Nebraska EHDI Tracking, Surveillance and Integration Program

Background and Need

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. Required activities of the NE-EHDI Program include development, implementation, and monitoring of statewide systems to track newborns with or at-risk of hearing loss; gathering required data and generating annual reports; and establishing guidelines for referral to early intervention services.

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 Hearing Information (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. 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 quality assurance and status reports.

Revision and expansion of the newborn hearing screening module is currently in progress. With HRSA/MCHB grant funds, the refinement of an audiologic diagnostic evaluation prototype module, development of hospital detail reports, and modifications to improve functionality have begun. With CDC cooperative agreement carry-forward funds, the contract amendment process has begun to refine the hearing risks prototype module, develop new summary reports, and facilitate the reporting of results through the ERS-II by receiving hospitals when a baby has been transferred. An Access® database system is being developed internally to generate and track notifications to PHCPs and parents. More detail of these revisions and enhancements will be provided in the Work Plan section.

Reporting protocols**.** From 2001 through 2006, birthing facilities submitted a manual weekly report to NE-EHDI that identified those newborns that did not pass the hearing screening prior to discharge or were discharged prior to screening, including transfers to NICUs. Notifications to the child's Primary Health Care Provider (PHCP) indicating the hearing screening results and requesting follow-up information were generated manually.

Beginning on January 1, 2007, the hearing screening results of all occurrent births have been reported to the NE-EHDI Program using an 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 (refer) or discharged prior to screening, additional information is collected, including 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 tracking procedure for newborns who did not pass or were discharged prior to receiving a newborn hearing screening consists of a 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 the results submitted to the NE-EHDI Program. Included with the PHCP notification is a parent education brochure, 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. 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. There are approximately 60 babies in the "Follow-up in Progress" category at any time.

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, form 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.

Early Intervention (Part C) and Children with Special Health Care Needs (CSHCN) records are available to the program manager of the NE-EHDI Program 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 referrals and services provided. Children with PCHL who also have other disabilities may be categorized according to a disability other than hearing impairment since the CONNECT system only list the primary disability.

In 2005, the NE-EHDI Advisory Committee recommended that the NE-EHDI Program track infants identified with PCHL for five years. A one-page status check form was developed to request the follow-up information. It is mailed to the PHCP so that information can be obtained during the child's annual well-child check. For those children receiving Part C services, the annual status check may be mailed to the services coordinator.

Collaborative relationships. The NE-EHDI Program is a highly collaborative program, beginning with the multi-disciplinary Advisory Committee that was established in 2000. The Advisory Committee is currently composed of over 20 stakeholders and has expanded to include three sub-committees: audiology, family support, and evaluation.

A current collaboration of six early intervention programs is implementing an initial point of entry approach for the parents of babies recently identified with PCHL. Of particular benefit to the NE-EHDI Program from this initiative is the EDN/Part C template for parent consent to release educational records which will provide child-specific developmental outcomes data.

Another current collaborative effort in the Lifespan Health Services unit is to determine approaches to integrating child-specific public health records. Led by the program manager of the Newborn Screening and Genetics (NSG) Program, the workgroup includes immunization, NSG, Women-Infants-Children (WIC), birth defects and NE-EHDI programs.

Work Plan

The mission statement of the NE-EHDI Program describes the program's role in relationship to the state EHDI system: "The Nebraska EHDI 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, nine system goals were reviewed and refined by a cross-section of stakeholders and the NE-EHDI Advisory Committee during a strategic planning session in June, 2007. The goals are: 1. The hearing of all newborns will be screened during the birth admission or, if born out-of hospital, by 1 month of age. 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. 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. 4. All infants with a confirmed hearing loss will have a medical home. 5. Families of young children with a confirmed hearing loss will have access to a family-to-family support system. 6. The hearing of young children will be screened periodically. 7. Professionals working with young children with a hearing loss will increase their capacity to provide appropriate services to young children. 8. The NE-EHDI Program will provide an effective structure for the early hearing detection and intervention system. 9. The NE-EHDI system will be promoted.

