NARRATIVE

Nebraska Early Hearing Detection and Intervention Program

INTRODUCTION

The Nebraska Early Hearing Detection and Intervention (NE-EHDI) Program began a concerted effort to reduce the number of babies who are categorized as "lost-to-system" in 2006 as part of the first group of EHDI programs to participate in the National Initiative for Child Healthcare Quality (NICHQ) Learning Collaborative. In 2007, the implementation of a data entry system based on the birth certificate increased the number of babies being tracked in the follow-up system from about 75 monthly to about 100 monthly, indicating that we were receiving information about more babies who did not pass the newborn hearing screening than previously with the manual reporting system. We have seen a modest decrease in the percentage of babies being coded as lost-to-system as a result of strategies learned from the NICHQ Learning Collaborative but further reductions need to be made since it is projected that there are as many as six babies with permanent congenital hearing loss (PCHL) in the lost to follow-up group.

The NE-EHDI Program uses the term "lost-to-system" in categorizing those babies who have not received the recommended follow-up services (lost-to-followup) and those who received the follow-up services but were not reported to the NE-EHDI Program (lost-to-documentation). Although it is not possible to determine which of the two sub-categories is correct until after follow-up documentation has been received, the approaches to reduce those not receiving services and those not being reported are different. Both are addressed in this proposal for funding to continue to work toward establishing the hearing status of all babies born in Nebraska.

The current HRSA grant, which also focuses on reducing loss-to-followup, required that plans be developed to reduce the number of babies for whom hearing results are not known. The progress that the NE-EHDI Program has made toward implementation of those plans is reported in Attachment 1A.

NE-EHDI Electronic Data System: ERS-II

Beginning in 2005, the NE-EHDI Program contracted with Netsmart Technologies, Inc., to develop a data reporting and tracking system that is integrated with the State's Vital Records ERS-II electronic data system. The hearing 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 second type of record is a detail record, the Hearing Screening (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 a Neonatal Intensive Care Unit

(NICU). Additional parent and disposition data, including the Primary Health Care Provider's (PHCP) name, preferred parent language, and parent phone number(s), are entered to facilitate follow-up activities. The data system includes basic Search functions for birth, HINFO, and HSCREENING records; five work queues in which pending records are placed for easy access by hospital personnel, and four aggregate and four detail reports.

Leadership at State and National Level

In the last five years, the Program Manager of the NE-EHDI Program has served on a variety of workgroups and committees in Nebraska: Together for Kids and Families (TFKF), the State Early Childhood Comprehensive Systems Grant, workgroups (Medical Home, Parent and Family Support), Boys Town National Research Hospital's (BTNRH) Integrated Services Medical Home Learning Collaborative, and the audiology continuing education committee of the Nebraska Speech-Language-Hearing Association (NSLHA). Development of the Nebraska Hearing Aid Loaner Bank (NCHALB) is a collaborative effort of the University of Nebraska-Lincoln (UNL) audiology department, the Nebraska Association for the Education of Young Children (NeAEYC), and the NE-EHDI Program. The NE-EHDI Program also has taken the lead in implementing the Early Childhood Hearing Outreach (ECHO) team to train Early Head Start staff to conduct otoacoustic emissions (OAE) hearing screenings.

The Program Manager has also provided leadership at the national level with EHDI. The American Speech-Language-Hearing Association (ASHA) has included the Program Manager on two workgroups to develop a Technical Report and a Guidance Document for audiologists to reduce lost-to-followup. The Program Manager has been President and is currently Past President of the Directors of Speech and Hearing Programs in State Health and Welfare Agencies, Inc. (DSHPSHWA) and received the American Speech-Language-Hearing Foundation's Louis M DiCarlo Award for Outstanding Clinical Achievement in 2007.

NEEDS ASSESSMENT

Since full-implementation of the newborn hearing screening module of the Vital Records integrated electronic data reporting system in January, 2007, the NE-EHDI Program has collected hearing screening data for all occurrent births in the state. In 2008, there were 27,083 births registered as Nebraska births in the Vital Records system and the NE-EHDI data system has 27,083 hearing information (HINFO) records. Of those births, 27,008 were born in a birthing facility and 75 were born out-of-hospital. Of the 27,008 hospital births, hearing screenings were conducted during birth admission for 99.2% (26,791) of the babies.

There were 107 babies who expired (0.4% of hospital births) and 110 (0.4% of hospital births) were discharged to home prior to receiving a hearing screening. Reasons for not receiving an inpatient hearing screening include equipment malfunction, parent refusal, or failure to follow the hospital's screening protocol. One small hospital with about 20

births annually has opted to only conduct outpatient hearing screening once a month when an audiologist is available at a local ENT clinic. Of the 110 not screened in the hospital, 88 passed an outpatient screening and five went directly to an audiologic evaluation and were determined to have normal hearing. Five parents had refused the inpatient hearing screening and no further activity occurred. There were 12 babies who were categorized as "lost-to-system" (follow-up not completed or reported). Therefore, 10.9% of the babies who were discharged prior to screening are lost-to-system.

Of the 26,791 babies who received a hearing screening during birth admission, there were 1,050 who did not pass ("refer") the final inpatient hearing screening in one or both ears. This is an overall 3.9% refer rate at the inpatient level.

In Nebraska, an outpatient re-screening may be conducted for those babies who did not pass the inpatient screening, although on a case-by-case basis, an audiologist may progress directly to an audiologic evaluation. Outpatient re-screenings may occur at the birthing facility, an audiology clinic, or a PHCP's clinic. Of the 1050 babies who did not pass the final inpatient hearing screening, 781 (74.4%) passed an outpatient re-screening. There are 29 who are still in active follow-up at this outpatient screening level, many with middle ear dysfunction as indicated by an abnormal tympanogram, and there were 132 who needed to have an audiologic evaluation conducted. In addition, there were 11 families who moved and follow-up could not be completed. There were an additional 15 parents who actively refused to proceed with an outpatient hearing screening. The remaining 82 babies were categorized as lost-to-system between the inpatient and outpatient hearing screenings. This is 7.8% of those at this phase of the follow-up process.

For the 132 babies who did not pass the final hearing screening, 94 completed an audiologic evaluation with 54 having normal hearing and 40 being identified with a permanent hearing loss. There are 16 who are in active follow-up, most with middle ear dysfunction and a transient conductive hearing loss, and two expired prior to receiving the audiologic evaluation. There are a total of 20 babies of this group who are categorized as lost-to-system, or 15.2% of those needing an audiologic evaluation. Of these 20, ten did not receive any evaluation services and ten received one or more evaluations but did not receive a final confirmatory evaluation to establish either normal hearing or hearing loss.

The NE-EHDI Program conducted active follow-up for 1,160 babies (110 discharged prior to screening and 1050 refers). Hearing status ("pass" for screening, normal hearing or permanent hearing loss for audiologic evaluation) was established for 968 (83.4%) of the babies. There are 45 still in active follow-up, 11 moved, two expired, and parents refused further services for 15 babies. The total number categorized as "lost-to-system" is 114 (9.8%) of those babies actively followed to establish hearing status. Excluding those babies who expired, the overall lost-to-system rate is 0.4% of those eligible for newborn hearing screening.

The last phase of the EHDI process is the provision of early intervention services for those infants identified with a permanent hearing loss. In 2008, 34 of the 40 infants identified with a permanent hearing loss were referred to Early Development Network (EDN/Part C). All but one of those were referred prior to 6 months of age. Of those referred, 30 were verified as eligible for special education services; two moved and the parents of two infants with hearing loss withdrew prior to verification. There was one infant who moved prior to referral and five infants who were not referred to EDN/Part C, a loss-to-system rate of 12.5%. An analysis of the five babies who were not referred for early intervention services indicated that two of the mothers were white and spoke English, two were Hispanic and spoke Spanish and one baby was in foster care. Four of the five were babies born with atresia. In 2008, eight of the babies identified with permanent hearing loss had atresia and only 50% of them were referred to EDN/Part C.

