OKLAHOMA UNIVERSAL NEWBORN HEARING SCREENING & INTERVENTION
HRSA 5-H61-10-001; CFDA 93.251

PROJECT NARRATIVE (PROGRESS REPORT)

Overall Project Accomplishments 4/1/09 – 3/31/10

The Oklahoma Newborn Hearing Screening Program (NHSP) performance data for 2007 became available in early 2009. Analysis of the 54,946 infants born in Oklahoma during 2007 revealed that 96.8% (53,241) were screened for hearing loss prior to hospital discharge. Five percent (2,662) failed hospital screening and were referred for further follow-up. Follow-up results were received for approximately 75% (1331) of the infants who did not pass the hospital screening. The NHSP tracked 2,906 (5.5%) newborns that passed the birth hearing screening but had risk indicators for later developing hearing loss. The NHSP also tracked the 3.2% (1705) infants not screened at birth.

For the 2007 calendar year, 108 infants have been documented with hearing loss. A total of 89 infants have enrolled in an Early Intervention program for children with hearing loss: 28 were diagnosed with hearing loss by the first month of life; 20 by three months of life; 17 by six months of life. This indicates that 76% of infants met the 1-3-6 goals set forth by the Center for Disease Control and Prevention (CDC) of 1 month screening, 3 months diagnosis, and 6 months placement in Early Intervention. It is important to note that this number does include some children who passed newborn hearing screening with no risk factors present but were diagnosed with hearing loss at a later date indicating possible late onset hearing loss. The program noticed increased reporting of risk factors during 2008 due to training efforts in Oklahoma birthing hospital by the Follow-up Coordinator. Comparison of 2006 data indicated that with the additional training efforts an additional 1099 (2%) of newborns were screened and reports were provided to the NHSP. Additional training is currently being provided to update providers regarding documentation for results and diagnosis. Data to date indicate that more infants are receiving follow-up at an earlier age and are being reported to our office. Most of the infants have met and exceed the CDC 1-3-6 goals.

Recent data indicates that loss to follow-up and loss to documentation are decreasing, but continue to be an obstacle for the Early Hearing Detection and Intervention (EHDI) program. While there has been improvement from previous years, it continues to be an overarching goal of this Project to assure that <u>no</u> newborn is loss to follow-up. The following represents our accomplishments during the 2009-2010 grant years. Each of these activities continues to be directed toward increasing the number of infants screened as well as those seen for follow-up after not passing the hospital hearing screening.

<u>Follow-up Coordinator:</u>

In 2005, the Oklahoma State Department of Health (OSDH) authorized creation of a Follow-up Coordinator for the Newborn Hearing program, funded by the HRSA Oklahoma Newborn Hearing Screening and Intervention Project. Primary responsibilities of the Follow-up Coordinator include engaging birthing hospitals, parents and other interested stakeholders to increase utilization of follow-up services and to decrease loss to follow-up and loss to documentation. This position was immediately filled upon receipt of grant funding with a Speech Language Pathologist and has subsequently filled by a Clinical Audiologist. Dr. Brandon Vincent has experience as a pediatric audiologist where he coordinated and implemented a hearing screening program for several local HeadStart centers, supervised and performed audiologic screenings, and performed audiologic evaluations on referred patients.

Increased Education on Screening and Follow-up:

In January 2006 the NHSP commenced educational training for the sixty-six birth facilities in Oklahoma. This training continues to be an effective method to increase education and awareness for hearing loss as well as to increase documentation and reporting of testing provided. The Newborn Screening Program (NSP) combined the efforts of the NHSP Follow-up Coordinator and Newborn Metabolic Screening Program (NMSP) Quality Assurance/Education Coordinator to develop presentations for all Oklahoma birthing hospital staff. Emphasis has been placed on the importance of supplying the NSP with accurate contact information for families and correct follow-up health care provider data to help reduce the number of infants who are loss to follow-up. Hospital staffs are encouraged to review hearing screening results with the family prior to discharge and provide additional resources for follow-up such as the NHSP brochure. New hearing equipment, purchased during the last grant period, was provided to sixty birthing hospitals, who also received an in-service training by the Follow-up Coordinator. In addition to the in-service training, contact with hospital staff has been maintained via phone and email. Sites have also been contacted to schedule upcoming in-services regarding a review and update on information previous presented. NHSP plans to schedule twenty in-services by the end of the current grant period.

The NHSP Follow-up Coordinator continues to provide educational opportunities for county health departments in Oklahoma through collaborations with Nursing Services. One achievement of the follow-up program is the collaboration of the WIC service to obtain newborn hearing screening results for each of their clients and to refer newborns for hearing screening and/or audiologic assessment when appropriate. This collaboration is enhanced by utilizing the NSP tracking system developed by Neometrics .The NHSP is currently working with Neometrics to enhance the current tracking software for better utilization. An example of current upgrades includes the ability to print screening results through the Public Health Oklahoma Client Information System (PHOCIS) that is primarily used in all county health departments.

Another important accomplishment is the continued collaboration of the Follow-up Coordinator with the Children First program. This is a voluntary family support program that offers home visitation services to mothers expecting their first child beginning before the 29th week of pregnancy and continuing until the child's second birthday. This program employs 140 public health nurses and serves approximately 5,000 families across Oklahoma. Once enrolled in the program, a public health nurse works with the mother in order to increase her chances of delivering a healthy baby as well as educating about child safety development. The NHSP is part of the routine training offered for new nurses employed by the Children First program. Additional training continues to be provided to new and existing staff of the program regarding the impact of hearing loss on literacy. At the request of the Children First nurses to provide information to parents regarding Newborn Hearing Screening, permission was obtained from

Utah State University to reproduce and utilize the Sound Beginnings videos created by the National Center for Hearing Assessment and Management (NCHAM). Each Children First nurse received a copy of the video in Spanish and English along with a parent education packet that includes examples of the hospital bloodspot form, hearing loss facts, and additional information on follow-up if a child failed at the hospital screening. Several additional videos were provided to regular county health department nursing staff to educate their maternity population. NHSP is working on a survey to determine how providers utilized the resources made available and additional assistance needed to educate parents regarding Newborn Hearing Screening and follow-up. The Survey will be completed by end of this grant period.