It is imperative that the NE-EHDI Program has the capacity to efficiently gather and effectively process data about the hearing status of all occurrent births in the state. Obtaining data on the evaluation and intervention services for infants identified with PCHL is equally important. Five additional program goals have been established to accomplish the continued development of the data reporting, tracking and surveillance system for the NE-EHDI Program (see Attachment NE-DataFlowChart).

Notes: 1. Unless otherwise indicated, the NE-EHDI Program Manager [PM] and Business Analyst [BA] will have staff responsibility for all activities in this work plan. 2. Timelines for individual activities are displayed in the GANTT chart in Attachment NE-WorkPlanTable.

DATA SYSTEM 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.

Objective 1.1** – The current ERS-II module will be refined to improve functionality and expanded to support the acquisition of audiologic diagnostic data (see Attachment NE-DiagReportForm) and the addition of birthing facility status reports.* [Timeline: June, 2009; Measure(s): completion dates and user reviews of improvements, implementation of HAUDIO record and availability of reports]. ***Current Status: State contract with Netsmart Technologies has been amended to include “Enhancement II” using HRSA/MCHB funds.

Activity 1.1.A – Netsmart Technologies will develop “Enhancement II” modifications to the ERS-II system per specifications on development site with Business Analyst oversight, preliminary testing, and approval.

Activity 1.1.B – "Enhancement II" will be moved to ERS-II test site for thorough testing and analysis by Business Analyst with corrections and revisions made prior to final approval.

Activity 1.1.C – "Enhancement II" will be moved to ERS-II production site for beta testing by Children's Hospital, Boys Town National Research Hospital, and selected birthing facilities.

Activity 1 1.D – Revisions based on beta testing will be made, tested and implemented.

Activity 1.1.E – Audiologists will be educated about the audiologic diagnostic reporting system and hospital hearing screening administrators will be made aware of the new reports.

Objective 1.2 *– The current ERS-II module will be refined to improve the hearing screening summary status reports and expanded to support the reporting of inpatient hearing screening results by non-birth NICU hospitals and the acquisition of risk factor data.* [Timeline: December, 2009; Measure(s): completion dates and user reviews of reports, reporting of screening results by receiving hospitals, functionality of risk factor transfer]. *Current Status:* Approval has been given to use CDC carry-forward funds, revised specifications for "Enhancement III" have been submitted to Netsmart Technologies for current price quote, and system to expedite the contract amendment has been developed.

Activity 1.2.A – Amend contract between State of Nebraska and Netsmart Technologies.

Activity 1.2.B – Netsmart Technologies will develop "Enhancement III" modifications to the ERS-II system per specifications on development site with Business Analyst oversight, preliminary testing, and approval.

Activity 1.2.C – "Enhancement III" will be moved to ERS-II test site for thorough testing and analysis by Business Analyst with corrections and revisions made prior to final approval.

Activity 1.2.D – "Enhancement III" will be moved to ERS-II production site for beta testing by Children's Hospital.

Activity 1.2.E – Revisions based on beta testing will be made, tested and implemented.

Activity 1.2.F– Hearing screening coordinators at facilities with NICUs will be educated about the new reporting system for reporting hearing screening results, including the new work queue.

Activity 1.2.G – Risk factors from birth certificates will be transferred to the Hearing Risk section of the HINFO record, entered by NE-EHDI staff when received on hearing screening or audiologic diagnostic reports.

Objective 1.3 – *The current ERS-II module will be refined to populate the HINFO record with additional demographics (maternal age, payment source) and expanded to calculate comprehensive year-to-date reports of all components of the EHDI system.* [Timeline: December, 2009; Measure(s): completion dates; availability, usefulness of reports]. *Current Status:* Specifications for “Enhancement IV” have been submitted to Netsmart Technologies for initial price quote and included in this budget (contractual line item).

Activity 1.3.A – Amend contract between State of Nebraska and Netsmart Technologies.