In an effort to understand more about the factors which may facilitate or hinder follow-up activities, the NE-EHDI Program conducted an analysis of data for 2007 births of five demographic factors and three program outcomes: timeliness of initiation of follow-up, lost-to-system, and referral to EDN/Part C. The five demographic factors were maternal age, maternal education level, maternal race/ethnicity, maternal marital status, and payment source. The results (see Attachment 1B) of the analysis showed that:

- Timeliness of initiation of follow-up was influenced by maternal age and race/ethnicity.
- Lost-to-system was influenced by maternal age, marital status and payment source
- Referral to EDN/Part C was influenced by maternal education level.

A more comprehensive analysis of the 2008 data will provide the foundation to inform approaches and messaging to encourage and support follow-through at both the inpatient and outpatient levels.

METHODOLOGY

The NE-EHDI system has done very well in screening almost all babies during birth admission and does well in encouraging and tracking the follow-up services for most. However, there are babies with permanent hearing loss who are categorized as lost-to-system and for whom active follow-up has ceased. In this section, the goals and objectives to reduce the number of babies in the lost-to-system group and the methods to achieve those goals are identified and discussed.

Goals

Two overarching goals span the scope of this proposed supplement for the NE-EHDI Program. The goals are:

Goal 1 **- The hearing status of all newborns in Nebraska will be established and reported to the NE-EHDI Program**

Goal 2 **- Appropriate referrals and interventions will be available to those identified with a permanent congenital hearing loss.**

Objectives

Four objectives are established for the first year to significantly reduce the number of babies who are lost-to-system. These objectives are:

Objective 1 **- Reduce the number of babies discharged without a hearing screening during birth admission by 50% to 55 by August 31, 2010.**

Objective 2 **- Reduce the inpatient "refer" rate to 3.0% for the state by August 31, 2010.**

Objective 3 **- Reduce the number of babies who are categorized as lost-to-system in the transition from inpatient screening to outpatient re-screening and audiologic evaluation components by 50% to 57 by August 31, 2010.**

Objective 4 **- Reduce the number of babies who are lost-to-system in the transition between diagnosis and early intervention (Part C) to 0% by August 31, 2010.**

Methods

The primary methods to reduce the number of babies categorized as lost-to-system may span multiple objectives. The methods to achieve these objectives are:

Method 1 **- Upgrade the hearing screening equipment available at birthing facilities.**

Objective 1 Objective 2 Objective 3 Objective 4

Method 2 **- Update ERS-II data system to require more data useful for follow-up activities.**

Objective 1 Objective 2 Objective 3 Objective 4

Method 3 **- Provide professional development opportunities for hospital hearing screening staff.**

Objective 1 Objective 2 Objective 3 Objective 4

Method 4 **- Quality Assurance reports for individual birthing facilities will include comparative statistics, outcomes and technical assistance suggestions.**

Objective 1 Objective 2 Objective 3 Objective 4

Method 5 **- Provide on-site technical assistance to hospitals with high refer and/or loss-to-system rates.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 6* - Increase parent access to educational materials about follow-up hearing screening and evaluation activities.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 7* - Increase active follow-up efforts with PHCPs and parents.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 8* - Provide professional development opportunities for audiologists to increase the quality of their pediatric evaluations.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 9* - Convene the new Medical Advisory Sub-committee to revise medical follow-up algorithms, especially for atresia and craniofacial anomolies, and include referral to EDN/Part C.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 10* - Expand the Early Head Start hearing screening program.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 11* - Examine the feasibility of expanding hearing screening and diagnostic evaluations into the rural and frontier areas of the state in Year 2.**

Objective 1 Objective 2 Objective 3 Objective 4

***Method 12* - Begin the development of regulations to establish a comprehensive system of evaluation, treatment, and intervention services.**

Objective 1 Objective 2 Objective 3 Objective 4

The rationale and activities to implement these methods are described in more detail in the following section.

Rationale and Activities

Method 1. Upgrade the hearing screening equipment available at birthing facilities.

Rationale - Most of the birthing facilities in Nebraska began universal newborn hearing screening between 2001 to 2003, at which time the Infant Hearing Act specified that hearing screening was to become the standard of care at all birthing facilities. In 2002 and 2003, sub-grants of $2000 were awarded by the NE-EHDI Program to 34 hospitals with less than 500 births annually to assist them with the purchase of equipment. As equipment has aged, there have increasingly been malfunctions which result in babies being discharged prior to screening and the hospital needing to make arrangements for

all babies not screened to return for an outpatient screening. In 2008, over 10% of the babies who were discharged prior to screening never received an outpatient hearing screening and were later categorized as lost-to-system. By reducing the number of babies who are discharged prior to screening, the risk of the baby not getting screened if parents don't return will be decreased.

In 2008, the average refer rate for birth admission hearing screenings in Nebraska was 3.9%. This has increased annually from an average refer rate of 3.4% in 2005. Reducing the refer rate during birth admission will reduce the total number of babies needing follow-up services and potentially reduce the number of babies who will not receive the recommended follow-up. PHCP and parent urgency to proceed with additional follow-up can decline when refer rates are higher than anticipated. Aging hearing screening equipment is one of the factors that also contributes to this increase. Each year there have been several hospitals that begin to see an atypical trend of refer results and then realize that there were equipment problems. While reported as refers in the ERS-II reporting system, these are not technically refers since they were the result of technical problems with the equipment.

Of the 18 larger birthing facilities (more than 500 births annually), all but three conduct newborn hearing screenings using either auditory brainstem response (ABR) technology only or a 2-step approach with both OAE and ABR technology. Since OAE screening technology has the highest refer rate (10.5% in 2007) compared with ABR (2.1%) and 2-step (2.5%), the three large hospitals conducting OAE screening are increasing the number of babies needing follow-up and all three are in the top eight hospitals for numbers of babies categorized as lost-to-system. Over 250 babies did not pass the inpatient in these three facilities in 2008 and 36 of those were categorized as lost-to-system. Converting these three facilities to conducting ABR screenings could potentially reduce the number of refers to about 65 instead of over 250 and may reduce the number lost-to-system from 36 to about nine babies.

Activities –

1. Birthing facilities with less than 500 births annually will be offered the opportunity to apply for sub-grants of at least $1,500 to upgrade the hearing screening equipment in their facility. It is anticipated that not all of the 45 facilities with less than 500 births will apply for the sub-grant because in 2002 and 2003 only 34 applied for funding. In a recent survey to determine interest, over 75% of the 26 smaller facilities responded that they would apply. Projecting that percentage to the 45 facilities, approximately 35 could be anticipated to apply, a figure that is consistent with the previous applications for sub-grants. The one hospital that screens its 20 births on an outpatient basis only will be strongly encouraged to apply for this sub-grant and begin conducting hearing screenings during birth admission.
2. Larger facilities with more than 500 births annually that do not have ABR technology will be offered the opportunity to apply for sub-grants of $8000 to upgrade the hearing screening equipment in their facility to include ABR.

3. The NE-EHDI Program will purchase two OAE hearing screeners and supplies to have as a loaner equipment to be shipped to hospitals when equipment malfunctions or is being calibrated to minimize the number of babies who are discharged to home without a birth admission hearing screening.

Method 2. Update ERS-II data system to require more data useful for follow-up activities

Rationale- The NE-EHDI electronic reporting system is a module of the Vital Records system. The basic HINFO record is populated from the completed birth certificate with baby and maternal data, including address and demographics. For those babies who do not pass the birth admission hearing screening a detail record, the HSCREENING record, is required to report the screening results, reasons for not screening, and information necessary for follow-up. Recording of the baby's PHCP is a required field and users select from a drop-down table of 1,528 pediatricians, family physicians and neonatologists in Nebraska. Physicians not listed in the table can be reported in a text box. Other data fields that are available for user input but not currently required are mother's preferred language and two phone numbers. Check boxes for PHCP notification and outpatient plans (re-screen at same facility, referral to audiology facility and appointment date) are also available for user selection.

