about the numbers and percentages of infants with hearing loss enrolled in the Part C Early Intervention (EDN) and Children with Special Health Care Needs (MHCP) programs. The annual CDC national survey is completed, as well as surveys by other organizations.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – To share child-specific information among programs, work will begin to develop a standardized referral form and release of information that would be applicable for the primary partners in the EHDI system: NE-EHDI, birthing facilities, audiologists, PHCPs, EDN, MHCP, RPSDHH, PTI-NE, Hands and Voices, NCHALB.

Model for Improvement for Goal 3.

1 – Exploration of strategies for audiologists to introduce the materials in the Parent Resource Guide to parents will begin with those who have already been using them. Provision of the

Guide by audiologists at the time of diagnosis of hearing loss will be spread to more audiology evaluation sites.

2 – Begin to include postcards in the Parent Resource Guide for parents to request contacts by Hands and Voices and PTI-NE to determine the level of requests.

3 – Include Experience of Care Parent Survey in the Parent Resource Guide.

4 – Develop a fax-back form for use by EDN to provide information to the referring PHCP.

5 - Three initial tests will be completed to explore the usefulness of the “roadmap.” The “roadmap” will be provided to the PHCP to give to the parent(s) when an infant needs to be referred for an audiologic diagnostic evaluation, will be included in the Parent Resource Guide, and will be inserted into PTI-NE’s health record folder.

System Goal 4 - All infants with a confirmed hearing loss will have a medical home.

EHDI System Activities.

In 2001, the Advisory Committee of the NE-EHDI Program established that the newborn’s Primary Health Care Provider (PHCP) would be the primary focus of the immediate follow-up efforts and would be based on established follow-up protocols for the metabolic/dried blood spot (DBS) program. This has been successful, with hearing levels (normal hearing, permanent hearing loss) established for 86.1% of the newborns reported to the NE-EHDI Program as needing a follow-up screening from the birth admission screening in 2006. However, for cases in which the PHCP is not correctly identified for a variety of reasons, the follow-up system can quickly break down. With the advent of the new ERS-II data system, the on-site training at the 63 birthing facilities stressed the need to accurately identify the PHCP, as well as the preferred maternal language and phone number for those cases in which parent contact is needed.

When an infant has been identified as having a hearing loss, the American Academy of Pediatrics (AAP) recommends that the child can best be served within the context of a medical home. The current follow-up protocol for the newborns who refer or were discharged prior to screening was reviewed by the Advisory Committee in 2006. The Committee recommended continuing the current system of coordinating initial follow-up through written first and second requests to the Primary Health Care Provider (PHCP). Based on the Advisory Committee’s recommendations, a third PHCP request is faxed and program procedures were adjusted to incorporate the new addition to the protocol. In addition, the tracking and follow-up protocol for infants identified with middle-ear dysfunction was adjusted to follow a similar schedule. In 2005, the Advisory Committee recommended that the NE-EHDI track newborns/infants identified with a hearing loss until age 5 years.

The NE-EHDI Program is involved with Together for Kids and Families (TFKF), Nebraska’s State Early Childhood Comprehensive Systems grant program funded by HRSA/MCHB, which seeks to achieve optimum outcomes for Nebraska’s young children and their families through comprehensive systems planning and collaborative effort among stakeholders. The TFKF Medical Home workgroup is co-chaired by Dr. Thomas Tonniges, Director of Boys Town Institute for Child Health Improvement, and the program manager for the NE-EHDI Program. The Medical Home workgroup is tasked with implementing two strategies: Developing and implementing a collaborative initiative to promote the medical home approach as the standard of care for all children and establishing a comprehensive program to promote regular recommended pediatric visits for children following the American Academy of Pediatrics

and the new Bright Futures guidelines. A workshop is planned for the annual Nebraska Head Start conference in November, 2007, that will focus on parent understanding of the benefits of a medical home. The trainers for the workshop are three members of the TFKF Medical Home workgroup: executive director of a large early care and education program, coordinator for PTI-NE's new Family-to-Family Health Information Center, and NE-EHDI program manager.

The NE-EHDI Program has begun an approach to use the dried blood spot (DBS) from newborn metabolic/DBS screening to assist in determining the etiology of congenital hearing loss. By statute, the DBS is stored for 90 days and destroyed within the next 30 days. The Advisory Committees of the Newborn Screening and Genetics Program and NE-EHDI, after discussions for more than a year, determined that procedures would be developed for the PHCP to retrieve the DBS with parent consent for those babies identified with a permanent hearing loss prior to 90 days of age. This would assist in establishing the etiology of the hearing loss, in particular congenital cytomegalovirus. The Advisory Committees of both programs will continue to pursue more expansive uses of the DBS to establish the etiology of hearing loss.

NE-EHDI Reporting, Tracking and Follow-up.

As stated in Goal 1, the first step of the NE-EHDI Program tracking procedure for newborns who did not pass or were discharged prior to receiving a newborn hearing screening consists of a letter to the PHCP identified in the birthing facility report. The PHCP letter is generated within two days of downloading the ERS-II hearing screening report which is done three times each week. The letter, which has been simplified over the last three years, reports the newborn hearing screening results and any recommendations made by the birthing facility, requests that the PHCP ensure that the recommended follow-up protocol is completed and submit the results to the NE-EHDI program. Included with the PHCP letter is a parent education brochure, available in ten languages, an algorithm that displays the recommended follow-up protocol and a listing of audiology testing sites. Current PHCP contact information is maintained from lists obtained from the Health Professions Tracking Center at the University of Nebraska Medical Center.

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 and a letter and parent education brochure are also sent to the mother. If results are still not received within one month, a third request is faxed to the PHCP, a second letter is sent to the mother, and the file is coded as "lost to system." The "lost to system" code was established by the NE-EHDI Advisory Committee in 2005 and marks the conclusion of active tracking by the NE-EHDI program.

The hearing 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.

In 2005, the NE-EHDI Advisory Committee recommended that the NE-EHDI Program track newborns/infants identified with a permanent hearing loss until age 5 years. As part of the NICHQ Learning Collaborative, a one-page status check form was developed to request the follow-up information from the PHCP. Responses from the PHCPs were good and use of the

status check form has been fully implemented. It is mailed to the PHCP during the month prior to the child's birthday so that information can be obtained during the child's annual well-child check.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – The Community Health Educator, a new position with the NE-EHDI Program, will begin more active follow-up by phone to the PHCP and parents at the first sign of system failure, such as PHCP being incorrectly identified or the parent not following through with the recommended follow-up.

2 – A fax back form to the PHCP, indicating the re-screening results and case status if the follow-up results are received from the birthing facility or audiologist before the PHCP report has been received by the NE-EHDI Program, will continue to be tested. This fax back form has been tested with PHCPs in one mid-sized city with good results and is ready for testing with additional practices.

3 – The one page audiologic reporting can potentially be used as a fax-back form from the audiologist to the referring PHCP. This application will be tried as a small test of change.

NE-EHDI Education and Technical Assistance.

Knowledgeable PHCPs are important to ensure that the EHDI system works effectively and efficiently and that the number of babies who are lost to follow-up is minimized. Key findings from the Newborn and Infant Hearing Screening Survey, developed by Boys Town National Research Hospital (BTNRH) and National Center for Hearing Assessment and Management (NCHAM) in 2005, are:

- 89% of physicians received newborn hearing screening results from the birthing facility.
- 89% knew that additional testing should be completed prior to 3 months of age.
- 22% thought that an infant could not be fitted with a hearing aid before 12 months of age.
- 12% thought an infant could not be referred to Early Intervention before 12 months of age.

Although the results indicates that the respondents had a good understanding of the initial benchmarks for EHDI, the lack of knowledge and understanding about accessing basic early interventions at the earliest possible age indicates an opportunity for professional development.