During this grant period, the NHSP and Oklahoma Audiology Taskforce (OAT) collaborated to create a subcommittee for additional family and provider outreach. The subcommittee is working on adapting the Sound Beginning videos and follow-up information, given to the Children First nurses, to be utilized in birthing classes throughout Oklahoma. Through the Follow-up Coordinator's interactions with parents, it is apparent that families are often uneducated about the newborn hearing screening process. Birthing classes are ideal for preparing parents about the topic of hearing screening and educating them about results and follow-up. One barrier to this proposal is the number of birthing classes taught in Oklahoma and the ability of the combined task force to contact each site and provide training. To alleviate this problem, the NHSP staff presented information to four colleges with undergraduate and graduate classes in Speech-language Pathology and Audiology to educate students in these programs about hospital hearing screenings, follow-up, and obstacles for families. Several students have signed up to participate in the OAT subcommittee to present information to birthing class teachers to implement in their current programs.

Increased Communication:

To reduce loss to follow-up, the Follow-up Coordinator continues to assist in the modifications of the NHSP tracking procedures for infants not screened at birth or who did not pass the hospital screening. Initial letters have been sent within one week of the receipt of the bloodspot form to families of infants who were not screened or failed. If no response is obtained by the parent or a follow-up provider to the NHSP, a second letter is generated to the parent and provider within 45 days of initial notification. In addition to the second notification, the Follow-up Coordinator contacts all families by phone who have not responded to the initial request for further testing emphasizing to the family the importance of determining the infant's hearing status and assists the family in obtaining the needed procedures in a timely manner. This intensive follow-up has resulted in a significant increase in the numbers of results received for infants whose families were personally contacted and encouraged to have hearing screened or assessed.

With increased contact to families to ensure follow-up is achieved, the Follow-up Coordinator noted that many parents had already completed the recommended rescreen for their child. Many parents indicated confusion by the follow-up phone call and reported concern that the follow-up screening was not accurate. Expanded efforts by the Follow-up Coordinator resulted in improvements in three following areas: 1) Increased communication with county health department providers as some had completed follow-up screenings but did not send results immediately to the NHSP. During previous grant periods, collaboration with other database programs in the OSDH system were implemented to allow the Follow-up Coordinator to validate demographics before calling the family and sending the second letter. In addition, the Follow-up Coordinator made further efforts to check for possible appointments with providers who completed hearing screenings at those sites. If an appointment was attended, the service provider was contacted by the Follow-up Coordinator prior to calling the parent. 2) Increased prioritization of data entry in the NHSP program prior to the second letter and follow-up phone calls to update charts and correct inaccuracies. 3) Increased compliance with state mandated reporting of follow-up screenings from both private and public providers. When results are reported by a parent report but have not received from the provider, the Follow-up Coordinator contacts the site to confirm results and provide education and documentation for future screenings.

Another activity that the NHSP program undertook during this grant period was to examine information sent to parents in the initial letter notification. The letter originally requested that families call the NHSP for information regarding where to complete a hearing screening in their local area. The trial consisted of adding a label with the corresponding county health department where services could be obtained. The goal was to reduce the number of daily incoming phone calls to the NHSP. Results of this trial indicated that the number of phone calls received for follow-up testing information was reduced by at least half. An additional benefit included more parents scheduling and attending follow-up screens in a timely manner.

Communication with Non-English Speaking Families:

The 2000 census indicated 5.2% of Oklahoma's population is Hispanic with many of these individuals speaking Spanish only. All NHSP printed correspondence to families has been available in Spanish since October 2005. A priority activity of this Project was to decrease the number of Hispanic infants who were loss to follow-up because of a communication barrier. . To accomplish this goal, the Follow-up Coordinator has been informing hospitals that information about hearing screening and follow-up letters are available in Spanish if indicated on the bloodspot form. Hospital staffs have responded positively and have started entering the information in the "Other" section on the form. Translation services are available through a language line for direct phone communication with the families in other languages including Spanish. Information about the availability of letters in Spanish and the enhanced language translation services continues to be shared with local health department staff, private follow-up facilities, and Women, Infants and Children (WIC) staff through in-service trainings. By December 2009, the NHSP will also have a new Quality Assurance/Data Coordinator on staff that is conversational in Spanish and can assist the NHSP with contacts to Spanish speaking families.

Hearing Equipment in Oklahoma:

The hearing screening equipment located at Oklahoma birthing hospitals through the state were initially purchased in 1999 with funding received in a cooperative agreement between the OSDH and Children with Special Health Care Needs (CSHCN). Many of these screeners had reached the end of their functional life. Newborns discharged without a hearing screening in the hospital generally do not receive a screening at an outpatient site. Through carry-over funding from a previous HRSA Newborn Hearing Screening and Intervention Project, five_ALGO 3 AABR screeners were purchased and delivered to sites with the oldest equipment. Between 2007-2009, state legislative funding was received to replace hospital hearing screeners with twenty ALGO 3 AABR screeners and subsequently twenty-eight ALGO 5 AABR screeners. A total of 11 portable ALGO 3i AABR screeners were also purchased for use in county health departments throughout Oklahoma. The NHSP continues to monitor all hearing screeners at Oklahoma birthing hospitals which include ensuring that hospitals obtain annual calibration, providing troubleshooting techniques as needed, and assisting with training. Funding for this grant is instrumental with this follow-up activity.