Activity 1.3.B – Netsmart Technologies will develop “Enhancement IV” modifications to the ERS-II system per specifications on development site with Business Analyst oversight, preliminary testing, and approval.

Activity 1.3.C – “Enhancement IV” will be moved to ERS-II test site for thorough testing and analysis by Business Analyst with corrections and revisions made prior to final approval.

Activity 1.3.D – Comprehensive NE-EHDI system reports will be generated monthly to monitor status, quarterly for Advisory Committee and Evaluation sub-committee review, and annually for the required annual report to the legislature and the annual CDC-EHDI Hearing Screening and Follow-up Survey (OMB No. 0920- 0733).

***Objective 1.4** – Supplemental data systems will provide for expanded tracking and administrative function.* [Timeline: December, 2008; Measure(s): completion date, accuracy, user feedback]. *Current Status:* Prototype of Access® database completed to manage and track PHCP and parent notification.

Activity 1.4.A – System to export data from ERS-II to Access® database to Excel® spreadsheet for mail merge to PCHP and parent notifications will be developed [Staff Assistant, BA].

Activity 1.4.B – Reminder for pending 2nd, 3rd requests will be developed [Staff Assistant, BA].

Activity 1.4.C – System will be tested and run parallel to existing system for confirmation of accuracy [Staff Assistant, BA].

Activity 1.4.D – Conversion to new notification and tracking system will be completed to begin with 2008 births [Staff Assistant, BA].

DATA SYSTEM 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. *Current Status:* Each occurrent birth has a unique, unduplicated basic hearing information record generated from the birth certificate within seven days of birth. A basic hearing record (HINFO) is created by the birth clerk/hearing information clerk from the each baby's birth certificate and is populated with identifying data elements for the baby and parent(s), if identified. Baby data includes name, date of birth, and gender. In addition to parent name(s) and address(es), the maternal demographics of race, ethnicity and education level are transferred to the HINFO record. The date and results of the final inpatient hearing screening are entered into ERS-II. If a hearing screening did not occur during birth admission, one of nine possible reasons is entered into ERS-II. Complete information needed for follow-up, including preferred maternal language and PHCP, is recorded in records with an inpatient “refer” or “did not screen” result. Notifications to PHCPs and/or parents are generated according to NE-EHDI protocol (currently 3 days, 3 weeks, and 7 weeks after initial report received). Outpatient hearing screening results are reported electronically or manually. Hearing screening data coordinator is contacted in cases of incomplete or potentially erroneous results.

***Objective 2.1** – Hospital-specific and system-wide status reports of hearing screening results will be generated.* [Timeline: December, 2008; Measure(s): Completion date; number and accuracy of reports; use of reports; change in practice/results from demographic analysis].

Activity 2.1.A – Dynamic, online ERS-II reports (numbers screened, passed, referred, did not screen, etc.) will be available to monitor status and to provide data for quality assurance.

Activity 2.1.B – Aggregate comparison reports that provide year-to-date results, including longer-term outcomes such as lost-to-system, and comparison with statewide averages for the same type of screening will be generated quarterly for each birthing facility (see Attachment NE-Reports).

Activity 2.1.C – Comprehensive monthly, quarterly and annual system-wide reports will be generated by ERS-II to complete the CDC-EHDI Hearing Screening and Follow-up Survey and state status reports (see Attachment NE-Reports) for program monitoring, Advisory Committee accountability and Evaluation Sub-committee analysis.

Activity 2.1.D – Analysis of demographic factors (maternal age, education, race/ethnicity, language), location (rural, urban), and site (birthing facility, PHCP practice) related to outcomes, especially lost to system and timeliness of re-screening, will be conducted semi-annually.

Audiologic Diagnostic Evaluation Results

***Objective 2.2** – Audiologic diagnostic evaluation results will be reported by the audiologist or PHCP within two weeks of the event to the NE-EHDI Program.* [Timeline: June, 2009;

Measure(s): number of audiologists participating in orientations, increase in evaluation reports, timeliness of reporting]

Activity 2.2.A – Orientation to state and national data requirements and the one-page audiologic evaluation reporting form (see Attachment NE-DiagReportForm) will be conducted for all pediatric audiologists by December, 2008 *(Note: travel funded through HRSA/MCHB grant)*.