The primary method of educating PHCPs about newborn hearing screening and the follow-up needed for those babies who do not pass the birth admission screening has been to clearly and succinctly present the information needed for the next step in the follow-up process at the time it is needed.

Educational material was mailed to all PHCPs in Nebraska in August, 2007, explaining the process to retrieve the DBS prior to its destruction to assist in determining the etiology of congenital hearing loss.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – The audiology resource list will be upgraded to make it more useful to consumers, both parents and PHCPs, in identifying audiologists with the necessary resources to conduct the recommended audiologic assessments. This resource list, coupled with the audiologic assessment recommendations developed by the Audiology Advisory Sub-committee, will assist PHCP and parents in making informed choices about accessing appropriate services.

2 - BTNRH is developing a web-portal for physicians on the www.babyhearing.org website which will contain information pertaining to newborn/infant hearing loss, including a special focus on etiology due to genetic factors. A fact sheet about late onset hearing loss has been

completed at BTNRH and work has begun on fact sheets about cochlear implants, new technologies, and the genetics of hearing loss. As these become available, they will be provided to PHCPs.

3 – A website for NE-EHDI will be developed. It will be included as part of the Newborn Screening home page (www.dhhs.ne.gov/nsp). It will include information for parents, birthing facilities, and PHCPs, audiologists; recommended screening and audiologic diagnostic evaluation procedures; reports and publications; links and resources; and contacts.

NE-EHDI Evaluation and Quality Improvement.

The follow-up completion rate of over 85% in 2006 indicates that the PHCPs, as well as parents and the professionals in the birthing facilities and audiology sites, understand the need to complete the recommended follow-up in a timely manner.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Ad hoc reports will continue to be developed from the ERS-II system to gain a more in-depth understanding of the progress of babies from one component of the EHDI system to the next, the relationship of various maternal demographics to the timeliness of initiation of follow-up and to lost to follow-up, and the communities, birthing facilities, and PHCP practices with high loss to follow-up rates.

Model for Improvement for Goal 4.

1 - The Community Health Educator (new position) will begin more active follow-up by phone to the PHCP and parents at the time of the third request for follow-up information when the baby is 2-3 months of age. This more intensified follow-up effort may result in a reduction in the lost to follow-up rate by identifying situations where follow-up has been completed but not reported to the NE-EHDI Program.

2 - A fax back form to the PHCP indicating the re-screening results and case status if the results are received from the birthing facility or audiologist before the PHCP report has been received by the NE-EHDI Program will continue to be tested. This fax back form has been tested with PHCPs in one mid-sized city with good results and is ready for testing with additional practices.

3 – The use of the one-page audiologic reporting form as a fax-back form for audiologists to provide to the referring PHCP, in addition to the NE-EHDI Program, will be a small test of change used with several different types of clinical practices.

4 – Develop a fax-back form for use by EDN to provide information to the referring PHCP.

5 – An initial test will be completed to explore the usefulness of the “roadmap” to guide parents through the sequence of recommended follow-up activities. The “roadmap” will be provided to the PHCP to give to the parent(s) when an infant needs to be referred for an audiologic diagnostic evaluation.

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

EHDI System Activities.

A brief survey was developed by the NE-EHDI Program in 2006 to identify family-to-family support resources in Nebraska. Most of the family-to-family support reported was informal although there were instances where educators of the deaf or audiologists had organized more formal efforts. There has been no organized statewide system of family-to-family support.

During the summer of 2007, a group of parents, primarily from the Omaha area, began to organize an effort to start a chapter of Hands and Voices. In September a statewide meeting was held to explain Hands and Voices and to generate additional interest in organizing a chapter. Using distance-technology, the meeting originated at BTNRH and was down-linked to three sites across the state. The NE-EHDI Program supported the effort by contracting with Janet DesGeorges of Hands and Voices to present and to arrange for the down-link sites. Parents have continued to meet and are taking the necessary steps to become an official chapter. In September, 2007, information about the new chapter was presented to the NE-EHDI Advisory Committee and also to audiologists at the NSLHA state convention during the NE-EHDI workshop.

Representatives from RPSDHH and PTI-NE joined the NE-EHDI program manager at the “Investing in Family Support” conference in 2006. The work plan that was developed at the conference was approved by the NE-EHDI Advisory Committee, including the formation of a Family Support Sub-committee. The Sub-committee received approval by DHHS as a volunteer workgroup in the summer of 2007. Seven family members have agreed to serve on the sub-committee. A leader from the start-up Nebraska chapter of Hands and Voices joined staff from EDN, PTI-NE, and NE-EHDI at the 2nd Annual “Investing in Family Support” conference in October, 2007, at which time the work plan was revised. It is anticipated that the Family Support Sub-committee will meet prior to January, 2008.

The program manager of the NE-EHDI Program is a member of the Parent Support workgroup of TFKF. This workgroup focuses on implementing a strategy to integrate parent-to-parent support systems into existing and new programs and services for families.

NE-EHDI Reporting, Tracking and Follow-up.

The NE-EHDI Program currently does not have any reporting, tracking, or follow-up mechanisms developed for family support services.

Plans for 2008-2009 to Reduce Lost to Follow-up

- 1 – Begin implementation of the “Investing in Family Support” work plan beginning with the first meeting of the Family Support Sub-committee of the Advisory Committee. Possible activities for the sub-committee to consider is a statewide parent conference, development of resource materials, development of a mentor system, and development of web-based support mechanisms.
- 2 - Provide meeting support, such as cost of meeting rooms or downlink sites, to family-to-family support initiatives.
- 3 – Determine the feasibility of establishing a Guide by Your Side program with the Nebraska Families for Hands and Voices chapter. The Guide by Your Side program is a national program that has been organized by Hands and Voices to provide family-to-family support to parents of children recently identified with a hearing loss. The support initially includes one or more home visits by parents who have been trained by Hands and Voices and who are paid for their work with the family.
- 4 - Begin to include postcards in the Parent Resource Guide for parents to request contacts by Hands and Voices and PTI-NE to determine the level of requests.

NE-EHDI Education and Technical Assistance.

PTI-NE, a federally funded Parent Training and Information Center, offers four workshops for parents of young children with disabilities, including hearing loss. The

workshops are Rebuilding Dreams, Early Development Network, Individualized Family Support Plan (IFSP), and Individualized Family Support Plan (IFSP) to Individualized Education Plan (IEP). The start-up chapter of Hands and Voices has been invited by PTI-NE to consider these workshops as part of their educational efforts.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Partner with BTNRH to organize a weekend workshop for parents of young children up to age 3 years who have recently been identified with a hearing loss, especially those in the rural parts of the state. The purpose of the workshop will be to provide an opportunity for parents to connect with other parents, begin to fulfill their psychosocial needs, and, with “toolkits” to be developed, understand the various aspects of hearing loss and its impact on their family. PTI-NE, RPSDHH, EDN, and NeAEYC will be invited to partner in this project.

2 – A parent panel will be included in the EHDI track of the Lifespan Health Services conference on April 16, 2008 for the designated hearing screening coordinator from each birthing facility. The parents will share their experiences with newborn hearing screening focusing on what worked well and what could have been improved. The panel presentation will occur as part of the portion of the training devoted to the NICHQ Model for Improvement’s Plan-Do-Study-Act (PDSA) cycle. Each participant will develop at least one PDSA to try a small test of change such as using scripts to present results to parents.

3 - Include Hands and Voices newsletters in the Parent Resource Guides to be presented to parents by audiologists and PHCPs.

NE-EHDI Evaluation and Quality Improvement.

The second goal of the revised “Investing in Family Support” work plan is to evaluate the effectiveness of the family support system in the state of Nebraska. Because family-to-family support is a new component for the EHDI system in Nebraska, there has not been any evaluation or quality improvement initiatives at this time.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Include the Experience of Care Parent Survey in the Parent Resource Guide.