Activities-

1. Edits (pop-up reminder boxes) will be added for maternal language, two phone numbers, PHCP notification, and outpatient plans to serve as reminders that this information needs to be recorded for a complete record. The edits will be functional for records reporting refer results or discharge prior to screening only; records indicating transfers to NICUs will not have these edits since this information is often not available and will be collected upon discharge from the NICU.
2. Physicians in western Iowa will be added to the drop-down table of PHCPs to facilitate better reporting for babies born in Nebraska who are Iowa residents. The hard-copy listing of physicians in western Iowa is available in the Health Professions Tracking Center's Directory of Nebraska & Western Iowa Healthcare Resources published by the University of Nebraska Medical Center which is purchased annually by the NE-EHDI Program.

Method 3. Provide professional development opportunities for hospital hearing screening staff.

Rationale-

Staff turnover at the birthing facilities occurs at the data reporter, hearing screener, and hearing screening coordinator levels. Identifying new data reporters is consistent because of the NE-EHDI Program must initiate the security access process. The

Business Analyst with the program, funded primarily with CDC grant funds, provides initial training for the new "hearing information clerks" by phone and, as needed, shadows the user's monitor to demonstrate how to report various results. Both the Business Analyst and Program Manager provide technical assistance by phone for individual questions from birth clerks and hearing information clerks on an as-needed basis.

Training of new hearing screeners has been the responsibility of the hospitals and, in an effort to increase the quality and consistency of the training, National Center for Hearing Assessment and Management's (NCHAM) Newborn Hearing Screening Training Curriculum: Competency-based Training for New Hearing Screeners DVD was purchased by the NE-EHDI Program and distributed free-of-charge to all birthing facilities in 2008.

The NE-EHDI Program is not always notified in a timely manner about new coordinators and it is often only through periodic contact that knowledge of a change of coordinator becomes known. With turnover, it's important to provide a systematic orientation to newborn hearing screening at the hospital and state levels. In April, 2008, a one-day workshop for hearing screening coordinators was included as part of the Lifespan Health Services annual conference. The content of the workshop included the background and status report of the NE-EHDI system, review of the data reporting system, preview of NCHAM's Newborn Hearing Screening Training Curriculum: Competency-based Training for New Hearing Screeners DVD, sharing of effective and emerging practices and discussions of challenges, a parent panel in which parents shared what worked and didn't work with the hearing screening process for their babies, and a presentation of the NICHQ Model for Improvement/small tests of change and practices which emerged as effective during the first NICHQ Learning Collaborative of which Nebraska was one of eight states to participate. Although only one-third of the birthing facilities were represented because the conference was located in the central part of the state, away from many of the hospitals, the evaluations were overwhelmingly positive. A recent survey of birthing facilities showed that 100% of the 37 respondents would attend (35) or probably attend (2) a day-long workshop.

Activities-

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 system, and the communities and birthing facilities with exceptionally high lost to system rates.
2. A day-long workshop for hearing screening coordinators in birthing facilities will be developed and presented at no cost to participants at six different sites across the state. Tentative locations are Omaha, Lincoln, Norfolk, Grand Island, North Platte, and Scottsbluff which are within a two hour drive for most birthing facilities. Nursing continuing education credits will be available for participants.

Pre-work for the conference will consist of completing a self-rating rubric based on the one developed by the Iowa EHDI Program in which the hearing screening coordinator will rate the facility on meeting statutory requirements, best screening practices, qualification and training of personnel, screening protocol, communication with parents and PHCPs, and quality assurance processes. The recommended screening practices section will be developed in coordination with the Audiology Advisory Sub-committee. The effective practices from the NICHQ Learning Collaborative, such as scripting messages to parents, providing written materials, making appointments for follow-up, identifying the baby's PHCP, recording multiple contacts, and results noted on discharge sheets, will be included in the rubric.

The workshop will consist of a NE-EHDI status report including the results of the relationship between maternal demographics and outcomes; review and discussion of the results of the self-rating rubric; a teleconference presentation by Ryan McCreery, audiologist from Boys Town National Research Hospital (BTNRH) about effective screening programs and practices; a parent panel which will initially be recorded for playback at each workshop but with supplemental live parent presentation by one or more parents from the area near the training site; sharing of effective practices and materials, including multicultural and health literacy issues; and planning for small tests of change using NICHQ's Plan-Do-Study-Act cycle.

Method 4. Quality Assurance reports for individual birthing facilities will include comparative statistics, outcomes and technical assistance suggestions.

Rationale-

In 2008, quality assurance reports began to be developed and were provided to all of the birthing facilities (see Attachment 1C). The reports include comparison with state data on key measures: refer rate by type of screening conducted; discharges prior to screening and the reasons; and percentage of parents educated about hearing loss, hearing screening, and normal speech-language-auditory development (a state requirement). Although the intent is to provide the reports on a quarterly basis, we have only been able to provide semi-annual reports. Two revisions of the ERS-II hearing module in 2008 resulted in needing to re-enter some information into the revised system which has been time-consuming and is almost complete for 2008 births. As part of this updating of records, a complete audit of 2008 records has been conducted, verifying that hard copy and electronic files are complete and match.

Activities-

1. On a monthly basis, the audit of recently closed and active files will be conducted and will provide updated records which accurately reflect the current status of each baby being tracked and which will be available to run the quarterly quality assurance reports.

2. On a quarterly basis the quality assurance reports will be developed and disseminated to the hearing screening coordinators. In addition to the information included in the discussion above, the number of reports that were overdue (older than 21 days except for babies in an NICU) and the number of PHCPs that were not accurately identified will be added. Outcome information that will be included in the quality assurance reports includes the numbers/percentages of babies who have completed follow-up, the results (normal hearing, permanent hearing loss, transient hearing loss, lost-to-system), and the timeliness of initiation of follow-up activities. Recommendations for hospitals to consider for improving the quality of hearing screening will be incorporated into the reports.
3. Concurrent with the dissemination of the first quarterly quality assurance report, an article will be submitted to the Nebraska Hospital Association for inclusion in the weekly electronic newsletter. The article will explain the quality assurance report and provide key state statistics from the quality assurance reports.

Method 5. Provide on-site technical assistance to hospitals with high refer and/or loss-to-system rates.

Rationale-

In preparation for a poster session at the 2009 EHDI conference, an analysis of each birthing facilities percentage of the state's births, percentage of state's refers, and percentage of state's lost-to-system was conducted for 2007 births (see Attachment 1D). For purposes of reducing the number of babies who are categorized as lost-to-system, focusing on refer rates, not percentage of the total refers in the state, and the number categorized as lost-to-system, not percentage of the total lost-to-system, will better identify the hospitals needing technical assistance. An analysis of 2008 births indicated there were seven birthing facilities with high refer rates (above 10%) and seven with high numbers of lost-to-system (more than 5). This analysis is presented in Table 1 with the critical values bolded and italicized. As can be

Hospital (de-identified)	Refer Rate	Number Lost-to-System
Hospital A - small	***34.8%***	***6***
Hospital B - small	***29.8%***	***6***
Hospital C - small	***27.8%***	0
Hospital D - small	***14.8%***	0
Hospital E - large	***12.9%***	***12***
Hospital F - large	***11.6%***	***19***
Hospital G - small	***11.0%***	2
Hospital H - large	5.6%	***24***
Hospital I - large	2.0%	***7***
Hospital J- large	2.5%	***6***

Table 1. Nebraska Hospitals with High Refer Rates and High Numbers of Lost-to-System

seen, several small hospitals have high refer rates as well as a high number of lost-to-system and while others with a high refer rate have no lost-to-system. Likewise, several larger hospitals have a low refer rate but a higher lost-to-system rate.

Activities-

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 system, and the communities and birthing facilities with exceptionally high lost to system rates.
2. Conduct a new statistical analysis for the first six months of 2009 to be able to document the most current refer rates and lost-to-system numbers.
3. Conduct on-site visits to hospitals with refer rates $\geq$ 10% and/or high lost-to-system rates $\geq$ 6 to provide technical assistance focusing on lowering the rates. An on-site visit is already being planned for Hospital A in Table 1 in October, 2009, which has a consistent history of staff turnover, high refer rates and high lost-to-system rates.

Method 6. Increase parent access to educational materials about follow-up hearing screening and evaluation activities.