Activity 2.2.B – Evaluation results will be submitted by audiologists via mail, fax or ERS-II, upon completion of HAUDIO module, by June, 2009.

Activity 2.2.C – Case status will be assigned in electronic record: "diagnosed" for infants identified with PCHL, "closed" for those with normal hearing, "needs follow-up 2" for those with middle-ear dysfunction/transient conductive hearing loss, and "monitor" for those with normal hearing but risk factors for later-onset hearing loss.

Activity 2.2.D – Tracking and surveillance activities will be implemented according to NE-EHDI protocol.

Objective 2.3 – *System-wide status reports of audiologic evaluation results will be generated.* [Timeline: December, 2008; Measure(s): Completion date; number and accuracy of reports; use of reports; change in practice/results from demographic analysis].

Activity 2.3.A – Comprehensive monthly, quarterly and annual system-wide reports will be generated by ERS-II to complete the CDC-EHDI Hearing Screening and Follow-up Survey and state status reports (see Attachment NE-Reports) for program monitoring, Advisory Committee accountability and Evaluation Sub-committee analysis.

Activity 2.3.B – Analysis of demographic factors (maternal age, education, race/ethnicity, language), location (rural, urban), and site (birthing facility, PHCP practice) related to outcomes, especially lost to system and timeliness of diagnosis, will be conducted semi-annually.

Early Intervention Results

Objective 2.4 **–** *Early intervention data will be available for each infant identified with PCHL.* [Timeline: Ongoing; Measure(s): Number of CONNECT records accessed, number of infants with PCHL with EI data in NE-EHDI records, time to extract data]

Activity 2.4.A **–** Individual child records in CONNECT data system for Part C and CSHCN programs will be accessed monthly.

Activity 2.4.B **–** Age at referral and verification, services recommended and services provided data for Part C and CSHCN programs will be entered into the NE-EHDI data system.

Objective 2.5 **–** *Child-specific outcomes will be reported for each infant with PCHL.* [Timeline: June, 2009; measure(s): Number of outcome reports received; percent of infants with PCHL with outcome reports; percent of infants with PCHL and verified for Part C with outcome reports]

Activity 2.5.A **–** Child-specific language outcome measures from the Department of Education's Results Matter program will be reported to NE-EHDI semi-annually for infants with PCHL with parent consent to release educational records.

Objective 2.6 **–** *System-wide status reports of early intervention results will be generated.* [Timeline: December, 2008; Measure(s): Completion date; number and accuracy of reports; use of reports; change in practice/results from demographic analysis].

Activity 2.6.A **–** Comprehensive monthly, quarterly and annual system-wide reports will be generated by ERS-II and NE-EHDI Access data systems to complete the CDC-EHDI Hearing Screening and Follow-up Survey and state status reports (see Attachment NR-Reports) for program monitoring, Advisory Committee accountability and Evaluation Committee analysis.

Activity 2.6.B – Analysis of demographic factors (maternal age, education, race/ethnicity, language) and location (rural, urban) related to outcomes, including lost to system, timeliness of referral and verification, and language abilities, will be conducted semi-annually.

<u>DATA SYSTEM GOAL 3</u> – Mechanisms to collect data about young children with late onset or progressive hearing loss will be developed.

Objective 3.1 *– A system to alert PHCP to monitor hearing based on risk factors will be developed.* [Timeline: December, 2009; Measure(s): protocol, materials, notifications]

3.1.A - Recommendations for monitoring protocol for infants with risk factors will be developed by the NE-EHDI Advisory Committee and other stakeholders, consistent with the 2007 Position Statement of the Joint Committee on Infant Hearing (JCIH).

Activity 3.1.B – Educational materials and strategies for audiologists and PHCPs will be developed and disseminated.

Activity 3.1.C – Notifications to PHCPs about monitoring will include recommended protocols.