Model for Improvement for Goal 5.

The family-to-family support system is largely parent-driven with professional support. The NE-EHDI Program will encourage both the start-up chapter of Hands and Voices and the Family Support Sub-committee to consider the NICHQ Model for Improvement using small tests of change as the first step of the PDSA cycle.

System Goal 6 - The hearing of young children in Nebraska will be screened periodically.

EHDI System Activities.

To begin the process of implementing periodic early childhood hearing screening in Nebraska, the Early Childhood Hearing Outreach (ECHO) project, developed by NCHAM and funded by the Office of Head Start, was delivered by the ECHO team in Nebraska to two Early Head Start (EHS) programs. The ECHO training team consisted of four audiologists, including the program manager of NE-EHDI; an educator of the deaf; an early childhood training coordinator; and the AAP EHDI Chapter Champion. Four additional Early Head Start programs were trained during 2006 to conduct OAE screenings with the infants and toddlers enrolled in their programs, joining two programs that had been trained in 2004. One of the EHS programs included other early intervention service providers (EDN, RPSDHH, public schools) in the

training and subsequent implementation. Monthly reports of the screening results of the programs have been provided by NCHAM and were periodically discussed with both the NCHAM staff and the EHS programs. To date, 739 newborns, infants and toddlers have been screened, with two children having been identified with a permanent hearing loss. Almost 85% of the young children screened eventually passed the screening. Due to high mobility among Early Head Start families, over 13% exited the EHS program prior to completing the re-screening process. A workshop focusing on hearing screening for children birth to five years has been conducted for the last three years at the annual Nebraska Head Start Association conference.

One of the ECHO team members, an educator of the deaf at The Omaha Hearing School (OHS), adapted the ECHO protocol and established a community outreach program, the Campaign for Healthy Hearing in Kids. She and another educator of the deaf at OHS have screened over 3,000 young children at health fairs and early care and education centers, including Head Start. Based on this experience in early care and education centers, the NE-EHDI Program has contracted with OHS to partner in providing training and technical assistance to EHS programs on a periodic and “as needed” basis.

Two health clinics, the Fred LeRoy Health and Wellness Clinic, which is the Ponca Tribe’s health center, and Boys Town Primary Pediatric Clinic, were participants in the NICHQ Learning Collaborative. Both clinics expressed interest in adding periodic OAE hearing screening as part of routine well-child checks and have just purchased the equipment. Training of staff from both clinics is scheduled to occur in November, 2007, based on NCHAM’s “Hear and Now” protocol, with a hands-on practice session during a WIC clinic at the Fred LeRoy Clinic.

Groundwork has been established by the NE-EHDI Program with Lincoln Action Program’s Clinic with a Heart to provide hearing screenings, including OAE screenings, as a practicum experience for AuD students in audiology at the University of Nebraska-Lincoln (UNL). This would provide the audiology students with multi-cultural experience since the Clinic with a Heart primarily serves the health needs of New Americans. Lack of availability of appropriate screening equipment initially delayed implementation of this project but the NE-EHDI program, as part of the ECHO program, has offered the equipment. UNL is exploring how to integrate this project into the practicum experience.

The Business Analyst for the NE-EHDI Program has explored ChildPlus, one of the two primary data tracking systems used in Early Head Start/Head Start, to determine how to adapt the system to the ECHO screening and tracking protocol. Once completed, the HSFIS data tracking system will be evaluated to determine how best to adapt it support the protocol.

Initial discussions were held with Early Head Start/Head Start directors and with the Head Start State Collaboration Office to begin consideration of reporting of the child-specific screening results to NE-EHDI PROGRAM as part of a longer-term tracking process, to identify those who may have been “lost to follow-up,” and to identify those with a later-onset or progressive hearing loss. A Memorandum of Agreement (MOA) has been considered to formalize the reporting and tracking process.

Plans for 2008-2009 to Reduce Lost to Follow-up

1 – Re-train Early Head Start and health clinic staff, as needed. Provide ongoing technical assistance, especially with EHS staff, with periodic conference calls and individual phone calls.

- 2 – Develop the MOA with EHS/HS programs to facilitate reporting of hearing screening results to the NE-EHDI Program to search for a match with the lost to follow-up category.
- 3 - Proceed with determining how best to structure the EHS/HS data systems to support hearing screening protocols.
- 4 - Support the Clinic with a Heart practicum site through loaning of OAE screening equipment.

System Goal 7 – Professionals working with young children with a hearing loss will increase their capacity to provide appropriate services to young children.

The progress in providing education and technical assistance to hearing health professionals has been presented in the Education and Technical Assistance section of Goals 1-7.

Plans for 2008-2009 to Reduce Lost to Follow-up

- 1 – The basic parent education and the follow-up brochures will be translated into other languages, based on the languages spoken by refugees with the state's refugee resettlement efforts and by new Americans in the state. The brochures will be modified to include photographs that better represent the ethnic and racial diversity of families in Nebraska.
- 2 - On April 16, 2008, a track for hearing screening coordinators will be included in the Lifespan Health Services conference. The content of the conference will include health disparities based on maternal demographics linked to outcomes (lost to follow-up, timeliness of initiation of follow-up), a training module in development by NCHAM, sharing of effective practices, parent panel of perspectives of newborn hearing screening and explanations of results, and NICHQ's Model for Improvement. The parents will share their experiences with newborn hearing screening focusing on what worked well and what could have been improved. The panel presentation will occur as part of the portion of the training devoted to the Plan-Do-Study-Act (PDSA) cycle. Each participant will develop at least one PDSA to try a small test of change such as using scripts to present results to parents.
- 3 - Individualized technical assistance will be offered to birthing facilities based on the results of monthly/quarterly comparison quality assurance reports.
- 4 – Parent letters and surveys will be translated to be available in ten languages (English, Spanish, Vietnamese, Russian, Chinese (traditional), Arabic, French, Dinka, Anuak, and Nuer). The letters include the initial and subsequent letters to encourage follow-up for refers and discharges prior to hearing screening, letters when follow-up is in process but not completed, and materials upon diagnosis of a permanent hearing loss.
- 5 – A website for NE-EHDI will be developed. It will be included as part of the Newborn Screening home page (www.dhhs.ne.gov/nsp). It will include information for parents, birthing facilities, and PHCPs, audiologists; recommended screening and audiologic diagnostic evaluation procedures; reports and publications; links and resources; and contacts.
- 6 – A day-long pediatric amplification workshop, presented by one or more audiologists from Boys Town National Research Hospital, will be offered to audiologists across the state to increase their capacity to provide services to very young children.
 - Katherine Beauchaine, Audiology Coordinator at Boys Town National Research Hospital, and the NE-EHDI program manager will complete the development of a 2 hour eLearning course for ASHA, Babies with Hearing Loss: Providing Audiological Care to Foster Successful Outcomes. The course will be released during Summer, 2008.
- 8 - A series of joint trainings for EDN services coordinators and educators of the deaf in the four RPSDHH districts will be developed and conducted in local areas to move the Initial Point of

Entry plan toward implementation. Part of the training will include resources for parents, including the Infant Hearing Guide CD for use with parents.

9 – The audiology resource list will be upgraded to make it more useful to consumers, both parents and PHCPs, in identifying audiologists with the necessary resources to conduct the recommended audiologic assessments. This resource list, coupled with the audiologic assessment recommendations developed by the Audiology Advisory Sub-committee, will assist PHCP and parents in making informed choices about accessing appropriate services.

10 - BTNRH is developing a web-portal for physicians on the www.babyhearing.org website which will contain information pertaining to newborn/infant hearing loss, including a special focus on etiology due to genetic factors. A fact sheet about late onset hearing loss has been completed at BTNRH and work has begun on fact sheets about cochlear implants, new technologies, and the genetics of hearing loss. As these become available, they will be provided to PHCPs.