Rationale-

In the last several years, the NE-EHDI Program has made progress in providing more appropriate and useful parent educational materials. Two brochures Can Your Baby Hear? and Your Baby Needs Another Hearing Screening, based on models provided by NCHAM, were adopted to meet the Infant Hearing Act's educational requirements and translated into the ten languages most commonly spoken in Nebraska. These are provided at no cost to all birthing facilities. As part of the first NICHQ Learning Collaborative, the NE-EHDI Program reduced the literacy level of parent letters and parent educational brochures and documented that more parents were calling to ask questions about how to arrange for the recommended follow-up. A roadmap, Learning About Hearing…A Family's Checklist (see Attachment 1E), which provides a listing of all recommended activities from initial screening through Early Intervention services, was also developed by the NE-EHDI Advisory Committee based on a NICHQ model. It has been translated into Spanish and modified for use at birthing facilities by using only the initial screening and re-screening panels. A Parent Resource Guide, a binder which contains many helpful resource materials, is provided by PHCPs, audiologists, and EDN/Part C services coordinators to parents when their child has been identified with a permanent hearing loss. A website for the NE-EHDI Program is ready to be finalized by the Department of Health and Human Services webmaster and contains a section specifically for parents. Also, the NE-EHDI Program is just finishing a radio public service announcement in English and Spanish which will be run on over 30 radio stations statewide during prime-time hours for six weeks.

Activities-

1. The NE-EHDI Program will contract with the Nebraska Chapter of Hands & Voices to participate in the development of Loss and Found…How to Find Out if Your Baby Really Has a Hearing Loss, a short video designed to provide parent-to-parent information and encouragement to follow through with re-screening and/or evaluation. Leeanne Seaver, executive director of Hands and Voices, will write and direct the video with support from a consortium of EHDI partners across the country. In a recent survey of birthing facilities in Nebraska, 100% of the hearing screening coordinators who responded indicated that they would show the video to parents when the baby did not pass the inpatient hearing screening.
2. Although the basic parent educational materials are available in ten languages (English, Spanish, Vietnamese, Russian, Chinese (traditional), Arabic, French, Dinka, Anuak, and Nuer), parent letters and the roadmap, Learning About Hearing…A Family's Checklist, are not. These parent educational materials will translated into eight languages in addition to the current English and Spanish versions.
3. All print materials include the phone number of the NE-EHDI Program Manager only. Parents may pay a long-distance charge to ask questions or to receive guidance on next steps. To eliminate this barrier, two toll-free options will be implemented. A toll-free number will be set up through the State's Office of Chief Information Officer which will directly access the Program Manager's phone. For calls during non-business hours, the Healthy Mothers, Healthy Babies Helpline will provide basic general information about newborn hearing screening and follow-up, as well as referring requests for specific information to the Program Manager. The Healthy Mothers, Healthy Babies Helpline is supported by the Perinatal, Child and Adolescent Health Program through a contract with Nebraska Methodist Hospital and is available to all programs in the Lifespan Health Services unit at no charge. Nurses staff this 24-hour service to the Maternal and Child Health population statewide.

Method 7. Increase active follow-up efforts with PHCPs and parents.

Rationale-

The hearing screening results of all occurrent births are reported to the NE-EHDI Program using the integrated electronic reporting system (ERS-II). The date and results (pass, refer, did not screen) of each baby's birth admission hearing screening are entered and, if not screened, the reason is selected. For babies not passing or discharged prior to screening, additional information is collected, including PHCP, mother's phone numbers and primary language, follow-up plans to re-screen or a referral to an audiology clinic. Birthing facilities are encouraged to report the hearing screening results within seven days after the birth.

The first step of the NE-EHDI Program follow-up procedure for newborns who did not pass or were discharged prior to receiving a newborn hearing screening consists of a written notification to the PHCP within three days of the initial data entry. The notification 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 that the results be submitted to the NE-EHDI Program. Included with the PHCP notification is a parent education brochure (available in 10 languages), the recommended follow-up protocol, and a listing of audiology testing sites.

If the results of a follow-up screening or 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.

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 electronic record 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 follow-up by the NE-EHDI program. This follow-up protocol often results in a baby being categorized as lost-to-system at 2 to 3 months of age. However, if follow-up results are received later, the coding is changed to reflect the new status.

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.

When an infant is identified with a permanent congenital hearing loss (PCHL) and reported to the NE-EHDI Program, a Parent Resource Guide is mailed to the PHCP to give to the parent(s). A one-page reporting form, included in the mailing, summarizes the recommendations for medical and early intervention services made by the audiologist. The form requests that the PCHP indicate the referrals that were made and the dates that services began.

As reported in the Needs Assessment section, the vast majority of newborns receive the recommended follow-up of either an outpatient re-screening or an audiologic evaluation. Of the 1,160 needing follow-up in 2008, there were 968 for which hearing status was established and 45 are still in the follow-up process, most of which have middle-ear dysfunction. This calculates to 87.8% of the babies receiving the recommended follow-

up services. The follow-up services are also timely with 72.2% having services initiated prior to 1 month of age and the average age at initiation of service is 29.0 days.

Of the 875 babies whose hearing status was established after not passing the inpatient hearing screening in 2008, 40 were identified with a permanent congenital hearing loss. Therefore, one of every 22 babies who did not pass the initial hearing screening was found to have a PCHL. With 102 babies being categorized as lost–to-system, there are potentially four babies with PCHL who either did not receive the necessary audiologic evaluation or, if evaluated, the results were not submitted to the NE-EHDI Program. Likewise, we can anticipate that at least two of the 45 infants still in active follow-up could have a permanent hearing loss.

Although babies who are Nebraska residents but who are born in Iowa are not included in the counts for the NE-EHDI Program, the NE-EHDI Program and the Iowa EHDI Program work closely together to coordinate follow-up efforts. Once Iowa has completed its active follow-up, the NE-EHDI Program is notified and begins an active follow-up process similar to the one conducted for Nebraska births. The NE-EHDI Program worked with both Children's Hospital and Boys Town National Research Hospital to establish reporting processes to the Iowa EHDI Program when a baby born in Iowa is transferred to Children's Hospital or receives outpatient services from either of the hospitals.

The other two neighboring states with more than an occasional "border" sharing of hearing screening information is Colorado and South Dakota. In these two instances, babies born in western Nebraska and need a higher level of care are transferred to Denver or Rapid City. For those transferred to Colorado, the NE-EHDI Program requests inpatient hearing screening information directly from the receiving hospital. For those transferred to South Dakota, the information is requested directly from the South Dakota EHDI Program.

The follow-up notifications and tracking of results is performed by a temporary Staff Assistant II and notification and tracking of the "Follow-up in Progress" and diagnosed cases are conducted by the Program Manager. The hiring of a permanent 1.0 FTE Community Health Educator II (CHE-II) to function as a follow-up coordinator has not been possible due to Personnel Service Limitations within the Division of Public Health. The creation of this permanent position in the NE-EHDI Program will occur only if a 1.0 FTE position becomes available within the division and is offered to the NE-EHDI program. Within the Lifespan Health Services unit, there is the need to create five permanent positions and the CHE-II position is ranked second of the five positions. Therefore, hiring a temporary CHE-II through the State's temporary employment service will provide immediate support to conduct more active follow-up than is currently possible at the first sign of problems or exceptions with the follow-up process.

In the situations where the current and proposed active follow-up activities have not resulted in either outpatient screening or evaluation results being reported, the outreach by a parent of a child with a hearing loss to the parent of the baby may result in

encouraging the completion of the follow-up recommendations. A contract with the NE Chapter of Hands & Voices to conduct calls to parents soon after the second parent letter has been sent and before the case is coded as lost-to-system will be initiated.

The NE-EHDI Program and EDN/Part C have had an Interagency Agreement regarding data sharing since 2002 (see Attachment 4A). In 2008, as part of the establishing a single point of entry for families when a child has been identified with a permanent hearing loss, the EDN/Part C services coordinators were provided with a template for the specific programs to include in the "other" section of the EDN/Part C coordinated consent form (see Attachment 1F). Early Intervention (Part C) and Children with Special Health Care Needs (CSHCN) records are available to the NE-EHDI Program Manager through view-only access to the CONNECT data system. The disposition of referrals to the Early Development Network (EDN/Part C) and the Medically Handicapped Children's Program (MHCP/CSHCN) are included in the system, along with the needs and services provided. CONNECT records are reviewed monthly by the NE-EHDI Program Manager to determine if a baby with PCHL has been referred to EDN/Part C and the status of verification for services.