Note: Objectives 3.2 and 3.3 are based on NCHAM's ECHO and HearAndNow programs; NE-EHDI resources obligated are allocated to HRSA/MCHB grant.

Objective 3.2 – *Early Head Start/Head Start (EHS/HS) conducting OAE hearing screenings will submit child-specific reports to NE-EHDI program.* [Timeline: June, 2010; Measure(s): Recording templates for two data systems, Memorandum of Agreement, annual reports]

Activity 3.2.A - Adapt EHS/HS data tracking systems (ChildPlus, HSFIS) to support the recommended hearing screening protocol.

Activity 3.2.B - Develop a Memorandum of Agreement between EHS/HS programs and NE-EHDI Program to facilitate reporting process.

Activity 3.2.C – EHS/HS programs report annual child-specific hearing screening results.

Objective 3.3 *- Community health clinics conducting OAE hearing screenings will submit child-specific reports to NE-EHDI program.* [Timeline: September, 2009; Measure(s): health clinic database, Memoranda of Agreements, child-specific reports]

Activity 3.3.A – Develop modification of Access database for recording of OAE screening results and recommended follow-up.

Activity 3.3.B - Develop a Memorandum of Agreement between participating community health clinics and NE-EHDI Program to facilitate reporting process.

Activity 3.3.C – Community health clinics report child-specific hearing screening results.

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

Objective 4.1 *– Birth defects implicated in hearing loss will be exported to the NE-EHDI ERS-II system.* [Timeline: June, 2010; Measure(s): Specifications, quote, contract amendment, number of hearing records with birth defect information]

Activity 4.1.A – Permissibility of providing birth defect registry data to NE-EHDI will be established with DHHS legal department.

Activity 4.1.B – Relevant ICD-9 codes will be identified.

Activity 4.1.C – Specifications for linking the two data systems (both Vital Records ERS-II modules) will be developed and submitted to Netsmart Technologies for price quote, followed by contract amendment.

Activity 4.1.D – Work queue in NE-EHDI ERS-II module will be developed to hold export record when specified ICD-9 code is entered in an infant’s birth defects record.

Objective 4.2 – *NE-EHDI data system will be integrated with Nebraska State Immunization Information System (NESIIS).* [Timeline: June, 2011; Measure(s): number of times accessed for updates, PHCP access protocol, plan to link/integrate, beta test results]

Activity 4.2.A – NE-EHDI staff will access NESIIS, as needed, to update data, such as PHCP, and address.

Activity 4.2.B – The options to link or integrate the records in the two data systems will be evaluated for ease of user access, functionality and opportunity to further a population-based child health data system.

Activity 4.2.C – The protocol for PHCP access to the NESIIS will be modified for more restrictive access to hearing records.

Activity 4.2.D – Proposed linkage or integration of the data systems will be submitted to the Information System and Technology department for approval.

Activity 4.2.E – If approved, proceed with software development to link or integrate NE-EHDI and immunization records.

Activity 4.2.F – Access to hearing summary records by PHCP and parents will be beta tested.

Objective 4.3 - *NE-EHDI data system will be linked to the Newborn Screening/Genetics Program.* [Timeline: September, 2010; Measure(s): number of dried blood spots retrieved, number with genetic/CMV positive results, shared PHCP database, plan to link]

Activity 4.3.A – The sharing of data will continue to support PHCP retrieval of dried blood spots to determine possible genetic and congenital cytomegalovirus etiology of PCHL.

Activity 4.3.B – Locally-developed data system of contact data for PHCPs in Nebraska and western Iowa will be shared by NE-EHDI and NSG Programs.

Activity 4.3.C – A proposed linkage between NSG and NE-EHDI data systems to update NSG names will be submitted to Information System and Technology department for approval

Activity 4.3.D – If approved, proceed with electronic linkage of NE-EHDI and NSG records.