11 – A website for NE-EHDI will be developed. It will be included as part of the Newborn Screening home page (www.dhhs.ne.gov/nsp). It will include information for parents, birthing facilities, and PHCPs, audiologists; recommended screening and audiologic diagnostic evaluation procedures; reports and publications; links and resources; and contacts.

12 – Partner with BTNRH to organize a weekend workshop for parents of young children up to age 3 years who have recently been identified with a hearing loss, especially those in the rural parts of the state. The purpose of the workshop will be to provide an opportunity for parents to connect with other parents, begin to fulfill their psychosocial needs, and, with “toolkits” to be developed, understand the various aspects of hearing loss and its impact on their family. PTI-NE, RPSDHH, EDN, and NeAEYC will be invited to partner in this project.

13 - Include Hands and Voices newsletters in the Parent Resource Guides to be presented to parents by audiologists and PHCPs.

14 – Re-train Early Head Start and health clinic staff, as needed. Provide ongoing technical assistance, especially with EHS staff, with periodic conference calls and individual phone calls.

System Goal 8 – The NE-EHDI Program will provide an effective structure for the early hearing detection and intervention system in Nebraska.

The infrastructure of the NE-EHDI Program will continue to be strengthened to create a more seamless, integrated EHDI system for young children with hearing loss, to develop additional follow-up activities to reduce the number of newborns/infants who are lost to follow-up and to provide the foundation for ongoing evaluation and quality improvement. Four components of the infrastructure provide the cornerstones for the NE-EHDI Program: ERS-II data system, Advisory Committee, emergency preparedness plan, and staff.

NE-EHDI Electronic Data System.

The NE-EHDI Program was awarded a CDC Early Hearing Detection and Intervention Tracking, Surveillance, and Integration cooperative agreement in July, 2005 to support the final development and implementation of the electronic data system and its linkage and integration with other child data systems. The newborn hearing screening reporting system is an integrated module of the State’s Vital Records Electronic Registration System (ERS-II), developed by Netsmart, Inc. The reporting component of the data system consists of two types of records. 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, as

well as maternal demographic information (race, ethnicity, age, and education level). Hearing screening event data for all newborns who pass the birth admission hearing screening is entered into the “Quick Record” section of the HINFO record by authorized birth facility personnel. The HINFO record also contains a summary tab for information about hearing screenings, audiologic diagnostic, medical and early intervention services. The second type of record is a detail record, the HSCREENING record, in which screening event data is entered by authorized hospital personnel for newborns who did not pass (“refer”) the birth admission screening or did not receive a hearing screening during birth admission, including transfers to an NICU. Additional parent and disposition data is entered to facilitate follow-up activities. The data system includes basic Search functions for birth, HINFO, and HSCREENING records; six work queues in which pending records are placed for easy access by hospital personnel, and ten aggregate reports.

Each birthing facility has ten quality and status reports available. The aggregate reports are automatically incremented each time new data are input into the reporting system. The reports available are: inpatient screenings completed, outpatient screenings completed, HINFO counts, intervention recommended, inpatient screenings not completed and reasons, outpatient screenings not completed and reasons, number of parents educated about hearing screening, refer rates, number of refers, and percent of newborns screened. These individual reports for each birthing facility, as well as the state-wide totals, are available to the NE-EHDI Program.

Each week, exception reports are generated to identify records (birth certificates without HINFO records or HINFO records without results, except those admitted to an NICU) of newborns that are more than 21 days old. The hospital-specific exception reports are faxed to the birth facilities responsible for reporting the results, followed by a phone call to provide technical assistance in completion of the overdue record. The weekly exception reports typically indicate less than 25 overdue records.

The basic architecture of the newborn hearing screening data system was developed to include audiologic evaluation and management data. The Hearing Audiologist Evaluation (HAUDIO) record, populated from the HINFO record, consists of six screens (System, History, Tests, Diagnosis, Disposition, and Amplification). Although the diagnostic audiologic component has been developed, further enhancements and modifications prior to dissemination are needed. The HRISKS record, populated from the HINFO record, contains check boxes for the risk factors for hearing loss. The risk factor (HRISKS) component has been developed but further enhancements and modifications planned prior to full integration within the data system. These enhancements will include modifications based on the JCIH 2007 position statement and automatic population of risk factors recorded in the birth certificate.

To achieve full integration within the ERS-II system, applications will be developed that link the hearing screening module with the birth defects and death certificate registry modules. The sharing of information between birth defects and newborn hearing screening will facilitate the inclusion of some additional risk factor data in the HRISKS record. Integration with the death certificate registry will serve to remove from active status the records of newborns and infants who have received a hearing screening but later have expired.

The evaluation work group of the Advisory Committee meets quarterly to develop the program evaluation and dissemination plans. An evaluation plan that includes both formative and summative parts has been developed and finalized using the Framework for Program Evaluation in Public Health as a guide.

NE-EHDI Advisory Committee.

The Advisory Committee for the NE-EHDI Program meets quarterly. The 22 members represent a cross-section of stakeholders in the EHDI system (see Appendix B). Two years ago new members were added to better represent parents and early intervention providers.

Specific tasks to be accomplished by the Advisory Committee are 1) to continue to increase the representation of stakeholders, 2) to review and, as necessary, revise the existing protocols to incorporate the electronic data system, 3) to develop new reporting, tracking and follow-up protocols to effectively link the NE-EHDI Program and the early intervention systems, 4) to increase the program's responsiveness to the expanding cultural and linguistic communities in the state, 5) to support the development of an effective professional development system, and 6) to guide the long-term planning and evaluation of the EHDI system in the state.

Recent activity of the Advisory Committee has included discussing and approving the "Investing in Family Support," and "Initial Point of Entry" work plans; analyzing the feasibility of screening for congenital cytomegalovirus (CMV), Connexin 26 and 30, mitochondrial, and Pendred syndrome and recommending a course of action to retrieve the DBS for babies identified with a permanent hearing loss; significant input into revision of the NICHQ "roadmap" of services; and participating in a strategic planning session with other stakeholders.

Sub-committees continue to be developed to create functional work groups and to engage a more diverse group of members in the development of the program. The Family Support Sub-committee and the Evaluation Sub-committee are current and the Audiology Sub-committee recently finished its work to review and revise recommended protocols so is now inactive.

NE-EHDI Emergency Preparedness Plan.

An emergency preparedness plan to address strategies to ensure that hearing screenings and follow-up would occur in situations of local or more widespread emergencies was developed for inclusion with the Lifespan Health Services' overall emergency preparedness plan.

NE-EHDI Staffing.

The staffing pattern for the basic operations of the NE-EHDI Program has consisted of the 0.5 FTE program manager, a 1.0 FTE temporary staff assistant, and a 0.4 FTE administrative assistant. The program manager is also 0.5 FTE with the Centers for Disease Control and Prevention Early Hearing Detection and Intervention Tracking, Surveillance, and Integration cooperative agreement. Approval has been given to create a permanent 1.0 FTE Community Health Educator II position to replace the temporary staff assistant and part-time administrative assistant. The Community Health Educator II position will function as a follow-up coordinator, taking a more active role in outreach with more difficult cases than has been possible with the current staffing structure.

The CDC EHDI Tracking, Surveillance, and Integration cooperative agreement has supported contracting with a 0.95 FTE business analyst to manage the final development, testing, and roll-out of the integrated electronic data reporting and tracking system. Subsequent focus, in addition to the ongoing development of the data system and administrative reports, will be on linking and integrating with other early childhood data systems.

Job descriptions for these positions and resumes for the program manager and business analyst are presented in Appendices D and E. The Community Health Educator II is a new position and will not be filled until late winter or early spring of 2008.

System Goal 9 – The Early Hearing Detection and Intervention system will be promoted.