Activities-

1. Hire a 0.4 FTE temporary Community Health Educator II to function as a Follow-up Coordinator. Based on multiple instances in the last several years in which the NE-EHDI Program has contracted with the University of Nebraska-Lincoln audiology program for projects such as development and management of the Nebraska Children's Hearing Aid Loaner Bank and literature review of congenital CMV and hearing loss, every effort will be made to recruit an audiology graduate student in the UNL AuD program, preferably an individual who is bilingual (English-Spanish). If none are available, recruiting of a graduate student in speech-language pathology or education of the deaf will be made. The primary responsibilities of the follow-up coordinator will be:
    - Contact birthing facility and/or parent to identify the baby's PHCP if the PHCP reported by the birthing facility is incorrect.
    - Two weeks after the second PHCP request and first parent letter, contact the PHCP and/or parent about the status of the follow-up plans and identify any barriers to completing the follow-up.
    - Follow-up with PHCP for the "Follow-up in Progress" cases in which additional evaluations are needed, much of the time following resolution of middle ear dysfunction.
    - Conduct initial follow-up with PHCP upon diagnosis of a permanent hearing loss, including providing a requisition to retrieve the newborn dried blood spot with parent permission for determination of etiology of hearing loss (genetic factors or congenital cytomegalovirus).
    - Assist with developing the quarterly quality assurance reports for birthing facilities.
2. Develop a contract with the Nebraska Chapter of Hands & Voices to provide parent-to-parent contact when follow-up has not been completed. The Hands &

Voices program coordinator will contact the parent soon after the second parent letter to encourage completion of the recommended follow-up. As with the CHE-II position, a bilingual individual is preferred.

3. 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 system, and the communities and birthing facilities with exceptionally high lost to system rates.
4. Review and update, if needed, the Interagency Agreement and revise the coordinated consent form based on the model consent form being developed by a workgroup convened by NCHAM.
5. At the next annual EDN/Part C Services Coordinator training, the single point of entry approach and coordinated consent form will be reviewed.
6. A form letter to parents notifying them that the NE-EHDI Program has referred their child to EDN/Part C will be developed and sent to parents if, during the monthly review of CONNECT records, a child with PHL, including atresia, has not been referred for early intervention. This is consistent with EDN/Part C's "family-centered policy" of notifying parents when their child has been referred.

Method 8. Provide professional development opportunities for audiologists to increase the quality of their pediatric evaluations.

Rationale -

The geography and population of Nebraska present some unique challenges regarding health care in general and audiologic services in particular. Over one third of the counties in Nebraska are designated as frontier (6 or fewer persons per square mile) and 43% of the population lives in the two metropolitan centers of Lincoln and Omaha, which are located within an hour of each other in the southeastern part of the state. Over half of the counties have Primary Care Health Professional Shortage Areas and over 75% of the counties are designated all or in part as Medically Under Served Areas or Medically Under Served Populations.

Audiology services follow the same general trend. Of the 33 facilities that provide audiologic follow-up services (hearing re-screening, evaluations), 20 are in the Lincoln-Omaha metropolitan area. Of the 80 audiologists working in the 33 facilities, 60 of them are in the metro area, leaving 20 audiologists to provide services for the remainder of the state. In an annual survey of audiologists that is still in progress, nine of the 13 rural audiology facilities representing 12 of the 20 audiologists practicing in rural areas indicated that 1% to 15% of their caseloads are babies less than 6 months of age and 1% to 20% of their caseloads are 6 to 12 months of age.

In 2005, the NE-EHDI Program provided partial funding for four audiologists to attend NCHAM's Diagnostics for Infants and Toddlers course. The on-line and on-site course provided professional development for audiologists to increase their knowledge and skills in the assessment of hearing loss for infants and toddlers. The latest course,

Diagnostics and Amplification for Infants and Toddlers, has been revised to include strategies to ensure appropriate amplification and intervention.

Consistent with the NE-EHDI Program's Goal 7 which is to provide opportunities for professionals to increase their capacity to provide appropriate services to young children, this course offers a mechanism for the audiologists practicing in the rural areas of Nebraska to increase their capacity to provide appropriate diagnostic and amplification services. This would reduce the burden on parents to travel great distances for a confirmatory diagnosis and most likely increase the timeliness of evaluations and reduce the number who are lost-to-system for both re-screenings and audiologic evaluations.

Activities-

1. Licensed audiologists practicing in the rural areas of the state will be offered the opportunity to apply for four sub-grants to enroll in NCHAM's Diagnostics and Amplification for Infants and Toddlers course. The sub-grants will include the cost of registration, course materials, travel and per diem costs.
2. Conduct a survey with the participants to determine the degree to which they are applying the knowledge and skills acquired during the course. Based on the survey, the sub-grant may be offered to an additional five rural audiologists in subsequent years.

Method 9. Convene the new Medical Advisory Sub-committee to revise medical follow-up algorithms, especially for atresia and craniofacial anomolies, and include referral to EDN/Part C.

Rationale-
One of the six activities established for the State Team Action Plan at the 2009 EHDI Conference in March, 2009, (see Attachment IG) was to "organize a medical sub-committee of the NE-EHDI Advisory Committee." In April, 2009, the NE-EHDI Advisory Committee officially approved the creation of a Medical Advisory Sub-committee to specifically address medical issues, just as the Family Support, Evaluation, and Audiology Sub-committees address relevant issues in those particular areas. The NE-EHDI Advisory Committee has members representing pediatricians (the AAP Chapter Champion and the medical director of the Children with Special Health Care Needs Program), family physicians, and otolaryngologists. Only the pediatricians have been consistent, active members. The plan for a sub-committee is to meet at least semi-annually to address medical issues only. Proposed topics for the Medical Advisory Sub-committee to address initially are: review and revise follow-up protocols with the PHCPs, especially for babies who have middle ear dysfunction, those with craniofacial anomalies including atresia, and those diagnosed with permanent hearing loss; coordinate with the Newborn Screening Advisory Committee about identification of congenital cytomegalovirus and the subsequent audiologic monitoring; develop an educational component for the residency programs at the medical schools in Nebraska; and outreach to the various medical communities.

As discussed in the Needs Assessment section, only half of the eight babies born with an atretic ear were referred to EDN/Part C. This indicates that the birthing facilities and PHCPs may not be considering the non-medical aspects of atresia, including conductive hearing loss and family needs. The NE-EHDI Program follow-up protocol, approved by the Advisory Committee in 2005, does not specifically address craniofacial anomalies or atresia, both of which have a more extended and intensive medical focus than congenital sensorineural hearing loss.

Activities-

1. Involve current medical Advisory Committee members (Drs. Uzendoski, Garvin, Thedinger, and Wergin) and those recommended during discussion and development of the State Action Plan (Drs. Tonniges, Holst, and Nabity) in developing the structure, composition and scope of the Medical Advisory Sub-committee.
2. Convene the Medical Advisory Sub-committee at least semi-annually to address the medical issues listed in the Rationale section, including an algorithm specifically for craniofacial anomalies and atresia.
3. Engage the EDN/Part C co-coordinators with the Medical Advisory Sub-committee in developing strategies that will result in referrals for babies with atretic ears to EDN/Part C by the birthing facilities, PHCPs, and specialists.

Method 10. Expand the Early Head Start hearing screening program.

Rationale-

The NE-EDHI Program established a Early Childhood Hearing Outreach (ECHO) team in 2004 to train Early Head Start (EHS) programs to conduct OAE hearing screenings using the curriculum developed by NCHAM. By 2006, six EHS programs had been trained and provided with an OAE screener as part of the project. Re-trainings have been conducted for new staff as requested. With the current expansion of adding 600 new EHS programs nationally to serve an additional 55,000 young children with funding through the American Recovery and Reinvestment Act (ARRA), Nebraska has an available funding level of $2,981,000.