Objective 4.4 – *Cross-border follow-up procedures will be established with neighboring states.* [Timeline: June, 2010; Measure(s): Letters of Agreement, number of babies in cross-border follow-up, comparison of lost to system cases]

Activity 4.4.A – Contact EHDI coordinators in MO, KS, CO, WY, SD, and IA to determine follow-up protocols and restrictions on sharing EHDI data for residents of one state born in the other and also transferred to hospitals.

Activity 4.4.B – Develop Letters of Agreement with each state to maximize the sharing of EHDI data to reduce the number of babies who are lost to system (follow-up or documentation).

Evaluation of progress in accomplishing the work plan and measuring the EHDI system's outputs and long-term outcomes is the fifth goal of the NE-EHDI Tracking, Surveillance and Integration Program (see the Evaluation Plan section for Goal 5, objectives and activities).

Collaborative Efforts

Current collaborative data sharing efforts for the NE-EHDI Program include the State's Vital Records Birth Certificate Registry, birthing facilities, PHCPs, audiologists, the NSG Program, Early Development Network/Part C and Medically Handicapped Children's Program/CSHCN programs. Accessing newborn hearing screening results for babies born in Nebraska and transferred to NICUs in neighboring states has been worked out with either receiving hospitals or the state EHDI programs in Colorado, South Dakota, and Iowa. Future collaborations include the Birth Defects registry, immunization program, and Department of Education, as well as enhancements on the collaborative activities with the current partners.

Other potential collaborative partners include the Early Head Start/Head Start programs and community health clinics.

Although audiologists are only required to submit aggregate results according to the Infant Hearing Act, they are increasingly reporting individual child-specific hearing screening and diagnostic results due to outreach efforts. PHCPs are submitting hard copy reports of the outpatient screening results and diagnostic results on routine follow-up requests.

Several early childhood programs have granted the NE-EHDI program access to their electronic data systems for follow-up and tracking. PHCP names and maternal contact information in the NSG Program’s Neogen data system are checked if the information in the NE-EHDI data system appears to be invalid. Nebraska’s Part C program, Early Development Network (EDN), provides the NE-EHDI program manager access to the CONNECT system for Part C verification and early intervention services data. The CONNECT system also provides similar information about the Medically Handicapped Children’s Program, Nebraska’s Children with Special Health Care Needs program.

A current working relationship to be enhanced during the first year of this project is to engage Boys Town National Research Hospital and Children’s Hospital in Omaha in a beta test of the audiologic diagnostic evaluation module to be finalized by Netsmart Technologies. Audiologists from both facilities were involved in developing the one-page evaluation reporting form (see Attachment NE-DiagReportForm) that is the template for the audiologic diagnostic evaluation record for the ERS-II integrated data system. When coupled with the demographics from the basic HINFO record, the diagnostic data set for the annual CDC-EHDI Hearing Screening and Follow-up Survey (OMB No. 0920- 0733) will be complete.

A collaborative initiative with EDN/Part C and other early childhood programs to establish a single point of entry for parents of young children recently identified with PCHL includes a specific provision for parent consent to release educational records to the NE-EHDI program. The Nebraska Department of Education is just beginning to implement Results Matter, a child and family outcomes system for children with disabilities, which includes child language and social-emotional outcome measures. The assessments are conducted semi-annually and, with parent informed consent to release the records, will be provided to the NE-EHDI Program to document child-specific outcomes for those children identified with PCHL.

Work has begun to compile a comprehensive listing of all PHCPs in Nebraska, based on data from the Health Professional Tracking Center, and western Iowa into a single database to be shared between the NE-EHDI and NSG Program for notifications to PHCPs.

During Year 1 of this project, collaboration with the Immunization Program regarding the new immunization information system, also based on the Vital Records ERS-II birth certificate registry, will be implemented. The NE-EHDI Program will be granted view-only access to the system to confirm PHCP, parent contact and name change information initially.

A joint meeting of the Advisory Committees for the NSG and NE-EHDI programs has been held to provide the basic information of the national and state initiatives focusing on electronic health records and the status of integrated child health records in public health.