Promotion of the EHDI system is a new goal for the NE-EHDI Program. Promotion has consisted of the following activities:

- 1 – The 2006 Annual Report, developed in conjunction with the metabolic (bloodspot) screening program, was disseminated to 343 stakeholders. An executive summary of the 2006 Annual Report was disseminated to 2,050 stakeholders.
- 2 – News release with key statistics from the Annual Report.
- 3 – Exhibits at conferences (Nebraska Speech-Language-Hearing Association, Nebraska Head Start Association, Nebraska Public Health Association, Nebraska Association for the Education of Young Children, and Minority Health)

Plans for 2008-2009

- 1 – CDC and BTNRH are developing Public Service Announcements. When they are ready for use, the NE-EHDI Program will use them to promote the EHDI system.
- 2 – The Parent Support work group of TFKF is linked with the Nebraska Children and Families Foundation's Learning from Day One campaign. The multi-media campaign consists of radio spots, press releases, newsletter articles, events, and email/mail materials for three months for each topic. Hearing screening is one of the selected topics and will be promoted during March to May, 2008, or March to May, 2009, to coincide with Better Speech and Hearing Month.
- 3 – Develop a marketing and promotion plan for subsequent years.

WORK PLAN 2008-2011

Notes: "Quarters" column indicates the time in which the activity will occur, beginning with Quarter 1 on April 1, 2008. Model for Improvement-PDSA = <small test of change included in this activity>. List of Abbreviations in Appendix C.

<u>System Goal 1 - The hearing of all newborns born in Nebraska will be screened during the birth admission or, if born out-of hospital, by 1 month of age.</u>	Healthy People 2010 (28-11) Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months.	
Program Objective 1.1 – Birthing facilities will submit hearing screening status reports for 100% of newborns, including transfers to NICUs.	Measurement – Number and percent of "refers," number and percent of discharges prior to screening, reasons for discharge, timeliness of reporting, error rate.	
Activities	Quarters	Person(s) Responsible
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; manual follow-up, reporting, and input (converted to electronic with revision of ERS-II)	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII; Hosp Staff
Revision of integrated electronic data system (CDC)	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst, Prgm Mgr; Netsmart; Adv Cmte

Training and orientation of hospital staff; technical assistance provided (CDC)	☐ 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.	Measurement – 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 NE-EHDI 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	Measurement – Number and percent of hearing screenings completed for out-of-hospital births.	
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 2 - All newborns who “refer” on the initial hearing screening will complete an outpatient re-screening and/or audiologic diagnostic evaluation prior to 3 months of age.	Healthy People 2010 (28-11) Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months. Healthy People 2010 (28-15) Increase the number of persons who are referred by their primary care physician for hearing evaluation and treatment.
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Program Objective 2.1 – Tracking of outpatient follow-up activities occurs with PHCP and/parent(s)	Measurement – 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 developed 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 parental permission to release audiologic/ screening reports to NE-EHDI program.	Measurement – Comparison of number of individual reports received with annual aggregate report	
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.	Measurement – 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
Revision of integrated electronic data system to develop HAUDIO module (CDC)	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst, Prgm Mgr; Netsmart; Adv Cmte
<Audiologic and amplification 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	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

Program Objective 2.4 – Confirmatory testing facilities will submit the annual aggregate report required by statute.	Measurement – Number evaluated, number with hearing loss, number without hearing loss	
Activities	Quarters	Person(s) Responsible
Notification of report requirements disseminated to audiologists	Q1 Q2 Q3 <u>Q4</u> Q5 Q6 Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	Prgm Mgr, CHEII, Auds
Audiologists submit annual aggregate report to NE-EHDI program	Q1 Q2 Q3 <u>Q4</u> Q5 Q6 Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	Prgm Mgr, Auds, CHEII
Reconciliation of aggregate and individual reports	Q1 Q2 Q3 Q4 <u>Q5</u> Q6 Q7 Q8 <u>Q9</u> Q10 Q11 Q12	Prgm Mgr, CHEII

System 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 6 months of age.	Healthy People 2010 (28-11) Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months. Healthy People 2010 (28-13) Increase access by persons who have hearing impairments to hearing rehabilitation services and adaptive devices, including hearing aids, cochlear implants, or tactile or other assistive or augmentative devices.	
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	Measurement – Number of referrals made to each EI provider	
Activities	Quarters	Person(s) Responsible
Referral protocols reviewed with EI and NE-EHDI Program subcommittee	<u>Q1</u> Q2 Q3 <u>Q4</u> Q5 Q6 Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	Prgm Mgr; EDN; MHCP, RPSDHH, PTI-NE, Adv Cmte, EHDI Chapter Champion
Referral protocols, including promotional information, disseminated to PHCP and audiologists	<u>Q1</u> <u>Q2</u> Q3 Q4 Q5 <u>Q6</u> Q7 Q8 Q9 <u>Q10</u> 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>	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Auds, PHCP, CHEII, Planning Region Teams
Referral reports submitted to NE-EHDI program through age 5 years	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	CHEII, Auds, PHCP

Program Objective 3.2 – Parents will access early intervention services through a single initial point of entry.	Measurement – Number of referrals and requests made through ChildFind	
Activities	Quarters	Person(s) Responsible
Initial Point of Entry plan will be implemented.	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> 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 Nebraska Children’s Hearing Aid Loaner Bank.	Measurement – Number of referrals made, results of referrals (hearing aid fittings, hearing aid loans, etc.)	
Activities	Quarters	Person(s) Responsible
NCHALB will be fully operational	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Prgm Mgr, UNL, NeAEYC
Hearing aid loans completed within one week of request	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	UNL
NCHALB will be funded through a variety of funding mechanisms	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Prgm Mgr, UNL, NeAEYC
Program Objective 3.4 – Audiologists will recommend, as appropriate, all infants with confirmed hearing loss for medical evaluations, genetic evaluations and family support.	Measurement – Number of referrals made, results of referrals (diagnoses)	
Activities	Quarters	Person(s) Responsible
Referral and reporting protocols developed by subcommittee and review of sources of payment for amplification.	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> Q7 Q8 <u>Q9</u> Q10 Q11 Q12	Prgm Mgr; Adv Cmte, EHDI Chapter Champion
Referral and reporting protocols disseminated to audiologists	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> Q7 Q8 Q9 <u>Q10</u> Q11 Q12	Prgm Mgr, NSLHA
Reports of recommendations results submitted to NE-EHDI Program	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	CHEII, Auds, Med Specialists
Program Objective 3.5 – The Early Development Network, Medically Handicapped Children’s Program, RPSDHH, and other early intervention providers will submit individual and annual aggregate reports of early intervention services.	Measurement – Number of referrals 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	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; EDN; MHCP, RPSDHH, Adv Cmte, OHS, BTNRH

intervention providers		
Reporting protocols disseminated to early intervention providers and orientation completed	Q1 Q2 Q3 <u>Q4 Q5</u> Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; EDN and Planning Region Teams, MHCP, OHS, BTNRH
Individual reports of services provided are submitted to NE-EHDI Program	Q1 Q2 Q3 Q4 Q5 Q6 Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	CHEII; EDN, MHCP, RPSDHH, OHS, BTNRH
Annual aggregate reports of referrals, eligibility verifications, and services provided are submitted	Q1 Q2 Q3 <u>Q4</u> Q5 Q6 Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	CHEII; EDN, MHCP, RPSDHH, OHS, BTNRH