In addition to fulfilling the NE-EHDI goal of periodically screening the hearing of young children, the potential exists that some of the babies enrolled in EHS programs are in the lost-to-system group. This was confirmed anecdotally in a recent EHS ECHO training in which a mother of a baby enrolled in the EHS program confirmed that she had not completed the recommended follow-up when the baby did not pass the birth admission hearing screening. In late 2008, the Nebraska Head Start State Collaboration Office, the Nebraska Head Start Association, and the NE-EHDI Program signed a Memorandum of Agreement (MOA) (see Attachment 4B) with implementation planned during the current year. One of the purposes of the MOA was to reduce the lost-to-system numbers by having individually-identifiable EHS hearing screening results reported to the NE-EHDI annually, as well as any children identified with a

permanent hearing loss. The reporting is optional, though will be encouraged, for each EHS program and submission of results requires parent consent.

Activities-

1. Work with each current EHS program in Nebraska to determine the program's willingness to report hearing screening data, how to modify the program's release form, and the reporting mechanism.
2. Increase the level of training and technical assistance to EHS OAE hearing screening programs in partnership with the Omaha Hearing School. (The contract for these services is being developed with funds of the current HRSA grant and is not a budget item for this proposal.)
3. Determine the potential number of ECHO trainings needed based on award notices for new EHS programs. Since it is unclear at this time if NCHAM will have the funding to provide OAE hearing screening equipment as has been done in the past the EHS programs participating in the ECHO program, the provision of OAE equipment is included in the budget for the second year of this proposal.

Method 11. Examine the feasibility of expanding hearing screening and diagnostic evaluations into the rural and frontier areas of the state in Year 2.

Rationale-

As discussed in the Rationale section for Method 8, there is a disparity in the availability of audiologic services, in addition to other health services, in the rural and frontier areas of Nebraska. While 35% of Nebraska births are outside of the two metropolitan areas, only 25% of audiologists who provide services to children practice outside of Lincoln and Omaha. Unless a birthing facility offers an outpatient hearing screening for the babies who don't pass the birth admission screening, the family may need to travel for several hours for follow-up care.

In the annual survey of audiologists that is still in progress, the screening and evaluation procedures available at each facility are being reported. With nine of the 13 audiologic practices outside of the metropolitan areas reporting to date, the following list displays the number of practices providing each audiologic service:

OAE – screening only	3
OAE – screening and diagnostic	5
ABR – screening only	0
ABR – screening and diagnostic	2
Sedated ABR	1
High frequency tympanometry	7
Amplification	4

The most apparent gap for the rural areas is the lack of diagnostic ABR capacity, especially sedated ABRs for those babies who are more than a few months old.

During the State Team Meeting at the 2009 EHDI Conference (see Attachment 1G), Dr. Patrick Brookhouser, Director of Boys Town National Research Hospital, discussed considering the use of BTNRH's telehealth network to support the provision of audiologic diagnostic services in the rural areas of the state. As a result of this discussion, the Nebraska State Team Action Plan included the activity to "use telehealth network for quality assurance" with Dr. Brookhouser suggesting that Dr. Michael Gorga and Dr. Mary Pat Moeller could be considered for implementation of this activity.

The co-coordinators of the EDN/Part C program have also reported a gap in the screening and evaluation of hearing for children up to age 3 years, including those who are receiving speech-language services. In their records review of young children receiving services, they reported that there are many instances when a hearing screening or evaluation had not been conducted. While not directly related to reducing loss to follow-up from newborn hearing screening, the co-coordinators indicated a willingness to explore strategies to make OAE screening available to babies who need an outpatient re-screening after not passing a birth admission screening, as well as to infants and toddlers receiving Part C early intervention services.

Activities-

1. Evaluate the options in Year 2 for increasing the number of audiology facilities in the rural areas to conduct comprehensive audiologic evaluations. Initial options include using BTNRH's telehealth network or the acquisition of Vivosonic electrophysiologic screening-diagnostic equipment for audiologic evaluations which reduces the need for sedation for older babies.
2. Partner with EDN/Part C and Regional Programs for Students Who are Deaf/Hard of Hearing (RPSDHH) to determine the feasibility of strategies to engage both programs in reducing the number of lost to system cases in Year 2.
3. Determine the need and interest of the EDN/Part C Planning Region Teams to begin conducting OAE hearing screenings for young children verified for services if a screening or evaluation has not already been conducted.

Method 12. Begin the development of regulations to establish a comprehensive system of evaluation, treatment, and intervention services.

Rationale-

The Infant Hearing Act of 2000 (Neb. Rev. Stat. §71-4735) specified that hearing screening was to become the standard of care in birthing facilities by December, 2003, and that at least 95% of newborns were to be screened annually. If not, regulations are to be adopted and promulgated. In further discussions with the DHHS legal department, there appears to sufficient authority within the Infant Hearing Act to develop regulations for other aspects of the EHDI system in Nebraska. Specific language from the Act that establishes this authority includes:

"The purpose of the Infant Hearing Act is to provide early detection of hearing loss…to enable these children and their families…to obtain needed multidisciplinary evaluation, treatment, and intervention services at the earliest opportunity …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."

"It is the intent of the Legislature that the tracking system provide the department and Legislature with the information necessary 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"

"The Department of Health and Human Services and the State Department of Education shall establish guidelines for when a referral shall be made for early intervention services under the Early Intervention Act. The guidelines shall include a request for an individual evaluation of a child suspected of being deaf or hard of hearing>"

"The Department of Health and Human Services shall adopt and promulgate rules and regulations necessary to implement the Infant Hearing Act."

Activities-

1. Establish a timeline and process for establishing regulations.
2. Determine the scope of the proposed regulations.

The eleven methods with accompanying activities have been developed to implement the four objectives of reducing the number of babies not receiving a hearing screening during birth admission, reducing the hospitals' refer rates, reducing the number of babies who become lost-to-system from hospital screening to outpatient screening to audiologic evaluation, and reducing the number of babies with PCHL who are not referred to EDN/Part C. The Work Plan in the next section identifies the time frame for accomplishing the activities and the persons responsible.

WORK PLAN

Note: In this table, the following abbreviations are used: Quarter 1 = Sep 2009 to Nov 2009, Quarter 2 – Dec 2009 to Feb 2010; Quarter 3 = Mar 2010 to May 2010, Quarter 4 = Jun 2010 to Aug 2010; PM = Program Manager (Jeff Hoffman, MS, CCC-A), BA = Business Analyst (Jim Beavers, BSG), CHE-II = Community Health Educator II/follow-up coordinator (to be hired).

Method 1- Upgrade the hearing screening equipment available at birthing facilities.		
Activities	*Quarters*	*Person(s) Responsible*
Offer sub-grants of $1500 to small hospitals:	1 2 3 4	PM, review team

develop RFP, assemble review team, review applications, make awards.		
Offer sub-grants of $8000 to larger hospitals to add ABR: develop RFP, assemble review team, review applications, make awards.	1 2 3 4	PM, review team
Purchase loaner OAE screeners.	1 2 3 4	
Method 2 - Update ERS-II data system to require more data useful for follow-up activities		
Activities	*Quarters*	*Person(s) Responsible*
Add "edits" to ERS-II data system to require specific information	1 2 3 4	BA
Add PHCPs from western Iowa to drop-down table in ERS-II	1 2 3 4	BA
Method 3 - Provide professional development opportunities for hospital hearing screening staff.		
Activities	*Quarters*	*Person(s) Responsible*
Ad hoc reports to study relationship of demographic and hospital variables and outcomes	1 2 3 4	BA, PM
Develop self-rating rubric to be completed by hearing screening coordinators	1 2 3 4	PM, Audiology Sub-committee
Workshops at 6 sites for hearing screening coordinators: determine locations, content, materials and presenters; promote event and manage registrations; arrange for continuing education credits	1 2 3 4	PM, Ryan McCreery (BTNRH), parent panel
Method 4 - Quality Assurance reports for individual birthing facilities will include comparative statistics, outcomes and technical assistance suggestions		
Activities	*Quarters*	*Person(s) Responsible*
Conduct monthly audit of files.	1 2 3 4	BA, PM
Develop and disseminate quarterly Quality Assurance reports.	1 2 3 4	BA, PM, CHE-II
Write and submit article to NHA electronic newsletter about Quality Assurance reports	1 2 3 4	PM
Method 5 – Provide on-site technical assistance to hospitals with high refer and/or loss-to-system rates.		
Activities	*Quarters*	*Person(s) Responsible*
Ad hoc reports to study relationship of demographic and hospital variables and outcomes	1 2 3 4	BA, PM
Analyze January – June 2009 files to calculate refer and lost-to-system rates.	1 2 3 4	BA, PM