Collaboration with the Birth Defects Registry will be approached during Year 2. Dependent upon an assessment of the legal permissibility of releasing the birth defect data to NE-EHDI, the ICD-9 codes with implications of risk factors for progressive or later-onset hearing loss will be identified. When an identified ICD-9 code is entered into the Birth Defects Registry for an infant, the case will also transfer to a work queue in the hearing module for inclusion in an HRISK record. Young children with HRISK records will be placed in a "monitor" status with periodic notifications to the PHCP for audiologic monitoring of later-onset or progressive hearing loss, based on the JCIH 2007 Position Statement.

NESIIS is being designed to support PHCP access to view and record data and to support parent view-only access and may serve as a portal to hearing records. Since the immunization module maintains a live link with both the birth and death certificate systems, integration with NESIIS for long term follow-up is advantageous. Restricting PHCP access to only records for which there is parent consent is a concern. If this concern can be resolved, it may be possible for the immunization system to be a hub of the child health data system.

Letters of partnership supporting the collaborations with the Nebraska Immunization Program, Birth Defects/Health Statistics, Early Development Network/Part C, Newborn Screening and Genetics Program, Children's Hospital, and Boys Town National Research Hospital are included in Attachment NE-PartnershipLetters.

Program Capacity

Since its inception in 2001, the NE-EHDI program has been organizationally located in the NSG 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 (see Attachment NE-OrgChart). 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

All but one of the birthing facilities in Nebraska have been conducting newborn inpatient hearing screening since 2003 when 97% of newborns were screened. The one exception is a small hospital that has been scheduling outpatient hearing screening prior to one month of age.

The NE-EHDI Resource Guide lists 65 audiologists at 28 Nebraska sites who self-identified as providers of pediatric audiologic services. Those sites are surveyed annually to provide aggregate reports about hearing screening, diagnostic and amplification activities. Sixteen sites reported conducting screening and audiologic diagnostic evaluations and six sites reported conducting only follow-up screening.

Preliminary results for all occurrent 2007 births indicate that 98.9% were screened during birth admission. Of the babies who did not pass the newborn hearing screening (“refer” or discharge prior to screening), 82.4% have had normal hearing established through a re-screening or audiologic evaluation, 4.7% are in the process of having hearing sensitivity evaluated, 9.3% have been lost to system and 3.5% are diagnosed with a PCHL, an incidence of 1.6:1000 births. Of those identified with a PCHL, 57.1% have been verified for Part C early intervention services and 95.8% of those have been verified at less than six months of age.

Staffing and Management Plan

The staffing pattern for the NE-EHDI Program currently consists of the 1.0 FTE Program Manager I, a 1.0 FTE temporary Staff Assistant II, and a 1.0 FTE Business Analyst. If final internal approval is given, a permanent 1.0 FTE Community Health Educator II position will replace the temporary Staff Assistant II and 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 proposed allocation of funding for the staff positions, to be supported by daily activity logs, is included in the following table:

Staff Position	HRSA/MCHB	CDC	Title V
Program Manager I	0.5 FTE	0.4 FTE	0.1 FTE
Staff Assistant II/Community Health Educator II	1.0 FTE	-	-
Business Analyst (contracted position)	0.05 FTE	0.75 FTE	0.2 FTE

Job descriptions and resumes are included in Attachments NE-JobDescriptions, NE-Resumes.

Evaluation Plan

The Infant Hearing Act requires that each birthing facility has a system for compliance review and to report specific aggregate data to the NE-EHDI Program for inclusion in an annual report to the legislature. The data entered into the ERS-II state system by the birthing facilities 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. The Act requires an annual report that is developed in conjunction with the NSG Program. In 2006, the Annual Report was disseminated to 343 stakeholders and the Executive Summary to 2,050 stakeholders.

A variety of administrative and ad hoc reports have been devised during the first sixteen months of operation of the ERS-II data system. To encourage the timely reporting of individual 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 exception report averages less than 20 babies per week (approximately 4% of weekly births) and the Business Analyst contacts the primary data contact of the birth facilities that have babies appearing on the report. 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 30 days of age.