System Goal 4 - All infants with a confirmed hearing loss will have a medical home.	Healthy People 2010 (28-12) Reduce otitis media in children and adolescents. Healthy People 2010 (28-15) Increase the number of persons who are referred by their primary care physician for hearing evaluation and treatment.	
Program Objective 4.1 – Birthing facilities will identify and report to NE-EHDI program 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.	Measurement – Accuracy of listing of PHCP on reports	
Activities	Quarters	Person(s) Responsible
NE-EHDI Program orients hospital staff about rationale for accurate PHCP identification	<u>Q1</u> Q2 Q3 Q4 <u>Q5</u> Q6 Q7 Q8 <u>Q9</u> Q10 Q11 Q12	Prgm Mgr; Hosp Staff
PHCP listed on hearing screening record of electronic data reporting system	<u>Q1</u> Q2 Q3 Q4 Q5 Q6 <u>Q7</u> Q8 Q9 Q10 Q11 Q12	CHEII; Hosp Staff
Verification requested through NE-EHDI Program notifications of hearing screening results to PHCP	<u>Q1</u> Q2 Q3 Q4 Q5 Q6 <u>Q7</u> 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.	Measurement – Number of medical homes established, number of referrals, number of dried blood spots retrieved	
Activities	Quarters	Person(s) Responsible
<“Roadmap” to recommended services and evaluations will be provided to PHCP to assist with parent follow-through for referrals>	<u>Q1</u> Q2 Q3 Q4 Q5 Q6 <u>Q7</u> Q8 Q9 Q10 Q11 Q12	Prgm Mgr, CHEII, PHCP
PHCP will retrieve dried blood spot to determine etiology for babies identified with permanent hearing loss	<u>Q1</u> Q2 Q3 Q4 Q5 Q6 <u>Q7</u> Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Newborn Screening & Genetics Program, PHCP
Develop a medical home promotion for PHCP	<u>Q1</u> <u>Q2</u> Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, BTNRH, AAP

		EHDI Chapter Champion, NeFPA, NePAA, MHCP, EDN, PTI-NE, TFKF
Implement medical home promotional activities	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, BTNRH, AAP EHDI Chapter Champion, NeFPA, NePAA, MHCP, EDN, PTI-NE, TFKF
Program Objective 4.3 – Primary Health Care Providers will submit individual status reports of children with confirmed hearing loss.	Measurement – Number of children with risk factors being monitored; number of children with risk factors identified with hearing loss	
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	Prgm 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

System Goal 5 - Families of young children with a confirmed hearing loss will have access to a family-to-family support system.	Healthy People 2010 (28-11) Increase the proportion of newborns who are screened for hearing loss by age 1 month, have audiologic evaluation by age 3 months, and are enrolled in appropriate intervention services by age 6 months.	
Program Objective 5.1 – Families of young children with a confirmed hearing loss will receive a resource guide of support services.	Measurement – Number of resources available, number of print guides distributed, number of web hits	
Activities	Quarters	Person(s) Responsible
Conduct inventory of local, state, regional, and national support services	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr; PTI-NE
Develop a print and web-based resource guide of available family support resources	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII
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 develop family-to-family supports.	Measurement – Number of initial sessions held, number of new groups established	
Activities	Quarters	Person(s) Responsible
Implement “Investing in Family Support” work plan	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE, EDN, H&V, RPSDHH, Prgm Mgr, Adv Cmte
Explore feasibility of a “Guide by Your Side”	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE, EDN, H&V,

program		RPSDHH, Prgm Mgr, Adv Cmte
Conduct needs assessment of current family-to-family system and resources in NE	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE, Prgm Mgr
Identify approaches to strengthening family-to-family network in NE	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE, Prgm Mgr
Identify groups of parents interested in organizing a local support group	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE, BTNRH, OHS, RPSDHH, Prgm Mgr
Support organizational meetings of parents	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE, Prgm Mgr
Workshops to organize local groups provided	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	PTI-NE
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, NeAEYC
Program Objective 5.3 – Early intervention providers will submit annual aggregate and individual reports of families participating in family-to-family support activities.	Measurement – 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, OHS, EDN, 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, OHS, EDN, RPSDHH, CHEII

System Goal 6 - The hearing of young children in Nebraska will be screened periodically.	Healthy People 2010 – (28-12) Reduce otitis media in children and adolescents. (28-14) Increase 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.	Measurement – Number of infants with risk factors, number of infants at-risk who are monitored, number of infants with confirmed 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	Q1 Q2 Q3 Q4 Q5 Q6	CHEII, Prgm Mgr, PHCP

exchanged between PHCP and NE-EHDI Program	Q7 Q8 Q9 Q10 Q11 Q12	
Determine feasibility of screening for congenital CMV as a risk factor for later-onset hearing loss	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Newborn Screening workgroup
Program Objective 6.2 – Early Head Start programs will conduct OAE hearing screenings of enrolled children aged birth to three years.	Measurement – 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 of infants-toddlers	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	EHS Prgms
Program Objective 6.3 – Community-based health services will conduct OAE hearing screenings.	Measurement – Number of clinics trained, number of partnerships established, number of children screened, number with hearing loss	
Activities	Quarters	Person(s) Responsible
Determine interest level of each community health clinic to conduct well-child OAE hearing screenings.	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
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
Program Objectives 6.4 – Hearing screening and monitoring status reports will be submitted to NE-EHDI program.	Measurement – MOU, number of hearing screenings reported, number of NE-EHDI Program “lost-to-follow-up” screened	
Activities	Quarters	Person(s) Responsible
Adapt EHS data tracking systems to recommended hearing screening protocol	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BAnalyst, HSSCO, Prgm Mgr
Determine the feasibility of EHS/HS reporting individual hearing screening results to NE-EHDI Program	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	HSSCO, Prgm Mgr
If feasible, proceed with developing a MOU between EHS/HS and NE-EHDI Program to facilitate reporting process	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	HSSCO, Prgm Mgr, NeHSA
Adapt existing reporting processes to meet needs of EHS/HS and NE-EHDI Program	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	HSSCO, Prgm Mgr, NeHSA
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

System Goal 7 – Professionals working with young children with a hearing loss will increase their capacity to provide appropriate services to young children.	Healthy People 2010 – n/a	
Program Objective 7.1 – Training needs of hearing health professionals will be assessed.	Measurement – Number of surveys returned, content of surveys	
Activities	Quarters	Person(s) Responsible
Hospital staff will be surveyed annually	Q1 Q2 Q3 <u>Q4</u> Q5 Q6 Q7 <u>Q8</u> Q9 Q10 Q11 <u>Q12</u>	Prgm Mgr, CHEII
The BTNRH project based on nurses' knowledge of EHDI will be piloted in Nebraska	Q1 Q2 <u>Q3</u> Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	BTNRH, NCHAM, Prgm Mgr, Hosp Staff
NE-EHDI Program will be represented on audiology education committee of Nebraska Speech Language Hearing Association	<u>Q1 Q2 Q3 Q4 Q5 Q6</u> <u>Q7 Q8 Q9 Q10 Q11 Q12</u>	Prgm Mgr
Program Objective 7.2 – Professional development resources will be inventoried annually.	Measurement – Listing of training resources	
Activities	Quarters	Person(s) Responsible
Educational opportunities will be compiled annually for inclusion on website.	Q1 <u>Q2</u> Q3 Q4 Q5 <u>Q6</u> Q7 Q8 Q9 <u>Q10</u> Q11 Q12	CHEII
New educational opportunities will be listed on website as they become available	Q1 <u>Q2</u> Q3 Q4 Q5 <u>Q6</u> Q7 Q8 Q9 <u>Q10</u> Q11 Q12	CHEII
Program Objective 7.3 – Professional development opportunities will be promoted to the hearing health professionals.	Measurement – Listing of educational opportunities, level of participation	
Activities	Quarters	Person(s) Responsible
Hearing screening coordinator track at Lifespan Health conference, parent panel, <PDSAs developed>	<u>Q1</u> Q2 Q3 Q4 <u>Q5</u> Q6 Q7 Q8 <u>Q9</u> Q10 Q11 Q12	Prgm Mgr, NCHAM, H&V, Hosp Staff
<Outreach visits to audiologists to promote professional development opportunities and explain new resources, including Parent Resource Guide>	<u>Q1</u> Q2 Q3 Q4 <u>Q5</u> Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Auds
Educational opportunities using distance learning will be developed for professionals in the EHDI field.	<u>Q1 Q2 Q3 Q4 Q5 Q6</u> <u>Q7 Q8 Q9 Q10 Q11 Q12</u>	Prgm Mgr, BTNRH
Joint trainings about implementation of Initial Point of Entry plan will occur across the state for EDN services coordinators and RPSDHH deaf educators	Q1 Q2 <u>Q3</u> Q4 Q5 Q6 <u>Q7</u> Q8 Q9 Q10 <u>Q11</u> Q12	Prgm Mgr, EDN, RPSDHH
Workshops will be presented at conferences	<u>Q1</u> Q2 <u>Q3</u> Q4 <u>Q5</u> Q6 <u>Q7</u> Q8 <u>Q9</u> Q10 <u>Q11</u> Q12	NHA, NeFPA, NePAA, NeHSA
Implement medical home promotional activities	Q1 <u>Q2</u> Q3 Q4 Q5 <u>Q6</u> Q7 <u>Q8</u> <u>Q9</u> Q10 Q11 <u>Q12</u>	Prgm Mgr, BTNRH, AAP EHDI Chapter Champion,