Conduct on-site hospital visits.	1 [2 3] 4	PM
Method 6 - Increase parent access to educational materials about follow-up hearing screening and evaluation activities.		
Activities	*Quarters*	*Person(s) Responsible*
Contract with NE Chapter of Hands & Voices for development of DVD: develop contract, obtain approval and signatures.	[1] 2 3 4	PM, Hands & Voices Board of Directors, system of contract approvals
Translate parent letters and roadmap into eight more languages.	[1 2 3] 4	PM, vendor
Arrange for toll-free number and Healthy Mothers, Healthy Babies Helpline.	[1] 2 3 4	PM, Healthy Mothers, Healthy Babies Helpline
Method 7 - Increase active follow-up efforts with PHCPs and parents.		
Activities	*Quarters*	*Person(s) Responsible*
Hire 0.4 FTE temporary Community Health Educator II: submit request, obtain approval, promote at UNL, approve hiring agency's choice.	[1 2] 3 4	PM, DHHS Human Resources, DAS Temporary Employment Service
Conduct follow-up activities: PHCP identification, phone contact with PHCP and parents; follow-up with "Follow-up in Progress" and "Diagnosed" cases, assist with Quality Assurance reports	[1 2 3 4]	CHE-II
Contract with NE Chapter of Hands & Voices for parent-to-parent contact prior to coding as lost-to-system: develop contract, obtain approval and signatures, develop scripts, HIPAA training.	[1 2] 3 4	PM, Hands & Voices Board of Directors, system of contract approvals
Ad hoc reports to study relationship of demographic and hospital variables and outcomes.	[1 2 3 4]	BA, PM
Review and update, if needed, the Interagency Agreement and revise the coordinated consent form based on the model consent form being developed by an NCHAM workgroup.	[1 2 3] 4	PM, EDN/Part C co-coordinators, DHHS Legal Department
At the next annual EDN/Part C Services Coordinator training, the single point of entry approach and coordinated consent form will be reviewed.	1 2 [3] 4	PM, EDN/Part C co-coordinators
Develop a form letter notifying parents that the NE-EHDI Program has made a referral to EDN/Part C.	[1] 2 3 4	PM, EDN/Part C co-coordinators

Method 8 - Provide professional development opportunities for audiologists to increase the quality of their pediatric evaluations		
Activities	*Quarters*	*Person(s) Responsible*
Offer sub-grants to four rural audiologists to enroll in NCHAM's Diagnostics and Amplification for Infants and Toddlers course, assemble review team, review applications, make awards.	1 [2 3] 4	PM, review team
Conduct survey of applicability of course in participant's practice.	1 2 3 [4]	PM
Decide about offering the sub-grant in subsequent years.	1 2 3 [4]	PM, Advisory Committee
Method 9 - Convene the new Medical Advisory Sub-committee to revise medical follow-up algorithms, especially for atresia and craniofacial anomolies, and include referral to EDN/Part C.		
Activities	*Quarters*	*Person(s) Responsible*
Developing the structure, composition and scope of the Medical Advisory Sub-committee.	[1] 2 3 4	Drs. Uzendoski, Garvin, Thedinger, Wergin, Tonniges, Holst, and Nabity; PM
Convene the Medical Advisory Sub-committee at least semi-annually to address the medical issues listed in the Rationale section	1 [2 3 4]	PM, sub-committee members
Engage the EDN/Part C co-coordinators in developing strategies for referrals for babies with atresia to EDN/Part C by the birthing facilities, PHCPs, and specialists.	1 2 [3 4]	PM, sub-committee members, EDN/Part C co-coordinators
Method 10 - Expand the Early Head Start hearing screening program.		
Activities	*Quarters*	*Person(s) Responsible*
Work with each current EHS program in Nebraska to determine the program's willingness to report hearing screening data, how to modify the program's release form, and the reporting mechanism.	[1 2] 3 4	PM, EHS Program Directors, HS-State Collaboration Director
Increase the level of training and technical assistance to EHS OAE hearing screening programs.	1 2 3 4	PM, Omaha Hearing School
Determine the potential number of ECHO trainings needed based on award notices for new EHS programs in the state.	1 [2 3] 4	PM

Method 11 - Examine the feasibility of expanding hearing screening and diagnostic evaluations into the rural and frontier areas of the state in Year 2.		
Activities	*Quarters*	*Person(s) Responsible*
Evaluate the options for increasing the number of audiology facilities in the rural areas to conduct comprehensive audiologic evaluations.	1 2 3 4	PM, Audiology Sub-committee
Partner with EDN/Part C and Regional Programs for Students Who are Deaf/Hard of Hearing (RPSDHH) to explore strategies for both to reduce the number of lost to system cases.	1 2 3 4	PM, EDN/Part C co-coordinators, RPSDHH liaison
Determine the need and interest of the EDN/Part C Planning Region Teams to begin conducting OAE hearing screenings for young children verified for services.	1 2 3 4	PM, EDN/Part C co-coordinators
Method 12 - Begin the development of regulations to establish a comprehensive system of evaluation, treatment, and intervention services.		
Activities	*Quarters*	*Person(s) Responsible*
Establish a timeline and process for establishing regulations.	1 2 3 4	PM, DHHS Legal Department
Determine the scope of the proposed regulations.	1 2 3 4	PM, Advisory Committee

RESOLUTION OF CHALLENGES

There are several challenges that may occur in implementation of the work plan for this proposal. And resolution of challenges can be based on strengths in other areas of the system components. One challenge is that not all hearing screening coordinators or PHCPs are completely "sold" on newborn hearing screening and the need to follow-up. Experience with the provision of technical assistance and the resultant behavior change is often based on a combination of a sound rationale and a good working relationship. Therefore, the meeting of colleagues face-to-face, presenting the facts behind the need to follow-up while acknowledging and problem-solving the challenges can begin to shift attitudes and behavior. The on-sites planned for hospitals and PHCPs associated with the smaller clinics, while potentially difficult and time-consuming, offer the potential to engage all of the professionals in some of the smaller communities with a willingness to stress the importance of completing and reporting follow-up services.

Finding and training a developing professionals in audiology, or related fields, to conduct follow-up with the cases that are not routine provide them not only with experience that is applicable in their professional lives after receiving their professional

degree but also engages them in an understanding and experience with the EHDI process at the beginning of their careers. Having worked with nine AuD or graduate students on projects in the last three years has not only extended the work accomplished but engaged them in meaningful projects, poster presentations at professional conferences and capstone projects. Finding the graduate student who can fulfill the follow-up coordinator role is critical to the success of reducing the number of babies who are lost-to-system.

Balancing the multiple and diverse demands on the staff of the NE-EHDI Program as a public health program is delicate. The direction is not always clear-cut, the options for growth and partnership are often in multiple yet competing directions, and as administrators we often see and hear the problems, rather than the times when the system worked well for babies and their families. Maintaining motivation and high performance levels with temporary staff is a challenge, yet the diverse professional experiences brought to the workplace by these staff can provide moments of opportunity, such as developing promotional materials or revising tracking systems, based on their individual backgrounds.

The time needed to visit all of the birthing hospitals, even in clusters, can be great yet very rewarding. The hospital visits to each individual hospital and the nursing and medical records staff in rolling out the new data system in early 2007 established a foundational relationship upon which questions, concerns and problems can be broached and resolved. The day-long workshop last year, although not well attended, has made it much easier to effect change in those hospitals that participated. The support to the hospitals to upgrade and update their hearing screening equipment may further solidify their commitment to the EHDI process.