The NHSP also maintains approximately 700 pieces of hearing equipment in Oklahoma county health departments. Diagnostic equipment is available at health department audiology sites in nine cites (Oklahoma City, Moore, Tulsa, Claremore, Lawton, Muskogee, Enid, McAlester, and Clinton). Additional screening equipment is available throughout the state in the majority of county health departments to obtain automatic auditory brainstem responses, otoacoustic emissions, tympanograms, and audiograms. Approximately half of the equipment was purchased over twenty years ago. Several of these screeners are no longer functioning well and parts are not available for repairs. During the beginning of this grant period, state audiologists completed equipment trials with three vendors to determine which equipment would be most useful and cost-efficient to replace existing models. By the completion of this grant period, four hearing screeners will be purchased to replace equipment in rural areas where equipment is aging to assist with hearing screening follow-up. Additional equipment will be purchased through state legislative funding over the next few years. In addition carry-over funding will be utilized for the purchase of equipment for hearing aid fitting/adjustments for an audiology suite in a rural county health department. This will assist rural families of children with hearing loss to obtain follow-up services such as routine testing, hearing aids adjustments and ear model fittings.

An additional activity during this grant period is a survey developed by the NHSP to determine usage of equipment by county health departments for reallocation to increase statewide coverage. This survey also addresses problems providers encounter with troubleshooting, calibration, and training. The survey will be distributed in January 2010 and will be analyzed shortly thereafter. The Follow-up Coordinator will utilize teleconferencing capabilities linked with each site to provide training as needed.

Enhanced Tracking System:
The Neometrics Division of Natus provides the tracking system used for follow-up for both hearing screening and metabolic screening programs. When audiometric information is received for infants with diagnosed hearing loss, specific test results for each ear can be recorded as well as the date of the procedure. Providers can enter information about the early intervention program in which the child is enrolled and the date of entrance into that program. Program staff can easily generate hospital-specific reports regarding the number of infants screened, the number that did not pass the screening, and the number at-risk for late onset hearing loss.

Though the Oklahoma NHSP has made tremendous efforts to screen, follow, and track all births in Oklahoma, additional measures are needed for quality assurance and surveillance to reduce the number of infants who are loss to follow-up and results that are loss to documentation. As mentioned, with the implementation of a Follow-up Coordinator through HRSA funding, follow-up calls are made to parents in whom the data system indicated the child was not screened or referred but did not complete follow-up. Through parent conversations and subsequent calls to the birthing hospital for confirmation, it has been noted that many hospitals rescreen a child who has failed after the bloodspot form is sent to the NHSP and prior to discharge. Though state mandates require that providers report these results, NHSP has been unable to determine if all results are sent unless otherwise told by a parent or physician. Funds are budgeted during this grant year to upgrade the current NHSP data system. With the placement of all new ALGO 3 and 5 screeners in all Oklahoma birthing hospitals, the Neometrics upgrade would provide direct input from the hospital screeners every 5-10 minutes creating an up-to-date record of all results for each individual child. Oklahoma NHSP is working closely with the Information Technology (IT) program at the Oklahoma State Department of Health (OSDH) and the Neometrics software developers to obtain the patient data electronically. Key issues of messaging strategized for safe and secure data transfer have been discussed along with potential sites to pilot the project. This would reduce a portion of the data entry needed at the OSDH Public Health Laboratory (PHL), reduce daily confirmation calls to hospitals due to parent updates, and provide a more timely receipt of results to generate needed follow-up actions by the NHSP. The pilot portion will be completed at no cost so that the program can ensure that grant funds for this portion of the project are justifiable and to ensure that data is linked to meet the needs of the OSDH. The pilot is expected to be completed in early 2010 to allow for purchasing of software prior to the end of the grant period.

Barriers/Solutions:

While the NHSP is making good progress toward the current Project goals and objectives, some barriers to providing appropriate and timely follow-up continue to exist. Records regarding diagnosis and entry dates for infants and toddlers with hearing loss enrolled into early intervention are housed in Oklahoma State Department of Education (OSDE) database. This database is not accessible to the NHSP program staff and therefore assessment and enrollment dates cannot easily be confirmed and entered into the tracking system. An interagency agreement between the OSDE and OSDH was been signed in 2008 to allow data to be shared between programs. A general release form is given to all parents upon initial enrollment of the referral process that ensures results can be sent between the two agencies. A direct result of this agreement is increased reporting by the county Early Intervention team to the NHSP for all children diagnosed with hearing loss who are receiving services. The quarterly tracking report includes demographic information for linking the NHSP Neometrics system, primary service provider, and dates of diagnosis, amplification, and enrollment in early intervention. This information has been helpful in determining if enrollment into early intervention services is completed prior to the national guidelines of six months. During the previous grant period, the compliance rate for submitting quarterly tracking forms was approximately 70% statewide. There has been some progress in the number of tracking forms received, however additional efforts are needed to increase compliancy. The information received on the Part C tracking forms has reduced loss to follow-up in that 20% of the children listed were seen by private audiologists who did not submit the proper documentation to the NHSP as required by state law. Once results have been received from the tracking forms, providers are contacted for verification of the information and reminded of state protocols.

In the previous grant period, Oklahoma audiologists were surveyed regarding the state NHSP, updates on childhood hearing loss, state mandated reporting, and continuing education opportunities most utilized by providers. The survey was sent to all licensed Oklahoma audiologists during Better Speech and Hearing Month in May 2008. Seventy perfect of the surveys were completed by providers. Analysis of results revealed that several providers were not aware of guidelines and the progress of the Oklahoma NHSP regarding screening, diagnosis, amplification, and early intervention placement. To address this need, the Follow-up Coordinator developed a presentation that discussed hearing results, timeliness of follow-up, ways to obtain initial hearing results received from the hospital, and state protocols requiring reporting of initial/follow-up results. Since many Oklahoma audiologists indicated they attended free continuing education opportunities through hearing aids companies, the Follow-up Coordinator paired with Widex and Phonak to pilot the presentation. Feedback from audiologists suggested that many did not know how to access the initial results and were not aware of reporting requirements. Many of these providers are now sending results on a consistent basis, which has decreased the number loss to documentation. With the success of the pilot and the need to reach more audiologists, plans to continue collaboration with other hearing aid companies and train Oklahoma audiologists to present the information in their regions of the state are tentatively scheduled for the upcoming grant year. In addition, the NHSP hired a new Follow-up Coordinator with a Clinical Doctorate in Audiology to work with providers statewide. The Audiology Taskforce has also created a subcommittee for outreach and education of pediatric audiologists.