		NeFPA, NePAA, MHCP, EDN, PTI-NE, TFKF
UNL graduate level classes for SPA472, SOED896E will explain EHDI and its impact	<u>Q1</u> Q2 Q3 <u>Q4</u> <u>Q5</u> Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
Staff from Early Head Start/Migrant Head Start, community health clinics, RPSDHH, and/or Educational Service Units will be trained.	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	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	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Prgm Mgr, CHEII, BTNRH, Auds
NE-EHDI Program newsletter will be developed and disseminated semi-annually.	Q1 <u>Q2</u> Q3 <u>Q4</u> Q5 <u>Q6</u> Q7 <u>Q8</u> Q9 <u>Q10</u> Q11 <u>Q12</u>	Prgm Mgr, CHEII
Program Objective 7.4 – The effectiveness of the professional development activities will be evaluated.	Measurement – Analysis of evaluations	
Activities	Quarters	Person(s) Responsible
Evaluations will be included as part of each professional development activity	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	CHEII
Evaluations will be compiled and analyzed	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	CHEII, Prgm Mgr, Adv Cmte

System Goal 8 – The NE-EHDI Program will provide an effective structure for the early hearing detection and intervention system in Nebraska.	Healthy People 2010 – n/a	
Program Objective 8.1 – Internal capacity of NE-EHDI program will be expanded and strengthened.	Measurement – Advisory Committee minutes, staffing pattern, data system, number and type of collaborations, website content, overall effectiveness of each component	
Activities	Quarters	Person(s) Responsible
Quarterly Advisory Committee will include representation by a cross-section of stakeholders	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Prgm Mgr, Adv Cmte
Working subcommittees will be established by Advisory Committee: Family Support, Planning and Evaluation, other	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Adv Cmte, stakeholders
Tracking and follow-up aspects of the NE-EHDI Program will be refined and maintained	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Prgm Mgr, CHEII
Integrated electronic data reporting system will be fully developed and implemented (CDC)	<u>Q1</u> <u>Q2</u> <u>Q3</u> <u>Q4</u> <u>Q5</u> <u>Q6</u> <u>Q7</u> <u>Q8</u> <u>Q9</u> <u>Q10</u> <u>Q11</u> <u>Q12</u>	Prgm Mgr, BAnalyst, NTSMRT

<Ad hoc reports will be developed to identify potential factors related to negative outcomes (lost to follow-up, benchmarks exceeded>	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, BAnalyst, CHEII
Additional funding opportunities will be pursued	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr
Formal and informal collaborations will be developed to build the capacity of the hearing screening and intervention system	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, organizations and agencies related to early childhood disabilities, specifically hearing loss
NE-EHDI Program information will be added to Newborn Screening website	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, CHEII, HHSS
Monthly, quarterly, and annual reports will be developed and disseminated	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, CHEII, BAnalyst, EDN
National surveys will be completed	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, CHEII, BAnalyst
Program Objective 8.2 – Current and accurate professional resources will be available	Measurement – Number of resources, frequency of updates	
Activities	Quarters	Person(s) Responsible
Audiology resource list of equipment, procedures will be updated	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, Auds
Recommended audiology assessments document is available to consumers	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr
Program Objective 8.3 – Parent education materials will be developed and/or provided for birthing facilities	Measurement – Materials in multiple primary languages, number of materials sent, survey results and analysis	
Activities	Quarters	Person(s) Responsible
Parent educational brochures and letters will be available in Spanish, Vietnamese, Arabic, Russian, 3 Sudanese dialects, Chinese, French, other languages	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, CHEII, translators
Parent education brochures translated, modified with appropriate photos	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII
Print and video educational materials will be provided to all birthing facilities	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	CHEII
Parent survey will be conducted semi-annually	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgrm Mgr, CHEII, Adv Cmte
System Goal 9 – The Early Hearing Detection and Intervention system will be promoted.	Healthy People 2010 – n/a	

Program Objective 9.1 – NE-EHDI will develop and access materials to promote the EHDI system	Measurement – Number of promotional opportunities accessed	
Activities	Quarters	Person(s) Responsible
News releases will be developed	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
Exhibits for conferences will be completed	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
PSAs that are available will be accessed and disseminated	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
Learning from Day One multi-media campaign will focus on EHDI	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr
Program Objective 9.1 – NE-EHDI will have a plan to market and promote the EHDI system	Measurement – Marketing plan	
Activities	Quarters	Person(s) Responsible
A marketing and promotion plan will be developed and updated periodically	Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12	Prgm Mgr, Adv Cmte

RESOLUTION OF CHALLENGES

There are two major challenges facing the NE-EHDI program in implementing the work plan. The first is that Nebraska has vast expanses of sparsely-populated frontier land with a lack of health specialists within a reasonable distance. Hospitals with only a few births per year do not gain screening experience and at times have high refer rates. Returning to the birthing facility for an outpatient re-screening is a strategy that has worked well in many communities. During the first eight months of 2007, over 20% of the babies that had a refer result for the birth admission screening were re-screened at the birth facility and, of those, over 60% had an appointment for the re-screening scheduled prior to discharge. The rural areas of the state are served by audiologists, but it is often through itinerant services of, perhaps, once per month. But availability does not mean that the necessary expertise to work with very young babies is present. Partnering with audiologists from Boys Town National Research Hospital to conduct training sessions is one strategy to approach this challenge. Another approach is to ensure that early intervention providers are knowledgeable in accessing travel and support resources for families if they do need to travel to access specialized diagnostic services.

Other than birth admission hearing screening, much of the compliance with the recommended follow-up re-screening and diagnostic evaluation protocols is voluntary, as is the reporting of individual results to the NE-EHDI Program. A similar situation occurred during implementation of the ERS-II data system when the voluntary reporting increased from only those who did not pass the birth admission screening to reporting the results of all occurrent births. Careful analysis of the data requirements to include only those elements that are needed and planning to create as much efficiency as possible in the reporting process minimized the burden of reporting and increased cooperation. Also, traveling to conduct the data system trainings on-site supported the development of productive working relationships with most of the hospital personnel and has resulted in increased professional interactions. Similarly, maintaining a focus on how particular items can maximize the outcomes for babies enlisted cooperation because the purpose was transparent. The plan to visit audiologists at their practice sites to visit

about the EHDI program and to request their engagement in the new strategies, such as a one-page checklist reporting form, professional development opportunities, and dissemination of the Parent Resource Guide, will increase the likelihood of compliance with a voluntary reporting system.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

The Nebraska Department of Health and Human Services now has seven years of experience administering the Early Hearing Detection and Intervention Program. The program has done well in organizing the health professionals in the state to implement a comprehensive newborn hearing screening program with very good outcomes. The focus is now on further developing the audiologic diagnostic, early intervention and family support components.