Although audiologists are gradually becoming more responsive to requests to improve practices and report results, those in rural areas for whom pediatrics is a minimal part of their caseload are not accustomed to reporting to the State. The provision of a one-page checklist to report results in a couple more practices beginning to report each year. The commitment to provide funding for additional professional development and beginning to upgrade diagnostic capabilities may further connect a core group of audiologists in the rural areas of the state with the importance of the EHDI process.

Time, as always, will continue to challenge the NE-EHDI Program. The limitations of staff hiring policies limit the expansion of the program and, although the contractual and temporary staff are exemplary, there are challenges such as breaks in service for temporary staff to continue, learning curves for new staff and the additional cost of contractual staff compared with permanent employees. The NE-EHDI system is growing and the establishment of partnerships in expanding and enhancing the system, in spite of some turf issues, is the basis upon which the future of the system depends.

EVALUATION AND TECHNICAL SUPPORT CAPACITY

In 2006, the NE-EHDI Advisory Committee approved the establishment of an Evaluation Advisory Sub-committee to develop and monitor the required evaluation plan for the CDC cooperative agreement. The sub-committee consists of a representative from the Vital Records department, the vice-president of Quality and Evaluation for the Nebraska Hospital Association, two epidemiologists from the Lifespan Health Services unit of the Division of Public Health, two hearing screening coordinators from birthing facilities, a professor of audiology from UNL, and an pediatric audiology coordinator from BTNRH, as well as the Business Analyst and Program Manager for the NE-EHDI Program.

The Evaluation Sub-committee developed and approved an evaluation plan that consisted of two components. One component specifically focused on evaluating the progress in implementation of the CDC work plan and the second component focused on key outcome measures for the NE-EHDI Program. A draft evaluation plan for this grant, focusing on reducing the number of babies who are lost-to-system, also includes two components (see Attachment 7A). The first component includes both outcome and process evaluation questions for this grant while the second part remains focused on the key outcome measures for the NE-EHDI Program. This draft plan will be reviewed and revised by the Evaluation Advisory Sub-committee at the next meeting and integrated with the current plan for the CDC cooperative agreement.

In preparation for a poster session on demographic variables and EHDI system outcomes for the 2009 EHDI conference, a smaller workgroup was formed and consisted of one epidemiologist from Lifespan Health Services, a graduate student from UNL, the Business Analyst and Program Manager. This workgroup conducted a descriptive analysis of the five demographic factors and 1. timeliness of follow-up, 2. loss-to-system, and 3. referral to EDN/Part C. Looking at 2008 data, the epidemiologist will determine the appropriate statistical analysis to determine the relationship of demographics and outcomes.

ORGANIZATIONAL INFORMATION

The mission statement of the NE-EHDI program is: “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.” By focusing on the various components that comprise the EHDI system and the literally thousands of professionals, paraprofessionals, stakeholders and parents involved, the NE-EHDI Program is in an ideal position to partner with other organizations to develop better and smoother linkages for families so that services are more timely and outcomes are improved.

The organizational chart that depicts the relationships of the NE-EHDI Program with other state programs, the Advisory Committee, partners, and providers is shown in Attachment 5.

The NE-EHDI Program has established the following goals for the two federal grants:

HRSA/MCHB –

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.

CDC –

Goal 1– The NE-EHDI Program's integrated electronic reporting system ERS-II will be capable of acquiring and processing complete, timely, and accurate child-specific hearing status data for all occurrent births in Nebraska.

Goal 2 – Progress toward meeting state and national EHDI system goals will be based on unduplicated, individually-identifiable hearing screening, audiologic diagnostic evaluation and early intervention results.

Goal 3 – Mechanisms to collect data about young children with late onset or progressive hearing loss will be developed.

Goal 4 – Child health and health-related data systems related will be connected to the NE-EHDI Program through data sharing, linkage or integration.

Goal 5 – The NE-EHDI tracking, surveillance and integration program will track and report process, output and outcome measures.

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 NE-EHDI Advisory Committee meets three to four times a year and Sub-committees meet quarterly, semi-annually, or annually, depending on the work that needs to be accomplished. The Advisory Committee consists of a cross-section of stakeholders, including parents, physicians, audiologists, nurses, administrators and program managers, educators, and adult mentor. At each meeting, there are from two to four issues that the Advisory Committee is asked to review, discuss, and make recommendations. The Committee has met with the Newborn Screening Advisory Committee twice to consider possible strategies to screen for congenital cytomegalovirus and monitor for later onset hearing loss. The Committee has also met in a joint session with the Advisory Committee of the new Family-to-Family Health Information Center.

State Legislation.

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

1. Hearing screening during birth admission is the standard of care.

2. Birthing facilities are to educate parents about hearing, hearing loss, and hearing screening.

3. Regulations must be written if the screening rate falls below 95%.

4. The Department of Health and Human Services would develop a tracking system, and annual aggregate reports are required for birthing and confirmatory test facilities.

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 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"

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 and adopt and promulgate rules and regulations

2. Gather required data and generate annual reports

3. Establish guidelines for referral to early intervention services
4. Educate parents with out-of-hospital births about newborn hearing screening
5. Apply for all available federal funding to implement the Infant Hearing Act

Data System

The newborn hearing screening reporting system is an integrated module of the State of Nebraska Vital Records Electronic Registration System (ERS-II), developed by Netsmart Technologies, Inc. The ERS-II application is deployed on a Citrix/Metaframe application server, and served via the Internet to Windows workstations running CitrixICA (Independent Computing Architecture) as the client software, and accessing the Citrix/Metaframe server using a standard Web browser (Microsoft Internet Explorer). This CitrixICA session enables the user to enter data into the hearing database tables. All data transmission between the State and remote users of ERS-II is encrypted using standard SSL (Secure Sockets Layer) 128-bit encryption. Print jobs are also encapsulated within both SSL and SecureICA protocols.

Users gain access to the application through an established login ID and password. The current GUI roles for EHDI include: Birth Clerks, Hearing info clerks (birth hospital), Hearing info clerks (non-birth hospital), Hearing Administration, and Hearing Audiology. Authorized users are able to enter, search, display and revise records, run reports and print documents based on their assigned security level.

At the birthing facility, a birth clerk or hearing information clerk creates an individual HINFO record from the birth certificate. The HINFO record is the basic record for each occurrent birth and is populated from the birth certificate with identifying data of the newborn and parents, as well as maternal demographic information (race, ethnicity, and education level). The HINFO record also contains a tab for summary information about hearing screening, 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 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 also entered to facilitate follow-up activities.

In late 2008, the revision and expansion of the hearing module was completed. Using both HRSA/MCHB and CDC funds, the audiologic diagnostic evaluation module was completed, new hospital summary and detail reports were developed, modifications were made throughout the modules to improve functionality, the hearing risks module was completed, and reporting of results through the ERS-II by receiving hospitals when a baby has been transferred was finalized. An Access® database system has been developed internally to generate and track notifications to PHCPs and parents based on exports from the ERS-II data system.

SUMMARY

The NE-EHDI Program is poised to make significant progress in reducing the number of babies who are lost-to-system, regardless of whether it is a result of the services not being provided or reported. The experience with the NICHQ Learning Collaborative, the solid commitment of many partners to work collaboratively to improve the outcomes for young children, the experience with developing and refining an integrated electronic data reporting system, the increasingly positive connection with parents, the small but dedicated and talented staff in the NE-EHDI Program and the increasingly diverse group of stakeholders being involved in an advisory capacity provide a solid foundation upon which to build additional assurances that babies and their families transition from one component of the EHDI process to the next. An email received today from a pediatric audiologist exemplifies the capacity of which the NE-EHDI system is capable: "Passing along a very positive comment from a mom of a 2-month old who said that she is very pleased with the Nebraska Early Development Network and mechanism for serving infants with hearing loss. The family came for a confirmatory test today and she had her red EHDI folder and an IFSP already in hand." Our goal is to make this mother's experience a reality for all parents whose children are deaf/hard of hearing.