Monthly status reports (see Attachment NE-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: working, closed, diagnosed, active follow-up (with and without middle-ear dysfunction), lost to system, expired, and errors. The timeliness of the initiation of follow-up activities is included in this report. The monthly status report also includes the numbers and ages of babies with PCHL who have been referred to EDN/Part C and were verified for services.

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 system" in 2006, the year the NE-EHDI Program was participating in National Initiative for Child Healthcare Quality's EHDI 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 (see Attachment NE-Reports) 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 with the state-wide EHDI system rates. Birthing facilities have requested the inclusion of outcomes to include numbers identified with normal hearing, hearing loss and loss-to-system.

Maternal demographics transferred from the birth certificate to the hearing information record currently include race, ethnicity, and education level. Maternal age and payment source will be added during Year 1. These demographic factors, coupled with birth hospital and PHCP locations, provide the capacity for a routine set of reports to identify relationships with outcomes, such as timeliness of initiation of follow-up activities, referral to Part C and loss-to-system. This analysis is beginning to provide birthing facilities and the NE-EHDI Program with the data to develop specific, targeted approaches to reduce the numbers of babies who are lost-to-system and perhaps to reduce health disparities. These approaches are based on the NICHQ Learning Collaborative's Model for Improvement.

Evaluation of the progress to implement the work plan and measuring the EHDI system's outputs and outcomes is the fifth goal of the NE-EHDI Tracking, Surveillance and Integration Program. The complete Evaluation Plan is included in Attachment NE-EvaluationPlan.

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

Objective 5.1 - *System-wide and site-specific quality assurance/status reports will be available.* [Timeline: June, 2009; Measure(s): Reports (real-time, state aggregate, comparison, summary, detail)]

Activity 5.1.A - Each birthing facility will access reports in real-time to track performance and to identify areas for quality improvement. In addition, the data system will provide aggregate reports for the state.

Activity 5.1.B – Quarterly comparison reports will be provided to each birthing facility.

Activity 5.1.C **–** 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.

Objective 5.2 – *Technical assistance for improved quality will be provided to hospitals.* [Timeline: March, 2009; Measure(s): Technical assistance plans, documented changes]

Activity 5.2.A **-** The site-specific quality assurance/status and comparison reports will be used to identify areas for improvement and to develop technical assistance approaches.

Objective 5.3 *– The NE-EHDI evaluation plan (see Attachment NE-EvaluationPlan for the complete plan) will provide a semi-annual measure of the progress in meeting the work plan deadlines and of the program outputs and eventual child outcomes.* [Timeline: ongoing; Measure(s): evaluation reports, meeting minutes,]

Activity 5.3.A **–** Evaluation Sub-committee will evaluate progress semi-annually in meeting the project objectives and NE-EHDI outcomes.

Objective 5.4 *– Dissemination plan will be finalized and implemented.* [Timeline: June, 2009; Measure(s): Dissemination plan, dissemination activities report]

Activity 5.4.A **–** Evaluation sub-committee will revise the dissemination plan.

Activity 5.4.B **–** Dissemination plan will be implemented.

The ability of the NE-EHDI Program to measure its progress toward national guidelines is a critical aspect of program growth and development. Increasingly the data to measure the progress is based on individually-identifiable child records in the ERS-II data system and linkages to related systems. Currently the NE-EHDI Program can acquire all of the data elements that will be requested for the CDC-EHDI Hearing Screening and Follow-up Survey for 2007 births, can measure 65 of the 105 performance indicators in the “National Goals, Program Objectives, and Performance Measures for the EHDI Tracking and Surveillance System,” and can document 20 of the 42 key updates recommended by the JCIH 2007 Position Statement as measured in the ASHA EHDI Program Checklist. Ongoing development of the NE-EHDI ERS-II data system and linkages with related systems will provide the data necessary to evaluate the program’s progress in meeting state and national goals and determine approaches to improve services and outcomes for young children with PCHL and their families.