While physiologic hearing screening equipment is available at more than forty-five county health department locations across the state, additional units are a continued need as machines are aging. Clinicians are willing to share these devices, but often, scheduling conflicts arise and units are not readily available at a given location to screen/re-screen an infant in a timely manner. If Project carry-over funds are allotted, additional screening equipment will be made available to these clinicians. Training and troubleshooting will also be offered by the Follow-up Coordinator to those new providers across the state.

Audiologists with pediatric assessment skills are primarily located in the major metropolitan areas of Oklahoma. One barrier that many families face is the distance that they must travel for an audiological assessment. Even with reimbursement for travel, meals, and lodging, many families are unable or unwilling to make such a trip**.** To overcome this barrier**,** OSDH has been successful in employing audiologists at several locations across the state. Contract audiologists are also present in communities where vacancies for full-time audiologists exist. These clinicians work tirelessly with families of infants who did not pass the hospital screening or are at risk for late onset hearing loss. They stress the importance of follow-up assessment and encourage the families to schedule needed appointments. These providers are unable to administer and monitor hearing aids and ear molds. This is due to the lack of a Medicaid contract to purchase hearings aids and needed equipment for follow-up services. Communities with private audiologists often do not accept Medicaid reimbursement and families must travel for all hearing aids needs. Discussions have begun at OSDH to determine methods for obtaining the funding to assist families that primarily reside in rural communities. Carry-over funds from the previous HRSA grant period were also requested to purchase equipment for hearing aid fitting/adjustments for an audiology suite in a rural county health department. This will reduce travel for families even if hearing aids are fit at another clinic as well as increase compliancy for hearing aid follow-up.

Progress on Specific Goals and Objectives

Goal 1: Assure 100% of infants that refer at birth have hearing tested by three months of age.

Objective 1: Educate hospital staff to obtain correct contact address for each infant at discharge and report it to EDHI program. 4/1/08-3/31/11

On-going Progress: Since April 2008, the NHSP Follow-up Coordinator has provided educational presentations to nursery staff at Oklahoma birthing hospitals across the state. The importance of providing the correct family contact information on the bloodspot form is strongly emphasized. Copies of the presentation recorded on CD/DVD media are left at the facility for viewing by absent and/or new staff at a later time. A packet of the PowerPoint and additional information is provided as references for each staff member. Presentations were made at all birthing hospitals one to two times each in the first two periods of this grant. During the vacancy of the Follow-up Coordinator position, the NHSP program continued communication with hospitals via telephone and email to ensure consistency of services. The current Follow-up Coordinator has plans to return to each of the birthing hospitals to train new staff and provide a refresher for existing screeners in the next two years. A minimum of twenty sites will be visited by the end of this grant period.

Objective 2: EDHI program staff will attempt to obtain correct addresses from health departments and other source databases on all returned correspondence with incorrect address. 4/1/08-3/31/11

On-going Progress: As mentioned in the previous continuation of this grant, all NHSP staff has access to the OSDH electronic Public Health Oklahoma Client Information System (PHOCIS) and the Oklahoma State Immunization Information System (OSIIS). The NHSP Administrative Assistant has years of experience using the systems and is quite adept at finding updated addresses for infants being tracked. The Follow-up Coordinator also validates addresses prior to calling families and sending the second letter. During this grant period, an informal review was completed of all returned correspondences for July 2009. It was determined that 32% of the letters were for children who failed or were not screened while the remaining 68% were for children with risk factors. Due to the importance of immediate follow-up for children who refer or are not screened, new protocols were adapted to include that all addresses on initial letters are validated using PHOCIS and OSIIS. These efforts have results in fewer returned correspondences as well as higher reports of follow-up services.

Objective 3: EDHI Follow-up Coordinator and other program staff will make phone and/or personal contact with families who do not respond to correspondence within six weeks of initial contact. 4/1/08-3/31/11

On-going Progress: The follow-up protocol, initially modified in 2005, continues to include telephone contact with families. If no response to written correspondence recommending screening or diagnostic assessment is received by the NHSP within six weeks, the Follow-up Coordinator attempts to reach the family by telephone. The importance of determining the infant's hearing status is stressed and the family is informed of locations where screening or testing can be obtained. A second letter is then mailed. For families without telephones, attempts to reach them through county health departments are implemented. If phone numbers are incorrect, the PHOCIS system is utilized for updated phone contacts. As mentioned in other parts of this grant, the Follow-up Coordinator ensures that all follow-up results are entered daily to reduce the amount of confusing or unnecessary calls to families.

Goal 2: Reduce to 5% the number of referring infants for whom demographic information is inaccurate.

Objective 1: Educate hospital staff about the necessity of obtaining correct demographics for contacting infant's family. 4/1/08-3/31/11

On-going Progress.**:** As mentioned above, the NHSP Follow-up Coordinator has been providing educational presentations for nursery staff at birthing hospitals across the state. During the hospital in-services, the Follow-up Coordinator emphasizes the importance of correct demographics for follow-up with families. That information is to be correctly recorded on the bloodspot form. The NHSP Administrative Assistant also calls hospitals when incorrect demographics are noted and request updates as well as reminders presented to staff on the importance of accurate reporting.