The manager of the NE-EHDI program is an audiologist, recently completed a graduate program with a concentration in public health and has many years of experience with administration in the early care and education field. This experience contributes to the formation of multidisciplinary partnerships that are focused on both outcomes and process.

The program manager partnered with the audiology coordinator from Boys Town National Research Hospital to write an article about the EHDI system and intervention strategies for babies with hearing loss that was published in The ASHA Leader. The two audiologists are now developing an eLearning course for ASHA about the same topic.

A local evaluation of the NE-EHDI Program is being conducted as part of the CDC cooperative agreement. The evaluation includes a specific focus on development of the electronic data, as well as a general focus on the program outcomes. The evaluation committee includes a cross-section of stakeholders and two epidemiologists from the Lifespan Health Services unit.

ORGANIZATIONAL INFORMATION

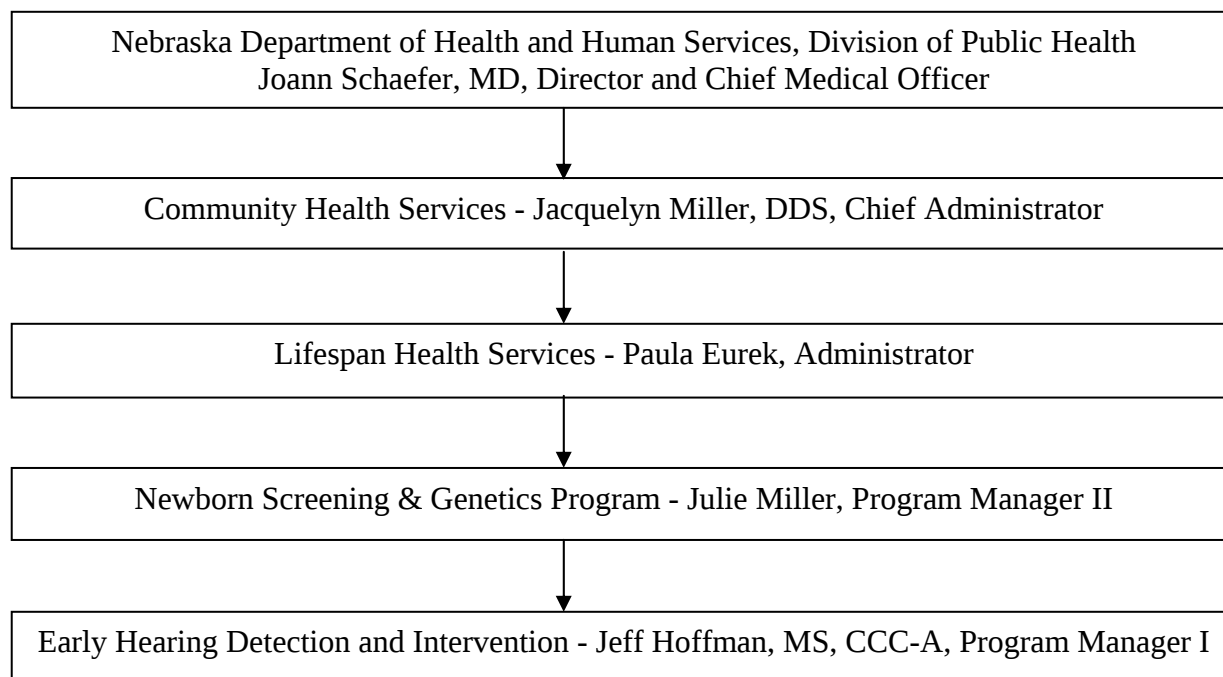
The Infant Hearing Act for Nebraska was passed in 2000. Key provisions included:

- Hearing screening during birth admission is the standard of care.
- Birthing facilities are to educate parents about hearing, hearing loss, and hearing screening. For out-of-hospital births, DHHS is to educate the parents.
- Regulations must be written if the screening rate falls below 95%.
- DHHS would develop a tracking system.
- Annual aggregate reports are required for birthing and confirmatory test facilities.

Until 2007, the NE-EHDI Program relied upon manual reporting and tracking systems. The new ERS-II data system is an integrated Vital Records system. The EHDI module is populated by the birth certificate, as is the birth defects registry. Integration with birth defects and death certificate registry is planned for the future. Linkage with other child health data systems has been considered but no decision has been made. These systems include the metabolic/blood spot screening system, the immunizations system currently being developed, WIC, and the CONNECT system that includes EDN/Part C and MHCP/CSHCN.

The Nebraska Department of Health and Human Services re-organized on July 1, 2007. Although the names of many organizational units have changed, the reporting structure remained much the same. The Nebraska Early Hearing Detection and Intervention Program is administratively and organizationally placed under the direction of the Newborn Screening and Genetics Program, within Lifespan Health Services, Division of Public Health in the Nebraska

Department of Health and Human Services. Other programs in the Lifespan Health Services Unit are Perinatal, Child, and Adolescent Health; Reproductive Health; Women's and Men's Health; Immunization; Nebraska WIC; and Pregnancy Risk Assessment Monitoring System. The NE-EHDI Program Manager is directly supervised by Julie Miller, Program Manager of the Newborn Screening and Genetics Program. The chart below depicts the organizational and administrative structure.



As a public health program, the statewide context within which the NE-EHDI program operates consists of multiple stakeholders and partners (Appendix G).

Staffing. The new NE-EHDI Program staffing pattern (Appendices D and E) will consist of the following staff:

Health Program Manager I	0.5 FTE - HRSA/MCHB	0.5 FTE - CDC
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Community Health Educator II	1.0 FTE - HRSA/MCHB	
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Business Analyst	0.05 FTE - HRSA/MCHB	0.95 FTE - CDC
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The allocation of the business analyst is contracted through the Department of Administrative Services/Materiel Division's master contract.

The Department of Health and Human Services appointed a multi-disciplinary NE-EHDI Program Advisory Committee to advise on the implementation of the Infant Hearing Act, to make recommendations regarding newborn hearing screening methods and protocols, and to participate in developing consensus on the best practices to promote newborn hearing screening. The Advisory Committee has worked closely with the NE-EHDI program staff to develop protocols for newborn hearing screening, follow-up and referral, audiologic evaluation, and amplification assessment.

The extended network of professionals involved with early hearing detection and intervention, including the staff at birthing facilities, audiologists, and primary health care

providers, have done well to implement the protocols. Some of the highlights of the effectiveness of the early hearing detection and intervention system in Nebraska include:

- All the current birthing hospitals in Nebraska were conducting newborn hearing screening in 2006. All but one were conducting the hearing screenings during the birth admission.
- The benchmark of 95% of newborns having a hearing screening during birth admission by December 1, 2003 established by Neb. Rev. Stat. §71-4742 has been met. In 2006, birthing hospitals reported screening the hearing of 98.9% of newborns.
- The overall refer rate during 2006 for initial hearing screening during birth admission was 3.8%.
- In 2006, follow-up re-screening occurred within one month of birth for 74.3% of those newborns for which follow-up activities were initiated. The average age at the time of the initiation of follow-up re-screening or diagnostic evaluation was 28.0 days.
- The average age at diagnosis of hearing loss was 55.4 days for those reported to NE-EHDI in 2006 and 88.5% of the evaluations occurred within 3 months of birth.
- The incidence of Permanent Hearing Loss identified and reported to NE-EHDI (1 per thousand in 2006) appears to be within the anticipated range of 1 to 3 per thousand.

The goals and activities developed for the next year have the potential to not only improve each of the measures listed above but will also further reduce the lost to follow-up rate and expand the scope of the NE-EHDI program to add additional measures, all indicative of better outcomes for very young children with hearing loss and their families.