Objective 2: Educate hospital staff in techniques to use with families that are likely to increase the accuracy of family's contact information. 4/1/08-3/31/11

On-going Progress**:** During hospital presentations, information has been given to the hospital staff on the importance of hearing loss on language development. Parents have had the opportunity to discuss with the Follow-up Coordinator their reasons for delayed response..Many parents indicated they did not know the impact on speech through hearing or the importance of timely follow-up due to a lack of education by hospital personnel at birth or shortly thereafter. The previous Follow-up Coordinator also presented information from her experience as a Speech-Language Pathologist in a cochlear implant clinic prior to coming to OSDH. Those experiences include working with numerous families who had received proper follow-up in diagnosing their child's hearing loss and entering early intervention as well as families who did not follow recommendations of the NHSP resulting in delayed treatment of their child's hearing loss. These examples have be instrumental in training the hospital staff on how to be more efficient in assisting parents in follow-up including presenting available resources in ensuring that their child is accessing all the sounds of speech and language. Future in-services will be completed by the new Follow-up Coordinator who has a Clinical Doctorate in Audiology and similar experiences.

Objective 3: Educate hospital staff in methods of supplying the EHDI program with updated demographic information. 4/1/08-3/31/11

<u>On-going Progress</u>**:** Hospital staffs have been made aware that all actions by the Newborn Screening Program (NSP), which includes Hearing and Metabolic, are performed using the demographic information provided on the bloodspot form. Most staff members were not aware that updates to their hospital's database were not automatically received at the state level. Providers are presented with contact information for the NSP program to send updates as needed. Continued reminders are needed and will be presented at all future presentations at birthing hospitals.

Goal 3: Provide "second" screening opportunities locally for referring and non-screened infants residing in rural areas.

*Objective 1: Provide additional physiologic screening equipment to health department sites in out-lying areas**.** 4/1/08-3/31/11*

<u>On-going Progress:</u> Many rural areas share equipment between counties therefore reducing the availabilities of appointments needed for families in obtaining a second screen. In 2008, eleven (11) additional portable AABR screeners were purchased with legislative funding. During the previous grant period, trials were completed to determine which OAE screeners would be purchased. Carry-over funds were requested to purchase four new pieces of equipment for rural areas where audiological services are not readily available. The NHSP plans to utilize funding for this grant period on four additional OAE screeners to ensure more efficient follow-up to hospital results.

Objective 2: Offer training to professional staff in the use of physiologic screening equipment. 4/1/08-3/31/11

<u>On-going Progress</u>**:** Health department audiologists have made trainings available to any health department staff members who have equipment in their area. Since April 2008, six trainings have occurred with seven counties present. All county health departments have been made aware of training opportunities and are encouraged to request training when new staff members are hired or new technologies are received. A survey will be completed in January 2009 to determine which sites continue to need training on hearing equipment available at their sites. The new Follow-up Coordinator, who has a Clinical Doctorate in Audiology, will provide training through video teleconferencing made available through OSDH resources.

Objective 3: Assure that health department staff offering screening provides culturally and linguistically appropriate services. 4/1/08-3/31/11

<u>On-going Progress</u>**:** It is a requirement that all health department staff receive annual cultural awareness training. To expand on that training, the NHSP is working on ways to educate providers and staff of issues related to Deaf culture , communication options available for children with hearing loss, and the response of various ethnic groups to the diagnosis of hearing loss in a child. The NHSP has also collaborated with the state early intervention training program in regards to this topic.

Goal 4: Provide to the infant's authorized medical home, the birth screening results, follow-up results, and diagnostic results through web-based viewing system.

Objective 1: Enhance the current EDHI tracking system to include web-based viewing capabilities of hearing results by authorized providers. 4/1/08-6/30/09

*<u>On-going Progress</u>**:** The NHSP currently utilizes the Neometrics system to manage hearing results and follow-up. New upgrades to the Neometrics system are available to electronically send all hearing results from the new ALGO 3 and 5 machines in the hospitals to the NHSP program. This upgrade also includes a web-based section for authorized providers to obtain information and submit follow-up results. The NHSP has worked closely with OSDH Information Technology (IT) staff as well as three birthing hospitals to develop of pilot to be completed in early 2010 to determine if the new upgrade will meet the program's needs. The initial phase will include the electronic data transfer. A later phase will include the web-based viewing system. Funding has been requested from this grant to purchase upgrades.*

Objective 2: Provide educational opportunities for physicians/health care providers regarding the importance of timely follow-up for non-passing infants. 4/1/08-3/31/11

<u>On-going Progress</u>**:** Since April 2008, the Follow-up Coordinator has completed four Grand Rounds presentations for pediatricians at Oklahoma hospitals along with a poster presentation at a statewide Obstetrics and Gynecology conference. Additional requests have been made to other hospitals to educate doctors regarding the importance of follow-up. Twenty additional trainings have been completed for health care providers including audiologists, speech pathologists, nurses, genetic counselors, local community coalitions and other related professions throughout Oklahoma. Information presented at all sites includes Oklahoma statistics on Newborn Hearing, state protocols, national guidelines, accessing initial hearing results, and follow-up resources available locally and statewide. The NHSP presented at the National EHDI Conference in February 2009 regarding successes and obstacles in hearing follow-up. Slides were given to the Oklahoma American Academy of Pediatrics (AAP) EHDI Chapter Champion. This pediatrician has presented the topic of newborn hearing screening and follow-up at five locations since the beginning of this grant. In October 2009, the NHSP presented the same information at the annual Oklahoma Speech-

Language-Hearing Association. Finally, the Oklahoma Audiology Taskforce has created a new subcommittee for Outreach to Other Medical Providers to expand on efforts to provide similar trainings at state conferences for medical providers working with infants who failed a screening or have a risk factor for late onset hearing loss.

*Objective 3: Provide instruction to medical homes as to how to obtain authorization to view and then how to view hearing results through the secure web-based system**.** 7/1/09-3/31/11*

In Progress: This objective will continue once Objective 1 has been completed. However, information specific to the Voice Response System (VRS) is made available to hospitals and primary care physicians during presentations and other correspondences. Providers are also encouraged to call the NHSP if they have difficulties locating updates for each child.

Goal 5: Continue to provide individualized case management/resource coordination services to families of infants who need hearing screening follow-up.

*Objective 1: Continued employment of case manager/resource coordinator whose job is to assist infants with possible hearing loss and their families**.** 4/1/08-3/31/11*

On-going Progress**:** From April 2008 to December 2009, this objective was completed with the full-time Follow-up Coordinator for the NHSP. When the previous Coordinator/Program Manager retired on December 31, 2008 a void was created in the position due to the internal promotion of the Follow-up Coordinator to the Coordinator/Program Manager position. The Follow-up Coordinator position became vacant on January 2009 and was posted one month later. Brandon Vincent, Au.D. filled the position in July 2009. This provider is experienced in working with children with hearing loss and their families.

Objective 2: Coordinate activities of the case manager with other EDHI staff, metabolic screening staff, and early intervention staff. 4/1/08-3/31/11

On-going Progress: Since April 2008, the previous NHSP Follow-up Coordinator has worked closely with both support and professional staff from the EDHI, metabolic screening and early intervention programs. The Follow-up Coordinator and NMSP Quality Assurance/Education Coordinator have worked to provide a comprehensive training package for hospital nursery staffs in Oklahoma birthing hospitals. The NHSP Follow-up Coordinator has interacted with nurses, speech-language pathologists, audiologists, child development specialists and early interventionists to assure that infants with possible hearing loss receive the appropriate assessments and needed connections to early intervention services. This collaboration between both the NHSP and NMSP has designed and implemented procedures to ascertain appropriate follow-up occurs for all tracked infants. The Program Coordinator continued these duties until the new Follow-up Coordinator was hired. Since being hired in July 2009, the new Follow-up Coordinator has worked closely with staff from the NHSP, NMSP, and Part C Early Intervention.

Objective 3: Assure that all services provided by the case manager are culturally and linguistically appropriate. 4/1/08-3/31/11

<u>On-going Progress:</u> As an employee of the Oklahoma State Department of Health, the Follow-up Coordinator is required to have annual training in the area of culture awareness. In addition, the NHSP has continued to have all written correspondence to families translated into Spanish. An OSDH-recommended Spanish language expert translated the letters that were then reviewed by Spanish speaking families to ascertain that their message was clear. A greatly enhanced telephone language translation service has been in place since January 2006; details are available elsewhere in this document. The NHSP Administrative Assistant has completed a basic Spanish language class for support personnel and will continue to improve skills through more training opportunities. The NHSP has also hired a new Quality Assurance/Data Coordinator that is conversational in Spanish and will assist the NSP team when working with families. The NHSP also continues to be sensitive to the special communication needs of deaf and hard of hearing individuals. Both relay service and TDD/TTY communication are available for contacting families with deafness. Language levels are always reviewed for any materials being developed for consumers.

Current Staffing

Sharon Vaz, M.S.G.C., R.N., Interim Chief of Screening Special Services, is the new Project Director for this grant. She serves under the administrative direction of the Deputy Commissioner for Prevention and Preparedness Services, OSDH. Ms. Vaz has served as the State Genetics Director, which includes the Newborn Metabolic Screening Program (NMSP). She has taken an active interest in the NHSP since joining the state Health department in 2005. She has worked diligently to further combine efforts of the NHSP and NMSP. This includes incorporating NHSP on statewide and multi-state genetics taskforces. She has strongly supported the program's efforts to employ a Follow-up Coordinator to lower the number of infants that are loss to follow-up. Ms. Vaz has also supported collaboration with the NMSP Quality Assurance/Education Coordinator to provide educational opportunities for staff at all sixty-six hospital birthing sites. No HRSA funds are requested for Ms. Vaz's salary.

Patricia A. Burk, M.S., CCC-SLP, LSLS Cert. AVT, serves as the new NHSP Coordinator/ Programs Manager. She previously served as the Follow-up Coordinator since October 2006. Patricia has experience as a Speech-Language Pathologist and Listening and Spoken Language Specialist, Certified Auditory-Verbal Therapist for an internationally acclaimed cochlear implant clinic where she provided evaluation and direct intervention services for children with hearing loss and their families. As the NHSP Program Manager, she is responsible for the overall day-to-day operations of the program. She assists in coordinating the health department's audiology services under the Child Guidance Division. Ms. Burk is the supervisor for the program's Administrative Assistant, Follow-up Coordinator, and Quality Assurance/Data Coordinator. The Program Manager is ultimately responsible for ascertaining that hearing screening results for all newborns are entered into the NHSP tracking system; that the newborn's family and PCP are made aware in a timely manner of infants who were not screened or did not pass the hospital screening; that infants who did not pass are seen for a diagnostic audiologic assessment; and that families with infants who have hearing loss are connected with intervention programs. Ms. Burk works closely with hospitals to ascertain that screening is accomplished and that results are forwarded to the NHSP; she interacts with the directors and coordinators of early intervention programs for infants/toddlers with hearing loss; meets regularly with coordinators and directors of OSDH programs including genetics, metabolic screening, child guidance, and child abuse prevention programs to ensure that families of infants with hearing loss are connected to appropriate services; and serves as a co-facilitator for the Oklahoma Audiology Taskforce. Nationally, Ms. Burk has been asked to serve on a Joint Committee on Infant Hearing (JCIH) Parent Involvement subcommittee to examine best practices in early intervention. She presented at the 2009 Early Hearing Detection and Intervention (EHDI) Conference demonstrating ways to reduce loss to follow-up utilizing a Follow-up Coordinator. She also presented Oklahoma's success in striving for 1-3-6 WEEKS instead of 1-3-6 MONTHS. Forty-three (40%) infants who were diagnosed with hearing loss in 2007 received a screening by one week, diagnosis and amplification at three weeks, and early intervention placement by six weeks. No grant funds are requested for Ms. Burk's salary.

Brandon Vincent, Au.D assumed the role of the Follow-up Coordinator position in July 2009. This position is funded by this grant. Dr. Vincent has worked as a pediatric audiologist where he coordinated and implemented a hearing screening program for several local HeadStart centers, supervised and performed audiologic screenings, and performed audiologic evaluations on referred patients. He has significant experience working with families and has presented a poster at the annual American Academy of Audiology national conference. One of his primary responsibilities is ensuring that families of infants, who were not screened or failed the screening at birth, are connected with appropriate providers. The Follow-up Coordinator contacts thousands of families each year emphasizing the importance of completing hearing screening for every newborn as well as needed follow-up. This provider also works closely with early intervention staff, WIC nurses, and other county health department providers to assist in timely referral for audiometric assessment and intervention when appropriate. The Follow-up Coordinator also provides educational opportunities for Oklahoma birthing hospitals regarding screening, reporting, and counseling parents on the topic of newborn hearing screening. Training will continue to be provided for all of Oklahoma's birthing hospitals to ensure that infants are referred for follow-up as soon as possible. Funds of $46,200 are requested for Dr. Vincent's salary.

Alice Maloy is the program Administrative Assistant, since December 2005. She has worked for the OSDH since 1986 both at the local and statewide levels. Ms. Maloy has had experience with the early intervention program and with follow-up hearing screening at the county level. Her responsibilities at the NSHP include the day-to-day printing and mailing of newborn hearing screening follow-up correspondence to the infant's family and primary care provider (PCP). She also serves as first contact when families call with questions about the correspondence they received, when they seek referral for additional screening or testing, and when they need information about intervention. She also enters data from follow-up screenings, assessments, and intervention enrollment into the NHSP tracking system. She contacts hospitals for missing or inconsistent screening results, inaccurate or incomplete demographics, and missing PCP information. Ms. Maloy has had many years experience using the OSDH electronic public health record database and the public health immunization record database. Using these two systems, she is able to find correct addresses for many families that would otherwise be loss to follow-up. No funds are requested for Ms. Maloy's salary.

Beginning December 2009, the NHSP will include a Quality Assurance/Data Coordinator to reduce the number of children loss to follow-up and loss to documentation. This position is funded by a newly received Center for Disease Control (CDC) grant. Employing one additional staff person will allow the program to provide quality assurance for all initial and follow-up newborn hearing screening results and would further strengthen the program's relationships with parents, hospitals, intervention programs, physicians, audiologists, and others. This position will be responsible for working with all Oklahoma birthing hospitals to assess compliance of state mandated newborn hearing screening reporting as well as analyzing sites' referral rates to ensure the results are within normal limits set by the equipment manufacturer. This individual will assist the Follow-up Coordinator when working with follow-up screeners to ensure accuracy and consistency in reporting of results in a timely manner. The Quality Assurance/Data Coordinator will continue to work with Neometrics on the implementation of and modifications to the data system, which includes monitoring surveillance and tracking needs of the NHSP. In addition, epidemiologic processes related to surveillance, data collection, and data analysis will be conducted to improve the annual CDC statistical reports/survey. These measures will assist in determining if the Oklahoma NHSP is meeting national CDC standards and ensure infants who are diagnosed with hearing loss are receive initial screening and appropriate follow-up.

Technical Assistance Needs

Although Oklahoma NHSP has made great progress in connecting databases statewide, much work still must be completed to link and analyze data. Currently, records from OSDH and OSDE cannot be linked. Information obtained, through interagency agreements , must be requested from each county health department site and manually entered into the Neometrics database. Access to the Oklahoma Health Care Authority , the state Medicaid agency, database is also limited. Initial planning for electronic linking of the NSP database with birth certificate records in the OSDH Division of Vital Records has been accomplished. However, technical assistance is needed to implement this plan to ensure that all Oklahoma babies receive a hearing screening shortly after birth. New upgrades to the Neometrics system are available to electronically send all hearing results from the new ALGO 3 and 5 machines in the hospitals to the NHSP program. Technical assistance to move forward in linking these systems is highly desirable which includes messaging, firewalls, electronic linkage guidelines, and software compatibility. Additional assistance is desired to support the NSP with providing hearing screening and metabolic screening results, to an infant's file in the Public Health Oklahoma Client Information System (PHOCIS), while complying with confidentiality requirements.

The NHSP has been working with national entities such as the National Center for Hearing Assessment and Management (NCHAM) and the CDC EHDI Program regarding technical assistance in areas such as management strategies for individuals with auditory neuropathy, methods for developing loaner hearing aid banks, and interstate linkage through vital records. This assistance has been instrumental in the development of many of our newborn hearing approaches and policies.

Program Linkage

The Oklahoma Newborn Hearing Screening Program (NHSP) was established in order to identify infants with hearing loss as early as possible. Since its inception in 1982, collaboration has been instrumental to the program's success. The NHSP works closely with local, state, and federal programs, both public and private. The NHSP, NMSP, Genetics Program, Lead Poisoning Prevention Program, and Oklahoma Birth Defects Registry programs are all administratively located within the Screening, Special Services Division under the administrative direction of the Deputy Commissioner for Prevention and Preparedness Services. The NHSP is funded through the Title V Block Grant, the Newborn (Metabolic) Screening Program revolving fund and HRSA project funds. As mentioned, the program has recently received a new CDC grant to fund a Quality Assurance/Data Coordinator as of September 2009.

Please note that as of November 16, 2009; the NHSP is no longer in the Family Health Services Division under the administrative direction of the Deputy Commissioner for Family Health Services at OSDH as noted in previous grant applications. The previous service area included the SoonerStart Part C Early Intervention program. Though programs are no longer in the same service, the two will continue to collaborate regarding matters of newborn hearing screening and follow-up.

The NHSP continues to work closely with all Oklahoma birthing hospitals to ensure initial and follow-up hearings screenings for all infants. Since hearing screening and reporting is state mandated for all infants, an additional Memorandum of Agreement (MOA) is in place for all birthing hospitals to use the state funded Algo 3 or 5 AABR hearing screeners. This includes all but one federally-funded hospital in the state. The MOA indicates that sites will screen, report, and provide maintenance of the equipment. Training is completed by the Follow-up Coordinator as mentioned throughout this grant.

In 1989, Oklahoma began contracting with Neometrics to provide case management and follow-up for Newborn Metabolic Screening Program (NMSP). It was determined that this system was an excellent data collection and tracking program. A hearing screening module was added as the most appropriate means for following newborn hearing results. The Newborn Screening Program (NSP), which includes the NHSP and NMSP, collaborated with the OSDH Public Health Laboratory (PHL) to integrate hearing screening and metabolic disorders results. The NHSP's data management system was merged into the NMSP system in July 2002. This system's software allows the programs to track infants with abnormal metabolic results, infants who failed the hearing screening, and infants who were not screened. A re-designed metabolic disorders bloodspot form was developed that included an area to record hearing results as well as a place to indicate risk status for later developing hearing loss. The OSDH PHL personnel enter demographics, metabolic results, and hospital hearing screening results into the system. The

NSP has a toll-free hotline at the OSDH that is manned during agency business hours with the availability of voice mail after hours for families and providers. Both hearing and metabolic screening results are available to an infant's authorized health care provider 24 hours a day through the Voice Response System that is a part of the tracking software. Updates to the Neometrics system during this three-year grant cycle have allowed for the tracking of the infant's hearing follow-up data including degree and type of loss for each ear, assessment tools used, name of audiologist, date of diagnosis, and amplification/cochlear implant data. Additional information about the early intervention program in which the child is enrolled and the date of entrance into that program can be entered into the system. Program staff can more easily generate hospital-specific reports regarding the number screened, the number that failed the screening, and the number at-risk. The NSP is currently exploring ways to make hearing screening and metabolic results available to authorized county health department staff through the agency's client record system, PHOCIS, as well as to other follow-up providers through a web-based tracking system. During this grant period, the NHSP is also working on the electronic linkage of hearing results from each birthing hospital. At this time, hearing information is sent to the NHSP via the bloodspot form as mentioned throughout this document. Any results sent after the bloodspot specimens have to be mailed or faxed at a later time and manually entered by NHSP staff. Results can be mismarked or missed at times. Therefore, the upgrade to the Neometrics software requested in this grant would greatly reduce loss to documentation and reduce the need for additional paperwork/data entry. The results would arrive minutes after the completion of the screen to ensure the most accurate and up-to-date information is in the NHSP tracking system for follow-up.

With limited access to pediatric audiologists throughout Oklahoma, especially the rural areas, the NHSP provides follow-up equipment, training, protocols, and supervision for all of the county health departments. Professionals such as nurses and speech-language pathologists complete a follow-up screening upon a child's discharge from the hospital if the child failed or is at risk for late onset hearing loss. If additional hearing screening or diagnostics are needed, providers refer to the five audiologists placed in local county health departments who are funded through the Child Guidance and the SoonerStart Part C programs. An additional five audiologists are contracted in rural areas as well as five programs in the metropolitan areas, which include cochlear implant services if needed. This process assists in reducing the number of referrals to audiologists with false positive hospital results, providing closer proximity to care for families, and decreasing wait time for families between follow-up appointments. Steps have been instrumental in helping Oklahoma infants with hearing loss receive appropriate follow-up in a timeframe that often exceeds national standards.

Previously one of the biggest obstacles for Oklahoma NHSP to meet national standards for follow-up was access to amplification for children diagnosed with hearing loss that were uninsured or insurance did not cover needed speech-language therapy. The NHSP continues to work closely with the non-profit Hearts for Hearing Foundation. Established several years ago to provide hearing aids to families with no means for purchasing instruments, they were awarded a contract by the OSDH for fiscal years 2006-2010. Funding is being used by the organization to assist needy Oklahoma families in obtaining hearing aids and appropriate intervention services.

Additionally, the foundation is providing educational opportunities to clinicians to enhance their skills in working with infants with hearing loss and their families.

The NHSP collaborates with Oklahoma Area-wide Service Information System (OASIS) Referral Service for Children and Adults with Special Needs. OASIS is a 24-hour hot-line that provides referrals statewide for families. The NHSP also collaborates with the Oklahoma Genetics Advisory Council. This group has a Newborn Screening and a Pediatrics Committee who act as an advisory group for Genetic Services. The NHSP Coordinator also serves on the Education Committee of this council to promote hearing loss in the genetics community. The Program Coordinator has also been instrumental in proposing and creating a new EHDI Workgroup within the Heartland Regional Genetics & Newborn Screening Collaborative. This organization links eight surrounding state newborn screening programs. Due to Oklahoma's active participation, an e-newsletter was also published on EHDI programs in the region as an effort to link hearing programs with state genetics communities.

Previously, the NHSP coordinated three taskforces to address specific issues related to early identification of infants with hearing loss and their linkage to appropriate management services. During this grant period, the NHSP has worked on improving the outcomes of each taskforce, which includes expansion of membership throughout the state. The Early Intervention Taskforce is involved with issues surrounding the provision of services to children ages 0 to 3 with hearing loss. The SoonerStart Part C early intervention program has assumed responsibilities of this taskforce. However, the NHSP remains a strong supporter and participant in this taskforce. Previously, the Screening Taskforce addressed issues related to the hospital screening process and the provision of results to the NHSP. The Audiology Taskforce dealt with assessment issues for infants and young children. These two taskforces were combined under the Oklahoma Audiology Taskforce leadership during this grant period for increased efficiency and productivity. Subcommittees have been created and will be implemented January 2010. These subcommittees include Outreach to Pediatric Audiologists; Outreach to Other Medical Providers; Genetics; Family Support; and Protocols/Guidelines/Data/Outcomes. All taskforces include participants from the public and private sector. The statewide taskforce has tripled in participation by combining these two taskforces and focusing on enlisting audiologists, deaf educators, early interventionists, parents, Deaf/Hard of Hearing consumers, and advocates from programs such as the Oklahoma Family Network (OFN) to ensure that family-centered services are being provided statewide.